The Role of Toxic Mold in Chronic Fatigue Syndrome

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Part 1

Introduction
Chapter 1 -- A New Paradigm

CONCEPTUAL TOOLS

Since I met my first CFS victim in 1980, I've watched this epidemic spread.

It puts me in mind of the vast herds of buffalo that were wiped out by small bands of hunters. You just pick off the leader, and the rest will stand there watching the others drop, one by one.

"Gee, there went Buffalo Bob. D'ya suppose those humans with the bang sticks had anything to do with it?"

"Nah, not a chance, they're too far away, he musta got hold of some bad grass."

I've tried to convince people that this damn thing is going all around the world without regard to lifestyle, attitude, mercury fillings, bad luck, stress or any of the other ridiculous random factors that get blamed for this.

I never could persuade my family that I wasn't just obsessively stressed. If you can't even get your own family to believe you, who can you possibly get to listen?

I finally just gave up. I figured when enough people drop, the reality of the situation will start to penetrate their thick skulls.

It's looking like by the time we reach that point, we'll be as gone as the buffalo.

-Erik (2001, SickBuildings)

*

Considering how many patients have literally fought the mold concept tooth and nail for years before finally uttering the words, "Well, that's just obvious," I have come to the conclusion that this is a paradigm shift of such magnitude that people are utterly lacking in the conceptual tools necessary to allow them to see it.

Imagine a Native American encountering a telegraph line for the first time, cutting it down, and being startled at the electric shock. How would he explain this to members of his tribe? What words could he possibly use?

Basically, just like in the old movies which depict such situations, there is little choice but to bring the tribe out to the spot and give them a demonstration.
SENTINEL CHICKENS

CFS got going when Dr. Peterson noted that clusters of illness were occurring among close knit groups:

The girls’ basketball team and the Truckee teachers.

The very fact that the illness could do this is an indication that it has much less respect for individual tolerances and variations that people who hope it’s a rare genetic illness would hope for. The illness just plain raced through groups in a manner unlike anything an individual problem could ever do.

The illness isn’t spreading nearly like an individual susceptibility as much as it appears to be something that can overwhelm just about anybody at any time without much warning.

- Erik (2006, CFSExp)

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Whether I am a "canary" or a "sentinel" is an important aspect that bears some examination.

The "canary concept" is predicated upon the susceptible organism succumbing first - as a useful warning to those with more endurance.

"Sentinels," on the other hand, are simply the first to encounter an encroaching phenomenon which has the capacity to overwhelm, regardless of whether one possesses a susceptibility.

If we encounter circumstances in which both susceptible people AND those of normal constitution succumb, the canary concept does not apply even if some of the fatalities happen to be canaries.

What you have is a "sentinel" situation.

This is an important distinction, because it completely alters the threat level of the phenomenon.

Canaries can no longer be counted on to serve as a warning. Analysis of a sentinel situation using a canary perspective will make no sense.
Consider the possibility that the cluster outbreak of which I was involved also contained people who were of normal constitution, although I personally do have the genetic susceptibility which would have made me a canary,

It still would not apply and has been superseded.

In this case, the type of warning people should take heed of is that of a sentinel chicken, similar to the ones placed to detect encroachment of West Nile Virus across the country.

In an exposure of gradually increasing toxicity, the first people to succumb would undoubtedly be canaries, but if a location swiftly became toxic in such a manner that people of varying susceptibility who entered were to show some signs of illness, they would be sentinels - a far more dangerous situation, with far less warning.

It's not that I'm trying to be obstreperous, but we all need to understand the difference between the two conceptual models, or we won't know it when we see it and make allowances for the increased threat level.

-Erik the sentinel chicken (2008, IAQ)

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The prevailing current viewpoint is that this is a hypersensitivity situation which only applies to abnormal individuals as a consequence of their own susceptibility.

This might be an error, based on the way society perceives the problem.

The steadily increasing numbers of dogs, cats and birds that have also manifested immune suppression and subsequent disease sequelae in the presence of these molds are not in accordance with the concept that mold toxicity is just a few isolated cases of susceptible humans to a fairly benign irritant.

It appears that whether or not a substance is currently considered toxic may very well be "scientifically" dictated by statistical averages.

When enough people and animals are made ill, then that substance will undoubtedly achieve universal agreement upon its "toxic" effects.

-Erik (2008, IAQ)

*

It's amazing how quickly things have changed.

You can see this in some old movies, like "Bad Day at Black Rock" with Spencer Tracy, Ernest Borgnine, Robert Taylor, Lee Marvin and a few other great actors.
It was filmed down at the base of Mt. Whitney, just north of Lone Pine, and you can see that the sagebrush was scrubby and sparse when it was filmed. Now the sagebrush is so luxuriant that there is no place to walk, and there's even grass and flowers growing out there. Never thought I'd see that out there.

And yes, some areas have lit up with so much mold in the last few years that when I pass through these areas of increased intensity, I see people all over with strange rashes, headaches, just looking miserable and it makes me wonder.

What are such vast numbers of people going to do, if this keeps on going the way it seems to be?

-Erik (2008, CFSU)

* 

I can't help but wonder what will happen when the gradual sense of awareness finally penetrates society that it is the environment instead of the individual.

I suppose the barren and remote desert locations like Indian reservations will be invaded by refugees from civil devastation.

-Erik (2010, SevereReactor)

**EXPLOSION**

>I'm not convinced there is suddenly an explosion in chronic illness,

It's an explosion all right.

It has been amazing to see people breaking their backs bending over backwards in the attempt to be oblivious.

-Erik (2004, EuroLyme)

**GROWING NUMBERS**

I know a former mold remediator in Reno.

He employed the logic that he was still here and healthy, years of working with mold had taught him that he was obviously not a weak person who might be susceptible.
The reason he is a "former" remediator is that he reached a point where he dares not go near any sick buildings anymore because they disable him for days afterward.

He is now charging people to be a mold consultant.

Considering the amazingly increasing number of remediologists and contractors who are now so reactive that they are in the same plight as the people they were trying to help, I can't help but think that it's going to be anything but business as usual.

This is really going to put humanity to the test.

-Erik (2007, IAQ)

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In a world of peanut butter eaters, where would someone fit in who is driven into anaphylaxis by a few peanut molecules?

Interesting how in the last few years, we've seen peanuts being driven out of their traditional domain of schools and airplanes by the extreme response of a minority.

Unthinkable that such a scenario could possibly arise with something as ubiquitous as mold, isn't it?

-Erik (2007, IAQ)

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I've seen people persist for decades in environments that I can scarcely tolerate for mere minutes.

That's why I drew upon the peanut allergy analogy to try and explain why I must act a certain way - while for others, there is no apparent need.

It wouldn't make sense for a peanut allergy person to try to tell a peanutophiliac to stop eating peanuts, would it?

We are forced to act within the dictates of our personal situation.

However, I am witnessing the emergence of a large population of mold responders who have little choice in the matter.

As I said to Dr. Cheney in 1985 during the Incline Village CFS epidemic, "If whatever is happening continues on as it has here, there will be vast numbers of people just like me."
Guess what...?

-Erik (2008, IAQ)

**MOLD AWARENESS**

Five years ago I made a point of asking plumbers if they had any unusual reactions after fixing leaks that had cause major water damage. I didn't even ask about mold because back then nobody had even heard of "toxic mold."

I would usually get a puzzled look for asking such a strange question and then they would say,

"Well, there was this time..." and describe the usual symptoms of a mold hit.

I know of a huge hospital that has a group of nurses who are sick and know full well that their hospital is a sick building but don't dare say anything publicly.

This is really getting interesting.

-Erik (2002, SickBuildings)

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It was just the summer before last that I talked to some Lyme patients who flew into Reno for treatment and became quite ill after landing at Reno Tahoe airport. They remarked how odd it was that the flight didn't affect them and it was only after they landed that the symptoms started.

After they described their symptoms in a little more detail, I told them about Reno's many spore plumes and that it sounded to me like they had walked through a Stachy cloud. They had never heard of Stachy and considered the idea that mold might have such an effect to be impossible.

How things have changed.

Stachy was just found in the terminal building and the local news is referring to it as "toxic mold" as if it was an unquestioned fact and common knowledge that Stachy is bad stuff.

Six years ago I called allergists and doctors at random in Reno to find out if they knew about Stachy and if not, did they want to learn. Nope. Didn't know and weren't interested.
I argued with one of the most prominent allergists and immunologists in town. He told me, "Mold reactivity is impossible" and said that my symptoms were from a "bad back" and ordered a spinal X ray. I asked him, "Why do I only have a bad back while in a moldy building?" and got no response.

Then I asked at the front desk, "If you believed that mold might have some bad effect on you and wanted it out of your house, do you know of any contractor who specializes in assisting to remove allergens?"

They said, "You are the first person who has ever asked us that question, so no, we don't know of anyone."

I was shocked and asked, "If you know that some allergens exist inside houses, don't you counsel them on removal of these irritants from allergic people’s environments?"

The response was, "No, we just give shots."

Now the number of people who have been evacuated from houses and the public buildings and schools that have been closed down from mold are too numerous to even list. But the most bizarre thing is how people are acting as if they knew all along that mold is harmful and that it is just common sense to move out of a house if it becomes contaminated.

I had arguments with doctors about this very concept and they swore that it was virtually impossible and that I was mistaken. Now some of the doctors who told me this was impossible have gone on to become "mold experts."

This is surreal beyond belief.

-Erik (2004, SickBuildings)

*  

Only three years ago I had to be careful about who I told about my severe mold reactivity if I wanted to avoid total scorn.

But my DeCon Camper got mold and I needed help from the local RV store. They thought I was crazy then as I tore out walls and replaced moldy panels.

I was just there again and this time they all ran to ask me questions. I had these employees all gathered around me while I described what it is like to live with this and they all took me completely seriously.

What's going on?

-Erik (2004, SickBuildings)
I bought a computer that was "bad right out of the box." When I called the manufacturer, the technician was a 20-something year old with a chronic cough.

I started asking him about his health and he said, "You know, it's funny. I started getting sick and tired shortly after I started working here. I've been taking vitamins and trying to exercise but it just doesn't seem to help. And up until then, I was as healthy as could be - a real Jungle Boy."

Of course this was about five years ago, before Melinda Ballard put mold on the front page of USA Today, so I couldn't even talk about it without people instantly giving me a ration of crap.

So I couldn't tell him a thing.

-Erik (2004, SickBuildings)

I had a Moldie take me to a place from her past that she had always associated with bad memories, arguments, and others acting strangely.... and sure enough! The place was a slammer.

She said, "After all these years, all that craziness finally makes sense."

While we sat outside the building on a bench, recovering from the hit and discussing it, two gals walked by after having just come from that building.

As they got closer, we could hear one say, "I don't understand it. I just burst into tears for no reason. Nothing has happened, and yet I feel so sad."

The other said, "Same with me. It was like depression, but I'm not depressed. Why would both of us suddenly feel that way?"

Their voices faded away as they continued walking.

I looked at my Moldie friend and asked, "Do you want to go after them?"

She said, "Naah. They wouldn't believe it."

This was only eight years ago. Back then, people just plain didn't believe it... and nothing short of a demonstration would change their mind.
This mold phenomenon has gone from "Impossible" to "Self Evident" in less than ten years. It is extremely scary to see how quickly this paradigm shift has occurred.

-Erik (2008, CFSU)

*

The implications for these “zones” are so horrifying that as the comprehension begins to sink in, people literally shut off their minds and begin to argue against it, as if sheer volume of denials and excuses will erase the reality.

Twenty five years ago, these arguments were conducted with such boisterous confidence that people would jeer at the very notion, and put laughter and scorn into their words about such theories.

But as time passed, their demeanor has changed to almost a plaintive tone, as if this can be wished away if it is ignored long enough.

Rumor of these places is reaching everyone’s ears.

One thing to watch for, as this paradigm progresses, is that although they might not believe you or take you seriously when you speak of this phenomenon, they aren't laughing anymore.

-Erik (2010, CAA)

MOLD PROFESSIONALS

Nearly a decade ago, Dr. Marinkovich told me about the numerous sick people who came to him with plastic baggies containing their suspect mold, which they would offer to sniff in his presence to prove (by collapsing) that this was truly the offending irritant - since no doctors appeared to believe them.

-Erik (2008, IAQ)

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Why didn't mycotoxins do this in the past! Here's where it gets interesting.

All the doctors who have jumped on the mold-bandwagon will swear up and down that it did, that it must have, and that nothing much has changed except that buildings are tighter, and we are "more aware."

Nonsense.
I went out of my way to interview remediators over the years to attempt to find out if something was really changing.

What I found was that they all had a conceptual framework that said, "Mold is bad, but only as an allergen."

I even had remediators who deal in flood damage tell me they had been identifying Stachybotrys for thirty years but had never seen or heard of the type of illness I described, and that they had never heard of people becoming reactive to the point I described.

I said, "Just wait, you will!"

Their lack of recognition of extreme responders tells me that a mold paradigm shift has truly occurred.

But what they are doing is jumping on the current wave of mold “hysteria” to say they have many years of experience in dealing with mold. This is misleading people into taking their advice, which is not aimed at this level of reactivity.

When pushed, most betray that they understand nothing about what it is like to be forced to run for your life from mold. But since they feel they are doing you a service to help clean up mold, they’ll be happy to take your money, even if their efforts do almost nothing in terms of helping with your illness.

Something had to have changed!

I only say that I am seeing the emergence of a CFS epiphenomenon, and that people had damned well better start paying attention, because whatever is happening has gone from a virtual public unknown before 1999 to a smoldering dread of toxic mold that is on the tip of everyone’s tongue these days.

That is one quick paradigm shift!

-Erik (2008, CFSU)

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As more people become aware of toxic mold, they are doing a strange thing.

Despite this phenomenon being almost completely unknown and disbelieved prior to 1999 when Melinda Ballard made front page news, they try to express it in terms as if it were already known but is just increasing.
Now, if schools had been closed in the past, buildings burned down, and people fleeing for their lives, doesn't it seem like there would have been a good record of this phenomenon?

Cities have certainly flooded in the past. There has been plenty of opportunity to have seen this before.

So why is it so unknown and disbelieved?

People who are learning about it now are barraged with so many people saying that this is common knowledge, and "We knew it all along".... that it belies there was a time when someone could launch a global epidemic of Chronic Fatigue Syndrome while talking about mold, and not one doctor had the slightest recognition that mold might be any more than a troublesome allergen.

What the mold "experts" have done is persuade people that nothing much has changed.

This makes people far less worried than they should be.

-Erik (2008, CFSU)

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I tried showing people that years ago, advertisements for air filters failed to mention mold.

I got out old phone books and said, "Look, see? No mold remediators. No 'sick building' advertisements."

I showed them the Indoor Air Quality "Proceedings" manual which said that a search of the medical literature shows that this problem was not listed prior to the early 1980's.

I reminded them that when I started talking about it, their primary argument against me was that they had never heard of this before, and this was something that could not be missed.

And now virtually everyone has either had a mold problem or knows someone who has.

I've been trying to get an idea of how many people are going to have to have their lives destroyed before society runs out of excuses to say that none of this matters.

Right now, I'm guessing about ten million.

-Erik (2009, SevereReactor)

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It's pretty clear that something has changed.

Old remediators didn't get sick before, although they didn't use face masks.

People did paint over mold, and got away with it.

Not any more.

-Erik (2010, SevereReactor)

MOLDY PLACES

Over the last twenty years, I've seen more of these toxic places crop up. Many places that used to be perfect for me have turned bad.

It's not my sensitivity that is changing. This stuff is spreading.

-Erik (2006, Locations)

*

Wherever plumes were, twenty years ago, there are more today. Larger, more pervasive, affecting more areas. There are so many places that used to be safe that have turned bad.

The plumes don't necessarily feel more potent to me than ones I am used to... mostly just larger. Much larger.

I encounter them far more frequently than just ten years ago... and I am seeing entire sections of cities that used to be safe turn into "no go" areas. The prevailing wind direction refreshes bad zones and keeps them hot.

There are a bunch of us who cannot live within fifteen miles downwind of certain areas, and yet we can live quite well scarcely a mile upwind.

It becomes increasing difficult to maintain an avoidance lifestyle.

So far, the plumes I am frequently passing through seem to mostly denature in about two days... but I know from bitter experience that there are situations in which the toxicity can last up to several years.

While it is tempting for people to say, "That's just YOUR susceptibility," it is disturbing to us sensitives to see increasing numbers of people, even as they protest their denial,
visibly manifest rashes, pallor, the “mold salute” as they hold their hand to their temple, and spider veins standing out on their reddened skin when the badness is active.

We don't think it's just us.

-Erik (2008, CFSU)

* 

Years ago, mold avoidance was much easier. This thing just keeps getting worse... more difficult.

I've been aware of my reactivity to bad zones for enough years to see that many, many places that used to be good have now turned bad. And I know that it is obviously not just me as people like to believe, since these inhabitants of new bad zones are showing the signs of impending illness.

Based on the swiftness with which a phenomenon that was totally unknown only two decades ago has turned into such a frightful mess, I think it would be a good idea for people to look beyond just moving.

Too many people have counted on moving as their solution, and their new place turned bad, leaving them right where they were. I think people really need to start thinking about "Plan B" as well.

-Erik (2008, CFSU)

* 

When I was first going out to the desert, it was with a camper. The camper was contaminated, so I'd wake up feeling like crap. I had to get away from the camper to feel better.

Feeling better away from the camper let me know that it WAS the camper. In time, I learned not to leave my camper in places where it picked up the badness.

But that's scary, if you don't feel better in the desert.

My friend in Texas confirms that when a storm goes through, while the bad places are badder, the whole darn place, everywhere, feels less than great.

That is not how our planet used to be. Not at all. Used to be a pretty nice place.

-Erik (2008, CFSU)
TRENDING DOWN

What I'm doing is hard, some people would say "life destroying."

But it's still a clue, because when I started, absolutely nobody believed in mold.

I warned it was going to be huge, then watched it happen.

And it's not slowing down one bit.

As bad as things have been already, I expect a quantum turn for the worse.

People had better prepare themselves.

-Erik (2007, Email)

*

I've pondered these issues at great length, and the more I ponder, the more complex the problem becomes and the more pressing the urgency for society to begin to address these issues.

This mold phenomenon is growing at an alarming rate, and if people don't start putting some pressure on the medical system to look into it... it won't get done.

A lot more people are going to wind up sleeping in their cars, wondering what the hell hit them.

-Erik (2008, CFSU)

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We are sailing in uncharted waters here.

The huge problem we Moldies see is that neither doctors or patients think this is really a problem as of yet.

I don't have the answers. I just got a clue.

Heck...we are still trying to find out what the right questions are.

-Erik (2008, CFSU)

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Whatever people used to think was normal for what happens around mold is not what is happening now.

Trying to extrapolate what is going to happen with people’s sensitivity would be based on what happened in the past.

Judging by what I see, that would give the wrong answer.

-Erik (2008, Email)

* 

This might be too big to treat. There is no mechanism that we see at this point which holds this phenomenon in check, so the potential does not seem to have any clear limitations.

Twenty years ago, the medical literature did not even have reports of people crawling from their moldy houses, expressing anything such as we describe.

Today, there are many thousands of these stories, with more every day.

Until science and medicine get involved, we are on our own.

-Erik (2010, WPI)

**PREPARING FOR THE FUTURE**

This is happening everywhere. I have stories from all over the world.

I’m afraid that the human race is in for some very difficult challenges ahead.

Based on what I see so far, the vast majority of the populace are trying to deal with this paradigm shift by denial of its existence, or at least mentally minimizing the scope of this phenomenon down to something that is more easily manageable.

Unfortunately, by the time someone becomes so intensely reactive that they can point at the specific irritant, they have also arrived at a level of disability which makes it almost impossible to deal with.

If this reactivity is detected early on, before major damage is done, and effective measures are taken in a timely fashion, one can improve their chances of achieving comfort and survival considerably.

-Erik (2007, CFSExp)
It is ten below zero in Truckee. Had I not planned for this eventuality, I would be completely hosed by now.

I don't know what to say. From where I sit, those who don't see what is coming, and make provisions, are going to be up shit creek without a paddle.

-Erik (2008, CFSU)

Judging by the increase in contamination at virtually all levels and on all kinds of products that we mold responders have witnessed, I would say that in the future, it will be difficult to purchase almost anything that can be automatically trusted to be mold contamination free.

-Erik (2008, CFSU)

I've had four RV's go bad on me since 1985, which is why I built my own.

The last one, I tried to keep the condensation low and not use the air conditioner, but it went sour on me anyway.

This has been really tough.

I don't know how others who wind up at this level of reactivity are going to make it.

From what I've seen so far, it looks like they just fall off the edge of the planet and disappear.

-Erik (2009, SevereReactor)

Mold didn't start creeping in until just a few years ago.

But when it finally hit, mold smashed down the door and said, "I'm HERE."

At this incredible rate of "from nowhere to everywhere," people who base their plans and expectations on a situation that is not increasing are going to be vastly disappointed.
As in, a safe room isn’t going to mean a thing when the entire ambient zone is overtolerance for the sensitized person.

I highly recommend that Moldies get started on obtaining a MECU for themselves, even if they are currently in a good place.

-Erik (2009, SevereReactor)

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From 1985 through 1997, people told me that what I described was flat-out impossible.

The conviction of this was so strong that there was always a fair degree of condescending derision to the dismissal.

Now, with houses virtually all around with "Toxic Mold" or "Biohazard" signs on them, where inhabitants had to flee, there has been a substantial change in people’s beliefs about this phenomenon.

Nobody is laughing anymore.

-Erik (2010, WPI)

*

I’m not trying to talk patients into doing anything.

This phenomenon is progressing at a fairly rapid rate, and researchers have steadfastly refused to investigate it.

I am just letting people know that this is coming, and when it hits, many choices that people thought were optional and within their power to decide become mandates dictated by the needs of survival.

-Erik (2010, WPI)

*

I’m getting stories from Japan, Hungary, Iran, Germany, etc.

Same thing. Doctors don’t believe and "never heard of this before."

Although the chemistry of this response is fascinating and it sure would be nice to have a miracle pill, I think it would behoove people to make some kind of physical provisions for the possibility that they might not be able to control this problem with chemotherapeutic measures.
But that's just my opinion.

-Erik (2010, SevereReactor)
Chapter 2 -- CFS & Mold

THE MOLD CAME FIRST

Mycotoxin reactivity is a symptom of CFS, and in many cases it preceded the viral infection associated with "mono" or the viral encephalitis implicated in "clinical CFS."

I was a patient of Dr. Cheney's in 1984, before the "Truckee Crud" went through. Dr. Peterson identified the "Truckee Crud" as HHV6a.

It was that viral illness that constituted my "sudden onset" of CFS.

The complaint that drove me to see Dr. Cheney before the CFS epidemic was a reaction to mold that nobody could understand, including him.

The illness that I had prior the HHV6a would have been called "chronic fatigue." It took the viral infection to ramp up my illness to "CFS."

The two are not even remotely comparable.

-Erik (2003, CFSExp)

*

It would be consistent with my experience to change the name of the Incline Village syndrome to ME and call the precursor susceptibility CFS.

I believe that the subsets will eventually be united by this precursor condition.

-Erik (2004, CFSExp)

*

I was a patient of Dr. Cheney's before the "Yuppie Flu" went through and dropped a bunch of us in our tracks.

Guess what my complaint was?

"Chronic Fatigue."

I told Dr. Cheney, "I have an inexorably increasing reactivity to mold that gets progressively worse no matter where I live or how well I take care of myself."

This is what brought me to Dr. Cheney's office in Carnelian Bay in early 1984.
So I was reactive to mold prior to CFS.

Afterwards my reactivity was absolutely life threatening.

Prior to the weird flu, my problems would have been adequately described as inexplicable fatigue, but after the "?" happened, the sensation turned into life-destroying godawful drop-dead neurological living death illness that was nothing like fatigue.

My susceptibility to mold was prior, not later as is automatically assumed, just as it was for the Truckee teachers and various other CFSers I have questioned about this phenomenon.

I thought that it was more than coincidental that this same mold that has such an effect on me showed up so often in clusters of CFS - especially the one that started it all, at my old high school, Truckee HS.

Interesting how Dr. Shoemaker's "24%" HLA genotype is suggestive of the "25% ME group."

-Erik (2006, CFSExp)

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Since the mold came first, it appeared to me that this type of exposure paved the way for creating extra severity when the HHV6a went through.

I proposed this to Byron Hyde, who replied, "You can't prove it without studies."

So as it stands, we have mycologists and remediators speculating whether mold is connected to CFS, and CFS researchers who are just barely beginning to wonder if CFS is connected to mold, but both disciplines strangely declining to put their information together.

-Erik (2008, CFSU)

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>How sick were you before you started to feel the burn in your throat?

It was so vague prior to 1985 as to be almost imperceptible to me.

All that changed when the "Yuppie Flu" went through. After that, it was like inhaling hot coals and gargling with battery acid.
The Truckee teachers described it perfectly, but air quality professionals found nothing, so it was forgotten.

-Erik (2008, CFSU)

*

What I told Dr. Cheney at the inception of CFS was that those of us who were already suffering these fatigue symptoms in the presence of mold seemed to have the absolute worst cases of the "Yuppie Flu."

"Yuppie Flu," "Tahoe Flu" "Mystery Illness" being the strange flu-like illness that went through Incline Village in 1985.

That flu-like illness is what was named "CFS."

I told Dr. Cheney and Dr. Peterson that until they figured out what CFS is, I was going to continue to stay away from that mold.

-Erik (2010, SevereReactor)

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I was up checking out the construction on the WPI and found a spot plume in one of the buildings next door.

I asked a person working in the office nearest to the colony, "How do you feel around here?"

Naturally, she was surprised at the question, but replied, "The only time I ever feel less than bad is on a perfectly clear high pressure day."

Yup. Seen that plenty of times. No biggie, tough people can handle it.

Then... one day, you get this funny little flu bug, and that's all she wrote.

Gotcha!

-Erik (2010, WPI)

ALL THE NUANCES

I don't have any actual etiological disagreements with Dr. Cheney. I just feel there is an extra demonstrable factor was clearly present at Ground Zero for CFS which has been overwhelmingly overlooked.
I just happened to have stumbled over this clue and must have been too zonked to pick myself up and hurry away without noticing it.

-Erik (2006, CFSExp)

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People generally leap to the conclusion that my assertions of mold are somehow in conflict with the CFS paradigm and that I am contradicting Dr. Cheney and Dr. Peterson.

But if you look over all my old statements, I say over and over that, "CFS happened exactly as described in Osler's Web."

There was just a little more to the story than was in the book, although the clues are there for those who know what to look for.

-Erik (2008, CFSU)

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My experience represents one portion of the CFS history that was never told for the simple reason that it appeared meaningless at the time.

Our expressions of an environmental component were so disbelieved that these clues were simply omitted or relegated to being nothing more than a result of the illness.

Events now indicate that these environmental factors were more relevant than they appeared.

-Erik (2009, Facebook)

**MOLD AND THE YUPPIE FLU**

The Yuppie Flu was quite real and quite devastating. The only thing I was trying to add was that all the people who shared this mold reactivity were the very sickest CFSers.

I don't know why it got so bad for a while. That's the mystery. Something happened and doctors won't help me figure out what.

-Erik (2007, Email)

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What do you think caused the CFS epidemic in Incline Village?

How about an immune-disabling exposure to extremely potent protein synthesis inhibitors from trichothecene mycotoxins at the very same time that a rare virus was passing through Truckee High School?

-Erik (2008, CFSU)

Since 1980, I had been going to doctors and complaining about intermittent fatigue. I kept pointing at mold, but doctors all assured me this was impossible.

Because I had the growing awareness of "bad places," I was amazed that when the "Truckee Crud" went through, it was people in these very environments who appeared to fare the worst with this flu-like illness.

I started asking the other members of the original CFS cohort about this connection, and it just kept cropping up again and again.

These people seemed to be just like me... especially susceptible to mold, perhaps even prior to the "Truckee Crud."

One might vaguely remember the tennis pro from Osler's Web. He had been in a helicopter crash and was pretty beat up, so he had a preexisting reason for falling apart. It wasn't until I checked out the apartment he was living in that I made the connection that he was another person who had been in the presence of mold.

Of course, I told all this to Dr. Peterson and Dr. Cheney, but they just kept saying that everyone was turning into a universal reactor, so mold was just another irritant.

My point was that no matter if it was cause or effect, if I could feel as good as I do by staying away from this specific substance, that it was well worth doing.

And that I wasn't the only one who could benefit, if someone was willing to go extreme.

To the best of my knowledge, nobody else from the original cohort has done much more than to just try moving from a particularly bad place.

-Erik (2008, CFSU)

The "Yuppie Flu" went through in 1985, just as described in Osler's Web.
Whatever it was, it sure did something and left a lot of ruined lives in its aftermath.

This effect is so weird that I can spend year after year telling people, but most can’t quite bring themselves to believe it until they actually come out and do the mold tour.

-Erik (2008, Locations)

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I only know what I saw:

That in certain specific biotoxin-laden Sick Building Syndrome environments, the "whatever" was capable of being very infectious by casual contact, with a savagely quick incubation period of 24-48 hours.

After that initial phase, the capacity for transmission seemed to just disappear.

I asked Dr. Cheney about this at the time. He confirmed that many viruses are no longer transmissible after the initial phase, but he dismissed the environmental component as probably being just a consequence of the flu-like illness.

-Erik (2009, CAA)

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When the "Tahoe Mystery Illness" raged through Incline Village, I was astonished to see the amazingly strong correlation between these bad places and those who went on to become chronically ill.

-Erik (2010, CFSKnowledge)

INCLINE VILLAGE PATIENTS

I have interviewed many other Incline Village CFS survivors and accompanied them to mold zones, and the specificity of the response to mycotoxins is a common denominator.

-Erik (2005, CFSExp)

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Whatever "went through" just slamdunked the hell out of people in a very strange and peculiar way.

It didn’t hit sick people in hospitals.
It didn't strike the weak and unmotivated.

Nope. It really seemed to hit those of us who were getting our butts kicked by mycotoxins from mold in a very strange and noticeably specific way.

-Erik (2006, Locations)

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From the very initiation of the CFS epidemic, this particular class of toxin just keeps popping up as the common denominator as a driving force in neurological CNS exacerbation of CFS symptoms.

Those of us in the Incline epidemic have different people testing positive for every damn weird thing in the book, and none of these have been the common denominator so far.

Some are Lyme, others Myco, most HHV6a, while CMV hits someone else.

But of all of the people I saw dropping like flies, there was one thing that truly kicked ass on everyone.

It was this darn "black mold." And there were no exceptions.

-Erik (2006, CFSExp)

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Remember the "Marathon Runner" that Dr. Peterson said "can't walk to the corner anymore"?

When I walked in front of her house, there was a consistent mold plume that knocked me flat - bad enough that I had to avoid that area.

Remember the "Tennis Pro" mentioned in Osler's Web?

I checked out his apartment at the racquet club. It was a grand slam.

Remember the "Champion Swimmer" who was in the Ampligen program?

After I educated Dr. Peterson about mold and he saw my recovery, he finally had her move out of her moldy house.

Remember the "Psychoneuroimmunology" experiment with Bill Collinge?
Another member of the original cohort who was there with me moved away and recovered somewhat - until he started working at a moldy casino and relapsed.

The "Crop Duster" pilot who blamed the OP pesticides he was spraying?

He fell apart whenever the wind blows from the moldy section of town and was calling the city council trying to find out what they know about this phenomenon.

This, of course, is in addition to the teachers and basketball team at Truckee who started the whole CFS deal.

I'm a graduate of Truckee HS and those were my teachers, and yes, that school was a slammer. Still is.

And then the small cluster at North Tahoe HS, which had a Stachy colony immediately adjacent to the teachers who became ill.

The size of the colony was about "the diameter of a baseball" and nobody believes them. They've been accused of living the life of luxury, taking advantage of the system by going on disability.

Remember Byron Hyde’s findings that ME seems to have a particular affinity towards clusters in institutional buildings?

Remember Dr. Erich Ryll's assertion that his "Infectious Venulitis" had the same "Sick Building" connection and that the phenomenon may be concurrent with SBS?

The connection of CFS to mycotoxins should be investigated.

-Erik (2006, CFSExp)

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My extreme sensitivity to Stachybotrys allowed me to perceive it on the clothing of the CFS patients in Incline Village.

-Erik (2006, CFSExp)

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All of us who survived the 1985 Incline Village CFS epidemic sure recognize the "20 vials of blood" scenario.

After bailed out of Dr. Peterson’s Ampligen program to pursue mycotoxin avoidance, I was sitting in Sierra Nevada Labs where he sends people for blood work ups (with those 20 vials) and getting mold slammed from their clothing as they walked by.
I started asking people who I perceived to be moldy if they were Dr. Peterson patients and I only got snookered once. Someone told me, "Not me, but my wife is." He was just there to drop off the large bag of vials.

One guy came in carrying his teenage daughter, who couldn't even stand up without help. As they walked by, I got the strongest hits of anyone so far. Their car was obviously contaminated since the girl started to recover somewhat as she sat in the waiting area. Yup - she was a CFSer!

After the 20 vials were filled and they were leaving, I stopped them outside in the parking lot and said, "I know this sounds crazy, but I have become hypersensitive to a specific mold which I can feel very strongly from your clothing. Will you allow me to do a test?" They agreed, looking amused and bewildered at my weirdness.

So I walked around them at a distance until I got downwind of them and felt slammed. Then I walked right in between them and got major slammed, and said, "Okay, that's good enough."

So I wrote down the name "Stachybotrys" and my phone number on a scrap of paper and handed it to them.

I said, "Please just do a computer search and compare your symptoms and tell me what you think. Avoidance of this particular mold has made the difference between lying helpless in bed and climbing mountains for me, and I can definitely feel it on your clothes."

I got no call, but my karma is good - I gave it a shot.

-Erik (2006, SickBuildings)

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My complaint from the first day of the CFS epidemic was that I have "an inexorably increasing reactivity to mold that grows progressively worse no matter where I live or how well I take care of myself."

This was the anomaly that doctors always considered to be the total consequence of the "Yuppie Flu" no matter how many times I explained that this preceded the infection that went through Incline Village.

Many people caught that strange flu-like illness at the same time, but not all went on to become chronically ill or eventually be called CFS cases.
I proposed that if not all people succumbed to perpetual illness, one might consider that a more primary cause of CFS might be whatever difference existed between those who recovered and those who did not.

A reactivity in the presence of specific mycotoxins was the commonality that I saw in the Truckee teacher cluster, the girls’ basketball team, and the teachers at North Tahoe High school - as well as many of the other original CFS cohort survivors who all manifested reactions when we encountered mold plumes.

Mycotoxin susceptibility appeared to be the common denominator.

The other members of the "Tahoe Mystery Illness" that I accompanied into mold zones appeared to be similarly affected.

As the "Yuppie Flu" epidemic progressed, I had the opportunity to accompany many of the other original CFS cohort members into moldy buildings and they all shared that same abnormal mold response, although they always blamed it on something else.

-Erik (2007, CFSResearch)

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Some days, I would drive down to the Carson City Stolport, a primitive airport, not knowing if I was going to feel well enough to fly when I got there.

But I knew from years of experience that when I got out to the desert I was much improved, and I would wait for this to happen. Sometimes it took a couple of hours.

One day in 1989, I saw a friend from Incline Village out raking the rocks off the strip and throwing up a cloud of dust with his efforts.

There is a tractor to do this yet he was doing it by hand. This didn't make sense to me, so I walked out to talk to him.

He seemed a little pensive and then he started to explain to me, "The doctors think I have Chronic Fatigue Syndrome."

Huh? Most of the people I know with CFS are fighting to be able to stand up, so how could this kind of activity be possible?

I almost started to say that he couldn't possibly have CFS if he was out here doing what he was doing, but then I thought, "Wait...I'm out here, doing what I'm doing... because there is something good about being out here in the desert that allows me to do what I'm doing."
And then he said the words which laid the whole thing bare. "I only feel good when I'm out here, so that's why I'm out here doing this."

Well, what do you know? Another one who is just like me.

-Erik (2008, CFSU)

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This was the interesting thing I saw in Incline Village.

The people who were the absolute worst were those who were living under conditions of high mold exposure.

-Erik (2010, CAA)

**MERCY HOSPITAL**

In 1975, the first reported epidemic of what later was called CFS occurred.

It involved health care workers at the Mercy San Juan Hospital in Carmichael, California. Most of those cases are still being treated by Dr. Erich Ryll of Sacramento, California.

I spoke with Dr. Ryll and he described symptoms to me that were perfectly consistent with mycotoxin reactivity, aka Sick Building Syndrome.

Funny thing about those moldy old hospitals!

-Erik (2005, CFSExp)

**CFS PATIENTS**

As my reactivity grew less, my sensitivity or ability to perceive grew more intense. And when I went to CFS groups to tell my story, I could feel "mold hits" consistently on almost everyone’s clothing.

They were virtually all complaining of the clues that led me to my conclusions, yet they would consistently discard my story and reject my proposal.

I even led people in and out of mold exposures and they would fall apart.

I would ask them, "What do you think that was?"
They would either say, "It's just me" or "Just a reaction to chemicals," even though the places I would take them had visible mold and little potential for containing chemicals.

Some even said, "You almost had me convinced because I could feel it for myself, but then I went to my doctor and he told me that this is impossible."

-Erik (2005, SickBuildings)

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It was wild talking to the Reno CFS support group at St. Mary's seven years ago and having them all deny that mold was a problem....

Even though they complained of exactly the same clues that led me to extreme avoidance and were reeking of so much mold that I had to step out of the room to get a breath of air.

-Erik (2005, CFSExp)

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I'm still looking to find a CFSer who isn't being affected by these toxins.

But because of the strange way in which the effect presents, very few people consciously implicate mold or do much in the way of proactively staying out of range.

I can take CFSers to various mold sources that were the very site of famous CFS clusters and people have a response consistent with the immune paralysis that appears to be of enough importance to make these sites stand out.

No matter whether this is the cause or result of the illness, these exposures are so devastating that proximity for a CFSer seems to be consistently deadly.

A bit of concerted effort at detecting and decontaminating from these toxic exposures appears to have benefits directly commensurate with the degree of avoidance.

If you're dealing with an illness of neurological deficit, doesn't it seem reasonable that addressing problems arising from a ubiquitous environmental neurotoxin might be of some slight benefit?

At the very least, the presence of toxigenic molds in association with CFS onsets is deserving of serious research.

-Erik (2006, CFSExp)

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I figured out what that "location badness" was, mostly because I tripped over it when there was nothing else around. No chemicals or anything, just mold.

Being a prototype for CFS, I thought that people might want to hear about this little oddity, especially since I recovered so much that I was out climbing mountains instead of lying in bed thinking about shooting myself.

I'm not saying that mold is the cause, just that this seems to be one hell of a clue, since so many seem to be affected even though they can't quite make the connection as to where this horrible feeling seems to come from. Mostly, by trying to tough it out, they stay in a situation where being tough doesn't much compensate for having your blood flow shut off.

So far, all the CFSers I know haven't done very well when they get around this type of mold, and when they complain that storms knock them out, I figure they are probably just like me.

Once they go with me to a mold zone and feel it for themselves, that pretty much narrows it down to a near certainty.

-Erik (2006, CFSExp)

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What I noticed at the beginning of the CFS epidemic was that sufferers were being dropped in their tracks by these types of mold exposures.

These exposures were occurring at a level so far below the ability of researchers to measure that they were going undetected and unappreciated.

Only a hypersensitive person who was aware that it was mold could detect these “bad zones.”

-Erik (2007, CFSExp)

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I sat outside that Hemispherx Ampligen infusion room, shaking with tremors from the mold hits I was getting from people’s clothing.

The Ampligen did help some people.

But I would ask these people drenched with mold about the vague clues of strangely getting better or worse at certain times and places.
I found that some were even so fortunate to have gotten clear momentarily and were wondering what had created this incredible good effect and how it might be possible to exploit it.

People just get sicker but I cannot tell them why - because until they are willing to try and get clear with full knowledge of what the goal is, they cannot believe that such an effect might really exist.

I think it is simply that, "The Eyes Cannot See What The Mind Cannot Conceive" and they just plain never heard of this before.

-Erik (2008, IAQ)

*I would venture that a study attempting to correlate CFS and moldy homes will produce results that would convince you that mold is merely a chance contributor.

If CFS and moldy homes had a strong correlation, people would have moved, noticed the difference, and the concept of moving as a therapy would probably be well known by now.

My words to Dr. Cheney at the beginning of the Incline epidemic were this: "I have an inexorably increasing reactivity to mold that grows progressively worse no matter where I live or how well I try to take care of myself."

I had moved many times, and there was just enough of a difference to let me know that that moving had a very slight effect.

But since that was the only effect that seemed to make any difference, I proposed to doctors that we attempt to find out exactly what it was and to try to extract the greatest possible benefit from this one seemingly slight trigger.

The type of avoidance I'm talking about is based on my military training in biowarfare protocols, as if I were passing through areas contaminated with nerve agent.

This has to be done on a moment to moment basis.

It is not something that most people would willingly undertake, but as I proposed to doctors, the very fact that someone who did give this a try got such good results is one hell of a clue.

-Erik (2008, CFSU)

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I couldn't sit on the wooden bench outside Dr. Peterson’s office. The chairs at Labquest, same thing.

So I would venture the concept that any doctor’s office that attracts CFS or mold patients has the potential to be contaminated beyond the tolerance level of a severe reactor.

-Erik (SevereReactor 2009)

**MOLD IN LAKE TAHOE**

No, I don’t believe that mold took over Incline Village.

I just want to find out what role the predisposing condition of mycotoxin susceptibility plays in this illness.

As far as I know, I was never exposed to more mold than anybody else and yet for some reason I have become unable to tolerate it.

-Erik (2003, CFSResearch)

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I have been given bad information by so many supposedly reputable sources that I have to rely on my own perception of this illness, and I have really watched it go from a negligible presence in my community to a nearly overwhelming one.

It's getting to be difficult to find someone who doesn't know someone with this illness - if they don’t have it themselves.

-Erik (2003, CFSExp)

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Incline Village mostly feels great if I stay out of moldy buildings.

-Erik (2004, Locations)

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I didn’t live in a tent while I was doing this mold avoidance craziness. I was right across the street from Dr. Peterson’s office.

It was just that I learned not to sleep in a moldy area and would decontaminate after exposures while traipsing around Incline Village.
There's a really ripping plume right down at the bottom of Village Blvd. that would knock me flat if I didn't decontaminate after passing through.

-Erik (2005, CFSExp)

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Remember the "marathon runner" mentioned during the Incline Village CFS epidemic? I lived three houses up from her. The killer spore plume is right down at the bottom of that very street, at the corner of Village and Lakeshore.

-Erik (2005, CFSResearch)

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Dr. Peterson often described a marathon runner who can hardly walk after the illness. That marathon runner lived four houses down the street from me. When I attempted to walk in that direction, after I had improved to the point in which I could walk, I would crash afterward. But if I walked the other direction, up toward the top of Incline, not only did I fail to crash, I gradually improved ever so slowly.

That marathon runner moved away from Incline and is said to have dramatically improved. This is seen as just a coincidence and a fluke, yet it was entirely consistent with the benefit that I gained by avoiding certain areas.

This was an effect that has made all the difference for me between a life of perpetual pain and having adventures that would never have been possible otherwise.

-Erik (2006, CFSExp)

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The mold was in various places, especially the sewer drains running down Village Boulevard in Incline Village.

-Erik (2007, Email)

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There is a wooden bench just outside Dr. Peterson’s office in the main hallway of the Washoe County courthouse building. It is where Peterson patients sometime sit.

It was so definite, just one small hit, but it was there in the middle of that bench.
The mold is mostly inside buildings, but does also occur outside in various places.

When the badness moved into Incline Village, half a block’s distance and a strategy of decontamination is what made the difference for me.

While I was growing up at Tahoe, a weird "effect" moved into town.

But I can't tell anyone about it. Telling has almost never worked.

Not because I can't say the words, which are clear and straight to the point.

It's because people’s minds refuse to believe my words, until I take them around Incline Village and show them where the effect is.

I've heard from many people who say that their illness can be traced back to a vacation to Lake Tahoe.

Yes, there is something environmental happening here.

There were these zones that did something by just momentarily passing through that would leave one wiped out and in distress for hours or days afterward.

I learned the hard way to stay the hell out of them.

This effect was so powerful that although the point sources of these zones were fairly localized and I could stay out of them, the cross contamination was so broad that the only way I could get clear enough to recover was by getting out to the woods or desert.

So that is what I did.
This strategy literally took me from being barely able to stand to climbing mountains.

-Erik (2010, WPI)

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>There is something else in Texas, worse than the regular badness. It blows up from the south and coats everything in a new level of toxicity. It puts an extra layer of toxicity on top of the mold toxins that are already there.

>Some of us started comparing notes and watching the weather. Whatever “it” is blows right on up into Oklahoma and Kansas when the winds are right. It also creeps into eastern parts of New Mexico, Colorado, and much of Louisiana.

This is what moved into the very heart of Incline Village back in 1984.

That's when the shit hit the fan.

Yes, there was a virus or something.

But there also was this.

And though we have some substantiating evidence that we can point to, this phenomenon has barely begun to get any attention.

So, the anecdotal evidence has far outstripped the official sources of information.

-Erik (2010, WPI)

TRUCKEE AND TAHOE HIGH SCHOOLS

The mold in Truckee High School also made me sick when I was a student there.

I was just back there a week ago to check it again and the place is still a slammer. I felt mold hits immediately.

One of my old teachers who was part of that cluster told me, "I could have killed the guy who put the sheet metal cover over the ventilation system. We could hardly breathe in there. It made our eyes burn."

A "baseball-sized colony" of Stachybotrys was also found immediately adjacent to a small teacher illness cluster at North Tahoe High school.
Of course, their fellow teachers accuse them of faking illness and malingering, just as with the Truckee teachers.

-Erik (2005, CFSExp)

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The "mysterious" actions of the workmen installing the weird air system at Truckee H.S. aren't so weird if you knew the problems with the school.

The south side of the school would get so hot that those rooms had to be abandoned in the summer. We had huge metal louvers outside to shield the windows and if the windows weren't bolted shut, someone would try to open them because the rooms would still get so hot that no one could stand it.

-Erik (2001, CFSResearch)

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I had been a student at Truckee, and the place had knocked me flat.

I knew from going to that school over and over that when it was stormy, it was godawful mold spore hell.

Approaching storms unleash vast spore clouds from these mold colonies and can increase the spore count from near zilch to a few gadzillion - in minutes.

-Erik (2006, CFSExp)

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I have to literally drag someone in and out of mold exposures, time after time, before it starts to sink in just how desperately this stuff must be avoided.

Truckee H.S., where CFS began, is still one of those places. You can go there and watch your veins go wild.

It doesn't feel like all that much. Certainly a strong-willed person could tough it out.

No, this response doesn't care.

If you're a Moldie, it will eat you alive, piece by piece, bit by bit, until you're nothing but a groveling pathetic miserable lump of flesh.

-Erik (2006, CFSExp)
How did they determine the size of the colony at Tahoe H.S.?

Visually, but they were only looking at one problematic satellite colony.

Finding one doesn't mean they've found them all, nor have they accounted for other sources of exposure.

-Erik (2006, CFSExp)

I sure wish I could take you to Truckee and North Tahoe High School.

Nobody who dropped there believes it is mold which is having this effect. It all seems impossible, improbable and contrary to science and common sense.

Even the Truckee teacher cluster disputes my craziness.

The teachers at NT are a bit more focused on this, because their illness corresponded to the exposure and leak in such a specific spot. But even they are baffled by the size of the colony immediately adjacent to their stations: "About the size of a baseball."

I never made any claims that mold could accomplish such a thing all by itself, only that when these people are re-exposed to unbelievably slight exposures to this same toxin, in the same place where they got sick - they drop in their tracks.

Just like me.

-Erik (2006, SickBuildings)

The tenth teacher from Truckee High School was growing so ill in that teachers’ lounge that he took his lunch out to Donner Lake and sat there in his truck.

He connected his progressive illness to that lounge and got out.

He was the one who recovered.

That was a clue that made me consider that mold was the mediating factor in whatever illness it was that passed through: the difference between those who got better and those who did not.
Those other nine who stayed under the influence of Stachybotrys in Truckee High School got worse.

It was only this one teacher who recognized that the burning eyes, coughing, inability to breathe, rashes, fatigue, headaches, and all the other crap that was happening in that mold-ridden teacher's lounge was having a deleterious effect on him.

And he bailed out.

He escaped CFS while those of us who stayed in moldy places while the "Yuppie Flu" was going through town did not.

-Erik (2006, SickBuildings)

>What happened to the other half of the girls' basketball team?

As far as I know, nothing happened to the rest of the team.

Just as nothing happened to the other nurse trainees, doctors and patients at Royal Free.

-Erik (2006, CFSExp)

Before anyone starts squawking at me about the girls' basketball team being at Incline instead of Truckee, that is part of the story. I figured that once I got my foot in the door, then I could explain.

-Erik (2007, CFSExp)

Truckee High School is not as bad as it was since they got rid of the moldy carpet which made the place such a slammer, but it's still pretty bad.

You know that "air hunger" people keep talking about? That's part of the mold tour.

When I dashed into Truckee to take pictures, I looked in the infamous teachers' lounge and saw a student struggling for breath.

If you understand what these toxins do and then combine that with a jaunt through the teachers' lounge, you can feel it all start to make sense.
Of the dozen or so teachers who regularly gathered in the makeshift faculty lounge at Truckee High, 11 developed symptoms of CFS.

No toxic chemicals were ever detected in the ventilation system or water pipes or anywhere else.

And they utterly failed to find anything beyond what might be considered "acceptable" amounts of mold.

When the same thing happened at North Tahoe High School some years later, there was still no satisfactory explanation. And then again at Elk Grove, still a mystery.

In fact, I've been watching the fail repeatedly for over two decades - and when they do, the incident is dismissed as some kind of fluke, and the survivors are dismissed and forgotten, although they remain ill.

Yet it keeps on happening, again and again.

People should be much more concerned than they are. You won't find a single survivor who ever dreamed that such a thing could happen to them.

-Truckee High School was never the worst building on the planet. Far from it.

But there was something about putting "The Yuppie Flu" and whatever is in buildings like that together that equalled more than the sum of its parts.

I've had CFSers go to Truckee High School, and they can feel that something is wrong.

Testing at the various CFS cluster buildings failed to find anything, so medical doctors ignored the fact that CFS patients continued to complain that they could still feel strange burning sensations and nausea in these locations despite the assertions of air quality experts that these areas had been pronounced safe.

Notice that I don't get much into toxin specifics, or really insist upon much of anything other than "the effect is there." And ever since the beginning of the CFS epidemic, researchers have used their own evidence of being unable to identify it as a reason to treat this effect as if it wasn't there.
This has made me extremely distrustful of testing, because all testing has done is prove that they don't know how to test for it.... whatever "it" is.

-Erik (2008, CFSU)

*

Just because the experts couldn't find it doesn't mean there was nothing to find.

Doesn't it seem noteworthy that a number of different retellings of this event make a special point of the peculiarity of that sole survivor who escaped the toxic sensation in that room and took refuge in his camper?

Why would this lone exception be worth mentioning?

It's almost is if people can vaguely sense that there might be a clue to be found somewhere in this anomaly, but they just can't quite make it out.

-Erik (2008, CFSResearch)

*

It was a burning sensation that was the important thing.

The whole school was musty, but something happens at certain times that makes things a thousand times worse: the "acridity" that causes that weird burning sensation and that unleashes itself over and above the mustiness at certain times.

I've found this same effect in many other buildings. The way it works seems very consistent and gives me an effective means of escape.

If I run for my camper at these specific times, I manage to avoid the major brunt of the phenomenon.

My old teacher, Mr. Kennedy, was exactly right about getting out of that room, except that he didn't do it!

-Erik Johnson (2008, IAQ)

*

At North Tahoe H.S., they found the black mold in the wall immediately adjacent to the two teachers who were the sickest. It was a colony of Stachybotrys, about six square inches, roughly the size of a baseball.

That's it. Just a dinky little mold colony.
But this wasn't found until after CFS was already off and running and nobody ever bothered to look back at this little clue… even though it was part of the circumstance that kicked off interest in clusters of CFS.

I've been collecting mold stories from CFSers ever since, and I've got quite a pile of them.

-Erik (2009, CAA)

*

I put off reading Osler's Web for a couple of years, because I had seen people misrepresent what happened and I thought, "Who is this Hillary Johnson? She wasn't even here."

But I was amazed to find out that her book bore out the facts in extraordinary detail. Enough that if you add mold into the equation, it begins to make sense.

Hillary didn't make many mistakes, but there is one small one on page 27.

If you read about the outdoorsman who had to get out of that teachers’ lounge to feel better, Hillary says that he drove all the way to “America’s largest alpine lake.”

Well, not quite. It was only Donner Lake, about a half mile to the west.

Driving all the way to Tahoe would have been a 25 mile round trip.

But why is Donner Lake important… instead of just getting out of the school?

It's because Donner Lake is upwind of Truckee High School.

Just getting out of the school and sitting in the parking lot wasn't good enough to get clear and damp down the immune response.

-Erik (2009, Facebook)

*

I would like to draw your attention to an abstract presented by Chester and Levine at the Albany CFS Conference.

Notice the inclusion of a somewhat peculiar thing to say.
"Nine out of the ten teachers who frequently used a single conference room in Truckee, California."

Viruses don't care if you are frequently in the same location. What should it matter?

Why even bother to mention that one teacher?

That one teacher noticed that the room was slamming the crap out of him, and he went out and sat in his camper, and it paid off.

He was using a direct intervention in response to the problem.

-Erik (2010, CFSKnowledge)

“THE CAUSE”

I never claimed I discovered the cause of CFS.

During the epidemic, I told Dr. Cheney and Dr. Peterson that I had a progressive and inexorably increasing reactivity to mold. I theorized that the reactivity was "infection induced."

When they told me that CFS was viral, I asked why a virus would care about mold and when they said that it wouldn't, I replied, "Then whatever's got me must be a bacteria because it seems to care a great deal about mold."

I have no idea what causes CFS and am not qualified to find out.

All I know is that when I was fighting for my life and had nothing else to try, mycotoxin avoidance worked....and that I have never met a CFSer yet who failed to complain about the very clues that led me to try this crazy scheme.

-Erik (2004, Locations)

*M*

Mold cannot explain all the abnormalities in CFS, which is why I have always taken special care to say so.

-Erik (2006, Locations)

*M*

I have never claimed anything more than what I have seen and limit myself to the observations I make and can show to others.
I don't use the words "causes CFS."

I only say that the mycotoxin connection is a verifiable part of the overall phenomenon, but that it's only visible to those who are willing to see and test the clues.

-Erik (2006, Locations)

*

Nowhere did I assert that mold is the sole cause of CFS symptoms.

I have I never even used that word "cause," for reasons of the instant rejection that using this word induces.

For decades, I have said that I simply observed that others who were in the original CFS cohort shared a similar response to certain molds but they were unaware that it was mold they were responding to.

-Erik (2007, CFSResearch)

*

People get so confused when I talk about my mold experience and still say that CFS is the exact illness that Dr. Peterson called the CDC for.

I never said mold causes CFS. Just that CFSers seem to be severely affected by mold.

All I was doing is taking advantage of this knowledge to reduce my pain as much as possible.

Since I'm one of Dr. Peterson's cohort that the strange Human B Cell Lymphotropic virus (later to be renamed HHV6 and then HHV6a) was found in, it'd be kind of silly for anyone to think I was saying that mold is the cause of everything.

What I said to Dr. Cheney and Dr. Peterson was that while they were figuring out what the "Yuppie Flu" thing was, I was going to exploit the benefit of avoiding the influence of that mysterious factor which blows in on the wind.

-Erik (2008, CFSU)

*

>Could EMF make us more vulnerable to Stachy?
Sounds like it could scarcely help but make one more vulnerable to Stachy. But the same could also be said for a million other things too, and is being said.

So this is good fodder for a discussion group that has the luxury to sit around and talk about such things. But for those who need to do something about their situation right now, they might want to put stuff like this on the back burner, or let the scientists handle it.

>But the scientists aren't handling it. Insofar as the hypothesis is CFS = mold + something, what might that something be? Chemical toxins, EMFs or what? What is it that potentiates Stachy and makes it become so very harmful?

Might be all of the above and even more. But as I say, I haven't been able to confirm any of it and am only acting on what I can observe and verify.

For all these years, I've seen that whenever I say, "Mold had this effect," it somehow gets translated into "Erik says that mold is the cause of CFS." The context is put in such a way as to mean normal mold, which wouldn't make any sense at all. So I have learned the hard way to be very circumspect in my answers.

It's like when Dr. Cheney identified the PFO "patent foramen ovale" (hole in the heart). People went leaping to the conclusion that Dr. Cheney had totally reversed everything he had said previously and was now claiming that this hole was the cause of CFS.

They were taking this one clue and extrapolating a conclusion that Dr. Cheney never made. All Dr. Cheney is doing is finding bits and pieces. Each one has been verifiable.

None of them add up to complete the puzzle, but all of them, because they fit the other pieces, are shown to be a part of that puzzle.

-Erik (2008, CFSU)

* 

People just hear what they want to hear, so they can think what they want to think.

I keep insisting that CFS happened exactly as described in Osler's Web, which means that we had a novel "HBLV" virus that Gallo-Salahuddin had just stumbled over in AIDS patients... and yet when I talk about "The Mold Connection to CFS," people twist it into, "Erik says mold is the cause of CFS."

Well, without the HBLV, the illness I think of as CFS wouldn't be what it is. So mold alone is clearly not what I am saying. And I use the word "mediated" instead of "caused" to describe the effects of mycotoxins on the cytokine cascade.
 Doesn't work. People just keep hearing, "Erik says mold - mold - mold is everything,"
 and there's just no way to stop 'em.

 - Erik (2008, CFSU)

 *

 What I said was "an effect from mold."

 People interpreted this as, "Erik says mold causes."

 And since mold is well known not to "cause," mold was ruled out and the clue was
 relegated to irrelevance.

 - Erik (2009, Locations)

 *

 From the inception of CFS, doctors have told me that mold doesn't matter, because this
 kind of reactivity is just the result of something else.

 So I said, "Fine. While you figure out what that something else is, I'm going to stay away
 from the mold."

 There's no doubt in my mind that this was a good choice.

 Who cares whether it is a result of P450 decoupling or anything else, if one can stay
 away from it and get a life back?

 - Erik (Email, 2010)

 IMMUNE RESPONSES

 AIDS patients know that when their CD4/CD8's fall below a certain ratio, their viral titers
 shoot up and secondary infections emerge. Sometimes treatment of these infections
 restores enough immune surveillance to restore the ratio and knock down the virus.

 So there may be many avenues for treatment that don't specifically address the
 fundamental dysfunction but have an apparent effect.

 I suspect that when CFSers try some crazy thing that has a wondrous effect, as
 mycotoxin avoidance has for me, it is just finding one of many ways to climb one rung
 up on the immunological ladder.

 I didn't say that mold was the cause.
I said that the vast commonality of this irritant is a clue to the etiology of the illness.

-Erik (2005, Locations)

*Sick Building Syndrome does not necessarily result in CFS, but it appears to be a potent cofactor in our little phenomenon.*

Toxicological data is lacking because it is predicated upon cell lysing from measurable amounts of applied toxins. Not applicable here.

This is a genetic reprogramming of immune response.

In SBS, you don't see specific "mold illness" where everyone falls apart in the same way. You see people inexplicably dropping from all kinds of things that have one thing in common... they all manifest an unexpected pathogenesis from infections that "shouldn't be doing this."

But if a powerful virus happens to go through town, it just might be possible that it hits some people a bit harder than others.

In certain specific places.

-Erik (2006, CFSExp)

*Since the beginning of the CFS epidemic at Truckee High school, I've seen people fall apart from transient "minor" infections in sick buildings. The infection that the doctors identify always gets the blame, even if it lacks the pathogenesis to create the level of illness that is observed.

Doctors see each case as individual, and tend to disregard the clue that a number of people fell apart in a specific location.

If they don't see an infective cause and the toxin doesn't keep creating the same effect, the relevance of the environmental exposure is regarded as incidental or inconsequential.

It is only when one understands that these toxins literally shut off immune response does it become clear that the apparent infective cause of these illnesses manifests its unexpected intensity as a result of an opportunity created by the combination of toxin induced immune paralysis and otherwise minor or benign organisms that may be passing through.
The mistake that virtually everyone made was thinking that this was just an individual problem.

They completely ignored the mold exposure and focused all their efforts on testing "what's wrong with YOU."

What they didn't stop to consider is that immune dysregulation from exposure to what is essentially nerve gas is not the abnormality.

It would be abnormal if one had no response at all.

Trichothecenes shut down immune response, so it's not a matter of a particular "mold" feeling as much as having a peculiar onset and persistence of various problems that got the better of you in a very unexpected fashion - and most likely in a particular place.

The term "CFS" can be traced directly to Dr. Cheney and Dr. Peterson noticing a peculiar onset of illness at Truckee High School.

I'm a graduate of Truckee H.S. and the place was a slammer. Still is.

It didn't "create" CFS, but the premises seemed to have a peculiar capacity to "enable" what happened there.

As Byron Hyde has noted, ME seems to have a peculiar association with such settings, as in:

Royal Free.
Mercy Hospital.
LA hospital.
North Tahoe High School.
Elk Grove.

-Erik (2006, CFSExp)
There's a well-known pox virus in AIDS called Molluscum Contagiosum. It's a child’s disease, easily controlled by a normal immune system.

The AIDS researchers know precisely what CD4-CD8 ratio allows the poxvirus to blaze into activity.

Virtually anything that boosts immune function just barely over the threshold that keeps Molluscum in check will drive it back into latency. It doesn't matter what it was that boosted the immune system - could be just about anything.

If one didn't know this mechanism, people trying to "cure" Molluscum Contagiosum would see success by many different "cures" and give credit to each one that worked indiscriminately.

In 1985, when I told Dr. Cheney about this weird effect, he said CFS was viral. I just replied that for some reason, mold had a specificity to it that made it worthy of investigation.

That specificity is the reactivation of latent infections of almost any sort.

-Erik (2007, Email)

HERPES FAMILY VIRUSES

> If 300+ students were out with “mono” at the same time, wouldn't that also sound like a sick building syndrome?

It would raise the suspicion that toxigenic mold may have been a factor in unleashing a peculiar cluster of noticeable mono in people who share a specific location.

I remember a restaurant that was being spore plumed enough to give me a very bad time in which all the employees who had herpes broke out in simultaneous flare-ups while the plume was especially active. Everybody remarked upon how strange the simultaneity was, but they couldn't feel the mold the way I could and were unaware of the connection.

-Erik (2006, CFSExp)

* 

Six years ago I was trying to engage the interest and cooperation of a CFS doctor in Reno to assist me in researching the mycotoxin connection to CFS.
As I related some of what I have seen with myself and other CFSers, he suddenly stood and asked if I would come with him to a certain room.

It was a mold slammer.

Turns out that everyone that spent too much time working in that room became ill. He had been forced to make it a storage area.

I talked about the many viral reactivations I’ve witnessed when people are hit with mold plumes, and one of his staff who had been listening suddenly chimed in that he had been gradually losing energy and stamina while he had been at this job - and had a work-up done which showed elevated EBV titers.

The doctors had been puzzled at this since he didn’t have an onset of mono, yet for some reason he appeared to be on the edge of a full-on reactivation.

This is what I saw in Incline as well. People in mold plumes would suddenly drop from one of any number of viruses - and the virus always got the attention while the mold exposure was discounted and disbelieved.

-Erik (2006, CFSExp)

**NEUROLOGICAL INFLAMMATION**

I discovered years ago that I have an extreme neurological reaction to unbelievably slight amounts of specific mold toxins.

Mold is prevalent and difficult to avoid.

After years of trying to avoid mold based on experts’ concepts of where mold is supposed to be, I realized that I was going about it in the wrong way.

My perception of exposure was the best indicator - not any tests.

I trained myself to recognized subtle symptoms of exposure by deliberately testing myself against various mold colonies.

I quickly found that a particular mold, Stachybotrys, had an absolutely devastating effect on me.

Soon, thanks to my ability to perceive it, I could feel that a vast number of people in CFS support groups carried either this mold or a lesser mold of higher toxin concentration on their clothing and were probably suffering a long term inflammatory response in the same way I was.
By avoiding this long-term inflammatory response, I have exerted more control over my CFS symptoms than anything else I've tried.

People always take this to mean that I am trying to assert that mold and the mycotoxins from mold spores are the cause of CFS.

Mold is not the cause!

The profound nature of the inflammatory response to this class of toxin is the cause of my symptoms.

I believe that identifying the mechanism that induced this abnormal response is the key to understanding this illness.

I have never claimed that other neurotoxic irritants like pyridostigmine bromide cannot have a similar effect. I am claiming that I feel mold on enough PWC's clothing to believe that constant neurological inflammation from prolonged exposure to mycotoxins produced by various molds is the driving force in many people symptoms.

-Erik (2003, CFSResearch)

Stachy is a potent and prevalent producer of neurotoxins.

Although there certainly are many other neurotoxins, Stachy has emerged as one of the most problematic.

Mycotoxin reactivity is an aspect of MCS.

Why do I focus on the role of Stachy in the "Feel Good Places" effect? It's because the neurotoxins from Stachy are contained in spores which can be carried with you long after you leave a contaminated area and be a driving force in neurotoxin mediated illness.

These spores seem to be one of the most difficult MCS triggers to avoid.

Not just in specific buildings, but "ambient levels of mycotoxins" based on the prevalence of spore plumes in a region.

That's the basis for my extreme mycotoxin avoidance strategy.

It's not a cure, but it beats the heck out of the alternative.

-Erik (2004, Locations)
INFECTION INDUCED REACTION

I would like to make it perfectly clear that Stachybotrys chartarum is not the cause of CFS.

If you have the immune defects that predispose for CFS symptoms, Stachy and other toxic molds will knock you flat.

This illness induces an hyperreactive response to levels of irritants that are considered ambient and safe for anybody else.

-Erik (2001, CFSResearch)

*I

I never believed that mold caused my illness and told Dr. Cheney and Dr. Peterson this the very first time I walked in their door during the epidemic.

I described it as "an infection induced reaction to mold."

I realize full well that despite mold avoidance, I still have the illness.

But just as being around mold makes you feel worse, being away from ambient levels of mold makes you feel better.

This is the source of the "feel good places" effect.

-Erik (2004, Locations)

* I'd like to point out that the gene expression paper noted this little peculiarity:

> The vulnerability of EIF4G1 to virus modification may have particular importance for the development of CFS after an acute virus infection 40.

"An induced reactivity to mold" was the first thing I said at the beginning of the CFS epidemic after that "flu-like illness" whipped through town.

It now appears that viral encoding of gene expression may be capable of achieving this type of effect.

And if you believe that the Ciguatoxin antigen epitope test is detecting similar ionophore toxins of the neurotoxin class, then an abnormal response to OP pesticides, mycotoxins
and Lyme neurotoxins are all grouped under the same susceptibility consistent with this dysregulated gene.

I wouldn’t be too surprised to include thimerosal susceptibility and Autism in this group.

This is why I keep saying that this is an illness of "induced susceptibility" rather than an overdose of stress and stressors, and asking people not to blame the car that was on the bridge when the bridge collapsed.

-Erik (2005, CFSExp)

* 

A variety of new conditions are linked not by mold, but by the commonality of an almost unprecedented and mostly unknown reaction to levels of neurotoxins that are considered benign exposures.

It is the lowered threshold of susceptibility to a response to neurotoxins that links these groups. And all within a suspiciously short time!

It's kind of a strange concept to identify the spread of an unknown quantity not by specific infections, but by looking for reactions of all varieties that are out of the normal range of human response and that are connected by proximity and timing.

But that is the effect that I am seeing.

-Erik (2005, CFSResearch)

* 

As I said to Dr. Cheney at the beginning of the CFS epidemic, this seems to be "an infection induced reactivity to mold."

It appears that the susceptibility is innate, waiting to be unveiled by some opportunistic cytokine cascade.

As a dental lab tech, I got to watch the dentists’ response when oral problems did a sudden paradigm shift.

They saw the metal toxicity, hypoperfusion and increased risk of endodontic failure. Some even saw the cavitations, although most went into a strange denial and said that this was an unprecedented fluke which they would likely never see again.

Even after seeing multiple cavitations, it’s as if their brains switched off. They would refuse to admit that this was something new in their experience that was increasing dramatically.
They blamed patients for bad diet, alcoholism, or drug abuse, no matter whether these factors were present. In a child, it would be "genetics" or too much junk food. Sufferers could protest that their diet and behavior patterns was no worse than others who were not suffering similar problems and the knee-jerk response is, "If you have these problems, then you must have!"

-Erik (2006, CFSExp)

* 

Dr. Shoemaker talks about the unveiling of mold susceptibility by Lyme and other triggers.

Once you are primed for a response, even if you clear the infection, the continued presence of mold/mycotoxins is a driving force in your continued inflammatory response.

-Erik (2007, CFSExp)

**MULTIPLE ASSAULTS**

> The human body usually works very well handling one problem at a time; sometimes it even handles two problems or assaults at a time. When it is broadsided with several assaults, it often fails.

> Looking for clustered assaults will likely be the way to go. Mold and cleaning products, after a flu or pneumonia, has been a serious problem in my experience.

Precisely.

This was the very question that medical professionals failed to ask at the inception of Chronic Fatigue Syndrome.

-Erik (2008, IAQ)

**RELATED ILLNESSES**

I don't believe that mycotoxin reactivity addresses a more restrictive patient population. I believe it may represent an inclusive precursor condition that is a much larger problem than anybody recognizes.

Mold reactivity is not obvious and many mold sufferers have literally been carried out of their house on stretchers without figuring out the connection.
I have argued against subsets and advocated a more inclusive definition and approach to the study of CFS, especially because a susceptibility to mycotoxins is a common denominator I see in the vast majority of people who are diagnosed with different definitions or names that attempt to define this concurrent set of abnormal complaints that so many are now screaming about.

No matter how many times I repeat that mold is not the cause but that mold reactivity is the result, people still say, "So you're claiming that mold causes your illness.”

No, it's a trigger for the symptoms - not the underlying pathological process that initiates the abnormal response.

I've seen people wearing respirators into a contaminated shopping center, though why they would continue to shop there after discerning the connection to their illness is a mystery to me.

I see this so routinely that I would be surprised at this point to find anyone diagnosed with CFS who is NOT reactive to mycotoxins.

What does this mean?

It means that when no doctor can prescribe any therapy or means of reducing your symptoms, there may still be a way to control a significant amount of neurological inflammation and symptoms by a concerted effort at reducing mold exposure.

-Erik (2003, CFSResearch)

*

A couple of years ago, a now defunct list "AutisMoldFungalResearch" explored the link between mold and autism.

Parents and they described the symptoms of mold reactivity in their Autistic children perfectly.

However, when I told them the importance of avoidance, they would contact their doctors and be told that this was "Impossible" or that the level of avoidance that I say is necessary to obtain good results is beyond the constraints of a normal life and is unreasonable to attempt.

I agree, but I wasn't given a choice.

-Erik (2004, SickBuildings)

*
Have you seen what is happening with "Mold Hysteria"?

The doctors are fighting with Moldies just as they did CFSers and telling them that this type of reactivity is impossible and has no physiological basis. Sound familiar?

I don't see CFS, SBS, GWI, MCS as being heterogenous.

They are all linked by the common denominator of an unfamiliar and totally disbelieved reactivity to what is considered to be harmless levels of neurotoxins.

- Erik (2005, CFSResearch)

Thanksgiving is kind of an important day for me moldwise.

Every year, I went to a relative’s house for Thanksgiving and would fall apart.

Every year, I was more determined to psychologically tough it out and not let the damned place get to me. Yet every year, it got worse.

Naturally, all my symptoms appeared to others as purely psychological.

Finally the lady of the house was diagnosed with CFS, although her complaints were the palest shadow of the real-deal postviral syndrome.

Then her husband started having serious cardiological problems.

I refused to set foot in that house again.

One beautiful summer day, he decided he felt good enough to do some chores he’d been putting off - like fixing that leaky pipe under the house that had mold growing around it.

So he got out his tools and crawled under the house.

No sooner did he come face to face with the water leak when all motivation disappeared and exhaustion overtook him.

He crawled back out from the house, went into the living room to sit down and rest for a spell, and just stopped breathing.

Years later, the lady of the house was out vacationing and reveling in her amazing energy that was somehow completely lacking when she was at home. When I remarked
upon how consistently this wonderful feeling she had corresponded to being away from the house, she said, "I wish I could stay on vacation all the time and never go home."

So we discussed the specific timing of her husband’s death and although the doctors don't believe a word of it, there is certainly no doubt in her mind what truly caused his heart to stop.

She has since decided to take that permanent vacation from her house and has never returned. She's gone from being semi-disabled with fatigue to a world traveler and is having a great time.

Curious that Dr. Cheney's work has centered upon cardiological anomalies, because heart palpitations have always been a consistent feature of mycotoxin exposure for me.

My own heart would go wild with palpitations when I was in that house.

Glad I decided to go the path I did.

I have a lot to be thankful for on Thanksgiving.

- Erik (2006, Locations)

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While out mountain biking the Downieville Downhill, an awesome single track near the Sierra Buttes that is well worth doing, I met a girl who described an unusual experience with her health.

She said that she felt really ill during the normal course of her job and home activities, and was much improved by getting out and about.

(Who ever heard of such a thing?)

She said that she took a long vacation and felt energized and healthy during her entire furlough but that as soon as she got home, she started to fall apart again.

This was prior to Melinda Ballard's USA Today front page headlines, which was really the turning point when total rejection of the mold concept started to become, "I think I heard of that somewhere."

She listened to my story, and I could see it really made her think. I warned her of the dangers of do-it-yourself remediation, but this is something that just never seems to make an impression on people until it is too late.

I met her again months later at Spooner Lake, the starting point for the famous Flume Trail, a single track carved right into the mountains on the east side of Lake Tahoe.
While we rode, she told me the follow-up to her peculiar illness story.

She made the correlation of feeling the most crappy while in her house and started to snoop around. She found that her basement smelled the moldiest and pulled up a corner of the carpet that covered the cement floor.

To her horror, it was covered with black mold. Certain now that my story wasn't as farfetched as people think, she immediately pulled up all the carpet and threw it outside.

The exertion seemed to have been more than expected, for she passed out with fatigue afterward. The next morning, she could hardly get up, but dragged herself to the bathroom and looked in the mirror.

And that was the last thing she remembers before waking up in the late afternoon on the floor. She was dizzy and nauseous, couldn't see clearly, and realized that she couldn't move and was almost completely paralyzed. She just lay there for hours unable to raise herself or do anything but wonder what had happened.

I can't remember if she said that someone found her or if she was finally able to crawl to a phone, but she wound up in the hospital and was told she had suffered a stroke.

I asked if she had informed her doctors about her illness, the mold, and the coincidence of pulling up the carpet. She said that she had, but that the doctors didn't think anything of it.

She has never totally recovered. This is a 38-year-old who was healthy enough to do a thirty mile bike ride.

This is how it goes. Nosebleeds, fainting, asthma and anxiety attacks, strokes and heart attacks - all after a mold exposure, and every one of them is just a fluke in the minds of doctors.

-Erik (2006, SickBuildings)

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When I was my helping my friend from Carson City move from his mold zone down to Texas, I made another believer out of his friend who was helping with the move.

We checked into one hotel. I lasted about an hour and went out to sleep in the moving van.

They thought I was overreacting until the next day when neither of them could wake up or move from being so achy and had blinding headaches.
Meanwhile, I was doing great. The fact that both of them felt identically bad, balanced against what I described and the way I had told them why I had to get out of there, all added up to "Hey, I think Erik isn't wrong about this."

The mold there felt pretty much like mold in Reno and Carson City.

-Erik (2008, CFSU)

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If there was a central database where Moldies from all over could input their sense of an area's increase in ambient badness, I am firmly convinced that these areas would have a correlation to more incidents of domestic violence and extra traffic accidents.

-Erik (2008, CFSU)
Chapter 3 - A New Mold Dynamic

AN “EFFECT”

Recirculating ionophore toxins need not actually infiltrate the cell in order to induce a self perpetuating genetic chain reaction.

The ability of the primed immune system to sense the toxin triggers a programmed response that, once initiated, takes on a life of its own, independent of dose. And yes, it appears this applies to certain genotypes, so the comparison to others around you as a baseline for illness is very misleading. Darn it. Wish I weren't one of them.

No doubt such susceptibilities apply to other bioaerosols as well. All that remains is to discover them, I suppose.

The clues lie in the explosion of mold stories in which the circumstances of illness seem to belie the customary outcome of water damaged buildings in the past. Something is going very wrong when people fall ill in droves from mold exposure that nobody expects would have the potential to create such a degree of suffering.

-Erik (2007, IAQ)

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Now, when I say, "Mold..." I guess that what I'm really referring to is an "effect that occurs in conjunction with mold."

Mold, as in "same old mold," is obviously not addressing what is going on. So if a person who is thinking "effect in conjunction with mold" collides with "same old mold," there is bound to be a paradigm clash.

In a clash of paradigms, it is inevitable to have a fierce debate between the laymen who interface with the phenomenon and the "experts" who have yet to be confronted with the paradigm shift.

Maybe we need to call it something like "The Mold Dynamic" so people won't think we are just talking about normal and customary effects of mold, and are including some unknown extenuating factor.

-Erik (2008, CFSU)

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Remember how I keep strangely saying that we shouldn't focus on studying mold toxins?

There is one thing we know about mold, even without detailed knowledge of these toxins. We know that people who were in high levels of these molds did not acquire a reactivity to them, such as we describe.

Dr. Eckardt Johanning's office told me, "I have seen Stachy dripping from the ceiling into babies' cribs without causing this."

In Dr. Croft's 1986 paper on the effects he was witnessing from trichothecenes, he made a fantastic observation. The effect was so completely out of proportion to the capabilities encompassed by classical toxicology that the result surpassed the expectation.

So it cannot be mold per se that is doing this, and that includes all the mold toxins that have been extensively studied and are in the literature.

The answer will not be found there. The mold is doing something extraordinary.

All concepts based on normal expectations of a mold toxin are off the table, and what is required to understand and grapple with this phenomenon is a new dynamic.

We must look at what the mold is doing now, that it wasn't capable of doing years ago, to uncover the source of what changed.

It might have been a huge mistake for doctors to think that an old mold can't learn new tricks.

-Erik (2008, CFSU)

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What we do know is that the studies on these toxins per se do not appear to explain the scope of the observed phenomenon.

That would make it highly counterproductive to view any of them as causative.

They seem to be more of an especially critical component of a process that occurs under certain conditions.

What we seem to be dealing with is an abnormal response to an external toxin "trigger."

The "New Dynamic" appears to be the weird way our bodies are responding to that trigger, for reasons that have yet to be totally understood.
Seems to me that doctors should be calling up the CDC/NIH and asking why so many people are complaining about mold in a way that nobody seems to remember ever seeing before.

- Erik (IAQ, 2008)

Back during the Incline epidemic, Dr. Cheney laid out his concepts that this illness was a "New Dynamic," something that totally defied conventional wisdom.

So whenever a concept appeared conventional to me, I would waste no further time, as that would be looking under the streetlight.

I only looked for unconventional explanations.

Not quite by accident, because I was looking to stumble... I tripped right over one.

- Erik (2009, WPI)

Studies show that satratoxins are indeed toxic but are at such a low concentration that no one should be made ill, regardless of how many people point directly at the problem and say, "There it is!"

This has been the same argument that has been raging since Stachybotrys was connected with the burgeoning epidemic of sick buildings in the early 1980s.

Vast numbers of people are becoming ill and are capable of leading a researcher to the point of impact.

Yet in all these years, researchers only find a "lack of evidence."

Meaning they are confused that they cannot find something that meets THEIR definition of profound toxicity.

This is undoubtedly because they do not understand the mRNA modulating effects of ionophores which interfere with cellular messaging - a genetic signaling dysfunction.

Until they redefine their notions of "toxicity," people will just have to continue dropping dead from "harmless" substances.
Years ago, I saw mold doing something absolutely wild.

Nobody believed me. Every time I insisted that this was important, they disbelieved by saying they already knew it was important and should be paid attention to.

But then they didn’t.

It was weird. Like agreeing that the house is on fire, but not calling the fire department. Or saying they understood the ship is sinking, but not heading for a lifeboat.

From my point of view, when the mold strikes, air purifiers are like using a fire extinguisher on a blazing gasoline tanker, or using a mop to deal with a sinking ship.

When it does its thing, it just isn't that simple and easy.

Mold must be addressed, but it is impossible to avoid.

People have some very difficult choices ahead of them, because air filters and trying to clean it up are of extremely limited effectiveness.

- Erik (2010, CAA)

Strontium sulfide appears to be complicit in the Chinese Drywall phenomenon.

Yet this alone is not enough.

To achieve its pathogenesis, it would require a special oxidative "effect" that we do not yet understand.

That is... "The Effect" in the zones that I'm talking about.

As Dr. Cheney suggests, it looks like that effect may very well be from Reactive Oxygen Species.

- Erik (2010, CAA)
Ascribing the “effect” to specific causes, like mold, cosmic rays, EMF’s or anything else, usually causes an instant rejection of the entire investigation, because, "It is well-known that mold, cosmic rays, EMF’s or anything else cannot do that.”

Proposing any specific cause gives the excuse for instant and easy rejection.

Referring to the phenomenon as a “new dynamic" or an "effect" removes that capability.

(That "new dynamic" is something I learned from Dr. Cheney, and his Reactive Oxygen Species concepts seem closest to fitting the facts for "the effect.")

-Erik (2010, CAA)

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>Cheney Research Newsletter #9

>Low birth weight, diastolic heart failure and CFS – Is there a connection?

>Two published studies show that diastolic heart failure (DHF) in the elderly and low birth weights at term in infants have occurred during the same time frame from 1990-2000. No one has an explanation for these anomalies at the ends of the age spectrum in humans but suspect an environmental factor or factors.

"Suspect an environmental factor or factors"... as in "an effect"?

Something screwy that is happening in certain places?

Places like... Incline Village?

-Erik (2010, CAA)

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Trichothecene mycotoxins are ubiquitous molecules.

I'm looking at how environmental biotoxins have changed their characteristics in the last couple of decades.

-Erik (2010, CAA)

**SPREADING**

Da Vinci Drawings Affected by Mold
By COLLEEN BARRY (Associated Press Writer)

December 21, 2007

MILAN, Italy - Leonardo da Vinci's Codex Atlanticus, the largest collection of drawings and writings by the Renaissance master, has been infiltrated by mold, officials said Friday.

The extent of any damage is not yet known to the roughly 1,120-page Codex containing his drawings and writings from 1478-1519 on topics ranging from flying machines to weapons, mathematics to botany.

But officials say any conservation measures will be very expensive and there are no funds for the work.

"The mold is not spreading," said Monsignor Marco Navoni, a historian at the Biblioteca Ambrosiana where the documents are housed. "We need to find sponsors to come forward to help pay for analysis to establish the necessary therapy, and then do the treatment."

The Codex is kept in a vault at the Biblioteca Ambrosiana, where temperature and humidity are constantly monitored.

Mold was first identified in April 2006 by an American scholar, and confirmed by the conservation experts from the Florence-based state conservation institute, Opificio delle Pietre Dure.

In a temperature and humidity controlled room!

If the Codex didn't used to be moldy, but now it is, what is their definition of "not spreading"?

If the Codex survived 500 years under more primitive storage conditions, yet is now suffering mold growth even under the most stringent environmental controls, did something change?

Everywhere we look it appears that molds of many different species are all acting in an unaccustomed and "unnatural" fashion.

-Erik (2007, IAQ)

POTENT STRAINS
Funny how people have been worried about the creation of antibiotic resistant strains of bacteria, and they completely forgot that mold reacts to antimicrobials by also developing mutant strains.

Oops!

-Erik (2007, Email)

*

Even that which selectively kills superbugs today has also consistently created the superior superbugs of tomorrow.

-Erik (2009, IAQ)

*

I realize that people are used to thinking that mold is a fixed value, and that it cannot possibly come home on clothing and hair and be a major problem.

But times have changed.

Nobody questions when bacteria develop resistance and become superbugs.

Is the assumption that mold cannot do likewise a reasonable assessment of microbial characteristics?

Or is it merely wishful thinking?

-Erik (2010, CAA)

CHEMICAL POTENTIATION

Molds utilize the principles of biological conservation of energy to metabolize complex molecules available from chemicals into potentiated "supertoxins."

Mycotoxins and chemicals are the same - only more so!

-Erik (2004, SickBuildings)

*

The level of recovery I've experienced by extreme mycotoxin avoidance is based upon the premise that my illness shares components of the mechanism responsible for Sudden Infant Death Syndrome.
I was surprised to hear that the psychotheorists’ attribution of Cot Death to parental "Munchausen by Proxy" syndrome has only recently been overwhelmed, since strong exclusionary evidence has been known for years.

The Richardson Hypothesis and Dr. Sprott’s compelling demonstration of the reduction of SIDS prevalence by the BabeSafe impermeable membrane to isolate infants from the potentiated mycotoxins produced by molds in mattresses containing flame retardants has done far more than cast the psychological causality theories of SIDS into doubt.

I'm presuming that the infants are not subject to the placebo effect and that their workplace stress may be considered minimal, though I'm sure that is open to debate.

The Richardson Hypothesis and Dr. Sprott’s measures may not provide the entire answer to SIDS, but the results have been sufficiently positive that general practitioners’ ignorance of this effect almost certainly constitutes medical malfeasance.

My experience is that a major portion of the driving force in my CFS is the influence of specific mycotoxins as an inflammatory trigger combined with a demyelinating neuropathological illness, a combination of the effects described on these two websites.

I set out to act in accordance with a concept that appeared to me as having a logical basis and demonstrated the results. My experience indicates that my case of CFS may be a variant of the mechanism responsible for SIDS.

-Erik Johnson (2004, BMJ)

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How did Black get to be White?

That is an extremely good question that needs an answer.

Did you know that a rattlesnake’s poison has variable toxicity according to geographic location, based on what the snake has to eat?

Molds are talented manipulators of complex molecules.

Just like snakes, give them the best food and they produce the most potent poisons.

We have supplied mold with some really terrific ingredients: pesticides and fire retardants.

These formerly benign molds are now churning out clouds of poison gas, mycotoxins, as suggested by the Richardson Hypothesis.
And just like nerve agent, you can't smell it, taste it or detect it. You only know it by what it does after it's done it.

Neurological damage.

Dr. Sprott figured the connection between Sudden Infant Death Syndrome and the potentiated mycotoxins from benign molds in mattresses and handed out free impermeable membranes (the BabeSafe system) to poor families as a means to preventing SIDS.

The results speak for themselves.

Now one might think that the medical community would see the spectacular results, rush to confirm the validity of his treatment and save hundreds of thousands of infants.

But, no. The doctors, researchers, scientists and the entire medical community did the same thing they did to Barry Marshall and the H Pylori/ulcer connection.

They basically said, "Where are your peer reviewed references? If you can't cite the literature backing up your claim, then no matter how many babies didn't die on your system, you still have no proof."

Isn't that amazing? They discount the living proof of non-dead babies because they didn't know about it already. So what is happening is long term neurological damage from specific mycotoxins rather than an allergy.

And unless you get to the point of identifying mold and bringing in a sample to throw in the doctor’s face, all he sees is idiopathic neurological damage with no apparent cause.

Mold still looks like mold, but what we are feeding it has turned it into a killer.

-Erik (2005, Locations)

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I grew up in an old hotel that had green wallpaper that was old enough to be a trimethylarsine Gosio's gas producer.

But my experience of getting slammed in a thermal while hang gliding over an area that had been firebombed by air tankers led me to suspect that the mold toxins had been potentiated by the fire retardant, since outdoor mold doesn't normally feel toxic to me.

So without the garlic odor of arsine gas, I suspect that it may be other chemicals like PBDE’s or organophosphates that are potentiating the mold toxins.
I had the same problem with the killer compost farm located right next to the air tanker base south of Carson City.

-Erik (2006, SickBuildings)

I put my story on the BMJ website and described the mycotoxin connection between SIDS and CFS as being mediated by potentiated toxins from common molds - and got not one single response.

I put this story in front of the SIDS parents who have spent years fighting their conviction of murder and Munchausen’s Syndrome by Proxy. They still fail to see that viewing the SIDS phenomenon from the perspective of the Richardson Hypothesis provides astonishing answers to unexplained phenomena such as SBS and CFS.

What does it take to get through to people if words will not suffice?

-Erik (2006, SickBuildings)

>At least 1,000 people suffer horrific burns from toxic leather sofas
>http://www.dailymail.co.uk/news/article-....ther-sofas.html

>The agent sprayed on the leather was...

>Dimethyl fumarate is used to treat psoriasis. It is a lipophilic, highly mobile molecule in human tissue. However, as an unsaturated ester, dimethyl fumarate reacts rapidly with the detoxifying agent glutathione by Michael addition. When administered orally, it does not survive long enough to be absorbed into blood.

Isn't that crazy? It’s a potent allergen but is especially chemically reactive by that "Michael addition" reaction to glutathione.

Kind of makes you wonder, doesn’t it?

-Erik (2008, CFSU)

Years ago, I saw the story of a couple of workers that were tearing up a moldy old wooden floor and hit a patch that just dropped them both.

Both had severe reactions that looked like burns. The one closest was more seriously burned with lesions all over his body.
The IAQ people had no explanation for this. I proposed that the mold may have been feeding on an adhesive which somehow combined to make a potent toxin that induced a Stevens-Johnsons Syndrome reaction.

Nobody commented and the incident went down as just another unexplained fluke: Soon forgotten and relegated to the dust pile of relevant, but not considered, clues about what mold might be doing.

-Erik (2008, CFSU)

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Years before I ever heard of Dr. Sprott and the Richardson Hypothesis, I told people that the mold lying on horizontal surfaces that was destroying my life must be the same mechanism for SIDS. A major portion of my avoidance strategy is based on understanding this effect.

Understanding this mechanism of spore accumulation and production of complex neurotoxins on horizontal surfaces means my very life.

This effect isn't limited to mattresses though, as you may recall in my story about Sick Thermal Syndrome in which I describe flying my hang glider through a thermal containing potentiated spores from an area that had been deforested by a fire that was fought with polybrominated fire retardants from aerial bombing.

I have never encountered strong mold spores in a natural setting unless that area had been treated with pesticides or fire retardant.

-Erik (2008, CFSU)

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The extraordinarily toxic combination of carpet cleaning chemicals and toxin-forming molds growing on carpet backing make Kelly Preston-Travolta's suspicions of these as triggers for her son's illness are a matter of great concern and consternation for all of us who have observed reactions to these specific irritants, yet repeatedly had our experiences dismissed as unprovable and anecdotal.

Any sensitized person who has had a violent reaction to specific areas of carpet after they have been cleaned is going to believe that there must surely be more going on in that specific setting than scientists suspect.

Science was intended to be a methodical means to interpret observations, not as an excuse to deny them.
Especially when the observation is independently reproduced so many times by people who were unaware of any particularly toxic reaction to carpet until after they had good reason to begin investigating it.

-Erik (2008, IAQ)

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Did you catch the story about the "Killer Wallpaper" and Gosio's gas that we were just discussing?

The wallpaper, despite its arsenic pigments, did not make anyone ill.

Brevicaulis Scopulariopsis was a common mold. It didn't make anybody ill either.

So why was it that so many people pointed at moldy wallpaper and said, "This stuff is killing me..." and it took so many years to find out?

Doctors and researchers used the harmlessness of both wallpaper and mold to deny that such a thing was possible.

It wasn't until Gosio put the two together, and explained, it's neither and it's both... it is what the mold is spewing out, when it grows on these arsenical pigments: trimethylarsine fumes, "Gosio's gas."

The entire time that I was talking about mold, I knew very well that mold had no history of doing what I was complaining of.

So if you look back over all my years of comments, at numerous points I take pains to say that I am not claiming that mold per se has the effect I am talking about.

When I told my commanding officer about this back in 1976, I wondered if the Nazis had left behind pesticides or delousing powder in old drums in deep storage under the Armory, and if perhaps mold and decaying old drums had finally met up with each other.

Considering how many people became ill, he listened to me.

But the effect seemed to abate considerably after the moldy boxes were cleared out of the Armory.

So I've always been saying, "This is an effect from mold..." just like Gosio's gas.

Perhaps common mold is now getting hold of something that was recently introduced into the environment, such as pesticides or flame retardant.

-Erik (2009, SevereReactor)
The comment in this post that outdoor mold doesn't usually feel toxic to Erik is rather perplexing.

By "outdoor" what I really meant was natural mold that is in pristine areas unlikely to have been contaminated with chemicals.

-Erik (2009, SevereReactor)

At the very top of the list is my prime suspect for the ubiquitous molecule being potentiated by mold into neural supertoxins: acetylcholine inhibitors which disrupt neurotransmitter function:

Brominated flame retardants (such as penta brominated diphenyl ether) used to treat fabrics. These have been found in breast milk and are suspected of interfering with hormone systems

-Erik (2010, WPI)

A Possible Explanation for SIDS: Could chemicals in mattresses combined with fungus cause crib death?

by Holland Franklin

Since WW II about 1 million infant deaths have been attributed to SIDS. SIDS deaths were quite rare before that time. It occurs almost exclusively in Europe, Australia/New Zealand and the United States. The United States alone continues to have over 3,000 SIDS deaths each year.

Many ideas have been proposed to explain SIDS, but none has been comprehensive or convincing until the theory presented by Barry Richardson, a British expert in materials degradation. His theory was validated by the research of Dr. T. James Sprott, a New Zealand chemist and forensic scientist.

Their research demonstrates that SIDS is the result of accidental poisoning due to toxic gases released from baby mattresses. These gases are produced by the interaction of common household fungi with phosphorus, arsenic and antimony, chemicals which are either present naturally in the mattresses or which have been added as flame retardant chemicals.
The fungi are harmless by themselves but feed on these chemicals. The byproducts are the gases phosphine (PH3), arsine (AsH3) and stibine (SbH3). These nearly odorless gases breathed even in small quantities for an extended time can interrupt the choline/ acetylcholine transfer of nervous impulses from the brain to the heart and lungs. This shuts down the central nervous system; heart function and breathing stop. The gases are heavier than air, and about 1,000 times more poisonous than carbon monoxide. A baby sleeping on its stomach is in the zone above the mattress where the gases are most dense. Repeated exposure to these gases, especially in combination with other insults to a baby’s immune systems, can result in toxic overload and death.

**BIOWEAPONS**

While it's good that people are starting to notice the relationship between CFS and Mycoplasma, they still miss my point that it doesn't just make mycotoxin exposure more severe. It causes a direct sensitivity to specific toxins.

I'm tired of being told that all toxic exposures are equal and that mycotoxin reactivity doesn't deserve to be singled out for investigation. The fact that damn near everybody I talk to is aware of their sensitivity to a change in the weather indicates to me that they are mycotoxin reactive.

My sensitivity crept up on me just like everybody else. I just kept getting more and more sensitive to Stachy no matter where I lived or how I tried to avoid it.

My sensitivity corresponds to the extent of the infection and not to my exposure.

Biowarfare researchers would have been looking for the most potent pathogens to attenuate for their evil purposes. They would have, in the late 1940s and 1950s, been aware of the Russian experience with Stachy.

If it is possible to incorporate the genetic material that controls production of secondary metabolites into a Mycoplasma, look at the most powerful pathogens first...they would have.

-Erik (2001, SickBuildings)

* Controlled animal studies of mycotoxin exposure for use as antibiotics and bioweapons has been done for fifty years.

At a time when the insurance industry, researchers, physicians and victims of SBS/ mycotoxin exposure are desperately trying to gather data, those who have such information have not produced it.
Why not?

-Erik (2004, SickBuildings)

INVESTIGATION

I feel like I just grabbed hold of enough information to barely make a dent in whatever is going on. There is no way that my understanding is complete and addresses the entirety of this phenomenon.

I need someone smarter than I am to go with me to these special places and bring their mass spectrometers, MIST testers, EMF potentiometers.... everything including the kitchen sink. And even then, I don't think we'll catch the full gist of it without comparative satellite electromagnetic geometric assay.

Whatever is happening, it's a butt whupper, and people should start thinking about some serious research.

-Erik (2008, CFSU)

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I am operating on the basis that since no doctors recognized this illness and that since medical science failed to explain it, all concepts which are grounded upon a conceptual framework which did not solve this problem may be flawed.

In fact, it would be more likely that whatever we already know has been repeatedly applied, and that since it didn’t fit the facts, whatever this illness turns out to be may be something that requires an entirely new science to address it.

So since I don't have a science lab at my disposal and all I have to work with is a weird effect, I put more time into exploiting the physical discernible parameters of that effect than I do into resolving whatever that effect is.

It could even be that mold is doing something so completely different that it does not fall within the current body of mycology-toxicology work at all.

-Erik (2008, CFSU)

*

There are many weirdnesses about this mold reactivity that need more research before one can really speak authoritatively.
I've been busy trying to beat it into some more researchers’ heads that they really ought to do this.

-Erik (2009, Email)

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As part of my military biowarfare training, it was stressed that although it is certainly good to know the chemical properties of the agent in question, this knowledge is unnecessary for the protocols and strategies involved in dealing with it to be effective.

There is "No Need To Know"

This is why, although I do pursue trying to find answers, my focus is primarily on tactics.

-Erik (2009, SevereReactor)

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I can understand that people would refuse to wrap their heads around this factor, because I can scarcely believe it myself.

You had to be there. And even then, it is still almost impossible to believe.

Unfortunately, it has not been identified and defies normal classification. I'm still trying to talk Santa into bringing me a mass spectrometer for Christmas.

-Erik (2009, WPI)

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I spent a great deal of time interviewing old timers in the remediation business, and they all disclaimed seeing any level of illness such as I describe in those places where they detected and measured extremely high levels of Stachy and other toxin producers.

The shift in symptoms started appearing around 1980.

Something changed!

This leads to believe that whatever we are looking for is not "your father's toxin" and must be a recent development.

For this reason, I suspect that until a hypersensitized mold responder leads researchers to the rarer place of this "novel mold toxicity," researchers will continue to look at the wrong substance and remain completely confused as to why the toxic properties fail to correlate to the illness.
I had really thought that just a few more repetitions would have been sufficient to get concerted research interest into an "effect" that gets repeatedly dismissed after testing finds nothing.

Yet even after 25 years, it appears that "you can't prove it" and "I don't think so" is not one bit less powerful now, as it was back then.

Instead of treating all the unsolved stories as an accumulation of evidence, the whole backlog is treated as irrelevant because nothing was found, so they were all considered successfully resolved by science... rather than the exact opposite.

The effect is still there.

Science hasn't caught up to reality.

-Erik (2010, WPI)

I don't have a chemistry lab in my back pocket, and explained to doctors and CFS researchers that I am unable to do much more than point at what was making us ill.

"There it is. You'd better find out what it is, because there will be millions of people like me. There will be carnage."

The answer I've received ever since the inception of CFS has been that there is nothing to investigate, "Because you can't prove it."

-Erik (2010, SevereReactor)

I believe that it would behoove researchers to bring better technology to zones which manifest strange effects, rather than to wait for the effect to come to them.

-Erik (2010, CAA)
Doctors tend to have greater knowledge than most folks, but this also gives them a better idea of "what can and cannot happen."

This works great, most of the time.

Until something happens that is so foreign to that knowledge that it cannot be encompassed.

In cases like that, people who haven't developed an encompassing conceptual framework, like children, can perceive it clearly and without question.

Since proposing any concept at all which lies outside the conceptual framework sounds outlandish, theories which propose to explain it will automatically sound ridiculous.

For this reason, it is best to stick with pure observation and call it "an effect."

By having "sensitives" move in and out of "the effect" and verify its presence, we can focus on veracity of "the observation" without dealing with the perceived "ridiculousness" of any weird sounding theories.

It's easy to knock down silly theories.

Not so easy to dislodge the observation that there are more and more of "us" who can verify its presence.

We need to recognize the need to look at this with different tools, such as the recent technology in mass spectrometry that only became available in the last few years.

-Erik (2010, CAA)
Chapter 4 -- A “Super Mold”

A REAL EARTH-SMASHER

This new breed of badness is so bad that without a crap load of planning and the willingness to engage in military biological warfare protocols, there just plain isn't any way to deal with it.

That's why I've been more interested in getting a researcher to get involved than in trying to advise people on mold avoidance.

It has pushed me right to the brink, and that's even using every trick in the book.

You'd think that people would want to know what is headed their direction.

But I really don't know what to tell 'em, except "brace yourselves for a real earth-smasher."

-Erik (2009, Email)

SYMPTOMS

There are complexities to this weirdness. This is why we need some real research.

I ran into a plume the other day and didn't have my Hepa system on, so the interior took a pretty good hit. Here's the deal.

As I lay on my cot, the heart palps would start in on me. But as I stood, the upper air in my rig had more of a burning sensation without palps. Similar to what we felt at Truckee H.S.

When I opened up all my vents, I could feel the burning presence zip right on out. Of course, I still couldn't use my cot until I replaced the contaminated blankets.

Then I went out to the campground at Boca and let the thing die down. Seems to take about a day to get back to feeling okay again.

My personal purely speculative notion is that different toxins emanate from the spores in sequential order. And the floaty toxins went up, while the spores stayed down.

Definitely some molds are better floaters, though. Stachy is the prize sinker with a hang time of less than an hour for fully hydrated spores.
The immunological meltdowns of people at Henness Flats were so different that they make it appear to others that they must be unconnected.

It is only us sensitives who say, "Well no wonder! The place feels like it could kill most anyone given enough time."

To really get the full sense, you have to hit it right when a storm is coming.

It's like a World War One battlefield, with clouds of "brain fog gas" wafting through.

-Erik (2009, Email)

Yet, as you say, there are weird differences in how this effect manifests from different sources at various times.

Same place - some days it's more heart palps and brain compression, while at others, seems to have more of a chemical feeling.

So difficult to describe, and so variable, that it's almost not worth it to try.

More like, "Just get a tent and see for yourself."

-Erik (2009, Email)

I made a point of taking non-mold responders through the Incline plume, to see what would happen.

Despite their ability to withstand other moldy buildings, this plume was enough to put them on their ass.

-Erik (2009, Email)
Yes, the super bad stuff was right there, at Truckee High School, in front of the teachers' lounge.

-Erik (2009, SevereReactor)

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Remember our trip to Truckee HS, where you had visible response of veins standing out, even though the initial exposure didn't seem to be all that bad?

That's it.

That seems to be one of the worst kinds of exposure for some of us.

But because it doesn't feel all that apparent, people refuse to connect that phenomenon with having their immune systems collapse later.

-Erik (2009, SevereReactor)

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There are zones in which people don't do very well.

A local hospital has such a room. The doctors don't believe it, but the nurses don't dare put anyone in this room who already has a poor prognosis.

I was told that among themselves, they call it "The Dead Baby Room."

These zones leave a lingering effect, as if immune function has been turned down.

You don't spot them by what happens.

They are detectable by a marked lack of immune response.

During the Incline epidemic, people in these areas fared the worst.

The only real way to get a clue they were there is by the strange way that people's immune surveillance seemed to diminish.

And the only confirmation was by what happened when people who were steadily declining made it out of these zones to a better place.

Many of us have noticed this effect, but it is a paradigm that defies explanation by conventional testing and does not seem to have indicators of classical toxicity.
The surest way to shoot down the existence of these zones is to assign a definite cause. People have implicated everything they know and each time these areas are extensively tested, "Nothing is there, so you're crazy."

We remain “crazy,” but these zones continue to exert their peculiar influence.

-Erik (2010, CAA)

**CHARACTERISTICS**

Insofar as mold being harmless outside, as always, my experience says differently.

I know of a killer compost farm that's throwing out a wicked plume across half a mile if anybody wants to feel the joy for themselves.

And I described my experience of hang gliding into a spore plume thermal over Mt. Hull when I was deliberately flying over an area that had been deforested by fire that was extinguished by bombers.

Perhaps it was the fire retardant that potentiated the toxins.

I only know what I felt.

-Erik (2005, SickBuildings)

*

I was at the parking lot for the trail to Delicate Arch. I sat down at a picnic table and got slammed.

The entire area for about thirty feet around that table was just rampant.

It was right next to the parking lot, so I thought perhaps someone with a moldy RV must have parked there.

Although the badness was centered on the table, and not the parking lot - I checked.

Crazy stuff. Too crazy for me to figure out.

-Erik (2009, Email)

*  

Dr. D and I were out camping and wound up downwind of aN RV that was so bad that at a hundred yards away, We were still running to get out of the plume.
She said, "I wonder how they can stay alive in that thing!"

But I don't think anyone could, it was so bad.

I feel certain it must have been coming out of the black water tank, from the vent on the roof.

-Erik (2009, SevereReactor)

*  

It seems to me that active mold colonies are capable of grabbing something right out of the air and turning this transient substance into complex neurotoxic compounds.

Dead stachy stays dead and doesn't change its properties.

Live colonies can be almost non-problematic at some times....pure murder at others... "suicide season."

This is why, in the winter, I have to be able to move fast, when a plume fires up.

-Erik (2009, SevereReactor)

*

There is a killer compost farm located right next to the air tanker base south of Carson City.

Some of the most fierce mold I found around that tanker base was in decomposing weeds in a drainage ditch leading away from the retardant loading station.

I wondered if my reaction was to the chemicals themselves, so to check, I wandered around the base and made certain to inhale fuel fumes and step in piles of spilled retardant. No reaction.

But that drainage ditch was pure murder.

-Erik (2009, SevereReactor)

*

The sewage sludge is implicated in the Saratoga Springs 1994 manual as being notorious for Stachy.
During the Incline epidemic, the first building complex I noticed that was really knocking me flat was right next to a settling pond.

Years later, I talked with another 1985 epidemic survivor in Reno who was constantly complaining to the city officials because every time the wind blew from the direction of the sewage ponds, he became ill.

Same thing in Carson City. There is a blanket of badness that stretches from the settling ponds out all over C hill behind the prison, a popular walking area that just turns horrible at times.

-Erik (2010, SevereReactor)

*

The sourcepoints are extremely unstable. They change potential and shift so rapidly that it is very difficult to create a usable map of these zones.

-Erik (2010, WPI)

FECUNDITY

Dr. D and I had an RV go bad on us.

Every time she entered the bathroom, she would have an instant nosebleed and could only tolerate the room for a short time before she would collapse. I literally ripped out all the walls until there was nothing left but the ceiling and floor.

It made no difference.

The ceiling had wood which used to be light in color and still was elsewhere. This was dark and discolored and had all the appearance of water damage, without any leaks in the roof.

It was purely from condensation.

Both of us could feel strong hits when we put our faces close to this area.

Using fans or trying to control humidity just doesn't work here.

The cold outside and the warmth inside creates a condensation interface that means some moisture on the exterior wood panel is absolutely inevitable.

I had to remove the roof and replace the plywood cap.
Nothing less had the slightest effect in diminishing our symptoms.

-Erik (2006)

*

I just got an e-mail from someone I evacuated from a moldy place outside of Carson City a few years ago. We abandoned the furniture but retained some wooden work benches that showed no signs of mold.

He contacted me to say that he was feeling ill around the workbenches and when he turned them upside down, the bottom of the plywood was covered with black mold.

These benches were never exposed to water or a relative humidity higher than being in the middle of a metal warehouse.

Why mold would be growing there, when mold doesn't normally just take off like that on an indoor workbench, remains a mystery.

Since the new place feels good otherwise, and the culprit was something taken from "the bad place," we have concluded that there must be something different about that mold.

The medical profession and toxicologists have repeatedly demonstrated that their testing reveals no "scientific" reason for these complaints.

The common failure of testing to find a plausible reason is an indication that if a sufferer wished to take matters into their own hands, reliance on professional testing as a guide to action is the last thing you would want to do.

Most people are finding out by simple experimentation what they should do to avoid the irritant in question - and most of the doctors call their actions "hysteria":

Which suggests that whatever the problem is, doctors would not have found it.

In my friend's case, the fact that the mold on this one object "followed" him to Texas and recreated the same symptoms tells him that whatever other contributors may have also been present in the plume from that compost farm, this specific mold alone was enough to be a driving factor even without other factors.

By taking the mold from one location to another and recreate the effect, not only do you narrow down the suspects considerably, but the cost involved was negligible compared to what testing would have been.

This is really getting scary. It's really looking like we are facing "Global Molding."
-Erik (2006/2008)

INCREASED PREVALENCE

I encounter conditions which have the potential to do this to me on a regular basis.

And these places have increased dramatically in number and size, in the last few years.

-Erik (2008, CFSU)

*

Yes, the moderate plumes are getting larger, and I am also finding more of this micro-superbad places.

Twenty-five years ago, I know of maybe half a dozen super slammers. I can't even count how many there are now.

-Erik (2009, Email)

*

I've been keeping tabs on the plumed area of Carson City.

Lots of stories. Even heard there's a guy named Eric and his wife who had to bail out of there.

Doctors, of course, are totally clueless and do not believe any of these stories might be connected.

Each one is a fluke, no matter how many.

I figured when it hit a few hundred, perhaps doctors would begin to put two and two together.

But instead, they pride themselves on “treating each patient as an individual, each with his own unique situation.”

-Erik (2010, SevereReactor)

LOCALIZED SOURCEPOINTS

The reports of individuals inside sick buildings who succumb to localized sourcepoints is increasing.
I just heard of a medical complex in which the “aware” doctors asked to be transferred away from a specific wall to the opposite end of the building and are observing their colleagues who remain as they gradually manifest increasing symptoms.

It is fascinating to hear the arguments between those who are located directly adjacent to a sourcepoint and those who are barely out of range, as the sensitized ones try to explain their situation to someone who is unaffected only a few feet away, in the next office or perhaps even the same room.

Both equally convinced. Neither giving ground.

-Erik (2007, IAQ)

*

Some buildings have, mixed in with normal bad mold, a few hot spots of the real bad stuff.

People can be just a few feet away, and if they don’t pass through, they remain oblivious and unbelieving.

Those who encounter it can drop in their tracks, while the person a few steps away from them wonders what the hell they are complaining about.

-Erik (2009, Email)

*

It had seemed logical that when enough people fell apart in buildings that had nothing odd about them except a few stray Stachy colonies, doctors, researchers and scientists would get a little concerned and look into the phenomenon.

Pointing at the common denominator of Stachy should have done the trick.

Apparently, victims must run into the millions for this to occur.

-Erik (2009, SevereReactor)

**SPECIFICITY**

This isn’t toxin overload.

That is one of the mistakes people are making about it. This particular substance has a specificity to it.
A COMPOST FARM

Sick Region Syndrome is a happening thing.

Here in Douglas County just south of Carson City I can give you a really spiffy example.

This is really big.

Remember my crazy story about Sick Thermal Syndrome when I was hang gliding about Mt. Hull in northern California?

Well, I was just out saying goodbye to one of my old haunts. A hang gliding training area where we used to fly on Johnson Lane.

(Isn't that great? A hang gliding bunny hill right off my very own street. Just coincidence.)

Anyway, the whole valley is being built over and my old hill is being bulldozed and constructed, and I wanted to look at it one last time.

I decided to walk instead of drive so I could savor the moment. As I returned, I walked past the airport.

I could feel a mold hit, but I was too busy nostalgiaizing to pay it much heed. It wasn't until I realized that I was into a full on mold slam that I knew I had better decontaminate or I was going to pay for this slammer dammer in a big way.

I sped up but this was huge. I started to run. I got back to the hangar where my decontamination camper was parked and my friends could see I was in trouble. I ached and burned. A searing bolt of pain shot into my skull behind my right ear.

I have felt this many times before.

Thank God, I know what to do about it. For so many years I would feel like this and it was just like my body trying to kill me and I had no way to get out of it. But now times are different and I knew exactly what to do.

Blazing past the worried looks of my friends who know my situation (and who believe me), I made for my camper. I dropped my clothes out the door and took a quick shower.
Within minutes I could feel the sense of total desperation start to subside. The aching in my head melted away and that feeling of having my entire body enveloped in some kind of radioactive fire diminished to the point where I could act semi-normal.

Hah! As if I could ever be normal.

My memories of old exposures that happened before I knew to decontaminate flooded back as I gave thanks for the incredible knowledge that allows me to control this living hell.

I remembered that experience of arcing into a graceful coordinated turn as I punched into the center of the thermal high over Mt Hull. Nothing could be greater than the joy of soaring and the mastery of kinetic energy as you soar into an elevator ride from a "cookin' thermal."

I felt like an eagle as I exulted in finding the perfect ride into the clouds until Toxic Hell reached up to smite me from below. I had deliberately flown over a burned out area from a forest fire because the bare ground absorbed more light and created the strongest thermals.

Suddenly I was so sick I could hardly keep my eyes open. I bailed out of the thermal and made for the landing area, seven long miles away.

I thought I was going to pass out. I rested my head on the control bar and frantically shook myself awake a few times, fearful that I might fall asleep and impact the ground before awakening.

Fortunately I recovered a bit before I got to the landing area. I mustered the energy for an approach and final flare for landing. But I didn't even take my harness off when I sat down and leaned against a log and didn't move for several hours.

Some fellow pilots brought me some water but I just couldn't shake this off. They thought I was airsick, but I've thermalled many times and never felt anything like this from getting bounced around. What was the deal?

I've walked many miles and sometimes I've felt these hits. But I knew I didn't get "walk-sick" either, so what was the deal?

I didn't know then. But I know it now.

It had taken me many years to find out what the heck that was that got carried up from the ground by the thermal and slammed me out of the sky.

Now I thought back to where I was walking when I felt the hit as I walked back from Johnson Lane. The compost farm. That must be it.
Yes. The wind was blowing from that direction across my path. It was a spore plume. No doubt about it.

I'm scared to walk down that road any more, except I know I can get away with it if I have access to a decontamination facility before I get a monster mold response. But the question is:

"I can feel it. Can others?"

I started asking a couple of people in that area if they associate particular feelings of anxiety and depression or lack of motivation to times of weather change and specific wind directions.

It's amazing how everybody feels that these emotional responses are signs of personal weakness and don't like to admit it at first. But when I talk about these as meaningful responses to toxic exposures, they open up and embrace the concept. They sound relieved to have a real reason for their so-called emotional feelings.

Once we get through the "I don't want to talk about it" stage, progress is rapid. Yes, they feel that way sometimes but never tried to associate it with a place or wind direction or (even crazier) when the weather changes.

"But now that you mention it...."

I let them think about it for a while and get back to me if they think this craziness has the slightest merit.

Now they have gotten back to me.

I think we've got the killer compost from hell here.

And I think we're seeing the beginning of the awareness of Sick Region Syndrome.

-Erik (2004, SickBuildings)

*  

I could show you a Sick Region surrounding a compost farm in Nevada.

Everyone that is downwind for half a mile is showing signs.

The owner of the compost farm is turning over operation to a manager because he is becoming too ill to work. The doctors can't figure out what is wrong with him and are calling it stress.

None of the people who are also noticing effects in that zone can figure it out.
All except for two of my friends, who listened to me when I asked them to correlate their feelings of depression and lethargy to a specific wind direction - the direction from that farm!

So whenever they felt like hell, they would go outside and check the wind.

They would ask each other, "How do you feel? When did it start? When did this wind start blowing?" and made a positive association between their health and the wind direction.

They said they felt hits from their possessions for a full year after moving.

-Erik (2006, SickBuildings)

*

My friends were driven out of their place by a plume from a manure farm.

The amazing part is that we were discussing the problem in a nearby restaurant and overheard a job interview at the next table.

The manager of this business was explaining to the prospective new manager that he had been getting so ill lately that he could no longer run his business and needed help.

Aches, pain, fatigue, rashes, blurred vision, headaches, the works.

He said that all the doctors were baffled (he cursed them roundly for being incompetent) and that there didn't seem to be anything he could do except slow down and reduce stress.

It was the manager of the compost farm.

That did it! I didn't need to say another word. My friends were out of there!

-Erik (2009, SevereReactors)

*

I have always wondered if the compost farm manager had an idea that the place was making him ill but didn't wish to admit it, and so he simply expressed the true statement that the doctors had no idea what was wrong with him.

-Erik (2008, IAQ)

*
I built my Mobile Environmental Control Unit within range of the plume from the compost farm, trusting that it was of materials that were sufficiently resistant to not be problematic after I finished and got out of there.

I could not have been more wrong.

The aluminum and plastic Econolite signboard that I used in the roof and overhang of the camper began developing spot zones that were increasingly troublesome, with the same sensation of pure unmitigated impending death that I was getting from the compost farm.

This wasn't cross contamination, this time.

There was some whitish fuzzy crap growing on the plastic.

Incredibly small areas, but absolutely fierce stuff.

Unfortunately, I had incorporated this composite plastic/aluminum material into support structure, making it extremely difficult to remove.

My summer was spent stripping my MECU right back down to the bare metal frame and rebuilding these structural components of different materials.

People may recall that my advice changed accordingly. I began warning against trusting plastic, and said that the basic shell should be of only metal and nothing else.

The stuff that got into plastic components of my MECU is as bad as anything I have ever encountered in the past.

Removal has been extremely unpleasant and the aftereffects of the surrounding contaminated area have been equal to the spot that was removed, although more diffuse and gradually dying down.

It's hard to know what to advise people when they reject the notion of using a bare metal trailer as a survival module starter unit as too difficult, since it might well be that nothing less even has the potential to avoid this horrible "stuff."

-Erik (2010, SevereReactor)

* 

Directly in front of this compost farm is an intersection on Hwy. 395 that is no different from a half dozen others on the same stretch.
But this one has ten times the number of head-on collisions and has gained a reputation for lethality.

-Erik (2010, SevereReactor)
Chapter 5 - Life In Lake Tahoe

PEOPLE

I spent part of Christmas visiting people in an area I identified as a Sick Region several years ago.

It's gotten worse!

There is an area of the house which is a new addition and had a small leak which was quickly fixed - yet it is the worst part of the house.

The occupants, who are not showing any overt signs of illness, tell me that a house nearby made the cover of the local paper when everyone became ill from a colony which got started after a TV dish was installed and the installer nicked a pipe with the screws.

The owners lost everything (as usual) and the house had to be gutted.

It's been resold and the new inhabitants seem to be doing well but the "sickies" have disappeared.

It looks like mold plumes in Sick Regions rake entire areas, just looking for that one slip-up, that one mistake, a leak, the slightest opportunity to get a colony started.

Under conditions like this, I anticipate a whole new generation of desperadoes.

-Erik (2005, SickBuildings)

*

Yesterday I was in Cedar Flat and couldn't "break the response," which is weird because I normally do pretty well at my parents' house.

We decided to go for a walk to help me feel better, and as we headed out for the woods, my stepfather pointed out a bulldozed area just behind his house.

He said, "Until two days ago there was a house on that spot" and described the weirdest construction project he had ever seen.

He said that a work crew had been working like mad on the place, which was a very nice house with no apparent reason for all this work - ripping off the exterior siding and all the interior panelling.
Right down to the bare studs.

And just when it looked like they were at a point to redo the entire sheathing and start replacing the walls - a giant bulldozer showed up and simply erased the entire structure, flattening the whole area.

Even removing the top layer of dirt.

Even though some people are replacing "old teardowns" at Tahoe with new houses by flattening unwanted structures, he says that he'd never seen anything like this.

The house was fairly new and looked good. The structure was sound, but the strangest part was that they put so much effort into working doing what appeared to be preparatory work, when suddenly the building, foundation and the ground beneath just "went away."

There was no debris at all, not a splinter left. Everything was taken away instantly, the moment it was torn down. Strangest project he ever saw.

Hmmm.

-Erik (2006, SickBuildings)

* 

It's getting a bit chilly up in Incline. We just had a bit of snow, but it didn't stick.

The spore plumes are acting up this time of years like they always do, and so I escaped out to tiny but scenic Watson Lake up in the mountains above Tahoe City. Not too many people camping this time of year.

But there was one other guy in a white Ford van. So we built a huge campfire and swapped stories. Turns out that he's living in his van and escaping just like I am because, as he said, "I get sick when I spend too much time in buildings."

He looks perfectly normal, has a steady job in town, but to keep from falling apart has to sleep in a pristine place.

Well, who'da thunk it?

-Erik (2006, Locations)

* 

Yesterday I was out hiking on the Pacific Crest Trail above Donner Lake, and I happened to meet an interesting guy on the trail.
We were swapping stories and had an amazing amount of information in common. He had an ex-wife with CFS. I asked if she had ever connected her illness with mold - and boy, did I get a story!

Turns out she was the "Mold Witch from Hell" and virtually everything in her life was dictated by a wild fear of mold.

I said, "Seen that one before" and pointed down to Truckee High School, which you can clearly see below.

I asked, "Do you know where CFS started? It was right there, down in that very building."

So it turns out that like so many others, his marriage was torn up by this illness and she was acting crazy, but she definitely pointed at mold just as I did in that very school.

We had quite the discussion. He guesstimated that seventy percent of the population is not susceptible to the effects of mold.

I was astonished. "How did you know that? Dr. Shoemaker has assessed the HLA DR susceptibility at 24%, so your guess is amazingly accurate."

Pleased, he replied that he had always been a bit intuitive about such things.

Damned good job, I say!

To this day, I still start the slippery slide to relapse if I hang around down there in Truckee too much. But up on the top of the pass, I feel just as good as I did all those decades ago when I escaped out here to get away from that horrible feeling that I felt down around Truckee High School.

I'm not trying to totally discount any role of EMRs and am still interested in pursuing this information, but there is a huge array of microwave paraphernalia immediately above Donner Ski ranch and I just about pass in the shadow of those towers when I go north on the PCT towards Boreal Ridge... and I feel nothing bad.

In fact, up there, I feel absolutely awesome.

-Erik (2006, Locations)

* The mold problem appears to be going wild like nobody has ever seen before.
Ten years ago, it was still pretty difficult to find anyone who admitted they had heard of such an odd thing.

Today, I am surrounded by people in my own Tahoe neighborhood who have been battling mold.

I am a charter member of the EAA "Experimental Aircraft Association," Chapter 1077, in Truckee. My fellow pilots believe me and are like minded people. They weren't familiar with this situation.

Now... the CalFire emergency wildfire base on the airport has been evacuated and closed off.

Everybody knows what mold illness is. That is one hell of a quick paradigm change.

Yet, every time you see this in the news, whenever you bring it up, people are trying to see each and every case as some kind of fluky thing - even though this fluky thing has blazed into the public consciousness faster than the worst wildfire in history.

-Erik (2008, CFSU)

*

I just found a local gal who bought a new house... and lasted for two weeks in it.

Ten years ago, I was talking my ass off to everyone and getting no recognition of the concept.

Now it's getting hard to find someone who doesn't have their own mold tale to tell.

Doctors, in their race to outdo each other and act knowledgeable, pretend that there was never a time when they didn't know about this. They aren't really pointing at the "Then vs. Now" paradigm shift.

And therefore, they are making no discernible effort to raise awareness of how quickly and drastically things are changing.

-Erik (2008, CFSU)

*

A few months ago I got a rave review from a family about some fancy expensive air cleaner they bought to put in a place they had moved to, which they felt to be a mold free place.

(Yes, they did abandon everything before moving, including their cars.)
A couple of weeks later, I hear they are outside in a tent again.

Whatever is going on, it's pretty darn crazy.

-Erik (2008, CFSU)

*

I knew someone directly above Donner Lake in the Armstrong tract who was selling the house, and who went down in the basement and found everything had become moldy. Had to throw all kinds of stuff away because it had visible mold on it.

Now, that's kind of weird. I grew up here, and this just isn't something that used to happen in these parts.

Last time I was up there, about eight years ago, it felt good, but I just don't know anymore.

-Erik (2008, CFSU)

*

Truckee is suckee right now. That's why I'm up early. I still have responsibilities around here, but I am getting closer to truckin' on down the road.

Pagosa Springs was totally awesome a couple of years ago. I worked like a madman - hard work, bailing hay - and felt great.

It was good to feel human again. Not so good around here anymore.

-Erik (2008, CFSU)

*

In the late 1990s, a new multistory hospital was being built in Reno.

Due to a subcontractor foul up, the sheetrock started going in before the roof was completed and it rained.

The entire top floor of a building five stories high lit up with mold.

The mold was tested and came up positive for Stachy.

It amazed me that this could happen so quickly.
Stachy is supposed to have a heavy spore, and airborne testing rarely finds so much as a single spore, so how did this happen?

According to the experts, "It shouldn't have."

But it did!

The actual manner of the phenomenon far transcends the belief systems of the experts, so whatever goes beyond what they believe will happen can go unnoticed, right in plain sight, simply because they don't believe what they are seeing.

And of course, the future hospital was remediated, by "expert" standards. Which means water damaged deformed sheetrock was replaced, but the rest was bleached and painted over.

How would you like to be a patient in that hospital?

-Erik (2009, Locations)

*

Melinda Ballard's place was in Dripping Springs, Texas.

A community in which it was later found that nearly all the houses had some kind of mold infestation.

It just seemed to blast out of nowhere, in a very quick paradigm shift.

Uncannily similar to what I saw in Incline Village in 1985.

That is part of the "mold tour."

So many places that are hideous now, in a town where such a thing was considered so impossible, that to this day people cannot conceive that there is actually a pattern to this progression.

-Erik (2009, SevereReactor)

*

It's still pretty good in this location in Reno, but I made a mistake.

I washed clothes up in Truckee and got them all contaminated. So now I have to wash them again.

Seemed like a fairly low mold day, but I guess I was wrong.
In 2000, I was out camping at Wolf Creek on Ebbetts Pass to get away from mold down in the Carson Valley, and the guy camped next to me caught my attention.

His campsite was throwing out a plume that I could feel at a hundred yards.

Given contamination levels like that, I figured he must have as story to tell.

I checked the wind, approached from upwind so I wouldn't be slammed too badly, and went over to talk to this not-so-happy camper.

Turns out we both grew up in the same area up on Sonora Pass and as teenagers, had even been rousted for partying in public by the same cop... "Elbert Miller."

We had a lot in common. We were both Army veterans and wow... I couldn't believe my ears, but he was out camping for the same reason that I was. His house was killing him and he couldn't figure out why. The only relief he got was to go camping.

I gave him the spiel on the mold, yet he couldn't bring himself to believe that mold was the problem. He didn't know what it was.

I warned him, "Just wait, the next time a storm comes through and stirs up the mold spores, you'll be hating life. Here's my phone number. Give me a call and I'll tell you what to do."

Sure enough, the next time a really bad storm hit, I got the call. It was about one in the morning and he was frantic.

He said, "I can't take this anymore. I've got to get out of here or I am going to kill myself. I'm taking my motorcycle to Mexico and camping out for as long as possible, and I'm never going home."

I said, "Wait, wait, there are ways of dealing with this."

But he was totally desperate. He replied, "I only know that camping is the only thing that keeps me alive, so I'm going for it, right now."

And that was it. He was gone.

Too bad he wouldn't listen, for there really are ways of doing this a bit less dramatically.

-Erik (2009, Locations)
I was at a Tiki Torch party in Truckee the other night and ran into a local "sickie" that I hadn't seen in a long time.

She told me, "I got your book Mold Warriors three years ago as you told me to, but it turns out that I don't have a mold problem. I was diagnosed with sarcoidosis instead."

I said, "Hmm, but you have all the same reactions to those places we discussed?"

"Yes, but sarcoidosis can cause all that."

So she is doing all kinds of supplements to control her pain but no efforts at avoidance.

And then, pow, a plume rolled through, just like that.

Truckee is pretty bad for that. The plumes roll on through at times, with no warning.

And she went down for the count, clutching her stomach in pain. Had to leave the party.

But she doesn't have a mold problem?

I had to bail out about an hour after she left, as I perceived that I was hitting my limit. I had enough and got out.

It's incredibly difficult to get clear long enough to build up tolerance for times like this.

And it doesn't take long for accrued tolerance to slip away again.

-Erik (2009, Locations)

HENNESS FLATS

It isn't negligence when someone doesn't know they are being negligent.

I watched the Henness Flats apartment complex as it was being built.

It caught our attention for its unusual modular construction, so I would drive past to watch.

The modules were lifted into place by cranes.

But it was done in the winter, and got soaked before the roofs were in place.
Winter construction is perfectly normal here in Truckee. Most of the time, it is not a problem because the roof is built before the sheetrock is installed. It's all part of a well-proven plan.

People didn't think of mold as being harmful. Aspergillus on stud walls is considered normal and nothing to be feared.

When a house of normal construction dries out, the mold dries out and dies.

Nobody thought the modular construction would be any different.

Since I had mold experience from years before, I told others, "These people are going to be screwed"... but I was the only person who thought so. They thought I was crazy.

So I am absolutely convinced that people at Henness Flats never dreamed that this was going to be a problem.

They are all in total shock at what is happening.

-Erik (2008, IAQ)

*

Last summer, I interviewed a number of residents at Henness Flats.

The neighbor of the SIDS incident gave me an interesting story.

"We went into the crawl space and smelled a funny smell that was on the wrapping of some leaky pipes. So that is how we knew it was formaldehyde."

Needless to say, I had my doubts that the formaldehyde was an adequate explanation for this occurrence.

-Erik (2008, IAQ)

*

Last summer, I walked around the Henness Flats apartment complex and randomly asked people, "What do you think about this formaldehyde concept?"

The instant response in nearly every case was, "I don't know anything about that."

(Which, of course, reveals that they do.)
I would proceed to say that I had no affiliations with any lawyers, insurance companies or agency of any type, and that I was just a private citizen who had experienced a similar problem many years ago and was just curious.

And then the floodgates would spill forth.

Far from being hysterical, everyone tried to minimize the situation, but they were clearly frightened.

One lady with two small boys, after first telling me she had no information and was not personally affected by this problem, after hearing my own story became more forthcoming and told me about her family’s strange problems after moving in.

Sleep disorders, headaches, rashes, increased allergies, susceptibility to infections... and of course, crushing fatigue.

I told them that I had experienced similar symptoms decades before, at Truckee High School on the other end of town, and that I had never quite recovered from this immunological assault.

Doctors just can't seem to figure it out and don't believe us.

In fact, they don't even care to listen.

I know. Believe me, I have stories of doctor disinterest that are beyond comprehension!

The boys were of particular concern to me, because they had the distinctive red rashes on their faces which are often a sign that a person is dangerously close to what I call hitting the wall: the point of complete immunological collapse.

I warned that I have seen this in myself and others, and if the rash spreads to their ears, and they begin to act semi-comatose....

Well, it's really not my place to tell anyone else what to do, but if it were me, I would get out at all costs... go out and sleep in my car if I have to.

Which is precisely what I did.

And damned glad of it!

I saw absolutely no evidence of hysteria.

Rather the opposite.

People weren't nearly as concerned as they ought to be.
Out at the Truckee Airport, the government wildfire agency CALfire had an inspector come out, and the place was flagged and sealed.

There was no talk of remediation or trying to save the place.

The employees have been moved to a new location and the building abandoned.

Meanwhile, half a mile away at the Henness Flats Apartment complex, we've got a SIDS death, a whole bunch of very sick people, a miscarriage, tumors, cancers, hypersensitivity... the works!

And the inhabitants are told that mold illness is unproven, so there is no reason for concern.

What a wild differential in the official response.

We've got dueling opinions out here in Truckee, and the inhabitants don't know who to trust:

The "alarmists" who were hired by the occupants? Or the “experts” who are employed by the owners?

The "experts" told the inhabitants of Henness Flats that the levels found were not alarming, so they should not be worried unless they begin to develop symptoms.

Trouble is, they are, but are trying to beat them using willpower.

I saw one young mother with several small children who denied having any problems at all, until I confessed that I was not with any government agency or insurance company... just a concerned citizen trying to gather information.

Then she let on that there were a couple of things.

Nosebleeds, headaches, fatigue, difficulty sleeping, allergic rashes and chemical sensitivities, but that these were still tolerable.

That's the bummer about this illness.

We all thought it was tolerable, until it wasn't.

And then it was too late, for there was no going back.
Another Truckee-ite tried to put in her two cents on the situation, but she told me that her letter didn't generate any response.

So we just get to stand by and watch this train wreck happen.

-Erik (2009, SevereReactor)

**FLORA AND FAUNA**

The bears have really been aggressive at Tahoe lately.

One charged the camper next to me up at Watson Lake, and refused to back down despite five pistol shots into the ground.

So the bear went ahead and got the cooler. No, nobody shot the bear. That's only in self defense, besides - you don't want to get them angry unless you've got some really large caliber.

Well, while I was up at Watson Lake, a bear came into Carnelian Bay and climbed into the neighbor’s window and cleaned out their refrigerator while the neighbors were asleep.

Then, the bear came back and ripped a plywood door off a shed and cleaned out my parents’ freezer.

We're talking some very well stuffed bears here. The problem is that they'll always come back to a place they've found food.

So I set up a bear trap. An eight foot pile of log rounds with a plank on top supporting jars of Pine Sol. I strung ropes between the logs so if they're disturbed, it pulls the logs toward the middle.

Hah. Nailed that bear but good! Plank came right down and bonked his head and splattered him with Pine Sol. Bear took off so fast it ran right through a closed gate and smashed it down.

Scared the "whiz" right out of him. There's bear pee right down to the driveway.

I've reset the trap, and I think it made a pretty good impression on him, but now the neighbors are going to have to be especially vigilant.

That's life at Lake Tahoe.

-Erik (2006, Locations)
I grew up at Lake Tahoe.

The alpine meadows used to reverberate with the sound of millions of frogs. It was fun to sneak up as close as possible, trying not to disturb them, and suddenly the closest ones would feel the vibrations of your feet and all would simultaneously drop instantly silent, like throwing a switch.

If you stood quietly without moving long enough, they would tentatively give out a few croaks - and then, reassured, they'd let loose again with a roar that would just about shake the ground.

Those same meadows are almost dead quiet now.

They're mostly gone - chytridiomycosis, I'm told.

Nobody knows for certain what weakened the frogs, some other infections like iridoviruses have been implicated as a possible co factor that left them open to chytrid fungus. There's the ubiquitous airborne pesticides that waft up from California. Some frogs that were sick down in the central Sierras were taken north and apparently whatever is killing them here is not quite so bad up there, for they seemed to do much better, at least for now.

This seems to point at an environmental contamination that is gradually putting a little more pressure on them than they can handle and edging them out of existence.

I've heard that antidepressants in the water table impede the ability of fish and frogs to function normally, and that the frogs are especially sensitive and susceptible. Preliminary tests by just placing amphibians in this water seems to indicate that this would be enough to make them disappear.

People from the city go up, admire the beauty of these meadows and think everything is perfectly normal. It's only those of us who remember how it used to be that know something is missing, and feel that the world is a much lesser place.

-Erik (2008, IAQ)

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The bears have been acting outrageously bold like we have never, never seen before around here. They got in my parents RV and raided it a few weeks ago. Last night, they ripped the locked door off my brother’s camper and thoroughly trashed the interior.

Those of us who spend a great deal of time in the woods have noticed that the deer, squirrels and bear are all acting a bit peculiar.
The frogs are nearly gone. Places that used to thunder with the sound of croaking frogs are now almost completely quiet.

If doctors don't believe all the sick people who are bitching about "something weird," you think they're gonna give a crap about the critters acting strangely?

Animals ain't "paying customers,"
-Erik (2008, CFSU)

*

All the dog owners I know around here are wondering why so many dogs are dying of cancer.

Dogs used to die from being hit by cars or old age. Cancer was rare.

Not so, any more. It's like #1.

-Erik (2008, CFSU)

*

After the huge fires that raked California, including the one at Blue Canyon just under Donner Pass, finally went out and the smoke cleared away, the skies were the sky-cobalt-bluest I've seen in years.

As if the particulates had temporarily scrubbed the normal levels of pollution.

Postcard picture blue! But just for a short time.

It's back to its normal sickly pallid blue-gray haze, now.

Most people come to Lake Tahoe and are surprised at my observation: "You call this polluted?"

So sad. They didn't see it thirty years ago, and they'll probably never see it that way again.

-Erik (2008, IAQ)

*

The static zaps were really strong in Reno last night.
My poor cat was scared to step off the bed. She would extend her paw down, then pull it back, over and over, knowing what was to come.

Then she finally set her paw down and I heard the snap.

Poor kitty.

It's not just us imagining this.

-Erik (2009, WPI)
Chapter 6 - Hyperreactivity

INFINITESIMAL AMOUNTS

As you say, when it comes to describing this nightmare, where do you start?

Let me tell you a story about this tent.

My girlfriend (a Moldie) and I got it as a backup for our RV, which gets contaminated when it's inside mold zones.

We set the tent up inside a mold zone and it instantly picked up a load of badness. Between it and our contaminated gear, we wound up sleeping outside the tent on the bare ground the first night of this backpacking trip.

My girlfriend was so pissed that she gave me hell for that, saying, "You of all people should have known better."

When I pointed out that I did know better and that it was her idea to set it up inside a bad area to check it out, she just said, "Well, you should have stopped me."

We spent the next morning washing all of our stuff in the lake and drying it out before we could get going.

Now you tell me. How do I go into groups and start talking about this kind of insanity?

I figured that if I just kept saying that I had a good story, it would hook some CFS doctor into checking it out.

Basically, you have to see some of this crap before you can believe it.

If I just try to tell someone straight out, they aren't going to believe a word of it.

-Erik (2008, Email)

*

I bought a book at a flea market in Santa Cruz.

One dinky little book, and the thing was like a biological weapon.

When I had examined the book in the open air, I hadn't noticed how bad it was. But as soon as I got it in the car, the disorientation and cognitive issues were overwhelming.
The enclosed space concentrated the effect in a manner that is worth taking notice of, for this is the enhancement that happens when bad objects are brought indoors.

I had to pull off the road and get rid of it. The aftereffect seemed to die down in a couple of hours.

When we can have a single book rock our world, it's impossible to project that an otherwise perfectly swell place didn't have someone bring such objects in.

-Erik (2008, CFSU)

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My sister-in-law is working in a doctor's office that has a mold problem in the back room. When I was really amped up, I couldn't sit in her favorite chair in her living room.

It wasn't that her house was that bad. It was just what she was carrying home on her clothes. But it made no difference to me if mold was growing there or cross-contaminated there.

-Erik (2008, CFSU)

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Some of the worst mold slams I've ever had were outdoors, as in the killer mold plume in Incline Village.

-Erik (2006, Locations)

**SUBCLINICAL EXPOSURES**

By moving into a really bad place, you become aware that the "effect" really exists.

But consider that if a slammer location can make you REALLY ill, what about all the minor hits that one might take at a far lesser level which might scarcely even be felt?

In Mold Warriors, I tell the story about seeing my captain in the Army drop after getting too close to me after I had a peanut butter sandwich. It seemed to me that if he was constantly being hit in a minor way, which might possibly happen if I had told people in my unit about his weakness and they all started smearing peanut butter everywhere, how long could he possibly last? Wouldn't this constant bombardment wear him down over time? Even if he didn't get too close, but people has still increased the ambient level of exposure?
When I started thinking about how my health gradually shifted in places and according to seasons, it made me wonder how much further I might be able to control the problem if I learned to sense subclinical exposures to this substance, which was concentrated in certain places, and treat lesser exposures as though they were having a long term effect - in the same theoretical way as peanut anaphylaxis might wear someone down.

I identified a sample of the mold that was most bothersome and took a bit out to the desert. After getting myself as clear as possible, I did proximity testing to see at what distance this tiny amount would still have a discernible effect.

It was astounding. Just like the peanut allergy in my commanding officer. Infinitesimal amounts were still creating sensations which were only discernible by the fact that there was a shift in symptoms.

For example, if I was slightly depressed, it would get slightly worse. If I had difficulty sleeping, the problem would turn into full on insomnia. If I felt slightly anxious, it would turn into a sense of desperation.

What I felt wasn't "mold" per se, like an allergy. It was the shift in symptomology. And because I had taken the mold to a place free of other variables, I concluded that this was the factor responsible.

I also learned that mold acts in a special context which differentiates it from other factors, so you recognize it by the way it moves.

-Erik (2006, Locations)

FAILURE TO PERCEIVE

Recently I've been taking people who haven't got a clue that they are reactive to mycotoxins into contaminated areas and watching them drop.

It's quite a revelation to them.

-Erik (2004, CFSResearch)

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To learn where the mold is, you have to trust someone who has been pushed to the limit, and has come back to tell the story.

Only people who have become hypersensitized know precisely where it is.

The rest only feel vague "Good Day / Bad Day" fluctuations in their illness.
Those who have not reached that point of discernment use their failure to perceive it as evidence that it isn't there.... and "It's just you."

-Erik (2010, WPI)

**BENIGN SUBSTANCES**

In 1985, I told one doctor that it wasn't unknown for people to have reactivities to antibiotics, and that antibiotics are made from mold, so it didn't seem that my complaint should be so outrageous that no one would believe it.

The doctor responded that this made some sense and that he could relate because he was allergic to penicillin himself.

But he said that my description that certain moldy places in houses were killing me was completely out of any normal range of human response, so he had his doubts about my description of such a profound reactivity.

In all these years, it's been amazing to me that CFSers have been aware that they are hyperreactive or susceptible to so many "benign" substances, yet have completely dismissed the idea that ambient levels of certain types of mold might be one of them.

Staying away from this stuff has sure been worth it for me.

-Erik (2006, CFSExp)

**PROXIMITY TESTING**

When I took a sample of Stachy out to the desert for proximity testing, I was shocked to find that an extremely small amount could still have a mildly discernible effect at a distance. If it could do that, then the implications are enormous.

This changed everything.

Anything that went through a moldy warehouse, anything at all - even something shiny-brand-new and wrapped in plastic - could have sufficient of this substance to keep me jacked up if I were within six feet of it.

Just driving through town, through a plume, can put enough of this stuff on my possessions to keep me vaguely ill.

The overt slams can be felt by most people, so that's what they pay attention to.
Yet the subtle ones can keep the immune system upregulated even if they are barely felt.

The longer the immune system is upregulated, the more anti-inflammatory cytokines are removed as the immune system tries to resolve the problem.

Can't smell it. Can't see it. The reactions are subtle.

Have to go by perceptions. Vague sense of cardio-distress and hypoperfusion. A few others.

Dr. Shoemaker says that by going to the extreme, I was calming things down enough to allow the immune system to reset itself. Which is funny, because twenty years ago, when I would take time every day to make my way out to a pristine area, I used to call it "breaking the response."

Even if one steps away from an overt mold slam, apparently that's not good enough.

One has to get really, really calmed down to allow the anti-inflammatory cytokines to reassert their control over the cascade of upregulation.

-Erik (2007, Email)

LOOKING FOR MOLD

When I realized that the warning signs were not what people think, I took a sample of mold from a contaminated area and trained myself to recognize the subtle symptoms of exposure.

A single contaminated article in from a moldy building was enough to set the entire immune cascade in action.

This has not been easy!

There is most often no odor, no sign, and nothing except your own reaction to use as a guide.

Not only that, but the response is often delayed four hours after exposure and can last for days afterwards, which complicates a strategy of avoidance to an incredible degree.

-Erik (2005, CFSExp)

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Mold acts in myriad bizarre ways that are so difficult to explain that it’s easier to demonstrate.

But the first thing is to not be too eager to rule out mold just because you can't see it, smell it, or find it with conventional tests.

-Erik (2006, Locations)

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I've been in plenty of moldy places which don't have any apparent effect on me. But on the other hand, I've taken articles that were knowingly exposed to Stachy out to the desert, laid out a tarp on the ground, positioned the parameters of the test, done a few experiments to see how close I can get to the lone bad object in an otherwise pristine environment - and the damn stuff knocks me for a loop at a distance of several feet.

So the trick is to identify where it is, what is cross contaminated - and stay just far away enough to be out of range.

-Erik (2006, SickBuildings)

MOVING

Moving never did all that much for me. I had moved many times and even though it made a slight difference, it was just enough to let me know "the effect" existed differentially in various places.

I know people who tried just moving and didn't feel much different, but they took their pillows and clothing with them.

This is the situation I described to Dr. Cheney: "An inexorably increasing reactivity to mold that grows worse no matter where or how well I take care of myself."

This reactivity is nothing like an allergy. It is so difficult to describe that I literally have to haul people in and out of exposures asking, "Do you feel it now?" over and over.

It really saves a lot of time - as in, years of trying!

-Erik (2006, CFSExp)

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If it were as easy as just going to the desert, virtually everyone would be in control of their symptoms by now.
It wasn't. Controlling cross contamination was the key.

-Erik (2008, CFSU)

**GETTING STARTED**

My experiment consisted of abandoning all my possessions and moving into a new camper. I wash everything that goes into the camper including myself. I sleep on a plastic sheet and use four sleeping bags that I wash every three days each so I can rotate any which become contaminated.

I wanted to take my experiment to the ultimate length I could manage to determine how much effect the mold was truly having on my CFS. To my astonishment, many of my symptoms disappeared completely and the ones that remain are greatly diminished and are gradually going away, leaving only the reactivity intact.

My experience indicates that moving does you little good if you take contaminated possessions with you. If you go somewhere that has this stuff and then carry it into your bedding, the upregulation during sleep would not give you sufficient time to rejuvenate.

My problem at this point is not the toxicity of the mold but my own response to amounts that are certainly no greater than parts per million, just as we see in an anaphylactic reaction to aflatoxins in peanuts suffered by those who have been sensitized.

I wish there were a pill for this mold or some easy way to spray bleach on it, but the toxin adsorbs onto virtually any material and any attempts to mechanically remove the colony can spread enough spores to make a sensitized person totally unable to endure the area.

-Erik (2000, SickBuildings)

**NO LIMIT**

My sensitivity crept up on me just like everybody else. I just kept getting more and more sensitive to Stachy no matter where I lived or how I tried to avoid it.

-Erik (2001, SickBuildings)

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It's hard to believe that there is simply no limit to how strong this reactivity can become. Most people tend to think that at some point it probably doesn't get worse.
When you reach the point that no amount of cleaning can remediate a perfectly washable piece of plastic or ceramic, then you find out that the hysterical people weren't kidding about this.

-Erik (2008, IAQ)

**BEYOND THE DESERT**

If I were to have followed the lead of MCSers who live in special communities, their measures would not have worked for me and my chemical sensitivities would not have abated.

Just moving out of mold wasn't remotely sufficient to address my problems. For years I have told people that I am practicing mold avoidance and they instantly dismiss my story because they sprayed bleach on the mold in their shower or moved from one house to another and that should have been sufficient to rule out mold as a trigger.

Not even close!

I'm talking about a level of sensitivity in which I have to test new furniture for a response because many warehouses are moldy.

People who have survived a mold exposure and realize that they are responsive to their possessions rarely stop to think that this may have happened to new clothing, food, furniture or virtually anything else that stored or manufactured in an area that had a similar level of mycotoxin contamination to the house that drove them out.

No expert can accompany you and test or protect you from the inflammatory response from a bombardment of mold hits from the endless number of contaminated items, buildings and spore plumes that you know full well are capable of causing a response.

If an item from the bad house can still hit you, so can anything that came from a similar environment.

Only learning to recognize the subtle symptoms of exposure and initiating an avoidance and decontamination protocol before it turns into a massive immunological response can give you the respite to abate severe symptoms.

You must become your own expert.

-Erik (2005, SickBuildings)
Part 2

Extreme Avoidance
Chapter 7 - Overview

I've lost all the usual stuff, "friends," family, relationships, jobs, my house, savings etc. etc., and it's pretty tough to find out after all of that, none of it was necessary.

If the doctors had listened when I first gave them the clues, it wouldn't have happened.

If I had trusted my own perceptions instead of their bad advice, it wouldn't have happened.

I know this is true, because I finally lost all faith in doctors when I was at absolute rock bottom, and still managed to crawl out of living hell and recover to the extent I did.

It hurts to think of so much of my life that was wasted needlessly.

What I found is that leaving isn't nearly enough - not for me.

"Perception, avoidance and decontamination" is what I keep hammering away at. The mold on my clothes, just as in many other CFSers I've seen in groups, is more than enough to keep the inflammatory response upregulated. Leaving is better than not, but not nearly good enough.

The trick is to break the response before the immune system is so fired up that it creates its own damage. That's why I went to the trouble of obtaining a special "mobile decontamination device." This is why I recovered as quickly and as well as I did, in about six months.

You could accomplish the same thing in a minivan by using a bucket to wash your hair, sponge bath, and change into fresh clothes - being sure to bag the contaminated ones to prevent cross contamination.

And this goes way beyond just the mold that I pick up by entering a building. Anything that has been exposed to mold is the same to me, new or not. Food or furnishings... anything!

This is the kind of lifestyle I still have to maintain to avoid relapsing. I never got over being mold sick. I just got so good at controlling it that no one can tell anymore.

If someone is made ill by mold, I find it hard to believe that taking the extra step to quickly decontaminate would be anything but helpful for everyone.

Until you've experience getting clear and have an idea of what you are trying to accomplish, it seems crazy though.
My reactivity to mold grew worse no matter where I lived. It was that this reactivity did not correspond to one bad house or specific location that made it so confusing. I was getting slammed in small doses all over the place.

It wasn't until I trained myself to stop trying to connect it to one major place and focus on barely perceptible hits from all over the place that I could even tell that the subtle burning sensation and not the smell of mustiness was actually an indicator of exposure.

Mustiness is from microbial volatile organic compounds, and generally not very toxic.

Incidentally, it was that very burning sensation that the teachers at Truckee High School described prior to the onset of their illness - the same burning sensation that I felt there as a student.

This isn't like an allergy with an "on-off" response, where you walk away and suddenly everything is normal again.

Although mold allergy is certainly a problem, mycotoxin illness is a matter of long-term exposure from a wide variety of sources.

It took me months of avoiding subtle sensations before I really knew that I was pushing in a good direction.

What better test could I do than offer to take people to Truckee High School - to the place where the first CFS cluster originated - and have them see for themselves what they feel there?

Of course, learning how to live like a mold avoidance maniac is a whole 'nother deal. It's not easy. But for me, it beats the alternative.

- Erik (2006, Locations)

* We all go through the stage where we'd like to avoid doing anything really crazy, like trashing everything we own.
I sure did. I fought this for many years with every conventional concept that doctors and "mold experts" were totally willing to sell me - while they watched me inexorably falling apart. And it didn't help much.

Finally I had nothing left to cling to.

Possessions meant nothing to me. I was gonna die. Nothing left to lose anymore.

So I had one more thing to try, and went all-out on avoidance on this one specific substance.

And, as you see, it worked out a bit better than anyone expected.

I'd rather live in a dumpster than go back to the way I used to feel.

It's ironic that people have to be dumped down to such a desperate stage that they are willing to do anything before they can experience this. So far, people who have done so only wish they had done it sooner and not tried to cling to possessions that gave every sense of trying to kill them.

I've had silly things like one old book totally permeate my safe zone with badness - and out it has to go.

Testing is worthless and counterproductive. One has to learn to perceive subtle mold clues and act in accordance with them at all times.

This is a strategy for the very desperate who are beyond the threshold of hanging on to their old life.

Trouble is, by the time most people hit the stage where they make this decision, they can't pull it off... and die.

What we need are special environmental units out in a pristine place where people can go to get an educated sense of this effect, before the decision is made for them.

-Erik (2007, Email)

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If someone had just given me the advice to "beware mold," I would have considered it the most important and precious gift I ever could have received.
But nobody knew, and I had to work it out on my own.

-Erik (2010, CAA)

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I was in the military, as a nuclear missile launcher specialist, and was trained in biological, chemical and radiological warfare survival protocols.

The Army knows that is not completely necessary for a soldier to understand what the agent is, to remember its chemical composition, or to know exactly how it does its damage.

The only thing a soldier really needs to know is how to detect, evacuate, avoid and decontaminate in response to these threats.

I noticed that where clusters of CFS had occurred, there was a slight palpable sensation that had a deleterious "effect" on people.

I conducted an experiment of treating these vague sensations using biowarfare survival protocols, and obtained results beyond anything I dared hope for.

This is not an easy way to go. I consider it to more of a clue than a viable therapy that everyone should start doing.

It's a desperate leap.

For those of us who have been able to pursue this avoidance strategy, a significant number have had very impressive results.

-Erik (2010, CAA)
Chapter 8 - Getting Started

OBLIVION

In 1997, I was helping the friend of a married couple with infant children move them into a house they had just bought. Back in those days virtually everybody fought with me about mold. It didn't do any good to say a word.

I was getting slammed in the house so badly I refused to go back inside.

While I was standing in the yard, I heard the owner, doing electrical work, call that the ground beneath the house had so much groundwater that the previous owners had tried to cover the entire basement area with plastic and that he could feel water below.

Meanwhile the two children inside were screaming as if with the colic. The mother came outside and said, "It's so strange. The kids were always so well behaved and quiet until the very day we moved into this house. Now they scream and cry constantly. I get no sleep. It doesn't make sense."

I told the friend of the couple, "You know the reason I can't step back inside the house. You know why the children are screaming. They are your friends and no one will believe me. Will you tell them?"

"No. There's nothing I can do and I don't think they'd believe it anyway."

When I think back on this it reminds me of Psalms 8.2: "Out of the mouths of babes."

If only people would listen.

-Erik (2002, SickBuildings)

* * *

The peculiarity that virtually all stories of mold illness have in common is that people don't recognize it until it hits a certain level. It was certainly having an effect, yet it was not really felt or treated as a serious threat.

The precursor state does not to be sufficiently noticeable to arouse people's suspicions enough to be consistently recognizable, as evidenced by the people who fail to notice and do not connect mold or SBS to their illness until they are extremely ill.
Chemical exposures have the capacity to induce a masking or blocking response in which the chemical is still doing its damage yet the body mysteriously shuts off the response.

This is what we see so often in the stories of people who didn't realize how much trouble they were in until they went somewhere else.

People in the midst of chronic damaging exposure are almost universally unaware of it. The only real exception is the class of people who finally become so ill that they connect the illness to their location even without experiencing the relative shift.

Going to a pristine location unmasks the masking response, and what was felt to be a tolerable exposure is suddenly unveiled as a source of toxicity and a hindrance to recovery.

Everyone I’ve seen who has returned from getting clear is surprised that sources of exposure they thought to be negligible were far more significant than they had previously perceived.

That's why I say that I pay attention to subtle exposures.

-Erik (2006, SickBuildings)

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A friend of mine moved into a moldy house six years ago. His allergies have gone wild and just keep getting worse every year. He's at the point now where pine pollen and smoke dictate where he fears to go.

But he likes his house, and it's easy to rationalize his progressive joint problems, achiness, headaches and increased allergy problem as aging.

That's the insidious problem if a house isn't a total slammer. It'll sneak up slowly and you'll never know how good you might have been unless, by some fluke, you happen to move and experience the miracle of having these symptoms disappear.

-Erik (2006, SickBuildings)

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If you examine the stories of people who were made ill by Stachy, you might notice a funny thing.

Almost none of them thought it was mold. People get carried out of places on a stretcher, and they STILL don't know what happened to them.
You have to take it upon yourself to find this out. Lots of people only stumble over this by moving and wondering why it made a slight difference.

-Erik (2008, CFSU)

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I can't tell you how many times I have heard people say that mold was the first thing they pointed at, "But my doctor told me that this is impossible, so it must be something else."

Most docs will test you for mold allergy and then tell you that you ARE allergic to mold "but mold doesn't cause the symptoms you describe."

I have no respiratory symptoms when hit by toxic mold. That's one of the differences between allergy and toxicity.

Most people are certain that if they were victims of mold, they would surely know it.

They are thinking of an allergy. This is what is misleading them.

Stachy is not particularly allergenic. Thus, people who are thinking allergy are in particular danger of being misled, as they are certain that if there was a serious mold problem, they would be able to detect it.

Until they get that notion completely out of their heads, they are viewing this from such a wrong perspective that meaningful action is not properly conceptualized.

About the only way I know of to make a dent in their preconceptions is to explain that the toxins emitted by mold are an entirely separate issue and that if one examines all the stories of people who hit the wall - the main thing they have in common is that they didn't see it coming.

-Erik (2008, CFSU)

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It seems that the only people who really wish to pursue this are the ones who stumble over the locations effect at some point, and who decide that they are at a desperate stage where they would rather take a flying leap at feeling well than try to cling to their former lives.

-Erik (2009, SevereReactor)

**UNCONSCIOUS AVOIDANCE**
Here one patient describes being helped by “healing peace,” but look at how he achieved his recovery.

>After five doctors in nine months, I was diagnosed with CFIDS. My doctor showed me scans of fatigued brains and said to avoid all aerobic exercise.

>I gave up my apartment. I had my things put into storage and moved home, thankful to have a place to fall back on. I was put on disability leave.

I gave up my apartment!

I had my things put into storage and moved home, thankful to have a place to fall back on!

Sound familiar to anyone?

Yet somehow this patient reached the conclusion that it was stress that he was avoiding.

This is "Unconscious Avoidance."

When I tested my reaction to Stachy by taking a sample to a safe place and found - much to my amazement - that stress/anxiety/depression was the consistent response to such exposure, I adopted these emotional responses as an indicator of toxic exposure and a guide to appropriate avoidance and decontamination protocols.

Depression is not what psychiatrists think it is. Depression is nature’s way of signaling immunological upregulation of inflammatory cytokines and is designed as a warning system of impending damage.

This patient’s story is consistent with mycotoxicosis. He experienced the immunological inflammatory upregulation and depletion of leucocyte subsets which allowed viral reactivation and he correctly observed the correlation of cytokine upregulation with his emotional responses.

His avoidance of the stress/cytokine response was appropriate.

His attribution of recovery by controlling stress was not.

It was avoidance of the immunological response to toxic exposures that induced the stress response that allowed his healing.

-Erik (2005, Locations)

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There are many who changed locations and attributed the change in their condition to other things.

Usually, as their ability to tolerate emotional stress increases, they perceive their lower stress levels to be "what changed." I have an absolute slew of stories about these misguided recoveries from CFS.

It drives me crazy, when I use the depression response as an indicator of toxin exposure. It's just like the connection between stress and ulcers being completely reversed for so many years.

-Erik (2006, Locations)

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I remember a gal who tried everything she could possibly try, and nothing helped in any significant way. And then, she just started improving "for no reason."

Mystified at her spectacular recovery, she said that she hadn't changed anything at all, and that there was no reason for this amazing improvement.

She said, "In fact, the only thing that has changed is that my husband has retired and is hanging around the house all day since he no longer goes to work."

Ain't it amazing?

Just like Osler said. Sometimes a patient can hand their diagnosis to you, even when they don't understand it themselves.

-Erik (2008, CFSU)

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In 1998, I talked with a CFS support group leader in Sacramento who described a situation of learning to avoid driving past a specific grove of eucalyptus trees because this would make her ill for several days afterward.

The alternate route added eight miles to her trip, but she considered not getting slammed to be well worth the extra drive. The doctors told her that she was likely allergic to eucalyptus terpenes.

But I asked her, "Do all eucalyptus groves bother you, since they would all have these same terpenes?"
She said, "No, that's the funny part. It is just this one grove. I don't know why the others don't seem to bother me."

Well, I had this same experience back in the early 1980s with a specific grove of eucalyptus up at the top of Lincoln Ave. in San Rafael. Simply going past it would knock me flat for days.

That's how I learned about mold avoidance - the hard way!

-Erik (2008, CFSU)

A lawyer in Australia became ill with CFS and simply abandoned everything - his work, his friends, his entire life, his possessions, everything - to go live in the Outback like an Aborigine.

Apparently, this formerly well-heeled lawyer preferred this life so much that nothing could induce him to move back to civilization.

It baffled everyone at how he had swapped comforts for hardship, yet seemed very content to do so.

The expectation was that the madman would simply wander off and die in the desert, but he didn't.

In fact, he liked it so much out in his cave that he refused to return to civilization and seemed quite happy to remain where he is - and his health appeared much improved.

That was the clue which made the results memorable. That's what stood out. He didn't fall apart from living under harsh conditions in the Outback.

Just the opposite. His results defied people's expectations.

If you read about the very inception of CFS at Truckee High School and the teachers’ lounge incident that is written about in numerous places, you'll note that many recounts tell the story of the one teacher who bailed out and was the only one of the group who get better.

Now, isn't that peculiar? Many people went in and out of that room without getting ill. Nobody mentions them.

Why would the story of just one of them who didn't get CFS be memorable? It's almost as if some subliminal clue makes the story memorable enough to make it repeated so often, yet people can't quite figure out what it is that makes this one story worth repeating.
"Eric Jordan" was the only one of that group who took direct evasive action based upon the evidence of his own perceptions, and he got direct results. The results directly defied people's expectations. That's why the story got repeated!

But the only way you would have any sense of what Eric Jordan might have been avoiding would be if you happened to go to Truckee H.S. and felt it for yourself.

-Erik (2008/2009, CFSU/SevereReactor)

RESPONDING TO MOLD CLUES

Years ago there was a woman who described feeling so terrible in her house that her husband forced her to spend as much time outside as possible with her face into whatever wind was available, since this was the only thing that seemed to help.

She described a few other complaints that are good clues to mold reactivity, such as feeling especially bad when storms are approaching.

I've practiced the "face in the wind" therapy often enough to be quite familiar with how it works, so I said that I had an explanation which I could give in 25 words or less.

"You are reactive to toxic mold."

"Mold is in your house and on your clothes."

"The wind reduces your exposure and decreases your response."

There was no response. Once again, my secret remains safe.

-Erik (2005, CFSExp)

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I can state the matter in a few short words: "I walked out of CFS hell by extreme of avoidance of mold and mycotoxins," but the words simply mean nothing to someone not ready to hear them.

And the dismissal of the concept comes before enough information is presented to make recognition possible.

The problem with describing symptoms is that people simply do not see them in themselves.
The only way I have found to consistently bypass the contradictions arising from a lack of conceptual framework is to literally drag people through "The Mold Tour" until they feel it clearly.

It seems to take a "mold aware" person to look at them and say, "Wait a minute. I just got a mold hit, and you look like you are responding to it too" before most folks give any serious consideration to the concept.

Even then, I have had people say, "I thought you were on to something, because I could feel it myself, but my doctor told me that mold reactivity is impossible, so..."

So I just keep banging away, bit by bit.

-Erik (2006, CFSExp)

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Someone who has been sensitized and is familiar with the inexorable progression can sense the mold, listen to the familiar pattern of complaints and warn people that they must evacuate before it is too late.

"You don't have to go through what happened to me."

Each and every one of us believes that we can help people by our experience and provide this timely warning.

But we find to our dismay that people do not believe us until it is too late.

Then those people join the growing throng of us who wander around like Cassandra in Delphi: "Gifted with the ability to predict the future, but cursed by Apollo to be disbelieved by all."

So our warnings fall on deaf ears.

-Erik (2008, CFSU)

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I've seen that even people who are looking will not respond to a list of mold clues.

It's weird. It's not the description that is at fault. People have such a strong preconceived notion that they don't see how this list applies to what they are imagining the situation must be like.
The only exceptions I've seen are when the mold levels are absolutely death-drop horrific. It's not even one in a thousand that people will admit it to themselves at lower levels.

The conceptual framework is so hard to break that I have literally dragged people into dozens of mold exposures and watched them deny each one in turn. Really searching hard for reasons not to believe it.

Over and over I ask, "Do you feel it?" They do, but they always find an excuse not to attach any importance to it.

I point at the dents in the skin. "Oh that? That happens to me all the time. It doesn't mean anything."

And then one day, when they have a sense of how they are feeling suddenly take a downturn as we enter a bad zone together, they just turn and say, "I feel something. Is this what you have been talking about? That's all? But it seems so minor."

And it just suddenly falls into place.

-Erik (2008, CFSU)

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CFSers have no means to mentally connect with the mold phenomenon.

The conceptual framework is one of allergy, and since this isn't acting like an allergy, the mold factor is considered to be effectively ruled out.

I have never found any means of convincing CFSers otherwise, without leading them in and out of toxin zones and repeatedly asking, "There it is, how do you feel?"

It usually takes dozens of times before they finally go, "That? That's no big deal, I'm tough. I can handle that."

Mentally perhaps, but the immune system cannot.

-Erik (2010, CAA)

NOT WANTING TO KNOW

I've gone to support groups and talked to people blazing with mold hits and complaining of all the right clues, yet they don't want to hear about it.
When I think of all the pain I've avoided and consider that they are just passing up an opportunity to do the same, I can scarcely believe that they would deliberately choose to do this to themselves.

I think that the concept is just too unfamiliar to be given serious consideration.

Only those people who lucked into a situation where they got to feel the difference can see that this is really something that is worth taking advantage of.

But there is one more thing.

The underlying implication of "Locations Effect" is kind of like saying, "You could take control of your illness if you really wanted to" and "If you aren't willing to move, then you don't want to."

Nobody wants to hear that. They just want their old life back.

I know I sure do, but based on the therapies that were available, this was not an option.

Hopefully, that will change.

-Erik (2006, Locations)

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A Hungarian friend of mine had a house in a region that was gradually going bad.

Over several years, I observed various people in my friend's region as they exhibited greater signs of unexplained illness.

My friend wasn't buying any of my "mold nonsense."

It was an amazing feat of total denial, even when an entire household of visiting friends suffered a subtle downturn simultaneously, while I was noticing that the ambient levels had increased so much that even my MECU parked next door was scarcely any better.

The excuses that everyone uses to suppress the possibility that their downturns may be connected to mold are absolutely amazing.

It actually reaches a point where people become desperate to not find this out.

But finally, one day, she just turned to me and said, "The air here is poison" and put her house up for sale.

I helped her move to a marvelous place out in Colorado, and as far as she is concerned that old place was nothing more than a bad dream.
My constant inputs may have helped shape her decision, but she never consciously admitted it. This paradigm is so horrifying that it appears that humans deal with it by applying a skepticism that is always vaguely unsettled by being challenged from the sheer weight of empirical observations that say otherwise.

It makes people extremely wary and suspicious of anyone with strange information that they don't want to hear. Even when you are only telling it like it is.

Up until the moment people realize that they cannot go on acting in a semi-normal fashion, they have a kind of kill the messenger mentality.

-Erik (2009, SevereReactor)

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Everything I know, the Army taught me in biowarfare training.

We were taught that if you see a foxhole full of soldiers acting strangely and discern the slightest trace of wispy haze, you would be better off facing a machine gun or running through an artillery barrage than you would in that foxhole even with your M17A1 face mask....since nerve agent is absorbed right through the skin.

Slim chance is better than no chance.

One point of emphasis is that nerve agent exposure is distinctly different from blister agents in that NA leaves its victims unable to cognitively bring their attention to the fact that they are massively impaired.

Completely bereft of the mental capability to recognize their situation.

Blister agents will leave no such doubt in anyone's mind.

When I saw how people in moldy buildings were aggressively denying their obvious impairment, I went, "Holy shit! It's the same!!!"

They are acting exactly the way the military said that soldiers will predictably respond to Nerve Agent.

And I said, "Lemme OUTTA this God damned foxhole."

-Erik (2010, SevereReactor)

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People who are being pushed toward the wall are scared and trying to hang onto their stuff. Their life and everything they've worked for are slipping away, and they're in fight mode to keep things the way they are.

They defend the concepts of filters, oils, remedies and "hang in there at all costs."

After one hits the wall, everything changes.

The "lesser stage" mold responders see what happened to us and everything we stand for as a threat, the enemy, and exactly what they don't want to become.

This is testable.

Just propose some extreme tactics in a group of lesser responders and watch what they do.

-Erik (2010, SevereReactor)

**NOT IN THE HOUSE**

In the mid 1980s, I was in a large room full of perhaps a hundred people standing in a long line when "the feeling" came over me.

I couldn't stand up any longer.

I knew it was going to look awfully strange to just sit down on the floor and that this would draw attention to myself. But I was swaying and couldn't help it. I was going to pass out. So I just went ahead and sat.

Sure enough, people turned to look, but to my amazement I had started a trend. I could hear others saying, "Good idea" and "I'm about to hit the floor too."

Within a few seconds about a dozen people just joined my little "sit in," all openly talking about how strange it was that they were overcome by dizziness.

"I'm not alone," I thought. "I wonder why no one is looking into this."

If you wanted to assess the prevalence of susceptible people, all you'd have to do is mount a camera in that place and count the people who are obviously swaying and having difficulty standing up to get a rough guesstimate.

And of course, this is one of the reasons why I discounted the idea that this illness just arises from any particular building and that fixing it will be enough to get you out of this mess.
Get enough slams like that and it doesn't matter if your own house is mold free. It'll catch up with you anyway.

-Erik (2006, SickBuildings)

**EVACUATING EARLIER**

If there is anything that should be self evident, it is that the people who decide to find out just how much mold is affecting them and evacuate before they are totally disabled have better outcomes than those who fight it to the end.

If you are in a place that requires major remediation to be livable, the experience of those of us who tried and failed says that it is more likely that you will just continue to become more ill until you have no other option but to crawl out or take your last breath.

It is better to make the jump sooner than later.

Even if the place was successfully remediated, it would take a long time before the ambient toxin level denatures and your recovery would probably be very slow.

If you went all-out on avoidance instead of persisting in a place that needs major work, your chances of improving swiftly and returning to work would be greatly increased.

-Erik (2006, SickBuildings)

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I spent every penny I had trying to save my house before I crawled out on my hands and knees.

Don't put all your eggs in one basket. Try to keep something aside for the possibility that you might have to just be crazy and get out at some point.

-Erik (2006, SickBuildings)

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There is a great deal of well-intended support which consists of offering alternatives in the form of vitamins, therapies, and filtration systems that have repeatedly demonstrated that they don't do much to help and that haven't really gotten anyone out of this mess.

They are offered in good faith as something that "might help," and perhaps in some small way, they do - a little.
But at the same time, people can literally squander all their money, and all their remaining energy and health, on these palliatives when repeated experiences have shown that they would have been far better off if they had done what they were eventually forced to do in the end anyway.

Get the hell out!

-Erik (2006, SickBuildings)

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I’ve seen this an awful lot. Some people just go into ballistic denial at what they don’t want to hear.

They're the worst, because they tell all the Moldies around them not to listen to people like us.

Then, at the very point they can no longer tolerate their situation, they crawl out and start practicing extreme avoidance.

But by then, they've depleted all their options and what health they could have retained... if they hadn't fought with us and got out at an earlier stage.

-Erik (2008, Email)

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It's an unfortunate conundrum that many ultra-reactors fail to make the choice to evacuate while still at a point in which they have some health, options and resources left, and put everything they have into remaining in a place that is still overtolerance.

The longer one persists in a place that is beyond their personal tolerance, the fewer choices and resources remain - until destitution and homelessness may be the only recourse to avoid demise.

Strangely enough, the forced plight of "induced homelessness" may be the best chance someone has at making a decent recovery.

-Erik (2008, IAQ)

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There is a point, a threshold, after which people are too neurologically impaired to take this upon themselves to undertake.
Once people transcend that stage, they are beyond redemption unless someone physically takes charge and removes them out to the desert for detox.

The outcome of those who received only conventional medical help has been extremely unfortunate.

-Erik (2009, SevereReactor)

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You'll scarcely find a single one of us who has been forced to run for our lives who didn't go through a point where we said, "I'm not there yet."

And when we finally crawled out to our cars because we could not stand one more minute inside our moldy houses, we sat there and cried for this cruel fate that had happened to us.

We wished that we had gone ahead and evacuated while we still had enough health left to think of it as an option, instead of waiting until we had no other choice left.

Because all we got for staying was getting even sicker, and we wound up having to get out anyway.

-Erik (2009, SevereReactor)

HITTING THE WALL

I've talked about carrying a doctor out of a sick building back in 2000.

Basically, it was a client from which I perceived mold hits on her clothing when she entered my office. This raised my suspicions that she was working in a sick place.

Each time I saw her, she seemed to be getting progressively worse, so I warned her that "there is no end to how ill you can become."

My advice was that if the decline is progressive and is not halted by whatever measures one chooses to undertake, i.e. supplements or remediation, the perception of an inexorable decline in health should be the guide to action.

I said that if a day comes when the skin turns red, blinding headaches and crushing fatigue occur, skin perfusion seems to stop, and depression feels overwhelming, that is the day to get out.

Ironically, the sense of paralysis will make this the last thing anyone will want to do.
So I made a point of stopping by to see my friend.

One day, I found her on the floor, telling me she felt like she couldn't move. She was bright red and had rashes on her ankles.

I couldn't stand watching this train wreck in motion, so I picked her up and took her out to the woods for decontamination and fresh air.

When she felt her symptoms begin to ease, the differential in symptomology told her what she needed to know and she decided to never go back.

-Erik (2008, IAQ)

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People are really pushing it when they get to the point of having swollen feet, as the lymphoedema is cutting off circulation, big time.

When their ears turn bright red and the cheeks/temples become flushed, watch out! That is just before hit-the-floor time.

And the closer they get to the edge, the more people deny it, as if wishful thinking can overpower toxic upregulation.

Not hardly.

-Erik (2010, WPI)

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In 1994, during the Lillehammer Olympics, I was watching the Tonya/Nancy show and hit the wall.

I wound up in the hospital and then in Dr. Peterson's office, where he gave me Benadryl to get me through the hives, rashes and outright unpleasantness.

I said, "That's it" and crawled out to my camper as I had done so many times before, because that was the only way to get myself clear of bad buildings.

I gave up on having a normal life and went all out on avoidance, because I really had no other choice.

People keep saying that I'm a fluke, but as I accompany other CFSers into these buildings, I can see that they are responding, just not as dramatically.

Most don't believe it, because they don't want to believe it.
But there’s no fooling those of us who can see the signs.

-Erik (2010, CAA)

**BEYOND MOVING**

It’s easy to take the illness with you by bringing contaminated possessions along when you move.

Terrible when people have to move three or four times because they didn’t know this the first time.

-Erik (2006, SickBuildings)

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If this were as easy as moving to a mold free house, I'm pretty sure that it would be a well established means of dealing with this illness.

I was beyond that point before CFS was created. This is how I wound up BEING a prototype for a syndrome that needed to be created, for a "mystery illness" that nobody understood.

I have to avoid mold at all times, so the concept of "Mold Free Housing" tends to create a misleading perspective of the problem.

The slight differential that I felt when I had moved was just enough to tell me that there was a difference... an almost negligible "something" that was better in some places and worse in others.

It wasn't much. It didn't seem like much, but when you are fighting for your life, you take whatever you can get.

All I did was try to maximize this one small effect, and I wound up getting more improvement than I ever dreamed.

-Erik (2009, Locations)

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> This article says that CNN anchor Campbell Brown has become an expert on mold after her house was affected. She’s moving to a new apartment but has yet to get all her possessions from the old house back.
Imagine what Campbell Brown’s "expert" mold advice would do to some of us, if she believes that she’s on the verge of getting all her possessions back after moving into that new apartment?

Funny, how quickly people think they have become expert on dealing with this and start running around, misguiding others into making the same silly mistakes.

-Erik (2009, SevereReactor)

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We've all changed locations many times, and this has not done the trick.

I took a wild leap at the concept that these toxins are ubiquitous, and that they can be carried on hair and clothing as easily as the CS gas we used as a biowarfare simulant during military training.

-Erik (2010, WPI)

THE MOLD SABBATICAL

I only went to the desert to get a baseline for exposure and get clear so that I could perceive mold better.

When I returned to town, I could then locate an area between spore plumes where I could live safely as long as I decontaminated after passing through.

After I located the areas of spore plumage in Incline Village, I didn't even have to leave town. Just not sleep in those areas and avoid them when they are acting up.

No, I don't sleep outside.

It snowed last night. About twenty degrees outside, brrrr, but I've got a roaring fire in my fireplace.

It takes a lot of work to locate places that are tolerable and not being plumed - but that’s infinitely preferable to the alternative.

-Erik (2006, SickBuildings)

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I was really done with this crap and ready to pull the plug... and then I went out to the desert.
Unbelievable. I thought I was a goner, but I wasn't, at least not quite yet.

Y'all know where the "desert" is? Just keep going past the Last Chance Gas Station....halfway to hell... and almost all the way to Bumphuk Egypt.

If you can get out to the desert or some really pristine location AND leave your contaminated possessions behind, it is possible to induce a remission that is so amazing and inconceivable that people who experience it are afraid to talk about this effect to their fellow sufferers.

But then, thanks to intensification reaction, if you run into even slight amounts of mold, it feels incredibly more potent. So much so that you wonder how you could have ever stayed alive in the place you previously occupied.

-Erik (2008, CFSU)

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If someone only does a bit of avoidance and only experiences a small amount of relief, it's hard to convince them to go extreme.

They'll stay right where they are and try to deal with it without upsetting their life too much.

Logistically it is better to work into this slowly... but without the impetus that is provided by a huge shift in wellness, will anyone do it?

Once you experience "as good as it gets," you feel much more strongly about not wanting to go back.

-Erik (2008, CFSU)

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You know, it's funny how virtually all hang gliding students say something like, "Well, I don't really know if this sport is for me yet so I'll just start out flying low and slow and not get too high, to see how I feel about it."

We instructors would just chuckle. We didn't bother to correct them, because they soon learned the truth for themselves. Once you get into the air, you realize that near the ground is the last place you want to practice maneuvers.

As the old saying goes, "It isn't the fall that kills you. It's the sudden stop at the bottom."

The higher you are, the more mistakes you can get away with and still recover.
"Low and slow, close to the ground" leaves no margin for error.

I've watched people just try to move without knowing what they were looking for.

It's a crapshoot. Nothing more than taking a chance, which has very good odds of being wrong.

Dr. Rea uses an "Environmental Safe Room" to provide a baseline, so people can unmask their reactivities. This is what mold responders can do for themselves in a pristine environment.

To learn the sensation that is to be avoided, the "Go to the Desert" experiment comes first.

And if a person is so ill that they need to be carried on a stretcher, then that is all the more reason to not make stupid and avoidable errors of moving without a definite purpose.

-Erik (2008, CFSU)

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I kept hammering away on "Godforsaken desert" type avoidance because all the stuff that other people were doing wouldn't have worked for me.

Pursuance of what they were doing would have left me in years of misery at best, or possibly dead, considering that I don't feel the way I would have felt is a life worth living.

Judging by the way most of 'em are still bleaching, blasting, bombing with chemical goodies... and still bitching about how it's not getting the job done, looks like it's not working for them either.

Yes, I understand their situation.

What they don't understand is that by doing something crazy like going to the desert, there exists the possibility that they could recover enough to accomplish things they can't even dream of while in their current condition.

-Erik (2009, SevereReactor)

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Dr. Sarah Myhill has found that many of her patients have a peculiar reactivity (she calls it a "mould allergy") that is not picked up by conventional allergy testing.

So Dr. Myhill advocates a simple but alternative type of test.
She says, "I'm afraid you will have to go on holiday," as the prime clue is a change in health by shifting locations.

It could go either way though. If you take your vacation in a place which confers a greater level of biotoxin exposure, you'd get worse.

We've seen this many times, but people misinterpret the results and think the test didn't work because they didn't get better.

Actually, the test did work, but in reverse.

-Erik (2009, WPI)

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The amazingness of "desertitude" is to get a sense of feeling human again.

-Erik (2010, CAA)

**IT PAID TO GET OUT OF THAT ROOM**

People are making this way, way too complicated by trying to make sense of the whole deal before taking action.

I've found from bitter experience that if you lay out the whole thing in one fell swoop, people are so overwhelmed that they just say, “I'd rather kill myself.” You lose them right there.

I think it’s a huge mistake to demand that all the minutiae and details be completely worked out before taking action.

"It paid to get out of that room.” That's pretty much the basis.

It paid even more to stay out of all such rooms. Even more so, to decontaminate after momentary exposure to the same sensation that was in that room, whenever and wherever that sensation is encountered.

Sure, it's nice to work out all the details. But completely unnecessary.

-Erik (2008, CFSU)

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It's getting people to take that first step which is the hard part.
WHO TO TRUST

We all wondered what it would be like when the public finally became aware of this problem, and now we get to see it.

Unfortunately for many of these new mold sufferers, rather than speak with survivors, they take their information from those authorities and "experts" who are just barely getting a clue as to what this is like.

They have the same belief we all did at first - that the mold can be easily cleaned up and that life will return to normal.

Too bad that they see fit to consider extreme mold responders as part of the lunatic fringe and consider our stories to be inapplicable, because they will be joining us soon.

-Erik (2006, SickBuildings)

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People suffer like crazy while everyone plies them with remedies.

And then, usually in the middle of the night, they die of heart failure... and people all bow their heads in sorrow and talk about how much they tried to help.

So glad I said, "Piss on y'all" and crawled out to the Godforsaken Desert...which, as anyone who has been there knows, is really the place where God hangs out.

-Erik (2009, SevereReactor)

TOO SICK TO MOVE

The problem is that people don't feel well enough to move, so they don't find out just how much better they would be if they did.

If someone has the mold clues of illness exacerbation according to exposure, those are the very indicators of how much pain might conceivably be avoided.

The thing that blows us away is that severe sufferers look at their limitations and say, "But I can't do that."
This is a weird kind of situation where you have to crawl out and practice some of this avoidance so you can practice more avoidance.

Getting clear opens up a whole new set of options as energy and function improves.

-Erik (2008, CFSU)

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>So maybe what people need in order to try extreme mold avoidance is someone who will feed and clothe them while they are in the wilderness.

Yes....and to try and convince them that the vague feelings of unease, depression, heart palpitations and skin hypoperfusion that they feel when they are around contaminated objects is not just in their imagination.

Nor is it "Just me....” because the other Moldies can feel it too.

-Erik (2008, CFSU)

GUARANTEES

I don't think anyone can guarantee results on something that is so dependent upon constant vigilance and self determination any more than I could send a hang gliding novice off a mountain and guarantee that they would find thermals, work them effectively... and "sky out."

Occasionally some students acted as if it were the instructor's failure if they didn't get a good flight, but the visible evidence of other pilots who were having a good time served as a demonstration that it wasn't the system which was lacking.

Based on what I've seen, I can almost guarantee that anyone who demands a guarantee is precisely the kind of person who won't make it.

-Erik (2008, CFSU)

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How am I supposed to predict what this will or will not do for others?

I saw a desperate chance to escape my condition of lying around in suicidal agony, and went for it with everything I had.

I had to look backwards over month long periods and try to compare to see if I was really getting better or just imagining it.
And then, after maybe four months. something shifted and my improvement just took off.

When my inability to withstand temperature ranges corrected itself, it was sudden. It literally happened overnight. I was so amazed that I went out and threw snowballs. I hadn't been able to do that for ten years without "Raynaud's-like symptoms."

So I can't say what is going to happen for others.

I'm just saying what I did, and "here is what happened," and that doctors are crazy for not looking into it. Until they do and we get some consistent data, I would imagine that everyone is going to be at least somewhat different - making predictions almost impossible.

And if the expectations are not met according to schedule, people will abandon the concept prematurely.

Seen it happen. Which is really too bad.

-Erik (2008, CFSU)

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Camping for a couple of weeks didn't do it for me. It took several months before I was certain it was really starting to make a difference.

I can't say that this strategy will work for everyone or that they are being affected by mold.

What I do know is that many people who searched for mold, filtered for mold, tested for mold, moved several times to rule out mold... finally got to the point where they realized that none of this means anything.

It only threw them off the track.

-Erik (2008, CFSU)

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> Is there a usual amount of time a person would spend camping in the desert in order to be well?

It varies, and depends on a lot of factors which seem to be subject to change without warning.
It took me about six months to really be certain that this was no fluke and was truly an intervention that was controllable.

Basically, I'm going at this blind.

I really don't know what avoidance can do, who it can help, how long it should take, or much of anything else.

But then, neither do CFS or mold researchers, because they won't look into it

-Erik (2009, Locations)

A “PICTURABLE” EXPLANATION

I think that the initial desert thing is something that needs to be done under guidance. There are many reasons, but I'll go straight to the most important one.

The way humans have trained to conceptualize a problem means that without a "picturable" explanation, they will refuse to respond as an animal might and go with their senses.

If it doesn’t make sense, we simply choose not to believe it until further notice.

I've observed people go through the same test of feeling better in good locations, over and over. Because the foibles are so weird, they cannot generate a full picture of this situation.

Without all the pieces in place, the whole puzzle collapses into a confused mess.

The greatest usefulness of an experienced person is to assure them, "Yes, I can feel it too, and no, you aren't imagining things.”

-Erik (2008, CFSU)

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If I tried to tell you how a hang glider really turns, it would take hours to explain all the nuances.

It's a crazy balancing act of so many factors that it's basically indescribable.

After all that describing, it is still extremely unlikely to the point of near impossibility that you could emulate the actions done by an experienced pilot.
We taught people how to launch and land and made sure they could fly more or less straight without stalling. Then we took them to a very high place to give them plenty of altitude to "work it out before you reach the landing area" and told 'em, "Go to it."

Half an hour of feeling it more than made up for an almost infinite amount of time spent explaining.

It's a tactile, perceptive thing. Gotta just get out there and do it.

Basically, that's how I see training being done, rather than trying to get this out of a manual.

-Erik (2008, Email)

PLAYING THE GAME

Don't blame me. I didn't make up the rules for this stupid game. I just learned how to play it.

-Erik (2008, CFSU)

*

I remember trying to think of how best to describe this.

What I came up with is that it is like trying to make your way through a maze whose walls are lined with barbed wire, razor blades and shards of broken glass... while blindfolded.

You pick a direction, proceed slowly and cautiously, and when you begin to feel something sharp... just as slowly, back away and try another direction.

The goal is to shred yourself as little as possible as you wind your way through the maze.

You start out with a tent and a sleeping bag and if they hurt you, back away and try different ones.

-Erik (2009, Locations)
Chapter 9 - Perceptifying

FINE-TUNING EXPOSURES

This is going to seem strange, I guess, but becoming hyperreactive was the best thing that could have happened to me.

It gave me the ability to fine-tune my neurotoxic exposures.

Imagine if a peanut responder hadn't identified the culprit yet, and was being kicked around by peanut oil, peanut butter on people's breath and packets of peanuts on airplanes, but was just wandering around wondering why he was getting slammed wherever he went.

Now imagine if that person knew to avoid products with peanut oil, could step away when people have been eating peanut butter, and only boarded peanut-free aircraft.

By being able to sense it and step away, the peanut person would actually do better than ever before.

-Erik (2006, CFSExp)

*  

If you have no obvious mold, which is most often the case, it's usually a matter of reaching the threshold of discernment in which your reactivity increases to the point in which it can no longer be ignored.

-Erik (2007, CFSExp)

SUBTLE INDICATORS

I know a "million" places that are contaminated.

But the problem is that the symptoms that I use for detection of mold are the very ones that are passed off as being "just me" or "from within with no apparent cause."

So the first thing I have to do is get people to do is unlearn their conceptions of what responses are emotionally induced as opposed to being an inflammatory reaction to toxin exposure.
The best way I know to do this is explain the symptoms, and then go into a contaminated place and share the upregulation while comparing severity of response.

And then go through a decontamination protocol and compare the relief.

-Erik (2004, CFSResearch)

*

My primary irritant was disputed by all doctors even though I could clearly feel that it was mold, so I adopted the expedient of hiring a mycologist to accompany me while I disturbed various mold colonies. When we found one that such disturbance released a cloud of spores and I collapsed on the floor, I said, "That's the one!"

It was Stachybotrys - and that was the first time I heard the name.

I knew that I had felt this "Stachy Hit" in many locations and that testing by conventional means was expensive, time consuming and would not give me a “real time” indicator of exposure, so I took a sample of a Stachy contaminated object to a pristine location and trained myself to recognize the most subtle sensations of exposure that I could perceive. In this way, I don't require a major slam to recognize that I have been exposed, and I conduct avoidance before my immune system is upregulated to the point of being painfully disabled.

Early recognition and consistent avoidance gave me the break I needed to get on top of the power curve and enjoy a level of recovery I had never been able to achieve prior to making this concerted effort to consistently avoid these specific exposures.

-Erik (2005, SickBuildings)

*

The hardest thing about this is not learning to perceive exposures.

It is learning to accept that certain subtle sensations are harbingers of disaster - and to bring yourself to act in accordance with the gravity of those indicators by understanding the consequences.

When I take people around to hot spots to demonstrate mold detection, most people can feel them. The difficult part is to unlearn the tendency to minimize the perceptual discomfort they cause.

"But that? That's nothing, I'm tough, I can handle that - if that's as bad as it feels."

How bad you feel isn't the point.
The stories you see of people driven out by mold have this in common.

We didn't realize that the minor sensations that we were trying so hard to ignore were actually harbingers of eventual immunological destruction.

It is difficult to listen to warnings that only "hysterical mold crazies" seem to be talking about.

Nobody wants to pay attention these symptoms and warnings until it's too late, and who can blame them?

We didn't either. That's why we're here.

-Erik (2006, SickBuildings)

* "Sensation of extreme lethargy that inexplicably abates upon rising."

That's a "mold clue" biggie. People are astonished that resting makes them even more tired, and that getting up and moving around refreshes them far more than they expected from getting the blood moving.

That's a characteristic of horizontal accumulations of spores which helps to differentiate toxic mold from other household toxins.

That sensation which steals your motivation is so consistent that it can be used as an indication of immune activation. The very time when you feel least able to crawl out and get away from this stuff is the very time when it is most necessary.

The more you notice that strange sensation that you are better once up, and the more that the butt-kicking lethargic Malaise Monster keeps trying to push you back into a horizontal attitude, the more you need to fight, fight, fight.... to stay upright and drag yourself outside for some fresh air.

Don't give in to the Monster. If you lie down, The Monster wins.

-Erik (2008, CFSU)

* Not being able to breathe. It doesn't say much, does it?

Maybe a few more clues, but only after long-term exposure.
Is that it? Is that the difference between health and sickness... the only clues that people are going to get?

Yes, that's it. That is all.

It's like the Army trained us for nerve gas exposure. "If you jump into a foxhole and the soldiers are slurring their words, pinpoint pupils, slight reddening of the skin...."

That's it. That's all the chance you've got. Ignore those little clues, and you are just as dead as they soon will be.

The very agent itself deprives soldiers of the mental ability to perceive what is happening to them. If someone else doesn't see it first, and help them get on their gas masks, and hit them with Nerve Agent Atropine Auto Injectors... their chance to get out is gone.

I know. It's frustrating, like there should be more warning. But there isn't. You can see by all the stories of people who failed to sense their plight that it just doesn't work that way.

-Erik (2008, CFSU)

*

Microbial Volatile Organic Compounds (mVOC’s) are a normal and often harmless byproduct of microbial decomposition. Trying to use musty smells as an indicator of exposure will have you running away from places that may be harmless. Mycotoxins per se have no odor, only an acrid "pungency."

The trick is to discern the burning sensation associated with trichothecone mycotoxins and use that as a warning sign. If musty places don't hit me, I make no effort to avoid them.

-Erik (2008, CFSU)

*

Remember that sensation, but bear in mind that as your reactivity levels change and due to the different toxins involved the warning signs will change.

Even more than how it feels, the fact that "something changed" should be taken as a sign.

And if all the usual suspects of various chemicals have been accounted for as being conspicuously absent and all that is left is the aftermath of water damage, time to suspect that the "suspect" here is mold.
>To get clear before you feel bad, you are using a preemptive leap of faith. What tells you to do that? Something makes me do that sometimes, and I can't really put my finger on it. A smell, but not really a smell. An uneasiness without reason.

Yes! That's it. An almost indefinable intimation of impending doom.

A vague sense of oppression and unfounded dread.

Like an invisible life-draining "nothingness" that is only discernible by feeling your energy being stolen from your body, and by little else.

It almost seems like the most problematic irritant of all carries the fewest indicators of its presence.

Like a cyclosporin, which doesn't really do much of anything except completely shut down normal immune response.

So many times, I've wanted to take researchers to a bad place and tell them, "Not there. Not where you think it is. It's over here."

A quarter century of watching Indoor Air Quality experts test the crap out of places, and utterly fail to correlate "the presence" with people's horrible illness, tells me reliance on their conventional tests is the worst mistake a Moldie can make.

-Erik (2009, SevereReactor)

"THE EFFECT"

It's so simple that it sounds absurd.

Go to a place like Truckee H.S.: Ground Zero for CFS.

Memorize the sensations.

Avoid those sensations as if they were plutonium.

There are innumerable details, but that is the crux of the matter.

-Erik (2006, CFSExp)
The problem with mold hits is they don't have a distinctive characteristic that sets them apart from a generalized inflammatory response.

You have to examine the situation in context to know whether it's a mold hit or something else.

-Erik (2006, CFSExp)

I make no effort at all to avoid normal molds.

There was just this one.... sensation. It happened in certain places, under certain conditions - so unlike mold that nobody believed it could be mold.

"Surely it must be some chemical," they said. But through all the various chemicals, the various places, the common denominator was this strange emission from mold.

I spent years just avoiding this effect. It kept cropping up from places where mold was the only common denominator. I knew that not all molds bothered me, so I figured there was something specific that needed looking into.

Finally in 1997, I hired a mycologist to accompany me while I wandered around to various mold colonies. When one floored me, I asked what it was.

That was the first time I heard of "Stachybotrys." The others didn't bother me, so I now say, "Stachybotrys" because my perceptions confirmed that this one was really bad.

But in general, I just stay away from the effect. Even if it were from other molds, so what? If it causes me to feel anything like the way I felt around that Stachy, I'm going to stay away from it.

If I wind up avoiding other things at the same time, I don't really care... just so long as it works.

-Erik (2008, CFSU)

The way I identified Stachy as an irritant was to lead a microbiologist around to mold colonies until I found one that slammed me and had him tell me what it was.

In all the years since, I have rarely found identifiable signs of the offending mold.
Just the sensation of its presence.

-Erik (2009, SevereReactor)

GETTING STARTED

That doctor I dragged out in 2000 was really working blind.

At the time there was near zero belief in mold. All she really had to work with was me taking her places and asking, "You feel it here?" when she really didn't want to.

And then one day, it clicked.

I got a call. "You have to come meet me at this laundromat."

So I traipse on down there and she says, "Watch this row of chairs."

It was a busy laundromat, and people spread themselves out along this bunch of chairs. Everyone who sat in this one section would jump up after fifteen seconds, leaving it vacant for someone else to do the same... over and over.

With pride, she told me, "I found it on my own! My Very First Plume."

That was a fun one.

-Erik (2008, CFSU)

DEEP BREATHS

>My lungs freeze up when I'm around mold.

Yeah, seems to be a consistent description. And the educated response is always to try harder - breathing exercises - deep breaths.

Ironic, isn't it? The body is trying to send a message to a mind which is too smart to be fooled into accepting it.

-Erik (2008, CFSU)

*

If you can remember Lisa's description of not being able to breathe at Henness Flats, it doesn't say much, does it?
Not being able to breathe. Maybe a few more clues, but only after long term exposure.

Is that it? Is that the difference between health and sickness? The only clues that people are going to get?

Yes, that's it. That is all.

It's like the Army trained us for nerve gas exposure.

"If you jump into a foxhole, and the soldiers are slurring their words, pinpoint pupils, slight reddening of the skin...."

That's it. That's all the chance you've got. Ignore those little clues, and you are just as dead as they soon will be.

The very agent itself deprives soldiers of the mental ability to perceive what is happening to them.

If someone else doesn't see it first, help them get on their gas masks, and hit them with nerve agent atropine auto injectors, their chance to get out is gone.

I know. It's frustrating, like there should be more warning. But there isn't.

You can see by all the stories of people who failed to sense their plight that it just doesn't work that way.

-Erik (2008, CFSU)

*

What a pity that breathing techniques are generally presented as a viable option which might render relocation unnecessary.

I found a "breathing coach" several years ago who was automatically recommending that people should learn to control their breathing in order to alter their anxiety responses.

I proposed to him that if one was breathing something toxic, pursuing better breathing techniques might not be the most productive course of action.

This struck a nerve. It turned out he had been through the mold experience himself, and all his techniques did not protect him from illness nor the necessity to evacuate. He spent years recovering.

After I brought it to his attention that the first reaction to a fear response should be to determine if a toxic exposure makes the fear warranted, he completely agreed.
I thought it was pretty funny that a breathing coach was himself a terrific example of the extreme limitations of the strategy, although he would strangely fail to mention it when trying to promote his product.

Such as, he didn't bother to say how difficult it is for most people to remember to do these techniques when they are in a moldy environment, asleep.

And besides, my cat, who appeared to be affected our shared mold exposure, wasn't interested in trying it at all.

She just repeated, "Me...OUT."

-Erik (2009, SevereReactor)

**DELAYED RESPONSE**

Amazingly enough, when I first started mold avoidance, there was no discernible reaction to mold for several hours. That's what made it a real bitch. I had to remember where I had been four hours before, and make the connection.

But the more I recovered, the more sensitive I became.

People think that the sensitivity is the illness. It's not. It's the body trying to warn you.

But people aren't listening to the warnings and are trying overpower it using "The Power of The Mind."

Big mistake! Should have listened to what the body was trying to say.

-Erik (2008, CFSU)

*

It was the delayed response to what I hadn't thought to be a bad place that shook me into trying to figure out subtle precursors that take a special effort to find. They were more important than I had thought.

After paying attention to these, my reactivity dramatically abated, and my ability to perceive became much greater and much faster.

-Erik (2008, CFSU)

*
When I drive or walk by a planter bed, the smell is so strong it makes me gag at times. Does this mean I am going through a mold plume?

It may very well be... but one cannot detect the bad stuff by smell, which may or may not accompany a toxin source.

The real clue is the way you feel afterwards, up to around four hours later.

It's tricky. If it weren't, everyone would already know.

-Erik (2009, Locations)

**CHOOSING A RESIDENCE**

I can't tell if a house is good or bad after I've been hit.

So I get clear and then go directly to the place and assess my response by trying to sleep there.

A lot of places that seem okay turn out to be bad for me if the wind changes directions, so I have to be there under various weather conditions and wind directions.

-Erik (2005, SickBuildings)

* The best thing is to get clear in as pristine a place as possible, and then go directly to the location you wish to "perceptify."

Before you go inside, face the wind and breathe for at least a minute.

Imagine a scale of how long you expect to live. As in, "On a scale of one to ten, how long do I think I am going to last?"

I call this "The Suicide Scale," because that is honestly how people feel when they are at this point of reactivity.

Put a number on where you fall on the SS. Doesn't matter where. If you are a "two" and think maybe another week of this crap and you are ready to pull the plug, then call it as you see it. The scale is arbitrary, so the only thing that matters is whether you are honest with yourself.

Now go inside and lay flat on the floor, with your nose pretty much down to the ground. If there is an accumulation of spores, this is where the highest intensity of toxin potential is likeliest.
If your heart starts pounding, get out! The place is over tolerance.

If not, sit up and ask yourself if the number on the scale has decreased. As in, you still want to pull the plug but now.... it's tomorrow or perhaps sooner.

A sudden downward shift in the depression response is the giveaway. Not acceptable!

But if you feel nothing, does that mean the place is safe? Nope. Only after you've been in there when the weather changes and the wind kicks up from different directions will you know that the place stays good during times of release.

Having to wait for the weather to find out makes it tough.

But if you have a car that feels okay, you can scope out places. When a storm comes, go to the place and find somewhere to park that is as close as possible.

Try to sleep in your car. Do the scale again. If it goes down - bad area. If not, get out of car and lie flat on the ground and try again.

When you have finally found a place that is utterly free of any shift on the "Suicide Scale," congratulations! You found what you are looking for, by checking to determine what DOESN'T happen.

-Erik (2008, CFSU)

Yes, it's worthwhile to move around and compare how you feel.

Sometimes people blunder into really bad places, and yet this gives them the information the need.

"Here it is, I can feel it. This is what I need to stay away from."

-Erik (2008, CFSU)

The toxins that get me have no odor at all.

I can smell associated smuts and mold odors, but that has nothing to do with perceiving the most important mycotoxins.

The only way I have found to determine if a house is okay is to sleep there.
I might know instantly if a place is bad, but I never know for sure if a place is good until I do.

-Erik (2008, IAQ)

*

Back in 1998, I met a Feng Shui gal who was doing "bad house tests" for her real estate buddies, who wouldn't touch any house she complained about. She told me, "I had to stop doing it, because it would make me so ill for so long."

Seems tempting to start a business to help people by going to their mold zones, but a few people who have done this have found that they can't do it for very long.

-Erik (2008, CFSU)

**ANIMAL RESPONSES**

I don't have kids. I only have the cat that the doctors blamed for my illness.

When we were stuck in a moldy place, while the weather was making the plumes go wild, she would act frantic and desperate.

She would make pitiful crying sounds that I have never heard her make in any other place. There is no doubt in my mind that my cat was expressing how bad she felt.

We got the hell out - the both of us.

-Erik (2006, SickBuildings)

*

My cat, the very same one the doctors told me to get rid of seven years ago as the "cause" of my reactivities, has gone everywhere with me throughout this entire experience.

She is quite the MoldKittyWarrior.

When we get caught in a plume, she jumps up on me, looking me squarely in the eye, and YOWLS as if to say, "You idiot. What are we doing here?"

This happened so many times that I am convinced that this long "meeeoooooooOOOOOWWWWWWW!!!!!!" is kittyspeak for, "Let's get the hell out of here!"
Of course, people’s first reaction is to say, "Oh, the cat is just responding to your emotional state.”

It does no good to point out that I could be asleep in the middle of the night and be awakened by a cat on my chest, screaming at me - and only then become cognitive that I was being moldslammed.

She's a great little fuzzy mold avoidance motivator. I hate to see my furry pal in pain, so we do what needs to be done.


*Dang it.*

A good friend has a house that is going bad.

I can feel it in the shower. You know, the usual tile glued directly to the sheetrock scenario.

I can only tolerate the place for a short time now, and it's getting worse.

Her house is near a training hill where I am preparing for my annual mountain climbing expedition to celebrate my recovery.

(Mt. Whitney five times and the John Muir Trail so far.)

I stop by to pick up her dog, who accompanies me while I hike.

The poor dog is wheezing and choking as she lies on the carpet.

My friend knows my whole story and is one of the people I mooched a couch from when I was driven out of my house during the Lillehammer Olympics.

But my friend is in total denial. She says, "It can't be mold.”

I say, "It's darn funny that the dog is just fine while we are out hiking, and doesn't do that wheezing and gasping for breath while we are outside and when the dog is running thirty miles an hour through the sagebrush.”

But what else can I say?

My friend knows the reality just as much as I do. She saw it almost kill me.

It's so hard to act on a sneaking suspicion and on the "little clues.”
This is the kind of problem where you have to hit the wall and have no other choice before you are prepared to make the hard decisions this situation puts you in.

I tell you what though.

That is one happy dog when I come by to pick her up for our little walk.

-Erik (2005, SickBuildings)

* 

This article says that cats can die of toxic mold poisoning.

What a damned shame for those poor kitties, when the way I hear it... all their owners had to do was spray the place with Thieves Oil and persuade the cats to do Ashok Gupta’s Amygdala Reprogramming.

-Erik (2009, SevereReactor)

NORMAL PEOPLE

I wondered if this was something that only a supersensitive person could do, so I tried demonstrating it to others.

It takes a while, but I've found that mold detection is pretty easy for most people. They always give me an excited phone call when they find their own slammer spore plumes.

-Erik (2005, CFSResearch)

PERCEPTIFYING A BOOK

>Did you and Lisa check out my book?

Yup. We both sniffed it out. We had it on the picnic table at the next campsite over - walking over and putting our noses to it. Must have looked pretty funny if anyone was looking.

I sniffed out the packing envelope, to try to rule out bad post offices.

I didn't feel anything other than on the book and plastic bag. And the plastic bag died down pretty quickly, once it was open and out in the sun.
I felt mild hits off the book. They were just a bit stronger than the hits I was getting when I received my copies of Mold Warriors.

I told Dr. Shoemaker that it was ironic his book was arriving "pre-molded," and he said he didn't have any control over that aspect of publication.

Still, that little "extra" suggests that your copy was in a bad place at some point, in addition to coming pre-molded.

But it sure wasn't the worst book I've encountered.

-Erik (2008, CFSU)

VISITING A STORE

>Today I noticed some areas of a store bothered me, and others didn't.

If you go back outside, get some fresh air for at least a minute, and go directly back to that spot without dawdling in "semi-bad" areas, you might even be able to pick out specific contaminated objects... or point right at where the badness is coming from.

-Erik (2008, CFSU)
Chapter 10 - Depression Response

IMMUNOLOGICAL UPREGULATION

The immunological upregulation involved in the "disease of a thousand names," CFS being the most recognized, is characterized by overpowering depression. Anybody who has experienced this knows that this depression is a physiological response and not one of attitude.

Doctors and psychiatrists are trying desperately to convince people that their depression is the result of physical discomfort and emotional stress. They have completely failed and will continue to fail because the depression response so clearly does not correspond to times of pain and stress, but rather occurs seemingly at random.

The exception to random onset of depression is at times of weather change. Many people recognize a connection but no sensible immunological trigger comes to mind that has the potential for such a profound response.

Neurotoxic volatilized compounds from mold spores are that immunological trigger. Mold spores are primed to release their toxins at times of weather change when conditions of wind and potential water give spores their best chance for dispersion and survival.

The first signs of immunological response to mold are depression and anxiety. Whenever you have sudden onset of anxiety, ask yourself if you might not have been exposed to mold because of a change in weather, wind direction, physical movement to a contaminated location or even someone who might have contaminated clothing moving into your space.

I have talked to hundreds of people with CFS and almost all of them have mentioned the same symptoms and clues that led me to my conclusions about this response to mold. The amount of mold required to trigger this response is so slight that it seems inconceivable to anyone who does not have this reactivity.

Once you recognize a relationship between mold as a trigger and anxiety/depression, no doctor will be able to convince you otherwise because the correlation can be felt so strongly. All I have to do is draw this to your attention. The mere consideration of this as a possibility will be enough to let you draw your own firm conclusions.

-Erik (2001, SickBuildings)

DEPRESSION AND GRIEF
My own experience is that depression and grief are only connected inasmuch as they can coexist and layer onto each other and feel similar enough to appear to be the same phenomenon.

I have grieved deeply for my lost life and the profound expressions of my grief correspond to the profound nature of this illness.

Depression never correlated to any emotional stimulus.

I could have bouts of depression that were layered onto my grief and make it seem like my emotional state had driven me into a supremely suicidal state, but it struck me as really odd that I could have sudden-onset depression when nothing in my life had changed that should have induced an emotional change.

At least it struck me as odd until I found that my depression had a perfect correlation to cytokine storm from exposure to my MCS irritants.

I discovered that my primary chemical trigger was Stachybotrys mycotoxins.

If I am exposed to Stachy, I still suffer from overwhelming depression that I cannot mentally control even though I know it is just a symptom of chemical sensitivity. I can eliminate the depression response through avoidance and decontamination. And I can do it quickly!

Having had the amazing experience of finding my primary "trigger" and being able to induce and control depression at will as a completely separate process from emotional responses convinces me that the article, “A Mind Under Siege,” in New Scientist is right.

http://www.newscientist.com/article/mg17022954.600-a-mind-under-siege.html

Grief is an emotion. Depression is a physiological process.

They might feel the same, but they're not.

-Erik (2001, CFSResearch)

TIMES OF MYCOTOXIN RELEASE

I noticed that my periods of depression and anxiety corresponded to specific places and exposures and determined to use my depression response as a guide to identify my primary irritants. By paying attention to my "emotional" state I soon identified Stachybotrys Chartarum as my primary immunological trigger.

Instead of doing Ampligen, I decided to pursue a strategy of extreme mycotoxin avoidance.
The results were more dramatic than I expected. I have made a spectacular recovery and have returned to an active lifestyle. By practicing a strategy of avoidance and decontamination after mold exposure I have been able to exert control over the inflammatory response and the resulting symptoms of anxiety, depression and fatigue.

I have been searching ever since to find an explanation consistent with my illness and recovery. I believe that Ritchie Shoemaker’s findings are consistent with my experience.

My familiarity with the symptoms of anxiety and depression resulting from mycotoxin exposure combined with my sensitivity allow me to witness varying degrees of the same response in others during times of mycotoxin release.

I believe that many behavioral disorders will eventually be connected to modulation by barometric pressure change and the resulting release of mycotoxins which induces an immunological response from the stimulation of bacterial intermediaries.

-Erik Johnson (2002)

THE SIXTH SENSE

When I found that relying on mold hits was insufficient guidance for a meaningful avoidance protocol, I changed to "the depression response" as an indicator of low level toxic exposures.

By correlating signs of capillary hypoperfusion along with the relative shift of an emotional response which had no associated mental stimulus, I was able to differentiate that portion of an "emotional state" that did not correspond to dysfunctional attitudes and isolate this characteristic as a useful indicator of neurotoxin exposure.

It really confuses people when I describe depression as the “sixth sense” and the most effective guide to detection of an inflammatory condition that nature could provide, since the customary model of depression is of an undisciplined and counterproductive mental state that serves no purpose.

My response to a doctor who offered me antidepressants: "What? Blunt my perceptions and deprive myself of my most effective means of detecting these toxins? I RELY on the depression response."

-Erik (2002)

*
People are so amazed that their "emotional" state is affected by mycotoxin exposure that it generally takes many repetitions of controlled exposure to overcome the longstanding conviction that depression is an emotional response.

But once you've experienced this, there is no denying it.

-Erik (2003, CFSExp)

*I believe that depression is not an illness. It is a warning.

It is the sixth sense - a perceptual interface with immune response.

Depression is to toxic exposures as pain is to a hot stove.

Depression is just the signal that tells the brain about the inflammatory response. It is not an illness in and of itself.

It is a desirable response designed by nature to convey a sense of immunological dysregulation.

It was by acting in accordance with this concept that I proposed the strategy that allowed me to identify my primary neurological irritants and devise an avoidance protocol which took me out of Dr. Peterson’s Ampligen program and back to mountain climbing.

All these years, psychologizers have told me that depression was the source of my illness when it was really means to a solution.

When I found that I depend upon the depression response as an indicator of toxic exposure, I tried to explain this to many hundreds of doctors, researchers and CFS specialists.

One responded with an offer of antidepressants. The offer showed me just how clearly my explanation had been misunderstood.

I replied, "Take antidepressants and blunt my most useful tool for escaping my CFS symptoms? You've got to be kidding. I depend upon the depression response."

I still depend upon it, every day.

Psychologizers have the relationship between depression and dysfunction exactly reversed, just as they did with ulcers and stress.
Yes, there is an association, but with full knowledge of the inflammatory cytokines released by bacterial infection, it comes as no great surprise that the brain might perceive elevated levels of "stress" while bacteria are busy boring holes in your intestines.

I turned my "weakness" into a strength by employing the strategy of using depression as an indicator of toxic exposure.

It was amazing to get CFS during the Incline Village epidemic when no one had ever seen anything like it and virtually everyone denied that such a thing could exist.

It has been equally amazing to find something that helped and have the offer to discuss it completely dismissed and vehemently denied by the very people who are looking for answers.

It has been incomprehensibly bizarre to find that the very "depression" that psychologists say is a result of disordered and maladaptive thoughts is possibly one of the most misunderstood concepts in human history and that it is the psychologists’ own concepts that are the most disordered and maladaptive of all.

-Erik (2005, CFSResearch)

*

The era of blaming depression on disordered thinking is at an end.

Depression is the sixth sense - it is a perceptual construct of relevant information about immunological dysregulation.

Robert Dantzer and Keith Kelley, professors in the department of animal sciences at the University of Illinois, report in Medical News Today 28 Jul 2004:

"Scientists build on case connecting inflammatory disease and depression."


"For the first time, we have evidence of a strong relationship between a molecular event and the development of psychopathology."

Dantzer and Kelley have demonstrated that mice develop fever and display sickness related behaviors when cytokines are administered directly to the brain and that when neuronal pathways from the body to the brain are severed, cytokines do not cause "sickness behavior."
People suffering from depression have sent a clear and consistent message to psychotheorists that their "sickness behaviors" are actually due to sickness instead of the sickness arising from mental attitudes or behavioral traits. Now there is proof.

Perhaps the psychotheorists can now turn their attention to analyzing their own dysfunctional behaviors and determine how people who demonstrate an obsessive preoccupation with theories of psychological causality can fail to understand these clear and simple words:

"We are depressed because we are sick - not sick because we are depressed!"

-Erik (2007, CFSExp)

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This response seems to be based on the innate immune complexes, a primeval arm of the immune system that predates development of antigenic programming, going all the way back to a time when our single cell ancestors only had the basic need to detect toxins:

A sensory mechanism that was so useful that it was overlaid by evolutionary refinements - but not replaced or discarded.

But it sure is amazing to find out that the people who said to "change your attitude and just be more positive" were giving the worst advice possible for this particular circumstance.

This simply shores up people's resolve to REMAIN in an unacceptable exposure level and sets them up for quite an emotional letdown when they find out that neurotoxicity might be endured a bit longer, but not quite overmastered by the power of the mind.

Our freakish numbers are increasing at a rather impressive rate, aren't they?

You would think that researchers would spend a little less time debating and a lot more paying heed to our ominous portents.

-Erik (2008, IAQ)

**ANY DUMB ANIMAL**

Avoidance is something that should come naturally to any animal in the kingdom. It should be the normal organic response to such a sensation.
One would expect that any "dumb" animal would wish to evacuate areas of discomfort and would appropriately act upon their impulse. It is only humans that would even attempt to overpower their discomfort by using mind over matter.

Others in my cohort could clearly perceive the same sensation in the same places, even describing it in Osler's Web. Yet, they also describe their failure to respond to that stimulus, with the exception of the lone teacher who escaped to sit in his camper.

Seems to me that they outsmarted themselves. Maybe I was just too dumb to talk myself out of running for my life.

-Erik (2008, CFSU)

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When I found that my "emotional" responses corresponded to specific locations, I decided that the psychologizers had it all wrong, and that this so-called depression was nature’s own way of inducing an animal to alter its circumstances.

If an uneasy mental state is a consistent response to a location, any "dumb" animal would eventually decide to be elsewhere.

Humans have decided they are much too intelligent to be fooled by these sensations and ignore them.

I was in a sick building and watched a woman come into the office and almost collapse, panicky and breathless, wondering what was happening. The people in the office went into counseling mode and started seeking out and inventing mental explanations for her discomfort:

"Anxiety from an unfamiliar environment."

"Hyperventilation as a response to altitude, since you just came up to the mountains from a lower level."

"A combination of unknown factors and accumulated stress."

"Fluky panic attack."

And the advice was to sit with her head down and BREATHE.

I walked over and said, "Ridiculous! This is a sick building, you are a mold responder, and you just got a good whiff of the spore plume down at the entrance."

I described where the plume was, and how I rely on my perceptions to detect such places and learned to hold my breath when passing through that area. I brought the
woman outside to the fresh air, instructing her about how to hold her breath through the "bad zone," and she quickly recovered.

Amazed, she put the concept to the test and learned that she can safely pass in and out of the building as long as she holds her breath while in the plumed zone.

Once her immune system was upregulated, the breathing exercise that others had counseled her to do in that bad building was counterproductive and only made her more anxious and scared.

Had she responded as an animal might, sensing the association between the discomfort and the place, she might have been guided to hold her breath and get the heck out of there as quickly as possible.

It was the "All In Your Head" rationalizations that intellectually overpowered what is basically a natural response to toxic perception.

This simple explanation is so straightforward and demonstrable that when people finally experience it, they always respond:

"Why, of course! It's just common sense!"

-Erik (2009, IAQ)

ANTIDEPRESSANTS

With a brain already scrambled by mold toxins and viral infection, I figured that it would be best to stay away from any kind of mood altering toxin (antidepressants). I have never taken a single antidepressant, although there were times when I sorely felt the need for a lot of help in this regard.

I take that ominous feeling as a portent of doom, unless I get myself to a slightly better place. This is where it paid off to live up near the top of Incline Village, as I could go into the woods fairly quickly.

-Erik (2008, CFSU)

PANIC

> If I go in damp moldy places, I almost get panicky in my efforts to get away.

Your body is sending you the correct message in that panic response, but most people view that as an emotional response which they should overpower and suppress through "strength of will."
Bad idea.

I rely on this emotional response as a guide to action: evasion of neurotoxic exposure.

So you can see why I'm kind of a crusader against psychologizers.

Their view is that these emotional responses are responsible for the illness and a result of "negativity," while my view is that the sudden shift in an emotional response which has no intellectual stimulus is a sign of your immune system trying to warn you of inflammatory upregulation.

Psychologizers have cause-effect completely reversed, and you ignore the depression response at your peril.

-Erik (2006, CFSExp)

**STRESS**

People "know" that stress caused their onset in the same way they "knew" that stress caused ulcers. They felt the stress first so they think that's the predisposing factor.

If you have bacteria boring a hole in your guts, it's just conceivable that you might have an inflammatory response.

As you read in "A Mind Under Siege," it seems that a hyperinflammatory response can be directly responsible for a depression response. When you try to rationalize the reason for your depression, you always find something in your life that could be responsible... you burnt the cookies or whatever.

I noticed that my depression was the first indicator of a toxic exposure and use it as a guide for avoidance. If I wait until I feel like shit, it's way too late and I'll suffer for hours.

By consistently doing this I gradually started feeling better and better.

-Erik (2001, SickBuildings)

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Stress is a factor, but not in the way people think of it as an immune depressing causative factor.

If at the moment you were feeling the onset of CFS you had only thunk happy thoughts, could it all have been avoided?
I know all too well the overpowering nature of depression and there is no way in hell you can "happythink" your way out of it.

Then I discovered that while sadness and grief are reasonable emotions to feel in the face of having your life stolen from you, my overpowering suicidal depressive thoughts seemed to come out of nowhere.

But that "nowhere" had a pattern.

My depression never corresponded to any emotional stimulus but had a perfect correlation to the inflammatory response to chemical irritants.

The incredible correlation of my depression to toxic exposure made me wonder if perhaps the entire basis of depression is misunderstood.

If nature wanted to induce an animal to change its location or eating habits to avoid toxic exposures, what "emotions" would serve better than anxiety and depression?

I decided to treat my anxiety/depression response as an indicator of toxic exposure and do whatever it takes to avoid areas and objects that induced a mood change.

The results were spectacular.

Far from being a useless byproduct of emotional instability, the anxiety/depression response turned out to be my most useful tool for avoiding toxic exposure and relief of CFS symptoms.

So I agree that reports of emotional stress around time of onset are significant. Not as indicators of a weak mind preparing to succumb to somatization disorder, but as a person wavering on the edge of MCS.

I have learned to become grateful for the gift of depression, because by paying attention to its earliest signs, I have learned to avoid not just the emotional aspect of the response but the later intense inflammatory response that leads to further damage and pain and fatigue.

Now that I have learned to recognize the signs, I can look back over many instances in which I remembered being emotionally overpowered, but in specific locations and under certain circumstances that represented a toxic response.

It wasn't my mental state. It was a toxic response.

I have accompanied enough CFS friends into areas of toxic mold and watched their depression response kick in to see that there is one hell of a basis to consider that depression in CFS is purely a result of chemical sensitivity.
If you could see how I use depression as a useful warning of impending inflammatory over response, you would know why I am so adamant that the role of "stress" in CFS is misunderstood.

-Erik (2003, CFSExp)

A DEPRESSING FRIEND

It does help to know that the "depression response" is just that. Not a reflection of reality, but just an immunological reaction.

"It's not YOU."

In fact, over time, you begin to view this sudden shift in depression almost like a friend, since it has come to warn you of something really important - something you really need to know.

Yes, your depressing "friend" gave you bad news, but it is more important to know the truth.

-Erik (2008, CFSU)

PERSONAL WEAKNESS

Having experienced the joy and mystery of MCS and being driven to the very brink of survival, I can see that many people would have subacute reactions to times of chemical exposure that affected me greatly and these people would be 100% convinced that these symptoms were their own personal weakness and just came from within.

There was no way I could convince them that the simultaneous timing of our responses suggested that they might be having a lesser reactivity.

The inflammatory response induced by MCS correlated so well to anxiety and depression that I use these "emotions" as reliable indicators of toxic exposure.

-Erik (2003, CFSExp)

CIVILIZED SOCIETIES

People go, "Oh my God, so THIS is what it feels like for a normal human."

A doctor friend did some missionary work in South America and was amazed by the happiness in the most utterly impoverished and desperate people she had ever seen.
"How can they be so happy when they have nothing, yet with all the comforts of civilization, I am so depressed? Don't they know they should be miserable?"

And strangely enough, doing this hard missionary work, she had never been happier and looks back upon this time with the fondest memories.

-Erik (2008, CFSU)

HURRICANES

> A survey of Hurricane Katrina survivors found that the proportion of people with mental illnesses nearly doubled after the storm, confirming widespread belief and anecdotal evidence of a heavy psychological toll.

Happens every Hurricane!

The blame is always put squarely on the "stress" engendered by fear, even in people who weren't even close to storm damage but who were just in areas that only had heavy rainfall and some flooding - along with those pesky roof leaks.

-Erik (2006, SickBuildings)

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> The primary purpose of the survey is to identify the current health status of individuals whose physical and psychological health remains negatively impacted from exposures to flood waters, hurricane sediment, water-damaged buildings, mold, formaldehyde and/or mold in FEMA-provided trailers, mobile homes, or park models, and/or other contaminants incurred during and/or after Hurricane Katrina, Hurricane Rita, and/or from other contaminant-laden post-hurricane housing.

At least this time they are trying to factor mold into the study.

That's an improvement over Hurricane Andrew when it was completely ignored.

-Erik (2008, IAQ)
Chapter 11 - Intensification Response

GETTING STARTED

Amazing that just when you think you are taking positive steps toward recovery, your sensitivity goes through the roof.

This is one of the peculiarities that leads people to believe they are taking the wrong approach: "Moving out didn't work. I just got worse. This is the wrong thing to do."

It takes somebody who has been through it to explain that what appears to be perfectly logical can be counterproductive, and that becoming more sensitive post-exposure isn't a sign of getting worse.

It's a normal consequence of detoxification.

-Erik (2006, SickBuildings)

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It is disconcerting how getting away makes you worse for a while.

Previous exposure "primes" you for much lesser tolerance. Stunningly so! It doesn't even seem possible to be reactive to such weirdly low levels.

If you didn't know it was a sign of getting better, you'd swear it was a sign of getting worse.

This lasted about six months for me, and then I just started getting better and better.

-Erik (2007, Email)

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The problem is that people can't help but think of this like an allergy - that if you get away from the mold, you will feel better.

That's not really how it works.

You can go out to the desert or some other mold free place and feel worse. This doesn't make sense to people, so they figure the concept is wrong.
The body senses a safe zone and starts dumping toxins. They feel more sensitive to toxins and conclude the concept is crazy.

It takes a kind of leap of faith to do this. Took me about six months of acting totally nuts before I was certain that this was the way to go.

I can't say for sure if it will help people who are "too far gone" or not.

This is just something I tried.

-Erik (2007, Email)

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I think that in terms of the question about whether one should feel better after leaving, the answer should be, "No!"

The expectation of "Yes" is far too misleading and throws people off the track.

People at a very early stage will feel better, but when once past that point, they feel worse because the intensification reaction is so strong.

Getting out unleashes a crazy detox which can make you react more strongly to unbelievably slight levels.

I was pretty confused about this too. Imagine getting out to the wilderness and finding that I couldn't get too close to my vehicle. Not even stand next to it.

I've seen this so many times, in people's descriptions. It convinces you that getting out is not the way to go.

-Erik (2008, CFSU)

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Here's the amazing part. The toxins that kick your butt so badly out in the new environment might very well be the very same toxins which you took with you.

This is the wondrousness of intensification reaction.

It appears that once the body senses it is no longer in a really bad place, it begins to unload toxins at the greatest rate it can. This makes the slightest re-exposure much more powerful, as it puts you way over tolerance.

It is very typical for someone to get out of a very moldy place, feel this worsening, and be unable to reenter the very place that didn't seem quite this bad before leaving.
It is very hard. But it wouldn't have to be nearly this hard if only there was a safe place to plunk you into. In fact, done right, it feels almost like a normal camping trip.

-Erik (2008, CFSU)

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Intensification reaction is an effect where the damping of inflammation allows the body to sense that it is okay to detox, and the fatty tissues start to dump toxins like crazy.

This is the brutal unhappy thing that separates mold illness from allergies.

Everybody thinks that with an allergy, you can hang in there until you can't take it anymore, and the moment you get out, you will feel better.

In mold illness, it's the opposite. You get out and go hyper, which misleads people into thinking that they've done the wrong thing.

Amazing, ain't it?

Experiencing a worsening of symptoms after getting out is actually a sign that you are starting to get better.

It's very counterintuitive. That's why it's taken so many years for people to figure this out.

-Erik (2009, Facebook)

THE BRUTAL TRUTH

I'd like to draw particular attention to the way you worded this:

"Reactive to everything, even mold on a lemon."

You are describing entering a very dangerous and precarious phase of intensification. When you leave, anticipate a heightened level of reactivity that will take you by surprise.

Those people who think you can stay in a bad place right up until you can't take it anymore, but will be okay because once you get out, it's all recovery from that point on...

Be warned.

This is not like you think.
You are going to wonder how you ever stayed alive in that place when proximity to mere items brought out will drop you in your tracks.

If you want to make it through, make provisions for total avoidance when this occurs.

Based on what I hear, I would advise that you retain help in packing and storing your belongings and do not return.

Intensification will do things to you that you never thought possible, and the doctors will try to damp it down with prednisone.

Which, as Dr. Shoemaker says, can be devastating if someone is both MSH and ACTH deficient - and is almost a guaranteed prescription for MCS.

The allergic model of illness predicts that getting out will result in guaranteed improvement quickly, but this does not apply here.

You are going to be in for a very nasty surprise in that things get much worse before they get better, just when you least expect it.

-Erik (2006, SickBuildings)

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People who try to persist in an overtolerance place are working under the concept that if they hit bottom, all they have to do is get out and the worst is over.

The feeling is, "I'll fight this as long as I can, but if I can't handle it any longer, I can choose that point to bail out and the nightmare will be over."

This is not how it works. I wish it were.

Intensification reaction unleashes a nightmare that is so counterintuitive that people have no idea what just hit them.

This is why I hate filters and Hepa vacuums. All they do is get people to stay in a place longer. The longer they stay, the closer they are to hitting this low point. The lower they are, the greater the Intensification.

Whatever happens, don't let a doctor give you prednisone. Dr. Shoemaker says that this is like trying to put out a fire with gasoline. Some people can place their full-blown MCS from the prednisone that doctors prescribed.

You really need to be elsewhere. For someone at your level, packing things up is totally not worth it. You have to get someone else to do it. And don't expect to visit your possessions for a long time without paying a high price.
I apologize for making it sound brutal. But the halfhearted approach to this problem has consistently shown itself to be far more brutal.

-Erik (2008, CFSU)

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I've seen people do a trial by going to the desert and then find, to their horror, that they cannot re-enter a place that just seemed "troublesome" when they left.

Holy crap. Now you're stuck between a rock and a hard place. It's "motel city" for sure.

So people who are steadily moving down the path of moldiness aren't going to act until they are forced.

Why would they? If you don't feel a serious need, who would do it?

But if you do feel the need, hell, you are already there.

Once people have no choice, intensification reaction puts them in a terrible position that they didn't plan for.

Really, the only solution I see is for "somebody out there" who recognizes the need to establish Plan B for the people who don't see this coming.

-Erik (2008, CFSU)

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I remember once so sleep deprived and needing a break..... just walking out into the desert, scattering rabbits like crazy.

I went out into the sagebrush and curled up on the bare ground.

This sure sucks all right.

-Erik (2008, CFSU)

**REACTIVITY VS. SENSITIVITY**

As intensification reaction proceeds, the body senses an opportunity to release sequestered toxins and does so.
This is a critical period in which a re-exposure is more devastating, since the body is pumping out the nasties as fast as it can.

One has to think of reactivity and sensitivity as separate entities.

Reactivity is how bad an exposure disables you, as compared to sensitivity being the ability to perceive things you never noticed before.

As detox proceeds, with any luck the sensitivity will increase, making you better able to sense and avoid future exposures, while the profound reactivity abates.

-Erik (2008, CFSU)

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It may be that one has to go through repeated periods of intensification reaction before the immune system trains itself for a quick enough response to make the notion of mold hit meaningful.

I've led CFSers and Lymies in and out of mold zones. They had no idea that they had any reaction to mold until I did this, because their reactions were initially subtle and delayed.

But having done this, they would get back to me and describe that with practice, the ability to perceptify came faster. And the more they conducted even the bare minimums of avoidance, the quicker they became.

I'm wondering if what we mean by mold hits is variable to such an extent that it is almost counterproductive to describe something too specific. It seems to work out much better to just have a Moldie lead someone around, asking, "Do you feel it NOW?"

-Erik (2008, CFSU)

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After you move out, be prepared for something you wouldn't expect.

As the reactivity dies down, the sensitivity increases. Places where you only felt mild problems start to drive you crazy. It feels like you might even be getting worse instead of better.

What one needs to look at is how profound the reaction is instead of just whether one feels hit or not. The pain grows less over time, but the ability to perceive can become so acute that you wind up pointing at the most unbelievable things - objects, people, places, air currents, sunshine on an area of carpet.
Everybody around you will say, "But you got out, so it is all behind you. What are you complaining about NOW?"
Prior to getting really clear and reprogramming the immune system for this heightened sensitivity, a person generally lacks the ability to be so specific - and the illness exacerbation seems to come out of nowhere.

You need to go through intensification reaction before the senses become attuned enough to become this precise.

It's a double edged sword because the increased sensitivity can either make your life living hell or be your greatest advantage... all according to whether you take action or try to tough it out.

Most people make the mistake of trying to tough it out.

-Erik (2008, CFSU)

UNMASKING

Your tent may be good. It may be bad. It may be good and then get bad.

If you don't unmask, how will you know? All you know is that you feel like crap, but where is it coming from?

To this day, after I've been in mold plumes, my MECU feels like crap when I get out to the boondocks. I can't feel it when I'm in the mold zone. I have to get out before I can feel it.

This is where the MECU concept serves to educate on masking by minor re-exposures, and unmasking during detox.

If you get out to the boondocks and you have a strong intensification response, but do not feel slammed by the MECU, then you know that the MECU is not what was driving you down and you were pushing it too hard in your other exposures.

As in work, play, wherever it was that you went.... even if it didn't feel all that powerful.

-Erik (2008, CFSU)

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After unmasking out in the desert, it was a real pain in the ass to find out that I could not stay in or stand downwind of my camper.

Basically, a really good pristine spot does you the service of allowing you to make your own educated decisions.
MCS people know about masking. If you have any tolerance left in your immune system, your body will mask a chemical exposure by making a correction, but the very effort of that correction is depleting your reserves. When you have no reserves left, you're in trouble no matter where you go... unless it is to a super-pristine place.

Notice how Dr. Klein had to go through so many hotel rooms before he found one that was tolerable.

Now, the way I see it, these places were probably not all that bad. He was in the throes of intensification reaction and was too amped up to find a safe place. (Been there, done that.)

Still, if a place is bothering you that much, you know that you must surely get out, regardless.

This is the most difficult and troublesome phase of the illness to manage. Without a MECU or tent in the desert (metaphorically - woods are good), it’s super-difficult to deal with. We’re pretty much stuck with moving on until finding a safe place that is reasonably non-hurtful.

Dr. Rea does understand the situation from firsthand experience and employs some sophisticated filtering technology in a Mobile Environmental Control Unit for his own personal benefit.

He also fully understands the rationale for getting clear to a pristine environment for purposes of unblocking.

This strategy applies regardless of whether the nature of the chemical injury is - either mold or some other chemical, or perhaps even both.

People who have not had the opportunity to unmask the increased sensitivity are missing out on a very effective means to enhance their own ability to perceive and avoid the irritant in question.

This allows better decision making for long term planning.
Dr. Rea also describes his own frustration in persuading people to undertake this strategy, almost as if people are hoping that a mental defiance will translate into physical control of their reactivities.

"You can talk yourself blue in the face but people simply won't evacuate."

-Erik (2008, IAQ)

**DISSOCIATION OF TOXINS FROM RECEPTORS**

> I feel bad at the moldy location but feel worse when away from it after a few hours. I am scared. I even feel faint after I eat.

Yes, that is intensification reaction.

It is the detoxification response of dissociation of toxins from the receptors, where they have been locked in place by electron glue.

The fact that you can feel it clearly now suggests that your MSH is very low and your ACTH is almost depleted as well.

Conventional doctors will try to supplement cortisol, which can make things much worse. Like trying to put out a fire with gasoline.

You can survive. You can get through this. We've done it. You can too.

You must find a safe place and not undergo ANY re-exposure until sufficient toxins have been dumped that the inflammatory response no longer goes out of control (lack of anti-inflammatory cytokine damping response).

Read Mold Warriors, P. 89, "Thiazolidinediones (TZD) and Gene Therapy!" about Actos and Avandia damping down immune over response.

This is a perilous stage of intensity. I got my friend through it by taking her to the desert. She had to sit most of the day in the wind outside the RV because she was so reactive. She's doing fine now, though it sure was tough at the time.

-Erik (2006, SickBuildings)

*This is described in Mold Warriors as dissociation of ionophore toxins from their receptors during intensification reaction.*
It isn't a matter of dose so much as being a kind of on/off switch for inflammatory response.

I've always had the perception that once the body feels it is safe to let these toxins go, it does so - and that any re-exposure then is far worse than when the toxins are being sequestered in the fatty tissue. This even leads people to think that "getting out was wrong, because I feel worse than ever."

But they should also notice that they often can't go back into the very house they came out of.

(If you can, it means you still have a little backup ACTH left.)

I think FIR saunas and Ultra Clear detox are good for this period. Have to watch it though. I remember kind of overdoing it on the sauna and winding up unable to move for hours.

At these times of setback, I would get outside as much as possible. The problem is, in many places, there is still enough badness outside that it isn't safe enough.

That's where I was lucky, because I lived at the very top of Incline. I noticed that at these times, if I went down toward the center of town, I would get far worse. The only thing that helped was to take a shower, change the clothes, and go out to the woods - so I did.

I can't predict how long this intensification lasts. I sure it must be different for everyone, and I've seen people who never get quite clear enough to come out the other side and just stay locked into that same level. It's the people who are willing to go to the desert or the coast and live in a tent, if necessary, who seem to get through this the quickest.

-Erik (2007, Email)

Dr. Shoemaker describes the immune reprogramming as dissociation of the toxins from where they are bound by the receptors. The process of releasing is like a switch. It's one of the cases where the dose doesn't count as much as the simple fact that the switch is being thrown.

Isn't it interesting how moving away from mold is what made you aware that the slightest re-exposure throws that switch like mechanism? That's one of the oddities that convinces doctors that all mold sufferers are crazy.

Their underlying mindset is totally convinced that getting out of a bad place must surely result in a decrease of the problem - so when the reality doesn't quite match their mindset, they conclude that YOU don't make any sense.
RELATIVE SHIFT

You tell the difference by noting the relative shift in your degree of reactivity between when you had just walked out of a bad place and walked right back in... and when you get clear and walk back into the same place.

If the intensification reaction is noticeably enhanced and your degree of reactivity is higher than you would expect, where did it come from?

From within.

- Erik (2008, CFSU)

* It's actually pretty easy.

Whenever you make your way to a good location, you generally feel better until you come into contact with something or have a re-exposure somewhere.

If that exposure is strangely worse than you'd expect, as in worse than the last time you were there or came into contact with that object, that's a sign of intensification reaction.

It's the relative shift of your response, correlated to the expected effect of known toxin sources, that tells you which it is.

Sounds confusing at first, but after going through it a few times, it starts to make a weird kind of sense.

And then it gets easier with practice.

- Erik (2008, Email)
Chapter 12 - Increasing Tolerance

LIFE IS MUCH BETTER NOW

Ritchie Shoemaker calls a response that lasts more than a few hours a "mold slam." The lesser ones are just "hits."

When I first started a concerted mycotoxin avoidance strategy in 1998, slams would make me sick for three or four days. Now my tolerance is up to a level in which even the very worst places have been reduced to hits.

I am never sick for more than an hour now. I'm even working full time in a building where I formerly couldn't stand momentary exposure...though if the Park Lane plume blows toward me I have to leave the area.

-Erik (2004, SickBuildings)

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After I left the Ampligen program, it took me six months of extreme avoidance to improve.

I couldn't measure the recovery by comparing symptoms over hours. I had to look at weeks.

But after getting to a higher level on the power curve, it takes me only minutes to improve after a neuroinflammatory exposure.

-Erik (2005, Locations)

*

There have been a few pretty good plumes recently that made me bail out for a while, but if I get 'em in time and hoist myself out to the boondocks, I really only have to resort to this a few times a month.

Amazed how much tolerance I've built up.

-Erik (2008, Email)

*
I found that by a consistent strategy of avoidance and decontamination that I was able to build up my tolerance beyond anything I dared hope for.

I am not nearly so cautious as I used to be, so I'm pretty sure my tolerance has massively improved.

Back in 1997, when I hit a really low point, I was worried that I might be stuck at that level of reactivity. Glad that wasn't the case, but I sure do have to watch it.

I now traipse all over the place and sure, I still have to watch it carefully to avoid falling below the power curve, but this is reclaiming more life than I thought that I was going to get.

I don't get all freaked out about bad buildings anymore.

I used to, you know. When I was moving various friends out of their houses, I had to park a long way away from their houses and use their cars, because I wouldn't take any chances of moving their stuff with my rig.

I am working full time in a place that I couldn't stand for 15 minutes, eight years ago.

I used to live in fear of even driving past Truckee High School, since the road is only a few hundred feet away. Contrast that with the way Lisa and I blazed right inside so Lisa could see the teachers' lounge.

It's amazing to go into places that I used to run from, knowing that I can stand it for a limited time - long enough to see a show, anyway - and still decontaminate before I get into serious trouble.

-Erik (2008, CFSU)

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If I carry the response after any exposure, I decontaminate, no matter where that contamination came from.

If it dies away, I take this as an indication that I was only hit with VOC's and not fungal detritus, and I often don't bother to decontaminate if I feel no lingering effects.

As I get higher on the power curve, I feel the need to decontaminate far less than I used to.

Places that used to feel horribly toxic are now fairly bearable.
I take this as further confirmation that although mold toxins are certainly becoming more toxic, a great portion of the way they felt toxic was primarily due to being so low on the curve and more susceptible.

I am going all kinds of places that used to scare me to death and hardly even having a problem anymore.

I don't have any problems at Home Depot now, not even the lumber, carpet or fertilizer sections.

Never thought that would happen.

Life is much better now.

-Erik (2009, SevereReactor)

OTHERS’ IMPROVEMENTS

> Did Dr. D do anything other than avoidance that might have decreased her own reactivity?

After we diagnosed that moldy CFS clinic and saw how the sick clinicians had utterly failed to help themselves at all with the resources and remedies which they were prescribing to patients, she totally abandoned their concepts and concentrated on pure avoidance.

We laughed all the way up to the top of Whitney at the absurdity of the situation.

Later on, Dr. D was outraged to find the doctor had claimed to others that her recovery was due to his treatments.

He had seemed so decent, so honest and caring.

It takes something like this to find out that it's all smoke and mirrors.

-Erik (2010, SevereReactor)

*

I've seen quite a few Moldies who struggle back up to a semblance of normalcy, but not a single one who ever went exactly back to where they were before.

And.... a few who did indeed continue on that downhill slide until they disappear into the "pit of despair" (cough, cough).
-Erik (2009, SevereReactor)
Chapter 13 - Mold Characteristics

ALLERGY VS. TOXICITY

Mycotoxins are chemicals.

That's why the allergists are so confused.

Mycotoxin reactivity is MCS.

As long as the allergists keep trying to treat this like it was hay fever, they aren't going to be able to help anyone.

-Erik (2002, SickBuildings)

*

Dr. Jens Ponikau at the Mayo clinic has identified a systemic response to inhaled fungal toxins and is reclassifying "allergic fungal rhinosinusitis" as "eosinophilic fungal rhinosinusitis."

The effect of fungal toxins is no mere allergy.

-Erik (2003, CFSExp)

*

When people talk about mold, the component they recognize is the allergic one. They keep wanting to use moldy odors as an indicator - and sniffing, sneezing, watery eyes as a sign they've been hit.

But there is another component, which is not so apparent.

It is the long term interference of toll receptor function by the blocking of these receptors by ionophore neurotoxins.

That's why the mycotoxin connection to illness could hide in plain sight.

People thought that the allergic reaction was the only phenomenon to be measured, and that any other peculiarities that took place in the presence of mold must be something else.

The mycotoxins cause a "panic attack" feeling. Makes sense - they're neurotoxins!
Yes, allergies can go along with this, but the "depression response" is far more useful and reliable as an indicator.

People are amazed when they find out that sensations they had absolutely ruled out because they didn't appear to be consistent with mold turned out to be an inflammatory response to mold toxins. And these toxins can be on something that had been in a moldy place, even though the spores are long gone.

This made people think that mold couldn't possibly be the problem. But the toxins are very stable and can last for years.

No reason to debate the issue. The tests are available. And then you know.

-Erik (2006, Locations)

*

Just like "mycotoxins," the initial "allergy" terminology that was coined by Baron Clemens von Pirquet to describe any abnormal response was applied by specialists to only a specific portion of the phenomenon, but this refinement didn't make its way into the dictionary.

When an uneducated person is quite certain that his description does indeed conform to the actual dictionary definition, he might think to himself that there might be refinements that underlie the terminology, but that he certainly was not being incorrect or inaccurate in any way to employ it in his presentation of the situation.

Wouldn't he ask, "So you are saying that the type of allergy I have is a chemical sensitivity?"

-Erik (2008, IAQ)

al·ler·gy
n.

An abnormally high sensitivity to certain substances, such as pollens, foods, or microorganisms. Common indications of allergy may include sneezing, itching, and skin rashes.
Informal. An adverse sentiment; antipathy: an allergy to cocktail parties.

IT WOULD APPEAR THAT.....
Mold avoidance is a matter of life or death for me, and if I were forced to rely on the advice of "experts" I would have been dead long ago.

The only thing about mold that is important is whether you are in an exposure situation that is enough to make YOU sick.

It would appear that:

Stachy spores fresh from the colony tend to be of such a large size that they don't remain airborne very long (an hour or less) and typically die before they ever make it as far as your mold plate - which it wouldn't grow on anyway unless it was Czapek cellulose agar or cornmeal media. Finicky bahstuds.

However, should a viable spore make it to your wet sheetrock, it would immediately reinforce its shell, build up its reserves and set itself up for the possibility of a long wait lest it be deprived of water again.

Once the damn things sporulate and go into "mold hibernation," they can easily last hundreds if not thousands of years.

Pharoah Out! or "Curse of the Moldy Mummies"

Isn't it interesting that in the Book of Leviticus, it says that if you entered one of those unclean moldy places, your clothes were unclean and shouldn't go home with you and make your house moldy.

Not only that, but you yourself became unclean at least until nightfall. It sounded like they had some sort of idea of how long fresh spores were extremely hazardous to your home's health.

Crazy. (Remember my observations about the hair being a good mold transporter.)

Finding water quickly is only important for Stachyspread.

Live or dead - makes no difference to your immune system.

If you live in a spore plume from your neighbor's house, you can bleach 'em, ozonate 'em, radiate 'em, shoot the damn things - doesn't matter.

As long as the spores or the parts thereof land in your space, you get to deal with the toxins.
Dust in the Wind

What happens to all those spores that degrade into unrecognizable fragments?

If the spores can release their toxins in sufficient amounts to contaminate stuff even though you wipe and wash and blast the spores to bits, does that mean that every stinking bit of the toxin has exited the detritus of the spore and is now on your possessions?

Not bloody likely.

Much of that harmless unidentifiable meaningless dust that no one stops to consider still contains more than enough trichothecene toxins to turn your stardust memories into Stachydust nightmares.

Sleepytime!

Stachy, being heavy, usually just drops to lie on horizontal surfaces.

If it's so hard to find airborne spores, why do we get so sick?

The spores release their dang toxic gas and we get to breathe it whether we are snorting dustballs under the bed or not.

But! Ever notice how sick you get when you're lying in bed with your face close to the horizontal surface of the bed.

Sometimes you wake up so groggy that you can hardly move, and GEEZ, I felt so tired I could hardly get up, but now that I'm up, I feel so much better for some reason.

How could that be?

I wonder if there's anything on that bed?

I've heard trichothecenes are pretty heat stable. I haven't heard of anything that degrades the toxin in a way that makes it safe for us.

All I know is that I've washed plastic stuff in hot water and left furniture out in the sun and it didn't make any difference.

I had a pair of waterproof binoculars that gave me palps every time I tried to use them. I washed 'em but it did no good.
The only thing that made the badness go away was time.

No way to predict how much time since every object has a different level of exposure, a different absorption/adsorption capacity, different levels of toxicity according to the properties of the mold and a varying propensity to outgas, depending on environmental factors such as temperature and humidity and barometric pressure gradients.

How long does this trichothecene crap last in a human body?

I'll bet the people that tested trichothecene as a chemical warfare agent would know, but there again, clearance probably depends on so many factors that it wouldn't be meaningful to attempt a broad projection to apply to so many variables in different people. I don't know, and they're not saying.

When does the toxin come out to play?

At times of barometric pressure change.

The spores seem to be constantly building up internal pressure so even though they're always popping a certain number, they're primed to release a staggeringly higher amount when the barometric pressure has a sudden drop. Kind of like a bunch of balloons that are blown up as much as they'll take and then you put 'em in the back of your minivan and drive quickly up a hill. Blammo!

That, I think, is why people complain so much about change in the weather and being able to sense a barometric pressure change.

It's not the air pressure. It's the mycotoxin release. At least it is for me.

I hear rumors that light and humidity change can set these critters off too.

Mold is pretty amazing stuff. When the experts tried to grow it in the lab it wasn't toxic at all. Turned out that unless Stachy has competition, it won't even bother to go to the trouble of producing toxins. How efficient!

And since the toxins it does bother to produce depend heavily on what it has to work with, toxicity varies considerably depending on the substrate it's growing on.

No good trying to even guess at toxic exposure based on toxicity measurements of a sample of spores. It changes even within the same colony.
Trying to measure someone’s exposure to mycotoxins by counting spores in a mold plate is like trying to measure someone’s secondhand smoke exposure by counting cigarette butts in an ash tray.

The only measurement that means a thing is whether you feel good or bad in that environment.

Do people become identically ill in the same environment?

Hah! Most people think you are totally crazy if you claim mold is making you horribly sick.

The group that just gets a bit of malaise and a headache know that mold is a bad thing, but think you're either exaggerating or perhaps a genetically weak person who needs to be weeded out of the gene pool. At least it'd be better all around if you'd just shut up about this mold madness.

Can't we come up with a test that'll tell us how much is safe?

If there's such a disparate range of response, to whose response to we tailor a test that determines how much is safe?

The person who thinks you're crazy can probably eat Stachyflakes for breakfast.

The headache people can take aspirin and keep their job. They're probably the majority, so in a democracy, we'd decide that a level that keeps them just under pounding migraine is a good test for the masses.

How much good is that going to do for you?

How happy would they be if you were King of the World and burned down all the places that give you fits but don’t faze them?

I know everyone who wants to legislate limits for mold is going to hate me for saying this, but I have to live with the reality that there is no standard that can possible apply to my level of sensitivity.

I'm not against creating a standard for mold exposure, especially in the workplace, but it won't help me. I can feel it on people’s clothes after they've been in a bad place.

Would mold limits have prevented me from becoming sick?
I don't think so. I never lived or worked or was anywhere that other people didn't share my approximate exposure. I can see that some of them are suffering a bit, but nothing like me. Go figure.

So if you're anything like me, the advice the experts are giving to give you won't even begin to reflect the reality of the extreme measures it takes to avoid feeling moldcrappy.

Why Me?

Been trying to figure that one out nonstop.

-Erik (2002, SickBuildings)

**STACHYBOTrys**

There's no guarantee that Stachy will get enough moisture to overgrow other molds. From what I hear, mixed colonies are usual.

-Erik (2005, SickBuildings)

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> My own experience is that different environments cause different symptoms with me.

That has been my experience too. It was easily apparent that this was no allergy to a specific mold but a reaction to components of mycotoxins from different molds.

Yes, Stachy has a large spore that requires comparatively more moisture than other molds. It doesn't stay airborne long.

That alone should have been a clue to the "allergy" theorists that this was not consistent with the entire aspect of the illness.

People are dropping in places where no airborne spores are found at all - but there's generally still some Stachy around. Why would people be so affected by a spore that is almost never inhaled? You do the math.

And of course, the toxins vary by moisture, substrate and pressure from competing molds so the toxicity can be variable in spores from the same species within the same colony.

-Erik (2005, SickBuildings)

*
When no doctors would help me to figure this mold problem out, I hired a mycologist to accompany me to various mold colonies so I could assess my reaction and have the offending one identified.

When we got to a black mold on some joists, I stuck my finger in it.

He said, "I wouldn't do that if I were you!"

And I replied, "This stuff? This isn't the one that is bothering me or I'd be slammed by now. Hell, I'll eat this mold on my peanut butter sandwich for lunch. This isn't the stuff."

And that one was "Aspergillus Niger."

Then we moved on to Penicillium, and that didn't do it either.

Finally we hit a mold which, when disturbed, put me down for the count. And as I was dropping to the floor, I said, "THAT'S THE ONE."

Stachy, of course.

Nothing like self testing when doctors refuse to help.

No question about the results.

-Erik (2006, SickBuildings)

*

Other toxin forming molds do the same thing, but Stachy is especially good at what it does.

-Erik (2007, Email)

*

Isn't it absolutely fascinating how people in Stachy ridden houses stubbornly keep pointing at that darn blackish mold, no matter how many times they are informed of other contributing factors which they aren't supposed to be discounting?

Wonder why they just won't give it up and just implicate all things equally?

Must be Stachybotrys Hysteria (StacHysteria).

-Erik (2007, IAQ)
In 1999, I asked Dr. Marinkovich about Ig testing to satratoxin, and he said it was unavailable. I asked how he was determining the degree of reactivity people had to Stachy, and his reply was that he was extrapolating it by the reaction people had to other measurable mold responses.

That's when I said that this wouldn't work, because, "Compared to Stachy, these other molds are less than a mosquito bite on my ass.”

Of course, I wouldn't have known this if I hadn't done my own proximity testing to find out.

So other patients, who had no way of knowing how fierce Stachy can be, may have been misled.

-Erik (2008, CFSU)

I have a woodbox in my MECU rig, to feed the fireplace.

The wood is covered with Aspergillus.... Niger, probably.

 Doesn't seem to give me any trouble at all.

-Erik (2008, CFSU)

Each and every spore contains a myriad of factors, from pre-sensitizers like beta glucans, to stable toxins like trichothecenes, to immune suppressors like cyclosporins.

They are all going to vary, based on species, substrate, water, competition with other microbes, and developmental and genetic differences.

So trying to think of this as one toxin with a predictable span of effects is pretty much doomed to failure.

-Erik (2008, CFSU)

This is how you can tell that CFS researchers don't know about the mold.
They talk about Sick Building Syndrome and conspicuously fail to mention it. Anybody who does know about it puts it at the top of the list.

There are many considerations in Sick Building Syndrome. But in general, people seem to make the mistake of leaning so far in favor of keeping innumerable other things in mind that molds and mycotoxins are often de-emphasized into inconsequentiality, and are left unconsidered or pushed to the back burner. Sometimes even for decades.

People are already somewhat accustomed to thinking of bacteria as harmful organisms, and therefore have a tendency to discount the input of toxic molds by comparison. I've seen many people eagerly seize upon formaldehyde or carbon monoxide as a much more agreeable and familiar alternative.

And yet throughout the myriad of contributing factors, Stachybotrys continues make its presence known and distinguishes itself with an disquieting frequency.

Lately, more and more people are finding out that mold deserved a little more attention than it received.

-Erik (2008, CFSU)

*

I use the mnemonic "Sticky-butt-juice" for Stachybotrys. No one forgets it.

-Erik (2008, CFSU)

MUSTINESS

I never use musty odors as a guide. They completely throw you off the track. There are lots of microbial Volatile Organic Compounds (VOC's) that are fairly benign and a normal part of the environment.

The ionophore toxins have no odor at all. At best, they induce a sensation of acridity or burning. At lower levels, you won't feel a thing - but they'll still be building up in your system, just like the cumulative effects of carbon monoxide.

I can go into many moldy and musty areas that don't bother me at all.

Once people discover toxic mold, they go crazy and start implicating all mold.

It's not a good idea to try to wipe out all mold. Without mold to do its normal and necessary job of decomposition, we'd be in a real mess.
The enemy isn't all mold, just a few toxin-forming species that have become rather ubiquitous in buildings - thanks to a rather unfortunate chain of events that people unwittingly set in motion.

-Erik (2006, Locations)

mVOC's are just the farts from what microbes eat.

That odor comes from mVOC's, microbial volatile organic compounds from normal metabolic function as mold colonies subsist on substrate.

Sure we can have VOC's without mycotoxins. Lot's of 'em.

The killer stuff that we need to worry about is the secondary metabolites: the antimicrobial mycotoxins that are packaged in the spore to give it protection from competitors as it wanders off to attempt to start a new colony.

Since all slimes, molds, smuts, yeasts and bacteria produce mVOC's as a normal non toxic byproduct, using a musty odor as a guide to avoidance will have you running from a lot of places where "good fungi" and bacteria are just doing their normal and necessary job of decomposing waste.

That's why I don't bother to run unless I perceive something a little stronger. Either VOC's that happen to also have secondary metabolites, or just the reaction even if I don't smell anything.

Mycotoxin avoidance is primarily dedicated to staying out of the range of toxic secondary metabolites that come from mold colonies in spore clouds - which, when driven by the wind in a specific direction, are called plumes.

-Erik (2006, SickBuildings)

The neurotoxic mycotoxins have no odor per se.

They creates an acrid, burning olfactory sensation.

The trick is to distinguish acridity from stench so there is no need to run from harmless mVOC's.

I only respond to sensation and not to musty smells.

Spores just drift around, armed with their antimicrobial defensive toxins.
Decomposing areas of mustiness can also contain aerosolized bacterial endotoxins which can be very nasty. I'm not saying that mustiness should be ignored, just that it's not a reliable indicator for the mycotoxins that really make my life miserable.

-Erik (2006, SickBuildings)

*Mycotoxins have no odor. Mustiness is a normal byproduct of microbial decomposition - mostly harmless. Because molds put out mustiness, the temptation is to use that as an indicator of toxic exposure. But it just doesn't work that way. Mycotoxins are a separate deal.*

-Erik (2007, CFSExp)

*Mold is a natural, normal, and necessary part of our environment. Without "good" mold, we would be in a real mess. I'm only concerned with the bad stuff, and make no effort whatsoever to avoid any type of mold that isn't bothering me.*

-Erik (2008, CFSU)

**SPORES VS. TOXINS**

I'm told that they have identified a housing project contaminated with Stachybotrys where the colony was so tightly sealed that no spores were escaping and the toxic volatile organic compounds alone were causing inhabitants to become ill.

The tests I have done on myself indicate that the VOC’s are sufficient to re establish all my symptoms without inhalation of the spores.

My sensitivity is sufficiently extreme to enable me to easily identify contaminated materials and correlate period of barometric pressure change to increased concentration of toxins as the mold sporulates.

-Erik (2000, SickBuildings)
Dr. Sprott’s work with controlling SIDS by covering moldy mattresses with an impermeable plastic membrane and my experiment with controlled exposure to a contaminated object under layers of blankets confirms the importance of understanding the mycotoxin effect.

My experience is that an avoidance strategy must take this into account in order to be effective.

-Erik (2002, SickBuildings)

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The mere presence of mold does not necessary mean that there are mycotoxins or spores in the air.

We all know that you can come face to face with Stachy and STILL find no airborne spores. Strange, but true.

And if one considers mycotoxins to be defensive secondary metabolites, then non toxigenic molds which produce none can be present in great quantity - but still no "toxins" are present.

-Erik (2006, SickBuildings)

* 

I tested my reactivity by wrapping a sample in a HEPA filter and placing it under six layers of blankets and trying to sleep on it to see if the "effect" could be filtered out. The results caused me to propose to Dr. Marinkovich in 1998 that the toxins sail right on through a filter and that spore inhalation is not necessary to create a response.

Acting somewhat surprised at what I had done, he told me that he had just heard about a housing project in Sweden where the inhabitants were all sick but airborne testing revealed nothing. When the walls were opened up, the colony was found - so tightly sealed that spores were not escaping.

But it made everyone ill anyway.

He said, "But this information has not been peer reviewed" as if to mean that it might be unreliable. Well, since it was consistent with the results I had from my own personal reaction to a sealed sample, I choose to act in accordance with the likelihood that the report was completely accurate.

Not much use concentrating on counting spores if the toxins operate independently.
"When the spores aren't releasing mycotoxins."

Those toxins don't just poof into existence on their own.

They have to start out from somewhere, don't they?

Once the spores degrade, you are dealing with toxin laden fragments.

Once the fragments are gone, the adsorbed toxins are another matter.

This is what I demonstrated to Dr. Marinkovich with the Hepa filter/blanket test.

-Killing Mold-

People with CFS often are hit by allergies to common mold spores. But the only mold component that I am concerned with is from specific mycotoxins that are produced by certain toxin forming molds feeding on building materials.

The most potent toxin formers have more limited range due to their large and heavy spores, so spore counts from weather reports tell you nothing about toxic exposure.

Mold toxins remain whether the spore is alive or dead, so bleaching or killing the mold by any means, including just depriving the colony of water, can dry out the colony. This can liberate clouds of lightened dead spores and increase your exposure to mycotoxins.

Like Dr. Shoemaker says, we have a great deal of experience with this problem - and the solutions sold by snake oil salesmen will only lighten your wallet but not your toxic burden.

-Killing Black Mold- without some warning that killing mold can actually release more toxins and make you sicker is a pretty good indication that the purveyor has leaped on the "mold is gold" bandwagon without a full understanding of the problem.
Killing mold doesn't necessarily do anything to remove or neutralize the mycotoxins, which are quite chemically stable and remain potent whether the spore is alive or dead.

Thanks to vast amounts of advertising, people go to great efforts to kill mold that is probably already nonviable after a few hours in the air without water - and do little about removing the spores, which still retain their toxic pathogenic potential.

-Erik (2008, CFSU)

IONOPHORES

This is why scientists can't find anything.

They don't understand that this is Ionophore toxicity.

These toxins adsorb by Van Der Waals type forces.

Their covalent bonds are dictated by electrochemical sub-molecular dispersion forces and are not governed by the physical mechanisms we usually visualize.

This is why I said that I must do preemptive avoidance rather than try to remediate anything.

Once an ionophore toxin gloms onto something by submolecular bonding, it cannot be removed by conventional means.

This is why Dr. Shoemaker uses CSM, because its long-chain polystyrene backbone has a specific electrostatic charge that has a special affinity for ionophores.

And that is also why I am suspicious about certain types of plastic, because they possess this same potential for toxin acquisition.

Certain materials must be kept away from the really bad contamination zones, period! Because once the ionophores take hold, there is no way in hell you can really clean them off, so far as I know.

-Erik (2009, SevereReactor)

MYCOTOXIN DEFINITION

In the lack of any doctors to help clarify the nature of this toxic-type reactivity that was apparently to a...

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my-co-tox-in
....I carefully took a sample of Stachybotrys with some tongs and walked into the wind while placing the mold inside a plastic ziplock bag and sealed it. I then took that ziplock bag, and again, walking into the wind, inserted that into another ziplock bag.

And then I washed the bag in soapy water and rinsed.

Despite taking these precautions to avoid contaminating the exterior the bags, I still felt mold hits which could not possible be from spores, as they could not penetrate two ziplock bags.

Despite the protestations of doctors that mold was merely an allergen, the nature of this reaction caused me to conclude that it was indeed a...

...and my solution was to devise a strategy of...

...avoidance, which led to a greater resolution of my CFS symptoms than anything else I ever tried.

So whether it is considered by "mold experts" to be a secondary metabolite or an MVOC, I will continue to practice a strategy of...

...avoidance.

-Erik (2007, IAQ)
With the onset of our illness phenomenon, we needed some means to describe the strange and unfamiliar paralytic sensation we were experiencing.

We had never felt anything like it before and reached for the closest and best descriptors we could find.

What came out was "beyond any fatigue I have ever felt" or "profound death-drop exhaustion that is indescribable."

And, most doctors merely picked out what they wanted to hear, what fit into their box - and ignored the entirety of our expressions, compressing everything down until it fit within their conceptual grasp, which wasn't even close to what we were describing.

So it is with "mycotoxins."

The dictionary is clear enough, "myco = mold" and "toxin = poison," so we employ it, hoping that "experts" won't fight with us too much, and maybe even help us out a bit.

If it comes from a mold and has the properties of poison, it's going to be quite an arduous job to argue with all the people who are properly using the term - as they will continue to roll right over "experts" by sheer force of numbers.

Trying to tell people that mycotoxin only refers to secondary metabolites without changing the dictionary is like saying "automobile" only means "cars from Detroit," and other vehicles are not automobiles. Why not just say "secondary metabolites," if they are the "mycotoxins" under consideration?

And now I see that we have another "SVOC" excuse to tell people that if they say the offending irritant appears to be a gaseous emanation that might be an MVOC, that there is still nothing to investigate... because they aren't asking correctly.

If perhaps, at the beginning of the CFS epidemic, researchers had investigated the phenomenon rather than debating us with by saying, "You aren't saying it right, so there is nothing to investigate," we might know by now if the offending agent involved is a mycotoxin, or a poison that comes from mold, or perhaps a bacterial interaction of some type.

It's staggeringly crazy to watch people having their mold suspicions stymied by experts whose doubtfulness and intransigence is based on semantics instead of a legitimate reason to be disinterested in solving this problem.

-Erik (2008, IAQ)
If "mycotic" means related to a fungus and "mycosis" is a reference to a disease caused by a fungus, how can "scientists" possibly reframe the terminology to exclude the basic essence and core meaning of these terms?

What would it serve to amiably adapt to the "scientific meaning" if it forces on to say,

"I was poisoned by nontoxic mold"

or have to ask,

"Is my fungal illness not of mycotic origin?"

To someone that has been made ill, and is clearly discerning a toxic effect from mold, it would appear that scientists must surely have lost touch with both science and sanity to deny that these words have relevance here.

-Erik (2008, IAQ)

Isn't saying that mold is not toxic but can produce mycotoxins a bit like claiming a rattlesnake in itself is not poisonous but you wouldn't want it to bite you?

-Erik (2008, CFSU)

The word "mycotoxins," although it simply means toxins from a fungus, has been misappropriated by mycologists to describe what was probably the first substance that was identified as being a specific toxin from a mold produced for a definite competitive advantage: the secondary metabolites.

These scientists have become very protective about this one restrictive usage, because they failed to leave room for any other undiscovered toxin from a fungus that they hadn't identified yet.

Without any foresight for what they might not have discovered yet, they didn't leave us any way to use the term, no matter how appropriate it might be.

Which leaves us without a convenient means to describe a toxin from a fungus that might not be in their literature.

I try to get around this by calling it "the response," "the badness" or simply "the effect."
But people don't want to hear this, because it means little to them.

Yet when you try again, and say that it is some kind of "toxin from a fungus, a myco-toxin," you immediately get shot down again on semantic grounds.

As long as we simply agree that this is an invisible substance that is emitted by biological organisms such as mold spores, which can be completely separate from the organism which produced it and still elicit a profound immunological reaction... I have no problem at all in just calling it "The Badness."

-Erik (2009, SevereReactor)

**SATELLITE COLONIES**

Mold will grow on cement, if the cement has absorbed organic materials which will support the colony or is adjacent to anything that mold likes to feed on.

Satellite colonies often appear in places where mold wouldn't ordinarily grow if necessary metabolites are replenished by plumes from the main colony.

Mold will even grow down the length of the strands of fiberglass insulation by passing along nutrients from the closest source. So as long as one portion of a mold colony on cement has access to food and the concrete is a source of moisture, mold can bridge the gap and spread onto areas where it otherwise wouldn't grow.

I suspect that the mold in this toilet is an opportunistic satellite that is being supported by another source somewhere in that bathroom.

I would look behind the shower first.

-Erik (2005, SickBuildings)

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If you see mold growing in a place that isn't really mold friendly, as with the example of finding Stachy on a radiator, it's a good bet that it's coming from somewhere else and that if you got rid of the mother colony, these places would probably cease to be a problem.

If you don't find the main source, you'll go nuts putting out spot fires.

-Erik (2006, SickBuildings)

*
Mold is morally superior to humans.

I observed how mold extended far down strands of fiberglass insulation for many feet away from the closest source of cellulose and moisture and asked myself, "If you stood in a food line and asked people to take what they need and ‘pass on the rest,’ how far would the cooperation of humans extend?"

Clearly, mold is a much more sharing and caring creature than humans.

By our own moral standards - a superior organism.

-Erik (2006, SickBuildings)

* 

The source of the “really bad stuff” is not likely to be found on windowpanes.

If mold is growing there, it's very likely being supported by a mixed mother colony somewhere that could very well contain a culprit neurotoxin producer.

But you don't want to mess with a mother colony! You don't even want to personally find it.

Trust me on that one.... they're a MuthaF.... and they whup you worse than a redheaded stepchild.

-Erik (2008, CFSU)

SPORULATION

Archeologists have opened Egyptian tombs that were hermetically sealed and had air pressure differential and that lit up with fungal growth as soon as they were opened.

Fungi still viable!

The "Curse of the Pharoahs" can still kill today.

I read recently about a researcher who dropped with Aspergillosis after examining Nefertiri’s starry vault.

But the properties of sporulation require reinforcement of reserves for such long periods of stasis. Spore plumes are fragile according to what I read.

-Erik (2005, SickBuildings)
When mold colonies get plenty of water, they increase toxin production because they have the biological means to do it.

But more water also makes colonies more cohesive with less spore release.

This is why Chin Yang and some others are totally against killing mold, drying out a colony or using fans.

It's when the colony dries out that these fresh toxin laden spores really begin to fly.

Once they are on the ground, they tend to stay there and decompose, releasing their toxins which helps clear out the area and pave the way for a future spore release, when another of their kind can make its way to a new patch of turf, since most of the ones which didn't reach water are already nonviable.

My understanding is that Stachy spores leave the colony with a very short window of opportunity. About an hour of viability is all they've got.

That's why it's almost impossible to get an airborne sample which tests for spores that grow in a media.

Too late. The show's over, and all that poor little spore can do is release its toxins in a final act of self sacrifice on behalf of its brothers.

But if a viable spore should alight on a place where it finds any moisture, instead of immediately trying to grow, it first reinforces its shell wall and builds up an internal supply of water, which makes it even heavier.

The spore isn't going anywhere now, but with its thicker shell and water reserves, it is prepared to go dormant for long periods.

That's what "sporulation" means. It's like hibernation, but for spores.

Amazing little trick, for the spore to have a Plan B.

If conditions stay so good that it can go on and grow, it will.

But if the moisture that a sporulating spore encountered was only temporary, it has built up reserves and is ready to go the long haul and wait until conditions are better.

The only downside for a sporulated spore is that it is now so heavy that it is unlikely to become airborne again.

-Erik (2010, SevereReactor)
PLUMES

To answer, "What is a spore plume?"

Mold colonies send off a cloud of microscopic spores when disturbed.

Think of these as plumes of spores acting exactly like cigarette smoke.

You can stand right next to a colony that isn't disturbed and have times when you feel nothing.

Or when it is windy you can be hundreds of feet away from a colony and if it is blowing a plume toward you, your life will be hell.

-Erik (2004, SickBuildings)

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If a microniche is in a location that makes it to act like a lot, then the overall ambient levels don't make any difference in your level of exposure.

It's like the difference between being in a bar full of diffused cigarette smoke or being directly next to one single ashtray full of smoking butts.

There is none!

Like those teachers at North Tahoe HS who got sick and were directly next to a small colony, and none of the other teachers believed them because they weren't affected.

Perhaps if they saw how a person next to an ashtray can get an overdose of smoke while people a few feet away don't even perceive it, then they'd see why the spores could affect just the people who were directly in the plume.

-Erik (2006, SickBuildings)

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I only started to take control of this illness when I learned to ignore concepts that didn’t fit the facts.

Lots of musty places don't bother me at all.

Lots of places that aren't musty will kill me.
So I go by perception alone - not by odor.

This gets picky, but once the spores have departed the mVOC producing colony, about all they possess is secondary metabolites since they aren’t actively breaking down substrate.

The only problem with calling a spore plume that is emitting these metabolites a "mycotoxin plume" is that toxins emitted by the spores mix with the air and dissipate before going far enough to be called "a plume.”

So I call the mixed air/toxin distance from spore accumulations that still gives hits "The Mycotoxin Gradient.”

My green binoculars should have not been emitting any spores, considering that I washed them off underwater in a pristine area.

But I could still feel the adsorbed toxins at about eighteen inches - even outside in the wind. The closer they got the worse it felt.

Changing the proximity reveals that the toxin gradient is a fixed value according to air dilution dictated by distance.

So if the mycotoxins are still associated with spore movement, I call it a spore plume. If the mycotoxins are not associated with spores, by having left the equation from decomposition or removal, and it’s just the toxins that are left, I call the residual toxic effect "The Mycotoxin Gradient" to differentiate it from spore plumes which contain mycotoxins.

- Erik (2006, SickBuildings)

**NO MAN’S LAND**

Remember Kathy Masera's contaminated California Job Journal offices where opposing fungal species created a two inch "no man’s land" between them?

Right in between some of the worst mold growth was a two-inch area that was totally free of mold and bacteria - thanks to the intensity of the battle between competitors.

We know that toxigenic molds sense competitors and respond accordingly. The more intense the competition, the more effort put into potentiating the toxins.

There is simply no way to reasonably project levels of toxin exposure by counting spores or trying to measure fungal ecology.
Toxin potential varies between individual spores of the same species even within the same colony. And since Stachy is often part of a mixed colony, examination of a single mold colony is really looking at an aggregate of species which confounds attempts to measure pathogenic potential ever more.

The science shows us that science is not at a point that can make reliable measurements of toxic exposure without recreating laboratory conditions which encompass all the known factors in a sealed environment.

The variables are so great that about the most reliable conclusions one can make regarding fungal ecology is that, "If you feel bad, it is bad."

Not very "scientific," but geez, take a look at the confounders compared to the total lack of controls for these variables.

-Erik (2006, SickBuildings)

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There was a moldy building in Sacramento back in 2000 where remediators found the most incredible phenomenon in a patch of carpet.

Two toxic competing molds that were producing some of the worst toxins they had encountered had cleared a "no man's land" between them. Several inches of separation where there was nothing. No mold, no bacteria, a virtual Dead Zone.

But then, there are always exceptions and complications, just to throw silly humans of the track.

I've heard that some molds are "way pavers" for Stachy, such as Ulocladium Chartarum. They seem to be completely compatible with Stachy and even soften up the terrain so they can grow together as mixed colonies.

Of course, if someone does a tape lift on the U. Chartarum part of the colony, it's even conceivable that they could miss the Stachy buried in another area.

These molds are amazing. Big mistake for humans to underestimate them.

-Erik (2008, CFSU)
Chapter 14 - Outdoor Mold

TOXIC IS TOXIC

"Safe outdoor molds"? Why would a mold spore that was dangerous to your lungs indoors suddenly turn safe if it happens to drift outside?

As far as I can tell, your lungs don't care if the mold you inhale has walls around you or not.

Only the Indoor Air Quality “experts” have this strange notion. I'm not sure why anybody believes it when this is so obviously wrong.

-Erik (2006, CFSExp)

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Toxic is toxic. Indoors or out.

I was really fortunate that my mold experience started so long ago that I wasn't misled by people who portray it as an "Indoor" problem.

You can't escape by just going outside.

The denialists are saying, "Mold can't be a problem, because the levels outside are as much as the ones that the mold crazies are claiming would create a sick building... and as we all know, Sick Building Syndrome means you have to be inside a building to get sick."

So all the people who are sick outside must be crazy.

-Erik (2008, CFSU)

PLUMES AND CLOUDS

The concept of a "plume" is to separate it from a "spore cloud."

A mold colony in still air will have a spore cloud around it. The radius of the affected area around the source would depend upon the hang time of an airborne spore based upon its size and water weight (and a few other ambient factors of humidity and barometric pressure).
Theoretically, if there were no wind around a mold colony, the hang time of the spores would dictate their radius of destruction.

Until the cloud is deflected by airflow: a plume.

A plume is just a spore cloud deflected by the wind. But the spores have to come from the colony, so no matter which way the wind blows, if you point upwind, you'll be pointing at the source... the colony.

If the wind is blowing, you could conceivably stand directly upwind of a mold colony and be unaffected. Conversely, the area downwind of the normal affected radius is dramatically extended to great distances. So a cloud is what one would expect around the sourcepoint, while the plume is the extension of that zone by airflow.

I felt a plume crossing the highway as I drove through Monterey. I'm pretty sure that it wasn't a spore cloud because it isn't always there, and it was windy. I didn't stop to try to locate the source.

Staying out of sick buildings is relatively straightforward, but watching out for the plumes they emit is another matter entirely.

-Erik (2008, CFSU)

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Plumes are all over the place and constantly move according to wind, humidity, weather change and physical disturbance of colonies. They are not fixed in place except at the source, often a bad building or sewer system.

That's why I say my hang gliding background was useful. Extreme avoidance is exactly like soaring. You're searching for invisible thermals and working them for maximum altitude... or you fall out of the sky as quickly as possible when you're tired of flying and want to get down fast.

You have to go it by feel.

-Erik (2008, CFSU)

MOLD ZONES

As for getting hit from a mold plume from somewhere you can't control...no choice but to move.

-Erik (2006, Locations)

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I refer to mold zones are ambient areas that have been repeatedly plumed. Any house within a mold zone is a bad house for me, since one cannot really stop whatever is outside from coming inside.

-Erik (2008, CFSU)

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I went nuts trying to remediate a house that wasn't really the source of the problem. I spent thousands.

We found a small colony in the house. Getting rid of it did nothing.

Then I started going to the woods to get clear, then back to the property without going inside, and I still got slammed.

I checked the wind direction, and it was coming from the sewer. "No house involved."

It finally sunk in that nothing I did inside the house was ever going to make that area safe for me.

I could have burned the house to the ground and built another and it wouldn't have made any difference in my illness.

-Erik (2008, CFSU)

**CONTAMINATION ZONE**

Isn't it funny how the mindset of mold "experts" seems to be that the spores stop at the door?

Why would they do that?

Or perhaps they think that this is an "Indoor Air Quality" problem, so those spores couldn't possibly be a problem outside. That would be defying the very definition of IAQ, wouldn't it?

Remember how I drove right past Truckee High School and parked upwind on the opposite side of the street, so we could gradually approach it from an area that is more favorable, due to the prevailing wind direction? Because that gave us the least amount of distance to go in the contamination zone?

There was a huge parking lot right in front of the school, easy to pull in, with lots of places to park. But it was downwind of the old bus sheds.
Of course there is a contamination zone around every sick building.

So now you have definite proof of how screwy the experts have been looking at this. The very name of their industry is a mistake.

-Erik (2008, CFSU)

YOUR NEIGHBOR’S PLUME

I checked out a business where a number of people are in various stages of mold illness. The friend who brought me there is the most affected. At times I got hits from my friend’s clothes that were so strong that I expected to find a horribly contaminated environment.

To my surprise, the building was not very bad. That is to say, it wasn't bad until the spore plume from the neighboring house blew directly toward it. Then the whole area became living hell.

A few months ago, the new owners of the house clearly did their own mold remediation. There were bits of kitchen counters and piles of sheetrock laying in the yard. Since that time the mold problem has become so much worse in that spore plume that I cannot stand next to my friend’s car after it's been plumed. My friend has gone hyperreactive and is looking for another job.

This is clearly going to be a contentious issue, to be driven out of your house or job by your neighbor’s mold. I have found entire sections of towns that I cannot bear.

-Erik (2002, SickBuildings)

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I moved into a place that had no mold inside at all. I went nuts trying to find it inside until I realized that I was getting hit outside, especially when the wind was from the southwest.

I wound up sleeping outside and upwind of the house in various wind directions until I could get a vector on the location of the colony. There was nothing I could do about it except try to be somewhere else when the wind blew from that direction.

I've found enough places drenched in spore plumes from somewhere else to know that if you are extraordinarily sensitive, even the most rigorous testing is no guarantee the place will be survivable.
The only way to get a sense if any potential dwelling will be safe for you is to sleep there while it undergoes different wind directions and weather conditions.

Isn't this fun?

-Erik (2002, SickBuildings)

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If your neighbor has a sick building and decides to install a central vacuum and blast the spores outside and your window is adjacent to their vacuum exhaust, your neighbor’s spores are now your spores.

-Erik (2005, SickBuildings)

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> The inside of my house is not moldy.

That's how our house was too. We couldn't find or feel mold inside.

The spore plume was blowing in on a southwest wind from elsewhere. I had noticed that we always fell apart whenever the wind was blowing from that particular direction.

I couldn't get my girlfriend to believe it until I took her out to a good place out in the woods to feel better, and then went directly to the upwind side of the house and had her lie down on a blanket.

Within five minutes, she was covered in a rash and in total agony - from something that obviously wasn't coming from inside our house.

She said, "That's it. We're out of here."

We walked out and only went back to pack up belongings.

And that's when the edema and a bunch of other symptoms cleared up for both of us.

-Erik (2006, CFSExp)

**AIR MOVEMENT**

> Historically, scientists believed that several days of ultraviolet light exposure would kill off any microbes traveling in dust clouds. Yet when Griffin and his colleagues screened air in the middle of the Atlantic Ocean, they found viable airborne microbe populations.
No wonder we are seeing mold growing in places it never grew before.

-Erik (2006, SickBuildings)

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>Everything in my tent suddenly feels bad. I don’t know what happened.

I went out to the Godforsaken Desert and found that this did not happen ever.

But when I went to other places that appeared to be barren GFD, but were downwind of metropolllution areas and civildevastation, it did.

So, my definition of a successful shift in location is to find a place where this never happens, regardless of whether the spot really is in the GFD or is downtown Reno, where I happen to be right now.

Strangely enough, a plume is sailing right past me down to the south. So this is good enough and I'm fairly safe.

Barring a change in wind direction.

The operative concept is whether or not the effect occurs and not really whether it has trees or no trees, or even has buildings.

Some people think that Reno is GFD, though.

-Erik (2009, SevereReactor)

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> These winds would let you know where smog from a city piles up against the mountains.

The lifting of the air mass causes a lot of the acids to nucleate and precipitate right on top of the "pristine" forest on the tops of mountains.

But places downwind of mountains tend to be more clear of toxins.

It's not fair to the trees up high which catch the acid rain that should rightly fall straight back down on the communities which create it.

We should have a law which calls for more particulates to be produced in cityscapes, so they can suffer in their own toxicity rather than causing innocent wilderness to suffer.

-Erik (2009, SevereReactor)
SICK REGION SYNDROME

There are virtual sick regions which are unsuitable for people like us.

The people who conduct the testing have a mindset of sick buildings only. It is rare to find someone who understands that if your reactivity transcends that type of exposure, finding little mold only serves to convince one that it is not the problem.

I wasn't able to take control of my illness until I abandoned the notion of testing and trained myself to recognize subtle mold hits (precursor indicators of biotoxin induced upregulation).

By responding to these indicators in a timely fashion with avoidance and decontamination, I was able to exhibit a level of recovery that was so unexpected that doctors didn't believe what they saw.

We are pretty much left to ourselves to explore this strange new mold paradigm.

-Erik (2008, CFSU)

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The swiftness with which this mold paradigm has gone from "not possible" to "everyone knows about that" suggests it is progressing at an extremely rapid pace.

I extrapolated the inevitable creation of sick regions, if this keeps going on as it has.

Who knows? Maybe we are already there.

-Erik (2008, CFSU)

A DOWNTOWN SHOPPING MALL

If you had tested any of a few thousand buildings downwind of the Park Lane Mall when they dozed it, they would all have qualified as sick buildings.

I was wondering what would happen when the mall was demolished. Would it make this area of Reno permanently worse, or would the removal of that nasty place get me a net gain?

It took a while for the demolition effects to die down, but the place is better for me than it was.

225
Erik (2008, CFSU)
Chapter 15 - Locations Effect

NOTICING THE EFFECT

I noticed the locations effect when I observed there was a vague correlation, but the contradictions seemed overwhelming and inconsistent.

Then I found that locations were not the overriding factor. It was the degree and persistence of immunological upregulation to neurotoxic exposures that changed just enough between certain locations to make the effect apparent and the inconsistencies that cause people to dismiss the locations effect were resolved.

So I learned to control the effect without leaving Incline Village.

-Erik (2005, Locations)

IT IS WHERE IT IS

We need to do a Mold Rating Guide for Travelers.

Just kidding. It wouldn't work due to the variable factors of spore cloud release from humidity and barometric pressure change.

Not to mention wind direction change and plume vectors as cold fronts pass through.

This lifestyle is darn tricky.

-Erik (2004, SickBuildings)

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I've found no particular correlation of high mycotoxin levels in snowy areas like Incline Village.

And Las Vegas is full of sick buildings.

-Erik (2005, SickBuildings)

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The most dangerous misconception people have is trying to project conditions which might be likely to be toxigenic waste dumps and make plans according.
I've been slam dunked in Vegas and had a wonderful time in Florida.

Some of the newest buildings are the absolute worst.

Trying to conceive of which conditions may cause places to be toxic and using these ideas as a guide will drive you crazy.

"It is where it is."

-Erik (2006, SickBuildings)

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As for the mountains, I don't see where altitude makes any difference in terms of mold potential. This stuff is where it is.

I've been through Arizona and parts of Florida, and some places were okay and others were not. I don't try to predict where mold is. Been proven wrong too many times. I just perceptify it to feel mold hits, and act accordingly.

-Erik (2006, SickBuildings)

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> Do you think the key for mold avoidance is to go high enough up, but where there is no city?  

No, the key is giving up on trying to predict where it is.

-Erik (2008, Locations)

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I know this is going to sound crazy, but all my experience tells me that trying to predict where the bad mold is, based on a set of climate or "old house" expectations, is so counterproductive that it can very well create the exact opposite of the desired result. 

Trying to predict just drives people nuts. It usually doesn't turn out how one expects anyway, so I just take it as it comes and take action accordingly.

-Erik (2008, CFSU)

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Any building can have Stachy.
Guessing is like judging a book by its cover.

-Erik (2009, SevereReactor)

A DIRECTION TO PUSH

What I found in the desert was a shift, not a sudden cure. It was just a direction in which to push.

I know of several people who couldn't get decent results anywhere in the USA, but did in other countries.

But as I told Dr. Cheney so many years ago, this was becoming more of a problem for me no matter where I lived.

If this were a matter of just moving, it would have been a fairly easy thing to notice.

It took a constant and concerted effort.

-Erik (2008, CFSU)

A SHORT TRIP

Talk about a "budget trip."

I can go one mile due north of Lake Tahoe - say, up to Watson Lake - and feel great.

The bad molds are lighting up like crazy all over the place in houses everywhere, but if I just barely get out of spore plume range, I do just fine.

-Erik (2006, Locations)

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Reno is feeling pretty crappy right now.

All I have to do is drive up to mountains around Tahoe, and I'm pretty much out of the badness. I'm about to do that very thing.

Hope the mountains stay feelin' good for a while longer.

-Erik (2008, Locations)
I've talked with people who went to Mexico and felt great there. But I can go about fifteen miles north and accomplish the same thing, so it's just an average commute... to a good location.

-Erik (2009, Locations)

> Did you get the impression that you could live a more or less full life in Greece without having to avoid mold?

Yes, that is exactly what I said to myself when I was there.

"If I lived here, I wouldn't have to do any mold avoidance at all."

But then, I feel that way whenever I just get up north of Tahoe. And that's within easy driving distance.

-Erik (2009, Locations)

THINK PRISTINE

Instead of dry or wet climate, think "pristine" as opposed to highly developed.

It is modern materials, types of construction, and specific chemicals that provide the basis for overgrowth of toxin producing molds.

-Erik (2006, Locations)

I've found tons of people who would go to a forest or beach and believe that the tranquility of nature was giving them "healing peace," when you could find plenty in their descriptions which showed that they were really reducing their inflammation from toxic exposure inside their houses.

-Erik (2010, WPI)

NEGATIVE IONS
> The ocean gives off a ton of negative ions.

So this would be consistent the observation of feeling especially good near waterfalls, even when the surrounding region is not quite as good.

But the really good "good locations" remain good, ions or not, which suggests that the ions are precipitating something out of the air in bad places.

It would be the bad stuff that is being subtracted out of the equation by negative ions which would be the culprit responsible for the differential between good and bad zones.

The way I see it, going to the desert and feeling good in all weather conditions regardless of ion influence tells me that it's not the ions per se.

If the ions play any part, it must be influencing something in "bad locations" that is not present to be influenced in those "good places" where one can be exposed to any level of positive or negative ion shift and feel no change.

I think we should be looking for something that is precipitated by ions and not so much at the ions.

-Erik (2006, Locations)

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> I bought a small ion generator.

I experimented with one of those too, and it did indeed cause a mess where particulates would drop right in front of it.

I just got back from Ft. Churchill, an old Civil War outpost and Pony Express station out in the Nevada desert. It felt great, as it always has. The weather can do anything it likes, emitting ions of whatever sort it chooses, and I still feel great.

As far as I'm concerned, that rules out ions for being the agent responsible for the shift in symptoms. If anything, the ions are precipitating "whatever" it really is.

-Erik (2006, Locations)

**PYRAMIDS**

> I wonder if anyone wants to hazard a rational guess why a person would feel well on top of a pyramid?
I would speculate, off the top of my head, that the shape and mass of the pyramid acts as an electrostatic-discharge-wick for the ground plane of the surrounding terrain.

And that similarly to Niagara Falls, the focused flow of negative ions cancels out innate inflammatory responses composed of high rates of free radical production.

So inflammation damps down and people feel a surge of wellness.

That is, if they have ion channelopathy occurring at a level which would dictate a change in how they feel.

If they were reasonably well, it is conceivable they might feel no change at all and would consider anyone who said they felt something to be totally insane.

-Erik (2009, Locations)

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Everything that exists possesses some kind of electrostatic potential.

Any differential between two objects sets up the conditions for a flow of current.

Whether or not one could call it "mystical," we do know that energy is there.

It has to be.

The question is whether the people who claim to feel it are mistaken or whether science just hasn't developed the tools to measure what these people claim to feel.

As to the power of pyramids to accomplish other things, humans seem to have great difficulty in sticking to the facts and avoiding exaggeration, which might possibly disguise a real phenomenon behind a wall of tomfoolery.

-Erik (2009, Locations)

KOA

I've been in some of those KOA Kampin Kabins - pre-fab log cabins - which were terrific. Very Kozy.

-Erik (2008, CFSU)

HOME DEPOT
A quick trip down through Home Depot would knock me for a loop.

I remember walking by the carpet aisle, and somebody looked at me and went, "Oh my God!"

I rushed to a mirror, and I had turned bright red. Like the Sith from Star Wars, but without the horns.

Crazy illness, eh?

I can go there whenever I want now though.

-Erik (2009, Locations)

CALIFORNIA AND NEVADA

Nevada is awesome. Very low mold, when you get outside of the cities.

I've had mild mold reactions to some piles of rotten wood, but nothing strong like Stachy. Most of the old ghost town buildings are so desiccated that I feel nothing there at all.

-Erik (2002, SickBuildings)

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Las Vegas is absolutely filthy with mold. Those darn air conditioners are mold heaven.

-Erik (2004, CFSExp)

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I used to live in San Anselmo, in a place that made me sick. Rainiest, darkest, miserablest, mossiest and moldiest area I ever lived.

SA, Ross and Kentfield get the heaviest rainfall totals of anywhere in the Bay Area. Spore plumes rampant everywhere you go. Very difficult place to recover, even if you do manage to find a safe house.

East Bay is better, but there are some ferocious plumes in Berserkely to watch out for.

-Erik (2006, SickBuildings)

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I used to live directly on the ocean, just about dead center of this picture.

This was my hang gliding class at Dillon Beach.

Of course, if the wind is blowing off the ocean, there can't be any mold.

But if I went up to the store at Lawson’s Landing, I was in the midst of houses. If they were moldy houses, as is very common on the coast, I was in the midst of mold.

So, yeah, right on the coast is good, just as long as there aren't any moldy places upwind.

If I weren’t constrained by financial considerations and had latitude to travel, I'd do my best to get out of the snow entirely. Cold weather is like a trap for Moldies.

Too cross contaminated and sick to stay inside…. too cold to crawl outside.

It is so much easier to deal with if you can get outside in the winter.

Although I didn't feel too well downwind of certain cities, the Southwest felt very good to me when I was moving a friend down to Texas a few years ago.

-Erik (2008, Email)

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If I had my druthers for a winter retreat, think I'd head for the Southwest. Arizona, Utah, southern Nevada.

But most of the low-population areas along the coast have been pretty good too. Big Sur was awesome.

Monterey and Morro Bay were killers. San Francisco…. well, ya just gotta get through as quick as you can.

North Bay, not so good until up past San Rafael.

-Erik (2008, Email)

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Down in Carson City, there are some plumes that had me down on the ground with the dry heaves.
Thank goodness for my MECU. I bailed out of the bad zone and went up to the woods to recover.

-Erik (2008, CFSU)

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Don't even think about San Francisco.

Mongo plumes running around the Bay Area. Used to be a real whack just south of Gilman, but north of University, in Berkeley.

Sacramento is bad, bad, bad. Ugh. There are plenty of places around there, like the Pony Express museum, Old Town and the KOA near the turn-off for Business 80 that made me turn and run. Too many stray plumes.

-Erik (2008, CFSU)

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Today, a local DJ described Death Valley as a "Feel Good Place" where somehow, for some reason, it just feels good out there.

Yaz-indeedy! And if there are any ticks out there, at least they're frying their little butts off while they try to get at you.

-Erik (2008, CFSU)

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Morro Bay was an absolute nightmare for me. All parts of town to the south of Morro Rock were death defying.

There is a campground next to the golf course and museum that I stayed at for two nights because the group I was with liked it there, but I could feel within minutes that the place was really bad. I won't be going back.

-Erik (2009, Email)

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I used to love Santa Cruz, and now I fear it. Within the last twenty years, the whole area has gone sour.
If you want a good blast of the “bad stuff,” go down the kayak shop at the entrance to the marina. I parked next to the place and within thirty seconds, I was fumbling to get my rig started as quickly as possible to get the hell out of there.

I am growing increasingly concerned about all of southern California. The last time I drove down that direction, I was amazed at how many more plumes I encountered than just a few years previously.

-Erik (2009, Locations)

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East winds are the worst time for me in Reno. This is a classic weather pattern from Coriolis Effect as a strong winter arctic cold front skirts us to the North. We call it a "Tonapah Low."

-Erik (2008, CFSU)

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It is so hard to watch our environment going sour, and it’s so unbelievable how little that people seem to care.

I just returned to my safe zone in the north of Reno.

The southern section sucks today. So it is good to be out of the worst of it.

I don't know how much longer this area will remain decent.

Last winter it was raked by sporadic plumes, and if it gets any worse, I'm going to have to bail out of here.

-Erik (2009, Locations)

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I remember when I was giving someone else a mold education here in Reno a few years ago and the Peppermill was right at my limit.

She had to get clear of Reno, and get all the way out to Fort Churchill, before she felt better. That was the clincher for her, in terms of believing what an incredible difference this makes.

The Peppermill has been much better since the old Park Lane mall across the street was demolished and carted away.
-Erik (2009, Locations)

**SOUTHWEST AND MOUNTAIN STATES**

Pagosa Springs felt terrific. In Durango there were a couple of bad places in town, but overall not too bad.

My friend in Pagosa Springs says she's doing well there. She's trying to talk me into moving there. Considering how good it felt to me, I've given it some consideration. It reminds me of how Truckee used to be, before it got so touristy.

And I recall out at Mesa Verde, looking at Native American cave dwellings, feeling so good out there, and thinking, "Oh yes... move me in!"

-Erik (2008, CFSU)

*

My Moldie friend was excited about going to a seminar at the largest and nicest hotel in Sedona. Not only were the rumors of vortexes interesting, but presumably the desert should be a very low mold area.

The hotel turned out to be a mold magnet.

She said that she felt trapped and ill the entire time, and that she had difficulty making excuses to her colleagues as to why she was avoiding nonessential functions at the seminar and was spending every possible moment away from the hotel.

It took her weeks to recover. She won't be going back.

(I've heard similar mold reports from Scottsdale and Flagstaff.)

-Erik (2006, Locations)

*

I just got back from Colorado and Utah.

I hit all the national parks - Arches, Bridges, Dead Horse Point, Canyonlands and that wondrous mold-free construction at Mesa Verde.

Awesome. Felt great. No mold except in town at Moab.

-Erik (2006, Locations)
The Southwest is generally pretty darn good.

But testing by going to a region is easily defeated by having the misfortune to find a bad place in a good region.

Like a friend and I did in Moab. Who'da thunk there'd be any bad stuff there?

-Erik (2008, CFSU)

Some of the worst areas for mold are the places everybody thinks are mold free, like some of the low-cost housing on Indian reservations in Arizona and New Mexico.

Dr. Craner and Linda Stetzenbach have identified hundreds of sick buildings in Las Vegas and Reno.

Moving to the desert won't get you out of this if you are living in a house with the potential for mold processed right into the building materials and have a leak.

While I believe that a desert gives you an advantage in mold avoidance, it means nothing if it's in your house.

-Erik (2002, SickBuildings)

FLORIDA

Florida was about like everywhere else, far as I can tell: sourcepoints surrounded by intermittent plumage.

Everyone told me that Florida would be the worst place on the planet for someone like me, yet I had a wonderful time in Clearwater, Tampa and Busch Gardens.

The only town that I remember being ambiently bad enough that I couldn't wait to get out of there was Tampa's Little Havana section.

This area felt about the same to me as Old Town Sacramento. Fun to visit. Can't stay long. Decontaminate afterwards.

And yes, I was a bit surprised that Florida wasn't worse than it was. That went a long way toward shaking me out of trying to make predictions on bad locations.

-Erik (2008, CFSU)
GREECE


Of all the places I've been, this was the best by far. I've heard from others who experienced "the miracle" in Crete.

-Erik (2008, CFSU)

*

I've heard from a number of people who went to Greece and felt great. Scarcely any need for avoidance, and the improvement was spectacular.

-Erik (2009, Locations)

*

I toured Crete back in the mid seventies, and felt fine the whole time.

When I went back in the early nineties, I was startled at feeling plumes where I hadn't felt them before. Some in Iraklion. Hania in particular.

I walked the city fortress walls that encircle Heraklion and had to evade a few plumes along the way.

Athens was troublesome, especially around the Acropolis and Plaka, yet I had much more energy climbing Lycabettus Hill to St. George’s temple.

Got a pretty good smack right at the Olympic Stadium, which really slowed me down as I walked the perimeter.

-Erik (2009, Locations)

*

> Belgrade is a good location because the buildings are mostly made of cement.

Greece shares this trait, as most of the structures are made with concrete. And mostly it felt pretty good.

But some of the new hotels and museums were absolute murder.

I did not find one bad place high up in the White Mountains or the Lasithi Plateau.
Delphi had a few plumes.

-Erik (2009, Locations)

AUSTRALIA

We are indeed in very deep trouble.

The country singer Waylon Jennings, who is a mold survivor, says he is going to move to the driest part of Australia to escape feeling like crap all the time.

Must be nice to have money.

But my experience says that this attempt to predict by climate is not how it works.

For instance, Las Vegas is rampant with plumes. Contrary to what everyone predicts, but that's the way it is.

-Erik (2006, Locations)
Chapter 16 - Weather

SUN AND RAIN

Mold spores are primed to release their toxins at times of weather change, when conditions of wind and potential water give spores their best chance for dispersion and survival.

-Erik (2006, SickBuildings)

*

Plumes are much worse during rainy weather.

Isn't it amazing that people have known for eons that a "blue sky day" is a happy feelgood kind of day, but had no idea why that was?

High pressure suppresses toxin release.

Low pressure, as in a prefrontal barometric pressure drop, causes "Times of Release."

Now, think about it for a minute.

You have felt symptom exacerbation before the rain even hit, so you know "The rain ain't it."

But what happens before a storm? The pre-frontal pressure drop.

And you have also felt the situation reverse itself.

Well, a low-pressure system also causes a shift in wind direction, so I would suspect that the more intense toxin level was unleashed elsewhere, and the Coriolis effect caused the wind to shift around until that area of toxin release had you right in its crosshairs.

The effect doesn't appear to be the cold, or the rain, but just the shift in pressure and humidity.

If we had a bunch of Moldies cruising around in MECU's, comparing toxin release, mold zones, escape routes and plume sizes... we could probably work up a decent cohesive working model of what is happening.

-Erik (2008, CFSU)
SUICIDE SEASON

The winter storms are stirring up the mold colonies and blasting out vastly increased clouds of spores which can go great distances.

Some bad places in summer are localized, but extend their range so much that I have to avoid going downwind of them in winter.

-Erik (2005, SickBuildings)

*

In fall, the increased moisture replenishes mold colonies and allows them to become more active.

-Erik (2006, CFSExp)

*

Mold is worse in winter.

I remember thinking that if I could only figure out how to control my mold exposure during the winter, at the very least I could expect to feel no worse during the winter than I did in summer.

To my amazement, a concerted effort at extreme avoidance of that substance did far more than I ever expected.

-Erik (2008, Locations)

*

I refer to October through January as "Suicide Season."

When the winter storms start unleashing the plumes in late October, the ambient badness seems to exert a depressing influence on nearly everyone. It seems to peak right around the Christmas holidays.

Yeah, I know. Everyone blames the Christmas blech on the "stress" of shopping, relatives, etc.

But the more you look at the peculiar lack of a real solid emotional stimulus to really correlate to just how much people lose it this time of year, I think you'll agree.
There is a generalized neurotoxin shift that puts the edge on everyone and it shows, if you know what you’re looking for. And it appears to me that every year, it gets just a bit worse.

By the end of January, sometime in February, it seems to start easing up.

-Erik (2008, CFSU)

* 

October through March are the months when I used to want to shoot myself, before I discovered that I could escape that seasonal downturn completely by mold avoidance.

So I called it “Suicide Season,” which is how I felt, but not quite so politically correct as "The November Factor."

http://www.pediatricnetwork.org/lyndonvillenews/jean/novemberfactor.htm

-Erik (2010, WPI)

* 

It seems like the winter downturn has been stronger this year, and much harder to stay free of this crap, no matter where we are.

We're only a month away from the time I normally associate with the effect beginning to slack off.

Hopefully, soon we'll get somewhat of a respite.

-Erik (2010, SevereReactor)

RAIN AND SNOW

>Wouldn't a rainstorm send all the spores to the ground?

You'd sure think so. But no, rain or snow doesn't clean the spores out of the air.

-Erik (2008, CFSU)

A STORM HITS

A storm hit Reno last night, and now everything has gone to crap around here.
The sourcepoints, like a few in this building, are all emitting their badness.

Just like clockwork. It is amazingly predictable.

So I'm about ready to head on up the hill.

-Erik (2008, CFSU)

*

Lisa got to witness a spectacular demonstration of storm release.

We were out at a campground, which is semi-downwind of Truckee.

Although there was no precipitation, a windstorm came up. (Lisa, remember how strong the wind was?)

First the campground felt good, and then it felt bad.

The plume laid down an accumulation which forced Lisa to get up in the middle of the night. (Remember? You were ready to hop in your car and bail out right at that moment?)

The next morning, the sun hit the accumulation and caused even more toxin release, which made the whole area feel terrible.

I said that it would dissipate in just a couple of hours.

I grabbed a stick and drew a diagram in the dirt, showing the Coriolis effect that makes a storm front passing to the north cause the wind to gradually switch around until we were right in the crosshairs of the plume.

We could have just gone further north to get out of it, but instead we went for a walk up the hill to get some fresh air. By the time we got back, the release was dying down.

It was having a hang glider pilot’s knowledge of micrometeorology that allows me to see this connection.

Whodathunk that being a hang glider pilot would be a significant advantage in surviving Chronic Fatigue Syndrome? That a hang glider pilot would have a background that allows him to see things that a doctor cannot?

But that is just how it happened.

-Erik (2008, CFSU)
Where I built my MECU, the area was being plumed. It occurred when the wind was from the southwest, so that seemed consistent.

But then, the sun would come up next day and we would all feel slammed. The spores that were freshly spread out would be set off by the sun's intensity.

I tried to discount the association because it seemed that there were too many contradictions. But then it just seemed to crop up again.

At first the "sunny day slam" seemed to disprove the weather association... but not really. There were just further effects that needed to be factored into the equation.

-Erik (2008, CFSU)

I talked my friends who lived near the compost farm to check the wind, to see if the sunny day slam correlated.

Sure enough, the day after the wind blew from that direction, about 9 - 10 A.M., POW, the ground would turn toxic.

This was predictable, reproducible and very compelling.

This is all part of putting the clues together about what kind of environment you are in and where the exposures are coming from.

-Erik (2010, SevereReactor)

Reno really sucks right now. The whole town is bad.

A storm went through and laid out a blanket of surface contamination which would not be noticeable unless anyone laid down and stuck their face on the ground.

Now the sun has come out and the toxin release is absolutely awful.

But of course, if they test the air for spore counts, they won't find a thing out of the ordinary.

They would conclude, as they have so many times before, that people who complain of this must be crazy.
FULL MOON

My intense reactivity to mold allows me to make observations that others have no interest in, but which are critical factors to me.

The intense gravity at the full moon initiates a greater propensity for mycotoxin release.

This is similar to weather changes, when areas of toxigenic molds should be avoided to escape increased exposure to mycotoxins.

- Erik (2006, CFSExp)

ION SHIFT

On our camping trip, Lisa and I were able to compare the relative shift of the ambient presence of badness after a plume was laid down.

We could determine that the place had been plumed by the fact that it had been good before the wind. The wind was coming from a bad place and the good place went bad.

We could evade the badness by going further north. Further confirmation.

What we could both feel at roughly the same time is that the badness would take off like a rocket at times of atmospheric ion shift, in the pre-dawn hours when the positive charge changes to negative.

So the working hypothesis is that the moon is exerting an ion shift in the atmosphere which is causing the badness to fire up.

The variability of the conditions which sets up this phenomenon make it seem so arbitrary and confusing that a positive correlation is not made until you set up the right conditions for the test with the right people who know what they are looking to find.

- Erik (2008, CFSU)

*

That 4 a.m. blanket weirdness didn't happen to me when I was out camping in the desert.

The only way I could recreate the problem was by deliberately taking blankets into moldy places and then bringing them out to the desert.
That narrowed down what it was, and what I had to do to keep from being slammed.

-Erik (2008, CFSU)
THE TOP OF THE CURVE

I don't freak out at the mere thought of being in a bad place anymore. I don't even decontaminate nearly as often as I used to.

As long as I stay on the good side of the power curve, it seems I can tolerate a fair bit of exposure before being driven to a point where the inflammatory response goes out of control.

I'm working in a moderately bad place in Reno. This is a place I couldn't tolerate at all about eight years ago, when I was stuck living in a mold zone down south of Carson City.

Sometimes my workplace gets over tolerance, but for the most part it stays about medium low.

When the place is medium or below, I can stay in Reno and have medium nights from the ambient mold load here.

But if the place goes zonkers, I may still be able to stand it while I work, but I have to compensate by running up to the mountains.

If I have a medium or above day, I want to really get myself clear.

So I kind of project, based on how the place feels during the day, what I am going to have to do in order to ensure I get a good night's sleep and stay on the up side of the power curve.

You know, this whole process is exactly like thermalling to a soaring pilot. Really!

Like gain a bunch of altitude in a boomer thermal and then you can relax. Glide down to a low altitude and you're sweating bullets, working like mad to stay out of the trees.

Very similar feeling.

-Erik (2008, CFSU)
You know how your car will buzz right on up a hill if you're at high rpm, but if you were to attack that same hill at low speed, the car will gradually lose power, slow down and stall?

The engine puts out more horsepower at higher revs. Not so much at the low end.

If you're high on the power curve, you're buzzing right along and can take a few bumps without slowing down.

Down low on the curve, there's no torque left to spare, and the bumps will slow you down to where the power drops off quickly and you stall out.

-Erik (2008, CFSU)

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>How do you make sure that you are on top of the power curve? What is your definition or "getting clear"?

You already know about "getting clear." You can breathe.

In hang gliding, some "techies" had instruments - altimeter, variometer, airspeed, barograph and GPS.

I was a kind of a throwback to the early days of hang gliding, a sort of subset called "the purists" who used none of these things, and who relied on our senses and skills alone. That was the joy of it.

If you could work your way up to great altitude by your own skill, I dunno, somehow it made the experience special, more of an accomplishment.

At altitude, there is only one way to tell if you are going up or down. Compare your "ground track" against the wind direction. Look sideways and find a low mountain or obstacle that you can look over. Locate something behind that you can identify for future comparison.

After a few maneuvers, chasing thermals, look over the obstacle. If you see your object and more, you're gaining. Can't find it anymore and see less distance, you're losing.

The power curve is a lot like that. Although altitude gives you leeway to work with, the idea is to always check where you are to see if you are gaining or losing.

Even if you're feeling good and have plenty left to work with, if you keep winding up in the sink, the consistent pattern of downward motion tells you it is time to punch out and seek out some other terrain where you can look for lift.

-Erik (2008, CFSU)
Passing through a plume can put you on the downside of the power curve of immune response for days.

The trick is to know where you are on the curve and stay above the threshold, no matter what it takes.

And sometimes, for a really ill person, that would be out in the desert and damn near nowhere else.

-Erik (2008, CFSU)

I use the "losing ground" concept a lot.

It is falling lower on the power curve, like an engine that is on the verge of stalling.

Whenever I feel myself going lower, I step up my avoidance tactics.

-Erik (2010, WPI)

**THERMALLING**

I compare this to thermalling in a hang glider.

At first, it’s hard work... scanning the ground for signs of terrain which is likely to gather heat, checking dust devils or spinning debris to show if a thermal has been triggered, correcting for wind direction to intercept the projected angle of the rising air, dipping in to see if it is up air or just worthless turbulence, comparing distant mountains to see if they are rising or falling to monitor whether you are gaining altitude.

It all seems so complex. So many factors to juggle simultaneously.

But with practice, it almost becomes second nature, done without conscious thought.

It is weird for other people though, when they are talking with you and you suddenly shift positions so as not to be downwind of them, because their clothing is drenched with spores. They have no idea what you just did and it isn't worth the time it would take to explain.

-Erik (2008, CFSU)
I encounter plumes constantly, virtually every day.

This isn't an "on-off," yes or no, walk away and the toxins disappear type problem.

It's the gradual buildup of receptor blocking ionophore toxins which stay locked in place, and these toxins have become quite ubiquitous in the last twenty years.

There is no such thing as not having mycotoxin exposure. The question is "how much" and for how long - even if you aren't aware of it.

-Erik (2006, CFSEp)

MOVING UP ON THE CURVE

The doctor that I carried out of her moldy house in 2000 moved to an area that was still pretty rampant with plumes.

She was doing somewhat better there than in the really bad place she escaped from, and blamed the residual achiness and fatigue on "it's just me."

I said, "The heck it is" and took her out camping.

She was so achy that she could hardly walk a half mile. I said, "Give it a few days."

Four days later, we climbed Mt. Whitney together.

-Erik (2008, CFSU)

DETOXING AND THE POWER CURVE

Whether the detox continues when you get back to civildevastation all depends on where you are on the power curve and how much neurotoxin you encounter.

If you have recovered enough to build up reserves, then masking/blocking kicks in. With reserves, reactivity goes down in response to minor hits. Without reserves, reactivity goes through the roof.

But whatever reserve you built up can be overwhelmed by a large mold slam, and then you’re back to square one.

See why hang gliding was a good model for my avoidance lifestyle? This is so much like "Airspeed-Altitude-Available Lift" versus "Sink."
GAINING GROUND

I've seen people gain ground while in a place that was intermittently kicking them around, but it is so difficult and makes things so difficult that it's a very unhappy way to get through this.

-Erik (2008, CFSU)

BALANCING THE BOOKS

>Does being super-fanatical about mold avoidance for a while help folks to survive onslaughts of mold later on?

Yes. This is what I mean by “moving myself up on the power curve" or "balancing the books" and getting back in the black.

I can now tolerate a full time job in a building that used to put me under the curve in minutes.

From what I've seen, the tolerance that people build up allows them to withstand higher exposure for short periods, but that is all.

This feels to very much like thermalling in a hang glider. You work your butt off to get a bunch of altitude, and it's great while you're there. But some nasty "sink" can wipe out all your gains in no time.

-Erik (2008, CFSU)

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Dr. Shoemaker describes how the prolonged inflammatory response continually removes more anti-inflammatory cytokines.

Theoretically, if one had all their anti-inflammatory responses neutralized, there would be nothing from stopping one single spore from creating an all-out systemic over-response.

But the good news is that the longer one can stay damped down, it appears that the anti-inflammatory responses might be restored.
At least that's how it's been for me. By extreme avoidance for a portion of the time, I build up a certain degree of tolerance for other times when I have to enter mold zones.

This wild variability of pro- and anti-inflammatory cytokines seems to be how people can go through various degrees of reactivity that are so insanely out-of-whack with the "dose-response" model of illness.

-Erik (2008, CFSU)

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I've come into my workplace, which is a moderately bad building.

I can feel a vague sense of brain compression. Skin almost feels too tight and like the beginnings of a sunburn. Heart is palping... just a bit, not too bad.

But I know what this means.

I have a limit to how long I can stay in this zone without slip sliding down the slope to mold-very-unhappiness.

Experience tells me about eight hours.

So I plan to be out of here in no more than six.

-Erik (2009, SevereReactor)

**HITTING THE WALL**

"Hitting the wall" is a pretty literal term. Must quickly lean against a wall or sit down to avoid passing out. Can't stand up after that. But unlike normal humanoids, no quick recovery.

But I have also used that same phrase to mean running into a wall of mold spores, as in "the edge of the plume." Guess I unconsciously associated the two, because hitting the edge of a plume generally meant that I was going to hit the wall.

Since reaching the point of hitting the floor goes along with reaching a threshold of tolerance, I resorted to employing the phrase that runners use when they are completely depleted: hitting the dreaded "wall."

Every long distance runner knows what "the wall" is. No mere tiredness there.

That is why Dr. Peterson used the description that CFS is like a marathon runner after a race.
I think that was his best attempt to refer to a phenomenon that only a long distance runner fully understands. When you hit the wall, there is no quick rest and recovery. You are completely out of steam and stay that way for a while.

From most stories I've heard, by the time people realize how much trouble they are in, it is already too late.

-Erik (2008, CFSU)

RUNAWAY TRAIN

Years of experience tells me what I can handle and what I cannot.

There is a complex interplay of where I am on the power curve, compared to the intensity of the plume along with whatever reasons I have for being in a bad zone. All are factored in.

Despite people continually chanting that, "Erik’s solution is a one-size-fits-all," I keep repeating that each person must act according to the dictates of their own situation.

But one thing is inevitable. If the downward progression cannot be halted with whatever people in a moldy situation are doing, the endpoint of the journey can be extrapolated.

Kind of like a runaway train. When you first notice that it is speeding up, perhaps you could jump off and break a few bones, but you might survive.

But if you choose to ride it out to full speed to the end of the tracks, prolonging the situation just makes it worse when the train wreck finally happens.

-Erik (2008, CFSU)

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After finding out that only responding to overt upregulation was far too late, I took a sample out to the desert to gain familiarity with the lowest possible threshold of exposure that I can detect.

Then I monitored my response to see how far I can go before there is no going back.

When I approach that threshold, I must take action of suffer the consequences.

If I do so in time, using military biowarfare protocols of isolating affected equipment and clothing for later decontamination, I have had no need to throw them away. Washing has been sufficient.
I get some level of hit every day, but my reactivity has abated to the point that I can function relatively well in society.

-Erik (2010, CAA)

GOING DOWNHILL

> Your exposures to mold in the 1990s made you sick, but the ones you’re getting now haven’t done that. What’s made the difference?

The difference has been paying attention to where I am on the power curve and completely ignoring how I wish I were in these various environments.

If a place is steadily driving me down, I must leave or fall apart.

That’s it. No debate. No quibbling, no arguing my way out of it.

To stay is to die...that’s it.

-Erik (2008, CFSU)

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I’ve been in places where I had various symptoms, but they were getting better and considering the lack of options in to getting to a perfect place, it was only the fact that they were getting better which made them acceptable to me.

If I had nothing more than "heavy exhaustion,” but it was getting worse, I suppose it would be the mere fact of it getting worse that would make staying there unacceptable to me.

-Erik (2008, CFSU)

SLEEPING PLACE

Dr. Cheney observed the incredible sleep deprivation effects in CFS and has seen some success in improving people’s condition by focusing on sleep.

I believe that this is so important that if I were to design another MECU, I would have an entirely isolated sleeping zone away from potentially cross-contaminated materials that one brings into living areas.

Naturally, this applies to the most serious and severe states of reactivity.
People are surprised that I make so little effort at avoidance now. This is because by balancing a good sleep zone against daytime exposure, somehow I managed to crawl back up on the power curve and am not experiencing such high levels of inflammation.

I know it sounds crazy, but these toxins are apparently not all that toxic without the inflammation.

Like the difference between someone who goes into anaphylaxis from bee stings and someone who doesn’t. If the extreme responder could somehow get the immune system to calm down its response, he might conceivably go back to tolerating a few stings now and then.

-Erik (2008, CFSU)
Chapter 18 - Exercise

EXERCISE AND CFS

We had champion swimmers, marathon runners, a tennis pro and a hang gliding instructor who ran wind sprints all day while holding onto students’ flying wires - and there was absolutely no toughing it out.

Completely impossible. Out of the question. This is a physical incapacity that absolutely did not allow for mental compensation when the body was unwilling to respond.

No amount of spirit enabled us to walk to the bathroom when we were forced to crawl.

-Erik (2006, CFSExp)

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Dr. Cheney was worried that people would become deconditioned, but attempts to stand up set a pretty strict limitation on what you could do.

Being able to participate in any sports or physical activity was completely off the table - gone.

But as we saw wild variations develop in people’s illness, it became pretty clear that the way individuals were affected was so unpredictable that we couldn't necessarily rule someone out of CFS just because they were able to exercise or think at odd times while not at others.

It's like the weirdness of being so slammed during times of weather change. It just seems to make no sense at all unless you know what is causing it.

All of us in Incline could be easily discerned even at a distance because we literally staggered with a peculiar and distinctive gait from places where we could sit to another place where we could lean or sit again.

Nobody could stand unaided for long, let alone walk fast or run. We couldn't hide our condition if we ventured out. Anyone could spot us.

When someone is clearly suffering with something that sounds really similar, I hate to say, “Your description doesn't fit,” but the inability to exercise or tolerate the aftereffects was the absolute hallmark of CFS.

Or at least, CFS as it was in the beginning.
This illness turned athletes into couch potatoes literally overnight.

These were people who enjoyed nothing better than the mountain biking, tennis, marathon running, swimming lifestyle, and all the other stuff that was stolen by this illness.

The exercise intolerance is totally dictated and mediated by immune parameters of illness. If being in good shape didn't ward it off, what basis is there to believe that once a person has been disabled for long periods, somehow the duration of illness has changed the situation?

A "deconditioned" marathon runner is still probably in better shape after a year of laying in bed than most people will ever be.

You can easily spot the people who don't understand post exertional malaise because that is all that they think it is.

Not only that, but they often think of exertion as jogging or doing something really active, instead of trying to walk to the bathroom instead of crawl.

When people talk about having their illness flare, with infections and cognitive dysfunction that are vastly exacerbated, you know they're talking about the real thing.

GRADED EXERCISE THERAPY

One of the hallmarks of CFS was the "push-crash" phenomenon.

Overdoing is not benign and without deleterious consequences.

Dr. Cheney wrestled with this problem, as CFSers tended to be some of the most motivated people on the planet, and would go out and hurt themselves over and over - until painful experience taught a hard lesson that certain limits are exceeded at peril.
So he recommended moderate exercise when one feels able, but take care not to push beyond an artificial benchmark or goal if the effort is too depleting.

GET is almost a diagnostic of whether one understands CFS, because the waxing and waning variability of CFS means that GET is inappropriate, inadvisable, and unreasonable.

There are times when one simply cannot improve on what they have already done.

Thinking that GET is appropriate is an indication that one thinks the fatigue is of the normal variety, which CFS is not.

Pacing, meaning "Do what you can, when you can," is the safe and sane approach that most have adopted, because GET was out of the question.

-Erik (2006, Locations)

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The "Graded" in Graded Exercise Therapy means setting a benchmark or standard, and pushing yourself to meet or exceeding that goal.

Exerting yourself up to that grade and charting a higher mark.

This is what determines whether GET is success or failure.

It is whether you can attain that level and surpass it... according to your degree of "motivation."

If you cannot set a benchmark and meet it.... either the GET is a failure, or what is lacking is your motivation.

Gentle exercise whenever you can is not GET. That is pacing yourself.

This is what the battle between GET proponents and sufferers is all about.

Sufferers say they cannot meet that goal due to the varying degree of illness and post exertional relapse, and must pace themselves.

GET proponents say you could, if you just had more strength of will, and you just need to push yourself.

To GETters, any time you don't get just a smidge better, it's your own failure to push hard enough (but we'll forgive you, just try harder next time).
Any illness that can take an athlete down to bedridden, and haunts them to various
degrees thereafter, is only vaguely related to deconditioning as a consequence of a
horrific immune-disabling monster of an illness.

Yes, it is good to do whatever you can to prevent deconditioning, but this is not the
phenomenon that we are primarily concerned about.

Prior to the illness, we never crashed like this after exercise.

It is not normal. It limits our lives to one of pacing ourselves and watching limits, when
we would rather exercise our butts off and get back to the kind of athleticism we had
before.

Most people I know do not need professional help to tell them what level of exercise is
going to make them crash. The disease is the master of that information.

But we do know this! If someone thinks that a CFSer can exercise and consistently
GET better just like a normal person, they are utterly clueless about what CFS really is.

-Erik (2006, Locations)

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We all had good days and tried to hit a peak of exercise capacity, only to relapse and
pay for it horribly.

We wouldn't have thrown ourselves into crushing agony trying to exercise if we were
intent on avoiding exercise.

That's what put me in shock when I found something that allowed me to exercise
without crashing. This was like a damned miracle.

So unheard of was it, for someone of our group to predictably exercise, that people take
the miracle that I exploited as proof that I couldn't possibly have "the real deal" and was
only included as a "lesser case," a fluke, or an outright mistake.

For the CFS that I saw, graded exercise was absolutely impossible, and there was
almost nothing we could do to convince people we weren't lying about this.

Other doctors in the community attacked Dr. Cheney and Dr. Peterson for their belief in
this abnormality and supporting us when we insisted that this exercise intolerance
wasn't something we could work through or overcome with willpower.

Obviously I am not against exercising, and if improvement were impossible, I wouldn't
have pictures of myself on Mt Whitney.
But if CFSers are forced to attempt graded exercise, the remitting relapsing nature of the illness make sticking to a program of constant increase a virtual impossibility.

This forces them to monitor their own activity and only do "pacing."

-Erik (2007, CFSExp)

EXERCISE AND MOLD AVOIDANCE

The peculiar difference between "FeelGood" and "FeelBad" locations was that the postexertional malaise and immune paralysis just didn't seem to happen.

It is only the confused doctors who think CFS has anything to do with deconditioning.

I never really got out of shape.

All I had to do is pursue the effect of staying away from FeelBad places, and my "deconditioning" vanished.

-Erik (2008, Locations)

EPO PULSE

I'd been using altitude gain based on the sheer experience of having it help, but had no idea why that might be until Dr. Shoemaker wondered why this helped me. He found that pushing the aerobic threshold only slightly without going anaerobic causes a pulse release of erythropoietin (epo), which damps down inflammatory cytokines and calms immune over response down.

Dr. Shoemaker calls it, "Going to the Erythropoietin Heights."

I have to exercise at a very controlled rate and be careful not to go anaerobic to get the results.

It's not the altitude. It's the shift in altitude that pushes the anaerobic threshold and releases a pulse of epo.

The pulse appears to last, but I don't know the specific effects on VEGF since I've never been tested.

Low or high altitude makes no difference. It's the push to a higher altitude from wherever you are.
I never had to move from Incline to take advantage of this. I started out by doing my maximum walk: the length of a driveway.

It is not the simple fact of living at a particular altitude that induces epo release. It's the barometric pressure shift to lower air pressure from high altitude which pushes the cells closer to the anaerobic threshold.

Even if the Vascular Endothelial Growth Factor (VEGF) remains elevated by reprogramming, the epo pulse does not and is only temporarily released in a pulse by hypoxia.

Any beneficial effects are quickly overcome by re-exposure to biotoxins. The epo is just one part of the protocol.

Epo is natural. Procrit is the drug. I do not use the two terms interchangeably.

I never did any Procrit.

-Erik (2005, CFSExp)

Shoemaker states:

"There is more good news about epo. Since the genes for VEGF and epo are both linked, that means that production of both is linked. When we see simultaneously normal levels of epo in blood and low VEGF, there is a gene transcription problem. Why does this matter? For some patients, the use of epo as a supplement can override what is called 'transcription block,' can boost VEGF as well. For these patients, a short course of epo 'resets' the genes, defeats the block and there is no fall in VEGF after the epo pulse therapy is over. Those patients return to health and maintain that improvement."

The epo is pulsed, the VEGF reprogramming is the result.

But the process can be overcome by re-exposure to the offending irritant that incites the inflammatory response.

Dr. Shoemaker uses Actos to calm down this response to keep the inflammatory response modulated in order for the epo reprogramming to be effective, while the cholestyramine to furthers this by adsorbing the recirculating toxins released by the shift in leptin signaling.
I accomplish this by removing all traces of the inflammatory irritant before inducing an epo pulse by whatever amount of exercise begins to push the anaerobic threshold, and maintain this state without going completely anaerobic.

I believe this is why GET is moderately effective in some people and completely destructive in others. It all depends on the level of inflammatory response before an attempt to induce epo is made.

It's the luck of the draw. People who are in an area of lesser toxins are allowed to reprogram VEGF while those in an inflammatory state demolish their Krebs cycle and crash.

I took the chance out of the equation by monitoring the inflammatory response during GET, and it paid off.

It's made an amazing difference for me.

-Erik (2005, CFSExp)

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> There is a contrast in your statement from Shoemaker's in that he states that some patients maintain this improvement after the short course of EPO.

Don't forget that little clause: "in some patients."

Those "some patients" are the ones who don't have the HLA-DR mold susceptible genes.

For those that do, once they are primed for an inflammatory response, a biotoxin re-exposure to the many sick buildings scattered around will drive us back under the power curve of immune response. For us, the effect does not last under those circumstances.

I trained myself to detect subtleties of mycotoxin exposure and do whatever it takes to control the inflammatory response in order for the epo pulse to have effect.

“Whatever it takes" means extreme avoidance which is far more complicated than one would think, since any contaminated possession brought into a safe place can still be a driving force in the inflammatory response.

Dr. Shoemaker says that Actos (Avandia) can subdue the response so that such exposures are more tolerable, but I am not a patient of his and have not tried this.

-Erik (2005, CFSExp)

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It turns out that allergists in the 1950s were quite familiar with altitude therapy and recommended going to the mountains, but Dr. Shoemaker is actively seeking the reasons which allow refinement of the concept.

It's nice to have validation for an effect that most doctors are quick to say is nothing more than a relaxing break from normal life.

-Erik (2005, SickBuildings)

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Forget elevation as an indicator for locations. Mold grows at all altitudes.

This is a very complicated deal.

There IS a strange correlation to altitude. If you read Mold Warriors, Dr. Shoemaker talks about the "altitude induced release of erythropoietin," which damps down the inflammatory response and protects the Blood Brain Barrier.

But this damping can be easily overwhelmed if you are not clear.

-Erik (2006, Locations)

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There are anecdotal reports that CFS patients living on mountains do better.

My experience indicates that altitude per se has nothing to do with it.

It is the shift in altitude which induces epo release.

I can do this down at Mount Diablo just as effectively as Mt. Whitney.

I sincerely doubt that this effect can be duplicated by merely breathing if one is not increasing altitude at the time.

-Erik (2007, CFSExp)

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Sounds like hypobaric chambers are worth a try, although the trials I've seen so far don't seem to equal the descriptions of those who have done the altitude/location shift.
I am not talking about injected epo, but natural release, induced by altitude shift as discussed by Dr. Shoemaker who checked C4a at different altitudes - and therefore recommends "Going to the Erythropoietin Heights."

This only worked when I was free of neurotoxic inflammation.

-Erik (2007, CFSExp)

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The epo pulse appears to be a transitory response to pushing the anaerobic threshold. Staying at altitude allows eventual equilibrium.

I believe that this is the effect Dr. Shoemaker simulates with Actos. I would go out and deliberately push myself to the limit of comfortable aerobic capacity and then increase altitude while maintaining the effect by adjusting pacing.

What I found was that I absolutely must be free of any inflammatory response before and during the exercise. If I walked through a spore plume, I would crash and suffer if I were to continue.

Sometimes I would be just sufficiently contaminated to make the choice very difficult to turn around and go to all the trouble of decontaminating and starting over, but I finally learned how important it was.

Bitter experience taught me not to mess around with this. It was absolutely necessary that the immune system be damped down or the exercise would be Counterproductive, spelled with a capital "C"rash.

-Erik (2008, CFSU)

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>So apart from making sure that you're in a good location and not carrying the response, are there other things that you do prior to exercise to make sure that your immune system is damped down?

Nada.

-Erik (2008, CFSU)

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It's not the altitude. It's the shift in altitude, so the start point doesn't matter. What I mean is that it doesn't matter if the start point of the exertion is at higher or lower altitude.
I've gotten the same type of epo pulse starting at sea level (Mt. Diablo) as I did when starting at 10,000 feet (Mt. Whitney or Wheeler Peak).

Dr. Shoemaker says it's so dramatic because the epo pulse significantly lowers cerebral inflammation.

It seems to be mainly the shift while maintaining an almost anaerobic state that does it. Sometimes in as little at 300 foot vertical gain.

I take my exertion up to the point of almost being unable to carry on a conversation, and then go whatever speed allows me to continue a conversation without being breathless. No matter how slow that is. The trick was to find hills that match where I am on the power curve and that allow a comfortable ascension at precisely this rate.

When I first started out, doing this, "level" was all I could handle.

Then I started getting better.

-Erik (2008, CFSU)

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I tricked my body into thinking it was increasing altitude by... increasing altitude.

I lived near the top of Village Blvd, and every day, I went up to the scenic turnout overlooking Incline Village.

It was amazing. There was "something" about doing this increase in altitude that really helped.

I wasn't the only Incliner doing this, either.

I found others who stumbled over the same effect, and we ran into each other while out practicing it.

It had to be a steady increase in altitude or it didn't work.

I tried this at various elevations, and going to a lower one ruined the effect. It had to be a steady increase from whatever altitude you are accustomed to.

It was really weird.

You had to breathe at the exact threshold of just barely starting to push the aerobic threshold, but not go beyond. Definitely not go beyond, or pay for it with a crash.
If I could maintain precisely this balance for about 30 minutes a day, the effects were near miraculous.

It made a difference in "push/crash" when nothing else made a dent.

-Erik (2009, WPI)

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Sometimes I ignored Dr. Cheney's advice and tried to "push through it."

This didn't work out so well, and I had repeated crashes and relapses.

But what could I do? Doing nothing was doing nothing.

I decided to keep trying even if it killed me.

And that's when I noticed that, occasionally, there were times that I didn't crash.

Since my movements were so limited, I could reproduce exactly what I was doing when I didn't crash.

I tried doing exactly the same thing again. Remarkably, I again didn't crash.

Or at least I crashed so much less than I would at other times that this gave me an "effect" - a promising direction in which to push my thinking to get maximum benefit.

I had no words for this, so I just called it "an effect."

The point was to reach and maintain a very precise level of breathing while ascending upwards from whatever altitude you are accustomed to.

Although I was working on increasing my range, which started out at half a block, this was not Graded Exercise Therapy.

I was aiming at a specific type of breathing for a controlled duration.

This resulted in additional exercise tolerance, It looked like graded exercise to them, so it looked to others as if I was accomplishing this through sheer will power. But honestly, GET has nothing to do with this.

Since I couldn't persuade people to believe it until they had a logical rationale that accounts for its existence, we've been waiting for someone like Dr. Cheney to connect his observations of impaired VO2 max with an actual breathing mechanism which might
put their science together with the "dumb luck" experience of those of us who tripped over this by sheer trial and error.

-Erik (2009, WPI)
Chapter 19 - Mold Avoidance Techniques

THE JOHNSON PROTOCOL

> Can someone tell me what the Johnson Protocol is?

"Feel mold.... run like hell, decontaminate before the immune system goes ballistic."

"Don't carry it home, particularly not where you sleep."

"If you feel mold in your sleeping place, it's not a place where you can sleep."

That's the basic idea. Pulling it off is the tricky part.

-Erik (2009, SevereReactor)

COMING TO GRIPS

> You've said that this is the hardest thing you've ever done in your life. What has made it so hard?

Mentally coming to grips with the reality that such a small and subtle seeming reactivity could totally take me to pieces, if I failed to act as if it were comparable with plutonium.

-Erik (2008, CFSU)

BIOWARFARE TRAINING

I don't think any of us just chose to believe how difficult this is. We got dragged into it, very much against our will.

We had to get slammed by this cross contamination process many, many times before it sank in that such a crazy thing could really happen.

It may have been a little easier for me, because I was in the Army and had biowarfare training with a tear gas "simulant," CS gas.

And the mold contamination was acting exactly like CS gas.
This is also why I probably had better results with a strategy of avoidance than many people, because I was simply acting out years of training in biowarfare battlefield survival protocols.

-Erik (2009, SevereReactor)

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It paid for some of us to stay away from that stuff wherever it was, regardless of what was “causing” the sensitivity.

I used to go sit in my Volkswagen to get away from it... and no, it wasn't the copy machines in the teachers' lounge at Truckee High School. This nasty stuff was biotoxins from mold.

I treat the burning sensation that Gerald Kennedy described as if it were plutonium.

By this, I don't mean like a nasty fart, where you hold your breathe and walk away.

Literally like plutonium. Like radiation poisoning, as if there are only so many rads that you can withstand in a given amount of time.

Whenever and wherever I felt it, I would do my best to get away, take a shower and change my clothes.

The more I practiced avoidance, the more sensitive I became.

This stuff is in a lot more places than people think, and seems to be affecting people even when they are scarcely aware of what might be bothering them.

We "hypersensitized" individuals who look at them and say, "The reason you feel like crap right now is not just you. I can feel it too, and it is in the air.”

The effects from this crap appear to be far more devastating that doctors think.

-Erik (2010, WPI)

MICROMETEOROLOGY

We all look at things from our own conceptual framework.

I know it seems incredible that hang gliding would have anything to do with mold illness, but the knowledge of micrometeorology necessary to safely practice the sport has been invaluable.
When the presence of mold didn’t seem to make sense, I looked at it in the same way a pilot gets indicators of wind speed and direction by looking at various visible clues, like smoke and flags.

The correlation to spore plumes was just as amazing as when you spot dust devils and chase them to a wispy developing Cumulus cloud and find the thermal that keeps you aloft.

-Erik (2006, SickBuildings)

FOCUSBING ON AVOIDANCE

I tried all kinds of stuff, but I just kept going back to how much better I felt out in the desert.

Finally, I just gave up on all other concepts and tried to recreate as pristine “desert like” environment as possible.

And once I found out how complicated this whole thing is, I decided to concentrate on tactics rather than comprehension of the fine details. After all, a soldier doesn’t need to know anything about the chemical constituents of nerve agent to practice biological warfare protocols.

-Erik (2008, CFSU)

SUBTLE EXPOSURES

Mold testing is ridiculous and counterproductive. You are your own “moldmeter.”

But you have to believe and you have to act in response to subtleties.

Exactly as you would if the exposure were "rads" and you only had the beeping of a geiger counter to warn you.

I treat subtle symptoms of exposure from mold as if it is doing more damage than the amount of discomfort would indicate.

The same as you would with radiation exposure if you had a geiger counter to provide the clues that radiation is present.

-Erik (2006, Locations)
I developed the term “mold hits” to represent a probative state of inquiry... like "web hits."

My friends and I use this to describe a noticeable presence that is a warning of mold contamination.

For instance, "I'm not too sure about this restaurant. I'm feeling a few hits of burning sensation, heart palpitations, shortness of breath and impending signs of brain fog."

“Slammed” is from failure to heed the hits.

As in, "Dang it. I wish we had just abandoned the food in that restaurant instead of trying to stay and eat. I slept horribly, my lungs ache, I had night sweats, my sinuses hurt, I had a bloody nose, I itched all over and I'm so tired I can hardly stand up. I'll never eat there again and if I feel those mold hits anywhere again, I'm going to run for my life."

-Erik (2006, SickBuildings)

LIVING IN CIVILIZATION

There is no way to avoid running into mold, but I find that if I can sleep free of the molds that are powerful enough to give me an inflammatory response, I build up a tolerance that allows me to withstand limited exposure to places that used to knock me flat.

I maneuver through spore plumes daily and if I make sure that I decontaminate and never carry enough spores home to allow my bedding to become contaminated with the more toxic molds that I encounter, I can still survive in areas that are far less than perfect.

By persistently avoiding really bad places and making sure I decontaminate whenever I perceive mold, I can now work full time in a building that I didn't dare enter several years ago.

I'm not happy about working in a place where there is any mold at all, but hey, someone has to pay the bills.

-Erik (2002, SickBuildings)

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> What do you recommend for people who can't practice extreme avoidance, for example, people whose work ends up exposing them to low levels of mold?
That's when you absolutely MUST practice a strategy of extreme avoidance so that you can build up enough reserve to tolerate some limited exposure, just as I'm doing now.

At this moment I am in a building that used to knock me flat in minutes, and now I can work all day here.

But to do that, I balance the books by constantly looking at indicators of exposure that are usually more subtle that ones people are usually referring to.

Responding to minor perceptive hits instead of just major slams.

People tend to quickly jump to the conclusion that they already know what I am describing when I say "extreme avoidance," often thinking that this just means a "tent out in the desert" even though this is not what I actually said.

-Erik (2006, SickBuildings)

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I say straight out that I am less than half a mile from where I was in 1985 when the whole CFS thing began... and people still ask me what desert I moved to.

I can't seem to make it clear that avoidance is more of technique than a location.

I have a zillion "feel good places."

But the one I like to mention because it instantly intimates that there is something weird about what I'm saying is that I feel great in Incline Village.

People are supposed to go, "Hey.... wait a damn minute" and ask what I mean... "After all, isn't that where...?"

So then I could say, "Why yes, yes it is! But it is still a feel good place.... as long as I keep my butt away from the mold plumes and control for cross contamination of spores."

-Erik (2008, CFSU)

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To the best of my knowledge, nobody else has ever done what I call extreme avoidance.

Just going out to the desert would be the closest approximation, and yes - that really paid off for some.
>Don’t you think if you spent less time in your office, you’d be doing better?

Lisa, you felt that plume down at the front door, in the foyer?

If I hold my breath when I go through and decontaminate after I leave work, it's been pretty tolerable.

But yeah, I see your point. I could probably do even better by spending more of my time elsewhere.

Say, doesn't this show that I'm not restricting myself to a life of total hermitude?

-Erik (2008, CFSU)

I felt that no mold avoidance at all was needed in the White Mountains on Crete, and for a whole lot of Greece, for that matter.

But it's amazing to be able to practice mold avoidance in sub-perfect areas and improve my situation wherever I am. That's what's kept me going.

-Erik (2009, Locations)

**SPOT PLUMES**

Dr. Klapow was a doctor who built a Hepa pressurized room for himself to sleep in.

I sat at his microscopy bench and was immediately slammed by a small mold plume that emanated from a corner that was adjacent to a crawl space which was under the building.

I told him, "I don't know how you can work here. This plume would take me apart, given enough time."

But although Dr. Klapow's reactivity was such that he had determined the need for a Hepa filtered environment, his sensitivity was not sufficiently directed to discern small plumes.

And so, he doesn't have the perceptual means to actively avoid them.
LIVING BETWEEN PLUMES

Even though some areas have a higher density of spore plumes, the critical thing is to live between them. It is possible to live in close proximity to powerful plumes just as long as you aren't sleeping in them or cross contaminating your environment by carrying spores home from passing through the plumes.

People who don't understand the principles of cross contamination require a huge mold free area to gain the benefits of mycotoxin avoidance.

A person who is highly skilled in controlling cross contamination can survive in a fairly dense scattering of plumes.

-Erik (2004, SickBuildings)

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The mobility allows me to keep on truckin' until I find a Feel Good location to squat.

I found a good place in-between plumes right inside Reno. I've been in the same place for about a year now.

I still have to decontaminate when I venture through the plumes, but this has been absolutely terrific.

I just got back from a thirty mile bike ride.

-Erik (2009, SevereReactor)

SPORES VS. TOXINS

There is no difference in physical response between spore toxins and toxins which have become separated from the spores, but there is a huge difference in how the situation is handled.

If I go through areas of toxins, I do it quickly and have not had the need to decontaminate.

But if the air is full of spores, this is another matter entirely, for now I will have high concentrations of toxins in a spore that is gradually releasing them.
The fact that they are still in spores means they can be cleaned to some extent.

Adsorbed toxins cannot, but then, it takes longer to adsorb.

This creates a tactical difference.

That's why I talk about preemptive avoidance.

By this, I mean staying out of toxin-alone concentrations so they don't have much of a chance to adsorb, since once that happens cleaning anything is pretty much impossible.

-Erik (2010, SevereReactor)

REINTRODUCING OBJECTS

When doing controlled tests on individual objects, there is another variable that is almost never taken into consideration:

Toxin effects are cumulative.

We've had the opportunity to watch lots of people bring their old possessions into a new house, piece by piece, cautiously, carefully, slowly.

Each one feels okay, so in it comes. More, more, more. Each one, held up to the face - no problem. And finally one last "harmless" object.. and POW.

The world stops turning. Everything goes right back to being bad. All of them. Each and every one suddenly lights up and you are plunged right back to where you were.

The effect is cumulative. It creeps up on you.

Every time this happens, it is the last "triggering object" which gets all the blame. Then you find out that it wasn't so easy.

Taking that one object back out doesn't get things back to normal. People wind up having to get ALL their stuff back out... or even move out.

People get themselves below the trigger point on the power curve and are amazed (and relieved) at how bad objects can just switch off as if they weren't bad at all.

It looks like you've won, you've done it - all cleaned up and safe again.

And then... you get enough of these sub-perceptible objects around you... WHAM. Right back to hell!
It's hard enough to accept that a single object can have such a strong effect, so factoring in the accumulation concept as a variable factor that regulates your reactivity to specific objects is one more leap that is pretty difficult to make.

So much so that it hasn't really done much good to warn people. About the best we can do is tell folks about it, so they'll be able to recognize what is going on when it happens.

-Erik (2008, CFSU)

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Easiest way to get through this.

Put everything in storage. Take nothing. Nothing. NOTHING. NOTHING! (Really... nothing!)

That way, if you feel hit, you know it's not from your stuff and can plan accordingly.

If you've found a safe haven, bring in things slowly.

Assess how you feel after each item is brought in.

Far, far safer to go it slow than face what usually happens to people when they take their stuff with them.

Wash stuff first, leave it in the sun, bring it in slow, slow, slow.

If you do suddenly feel like crap, bear in mind that this illness is the generally sum total of a lot of hits from different sources, so you can't conclude that it is just the last thing that you brought in.

Or that taking the one thing back out will help.

It was just the last bit of straw that finally broke the camel's back.

To get the camel back functioning again, removing that one piece of straw is not going to do the trick. You have to lighten the camel enough that he can recover.

If that means taking everything back off the camel... urgh... I know, it sucks, but that's how it is! The camel needs some serious rest and recuperation, after his back is busted.

-Erik (2008, CFSU)

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I can't think of anything worse to bring out of moldy house than a bed.

Some people who have bought new mattresses to put in a wood frame have found that the frame itself is too contaminated to tolerate.

But there is no need for you to be in doubt, or have to take anyone else’s word. You can test this for yourself.

Clean the bed frame as best you can, and put the mattress in one of those allergy dust mite envelopes that are available at bedding spores.

This won't keep the toxins in, but it does seem to help keep fragments and detritus from cross contaminating the room.

Then just try sleeping on this mattress one night, and another the next, so you can compare.

Shouldn't take too long to make your determination.

For things that come out of really bad mold zones, one night might be enough.

Don't beat yourself up for asking. Very reasonable, under the circumstances.

This whole thing is just too crazy.

I had to ruin many a night’s sleep experimenting with this before I could finally bring myself to believe it.

-Erik (2009, CFSU)

A STORAGE SPACE

>What if I rent a two bedroom apartment and store the objects from my moldy house in the closed-off room?

I tried doing exactly that - a separate room with the door sealed up with duct tape. It didn’t work for me.

I know. It’s hard to believe. All common sense says this would be more than adequate.

I wish it was!

-Erik (2008, CFSU)
**STATIC ELECTRICITY**

In an RV, you're insulated from the ground plane of the earth by the wheels.

My cot has a metal frame, and it's connected to the body of the rig. In an effort to control the static buildup, I throw a couple of buckets of water to increase conductivity down a couple of feet to wet soil, and put down a ground-strap from the frame.

It doesn't seem necessary when I'm not in a mold zone, but when I am.... I ground myself to the earth, and it does seem to help.

But scarcely a smidge as much as being in a good zone does.

-Erik (2008, CFSU)

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> I wrapped my mattress with mylar because the smell of it was making me sick. Now I can stand it smell-wise, but it builds up a lot of static electricity. I wonder if I should ground it.

The mylar might prevent direct facial exposure, but unless it's an airtight seal all the way around, some badness will still sneak out.

Toxins from a bad mattress can certainly fill an entire room.

I think REM sleep is far too precious to make compromises.

I'd get another sleep system before trying out grounding.

> When I said the smell of my mattress was making me sick, I meant chemical-wise, not mold-wise. I wouldn't keep a mold contaminated item in my house.

That's why I just said "toxins" without specifying mold. If it bothers you, then it's something you probably shouldn't be sleeping near.

Try running a wire from your bed frame to metal plumbing, or out to a stake driven deep in the ground and see if works any better.

Mostly, from what I've seen, if the static zaps are really bothersome, this is a sign that the area is beyond personal tolerance.

-Erik (2009, Locations)
IN A BAD ENVIRONMENT

I can't move. What should I do about the mold in our bathroom?

It's hard to draw a middle ground between trying to scare you out of there by our horrible stories and trying to be supportive of a decision to stay in an environment that may very possibly be worse than any alternative.

A lot of us were driven out to sleep in our cars in the dead of winter because we could not survive for another hour inside.

But if I were in that position and was trying to stay, I would rig up a Hepa air filter with an exhaust ductwork "downstream" to pull filtered air from the bathroom and out through the window. Then I would seal the door shut with tape.

Hopefully, creating a low pressure system in a closed bathroom would draw spores in the walls back toward the filter to trap them, and the VOC’s would go out the window.

I would devise some alternate toilet facilities so that the sealed bathroom can stay sealed. It sounds unthinkable to go to extremes like this, but when you've seen what it is like to sleep in a freezing cold car out in front of your nice warm - but killer - house, using a bucket isn't so bad by comparison.

I'd suggest spending every moment away from that bad zone to break the response as much as possible.

Your bedding is contaminated. I would cover the bed with plastic and wash a cotton mattress pad to put over it.

All bedding and clothing should be washed in a laundromat - not your house - so you can have a lower degree of exposure, especially while sleeping.

Have a stack of fresh bedding that can be rotated through the normal course of spore settling, which forms an accumulation on horizontal surfaces.

Try to sleep as close to an open window as possible, no matter how cold it gets.

When you are at your absolute worst and have the greatest difficulty trying to arise, and just want to lay there and give up, that is the very time when you must drag yourself outside at all costs.

I would have the situation assessed by an environmental specialist who expresses knowledge of the difficulty of successful remediation. I would not trust anyone who says it is easy or cheap.
Your landlord will probably try to convince you that he knows a contractor who can just go in, clean up the mold, spray with bleach and your problems will be over.

For many, that's where the nightmare begins.

-Erik (2006, SickBuildings)

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>I have to spend time temporarily in a really bad environment. Is there anything I can do to minimize the effects?

Try to get outside as much as possible.

Wash your hair thoroughly just before you lay down to sleep. Every time. No exceptions.

Use fresh towels, no pillows. When you wake up in the middle of the night, fighting for air, switch to a fresh towel.

-Erik (2008, CFSU)

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In a less good location, I will use piles of blankets at night.

They all have to be washed in a good location. And then, when I wake up feeling even slightly hit, I get rid of the top blanket to get a fresh surface to put my head.

I'm in Reno right now. It was a "two blanket" night, last night.

-Erik (2008, CFSU)

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This is the first winter in ten years that I haven't had to get up in the middle of the night and run for it when plumes roll through.

So far, washing clothes and blankets has been enough to keep the badness down to a dull roar, and I haven't had to pick up and run.

There have been times when I should have moved, but by changing to new blankets every fifteen minutes, I got through it.
When things hit the max this winter, I must have gone through a dozen blankets. And I have them double folded to maximize their use.

It was a pain, but I didn't have to move. In the past, I ran out of options except to make a run for it.

So that's an improvement.

This may not mean much to "normies" who can't conceive of what it's like to have to get out of town under bad conditions, but I consider it a bit of a relief from a fairly complex and difficult situation.

I found a place in Reno that is averagely okay. To get out of Reno I would have to pass through plumes of sufficient intensity that the whole rig would be bombarded anyway.

It's a judgement call between staying at a moderately bad place or try to scream through a really bad plume which can really leave strong effects.

Since I can't do both, I'll never know which was the better choice.

I can only guess at it.

-Erik (2010, SevereReactor)

TEACHING OTHERS

I've been frustrated when people ask me to "just point at the mold and get it out of my life so I can go on" and I have to tell them that this would be useless.

They must learn to assess their own response and comfort level, and act accordingly. Living with this type of sensitivity means that no one can do it for you, unless you are living with them full time.

-Erik (2004, SickBuildings)

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Certainly it is good to have a book that describes the principles of flight so one can basically understand what the controls are doing, but this used to work against us in hang gliding in a sort of unexpected way.

People would assimilate a concept that they "need to do something to the glider to make it go" and would wind up with a false notion that would have them trying to do all kinds of complicated but totally wrong control inputs.
It was actually much easier to just get them out on a flat lawn and run with the glider to see how it feels.

Students were often confused at the lack of information prior to picking up a glider, but it was quite intentional the part of the instructor. You had to get a sense of what a glider does before trying to put all the information together.

This is an incredible amount of information. Before it makes sense, it all has to be "ordered."

When it finally does, things just click. But trying to assimilate it all in a short time is like trying to remember everything you saw at Disneyland.

-Erik (2008, CFSU)
Chapter 20 - Supermold Avoidance Techniques

STAYING HIGH ON THE CURVE

I used to be so scared of the supermold that I remember, after a really bad slam, taking a shower and standing in the middle of a room... too scared to move.

Too scared to put my clothes on, too scared to lie down, touch anything.

I just stood there and cried. I had no idea how I was going to stay alive with a problem like this.

I can't believe it, but you saw how cavalier I can be about decontaminating.

It took years of practice, but somehow I just developed a sense that allows me to feel my way around.

As long as I act in accordance with that sense, and exert additional effort when I start to fall lower on the power curve, I am amazed at how well I do in places that used to scare me to death.

I think that after a few months in your Casita, you will move higher on the power curve and feel much more in control about venturing into the bad places.

Scary, but not quite as scary, and as time goes along, a certain confidence builds up, based on experience.

-Erik (2009, Email)

CARRYING THE RESPONSE

Remember how I described parking across the street from that apartment complex because it was lateral to the prevailing winds and allowed us to enter the zone from the side, which allows for a quick escape?

If I don't carry the response with me after leaving a zone like that, I don't necessarily have to decontaminate right away... so I don't.

However, if I get out of a place like that and feel that my clothes are contaminated, that's another matter.

-Erik (2009, Email)
SHIFTING BY YARDS

Just yesterday, I was hit by a wayward mold plume and felt the change in skin perfusion and "static zaps."

I know by years of experience that there is only so much of this that I can take before it hits a critical threshold. So I bailed out. Ran for my life.

I've never found anything that holds a candle to the ability to just get out of that situation.

Sometimes I only have to move a few hundred feet.

It's like dancing around cigarette smoke by dodging and ducking at the first hint of smelling the wafting threads of a drifting fume. Only, in this case, it's a mild burning sensation, slight brain compression and sudden change in the zap factor.

What a crazy life this turned out to be.

-Erik (2008, CFSU)

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It is definitely worth my while to move short distances around Reno, according to wind direction and how certain places are acting up.

Not that Reno is a wonderful place, but there is a lot happening in Reno now.

The super bad mold seems to be very localized at the moment.

That is the main stuff that calls for immediate relocation.

It is amazing to me how much better the area around the Park Lane Mall location is, now that they finished demolishing the last of the foundation and hauled every last bit of it away.

I knew it was the center of badness for that particular part of town, but I had no idea how much it would improve the area just to have that one sourcepoint disappear.

Reminds me very much of hang gliding.

This is how one works thermals. Gravitate toward the up, and speed up to get out of the down.
Over time, how well you do this dictates whether it was a good flight or not.

-Erik (2009, SevereReactor)

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I keep telling people that I shift locations by yards, and for some reason, the debate changes to shifting countries or continents.

I have been to different continents and while there, I still had to shift locations... by yards.

-Erik (2009, Locations)

CONSTANT VIGILANCE

Branislav says that the supermold is inherently supertoxic, even though he describes getting hits from people who are carrying it on them that are entirely unaffected.

This says to me that although the supermold is superbad, it still requires a certain degree of sensitization.

The way he says that the supermold doesn't die down is contrary to everything I've experienced, unless one is in a bad zone which is keeping them low on the power curve.

In a place like that, just as you say, you continually become more sensitized and the very same toxin feels worse. As you've seen, sometimes it's not until you get to the desert that you find out how much different a desert feels.

That's how it was for me. I really didn't know that the whole damn town was ambiently below the curve until I got to a place that was good enough to show me that things could be better elsewhere.

And you are right that your Moldie friend will not be okay forever.

It isn't a "do it once and you're out of this mess" type of deal.

It is staying constantly vigilant in a manner that moves you up the power curve of tolerance that allows you to withstand the occasional supermoldslams.

-Erik (2009, Email)

SUPERMOLD VS. REGULAR BAD MOLD
Just a few minutes ago, I returned from doing errands and carried my knapsack, which I know to have been in bad places, into my rig.

The store I shop at is okay, and the knapsack was only moderately hit.

The knapsack doesn’t seem to be a problem for the things I put in it, but I do keep it outside without washing, because I am going back into some bad places again and the effort would outweigh the benefit.

I must be getting careless, because I set it inside by the door while I was unloading its contents and left it there while I put them away.

Sure enough, in the enclosed space, the thing started acting up and I tossed it back outside, with instant relief.

In the Army, I would have been disciplined for this breach of protocol.

The isolation area should be established outside at a good distance, but what the heck?

You get to a point where if controlling it has been fairly easy, you begin to cut corners.

This is all just for normal bad mold though.

The really bad stuff, of course I just run and decontaminate.

Bag my clothes and store them on the roof, figure out what to do with them later.

Lately though, I haven’t hit the really bad stuff.

--Erik (2010, SevereReactor)

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>How have you managed not to hit the really bad stuff?

I turn and run, that's what I do.

I was in a shopping center on the north end of Reno that has consistently felt good to me, and I got too close to some shoppers that had the killer stuff on them. I did a quick 180 and escaped.

That stuff is SO bad, I wonder how they stay alive?

Lately, I have only gone to usual places, but there is a shopping center on the south side of Reno that really knocked me flat a few years ago.
In the next couple of days I intend to go check it out, to see if it still has the same effect.

-Erik (2010, SevereReactor)

**PLASTIC BAGS AND A COOLER**

> If you want to keep mold from contaminating your clothes, seal them up with aluminum foil.

Can't imagine how foil could possibly work unless it was sealed airtight.

I did a demonstration with a new Moldie who was utterly convinced that plastic bags must work.

We zip bagged a sample of the really bad mold, washed the bag, sealed that inside another ziplock bag... washed it. stored it outside in a cooler for a few days to let it get ripping... and then did the proximity test.

The toxins apparently penetrate the plastic bags.

Gotta do something else.

(Had to throw away the cooler too.)

Oh, I'm sorry. I was responding to the quote of Dr. Rea advising bagging to keep toxins in, rather than your advice of foiling to keep the bad stuff out.

For purposes of protection of uncontaminated stuff, sounds like a terrific idea, and would most likely work for me.

>Erik, it sounds here like you were under the impression that spores cross-contaminate while mycotoxins do not.

>> I noticed that some contaminated places give me a huge hit but that I could walk away and recover without decontamination. Other places might hit me less, but I would carry the reaction with me. This led me to believe that the neurotoxic reaction was to aerosolized mycotoxins and not necessarily inhalation of spores.

>> I tested this by placing a contaminated article in HEPA filters and taking it to my clean place. I put it under six layers of blankets and slept on it. I got the usual reaction and removed the article but went back to sleep on the same blankets. The reaction was
gone. This convinced me that that spores had not penetrated the filter or blankets and that the toxic gas was truly my primary irritant.

>>This was confirmed by Dr. Marinkovich, who told me that a housing project in Sweden had recently been identified with sick inhabitants but no spores could be found. Only when the walls were opened up were the colonies found, but they were so tightly sealed in the walls that only the toxic gas could escape.

>> Many places that give me mold hits are strictly VOC hits and not spores. When I leave these areas I do not have to bother with decontamination.

Yes, exactly.

I didn't bother to determine if the differential in places where I carry the response really is spores or not.

Although I suspect this is the variable, based on the "blanket test" and other observations, it really is not necessary to know, if the strategy works.

It would be nice to find out, but it is not necessary for the time being.

So until researchers get off their duffs, at least I can keep doing what appears to work.

I couldn't handle areas that are overtolerance, and trying to outguess all the factors was too overwhelming.

>What kind of sensation did you get from the toxins that penetrated the plastic bag?

Filtering out the spores seemed to result in more of a burning sensation, without the heart palps.

>How much mold did you put in those plastic bags, that the mycotoxins that got through cross-contaminated the cooler?

Full HazMat gear, facemask, gloves... the works!

Had ziplock bags laid outside, upwind of the area where bad mold had been previously identified.

First bag had distilled water to feed mold.

Obtained sample, walked upwind, picked up bag and while still walking upwind, put in ziplock and dropped it on ground.
Did standard “walk into the wind” removal of HazMat gear.

Decontaminated.

Went back and picked up sample.

Washed bag.

Carried first bag upwind to second bag.

Placed ziplock inside second ziplock.

Put that in cooler which had never been near bad zone.

Left cooler outside for several days.

Brought friend who stood upwind while I removed ziplocks from cooler.

Had friend approach slowly until friend discerned the presence.

Man! The things you gotta do to convince people!

> There’s a big difference between what you describe with your cooler and carrying clothes in plastic bags through a moldy airport.

Agreed. I thought that whatever came through was going to dissipate quickly and not really contaminate stuff outside the ziplocks.

At the time I did this test, I didn't think I was going to have to throw away the cooler.

But after I felt somewhat crappy after washing it out, I said, "The heck with taking a chance," and tossed it.

-Erik (2009, SevereReactor)
Chapter 21 - Decontamination

A LIFEBOAT

My lifeboat consists of an avoidance and decontamination strategy.

I know that this strategy is a lifeboat, for I see others sink when they encounter the same moldy milieu and fail to respond by removing traces of this substance. This makes it exceedingly difficult for them to tread water.

-Erik (2010, WPI)

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The key to my success was building a Mobile Environmental Control Unit that allows me to quickly decontaminate.

Regardless of whether you have a safe zone at home, you still need to decontaminate within a few minutes of a mold hit, before the inflammatory response to the toxin turns into a self perpetuating cytokine cascade that keeps on rolling independently of the initiating event.

That's why the MECU has to go along with me for quick decontamination.

No, it's not exactly what I had planned for my life, but it sure beats the heck out of what I was going through before.

-Erik (2010, CAA)

BIOWARFARE PROTOCOLS

I had a real advantage, especially from the military training in decontamination.

When I realized that mold was hanging on me just like CS gas, all I had to do was slide back into my biowarfare protocols.

But it is ironic that one of the major reasons I got out of the Army is that I hated playing that stupid game.

And here it goes and saves my life!

-Erik (2008, CFSU)
TEN SHOWERS A DAY

I test myself before and after entering a suspect zone to see if I am carrying the response on me. If not, I don't have to decontaminate right away.

If I don't feel at least somewhat better, I know that I am covered with spores and must get the little buggers off me as quickly as possible.

When you have the mold all over you, you cannot tell.

So you decontaminate and start over. And then you can tell.

This allows you to define where the plume is so you can live right next to it - even pass through, just as long as you can decontaminate afterward.

I gave up trying to predict where it is. Too many surprises.

I just react to my perceptions.

There are far worse therapies than taking a heck of a lot of showers.

-Erik (2008, Email)

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The key to "what Erik was doing," and what allowed my friend to recover fairly quickly back in 2000, is moving the MECU quickly whenever we thought we had hit an outdoor mold plume - and then showering.

Over and over, again and again.

Seemed crazy to people that sometimes I was taking up to ten showers a day and changing my clothes every time.

But that's what I did.

Every time I felt a mold hit, even if it were slight, I'd run to my rig and take a shower, change clothes, and bag clothes in a separate compartment for washing later.

"Preemptive," "Preemptive," "Preemptive"!

Catch the response before it has a chance to go ballistic.

After years of watching so many people try other stuff, I am glad that I went this route.
Swift action relieved me of so much pain.

Trying to remediate, clean up, and keep going after you've been upregulated is such a bitch.

If there is anything one can do to avoid it....

Well, that's what I did.

-Erik (2009, SevereReactor)

HAIR AND CLOTHES

Hair is a really good transporter for mold. I could never use any wool that has been exposed to Stachy.

I read the story of a woman with CFS who tried for years to control her symptoms, totally without success.

Suddenly her condition improved, but she wasn't doing anything different. In fact, absolutely the only thing that had changed was that her husband had retired and was hanging around the house all day.

Her statement goes right to the heart of the matter.

Her husband was probably carrying spores home from work and what he carried in his hair was contaminating the bedding sufficiently to keep her in an inflammatory state.

When you have this level of reactivity, that's all it takes.

-Erik (2002, SickBuildings)

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> Change into the clean clothes before you get back into your vehicle and keep your mask on. Put your other clothes into a plastic bag to be washed later. Same for the shoes. You might also consider covering your hair during the visit.

Great advice.

This is a somewhat less intense version of what I do.
The variation is that I use an RV that has a shower, make sure I don't park it in a spore plume, and keep it always handy to break the response before the cytokine storm gets so out of control that it makes me ill for days afterward.

(That is a really big "before.")

-Erik (2006, SickBuildings)

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> I should go to the shower carrying the new clothes and bag my present clothes which were contaminated by driving in the car all day, take a shower and put on new clothes, leaving the contaminated clothes in a new plastic bag? Are plastic trash bags okay to use?

Yes, that's exactly what I do.

Plastic bags are great to control cross contamination, but they don't stop mycotoxins, so the bag should be someplace far away, at least in another room.

I do this whenever I feel even the slightest hit or have gone anywhere that I've been slammed in the past.

-Erik (2006, SickBuildings)

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Whenever I feel that I've been in a really bad place, I take a shower and change my clothes out in my RV.

If it's a really bad place, I stand in the door of my rig and throw the clothes outside so they can be bagged for later washing. Don't want that crap to cross contaminate my safe zone.

Hair washing is really important after a serious mold slam, as it is really hard to completely get the spores out of hair and the hair itself seems to have an ability to assimilate the mold toxins that the spores release.

-Erik (2008, CFSU)

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I just take a normal shower and wash my hair. I don't use a brush.

Not only do I not use anything special, a lot of my decon showers are nothing more than water. For just a quick decon, shampoo or soap doesn't appear to be necessary.
I find that anything under an outer piece of clothing doesn't give me hits the way the outer clothes do. That's why I just use a hat to cover my hair, or just get rid of my shirt after being in a bad place, since this makes a large proportional difference.

-Erik (2008, CFSU)

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I don't wash things for decon purposes if they aren't bothering me.

-Erik (2008, CFSU)

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I didn't do any of that head shaving stuff.

Hey, it gets cold up here. My ears would hurt without my hair.

A preemptive strategy made it unnecessary.

-Erik (2008, CFSU)

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I try to keep my sleep zone as pristine as possible, and avoid bringing mold spores in by taking a shower and changing clothing to prevent cross-contamination when I get home.

It's mostly a lot of washing, using normal soap and water.

If you examine the stories of Moldies, you'll see we spend a lot of time washing things.

-Erik (2009, Locations)

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>What do you do to keep from contaminating your RV with your clothing?

I drop my clothes on my porch and shower. My "outside" clothes and shoes go into a metal ventilated box.

The crap does sneak in anyway.
But the construction of my rig is almost identical to a "porcelain trailer," so it is much easier to clean than any normal RV.

-Erik (2010, SevereReactor)

TIMELINESS

I've learned by much experience that if I wait too long, my response goes absolutely nuts. So the trick is to consistently decontaminate before the immune system turns the mold hit into a mold slam.

I maintain a safe sleeping area that is not in a spore plume, as per my ability to perceive it.

I decontaminate before I sleep and allow nothing that has been exposed to mold into this area.

Sometimes it doesn't feel like the mold hit was even bad enough to be worthy of a decontamination - but years of experience has indicated that this is wrong.

Any exposure that is enough to be sensed is more than enough to maintain a low level response that wears me down.

-Erik (2005, CFSResearch)

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There are parts of Carson City that are so bad that if I spend too much time there, I'm on the ground puking my guts out.

I have to maintain a safe zone that is outside of bad regions, so that I can drop my clothing and take a shower.

I have to do this fast. So fast that I cannot delay.

For this reason, I have to have an "Mobile Environmental Control Unit" in the form of an RV. I keep this parked outside of bad places and retreat to it when necessary for a quick decon.

Mold avoidance is the only thing I've found that really kicks ass.

I have to do whatever it takes.

It's not a happy solution, but beats the crap out of the alternative.
I started doing this in 1985, and over the years, I've gotten pretty darn good at it, but I'd be in a world of hurt without my MECU.

Now, it's just a matter of getting enough "oomph" to get doctors to listen. I don't know of any other way to save people's lives.

Nothing else really seems to help.

-Erik (2007, Email)

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>Sunday evening I opened a used book that I had ordered. When I opened it, wham, musty. Instant headache. I didn't sleep well at all. Monday was a bad day. Today I got up with a headache again. Now I have giant swollen glands in my neck.

When that happens... RUN... don't walk... to take a shower and change your clothes. Wash your hair really well.

After you've done this a few times to see how much aftereffects you can escape, the necessity for having an MECU becomes super apparent.

-Erik (2008, CFSU)

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Timely decontamination is something that one has to try before they can fully appreciate the benefits.

And as one begins to perceive that benefit, the desire to possess an MECU is akin to surviving a shipwreck, treading water, and thinking that a lifeboat would really be a nice thing to have.

-Erik (2008, CFSU)

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An MECU is a necessity for people at our level of reactivity.

Trying to fake it with a bucket of water in the back seat of a car really sucks.

But it really is phenomenal if you can consistently decontaminate in a timely fashion.

I thought that I was going to be completely screwed - having to live in the desert.

But I can pretty much go where I want and do what I will.
That's how backwards everyone has it. I do the MECU thing so I don't have to live like a total hermit.

-Erik (2008, Email)

**AWAY FROM AN MECU**

Go jump in a lake. Seriously! I have been so desperate at times that I did just that.

If necessary, I would grab a garden hose to wash my hair and change my clothes in my car.

As long as cars aren’t parked in a spore plume or is badly contaminated, they serve as pretty decent decon units when you are in a pinch.

-Erik (2008, CFSU)

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People like us are known to cover their car seats with plastic or towels and drive with the windows open.

I've been so desperate after going through Carson City that I stopped at a lake and washed my hair.

(Whew! Don't have to do stuff like that anymore!)

I reckon that having a washtub and water in the car would be real handy for when you feel the need to lighten the spore load.

-Erik (2008, Email)

**PETS**

I've dragged others out of mold hell and brought their pets out too. It wasn't much of a problem.

Dogs washed easily enough and stayed outside for a day.

For a cat, just cover the furniture to prevent cross contamination and wash the coverings the cat lies upon.

-Erik (2004, SickBuildings)
Chapter 22 - Clothing and Bedding

BEDDING

When I am out in the boondocks with my MECU, I can use virtually anything for a mattress. When I'm in mold zones, a sheet of aluminum doesn't work.

How do I know this? By going back and forth between pristine areas and mold zones.

When my bedding got contaminated, I kept getting rid of it until I was down to the metal structure under my bed and tried to sleep on that.

And when that didn't work, I finally just gave up and drove out to the woods.... and had a wonderful night's sleep (for the rest of the night anyway).

-Erik (2008, CFSU)

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I would say that there is absolutely nothing I do that is more critical than making certain I am sleeping on a benign surface.

It doesn't matter what it is - foam, feathers, block of wood or sheet of aluminum. The only consideration is whether it can be kept free of contamination. Things which cannot be washed cannot be kept toxin free.

If I were to never enter a bad zone or never carried spores in my hair, a conventional mattress would be just fine.

But I have to work, and that means going into bad places.

So I use a sleeping system that lends itself to my requirement for decontamination.

I haven't used a mattress or pillow in ten years. It's too difficult to control cross-contamination.

I've got an extra large camping cot. I have a washable backpacking sleeping pad and pile extra blankets on it for padding. I use a rolled up towel for a pillow.

It's breathable, so low condensation. Washable and "put out in the sun-able."

Towels and blankets are things that I like to wash in a machine - just about anywhere - but dry in my MECU. Since they are directly affecting my sleep, they are high priority
I have to keep bedding and clothing bagged and stacked up.

Sometimes I've taken my bedding out to the woods and washed in the lakes - dried in the sun - so I could get a decent night’s sleep.

During the day, I keep my bedding covered with a plastic poncho.

-Erik (2008, CFSU)

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I was so desperate that I tried a Magnetico sleep pad, with my head facing north.

It seemed to work like a miracle for about a week, and then it just stopped. The magnet theorists told me that one has to stop using it for a while to restore its effect.

But then I found that I could get the same temporary improvement by just covering my mattress with a sheet of plastic.

I said, "It ain't the damned magnetic waves that helped. It was just having a fresh mattress that hadn't been contaminated yet!"

So I started using the equivalent of Dr. Sprott's BabeSafe system. It did help, but only for a while. And not much when the killer plumes hit.

-Erik (2008, CFSU)

PILLOWS

One contaminated pillow can be more than enough to keep a Moldie from getting clear enough to calm down the response.

-Erik (2006, Locations)

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I gave up on pillows completely in 1994. I only use a rolled up towel inside a pillow case.

But it does no good if you wash it and then use a dryer which is in a mold plume - as your "clean" towel is really acting as a filter and catching spores from the air circulated through the dryer.

Isn't that just what you need?
To rest your head upon and be in direct contact with a concentrated dose of mold from a filter used in a moldy house?

Because that's what your clothes are if you dry them in a mold plume.

-Erik (2006, SickBuildings)

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>What about this washable camping pillow?

Looks good, but I would need at least three of them.

If I so much as wake up in the night, I assume that my sleeping surface is less than pristine, and automatically switch to a fresh "pillow" to lay my head on.

The whole idea of a "pillow" is that it is something that stays in place on a fairly consistent basis. That doesn't satisfy the degree to which I wish to create the best possible sleeping scenario.

-Erik (2008, CFSU)

**STILL IN A BAD PLACE**

If you haven't completely eradicated the mold and removed the colony, it is waste to get a new mattress and furniture. It'll just get contaminated.

If you cannot leave a moldy place and are just trying to reduce exposure, I recommend covering your mattress with plastic and covering the plastic with a washable cotton pad.

-Erik (2002, SickBuildings)

**CLOTHING**

In terms of clothing, I'm in favor of having lots available.

Used clothes are fine.

I've bought enough "warehouse bad" stuff that I wash and line dry all new clothing.

-Erik (2008, Email)
LAUNDRY

Washing clothing is a critical aspect of avoidance.

When and how I wash is contoured around times of release of mold spores.

If it’s low sporage, no worries. If it's a bad day, I put it off, or go elsewhere, or hand wash and air dry.

-Erik (2008, Email)

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Yesterday, the plumes were acting up a bit and raking the Truckee area.

So I only washed my laundry there and then hung it up inside my much safer MECU to dry in a good place, rather than use the dryer.

I found from bitter experience that in a dryer, the clothes become the filter that scrubs spores out of the air, so I try very diligently to only do laundry when the plumes aren't active.

Laundry which has become laden with spores usually has a limited range. Not sure why, but I usually only become aware of bad laundry after I put it on. Perhaps the heat from the dryer stabilizes the spores a bit more than might otherwise be the case.

Now, I know this sounds a bit over the top, like everything else I do, but there is a very good reason why I have a wood stove in my MECU.

When it is zero degrees outside, I can get that sucker glowing red hot and pump fresh air through like mad. This lowers humidity and dries everything out - especially the laundry I have hanging on a special rack in front of the window.

-Erik (2008, CFSU)

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Yeah, I tried the laundry ball. It was my Mom's idea. Bleah!

I asked a bunch of people about those integrated RV washer/dryers. Most folks hate them. Not a very powerful washer, and the dryer takes forever.

I find a decent place to wash clothing. As long as the washer doesn't feel moldy to me, spinning clothes around in the water doesn't seem to be a source of mold exposure. Grabbing them out and drying them on my special rack in the MECU gives me the best results by far.
I also carry around a large plastic storage container that I use to wash blankets when I'm out camping.

-Erik (2008, CFSU)

*

I can wash things even in a moderately contaminated laundromat, but I can't dry them there. I can't hang them in a bad zone, either.

So I do small loads often and dry them on a rack in my MECU while parked in a good place. I keep a constant rotation going so it doesn't build up.

-Erik (2009, Email)

*

Since it's so hard to find a good laundromat, I have my own wash facilities inside my rig, along with a clothes drying rack.

-Erik (2009, SevereReactor)

**STORAGE BINS**

I used to keep my clothes in plastic storage bins. But as time went along and my reactivity decreased, I just started stacking on the principle that it is only the top one that is likely to be much of a problem.

This is similar to removing the top blanket when sleeping, and working my way down.

This is why I don't use sheets. I have about ten blankets, and they get washed every couple of days.

In fact, I just washed them all yesterday. I built a huge fire in my RV and dried them on my drying rack in front of the fireplace.

-Erik (2008, CFSU)
Chapter 23 - Cross Contamination

MILITARY TRAINING

When I realized the nature of my response to mycotoxins and recognized that it was comparable to battlefield nerve agent attacks, I responded by using the CBR warfare training I received as a Nuclear Missile Launcher specialist.

It was responding to my training in nerve agents that made the difference between being overpowered by exposure and taking control of my symptoms.

However, the lack of response from "mold experts" and MCS specialists in my story indicates that they would rather rely on herbs and medicines to counter what is essentially a scenario of controlling nerve agent exposure.

The reported results of these approaches suggest that they are somewhat less than effective.

-Erik (2005, SickBuildings)

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Moving only gave me enough of an indication of a shift in symptoms to let me know that there was an "effect" which might be exploited.

The complications and logistics of cross contamination are absolutely formidable.

I just applied my military training in biowarfare and built myself a "Mobile Mold Decontamination Module."

Until I took extremely proactive measures of avoidance, I was unable to take significant control over mycotoxin exposure.

This isn't so much a "therapy" as an act of total desperation.

-Erik (2006, Locations)

*

I can't keep a mattress pristine.
I guess that my military biowarfare training really gave me a different picture. Soldiers were warned not to avoid washing fatigues simply because they didn't feel like the CS gas had been strong enough to worry about.

We were especially warned not to hang contaminated jackets in our locker where they could touch other garments. Field jackets were expensive to wash and starch, so there was always someone who thought, "This isn't so bad" and would hang it in their locker.

It was pretty funny, because the inflammation would slowly sneak up on them. Suddenly they would start screaming and run for the barracks to take a shower. And once they were jacked up, anything that the contaminated article had touched would slam them as well. So they had to wash their clothing anyway - and everything it had touched.

I know that most people don't have to think of cross contamination in these terms, but I do.

My experience is that mattresses are so difficult to avoid contaminating that I gave up trying. Just gets real expensive as you throw them away.

-Erik (2008, CFSU)

*

About the only real trick I've got is that the military drilled it into me to be extremely determined about controlling for contamination.

So although I totally despised this training when I was receiving it, and desperately never wanted to be stuck playing the stupid war game lifestyle again, the constant drilling made it almost second nature.

Ironic.

-Erik (2010, SevereReactor)

**HITLER’S MOLDY BUNKER**

I was stationed in the Army in Hitler’s moldy headquarters in Germany, and I couldn’t figure out why I was so sick there.

When I got home, I had a great summer. Then my stuff arrived. Stereo, records/tapes, clothes, etc.

I was so happy.
Unpacked everything. Hooked up the stereo. Listened to some music I hadn't heard in while.

Passed out.

Couldn't believe it. Went right back to feeling like crap.

That's all it took!

And you know? It's funny that people blamed it on stress.

I'd say, "About what? I just got out of the Army and couldn't be happier," but the stressologizers just won't let it go.

Their response is, more or less, "Well, what you complain of is caused by stress, so you must be under stress. Maybe you just weren't happy enough lately to recover from all the stress you had in the military - and your stuff brought back unconscious memories."

Psychologizers are like that. There's just nothing they can't dream up, except perhaps that a physiological explanation might just be real.

-Erik (2006, SickBuildings)

**FINDING THE PROBLEM**

One CFS sufferer tried to conduct avoidance years ago and stripped a van down to bare metal - taking it out to the desert where he felt better. Yet something went wrong and he just stayed ill.

He couldn't understand why this didn't work and reported being forced to sleep in the cab of his van.

It should be obvious that if "whatever" was in his stripped out van was not in the cab, his experiment was almost successful. But he wasn't controlling for "whatever" and it came into his presence, but only on his possessions. So if his stuff was hit with "whatever," what could it be?

You know darn well that if something doesn't bother you, it is not inherently bad and must have picked up something bad along the way.

So how do you find out what "whatever" is? You keep track of it from when it wasn't bad and test the place and time where it did.

If you repeat this test often enough and successfully reproduce cross-contamination with "whatever," then you know what "whatever" is, and where it is.
Yes, I know it sounds a bit complicated, but it's actually just a simple process that becomes easy with practice - almost to the point of being second nature after a few years.

-Erik (2008, CFSU)

**A STUPID LITTLE THING**

Can a place be cross contaminated easily? Hah! You bet.

I remember one guy who tried to denature some books and papers by putting them in a warm oven.

Oops. Caused such a release that he had to bail out of his house for several days.

-Erik (2007, Email)

*

If this were easy, people would have figured it out long ago.

Let me give you an example.

I'm working in a pretty bad building.

I have to decontaminate after passing through a spore plume right down at the front door.

I have to hold my breath when I pass through it.

Well, day before yesterday, I thought, "It's not so bad today" and just put my contaminated clothing up in the overhead of my RV.

Dang it. It wasn't a big mistake, but I had a less than perfect night's sleep.

So yesterday, I went through, stopped and "perceptified" my clothing.

Yep. It's just a bit more than I care to deal with, so I schlepped them up into the exterior compartment.

Oh, yes. Much better. Slept great last night.

See? Such a stupid little thing. Just some contaminated clothing.... and things like this can come at you from anywhere.
If anyone in the house has been through a plume, freshly washed clothing is instantly contaminated.

We have to develop a completely different concept from "clean" and "dirty.

This is different. One slam and it's on anything!

And if anything which has been slammed comes into your presence, the safe zone isn't safe anymore.

-Erik (2008, Email)

*

Ever since my mold slam, I haven't had anything that failed to pick up a toxin load inside moldy places.

Even me. That's why I have to take so many showers.

-Erik (2009, SevereReactor)

PREEMPTIVITY

I found cross-contamination to be absolutely critical.

In fact, controlling cross-contamination was the entire key to my recovery.

That is why I call what I do "Extreme Mycotoxin Avoidance." I am quite certain that my level of recovery is directly attributable to this stringent protocol.

But even I mess up now and then.

I watched a friend fall apart by working and living under conditions that were obviously putting her under the curve.

I warned her incessantly to minimize exposure to the degree that her symptoms were at least no longer progressive.

But nobody believes this until it happens and then it's too late.

She collapsed and I couldn't stand this nonsense any more and carried her out of that mold infested hell hole. I took her out to the desert where she soon started to recover.
That was in 2000 and this mold "hysteria" was still so unknown that not one doctor or family member believed her. They told her to see a psychiatrist and accused me of mentally manipulating her into believing that mold could have this effect.

Now I've created a monster.

I sat down on the couch after a momentary visit to a place that we know to be contaminated and she yelled at me.

She was right. I know better than this. So I had to grovel and run off to decontaminate. Fortunately the couch was all right.

We worked too hard to recover to put up with cross-contamination from a careless act. And I know from sitting in too many cross-contaminated chairs (like in Dr. Peterson’s reception room) how easily this can happen.

-Erik (2004, SickBuildings)

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Just a couple of really bad pieces of firewood I snagged for campfires left a bad zone where I stacked them at my campsite on my trip to Mt. Whitney.

Glad I was careful and boxed up the wood in cardboard boxes sealed with duct tape and set on the roof of my camper for the trip down.

It would have been terrible if my trip had been ruined by contaminating my camper.

But I did it right, and the only harm was that there was a zone next to my campfire that I had to avoid.

Needless to say, I burned up the bad wood straight away. Takes a couple of days, but the zone goes away after the moldy wood is gone and then it's all back to normal.

-Erik (2005, SickBuildings)

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More effort at heading off contamination translates into untold amounts of time that isn’t spend trying to clean up after the fact.

That really saved me when my air conditioner went bad. I was up there unbolting the thing right away.

And it still darn near drove me out.
Almost, but not quite, because I was right on it.

- Erik (2009, SevereReactor)

*

I found that all my efforts at decontamination were so overwhelming and less than productive that I massively switched my focus to establishing a safe zone and doing everything I could to prevent the badness from entering it instead.

More bang for the buck.

- Erik (2009, SevereReactor)

**SPORES VS. VOC**’**S**

It's absolutely awesome to hear someone else describe the ability of hair to maintain and transport the mold. I found that wool garments are no different.

I noticed that some contaminated places gave me a huge hit but that I could walk away and recover without decontamination. Other places might hit me less, but I would carry the reaction with me. This led me to believe that the neurotoxic reaction was to aerosolized mycotoxins and not necessarily inhalation of spores.

I tested this by placing a contaminated article in HEPA filters and taking it to my clean place. I put it under six layers of blankets and slept on it. I got the usual reaction and removed the article but went back to sleep on the same blankets. The reaction was gone.

This convinced me that that spores had not penetrated the filter or blankets and that the toxic gas was truly my primary irritant. This was confirmed by Dr. Marinkovich, who told me that a housing project in Sweden had recently been identified with sick inhabitants but no spores could be found. Only when the walls were opened up were the colonies found, but they were so tightly sealed in the walls that only the toxic gas could escape.

Many places that give me mold hits are strictly VOC hits and not spores. When I leave these areas I do not have to bother with decontamination.

- Erik (2002, Klein)

**SCATTERED OBJECTS**

It should be immediately apparent to anyone who suffers from exposure to so much as a single moldy item taken from their old mold castle that their hair, clothing, objects,
purchases or whatever has passed through moldy buildings will be similarly problematic.

No matter how much you remediate your safe zone, if you have the level of reactivity that requires a safe zone, you will soon be adopting decontamination protocols to avoid cross contamination - or you will suffer.

I didn't write the rules to this game. I just learned how to play it.

-Erik (2006, SickBuildings)

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I know a guy in France who was being driven wacko by a bedroom set that had been in his family for generations. It wasn't the house, nor his room, just the furniture. His family is ready to disown him because he wants to get rid of "precious family heirlooms."

This may be what is happening to you. If the place was really bad, you'd probably feel rotten in more places.

The way you describe "whiffs" suggests that you probably moved to a lower concentration of badness... and your sensitivities shot through the roof.

-Erik (2008, CFSU)

*

Can just one object be contaminated?

Years ago, I was out breaking the response by getting out to the wonderful pristine mountains above Twin Lakes just west of Bridgeport, and I just couldn't shake the badness.

Well, one of the tricks I use when I am entering a known mold zone is to wear a hat, just so I can take it off afterward. Keeps the hair contamination down considerably.

And I was wearing a hat I had used for this purpose!

I took off the hat. The response (rage, anxiety, brain compression) all died away.

Put hat back on. The response came back.

Repeated a couple of times to make sure.

Got rid of the hat. It has served its purpose well, but now it's time for it to get gone.
In 1998, I had already got out of the bad place and was in the midst of intensification reaction.

I could tell by the way I was able to exercise more that I must be getting better, but my sensitivities shot through the roof. I was trying to get doctors to do some research on this.

This is the point where I contacted Dr. Vincent Marinkovich, a mold doctor.

It was pretty clear that I was different from his other patients. They thought nothing of going into his reception room and sitting in the chairs.

I could not do this. They were too badly cross contaminated, so I had to stand.

The receptionists were a bit baffled at my behavior, which is another indication of their unfamiliarity with people like me.

This was further confirmed by Dr. M when I demonstrated my ability to detect spot plumes. He said that he had never seen anyone with the ability to do this before.

- Erik (2008, CFSU)

** ADSORPTION **

My experience tells me that anything that was only temporarily contaminated is easily cleaned or dies down without any cleaning whatsoever within three days. But stuff that has been exposed for a long time not only doesn't clean up by any method I've tried, it stays bad for years.

The problem is that people have a mental image of spores that can be semi-easily washed off, when they should really be thinking adsorbed toxins. The flawed conceptual basis misleads people into predicting the type of results that would be expected if spore removal solved the problem.

People are confused when their expectation isn't matched by the results. They should take this as a clue that their concept needs a little tweaking.

Toxin adsorption from decomposing spores is so variable, depending upon a vast myriad of factors, that no projection of success with long-exposure materials by washing can yield predictable results.
BAD FROM THE BOX

I was over at my brother’s home when he brought in a take-and-bake pizza. It was delicious, but I got sick with the same symptoms I always get when I go into a Stachy contaminated place.

I thought it was just a fluke until I went into the pizza place and got knocked flat with a mold hit.

I don't have reaction to pizza in general, so it's pretty obvious that the mold contamination made the difference.

(Obvious to me anyway.)

-Erik (2003, CFSExp)

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It’s not difficult to find the mold in Home Depot.

Just stroll through the lumber section.

Check out the plywood. You can't miss it.

-Erik (2003, CFSExp)

ELECTRONICS

It’s expensive to keep throwing away computers.

I never had the sense that computers could cross-contaminate things.

Yes, my girlfriend and I couldn't use them except temporarily, but unlike other moldy objects, the hit seemed to be pretty well stuck to them and didn't spread.

We wound up putting the tower directly under a window in the spare bedroom of a place we moved to, got the keyboard on a table as far away from the window as the cord would reach, and used a fan to blow the badness out the window.

It only seemed to slam us when we were in proximity and didn't cross contaminate, so we just limited the time we used it.
You could extend that time with lots of fresh air.

That's basically what Dr. Shoemaker is doing with his computer.

It becomes a matter of personal choice - economics vs. pain.

So I'm thinking that if people take measures, they can still use a computer even if it's pretty bad.

Just not for too long, and not in the same room where you sleep.

-Erik (2008, Email)

*

Strong electromagnetic fields seem to have a propensity to attract statically charged particles, including spores.

Activation of the field oxidizes the spores and causes mycotoxin release.

I've operated electronic appliances and had no trouble with them until they were operated in a moldy environment and thereafter could feel the difference.

I've gone rounds with normies who insist that such a reaction is impossible and with MCSers who say that it is, but will swear that it must be off gassing of the synthetic materials and cannot be mold.

It seems to make no impression on their brains when you say, "But I operated it before with no problem and this only started after it was used in a contaminated environment."

The question you always need to ask yourself when you react to something is, "Do I react to all examples of this material?" and "Was I reactive to this particular object at some time in the past?"

-Erik (2004, SickBuildings)

*

My girlfriend didn't believe me how electronic appliances which are operated in a moldy environment acquire a badness beyond compare until I had her operate a new microwave that we had just bought and that did nothing to her.

Then we took it into a bad place and within minutes of operation, she couldn't be within ten feet of it.
To complete the test, we then took the microwave back out and operated it in a safe zone.

Sure enough, the thing had turned bad.

She went right out and bought another microwave, careful to never operate it in a bad zone.

The other brand new microwave went into storage.

It did die down after a couple of years, and I gave it away.

It's always amazed me that people blame the EMF's or the inherent composition of the electronic gadgetry, when it is so easy to do this test and find out how virtually any electronic device can pick up the badness in a mold zone.

This acquisition of badness is so predictable that it can be used as a diagnostic of bad places.

If you aren't quite certain, take some electronic device which doesn't bother you into a suspect place and operate it for a while. Then take it back out to a place where you feel good and turn it on.

If it slams you, this tells you that the electrostatic attraction of the EMF's from the device concentrated the ambient level of toxins up to the point of clear discernment.

-Erik (CFSU, 2008)

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My computer was good, then it went bad, so I figured that it surely couldn't be the computer itself.

The computer must have picked up a toxin load.

I tested this by perceptifying electronic equipment in my safe zone. After making sure it didn't bother me, I would take it into a known bad place and sure enough, the computer (or microwave or whatever) would pick up the badness.

Now, there is no way in hell that I can remediate the inside of an electronic device.

This stressed upon me the importance of preemptive action to ensure that objects which have the capacity to pick up a toxin load not be allowed to do so.

As long as I do not operate my computer in a bad zone, it remains non-bad.
And for the computers and various items that I tested by taking them in and out of bad places... I am certainly not going to waste my time in proximity with these slammers by trying to get at the innards where remediation is basically an impossible goal.

-Erik (2009, SevereReactor)

*

Computers would get really bad when activated.

But by testing in both on and off positions, it became clear that electronics could pick up the badness regardless.

Activating them just made it mega-worse.

-Erik (2009, SevereReactor)

OUTDOOR MOLD

I was tent camping when I drove through Moab. The plume was in the center of town.

I stopped to get some ice and realized I was parked in a pretty bad zone. I jumped back in the car, but it was too late. The car felt like crap for about a day or so afterwards.

I had to drive with the windows open and spend more time out of the car. I was knocked out for about twelve hours afterwards.

Contamination happens just this easily.

That's what makes this a real challenge. I pretty much have to stay out of plumes and avoid contact with anything that was in a bad zone, even if it is carried into my presence by someone else.

This is very much like thermalling in a hang glider: constantly steering out of the sink (cold downdrafts) and trying to locate good air that is going up - all by your perception of which way things are going.

The better you do it, the more altitude you gain.

Blunder into the sink and down you go.

-Erik (2008, CFSU)

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This stuff is growing in dumps, sewage systems and decomposed foliage, so it can certainly be in areas that have no buildings.

However, I have yet to experience anything larger than a building which was rendered bad for me by cross contamination alone.

-Erik (2009, SevereReactor)

THE RELATIVE SHIFT

The MECU strategy is not only more of a tactic than an actual device. It is the only training tool that really allows mold sufferers to gain special insights into the mechanics of the situation.

Especially something I call "The Relative Shift."

A friend of mine had a house in a region that was gradually going bad.

The house was acting just the same as my MECU does when I take it in and out of a contamination zone. Fine some days, horrible on others, yet the house itself felt too good to be the culprit.

The house itself wasn't the source, but it would pick up a toxin load every time the plumes rolled through.

The frequency of plumes increased the background noise of low level contamination that is not readily discernible - or not even discernible at all.

Now, consider this.

My MECU had a set value of badness.

When I enter a contamination zone of subliminal increased ambient levels, I cannot always feel that low level.

But what I CAN feel is that any minor sourcepoint such as a mildly contaminated object will suddenly feel much more potent.

I knew that this sourcepoint/object hadn't really become more potent.

This was established by simply testing. I would drive back out to a pristine place, and the sourcepoint would revert back to its former level of badness.

The increase in toxic potential wasn't due to inherent toxicity, but rather to increased background noise even when I couldn't necessarily feel that low ambient level.
This taught me that I can use the relative shift of a known potential of a sourcepoint to help me identify subliminal contamination zones.

-Erik (2009, SevereReactor)

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>Let’s see if I understand you. Say you have a hat that's mildly contaminated. Then you a low-level contamination wafts through the area. You don't necessarily "feel" the low-level background noise, but the hat feels worse, which indicates the change in the ambience of the area? And so can be demonstrated by the fact that if you leave the area, the hat resumes its lesser level of ick?

Yes, I could take something out to a pristine area, and it would settle down.

I thought, "Okay, I think I'm starting to understand. It was my immune response which changed when ambient levels got worse, and not the object."

And then everything got turned upside down again when intensification reaction set in.

The opposite effect started to happen.

My senses then went hyper to that contaminated object, which I figured was probably still roughly the same potential as when I carried it out to the desert.

I felt absolutely great while away from the contaminated object, be it MECU, binoculars, or whatever... and the shift in my symptoms to the object was even more dramatic than while in the bad zone.

That's when I realized that this relative shift was trying to tell me something.

It means that I have to get clear in order to detox.

The body won't allow it while in an upregulated condition.

Even a low level that is barely perceptible still qualifies as upregulated, in terms of not allowing detox.

The degree to which intensification set in told me how much body toxins I had accrued while in the bad zone.

The longer I go without occasionally getting clear to allow detox, the greater the intensification will be.

This let me know that I cannot wait to feel bad before bailing out of a bad zone.
I have to get clear as preemptive leap of faith before it becomes absolutely necessary.

'Cause when it does become unavoidable due to feeling so bad in a bad zone, the intensification reaction from a long-term body buildup of toxins can be very, very unpleasant.

(An understatement, of course.)

-Erik (2009, SevereReactor)

**SETTING OFF THE SPORES**

If you go into a building contaminated by Stachy during high pressure when the spores aren't releasing mycotoxins and get intact spores on your clothing, you can carry them around and not have much of a response until they dry out or you get into an elevator or drive up a hill in a car or go into an air conditioned building and set them off.

Things like this lead to what are apparently impossible contradictions in an association between contaminated areas and symptoms.

There is a fine art to mold avoidance that cannot be understood by "experts" who lack the sensitivity to understand our complaints.

-Erik (2005, SickBuildings)
Chapter 24 - Remediating Objects

BONDING CHARACTERISTICS

Since low molecular weight T2 toxins from decomposing spores can adsorb via intermolecular dipole attraction onto smooth materials, the concept that spores can be washed away from hard surface materials is very misleading since the toxins can still remain.

Just because it's glass, plastic, or a hard surface is no guarantee it's toxin-free after remediation of fungal conidial detritus.

-Erik (2006, SickBuildings)

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The way you are looking at this is dictated by your underlying mental picture of an allergic reaction to spores.

That is correct as far as it goes. But the spores also have toxins, which adsorb onto hard surfaces by Van Der Waals forces.

These are locked into place by molecular bonds and cannot be cleaned by conventional methods.

These toxins have been shown to be heat stable up to 500 degrees F. and most of our possessions don't handle that temperature too well. Darn it.

We have to wait for them to denature.

One has to think of this as a toxin which has been liberated from decomposing spores but still persists in an undetectable form... except to us hyper-responders.

Drives us nuts - and doctors don't think it even exists.

-Erik (2007, Email)

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The concept of Stachy growth as being the problem is not really relevant.
It's the toxins.

They seem to have the ability to stick to whatever they want to, even bare metal under certain circumstances.

Leather is especially tough, for some reason.

-Erik (2008, CFSU)

THE GREEN BINOCULARS

All my stuff went into storage and I was too scared to touch it for years. Otherwise I guess I would have thrown everything away.

One of the things I did attempt to use after fleeing the bad place was a pair of binoculars. They were waterproof so I washed them off in the sink.

I went hiking and was right on top of a mountain feeling just as mold free as I could possibly be.

I raised the binoculars for a look at all the scenic splendor.

Instantly I went right into brain fog and heart palpitations. I could move the binoculars close to my face and get the response, and then move them away and recover.

But wait, this was just one small item and it had been washed thoroughly. How the heck are you supposed to remediate something coated with a waterproof covering better than washing it off under the tap with liberal amounts of soap and water?

I then did some experimentation with various objects that "experts" told me could be remediated and found that no amount of washing removed my "imaginary response" to them.

I then found out about the properties of adsorption at a molecular level that prevents mechanical removal of these toxins.

So I am really suspicious of taking advice from "experts" that possessions can be successfully remediated in short order. You must rely on your perception of a response to anything you attempt to take with you and trust nothing else.

At the same time, I remind people that the objects that dropped me in my tracks years ago have denatured and feel perfectly safe. I wouldn't trust most furniture and certainly not bedding, but other than that, I wouldn't advise throwing stuff out wholesale. You might just get it back someday.
What my binoculars taught me:

If someone is responding to adsorbed toxins, the spores and detritus could be long gone - but the toxins remain.

And so does the reactivity.

Reactivity is what counts - high mold, low mold, or no mold.

As you see with the binocular story, if an object is too close to me that has been slammed in the past, it's just the same to me as if I were in a sick building.

I've been in lots of bad houses that weren't really bad at all. I was just getting hit by the stuff that people brought in.

I washed my green binoculars in soapy water and felt that if any spores remained, they must surely be at such a low level that the binoculars would be safe.

I had climbed up to the very highest peak above Donner Lake, pulled them out to look at stuff, and that's when I could scarcely fail to notice that something horrible had happened between having them at lower altitude and bringing them up high.

That was my epiphany.

I knew at that moment that everything conventional perspectives were saying about this effect must be completely, utterly and unequivocally wrong.

>What happened when you brought your binoculars down to a lower altitude?
The effect diminished.

That is when I began moving objects to higher altitude, hoping that this intensification of the effect meant that toxins were being given off and, hopefully, denaturing the object.

-Erik (2010, SevereReactor)

**TAKING TO ALTITUDE**

Things don't exactly denature in the way the current theoretical model would predict.

Yes, I do put things out in the sun, but there is another way that is so crazy that I scarcely dare talk about it.

Remember what I said about barometric pressure triggering toxin release?

If my MECU gets hard hit, I drive the whole darn thing to the highest possible altitude.

It feels terrible when I do this, but it seems to cause a massive release of toxins and everything is much better afterward.

I've demonstrated this to people in various automobiles, but nothing is more compelling than using this technique on an entire RV.

-Erik (2008, CFSU)

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I took my MECU up to the mountains last night, and the exterior went "Poof." I could hardly stand next to it.

Then I turn around and come back to Reno, and it feels much better for a while.

I have to keep my blankets covered, since the top one turns to absolute hell after a release.

The stickiness can be taken advantage of. Once it's stuck to the top blanket, you get rid of it.

But since this crap is trying to glom onto everything, if you aren't in a plume, the rest of it is already glommed onto something else.

So you've decreased exposure, while still in the midst of contamination.
-Erik (2009, Email)

PROMPT DECONTAMINATION

My experience has been that items which were thoroughly long-term soaked with toxins in a Stachy zone can be bad for five years. But items only transiently contaminated can denature on their own in as little as two days.

If something hasn't been badly contaminated, it needs no special treatment. If something HAS been in the presence of these toxins for a long time, no special treatment seems to work.

So I make it a point to only allow things to become minimally contaminated.

It's not quite as difficult as it sounds. Just a matter of practice.

-Erik (2008, CFSU)

LONG-TERM STORAGE

Am I the only one who has had possessions in storage for longer than five years and found that things that used to knock me flat no longer have any effect?

I'm finding that a lot of my stuff that I thought was doomed forever isn't so bad after five or six years. I wouldn't keep cheap furniture and definitely not bedding, but just about everything else is getting usable again. I'd put everything in storage and worry about it later.

I know I have not lost my reactivity because I can still feel the response with great intensity in moldy buildings and on things that have been these buildings, but the toxins on my belongings have clearly lost their potency over time.

And who knows whether some method of denaturing the toxins might be developed?

I agree with the warning that contaminated items must not accompany people when they move, but I see no downside in storing things for future reclamation other than the expense of a storage unit.

-Erik (2002, SickBuildings)

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Most of us have learned the hard way that we cannot take our stuff with us when we move or the illness simply will not go away.
But even without any cleaning of any kind, after five years of dry storage the stuff died down. Now I can handle all of my things without any problems.

I decided to say "dry" storage because I've seen people put their stuff in those cheap leaky metal sheds and in damp basements. This type of storage provided the mold with enough water to keep growing.

Their stuff is still untouchable.

It must be dry storage.

I'm not trying to claim that my experience or my flavor of Stachy speaks for all. Some is more toxic than others.

But what is the pain of paying for storage compared to the loss of treasured possessions?

Why not store it?

Try to reclaim an item or two from time to time and see how you feel.

(Might be a good idea to wear a respirator and decontaminate after visiting your stuff.)

You might be happy to have your possessions back someday and it gives the appearance of being less crazy to store things than to throw virtually all your stuff away.

-Erik (2004, SickBuildings)

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When my possessions were dying down, I noted that the toxic response gradually abated and was replaced by an increase in the allergic component. After remediation, that was gone but extreme facial proximity brought on a bit of lingering toxic sensation.

-Erik (2005, SckBuildings)

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One can't kill a toxin, and if spores have been cleaned off, toxins are all that is still left.

If an object is stored in a very dry location with good air circulation, there is a good possibility that the toxins will lose their punch over time.

I packed my books very loosely so the air could flow around them and put them in a desert storage facility. After five years, they didn't bother me at all.
I'm reluctant to tell people to trash everything. There is a psychological response to destroy everything while in the depths of this illness that might no be appropriate later, when the reactivity is more under control and toxins are less potent from denaturing.

My storage area was out at Red Rock, north of Reno, so basically it was in one of the hottest and driest places I could possibly find.

It must have hit 150 degrees in that metal shed on a regular basis during the summer, and I think that accelerated the denaturing process considerably.

After I stopped Dr. D from packing things in plastic, she switched over to loosely packed. She told me that after five years, the only things that still bothered her were the tightly wrapped possessions. Upon initial opening of the packages, the burst of badness was still pretty impressive.

I don't know about humid climates. Heck, things might even get worse.

I would think it would be well worth it to have whatever is worth saving trucked out to a desert storage facility. I'll bet it would cut the detox time in half.

- Erik (2008, CFSU)

Although trichothecenes are stable up to five hundred degrees Fahrenheit, heat is still a catalytic accelerant for most chemicals.

Naturally, just like everything else, I can't prove it, but I've heard better reports of toxin denaturing from desert storage than I have from damp climates.

I've heard that in some particularly damp climates.... damned if the stuff didn't get worse over time in storage.

- Erik (2009, SevereReactor)

SORTING STRATEGY

All the stuff that gave me hits went into storage. I only brought things along with me that fail to make me feel like crap.
Over the years, the stuff in storage died down and became harmless, to the best of my ability to discern.

But I wouldn't trust anything associated with sleeping. Even if things that didn't bother me, I just don't trust 'em and why take the chance?

Other stuff. Even if it's a little bad but I'm not going to be in contact with it for long, I'll go ahead and use it and then get away.

That's why I can't understand why people would trash valuable paintings. Just how close do they intend to get to it? Can't they enjoy it from a distance?

If I am out of range of a moldy object, that's good enough as far as I am concerned.

-Erik (2008, CFSU)

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I remember in 1999, Melinda Ballard talked about having to abandon a picture of her family with President Clinton because it was contaminated and could not be saved.

I jumped up and down, and yelled at the television... "No, no, you don't HAVE to!"

If a picture has been cleaned, it won't be giving off spores, and the likelihood of it contaminating anything else is low.

The only thing you have to worry about is its range of toxic effect, probably not more than six or eight feet.

And if the wind is blowing laterally, as many people use a fan to blow air from the side so they can hold and manipulate contaminated objects, you can use and enjoy your possessions without having them hurt you.

And who knows? Maybe, if given enough time, the toxins might break down - even if it takes a hundred years.

Think I'm going to toss a "Rembrandt" because I can't hold my face up to it?

No way! It's going to be on the wall, at a distance. I can still have my priceless possession... but just have to watch how I approach it.

If my sleeping area is safe, I build up enough tolerance to work with many contaminated places, objects and possessions. I don't have to give up everything.
So I tell others not to go crazy and toss everything. (Or if they do... send it to me, and I'll keep what I want and sell the rest.)

People need to calm down, listen carefully and do some planning before they take actions which are irreversible.

-Erik (2008, CFSU)

**SUNSHINE**

I reckon just about everyone uses sunshine to decontaminate.

In Europe, in the old sections, the people of experience still hang their mattresses out the windows whenever the weather is good.

I hang blankets off the sides of my MECU when out camping... but I don't do it in mold zones, because this would precisely the opposite of the desired effect.

I do it for the UV. But unfortunately, mold toxins are pretty stable, so if I really feel hits from the blankets, washing is unavoidable.

-Erik (2008, CFSU)

**OZONE**

I've learned the hard way that there are no end of experts claiming to have the answers - answers which very often conflict with my perceptions. So I test for myself.

I put possessions in a closet with an ozone machine and taped the door shut. Let it rip for a few days and found that it made no difference at all.

There's a huge range in toxicity of spores, even of the same species. Some give off their toxins within a few days. Others seem to have enough toxic potential to give a mold responder fits for years.

My suspicion is that people who have success with various treatments like ozone or "blowing off the spores" would have gotten similar results by removing items from a spore plume and just waiting for that same amount of time to pass that the treatment took.

Just my experience.

-Erik (2004, SickBuildings)
I've seen people ozone the crap out of everything to extremely disappointing effect.

Lots of people try 'em. Even if it somehow helps anyone, never seen it be enough.

-Erik (2008, CFSU)

**CHEMICALS**

As I watch others reproduce my identical experience, I see them trying all the same things, over and over.

It's been a great boon to the various purveyors, because each person tries each thing at least once before finding out it didn't really work as well as they hoped.

So I'm just sticking with what I know best until I see some really compelling evidence otherwise.

No chemicals. Just avoidance.

Even if some wonder chemicals could decontaminate stuff, would someone with MCS feel safe around those chemicals?

I suppose that if what I am doing stops working, this would be of more interest to me.

However, I have never yet seen a cavalier interference with normal ecological flora and biodiversity be completely free of untoward consequences... consequences that were never appreciated beforehand and only became apparent after the damage unhappily manifested itself with unexpected results.

At which time, it has been savagely difficult to undo or reverse.

For this reason, my life is as free of chemicals and microbiological experiments as I can reasonably attain, given the current state of affairs.

-Erik (2009, SevereReactor)

* I just gave up trying to remediate.

Too difficult, costly, time consuming. It's just plain hard work for darn little results.
My focus has been to keep my mobile living quarters in a pristine place and carefully control what goes near it.

After venturing into mold zones, if the hit is bad enough, I decontaminate and put my clothing in a bag, at a discrete distance.

Normal washing has been enough to return the clothing to usefulness, just so long as it hasn't been contaminated for a long time.

My experience has been that prevention is easier than redemption.

I have been told numerous times that, "Your strategy isn't the only one."

Perhaps not, but all the time that others are spending on washing things is time that I spend hiking, kayaking, mountain biking and generally being free of feeling like crap.

It's not easy to get this reactivity to go down.

That's why I'm not much in favor of spending time in contact with contaminated stuff, trying to remediate.

Time spent on that is more than enough to keep people upregulated.

-Erik (2009, SevereReactor)

BOOKS

I've never seen anyone successfully decontaminate documents or books, although I've had a few denature over a period of many years - five or more.

-Erik (2006, Locations)

*

I remember hearing about a guy who tried to denature a book using an oven and was forced to flee his house for three days.

Can't wait to hear what happens with a microwave.

But I'll let somebody else do that experiment.

-Erik (2010, SevereReactor)

A SICK TENT
I lost a tent up at Watson Lake.

The dang thing had been iffy, but then it acted up for both me and my Moldie girlfriend. It wasn't just me. It drove us both out.

It was horrible. It just went so bad that we couldn't stand next to it.

Since there was a lake handy, I washed it.

I washed it again. And again.

And yet again.

I used all of our soap on it.

I let it dry out in the hot sun.

And then I washed it again.

And then we drove into town and got another tent.

We had opened it up a place which we knew to be not so good.... and from then on, over the next couple of days, it just kept getting worse.

As if the material had some kind of special affinity or property which enhanced "whatever" is going on.

Washing failed so miserably that I said that I've had enough of trying to decontaminate.

If any object plays that game with me, I just get it out of my life.

The similar effect happened to some plastic sheeting inside my RV, so I stripped it all back out again.

Looks pretty ragged, but at least the RV is livable again.

I'm still considering my options for a replacement wall covering.

-Erik (2009, SevereReactor)
Chapter 25 - Air Filters

A BURNING POT

Using filters is like dealing with a sinking ship by installing a pump to bail it out instead of fixing the leak.

Doesn't solve the problem. Just slows it down.

The "filterists" like to promote filtration as a cure, when the reality is that the most you can expect is a reduction in exposure that may or may not be enough, depending on a multitude of factors.

I believe we had a study not too long ago that claimed success by installing whole building filters because sixty percent of the people said they felt better. Not too successful if you were one of the people who didn't though.

-Erik (2006, SickBuildings)

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I am very much opposed to air filters for anything except adjunctive or temporary use.

I've seen too many people try to rely on them in a "over tolerance" situation. Although they help a bit, sometimes it's just enough to keep people where they are so they don't move on and experience real improvement. The balance I've seen has been that they do far more harm than good.

But above a moldy basement? I would guess that in a place like that, the benefit might hardly even be noticeable.

And then just wait for a dark and stormy night when the plumes come out!

-Erik (2008, CFSU)

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You can see that the main result of attempts to filter is a reinforcement of an ability to remain in a set of circumstances for which the long-term outcome is far worse than the short-term gain that one believes there is to be had by using filters.
Generally people won't realize it until later, but all those filters did was allow them to descend to a poorer state of health. Then they try to tell others not to make this mistake, and it looks like they are just being argumentative for no logical reason.

-Erik (2009, Email)

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I found air filters to be most unhelpful, as they play a trick with people’s imaginations. Because they do help, a little, it persuades you to take lesser action against the problem.

Kind of like a thin hot pad on a burning pot. You only burn yourself "a little."

But if you didn’t have the hot pad, you wouldn’t grab the pot at all and you wouldn’t get even a little bit burned.

To my way of thinking, if you are in a place that needs an air filter, what you really need is to be in a better place.

-Erik (CAA, 2010)

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The only time air purifiers have the potential to work is when the problem is so minor that subtracting what the purifier catches is enough to make your sinuses catch so little that it breaks the power of that "whatever."

In other words, air purifiers tend to be slightly palliative, and this can be harmful.

If it convinces you that it helped a little bit, this will delay your departure from an environment in which air purifiers are woefully inadequate to solve your problems.

We see this all the time in sick buildings.

The temporary reduction in symptoms is perceived as a sign that it’s working.

But this diverts their attention away from just how much it isn’t working.

-Erik (CAA, 2010)

**LEARNING THE HARD WAY**
The difficulty of maintaining a sufficiently low level of exposure in populated areas has grown noticeably more difficult in the last few years.

Objects that have had long-term exposure stay bad for a long time. Things that have had only momentary exposure clean up readily.

I used to have a forced "outside-air" Hepa system on my RV to maintain positive pressure of filtered air. I thought that this would allow me to stay more comfortable in a contamination zone.

But all it did was allow more time for my entire RV to build up an intolerable level that takes longer to die down.

So I removed the filter system. Better to get the bad news immediately and act immediately. Otherwise the consequences of toxin accumulation are intensified beyond anything that I can handle.

So all my possessions have not been in spore plumes long enough to be a problem. The objects that I have bought which were "pre-contaminated" by storage in a moldy warehouse or even during manufacturing, I have been forced to abandon.

I do my best to perceptify things before I buy them, but I'm not always successful and only find out that I cannot tolerate it after bringing it home.

This gets expensive, but I wasn't given a choice in the matter.

I didn't get to make the rules. I only learned how to play the stupid game.

-Erik (2006, SickBuildings)

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It isn't the brand of purifier that is wrong. It is the concept.

Did you see my story about CS gas training in the military? They would warn us not to think that just because that day's training was only a mild CS (military tear gas) exposure that you might want to put your field jacket in your locker without washing.

Sure enough, someone would always go, "Nahh, this ain't so bad" and hang it up. Next day, in formation, you'd see the guy start screaming and run for the barracks.

Yup. Kinda "gets ya" after a while. And now that they are jacked up, not only do they have to wash the jacket, but they also have to wash the clothing that was adjacent to the jacket.
I know, I know. People just don't want to believe it. That's why we would laugh our butts off when we saw someone screaming in formation after reacting to their clothes.

It's just another soldier who had to learn the lesson the hard way.

-Erik (2008, CFSU)

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I did a lot of Hepa-ing before I got fed up with spinning my wheels.

Kind of disheartening to spend so much time, if the whole shebang is just going to get spore-slammed again. In the space of a single plume, you can be set right back to square one as if you hadn't done a thing.

After a while, seeing all that hard work erased in a single poof of wind, you get to the point of:

"What am I doing? I'm outta here."

-Erik (2008, Email)

OUTSIDE THE HOUSE

I remember one woman insisting that there was no mold in her house - that she had the cleanest house in town and was running six Hepa filters at all times.

She said, "I know the problem isn't in my house. In fact, I feel somewhat better in my house than I do outside."

Well, there it is. The whole area around her house is bad and she is only reducing her exposure by the amount that the Hepa filters manage to subtract.

But the inability to recover is an indication that she is not managing to lower overall exposure enough. Difficult to do when the Hepa filters are really just catching the spores that manage to miss being inhaled while on their way to the filter.

About the only real way to find out for sure is to take a vacation out to some other environment and look for a shift in overall symptomology.

Having a Mobile Environmental Control Unit is the best way to really find this out. If it feels perfect out in the desert and then you drive into a moldy part of town, you know
that the unit itself was good right up until the time you entered a mold zone - so it wasn't
the house itself that is the problem at all.

It's the ambient levels in the mold zone.

-Erik (2008, CFSU)

THE SOURCE OF THE BADNESS

I was just visiting a friend who lives in a spore plume, so I ran the Hepa filter in my RV to
minimize contamination of the interior while I was there.

Now that I am back out of the plume, I cannot tolerate the toxins concentrated in the
Hepa filter.

But it did its job and kept cross contamination down to a minimal level.

Usually the toxins denature over several weeks and the Hepa filter will be good again
for future use, but I still stay away from it.

-Erik (2005, CFSExp)

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Once a filter becomes loaded with mold spores, it becomes the source of the badness.

This can happen quickly, depending on ambient levels of mold. One plume and the filter
is drenched.

Lots of Moldies have made the mistake of taking the air filter with them when they
move. They turn it on in their new location and within a minute, they've contaminated
the entire area - making it feel just as bad as where they came from.

-Erik (2006, Locations)

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You have to take into consideration that if a place is really bad, and beyond your
capacity to tolerate, a filter might wind up being one more expensive possession that
has to be left behind.

-Erik (2006, SickBuildings)

*
I got a new Hepa vacuum when I was still trying to fight "the bad place." It was a nice one, a Miele.

Seemed to help for a while. But a strange thing happened. The vacuum itself started to hit me.

Of course I changed bags, blew out the inside, washed it... but it just kept getting worse and worse. Finally I couldn't get within ten feet of the damn thing.

It was about this time when I started asking myself, "Haven't I tried hard enough? What more can I do? I think it's time to get the hell out of here."

Here's the irony. It's better to have moved into a superbad place than a moderately bad place.

The superbad will force you out, giving you the opportunity to get much better.

But a moderately bad place will just keep you there, vacuuming, washing. Hepa-ing, searching for mold-ing. wasting your life-ing.... and remove-ing your chance to get the hell out and feel like a human is supposed to.

-Erik (2008, CFSU)

IONIZERS

I did try an ionizer. They do seem to precipitate some airborne irritants onto the floor (and make a mess in front of the machine), but I just wasn't having comparable results to being out in a pristine location. So I made finding such a "feel good location" a primary goal.

This paid off so much that people couldn't believe that I had ever been ill.

-Erik (2008, CFSU)

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People have been doing the negative ion stuff for years.

Just makes toxins fall down to horizontal surfaces. Great, while you're standing up. Not so great when you lie down.

I had this same difference of view with the professor in Kansas who was designing MECU's that were comparable to rocket ships.

"Why would I want to live like that?"
If living there requires anything like that...hell, I'd rather just move to some place that doesn't.

-Erik (2008, CFSU)

**ELECTROSTATIC**

Back in 1997, Prof. Harriet Ammann warned me against electrostatic air purifiers, right after I had just bought one!

She told me absolutely not to use it, that it would just release more toxins.

Prof. Ammann told me that the oxidizing plates of an electrostatic filter would "oxidize" the spores, and the toxins could not help but be released as a gas.

So my money was wasted and I tried installing Hepa filters.

Hepa filters do not degrade the particle, so more of the toxins stay caught in the filter along with the particulate matter.

Isn't this fun how we all have to learn this the hard way?

-Erik (2010, SevereReactor)
Chapter 26 - Detox

GETTING CLEAR

Years of dinking with this damned response to mycotoxins led me to the conviction that the dissociation constant of neurotoxins stored in the lipids is determined and modulated by inflammatory cytokines.

To put it simply, as long as you are suffering from an inflammatory response to this particular trigger, the body won't allow it to be metabolized.

I came up with the bizarre notion that if I could do whatever it takes to completely free myself from any exposure for at least an hour a day, it would allow the body a chance to break the response and allow dissociation of mycotoxins.

Much to my amazement, it worked for me and another person I taught this to.

I've been practicing this concept for years but have run into problems in neighborhoods that have spore plumes rolling through. If I walk into a spore plume, then I am back into the inflammatory response and any further effort is wasted. I have to go back home and decontaminate and take another route to get the benefit of the detoxification process.

-Erik (2002, SickBuildings)

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My own personal opinion is that the body will not allow dissociation of toxins while in an inflammatory state.

I believe this is why MCSers have to go to the desert to recover and have very limited success by merely reducing exposure.

The slightest hit and detox turns off.

-Erik (2004, SickBuildings)

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->If you've got a lot of toxic mold in your house, wouldn't it be all over your clothes? And in that case, wouldn't C4a be upregulated all the time, meaning that you never would detox?
I'm not so sure about that. While it seems logical on the face of it, it almost feels to me like the body is constantly testing the waters, trying to detox, even when you are in a bad place.

If it's a relatively lower mold day, sometimes it strikes me that the body has no other choice but to try to damp itself down and start to dump toxins anyway, as a survival mechanism.

Don't know, just my impression.

-Erik (2008, CFSU)

IN THE “DESERT”

The glorious thing about the deep woods or godforsaken desert is that I could Intensify to a point at which the toxins must surely be blazing forth from my body, judging by the incredibly acute reactions I would get by simply coming back in contact with anything from my camper.

Amazing how I could sleep reasonably well in the thing while in a mold zone, and yet when my body sensed the opportunity to rid itself of toxins out in a really pristine place, my sensitivity would just go nuts.

But if I stay in that really pristine place and manage to avoid re-exposures, this process is relatively painless. It's doing something that would be extremely painful in a place where small random exposures would keep knocking me about.

That's why I am so adamant about going to the “desert.” It doesn't really have to be "Lawrence of Arabia" type desert. The deep woods are good enough too. It's the pristineness that counts.

As far as I can tell, it's the quickest, best, and least painless way of letting the body sense that it is okay to let loose of the stored-up toxins.

And to most people, it appears to be about the same as a camping trip, which is what a bunch of us call "having fun."

-Erik (2008, CFSU)

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Basically, I stumbled over this when I was out in the desert and spent a lot of time outside. I found that after a couple of days, I could scarcely stand to be next to my camper.

"How odd," I thought, "that I could even be alive in an environment that could somehow contaminate something to feel worse than the bad environment itself. Something's not right with this picture."

And then it occurred to me that I must be detoxing. That this weirdness of getting worse was actually a good thing, because that was the way to get better.

So I set out to reproduce these conditions, to routinely detox in a preemptive fashion.

-Erik (2008, CFSU)

**PROACTIVE DETOX**

To keep myself from falling back into that level of reactivity, I have to proactively put myself in a state of detox on a regular basis.

I do this by getting out to a pristine location, breaking the response, and exercising to the point of inducing leptin signaling.

The body appears to be "smart enough" to allow just enough detox so the process is tolerable as long as I don't hit a re-exposure.

I believe this is the reason for post-exertional malaise. People induce a detox reaction, get back into an exposure situation and fall apart.

-Erik (2008, CFSU)

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What I have been doing all these years is preemptively seeking those pristine places that induce an intensification reaction, on the basis that, "This is detox... and I need to detox often to keep myself from falling lower and lower on the power curve of immune activity."
Sometimes I would get out to the woods and start to intensify, and my fingers would swell up like crazy. I took another Moldie with me and we both experienced the same thing at about the same time.

Yes, we thought, “It is consistent with the illness.”

It looks like a bad thing, yet it is a good thing in disguise.

A little bit of weirdness now, for a whole lot less suffering later.

-Erik (2008, CFSU)

DETOX PROCESS

> If you go out into the “Godforsaken desert” now, does your intensification reaction still go up beyond what you get staying in campgrounds near Truckee?

Yes, I get a more intense intensification when I go down to Lone Pine for my annual Whitney climb.

As you saw from our campsite just outside Truckee, it's got its moments when the ambient levels are still enough to keep you upregulated.

But did you notice how things changed when we got further out in the woods up by Jackson Meadows? I stayed up there a couple more days after you left, and the residual hit eventually died down completely. It seems to take about a week.

I hate having to go back to Reno and dive into the muck again, but at least when I do, my tolerance has increased pretty dramatically after the desert detox.

-Erik (2008, CFSU)

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>I went camping in the Godforsaken desert this weekend. The air was absolutely amazing. Then I went to bed in the tent and slept really fitfully, worse than I had in a long time.

>When morning finally came and I put on my glasses, I realized they were all fogged up. I concluded that maybe I had been detoxing like mad through my breath, and that breathing that stuff back in had been making me feel bad. I had an annoying headache and felt really icky for about four hours.
So that night, I took the rainfly off the tent. I slept fine for four hours and then woke up. The air felt kind of stale, much worse than outside. I realized I hadn't unzipped the rainfly part on the flaps on either side of the tent, so I did that. By now, it's almost all mesh. Like being in a screen room. Then I turned my sleeping bag and changed pillows.

But the damage was done. I was up for three hours. Finally I went back to sleep. I slept fitfully again (perhaps in part because it was close to daybreak). When I woke up, there was a whole lot of condensation on the sleeping bag nylon where I was breathing. This despite the fact that the Godforsaken desert in NM is dry as a bone. I had another headache and didn't feel back to feeling really good again for hours.

After getting back to normal, I checked out the tent and its contents to see if it would give me a reaction. It didn't bother me at all.....despite the fact that later that day, when I left the park, my sensitivity went off like crazy just about everywhere I went.

What am I doing wrong?

Youaren't doing anything wrong. I had that same exact reaction to my tent.

It is horrible to be trapped between bad zones which turn off intensification reaction, and pristine zones which switch it on in a big way.

What I had to learn the hard way was to create a balance between spending time in bad zones and preemptively spending a great deal of time in pristine areas to do that detox through the breath that you describe so well.

Continually doing this is what kept me on the up side of the power curve. When this is done successfully, the pain in each zone is minimal.

I went back to the Godforsaken desert. The sleeping bags had more moisture on them. Apparently I'm not only breathing out toxins, but I'm breathing out a lot of moisture. Another perplexing thing about going into the wilderness is that I seem to lose a huge amount of edema. Do you think the sleeping bag will be okay for future trips?

Agreed about the moisture.
It was when that edema response finally stopped happening that my thermoregulation kicked back in, and I could withstand a much greater range of temperature without feeling super uncomfortable.

Sleeping bag should be okay for future use. I just wash, and it seems to work. And I don't wash things for decon purposes if they aren't bothering me.

-Erik (2008, CFSU)

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It's a pain in the ass, but where you breathe while in detox mode is a powerful consideration that has to be factored in. I try to ease people into it without bringing it up by talking about sleeping on a cot, using blankets for a mattress, and swapping out the blankets as they go bad.

It doesn't really matter whether they go bad from ambient mold or from one's breath... just so long as you do it.

Once someone is used to the concept and feeling the benefit from it, it's easier to explain the detox through breathing without having them realize just how horrific this situation is.

-Erik (2008, CFSU)

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> Does the amount of toxins that you breathe out each night seem to remain constant regardless of how long you remain in the Godforsaken desert? Or does it seem to start to diminish after you've spent a few nights there?

The first night, I have to move my face to a fresh sleeping surface about every fifteen minutes. It seems to taper off somewhere between 24 and 48 hrs. After that, it's clear sailing.

Makes you want to stay out in the woods.... permanently.

> You move your face every 15 minutes?
The fifteen minute rule is a worst case scenario after superbad slam.

If I fail to move when I wake up and notice that I'm not feeling so hot, I pay for it with aftereffects that far exceed what one would think from just a few heart palps and slight brain compression feeling. But like I say, this is only after bad slams, and not a total way of life.

It has proven to be much better to swiftly wake up and make the move than try to ignore it.

-Erik (2008, CFSU)

As far as I can tell, one just has to keep moving during intensification or the heightened sensitivity allows you no peace.

I kept having to tell myself, "Although it feels bad, this is a sign that I'm detoxing."

After a while, I began to notice that I could feel mold strongly but that it wasn't bothering me so much. It was just that I could perceive it.

I took this to mean that my body had intentionally created this incredible sensitivity as a means of keeping me out of future trouble.

-Erik (2008, CFSU)

**DETOX SYMPTOMS**

One of the bizarre things (that doctors had never seen before and said was impossible) was that some people became reactive to their own perspiration.

-Erik (2006, CFSExp)

I've heard a few reports of people who thought they were allergic to themselves, particularly to their own sweat.
What if it isn't an allergy but a response to toxins?
Toxins which are not metabolized or broken down, but excreted intact?
Such as through the sweat glands?
And what if the allergists are unaware of this because they lack the diagnostic tools to assess toxin-induced activation of immune response?

-Erik (2006, SickBuildings)

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>Did you feel worse when you were detoxing mold? Did your arms and legs ever feel weak?

Weak? Some mornings I thought for sure that the circulation had been cut off beyond the point of no return: totally cold and dead.

I had peripheral necrosis that looked like frostbite.

I had many scary hours trying to regain circulation and believing that I might be facing amputation. Dr. Shoemaker writes in Mold Warriors that some people weren't so lucky as to keep all their toes.

Dr. Cheney noted this anomaly in the curious loss of fingerprints that some of us had.

-Erik (2006, SickBuildings)

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The depression response is an excellent indicator of detox.

-Erik (2007, CFSExp)

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The dead arms were particularly frightening to me.

There were times when I was certain they were really dead, and had to spend an hour trying to get enough blood back in so I could make my hands work.

-Erik (2008, CFSU)
The complications after gall bladder surgery should have been a clue to doctors that an avenue of detox had just been removed.

I was amazed at the black-gunk-in-the-poop when I detoxed.

Disgusting topic, but that's how it hit me too. I could correlate the same feeling as being IN a mold exposure to what was coming out.

Asked a local surgeon whether he had encountered this phenomenon, and he said that in twenty years of various intestinal operations, he had never seen anything such as I describe and was quite certain that it did not exist.

So what am I supposed to think? My memory tells me that I saw it.

-Erik (2008, CFSU)

You know, it's funny that when I was living in a mold zone ten years ago, I kept having nightmares that all my teeth were falling out.

I got out to the desert and numerous abscesses lit up like crazy, then just went away.

So I agree that this seems to be a detox rather than just a progressive dental problem.

I started watching for this weirdness in people who I perceive to be living in bad places.

It seems to be pretty consistent, as I've seen others describe it many times.

-Erik (2008, CFSU)

The fingers would swell up like balloons too. What fun we have with this illness, watching our bodies do weird things!
I am certain the fingers swelling is a detox sign. I have taken other Moldies on hikes in pristine areas and observed simultaneous swelling.

After many months of concerted avoidance, it stopped happening completely. And it has not recurred in years and years.

-Erik (2008, CFSU)

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That was one of the weird things we noticed during the Incline Village CFS epidemic.... that we had become "allergic" to our own sweat.

I don't recall checking for color.

But reacting to sweat didn't strike me as being quite so bizarre as just breathing on something and having it turn bad.

That still happens to a mild extent when I spend too long in a bad place, so it seems suggestive that exhalation might be an unappreciated avenue of detox.

-Erik (2009, SevereReactor)

DETOX HELP

I did the detox and bought my own HealthMate FIR years ago and I wish I'd stopped listening to doctors and done it sooner.

-Erik (2003, CFSExp)

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The CSM/bile binding salts have the proper molecular weight for biotoxin binding and transport.

Psyllium is probably a good thing but people have tried it for many years without addressing the illness.

-Erik (2004, SickBuildings)

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I thought that Ultraclear was about the best thing for me, when blazing into detox mode.
IONOPHORES

Detox regimens are easy to understand for some toxins, but others are a bit more complex.

Ionophores don't conform to the concepts of classical toxicology. They don't need to enter the cell to do damage, nor are they metabolized and broken down for excretion - except through the anion organic transport system, which is very limited in its capacity.

Think of Ciguatoxin as a model - how it moves up through the food chain because it is permanently sequestered in the tissues of large fish. And isn't it interesting about Dr. Hokama's "Ciguatoxin Antigen Epitope"?

I find it hard to believe that this is a coincidence. More like the science is closing in... but from different directions.

-Erik (2008, CFSU)

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Another good reason to take a shower is to remove the salt from the skin and lower the epidermal conductivity.

I think the static correlates better to efficiency of detox than inefficiency.

My mother is not affected by mold, but after I discern a plume going through and as I am suffering from the aftereffects, her wristwatch stops.

We've watched this happen over and over again, like clockwork.

-Erik (2008, CFSU)
Chapter 27 - Cholestyramine

GETTING DAMPED DOWN

In order for CSM to work, the body must first release the sequestered toxins by damping down the inflammatory response, which controls the toxin release by leptin signaling.

CSM is wasted otherwise, and it's not an easy therapy either!

This leads some people to the conclusion that the therapy just plain doesn't work, which sounds reasonable but perhaps is not necessarily correct.

People should probably not waste their time and money on books and tests unless they are willing to undertake a difficult and arduous approach that has no guarantee of success and depends greatly upon the individual’s efforts, which require far more than just ingesting powder.

Dr. Shoemaker’s protocol is an easy one to fail if done incorrectly.

Amazing how much this reminds me of hang gliding!

Almost everything about that sport was disbelieved until people saw it done right in front of their own eyes.

Those who are experiencing a lot of difficulty are going to have to wait until they see others succeed before they start to wonder if any success is even possible.

-Erik (2005, CFSExp)

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Dr. Shoemaker does employ some corrective chemotherapies, but I cannot overemphasize enough that these cannot take the place of an avoidance strategy.

The extreme danger is that attempting to overcome continued mold exposure by resorting to drugs will make the therapy appear ineffective and create more damage.

I am not a patient of Dr. Shoemaker and am only trying to understand his work so I cannot speak for him or his treatment, but to the best of my ability to comprehend, removal of the patient to an environment which is pristine enough that upregulation does not occur is the critical first step in recovery.
Cholestyramine (CSM) can and does help while in a bad environment, but it only helps scrub toxins after they have passed through after the fact. So any resolution is only a partial alleviation of the problem.

-Erik (2009, Facebook)

**TRYING CSM**

CSM wasn't around when I started mold avoidance.

I did try doxy in 1999 and CSM in 2001, but the relief I get from avoiding mycotoxins is so much better than anything else that I just concentrated on extreme avoidance alone while I await definitive information on what the heck is going on with this damned illness.

-Erik (2005, CFSExp)

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If you read Mold Warriors carefully, it tells you straight out that this toxin binding CSM is limited, only scrubbing toxins that have already passed through your system.

If the CSM can't scrub faster than the rate of mycotoxin exposure, it's not going to do much. The key is, if you are a Moldie, to keep exposure level below the point at which CSM has a chance to be effective.

In 2001 I moved into a place that put me below the power curve of long term exposure, more than I could endure.

Wasn't all that ferocious, not like walking into a sick building, but this adds up over time. I could tell that I was gradually slipping and heading in a very bad direction.

CSM only scrubs toxins after they've passed through and done their damage. It's like cleaning up after the hurricane. It doesn't really protect you in the midst of the storm.

For people on the edge, it helps a lot by keeping the mess a bit better under control, but as long as the mess keeps piling up, eventually you're gonna get buried.

I did try the CSM at that time, and it did seem to help, just a bit, but my digestive tract came to a screaming halt.

I finally decided that I had "had enough of this s--t" and just concentrated on total avoidance - and that's all I do.

-Erik (2006, CFSExp)
CSM EXPLANATION

>I do not think the body is unable to eliminate neurotoxins, I think CSM is mostly symptomatic treatment.

Well, just look at Ciguatoxin poisoning, for example.

The toxins build up in the food chain and are concentrated in the tissues of the larger fish? (Don't eat the big 'uns.)

Not an infection, just an accumulation of toxins from ingesting other fish who have been exposed to the dinoflagellates and absorbed their toxins.

If Dr. Hokama had identified an epitope in CFS that is similar enough to act like ciguatoxin, isn't it reasonable to suspect that it may also have this property and cannot be metabolized?

-Erik (2005, CFSExp)

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> Why do you think it is that some of us are able to basically go about our business after being so sick, while for others only extreme avoidance allows them to be healthy?

Dr. Shoemaker explains this most eloquently in Desperation Medicine. It is the dissociation constant of toxin release from receptors.

This is not solely a question of toxic dose from exposure to toxins outside the body. Biotoxin illness is mediated by whether sufficient upregulation occurs to disturb the equilibrium of the ion gradient that keeps the ionophore toxins bound to their receptors in the fat cells in a "molecular bear trap."

This is a process that can be visualized by thinking of osmosis, except that instead of water molecules responding to disparity of solute concentrations, dissociation of toxins is based on electrostatic principles of attraction.

CSM can soak up enough recirculating toxins to cause dissociation.

The sudden release of endogenous toxins causes an inflammatory cascade which increases the level of cytokines so dramatically that the intensification reaction can be more damaging than an exposure to a toxic building. If someone with the double dreaded mold gene goes through this intensification, they have the most extreme form of metabolic inadequacy to clear these recirculating toxins.
This really throws people off the track, because they suffer even more intensely just when the allergy model of illness says they should be improving.

Surviving the "Herx" (it's not really a traditional Herx, but the word works anyway) is absolutely brutal, but Dr. Shoemaker has worked out ways to dampen down the upregulation with Pioglitazone. I haven't tried this myself, but I like the fact that Dr. Shoemaker is proposing an incredibly logical explanation for all the sensations I have experienced. And others have benefitted by this protocol.

To understand what separates the fundamental mechanism of biotoxin mediated responses that are upstream of genetic HLA variables, you must read "Solving the Herxheimer" in Desperation Medicine.

-Erik (2006, SickBuildings)

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By lowering the levels of recirculated toxins in the intestines, the osmotic imbalance can induce a dissociation response as the toxins try to leave the fat cells, which makes you feel worse when the toxins are reentered into the bloodstream.

See Dr. Shoemaker's chapter "Surviving the Herxheimer" in Desperation Medicine.

People jump to the conclusion that if a medicine makes you feel worse, it's not the right thing to do and you should immediately stop.

Perhaps not always. CSM is not an easy therapy.

This illness is the very devil, isn't it?

-Erik (2007, CFSExp)

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Dr. Marinkovich's prescription of agar is an indication that he might not understand the mechanism involved in the long chain polystyrene electrostatic charge of CSM that confers its special ionophore toxin binding qualities.

-Erik (2006, CFSExp)
Chapter 28 - MECU Decision

MECU

MECU was coined by a professor in Kansas who used to work for the CDC and was forced into this lifestyle. He was trying to get funding to research and develop "Movable Environmental Control Units."

I had been using the term "Mobile Mold Decon Device" until we corresponded. I liked MECU better than MMDD, and changed it just a bit to "Mobile Environmental Control Unit."

This professor got no cooperation or assistance from doctors, researchers or mold advocates, so he gave up and bowed out of the mold game.

Leaving me to carry on with my little old MECU.

-Erik (2008, CFSU)

A SAFE PLACE

It's horrible being trapped wondering if you can go anywhere, stay anywhere or do anything without being slammed and having no options.

That's why I got a mold-free camper to take with me everywhere, so I can decontaminate whenever I need to, bail out of a place whenever I need to, sleep safely whenever I need to, and just feel safer having a "Plan B" at all times.

Having a "Mobile Mold Decon Device" is a total necessity. I absolutely wouldn't have an acceptable level of control over my illness without it.

-Erik (2005, SickBuildings)

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Every time I run the custom mold-free RV concept past people who you'd think would have the greatest vested interest in pursuing this, I am struck by their total lack of enthusiasm.

When I think of all the pain I've avoided by having an "Escape Moldule" handy - and think of what it is like for people in my situation not to have one - it boggles my brain that people wouldn't put a mold-free Plan B at the very top of their wish list. Above everything else.
Imagine what it would be like to be able to just leave your mold symptoms behind? Whenever you want! It's a miracle.

Sure I'd like to have a magic bullet that makes all this madness go away but until then, I'm sticking with a rock solid strategy of extreme avoidance.

The toxins you don't breathe can't hurt you!

-Erik (2006, SickBuildings)

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After our camping trip up Hwy. 89, I went back to the "bad place" I showed you in Reno. Sure enough, it's acting up as per usual. Not horrific, but over tolerance for me.

I worked for a few hours, and then retreated to my MECU. Having a mobile refuge is so, well, you know....

Necessary! To pull this off with dignity and aplomb.

-Erik (2008, CFSU)

* 

I tell you, having a MECU gives back a stunning amount of control.

A storm hit a couple of days ago, and I was forced to make a quick getaway.

It's only after you've done it a number of times and realized the fullness of how much agonizing mold-dreckiness can be successfully evaded that the concept really speaks to itself.

-Erik (2008, Email)

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I was forced to forego a great many things, and found that locating suitable housing was such a shot in the dark that I wound up building my own custom RV out of metal and plastic, with no formaldehyde or materials to give mold a foothold.

This way, no matter what, I still have a "Plan B."

This system conferred such an advantage that I thought anybody in a similar situation would be instantly drawn to the concept.
The reality has been totally the opposite, with nearly everyone preferring to do with battle their local environment right up to the point in which they realize that this is no longer possible.

But by then, they rarely have the resources to plan a "Plan B.”

-Erik (2008, IAQ)

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I believe that an MECU should be made available as a refuge during the course of any suspected sick building incident or remediation, for quick removal of inhabitants to a safe zone when necessary - to better enable them to sense the shift of symptoms and shape their decisions accordingly.

Generally, nobody thinks they are susceptible until it is too late.

-Erik (2008, IAQ)

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Here's the deal.

Regardless of whether your house is good, if a source point gets going upwind of you, whatever you do in your house doesn't matter.

I never wanted to be trapped again without an escape route. That's why I bang away so hard on the need for an MECU. Nobody would think to plan for this. Nobody says to themselves, "I really need a camper, or some place I can move if my whole neighborhood goes bad."

The lucky ones are those who already have an RV. Hopefully it wasn't too badly contaminated, but very likely it is.

After it's happened and people have gone the rounds of doctors who found nothing, and after they spent all their money trying to remediate their house when it was the whole area that put them under the power curve.....

What are they going to do if they have no MECU?

Well, I can tell you. They just go from hotel room to hotel room, from house to house, trying again and again to find a safe place to sleep.

And it ain't no fun.
People who haven't gone through this yet have no idea how much they need one, if they are headed towards this kind of reactivity.

The only people who can advise them in advance are those who have gone through it. Who can observe the badness in someone, see the recognizable signs, hear the clues, and warn them of how this progression winds up.

And just how rotten it is to have no decent place to turn.

-Erik (2008, CFSU)

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Of course I would love to be able to just go to the desert and be as free of this crap as possible.

This is just a technique that allows me to live on the fringes on normalcy and interact with people in a way that would otherwise be impossible.

MECU's confer an advantage, a functional solution to a problem that has very few other solutions (that I know of, anyway).

This is why I'm forced to reach a conclusion about people's level of reactivity when they tell me, "I couldn't live that way."

If one cannot move to the boondocks, what's the alternative? Intense agony, total dysfunction and ultimate death?

They can't possibly mean that, unless it is still an optional choice for them.

-Erik (2009, SevereReactor)

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Places that are tolerable in summer often ramp up horribly in winter. It's winter that one has to really plan for.

Need to get Plan B in place before the cold weather happens and you wind up trapped with no way out.

It's not my place to specifically tell people what to do since we all have our different situations and considerations, but I will tell you what I did, and what I would do again if I were shoved back in time.

An MECU would be my absolute first priority.
IT'S A STRATEGY

It's not just a matter of having an MECU. It's how you use it.

That's why I like the hang gliding analogies. The basic skills of maneuvering the glider is one thing. Learning how to chase lift is another thing entirely.

It's how well you combine the skills that determine how well the flight goes.

-Erik (2008, CFSU)

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The MECU is not a specific design. It is a strategy. One can do it in a car or a tent.

So that's not a good argument for saying that people can't do it. They're just looking too hard to find excuses.

-Erik (2009, SevereReactor)
Chapter 29 - MECU Options

CHOOSING THE MECU

If I were in your position, I'd try to find a dealer who would let me sleep in the RV before buying.

If it felt OK, I'd go for it, and if it started to feel not so good, then I would do whatever it takes to correct the problem.

The basis being that "whatever it takes" would not be all that much different than starting from scratch. At least you might have some fun before it goes bad.

-Erik (2008, CFSU)

AIRSTREAM CONVERSIONS

I talked with a guy who modifies Airstreams for MCSers four years ago. He agreed that this specialty rebuild is economically out of reach for most financially devastated people.

He told me that aluminum Airstreams are good as long as the metal frame doesn't make contact with cellulose or any mold supporting media.

So an aluminum trailer is fine as long as condensation doesn't reach mold suitable substrate.

That was one of the modifications he made to his Airstreams.

They still have a plywood floor, so that area still retains unsafe potential. If you want to see just how unsafe, go to an RV wrecking yard and find some old, well-used rigs and smash the plywood apart. You will be amazed at what you find hidden in the glue layers.

Not only that, but the metal skin of an Airstream is highly condensation intensive, more than enough to provide interior wood walls with sufficient moisture.

-Erik (2005, SickBuildings)

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I wouldn't recommend buying a new Airstream. I'm talking about getting an old one, gutting it, and completely redesigning the interior. Even aluminum trailers aren't mold proof if the condensation can reach anything that mold can grow on.
I talked to someone who rebuilds Airstreams for MCSers and he said that even though the ribs are metal, the panel is still too close to the walls to be mold proof. He has seen a lot of mold in conventional Airstreams.

I just looked at an Airstream the other day that had mold on the foam carpet backing. They can be as bad as anything else, if they aren't modified.

-Erik (2006, SickBuildings)

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Maybe one of those dinky Airstreams? Don't they have "oldies-hopefully-not-moldies" down to about seventeen feet for sale?

At least you'd know that you could gut the thing and have a bare metal starter MECU. Less painful to gut a used trailer, anyway.

-Erik (2008, CFSU)

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I think that if something happened to my camper, I would be trying to snag a used Airstream, on the premise that I would have a helluva good chance of making it right.

There's another good thing about Airstreams. They are considered classic antiques, so you get extra points for style.

-Erik (2008, Email)

**RV MANUFACTURERS**

After looking at all the problems with conventional RV design, I decided that I didn't really trust any of them.

There are a few companies that come very close. If they would simply change out flooring material and roof caps with non-cellulose, I believe they would be quite reliable.

It seems to me that anyone who really knows and understands what this illness is like would instantly see the benefits of an "MCS special" that, if produced in sufficient quantity, need not be top of the line and so ferociously expensive as a custom modified Airstream.

We need a group to collectively approach an RV manufacturer and propose such a modified design
All the conventional RV's I saw that were properly built for long term use were far out of my price range.

But there are some medium priced RV's that are so close to being safe that if you could intercede at the factory and substitute aluminum roof caps and floors instead of plywood, they'd be very trustworthy.

The only way I see to get reliable RV's for Moldies at reasonable cost is to persuade RV manufacturers to make some modifications.

As mold remediators are going to be at the forefront of dealing with desperate people in dire situations, it seems that they would be the logical ones to make a cooperative effort to press for such a Plan B for their clients.

-I Erik (2006, SickBuildings)

I haven't found any brand that I would trust. The materials have really gotten bad since wood prices went out of sight and good kiln dried wood became a thing of the past.

-I Erik (2007, SickBuildings)

The MECU has been my lifesaver. If you catch any impending signs of a killer slam, the MECU gives you a way to neutralize it before the immune system gets out of control.

Really, I know it is disappointing that I rely so heavily on the tools I developed to help me deal with this situation.

I know that not everyone can build a MECU. Not everyone can build a car either, but a lot of people can drive one. If such things were made available, those who need them would stand a much better chance of getting them.

There is a need that needs addressing.

-I Erik (2008, CFSU)

COMMERCIAL RV’S
I've been eyeing those fiberglass cargo van body conversions, thinking this would serve as a much easier basis for an MECU even if it is less stealthy than a Sprinter.

-Erik (2008, CFSU)

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Holey Moley! Check out the new Ecologic lightweight trailer from Dutchman. Pretty darn cool.

-Erik (2008, CFSU)

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I've been looking at a nifty Winnebagel van conversion called View. It's about the right size, mobile, mostly aluminum frame, good mileage, and looks respectable, which goes a long way toward pushing the boundaries on parking.

-Erik (2008, CFSU)

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If I had it all to do over, I'd sure go with the Sprinter.

I was thinking about the shower/bathroom situation, and this takes integration of so many systems, hot water, cold water, electricity, black water, grey water, holding tanks that it would really have to be performed by someone with real RV expertise.

It can be done, for sure, but not by Joe Average. Still, there's gotta be people out there who can do this kind of work. It's just a matter of finding them and getting it done.

-Erik (2008, CFSU)

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I saw a whole crapload of really neat RV's this weekend that were in the right size range and far cheaper than having that custom place do a Sprinter. Heck, you could get a fiberglass Chinook or even a Winnebago View for far less money, and strip it of everything that bugs you.

-Erik (2008, CFSU)

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I've been going back and forth about Casitas, and I'm unsure what to do.
Some people have bought Airstreams, stripped 'em down to the bare frame, and are still plagued by the wooden floor.

Or are they? So how do I know that perhaps the Airstream wasn't the problem at all?

And maybe that's how it is with Casitas. If you find ONE that doesn't bother you, then it would seem logical that the inherent materials in the Casita isn't the problem.

If that's the case, then a Casita should be fine or at least fixable.

About the only thing I can think is to see if you can sleep in it for a day or two. (That's what I did when I bought a used camper in 1999, and it WAS good...but only until it grew mold.)

We're really covering some untrodden terrain here.

-Erik (2008, Email)

I think the Casita is so close to being as good as it gets that I would just go ahead.

What would be worse?

Starting from total scratch, or trying to get something that was bad out of a mostly good RV?

About the only part of a Casita that I could see as being extremely difficult would be the floor.

So the question is whether or not they use bad plywood in construction.

I'd have to sleep in one to know for sure, or go to the factory.

-Erik (2008, Email)

>What do you think of this trailer?

>http://www.livinlite.com/camplite-overview.php

Trailer looks too awesome for words!

Perfect.
HORSE TRAILERS

I was just looking at some beautiful horse trailers. Very nice.

But did you see how heavy and strong those trailers are? Lots of unnecessary weight, for our mission-purpose.

Horse trailers are also a bit overbuilt and small for the purpose.

If I ever got enough money to move up to a bigger MECU though.... hey, they're pretty neat.

There are some dandy little bare metal-fiberglass trailers that look like they'd work out great. They look pretty good on the outside, which is a consideration in where you can park.

I almost went for this option when I was building mine. But I wanted to go with extreme mobility, so I did the RV thing.

-Erik (2008, CFSU)

PLASTIC

Some plastics have an absolutely amazingly unexpected way of accumulating badness.

I don't know whether or not fiberglass has this affinity. So I would hate to counsel obtaining a proposed MECU which might have this characteristic.

-Erik (2008, CFSU)

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I'm still very uncertain as to how well someone in our position can tolerate fiberglass.

How would you ever know if it was affecting you at a low level, maybe not enough to notice, but still enough that you'd be better off with something else?

It'd be good to have some means to know in advance, but I just don't have any track record in that regard.
There is a weirdness here, a complication that throws me off.

You see, when driving along, a car builds up a static load like a capacitor.

Remember that electrostatic attractant quality I was speculating about? Sometimes it felt to me like driving through a plume had the effect of concentrating toxins on plastic parts of my MECU, over and above the metal components.

So the fact that the unit is moving plays a part in toxin agglomeration.

Yeah, I know. Crazy! Just like everything else. Can't swear to it, and haven't done deliberate testing of the concept, but it was scary.

And I would hate like hell to tell someone to get a plastic-based MECU and find out later that the whole darn thing turned into a mobile electrostatic ionophore bear trap...as Dr. Shoemaker describes the effect in regards to cholestyramine.

When my last camper went bad and left me stranded in the desert, sleeping in a tent, I wanted a quick way out.

But having been burned so badly, I tried to be cautious.

I checked out a whole bunch of brand new campers, and not only were they obscenely expensive and overpriced, many of them were intolerable to me right from the factory. Long term prognosis, not good.

There are two brands of RV, Titanium and Prowler, that I feel must be coming from a moldy place of manufacture. They all feel like shit at all the dealerships, no matter where.

Lance campers...some good, some bad.

Fleetwood, all have been good, except that was the brand that eventually went bad on me.

The only thing I can think is that some supplier for certain materials must be bad, but it's not consistent.
I'm out of my realm too. I'm in way over my head.

It's like a miracle that I was crazy or stupid enough to build this MECU thing, and even then, when I take it to certain places at certain times, it has an unbelievable propensity to acquire badness that is almost beyond description.

I believe there is an electrostatic factor of attraction to the equation that people simply do not have enough knowledge of to be able to incorporate this utterly bizarre phenomenon.

It is so difficult to master the places where an MECU can attract the badness that anyone who isn't totally into details would likely have far greater success with a trailer that they can leave in a "feelgood place" and allow their car to be the sacrificial transportation.

One of the guys I know has decided that he wants better mobility than the large Airstream clone he was gutting and is looking into a fiberglass Casita. I'm really impressed at this plan and his choice of trailer.

I might even have been better off if I had gone this route.

I was kind of hoping that your experience would induce doctor interest in following up.

It's awful damned hard to make plans when the problem is such a complex weird maze of things that don't seem to make sense. And it's hard to advise anyone else, when the outcome of a bad choice is so painful.

-Erik (2008, Email)

That's what scares the crap out of me about advising anyone on what to buy or build.

I originally insulated my MECU with standard fiberglass insulation so I could get it done quick.

But the plan from the start was to replace it, to get rid of formaldehyde.

I started having problems in Reno. The MECU was picking up badness in the most incredible and horrific way.

If I didn't bring it into town, or stayed out for weeks, it would die down.

But if I so much as spent two days in Reno, it would literally go to hell.
I replaced all the fiberglass with that styrofoam, and it made no difference in badness acquisition.

I simply couldn't believe it, but my senses were telling me that the double walled plastic liner that I had on the walls, Coroplast, was the culprit.

"Coroplast" is plastic configured just like cardboard. I figured, "Can't grow mold - must be good."

Turned out, not true.

That plastic doesn't bother me when I'm out in the woods, so it doesn't seem inherently bad, and yet the stuff would turn to killer hell in Reno.

I became convinced that the electrostatic qualities of the plastic, probably in conjunction with the Faraday Box of aluminum construction, was combining to create an attractant well for ionophore toxins.

I removed all the Coroplast, which is why the interior of my camper looks like shit. Used to be much nicer.

And I've been thinking about what I could use which would lack this electrostatic quality of attraction. I've got some ideas but haven't experimented yet, so I don't know for sure.

In the face of a phenomenon like that, how am I supposed to tell people what to do?

It's going to sound crazy to say, "Plastic is fine as long as you don't take it into a mold zone, in which case plastic can be your worst nightmare. But don't use wood, because it can grow mold."

I've been leaning in the direction of just thinking that this is too complicated for any sufferer to deal with, and that until some researcher decides to go around with me and see this - as you did - and get a sense of these different factors that I'm dealing with, a mold sufferer would be better served by just finding some means to get out of mold zones and stay out as much as possible.

I heard from the guy looking at the Casita. He still has the Airstream clone and it seems to be working pretty well where it is out in the boonies, all except for when the wind kicks up.

-Erik (2008, Email)

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One wouldn't think an all fiberglass box would set up a Faraday effect of electrostatic attraction.
It seems counterintuitive. But I'm not so certain. My experience suggest that this might not be the case.

Under those conditions of atmospheric ion shift we discussed, it would go electrozap crazy.

And then it felt like the camper was trying to kill me. I almost threw the whole thing off a cliff.

I couldn't believe it. All that work... and what the hell? What more could I have done to make it safe?

I repeatedly took the walls out, reinstalled them, changed locations, test after test.

The effect was reproducible.

Plastic x mold zone + ion shift = toxic effect acquisition.

Our conceptual framework is that something is either good or bad. This defies all that in a big way.

This is a huge intellectual challenge, because to predict badness potentiality, one has to balance the affinity of a specific material to attract ionophore toxins (the badness), against where the badness is, and at what times the badness is in effect....and then reduce the material the MECU is made of to accommodate that cumulative combination of complex factors.

So much easier to just stay out in the boondocks.

That's what most PIR 5 (Personal Impact Rating- Extreme) environmentally reactive nutcases are forced to do.

But the attractant effect is manageable, if one knows how to predict it and intercedes in time.

In all the years I've been trying to explain this to people, if I go too far it tends to shut them down completely.

Virtually everyone says they are ready to hear it until they hear that, and then a wall goes up.

All communication stops.

So I've been trying to figure out a way to sneak it in slowly.
STEALTH

I've seen everything from school buses, to those big UPS type laundry vans, to horse trailers and toy hauler fifth wheels being used by people.

But none of these lend themselves to parking on the street.

Even out here it is getting progressively more unacceptable to park an RV in most places. Moldies have to hide their disability in plain sight, and get no understanding or cooperation. So I lean further and further toward the need for stealth.

When you need the dang thing, you really need it.

I like to visit people, but can't always sleep in or in front of their houses.

I have a need to keep my MECU handy, so it had to be something that I can park almost most anywhere. I chose to make it a camper.

If I were to get a Sprinter now, I think that I would do without the windows in the interest of making it look less like someone is sleeping in it.

I have been sorely tempted to get a large van and try to make it look official. I was only half kidding about getting a Sprinter and outfitting it with a satellite dish and a phony "Channel 69 Newsmobile" logo, thinking that they'd probably let me park anywhere.

Like I say. When you're fighting for your life with this problem, people don't understand why you would be doing such a thing as sleeping out on the street in a vehicle when you have a nice warm house available, and they don't cut you any slack.

-A Erik (2008, CFSU)

AUTOMOBILE

>Do you have a sense for the susceptibility of cars to be contaminated? I would think that the circulation of air outside the car would help.

That's what I thought too, until I tried driving at 100 mph to "blow the spores off."

Didn't do a damn thing. I just learned the hard way to make sure that my car isn't parked in a spore plume. One can pay a very high price for making this mistake.
A couple of people have already gone through multiple cars, even stripping out the upholstery. Once a car goes bad, it is very hard to get it good again.

-Erik (2008, CFSU)

*

Last time I've resorted to car camping was out to the rental car, when on a trip and the hotel was bad.

Kinda sucks to do this for much more than a week, unless it's really warm. Getting soft in my old age.

-Erik (2008, CFSU)
Chapter 30 - The Custom Built MECU

BAMBOO BOMBER

The thing I wanted doctors to examine is how I use my Mobile Environmental Control Unit.

It's like the old precursors to hang gliders, the "bamboo bombers" which led to high performance flying machines.

People conceived of a flying device and built rudimentary models, which were refined over time into amazingly high performance tools for flight.

I was trying to instill the need to create a survival tool and then, how to fly it best through this maze of random spore plumes we live in.

To perform the MECU strategy, you would need to have some basic mold-free vehicle which can serve the fundamental purpose.

-Erik (2007, Email)

*

Man, this is like trying to get people interested in hang gliding back when it was "bamboo bomber" days and you had to build it yourself.

It's like you need the aircraft to create a person who flies, but you need the flyer to first conceive of the aircraft before it can be built.

-Erik (2008, CFSU)

*

Lordy, but I do love my MECU!

After a day going in and out of moldy buildings, I put my clothing aside, took a shower and had a wonderful night’s sleep.

Picked up my clothes from yesterday and got instant heart palps. What a great feeling to be able to break free of the badness and put yourself back in control.
This reminds me of the progression of hang gliding. First, people had to see a "Rogallo Wing": a NASA experimental design, then envision the possibilities, and then try to build and fly them.

The first attempts were crude, bamboo and visqueen held together by duct tape. The came "The Standards,” and hang gliding was on its way.

Nowadays, we have gliders that are almost up to sailplane performance range. But it had to start with an idea that it could be done.

-Erik (2008, CFSU)

**A BARE TRAILER**

A bare panel-van or simple trailer works great as a starter because you can build it from the inside, so areas can be made accessible to take care any future problems.

You can choose whatever size that suits you best.

-Erik (2006, SickBuildings)

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In your place, I would just get a bare trailer and work on it as time went along.

There are some pretty nice ones that don't attract a lot of attention.

Just a bare, safe, lockable place that serves as a refuge. Can build it up with the comforts, over time.

When I first put the camper on my truck, there was nothing in it. Just a shell.

No toilet, shower, water, lights... nothing.

Used an electric heater with an extension cord. Cooked on a portable barbecue.

Pissed in a bucket. Washed with a tub. Slept on a backpacking pad.

Compared to how I had been feeling, I was in absolute paradise.

So, if my camper were destroyed and I needed to start over, that would be my best option.

-Erik (2008, Email)
The only critical aspect is mold unfriendliness. Everything else is up to the assembler’s discretion, and that leaves an almost infinite number of possibilities.

The doctor I carried out of a moldy place years ago bought a bare metal trailer and just put camping gear inside slowly, one piece at a time. Pretty crude, but it's better than being stuck in mold.

I run into someone else quite frequently out in the boondocks who has a plain white van. There again, it's not exactly the Hilton, but preferable... for him anyway.

It's not so much the design as it is just doing it.

-Erik (2008, CFSU)

After a great deal of discussion about trying to make the best of an absolutely horrific situation, my friend who went through the whole "desert detox" drill made the decision to buy a bare metal and fiberglass toy hauler type trailer as a "Plan B," should the need ever arise again.

She stocked it with basic camping gear, a cot, and an electric heater with a LONG extension cord.

Rough, but it works, which is the main thing.

We both had too much heartbreak of conventionally built RV's going bad on us.

If I were slammed back into that level of reactivity and lost my MECU, that is precisely what I would do.

What other choice would I have, besides getting out my old semi-reliable tent?

Toy hauler just refers to the ramp-style door on the back.

Hers does have a wood floor, and she's acting on the basis of, "If it goes bad, I'll rip it up and replace it."

Which is probably how I would go, because I'd want to build a metal floor that has at least six inches of insulation under it.

You just have to find a trailer that suits you.
There's another reason to start with a bare trailer: so you can build interior "false walls" with an air gap.

The condensation will always be there, but at least with an air gap, it can dry out and the condensation isn't touching much of anything that mold can easily grow on.

That's how I built mine.

-Erik (2010, SevereReactor)

A MOLDIE'S DREAM

I decided to go all-out on my little experiment and built a special RV out of mold resistant materials, with no wood or paper.

It's been so beneficial that I've just stuck with the RV lifestyle. I never had so much control over my illness until I did this.

Not for everyone.

Not a cure, but a heck of a clue to neurotoxicity.

-Erik (2005, CFSExp)

*

Maybe I should mention that one of the reasons for perpetuating the RV lifestyle is that after my old camper went bad on me, I "spec'd" out a bunch of rental apartments.

I found a number that were okay.

But there was a huge problem.

They don't accept cats.

It didn't matter that my kitty is a female and doesn't spray. There are so many people with cat allergies now that many apartments simply don't want any cats at all. Period.

Cat dander would bother any subsequent renter who had cat allergy, so no more cats.

I hated being put in the squeeze of having to locate a mold-free place, having to wonder if I might sign a lease and be stuck if a neighbor's plume wafted over, AND dealing with the lack of cat friendly rentals.
I wanted a rock solid reliable Plan B for me and my kitty. And I can't trust conventional RV materials and building methods.

So I built my own.

It has worked so well and been so much fun that I never went back to the rental trap.

I know that not everybody can build an RV.

But if such a Plan B can be constructed, and if the concept is inherently useful to all people with this problem, it seems to me that when enough people demand such an option and signal their desire, it will come.

I have my kitty to thank for pushing me into adopting and maintaining the RV way.

Thanks Kitty!

-Erik (2006, SickBuildings)

*

I decided to go with my own design, which allows the condensation to run down the inside wall and out the bottom without encountering anything that could grow mold.

Well, actually, there's nothing in the camper except metal and plastic, so about the only thing it could possibly find would be accumulations of organic material and dust inside a wall.

I bolted together a basic aluminum frame, used steel studs for a four inch wall, and pop riveted on the exterior aluminum skin. Cost about $4,000 in materials.

Rather than trying to minimize condensation, I built it in such a way that no amount of condensation is a problem. I could wash the inside with a garden hose if I really had to.

Also I built it as a shell with all areas accessible from the interior so that if somehow there was a problem, I could take the wall apart and replace virtually everything but the metal frame and skin.

Just in case something were to happen in the winter, which is the most "condensation intense" time.

I really did get tired of getting kicked around by this stuff.

-Erik (2006, SickBuildings)

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> If your RV is just metal and plastic, does that mean it has no insulation?

It's probably one of the best insulated, warmest RV's around!

Four inches of styrofoam in the walls, and eight in the floor and roof.

Not only that, but I put a solid titanium wood stove in it.

The whole fireplace weighs eight pounds and keeps me toasty warm in subzero weather. I pick up wood at construction sites, so my heating bill is almost zero.

I pump so much heat through the place that I have the windows and door open in the dead of winter. That really helps keep the condensation down.

I got really tired of having RV's go moldy on me.

-Erik (2006, Locations)

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After my tent in the desert experience, I decided that I absolutely had to have a domicile that was mold and formaldehyde free, and so constructed my own RV with inert metal and lowest off gassing plastic I could find.

I used mechanically mixed styrofoam for insulation.

-Erik (2008, CFSResearch)

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Conventional RV construction is pure mold murder. That's why I custom built my own rig out of mold-unfriendly materials.

I've had four RV's go bad on me, and couldn't bear the thought of going through this again. That's why, in total desperation, I built my own.

You know how we were talking about fate pushing me down this path? By a weird and completely improbable confluence of events, for a brief moment in time, I had access to a shop where I could build my MECU.

When this opportunity opened up, I remember thinking, "Here is my one chance to start from scratch and do it right" and I jumped on it.

Even now, I look around at all the work I put into my MECU and think, "I must be crazy. Was it really necessary?"
And then I hear more stories and am glad I did it.

Seems to me that Moldies should band together and ask RV manufacturers to construct a totally mold free RV.

-Erik (2008, CFSU)

*

My MECU is very highly insulated, with four inches of styrofoam in the walls, and six in the ceiling and the floor.

Between all the insulation and the wood stove, this is about the only RV I've ever seen that has the door/vents/windows open when it's snowing like crazy and temperatures are down in the teens.

If one has a need for lots of fresh air, even in the coldest weather, this is the hot ticket.

-Erik (2008, CFSU)

*

I built the Mobile Environmental Control Unit as my escape module out of aluminum RV siding, steel studs, and four inch thick styrofoam insulation - with a quarter inch air gap between the foam and the exterior wall to allow for the unavoidable condensation.

Works like a charm.

-Erik (2008, IAQ)

*

I was just looking at my custom built mold resistant RV, thinking how much work I put into staying alive and how hard it was.

Now it all just seems like a bad dream. The custom RV makes it all possible for me.

-Erik (2009, Locations)

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I am writing this from my mold-resistant "Mobile Environmental Control Unit" that I built several years ago.

I am parked next to a house that has intolerable levels of mold.
I can go in and visit, but when the badness starts to get to me, my refuge is waiting.

It's got a wood stove, which is burning right now and keeping me more than comfortably warm, even though it is below freezing outside.

This thing is a "Moldie's dream," and as far as I'm concerned, it's the only way to fly.

-Erik (2009, Locations)

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At the inception of the CFS epidemic, I told Dr. Cheney that I had a reactivity to mold that kept getting worse "no matter where I lived." Some places were better, some worse, but the overall effect was that I kept moving further down on the scale.

It just kept getting harder to stay on the good side of the power curve of exposure.

Like so many others, I tried to find a good RV.

I had four of them go bad on me since 1984.

It seemed to me that if things kept going this way, I would have no options left. This scared me about what might happen in the future.

So out of pure desperation, I started from scratch and built my own.

It's not the layout or design so much that matters, just that it must be highly mold resistant and mobile.

I'm completely self contained.

I obtain my water from a spring up in the mountains, and heat my RV with an interesting wood stove that is made from titanium, so the whole thing only weighs eight pounds, with superior heat dispersal than steel.

Everything is twelve volt.

Portable generator which, amazingly enough, I have to make excuses to run, because I don't need it very often.

I have a "Super Fan" above the shower to extract moisture quickly, but it probably isn't necessary.
The wood stove in my rig puts out so much heat that condensation is a non-issue down to 0 degrees.

The single pane windows don't even ice up.

-Erik (2009, SevereReactor)
Chapter 31 - MECU Design

MOLD RESISTANCE

If you want a fascinating education on construction lending itself to mold growth, visit an RV repair shop.

I toured an RV yard full of recreational vehicles in various states of repair after collision. Though they looked fairly new and no visible indication of mold growth was apparent on interior walls, the insulation, backing of the panelling and wood frames were loaded with mold.

This includes recent model RV's. In fact, some of the newest ones were the worst.

This is consistent with mold hits I've felt in many RV's.

Recently I found several manufacturers that are using moldy panelling right from the factory. The RVs were bad from the moment they were made.

I had a camper turn bad and literally stripped the inside of panelling because mold was growing inside the plywood laminations where it couldn't be seen.

I've visited RV people with inexplicable health problems and gotten slammed in their rigs. Most were already too ill to even think about changing their living circumstances, and since their poor health left them unable to work, barely able to move, and relatives were generally unsympathetic, It leaves them almost zero options for recovery.

After seeing the propensity for mold growth in recreational vehicles, I caution any mold sensitive people about the danger of trying to spend a winter in an RV.

-Erik (2004, SickBuildings)

* * *

A couple of years ago, Dr. D and I moved out a mold region and were recovering in the desert doing the RV lifestyle.

It worked great until winter and the trailer went bad. We were forced to run for our lives yet again.

I visited many people in other trailers and found that for long term RVers, their mold problems were worse than house dwellers.
The roof cap is usually made of plywood and the condensation is pretty much impossible to eliminate. I wanted to find out if any make of RV was particularly immune so I toured RV wrecking yards. Looking inside the damaged walls told the story.

New looking RV's that were damaged had hidden mold.

The best way to get a sense of what you are facing with an RV is to just tour an RV yard and see exactly what types of areas and materials show the greatest mold growth.

I'm still in favor of RVing for MCS'ers, but I think that the plywood roof cap in most RVs is a hidden and unsuspected danger.

-Erik (2005, SickBuildings)

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There are an awful lot of "really great deals" on used RV's.

"Oh, we just decided it's time to sell and want to get rid of it immediately. There's a little mold, but don't worry about that."

-Erik (2006, SickBuildings)

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> What makes it easier to find a mold-free RV than a mold free apartment, condo, or house?

It isn't. The problems are the same, but the reward is that if you succeed with an RV, you can take your Plan B with you as you try to make your way through various future sources of mold exposure. When you are house hunting, it's nice to have a backup plan available.

I found two brands of RV that were totally contaminated right from the factory. Not only that, but the condensation inherent to such a small space makes RV's extremely high risk for developing a mold problem.

That's why I was calling for a custom design utilizing mold resistant materials.

It wouldn't be difficult for RV manufacturers to change their materials. They are just now starting to make these modifications, just as the housing industry has begun to do as they recognize the market for it exists.

-Erik (2006, SickBuildings)
I had four campers go bad on me before I gave up on conventional RV design and built my own. Some of the worst sick “buildings” I have ever encountered were sick trailers.

The flaws in normal RV’s are twofold. They make little or no provision for condensation buildup, and even if they have a metal frame, they still have interior wood panels and plywood floors that mold will grow on.

Redesigning and correcting these problems is so complex that it is easier to just start with a metal or fiberglass shell.

I used metal studs placed vertically. Rather than worry about minimizing condensation, I allow condensation to run down the interior wall to a catch trough, where it can escape, no matter how much there is.

-Erik (2006, SickBuildings)

>Why do RV’s go moldy so easily?

Wooden structure itself is the worst culprit. Given the high condensation and no real escape route, plywood roof caps, wood floors and wall joists are perfect places for hidden mold. A tour through an RV wrecking yard is very enlightening.

-Erik (2008, CFSU)

The "mold unfriendly materials" refers to the fact that you don't want the MECU to grow mold.

The possessions that I have remediated were not growing mold. They were just in a moldy place, and they cleaned up easily. Just as my MECU has been in many moldy places but isn't growing mold.

-Erik (2008, CFSU)

A mold-resistant MECU in a mold zone feels just like a sick building to me.

I don't want it to grow mold, because then it won't get better when I go out to the woods, but the fact that it isn't growing mold doesn't make it livable for me if it's in a bad place.
So, the way I see it, an RV need only be as mold resistant as the use it is put to, and the potential for it to become contaminated with viable spores.

-Erik (2008, CFSU)

GOING MOLDY

I thought I had my camper pretty well remediated. It had been feeling pretty good to me, but then I started having some problems that I could feel when my heater fired up that kept getting gradually worse.

I pulled off the heater cover which gave me a view into the wall behind the shower. There was a slow drip from a pipe that had cracked from freezing. Damn it!

It was just starting to bother me and I fixed the leak and bleached the crap out of everything. I sure hope I got it in time, because when I go camping out in the desert, I feel almost normal.

-Erik (2002, SickBuildings)

*

I bought a camper and moved it into the woods and had a great recovery, but eventually the camper got bad. I started looking for the mold in places where I felt hit but the wood simply didn't look moldy.

After going crazy insisting that I could feel the mold in a specific place that didn't look bad, I finally just cut the wood out.

Only then did I find that the mold was in the glue layer of the plywood. The wood had no visible indications of mold on the exterior.

-Erik (2002, SickBuildings)

*

I've found that the condensation problems in most RVs are so bad that mold growth is almost guaranteed from long-term use.

The benefits of being able to drive away from a spore plume are so great that it is still worth it, but the care that must be taken is almost beyond belief.

I've found many inhabitants of "sick trailers" in my RV career and only a few figured it out.
I had four different RV's go bad on me over the years.

Couldn't believe it! Despite my best efforts to keep the condensation down, they all grew mold and drove me out. In the middle of winter, of course.

So I gave up on conventional RV design and built my own out of metal and plastic.

Even if you have a mold-resistant RV, you still cannot park in a moldy area.

Even if the rig doesn't grow mold, you can still be drenched in spores from elsewhere.

So Moldies are modifying Airstreams and metal trailers similarly to MCSers, except with an extra emphasis on mold resistance.

>I am tempted to dismantle this RV and see if I can find the mold.

I should send you pictures of when I attempted to do precisely that, with a camper "gone bad" that I bought new in 1999. I was so mad that I decided to keep ripping it apart until I found the mold or there was nothing left!

I kept removing parts and finding more mold, until there was nothing left but the floor.

And when I took that away, the area where the camper was dismantled slammed me, even though there was nothing at all left but a bare patch of cement on the hangar floor.

If a regular RV starts to get mold in it, it should conceivably be possible to remove the moldy area and be OK, if it's done quickly.

Wooden structural frames are impossible to fix without ripping off the exterior, so conceivably, if the structure was aluminum, there shouldn't be a problem that can't be fixed from the inside.

However, I've had four RV's go moldy on me since 1984.
In the first one, the mold was directly under the sink on the plywood floor, where a long term leak had been happening. I tried to clean it up and sand it out, but it just didn't make a real major difference in my symptoms.

Every camper or trailer, I thought that I would surely catch it before things got out of hand and drove me out. And each time, mold got going in a place where I couldn't get at it. Damn!

-Erik (2008, CFSU)

AIR CONDITIONER

I had an air conditioner almost drive me out of my rig.

Couldn't believe how it suddenly just started blowing “badness.”

Fortunately, I unbolted it right away and got it off the roof before it did too much damage.

I will never have another AC again. I don't care how hot it gets. Just isn't worth the risk.

I built a canvas roof to shade my RV, and this year I'd like to get an outdoor misting system.

But no more AC for me.

-Erik (2009, SevereReactor)

BLACK WATER TANK

>How can I keep mold from growing in my black water tank?

I wish to heck I knew.

I poured every nasty noxious chemical I could think of inside the damn things, rattled them around with rocks and gravel, left them to dry in the desert sun for months, both black and grey, but lost the battle.

Tanks need to be removable and replaceable.

Or constructed of aluminum or steel.

-Erik (2009, SevereReactor)
CONTROLLING CONDENSATION

My MECU was designed with the basic premise that leaks shouldn't matter.

Condensation can roll. I could wash this thing out with a water hose if I wanted.

I left a generous space between the styrofoam and the metal, so condensation can freely run down and out.

I didn't want to have to even worry about any leaks. Not that I am saying they are unimportant. It's just that condensation levels in full-time RV living are so high that whether or not one has a leak is almost immaterial to the fact that everything is going to get wet anyway.

This is why I have a cot in my camper instead of a mattress. No matter what kind of mattress you have, eventually it will get soaked in this kind of environment. It's unavoidable.

The first sign you will have that your mattress has gone bad is that you finally are able to discern it, which means that it had probably been creeping up on you for many crappy nights. So why even go there?

-Erik (2008, CFSU)

*

My Mobile Environmental Control Unit (MECU) is a custom built RV that has nothing for mold to grow on.

Considering the condensation problems in RV's, leaks don't even matter. In the winter, there's going to be plenty of water whether there is a leak or not.

So better to just construct the habitat out of mold-unfriendly materials, so it could leak and it still wouldn't matter.

-Erik (2008, Locations)

*

Without suitable substrate to grow on, there will be no mold no matter how much condensation is present.

That is why I built my custom RV with a metal frame and with a quarter-inch air gap between the interior styrofoam and exterior metal shell - to allow condensation to occur at any level yet remain harmless.
Unlike conventional RV construction, I have no need to control condensation at all.

> As you drive that RV down the street, you will create various pressures all around the unit. As a result particles will migrate in and around the interior layers. Thereafter when the condensation occurs you now have a food source and moisture. That would present a reasonable ecology for growth.

I guess I should have mentioned that it has an external aperture that feeds a Hepa positive air pressure system, to account for that very phenomenon and also to allow me to drive through mold zones without contaminating the interior with spores.

> Mold grows very well on wet duct. If you visit Great Britain you will note that they have a problem of mold growth on glass: the mold grows on the dust that adheres to the wet glass.

Mold can only grow on the substrate of dust and organic material that is stuck to the metal and glass, but not on bare metal/glass itself, to the best of my knowledge.

This is why metal ductwork is so problematic. The electrostatically charged dust particles glom onto ductwork, providing a feast for spores if condensation is also present.

However, I did take this into account by constructing my rig with interior walls/insulation that are removable from the inside, giving me access to any problem that might potentially develop.

But I'm sure doing my best to make it tough for the little buggers to get a foothold, and it's paid off so far.

-Erik (2008, IAQ)

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After going through four RV's in what is considered an extremely dry climate, I decided that condensation is an unavoidable fact of life.

I built my own RV out of metal and plastic, because I didn't want to have to crawl out and live in a tent in the middle of winter again.

Better to have nothing inside the RV that mold can grow on, and then you don't have to worry about condensation.

Or at least, that was my philosophy.
Wonder if there's a rigid foam manufactured with channels so it could vent bottom to top?

This is why I built my RV with aluminum exterior that is riveted to the metal studs. This automatically created that vertical channel for an airspace to create convective drying in inaccessible places.

The water can condense on the outer aluminum sheath all it wants. It simply runs down to the lower frame, and out through drain holes.

If you go to the RV wrecking yard, you see that walls are constructed in such a way that moisture can never escape, and that even in rigs that never leaked, the wood at the bottom of the wall is rotted out from interior condensation alone.

I looked at that, years ago, and said, "I don't need this crap."

Since manufacturers didn't seem to understand the problem, I had little choice but to build something the way I wanted it.

- Erik (2009, SevereReactor)

ROOF CAP

Dr. D and I had a new trailer go bad on us a few years ago.

Every time she entered the bathroom, she would have an instant nosebleed and could only tolerate the room for a short time before she would collapse.

As winter progressed and condensation got worse, the bathroom became progressively more intolerable.

It's fascinating how people we described this to would say, "Maybe you brought in some chemicals" and invent all kinds of fanciful explanations as some alternative to avoid admitting that it might just be the mold as we claimed it was.

It had been good.

Mold grew.
It got bad.

The more the mold, the worse it got.

Is this so tough?

I ripped out virtually everything in that bathroom, until there was nothing left but the ceiling and floor. All facilities. All the walls. All the insulation. Everything.

It made no difference. I couldn't get rid of the badness.

It was an empty shell except for the roof, which didn't appear to be as bad as we would imagine it must to cause such pain.

The ceiling had wood which used to be light in color, and still was elsewhere. This was dark and discolored and had all the appearance of water damage, without any leaks in the roof. Purely from condensation.

Both of us could feel strong hits when we put our faces close to this area.

When I chiseled into the layers of wood, there it was!

The plywood roof cap was growing mold inside the layers and the condensation there was unstoppable.

Lowering humidity or using fans or trying to control humidity just doesn't work here.

The cold outside and the warmth inside creates a condensation interface that means some moisture on the exterior wood panel is absolutely inevitable.

I had to remove the roof and replace the plywood cap.

Nothing less had the slightest effect in diminishing our symptoms.

So now I have an RV with a roof cap made of a signboard material called Econolite. It's a sandwich of two sheets of aluminum over a corrugated plastic matrix that makes a terrific replacement for plywood. The guarantee to be mold proof is written right on the Econolite.

No worries!

-Erik (2006, SickBuildings)
I agree about the cover for the slide out, but long term I find that the roof cap is the most troublesome spot. That's where most condensation in RV's is concentrated. You can see the wood swell and bow up in the plywood capped RV's that people are using year round.

Been in plenty of sick RV's. Just like with sick buildings, people very often have no idea why their health is so bad.

If I were you, I'd take the summer to replace the roof cap with a mold resistant material, even if it is a new RV.

Seems crazy, but it is horrible to have your refuge go bad in the middle of winter. Been there and done it.

-Erik (2006, SickBuildings)

STAYING WARM

If I had nothing more than a car to help me deal with this, it would preferably be a van of some kind.

I would avoid parking it in a place I perceived to be a mold zone.

I would spend as little time as possible in the bad house, and as much time as possible in the car.

Actually, that's exactly how I first got started.

Volkswagen Westphalia. You know, the pop-top camper model.

Piece of junk, very cold. It was weird. In cold weather, it was often colder inside than outside unless the heater was running full blast. But somehow, I still have fond memories of it.

I guess that was because it was still better than the alternative.

I got an old propane forced air furnace from an RV wrecking yard and installed it in my van, with a spare battery and a battery isolator so as not to drain the main battery. That leaves you unable to start the engine.

Mechanics won't touch this sort of thing because of the danger of explosion and liability issues, but even they will acknowledge that if you follow the rules, it can be done safely.

-Erik (2006, SickBuildings)
Another reason for building my own MECU is that RV manufacturers are dumb when it comes to designing for very cold weather. One can just go around to RV parks in the winter and see all the ways people are trying to keep their rigs from freezing up.

Not only do I have triple the normal amount of insulation for an RV, but my entire water system is inside.

But if you have to, heat tape around the outside pipes. Covering with a thermal tape wrap gives you the option of unfreezing with little trouble.

I would get a dual stage RV propane forced air furnace. Nice and quiet at the low setting, but powerful enough to heat an entire trailer.

People will look askance, and say that is too much for such a small space, but I'd do it anyway. That way, it would be more than enough heat for the times when a fresh-air mix is needed to compensate for interior contamination.

-Erik (2008, CFSU)

*  

>There is a school bus made into a camper in the parking lot here.  
There's one in my RV park.  

But with all those windows and no insulation, the thing must be dang cold when it gets down to seventeen degrees.

You can see that the windows are totally iced up.

I like a bit more insulation.

Okay, a lot more.

-Erik (2009, SevereReactor)

**WOOD STOVE**

I started out with an oil-filled safe radiant heater and a long extension cord.

Later I added another electric heater, a propane heater and finally a custom built titanium wood stove.
It's a comforting feeling to know that as long as there is a stick of wood to be found, I never have to be cold again.

The fireplace has an external air intake so I don't have to worry about oxygen depletion.

It's kind of like a Franklin wood stove.

Since the fire is already going for heating purposes, I use it for most of my cooking. Cuts my propane bill down by 90%.

I had the stove built for me by this guy. He builds them to order.

http://www.fourdog.com/

I knew it was going to be really useful so I splurged. It's the Ultra Lite 1, because I wanted to keep it light as possible.

I get a lot of strange looks from people who are surprised to see a smoke coming from a stack on an RV. But when they see how it works, they all want one.

I simply modified a wood stove to have an external air supply and made a slide valve to control how the fire is banked for a slow burn. I bank down the coals and it keeps the RV warm all through those snowy nights.

But one has to be selective about the wood, of course.

I gather it, box it, bag it, and it goes through a process of careful consideration before it comes in the door.

The wood that gives me hits is used only for outdoor campfires.

-Erik (2006, SickBuildings)

* * *

>When in the Godforsaken desert, how does sleeping in the camper vs. the tent compare for you?

No difference at all between tent and camper.

This is where the wood stove I installed really shines. When I'm in recovery intensification mode and get that hit from the breath, I get the stove glowing red hot and open up the roof vents.

So I have massive amounts of fresh air pumping through a small but warm and comfortable space.
There is rather an art to wood stoves.

Everyone tells me that I shouldn't recommend it to anyone and that most people would kill themselves with carbon monoxide if they tried to operate a wood stove in a small space like I do.

To make mine more controllable, in addition to the slide valve on the door and the damper in the flue, it has a variable external feed for outside air.

I grew up with wood stoves, and it is a bit of a foreign concept to me that some people don't know how to control them.

I know that there are folks out there who don't have enough experience to do this safely. But I don't see any reason that they couldn't learn, if they wanted to.

One could put a really huge forced-air propane furnace in their rig and get the same effect, but since I am out in the woods so much, why not burn wood? It's free, so my propane bill doesn't change from summer to winter.

I know it sounds silly, but putting a wood stove in my RV has been one of the most effective therapeutic interventions I could ever have conceived of.

-Erik (2008, CFSU)

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That fireplace is one of the best damn things I ever did against all the advice of others.

It's in the teens around here, and I've got the back door open. Kitty's peeking out.

Hell, even she doesn't want to go out. Just look.

She mews at me as if to say, "What is this crap? It's cold out there."

-Erik (2008, Email)

*

The other totally awesome function about the wood stove is that it draws so much air during combustion that my inside air turnover rate is phenomenal, while still staying warm.

Of course, one wouldn't want to close up the rig too much and risk dying of oxygen deprivation.
Most people tell me not to advise others on this, because handling a wood stove is a kind of art form and can be quite dangerous.

But fast air turnover has proven to be a real advantage.

-Erik (2010, SevereReactor)

SLEEP SURFACE

Somewhere I have a picture of the mattress from my new RV after some months of use. I wrapped it in plastic straight off and thought that this was a good preventive measure.

But eventually even through the plastic, I could feel that this the mattress went bad. When I unwrapped it, you could see the outline of where I sleep delineated in pure mold.

Mold really grows well on the foam cushions in RV's. I fought with that for years and kept replacing with more foam.

Just smell that new foam that they use. Loaded with stuff that I don't want to breathe, and there's no real reason to. I just use towels blankets folded to approximate the size of the zippered covers.

They look about the same. But this way, you can wash them if you get spore plumed.

The closed cell Therm-a-rest backpacking pads, available at any mountaineering store, wash easily and are supposed to be CFC free. That's the best sleeping system I've found.

-Erik (2006, SickBuildings)

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While my chemical intolerances have abated to the point that I could use a vinyl inflatable, I see absolutely no value in trying to achieve restorative sleep on such a highly questionable surface when better alternatives can make such a difference.

Plus the dang things have no insulation and are freezing cold. The air circulation just sucks the warmth right out of you.

They required so much insulation on top that I could pretty much sleep on just whatever material I used for insulation, so that's what I did.

I recommend the backpacking solid foam Thermarest mattresses, since they can be easily washed and quickly dried after cross contamination.
I washed five or six sleeping bags in a good laundromat, kept them in plastic bags until use, and piled them up to make a mattress.

When the top one became contaminated, I'd just put it to one side and move to a fresh surface. By keeping rotation going of a pristine sleeping surface, I could make my nights much more comfortable.

And setting up a tent with one of those safe electric oil-radiant heaters from Home Depot inside is fairly comfortable. Plus you can run a Hepa filtration system inside the tent and reduce overall spore exposure slightly.

-Erik (2006, SickBuildings)

HEPA FILTER

I just have a cheap HEPA that I use to keep contamination of my RV minimal.

It serves as a catch filter, but then I have to get it away from me.

Once it's contaminated, it throws out its own zone.

-Erik (2005, CFSExp)

*

I have a Hepa positive air pressure system that force feeds air into my sealed RV so that I can move through spore plumes without getting too blasted on the inside.

This allows me to pass through plumes with greater impunity, but not to remain in one.

If my MECU is parked in a bad zone for long, I can't even stand next to it due to the contamination on the exterior, so I carefully "perceptify" wherever I propose to park.

When my rig gets plumed, even if the badness is on the outside, I can't even stand next to it.

That means that even when I get out of a bad zone, I can't open a window, door, vent, or be within twenty feet of it without feeling hit. Not really acceptable.

So when my rig is being blasted with spores, I make every effort to minimize the time it is in a spore plume.

Still, I have been caught from time to time. When Park Lane Mall was being torn down, I just plain had to get me and my MECU out of there until the worst of it was over.
And when I get hit by a plume, my tolerance goes down and I am less able to withstand mildly contaminated objects that would otherwise be fine.

-Erik (2008, CFSU)

* 

> You tell people not to use filters but then have one in your MECU. Are you doing something different with it?

Ah, yes. I do indeed see it much, much differently! In how I use it.

This is only to protect the interior as much as possible while I pass through plumes or park temporarily in a moderate zone.

If an area is bad enough to require a filter, it is no place I want to be. When a wayward plume comes my way, the point at which I would perceive a filter is necessary is the precise point at which I know that I had better not stay there for very long.

I don't use a filter to try to remain in a bad place. My pressurization system is only to reduce contamination while I bail out.

-Erik (2008, CFSU)

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>I wonder what would be involved in getting a HEPA pressurization system in an RV.

The pressurization system is easy. That's something that anyone could do. I predict that Hepa pressurization will be standard in automobiles in about two years.

I would probably cut a hole in the floor for an intake and simply route it through a filter system. There's nothing complicated about it.

Just something that takes exterior air and pressurizes the interior through the Hepa filter so some of the nasties stay outside. Like unhappy mosquitos that glare at you through the window, frustrated because they can't get in.

-Erik (2008, CFSU)

* 

This is the marvelous advantage conferred by a MOBILE Environmental Control Unit.
One uses their perception of exposure to remove it from mold zones before it becomes problematically contaminated with fungal detritus, regardless of whether this also contains viable spores.

Mine is pressurized through a Hepa system so I can pass through plumed areas with relative impunity, but parking in one for extended periods is beyond my tolerance level.

-Erik (2008, IAQ)

FORMALDEHYDE

Where did you see me recommending trailers that have formaldehyde, or to just buy any RV or trailer indiscriminately?

Campers like EagleCap are using aluminum frames, fiberglass shell, styrofoam insulation and high-quality paneling containing a minimum of formaldehyde - construction more suitable for people with sensitivities.

-Erik (2006, SickBuildings)

MINI MECU

Behind the seat of my RV, I have my own "Mini MECU." Kind of a Plan C.

It's a fully stocked backpack, ready to pick up and go. Tent, bags, food, cooking gear.... everything except water.

It's what I use if my MECU gets too screwed up to handle because I got hit with a mold plume that I didn't catch in time to get safely out.

I've only had to use my mini-MECU about half a dozen times in the last five years, but I was awful glad to have it ready when I needed it.

-Erik (2008, CFSU)

RV PARKS

Got to be careful. There are of bad RV parks.

And there are lots of bad RV's that you wouldn't want to be parked next to. Worse than bad buildings.
When I am in a bad RV park and get hit by a wayward spore plume - or even when I'm out in the mountains, as I was at Wolf Creek when a bad RV pulled in upwind of me - I have to move just as surely as if I were in a moldy building.

Watch out for those too good to be true RV deals.

Reno is an expensive area with few RV parking options inside populated areas, but there is no extra charge for water or electricity in these parks. TV and phone are often included.

Local monthly rates range from $430 a month to $560.

Propane is the major expense for most people.

Apartments around here start at about $900 a month.

I spend a lot of time in the mountains.

Not only is it cheaper and makes me feel better, but the scenery is much nicer.

This lifestyle wasn't dictated by expense or choice, but by pure necessity.

-Erik (2006, SickBuildings)

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I anticipated not being able to stay in campgrounds, near moldy trailers.

But lately, my tolerance level has risen to a point that I'm not having any serious problems in Reno.

So that's where I am now, at an RV park.

I had to go through a dozen RV parks before I found one that is good enough. Still, I park on the upwind side to avoid the other moldy RV's that are certain to be here.

That's the advantage of extreme mobility with an MECU.

If the wind shifts, I simply drive away until the plume dies down.

If I'm quick about it, the contamination has been tolerable for me.

Many times, I've been out wilderness campgrounds and had to move, because some bad RV parked upwind of me.

-Erik (2009, SevereReactor)
Chapter 32 - MECU Use

DECONTAMINATING

There is a reason why I absolutely required an RV with a shower: so I could conduct decontamination based upon the circumstances whenever and wherever the need arose.

When I first started practicing avoidance, I would sometimes take six showers a day, along with a change of clothing.

-Erik (2006, SickBuildings)

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MECU needs are very specialized and specific. Decontamination is first priority.

There are plenty of places where I wouldn't need to be mobile if I could stay there all the time.

But if I want to go into civili-devastation with relative impunity, I need to have my decon unit with me.

A small sit-down shower would be terrific, and I think it would fit quite nicely. Yes, it would have to be shoehorned in, but I'm pretty sure it can be done. There was an even smaller minivan conversion called the Tiger which had a dinky little shower.

-Erik (2008, CFSU)

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I needed a Mobile Environmental Control Unit to allow me to decontaminate after going through mold plumes.

Even if one found good mold-free housing somewhere, they would still need to deal with the random plumes.

Either that or they would be trapped in their house.

-Erik (2009, Locations)

* 

> Hey, how bout a school bus for a mold escape vehicle?
You could always paint it with geometric squares, wear paisley shirts and stripy pants, and hum, "Come on get happy" and "I think I love you" through the security checkpoints.

I bet they'd let you through in no time.

I think an old bus would be great, but no matter what, I would still need some kind of small MECU to go into town, so I can shower and decontaminate quickly when I go through plumes.

I've increased my tolerance enough that I can now go through places like San Francisco and kind of make it, but it's just barely.

The only way I can do it semi-comfortably is to take my MECU along.

-Erik (2009, SevereReacto)

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If I lived in a completely pristine area but still had the need to venture into mold zones, a decontamination device such as my MECU is absolutely essential for my comfort and well-being.

Short of finding some miracle cure, I wouldn't do it any other way.

-Erik (2009, SevereReacto)

GETTING OUT OF MOLD ZONES

I can live inside Reno and bicycle to work, but I cannot park in a mold plume specifically.

If that trailer park you are in is suspect, are you sure that the problem is inside your trailer? I've been forced out of a number of RV parks but had no mold growing in my custom mold-unfriendly RV. It soon settled down again and felt good when I moved to a safe zone.

-Erik (2006, SickBuildings)

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Who could even make this up?

Came back to Truckee last night, started coughing again. Had to resort to all the blanket changes and tricks to get through the night that I don't have to use when I'm out in the woods.
There is absolutely nothing more compelling than feeling the difference when you move an MECU in and out of mold zones. Because everything else stays the same, the only variable is the zone.

It's difficult to imagine a home feeling so bad by wayward plumes alone, until you have your trusted and mold-free movable home turn to absolute craperoo on you.

So that's the neat thing about the MECU. It helps you to believe that it really is something in the environment, and that it isn't "just you."

If you can control it 100% by getting out to the woods, it ain't just you.

-Erik (2008, CFSU)

* 

People tend to accept their neighborhood as a base value.

It's really difficult to get someone to accept that their house isn't as much of a problem as they think, and that it's the whole darn place that is bad.

Having an RV and going back and forth between a really pristine environment and a mold zone is the only real way I know of to instill this sense of the differential.

The beauty of an MECU is that when you get it out to a good place and get used to it, then take it into a mold zone, you know that the problem is not in your "house." And you know not to waste time remediating it, because that is not where the problem lies.

It's hard to believe that perfectly good looking areas and beautiful homes could all be enveloped in an invisible cloud of something that can keep your immune system from ever getting the break it needs to reset the cytokines.

The MECU is a teaching tool that is almost indispensable.

-Erik (2008, CFSU)

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This is where a Mobile Environmental Control Unit is a terrific research and training vehicle.

When you experience the ion-shift phenomenon in full force, and then simply drive your "escape moldule" out of a zone in which this effect is happening, out into a pristine area where it is not....
That pretty much seals the deal.

It is external, and environmental.

-Erik (2009, SevereReactor)

*I have some items in my tent that suddenly feel bad.

That just happened to me in Truckee.

I escaped it by relocating to an area “between plumes” that I painstaking found in Reno.

I knew from years of experience that it feels like my own local contamination is the prime culprit, but that by shifting locations, my MECU would magically lose its toxicity.

There would be a huge initial drop in symptomology, and then a gradual dying down of reaction to possessions as the toxin accumulation denatures.

This shows me that the effect is more due to ambient environmental conditions. 
Otherwise the shift in location would have had little or no effect.

-Erik (2009, SevereReactor)

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An MECU is a massively useful learning tool for exploring the differential between zones.

By spending time in the desert, your "home" dies down to as good as it gets, and then you can feel the difference upon entering various points of "civildevastation."

Since you know that your "home" didn't instantly turn bad, it is easier to sense just how much these contamination zones are influencing your level of reactivity.

What better way to let people feel for themselves that although it may seem like their house is the main problem, it's really the whole area?

-Erik (2009, SevereReactor)

**SIDESTEPPING PLUMES**

Remember my scribblings in the dirt, showing how I sidestep plumes?
When the old Park Lane Mall plume was headed my direction, I'd assess the wind direction and go sideways or upwind while it lasted.

It's amazing that there are many times when a really forceful plume can be avoided by sidestepping just a few hundred yards.

Takes a really mobile MECU to exploit this, and anyone who didn't have the experience of being able to sidestep plumes in this way would be unlikely to appreciate that it is even possible.

I typically take the wind direction and move perpendicular to the airflow. When one doesn't know the size of the plume, dead sideways is statistically the closest way out.

Usually when I exit the plume, I feel slightly better. I stop and get out of my rig. If the hit feels worse on my clothing than the ambient terrain, I know that I'm out and can proceed to decontaminate.

The rig is a bit of problem. I can wash it if it's really bad, or go inside and turn on the Hepa pressurization system so the badness remains outside while I have filtered air within.

-Erik (2008, CFSU)

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Not only have I found no cities that are devoid of the really bad mold, some are casting a shadow for many, many miles downwind.

However, I can often move upwind or laterally just a short distance in a timely fashion, and be out of it.

Remember when I was making drawings in the dirt which showed plume vectors and how staying to one side and then taking a perpendicular path across would dramatically shorten exposure time in the bad zone?

My point was if you don't know the sourcepoint, moving upwind is a crapshoot, while laterally gives better odds of being the quickest way out.

This is precisely the same way the biowarfare drill instructor shows this concept to the troops, out in the field, drawing diagrams in the dirt.

One never advances through a battlefield with suspect chem/bio by advancing into the plume, if one can evade it by just a few steps to the side.

I never would have expected that biowarfare training would have been the thing that got me through this. But in a way, it does seem to make a certain amount of sense that
someone with this background would naturally be in a better position to live to tell the tale.

-Erik (2009, SevereReactor)

A QUICK ESCAPE

I didn't bother to do move to a different climate. I just stay out of plumes.

The best part is the mobility. If you wind up in a spore plume, it's easy to move.

I just drive into town to work and decontaminate afterward.

It's raining and snowing today. It has no effect on me because I went to the effort to find a safe zone to park my RV in.

But there is a fairly large plume just to the south. When it blows from that direction, then rainy weather bugs me. So I just put the key in the ignition and drive out of it and stay somewhere else until the plume is over.

I can scarcely tell you how good it perceive the warning of the impending rainy weather response, and simply escape it in minutes.

Thanks to having the kind of mobility that the RV lifestyle gives, I don't have to put up with being beaten up by mold.

Perhaps not the lifestyle others would choose, but I sure like it better than having to just sit and take it when plumes blow over wherever you live.

Naturally it would just be better to live out in the woods, but, you know, gotta work.

-Erik (2006, SickBuildings)

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An ounce of preemptivity beats a ton of remediation.

When I was contouring my MECU strategy, having a trailer would have been cheaper and roomier, but I need fast mobility to evade plumes.

Small and highly mobile was my choice.

So it had to be a motor home unless I planned to leave it out in the desert.
Funny how so many people try to twist what I am doing into an excuse not to, as in, "I wouldn't be able to see family and friends."

It's the complete opposite.

If I didn't have a bailout plan, I wouldn't be able to go into mold zones, visit with people in their moldy houses, spend time acting like a normal person... and still be able to decontaminate before my immune system goes bonkers.

-Erik (2009, SevereReactor)

A LEARNING TOOL

To help me cut my way through this intractable Gordian knot of entangled complexities, I constructed a Mobile Environmental Control Unit:

A custom built RV that was made out of the most chemically benign and mold resistant materials I could find.

This creates a "tabula rasa" baseline for symptom assessment from which the differential measurement of exacerbation or improvement gives real world clues about the nature and location of the exposure, and about what type of actions are necessary for my situation at any given time.

Reactivities wax and wane according to the duration of inflammatory response, which makes the very notion of trying to establish some kind of standard safe level utterly unreliable and useless.

One must act in accordance with their own varying level of reactivity according to their own current requirements.

I took my experimental MECU to a pristine location to achieve "as good as it gets" for comparison. I recommend the desert for this purpose, although others such as the forest or parks are pretty good as well.

-Erik (2008, IAQ)
Chapter 33 - Environmental Testing

SUITABLE INFORMATION

People express dismay that I am suggesting the possibility that testing might not give you suitable information - that you can be "moldsick" despite your environment testing perfectly normal.

But that is really how it is.

I just saw a story about a guy who spent tens of thousands of dollars on testing, starting thirteen years ago, to find out why he, his family, and some of the guests in his recently built house were getting sick.

The testing repeatedly found nothing. Assured by the “experts" that the house was OK, he stayed there.

The whole family now has MCS. He went on to say that the least credentialed of the experts he hired took him aside and told him “off the record" that none of his clients with a problem like this had ever found the problem before running out of money.

Yep. That's the way of it. Seen that a lot.

Heck, I've been back to the house where I fell apart in Incline Village and the mold isn't even in the house. It's just down the street about half a block away.

-Erik (2008, CFSU)

AIR TESTING

Air sampling is misleading.

If you do get a result from air sampling it confirms the problem, but if you get a negative it rules out nothing.

Knowledge of the principle of variable toxicity from substrate and competing molds alone would make it unreasonable to try to assess toxic exposure by counting spores.

The intermittent nature of spore plume release means that airborne spore concentrations is far too inconsistent to reliably determine inhalation potential.
High levels of mycotoxins can come from colonies below cement slabs or from sewer pipes right through materials that stop the spores.

Mycotoxin release from spores means that ambient levels of VOC concentration are completely independent of the presence of spores.

Another complicating factor that they are finally starting to realize is that individual susceptibilities makes VOC testing futile except as a theoretical value for a baseline for acceptable exposure for a "normal" person.

I have found many places that give me a VOC response without significant spore contamination.

I'm not totally against air sampling but my own experience is that it means so little as to be almost worthless.

-Erik (2002, SickBuildings)

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The Indoor Air Quality paradigm has been that one can test a building by detecting spores. In fact, the entire industry is devoted to and counting upon this concept as a reliable means of testing.

They should know better! All one had to do is examine their own records, which show that it is relatively difficult to find even a few airborne spores of Stachy, even though Stachy is the mold that is commonly associated with sick people.

It was apparent that the model didn't fit the facts.

Fortunately for me, I had already done my own experimental testing which convinced me of this, and so paid no heed to the partial advice which would have kept me in an exposure situation when the spores were not found.

Think of it for just a second. If Stachy is the one implicated as the worst toxic mold, yet the experts know full well that it is so difficult to detect, how are people being exposed to it?

We know now that for every airborne spore, there are at least five hundred mycotoxin laden submicron fragments that can still induce a toxic response. This fungal detritus looks like nothing more than common dust.

For all these years, spore testing has been based on a flawed premise. Just think of all the people who had their houses tested and were relieved that no toxic mold was detected?
Yes, testing can detect mold. But finding none doesn't mean no mycotoxin exposure.

-Erik (2008, CFSU)

INDOOR VS. OUTDOOR MOLD

If comparing indoor against outdoor spore counts is the state of the science, I would say that they have major misconceptions about mold exposure.

Mold at toxic levels indoors is still a toxic exposure outdoors.

I moved into a place that had no mold inside at all. I went nuts trying to find it inside until I realized that I was getting hit outside, especially when the wind was from the southwest.

I wound up sleeping outside and upwind of the house in various wind directions until I could get a vector on the location of the colony. There was nothing I could do about it except try to be somewhere else when the wind blew from that direction.

I've found enough places are drenched in spore plumes from somewhere else to know that if you are extraordinarily sensitive, even the most rigorous testing is no guarantee the place will be survivable.

-Erik (2002, SickBuildings)

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Unless you have a mutual understanding that there can be colonies hidden below cement slabs, or in community sewer systems, or in a neighbor’s house that can still drive a hypersensitive person to an unacceptable inflammatory response, there will be no understanding of the success or failure of remediation.

-Erik (2003, SickBuildings)

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What’s the obsession with indoor vs outdoor mold?

What does it matter if you inhale spores while you are enclosed by walls or not?

The spore plumes I encounter outdoors feel no different to me than the ones I find inside.
If you find airborne spores outside at slightly lower levels than inside, would you consider that area perfectly safe until the moment you built a couple of walls around that spot and suddenly turned them into "inside spores"?

-Erik (2004, SickBuildings)

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When you talk to most people about IAQ it is as if they believe that outside mold is mysteriously harmless which struck me as an odd way to look at it.

The vast majority of people I talk to about mold are already sensitized and listen to "experts" who say that they cannot possibly be reactive in outdoor settings and remain ill as a result of not taking this into consideration.

-Erik (2004, SickBuildings)

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Before I ever heard of Sick Building Syndrome or that this was an "indoor" problem I already knew that it made no difference whatsoever.

Where it is, is where it is.

Indoors or out.

When a stachy spore hits your lungs, somehow it just doesn't mean that much if you happen to have walls around you or not.

This seems so obvious and yet people seem to think I'm absolutely crazy for disputing the word of "experts."

-Erik (2005, SickBuildings)

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My lungs stubbornly refuse to listen to me when I tell them that the experts say the spores should be perfectly safe to inhale at the moment I clear the doorway and step outside.

-Erik (2006, SickBuildings)

*

I see many people who are severely hampered by some flawed concepts that are based on misinformation from doctors that is generated by a partial belief system.
One glaring example of wrongness is inherent to the very name of the "Indoor Air Quality" industry.

This alone creates the conceptual framework that we have an indoor problem that is not present outdoors.

The methods they use of comparing indoor to outdoor spore counts confirms their weird viewpoint.

It's pretty silly, but a toxic mold spore really doesn't care whether you are surrounded by walls when it hits your lungs.

A person who is directly downwind of a sick building is demonstrably exposed to levels of the same irritant that would be considered problematic if you were in that building..... but the screwy "indoor" mindset means that the lack of walls proves that your complaints of still feeling mold hit outside are baseless.

(So it must be All In Your Head.)

I was very lucky to have had my mold experience happen so long ago that these IAQ concepts hadn't even been developed yet.

Thank goodness! Because many of them sound so logical at first glance and are represented by "The Voice of Authority," one doesn't stop to even think, "Hey... that makes no sense at all."

-Erik (2009, Facebook)

TEST KITS

The mold plates are pretty much useless since the most toxic mold, Stachybotrys, doesn't even grow on most media unless it's Czapek cellulose media or cornmeal agar.

That's if you even manage to catch a viable spore. Stachy has a exceptionally large and heavy spore that doesn't stay airborne long and most are on the ground and dead within an hour of leaving the colony.

Airborne testing is almost as unreliable as mold plates and finding any airborne spores at all indicates a very serious problem.

"Following the water" and doing a direct tape press on the mold to send to the lab is the most reliable way to identify a Stachy problem.
You can send samples yourself without hiring a remediator, which could destroy your house's resale value since many states are now writing disclosure laws for mold.

-Erik (2003, CFSExp)

*

I gave up on all the testing, mold plates and such years ago as being completely useless as a personal guide. I only perceive their use as a demonstration for someone else.

So I don't know where to get them anymore.

Usually people have good mold indicators all around them without the need for any plate.

Shower enclosures, toilet tanks, cutting boards and vegetables give me all the signs I need.

Onions in particular are exceptionally good for mold detection.

In my mother’s house, you can leave onions out until they dry up so pristinely that they look like they could be used as dried onions for cooking.

In the mold castles that make me feel like crap, onions always show concentrations of various molds.

-Erik (2005, SickBuildings)

*

It's no good doing those tape lifts.

The only time tape lifts ever find anything is if they are pressed directly to a wet colony, and if you luck out and hit the toxin former buried in the midst of other molds which prepare the ground for the bad stuff which is mixed in with other molds.

All those tape lifts do is cause more disbelief and confusion, because they don't find the real source of the problem.

That's why I led a mycologist around and directed HIM to tape lift directly on mold that slammed me.

He did a lift on mold up in the attic and identified it as Aspergillus. I immediately took a swipe at the stuff, roiled it up, and said, "This stuff? Hell, I'll spread this on my sandwich with peanut butter... this ain't the problem."
If I hadn't been pushy on this, we very well might have stopped at Aspergillus, and not kept going until I identified the slammerstuff.

And you know what? Even if we hadn't, that still wouldn't have changed what I felt in that zone, my having to bail out.

Considering that my mind had already been made up, and that I was already on my way out, finding Stachy was a good confirmation... but it wasn't necessary and didn't change anything. It was just an expensive way of finding out what I already knew.

(Although it WAS good to have a name for it.)

-Erik (2008, CFSU)

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If somebody figures out that mold is kicking their butt and then they find some, that last bit of information is generally just the final thing that scares them into taking action.

The trouble is that these kits aren't reliable, so if something isn't found, they get "unscared" back to square one about mold and focus elsewhere. The best I've seen them accomplish so far is confirm what was already pretty much obvious.

Even if you find something by current medical standards, it's not enough to make you ill. Even the very worst moldy places still have the experts baffled at how sick people are becoming. So how will a mold test convince anyone?

-Erik (2008, CFSU)

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The really useful lesson from having a Mobile Environmental Control Unit is to find out just how worthless ERMI or any mold tests are.

When you have a controlled environment that feels consistently good when parked in a pristine zone turn to feeling just the same as a killer "sick building" simply by parking in a wayward plume, you see that the transient nature of this phenomenon means that testing cannot account for the real time shift in conditions.

You spent your money having a test done, found nothing.... and then the wind shifted and it's right back to square one.

-Erik (2008, CFSU)

*
What is the best lab to use to detect mycotoxins?

What will it mean if the lab detects some?

What will it change if they don't?

-Erik (2008, IAQ)

MISLED BY “EXPERTS”

Mold testing has such weird contradictions that at times it almost seems to prove that the problem couldn't possibly be from mold.

-Erik (2006, SickBuildings)

*

I advise against testing. Means nothing, but people rely on it anyway.

Can't tell you how many times I've accompanied people into mold zones and when I start reacting, look over and see they are too.

I say, "This is mold here."

But they argue with me. "But Erik, that's what I thought too, but testing showed nothing and my doctors tell me this is impossible, so it must be something else."

Yeah? Like what?

-Erik (2008, CFSU)

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Remediators often cannot find detectable Stachy... yet Stachy is the "bad mold." It means that testing for stachy is reliably unreliable.

Unfortunately, people’s mistrust of their own perceptions caused them to only rely on testing, and so even the evidence that testing could not be counted on was discounted.

One can see how Moldies divide themselves into distinctly separate mentalities.

There are those who say, "But I can feel it" and run for their lives.
And there are those who counter, "Yes, I can feel it too, but my doctor says this is impossible, so....I'm just going to wait."

And then their experience is pushed back into the realm of "unexplained illness."

-Erik (2008, CFSU)

*

What I do know is that many people who searched for mold, filtered for mold, tested for mold, moved several times to rule out mold... finally got to the point where they realized that none of this means anything.

It only threw them off the track.

-Erik (2008, CFSU)

*

The point here is that since testing didn't find the stachy, the toxicologist dismissed it in favor of concentrating on formaldehyde. If the tenants hadn't been dissatisfied and called someone else, they would have continued to think it was just formaldehyde.

That is the problem that faith in conventional testing inadvertently creates.

-Erik (2008, CFSU)

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The entire mold industry has been predicated upon detecting and counting viable spores... you know, like the crude "mold trays."

If one knows that the toxins are not only on the spores - no more than nerve gas will stay stuck to the canister or bomb that delivered it - you know their entire conceptual framework is wrong.

Yet they refuse to admit it, do not develop tactics that match the phenomenon, and in general, mislead people into a false sense of security because their tests indicated that there should be no problem.

So those of us who are beyond the point of being misled are very much on our own. We have to work out what works for us.

It's not easy, but it's better than continually trying to make their flawed concepts work when we know that it's not even possible that they ever will.
I went out of my way to ask “old time” remediators if they were familiar with this mold hysteria description of illness, which causes people to abandon their homes. They all said no. So if you have testing performed by one of these people with massive mold experience, they will tell you that mold is troublesome, but not in the way that you are complaining about. The mixed replies of those who are getting a clue and those who still think that mold is exactly as it used to be are creating no end of confusion for those who are trying to get help.

I know for certain that for others at this level of reactivity, conventional testing only served to confirm a lack of physiological basis for their complaints - which added greatly to the disbelief of people who doubted their illness. People must learn to disregard testing if it conflicts with their perceptions.

What I have told people is that the type of testing they are recommending is not usable as a guide to action. Their response is that they understand this but just want to use them to gain a sense of the problem. That means they are relying on the test as some kind of indicator of exposure, which means they don’t understand the problem. To try and shake them out of this, just look at the inability of airborne testing to find more than just a few Stachy spores. Yet the sickest people seem to be in Stachy infested houses.
That should have told them right there that if they are trying to use mold plates and airborne spore testing to get a sense of the problem, they are almost 100% guaranteed to be misled.

-Erik (2009, SevereReactor)

**IN YOUR HOME**

I was driven out of a house by a spore plume that wasn't even on the property. You are going to see a lot of this.

Unless you have a mutual understanding that there can be colonies hidden below cement slabs, or in community sewer systems, or in a neighbor’s house that can still drive a hypersensitive person to an unacceptable inflammatory response, there will be no understanding of the success or failure of remediation.

-Erik (2004, SickBuildings)

* 

My major sources of exposure weren't in the house at all. Sometimes they were coming from such unexpected places as a moldy thermal as I was hang gliding over an area deforested by fire north of Mt. Hull.

And that's what I saw in others around me, like the cluster of teachers at Truckee High School.

All it took was a few hours in the wrong room when the spore plumes were acting up. That was it.

Testing that is conducted just a few feet away doesn't show it, and testing done at home because you feel so bad certainly doesn't tell you anything about these other exposures.

I guess that testing isn't worthless if it confirms an exposure. But for the most part, I find it such an unrealistic guide to action that it is nothing I would rely upon.

It wasn't until I learned to rely solely upon my perceptions of exposure that I finally managed to take control of this problem.

-Erik (2006, SickBuildings)

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One of the reasons I "diss" testing is that I've seen so many people become ill from the accumulation of exposures from sources that were not in their house or place of employment.

Many times, the one place they want to have tested was nothing more than the final straw that broke the camel's back.

It was where they were going, sometimes not even on a regular basis.

Just passing through some really bad plumes was enough.

Once one shifts from the notion of testing to using perceptions, the only thing testing can possibly be good for is purposes of litigation.

By perceptification, if it was in your home or work, you would rely on your own senses and testing would not be needed.

From where I sit, it looks like most people's illnesses are driven by total toxic burden from many sources that they will never find through conventional testing.

-Erik (2009, SevereReactor)

UBIQUITOUS

Avoiding exposure completely is impossible.

It's impossible to completely eradicate down to the last spore.

In 1997, John Banta of Sacramento-based Restoration Consultants told me that there is not a single house that is completely free of Stachy.

In 1998, Cornell did a study that found significant Stachy in one out of five large buildings in a study of several hundred buildings accompanied by people with known symptoms of reactivity to mold.

I am all for getting the levels of mold that affect me out of buildings, but I cannot figure out how to quantify it in any meaningful way.

The variability of secondary metabolites generated by access to specific substrates and factors of competition between mold species means that some stachy can affect me at levels below detection while other Stachy at high concentrations does not constitute a "toxic exposure."

So my aim is not to avoid mold based upon testing. It is to stay on the upside of the immune power curve of exposure to a ubiquitous irritant.
-Erik (2006, SickBuildings)
Chapter 34 - Your Own Testing

THE BEST INDICATOR

If you want to get out of this, you are going to have to quit looking for tests and rely on the best indicator of exposure you've got.

Yourself.

-Erik (2004, SickBuildings)

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When I was trying to figure out how to test, what to test, and if testing was applicable, I got ahold of a prof up at U. of Wash who asked me a funny question.

"What good will it do you to find something?"

Huh?

Basically, his point was that finding a toxin still didn’t do much in the way of proving anything or taking control of the situation.

Yeah, he was right. All that really mattered was whether I felt better or worse under certain exposure situations.

Take action now.... work out the details later.

-Erik (2008, CFSU)

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If people accustom themselves to reliance on their own perceptions, mold testing becomes entirely unnecessary.

I was scoping out a house and wound up pointing at an area where I could feel the badness.

It was behind a beautifully tiled shower wall, and the tiles were non-replaceable.

The contractor couldn't believe that the owner would direct him to demolish a perfectly good appearing shower that would take thousands of dollars to replace.
But after much persuasion and having it pointed out that he was being paid to do a job and not to question the owner’s judgement, he opened up the wall.

And there it was. No testing done at all.

Humans are far better at sensing things than they give themselves credit for.

-Erik (2008, CFSU)

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You can always do what experienced realtors do: Find someone who is a Moldie (mold sensitized) and have them go around with you to suspect places.

If you feel something and they tell you that the place is kicking their butt, it might just be mold.

I've done this for lots of people, but I do have to watch it. Yes, overdoing it can certainly drive you below the power curve.

I remember in 1998 talking to a Feng Shui practitioner who was performing this service for friends who used her to determine if a house was a good investment. She said, "I had to stop because I got so sick that I just couldn't take it anymore." But she didn't know about decontamination protocols. It could have saved her a lot of trouble. Sure has for me.

I wondered if it would be possible to train people to act as their own detectors, since everyone was firmly convinced that this was unknown and unheard of, and therefore, was a degree of reactivity that only a few people could possibly have - since, "I've never heard of this before."

It was remarkably easy. Mostly it consists taking people into mold zones and telling them, "No, it's not just you, because I can feel it too."

-Erik (2008, CFSU)

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I am hearing of an increasing number of real estate agents who desire accurate information on their own prospective purchases.

For their private decisions, they don't call a mold remediation professional.

They call a mold sensitized person to do a walkthrough.

If this trend continues, we can predict a steady erosion of trust in the Indoor Air Quality profession.
The US Army takes a very straightforward approach for ensuring the fit of M17A1 gas masks. They simply run you through a cloud of CS gas. The results leaves no room for doubt.

I never managed to take control of my illness until I totally gave up on the concept of testing for mold in any conventional way. I shifted to the paradigm of what it must be like for a "peanut responder," who must avoid infinitesimal amounts of peanut residue. Testing for mold is about as futile as it would be for a peanut responder to have his house tested for peanuts. The way I detect "the presence" has been by training myself to recognize subtle symptoms of exposure... and using those symptoms as indicators of exposure.

EXTREME REACTORS

When someone has reached a level of reactivity to be put into agony by exposure to a few possessions that have been removed from the contaminated environment, a "mold expert" who doesn't appreciate the situation will tell you that he has done his job according to specs and clearance testing affirms his work and that any further problems on your part must be psychosomatic. Since I've seen many people who are far beyond the level in which remediation will work, I anticipate many lively conversations between IAQ professionals and mold responders who don't recover after their houses have been "successfully" remediated.
People point out any mold they see on bread or cheese and say, "There it is - your mortal enemy. You have to run, right?"

And I say, "Hell, I'll eat that stuff with my peanut butter sandwich."

I don't give a damn about mold that isn't of the toxin producing type.

My fight with doctors was that only a few specific molds were bothersome to me.

I've had mold all over the place that doesn't worry me at all, as long as I'm not reacting to it.

But on the other hand, I was perceptifying a friend's house and felt the "wrong stuff" in the tiled shower walls in the bathroom.

I pointed at the spot and said, "There."

We busted through the tile (under full HAZMAT protocols) and there it was.

My green binoculars were steeped in stachy and knocked me flat even after being washed and completely submerged in soapy water.

Conversely, lots of dirt floors and moldy basements don't bother me at all.

None of this "testing" discussion applies to people like me.

We are way beyond being able to use tests as a useful guide to action.

-Erik (2005, SickBuildings)

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Studies and statistics using normal people as controls do not reflect the needs of extreme mold responders, and testing cannot address the changing environmental conditions in a viable real time manner.

Anyone who manifests a response to contaminated articles brought out of a contaminated house is misguided to believe that their problems are over because their new environment was tested.

At best, even "perfect" testing can only establish a baseline for a pristine environment. Those of us who have tested ourselves by temporarily retreating to a pristine environment can attest to the ease in which contaminated articles may be introduced and alter our comfort level beyond an acceptable response.
People at lesser stages of this illness can be identified by those of us who have been pushed to an extreme, yet they will reject the concept until they become too ill to ignore it any longer.

It will sound counterproductive that I am expressing a lack of confidence in the very people who seem most interested in helping and appear to be the best source of information, but their concepts would have accomplished little or nothing for someone at my level of reactivity.

-Erik (2006, SickBuildings)

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Look at the inconsistencies in the way you are approaching this!

Your basement is filled with "black furry Stachy" and yet you are fearful of putting "microscope slide’s worth of mold next to your nose.

You call for "accuracy in testing" when your description has already indicated that you are aware that unbelievable slight amounts brought into facial proximity can be a driving force in your response.

What kind of test can cover every item that is potentially contaminated with that small amount you are afraid of?

It sounds as if you hope that some miracle of identification is going to alter your response or enable some means of dealing with exposures that you already know cannot all be tested and dealt with piecemeal.

Your body is telling you what to do, yet your brain is grasping at "tests" and potions or chemical magic bullets to bail you out of this mess.

They don't exist.

You are following a bad path. Can't you see where this is leading?

-Erik (2006, SickBuildings)

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If "successful" testing fails to reveal exposures that are significant to the sensitized sufferer, whether or not the testing accurately identified spores or fungal debris is completely moot.

Spore testing is a case of, "The operation was successful, but the patient died."

424
I'm glad I decided to simply determine this for myself rather than rely on a flawed conceptual premise.

-Erik (2007, IAQ)

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I'm afraid that inspections would be good for normal people, but would be misleading for people who are my level of reactivity.

It's kind of like being a peanut responder and paying someone to check your house for jars of peanut butter.

It's just not going to account for the peanut oil and hidden molecules from all the other sources.

Most mold testers don't even have people like us in mind when they try to do their job.

They can't even conceive of what it is like.

It wasn't until I completely abandoned the notion of testing and relied on my perceptions alone that I really started to get a handle on this.

-Erik (2008, Email)

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I believe that conventional mold testing is the worst thing you could possibly do. The thing is, you may wind up trusting results that have nothing to do with your level of reactivity.

Beyond a certain threshold of reactivity, your own perception must be your guide... and nothing else.

Once a person realizes they are getting hits from objects, "All bets are off" when it comes to conventional testing.

It seems like a logical thing to do, because how can finding something not be helpful?

But a person at this level may very well be getting hits from something taken out of "Moldville," no matter whether there is something in the environment to be tested or not.

Generally, a person who is getting hits from objects is only confused when a test shows no logical reason for them to be sick. It's almost like a scientific determination that you really ARE crazy, and lots of folks take it exactly this way.
Now if you take a single contaminated object out to a pristine place and get clear to induce intensification reaction,” it is that level of reactivity which determines what you must do. If a book or something like that can slam you down and make you miserable, there is no way that these tests are going to give you any useful information.

The ironic thing is that if a person decides to ignore conventional mold testing and goes to a pristine place to get clear, they can easily feel where the badness is when they return, and what they feel is more reliable than any test anyway.

-Erik (2008, CFSU)

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If you rely on tests, what chance do you have of ever finding that plain old normal-looking cardboard boxes that you brought into your "safe zone" are slamming the crap out of you?

Are you going to vacuum up particles from each box and have them sent off for testing?

I've spent years being called crazy for saying that boxes were slamming me.... and then, poof, just like that!

A test comes out and suddenly I'm only half as crazy as people said.

The crazy half that people still think of me is that I am relying solely on my perceptions.

That's pretty funny, because I think that an over-reliance on testing makes others the crazy ones.... since they can't possibly test each and every box.

And they are going to be affected by every contaminated box that they can't test.

-Erik (2008, CFSU)

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Many of the well-known "mold experts" are still mired in their old paradigm of testing.

Some are slowly recognizing the exceptions which show that their model of mold illness is not adequate. But lacking our kind of reactivity, they also lack the conceptual means to address it in others and give meaningful advice.

One person has been out of her moldy workplace for years but is still quite ill. She is still trying to apply the paradigm of these mold experts and does not define her current house as being moldy,
Her description tells me that it is beyond her personal tolerance. Not only is she reacting to her computer, but she can't even have plants in the house as the mold in the dirt affects her. Nor can she lie on a chair on the ground.

She is a classic of how "helpful advice" from the wrong conceptual framework can keep a person perpetually stuck.

-Erik (2008, CFSU)

BY THE SEAT OF THE PANTS

Since I can perceive mold plumes, I could see that it didn't make sense to rely on airborne testing when the spores don't diffuse evenly through a room.

They waft just like cigarette smoke.

One can simply move to one side of the plume and alter the result dramatically.

Someone who understands and perceives mold plumes would find it easy to manipulate findings in any direction that is desired.

These IEQ types have a lot to learn.

-Erik (2006, SickBuildings)

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What good would it do to plan a fixed strategy that is based on a certain level of reactivity when that level changes dramatically - even within a single day?

I don't bother to try and use my perceptions to fly by the seat of my pants.

If I've flown up to a good altitude, I have some leeway to relax. But if my threshold has been challenged by a lot of exposures and my built-up tolerance is low, I take fewer chances and increase my level of avoidance accordingly.

The notion of testing (and acting on the basis of a test) implies a fixed value for both the environment and the level of reactivity. Neither situation is realistic.

But the conventional wisdom says testing is a good thing, so it really confuses people and makes them angry when I say that it is really counterproductive.

-Erik (2008, CFSU)
Chapter 35 - Construction

“MOLD-FREE” HOUSING

The problematic mold is almost never growing somewhere that it can be easily destroyed by spraying something on it. The mold hides inside walls and in dark damp places under foundations.

Regardless of whether the spores from these hidden colonies dry up and die, the toxin will remain toxic. Killing it doesn’t matter.

Moldy spots in bathrooms and on window sills only are indicative of a mold infestation somewhere else. Killing this mold solves nothing.

Now surely if someone is knowledgeable enough about mold to develop and produce something that kills it, it stands to reason that they must know about this.

Salesmen who tell you that they can sell you a mold-free house are generally talking about construction that reduces water leaks and special mold-resistant sheetrock.

This is only part of the overall problem and can easily be overridden and rendered a moot point by mold from another source.

Really, this is not much different than all the semi-useless vitamins that are sold to CFSers on the basis that vitamins help, so their product is helpful.

My experience tells me that if you are a Moldie in a moldy area, your house could be made of solid stainless steel and it would make very little difference in your condition.

For a Moldie to respond to the "mold free" sales pitch without checking what they really mean by this and to trust them would be the same as putting one’s faith in the vitamin sellers.

-Erik (2009, Locations)

CONSTRUCTION TECHNIQUES

My experience is that the most toxic molds are heavily reliant upon substrate and conditions to produce the specific toxins that bother me, and that controlling these conditions neutralizes toxic properties even if mold growth is still present.
I refuse to go nuts worrying about all mold. Mold is natural and necessary to life on this planet. It is only the toxin producers that require my attention.

I think that the real recipe for disaster is not so much what mold on a wood structure does just while growing on that wood as what the mold is capable of doing when condensation in the walls combines with the mold's access to the the paper backing on fiberglass insulation and "mold-preloaded" wallboard.

I take issue with the entire concept of reducing relative humidity in the middle of a room to prevent mold. This does nothing to prevent moisture at the condensation interface on the exterior of the walls.

I don't give a damn what the "experts" say. You see this even out in the desert where the relative humidity is lower than one could ever achieve in a humid climate with even the most powerful dehumidifiers.

Open up enough walls and you will see this effect for yourself. Look on the north "cold" walls of houses where the paper backing has been reversed to the outer wall and you will see that the enhanced mold growth correlates to the area of greatest condensation potential, often enough to confirm the basic concept that the building design lends itself to disaster.

And if one provides mold with the proper ingredients at that vapor interface of semi-decomposed cellulose in the form of paper backing, the mold will take full advantage of the opportunity.

The "vapor barrier" is a rotten idea when the vapor is encouraged to form in the exact location on the ideal material that mold utilizes to produce potentiated toxins.

-Erik (2005, SickBuildings)

**PRE-MOLDED MATERIALS**

The way mold explodes out of sheetrock in multiple sealed walls made me believe that the mold is actually incorporated into the sheetrock. Using poor quality decomposed wood contaminated with mold to make the paper on sheetrock would give the mold ample water to sporulate and lie dormant until it gets a consistent water supply.

My sensitivity convinced me that there was mold behind a shower, so I cut a square out of the green board. Sure enough, there it was.

This is a three year old house in perfect visible condition, so the contractor couldn't believe it until I showed it to him. His response was, "Holy shit!"

All the new houses I see are built with the sink and shower tiles glued directly to green
I took a plastic bag and some water to a new house where the sheetrock has just been nailed up. I took some samples and put them directly into some water (in a plastic bag to prevent cross contamination). Within a week, the backing on the green board was covered with mold. The standard sheetrock looks okay.

Since the green board is the one that will be in contact with water should the tile grout fail, the incorporation of mold is the worst possible scenario.

It's a simple experiment. Find a house under construction and do it yourself.

-Erik (2001, SickBuildings)

*I walked around various construction sites and picked up sheetrock samples which I dropped directly into a plastic ziplock bag with a little distilled water.

All the samples exploded with mold.

The mold didn't start at one corner and spread across. It literally erupted equally across the entire sample.

The green board was the worst. The green side that is supposed to be mold resistant did okay, but the opposite side sprouted mold like crazy. I can't see what good green board is supposed to be when the water can go right through to the side that isn't mold resistant.

It looks to me like mold is processed right into the paper backing on sheetrock.

Don't take my word for it. Try this yourself.

--Erik (2002, SickBuildings)

*Some of these homes are moldy right down to the frames.

I spoke with contractors several years ago and they said, "It's not our fault. The wood is not what it used to be. We have to work with what we've got, and it's just impossible to get good kiln-dried wood the way it used to be. We're just doing our jobs."

Imagine all those brand new mold castles out there.

Imagine living next to them.
Imagine living downwind of an entire neighborhood of them.

Nobody said this was going to be easy.

-Erik (2006, SickBuildings)

*

One of my Moldie friends was searching for better housing and toured a brand new subdivision that was still under construction. She went into a house that had just been sheetrocked, and felt sufficiently hit that the place was instantly deemed unacceptable.

Out of curiosity, she checked out the places that hadn't been sheetrocked yet and found enough mold on the wood that she felt such a place would never be safe for her.

She said, "I couldn't live here if you gave me one of these houses."

-Erik (2008, CFSU)

NEW CONSTRUCTION

I find that new construction is even more likely to be mold ridden than old.

They built a new library in Incline Village. The old one was fine. The new one has sucked, from the first day they opened the doors. While under construction, they messed up and it snowed before the roof was done.

-Erik (2008, CFSU)

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North of Reno in Spanish Springs, a brand new community has sprung up in the bottom the valley. Complete with Starbucks, Home Depot, the works, many new shops, hundreds of nice new buildings... in a flood plain that has no outlet.

Long time Reno-ites drive past and remember when the whole area was inundated and ask, "What are they thinking?" "Whose brilliant idea was this?"

We're having a dry spell out here. Nothing has happened yet, but the old timers have no doubt that it will.

-Erik (2008, IAQ)
METAL BUILDINGS

I like the metal buildings with cement floors, hangar style.

They are getting quite good and even look like regular homes now.

They understand thermal bridging and can control for a fair degree of heat loss through proper insulation.

If I were to erect a permanent structure, I would choose a metal building.

But as I've found, if my neighbor is letting out a ripping spore plume, it negates the whole point. So it would have to be fairly isolated to be really trustworthy.

-Erik (2005, SickBuildings)

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I've lived in airplane hangars and they're wonderful, but they are difficult to keep warm.

The problems of thermal bridging of metal framework are enormous in a cold climate.

Airstream trailers are notorious for their condensation problems. The metal frame will channel enough cold through the wall to cause condensation and mold growth on interior panels.

There was a flat roof school with a dropped acoustic tile ceiling whose Stachy growth was fed by the metal straps conducting cold down from the roof. It wasn't even leaking.

To keep the metal parts from simply conducting the cold right through the insulation, the metal parts need to be separated by a thermal insulator. I used an interesting corrugated plastic panel called Coroplast.

But this is compensating for a problem you wouldn't have if you built using the Amvicsystem.

I still like metal buildings in a warm climate, but I would go the extra expense for Amvicsystem in a cold one.

-Erik (2006, SickBuildings)

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Amvicsystem, metal truss and roof.
Do you have any experience with metal buildings?

Yes, I felt great in a hangar until a darn compost farm business got started a quarter mile away.

It blasted the whole area.

All the people for a half mile started having "strange complaints."

One day I was sitting in a restaurant and overheard a guy doing an interview for a prospective business manager to run someone’s business for him, because of failing health.

It was the compost farm owner.

Just guess what his complaints sounded like!

-A Erik (2006, SickBuildings)

A lot of old places have condensation areas of micro-niches which will support Stachy, but a viable spore just hasn't made it there yet.

A funky trailer or old building full of leaks that is not in a plume can go forever with no Stachy.

A brand new building that has one slight condensation problem but is being bombed by a plume will have Stachy growth as soon as a viable spore arrives and finds what it needs.

It's a case of opportunity meets conditions.

I was surprised at the number of metal buildings in an industrial area which were intolerable, despite appearing to have few areas suitable for growth.

It looks like those "few areas" are more than enough, if the entire area is being sporadically plumed with viable spores.

-A Erik (2006, SickBuildings)
CONDENSATION INTERFACE

Remember the last time you were doing something outdoors on a sizzling hot day and got a cold canned drink out of the cooler? No matter how hot and dry the weather, that can would blaze forth with condensation.

Well, houses in the desert are like that. If it's really cold outside and you've got the heat on, moisture will form at the "condensation interface,” particularly on the north-facing wall.

No matter what the relative humidity, it's gonna happen.

And if mold finds suitable substrate at that "niche" of unavoidable moisture, it's going to thrive! The paper backing on insulation is perfect. One often finds a hidden colony right at that narrow area that is just right for mold survival.

The only reason the toxic types of mold haven’t grown there in the past is that it takes a viable spore to find that niche before anything can get going.

Well, these certain types of mold are now being blown around on the wind in a geometric progression as mold begets more mold.

The more sourcepoints, the more plumes there are. The more plumes there are, the more chances these viable spores have to make new sourcepoints.

Years ago we had medical building under construction in Reno that had the walls being sheetrocked before the roof was finished, and it rained. This was a multistory building and the top floor instantly lit up with Stachy in multiple places.

Seems to me this is good evidence that there is another sick building or "zone" nearby and that while the storm was going on, it was raining viable spores onto that top floor.

This particular situation was detected and corrected. Usually it isn't, and they just paint over the problem.

-Erik (2008, CFSU)

*  

A surprising number of houses are constructed with the paper backing on the fiberglass facing outwards.

"Wrong-side out" must be a labor saving technique, but has the very unfortunate consequence of placing the paper (perfect substrate) in the condensation interface.
This creates a hidden mold reservoir that is very difficult to locate, as it doesn't require any water leaks to keep mold growth active.

It’s often found on the cold side - the north-facing wall.

-Erik (2008, IAQ)

VENTILATION

Many brand new ventilation systems installed in moldy environments give instant hits that mold responders associate with cycles of operation.

Disturbance of spores creates an increase in neurotoxic exposure that sensitive people can easily detect.

This is one of the clues that indicates that spore counting is inherently flawed in assessing mycotoxin exposure.

Every mold responder who experiences the hit differential from a ventilation system that does not contain mold growth can clearly feel that although the ambient average of spores remains an average constant, the exacerbation of symptoms from conditions of mycotoxin release through aerodynamic forces changes the level of neurotoxic exposure dramatically.

There is simply no comparison between the symptoms from ambient levels of spores and the exacerbation from the same amounts of spores which have been subjected to change in velocity.

You don't require scientific analysis to validate this anomaly. You can feel it.

-Erik (2006, SickBuildings)

*

Las Vegas is full of bad buildings that have toxic molds growing on nothing more than the organic debris in heating and air conditioning ductwork.... which is steel.

The dust sticks to the metal ductwork, and the condensation supplies the rest.

-Erik (2008, CFSU)

INSULATION
I once read an article about “blown-in insulation” that was provided free of charge to low-income housing.

A lot of people took advantage of this service.

It turned out that the materials, which included old newspapers that they were shredding, were moldy prior to processing.

I got to see some of this stuff.

It didn’t matter how good it looked. It was still bad.

Some of these places had to have the material sucked back out under Hazmat protocols because it was making people ill.

If I remember correctly, the cellulose was moldy at the time of shredding and, of course, the toxins remained, although there was no mold growth after processing.

-Erik (2006, SickBuildings)

SEWERS

Millions of houses are built with shower tiles glued directly to sheetrock.

There have always been mold free alternatives to this. It was a bad construction technique that is affecting huge numbers of people.

Daily use of the shower and capillary action in the grout keeps the mold supplied with the perfect rate of water flow.

But the damage doesn’t stop inside the house.

When the spores are flushed into sewer systems and the mold grows on toilet paper and sludge, the air vents that are distributed along the sewer main can serve as the source of spore plumes that will knock a sensitive person flat.

If the back pressure from the main drain is so great that it resists plugging and there is mold in the sewer, you could raze, burn, bulldoze, rebuild and still be right back in mold infested hell.

I went nuts trying to get all the mold out of a house until I discovered that I felt bad outside, even when I was upwind of the house.

I finally correlated my symptoms with wind direction and it pointed right at the sewer.
There wasn't much I could do about that but move.

-Erik (2002, SickBuildings)

SHEETROCK

>My contractor has waterproof sheetrock available.

Yes, and they will certainly sell it to you whether it does you any good or not.

Even if they know it is unlikely to do you any good.

The sheetrock is completely immaterial to the point. I would have no problem at all with putting plain old ordinary sheetrock in my house.

It's kind of like a news segment I saw on tests of fecal bacteria in ice that is served in restaurants.

The employees aren't washing their hands, they use their hands to grab ice, and the bacteria can survive in the icebox... so you wind up with bacteria in your ice.

The news anchors said, "I'll never get ice from a restaurant again."

Well, what about their drinking cups which were handled by that same employee? Their silverware, plates, food, doorknobs and everything else?

The ice is not the point. Getting the employees to wash their hands and control the bacteria is the real issue.

Not using ice isn't going to do anything about the same bacteria from anything except the ice.

So what's have they really accomplished by choosing not to use ice anymore? They took one piece of the premise and jumped to the wrong conclusion.

There is no problem with normal sheetrock. It's how that sheetrock is used.

-Erik (2009, Locations)

* 

> Dragonboard is made in China and contains some amount of unspecified fiber, which is probably cellulose. It's also stored in a warehouse in Texas, because that is where the distributor is. Texas is known for having mold and pollution in the atmosphere. For a
drywall alternative, I lean more toward Magnesiacore, which is solid magnesium cement and is made in Canada.

Funny how they don't tell you what the fiber is.

And I agree, since they don't mention what it is, then it's probably something inexpensive.

And cellulose is what they probably use, if they don't go out of their way to specify something else.

If that fiber were something that mold couldn't grow on, you'd think that they wouldn't forget to point that out.

-Erik (2009, Locations)
Chapter 36 - Remediation

REMEDIATION BASICS

The "paint over it" school of thought comes from the philosophy of, "No spores. No problem."

If you suffer from the delusion that spores are actually producing a toxic gas, you can create a hysterical imaginary response to mold that is sealed tightly inside places where no spores can escape.

Of course, the doctors will tell you there is "no evidence" that mold produces any such gas and even less that "neurotoxic T2 tricothecene mycotoxins" have any bad effects on people.

I guess it's all in what you believe.

-Erik (2002, SickBuildings)

*A few tips if you think mold may be a problem in your home. If you have a leak, make sure you get it fixed. Run fans and a dehumidifier.

Those are some good tips on how to really destroy your life and put the finishing touches on creating the ultimate mold disaster.

1. Fixing the leak reduces the gelatinous quality of the colony and creates the potential for more dried spores to become airborne.

2. Dehumidifying after the mold is already present makes this happen much faster.

3. Running the fans will spread the dried spores even further.

Once again, advice from the "experts" that is completely counterproductive.

-Erik (2004, SickBuildings)

* Be wary of allowing anyone to disturb the mold colony, as this can release a vast increase in spores which would make the situation worse by several orders of magnitude.
Remediation of toxic mold must be performed by a knowledgeable person using Hazardous Materials protocols.

(Not your landlord with a fan.)

-Erik (2006, SickBuildings)

* 

To the best of my knowledge, once spores are rendered fragmentary and non-viable, the relevant consideration for dead spores and fungal debris is the residual capacity to inflict pain upon a sensitized person.

An incautious remediation procedure can spread fungal detritus far and wide, turning an intolerable area into one that is semi life threatening to a mold susceptible individual.

It would behoove people considering this process to have a back-up plan for living accommodations.

-Erik (2008, IAQ)

REMOVING MOLD

As Chin Yang of P&K Microbiology Services said, "If the mold is Stachy, removal is the only option." He had good reasons for saying so.

If the colony is anything beyond miniscule, successfully killing Stachy without removal liberates an increased non-viable toxin load that poses the problem that whatever problems already exist possess the natural propensity to become far worse unless some mitigating factors interfere with the normal progression of dead-colony dispersion.

Thermapure is a dangerous option, if it is successful in killing a hidden toxin former:

"The operation was successful, but the patient died."

I absolutely agree with Chin Yang, as he is being extremely practical in terms of placing human health above misguided short-term economic concerns. Total removal is the only realistic means of achieving this goal. Anything less is false economy.

If a failed remediation eventually leads to total removal anyway, the cost of the inadequate remediation is totally wasted and all human illness induced in the interim can be added to the ultimate cost of not doing it right the first time.

In those partially treated buildings which give the impression that toxin potency has abated, the sequelae of chronic low level exposure is hidden but not absent. The
suffering is deferred and the true cost will probably never be known, only suspected by the people who wonder why they and so many others who worked in the same place went on to develop various rare cancers, CFS, fibromyalgia, Multiple Chemical Sensitivities and other mysterious illnesses which the medical profession is unable to explain.

What is my advice to people who cannot afford total removal?

To remove themselves from the premises, because although they won't see the price they will pay until later, they cannot afford not to.

-Erik (2007, IAQ)

Certainly the situation can be controlled with lesser measures if the mold is not a toxin producer. But then, if the mold were not, would the building have sick inhabitants and complaints have been registered?

In sick building instances, what of the folks for whom the least invasive action condemns them to chronic illness? Are they to be considered collateral damage and acceptable losses in the war on mold?

In those cases where a chemical does kill hidden toxin formers, logic dictates that the natural dispersion of nonviable material can be expected to increase toxin exposure. This style of "remediation" is of benefit only to those who avoid the area for the duration of enhanced aerosolization and the foreseeable aftermath while dispersed toxins denature.

Prescribing a solution that involves vastly increased potential toxin dispersal as a normal result might raise a few eyebrows if the inhabitants realize what they are in for.

The long term effects of even low levels of exposure to T2 mycotoxins appears to be such that deciding removal is economically unfeasible is much like the Roman Empire deciding that removing all those vast numbers of lead joints in their pipes would be unthinkable and simply cannot be afforded.

-Erik (2007, IAQ)

Some people view this as dose response and don't appear to believe in low level T2 genotoxic dysregulation. So, from their viewpoint, not all of the toxin needs to be removed.
But, imagine if low levels could be hypothetically problematic, and some toxin source and the route of exposure still remained intact.

In this circumstance, there would be nothing to prevent illness, regardless of being unaware that they are being chronically poisoned.

-Erik (2007, IAQ)

**STACHY GROWTH**

John Banta of Restoration Consultants in Sacramento told me that there is literally no house that does not have at least a few stray Stachy spores.

Two teachers at North Tahoe High School became chronically ill while working in a room that had a baseball diameter sized colony of Stachy.

The rest of the teachers in other areas believe that these teachers must be lying and malingering, since others in that school didn't all succumb.

The concept of ambient spore testing is meaningless when a sole plume in an isolated area can lash out and affect just a couple of people, leaving others in close proximity wondering what those complainers are whining about since it didn't do the same thing to everyone.

So yes, Stachy can be found in a building that isn't sick.

And there are many buildings which are quite safe except for one small area that can be quite exceptional in its effects.

-Erik (2006, SickBuildings)

**REMETIATING FOR MOLDIES**

The remediologists I've spoken with who have desperately tried to make a house livable for hypersensitive people tell me that they can often get a house to a level that has normal levels and can be tolerated by "Normies," but that Stachyterians usually have to move.

The level of sensitivity you describe suggests to me that even if you did get your house to a point that wasn't noticeably affecting you, still you would always wonder in the back of your mind if you were truly unaffected and might not be better off elsewhere.

I would plan on moving if I were you.
My new house was good, but now there is some mold growing. How can I remediate it when I can’t even remediate a wooden chair that I like?

My experience and the concurrent anecdotes I’ve heard from others is that if an object is exposed on a long term basis to mycotoxins, it will build up a considerable charge of badness that may not go away for an unacceptably long time.

Things that have only momentary exposure which are of a nature that surface spores can be easily removed clean up with no problem.

But even hard plastic or wood that has been exposed long term has a long term effect on me despite any amount of remediation.

So if your chair was exposed long term, it can stay bad for a very long time. But if the wood structure of the house had a mold of lesser toxicity and lower duration of exposure, resolving the mold and preventing recurrence would probably suffice, at least for me.

But there are some caveats.

There is a point of no return to this immune inflammatory progression. Once a person has gone over the threshold, coming back takes actions of an extreme nature that are incomprehensible to anyone who has never been close to dropping into this living hell.

The question at this point is not whether any objective tests of the materials can point you at a proper course of action. It is whether you are at a point beyond which your reactivities will allow you to deal with the variables at hand.

These reactivities are of such specificity and variability that determining acceptable levels of contamination cannot be realistically assessed by any other person.

Learning to do this is very much like flying your own plane.

An experienced person could do it for you, but if you want to do it on your own, you have no other option but to rely on your own expertise and "fly or die" accordingly.

I tried the fresh air supply from outdoors concept seven years ago and was dismayed and amazed when it so totally didn’t work.
It was only then that I went to the desert to get clear and then returned to test the exterior of my moldy house without going inside, and found that I was being plumed from a sewer vent that wasn't even on my property. There was absolutely nothing I could possibly do to make the area livable.

I could have burned the house completely, bulldozed the ground, and sterilized the property with Napalm and it wouldn't have done one damn bit of good.

I debated the ethics of selling the house, but I didn't create the problem, I didn't contaminate the neighborhood, and certainly nobody helped me in any way. They all were willing to fight me to the death while I was struggling for my life.

Nobody would have believed me anyway, so I sold it and bailed out.


*

I'm not saying that everyone needs to bail out at the slightest hint of mold or that remediation can't be successful.

But there will come a day when you will walk into someone’s house, and they will tell you that they have been dealing with it very well and maybe even have successfully remediated....and despite their assurances that they know what they are doing and are in control of the situation, you will look at them and see the signs of illness and know exactly where they are heading.

-Erik (2006, SickBuildings)

*

Think you'll ever feel completely safe again, in a place that beat you up so hard, no matter how much you clean it? Won't it be always in the back of your mind, "I wonder if there's still some left" and "How much better might I be if I were somewhere else?"

The way I see it, if a possession or object from your mold castle picks up a toxin potential that hurts you later - whether in storage, new house, wherever - no matter how much you try and remediate that object, the place where it came from is no less likely to retain that same potential. Surely one cannot address an entire house with the same concerted effort that is applied to that one bad object.

If the perception of badness from an object taken to a different location is apparent to you, then you are at a level of reactivity that means the house itself will certainly do no less.
That makes "remediation" a testable proposition. If you can't successfully remediate to your own satisfaction each and every object taken from a bad place, you won't be able to free the house from having that same effect.

-Erik (2008, CFSU)

*

I had stuff that I put in well-ventilated storage out in the godforsakenhotterthanhell desert north of Reno finally die down after five years of cooking in a hot metal storage unit.

So if all further mold contamination at that house had been halted, and we reproduced the one hundred and fifty degree temperatures of that desert storage unit for the entire house, we can guess that the house had no potential to become safe for me in anything less than that five year span no matter how well ventilated it was.

-Erik (2009, SevereReactor)

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> My moldy house made me very sick. I am having it torn down and a new one built to replace it. How can I decrease the likelihood the mold won't come back?

Some locations require that a significant layer of topsoil be removed to reduce the chances of another go-round with mold.

Your concern about what will surely penetrate into the ground when the house is demolished is enough to warrant action.

If the issue of ground contamination is not resolved to your satisfaction, what peace of mind will you ever have in your new house when lingering doubts come back to haunt you in the night?

Especially when there is a fairly easy way to remove them, if you do so before construction begins?

For that alone, I recommend removing and replacing the soil to a depth of at least one foot.

> You said, "I recommend removing and replacing the soil to a depth of at least one foot." Seriously?
As we used to say in the Army, "I'm just as serious as a heart attack!"

I wouldn't recommend these measures to everyone any more than I have asked people to flee from houses which are beyond my own personal mold tolerance, if it doesn't seem to bother them and they seem content with their environment.

-Erik (2008, IAQ)

CHEMICALS

The thing that concerns me is that our society has been educated to resort to chemicals as solutions. This is so deeply ingrained that many people actually think that plug-in "air fresheners" create healthier air.

If everyone who has a mold problem duplicates our experiments in trying to eradicate mold with chemicals, this will be another toxic assault on our environment that will just damage it even further.

-Erik (2006, SickBuildings)

*

The first thing people want to do when they start looking at a "mold problem" is chemicalize the situation.

Considering the extent to which mold is growing, just imagine what it would do to the environment if every person who gets worried about mold starts splashing toxic anti-mold chemicals all over the place and into the water system.

If people respond in the way that they have done so far, I expect the sheer volume and toxicity of the chemicals being deployed will merely pose another threat to life on this planet and will probably do very little to slow down the mold.

-Erik (2008, CFSU)

*

Mold sensitized individuals feel sufficient prevalence of mold in so many buildings that we can only imagine what kind of environmental catastrophe would ensue if every building that had mold was treated with toxic chemicals that eventually wind up in the water system.

The recent media discovery that antibacterial soaps and wipes are actually wiping out friendly bacteria and helping create a niche for resistant bad bacteria should be a cautionary tale.
We simply do not have the ability or the technology to accurately predict and control adverse effects from chemicals.

We should emphasize creating mold unfriendly environments by proper building techniques instead of toxifying bad buildings even further.

-Erik (2009, IAQ)

OZONE

It seems to me that if ozone were used preemptively to keep colonies from forming, it would help keep new growth out of your house and would be a good thing.

But if you kill mold with ozone or bleach or denying it water, the dead spores are still going to become airborne and cause you problems. Stachy needs enough water to grow that the very moisture content helps keep the spores heavy and from going too far.

Mold spores have the same toxin, viable or not, so killing it with bleach or ozone or simply denying it water doesn't help me one bit if the colony can still dry up and drift around.

Fixing a leak or otherwise killing mold without removing the colony may be the precipitating factor that allows dried nonviable spores to blow all over your house and make your problems worse instead of better.

I want to kill mold as much as anybody, but not if it means that the colony loses cohesion and spreads dead (but still toxic) spores around, making the place completely uninhabitable.

-Erik (2002, SickBuildings)

*

I was being spore plumed by a sewer vent outside my property and beyond my control, so killing the mold was not an option.

Before I knew that spores were equally toxic alive or dead I listened to the information from ozone machine purveyors and bought one.

I knew instantly that this was nothing I wanted to be around.

Since killing the mold was a moot point, the only use I could think of was to try to clear the air and denature the toxins by running the machine when I wasn't around.
According to my perception, it did neither.

I called Prof. Harriet Amman and asked about the claims of ozone machine manufacturers. She told me about the class action suit and warned me against its use.

That was good enough for me.

-Erik (2002, SickBuildings)

The debate over ozone is so contentious that it's impossible to make a decision about whether it is likely to work based on what you read or hear.

My recommendation is to not take anybody’s word for it and find out for yourself.

Find a place that feels safe to do this experiment.

Make sure you feel good and are not reacting to anything in the safe room. Bring a contaminated object into the room and make sure you have established a definite change in how you feel based on the presence of that object.

Ozone the living crap out of it. (Don’t breath the ozone unless you want to lose more lung function. Again, you don’t have to take anybody’s word for this. You can probably feel pretty quickly that ozone may not be the best thing to breathe.)

See if it made any difference. If not, remove the contaminated object and see if the place reverts to feeling good the way it did before you brought in the object.

Now you know.

-Erik (2002, SickBuildings)

SELLING TO OTHERS

I would remediate up to whatever the remediologist considers safe and sell out.

Just as with a peanut reactivity - would you have any qualms about selling peanuts to somebody who doesn’t have that problem?

From what I can tell, Moldies are just like Peanutties.

Others need not be scared, and if you go around trying to tell them they should be, they’ll think you are a lunatic.

448
And considering this is how you would view a Peanuttie who told you to beware of peanuts, maybe they'd be right.

We're like a new breed of misfits. We have to make our own way through society, on the fringe.

I would say that if the remediators are satisfied your stuff is safe, then you should be too.

At least until further notice.

-Erik (2007, Email)

*

I've seen non-responders existing reasonably well for decades in places that I find intolerable. I might tell them they could perhaps feel a bit better, but it is not my place to advise the world to act as crazy as I do about it. Just that it's a possibility that might be worth doing.

By my standards, we'd have to destroy twenty percent of all buildings, and that just isn't realistic.

Personal choice. Remediate to the current acceptable standard and bail out.

-Erik (2008, CFSU)

*

The Indoor Air Quality groups are in absolute turmoil.

Some of the remediators have themselves become so ill by their work that they've been sensitized and can appreciate what it is like. Others are still of a mind that you can "dry it out and and paint it over" without fear.

So everyone is remediating according to their own concepts of how much mold can affect a person. No matter what level they are at, they tend to discount anyone who is operating at a higher level of reactivity.

So a "Paint Over" thinks the "Get Rid Of's" are exaggerating, and the "Get Rid Of's" seem to think that the "Run for Your Lifers" are going too far. And the "Run for Your Lifers" seem to think that "Live in a Tenters" are way off the charts.

Piss on it! Remediate, using the guy who employs the minimum stringency that can still get you past legal requirements, and move on with your life. Don't sweat the bastards, for they sure aren't sweating over your problems.
-Erik (2008, CFSU)

**WIZARD STICK**

For multiple points of reference, incense makes a good "poor man’s wizard stick."

I would guess that the particulates do not retain heat for long, removing thermal buoyancy from the equation.

To the best of my knowledge, smoke particulates do not rise simply because smoke rises.

Out of range of the incendiary inducer, they are basically nothing more than dust and would reflect whatever the airflow is doing.

If I wanted to observe the effects in multiple places simultaneously, I would need to buy multiple wizard sticks.

Incense is cheap and readily available to do-it-yourselfers.

Possibly something they would be more likely to go out and buy.

Plus, one can also use their sense of smell to track the airflow, to determine where it first comes out after passing through a wall.

Just another possibly useful trick for the arsenal.

-Erik (2008, IAQ)
Chapter 37 - Symptoms

ALCOHOL TOLERANCE

Until I started a strategy of extreme mold inhalation avoidance, I had to give up alcohol. Red wine in particular seemed to knock me flat with killer headaches.

It was easy to test the variance in the effects of alcohol by simply drinking the same amount (lots) in a moldy environment and then doing the same out in the woods.

I expounded upon this to my doctor friend that I carried out of a moldy house back in 2000.

She was stunned to learn the difference, and exclaimed upon all the times she had woken up feeling drunk and hung over in a moldy place even with no alcohol.

And yet, out in the boondocks, we could get perfectly blasted with no morning-after residual effects.

This is such an easy test to perform. No doctors, no lab work, and no need to wonder.

Just go out and do it yourself, and then you know!

-Erik (2008, CFSU)

ALTITUDE SICKNESS

I just chose Whitney as a symbol, and it's the altitude that really gets people more than just the effort involved. It's very doable when the exercise intolerance is gone.

Exercise capacity is back to 100% as long as I avoid mold consistently. I do it in one day. Twenty-two miles and 5,000 altitude gain. My record time is nine hours.

I did this to make a compelling statement about a clue to the nature of the illness that others simply could not ignore.

There have been so many fluke recoveries and snake oil stories that I know it's hard to trust anyone, but you can't fake walking out of the Ampligen program and having results like this.

-Erik (2006, CFSExp)
Mold avoidance was a process, not an instant fix.

When I first began this process, I thought that I would have to move to a lower elevation. I just wasn't getting enough air at Tahoe altitude.

Much to my amazement, after six months of concerted avoidance, I could breathe again and altitude had no effect on me.

This is one of the reasons I chose to do Whitney.

So I could demonstrate this strange effect to Dr. Peterson, and get some research into what the heck it was.

-Erik (2006, Locations)

I was shocked to “get clear” and find that respiratory problems and altitude sickness gradually disappeared.

It was fun to drag a sick doctor out of a bad place and see her go from barely able to walk a quarter mile on the level to eventually climbing Whitney with me. Stuff like that makes a real believer.

I wouldn't recommend going straight to a mountain and trying to climb anything immediately. Any recovery takes time.

But mountains have been places where I, and the Moldies I've taken with me, always feel the best, thanks to low ambient toxigenic mold levels.

-Erik (2006, SickBuildings)

I suffered my whole life from altitude sickness until I discovered that cross-contaminated clothing made all the difference in the world.

One of my trips up Mt. Whitney, I didn't take particular care to control contamination and that was the only time I started to suffer from the altitude. The other six times were no problem at all.

All these years, people told me my altitude problems were, "Just your own weakness."

Nah, it was mold.
Let these people who said it was normal for me to suffer from altitude sickness accompany me on my next Whitney climb - and let's see who gets to the top first!

-Erik (2006, SickBuildings)

*

I feel awesome on top of Mt Whitney.

Like a superman! No altitude sickness at all.

There are people all around with blinding headaches, numb, cold, and turning back because they can't hang out at this altitude... and I'm doing great. No sign of ANY altitude problem.

Unbelievable!

And I used to suffer from altitude sickness at Lake Tahoe level!

The only time I had the slightest difficulty on Mt. Whitney was when I was lax on decontamination protocols.

-Erik (2007, CFSExp)

*

When I was growing up, I always had altitude sickness.

Back when Dr. Peterson told me I was pretty much doomed, I was thinking that I couldn't live at Tahoe altitude anymore and that I might last a bit longer if I moved down lower.

Some people did just that, and it did seem to help.

So, imagine my amazement when after six months of acting like a mold maniac, I had no altitude problems at all. None.

In fact, it's like I do better at high altitude, which may be in line with some of Dr. Cheney's hypotheses about oxygen transfer.

But I wasn't that way without mold avoidance. Nope. I was gonna die.

So now, here I am in my decrepit old age, climbing up to 14,500 feet whenever I want, with nary a trace of altitude sickness.
I see all these kids up on the summit laid out with headaches, gasping for air, having to get started back down quickly, because the longer they stay the worse they get... and these kids are in better shape than me!

So, I can't help but think that, as healthy as they look, perhaps they could learn a trick or two from this old mold dog.

-Erik (2008, CFSU)

**ASPENGILLOSIS**

From all I've heard, Stachy can't actually grow in tissue, but Aspergillus can. Especially A. Flavus. And the trichothecenes from Stachy are protein synthesis inhibitors which shut down immune function so that Aspergillus can get a foothold where it might not otherwise.

This is where a lot of doctors made their mistake.

Normally Aspergillus isn't pathogenic enough to get going on its own, so they treated each Aspergillus infection as a fluke and didn't really think to look at some other mold toxin which might be acting as an enabler.

-Erik (2008, CFSU)

**“AT REST”**

The words "at rest" throw the whole thing upside down and backwards.

When I was at rest, I was in a moldy place and having my worst symptoms. It was when I was outside trying to get my butt out of this that I felt less affected.

Remember the part of the CFS definition that says, "not alleviated by rest"?

What I was describing was more like "exacerbated when at rest."

-Erik (2008, CFSU)

**BLOOD PRESSURE**

Someone I taught mycotoxin avoidance to had to change to a different doctor’s office to get an accurate blood pressure reading because the office was contaminated.
The doctor also has high blood pressure that he cannot explain or control, but of course there is no way to educate him on this subject.

- Erik (2003, CFSResearch)

**COFFEE**

When I was in the bad zone, coffee would knock me for a loop.

Funny, I can drink the stuff all day long now.

Except if I go back into the zone on a bad plumage day, more than three cups will give me the shakes.

- Erik (2008, CFSU)

**COUGH**

When the plumes are acting up, say, in Truckee, Reno or Spanish Springs, I noticed that not only do I get a chronic cough, so do a bunch of others around me.

Funny how people never connect the simultaneity. Each person passes it off as, "It's just me" even while others around them are coughing.

I just drive up north a few miles to get out of the plumes, and the cough disappears like magic.

Every time.

- Erik (2008, CFSU)

**ECHOCARDIOGRAM**

Joe Salowitz list made a terrific observation about the difficulty a technician had in performing an echocardiogram after a mold slam, and the technician apparently knew about this free-radical effect.

Amazing!

It looks like Joe has really hit on something, as he also included information about a testing method called "The Aerocrine system" which can detect this in asthma sufferers.

- Erik (2009, Locations)
EMF SENSITIVITY

The EMF sensitivity was the first symptom that backed off after I really got nutso about mold avoidance.

-Erik (2009, SevereReactor)

MOLD FACIES

>I had rashes on my face when living in the mold, and my eyes would swell.

Dr. Shoemaker calls it "mold facies."

Sounds like a cutesy name for a rash on someone’s face, but it's actually a medical term.

Facies:
Medicine. The appearance or expression of the face, especially when typical of a certain disorder or disease.

-Erik (2006, SickBuildings)

*

> My nose and the area around my nose swells.

Hurts like your nose is going to fall off, doesn't it? Do you get that really red area just above the bridge of the nose, right between the eyes?

-Erik (2006, SickBuildings)

*

I just got a call from a Moldie who said her symptoms had suddenly shifted to burning lips.

This gets to the point where you just gotta ask, “Is there anything that doesn't hurt?”

-Erik (2008, CFSU)

FATIGUE
We simply do not have words to describe it.

"Crushing fatigue" is the closest that most people come. "Unable to move" is common, but once doctors hear that, they think, "Too tired to move."

Once they fixate on the first description they heard, it is almost impossible to revert them back to thinking, "Really unable to move."

We know, as we all spent millions of words in the attempt. To little avail.

I agree that there is a great deal of the sensation one could describe as fatigue, but that is not the primary complaint. Doctors don't understand that losing your ability to do math, getting lost on your way home and not being able to write legibly may seem like trivial things, but that they actually are the important things.

And this is why allergists know nothing about mycotoxins and cannot help anyone who says that mold is killing them. Yes, there is a component of mold allergy but it is not the important component.

So doctors derailed themselves by not taking all of the details into account.

-Erik (2008, CFSU)

FEET

> It is only my ankles that swell, not my feet, so I don't think it is caused by a circulation problem as such.

I had that exact problem with the ankles swelling when getting mold exposures. Sometimes the swelling would extend down to the top of my feet so the skin would appear perfectly flat.

-Erik (2004, CFSResearch)

FINGERPRINTS

The fingerprint loss isn't totally apparent unless you do an ink smudge. The lines are still there, but the prints come out flattened with less and less distinction until they become meaningless.

The tips of the fingers and toes become itchy and have a strange shiny quality. I suspect that some people probably have degraded fingerprints but haven't tested themselves to see if they are disappearing.
I got them back after I started practicing mycotoxin avoidance and achieved a restoration of perfusion.

-Erik (2005, CFSResearch)

*

There were a few odd times when CFSers would have some need to be fingerprinted, and the difficulty trying to get a print was startling and memorable to people who were skilled at taking fingerprints.

The fingertips would get a burning sensation and gradually become smooth and shiny. And then the ridges would be too flat to get a print.

People who saw this instantly leaped to the conclusion that it was peripheral necropathy from poor circulation.

But here's the weird part. It was the index and first finger that would be the most affected first, instead of the smaller fingers.

Since everyone seems to agree that circulation would affect the little finger the most, it seemed contrary that this would be the last finger to retain decent prints.

-Erik (2007, CFSExp)

*

The weird thing about the skin coming off the fingers and toes was the way the little fingers and toes were affected the last and least.

That was exactly the opposite progression to what you'd expect, if the problem were purely circulation.

And when the skin was gone, the fingertips were red, shiny and devoid of fingerprints.

Pretty crazy to do mold avoidance and have the fingerprints gradually come back.

Took about a year.

But they are still exceptionally smooth. Markedly different from how they are supposed to be.

-Erik (2008, CFSU)

*
My fingertips feel like they're burning.

Isn't it happening to your toes, too?

And take note of the peculiarity that the largest fingers (and toes) seem to be the worst.

If it were poor circulation, as many doctors think it is, you'd think that the smallest fingers would be affected more.

-Erik (2009, SevereReactor)

**FLU SEASON**

I noticed in 1999 that the "flu season" corresponded to times of mycotoxin release and started telling people that it was no coincidence.

-Erik (2003, SickBuildings)

**FOOD SENSITIVITIES**

I saw a study a couple of years ago that even momentary exposure to stachy altered intestinal flora.

That was on the Defunct MoldAutismFungal Research list.

I can just say from my personal experience that I tried everything I could afford to improve intestinal function, and though a few cleanses and probiotics seemed to help a bit, they didn’t have a fraction of the effect that getting out of the mold zone did.

Avoidance cleared up my digestive problems, so I am prepared to believe that this is a very significant factor in chronic mycotoxin illness.

While in Moldville I had to give up drinking wine, eating cheese, bread, nuts. It seemed like everything was making me sick. And people kept blaming it on the food.

Now I eat any damn thing I want and it feels great!

Changing my diet (which everybody thought was so important) meant nothing.

Changing my location meant everything.

-Erik (2002, SickBuildings)

*
Six years ago, when I was really sick and in the Ampligen screening protocols, I couldn't tolerate any of the foods likely to be contaminated with mycotoxins.

But extreme avoidance of airborne mycotoxins lessened my reactivity and I don't have problems with any foods at all now.

-Erik (2004, CFSExp)

*I*

I never had noticeable problems with gluten until mold illness set in.

But since doctors don't believe in mold illness, when that genetic susceptibility was unveiled from biotoxin exposure, doctors only looked at "the car on the bridge" instead of the agent which undermined the ability of the structure to carry the same load that it supported prior to being triggered.

Dr. Shoemaker has determined that the celiac alleles are on the same pathway and initiated by a cytokine cascade.

The amazing thing is that extreme mycotoxin avoidance allowed me to revert to my old beer-drinking, bread-eating ways.

As soon as I had the capacity to return to my former life in any way, I went right back to those behaviors that people implicated as being causative - despite the long history of these factors utterly failing to result in CFS in any consistent or noticeable way in the past.

Despite my lack of discipline, the anomaly remains that the biotoxin exposure appeared to be the more critical factor.

I feel like someone who became hyperreactive to peanuts.

As we all know, you can't induce this type of reactivity by eating too many peanuts. So as soon as I found the agent which modulated that downstream response, I went right back to enjoying my peanut butter sandwiches as I had always done before.

It's back to the bridge analogy.

As much as people tell me not to neglect the cars on the bridge, I keep wanting to restore as many stresses and stressors to my life as possible - for this is the condition that others refer to as "normal life."

-Erik (2006, CFSExp)
Not all peanuts are mistreated, poorly processed and full of aflatoxins.

The first time I climbed Whitney after leaving the ampligen program to pursue mycotoxin avoidance, my partners carried Power Bars while I ate peanut butter sandwiches and trail mix.

All the Power Bar eaters were doubled over with stomach cramps after the hike, while I had no problems at all.

Mycotoxin avoidance doesn't mean automatically excluding all foods which may have mold, only those that do.

-Erik (2006, CFSExp)

Before going all-out in staying away from inhalation exposures, I tried avoiding foods that were said to contain mold. It did nothing to alleviate my condition.

I switched to avoiding inhalation exposures alone, and now I can eat anything.

The person I dragged out of a moldy place in 2000 was finally convinced that I wasn't kidding about this after personally experiencing the same disappearance of food sensitivities.

A couple of years ago, I saw it again. A friend was absolutely convinced that she had wheat allergies and went on a restrictive diet, which did help. But when she got out and got to a good place, the diet became unnecessary.

As Dr. Shoemaker describes in Mold Warriors, ionophore toxins switch on latent genetic tendencies which mimic real genetic illnesses.

It's hard to believe, but if the genetic programming for a reactivity are not being expressed, there is no need to avoid the trigger - for the body no longer sees it as something it should attack.

Kinda like a peanut allergy person being restored to a state of non reactivity, and being able to eat PBJ's with no more harm than is considered customary.

-Erik (2008, CFSU)
I helped a friend move out of a mold zone three years ago, and boy! Was it a pain. I hated to go into that area, but this is a long-time friend.

(This was the gal who stepped outside one day and spoke the immortal words, "The air here is poison.")

She had become increasingly reactive to gluten. Based on how much better she felt on a strict diet which eliminated wheat and gluten, she felt totally confirmed that she had celiac disease.

Of course, I told her all about that chapter in Mold Warriors which describes how the differential regulation of genes can mimic leaky gut and celiac sprue, but the words just seemed lost on her.

She reached the firm conclusion that she had true celiac disease because avoiding gluten decreased her symptoms and re-introducing it exacerbated her problems again.

And she certainly knew that when she returned from work, she sat down and barely had the strength to prepare a meal, and couldn't stay awake long enough to even watch a movie.

When I drew the parallels between her progressive debilitation and my own mold situations, pointing out that she had never been reactive to gluten before occupying this mold house, she started to get mad at me: "I am talking about emotional stress from work and a genetic gluten intolerance, and you keep wanting to change the subject to mold."

I gave up trying to explain it and just helped her move out to a new place that feels absolutely great to me.

She called me from her new digs after a couple of months: "You know, it's funny, but my gluten intolerance has gone away and I'm back to eating whatever I want with no problem."

I just said, "That's great! Congratulations."

-Erik (2008, CFSU)

*  

In Mold Warriors, Dr. Shoemaker describes that the cellular response to the presence of these ionophore toxins is to release a blast of inflammatory cytokines - which, in turn, flip on the anti-gliadin antibodies, anti-cardiolipin antibodies, or anti-myelin basic protein antibodies based upon whatever HLA DR genetic profile you happen to have.
So the leaky gut is apparently not exactly a direct response to the toxins, but rather is a process that is mediated by the inflammatory response to the presence of toxins.

Many years ago, I remember my shock when a friend suddenly acquired wheat intolerance overnight.

"But why would someone suddenly get a genetic illness?" I asked.

"The doctors don't know," he said. "But I guess my beer-drinking days are over."

Pretty wild to think that if one can stay away from mold successfully, the genetic switch can actually be flipped back to the "I can go back to drinking beer with no problems" position.

-Erik (2008, CFSU)

GALLBLADDER PROBLEMS

Yes, we know about this gallbladder weirdness. It's the enterohepatic release of ionophore toxins through the organic ion transport system.

By ion transport system, I was thinking of the anion organic transport system which is a special avenue the body possesses for getting rid of these problematic types of toxins.

So it's not really the cause or the effect. More of conduit of egress for wherever those toxins came from: Lyme, pfiesteria, mold, whatever.

-Erik (2008, CFSU)

HAIR

Every time I took a shower in my moldy house, it looked like a mouse died on top of the drain. I couldn't believe how quickly my hair was disappearing.

I initiated a strategy of extreme mycotoxin avoidance and the problem completely stopped. I still have all my hair.

Avoidance isn't a cure, but it sure beats the hell out of the alternative.

-Erik (2006, CFSExp)

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In a moldy place, my skin became, well, greasy. It was pretty disgusting, and went right along with losing so much hair when showering that I would clog up the drain every time.

After a shower, it looked like a mouse was sitting on the drain. That's how much hair I was losing. I thought I'd be bald inside of another few months.

Just imagine how amazing it was to get going on mold avoidance and keep the hair, lose the grease, and no more rashes on the face.

-Erik (2008, CFSU)

HEADACHES

Years ago, I used to resort to aspirin for my blinding godawful headaches. Now I decontaminate before they get going and haven't had to use any headache remedies at all for six years.

In a world where headaches are a big problem and big business, you'd think that someone else on this planet would be interested in this little peculiarity.

-Erik (2006, SickBuildings)

LOGIC

If people have no problems seeing logical decision making impeded by alcohol, shouldn't we accord neurotoxins the same ability?

Some behaviors that are often considered to be primarily maladaptive thought processes actually may be a direct result of neurotoxicity.

I agree with cautions about falsely advising a positive outlook, as this tends to de-emphasize the severity of the situation.

Sometimes the prognosis is extremely pessimistic, and failure to present a dire circumstance might lead people to delay taking more aggressive action.

There are many factors to balance, when giving advice.

Speaking of which, "often getting sick" after an investigation is a sign of impending ACTH depletion.

If you've read Mold Warriors, and know what happens when both MSH and ACTH are finally exhausted...
Well, let's just say, it's very dire.

-Erik (2008, IAQ)

*

One of the most incredible neurological effects that I have consistently observed from chronic mold exposure victims are dissonant interpretations of statements.

It's as if the fight-or-flight mechanism is so acutely activated that every stimulus, both physical and mental, is perceived as a contradictory challenge.

I have taken people out to the wilderness for extended periods and observed restoration of conversational equilibrium.

I believe that a recognizable pattern of communicative disproportionalism may very well be a consistent and recognizable feature of chronic neurotoxicity.

-Erik (2009, IAQ)

SUPERNATURAL ATTRIBUTIONS

It does seem to me that a significant number of sufferers attribute their problems to metaphysical phenomena. This seems to be common enough that I anticipate that most remediologists will encounter this belief system at some point.

I initially assumed that this must be merely the attempt to grasp at a nonscientific explanation in the face of a situation that medical professionals claim cannot exist, but there may be additional factors which strongly influence this conclusion.

The mind will always attempt to make sense of a situation. In the lack of a logical explanation, theories tend to cover a very broad range of suspected possibilities, from the logical to the absurd.

People suffering from neurotoxic syndromes suffer from extremely vivid dream states while simultaneously experiencing a reduction in high-order "executive function" type mental processes: a lapse in logical faculties.

In the throes of neurotoxicity, a decreased threshold in mental function may allow assimilations of rationalizations which might otherwise be rejected.

Rather than debate or directly challenge metaphysical explanations, I simply offer the possibility that the "presence" one senses might actually be the attempt of the mind to
project substantive recognition to a subliminal fight-or-flight inducing neurotoxic threat from a very real unseen danger.

And add that this is just my belief system about what is going on.

-Erik (2008, IAQ)

*

I think this is a terrific subject.

People's attribution of symptomology to supernatural causes does not appear to fit the normal psychological profile of paranoia.

The metaphysical descriptions that I have heard tend to sound more like an earnest desire to explain a phenomenon that, having been discredited by "science," becomes automatically subsumed by the paranormal.

Why not consider the possibility that a combination of neurotoxicity and subsequent unveiling of a willingness to make supernatural attributions might just be responsible for some haunted mansions?

We've got a model for this type of human response in the mycotoxin ergotism hypothesis for the Salem Witch Trials.

People had a chance to suspect poison, but opted for a metaphysical explanation instead.

Perhaps we haven't changed much in the last 200 years.

Maybe "Ghost Hunters" should have included some Indoor Air Quality professionals on their team.

-Erik (2008, IAQ)

**READING**

I used to read voraciously. Reading was great pleasure for me.

Ever since the Incline Village phenomenon, I take no joy in reading the way I used to. It is nothing but hard work. Nothing like it was.

If I am out in the woods, in a really good environment, I can almost.... almost...
If I could stay in a pristine place forever, without having to dip in and out of mold zones, I feel sometimes that I could just about get the pleasure of reading back. But I haven't had that opportunity.

-Erik (2008, CFSU)

**SLEEP**

It is absolutely terrific to be able to sleep well, without all those nasty neuro-nightmares.

-Erik (2006, SickBuildings)

*

Remember the "Shrieking Dream Response" that correlates to neurotoxin exposure?

I complimented Dr. Shoemaker that he was perspicacious enough to notice that patients often mentioned it.

I told Dr. Shoemaker that my leap of faith was to consider that this is a normal animal response to toxic situations, and is the attempt of the immune system to induce a meaningful response:

Fight or Flight.

(You can't fight a dream, so that only leaves the other option.)

Trouble is, humans try to flee in their minds, without using their legs, as any ordinary animal with no common sense would do.

By moving my MECU in and out of toxin zones, I was able to make a positive correlation with neurotoxic exposure and the "Shrieking Dream Response."

-Erik (2008, CFSU)

**SMELL**

I can well remember my sense of smell literally disappearing. I brewed myself strong cups of hot chocolate, and hovered above them, trying hard to gain some sense of delicious flavor.

Nothing! Try to explain that to a doctor!

-Erik (2008, CFSU)
SMOKE

It wouldn't have been too difficult to convince Dr. Klein about that cigarette smoke phenomenon. He was wildly reactive and had to avoid wood smoke as well.

But the interesting part is that in the course of his work as an orthopedic surgeon, he was also similarly reactive to the electro-cauterization smoke from burning human tissue.

So none of the compounds inherent to cigarette smoke was the culprit.

If one wanted to construct a study, it seems to me that the starting point would be an attempt to find out what, if anything, these disparate triggers might have as a common element.

-Erik (2008, CFSU)

SORE THROATS

> I'm beginning to think that my sore throats could be my mold indicator as they occur very quickly. I suffer from asthma. Would that be a reason why I get the sore throats so quickly?

This appears to be from exhalation of powerful nitric oxide radicals produced in the lungs.

The radicals occur immediately upon the exhale.

But it usually takes a bit of time to really inflame the throat, so I'm surprised that your response is quicker than other indicators.

I guess asthma is the thing.

In my case, the sore throat takes too long to use as an indicator,

-Erik (2009, Locations)

TEMPERATURE INTOLERANCE

After six months of concerted mycotoxin avoidance, my problems with thermal dysregulation disappeared.
My fingers had no reaction to the cold. A miracle!

That was eight years ago.

The only time it started to return was when, due to unfortunate circumstances, I knowingly allowed myself to fall under a level of exposure that I knew to be enough to make me relapse.

But I could feel it creeping back and reverted to my extreme mold avoidance strategy, and again exerted an amazing degree of control over this phenomenon.

-Erik (2006, CFSExp)

*I*

I guess it was about 1999, after continually attempting to refine avoidance techniques, that suddenly my hands felt warm.

It was like a switch.  Something kicked.  This wasn't gradual improvement. It was like night and day.

I ran outside and shoved my hands in the snow.  No Raynaud's, no blanching, no purple finger chilblains, like a normal person.

I couldn't believe it.  This was the first time my hands had felt normally warm since the Incline Village "mystery illness" epidemic.

To test if this was as good as it felt, and to celebrate this amazing thing, I stood outside and made snowballs for a half hour.

And to really make the occasion special, I walked across the parking lot to Dr. Peterson's office and pasted his Hummer with snowballs.

Nothing had ever helped before, but mold avoidance did.

-Erik (2010, SevereReactor)

**VERTIGO**

The severe vertigo, photophobia and photosensitive epileptic seizures were the very first symptoms to disappear. Long, long ago.

When I fell under the power curve again in 1994-1997, the vertigo was coming back, but not the photophobia or seizures.
VIRAL REACTIVATION

When I was working in a restaurant next door to Dr. Peterson’s office, we were getting spore plumed by mold.

Thanks to being hypersensitive, I was aware of this while people of lesser reactivity were clueless regarding this variable.

Much to my amazement, every employee who had herpes broke out simultaneously. I don't have herpes, but I felt horrible all the same.

When the weather changed and the plume died down, so did people’s herpes infections.

It was amazing to see the correlation between mold exposure and viral exacerbation.

All the people with flare-ups out said their lesions were nothing more than cold sores, until their breakouts got so bad that they could no longer deny that this was indeed herpes simplex type 2.

I had no idea that so many people I worked with had HSV until they all broke out simultaneously at the same time the mold became particularly bad in that building.

-Erik (2006, Locations)

* 

I saw viral infections of all kinds emerge in people when a mold colony acts up and plumes the place.

I even know a medical lab technician working in a moldy CFS clinic who started becoming ill after working there. Fearful of CFS, he began running his own EBV titers and saw his viral load inexorably climbing as time went along.

None of the doctor’s remedies were altering the course of his slippery slide into full blown EBV reactivation.

(How often do you find a clue like that?)
Last I heard, the doctor was trying to break his lease and move his clinic. But in the meantime, employees are forbidden to spend time in the worst affected areas of the clinic.
VISION

>When I am in an area that I believe to contain some sort of contamination, things are blurry to read.

Yes, you just got an indicator of a mold hit.

Not enough to be a full upregulation, or slam, but enough to let you know that you got swatted by a bit of mold.

-Erik (2006, SickBuildings)

*

When I was at my worst, everything appeared so dim that I needed a flashlight to read - during the day.

It was bad enough at all times, but when my face got close to a contaminated object, it would get insanely worse.

I got some oxygen, but it didn't seem to help me at all. The dimming felt like I was hypoxic, similar to high altitude in a sailplane, so oxygen was the natural choice.

But the oddity that it didn't help is borne out by Dr. Shoemaker's concepts of low VEGF, which cuts off circulation in the microcapillaries.

Doesn't matter if the blood is oxygenated or not, if it can't get to the tissue.

So damping down inflammatory response takes precedence over oxygen delivery.

-Erik (2008, Email)
Chapter 38 - Multiple Chemical Sensitivity

MOLD AND CHEMICALS

Molds produce mycotoxins.

Mycotoxins are chemicals.

Mycotoxin reactivity is chemical sensitivity.

-Erik (2004, SickBuildings)

Certainly chemicals kick people's butts, but when someone gets away from that particular exposure and the horrific immunological attack just keeps going on and on, why not consider the possibility that an unsuspected but very prevalent toxin is what is keeping the response going?

-Erik (2006, SickBuildings)

This one mold reactivity stood out as a specificity.

I just concentrated on it - and much to my amazement, the other sensitivities just faded away.

-Erik (2006, CFSExp)

I had become reactive to many chemicals, more and more as time went along. This is a process well known to MCSers, called spreading.

As I moved from place to place, I was reactive to different substances in different places, and they all had an equal effect.

It's just that I remembered that my problems had started with mold, so I attempted to treat that as my primary.

This is something that MCSers never do, as they only track their illness back to the chemical exposure that they believe triggered their illness.
Since I had mold problems prior to chemical problems, I shifted my focus to mold.

What I found was that no amount of chemical avoidance abated my reactivities.

But mold avoidance alone reduced them all.

Any MCSer would clearly understand and expect that avoiding the primary chemical would have this effect.

What they missed for all these years is that biotoxins from mold are chemicals.

The MCS community thought that we Moldies were just complaining about a bad mold allergy.

So I just thought it was kind of interesting that no amount of trying to avoid all these various chemicals did anything to reduce my all my chemical reactivities, yet when I concentrated my efforts on mold avoidance, eventually it did make a difference.

That's why I told Dr. Peterson, "There is a specificity to this one irritant" and asked that it be investigated.

But up until Dr. Shoemaker, this didn't make sense to anyone, as they all seemed to think that, "All toxins are equal."

Dr. Shoemaker found that the C4A complement activation says that the body does indeed react as if mold is something pretty special.

-Erik (2009, Locations)

**MCS ABATEMENT**

I managed to resolve my non-mycotoxin chemical sensitivities and have no further problems with carpets, perfume, Home Depot or any of the other chemical exposures that used to drop me in my tracks.

All I had to do was stay away from mold and the other problems just disappeared.

Now I drive a diesel truck, work right here at this computer that used to knock me flat, and have no problems driving past the auto paint shops which I had to detour around.

Perhaps that's not "getting rid of MCS," but it's good enough for me.

-Erik (2004, SickBuildings)
When I first started this avoidance thing, I was so reactive that I couldn't stand just about everything. Dr. Peterson said I was a universal reactor. I remember having problems with trees, diesel, new cars, paint, carpet, outgassing plastics, stores.

It was overwhelming.

This focus on mold was just a wild leap because I remembered that it was the very first thing I became reactive to - and that all the clues seemed to point at specific molds as primary in my chronic inflammatory response.

I was amazed at how many other irritants ceased to be important if I only stay away from mold well enough. I can even enjoy perfume again.

The only exception is after I've been mold hit. Once my immune system is upregulated, I become more MCS again and places like the carpet department in Home Depot will start to get to me.

After I decontaminate the mold, I can turn right around and go to the very same places without any trouble.

-Erik (2005, CFSExp)

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>When you use the word abatement, you don't mean cured do you? Because I recall you still can be affected by MCS.

a·bate·ment
n.
Diminution in amount, degree, or intensity; moderation.
The amount lowered; a reduction.
Law. The act of eliminating or annulling.

"Abatement" seems to fit my situation perfectly as I find them to be vastly reduced, without making the claim that I am now completely immune at all times.

My chemical reactivities had gradually increased over several years by spreading, extending to more irritants until, as Dr. Peterson told me, "Life has become intolerable for you."

I was only hoping to reduce the primary exacerbation that I had always connected with mold.
I had no idea that by focusing on mold, my other chemical irritants would cease to be a major driving force in my illness. The secondary reactivities abated in the reverse order of appearance as a result of mold avoidance.

I was surprised, but very happy that I went in this direction.

I don't use the word "cured" because even though these chemicals no longer seem to bother me as they once did, if I am exposed to mycotoxins the other chemical reactivities soon begin to manifest again - scarcely a "cure."

The interesting thing about mold avoidance was just that it really helped when I had run out of other things to try.

Not a guarantee. Not something I can say will apply to everyone, only a last ditch strategy that got me some results when nothing else did.

-Erik (2006, SickBuildings)

*I*

I was working in a moldy office several doors away from a bathroom.

People would use the facilities and then spray that nasty stuff they call "air freshener." I would be working and suddenly feel nauseous, and my vision would go dim. I would be forced to leave until it dissipated.

I would sneak into the bathroom and throw away all of what I call "stink spray" from under the counter. Later I would often hear someone calling, "What happened to all the spray? We just had a full case and now it's all gone. This is impossible."

It is difficult to go from liking nothing better than the presence of a perfumed woman to being forced to flee the very object of your desire, and then being called a liar and told that your behavior is all imaginary.

It was stunning to find out that persistent mycotoxin avoidance allowed me to enjoy perfume again.

-Erik (2006, SickBuildings)

*I*

After Lisa and I toured my workplace (where I'm sitting right now) which is somewhat moldy, we got to experience the chemical upregulation at a store which is normally pretty darn good.

That is the test of which is primary.
If you can avoid chemicals but it does nothing to reduce mold reactivity, that sets the stage. Yet, if you can avoid mold and the chemical reactivities abate, that completes the act - and mold is the lead player.

-Erik (2008, CFSU)

OTHER MCS SUFFERERS

If I take an MCSer to a mold exposure and they respond, that's an indication that they are specifically reactive and cannot afford to overlook mycotoxins as a driving force in their illness.

The fact is that many MCSers are failing to control for mold and mycotoxin exposure because doctors have them convinced that molds are an allergy.

I did the same thing too, until I couldn't listen to them anymore and pointed at specific molds saying, "These are slamming me just like chemicals. Are you certain that they are not?"

They were quite certain. Fortunately for me, I didn't believe them.

That is why I thought it was incredibly stunning that Cindy Duehring, co-founder of the Chemical Injury Information Network and winner of the Right Livelihood Award, suddenly shifted her focus at the end from manmade chemicals to mold.

I believe that she may have reached a point where after ruling out all else, mold was all that was left.

-Erik (2006, SickBuildings)

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I got rid of MCS seven years ago, but doctors blew the chances I gave them to learn from my experience.

Many patients responded that if anyone had actually done so, they would have heard about it from doctors.

And that since they hadn't heard about it, it couldn't possibly be true.

-Erik (2005, IAQ)

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My MCS disappeared through mold avoidance alone. Don't know why people just want to endlessly dicker and dither about this. Doesn't make a lick of sense to me.

Especially now that lots of other folks are reporting the same good effect when mold is successfully avoided.

I have one friend in Iceland whose entire family went through the same mold experience that I did.

It took a lot of effort and several moves to finally locate a really good home, but their chemical reactivities have abated sufficiently to allow them to roam into places that used to be beyond tolerance.

We both thought that MCSers would want to know that molds really do produce chemicals.

But as my friend observed, saying "mold" makes people think "allergy."

And when they think "allergy," mold is dismissed because MCS is not an allergy.

-Erik (2008, CFSU)

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The person I carried out of a moldy house in 2000 suffered from chronic eye pain and increasing chemical sensitivities.

Her eyes kept getting worse and her ophthalmologist father prescribed eye drops. She kept swearing to him that the eye drops intensified her pain, but he insisted that this was impossible. So she kept using them.

After she progressed to the point where she had almost lost her sight, he consulted with his colleagues who all agreed that her attribution of eye drop exacerbation was without basis and just something that she had mentally seized upon as a result of her hysterical distress at having an infection that was not responding to treatment. He recommended increased use of these same eye drops.

Out of sheer desperation, she started researching the eye drops herself and found that a vastly increasing percentage of the population is suffering from an intense reactivity to the preservative used in some brands of eye drops - Benzalkonium Chloride, a substance considered to be so utterly safe and innocuous that it wasn't even listed as an ingredient.

A call to the manufacturer revealed that this was indeed the preservative being used.
Benzalkonium Chloride has since been implicated in masking and enabling ocular infections in a significant percentage of patients - a peculiarity that is better known among groups of chemically damaged persons than among ophthalmologists, who adhere to the manufacturers’ claims that it is not proven to be harmful except perhaps for a few individual flukes who can only blame themselves for a reaction to a substance that is harmless to most people.

The interesting part is that after a few years of mold avoidance, she had another encounter with BC and the reaction was far less. My Moldie friend remains unconvinced that her prior reactivity to BC was exaggerated and has reached the conclusion that mold avoidance had an unexpected effect in decreasing her response to this chemical.

Naturally, this has been met with total disbelief by her doctors.

Since I had the experience of chemical sensitivities abating as a result of mold avoidance, I see no particular reason to doubt her.

-Erik (2006, SickBuildings)

A CYTOKINE STORM

If you were a mold responder and were chronically exposed to an environmental irritant of which you were unaware and then had a cytokine storm, this just might “strip the MSH/ACTH gears.”

From that point on, even though you might be doing everything possible to control for manmade chemicals, it might be insufficient if you were still exposed to the neurotoxic molds which were now the main driving force in your continued inflammatory response.

Once the infection or toxic exposure overwhelms and depletes the capacity of the hypothalamus to compensate for toxic exposure, it is the genetic susceptibility to mycotoxins that is "unveiled."

This means that even though the initial chemical onslaught has been removed, the pro-inflammatory cytokines are still kept upregulated by the unmasked response to common and prevalent mold toxins.

Dr. Shoemaker says that this over-response is mediated by biotoxins - and that although it can be initiated by mycotoxins alone, this response also can be triggered by a number of different cytokine events.

This is far from claiming that mold is the cause of everything:
"Many SBS patients also begin to notice that they become more sensitive to fumes, smells and chemicals. With repeated exposures, the sensitivity for some becomes more pronounced. In the full-blown sensitive patient, someone with Multiple Chemical Sensitivity (MCS), just a few seconds of smelling fumes is overwhelming. Mere seconds of "off-gassing" coming from computers and phones, new paint, new carpet, freshly printed reading material, or even just a ream of copy paper can make patients sick for weeks. Our treatment protocols for "Multiple Chemical Sensitivity" may bring order to this difficult-to-confirm diagnosis if the illness is caught quickly after it appears. To date, having seen over 500 MCS patients, I have yet to find one who wasn't made ill early in the illness by exposure to water-damaged buildings. I continue to look for sources of the origin of MCS other than mold exposure - so far without success."

Page 53, "Why the Courthouse was Dangerous," Mold Warriors.

Now you have to look carefully at what Dr. Shoemaker is saying here. MCSers who had a triggering chemical exposure recoil and get angry at this paragraph because their perception is that this claims "mold is the cause of everything" - which is not the case.

If you read the entire book, what Dr. Shoemaker says that the HLA susceptibility to molds is unveiled by a cytokine storm from various infections and toxic exposures.

So different triggers unleash the inflammatory overkill and the biotoxins - which include mycotoxins - then become the chronic mediators of the illness.

Perhaps the chemically sensitized patient managed to successfully avoid the exposure that initially unleashed the illness, but if he has the genetic susceptibility for cytokine storm from mycotoxins, the immune system is kept upregulated by a completely different, ubiquitous and difficult to avoid toxin.

Read Chapter 24, "21st Century Medicine: It's the Inflammation, Stupid," for an explanation of this.

-Erik (2006, SickBuildings)
Chapter 39 - Personality Issues

AN ATTITUDE CHANGE

After a night in a bad building, I'd typically start out my day feeling like, "What's the use? I'm probably down to my last few days of life anyway."

But I knew that my attitude was going to change considerably when I'd get clear.

So I used to tell people, "Don't ask me anything right now, because I'll probably give you a completely different type of answer later, after I've had a chance to get outside."

And sure enough - an hour or two outside and I was a different person.

-Erik (2008, CFSU)

BLAMING OTHERS

Most people I know living in moldy places have simultaneous reactions of anxiety, irritability and depression at times of mycotoxin release.

With no apparent reason for their discomfort, they blame their own increased irritability on the bad mood and strange behaviors of the person next to them - little realizing they are both doing the same thing.

A perfect recipe for mold-induced divorce syndrome.

The other thing is that higher mental functions diminish considerably during exposure.

People having neurotoxic reactions seem not only incapable of using logic, they lose the very recognition of the need to consider logical arguments as being more relevant in problem solving than act from purely emotional considerations.

-Erik (2005, SickBuildings)

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A couple I know were having relationship problems. They felt anxious, irritable and had great difficulty sleeping.

When one was feeling like crap, so was the other. So they blamed each other for bringing negativity and stress into their lives.
I asked them to correlate their mood swings and sleeping problems to times of wind shift, because I could feel that the place was being plumed from a compost farm a quarter mile away.

They were amazed.

It was incredible when they finally correlated their "emotional problems" to the wind direction from the compost farm and realized it was something they were both going through together and not the other person’s fault.

Heck, I might wind up saving more relationships than Dr. Phil!

"Marital Mold Counseling." What a concept.

-Erik (2008, CFSU)

A TOXIC PERSON

When an unknowing mold responder encounters someone who is drenched with mold and goes into depression response, guess who gets the blame?

"Just being around you makes me feel depressed. You’re a toxic person.”

Well, kinda, but it might not really be a personality issue.

I remember this one guy that people would say, "He has a black cloud over him. He brings everybody down with his negative vibrations, just by walking in the room without even saying anything.”

That guy wasn't "like that" at all. And when he stopped working in a bad place, his magic negative vibes on everybody just vanished.

-Erik (2008, CFSU)
Chapter 40 - Societal Issues

A NATURAL DISASTER

Who takes the "hit" for a moldy house?

You can just go look at any new construction and see that the materials are moldy even before the building begins.

If someone has a response to these materials, should your house be devalued?

Should you have to prove that your house is toxic and worthless, even if it was built that way and if is fairly normal for houses to have that amount of mold?

When I was out scavenging construction leftovers to get firewood for my annual Mt. Whitney trip, I was slammed by a few pieces. I couldn't stand to be near just a few bits of what was used to construct some extremely expensive new houses at Tahoe. When I drive past these houses, they look terrific, but I can't help but wonder how the inhabitants are doing.

If they start to feel it, who is liable?

Is it an "Act of God"? for creating mold?

The owners? because they ignorantly bought it?

The builders? because they don't see anything out of the ordinary since all their houses are built this way?

The architects? for unknowingly choosing to use materials that can do this?

The lumber companies? for not being aware that their materials can be toxic under certain circumstances?

The medical profession? for failing to detect the problem and warn society that their houses are killing them?

Society? for failing to listen to all the people who crawled out of their houses as visible evidence that something is seriously wrong in exactly the way the Bible described and warned us about in the Book of Leviticus?

Who is responsible?
Is is all of us? because none of us took any responsibility for averting this disaster even though we were warned?

-Erik (2006, SickBuildings)

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Focusing on individuals as ultimately responsible and blaming building design as automatically culpable without regard to ambient circumstances ignores the nature of spore propagation and satellite colonies in the perpetuation of this emerging phenomenon.

Any building subjected to a spore plume of viable conidia is going to become an opportunity for mold to reproduce whether the building is constructed well or poorly - at any opportune site that presents itself.

All buildings have suitable substrate and condensation no matter how well they are built. Put a perfectly constructed building in the path of a spore plume and the results are inevitable unless that building has abnormally good mechanisms for condensation control or a total lack of any cellulose substrate at the condensation interface on exterior walls.

I've spent years listening to hopeful concepts of reducing humidity in buildings which sound like a logical solution and give the appearance of good science but are meaningless when the condensation interface at exterior walls is going to be present no matter how much the humidity is reduced in the center of the building. The interface exists even in the driest desert climate, if the air outside is cold enough.

If suitable substrate, the condensation interface and viable spores all come together at the same point, the results are unavoidable. We have seen that an HVAC system subjected to a stream of viable spores can easily create colonies on bare metal, with only the organic material and customary condensation to subsist upon. This cannot be corrected by changing the design.

Placing the blame upon the HVAC doesn't make sense when the basic materials and function do not support mold growth without the spore stream.

Blaming the building itself is counterproductive if the basic materials and design are not normally conducive to mold growth and only was unfortunate enough to be subjected to a viable plume from elsewhere.

"Good design" isn't good enough if the structure is downwind of a mold colony.

This mold is another "cell from hell" like Pfiesteria.
It makes little sense to blame the owner of the lake you were swimming in when you got sick when the lake owner himself is being wiped out and destroyed by ecological circumstances beyond his control.

The process destroying that lake is pan-ecological and far beyond the ability and means of an individual or property owner to correct.

Society has been slow to identify the scope of this phenomenon just as it has with other comparable biotoxin scourges, only looking at the most noticeable effects and not the source.

Sick Building Syndrome is not a matter of bad building design.

It is a Natural Disaster.

-Erik (2006, SickBuildings)

LEGISLATION

Legislation wouldn't apply to someone like me.

I get sick in places that don't bother anyone else.

Any definition of "toxic mold" that applied to my standards of exposure would mean burning down about a fifth of all buildings. I feel it's pretty safe to say that I am the only person to complain of "Sick Thermal Syndrome."

I was hang gliding over Mt. Hull in northern California when I spotted an area where a forest fire had burned away all the greenery. Places like this are just honking for thermals so I flew over to check it out. Sure enough I hit a 3,000 fpm vertical elevator, but within a couple of turns, I got so sick I had to bail out.

It was seven long miles to the landing area and I flew the whole way with my head laying on the control bar. I thought I was going to pass out and never wake up before ground impact.

I had just enough strength to do a landing approach and flare. I crawled out and leaned against a log for hours afterward wondering what the hell had happened to me.

I didn't know then, but I do now. That sensation has become quite familiar to me.

-Erik (2004, SickBuildings)

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Lots of people pass through Reno Tahoe airport without becoming ill, but I have seen a consistent pattern of people flying in for treatment of Lyme Disease becoming violently ill after passing through the terminal.

I knew there was mold there because I learned to recognize it, but stachy was only found recently. They still haven't found out about Park Lane Mall yet.

I just dropped off someone at the airport. I didn't go inside the terminal building but I can sure feel it outside.

I think it would be useless for me to ask for legislation to address a level of mold that drops me and Lyme patients in our tracks but has no effect on the great majority of travelers.

When someone is living at my level of reactivity in which simply walking through a stachy spore plume can ruin my day (without decontamination), trying to legislate mold levels that apply to my situation is probably impossible.

I'm all for trying to make buildings safer but I have to admit that it is ridiculous to remediate a building to my standards if other people aren't getting sick there.

-Erik (2004, SickBuildings)

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If legislative standards were to be set, would they be based on normal HLA, Mold Susceptible HLA, or Double Dreaded HLA?

There are too many people who aren't reactive that wouldn't allow their property to be devalued for the sake of "susceptibles" when it doesn't bother a "normie."

 Asking them to make it safe for your highly reactive state would be like a cat allergy sufferer saying the property is worthless because a cat lived there, or for a peanut allergy sufferer to ask that a country bar be burned down because of the crushed peanut shells on the floor. It's only worthless to them.

What would you do if a neighboring MCSer complained that your new car was blasting them and asked you not to park it on your property, because that was too close?

Probably in order for a legislative standard to be enforced, everyone will be required to have their HLA tested. Then if one wishes to work, go to school, or reside in a mold zone, they would have to sign a waiver or liability or legal release in order to have the privilege of trying to suffer and survive alongside "normies" - basically still taking the burden of their susceptibility upon themselves.
For someone like me, who has to dodge mold inside or out, no standards can ever be developed which can possibly apply that wouldn't be an unreasonable burden of those of lesser susceptibility.

I think that we "Double Dreaded Mold Genies" are pretty much flying solo with this problem.

-Erik (2006, SickBuildings)

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> Maybe we should buy and sell health credits, like we are doing with carbon credits.

We could do the same thing with "spore credits."

If the Sick Building inhabitants are ill from toxic mold, but the neighbors aren't, the "mold liability" is simply shifted to where it doesn't matter so much.

Sick Buildings can be equipped with huge fans that suck everything out and shove it through a tall smokestack.

People who don't aren't reactive to mold can sell the rights to spew out toxic spores to those who desperately need to get rid of them.

"The solution to pollution through dilution" and everybody benefits by this system.... at least up until the point that everyone is equally ill.

-Erik (2008, IAQ)

ACCOMMODATIONS

For a mold sensitized person, that line is "The Threshold of Discernment," regardless of what that level does to anyone else.

If the Moldie can perceive it, that is the point at which he must make the decision to continue to feel the pain, or to do something about it.

Someday, when enough Moldies come out of the closet to be a problem for society, the discussion will be similar to peanuts in schools and on board airplanes.

There was once a time when it was unthinkable that a PBJ shouldn't be served in schools, or the little packets of peanuts on airplanes.

Amazing how times have changed.
The requirements for survival automatically make MCSers the enemy of society.
I don't see how there can be a policy for MCS safe housing.
The complexities are too difficult, too variable and too extreme. It would be impossible for any agency to take responsibility for controlling all the factors involved.
MCSers are totally on their own.
If there is no medical way to fix them, the public politely but firmly wants MCSers to quit raising a fuss and simply disappear.

LITIGATION

There is a narrow window of usage for spore testing, and most people don't realize that what they are trying to use a test for is not going to get them the answers they need, healthwise.
They might be good for litigation purposes, but the people I see are fighting for their lives.
When it comes to this kind of illness, these tests are worse than useless.
They are utterly misleading and provide no accurate guide for action.
For 25 years, I have watched testing identify SOME mold, and then use the argument that "science has proven that this amount cannot cause your level of illness" as a weapon against the very people who called of the building to be tested.
For me, none of that mattered anyway, because I was getting slammed outside the building in question.
And when I accompanied people who wanted the inside of the building tested through outside spore plumes, it sure looked to me like they were being affected... even as they made every effort deny it, because only a positive finding inside the building would substantiate their case.
(They remain ill, and their suffering has been great... those who are still alive.)
This situation is beyond litigation. Thinking that you are fighting for your life by insisting that conventional testing parameters are relevant and can apply to severe reactors is false economy, as dead people have very little use for money.

-Erik (2009, SevereReactor)

**WORKPLACE**

A remediation company tells me they routinely do white blood cell baseline testing on employees.

A sudden shift in white blood cells suggests their immune system has been affected, indicating both susceptibility and exposure.

Not an attractive proposition for employment, when your work carries the very real risk of making you lose your job... and your health.

-Erik (2010, SevereReactor)

**INSURANCE**

A doctor who is following my strategy recently called me to say that insurance malpractice renewal now contains an exclusion for the coverage of claims from patients becoming ill from mold, fungi spores, mycotoxins or any product, emission, toxin or volatile compounds from molds while in the doctor’s office.

It’s a repeat of the CFS scenario in which the insurance companies were writing exclusions and denying benefits to anyone diagnosed with CFS while all the doctors were saying that CFS does not exist.

The insurance companies are first to recognize the reality of anything that affects their profits.

They are more reality based than most doctors, who cannot believe anything they can see with their own eyes if it is not confirmed by some test they can charge you for.

-Erik (2003, CFSResearch)

**REAL ESTATE AGENTS**

A friend of mine was looking to buy some property in Texas and was flying down to inspect some properties that were for sale at a price that was almost too good to be true.
"Not near Dripping Springs and Toxic Tara?" I asked half-jokingly.

"What's that?" So I told him the whole mold thing and warned him against any suspiciously good deals.

"These realtors will knowingly sell you a moldy house and you'll be hating life in no time," I said.

Amazingly enough, one of the places was only twenty miles away from Dripping Springs.

When he got back, he had the most interesting story to tell me.

The place was absolutely dripping with mold. He felt it as soon as he walked in. The owner with whom he had been negotiating had just died. The widow was still willing to carry on with the sale.

As he felt his lungs tighten up and smelled the mustiness in the house, he turned to the realtor and asked, "I heard that you've been having some mold problems here in Texas. Do you think it is safe to buy here?"

As my friend related to me later, "The realtor took two steps back and turned white as a sheet."

Up until then, it had looked like an unbelievably good deal and my friend was most thankful for my warning.

He said, "Thank God you told me about the mold or I would have bought that place."

So watch out for those realtors who are doing the "Texas Two Step."

-Erik (2004, SickBuildings)

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Yesterday I was having a conversation with realtor in Reno and casually asked, "Have you run into any of this toxic mold stuff that people are talking about?"

"Never," he said. "There is no toxic mold in Nevada. Some Californians are scared to death, but people around here don't even ask any more. That whole thing has died down and I think the crazies have given up."

Wow.
Just before Easter weekend there was another news story on Channel 8, and it's been on the front page of the Reno Gazette-Journal a number of times.

Heck, you can just google "Mold Reno" and see a bunch of local buildings (like the DMV and Sheriff's offices) that have had serious problems (like the DMV and Sheriff's offices.

Bottom line is, saying there is no toxic mold in Nevada is about like growing up in America and saying that nobody ever told you to brush and floss your teeth or never told you that smoking is hazardous to your health.

A lot of people don't brush and smoke like factories. They sure didn't listen, but to say they never heard about this is damn near impossible.

This realtor didn't give me any "vibes" just as I am given to understand that Ted Bundy was a charming and believable fellow, for a mass murderer. I'm sure that most people would say, "Don't worry about that realtor. It's no big deal. He's probably just forgotten. Don't make such a fuss, it's just a little white lie."

But you know what? This guy is "in the biz." Since Stachybotrys has been talked up the way it has, he can't help but know about "this toxic mold stuff."

When your life is destroyed and you are fighting devastating health problems after being financially ruined, and are forced to live in a tent - it is kind of a big deal.

Is this realtor all that much different from Ted Bundy?

-Erik (2006, SickBuildings)

"DUE CAUTION"

Look here:

>The level of risk associated with exposure activities are unknown for these vulnerable populations. Due caution is recommended.

See? CYA, "Cover Your Ass."

They threw the ball back into the "vulnerable populations" court.

If someone proves themselves "vulnerable" by becoming ill, they obviously shouldn't have followed the recommendations for the non-vulnerable population, and failed to practice "Due Caution."

So it's their own damned fault... the dummies.
BIOTERRORISM PREPAREDNESS

I remember when Sen. Daschle's office was contaminated with anthrax.

The NIH was trying to reassure the public that they knew how to handle such situations, and showed a video of a disaster response team, using a smoke simulant to represent the biohazard.

The fully protected guys in moon suits rushed a victim on a stretcher out of the smoke and right into a waiting ambulance, whose unprotected driver was holding the back door open.

While others around me seemed convinced that this was compelling demonstration of proper response, I'm gaping at them... "But they just killed the driver, contaminated the ambulance, and are carrying cross contamination to the facility that the ambulance is going to... killing whoever is there."

Where was the peripheral decon facility?

Of course, since the people on TV are the presumed experts, merely questioning them makes me the ignorant asshole, and my objections are dismissed as laughable.

The military would never do it that way.

There would be no survivors. Is that not obvious?

How can it be possible that commonly practiced standard Army protocols appear to be completely unknown to civilian response agencies?

- Erik (2009, SevereReactor)

CONTAMINATORS

Grave actions have already been taken against the human population by contaminators. Not with a gun, but just as deadly.

And the perpetrators escape repercussions by reframing their actions within a context of lack of scientific proof, when their knowledge of what these contaminators are almost certain to do means they could scarcely have expected a benign outcome.

- Erik (2010, WPI)
Chapter 41 - Making Decisions

ALL MOLD RESPONDERS

The scope and variability of this illness is so complex that dealing with it requires an individualized strategy tailored to your own personal requirements.

People not only have different symptoms from each other, they also have different symptoms and levels of reactivity over time.

But it's counterproductive to say, "We are all completely different and you cannot project your experience upon others."

The fact is that in some fundamental ways, we are very much the same.

We all have an extraordinary reactivity to mold.

We have to learn how to deal with it as best we can.

Staying away from mold is better than not.

If someone is steadily losing it due to exposure beyond their tolerance and all accessible therapies have failed to stop the decline, a more concerted effort at avoidance is all they have left to try.

When one is dealing with an exposure level that results in inexorable decline, taking measures sooner gives people a better chance at survival than waiting.

I feel pretty safe in saying that this applies to everyone who is a mold responder.

-Erik (2006, SickBuildings)

PERSONAL IMPACT RATING

PIR, Personal Impact Rating, is a way that Carl Grimes developed to objectively assess just how seriously a person is affected.

A lot of people claim that they are severely afflicted, even though they haven't lost their jobs or crawled out to live in a tent.

So you can evaluate a person’s statements about what type of actions they are forced to take and put their level of affliction - or "Personal Impact" - into an objective context.
This allows you to give advice based upon their individual circumstances.

A PIR 3 or 4 is trying to hang on and would consider it almost unthinkable to abandon all their possessions.

A PIR 5 or 6 wouldn’t think of doing anything less.

-Erik (2006, SickBuildings)

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You have to act in accordance with your perceptions and conduct avoidance to the degree that you feel is appropriate to your degree of distress.

Having people of all degrees of reactivity talking about their needs without regard to their Personal Impact Ratings leads to confusion and cross purposes of communication.

If someone has a PIR that allows them to stay alive in a specific house and they wish to stay, that is how they base their approach and their responses. It may well be the best option for them.

If someone with a higher PIR were to advise to them immediate abandonment of all possessions and tenting in the desert, that would be talking at cross purposes.

As someone who was forced to live in the woods in a tent until the tent was contaminated and I had to abandon that too and sleep in the open, it sounds a bit strange to hear descriptions of concerns about affordable housing being the limitation governing actions. But one has to recognize that we are all at different levels.

At an extreme PIR, priorities are completely different.

When survival is at stake, affordability and comfort become relatively irrelevant.

Mold illness can really drive you to this level of desperation and leave you no other options for survival.

That's the reality.

-Erik (2006, SickBuildings)

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I don't think you will find anyone who was forced to run that didn't at some point think it was impossible and unrealistic to turn their life upside down and act like a crazy person.
Just as a person who is not reactive has difficulty understanding why anyone would bother about mold at all, it is difficult for someone at a lesser PIR to understand the dictates of a more extreme Personal Impact Rating.

None of us would live like this unless we had no other choice.

-Erik (2006, SickBuildings)

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Whether or not you improve after leaving a building all depends on your Personal Impact Rating.

If your PIR is beyond that which can be dealt with by just leaving a sick building, it’s time to move on to the next step - avoiding mold wherever it is.

This causes Carl to assess people at PIR 6, which is equivalent to requiring a tent out in the desert because nothing else seems to work....

That is, unless you can detect mold and avoid it with sufficient degree of refinement that you can successfully operate inside contamination zones which would be otherwise intolerable to you.

I’m PIR 6 except that my military training in biowarfare allowed me to evolve a strategy that enables me to survive inside towns by living in-between spore plumes by avoidance and decontaminating after passing through them.

I have been able to drop down to a PIR 4 by building up tolerance so I can work in a semi-bad building by shifting even more effort into compensating by sleeping in an exceptionally pristine safe zone.

If I weren’t dodging mold plumes and decontaminating after passing through, virtually the only places left that would be safe for me would indeed be out in the woods or desert. But by getting these spores off before the immune system has a chance to upregulate, I can live in close proximity to mold plumes without fear.

-Erik (2006, SickBuildings)

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I think it was back in 1998 when I was trying to develop a scale of intensity for places that slammed me and strategize what I wanted to do about it.

One place that usually immobilized me within an hour of exposure had inhabitants that were suffering from vague health problems but seemed to be hanging in there. The owner had heart problems and his wife was diagnosed with CFS.
One beautiful warm summer day, the owner was feeling particularly energetic and decided to tackle some chores around the house. He had detected a small water leak in the basement which was aggravating some mold growth, and so he got out his plumbing tools and crawled under the house.

Suddenly he felt so tired and weak that he couldn't even lift a pipe wrench. He crawled out from under the house, collapsed into a chair in the living room, and his heart just stopped.

Naturally, thanks to doctors who won't listen to clues, the cause of death was attributed to overexertion and weak heart.

But his widow is convinced that the way he felt so good right up until the instant of coming face to face with mold and then dropping is no coincidence. Perhaps his heart condition would have killed him eventually, but as far as we are concerned, it was mold.

So, just having a PIR that allows you to remain in a moldy house is no protection against an overwhelming exposure.

-Erik (2006, SickBuildings)

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Personal Impact Rating is a 6 point scale based on the overall impact mold exposures have on your life.

PIR 1 - No impact.

PIR 2 - You recognize an impact and a need to do something, but are easily distracted and ignore it.

PIR 3 - It can't wait. You must do something now. But it is easily remedied and you can fairly quickly get back to a routine.

PIR 4 - You have no routine because you react to so many exposure sources so strongly that you are almost always sick, recovering from exposures or avoiding locations that have made you ill in the past. You experience many complaints, many doctors, many diagnoses and many treatment failures. The impact is disruptive and life altering. The remedy is life altering.

PIR 5 - Disability. You are too sick to work or take care of family, let alone yourself. Financial ruin is the rule.
PIR 6 - The dispossessed. They are the individuals who can get slight relief only by isolating themselves from as many exposures as possible. They live outside in tents or porcelain trailers, sometimes moving to high desert regions.

The state of the Indoor Environmental quality (IEQ) industry is now at best a 3 to 3+. A few can help the lower 4s but most avoid them.

-Carl Grimes (2006, SickBuildings)

AN OBJECT BY OBJECT BASIS

I bought a book at a flea market many years ago.

I opened it up for a read and it almost dropped me in my tracks.

I knew right away it had come from a mold-infested hell hole and tossed it. But I wanted to read that book so I went out and bought a new copy which gave me no problems at all.

It didn't matter if it was an "indoor" or an "outdoor" book either.

There was simply no way I could be near it.

I cannot survive near anything that has been contaminated in such a way. No remedielogist can test an area and tell me if it is good for me. This is something I have to determine for myself on a moment to moment and object by object basis.

I see that many people have reached this level of reactivity and are still trying to live a normal life and recover in places where they perceive the presence of something that is beating their immune system's potential for reactivity to death.

I have encountered people who have been slammed down to the point where they could no longer physically stand up or take any measures to avoid their mycotoxin "trigger."

If such people don't have someone who understands the problem and can remove them from such a level of exposure, their outlook is very bleak.

-Erik (2004, SickBuildings)

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Cross contamination is a huge problem if you are living at an extreme level of sensitivity. People who aren't sensitive don't remediate at all and go on with their lives.
Some people who catch this in time can get mold levels low enough to stay where they are.

Others can't bear to be in contact with so much as a single object brought out of badly contaminated place.

No individual's experience can act as a guide for all of these varying degrees of response.

Not only that, but each individual's reactivity changes over time, so what is an appropriate response at one level may be ineffective when that level changes.

There are factors of differential toxicity even within a single colony of the same species. It doesn't do much good to try to guess at how someone should respond when there is an ever changing and almost limitless variation in individual responses to molds which likewise have toxicity (even in Stachy) that ranges from non toxic to highly pathogenic.

The only reasonable way I can see for people to construct a strategy that is relevant to their needs is to base it upon their own level of response.

-Erik (2004, SickBuildings)

THE SEVERE REACTOR

It's hard to define exactly what a severe reactor is, because some people are definitely severe reactors, but they act like they are oblivious and stay in over tolerance areas until they die.

When someone says to me, "I couldn't live like that," they are basically saying that they are not so desperate that a prolonged camping trip (which some people call "fun") is acceptable.

They may well physically be a severe reactor, but are in denial, which kind of makes them "not."

That is the point of demarcation which I use for a severe reactor.

Whether they are or not, their consideration of this being some kind of optional "choice" means that they are not ACTING like a severe reactor.

There are others for whom it may actually be an optional choice.

They haven't reached a point of desperation, and yet they realize that this could make them feel fantastically better and decide to act in a more concerted fashion for that reason alone.
Although their reactivities have not forced them to do it, they are ACTING like a severe reactor although their perceptual “sensitivities” may be more mild.

So I suppose you could say, their behavior puts them into the severe reactor category even without the total necessity.

-Erik (2009, SevereReactor)

**A “CONSERVATIVE” APPROACH**

I used to hang glide at a large coastal sand dune where the landing zone (next to the parking lot) had a large stretch of swamp between it and the launch site.

We called it the “frogwater” because not only was it loaded with frogs, it was a murky green color that could have been reminiscent of stewed frogs. None of us went out of our way to lift up a frog and smell its ass, but we all agreed that the water smelled like frog shit.

(Funny how we never thought to check our basic premise... or maybe we did, but just thought better of it.)

But anyway. The frogwater was right where a standard training glider flying at maximum performance would just barely make it.

The Landing Zone (LZ) was just “a frogwater too far.”

People would try to come in with the greatest amount of altitude and just sit there, fighting the headwind, until they ran out of airtime....plopping square in the middle of the frogwater.

It was great fun watching people trying to make it over the swamp.

If you were coming up short before you reached the swamp, it was always an option to land on the other side and walk around.

But that was a quarter mile of hiking with eighty pounds of glider on your back.

If people felt there was any way they could clear the swamp, they would try, and it sure was enjoyable to see people stretching their glide as far as possible.

Some people held up their legs and just managed to skim in, barely getting their feet wet.
Others would stall right into the muck, throw up a wave of green sludge, and climb out like the "Swamp Thing," spitting weeds and epithets.

Well, I figured out a way to make it over the frogwater every time.

It wasn't difficult. If I was coming up short, rather than try to fight the headwind, I would use my remaining altitude to dive at the last sand dune. Not only would I build up a lot of kinetic energy in the dive, but I would get even more catching the lift deflected up by the face of the dune. By pulling up in the ground effect, I had the advantage of compression lift under the winds. So, by coming in hot, I had all the speed from a dive, the lift from the last remaining source AND ground effect to help me cross the frogwater... and I wasn't fighting the headwind, because I was only inches above the water.

It never failed.

But to my surprise, aside from one or two others, nobody else picked up this trick.

Strange! It worked, gangbusters. So why not? I asked.

The "dive at the dune" bothered them a bit, although this was a fairly normal landing practice. No, it was the fact that I was so low over the swamp with no air left under me (even though I was "space trucking" right along).

I had the appearance of having insufficient altitude at a place where running out of height meant "hitting the swamp."

They couldn't see how much kinetic energy I had.

And without trying it for themselves, they had no way to know.

So, because things didn't look right, they made up their minds that it wasn't workable and didn't try it, no matter how many times they saw me not go face first into the muck.

As far as they were concerned, other people cleared the swamp too, so my making it was not all that unusual.

The conventional approach of the others who made it was done without the “risk” of being so low over the frogwater, so it looked like the superior option.

I could even explain to people that I had never failed to make it over the swamp, thanks to all the combined factors that were working in my favor, but this didn't persuade them.

They had a mental image of "Erik the Crazyman" diving headlong over the swamp at breakneck speed, and considered this to be a brazen stunt done purely to show off.
Some even asked me not to do this, as it was a bad example to people who fly “conservatively.”

They talked about me:

"Erik, the arrogant bastard! Always showing off. Always talking about his own crazy way of doing things. Flaunting his so-called prowess in front of others to get attention. There's other ways to fly, you know! Other people fly safe... not like Erik."

Perhaps. But I got to watch the "safe flyers" go face first into the muck, breaking down tubes and drenching their equipment.

And despite them thinking they were playing it safe.....thanks to the extra airspeed, I never was even close to stalling and was getting perfect landings every time.

They should have smelled the frog's ass.

They should have checked their premise about the importance of airspeed.

Sometimes, things just aren't the way they appear.

-Erik, the crazy arrogant bastard (2009, SevereReactor)

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I haven't figured out how to convey to the "conservatives" that this is not the time to act “cautiously” around mold.

I’ve seen far too many people think that it makes sense to Hepa filter, bleach, kill, destroy, ammonia-ize and blast the crap out of mold with every chemical they can think of.....and they just wind up worsening their chemical sensitivities.

If people are so close to the edge that they need to crawl out to their car... experiences of others who didn't have shown that they would have done better to turn the key, drive away and never go back.

The Godforsaken Desert works pretty good for a safe landing zone.

-Erik (2009, SevereReactor)

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I remember when this philosophical difference was discussed at gnarly-ass mountain "high altitude" flying sites out in the desert, with booming thermals and dust devils swirling all around.
Some people thought they were being conservative by "cautiously" approaching for landing at just a bit above the glider’s trim speed.

Others went for a middle course, by flying just a little bit faster in turbulent landing zones. Sure, they'd get kicked around more, but the glider could take it, and at least they had more airspeed for sudden downdrafts.

And then there were those of us who would throw our gliders into a dive at the slightest provocation, plunging straight down if we had to, just to make sure we had some airspeed before we reached ground level. We had seen the consequences of "too low, no airspeed," and it wasn't a happy place.

It was ironic that the people who thought they were being more conservative were the ones who had the worst outcome, as those of us who were the most radical were the ones who crashed the least.

And strangely enough, when we tried to talk about our reasons for throwing ourselves into the wildest maneuvers, the "conservatives" seemed to think this was bragging, like it was some kind of courageous act to put your glider in a full dive at the ground.

It was nothing like that!

There was no meeting of the minds between our outlooks.

They just never seemed to understand that as scared as they were of flying this way... we "radical pilots" were actually more scared to not do it.

-Erik (2009, SevereReactor)

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The problem with saving this strategy as a last ditch effort is that when people wait for all other things to fail, they are nearly always too ill to undertake something of such difficulty and complexity.

And they don't make it.

It's a real conundrum.

This is why there are only a few of us.

-Erik (2010, WPI)

DESPERATION
There wasn’t much room for compromise, at least, not in my situation. Partial measures didn’t work.

It was down to a choice between trying to maintain a semblance of normal life by hanging on to all my stuff and be horribly ill, or leave it all behind and take a wild leap at feeling like a human but at an incredible cost.

Kind of like surviving a hurricane or a fire.

For me it was down to the fact that I had no choice left.

It was do something drastic or suffer drastically, so I had nothing to lose by going all out with this.

I just thought it was amazing that when all doctors had given up on me, there was still one thing left that got real results.

-Erik (2010, WPI)

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As a child, I would rather choose to have active parents who are not in constant pain than ones who are semi-invalids because we were trying to hang onto a normal appearing lifestyle.

I did everything within reason to fight this illness.

The only thing that really helped was something beyond reason.

The strategy involved taking steps that most people consider unacceptable. The things that people think are more reasonable tended not to have much effect... at least for me.

This strategy is probably only for those who are at the end of desperation and don’t have other options. Except by then, the very fact of being too ill usually makes it impossible.

So this is something that is better started sooner than later, if at all possible.

-Erik (2010, WPI)

**BAILING OUT**

If you are being slammed full time, you need to bail on that area.

You might not have to move to the desert, but I think you probably need to move.
You say you can't do it because you have a daughter?

Sounds to me like you must do it BECAUSE you have a daughter.

What's the alternative?

-Erik (2002, SickBuildings)

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I found out that my house was located in a spore plume and that if the whole thing was burned to the ground and bulldozed out of existence, it still wouldn't have made any difference to how I felt there.

My solution was to obtain a Mobile Environmental Control Unit. So I guess that I'm really living in the solution instead of the problem.

If the ultimate source of the mold cannot be resolved, a susceptible person who has been primed is probably wasting their money, time, and precious remaining health trying to block these toxins.

Even if the source can be resolved, if the environment has built up an accumulation of adsorbed toxins, it will still keep a primed person ill for years before the toxins denature.

Making that decision to leave has to take so many factors into account that what must be done arises from your own individual circumstances.

A person less reactive will consider it unthinkable to crawl outside in the snow and pitch a tent. A person at a greater level of desperation wouldn't think of doing anything less.

The only way I see to help enable people to find out just how concerted their efforts need to be is to let them experience a taste of what life would be like if there were no mold.

From then on, it's a matter of their own efforts at balancing how bad the circumstances are against what can possibly be done with the resources they have.

It's horrible being trapped into a situation where you know that what you must do is going to financially destroy you.

But what is the alternative? If you are steadily going downhill, the further you go that direction, the harder it is to climb back up.

Been there and done it, and from my perspective, it's better to walk out sooner than crawl out later.
If your environment is beyond something that you can handle, evacuation of the premises and abandonment of possessions puts you far ahead of what happens by remaining there.

You won't hear this from the hopeful people who have not yet been driven to such extremes but are still headed there.

All of us who were pushed out in the cold were once in a stage where we did our very best to ignore the fact that we were still getting worse, despite our best efforts and throwing all our money at this problem.

-Erik (2006, SickBuildings)

Anyone who has been forced to evacuate in order to save their life would realize that financial considerations have nothing to do with this. The choice has been taken away.

It's get out or die.

Any severe reactor who has reached this point can look back at others who are steadily progressing toward a very bad place, and tell them that what they think is a lesser evil and being more cost effective is false economy.

They are squandering their health and what remains of their resources when they would be much better off if they did what needed to be done sooner rather than later.

If your situation is getting steadily worse, and if all your interventions have not stopped this downward progression, you can extrapolate where you will wind up.

It is better to get out no matter what your current lack of resources may be, because later you will only have less to work with.

-Erik (2009, SevereReactor)

There's just no way of telling which way different people will decide to go when confronted with this situation. Some people just "do what comes naturally" and bail... while others fight to the death.

I've watched people die in bad places after being told that their only chance is to get out. But they chose not to.
And on the other hand, when I was out at the airport building my MECU, I met a lady pilot (with a neat little aerobatic plane) who was wondering what I was doing with my strange RV contraption. When I told her, she had a tale of her own to tell.

She had her dream house in a beautiful location. Wanted to stay there the rest of her life.

But she just didn't feel good there. Naturally, doctors hadn't a clue, so she got all the usual psych diagnoses. She really liked the place where she lived, but it just seemed to be sucking the life out of her for no apparent reason.

She said, "I just got sick and tired of being sick and tired, so I moved."

And get this. Her mold house was right across the street from where I carried my sick friend out, back in 2000!

-Erik (2008, CFSU)

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It's interesting that although you can go back and read the stories of the "get-outers," it is the tales of the "stay-and-be-sickers" which completely overshadowed and overwhelmed those of us who tried to talk about this clue.

This dominated the depiction of the illness, reinforcing the concept that there was nothing that could be done even as others of us were actively doing it.

I saw this strangeness at Truckee High School.

There were those of us who got out, based simply on what we could feel.

And then there were those who insisted that what they could feel did not have any logical basis, so there was no direct action they could take.

So they stayed and got beaten up by "whatever."

Identical situation. Completely opposite conclusions.

-Erik (2009, Locations)

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It actually helped that I got myself into a really bad place.
I could have gone on fighting with lesser buildings of badness for the rest of my life if I hadn't been forced into really taking a good hard look at this and into deciding to maximize whatever good there was to be had by getting "real gone."

-Erik (2010, SevereReactor)

A PLACE TO LIVE

The reason for systematic self testing is so you know what you are looking for if you make a move.

It's tough to talk a prospective landlord into letting you sleep in a place before you rent it, but that's what you have to do.

As a Moldie, it's important to know that you have to ask for this or you can't even take a chance on renting.

-Erik (2006, SickBuildings)

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The #1 problem I see that most people have is that they try to perceptify a safe place, commit to a lease... and find out that it is not tolerable.

Don't commit to nuthin' until you have had some practice with mold avoidance.

-Erik (2008, CFSU)

GIVING ADVICE

I'm not proposing that anybody do what I do.

-Erik (2004, Locations)

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I don't tell anyone to adopt this if they don't want to.

I don't espouse it unless they are in my shoes, suffering.

"In my shoes" was to do something radical or die.

Yes, if I see someone like that, I have no qualms about telling them to run for their lives.
For all others, it remains optional. Their choice.

Although I see many people who are suffering so much that it is a mystery to me why they refuse that choice, it is not my place to tell people what to do.

-Erik (2009, Email)

**TAKING CHANCES**

Remember the Pharoah’s curse?

They found wood in a state of near perfect preservation inside the Pyramids, but the mold toxins were murder.

I recall that years ago, an Egyptologist had an opportunity to visit Nefertiri’s Starry Vault, which is falling apart from humidity and mold and is closed to the public.

She was worried about the mold, because her health was not the greatest, but this was the chance of a lifetime.

Unfortunately, she returned with Aspergillosis and died.

And there was a story on Discovery about a tomb that had been only partially ransacked, because the toxin levels were so high that the tomb robbers became so ill that many died in the attempt, and some never made it back out alive.

The ones who did probably didn’t get to enjoy the profits from their looting.

-Erik (2008, CFSU)
Chapter 42 - Lifestyle Choices

CHOOSING

Probably the hardest part is choosing which to do.

Some people move to Mexico, find a good place, and do fine. Others try, don't find a good place, and wind up in a tent.

Houses which are out in the middle of nowhereville seem to be just fine for me. Special construction isn't necessary.

If you have the ability to be a snowbird, I guess you could just go south and look for a good place to roost, rather than fuss with all this MECU stuff.

I adopted the MECU concept so I wouldn't have to do that.

Probably, the best way to reclaim something that looks like a normal life is like "The Maritime House."

Normal materials, but in a good place.

And then when you want to visit folks in bad places, some kind of MECU that allows you to decontaminate and gives you a safe place to sleep.

-Erik (2008, CFSU)

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The Maritime House

Out in Austin, Nevada, there is a peculiar house called "The Maritime House."

It was on the local news, years ago.

This gal found that she couldn't live on the coast and needed a dry climate to survive.

But she loved coastal ambience and missed it terribly.

So her husband built her a blue-and-white Cape Cod cottage out in the middle of the desert. It’s surrounded with nets, sand, starfish, barnacles, anchors and all kinds of marine flotsam and jetsam.

That's where she stays, never going back to the coast.
The interesting thing is that the doctors had no idea why she couldn't live on the coast. Mold was never mentioned.

This was just something she had to do so that she wouldn't totally fall apart.

I thought the whole thing was just brilliant.

-Erik (2009, SevereReactor)

> I would live like Erik if I didn't have a baby and husband.

Living in an RV park in a custom built mold-resistant RV?

Traveling to the woods nearly every weekend?

Doesn't really sound so bad, does it? At least, not compared to feeling lousy all the time in conventional houses.

Many guys have told me that they envy my lifestyle.

I don't see how a baby would mind. There are other people living like I do who have children.

Kids seem to think it's pretty cool.

My cat certainly seems to like it. She is out prowling, even as I write this.

-Erik (2009, IAQ)

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It's a beautiful day here in Reno. There are mold plumes just to the south, and a few stray sourcepoints up north, but I found a good place to plant myself, in between them.

If I'm careful about bringing in contamination, I can keep this good spot pretty good. So far anyway.

Feels great here. Terrific sunny day. The awning is out, blankets hanging in the sun, been cutting firewood, had a barbecue. For all intents and purposes, I am not living much differently than the other RVers I'm next to.
And people would rather live like a "normal person" and put up with a moldy house rather than do this?

-Erik (2009, SevereReactor)

**NO CURE**

This protocol has its downsides - to put it mildly.

This was an act of total desperation and this lifestyle would be considered devastating in and of itself to anyone who isn't fighting for their very lives.

-Erik (2005, SickBuildings)

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I took a wild leap at the chance that these mold toxins were what was keeping me chronically ill, and I'm glad I did. I've had quite a few adventures that were only made possible by mold avoidance.

I never claimed to be "cured."

I said that by using a strategy of extreme avoidance, I can spend my time climbing mountains and acting semi-normal instead of feeling like mold susceptible people do when they are having a reaction to toxic mold.

Not a cure, but hiking the Evolution Wilderness is sure a lot more fun than lying in bed hoping to die.

-Erik (2006, SickBuildings)

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I'm always camping. I haven't been able to successfully live in a house since 1994.

People go ballistic on me and say, "That's no cure."

Well, sure, but it's a clue. And it beats the alternative.

-Erik (2007, Email)

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Bad as it is, this beats the crap out of being beat to crap.
When people first hear me talk about mold avoidance, their usual experience is with someone who is trying to sell them a miracle-cure therapy, and their response tends to be from that perspective.

"Erik, but what you are doing is not a cure."

No, it isn't. It's just what I had to do in order to have any kind of a life.

Naturally, if a miracle cure pops up, that would be great. But I'm not holding my breath, waiting.

HOUSENESS

Would you be willing to live like a vagabond, if it gave you control over your symptoms?

I don't have a house.

I'm just living in a custom built RV that is made entirely of metal and plastic.

I used to feel sorry for myself and longed for "houseness."

Seeing as how things are going, now I feel totally sorry for homeowners. They are really in one heck of a jam.

I'm beginning to wonder about real estate, in general, as an investment.

If things keep going the way they have been, it does no good to have a mold free house in a mold region.

Every building is a bad building.
THE GREAT OUTDOORS

People asked me if I wasn't a bit concerned about being off in the woods with nobody but my kitty to protect me.

Huh? You mean... me, kitty and my buddies... "Smith and Wesson"?

-Erik (2008, CFSU)

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I guess the word “camping” conjures up images of miserable people huddled in a tent, but my family extends this RV's too. And they have everything a house does.

The camping is meant to get a sense of "pristine-ness" to let you know what it feels like. After that, you can do anything you want to achieve it.

Some people who can afford it are building very nice mold-free mansions in pristine places. Most of us can't do that.

-Erik (2008, CFSU)

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With all the systems in place, in a functional MECU, the difficulty seems like nothing more than a camping trip with an extra bit of washing.

-Erik (2009, Email)

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I've had people get angry at me and say, "But this isn't fair. You always loved camping and being outdoors, so this isn't even a big change in your lifestyle."

OK, I admit it. I cheated.

-Erik (2009, SevereReactor)

HITTING THE LIMIT

They are tearing down the Park Lane Mall in Reno, about a half mile west of where I am sitting.
This place knocked me flat for years, and the demolition is unleashing clouds of spores.

Yesterday, I hit my limit and had to bail out of here.

Thankfully, I have my safe zone located elsewhere and was able to get free and decontaminate before the immune upregulation went insanely hurtful.

If I stay too long in a place that hits me, as this zone does while this disturbance of mold colonies is taking place....well, I'd be screwed!

I have to get out of such zones no matter what it takes and get the spores off me.

I must do this in a timely fashion or face the consequences.

What I have seen since the beginning of CFS is that others share this same susceptibility, but that they aren't taking sufficient measures to control it.

That is the difference between me being laid out bedridden or dead - and being on top of Mt. Whitney.

-Erik (2007, Email)

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Yeah... I got slammed yesterday far worse than I like to let on. I'm still not quite back to normal.

You know how we went to the store where I said that I'm usually just a bit upregulated after being at work?

After that slam, I could hardly stand up in there.

Not only did I have to decontaminate in Reno, but then I had to run up to Donner Pass to get clear.

And then, just standing next to the camper, my heart was pounding like crazy.

I had been a bit suspicious about the weather. Wind was coming from the east, which means that a large low pressure system is going through. Bad sign. So I kept my Hepa system on the whole time I was in Reno.

Thank God! If I hadn't, I'd have been out in a tent!

As it was, just the contamination coming in from the exterior meant I had to keep changing blankets.
But, I can't complain.

I can remember what it was like having no options... no way to get clear.

Thanks to having the MECU, I spent the day hiking up on the Pacific Crest trail instead of suffering in shrieking agony and seriously considering calling Dr. Kevorkian.

I'm thinking that what I'm doing here is too much for me and that I better start seriously considering moseying on down the trail. Hate to! I love it here, but there's just too many plumes.

-Erik (2008, Email)

**FUN STUFF**

My lifestyle choice was to combine every chance to get clear with having as much fun as possible.

To everyone else, it appeared that I just chose to be outdoors all the time, to the detriment of pursuing career and ignoring other vital aspects of a normal life.

The focus I placed on camping, hiking, kayaking and doing all kinds of other fun stuff was the result of discovering that if I didn't, I soon would be unable to stand up, would be wracked with pain, and would be losing ground in terms of my susceptibility to mold.

-Erik (2006, SickBuildings)

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This is an example of turning what people consider the "weakness" into a strength.

After I gave up trying to lead a normal life and started using my sensitivity as a guide to action, I finally took significant control over my illness - and was able to go out and have adventures rather than being flat on my back and totally miserable.

-Erik (2008, CFSU)

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Hiking is good.

Being out in a pristine environment, sweating out the toxins naturally, all while enjoying the scenery and fresh air.
Yeah, that's my therapy.

-Erik (2008, Email)

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I climbed Mule Pass yesterday, at the base of Rock Island above Twin Lakes.

The whole time, I'm thinking, "This sure beats the crap out of being beat to crap.”

And...

"How strange that sick people with all the same clues to mold reactivity would choose to debate 'extreme avoidance' out of consideration. Are they sufficiently satisfied with how their life is to revile this strategy as a completely unacceptable option?"

If I hadn't gone this route, I know from my experience with relapsing that my life would have been just as miserable as sick people say they are.

So, all things considered, I'd rather be out here doing this.

Next week.... Whitney bound.

-Erik (2008, CFSU)

**SOCIALIZING**

Contrary to what people think, this lifestyle has allowed me to interact with friends and family in an active, healthy way that is pretty much impossible for someone who is laid out in a darkened room in shrieking agony with blinding headaches and photophobia.

Unfortunately, dipping into mold zones is still a real chore.

At least I can do it with much less pain than I used to.

-Erik (2008, CFSU)

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I remember having friends enter my safe zone and having to assess them before allowing entry.

"No, no. Don't sit there. You have to sit in THIS chair....over here on the towel, so I can toss the towel outside after you're gone.”
Wow, the crap that we’ve survived!

-Erik (2009, SevereReactor)

WAITING FOR A PILL

Yes, this is one heck of a lifestyle shift.

Won't it be great when some genius comes up with a pill?

I'm not holding my breath, waiting.

Heck, hardly seems that the geniuses have figured out that there is a problem... yet.

-Erik (2008, CFSU)

PERCEPTIONS

I never would have said "The Desert" if I had known that people were going to take it as if I meant that nothing less than a desolate Godforsaken drought-stricken snake-infested patch of barren sand was good enough.

I probably never should have used the term.

Really, I just intended it as a metaphor for getting out to the wilderness.

-Erik (2008, CFSU)

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People think I'm playing Lawrence of Arabia.

Maybe I should get a turban.

-Erik (2008, CFSU)
Chapter 43 - Others’ Responses

DISBELIEF

I know a gal up in Truckee who is living in a trailer at the opposite end of her property from her moldy house. I told her that this was dangerous since you can drag in enough spores to make the trailer unlivable, not to mention that the wind direction could spore plume her right out of there.

It was good to find other people in the area suffering from my problem since my family never believed a word I said until they heard it from someone else. Kind of painful since I have always taken pride in my credibility.

I asked them, "Since when have you considered me a liar?" and they said they thought I had just been mistaken.

-Erik (2002, SickBuildings)

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Three years ago, I taught a doctor my avoidance strategy. She comes from an entire family of doctors.

None of them believed her and damn near disowned her. They contacted their doctor buddies at Stanford who told them, "Mold reactivity is impossible." They have reached the conclusion that I mentally manipulated her using my Svengalian powers.

Her parents’ house is bad and they simply cannot understand her reluctance to visit. She recently attended a family function and immediately got a bronchial infection that she's still trying to recover from. She REALLY doesn't want to visit there anymore.

Despite all the media stories, they still blame me for "creating" this delusion of mold reactivity.

They say, "You can find anything you want on the Internet. Doesn't mean it's real."

Years ago when I saw that mold was going to kill her and started insisting that she really must start practicing avoidance, she could hardly walk a quarter of a mile. After a few months of serious avoidance, we climbed Mt. Whitney together.

When she started seeing signs of mold reactivity in her coworkers and started trying to warn them, they reached the conclusion that she was insane and lost her job. Now she knows better than to try to be a do-gooder.
It's absolutely unbelievable how easy it is to demonstrate the reality and still be contradicted on this.

-Erik (2003, SickBuildings)

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Since people are unwilling to take my word for anything, it is generally a waste of time to tell them what I am doing.

Even people who have an intellectual understanding of my situation still have no emotional or adequate conceptual grasp of the reality. My family still tries to seize upon any perceived inconsistency in my explanation to attempt to poke a hole in my entire concept, as if my reactivities would unravel or disappear if they could find an inconsistency in my logic.

I told my brother that the toxins could "adsorb" onto plastic and metal surfaces and be impossible to clean. He didn't quite understand what I meant as evidenced by the constant way he says, "You told me that mold can even grow in metal."

That isn't quite what I said but as far as he is concerned, he thinks I've made a claim that is so utterly insane as to call my entire premise into question.

-Erik (2004, SickBuildings)

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My character traits are completely immaterial in regards to physical nature of this clue, yet somehow, this is still seized upon as a suitable reason for manifesting skepticism.

-Erik (2006, SickBuildings)

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Nobody in my family believed me. No doctors, and only a very few very good friends.

Until Melinda Ballard's story broke on the front page of USA Today, I could count on the fingers of one hand the number of people who failed to tell me I was wrong or exaggerating or just plain refused to listen - and I have seen more doctors than most people have.

I still carry that newspaper article around with me.

-Erik (2006, SickBuildings)
People always attempt to dismiss the mycotoxin connection by saying that I must inadvertently avoiding chemicals or other exposures and mistakenly attributing it to mold.

Rather than simply test the concept and find out, the tendency is to reject the possibility outright.

People have thrown up so many obstacles that it's not worth endlessly debating with people who are already dead set on disbelief.

If someone is prejudicially determined to dispute the concept, there are innumerable ways to question it which take endless explanation and which consistently fail to sway anyone with their mind set on "It must be something else." So I'm pretty much at the point that if someone wants to argue about it, fine.

They can pursue their own concepts, and I'll be happy to see their results.

But this is the direction I'm going until we find something better.

-Erik (2006, Locations)

This whole thing is nuts.

Especially the fact that, "If things could be so easily cross contaminated as evil spores jumping into your hair, then everything in the world would already be contaminated... so your stupid mold theory doesn't make any sense."

See? It's so easy to demolish the entire notion or make it look like pure insanity.

Just one little problem. More and more people are becoming identically insane before they heard of other Moldies and weren't influenced before they reached their crazy conclusions.

-Erik (2008, CFSU)

Even without knowing the mechanism, we can observe that a certain percentage of SBS victims do not fully recover. Basically, this has been the battle all along.

Victims insist that they have not recovered.
Doctors insist that they must have, and that all that is left is residual fear whenever they merely imagine that they might be in the presence of more mold.

-Erik (2008, CFSU)

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It's pretty wild when you find out that the "effect" of a single object is literally beyond belief.

You know it is, because you try to talk to people about it and nobody believes it.

-Erik (2008, CFSU)

SIGNIFICANT OTHERS

Sorry to hear about all the relationships that are collapsing.

Been there and done it. Really sucks.

Prior to the naming of CFS, Dr. Cheney half-jokingly told me that this illness should be called Divorce Disease, because it really puts relationships to the test.

Does your husband understand that the more clear you can get, the better chance of returning to a functional life in the shortest possible time?

But I know from my own experience that when family members choose not to believe, it's really not an evidence-based decision.

Have you done an exposure assessment "before and after" of comparative C4a values to show your husband how astronomically the innate immune system is activated by your house?

-Erik (2008, CFSU)

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I've seen non-responder women be no less brutal to their moldsick husbands.

Two of us Moldies were in a doctor’s office (at the doctor’s request) to try to explain the situation to a guy whose wife was completely unsupportive. She had no hesitation in saying we were delusional, that they had lived in that house for years and there was no way she was moving out for some crazy mold nonsense that she had never heard of before.
He tried moving into his son's house for about a week but took all of his clothing and bedding with him. He didn't feel much better, so he abandoned all concepts of trying to avoid mold. It was pretty clear that the pressure to do nothing was from his wife.

The doctor, who was in the throes of having to abandon his own house, was disappointed that he couldn't help his patient, who was a personal friend.

-Erik (2008, CFSU)

**MOLD THEORY**

I get a kick out of the way people who aren't reactive call it a "Mold Theory."

What theory? You come into contact with mold and get sick and somehow it's a "theory"?

If you see flames in the fireplace, you've got a "theory" that it might be hot.

When you stand too close and burn your buns, is it still a "theory" to the person who hasn't been burned yet?

-Erik (2004, SickBuildings)

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People in bad zones that a sensitized person tries to warn them about almost always reply that they are immune and have no reason to be concerned, as they do not share your weakness.

They very much resent your "hysterical" warnings and wish that you had not tried to project your "phobia" upon them.

But then a significant number of these people who believed that the warnings were inappropriate eventually become ill themselves and are forced to take action anyway.

This happened with my sister - and she tried to conceal from me the fact that she had to have her house remediated of the Stachy I warned her about.

-Erik (2008, IAQ)

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It's amazing that by simply referring to something as "your theory" and "controversial," it is possible to suck the meaning right out of it.
What theory? The mold was there and we could feel it.

Is that a theory or an observation?

I stay away from it and feel better, and I'm not the only one.

What is controversial about that?

-Erik (2008, CFSU)

**MISATTRIBUTION**

I can be reactive to mold spores that my cat carried into my house from somewhere else and then demonstrate that I had no allergic reaction to my cat later, but the doctors still rejected my insistence that it was mold and not the cat.

-Erik (2002, SickBuildings)

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My cat perked up considerably after we got out of mold hell.

When the doctors insisted that the reactivity I was experiencing was due to my cat and told me to kill her, I cried and thought about if for a while.

When everyone was calling me a liar, my cat was my best friend. My cat suffered right there with me and there was no doubt that the mold was affecting her too.

I decided that there was no way in hell that I was going to betray my best friend the way doctors, "friends" and family let me down.

My cat and I are going to make it or go down together.

So far, we've done pretty well.

I feel guilty and weak that for a brief moment I even considered betraying my friend. It will never happen again.

-Erik (2004, SickBuildings)

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I know about a school that is full of "problem children" that throws off a plume that hits me half a mile away.
I was in town standing next to a child coughing in a pharmacy and heard the mother say that the doctors couldn't figure out the kid’s strange cough and allergies. The kid was wearing a team shirt from that school.

I heard of one girl from that school who was acting out, achy, fatigue, couldn't get along with anyone, couldn't get up in the morning. It was weird because she had been a great student before going to this school.

So the parents blamed the lousy teacher, poor counselors and bad schoolmates.

They got her into another school and this girl shaped right up and returned to her former self, like a miracle.

The parents prided themselves on recognizing the problem with the bad teachers and made a point of telling everybody how rotten and poorly run that school system was.

Of course, the teachers were undoubtedly being affected as well.

It’s hard to be a great teacher when your brain is fried.

That whole area was known for peculiar levels of violence and domestic disputes, even though it was just another normal appearing middle class neighborhood.

-Erik (2010, Email)

NEIGHBORS

That’s a darn shame about that poor gal who is having her "bubble" shed home taken away from her.

That's why I went out of my way to make my MECU both mobile and stealthy.

You don't get much sympathy for your intense efforts to try to stay functional with this illness.

I was thinking they should put the thing on a flatbed trailer, take it away for a few days, then bring it back but park it as a temporary trailer so it's not officially a shed.

I figured that would make it harder for the neighbors to fight them.

-Erik (2008, Email)

WORKPLACE
We've all had to fight, argue, debate, assert, scream, yell, contradict and defy our doctors, "friends," family and pretty much all other humans to get validation for a problem that, when it comes right down to it, can be so easily demonstrated as to be clearly self evident to anyone with a semi-rational mind.

I heard of a teacher in a temporary classroom structure (temporary meaning at least 20 years) in the Bay Area who claimed that something in the wall right next to her desk was making her violently ill.

The school authorities treated her like she was crazy. They never took any action except to make her appear like a crackpot and undermine her credibility in front of her students.

So one day she came to school armed with a hammer and right in front of her class turned around and broke through the wall.

Black mold spilled out.

She collapsed on the floor and couldn't move.

Her students evacuated the room and the school authorities left her lying there until the police arrived and detained her for being mentally unstable and damaging school property.

Obviously unfit to be a teacher, she was fired.

I got that story from one of her students, who recounted it to me after I told of my own bad experience with the medical profession.

She must have been a good teacher, though, because this lesson made one hell of an impression on her students.


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Just wait till you see what happens to the first person in a sick building who notices that something is wrong and tries to bring this to the attention of coworkers.... who start to think about what this might do to their jobs.

The usual reaction is that not only the managers and building owners will make you their enemy. So will all the people who feel that your information threatens their jobs.

The people who don't believe in mold illness will just hate you for spreading hysteria.

You would think that people's concern for their own health would prevent them from launching themselves at you.
This has not been what really happens.

-Erik (2008, CFSU)

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I identified a mold responder years ago who, in turn, tried to help a coworker who was complaining of the early signs that give it away.

The coworker not only didn't believe it but helped spread the notion around the office that my friend was crazy. The boss wound up demanding a physical exam from an allergist to confirm the reality of my friend's claims.

When the allergist said there was no medical basis, she was fired.

This actually turned out to be good thing, because after getting out of the moldy place, she recovered.

The coworker that she was trying to help?

She's diagnosed with fibromyalgia, depression and arthritis. She can barely work part time, and her husband is thinking about divorce.

Oh, and the doctors can't find out what is wrong, of course.

And she never contacted my friend about those strange warnings that she was trying to give.

-Erik (2009, Facebook)
Part 3

CFS & Mold Theory
Chapter 44 - Early Comments

I'm one of the 1985 Incline Village epidemic. I've been saying since day one with this illness that mold is primary in my illness.

I decided to trust my perceptions and conduct my life as if my symptoms of anxiety and depression and fatigue represented an exposure to toxic mold.

In the two years since I've applied my mold avoidance strategy, I have eliminated almost all of my long standing CFS symptoms.

My recovery continues but at present I am finally able to work full time. I have no headaches or cognitive dysfunction, and no fatigue. If it weren't for the reactivity I have to people and objects who come into my presence from contaminated buildings, I could live a completely normal life.

I have been trying to tell doctors and CFS patients about this but despite seeing my recovery, nobody thinks it could possibly apply to them. While they tell me this, I'm shaking with the reaction I get to their clothes.

I know after the 48 Hours special that some people want to look into this but find little information. So far, I've had no feedback from CFS patients with this experience.

Even if Stachybotrys is not the primary cause of CFS, I believe that there must be a connection between the illness and an extreme reactivity to mold.

-Erik (2000, SickBuildings)

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During my research on mold several years ago, I located Rich Kelly and have spoken to him on several occasions.

It still wouldn't make sense to me that simple exposure to even this very toxic mold could act so much like a pandemic if it was not intimately related to some infectious pathogen.

While it's true that by just acting as if the one mold alone was responsible for my condition has resulted in an incredible and dramatic improvement, I have never lived under circumstances that would expose me to higher levels of this toxin than the other people around me.
While most people assert that I must have a genetic susceptibility or dissipated lifestyle or immunosuppressive negative attitude that is responsible for leaving me open to this illness, I'm not buying that for a second.

While I do not rule out a virus as the cofactor, I lean toward an infectious organism that has a vested interest in disliking mold. Garth Nicolson's Mycoplasma Fermentans appears to me as a more likely candidate, and indeed I have tested positive. But enough people have tested negative to convince Prof. Nicholson that Mycoplasma is probably another opportunistic pathogen capable of complicating CFS but not primary to the illness.

Onward to the next bug.

Dr. Klapow in Burlingame has identified a high percentage of CFS patients with a nasty little tropical parasite he calls Cryptosporyngus Pulmoni.

I had a gradual onset of irritating but vague CFS symptoms until the flu-like illness totally destroyed my immune system on August 5, 1985. I propose that gradually increasing numbers of this critter could account for the gradual onset and gradual increased reactivity until immune challenges like Mycoplasma, toxic mold, HHV6 or the organophosphate pesticides that some people say have triggered their major onset slam you into classic CFS.

Dr. Klapow believes it is not the extreme toxicity of the irritant that matters as much as the depth of your immune response to it. The allergic response is key to the body’s defense against parasites, and these little devils apparently counter any allergic response by secreting enzymes that stimulate a diversionary antiviral response.

I have been to Dr. Klapow's lab and find his evidence compelling. He is working up a Polymerase Chain Reaction test for this parasite that will hopefully be available soon.

CFS is a worldwide problem, and while I recognize my own connection to trichothecene mycotoxicosis, I will not be satisfied with any model of this illness that does not link it to some infectious organism.

-Erik (2000, SickBuildings)

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Apparently Sweden is way ahead of us in studying the effects of mold exposure.

I'm told that they have identified a housing project contaminated with Stachybotrys where the colony was so tightly sealed that no spores were escaping and the toxic volatile organic compounds alone were causing inhabitants to become ill. The tests I have done on myself indicate that the VOC's are sufficient to reestablish all my symptoms without inhalation of the spores.
My sensitivity is sufficiently extreme to enable me to easily identify contaminated materials and correlate periods of barometric pressure change to increased concentration of toxins as the mold sporulates.

My experiment consisted of abandoning all my possessions and moving into a new camper. I wash everything that goes into the camper including myself. I sleep on a plastic sheet and use four sleeping bags that I wash every three days each so I can rotate any which become contaminated.

I wanted to take my experiment to the ultimate length I could manage to determine how much effect the mold was truly having on my CFS. To my astonishment, many of my symptoms disappeared completely and the ones that remain are greatly diminished and are gradually going away, leaving only the reactivity intact.

When I first moved into the camper, I measured the time between exposure and full reactivity as about four hours. The more successful I became at avoiding mold, the quicker my reaction.

After two years of practicing avoidance, my reaction time is now almost immediate for Penicillium and about five minutes for what I believe to be Stachybotrys.

My experience indicates that moving does you little good if you take contaminated possessions with you. If you go somewhere that has this stuff and then carry it into your bedding, the upregulation during sleep would not give you sufficient time to rejuvenate.

My problem at this point is not the toxicity of the mold but my own response to amounts that are certainly no greater than parts per million, just as we see in an anaphylactic reaction to aflatoxins in peanuts suffered by those who have been sensitized.

I wish there were a pill for this mold or some easy way to spray bleach on it, but the toxin adsorbs onto virtually any material and any attempts to mechanically remove the colony can spread enough spores to make a sensitized person totally unable to endure the area.

Not everybody is going to be willing to go to the lengths I did. I've been telling people with CFS about this for two years and no takers so far.

But I had just about had it with feeling sick all the time. I would be willing to sleep in a car in the desert to feel as good as I do now, but it's not necessary.

I think the skills necessary for avoidance can be taught. One only needs to think like a mold spore, and with the level of cognitive dysfunction we suffer, that's pretty easy!

-Erik (2000, SickBuildings)
My family has been telling me for years that my problems are all in my head and are a result of an obsessive/compulsive personality. I have arguments with them almost every time I see them over this issue.

They tell me that with a little mental discipline, I can just forget about this whole thing and go on and have a perfectly normal life. It's funny how all the people that tell me about the awesome power of the mind can't even conjure up enough mental control of their own to beat a common cold or lose a couple of pounds without resorting to exotic diets.

Now that I found out how to beat this crap, they all think I just improved my attitude. I have to reassure them constantly that I haven't changed my attitude one bit.

I know exactly what is giving me most of my problems, but I don't know exactly why. I've got a couple of damn good leads though.

Soon Dr. Klapow should have his PCR test for parasites done and if it's not that, then I lean toward the Mycoplasma Fermentans.

Since there have been reports of CFS long before chemical warfare agents and toxic pollution, I must concentrate on natural pathogens as culprits though I wouldn't rule out anything that cannot be disproved.

I acquired severe mold reactivity with a flu-like illness, and I believe that is consistent with Mycoplasma as it is known to be exacerbated by certain mold toxins. The question is, why?

I've seen several reports that onset of CFS occurs most often in fall/winter months. I just read that most Mycoplasma infections occur at that time of year too. This is the same time of year that always gives me my worst symptoms. Until last year, I just suffered through it and tried to stay alive. No more! Now I know what to do and it's working great. I just improved this winter.

Mycoplasmas are airborne pathogens but they usually don't get past a normal immune system. But what if your lungs were fighting a mold so toxic that exposure to this mold alone could create the symptoms of CFS? Perhaps the Mycoplasma could breach your defenses and set up a chronic infection. Perhaps any immune compromising event could cause a commensal pathogen to exploit an opportunity just as we see in pox-virus infections.

I have experienced my own inability to make any headway against this illness while my immune system is upregulated by mold exposure. The curious thing is that it is not the quantity of toxic exposure that inhibits my recovery, but rather the duration, especially during sleep.
I think that Mycoplasma + Mold is the likeliest scenario for this epidemic and that Mycoplasma + other toxic exposures would have a similar outcome. This is just speculation, but my vivid imagination has served me well on figuring out how to deal with Stachybotrys.

It just seems to me that some casually contagious organism has spread around the world and just waits for an immune compromising situation to exploit, and the more chemically toxic the situation, the better it is for this critter. I just jump up and down about mold because I've found that it's the major player in my game and it would explain some of the situations where people had no possible toxic chemical exposure.

-Erik (2000, SickBuildings)

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Look at the CDC's attempts to disprove the existence of CFS and GWS and the misappropriation of funds designated by Congress to determine the truth. After the outcry, some scrutiny is in place but it is still clear that the underlying philosophy is to suppress rather than investigate.

I read some time ago that several millions of dollars were to be used to determine if antibiotics were therapeutic against GWS and at the same time almost double that amount was given to shrinks and psychoanalysts to see if Cognitive Behavioral Therapy would resolve the symptoms of GWS. In short, twice as much credibility is accorded to those who believe GWS is stress related.

What a bunch of weak-minded wimps we must have sent to the Gulf War, to have so many of them come back with Post Traumatic Stress Disorder. It's a wonder we didn't all take one look at the lousy climate and sand fleas, and beg Saddam to just take the whole damn thing so we could just go home.

I still think Garth Nicolson has the likeliest scenario. I believe I was infected with something that hates mold but can still manifest with other toxic exposures or immunosuppressive circumstances.

I believe the vast majority of CFS starts with a flu-like illness and concurrent onset of reactivity to penicillin. I think the epidemic of mold sensitivity that is now being reflected in the media is a sign of the scope of this contagion.

Of course all this sounds crazy, but the story has to fit the facts, and blaming mass hysteria for this mess just doesn't cut it.

-Erik (2000, SickBuildings)

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I've been busy dealing with mold this summer. I've been helping my friend learn to identify and avoid mold.

It's incredible. Our sensitivities are nearly identical. When we come into contact with a contaminated place or object we both look at each other for confirmation, then turn and run.

I had to throw away my computer tower because it came from a contaminated warehouse. I called the supplier to talk over some problems I had been having with it.

The guy on the phone was coughing constantly. I asked him about his health and even though he identified himself as a young healthy jungle boy, he said he was developing a chronic sinus infection that had been getting steadily worse over the last year and a half. He couldn't understand why an otherwise healthy, athletic person like himself should be having this problem.

I do understand, but I can't seem to explain it to anybody in less than about six months.

So anyway, my friend and I were both having a terrible response to the computer so out it goes.

She was living in a sick house. I finally convinced her, not only from my arguments but by witnessing her own responses and correlating it to exposure, that we needed to run for our lives.

We have now trained ourselves to sense this rotten stuff and face the reality of it.

When we decontaminate a possession and bring it into the new house, if we still get hits off of it, out it goes!

We just took the microwave outside, because we can feel a response to it. Our theory is that particulates are attracted to the electrostatic field of motors, spores are oxidized and mycotoxins are then volatilized by the electric field.

We are amazed at the odd things that don't fit our preconceptions of what should be contaminated and what should have been easily cleaned, but we have learned by now not to question our senses. This stuff is where it is.

I keep sensing hits off Dr. Peterson's CFS patients that I run into getting blood draws at Labcorp. One time I was standing in front of the receptionist at Labcorp and I got strong hits from a fellow that walked up behind me. I turned around and saw that he was holding the huge bag of tubes that Peterson needs for all his blood work. I asked him if he was a chronic fatigue patient, and he said, "No, but my wife is."
While I was in his reception area, I got huge hits off of his clients, which tells me everything I need to know.

Rick Kelly, M.S., at Lawrence Livermore Labs actually traveled across the country to tell of the connection Stachybotrys has with CFS and was totally ignored. People think this is like an allergy, walk away from it and your problems disappear. It took me months before I was certain I was on the right track. It takes diligent avoidance for long periods. Especially critical is to make sure you are not being affected while trying to sleep. I measure my success in avoidance by rating the quality of sleep.

I have permits to climb Mt. Whitney in October. What a huge change from lying in bed on beautiful summer days, cowering from killer headaches, shaking with chills, listening to distant laughter from people outside and wondering if I would ever feel normal again.

It is now believed that MS may be caused by an infection of Chlamydia Pneumoniae of the spinal fluid which can be treated with long term doxycycline. Rheumatoid Arthritis and CFS are linked to Mycoplasma Fermentans and treated the same way. The reactivation of EBV that was linked to RA is, I believe, just that.

I think that the Mycoplasma causes reactivation of the herpetic viruses and while they do complicate matters, they are not the cause and their elimination will not be the cure. We have seen people on Ampligen normalize the Rnase-L pathway without achieving remission. I stand by my statement that persistent Mycoplasma infection results in reactivity to specific mycotoxins and that the MCS is the result of spreading, not environmental overload.

Mycoplasma, I read, has the demonstrated capacity to incapacitate the mitochondria and destroy cells’ capacity to detoxify. Mycoplasma causes extreme reactivity to Penicillium mycotoxins. Stachybotrys is more toxic than Penicillium. I believe there is an intimate connection that is more than dose related.

The bottom line is whether what I'm doing works. So far, It works.

Oh yeah, the tingling in the lips upon exposure. I that too and have described it to people for years. Do you have Fordyce granules in the lips, as I do? They're little white spots deep in the tissue.

Doctors will tell you they are "clinically insignificant."

"But then, why do they hurt when I'm exposed to mold?"

"That's impossible."

I think those are encapsulated colonies of Mycoplasma. I asked Prof. Garth Nicolson to help me verify this but he declined, saying that the difficulty in handling the material
might result in false positives and that in the past, most complaints of unusual things emerging from the skin were "mostly neuralgias."

Well, after six months of doxycycline these "neuralgias" are being kicked out. Nothing else I've tried in all these years has had any effect. That, in itself, is diagnostic.

-Erik (2000, SickBuildings)

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My girlfriend and I believe our mold reactivity is due to a contagious pathogen.

Some people get sick and others aren't affected at all. We never lived in places where other people weren't living too. Most of them didn't get sick and the ones who could feel the mold's effect didn't get violently, horribly, deathly ill like me.

I've totally had it with people saying I brought this on myself. When this started affecting me I was in the best shape of my life. It's overwhelmed me just like the Gulf War veterans.

Taking vitamins and eliminating soft drinks are pathetic attempts to deal with something that so utterly destroys you.

I have to look at the clues I'm presented with and I still say it looks like a synergism between a bacterial or mycoplasma infection and a fungal infection.

-Erik (2001, SickBuildings)

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I've been talking to the phone contact man for the Reno CFS support group, and he has the same symptoms that led me to Stachy.

My girlfriend and I have reactivity to the fumes that come from the sewer system, and we avoid the local sewage treatment plant like the plague. The contact guy actually used to live near here and had the same experience. He remembers being knocked down by fumes when the wind was blowing from the plant.

He moved from Carson City to Reno and is about two miles from their treatment plant and says he feels bad when the weather inversion concentrates the fumes in his neighborhood. He even called the city officials to complain that some horrible bacteria must be coming from their treatment plant, but of course, you know what their response was.

I thought I was about as disabled as you can get and still be alive. I was so chemically sensitive that I had to abandon a truck I just bought (I bought a different one because
the one I had was giving me problems). I tested it beforehand, but before they gave it to me they sprayed it with New Car Smell. I went cross eyed and couldn't think. I barely knew what side of the road I was supposed to be on. They steam cleaned it but it didn't get rid of it. I lost $20,000 on that deal alone. I thought I was going to die.

But just like in that article in the Reno Gazette, consistent persistent obsessive avoidance has given me relief I never thought possible. This mold is in a lot of places, so I'm glad I take my camper with me so I can decontaminate whenever I go into a bad place.

If you made a movie of my life, no one would believe it. I've seen people in pain. I've heard of people living in porcelain trailers in the desert (I was almost right there with them), but to be able to reintegrate myself into an apparently normal life by avoidance of one silly stupid thing, and then find a girl to live with who has to do the same precise thing, is just bizarre beyond anything I've ever seen.

-Erik (2001, SickBuildings)

*I*

I tested positive for Mycoplasma Fermentans at Garth Nicolson's lab. I've been on doxycycline almost a year now. Mold avoidance and doxycycline has made all the difference in the world.

I used to have sleep disorders and blinding headaches and other problems too numerous to mention. I got rid of all of them. I have complete control over whether I get a headache. Sometimes I don't adhere rigidly to my mold avoidance procedure and suffer the consequence, but I know how to get rid of headaches now.

My brave girlfriend is working in a moldy office and suffers greatly. I do my best to decontaminate and take care of her, but it's hard to watch someone you love in so much needless pain. We're in Carson City, just a few miles south of Reno where the front page news story occurred. We thought that would make others in that office take notice and help our credibility, but they don't believe it.

The receptionist there told me that she can't relate to my reactivity to mold because she isn't allergic to anything. Meanwhile I'm noticing the dark circles under her eyes, red hands, veins standing out, and the fact that she is chronically ill and has been diagnosed with fibromyalgia. At the moment that I was talking to her about mold, she had to get some more aspirin because she has a blinding headache.

I take antibiotics, I avoid mold, I kick ass! Believe it or not.

-Erik (2001, SickBuildings)

*I*
Dr. Garth Nicolson’s work is controversial and is predicated upon the existence of a genetically modified Mycoplasma whose pathogenesis is unexplored.

We cannot prove that this therapy is directly impacting a Mycoplasma infection without scientific help. We only know that it does decrease some of the symptoms. It would be nice to get some help determining why this treatment works instead of insistence that it cannot work.

I have watched my sensitivity to mycotoxins decrease with this therapy. That may not have "clinical relevance," but it makes all the difference in the world to me.

I have searched desperately for a way out of my debilitating symptoms for years. Mold avoidance and antibiotics have been effective beyond anything I dared hope for.

The relationship between my specific sensitivity and this illness is no coincidence. My circumstances and symptoms match the complaints of so many people that I find it difficult to believe that this concurrence could be attributed to random factors or simply increased prevalence of mold exposure.

-Erik (2001, SickBuildings)

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There was a famous cluster of CFS in teachers at Truckee High School where all of the people who took breaks in a common room became ill. One person who felt stifled in that room spent less time there and was the only one who recovered quickly after the flu-like illness and avoided chronic illness.

I believe that Stachy provides local mucosal immunosuppression and allows the unknown pathogen to gain a foothold in the sinuses, parasitizing the fungus it finds there. I speculate that the epidemic of sinusitis is part of the process of this illness.

I believe that the infectious organism gets coughed in everybody’s face, starts in the sinuses where it is held at bay by people with normal immune systems, and only becomes disseminated with an immune challenge.

Many people report onset of CFS with vastly different events, from surgery to toxic exposure or flu. What happens next is generally the same.

The clusters of people with sudden onset appear to happen with exposure to Stachybotrys. I think Mycoplasma is a good candidate because it is contagious, feeds on cholesterol which it can steal from fungal infections, is commensal in the sinus or saliva but is pathogenic in the blood, and, as an intracellular infection, can disable the mitochondria and the ability of the cell to detoxify itself. This means that normal-
appearing people might suffer from Alimentary Toxic Aleukia with exposure to "normal," ambient levels of mycotoxins.

If it weren't for the xenobiotic red inclusions of the C. Tropicalis I see, I'd be totally sold on mycoplasma.

One of my first questions during the Incline Village epidemic was, "Why does this infection care about mold?"

Answering that question will be the key to treatment.

-Erik (2001, SickBuildings)

*

Stachybotrys (satratoxin) is a protein synthesis inhibitor. It suppresses the immune system. Molds contain ergosterols. Mycoplasma disables cells from the inside. Mycoplasma feeds on sterols. Coincidence?

Those teachers in Truckee have a disproportionate response to mold. I found that the most powerful therapy for my CFS was extreme mold avoidance. I tested my idea on my girlfriend who has the same identical response.

I don't know if mold exposure is directly affecting Mycoplasma or the fungal infection, but I know there is a direct connection. All I have been asking for is some help in clarifying a connection that I know to exist.

I thought that by demonstrating incredible health benefits by exploiting this observation, I'd get someone to assist. It has been staggering that all the CFS specialists have turned me down. If I saw anyone as sick as I was make this kind of recovery, I'd be camped on his doorstep until I found out what the hell he was doing.

The problems I have with the virus concept is that I never understood why a virus would care about mold and that viruses tend to be very species specific. People with CFS talk about sick pets.

I don't claim to be qualified to make any determination about the etiology of this illness. I am just saying that I've got some clues that are being completely ignored.

-Erik (2001, SickBuildings)

*

I see a trend in the general feeling about many diverse complaints like candidiasis, mold reactivity, Chronic Fatigue Syndrome, skin parasites and many others. The conclusion that more and more people are coming to is that their doctors are right in saying that
these things should not be affecting healthy people to the extent that is being claimed. Rare and incomprehensible immune problems are showing up in unbelievable numbers.

Everybody who identifies a bizarre problem focuses on it and figures they just have some genetic susceptibility or bad luck until they find out how many other people it happened to. When you see how many people are saying that within the last 20 years, they have had their lives ruined by something that didn't even seem to exist before, it becomes apparent that some sort of non-HIV AIDS is spreading around the world. It doesn't kill you like HIV, but it sure makes your life a living hell.

I visited the national unidentified skin parasite association’s website. They are suffering from an incredible variety of skin infections. Everyone wonders if they've been exposed to some supercharged mutant variety of parasite to be overwhelmed by something that is not supposed to be that pathogenic.

There is no shortage of critters that will eat us when we're dead. The question is, "Why aren't they waiting anymore?"

It’s no good blaming CFS on mercury from your fillings when it's happening to kids that don't have any yet.

If hospitals, schools, office buildings caused people to be a sick as they seem to be now, where is the record of it? Even if you didn't know it was mold, surely someone somewhere would have noticed that buildings were killing people and written about it.

I feel from my own experience that this mold sensitivity is sign of the immune dysfunction that is causing such diverse problems.

I feel like this is the stage where every single room on the bottom deck of the Titanic has water in it, but every inhabitant thinks it's just an overflowing toilet, or clogged sink, or broken shower in his particular room and only a few people have gone into the hall and seen that whatever the problem is, we're all in the same boat.

-Erik (2001, SickBuildings)

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I do have a wild reactivity to Stachybotrys, but it developed slowly and independently of exposure. It simply doesn't correspond to where and when my exposure took place. Other people were sharing the same exposure I had and they didn't get sick.

Look at all the kids that are showing up with peanut allergies. Now we can't even serve peanuts on airplanes for fear that some of the passengers will drop dead. Did all of those people simply eat so many peanut butter sandwiches that their immune systems went nuts?
Something has happened in their immune systems that creates this reactivity. Every day more children are eating their very first peanut and discovering that they can't stand aflatoxins. Duration of exposure to aflatoxins had nothing to do with it.

Message boards are filling with people who are discovering sensitivities to mycotoxins, benzalkonium chloride, thimerosal, mercury fillings, organophosphate pesticides, etc. and the list grows daily. A recent poll in California indicated that 19% of people self reported life altering chemical sensitivities.

The epidemic of CFS/GWI shows a consistent TH1/TH2 (cell versus humoral mediated immunological response) shift that is a strong message that some nasty intracellular critter has crept into our mitochondria and disabled the cells’ ability to detoxify themselves.

Mold has been around for a long time. Droves of people crawling out of sick buildings with their lives in utter ruin is a fairly new phenomena.

The Great Climate Debate between arthritis sufferers and doctors is that people with rheumatoid arthritis swear there is a strong and direct correlation between their symptoms and weather change. Doctors can't find any evidence for this so it's “all in your head.”

Rheumatoid Arthritis is now linked to a Mycoplasma infection. Mycoplasma is small enough to occupy a viral niche. Is is not possible that it could activate an antiviral pathway and be responsible for the Rnase-L depletion that is getting researchers to concentrate on a viral etiology for CFS?

I suspect that Don Scott’s Brucella Melitensis, Luther Lindner’s cell wall-less bacteria and Garth Nicolson’s modified Mycoplasma are all going to turn out to be one and the same organism, and that Multiple Chemical Sensitivity and reactivity to mycotoxins correlate directly to the extent of infection with this pathogen.

I do think that Stachybotrys is a horrible nasty mold and I wish the Department of Defense would release their animal studies that were conducted to determine if satratoxin could be used as a biological warfare weapon. I suspect that a great deal of effort was made to assess and quantify the exposure/effect relationship and that this would clarify whether our symptoms are consistent with our trichothecene levels.

But I'm not buying that I'm a genetically susceptible biological canary who deserves to be weeded out of the gene pool. I believe that my illness is only linked to Stachybotrys to the extent that it has a direct effect on an infection I already had.

The concurrence of symptomology described on message boards concerning MCS, FM, GWI, CFS, Stachybotrys, candidiasis and parasitic infection leads me to conclude that all these disorders are from the same intracellular defect. Only the names have been changed to protect the innocent opportunistic pathogens.
-Erik (2001, SickBuildings)

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While it's good that people are starting to notice the relationship between CFS and Mycoplasma, they still miss my point that it doesn't just make mycotoxin exposure more severe. It causes a direct sensitivity to specific toxins.

I'm tired of being told that all toxic exposures are equal and that mycotoxin reactivity doesn't deserve to be singled out for investigation. The fact that damn near everybody I talk to is aware of their sensitivity to a change in the weather indicates to me that they are mycotoxin reactive.

My sensitivity crept up on me just like everybody else. I just kept getting more and more sensitive to Stachy no matter where I lived or how I tried to avoid it.

My sensitivity corresponds to the extent of the infection and not to my exposure.

Biowarfare researchers would have been looking for the most potent pathogens to attenuate for their evil purposes. They would, in the late 1940s and 1950s, have been aware of the Russian experience with Stachy.

If it is possible to incorporate the genetic material that controls production of secondary metabolites into a Mycoplasma, look at the most powerful pathogens first...they would have.

-Erik (2001, SickBuildings)

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I've been on the undenatured whey protein for 4 years now and I agree that it has been the supplement that seems to do me the most good. Definitely not a cure and it didn't wipe out the Mycoplasma, but it seems to help. Lots of people have been using both the whey and guaifenesin stuff for a while now. I haven't heard that it's a magic bullet.

I've tried every damn thing that I could afford and nothing did much more than help a little bit until I tried this crazy mold avoidance thing.

I just got back from climbing Job's peak, about a 5,000 ft. altitude gain. After 13 years of godawful living hell, I never dared hope that I could recover to the extent that I have.

Let me ask you this. If toxins are the prime mover of CFS and GWI, how do wives and children get it?
There is a smoldering infection just waiting to blaze with a toxic exposure, surgery, mold, stress or any other thing that pushes you over the edge. You wouldn't have a glutathione depletion if there wasn't something that used up everything you got and more.

You've seen the huge increase of people complaining about Stachy. That's just the beginning. Uncontrollable fungal infections and chemical sensitivities come next.

-Erik (2001, SickBuildings)

*I*

I took 300 mg. of doxycycline a day for a year and it helped, as I say, a little bit. I had to stop because yeast got out of control. I think it was worth it though.

Garth Nicolson says the antibiotics are just bacteriostatic and it takes a healthy immune system to get rid of them.

Absolutely nothing that I have done compares to the results I get by avoiding mold. I taught my girlfriend to do it and she has the identical response.

I know that any toxic exposure that you happen to be sensitive to can set off the response, but avoiding paint, perfume and petroleum products never lessened my reactivity to mold. Avoiding mold decreased my reactivity to everything else.

That still might be considered just my own personal fluke, except I noticed that almost everybody with CFS that I talk to complains about the same things that led me to suspect that mycotoxins were my primary reactor.

And then, repeating my experiment with a girl I met who complained of similar problems, and getting identical results, reinforced my concept in a big way.

I asked Garth Nicolson if constant low level exposure to mycotoxins might not have the same effect on mycoplasma as giving somebody penicillin. He agreed that might certainly be the case.

We are all infected with something that hates mold. PTSD is right, Perpetual Toxic Shock Disorder!

-Erik (2001, SickBuildings)

*I*

As bad as mold is, it just shouldn't be doing this to me. And I don't think I'm a canary either. I got a flu-like respiratory infection over 20 years ago and I've just never gotten
over it. My sensitivity to Stachy and other molds grew worse no matter where I lived or how healthfully I tried to live.

I've been diagnosed by two of the best known CFS specialists in the world as being the perfect case of CFS and through it all I kept asking, "Why is mold killing me?" There has never been any attempt to address this question.

I've been watching this whole thing develop into a monster. I've watched people acquire this illness and start complaining about all the same things I complain about. I've been in their contaminated houses and work places and I see the same thing over and over again.

Some people get sick and some don't. It creeps up on you slowly until one day your immune system collapses, and it doesn't have to be mold to do it. Other toxic exposures or immunological challenges do it too. For some reason, Stachy is the most common irritant, but it is clear to me that Sick Building Syndrome is only the most visible manifestation of a far wider infectious immunological problem.

Gulf War vets complain about the lasting problems associated with their toxic exposure. American and UK soldiers had multiple vaccinations and show a high prevalence of CFS-like symptoms. French soldiers were not vaccinated but given prophylactic antibiotics, and they have had no problems with Gulf War illness. If that isn't a smoking gun, then somebody shoot me.

-Erik (2001, SickBuildings)

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If somebody can show me that mold has used modern materials to increase its toxicity and prevalence, maybe I could blame just the mold. But the spread of this problem is behaving like an epidemic.

I was at my physical peak when this illness struck me down. The last time I remember feeling good was before I was vaccinated in the Army.

Yes, mold knocks me out. Why me?

-Erik (2001, SickBuildings)

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Mycotoxins are mold toxins and Mycoplasma are cell wall-less bacteria that are so small as to be virus-sized.

I believe that Sick Building Syndrome may be a manifestation of the Mycoplasma epidemic that causes CFIDS and Gulf War Illness.
A combination of mold avoidance and antibiotics directed at Mycoplasma infection have resolved my CFIDS symptoms and mold reactivity to such an extent that I've resumed a normal appearing life and can even stand a fair bit of mold exposure, though I still have to be careful.

Based on my own experience, I had been warning people for years that a mold epidemic is certain to happen. It's been pretty phenomenal watching this whole thing progress.

-Erik (2002, SickBuildings)

> Some states have managed to track down a cause. In New York, an outbreak among 242 elementary and middle school students (representing seven percent of the population of their school district) between January and April was determined to be the result of parvovirus B19, which causes fifth disease, an infection of red blood cells.

The reference to parvovirus B19 reminds me of Candace Brown’s description of the Huntsville Mystery illness and how her theory that parvovirus B19 had infected the DNA of the mycoplasma involved in her son’s illness.

-Erik (2002, SickBuildings)

> In a normal person, the cytokines will go away as soon as the threat subsides. Sometimes, though, the immune system overreacts, can't regulate itself, and that leads to autoimmune diseases, Morgan says.

What if the immune system doesn't perceive that the threat has subsided because the pathogen is hiding from immune surveillance inside yeast and elsewhere in the body, on the periphery of immune function, and still pumps out T-cell disabling superantigens in response to chemical challenges that threaten it (i.e. antibiotics or mycotoxins)?

-Erik (2002, SickBuildings)

The Gulf War vets were found to have a genetically induced deficiency of paraoxonase type Q. Those that were ill had the lowest levels. Then their wives and children had soon acquired this same genetic deficiency after their return.

Since toxic pollution isn't contagious, but the PonQ enzyme deficiency is, it might be reasonable to think that this is an infection induced deficiency of regulatory genes.
Almost 20% of Californians self report chemical intolerance. Why would anybody make up such nonsense if it weren't true? I wouldn't join a group of crazies and face the abuse of my family and friends and doctors just for kicks.

People can argue about the fine points all they want, but there is no doubt that this unprecedented mycotoxin/chemical intolerance is spreading like a contagion.

Is there any record of buildings, schools, jobs or homes being abandoned by people claiming that this "place is killing me" even remotely suggestive of what is happening now?

Judging by all the doctors, mycologists, microbiologists and toxicologists who've said that this is absolutely impossible, I'd say we're dealing with a new and unprecedented phenomenon.

-Erik (2002, SickBuildings)

* 

I'm a graduate of Truckee High School and a survivor of the 1985 Incline Village CFS epidemic described the book "Osler's Web."

Dr. Cheney told me that I was one of only 19 people that had been found to be EBV negative, so they used my blood to demonstrate that CFS was not CEBV. So in effect, the parameters of CFS are in part based on me.

I never found any therapy that directly addressed my symptoms until I came up with a strategy of extreme mycotoxin avoidance.

One of my first questions during the Incline Village epidemic was "Why is mold killing me?" But I was told that this was impossible so I didn't pursue the mycotoxin connection until it became apparent that no one was going research the role of mold in CFS or help me devise an extreme avoidance protocol.

I proposed this concept when I was sick enough to be "at a point where most people with CFS commit suicide" and was told that, "Mold avoidance won't work and only Ampligen can help you."

I couldn't afford the Ampligen and went ahead with my strategy of extreme avoidance. Within six months I had resolved my MCS and CFS symptoms and celebrated my recovery by climbing Mt. Whitney.

I've been mountain climbing, backpacking and mountain biking ever since with no relapses. I've told my story to hundreds of doctors, researchers and people in support
groups but so far, Dr. Ritchie Shoemaker is the only doctor who understands what I'm talking about.

I recently did a ten day backpacking trip up the John Muir trail camping at up to 12,000 ft. altitude. Quite a difference from being laid up in bed unable to move, and yet the only people who believe me are those who were there when I proposed this concept and then used it to recover.

I still don't know what causes CFS, but I know that my strategy is the only therapy that has allowed me to escape symptoms.

My experience is a spectacular demonstration of the mycotoxin connection to CFS.

-Erik (2002, SickBuildings)

*I've watched people do the most amazing diets - each one thinking that vegetarianism, proteinism, fruitarianism, breathairianism and every other stinking "ism" must surely be the cure for this problem.

I haven't seen awesome results come out of any of these diets.

I decided to pursue the association between exposure to mycotoxins and exacerbation of symptoms years ago.

I took myself out of Dr. Peterson’s CFS/Ampligen program and have been mountain climbing and otherwise exercising a degree of control over my problems that is unmatched by any other therapy.

I've also been contradicted - told I am outright wrong, crazy or delusional - ever since.

I offer to get extra permits for climbing Mt. Whitney to swap theories together and see which CFS theory makes it to the top first, but no takers.

I also try to nudge the "experts" in the direction I have taken, but have only convinced them I'm nuts. So I just wait for more people to drop and try to post enough clues out there to eventually get the attention of a serious researcher who can take advantage of the lessons I've learned to make some extra headway on this problem.

I can assure you that no government legislation over mold levels could ever help anybody who has acquired this level of sensitivity.

When there is a period of barometric pressure change, I simply cannot be anywhere near accumulations left by spore plumes, indoors or out.
I'm actually lucky that the "experts" abandoned me in my efforts to explore to connection between my symptoms and mold exposure. Their understanding of mold is so wrong that taking their advice is counterproductive and would lead you to think that the problem could not possibly be from mold at all.

If you go into a building contaminated by stachy during high pressure when the spores aren't releasing mycotoxins and get intact spores on your clothing, you can carry them around and not have much of a response until they dry out or you get into an elevator or drive up a hill in a car or go into an air conditioned building and set them off. Things like this lead to what are apparently impossible contradictions in an association between contaminated areas and symptoms.

There is a fine art to mold avoidance that cannot be understood by "experts" who lack the sensitivity to understand our complaints.

I am certainly not advising against diet to try to address this problem. In fact, I'm willing to explore anything that seems reasonable.

Until then, I haven't found anything that deals with the symptoms as well as strict avoidance of the perception of exposure to mycotoxins.

My girlfriend fell below the immune power curve by not carefully regulating her overall exposure to mold. This summer was hell and it took every trick of avoidance I've learned to get her functional again, but we did it. We climbed Mt. Whitney together on September 21.

We feel sorry for others in our situation who are subject to this horrible reactivity but have no effective means to deal with it. But our efforts to help others who are obviously suffering from the same reactivity is totally rejected in favor of advice from doctors who are completely clueless.

I think Ritchie Shoemaker offers the best hope for a doctor who will eventually arrive at an understanding of the nature of this reactivity. I want him to have every clue available to resolve this as quickly as possible, because I sure am tired of living this crazy mold avoidance lifestyle.

-Erik (2002, SickBuildings)
Chapter 45 - Causal Theory

AFTER A SLAM

Dr. Shoemaker has identified an entire chain of sequential cascade activations, which go on for a lousy week after a really good slam.

The initial "what you can feel" may die away after a day or two, but that doesn't mean your immune system doesn't continue to be thrown into prolonged turmoil for much longer.

The ripple effect of cytokines cascades through a number of different processes, as the immune system sequentially tries to reset itself.

It's considerably different from the normal processes of tiredness. Watch for an increase in oral candida during this phase.

-Erik (2008, CFSU)

BLOOD-BRAIN BARRIER

The interesting thing about responses to neurotoxins is that they actually outstrip the speed of the blood to the brain.

This is a true neurological response channeled to the brain through olfactory nerve stimulation. Certain scents are well known to have this direct neural stimulation.

I suspect that we're simultaneously dealing with components of at least three different types of responses that all come under the heading of "allergy" and that still remain to be sub-classified in a meaningful way.

I would be amazed if we weren't having an allergic response to inhaled antigens, plus a systemic eosinophilic response, plus a neurological limbic kindling response to those nasty neurotoxins.

Wouldn't it be great to find one kind of doctor who knows about all the different allergic responses rather than having to see three?

Doesn't it feel like mold is a triple whammy?

-Erik (2003, SickBuildings)
Dr. Shoemaker gave an explanation for how Matrix Metalloproteinases act as enablers for inflammatory products to sneak through the blood-brain barrier.

-Erik (2008, CFSU)

> When all the MAST cell binding sites for an allergen are bound, the MAST cell membrane tunnels all open up, releasing many different compounds into the blood.

Tests show that while the mast cells certainly do degranulate eventually, there remains an unexplained component of reactivity that occurs too quickly for this explanation to fit the facts.

Only direct olfactory stimulation of neural inputs seems to fit the bill.

Martin Pall suspects the vanilloid receptors.

-Erik (2009, SevereReactor)

HEART

Don't prejudge Dr. Cheney's work by focusing on this aspect as if he might be claiming that "CFS is nothing more than heart disease."

The Johns Hopkins work points to a circulatory disorder that consists of an irreconcilable conflict between the circulating catecholamines from the tissues telling the heart to deliver more oxygen - and the mechanoreceptors in the heart which sense excess pressure from irregularities induced by autonomic dysfunction and cause the left ventricular pooling.

Like a combination of Lerner's viral defect and Krebs cycle metabolic dysfunction.

It's the "irreconcilable conflict" that must be opening up the hole, which might even be an evolutionary cardiological safety valve.

-Erik (2006, CFSExp)

> Interesting to note is the shunting of blood from the left heart atrium to the right which can happen with PFOs and leads to sending unfiltered mini clots, debris and toxins to
our brains and body. This can happen under various circumstances, but I think for PWCs is this can happen from simple exertion.

Brilliant!

And it sure seems to go along with "sudden onsets" who go from athletic to immobile literally overnight.

Something happens that screws up Q, heart PFO goes bust, and there you are!

-Erik (2007, CFSExp)

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—I was really tired, and then I got palpitations and dizziness. It seems to have started in my neck. I was shaking from head to foot. Medical tests turned up nothing. Has anyone else had this happen?

Indeed, this did happen to me as well.

It's a devil to figure this one out.

It was a very important clue.

This struck me as being an irreconcilable conflict between peripheral "messengers" of arterial perfusion, the circulating catecholamines, and the safeguard system of autonomic mechanoreceptors in the heart.

Capillary beds are desperately calling for more oxygen, and the heart is already in danger from pumping too hard.

Something has to give.

First the extremities, and then the brain.

-Erik (2009, WPI)

* 

It's the hole in the heart, "Patent Foramen Ovale."

It closes up after birth, but remains a weak point.

It's a flap, so it can mess up intermittently.
This PFO phenomenon is known in scuba diving for causing divers to suffer a savage case of "the bends" while decompressing from depths that would otherwise be well within the safe range of the rate of decompression.

Dr. Cheney seems to think that pressure is forcing it open again.

Under the circumstances of wild cardiac pressures, loss of Q and T rhythm abnormalities, this sounds like something that could happen.

But I think that an additional mechanism is at play and unveils the PFO in a number of cases.

-Erik (2009, WPI)

**HHV6A**

I'm wondering if a herpetic B cell viral infection could be shifted to an autoreactive T cell proinflammatory cytokine illness (as in MS) by some lymphocyte subset depleting trigger or immunological challenge that allows penetration of the blood brain barrier and results in lymphoproliferative disease.

Might the sudden onset be the exposure that results in that shift?

If the regulatory genes are coding for the appropriate response, wouldn't the gene expression also shift to reflect the change?

The UBO's (unidentified bright objects) in the brain that are similar to MS but without the severe myelin scarring and axonal dysfunction suggests to me that CFS might be an illness of neuronal "autoimmunity" that has similar inflammation but less destruction.

-Erik (2003, CFSResearch)

* I am perfectly willing to agree that the evidence for HHV6a as causative may dwindle, but that as a cytokine inducer it may have very well have unveiled immune dysfunction and precipitated CFS in the same way so many other cytokine challenges have resulted in a similar effect.

-Erik (2004, EuroLyme)

* If there are differences between what Dr. Bell was seeing in Lyndonville and the phenomenon that lured Kaplan and Holmes out to investigate "Tahoe Mystery Illness,"
the difference that Dr. Peterson was trying to convey may very well be the difference made by a particular strain of HHV6a.

This may account for why we described the illness in terms of paralysis, while EBV onsets tend to describe it more like fatigue.

-Erik (2008, CFSU)

* 

The HHV6 that Dr. Peterson has identified in the spinal fluid causes swelling and pressure. This is reflected in the high opening pressure on lumbar taps.

For whatever reason, the people I saw with "Tahoe Flu/HHV6a" were especially responsive to the toxins from Stachy, and the presence of that toxic substance made this neuroinflammatory problem unbelievably worse.

-Erik (2008, CFSU)

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Dr. Peterson's initial theory was that Ampligen would be highly effective against HBLV, later called HHV6 and then renamed again HHV6a.

But despite its seemingly being able to knock down HHV6a, the patients had a wide range of response to Ampligen. And if the drug truly is an effective antiviral, why did it take so many months before some people improved? Why would some relapse so dramatically when it was stopped?

Peterson, Cheney and De Meirleir now seem to think of Ampligen as being more important as an immune modulator than an antiviral.

By carefully controlling my exposure to a ubiquitous neurotoxin, damping down an immune reaction seemed to be what I was doing.

I am mostly just speculating that since Dr. De Meirleir confirmed to Dr. Shoemaker that mycotoxins cleave Rnase-L, mold avoided is Rnase-L not cleaved.

-Erik (2008, CFSU)

**IMMUNE REPROGRAMMING**

I remember seeing a fascinating article about a link between an intestinal autoimmune response an Autistic child and mold by way of cows.
A mother noticed that her Autistic child did not have a reaction to a certain kind of milk. Since the doctors had said the child’s reaction was to milk proteins, the miraculous exception to the rule caught her attention.

Amazingly enough, she had doctors who didn't immediately dismiss it and say, "That's impossible." After all, a simple test of giving the child the milk demonstrated the existence of the anomalous lack of response. (Don't you wish you could find such doctors?)

An investigation showed that the intestinal autoimmune response was to milk consumed by cows that had bovine mastitis caused by Aspergillosis. But the really interesting part was that the Aspergillus toxins weren't passing through in the milk. It was the bovine immunological response to Aspergillus that programmed the intestinal autoimmune response in the child.

"Bovine Mycotoxin Transfer Factor" and not the presence of the toxins caused the milk intolerance in this case.

This was an incredible way of looking at a mechanism that might program a human immunological response to mycotoxins, but I haven't seen any follow up on this line of research.

But I see no reason at all that exposure to ingested mycotoxins would not create symptoms of Crohn’s Disease in someone thus programmed.

- Erik (2004, SickBuildings)

*

No discussion of what constitutes biotoxin mediated illness would be complete without mentioning that the reason this problem is so misunderstood is that the actions of ionophore biotoxins is not solely a case of classic toxicological cytotoxicity.

It is also a matter of altered expression of genes by toxins.

The far more important technical problem than pursuing conventional cytotoxicity effects from mycotoxins is the necessity for understanding immune reprogramming by innate complement activation factors in biotoxin mediated illnesses, which is what makes these types of illness a mystery from the normal toxicological point of view.

- Erik (2006, SickBuildings)

*

Dr. Shoemaker says that our HLA DR genetic profile is unveiled by the cytokine insult. And if one has a susceptible profile, which 24% of the population does, it can explain
why there can be instances where some people are made horribly ill and others are immune to that same toxic challenge. Makes it look confusing and crazy.

Doesn't matter whether your profile is unveiled by Lyme, Pfiesteria, mold, or microcystis. Once it has happened, you are primed for subsequent exposure to ionophore toxins no matter where they come from.

Drove people nuts that they could get Lyme and become Sick Building Syndrome even if they weren't in a sick building, or get exposed to red tide in the Gulf and then have problems in the Chesapeake, but there you go.

Took a Shoemaker to figure it out.

-Erik (2008, CFSU)

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Dr. Park, thanks for your important work on arteriolar vasculopathy.

Dr. Zamboni's findings in MS of increased iron deposits which were allowed to accumulate by lack of proper microcirculation appears to be further confirmation of your hypothesis.

And appears to be consistent with Dr. Erich Ryll's 1975 terminology for the illness of "Infectious... See More ... See MoreVenulitis" which predated the coining of "CFS" by more than a decade.

However, if the virus were a retrovirus that directly removed critical programming from leucocytes, which are now incapable of recognizing and responding to pathogens, might this not be a situation in which that particular virally induced dysfunction does indeed become the main point?

-Erik (2009, CAA)

** IMMUNE SYSTEM **

Dr. Cheney told me that the immune system was upregulated against something that had yet to be identified and was wearing itself out by a constant response.

-Erik (2004, Locations)

*
>My ratio of the LMW Rnase -L is correct at 0.4 but I have the Rnase-L activated. A friend of mine has the ratio completely out of the limit at 6.7 but she has no activation of the Rnase-L.

Wouldn't that indicate your friend's Rnase-L is now depleted since the abnormal 37kDa is associated with elevated apoptosis/severity, while your activation of Rnase-L hasn't yet shifted the ratio from the 80kDa?

-Erik (2006, CFSExp)

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T2 trichothecene mycotoxins are powerful protein synthesis inhibitors that are known to inhibit macrophage burst function.

 Basically, you've got macrophages, so testing to see if you got them doesn't tell you that their function is impaired.

Fungal eye infections, "Keratinomycosis," sinus infections, "Eosinophilic Fungal Rhinosinusitis" and immune suppression can run rampant in sick buildings.

-Erik (2008, CFSU)

* 

As best I understand it, the chronic inflammation from innate activation complexes derails the very programming necessary for the WBC response that doctors are looking to as an indicator of illness.

The lack of response misleads them. The illness is the indicator, not the tests which fail to detect it.

-Erik (2008, CFSU)

**INTRACRANIAL PRESSURE**

The stories of people who have been desperate enough to undertake surgery for "sudden onset Chiari Malformation" to relieve CFS should be enough to demonstrate that there is a correlation between a chronic inflammatory state of the brain and spinal cord that is reduced by this surgery.

Chiari malformation should no more have a sudden onset than exercise intolerance.

-Erik (2004, OneClick)
I have horrible pressure with pain in the back of my head and neck. It has become worse this year and reacts to the barometer to an extreme, to the point of puking and staying in bed for long periods. I can’t remember what they call this.

Intracranial pressure.

I have seen many other people with this specific complaint. Extreme mold avoidance gives me total control over this symptom.

-Erik (2006, SickBuildings)

Another one of the symptoms that wasn't considered important was patients pointing to the base of their skulls and complaining of pressure and pain. To the extent that some people resorted to surgical stenosis to relieve "Chiari malformation."

It always struck me as rather odd that doctors were quick to consider that the brainstem "outgrew the cranial aperture" and caused pressure, instead of looking for some inflammatory process that might have caused spinal cord swelling.

But since people pointing at the top of their spines and complaining about a specific area that disturbs them looks like nothing more than a headache, it's not considered to be relevant.

No matter how many people point and try to call attention to it.

-Erik (2006, SickBuildings)

Do you see why I have to stick to the original CFS description as being CFS?

Whereas some people may have a generalized fatigue from mold, the CFS that I know does a bit more than what we see in a lot of fairly similar appearing conditions.

The spinal pressure is a huge clue.

This literally separates the brain from being able to accomplish its job of controlling muscles.

-Erik (2009, Email)
Remember the elevated pressure on lumbar spinal taps that Dr. Peterson was using as evidence of possible CNS inflammation?

Well, Dr. Baraniuk and Dr. Ravindram at Georgetown University have been testing proteins in spinal fluid, and they noticed an amazing thing:

After a draw of fluid, the patients’ cognitive symptoms and brain fog would dramatically improve.

But this only lasted for several hours, and then they were back to being messed up again.

A clue!

-Erik (2008, CFSU)

* 

>It would go like this: change in mood (depression), tightening in the head and neck (brain compression), then, if I hadn't left, migraine. Then floor.

You are the best representer of why I am unwilling to alter my presentation of CFS.

This is the specific mechanism that what I am doing with the avoidance strategy somehow manages to intercede.

This is the process that requires direct research.

-Erik (2008, CFSU)

* 

Look at this post from February 2000 about a woman with ME who drilled a hole in her head.

Sounds crazy, but she researched it and knew precisely what she was doing.

-Erik (2008, CFSU)

* 

That pressure at the base of the skull seems to be a result of the elevated cerebrospinal fluid pressure often seen in CFS.
Sometimes people are misdiagnosed with "Chiari Malformation," a genetic condition where the cranial aperture is too narrow and puts pressure on the spinal cord.

They go through a horrific procedure called surgical stenosis to carve out the bone and widen the aperture.

And then the problem just comes back.

Doctors can’t seem to figure out that a neurological inflammatory condition actually causes swelling.

Many chiropractors are capitalizing on the fact that they can relieve this symptom by misconstruing this to be the cause of CFS/FM.

And, of course, claiming that they have the cure.

Which they cure again and again, no matter how many times it comes back.

-Erik (2009, Locations)

*

At the Reno conference, I heard Dr. Peterson talking about the remarkable remission that has been observed from surgical stenosis to address Chiari Malformation.

But we are just doing it naturally, the old fashioned way.

By avoiding neuro-inflammatory irritants which cause the swelling.

-Erik (2009, Facebook)

*

I thought my cranium was going to explode and spew spinal fluid all over the place.

I just heard that another Ampligen group patient had surgical stenosis for Chiari malformation.

It never did make sense to me that doctors treat this as if the problem is that the cranial aperture is too small, rather than the spinal cord growing too large by swelling from inflammation.

If one could damp down that inflammation, it would seem obvious that no surgery would be needed.
And if the inflammation continues on, unabated, what prevents the spinal cord from swelling more, after the surgery?

I talked with Dr. Ravindran at Georgetown University, part of the Baraniuk CSF study, about this. He told me that after a lumbar tap, many patients experience an amazing degree of remission for several hours.

But then it returns.

-Erik (2009, WPI)

*

After starting avoidance in 1997, that pressure at the base of the neck diminished and then disappeared.

I stopped bothering to carry aspirin around ten years ago.

Whenever I get too lax on the avoidance routine, I go below the immune power curve and my back starts to kill me big time.

-Erik (2010, WPI)

**MYCOPLASMA**

It's interesting that Dr. Peterson found HHV6a in close to 80% of CFS.

Garth Nicolson found Mycoplasma infections in 80% of GWI/CFS.

-Erik (2004, EuroLyme)

*

I certainly haven't forgotten about bacterial gene swapping-plasmids.

If it is a genetic sequence that crosses bacterial boundaries, who is to say that Mycoplasma or spiroplasma didn't conjugate extraordinary plasmids until we test for cross commonality?

If that were the case, then someone with, say, Mycoplasma Fermentans might have the same mRNA disrupting sequence from a different pathogen.

All I'm saying is that the strange disparities such as the simultaneous emergence of so many different spirochetal species should be addressed before we consider the case to be closed.
Just being cautious after "Bug of the Month Club" for so long.

-Erik (2006, Locations)

* 

Back in 2000 to 2002 was the closest I’ve come to implicating a specific organism of Mycoplasma infection as a co-factor in this type of illness.

> Are you saying that mycoplasma infection is most likely part of my problem with my reactivity?

Since I don’t have access to a lab, I’m still waiting for scientists who have all the tools to duke this out and tell us what science has to say upon the matter.

I did not have any problem at all with the antibiotics, but then, I was already at a good stage of improvement through sheer mold avoidance.

This was an attempt to get out of having to be a mold maniac for the rest of my life, to get rid of the reactivity.

In 1999, when I described this situation to Prof. Garth Nicolson and his microbiologist, Dr. Gann, they were both amazed. They had been completely unfamiliar with this type of mold reactivity, but Garth had just heard from some European Mycoplasma patients that they had just identified their own "extreme reactivity to mold."

That got his attention!

Garth told me that if I could come up with funding, he would be happy to use his lab to investigate this mold connection.

I thought, "That shouldn't be so difficult. Millions of people are wondering what CFS is, and as a prototype for CFS, any serious researcher who is looking for clues will take an interest in an Incline Village survivor who walked out of the Ampligen program and returned to an active lifestyle by mold avoidance."

No problem.

Hah.

-Erik (2009, SevereReactor)

**NATURAL KILLER CELLS**
The NK Cells are low, and even the ones still floating around aren't doing what they normally do in the presence of an antigen.

Low and low function.

This is something I find really fascinating in light of an old study that showed that NK Cells completely lose their orientation after a single exposure to JP-8 Jet Fuel.

Even worse, these confused and aimless NK Cells could be removed and placed in blood containing normally active NK Cells, and, wouldn't you know it?

The darn NK Cells in the "never-exposed" blood started acting just as confused as the ones with direct JP-8 exposure.

Once the immune assault had been removed, the genetic switch had been flipped and the cells seem to have the ability to transfer this information without any trace of the original problem.

I thought this study was absolutely staggering in its import.

JP-8 is a special military jet fuel with an additive to lower the flash point so the fuel tanks can absorb more battle damage and allow more time to evacuate the craft in the event of fire.

That's why I find the peculiar location of several leukemia epidemics around military airbases to be of some slight interest.

If people at lower levels of exposure elsewhere could possibly still have confused leucocytes, perhaps at an occult subclinical level that doesn't directly result in an identifiable epidemic, might it not be possible that symptoms and eventual illness would be very broad and non-specific?

So one would never know why or where the immune system lost its way?

-Erik (2006, CFSExp)

*

>I found the following in PubMed. It suggests that mycotoxins could be responsible for CFS.

Spectacular! And when you factor in the pre-sensitization of Beta Glucans that upregulate response to T2 even further, you wind up with a mouse model that approximates our situation.

-Erik (2006, SickBuildings)

Toxigenic mold activities produce metabolites that are either broad-spectrum antibiotics or mycotoxins that are cytotoxic. Indoor environmental exposure to these toxigenic molds leads to adverse health conditions with the main outcome measure of frequent neuroimmunologic and behavioral consequences. One of the immune system disorders found in patients presenting with toxigenic mold exposure is an abnormal natural killer cell activity. This paper presents an overview of the neurological significance of abnormal natural killer cell (NKC) activity in chronic toxigenic mold exposure. A comprehensive review of the literature was carried out to evaluate and assess the conditions under which the immune system could be dysfunctionally interfered with leading to abnormal NKC activity and the involvement of mycotoxins in these processes. The functions, mechanism, the factors that influence NKC activities, and the roles of mycotoxins in NKCs were cited wherever necessary. The major presentations are headache, general debilitating pains, nose bleeding, fevers with body temperatures up to 40 degrees C (104 degrees F), cough, memory loss, depression, mood swings, sleep disturbances, anxiety, chronic fatigue, vertigo/dizziness, and in some cases, seizures. Although sleep is commonly considered a restorative process that is important for the proper functioning of the immune system, it could be disturbed by mycotoxins. Most likely, mycotoxins exert some rigorous effects on the circadian rhythmic processes resulting in sleep deprivation to which an acute and transient increase in NKC activity is observed. Depression, psychological stress, tissue injuries, malignancies, carcinogenesis, chronic fatigue syndrome, and experimental allergic encephalomyelitis could be induced at very low physiological concentrations by mycotoxin-induced NKC activity. In the light of this review, it is concluded that chronic exposures to toxigenic mold could lead to abnormal NKC activity with a wide range of neurological consequences, some of which were headache, general debilitating pains, fever, cough, memory loss, depression, mood swings, sleep disturbances, anxiety, chronic fatigue, and seizures.

PMID: 14625399 [PubMed - indexed for MEDLINE]

*I don’t know my NKC activation, but my NKC count is high. Shouldn’t it be low in CFS?

Perhaps your overall numbers were driven up by Lyme, and might have been even higher still if it weren't for the mold exposure.

Lots of doctors look at NK numbers alone, and don't stop to think.
Dr. Cheney explained to us that the numbers are fairly meaningless, if the NK cells aren't programmed.

While our numbers were low, the function was even lower than one would expect. Those NK cells that were in the presence of pathogens didn't seem to want to even try to do anything about it.

Little bastards!

We've seen some people who have normal NK numbers, but the NK cells are inert and don't do anything but wander around like they are completely lost.

It's even possible that one could have elevated leucocyte subsets to one pathogen, a bacteria for example, and still be completely derailed against another... like maybe a virus.

-Erik (2009, SevereReactor)

http://www.jimmunol.org/cgi/content/abstract/139/10/3306

What Dr. Cheney and Dr. Peterson saw was that it wasn't a case of EBV starting the disease, so much as it was something deeper that derailed NK cell function and allowed viruses such as EBV to jump out.

We should have been looking for that deeper dysfunction all along.

-Erik (2009, WPI)

**OXYGEN TOXICITY**

There was something weird about my uptake of oxygen, a kind of "effect."

As far as I can tell, this weird oxygen effect from going to altitude is a confirmation that Dr. Cheney's oxygen toxicity concepts are correct.

For that reason, I am worried about people who are on oxygen.

This might be creating more damage in the long run.

-Erik (2009, WPI)

**PATHOGENS**
I never saw any coral being manufactured in Incline, and I hate fish.

I've read that various marine critters that employ Tetrodotoxins or Maculotoxins similar to Ciguatoxin actually obtain it from various bacteria (including Pseudomonas).

If there is an infectious biotoxin producing bacteria that could create flu-like symptoms with an uncharacteristic lowering of body temperature and act like an epidemic, that would fit the facts a bit better.

-Erik (2003, CFSExp)

*

Just as it has been proposed that Incline Village HHV6a CFS is a subset of the illness, there's no reason to suspect that CFSinclusive is a disease entity totally unto itself.

We have to follow wherever the clues lead us.

Perhaps many illness find their origin in this Ciguatoxin common denominator and branch into various disease subsets according to HLA and co-morbid infections/toxic exposures.

Anything that resembles Pfiesteria toxin so closely surely cannot be a good thing for anyone.

I haven't seen evidence that viruses can create any such toxin, but there's plenty of evidence that dinoflagellates do.

-Erik (2004, CFSResearch)

*

Remember the myelin inflammatory illness and "Unidentified Bright Objects" described in Osler's Web?

It's the autoimmune response triggered by the toxic encephalopathy. Just like Dr. Shoemaker says, these toxins just don't want to go away on their own.

I think it would be worthwhile to get tested for Mycoplasma to build up a conceptual model of the etiology. Plus we need to figure out the role of Lyme, but like Shoemaker says, he's seeing the cytokine response without Lyme in the presence of the HLA + MARCoNS.
As far as the mono goes, I've seen elevated EBV in people in moldy buildings. Also, Dr. Shoemaker suspects that the HHV6a in Incline Village is an exceptional cytokine inducer.

-Erik (2004, SickBuildings)

* 

What we do know is that doctors and nurses are particularly at risk for developing the illness when they work closely with CFSers - especially if they get a needle-stick direct blood contact.

-Erik (2007, CFSExp)

* 

If mold susceptibility is unveiled by another cytokine upregulating challenge, it may well be that it is the intensity of that challenge and not just the mold itself that is a major factor the degree of HLA expression of that susceptibility.

That might be why some people feel so much better on antivirals.

-Erik (2008, CFSU)

* 

"Sputnik" Virophages in plankton blooms.


-Erik (2009, SevereReactor)

RADIOMIMETIC

Dr. Croft,

I previously cited your work from the Saratoga Springs 1994 Conference "Proceedings" on the toxicogenomic aspect of Chronic Fatigue Syndrome.

For many years, I've been telling people that I must avoid Stachybotrys "as if it were plutonium" and I was struck by your comment on the "radiometric" effects of satratoxins.

Can you elaborate on the immunological effects involved?

Thanks for your work.
Tissue or cells of the body that were exposed and damaged by radiation can be observed in the cells of that body.

Radiation prevents the development of normal cells called differentiation or maturing of cells.

I think it is interesting that trichothecene mycotoxins have a radiometric effects on the body.

I have observed in the trachea and the uterus of young female adult at autopsy.

I do not know about the other parts of the universe, but this rule holds on planet earth.

Each disease has the pathology identified before it is called a disease. I hope this helps.

There are only a few poisons that do not have a fingerprint at autopsy because death may happen so rapidly, and those poisons are checked or assay for.

-Dr. Croft (2007, IAQ)

* 

Dr. Croft, who wrote the groundbreaking peer reviewed literature on trichothecene exposure in the US in 1986, speculates that the peculiar association of illness with Stachy is not from classical avenues of toxicity.

Certain aspects of the illness indicate more of a "radiomimetic" effect of genetic dysregulation.

The inability of the medical profession to make a direct "dose response" theoretical model of mold illness may be reflection that they are measuring the wrong immune dysregulation.

Suppose you had a "Stachy vs. Chaetonium" comparison in which the "toxicity" was measurably worse in one.... but the other had the far "lesser" and seemingly minor effect of simply making your immune response disappear.

If you weren't exposed to any pathogens during this mold exposure, you might not even notice the decrease in immune surveillance.

And if scientists didn't consider an unexplained loss of immune competence to be associated with that particular mold, a whole bunch of people in close proximity to this
mold could become simultaneously ill with different infections right in front of doctors, and they wouldn't see the connection.

-Erik (2008, CFSU)

* 

Now, think for just a moment about the "Proceedings" manual of 1994. The effects of Stachy were so far out of line with what a toxin does that Dr. Croft proposes that they suggested a radiomic effect of genetic alteration.

Now we know that the protein synthesis inhibitors of stachy exert a direct influence on macrophage function, not as a classic toxin, although toxins are surely present, but as an inhibitor of genetic function.

So given all that, when we see an illness of intraphagocytic innate-immune dysregulation that is strangely influenced by a mysterious substance from mold that also has an unexplored similar genetic-altering effect on macrophages, wouldn't it make sense to consider that the mycotoxin connection to CFS is no accident?

That's why I tell people not to get all worked up on seeing mycotoxins as classic toxins, as this puts them in a misleading contextual framework.

The data suggests that the true toxic value of mold exposure undoubtedly lies in its genetic dysregulatory properties.

-Erik (2008, CFSU)

REDOX

>It seems that the systemic presence of satratoxin leads to reduced levels of available glutathione.

So there you have it! If satratoxins of a peculiarly violent nature are capable of setting up a redox state, all theories of allergy and classical toxicity can go right in the garbage. They wouldn't apply.

Trying to impose the limitations and rules of allergy and classical toxicity are just going to drive you crazy, because they won't fit.

-Erik (2008, CFSU)

SED RATE
During the Incline Village "Mystery Illness" epidemic, the low sed rate was the very first abnormality Dr. Peterson and Dr. Cheney took note of that was crazily out of line.

Dr. Peterson told me, "Most doctors are taught that the lower the sed rate, the better, but a zero sed rate is ridiculous. It is an abnormality."

There are only about four illnesses which have a zero sed rate, and all of them are nothing less than serious.

Dr. Cheney, Dr. Byron Hyde and Dr. Burke Cunha consider this "pathologically low erythrocyte sedimentation rate" to be one of the purest indicators of just how whacked this illness is.

The altered sed rate appears to be a disruption in Smoluchowki's "sphere influence" which surround red cells.

This Brownian Motion keeps all those little cells dancing around in constant motion and separate from each other when you look at them under a microscope.

The loss of this surface energy influences the stacking effect, or rouleaux formation, which is critical in the red cells’ ability to perfuse microcapillaries.

It would make sense to explore mechanisms that affect globulins and fibrinogen, since they control this Brownian Motion.

Isn't it stunning that we could have such a dramatic compromise in normal red cell function, and nearly all doctors are not inspired to think this might be a sign of something wrong?

http://en.wikipedia.org/wiki/Erythrocyte_sedimentation_rate

The red cells have obviously lost their negative charge:

The Zeta Potential.

Zero sed rate = Zero Zeta Potential.

Dr. Shoemaker’s work is on ionophore toxins, which transport exogenous products in the blood across the basal cell membrane (where they otherwise could not go).

These ionophores literally short out cellular circuitry and steal the ion potential from cells.

If we have ion channelopathy in CFS, it seems like this would be a promising direction to look for a few answers.
>I had a sensation that was like fire ants dipped in acid eating the marrow out of your bones.

>This was usually in the extremities...and most likely, according to Dr. Shoemaker, due to faulty oxygen transport and misshapen red blood cells, which also could have something to do with the extremely low sed rates a lot of us have.

I had the bone pain, but I found something that helps.

A pathologically low erythrocyte sedimentation rate (sed rate) is one of the hallmarks of ME, and is reflective of the process responsible for the bone pain.


This might go a long way toward explaining the high rates of TMJ and cavitational osteonecrosis.

-Th1/TH2 SHIFT

Dr. Cheney suggested that the viral infection had us so overwhelmingly upregulated that common colds don't get a foothold.

He called us "The Invulnerables" when this little quirk of not catching stuff showed up.

I haven't had a single cold since 1985.

I've heard that the ability to catch colds again correlates to restoration of TH1/TH2 ability to shift back and forth as it should.

So I take it as a bad sign that I've never got one stinking cold.

Darn it!

-Erik (2006, CFSExp)

-I haven't caught one cold since 1985. Not one.
During the Incline epidemic, the prevailing concept was "depleted immune system." Virtually everyone, even Dr. Cheney and Dr. Peterson, had the suspicion that the very next cold or flu was going to kill us off for good.

What a surprise, when not only did we not all suddenly drop dead, we didn't even get sick!

Dr. Cheney called us "The Invulnerables."

http://www.prohealth.com/library/showarticle.cfm?id=2911

The TH1/TH2 is supposed to switch between intracellular and extracellular modes periodically.

The intracellular and extracellular responses can't both work at the same time. So the immune system picks one or the other, depending on circumstances.

When it's in one, the other is automatically downregulated.

It's equally bad to be stuck in either process.

The strange invulnerability is what really shows that denialists' concepts are totally wrong and that it really is an abnormal situation.

TH1 / TH2 is obviously switching back and forth in certain people, but can stay stuck in either mode for years.

Some people thought that catching a cold was a sign of returning to normal, but then they caught every cold and flu that went around.

This was so far the other way that they begin to say, "Wait, this isn't right, and besides, I'm not getting better."

-Erik (2010, WPI)

“THE EFFECT”

I don't think this conflicts with WPI's concepts at all.

I believe we are looking at the result of a combination of several different “inputs” that are being approached by several researchers from different angles.

Dr. Peterson and Dr. Mikovits' viral concepts.

Dr. Cheney's Reactive Oxygen Species,
And Dr. Shoemaker's observation of characteristics of ionophore toxins.

They all have to be combined to complete the puzzle.

For now, it looks like a competition between opposing theories.

But isn't this how puzzle pieces always look, until you turn them just the right way and see how they fit together?

I cannot break these concepts down easily.

Some of it sounds like total science fiction, unless you look into long enough and go, "Oh my God, such a mechanism really exists."

Dr. Cheney's "Reactive Oxygen Species" concept is absolutely mind-numbing.

-Erik (2009, WPI)

**TMJ**

There is a trick to neurotoxic-neural mediated TMJ that I could tell you about, but it would take hours, and I would have to explain Peter Dawson's "Principles of Functional Occlusion" and correlate his findings to neural activity mediated by mold.

To make this correlation, one has to have special knowledge in at least three different specialties in addition to being a Moldie oneself. So I can't talk to anyone about it yet.

> Does this qualify as one part of the specialties required?

> Clinically, the difference between the two occlusal positions can usually be easily determined by closing the mandible in its rearmost (and uppermost) position by manual guidance until the first contact is established. This is the retruded contact position. If the patient is then asked to squeeze the teeth together, a protrusive movement, sometimes with a lateral component, allows the mandible to slide towards the intercuspal position. In some patients, however, location of the retruded axis position can prove more difficult. Habitual closing movements, because they are performed repeatedly, will tend to end in the intercuspal position, rather than the retruded contact position. The precision with which ICP can be located on each successive closure is the result of a conditioned reflex, generated by a 'memory' in the neuromuscular system, known as an engram. In some individuals, the conditioned reflex makes manipulation of the condyles into the retruded axis position very difficult to achieve. This 'memory' must be constantly reinforced by tooth contacts in the intercuspal position, and if tooth contact is prevented by using an anterior jig or bite plane for a short period of time (approximately 10 minutes
is usually adequate; Lucia, 1964) the proprioceptive feedback leading to reflex closure in ICP is broken. The mandible can then be more easily guided into the retruded axis position.

You've gone straight to the problem.

Dr. Peter Dawson discovered that "Uppermost Midmost Rearmost" was completely wrong.

Instead, Centric Occlusion must be commensurate with Centric Relation according to the position of the TMJ disc.

Dentists are actually creating the mismatch which sets up bruxism by adhering to a flawed principle.

I attended Dr. Peter Dawson’s lectures where he spoke of the necessity to establish the condition of the disc-condyle before messing with equilibration.

When the disc is shifting around and there is no stable TMJ relationship, it's counterproductive to try to establish occlusion based on a false notion of a fixed relationship. Doppler Auscultation is used to "listen" to the motion of the condyle and find out just how badly the disc is shifting out of place. Starting point to determine what measures need to be taken.

Actually, bruxism results from the inability of the brain to complete a normal programmed function to develop proprioceptive engrams of such precision that the gnathological processes of mastication operate within the tolerance of a grain of sand. Whether the dysregulation is created by neural deficits or physical excursive obstructions, the point is that clenching and clearing is a normal and desirable occlusal process that must be conceptualized as an attempt to achieve functional occlusion instead of eradicated as if it served no purpose.

Since possession of functional occlusion is a matter of life or death to an animal, the body will go to great efforts to complete the process.

"Centric relation = Centric occlusion.

http://www.dawsoncenter.com/about/about.html

So then TMJ occurs as the body fights to complete engram cycles that mold toxicity in the CNS has disrupted.
Good God! Do you have the slightest notion of how hard I have tried to get people to give this the slightest consideration, without success? Hours and hours of trying to just suggest this one little possibility.

And you are right on top of it.

-Erik (2008, CFSU)

**XMRV**

The situation with XMRV reminds me of when everyone was so hopeful that the cause of "Tahoe Mystery Illness" was found in Chronic Mononucleosis Syndrome.

Seemed like treatment was right around the corner.

Then I got my test results from Nichols lab.

Dr. Cheney looked at them and boldly circled the part of it that changed everything.

"EBV negative."

EBV was merely reactivated in this illness.

A single exception disproved the rule.

The basis for changing the name from CEBV Syndrome to something else was the core body of evidence that the Tahoe Flu was capable of acting entirely independently of EBV or CMV yet still remain essentially the same illness.

To get at the true cause of CFS, one must separate inherent factors from ancillary ones.

The lesson from this is that if so much as one prototype for CFS is non XMRV, but still has all the other goodies, we may be acting prematurely by using XMRV as the sum total of causality.

-Erik (2009, WPI)

* 

If a discrete cluster cohort - like the Truckee teachers, Incline Village girls’ basketball team or the symphony orchestra - all acquire the illness in a shorter time than XMRV's incubation period allows, it would appear that the only way this could possibly happen is if the "Agent X" were already in residence and they were all triggered by something else.
- Erik (2009, CFSResearch)
Chapter 46 - Shoemaker Work

THE BIOTOXIN PATHWAY

Right after the preface and on the very first page of Dr. Shoemaker’s book, Mold Warriors, there is an important chart depicting "The Biotoxin Pathway" which explains the nature of biotoxin mediated illnesses.

This chart outlines the properties of ionophore toxins for binding surface (toll) receptors, which in turn cause the unregulated release of proinflammatory cytokines that reprogram immunological responses in genetically susceptible individuals.

The effects of the chronic inflammation cascade through the neuroendocrine system in a sequential progression called the biotoxin pathway.”

You can trace the downstream effects by following the chart.

The activation of the innate immune response by neurotoxins is upstream of antibody programming, so this chart provides a graphic representation of why concepts of classical allergy don't apply to mycotoxin illness.

It's partly a matter of "no more," but even more important, it is a matter of "no longer,” explained in Chapter 24, "No, It's the Immunity, Stupid - Innate, Acquired - Both!

-Erik (2006, SickBuildings)

SICKER, QUICKER

I told Dr. Cheney that, "I have an inexorably increasing reactivity to mold that grows progressively worse no matter where I live or how well I try to take care of myself"

Dr. Shoemaker talks about a phenomenon he calls, "Sicker, quicker.”

What he means is that with every bout of upregulation, a bit more anti-inflammatory cytokines are removed.

The more exposures you get, the more your immune system is unleashed to try to do something about it.

It is very difficult to calm down the immune system enough to start restoring these anti-inflammatory check valves on a runaway response.
There may come a point at which the immune system is so unrestrained that nothing can pull a person back. We just don't know. This can get really, really bad.

This sounds pretty dismaying, but the good part is that some of us who realized that this runaway train has to be stopped at all costs have successfully done so.

It wasn't easy. We had to be driven to a point of total desperation to take such desperate measures.

It was "turn this thing around... or die."

And the desert, or even some woodsly wilderness places, are absolutely great for doing this. But wow, it can be difficult.

That's why I had to build myself an all metal and plastic Mobile Environmental Control Unit, which I also sometimes call an "Escape Moldule."

Naturally when you hit this point, all the reasons people have for not undertaking extreme avoidance disappear - because when you're dead, you're not going to have any possessions or relationships with anybody.

But once you get out and start doing it, it’s amazingly not so bad.

And once you've climbed up the ladder to "Sicker, less quicker," you can dip back into your former life.

The restoration of lost enzymes and re-acquired anti-inflammatory response is felt by how you don’t become sick quite so quick anymore.

No doubt there will be drugs for this at some point.

But for those of us who had to do it without the benefit of any help, pure avoidance gave us more bang for the buck than anything else.

-Erik (2009, SevereReactor)

RESPONSE DURATION

The entire point of my story in Mold Warriors, and the reason Dr. Shoemaker wanted me to tell that particular story as opposed to all the others I have about mold and CFS, is that he wanted to highlight the way mold reactivity does not fit the standard concepts of toxicity any more than it fits the allergy paradigm.
This is why I continue to say that doctors still aren't looking into this, meaning that they are not investigating the aspect of the phenomenon that defies their conventional perspective.

The very concept of testing for mold toxification is compressing the paradigm into a dose response relationship, which clearly does not fit the facts.

See Dr. Shoemaker's "Mold Warriors" chapter on chronic-inflammation for an explanation of why this is important.

-Erik (2009, Locations)

VCS

People who recover somewhat on CSM and then relapse by re-exposure to a moldy building tend to have a negative VCS.

I have been so successful at modulating inflammatory cytokines by paying attention to toxic exposure that I'm pretty sure I wouldn't show up +VCS.

-Erik (2003, CFSExp)

*

> I passed the computer VCS test but not the handheld one.

The handheld test is more accurate so it makes sense that the handheld would pick this up if the computer was inconclusive and you were borderline.

I've heard that there is a peculiarity in which the inflammatory response to biotoxin re-exposure after treatment doesn't always generate a negative Visual Contrast Sensitivity deficit, which I take to mean that a positive result is positive but a negative result can be a false negative, possibly because cortisol has been restored just enough to protect vision unless one hits the wall again.

Other tests of cytokine release would be needed to confirm an inflammatory response after exposure to biotoxins.

It's the elevation of Immune Complement Activation factors after a controlled biotoxin exposure that confirms the diagnosis.

Without access to immune measurements, I've just accompanied people during a controlled exposure and then ask them how they feel and establish the presence of reactivity the layman's way.
The basis for the Functional Acuity Contrast Test used by Dr. Shoemaker to diagnose neurotoxic illness is the observation of retinal hypoperfusion in the Lamina Cribosa, the cells contained in a key layer of the optic nerve head, by using the Heidelberg Retinal Tomogram Flow Meter.

Reduced capillary flow is a sign of increased Tumor Necrosis Factor (TNF), a predictable cytokine effect of neurotoxic exposure.

The Functional Acuity Contrast Test to measure Visual Contrast Sensitivity (VCS) is a low budget, but accurate, equivalent of the HRF Heidelberg Retinal Flowmeter for detecting Contrast Sensitivity deficits. CS testing is also used to diagnose glaucoma in which the extra pressure in the front of the eye squeezes the blood vessels in the optic nerve. Glaucoma induced CS deficits are static while TNF induced CS dysregulation occurs quickly, just hours after exposures to neurotoxins.

It isn't enough to just detect the contrast deficit. The process must be understood in order to point toward the manner in which the deficit occurs to refine the diagnosis. As Dr. Shoemaker says, "a physicist ‘sees’ the neutrino by the trail it leaves behind."

This is how one finds biotoxin mediated illness - by measuring the aberrant responses peculiar to neurotoxic dysregulation.

Visual Contrast deficits are a consistent with neurotoxin mediated illness. FACT scores are the fundamental basis for initiating diagnostic protocols to separate a negative result from other illnesses and refine the source of biotoxin exposure.

The VCS doesn't necessarily mean mold. It can also be positive from pfiesteria, ciguatera, Lyme or cylindrospermopsis, all of which have specific types of toll receptor blocking ionophore neurotoxins.

The VCS is just a starting point on the biotoxin pathway. To find out where it leads, one needs to go through the Shoemaker assessment protocol.

The VCS indicates the effect of neurotoxin-induced capillary hypoperfusion on the nerve heads in the retina. The eyes are the quickest areas to show measurable responses to neurotoxic exposure, and it is the fact that there is some kind of difference to be measured that gives the diagnosis when placed in the context of Dr. Shoemaker’s other tests.
While the VCS test doesn't definitely tell you what is wrong, it definitely tells you that something IS wrong - a type of hypoperfusion that is a typical result of cytokine induced damage. The other tests narrow down the focus to identify the culprit.

Dr. Shoemaker describes the meaning of the other tests needed to make the diagnosis in Mold Warriors, but it's not straightforward as in "testing directly for mycotoxins.” It's more like telling the difference between a crocodile and piranha by dangling your feet in the water so you can look at the bite marks.

Once you see the big tooth marks, you know it's not a little fish.

The false negatives have been a confounder that let some people slip through the cracks. After the initial cytokine cascade that depletes MSH, if the thalamus isn't wiped out and ACTH can rebuild, it looks like the VCS can normalize.

But once you are primed, constantly enduring elevated innate immune responses from occult subclinical exposures that can keep you worn down.

You can sure feel the big mold hits though - such as when a weather front unleashes a vastly increased ambient mycotoxin load from spore plumes.

-Erik (2006, SickBuildings)

*I've heard rumors that people who have been slammed down to a very low point and then have a slight recovery can sometimes pass the VCS.

As Dr. Shoemaker says, a sick person might pass, but a healthy one wouldn't fail.

When the backup enzyme ACTH kicks in to support low MSH, the “boss hormone,” then adrenal function kicks up a notch and you pass the VCS. When MSH and ACTH are both depleted, you crash and become MCS.

Skyrocketing C4a still tells the story, even for those who pass the VCS.

-Erik (2006, SickBuildings)

**IMMUNE SYSTEM ALTERATIONS**

The sense that I get is that every immune function really does have a purpose which cannot be interfered with if there are no compensatory actions or alterations which will allow whatever it was doing to be impeded with impunity.
I assume that the condition which called for the immunological response which was negated by Actos was still ongoing and removal of the response without addressing biotoxins resulted in exacerbation.

Perhaps this could be a reason why just taking Actos alone without the rest of the program resulted in failure for some.

This protocol isn't a "take this pill and call me in two weeks" type of program. It's a concerted effort to bring a lot of factors into an improved homeostasis under some extremely adverse circumstances.

-Erik (2005, CFSExp)

**ACTH AND MSH**

Dr. Shoemaker found that a backup enzyme, ACTH, kicks in to prop up the MSH deficiency, but only acts until it too runs out.

It was puzzling at first to find that people in moldy buildings with the dreaded mold gene were low in MSH, but had normal ACTH and no serious symptoms.

But with continued exposure, suddenly people ran out of their backup ACTH and hit the wall.

Low MSH + depleted ACTH = disaster.

This is normally when doctors prescribe prednisone, which Dr. Shoemaker says is “like trying to put out a fire with gasoline.”

I've talked to a number of people whose MCS and most devastating symptoms started after taking prednisone.

So, even though it sounds strange, sometimes a mild mold exposure appears to initiate a suppressive response which disappears when ACTH is depleted, and then a mold responder will eventually feel worse than ever.

-Erik (2005, CFSExp)

*

Here's another fun little complication. Dr. Shoemaker was amazed to find lowered MSH / VEGF in people occupying Water Damaged Buildings (WDB’s) with high levels of toxin producing molds who had no symptoms.
They had the immunological precursors to hitting the wall, but they weren't showing it. But then Dr. S then found that the cortisol "backup enzyme" of ACTH was propping up their immune systems as a last ditch effort to keep them from total collapse.

The release of emergency ACTH was good enough at blocking the inflammatory response that people who are on the verge of full blown biotoxin illness can go into a lesser exposure and feel better.

But only until the ACTH is also gone.

This is why Dr. Myhill has made the anecdotal observation that testing fails to reveal mould sensitivity and you have to "go on holiday" to make this determination.

In order to unveil the full level of progressive debilitation, you must get free enough of mold so that ACTH isn't obfuscating the ability to detect low levels of exposure. This is simply unmasking the blocking effect that is well-known to people with MCS.

Because that's what we're dealing with here: mold toxins as a ubiquitous chemical irritant to people with an abnormal sensitivity.

-Erik (2006, Locations)

* 

If you read Mold Warriors carefully, you'll note that Dr. Shoemaker was surprised that some people in sick buildings were low MSH but weren't showing overt symptoms.

Then he made the correlation between the simultaneous MSH and ACTH depletion.

You have mini-recoveries when ACTH (the backup enzyme) starts to replenish, leading to a false sense of security. You can still be perilously MSH depleted, and all it takes is one really good hit to blast out the ACTH - leaving you completely immune-vulnerable.

This is when people hit the floor. They go to a doctor in a full on cytokine cascade. The doctor sees they are low in cortisol and prescribes steroids.

Which, in Dr. S's words, "is like trying to fight a fire with gasoline."

This is where mold illness can be precipitated into full blown MCS. Some MCSers can even point at the very moment when the steroids they took pushed them right over the cliff.

I know that when you feel better, the temptation to dive in and fix things is overpowering. But until you see what happens to enough people who have a very sad result when they do this, you just don't know what you are messing with.
It's like a freight train slamming you. One minute everything seems okay and the next, you can't believe this is happening.

-Erik (2008, CFSU)

LYME

People think that Dr. Shoemaker doesn't believe in Lyme because they misinterpret what he is saying.

If the problem is persistent infection - sure, treat it.

But if it's recirculating Lyme ionophore toxins, it's just a waste since the primary problem is the toxins - which, of course, are not alive and cannot be killed.

-Erik (2006, CFSExp)

COMPLEMENT

What test would give me relevant information about a situation in which the place that was slowly killing me somehow did not, and yet the mere presence of objects from that place was now doing so?

Only one that I know of. The inflammatory markers for complement activation factors used by Dr. Shoemaker.

If you are at this level of reactivity, there is no conventional test that will do anything but make you appear crazy. And the place that was the real illness instigator might not even be the place you are testing.

Until you have a real-life diagnostic demonstration of an immunological response to such a low level exposure, your own mother will look at the way you complain about being "slammed by my stuff" and say that you must be completely insane.

But if you can't carry around Shoemaker's tests to help you determine on a moment to moment basis what is going to slam you or not, you have only one recourse.

Use the best test device that nature could devise - you!

There's no other way.

-Erik (2005, SickBuildings)

*
C4a is a response, so it varies. It doesn't mean much to just measure C4a.

If it's not particularly elevated, it just means you aren't upregulated at that moment.

If you are, what does it tell you, other than this particular innate response has been activated... by what?

To extract meaning from the test, it has to be place in context of exposure to a particular substance. That's why Dr. Shoemaker calls it his "five step exposure assessment protocol."

-Erik (2008, CFSU)

**DR. SHOEMAKER’S PROTOCOL**

The uncertainty about Dr. Shoemaker’s protocol reminds me of being a hang gliding instructor and seeing some people struggle to pick up the glider while holding it in a "pitch down" negative attitude to the wind which would force the glider down.

They would struggle, grunt and groan, and I'd say, "You're trying to overcome the downward force of a glider that develops more than enough force to pick you up. You cannot hope to overpower anything that powerful and have to work WITH the glider to make its lifting power agree with what you want it to do."

And I would demonstrate that a simple "pitch up" would get the wind under the glider and develop enough lift to make it rise effortlessly into launch position. I'd even let go of the glider to show that it was rising completely by itself with no effort.

Some would see that the effect had just demonstrated itself by a simple movement and learn to do it by just by seeing it once.

Others would retort that this was impossible since they had felt the sheer weight of the glider and assert, "You just made that look easy because you're the instructor and have had plenty of practice."

Strange to see that response, because anyone who has ever stuck their hand out the window of a moving car understands the principle that controlling the pitch attitude of your hand makes it go up or down and to deny what they had just seen was literally denying the evidence of their own eyes.

If you are a mold responder, of which many are who are completely unaware, Dr. Shoemaker’s book has demonstrably shown people how to fly out of their situation, while others can watch them do it and are still stuck on the ground, bewildered at what they just saw.
For those who can see it and apply the lessons, Desperation Medicine gives them all the information they require, and Mold Warriors is even more explicit.

If you are VCS positive for neurotoxins, these books can give you all the answers you need to get started toward recovery.

-Erik (2005, CFSExp)

*I've heard of a few doctors who are starting to pick up on Shoemaker’s methods, but if you have a decent doctor who might consider going over the test procedures outlined in the book, your doctor would be at the leading edge of a new paradigm.

This testing isn't really "for mold" as much as it looks for signs of an inflammatory response to mold. As Dr. Shoemaker describes: "A physicist ‘sees’ the neutrino by the trail it leaves."

And because this is a systemic response, it just doesn't match people’s conceptual model of what a reaction to mold must feel like, so the connection is rarely made - despite what you'd think.

Lots of people became suspicious, but discounted it when their doctors told them it was impossible.

It's not.

-Erik (2005, CFSExp)
Chapter 47 - Channelopathy

MAGNETS

When I first heard about people selling magnets to help with pain, I was furious. I figured anybody stupid enough to fall for such a scam deserved to be ripped off.

Then I started hearing people who had no reason to mislead me say that the magnets really helped. I figured this must surely be the placebo effect and that there would be a correlation between how well the magnets worked and how metaphysical the person’s belief systems were.

Then these damned magnet people started demonstrating the effects of magnets on dogs and horses.

If there really is any benefit, what could it be?

Shoemaker describes the degradation of the ion gradient in neurotoxin mediated illnesses.

Could it be possible that the magnetic field increases the differential that potentiates the gradient?

If there is an effect, there must be a reason. Let the science follow the observation rather than dismiss the observation for lack of science to explain it.

Might it be possible that if some people report improvement from any of these "miracle machines," it could be a serendipitous influence on the ion gradient and not smacking down a bug at all?

The history of invention show us the most of the best discoveries came about in just such a fashion.

-Erik (2003, CFSExp)

SODIUM ION CHANNELS

The ciguatoxin paper makes one of your symptom sets seem more likely to come from [sodium channel opening to norepinephrine and acetylcholine release] than from TRPA1 stimulation as I had previously hypothesized. It says the sodium influx can cause heart cell swelling. Would that account for the heart pain?
Dr. Chaudhuri and Prof. Behan have been looking at sodium ion channelopathy in CFS, which is consistent with a Ciguatoxin antigen epitope.

But Ciguatoxin opens sodium ion channels.

TTX (Tetrodotoxin) is produced by different species of bacteria and blocks sodium ion channels.

There is evidence for bacterial biogenesis of TTX and saxitoxins (bacterial family Vibrionaceae sp. Pseudomonas).

The toxin in living animals acts primarily on myelinated peripheral nerves and does not cross the blood brain barrier.

This neurotoxic impairment might account for the inability to withstand the potent neurotoxins from Stachy that I'm always screeching about. (But everybody thinks I'm crazy.)

So all we need to do is find the biotoxin forming bacteria that produces the Ciguatoxin antigen epitope but blocks sodium ion channels.

-Erik (2002, SickBuildings)

* 

Obviously, none of us in Incline Village were even close to any known sources of Ciguatoxin.

When Dr. Hokama released his findings I started looking for an alternate possible cause for the antigen epitope.

I remembered that Behan and Chaudhuri had noted sodium ion channelopathy that was consistent with blocked channels, while Ciguatoxin appears to open sodium ion channels.

When I searched “blocked channelopathy” I came up with Tetrodotoxin (TTX), which is produced by marine dinoflagellates and sequestered in certain species of octopus as a weapon.

Marine biologist Peter Anderson had an interesting speculation that TTX wasn't actually produced for toxic purposes by the dinoflagellates, it just happened out to be serendipitous for the bacteria. He proposed that TTX is produced as a potent ion manipulating molecule that the bacteria use to take advantage of the marine ion gradient to power the proton pumps that fuel their flagella.
TTX molecules have an affinity for binding receptors in the myelin sheath. It seemed awfully damn coincidental that people with CFS and Lyme disease have an immune response that seems very determined to attack the myelin sheath.

If marine dinoflagellates produce this extremely potent molecule as a spectacular manipulation of the ion gradient, why wouldn't other flagellates such as Lyme spirochetes have a similar need to power their proton pumps in a similar manner and produce the same sort of molecule?

Perhaps the molecules have a less spectacular effect but still bind up myelin receptors in a "lesser" way that is not apparent until a stress or stressor makes the neurological dysfunction apparent to immune surveillance and signals the inflammatory response that induces the pathogenic encephalitis.

If Lyme ionophore toxins have the same incapacity to be metabolized as Pfiesteria, Ciguatera and mycotoxins, it wouldn't even be necessary to have Lyme disease.

Simply drinking water from a river that had been polluted by a dead animal with the Lyme or eating meat or cheese from an animal that had the illness and released these molecules would build up your toxic load in exactly the same manner that large fish store large amounts of Ciguatera toxins.

-Erik (2004, CFSResearch)

*

I still believe that the Ciguatoxin antigen epitope is actually ion gradient manipulating molecules from bacterial proton pumps.

-Erik (2005, Locations)

*

“The fifth speaker was Dr. Abhijit Chaudhuri, who works with Professor Peter Behan in Scotland. They are looking for the biochemical mechanism that produces the fluctuating symptoms of PWCs.

“It is Dr. Chaudhuri’s opinion that there may be more than one factor leading to the development of CFS in a patient (such as different viruses, chemical exposures and so on) but that the final disease process is the same for all patients.

“Dr. Chaudhuri described the way the membrane of excitable tissue, (i.e. the brain, heart, muscles and nerves) has an “ionic equilibrium.” This equilibrium alters when activity occurs. In PWCs, the equilibrium is upset, and the body wastes energy attempting to restore the balance. Therefore less energy is left over for normal physical activity. The
biochemical process that is behaving incorrectly in PWCs is the transfer of sodium among cells. The channels that facilitate this transfer are blocked. Symptoms such as hot and cold hands and feet, and temperature sensitivity, are a result of these blocked channels. The cause of the blocked sodium channels is not certain."

“Dr. Chaudhuri emphasized that CFS is a genuine illness, and one that is causing widespread economic problems as a result of the many formerly able people who are now chronically ill.

“Dr. Chaudhuri pointed out that the high numbers of PWCs who cannot tolerate anti-depressant medication is evidence that CFS is not depression.

“Dr. Chaudhuri made the interesting point that ion channel disruption occurs in both CFS and Multiple Sclerosis, and the fatigue is also a significant symptom of MS. He suggests therefore that the two conditions might be related.”

> Chaudhuri doesn't make any sense to me. Some of Goldstein's favorite CFS drugs were sodium channel blockers like lidocaine and lamotrigine.

If the cells were flooded by voltage gated channelopathy locking them open and being overwhelmed with calcium until potassium ions have no place to go, the scenario might possibly fit both Chaudhuri and Goldstein's concepts.

I guess it would depend on being "blocked by WHAT?"

-Erik (2009, SevereReactor)

*

Fascinating post about the Acid Sensing Ion Channel protein.

This is the first that I've heard of it.

My conclusion that the morning effect correlated to ion shift instead of other factors was based on comparative observations which ruled out other possibilities.

-Erik (2009, SevereReactor)

**STATIC ZAPS**

After a mold plume is laid down, the area becomes subject to a strange electrostatic phenomenon.
Dr. Shoemaker notes the static zaps which Moldies complain of.

Sunlight and weather change apparently trigger this shift.

-Erik (2009, SevereReactor)

*

The Truckee "Whoosh" is sailing past me just a bit to the north at this very moment. I got caught right on the edge about three hours ago, and the electrostatic phenomenon was like sparklers going off in my MECU.

Every year, it grows just a bit stronger.

-Erik (2009, Locations)

TRIGGER POINTS

Fibromyalgia was a term originally developed for regional achiness in the 1970s (when the term Lyme was coined) but had fallen into disuse.

It was snapped up by the "trigger point people" who needed some way to differentiate their trigger point phenomenon from the muscle aches of CFS.

The overwhelming number of people who received an FM diagnosis on the basis of what appears to be little more than a flip of the coin overpowered the trigger point people, and now FM has reverted to a mish-mosh of those who probably have no difference in their illness from Lyme or CFS and the people who wonder what the heck happened to the growing awareness of the trigger point phenomenon.

Instead of becoming more associated with FM, the trigger points have become less and less.

I remember when the illness that was later called Fibromyalgia showed up in support groups in Incline Village.

What was amazing is that the tender points not only responded to the slightest feather touch, but that some people were thrust into agony by simply putting a finger close to the skin without touching it.

My stepfather was familiar with the works of Robert Becker, and this strange complaint immediately suggested mediation by ion channelopathy.

Of course, if one cannot conceive of such a mechanism, this is considered "impossible, so it must be all in your head."
FMers learned that they must say "pressure" instead of "proximity" to keep themselves from instantly being diagnosed with mental illness.

-Erik (2010, CFSKnowledge)
Chapter 48 - The Aviator

The totally unexpected levels of extraordinary innate immune system activation to these fairly ubiquitous toxins suggests that the source of this phenomenon is not to be found in solely the inherent qualities of the toxin itself, and we have to look elsewhere for a novel mechanism that might be responsible for this amazing feat.

So, in the spirit of coming out of left field (or Monty Python: “And now for something entirely different”), my response is in "The Aviator.”

-Erik (2008, CFSU)

* Remember the Howard Hughes bio-movie, "The Aviator"?

There was a terrific scene when Leo DeCaprio, playing Howard, is caressing his super smooth race plane after having all the rivets ground flat and whole plane polished to a glossy mirror sheen.... trying to squeeze every bit of speed out that he can.

Yes, this baby ought to go fast!

But what would Howard do if the plane didn’t go faster?

They tested it out prior to polishing, so they know how fast it went.

What if the plane not only didn’t go faster, it actually slowed down?

By almost 10%.

Now, how can that be? Smoother = slicker = faster. Right?

Test, test, test. And every time, the plane just doesn't go any faster. It's even slower than it was.

Doesn't make sense.

What should Howard do?

What do you do when the predicted results don't match the model?

What then?

-Erik (2008, CFSU)
Aviation is full of the most incredible phenomena where things are totally not what they appear to be.

I was on my way to Fort Funston, where I had been flying for about a year, when I looked up and saw a glider nearly three times as high as I had ever seen there before. This was well beyond the best "ridge lift" soaring conditions that the place offered. It seemed absolutely impossible, one of those things that if you had "maxed out" the site and never gotten this high, you'd think it couldn't be done. But there it was, and this is what it looks like.

When the camera pans straight down, that's where the launch site is.

http://www.youtube.com/watch?v=NrLIUwTxYWy

This was one hell of a neat trick, when you know how it's done.

Just like so many other weirdnesses in aviation, since this phenomenon wasn't something that you would ordinarily encounter. The only way for pilots to learn that trick was to observe someone doing it.

Very few pilots have even conceived that this effect exists, let alone used it.

But it's right there, in plain view of vast numbers of San Franciscans who have no idea what they're looking at.

-Erik (2008, CFSU)

No answers on "What would Howard do?" This is sorta important.

The plane flew faster before it was made smoother, so instead of trying to make it even more so, you put it back the way it was with all its rivets and imperfections.

It took many years before the airstream microbursts of skin-friction were understood. The Airbus A320 uses special tape "microturbulators" to essentially roughen up the skin of the plane for better efficiency by 'tripping the boundary layer."

So when you bring a remediated object into your safe zone and conventional views would have you believe that the thing couldn't possibly be toxic, you don't try to wash it more because it seems almost impossible that this is not the right thing to do.
You act in accordance with the observation instead of the expectation.

-Erik (2008, CFSU)

*

You've seen the video of the glider at unexpectedly high altitude above a cliff that is well known for ridge lift that can only take a glider up several hundred feet. Isn't the natural question, "How can it do that?"

Suppose you showed that video to student hang gliding pilots. Wouldn't it be amazing if they didn't ask that question? They want to learn the tricks of flight, don't they?

That's how I got my peculiar attitude toward CFS groups and CFS doctors. They are looking for clues, aren't they?

-Erik (2008, CFSU)

*

It's critical for people to understand that learning this stuff is a long process of learning new paradigms, and of trying to dislodge old ones.

A problem is that people want to hear this in twenty five words or less, and then they lose interest.

If it were as simple as that, we'd basically be telling people what they already know. This is a whole different deal, just like that glider at such high altitude.

Understanding how it got there, and learning to do it, is a long, drawn-out process of discovering "invisible" things that most people never have any reason to think might even exist.

-Erik (2008, CFSU)

*

What else could you expect, from someone crazy enough to build and fly one of these?

It was quite the experience, rolling this thing out to the runway and taking off for the first time.

"Phew! It flies!"

Now then, in terms of the "skin friction" phenomenon, about a plane actually flying slower when it was smoothed out....
If someone hadn't kept insisting on how bizarre and unexpected this outcome is, the need to investigate why such a counterintuitive result would happen is never mandated.

It's not a matter of trying to make it smoother still. It is a question of pondering how on earth the actual effect would be in total contradiction to the expectation.

One doesn't need to know what that effect is in order to use this information. Until one figures it out, you simply do not go to great lengths to make a plane shine like a mirror, when you know from experience that it might just make the plane slower.

-Erik (2008, CFSU)

* Picture “hang gliding” and what do you think? Of people soaring around under flexible wing, delta shaped gliders... suspended by a strap, which is what puts the "hang" in hang gliding?

There was a time when nobody was doing that. There had to be a conceivable first person to strap in, and step off the mountain, and into the history books.

But where would that point be?

If you look at Wikipedia’s history of hang gliding, you see that people have been trying to do this for hundreds of years. But they were different contraptions, not maneuverable, not controllable, not successful, or needed to be towed up or launched from skis or a moving platform.

So where did the picture of hang gliding assume its current form?

It's hard to find where that critical shift happened in the histories. The only real clue looks like this: "Appears to be the first flight without skis."

That's it. That was the change.

Well, there were a number of close calls where people towed up, or launched from skis, or even had short "foot launched" flights in sand dunes.

But the picture of hang gliding that we view today started on September 6, 1971, when Dave Kilbourne took a ski-tow glider up to Mission Ridge, south of San Francisco, and performed the first prolonged controlled foot launched flight which matches what we think of, when we picture the sport of hang gliding.

He put all the elements together into one hang gliding package, and that changed everything.
People who don't picture hang gliding as a flex wing - foot launched sport can easily point to rigid wing gliders of the 1930's... or “not quite controllable because they had no hang strap” type gliders, and say, “Dave wasn't the first.” But that wouldn't be hang gliding as we picture it today.

We know that there was a time when there was no CFS. Conceivably, there were people who were part of the events that changed this time when there were a bunch of elements that went into the creation of CFS.

It seemed to me that when someone wanted to know how these elements came together, they would conceive that such people who took that first step would exist, and it would be to us that they would come for answers as to how it all got started.

And this has been the biggest surprise.

The mere notion that real people were actually present and can speak to how it happened is an unpalatable concept, and asking us is pretty much the last thing that people want to do.

-Erik (2008, CFSU)

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The point is:

If you see a phenomenon clearly stepping outside any projected potential of the theoretical model, there comes a time when one has to stop trying to pound a square peg into a round hole by stretching the old mechanism beyond all reason and look for an entirely different theory to explain the discrepancy.

-Erik (2008, CFSU)

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Many of the components of bio-aerosols are pathogen-associated molecular patterns (PAMPs) that bind specific recognition molecules and activate innate immune pathways. The most frequently detected PAMPs in bio-aerosols are endotoxin, peptidoglycan and β-(1?3)-glucans.[26]

Endotoxin signalling is being achieved through TLR4 (Toll-like receptors) pathway, a PAMP recognition molecule. Immune cells first develop tolerance to repeated exposures to endotoxin. Then, there is increased expression of TLR4 on the cell surface that leads to increase in the inflammatory response to lipopolysaccharide (LPS). Respiratory
Syncytial Virus (RSV), present in bio-aerosols in domestic and day-care settings, increases TLR4 expression and sensitizes respiratory epithelial cells to endotoxin. [27] Although endotoxin causes inflammation in everyone, people with asthma tend to be more sensitive. Certain proteins found attached to white blood cells and floating free in blood and fluid surrounding lung cells are involved in a person's reaction to endotoxin. A protein called CD14, a mannose receptor specific to LPS and found on the surfaces of mature macrophages, [28] is present in higher levels in people with asthma. EPA (US Environmental Protection Agency) researchers examined healthy controls and asthmatics to investigate the relationship between CD14 and severity of response to endotoxin. They measured CD14 levels in samples of the participants' sputum collected both before and after the exposure and showed a correlation between levels of CD14 and the severity of the inflammatory response; when levels of CD14 were high before exposure to endotoxin, the inflammation was more severe. [29] Estimation of CD14 in serum by enzyme immunoassay (EIA) [30] can be used to predict the severity of a person's response to endotoxin. Exposure to endotoxins is associated with increased severity of asthma and BRI. [31],[32]

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Aviation is rampant with effects that look like an extension or an extreme case of the normal process, but turn out to be completely unrelated.

Whatever was happening, although it was associated with the normal understood phenomenon under scrutiny, turns out to be something else entirely.

No matter how hard you try to stretch the phenomenon into making sense, it just doesn't. You have to look for something else.

The P51 Mustang is a good example of this. That big belly scoop slung under the plane?

Looks like a drag bucket. Taking it off must surely reduce drag and make the plane go faster, right? So why is it that when they do, the plane slows down?

Hmmm. We already covered the skin friction weirdness, and that ain't it.

But how on Earth could taking off such a huge source of drag actually increase it? (At least, it appears drag must be affected somehow, since that's what determines faster or slower, since lift + thrust are staying the same.)

Turns out, it is.

As the plane moves through the air, the low pressure above the wing tries to draw air from under the body of the plane. The sharper the angle at which this air is deflected while it moves upward, the more drag. The scoop is filling in an area from which are
would be sucked up behind the wing at a very sharp angle, and keeps the air moving more "straight-line" down the length of the fuselage.

It's called "area rule," but nobody knew how to predict it until computers were developed that could model airflow.

The P51 was designed in the 1930's with a slide rule. How did they do it?

I dunno. At the time, this was just a theoretical effect, and one had to go with what works even if it didn't always make sense.

Now, we have a conventional view of mold toxins and what they do.

The effect we are seeing doesn't fall within the potential of the construct of what we know about how these toxins work.

Just like so many other effects through history, we miss an opportunity to exploit the effect if we insist on applying the wrong paradigm... as in, "But the damn plane must fly faster without the scoop!" or "Smoother is always better... so we just have to try harder to make the plane smoother still."

See my point? All the people who ignored the way the effect didn't fit the facts were allowing their conceptual model to dictate their actions, and their actions were wrong.

In retrospect, obvious. But when the effect is still unknown, it never is.

So when one tries to treat mold toxins as acting within the parameters of "what mold toxins do" when they are clearly transcending their potential, we either have to find out why these toxins are acting outside their limits or look for an associated-but-possibly-unrelated novel mechanism.

Until the time comes when somebody figures out what is going on, if you want to fly faster than anyone else, you better stick with what really works... even when the scoop and the rivets seem totally opposite to what you would think and make no logical sense at all.

-Erik (2008, CFSU)

*

If Respiratory Syncytial Virus can remodulate Toll Receptor response and upregulate innate-immune system complement activity in the presence of LPS's/Pathogen Activated Molecular Patterns, what might HHV6A do?

-Erik (2008, CFSU)
Syncytial giant-cell hepatitis is a rare but severe form of hepatitis that is associated with autoimmune diseases, drug reactions, and viral infections. We used serologic, molecular, and immunohistochemical methods to search for an infectious cause in a case of syncytial giant-cell hepatitis that developed in a liver-transplant recipient who had latent infection with variant B of human herpesvirus 6 (HHV-6B) and who had received the organ from a donor with variant A latent infection (HHV-6A). At the onset of the disease, the detection of HHV-6A (but not HHV-6B) DNA in plasma, in affected liver tissue, and in single micromanipulated syncytial giant cells with the use of two different polymerase-chain-reaction (PCR) assays indicated the presence of active HHV-6A infection in the patient. Expression of the HHV-6A-specific early protein, p41/38, but not of the HHV-6B-specific late protein, p101, was demonstrated only in liver syncytial giant cells in the absence of other infectious pathogens. The same markers of HHV-6A active infection were documented in serial follow-up samples from the patient and disappeared only at the resolution of syncytial giant-cell hepatitis. Neither HHV-6B DNA nor late protein was identified in the same follow-up samples from the patient. Thus, HHV-6A may be a cause of syncytial giant-cell hepatitis. 2008 Massachusetts Medical Society

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News and Views
Immunology: T cells hang in the balance
Emily A. Stevens & Christopher A. Bradfield

Abstract
Equally important as the immune system's function in fighting invaders is its ability to tolerate self. But environmental toxins could shift the equilibrium between these activities one way or the other.

To ensure the efficient execution of its various activities, the immune system has distributed responsibility between different sets of its cells. But disease, pathogens and pollutants might disrupt the levels and functions of these cells.

1. Emily A. Stevens and Christopher A. Bradfield are in the McArdle Laboratory for Cancer Research, University of Wisconsin, Madison, Wisconsin 53706, USA.
Editor's Summary

1 May 2008, Toxins and autoimmunity

The aryl hydrocarbon receptor (AHR) is a transcription factor best known for mediating the toxicity of aromatic hydrocarbons such as dioxin: its activation leads to the production of detoxification enzymes. AHR has been intensely studied in relation to toxicology and cancer research, but no mechanistic connection to the immune system was known. Now two groups report a role for AHR in maintaining the balance between two T-lymphocyte populations — the Treg and TH17 cells — that are part of the immune regulation system dealing with tolerance of self-antigens and pathogen clearance. Both groups also show that AHR affects the severity of experimental autoimmune encephalitis, a mouse model of multiple sclerosis. This work raises the possibility that stimulation of AHR by environmental factors could be involved in the development of autoimmune disease, and point to AHR as a possible drug target for immunomodulation.

* Notice the effect of depolarization on the receptor binding region.

"Shocking," isn't it?

-Erik (2008, CFSU)

The Effect of Losing Glycosylation Sites Near the Receptor-Binding Region on the Receptor Phenotype of the Human Influenza Virus H1N1

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The Effect of Losing Glycosylation Sites Near the Receptor-Binding Region on the Receptor Phenotype of the Human Influenza Virus H1N1
V. P. Marinina1, A. S. Gambaryan1, N. V. Bovin2, A. B. Tuzikov2, A. A. Shilov3, B. V. Sinitsyn3 and M. N. Matrosovich1
Abstract The receptor properties of influenza virus A/USSR/90/77 isolates are studied. The isolates are peculiar for losing glycosylation sites at the Asn131 receptor-binding region (GS131) after passaging in mice and at the Asn158 region (GS158) after cultivation in the presence of mouse serum. The loss of each carbohydrate residue increases the influenza virus affinity for carbohydrate chains with the terminal group Neu5Ac2-6Gal and reduces its affinity for Neu5Ac2-3Gal receptors. The effect is more pronounced in the GS158-depleted virus. Upon substitution of asparagine by aspartic acid, the electrostatic component of virus binding to the receptor is altered because of the increased negative charge on hemagglutinin. The virus receptor phenotype changes depending on the cultivation conditions. The isolate adapted to mice has higher affinity to mouse lung cell receptors, while the virus propagated in chick embryos in the presence of inhibitors has higher affinity to allantoic membrane cells.

influenza viruses - glycosylation sites - receptors

* First thing: we have to build a conceptual framework that is comprehensive enough to recognize when critical parts are missing and gaps need to be filled in.

Okay, now we have a situation of SBS strangely resulting in CFS sometimes.

We know that toxins are involved, but they don't quite cut it.

We know that viruses are involved too, but somehow they don't quite fill the bill either. At least, not in a clearly reproducible manner.

But what about this "static zap" thing that sufferers keep complaining about? What happens when we factor that aspect in?

Why, looky here! We have a complete shift in how receptor sites are being manipulated in order to receive that viral infection!

Now, isn't that interesting?

-Erik (2008, CFSU)

*
This whole "sed rate" thing is where Dr. Cheney was a really good teacher and role model.

He called the illness "A New Dynamic" and showed me that if the theory doesn't fit the facts, you just keep on truckin'... instead of slamming on the brakes at the first thing that almost looks like it might fill the bill.

-Erik (2008, CFSU)

INTERNATIONAL INSTITUTE OF BIOPHYSICS

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This work was supported in part by the grant from the RHSF #99-06-00268A HIGH-TEMPORAL-RESOLUTION OF RED BLOOD SEDIMENTATION DYNAMICS REVEALS NON-LINEAR AND COOPERATIVE PROPERTIES IN WHOLE BLOOD


Moscow State University, *Central Clinical Hospital of the Railway Ministry of the Russian Federation, Moscow

Erythrocyte Sedimentation Rate (ESR) determination in whole stabilised blood is a widely used diagnostic test indicative of severity of an illness. It is well known that ESR is elevated in many clinical conditions, e.g. malignancies, infection diseases, collagen diseases, etc. It is generally accepted that the mechanism of erythrocytes sedimentation is based on the Stocks law of sedimentation of dense particles in the viscous medium. However, there are a lot of peculiarities in the behavior of individual blood specimens, which show that the behavior of sedimentating blood does not agree with this law. For example, it was noted long ago that if measurements are taken each 10-15 min non-monotonous rate of blood sedimentation can be revealed.

In order to achieve high-temporal resolution of the process of red blood sedimentation we designed an automatic scanning device allowing to register the position of the boundary between red blood cells and plasma each 30 sec with a precision 10 mkm. Information from the scanning device is processed by a PC and is presented as plot of immediate rate of red blood sedimentation vs time (ESR-graph). The results
demonstrate non-monotonous character of the rate of red blood sedimentation; reveal macroscopic stages in the whole processes. Amplitude and frequency of oscillations, duration of each stage are characteristic for blood of each particular donor, and they change in the course of patients' medical treatment.

Several unexpected phenomena in sedimentating blood have been observed. First, in most cases upwards movements up to 1 mm of the boundary between red cells and plasma were noted after its initial sedimentation for 2-3 mm (Fig. 1). Second, in many blood samples of patients with different pathologies sets of low frequency (1-10 milliHz) oscillations were developing in blood and continued for many hours. In healthy donors' blood these oscillations were absent or emerging after a prolonged «latency» phase (dozens of minutes and more), and they were highly periodic (Fig. 2). Notable also are sharp variations in ESR-graphs of iscaemic disease patients at the days of geomagnetic storms. These results show that blood is a complex non-linear system with a long-range memory.

The behavior of sedimenting blood reflects, on the one hand, mutual interactions of red cells that associate in a 3D-network constructed of the so called «ruleaux» or «piles of coins» threads. Breaking down or shrinking of several or even one thread should be followed by a cascade of collapsing of several other threads, and this is observed as a downfall event of the interface. Then the system may rest for some time in a quasi-stationary state before the new cycle evolves. On the other hand, white cells, as some of our observations suggest, also play a significant role in the dynamic process. WBC need oxygen for their survival, and RBC are the only oxygen source under the condition of ESR measurements. Most WBC are normally located at the top of the red cell pile, but according to our observations they immerse into the red cell mass from time to time, take a «breath» there and dissociate from erythrocytes. Such events may provoke shrinking of a part of the 3D network of erythrocytes. From this point of view the «negative rate of sedimentation» may be tentatively explained as the network swelling and release from it of a white cells together with some erythrocytes. Highly periodic dynamics developing in the healthy donors' blood shows that interactions of WBC and RBC are well organized. This organization can be distorted to a more or less extent under pathological conditions. We suggest that the process of blood cells sedimentation reveals the active reaction of blood, as of a surviving tissue, upon such stress factors as hypoxia, hypodynamia, action of gravitation, contact with the alien surface of glass. The parameters of this reaction depend upon the metabolic potential of blood, the functional state of all is cellular and plasma elements, and in a complex they reflect the physiological state of the individual. Thus, ESR-graphy may provide significantly more information of patients' state than the usual ESR test. Studies of blood sedimentation dynamics will allow also to get better understanding of the physiological as well as of physical-chemical processes that take place in blood - a surviving tissue outside an organism.

Cancer Causes Control. 2009 Jan 25.
Delayed exposure to infections and childhood lymphomas: a case-control study.
Division of Infectious Diseases, First Pediatric Department, University of Athens, Athens, Greece.

OBJECTIVES: Delayed exposure to common infections during childhood, have been implied to cause strong immunological response to a single infectious agent that eventually triggers leukemogenesis. The aim of the present study was to investigate whether decreased exposure to infections, as reflected in a more seronegative spectrum to several common infectious agents, is associated with increased risk for the development of childhood lymphomas.

METHODS: All 125 children (up to 14 years old), with Hodgkin (HL, n = 52) and non-Hodgkin lymphomas (NHL, n = 73) diagnosed through the national network of childhood Hematology-Oncology units during an 8-year period were enrolled in the study along with 125 age- and gender-matched controls. Past exposure to nine common infections [respiratory syncytial virus (RSV), influenza A and B, parainfluenza type 1, adenovirus, Epstein-Barr virus (EBV), cytomegalovirus (CMV), human herpes virus 6 (HHV6), Bartonella henselae] was assessed using serological markers.

RESULTS: After controlling for possible confounding factors, the overall seronegativity status upon diagnosis was statistically significantly associated with NHL [odds ratio; 95% CI: 1.45 (1.10-1.93), p = 0.01] and less so with HL risk [odds ratio; 95% CI: 1.30 (0.83-2.05), p = 0.25]. A statistically significant association of seronegativity with the development of NHL was evident for RSV [odds ratio; 95% CI: 7.27 (1.59-33.28), p = 0.01], EBV [odds ratio; 95% CI: 6.73 (1.45-31.20), p = 0.01] and suggestive association for influenza B [odds ratio; 95% CI: 2.60 (0.90-7.55), p = 0.08] and influenza A [odds ratio; 95% CI: 2.35 (0.81-6.80), p = 0.11]. In contrast, there was no evidence for association of HL with negative serology for any of the infectious agents tested.

CONCLUSIONS: The risk of lymphomas, especially NHL, might be higher when, due to lower exposure to several infectious agents, the relatively unmodulated immune system of a child is challenged by environmental stimuli that can trigger development of lymphomas. The results, however, need further confirmation, through more pertinent methodological designs.

Read that conclusion again!

CONCLUSIONS: The risk of lymphomas, especially NHL, might be higher when, due to lower exposure to several infectious agents, the relatively unmodulated immune system of a child is challenged by environmental stimuli that can trigger development of
lymphomas. The results, however, need further confirmation, through more pertinent methodological designs.

"Relatively unmodulated immune system."

CONCLUSIONS: The risk of lymphomas, especially NHL, might be higher when, due to lower exposure to several infectious agents, the relatively unmodulated immune system of a child is challenged by environmental stimuli that can trigger development of lymphomas. The results, however, need further confirmation, through more pertinent methodological designs.

If the pathogen associated molecular patterns which trigger NHL are different, while an environmental "unmodulator" remains as the common denominator in clusters of illness...

Wouldn't that particular factor be worthy of some kind of special attention?

-Erik (2008, CFSU)
Chapter 49 - CFS Causality

EPIDEMIC

The implication of most local factors as causative for CFS never made much sense to me.

When CFS struck Incline, people were wondering if it might be in the water system. I asked why they would even suspect that if CFS also emerged at the same time in places that were on different water systems.

All of these local "causes" can be tossed out simply because CFS isn't restricted to these areas.

- Erik (2005, Locations)

Isn't it amazing what happens when one factors in the context?

Doctors look at each patient “as an individual" and pride themselves on it. They say they wouldn't think of doing this any other way, as this would be a "disservice to the individual patients."

But if "it" happens like an epidemic, as "it" did in Incline, then one has to take that into consideration too.

Anything that absolutely cannot act like an epidemic can be taken out of consideration. Eliminates a lot of unnecessary looking that way.

- Erik (2008, CFSU)

SUBSETS

I think that it is an endless task to concentrate on all the variables that separate CFS into subsets.

We are bound together as a syndrome by our concurrences, not defined by our differences.
Is there anybody whose symptoms have remained so constant through the course of their illness that if a subgroup had been developed on their precise symptoms, they would have stayed in their own subgroup?

Since this illness is so variable, subgrouping is counterproductive. I've gone through every symptom in the book at various times and have been forced to run from doctor to doctor since they only treat the CFS symptoms that they specialize in.

I would like doctors to recognize that the permutations of this illness don't mean it's a completely diverse illness, just a changeable one.

I am sure there are as many CFS subsets as there are secondary pathogens and the limitless number of different combinations of these secondary pathogens that come together in different ways to create symptoms.

Add variables of individual susceptibility, environmental exposures and all the varying degrees of each, not to mention the changes that everybody experiences during the course of illness progression, and I'm certain that the number of subgroups has the capacity to be just slightly less than infinite.

Breaking this illness down into subgroups eventually leads to the uniqueness of each individual case.

As long as people will tolerate doctors telling them it is normal for people to just fall apart in a way that nobody has ever seen before, and that all of this is completely unrelated and due to your own personal weakness, they will.

They are going to subset you to death without trying to get to the bottom of this.

-Erik (2003, CFSExp)

* 

In what subset do you put people who are capable one week and flat on their back the next?

And what if, as with Dr. Bell's kids, a large percentage improve to the point that they no longer fit their own subset?

Sudden onset vs. gradual even though their symptoms are identical?

The way people are trying to subset CFS makes me think that if HIV had not been discovered, AIDS would still be divided into subsets comprising all the identifiable infections that make up their particular illness presentations.
Remember when this subset approach was applied to AIDS and doctors kept trying to prove that all these formerly benign infections had now turned super pathogenic because of homosexuals' perverted lifestyle and mental condition?

All the things that CFSers are pointing at have this one thing in common.

None of them are known to cause CFS.

-Erik (2005, CFSExp)

*

CFS is not heterogeneous. The reason it was turned into a syndrome is that we all shared the same signs and symptoms.

CFS was the opposite of heterogeneous.

Amazing how people say "heterogeneous" if it were obvious and unquestioned. They need to, in order to promulgate an "anything and everything" concept.

But take another look.

The entire reason for the creation of CFS is because we all had the same signs and symptoms after the Yuppie Flu passed through.

If it had been heterogeneous, the connection between our illnesses wouldn't even have been made.

If the CFS one is speaking of is so unlike CFS that it doesn't share the same core symptoms, it's not part of the syndrome and is not CFS.

-Erik (2006, CFSExp)

**TOXIC OVERLOAD**

If you subscribe to the theory that we are suffering from toxic overload - the so-called rain barrel theory - then you must also believe that the greatest prevalence of illness will occur in places of greatest toxic burden.

In short, everyone in Los Angeles and Mexico City will become ill before a single person in a pristine place like Incline Village, Nevada.

Perhaps one might argue that the food has lost its nutrient value and malnourished produce and antibiotic laden meats have caused people to have dysfunctional immune systems.
Is it likely that the mountain bikers, skiers, marathon runners, tennis pros and hang gliding instructors involved in the Incline Village epidemic made such poor food choices that they had a susceptibility to illness that made this problem emerge there, rather than some economically repressed place where people made more enlightened nutritional choices?

The theory must fit the facts, or it must be discarded.

-Erik (2003, CFSExp)

* 

>The kinds of toxins Sherry Rogers is talking about are not only what you would generally consider as pollution (smog) but a much more prevalent and insidious kind of pollution from the outgassing of everyday items found in our homes and workplaces.

Yes, I've heard all that. Many, many times.

It doesn't fit.

This theory has been stretched so hard as to be far beyond the snapping point of reason. Just like the nutritional deficit theory that keeps insisting that, “Since you have the illness, you must have been poisoned by the standard American diet.”

People try so hard to stretch these types of theories that I've even heard things like, "Well, if you weren't eating Twinkies, then perhaps while you were eating healthy food you were thinking about eating Twinkies and fooled your body into an unhealthy perception of what it was eating.”

Anybody who has experienced the reality of this illness knows that it is so far outside the range of normal human experience that you can't even get your own mother to believe you're not exaggerating it, let alone your doctors.

The exposures that people implicate don't even come close to explaining a most abnormal situation.

I find it hard to believe that there is such a level of toxins, pollutants, off-gassing cheap furniture, mercury-using dental practices, stores selling bad produce or anything else that people blame to be found in Incline Village at such a degree of exposure as to make it the worst choice of places to live in 1985 while other places went untouched.

The toxic overload theory doesn't fit the facts on any level.

-Erik (2003, CFSExp)
The theory has to fit the facts. I've just found that many doctors will come up with a theory and when I tell them it doesn't apply, they appear not to hear me and proceed as if the issue was completely resolved.

If we hadn't so consistently rejected theories of psychological causality, research would never have been inspired to progress beyond "It's All In Your Head."

The toxic overload theory is a good one. It contains a lot of common sense. I tell people that I am certain that it will be a factor in people’s health and that it is bound to happen.

But you would expect toxic overload to manifest first in sick people living in places of greatest toxic exposure. If the illness doesn't match this profile, shouldn't the people who were in a position to see this contradiction point it out so that research can explain the discrepancy?

The illness that I saw seemed to hit the very people everyone considered the least likely to succumb.

I appreciate the fact that the CDC is finally looking into CFS but was appalled to see them trying to create a model for this illness by measuring "fatigue" states in overexerted healthy people.

The fatigue I felt was nothing like any overexertion I ever had. I don't believe the process is even comparable. No matter how hard you try to explain this, all the researchers hear is "very tired."

If people who experience CFS fail to tell these researchers that there is a major difference between their concept of fatigue and ours, how are they to know that their model may not be accurate?

There is an old science joke about a drunk who is searching for his car keys under a streetlight. A cop happens along, and after appraising the situation, asks the drunk where he had last seen the keys. The drunk points toward a dark alley.

"Then why aren't you looking over there?" asks the exasperated cop. The drunk looks up and replies, "Because the light is better over here."

I hate to be the one to get people exasperated by pointing out that a really great theory doesn't fit the circumstances, but if I don't, how will they know to stop looking where the light is?

-Erik (2003, CFSExp)
Absolutely, the spread of pesticides is horrifying.

I’ve been looking all over to try to find some way that the theory fits the facts and can explain the apparent contradiction of an illness cluster occurring in one of the most awesome places you could ever hope to live. If there's any way that volatilized compounds could jump out of their areas of application and concentrate in pristine regions, then I want to know about it.

Walter Crinnion says that VOC's do indeed volatilize in warmer temperatures and concentrate in colder areas because of the decreased potential to re-volatilize. When I asked Rob Napier if it was more likely that someone might become ill in the Arctic than in the areas where the chemicals were applied, I considered that the explanation didn't fit the facts. But the concentration of VOC's in colder areas might just create this very effect.

As long as someone gives me something that explains the apparent contradictions to exclusionary evidence, it cannot be excluded.

It just so happens that the shape of the mountains around Incline Village funnel the prevailing southwest winds that come across Lake Tahoe into a sudden updraft that causes a phenomenon known locally as "The Incline Cloud."

If large amounts of VOC's from the valley swept over the Sierra Nevadas and across the lake until the sudden drop in temperature caused the condensation responsible for the cloud, it is possible that Incline could be a trap for catching these VOC's.

Truckee has similar qualities that could account for a concentration there. It is in an aerodynamic sink that is well known for its cold weather inversion and often makes it one of the coldest temperature reporting stations in the U.S. Combine that with the Highway 80 gorge that funnels weather right down the Highway 80 corridor and it looks like Truckee would have great potential for VOC capture.

I wonder if it might be worthwhile to create an "area of potential VOC capture map" to see if illness clusters even remotely correlate.

I'll buy anything as long as it fits the facts.

-Erik (2003, CFSExp)

* 

The glaring disparity between the toxic exposures that most people endure with complete impunity and the sensitivities that manifest in people with CFS leads me to believe that when a cluster of people simultaneously start complaining of chemical intolerance in a way that others around them (who presumably shared a similar
exposure) dismiss as a complete impossibility, it must be questioned if the chemical induced the illness or the illness induced the intolerance.

-Erik (2003, CFSExp)

*

The reason I fight the canary concept so hard is that the presumption is that these susceptibilities are the result of toxic overload or lifestyle or perhaps preexisting genetic susceptibility in response to a toxic exposure, if they have a sudden onset.

The way this illness moved through my community is inconsistent with the canary concept.

What I saw is the creation of a manifestation of subtle susceptibilities in a very pristine setting amongst people with a strong dedication to a healthy lifestyle, after a flu-like illness passed through. That suggests to me that the susceptibility/precursor condition still doesn't meet the model for toxic overload, while a post-infection syndrome does.

If the susceptibility were an inherited genetic predisposition, the failure of the syndrome to manifest under conditions of stress and toxic exposure in a consistent way in the past suggests that something changed.

The spread of complaints under these conditions matches the model of a contagious organism more than environmental factors - though the environmental factors play enough of a part to be the symptom inducers and receive the blame for causation.

Like my story about blaming the car that happened to be on the bridge when it collapsed. Yes, the car was the trigger. No, it cannot be the cause because cars are well known not to be bridge collapsers.

-Erik (2004, CFSExp)

*

If you look at the damage done by the synergistic combinations of heavy metals and endocrine receptor disruptors, the true horror is that pure toxin overload is not required.

It is the dysregulation of gene expression by receptor binding that does the damage.

Where the theories of toxin overload don't fit, we need to try to apply concepts of genetic manipulation by seemingly insignificant exposures.

Limiting the dose of a toxin means little when the available receptors are bound up by parts per billion.
If the model of toxin overload doesn't fit, rather than twist the facts to say it must since people are sick from chemicals even in pristine places, it seems to me that this calls for the need to identify a different mechanism.

What I saw was an illness of induced susceptibility rather than one of toxin overload in a mountain community that people would run to in order to escape toxic overload in chemically drenched places elsewhere.

It always struck me as odd that people would describe the rain barrel effect to me and become confused when I say, "How do explain the rain barrels filling up in the desert first, rather than in the rainy places that would be consistent with the concept?"

I believe that dysregulation caused by genetic expression from receptor binding which doesn’t depend upon the dose of chemicals does a better job of fitting the facts than the overload theory.

-Erik (2004, CFSResearch)

* 

Incline Village is located high in the Sierras.

Playground for the rich in a pristine mountain setting.

Whatever waste we put out goes down the Truckee River to Reno and Pyramid Lake, thousands of feet below.

Other than the mold plumes I run into, Incline is more free of normal pollution than any place I can think of.

Naturally, I'm not in favor of sticking my head in a microwave, and the entire planet is being nuked with levels of microwaves that are bound to have at least some kind of effect, but in terms of exposure, I would suspect that Incline is not an area of greatest risk.

Toxic overload is a great concept, and I'm sure that as pollution increases, it will necessarily be a factor, but CFS happened remarkably sooner in Incline than in those places where you would suspect that toxic exposures must be far higher.

-Erik (2006, CFSExp)

GENETICS
The very fact that this illness can sweep through communities in large clusters in such an unprecedented manner means that even though canaries may be susceptible, the illness has the capacity to transcend that factor.

-Erik (2004, CFSExp)

*Lately, it seems like everything is "genetic."

Well, of course it is. That's not saying much. Every structure and function in the body is "genetic."

The question is, "Does this illness fit the model of a genetic trait?"

If this is an emerging illness that didn't have formerly have a prevalence consistent with the numbers of people who now manifest this possible genetic defect, then it would be whatever induced the expression of that genetic defect that caused the increase.

If something blazed through the population and unveiled a genetic problem that somehow escaped notice until twenty years ago, what would the prevalence of the unveiled genetic defect be?

It'd have to be pretty darn prevalent if this genetic predisposition could be unveiled in such high percentages as to account for, say, nine out of ten teachers in a room at Truckee High School. Or half of a single symphony orchestra. Or half of a basketball team.

That's some serious prevalence data. Almost like the genetic predisposition for having hair.

It almost seems like genetics is almost inconsequential in comparison to whatever unveiled the susceptibility.

So given the fact that everybody is genetically different, there must be variations that predispose some to be more susceptible than others.

But if this illness can slammer dammer overwhelm clusters like Royal Free without relying on a rare gene to allow this illness to manifest, does it really matter?

-Erik (2005, CFSExp)

*Genetic variability suggests that there will always be some component that is variable due to genetic differences. But when illnesses increase at a faster rate than the
reproductive capacity of a species to generate an increased prevalence of the illness, the cause is to be found elsewhere.

Autism has gone from one in ten thousand to more than one in two hundred in the last thirty years.

CFS has gone from being "I've never seen anything like this before" to a household word with scarcely anyone left who doesn't know someone with the illness in only twenty years.

As far as I know, neither autistics or CFSers are out there reproducing at a rate that can account for such a dramatic increase.

So even if there is a genetic correlation, there must still be an "X factor" that is causing these genes to be expressed at an increasing rate of prevalence which exceeds reproductive possibility.

-Erik (2006, CFSExp)

*

Photo sensitive epilepsy was a constant topic in Incline.

We had all suddenly become unable to watch TV, couldn't stand fluorescent lights (especially the ones that had a bad ballast and the flicker was occurring at a reduced rate in comparison to the other bulbs), or even stand the flash from the ripples on Lake Tahoe.

Yes, I know everyone is going to look up PSE and read about the "genetic component."

But whether there was a predisposition or not, none of us had ever seen this phenomenon before the illness swept through town.

Then we all got to see it.

If this susceptibility was unveiled by the illness, the degree of prevalence shows that these genes are anything but rare.

That puts the ball back into the "What changed?" court.

We've heard that a few individuals in the world are genetically HIV resistant. Would researchers say that, therefore, HIV is a genetic weakness for everybody else?

-Erik (2006, CFSExp)

*
Calling CFS "genetic" is like leaving the flood out of the equation and saying that drowning is genetic, since some people are "born swimmers" and would survive while the "drowners" are not.

If there were no flood, a genetic superiority or weakness wouldn't matter.

Relying on inherited prowess to swim better is scant comfort and a rather bizarre way of responding to a rising tide.

Individual susceptibilities aside, this illness raged through and struck down people like an epidemic rather than an inherited illness.

-Erik (2006, CFSExp)

* 

If bridges that had long stood the test of time suddenly started crumbling in a manner never before seen, it seems to me that an engineer would look first at "what changed" rather than implicating all the normal stressors that the design had always successfully withstood.

I think that those who are concentrating a complex, multidimensional explanation for CFS have been over stressing the primacy of individual weaknesses, when the scope of the phenomenon is pointing at a massive earthquake.

-Erik (2006, CFSExp)

* 

Down in the San Joaquin Valley of California, a bunch of kids are getting sick.

They traced the problem back to a "genetic intolerance of pesticides."

Pesticides aren't making all kids sick (yet), so until pesticide illness hits people who don't have a genetic susceptibility, it is considered a genetic illness rather than a horrible toxin problem that shouldn't be in the environment at all.

But the fact that doctors would conceive of pesticide illness and refer to it as primarily a "genetic problem" speaks volumes about how they view the situation.

-Erik (2008, CFSU)

* 

What a shock, to find out that it really is all the patient's fault by virtue of bad genes.
Why, there never was a "polio epidemic."

Just a bunch of people who weren't resistant to polio. And those poor sick fools never thought to look at themselves as being the reason for their own illness.

They should feel bad for dropping like flies and scaring healthy "good gene" people unnecessarily, when THEY had nothing to fear.

-Erik (2008, CFSU)

MULTIFACTORIAL

Remember when AIDS was thought to be a multifactorial illness caused by a combination of different immunological insults that homosexuals brought upon themselves by their lifestyle?

You can call AIDS multifactorial because the result is the sum of all the different opportunistic infections that cause final collapse. But none of these various secondary illnesses in any combination causes AIDS. For that you need another factor.

So is AIDS multifactorial?

In retrospect it seems obvious that since none of these illnesses had a history of causing AIDS, there is a requirement to look for another element.

But it didn't occur to many people at the time. They were content to blame the sufferer and attribute the spread to diet, attitude, lifestyle and a mysterious blend of infections and exposures that somehow caused AIDS now even though they had never done so before.

In a similar way, CFS may be the sum of the illnesses that afflict a sufferer. However, if you want to find the difference between the insults that cause it now and the illnesses that failed to cause it before, you must rule out the ones that are known not to cause it.

If you believe that CFS is purely a multifactorial collapse of toxic overload and ambient pathogens, then you should ask why such an illness could demonstrate the capacity to spread quickly through clusters such as the Los Angeles Hospital, Royal Free, Lyndonville, the symphony orchestra, Truckee High School and Incline Village.

Doesn't that suggest a commonality of a factor that is more specific than a generalized immune collapse?

-Erik (2003, CFSExp)
We've seen all along that the final plunge into CFS can be triggered by almost anything.

Clearly this points at a deeper dysfunction.

It is hard to believe that so quickly after seeing this same misplaced "multi-causality" confusion applied to HIV/AIDS that the same exact thing would be done to CFS.

No candidiasis, Kaposi's Sarcoma, staph, strep or any combination of the other infections involved in AIDS are capable of causing AIDS.

Even when you add in "Gay Perversion" and "Modern Stress," as doctors attempted to do, there is still no way that any such illness can result.

When CFSers swear that something not known to cause CFS actually does cause it, and then achieve a limited level of recovery by addressing that non-CFS causing agent and swear that this must be the true cause, it really confuses the situation.

It’s unbelievable that doctors have just accepted that it is perfectly normal for normal people to be destroyed by normal infections.

It is the very fact that so many formerly benign pathogens are now whupping ass on so many people that should raise the alarm that this is definitely not normal.

-Erik (2005, CFSExp)

"Multifactorial" is almost as confusing as "stress," since some people construe it to mean "anything and everything that contributes to an illness."

The multifactorial model has failed so many times that unless there is a clear reason for using it, people need to concentrate on determining what changed rather than focusing on all the known factors that didn’t.

I do believe that CFS consists of multiple factors, and that the Incline Village subset is a result of a specific pathway that branched out from a common denominator.

I believe that this common denominator will be found in the genetic flipping of the switch initiated by specific toxins instead of the model proposed by toxic overload.

-Erik (2005, CFSExp)
One of the early support group meetings was at the local hospital. It was full of marathon runners, champion swimmers, tennis players, mountain bikers, hikers and generally the most active and health conscious people you are likely to find anywhere.

I didn't see any of the Twinkie eating, alcohol abusing, chain smoking, cocaine snorting, sickly, deconditioned, hysterically depressed, weak minded "suggestible" hypochondriacs that doctors say are the people that are predisposed to CFS.

Yes, eating good is good.

But I never ate "bad" and if you had seen the other people who showed up at the early CFS meetings, you would know how ludicrous the concept is that "people brought this on themselves from their bad choices."

-Erik (2003, CFSExp)

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I remember one CFS doctor who talked about improving diet and didn't like it when I said, "These are good suggestions, but why would you have cause to believe that a diet such as this might help when a regimen that was superior failed to stave off the illness?"

He fumbled around, but the gist of it was that his underlying assumption was that if one had CFS, they brought it upon themselves by a bad diet.

As we know, there are plenty of exemptions to show that this is not the case.

-Erik (2006, CFSExp)

MERCURY

Certainly glutathione supplementation and mercury detoxification are terrific concepts and I fully support therapy directed at restoring glutathione and removal of mercury.

But do these factors fit the facts in a manner that allows them to be presented as causative?

Not if autism or CFS develops prior to thimerosal exposure or independently of inordinate levels of mercury.

Hair studies demonstrate that the premiere characteristic in autism is not one of toxic mercury overload, but rather of impaired mercury excretion compared to normal controls.
This would make the apparent overload an effect of metabolic dysregulation of excretion.

If this impaired secretion factor does not fit the model of genetic transference by statistically increasing at a rate which transcends the model of heritability, then any genetic abnormality can only fit the facts if it was genetically inserted without regard to inheritance.

An induced susceptibility instead of a normal response to overload.

-Erik (2005, CFSExp)

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I had my amalgams out in 1987. It didn't make any difference at the time, but who knows? Perhaps it was a factor in improvement later on.

Can't rule it out. Just like EMF's. Could be, just don't have a way to know.

-Erik (2006, Locations)

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Doesn't it seem clear by now that the vaccinations must be just another neurotoxic trigger that unveils a much larger (and growing) phenomenon?

-Erik (2009, CAA)

EMF’S

I haven't been able to locate EMF zones which contain molds that are any different, nor do I have any reason to believe that Stachybotrys is any different at various elevations.

I have climbed to the microwave towers above Norden, Slide Mountain, Fremonts Peak and Squaw peak, and a few others, and felt nothing bad there.

I have taken mold responders to mold zones connected with sick buildings and they bitch about it just like I do. Then we go up to the microwave towers and they don't seem to have any more ill effects up there than I do.

Quite the contrary. Many of these towers are high up on mountains, and we feel better there than any place else.

I have camped up at Lake Mary above Sugar Bowl for extended periods, directly below the microwave towers, without adverse effects.
Whether microwaves exert some force in this phenomenon, I cannot say.

But I do know that other CFSers are observably slammed in mold zones surrounding water damaged buildings just as I am, and that these locations of badness do not give the appearance of being directly linked to the presence of microwave towers as far as we can tell.

-Erik (2008, Locations)

Dr. Peterson considers "his" CFS outbreak to be HHV6a and described the differential in pathogenesis between his cohort and others as corresponding to the neurotropic and pathogenic qualities of this particular virus.

I don't doubt that EMFs are harmful and don't see any particular reason why they wouldn't be a contributing factor in creating a climate of immune susceptibility, leaving everyone open to all these various pathogens that are cropping up.

But when one had the illness prior to the existence of the proposed cause, it's fairly straightforward to state, "Not in my case."

According to the Freiburger appeal, the pulsed microwaves they implicate weren't introduced until 1992.

We had CFS before then.

Their model projects that, "Pregnant women, children, adolescents, elderly and sick people are especially at risk."

This is strikingly opposite to the demographics of the CFS outbreaks at Incline and Yerington, but I suppose would be compatible with Dr. Bell's pediatric outbreak at Lyndonville.

I think it's probably not a good idea for the human race to conduct this microwave experiment with no fallback plan, should it turn out the way the evidence suggests, but it still looks like our little CFS problem may have predated this one.

If the spillover from the towers on Mt. Judah above Norden were causative and exposure should theoretically correspond to this type of exposure, one might question why the other repeaters failed to reproduce this correlation - and why the vast majority of CFS cohorts emerged in places with no microwave towers at all.

If someone can get themselves better by avoiding microwaves, I'm all for it.
Like others, I've often pointed out that the illness process we are suffering from preceded the invention of cellphones and manmade EMF's.

But this is not sufficient reason to completely discount the harmful effects of EMFs or to disregard the possibility that the massive increase in prevalence of ME/CFS may very well be connected.

Perhaps the basic mechanism for CFIDS/ME existed prior and that the EMR is dramatically bringing this phenomenon to the fore.

We know that outbreaks of this illness preceded the invention of electronic devices, but they always seemed "self-limiting" in that they didn't spread out and plague the world by sheer numbers.

I don't doubt that EMR are involved in the massive increase, but modern microwaves certainly cannot account for these cases of illness from a hundred years ago.

It seems much more likely that EMR is a contributing factor, albeit an extremely important one.

- Erik (2006, Locations)

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> There is the possibility that geopathic stress, which causes similar symptoms to EMR exposure, played a part in these earlier CFS cases.

Yes, I agree that this does sounds consistent as a possibility for earlier cohorts.

As the magnetic poles grow progressively weaker prior to the periodic reversal of polarity, the magnetic flux is creating variable short-lived electrostatic focal points all over the planet.

This might confer a slight shift in valence electron potential, which makes them more likely to pick up a free radical and become a reactive oxygen species of special circumstance.

Perfectly consistent with removing the surface free energy which creates the brownian motion necessary for proper red cell function and rouleaux formation.

This effect may combine with certain intracellular pathogens in creating that peculiar hit-and-run aspect of ME/CFS.
Sounds reasonable to me.

-Erik (2006, Locations)

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If there is a correlation between EMRs and CFS, it would seem that this an extremely testable hypothesis that would show up on a map.

-Erik (2006, Locations)

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>Despite all the jokes about aluminum hats, it is a known fact that aluminum does block microwave radiation.

I haven't tried wearing an aluminum hat, but I have been living in an aluminum box (custom RV) since 1994.

> So you're saying that your response to the illness is caused by aluminum protection as well as mold avoidance?

No, just pondering that if someone had the conviction that aluminum could provide protection, they would probably hear about my Mobile Environmental Control Unit and simply conclude that it was living in an aluminum shell that was really giving me the most benefit.

It does seem reasonable that microwaves are harmful and could be adding to the problem. But it's difficult to factor them in when so many of us became ill before cell phones were invented, and high up in the Sierra Nevadas where you still can't get decent cellphone signals.

So I'm not outright denying the role of microwaves, but trying to see where this might be placed in a context that makes it fit the facts.

-Erik (2006, Locations)

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> "When our bodies are exposed to an environmental stressor, the cell membranes close. In some people, Dr. Carlo estimates up to 40%, the body has an overreaction and the stressor causes a massive shut down of the cell membranes. Since our bodies have not evolved with information carrying radio waves, for this 40% of the population, our
bodies interpret the waves as a potential threat and go into the protective closed cell membrane state. Dr. Carlo has termed this Cell Membrane Sensitivity Syndrome.

I think this CMSS is really neat stuff, except that the illness seems to be clearly described long before cellphones were invented.

I certainly wouldn't rule it out as a contributing factor, though.

-Erik (2009, Locations)

**IMMUNE RESPONSE**

Remember the correlation to Type A personalities that got this illness the monicker of the “Yuppie Flu”?

Seems like this illness has more of a propensity to strike people with the strongest immune response.

Looks like the immune system is going after something that it just can't get at as hard as it can.

It almost appears as if CFS doesn't kill you outright and quickly because just about the time you feel sickest, your immune system runs out of steam and gives you a bit of a break.

-Erik (2003, CFSExp)

*Perhaps even more peculiar than the inability of doctors to see just how physically ill you are is the bizarreness of being so sick and not dying.

I've heard of a similar phenomenon in AIDS in which people at the final extreme have their symptoms improve slightly as their immune system stops working - but then right after that they succumb to infection.

It feels as if a great deal of the damage is from immune over response alone and the reason you don't die is just about the time you are going to, the immune system stops working and you improve just enough to keep going.

-Erik (2005, CFSExp)

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The peculiar thing about ME at Royal Free and CFS in Incline is that the illness didn’t target those who these theorists say would be the very ones to succumb.

It honed in on athletes, schoolteachers, unstressed children and just plain normal folks.

It really seemed as if you would have been better off if you had been a drug user, alcoholic, person with clinical depression or patient in a hospital. They didn’t seem to catch the illness.

That’s why I say the illness hit hardest the very people that the "burned out and run down" theorists say would be the least likely to get it.

When you go from athlete to bed bound, to make you fit their theory, they say, "If you succumbed, then you must have been a drug user, bad eater, or had some stress, ‘fess up."

Wish I had. Probably wouldn't have got sick.

-Erik (2006, CFSExp)

SPANISH FLU

We called the infection that originated in Truckee before spreading to Lake Tahoe the “Truckee Crud.” Dr. Peterson identified it as HHV6a.

I keep reemphasizing the athletic nature of the people in the CFS cluster because people keep claiming that these are the types of people who should be immune because CFS is an illness that targets people who are already overwhelmed by toxins, bad diet and stress.

The demographics of the Spanish Flu were equally bizarre.

It was found that the people most likely to succumb were soldiers and young adults between 19 and 29 in the best apparent health.

It appears now that the severity and mortality of the Spanish Flu were dependent on the strength of the immune response rather than the lack of response from a weakened immune system.

I believe that the types of people that were afflicted during the Incline Village epidemic calls for a similar rethinking of who this illness strikes.

-Erik (2003, CFSResearch)

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The illness in Incline Village hit a high number of athletes and people in the greatest apparent health while bypassing the sickly and sedentary.

Just like Spanish Flu.

Just like Royal Free.

This "hits the strongest hardest" in the CFS scenario does not appear to be inconsistent with the RNA dysregulation of the Non Structural One protein produced by virally encoded cells, which gave the Spanish Flu its exceptional inflammatory provoking capacity for self destruction.

The peculiar demographics of the Spanish Flu were that those who had the greatest apparent capacity for an immune response were the very people with the greatest mortality. It was the very strength of their immune response that killed them.

The encoding for the N1 protein is separate from viral replication and presumably might be retained in the regulatory genes after the virus is gone.

I've always wondered if the "junk genes" still retain the encoding for the inflammatory response downstream of Spanish Flu survivors - only waiting for a cytokine event to dysregulate it once again.

-Erik (2005, CFSExp)

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The interesting point about the demographics of Spanish Flu is that the postviral sequelae were described to me as including unusual sensitivities to chemicals.

My grandfather was a Spanish Flu survivor and developed MCS.

Another interesting thing about Spanish Flu is that the mutation that made it so deadly was conjugation of a gene sequence that programmed the cells to produce NS1, Non Structural One protein RNA dysregulator of inflammatory response, as a separate entity from the virus. It is no great secret that Spanish Flu achieved its pathogenesis from a specially enhanced inflammatory response.

People keep pointing to stress-induced Neurasthenia in World War One as an example of extreme stress resulting in an epidemic of mental illness and keep telling us to forget that these soldiers had all been exposed to Spanish Flu.

If humans have conducted wars on a fairly regular basis throughout our history, and if such battlefield trauma was not consistently associated with such mental disorders, then
might it not be more likely that the connection between Neurasthenia and this particular war was that these soldiers were postviral survivors?

And if the NS1 inflammatory response iscellularly programmed separately from the virus, might not that programming remain and possibly be somewhere in those "junk genes"?

Just waiting to be expressed by a cytokine inflammatory illness?

-Erik (2005, SickBuildings)

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While this illness drives PWC’s right to the edge, the most amazing thing that it so consistently leaves people alive to interminably suffer and die later.

It's like a skilled torturer who knows how to back off and keep the victim alive as long as possible to inflict maximum pain.

When I look at the demographics of the Spanish Flu, in which it appears that it was the strength of the immune response that dictated mortality in people who had the greatest apparent immune strength, I see a parallel in that the most severe ME/CFS symptoms seem to run out of steam just before they kill you off - as if the immune system simply runs out of energy just before total collapse and death. If you have no other illnesses or complications, CFS leaves you to go on and recover to the point where the immune system can regain strength and attack you again.

If CFS is an induced self-directed immunological inflammatory response, enhancing immune function without determining what it is targeting might just be adding fuel to the fire.

Not that I am advocating immune suppression as an alternative, just observing that the peculiar "leaves you alive to suffer" component of CFS occurring suddenly in young people is a stark distinction from the type of mitochondrial dysfunction resulting from long-term cellular stress models of old age.

This illness is not a matter of adding vitamins and recovering.

-Erik (2006, CFSExp)

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I focused on the Spanish Flu because it shared the same demographics as Royal Free ME and the Incline Village CFS phenomenon.
And also because I spoke with an old time doctor who said that he routinely observed MCS in civilian Spanish Flu survivors who had not appeared to have been exposed to inordinate amounts of chemicals.

The other interesting feature is that:

"A study attempted to reason why the disease had been so devastating in certain localized regions, looking at the climate, the weather and the racial composition of cities. They found humidity to be linked with more severe epidemics as it ‘fosters the dissemination of the bacteria.’" (Committee on Atmosphere and Man, 1923)

Except, of course, that Spanish Flu wasn't a bacteria.

-Erik (2006, SickBuildings)

**SUSCEPTIBILITY SYNDROME**

It has not been established that CFS is a heterogenous illness.

If there were an immune dysfunction so primary, so subtle and so basic to cellular function that it had no specific manifestations of a peculiar infection, only an immune dysregulation, it could be that the entire range of immunological dysfunction can be traced to one primary cause.

Immunological stressors are certainly increasing, but if there can be clusters of sudden onset or even a "patient zero," wouldn't that mean that there is a pathogenic process connected to a common organism or a common environmental exposure (or perhaps the two together) that is overwhelming?

As I just wrote these last words I'm watching the story of an entire family sickened by "Hot Tub Lung Disease" - aerosolized bacteria from an indoor hot tub. Who ever heard of such a thing? Have the bacteria just become so powerful that normal immune systems cannot resist them?

Drs. Heitmann and Perfect at Duke University assure me that immunocompetent people should not be overcome by candida. I see the fact that so many non-PWCs are being overwhelmed by candida as evidence that there is a spread of an underlying immunological dysfunction that is even more widespread than clinical CFS.

Looking at the wide variety of formerly benign pathogens that have suddenly demonstrated unprecedented capacity has made me doubt that all of these critters suddenly and simultaneously developed supercharged mutant powers.

There are no end to the numbers of Saprovores and Saprophytes that are eager to return us to the dust from whence we came.
They used to show more patience about waiting until people were dead.

The question is:

Why aren't they waiting anymore?

-Erik (2003, CFSExp)

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As a dental lab technician, I've been a good position to see the complaints of patients to dentists about various alloys.

Dentists are stunned at the number of crazy people claiming to be reactive to certain metal alloys and who are bringing in Clifford Biocompatibility test results to indicate the alloys they are least reactive to. Somehow these crazy people have the awesome mental power that allows them to create discolored gums adjacent to their restorations.

Most dentists simply dismiss these abnormalities in the same way they dismiss cavitation osteonecrosis - by pretending they don't exist.

What I see is not mercury poisoning from abnormal amounts of mercury.

I see an induced reactivity to normal amounts of heavy metals.

Basically the same thing I've been seeing with mycotoxin reactivity.

An abnormal response to exposures that are considered benign.

-Erik (2003, CFSResearch)

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> We hypothesize that an increased vulnerability to oxidative stress (environmental and/or intracellular) may contribute to the development and clinical manifestations of autism.

What a concept: an “increased vulnerability” to oxidative stress.

It sure doesn't take much of any altercation to induce a crash in CFSers.

That's why I find it difficult to understand why all CFSers don't present their illness as one of extremely abnormal susceptibility to - instead of caused by - antibiotics, stress, weed killer, allergies, etc.
I probably will never understand how people could have seen this any other way, since the stress and stressors that were implicated were well known not to result in the illnesses they were blamed for creating.

Unless genetic factors ("retro-elements") are being inserted, as recent evidence suggests may be occurring, the evidence would sway toward environmental factors since any genetic factors so prevalent as to allow an illness to strike up to a hundred percent of people in a single room would make these genetic factors pretty much universal and not inherited in the usual sense.

And even when researchers refine their wording to say "genetic expression," it still isn't saying much.

Is there any cellular function at all that isn't the result of genetic expression?

It has to placed in some kind of restrictive context to even be worth saying.

-Erik (2005, CFSExp)

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I started seeing the most amazing complaints after the CFS epidemic went through:

Metal sensitivities to various alloys that the dentists all deny.

Cavitations, which the oral surgeons "don't believe in."

Discolored pale gum tissue which the doctors say is consistent with alcohol abuse and career smokers, although the people with this problem do not match that description.

And of course, massive amounts of endodontic treatment failures which are always dismissed as idiopathic.

I've seen a few people who felt so much better after their failed root canals and cavitations were treated that they blamed these for their CFS, although they haven't quite recovered.

I was in a position to see the pattern of these factors change and the usual doctor denial response, and I still believe that this is an illness of induced susceptibility rather than one caused by all these heretofore rare, unknown and disbelieved manifestations of the illness.

Just like the mold "hysteria" epidemic that we are witnessing.

Nobody has ever seen anything like it before, and that is why it meets with the usual derision, disbelief and scorn (even if it isn't called CFS).
If you examine the multiple "causes" or triggers for CFS/ME, this syndrome is completely consistent with an encroaching susceptibility in which the sufferer tends to blame the final straw.

Unfortunately, most people know full well that the "cause" which is implicated has a long and well established history of not causing CFS/ME, so the description is immediately relegated to insanity or mistaken beliefs.

There are secondary infections in AIDS which are known to emerge when subsets of leucocytes are depleted. Restoration of just enough immune function past the threshold can result in a dramatic change even though the shift was not all that great.

I think there are a lot of people who address a co-morbid situation just enough to jump to another level. This gives the appearance of being cured, just as the emergence of the secondary pathogen gave the false appearance of causality.

If someone already had a good diet at the time of onset, I would say that this is unlikely to be a factor which will make a difference.

But it just might for people who were somewhat immune suppressed as a result of their former nutritional choices.

Isn't it painfully apparent by now that this is a susceptibility syndrome?

The multitudes of triggers speaks to the meaninglessness of those triggers as a true basis of the primary dysregulation.

The multitudes of various means that some people have used to recover means that they lifted the burden sufficiently to get on top of the power curve.

When you combine the former inability of stress to result in any such illness with the way this illness moved through the population, and add in the knowledge that herpes sufferers correlate flare-ups with stress, what you wind up is an infection that is mediated by stress rather than stress creating an illness.
We should be no more satisfied with doctors’ recommending stress reduction than herpes sufferers would be if doctors decided to stop giving them Acyclovir and only offer cognitive behavioral therapy as a means of dealing with their viral infections.

If whatever stress or stressor existed before but didn't cause the illness - keep looking.

If whatever means of recovery only address those stresses or stressors that are pre-existing factors that are not known to cause CFS - keep looking.

If it existed before but didn't cause CFS in any combination or level of intensity, and if nothing about it has changed - keep looking.

-Erik (2006, Locations)

*

A few years ago, dentists started seeing patients show up with Clifford Biocompatibility Test results.

These patients carefully explain that they have reactivity to certain alloys and that their restorations must be made with the ones they are not reactive to.

Sometimes the dentist just says, "Go ahead with your normal alloy and we'll tell them we used whatever it is that they wanted.”

Other times a dentist, usually not believing but wanting to avoid a possible lawsuit, says, "We have to humor them and give them the alloy they ask for.”

Most dentists don't believe a word the patient says, even though they can see the blue gums and oxide buildup on the offending alloys and restorations. Dentists just say, "Huh, must be galvanism, but it's harmless. Any complaints you have must be exaggerations or somatization.”

I can see this is a real paradigm shift by the way the dentists are going into such total brain lock. Even with increasing numbers of people, dentists just keep coming up with excuses why this cannot be happening, why so many people are becoming hysterical, and how the "metal toxicity crazies" are out there hyping this concept and creating problems where none exists.

And you though MD's were the only crazy doctors!

-Erik (2006, CFSExp)

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Are you certain that your illness wasn't accompanied by an increased susceptibility to stress which made it appear causative, just as people were so firmly convinced that stress caused ulcers until it was found that they had it exactly backwards?

The heightened inflammatory response to bacterial infections simply decreased their threshold of tolerance until any stress that had a "logical basis" received the blame.

And this reversed cause-effect concept persisted for over a hundred years without serious opposition, although it was completely wrong.

-Erik (2006, CFSExp)

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It seems to me that if a conventional opthamologist found nothing abnormal, the next step would be to consider some lesser known eye condition that is mediated in direct correlation to illness exacerbation.

-Erik (2007, CFSExp)

HISTORICAL PREVALENCE

I've based some of my concepts of CFS as an illness that has had a wild increase in prevalence based on the notion that something as horrific as this couldn't possibly have been ignored.

How could people be so oblivious as to say that they never heard anybody complain of such a thing if this existed in any significant numbers in the population?

However, I am forced to admit that "friends," family, physicians and humans in general have demonstrated that they can watch a million people go down with this illness and pretend they see nothing.

After witnessing the degree of denial that people have proven they are capable of, it seems conceivable that this illness could have destroyed the lives of millions and that every single person could have been told that they are the only one with such unbelievable symptoms.

-Erik (2004, CFSExp)
Chapter 50 - Psychologizers

STRESS

I remember when herpes swept through the population.

The interesting thing about people with their new herpes infections is that they would swear up and down that "stress causes herpes" and that by avoiding stress they "didn't have herpes."

Soon, of course, their significant others had herpes too and they too were similarly swearing that under periods of stress, their outbreaks would flare into an outbreak.

It's just amazing that no amount of explaining that "stress cannot create a virus" and that "no amounts of stress, however extreme, can create herpes infection flares in people who do not have the virus" could get people to quit saying "stress causes herpes."

As a herpetic virus, it doesn't seem like too far of a stretch to suggest that HHV6a might just respond in a similar manner and that some mind/body fanatics simply cannot let go of the fact that stress is only exacerbating their herpetic infection into a flare.

So I don't completely discount the concept that these people really might have ME induced by HHV6a. I just think they are befuddled by "The Amazing Power of the Mind" when their stress reduction techniques actually seem to make a difference in the intensity of their illness.

-Erik (2004, OneClick)

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The extension of "stress" to include anything and everything that perturbs the immune system in any way means that "good nutrition" and "happiness" are stressors and could be implicated in any sort of dysregulation. People who die a lingering death from being shot or stabbed could be said to have succumbed to the stress of their wounds.

It makes the whole concept of stress meaningless and only further confuses the semantic ability to define something as causative.

But it allows psychologizers to say that any illness consists of stress as a significant factor.
Using this stressologizer logic, one might argue that since hangnails and hemorrhoids cause pain and therefore create stress, they must necessarily be a factor in the case of anyone who succumbs to a stress-induced illness. If one argues that CFS is the sum of all stresses and that relieving the immune system of any part of that burden constitutes a treatment, then manicures and Preparation H could be called effective treatments if they reduce any portion of the pain and associated stress.

While relieving stress is good for anybody, the lack of correlation and consistent failure of any level of stress to cause CFS means that it is a factor that has no more than an incidental role and should not be implicated as a significant factor any more than one would blame hangnails or hemorrhoids - painful though they may be.

-Erik (2005, CFSExp)

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What if the physiological effect of metallo-enzymes released as a normal consequence of emotional stress actually alter basal cell membrane inflammatory responses at a level that formerly didn't signal pain but now do?

In other words, what if there IS a physiological component, but one that didn't formerly result in debilitating symptoms until the altered threshold of susceptibility turned a formerly benign response into a devastating neurological dysfunction?

Polly Matzinger’s immunological concepts of "pathos instead of foreign" suggest that the immune system responds to signals sent from distressed cells rather than simply going after any xenobiotic intruder. When viewed in this way, the task is to separate normal and known responses to stress (ones that are well known not to result in CFS) from the abnormal response.

People have always been under stress, but it didn't cause CFS.

If it manifests the apparent capacity to do so now, the logical thing is to identify what changed in the response to that stress, instead of trying to identify ways in which to stretch the subjective effect of stress completely out of reasonable proportion.

As we have seen, there is simply no limit to how far stressologizers will stretch their conceptual model of the effects of "stress" to try and make it fit a level of pathogenesis which it consistently failed to achieve throughout the history of humankind.

-Erik (2005, CFSExp)

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What stress? You mean living in that horrific hell hole Incline Village?
I think most of us rather liked it up there and were pretty satisfied that there was no finer place on earth.

I didn't see many unremitting, long-term stressors lurking around there. They didn't appear to be any kind of a factor at all.

I suspect that as long as CFSers present their illness as being self-induced from emotional over responses and an inability to PACE themselves physically, doctors will view this illness as such and treat CFSers accordingly.

-Erik (2005, CFSExp)

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When I was in the Army, our unit was attacked.

A 100,000 gallon POL tank was blown up, an officers’ club was hit with grenades, and half a dozen soldiers in an outpost barracks were killed in their sleep.

Stress had us wired beyond belief.

I didn't see anyone succumb to exhaustion. Far from it.

When we slept, it was controlled and chosen.

I wonder what kind of stress people are thinking of that is worse than the prospect of being shot or blown up?

Are our soldiers in Iraq suffering from chronic fatigue in the way that doctors think stressed civilians are?

-Erik (2006, CFSResearch)

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No bad job, marriage, burnout, Auschwitz, or any stress known to mankind has ever consistently or even sporadically caused CFS.

If someone is shot, stabbed, or overwhelmed by infection or toxic exposure, these things are not called stressors.

They are called trauma or infections.

If someone gets West Nile virus, no one says the real cause of their illness and death is from the stress of having West Nile virus.
The "Damned Disease" or "Living Hell" that came to be called CFS is no different.

If anyone expresses it otherwise, and insists upon the concept that this is some kind of normal illness that can result from an overload of "anything and everything," the only logical conclusion is that they cannot be referring to an illness that stomps the living crap out of people’s lives in a way that nobody seems to recognize, no matter what their burden of stress or stressors.

If someone is absolutely insistent that stressors can cause CFS, I have no other choice but to conclude that they must be thinking about a type of illness that stress can cause - and that isn't CFS.

At least, not original CFS.

-Erik (2006, CFSExp)

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Imagine getting blisters after a one-night stand and going to the doctor at the same times as a person who scalded themselves with hot water.

You both want effective treatment for your blisters, but the doctor just gives you the same salve as the burn victim.

You say, "That's not how I got these. I don't think your therapy is based on the circumstances or how this appears to be an infection of some kind."

And both the burn victim and the doctor reply, "That's just political and you are just bickering about trivial details. A blister is a blister. Many things can cause blisters. It's pointless for you to argue that your problems didn't come about in the same way, when you should be more concerned with taking care of the problem. Here is your skin salve - take it or leave it."

-Erik (2007, CFSExp)

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People cite "stress and stressors" as if they were going to accord emphasis to pathogens or toxic exposure, and then they keep reverting to what is truly on their minds: "It’s your fault because you’re an emotional basket case."

Not that any of it matters, because prototypes for CFS were selected on the basis of a paucity of stress and stressors instead of the reverse, indicating just how backwards people are looking at this.
Stress, whether emotional or otherwise, used to be thought of a something that was above and beyond normal.

It didn’t used to make sense that someone would be stressed by anything usual, any more than an airplane is stressed by a normal flight or a bridge is stressed by its customary burden.

The term was invoked to mean that something extraordinary was placing extra deformation on a system.

Lately, it seems that since no significant or suitable stress was found to account for the equivalent of "wings falling off" or "bridge collapsing," rather than abandon the "stress concept," the "You brought this on yourself" blamers simply cited Selye and extended stress to include virtually anything and everything that moves a single atom sideways.

Great plan, because they can slyly sneak in their emotional stress concepts. Yet when some highly infectious pathogen that overwhelms a normal immune system is identified, they can still say, "See? Stress!"

But what is the good of having a word for stress there is virtually nothing in the universe that isn’t stress?

-Erik (2007, CFSExp)

*I’m well aware of this all-encompassing "Selye Stress" definition.

It pretty much extends to anything that even theoretically perturbs immune function by so much as a single molecule’s worth of response.

Using the word in this way is about like saying something is "genetic."

We have presuppositions about that word which creates a conceptual image of "inherited" in most people. Those who employ the wider view say, "You don’t understand. Genetic means that this response is controlled by the expression of genes."

Blammo. We are playing "semantic switcheroo" and suddenly genetic is transformed from "inherited illness" to something very broad. Something undefined and literally without constraints, because virtually every structure and function of every living cell is determined by genes. If it has to do with life, there is virtually nothing that is not genetic.

Of course the illness is genetic now. What isn’t?
Then, having obliterated the term into uselessness, people assign arbitrary and unpredictable meanings with strong implications, which magically vanish when you try to pin them down on a precise example.

So I am frustrated about the miscommunication and misunderstanding surrounding this word "stress." It has to have constraints in order to have meaning.

The old usage actually conveyed something quite relevant. It referred to an exceptional and unaccustomed force that was in excess of a normal state. One didn't think of sitting as stress unless it was sitting for long hours. One didn't think of breathing as stress unless it was difficult because of altitude or exertion. Now we are not allowed to use it this way, because people will say that the act of sitting or breathing is stressful unto itself, no matter how quietly it is done or how short the duration of the process.

So, in one fell swoop of redefinition, all those normal processes which people consider to be a customary part of life have become implicated as potential triggers for illness.

And we can't get people to stop doing this!

"But I was relatively happy at the time of onset."

"Doesn't matter. Happiness exerts an influence on your immune system. Can you deny that physiological processes are involved with happiness?"

"But happiness has never caused CFS."

"Everything that perturbs immune function puts stress on it. You cannot claim that happiness has no effect."

Good God. It was an illness! And after twenty years, we still have to listen to this?

-Erik (2007, CFSExp)

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People should do whatever they can that helps.

I refer back to a time before Acyclovir - when people were trying to cure herpes by making themselves more serene than Buddhist monks.

Sure, it helped reduce flare-ups and was a worthy thing to try.

No amount of stress can cause a herpes infection. It can only mediate something that is there to be exacerbated. Unless one is only talking about causing a flare-up, the word "cause" is inappropriate.
But we are in the situation of the ulcer sufferers of years ago who heard the rumors that they cleared up with antibiotics.

We would like doctors to rethink their attributions and stress associations - and seize upon this clue that shows the illness is not what they think it is.

Saying, "I don't care what anybody thinks. My ulcers got better when I reduced stress. This is solid evidence that the mind controls the body and that there is no dividing line between physical and psychological" is not going to get doctors, or anybody else, to reconsider their entrenched beliefs.

If anything, this type of wording reinforces their dogma even further.

It helps them to ignore that tiny little clue that children who weren't under any stress could suddenly acquire ulcers for no apparent reason.

Sure, the child is acting out and seems more stressed, and probably even says so, but that sudden acquisition of stress intolerance clearly delineates the dividing line between mind and body - because that body didn't have those problems until the illness hit.

You know, it's really funny that the mindbodyists have virtually everything backwards.

Among other things, they got completely reversed. They say that their mental control techniques represent a new way of looking at illness that demolish the old entrenched beliefs.

But wait..when you look over the history of medicine, weren't just about all illnesses "psychologized" until proven not so?

-Erik (2007, CFSExp)

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How can you not be stressed, when you are fighting for your life?

Sheesh. It drives me to distraction, to hear, "You're too stressed" from people who have no concept of what it is like to abandon so much as a sheet of paper, let alone their entire lives and everything they worked for... because these precious things assumed the aspect of nerve gas exposure.

-Erik (2008, CFSU)

*

I have never denied that stress has consequences.
I only said that stress has existed once or twice in the course of history, and that it is well known not to do what people seem to think stress is doing now.

-Erik (2008, CFSU)

*

I'm in my mid fifties, and feel so lucky that I got a taste of real human life before this happened, with all its normal emotion, ups and downs, fear of failure, exultation of victory, and pure excitement. The way humans were meant to live.

Not like the pathetic mediocre vegetable-ized "no stress" life that psychologizers hold up as the ideal way to be.

That is not a human life.

-Erik (2010, WPI)

**POWER OF THE MIND**

Infections occur regardless of what any individual might think about it.

Many infections don't even seem to care if the individual is conscious or not.

Using the "power of the mind" to control infections has been historically unproductive. However, psychologizers adhere to the concept that if you fail to control your illness, it is due to your own weakness of mind and lack of willpower.

And when you point out that it is not uncommon for physiological illnesses and infections to be unresponsive to mental control, the usual response is, "You cannot separate the mind and the body."

Actually, you can. Bacteria, viruses and parasites can be cultured in a chunk of meat and demonstrate cellular pathogenesis.

Of course, the next response is, "You are only ill if you allow yourself to believe that you are ill."

Which is quite a separate issue to doing what is necessary to eliminate the infection.

-Erik (2006, CFSExp)

**PAIN AS THE CONSEQUENCE**
I guess I dismiss stress concepts so strenuously that it looks like I'm totally dismissive of stress as any kind of factor. But really, I've also felt the benefits of "the relaxation response" and am doing my best to avoid stress wherever possible.

I didn't need anyone to forcefully convince me that reducing stress is a good thing and I don't think that other CFSers need to pay doctors to get advice on stress reduction unless they specifically ask for it.

This is an illness of total susceptibility and we see all kinds of contributing factors which people focus on as causative, even though they have no history of causing CFS.

Take mold, for example. I found that certain types of mold were such a driving force and a major factor in my illness that I was able to resolve a great many symptoms through a strategy of extreme mycotoxin avoidance.

But as we all know, mold has been around forever and has no history of consistently resulting in CFS at any level of exposure.

I found that other Incline CFSers shared this neurotoxic susceptibility and have even found others who conduct some level of mold avoidance, so I promoted this mold specificity as a means to helping CFSers with their susceptibilities.

But everybody jumped on me exactly as the doctors did and misconstrued my statements as, "Erik says that mold is the cause of CFS," which is not what I said.

I said that these neurotoxins are a driving force in many of my symptoms and avoidance is extremely helpful, but not that mold is a cause or that avoidance is a cure.

If anything, my emotional states are a great indicator of neurotoxic inflammatory exposure.

When psychologizers witnessed my recovery after practicing mold avoidance, they said, "I'm so glad to see that you have reduced stress. Don't you wish you had done this earlier? See how much happier you are now that your attitude is so much better?"

I couldn't believe it! I said, "My attitude is better because I am feeling better. Don't you see that my ‘bad attitude’ was a reflection of just how bad I felt? If anything, my attitude that my ‘negativity’ is an accurate manifestation of illness is more firmly fixed than ever."

Why is it that when a person smashes their finger with a hammer, their expression of pain is considered to be commensurate with the stimulus and that the person is honestly justified in letting out a scream, but when a person is dying of cancer and says, "I'm dying," psychologizers respond, "That's just your negative attitude and you'll never get better if you think like that."
At what point does a person’s accurate representation of pain turn from the "consequence" to the "cause"? Only when it is serious and chronic?

Next time someone smashes their finger, would it be better to yell at them? "You're exaggerating and the louder you scream, the longer it will take for the pain to go away. Ignore it, and it doesn't exist."

Do psychologizers ever stop to think that a person who expresses serious expressions of pain might just be telling the truth? And that if there is any correlation between smiley happy thoughts and improvement, it might just be that these people perceived themselves to be less ill and more likely to improve than a person who is really dying and says so?

So I'm not in any way opposed to reducing stress, just to people who keep insisting that it is only your negative personality traits and individual failure to control stress that separates you from healthy people such as themselves.

-Erik (2005, CFSResearch)

THE “CFS PERSONALITY”

"Why didn't everyone become ill?" is a question that presumes everyone had the same exposure. Why doesn't everyone get malaria, tuberculosis, AIDS, or anything else? Who would speculate that if a cluster of people in a building got E coli or hepatitis, any who did not must have had some mental factors that made the difference?

Wouldn't people say it was just common sense that the sick individuals were the ones who had the exposure?

Correlation is not causation, but the epidemic cohorts show that at least under certain conditions, there is no correlation of personality traits to be found.

I believe that there is no lack of exploration into the "CFS personality" from any possible physiological changes or gene alterations.

Professor Wessely and the Nijmegen School of Psychiatry have long been intent on demonstrating that despite protestations of people claiming that they simply became ill, such a connection must surely exist.

I believe that when it comes to attributions of hysteria and concepts of behavioral maladaptive processes that have been historically applied inappropriately to emerging illnesses, no last word is necessary to know that diseases that now have an identifiable etiology can no longer be categorized as mental illnesses as they once were - but never should have been.
In retrospect, there never was suitable evidence to formulate that hypothesis, let alone pursue it with such vigor.

-Erik (2006, CFSExp)

**SOMATIZATION DISORDER**

It beggars belief that proponents of psychological theories of causality for CFS/ME fail to understand that their arguments are moot.

Their somatization disorder concepts of instant deconditioning and exercise intolerance after a flu-like illness have always been insupportable.

The selection of the trivializing "CFS" after earlier dismissive abusive attempts at minimizing this illness such as "Lake Tahoe Mystery Illness" and "Yuppie Flu" shows that the illness naming process itself makes a statement about the mindset and conceptual abilities of the physicians who had the power to make such determinations.

The fact that it has taken so long for the psychiatric theorists to respond to inarguable evidence and the vehement assertions of their clients demonstrates that a serious unscientific mental methodological flaw afflicts those who currently hold the reins of etiological investigative processes.

The lesson to be learned from this debacle has far reaching implications for all emerging illnesses.

Will physicians who instantly promulgate psychological theories to explain unfamiliar complaints be left in positions from which they can also dismiss unusual signs and symptoms from Sarin, Ricin, Anthrax, Smallpox, Aflatoxins or any other biological weapons that terrorists are attempting to acquire and deploy on civilian populations?

-Erik Johnson (2004, BMJ)

**DENIAL OF EVIDENCE**

Why did it take a housewife to discover the Lyme epidemic? What lack of scientific method, behavioral problem or mental flaw made doctors oblivious to what a Polly Murray, a housewife armed only with an arsenal of common sense, could see so clearly?

The "genetically induced Juvenile Rheumatoid Arthritis" that doctors were diagnosing in Lyme Connecticut occurred at a rate of increasing prevalence distinctly uncharacteristic of a genetic illness. Polly Murray’s book "The Widening Circle" describes her battle against doctors who insisted that the Lyme epidemic was "all in your head" despite
unimpeachable evidence to the contrary. Even after the contradiction of the "statistically almost impossible" increasing prevalence was pointed out to doctors, they still failed to respond in a scientific manner.

Physicians have the audacity to produce "scholarly" papers on the mental behaviors of obstinate patients who refuse their recommendations for mental health interventions while evidence continues to mount that the entire crisis of patient confidence is being created by the inexplicable behaviors of the physicians themselves. Where are the studies that explain these repetitive failures of a common sense approach in doctors?

No patient expects all doctors to be all knowing, but at the same time, denial of incontrovertible evidence and skepticism in the face of obvious abnormalities by a significant number of doctors is undermining the credibility of an institution whose function absolutely demands it. The errors of omission that are so consistently being made were the point of a lesson by the renowned physician, Sir William Osler, who taught his medical students the importance of keen observation.

A memorable example occurred one day when he showed his students a small bottle of a patient's urine and told them, "This bottle contains a sample for analysis. It is often possible by tasting it to determine the disease from which the patient suffers."

He demonstrated this by dipping his finger into the bottle and tasting it, after which he instructed his students to do exactly as he had just done. The students, with some trepidation and each in turn, dipped their finger and sampled the bottle's contents, trying to determine what important lesson they were about to learn.

Osler surprised his students by holding up the bottle and saying, "Now you will understand what I mean when I speak about details. Had you been observant, you would have seen that I put my index finger in the bottle but my middle finger into my mouth!"

I believe that any physician who survived a course of study under Sir William would have seized upon the clues that modern day doctors overlook in favor of total reliance on their catalog of lab tests. It is the power of observation that distinguishes a diagnostician from a pill purveyor. It is training of the sort that Sir William Osler conducted which is required to stem the crisis in confidence created by those doctors whose practice includes medical malfeasance.

-Erik Johnson (2004, BMJ)

THE FLAT EARTHERS

Watching the debate between psychotheorists and CFS/ME sufferers is like stepping back in time and having a window seat on history that allows you to view the furor in the Flat Earth Society meetings as each new bit of Round Earth evidence is introduced.
It is amazing to watch the fervor with which psychologizers defend a doomed concept. Every person who has experienced the reality of CFS/ME knows the debate is moot and that the outcome is certain.

Eratosthenes calculated the circumference of the earth in 230 BC by measuring the shadows in a well in Syene during the summer solstice. Over 1700 years later some people were still wondering if Columbus was going to sail off the edge of a flat earth.

Some people can be convinced by a single piece of evidence that confirms a theory because the concept can have no other explanation. Others cling to obsolete theories by refusing to consider any evidence that endangers their beliefs and reshapes their world.

As the pointless debate continues and more evidence accumulates, the question to psychotheorists is the same as it was for the Flat Earthers.

"How much more proof do you need?"

-Erik Johnson (2004, BMJ)

**IMAGINED TRAUMA**

If the psych theory doesn't encompass the facts, as in "But there was no childhood trauma," psychologizers simply broaden their definition until it does.

Like "imagined trauma" in which the child creates a "beliefsystem" in which they believe themselves to be traumatized, regardless of whether they were actually subjected to "empirically verifiable" trauma.

You can't prove the child isn't hiding some internalized perception of trauma, so the mere absence of "real trauma" is not considered by psychologizers to be relevant or capable of disproving the concept.

I can't believe that after all these years, these wild mental meanderings are received with anything but laughter.

-Erik (2006, CFSExp)

**PERSPECTIVE CHANGES**

Perspectives can change in a moment.
The abstract on general practitioners’ perceptions of CFS compared to IBS has an entirely new meaning when read with the knowledge of the molecular defect found in IBS.

Suddenly it is the general practitioners who are the obstinate ones. No wonder their patients challenged their authority and refused referral for mental health interventions.

Now that psychotherapists have had another one of their behavioral illnesses stolen from them by science, will there be any apology to the patients who only insisted that their suffering was as real as they claimed? Will the psychotherapists now be any less resolute in trying to fit CFS into their psychological framework?

How many more illnesses must go through this psychoprocess before theories of psychological causality are removed from physicians’ front line of defense against their patients’ insistence that they are truly ill?

-Erik Johnson (2004, BMJ)
Chapter 51 - Lyme

CFS VS. LYME

It's hard to match the description of Lyme onset with CFS when the variability is so extreme.

How does one explain such differences in individuals when there are CFS clusters in which everyone's symptoms are almost identical and severe to the extent that the lucky ones are those who can still stand up and feed themselves?

-Erik (2004, EuroLyme)

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The blood cells of CFS/ME sufferers have been found to be overloaded with CWD (cell wall deficient) Borrelia bugs.

I'll agree that this is associated with CFS, but is it causality?

If multiple CWD bacteria and infections are found that existed prior to the CFS epidemic without creating that epidemic, then what changed?

I wonder if the diagnostic criteria or illness perception of sufferers could have precluded knowledge of such hypothetical prior "unobserved" epidemics.

When CFS/ME shows up in clusters, it is almost impossible to miss.

Situations like Royal Free, Lyndonville and Incline Village are absolutely stark manifestations of illness sweeping through a population leaving athletes as invalids.

I find as an example of the difference between the fatigue described by Lyme sufferers and CFS sufferers that Lyme people are not overly uncomfortable with describing their sensation as "fatigue" while CFSers scream, “It is not fatigue!”

As far as post-exertional malaise goes, there was no possibility to exert oneself above attempting to stand or take a few short steps - not exactly what people think of by exertion.

I agree that doctors and observers have the incredible capacity to deny, denigrate and ignore such symptoms, but the sufferers cannot.
Surely illness descriptions of this type would not be so completely unknown unless something changed, though doctors are certainly doing their best to prove they are capable of ignoring virtually anything.

I've asked many old farts if they've ever seen anything like this before.

"Never."

-Erik (2004, EuroLyme)

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The illness represented by the term "CFS" was being diluted by denialists even before the name was invented.

When you see tired people with a few vague symptoms who have been diagnosed with CFS, you are not looking at the illness that CFS was based on.

The illness that raged through Lake Tahoe/Incline Village was absolutely life-destroying in a manner that could not be ignored.

Nobody, nobody, nobody recognized this illness.

Not doctors, not friends, not family - nobody.

I'm having great difficulty with this concept that Lyme has been around but was ignored by bad reporting.

Despite the extreme efforts made by everyone you thought you could trust to try to ignore you to death, it simply cannot be done.

I am seeing people with Lyme who are just as sick as anybody I ever saw with CFS, but there are others who don't even come close.

Even if every single ME/CFS person is diagnosed with Lyme, this question must still be answered:

If Lyme has been around so long, why didn't it do this before?

Maybe Lyme is a necessary precursor to CFS.

Maybe it takes some reactivated virus to create the symptoms consistent with CFS.

Maybe CFS is some "end stage" of Lyme after immunological collapse.

I am perfectly willing to go along with any concept that fits the facts.
I just know what I saw, and when people say, "Lyme is CFS," I have to say that this is not necessarily so.

-Erik (2004, EuroLyme)

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I would never minimize the tick borne diseases. It's just that the mycotoxin connection gets so little attention when it appears to be so huge.

-Erik (2006, CFSExp)

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Dr. Bell and his wife Karen were Lyme literate at the outset of the Lyndonville epidemic, with Karen the first to diagnose a case of Lyme in Massachusetts.

Dr. Bell and other CFS researchers have no vested interest in dismissing Lyme, and to the best of my knowledge are not closed to the possibility.

Yet they are not satisfied that it addresses the extent of the CFS phenomenon. Neither is Dr. Cheney, who has seen intestinal health destroyed and financial ruin result from long term antibiotics that accomplished nothing.

-Erik (2007, CFSExp)

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Sed rate is routinely elevated in Lyme, depressed in CFS.

Depleted RNase-L in CFS, normal in Lyme.

Even if a CFSer has Lyme disease, in order to "see" the CFS, one has to think of them as separate entities.

-Erik (2010, CAA)

WHAT CHANGED?

Is it viruses or toxins that turned Lyme into an illness that absolutely could not be overlooked after being around for so long without causing such a fuss?

It may well be that I have a European strain, since I had an interesting experience in Giessen, Germany that strikes me being awfully darn suspicious.
But that wouldn’t account for the others involved in the Incline Village epidemic.

No matter how much the doctors tried to fight us, this illness simply could not be ignored. News of this spread despite all the efforts of doctors and media to squash it and make it disappear.

Good reporting or bad reporting made no difference. This illness was far too devastating to have been overlooked if it had happened in any significant numbers before.

Could all these various CWD’s have simultaneously been weaponized or assimilated new pathogenesis by genetic conjugation?

Or are they formerly commensal bacteria that were unleashed by something else?

-Erik (2004, EuroLyme)

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I asked a local LLMD if Lyme was the same illness it had always been, and he brain locked on me.

As far as he is concerned, if he sees spirochetes then your illness is Lyme, that's the cause, and that's it.

"My patients are improving on doxy and that's good enough for me."

Good enough for him, but not for me.

If Lyme shows up in the stored specimens and has obviously been around for a while, then what the heck is making Lyme so killer now?

If we're seeing people dropping, as Lida and Joanne are, in an unprecedented manner from various species, then either all these bugs have simultaneously increased their pathogenesis (seems unlikely, though bacteria certainly can conjugate new genetic properties to account for this), OR the true reason for their increased ability to create a devastating illness is that some other process opened the door for them.

In which case, the true cause of the epidemic wouldn’t actually be Lyme. The cause would be the enabler that allowed these former commensals to kick butt.

-Erik (2004, EuroLyme)

SPREAD
Perhaps some effort should be made to analyze this illness by the manner in which it has spread.

An illness that has spread around the world in a few decades is unlikely to be caused by anything limited by geography.

Is a tick borne illness consistent with the spread of CFS?

-Erik (2003, CFSExp)

CAUSALITY

Borrelia and candida both existed prior to this epidemic.

It seems unlikely that these preexisting factors could have left the illness unrecognized, unknown and totally disbelieved if they resulted in this type of illness before.

So the question is, if Lyme in combination with other infections can consistently result in CFS, then why did it fail to do so in people who were identified with Lyme prior to the current situation?

I don't have any reason to believe that CFS is not the result of the interplay of multiple factors, but it certainly not the consistent and predictable result of all the various formerly benign infections that are being implicated. If these factors didn't consistently result in illness before, it is unlikely that they are doing it now unless something changed.

-Erik (2005, CFSExp)

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>Here are two possibilities - ordinary strain mutation because of inadequate treatments and weaponization.

Definitely. But if strains had been weaponized, those particular strains would swiftly emerge as the dominant pathogens, unless all the emerging infections had been imbued with new pathogenesis.

What we are seeing is the vast emergence of a huge number of formerly benign infections and apparent pathogenesis of ridiculous levels of stress which have no historical capacity to cause the level of suffering which they now create.

If a weaponized pathogen were responsible for this illness, wouldn't you expect to find a particular infection swiftly attain preeminence? Seems like people are having problems with a huge variety of spirochetes with only Borrelia taking the lead.
While treating these identified infections may be appropriate, they should not be implicated as primary to development of the illness since that guarantees a stop to any further investigation.

The only way this model works is if all these bugs were weaponized. Even then, this is complicated by the genetic/individual/environmental response, which leaves large variables in the ability of these infections to create the eugenic effect proposed by this "weaponized to weed out" hypothesis.

And of course, there is that one little problem that anything intentionally designed to have this degree of pathogenesis means total destruction of the earth as we know it.

Which would mean either an accidental release of some agent that has the capacity to introduce such pathogenesis to other Lyme species or that all these disparate species got out of the lab around the same time.

If they all got out simultaneously, that would mean someone messed up really badly or that was willfully self destructive.

The other alternative is that something has semi-universally decreased immune function and allowed all these formerly less destructive infections to have apparent increased pathogenesis and that we just haven't found it yet because we aren't looking.

-Erik (2005, CFSExp)

* > Soften up the enemy without ruining the infrastructure. Many strategies, many bugs.

I am somewhat familiar with that doctrine since I was a Nuclear Missile Launcher Specialist for the hypothetical Neutron Bomb.

The Lance Missile was designed for a nuclear airburst, which would douse the ground with intense concentrations of Alpha Particles and decrease the intensity of Gamma contamination.

We were supposed to walk into ground zero two days after the blast and all the buildings are left standing but everyone is dead. Yes, the military certainly thinks this way.

I have no doubt that Borrelia has been weaponized, but in order for the current situation to fit the model, wouldn't testing reveal Bb as the linking pathogen in our illness?

If Igenex or Bowen’s tests are accurate and Bb has been weaponized, wouldn't it fit the model by emerging as the preeminent pathogen?
But if a large percentage of people are truly negative (speculative at this point), then one would have to look for a reason why so many disparate spirochete species have suddenly assumed an apparent pathogenesis that is not entirely consistent with their historical capacity.

-Erik (2005, CFSExp)

**CHANGING SYMPTOMS**

Lyme doesn’t necessarily include the neurocognitive deficits characteristic of CFS.

Yes, most Lymies have the symptoms now. What isn't explained is why the pathogenesis in Lyme from years ago didn't consistently manifest in the same way.

There is a piece of the puzzle missing. What changed?

-Erik (2004, EuroLyme)

*Although Lyme is present is a vast number of undiagnosed cases of illness, the peculiarity is that the Lyme epidemic in Connecticut that identified the emergence of the phenomenon contained the concurrency of being mistaken for Juvenile Rheumatoid Arthritis.

The clusters of CFS in which other people shared concurrent symptoms were not remotely like JRA.

The "ME/CFS is Lyme" proponents discard this by saying that, "Lyme is unpredictable and can cause anything."

If Lyme were predictably unpredictable, why would it cause an epidemic that was consistently mistaken for JRA in one instance while consistently causing Ramsay-ME in another?

If Lyme caused the historical clusterings of illness that resulted in so many false starts and different names, then what changed to turn what appeared to be a limited-outbreak type of illness into one that is now a global epidemic?

If something enabled this alteration in spirochetal pathogenesis, attention is not drawn to "what changed?" by insisting that Lyme disease is sufficient to explain the nature of the phenomenon.

-Erik (2006, Locations)
If Lyme consistently masqueraded as JRA when it first made a cluster appearance, what would make the difference between the JRA-like clusters in Old Lyme and the drop dead devastating illness that happened in Incline which could not possibly be mistaken for JRA?

Bb subclinical till "unveiled"?
Myco co-factors?
HHV6a?
Mold?

What's the deal here?

-Erik (2006, CFSExP)

The illness that was originally called CFS had really spectacular and distinctive neurological weirdnesses that Lyme patients didn't complain about for twenty years.

Strange, but lately the Lymies are sounding more and more like us.

Look at the recent descriptions of Lyme disease. They have been extremely neurological.

Years ago, people didn't describe Lyme disease quite that way. The kids in Lyme, Connecticut were diagnosed by doctors as having JRA: Juvenile Rheumatoid Arthritis.

The description has changed every year to be more and more like ME/CFS.

Now when people get Lyme, complete with bulls' eye rash, they appear to have all the same neuro complaints as viral induced ME.

Whereas there used to be little doubt that they were different, lately more and more people are swearing the Lyme and ME are the exact same thing. Isn't that peculiar?

-Erik (2008, CFSU)

CHARACTERISTICS

I don't believe there is any test currently available that is completely reliable in ruling out Lyme.
Everything I have learned about Lyme makes me believe that these bugs are so good at hiding that I would be amazed if they were not fully capable of persisting in dead skin and fungal infections inside hair shafts in addition to the intracellular niches that Lida has identified.

-Erik (2003, CFSExp)

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I know two LLMD's who have looked with their Bradford Darkfields and are finding spiros in people who don't have CFS symptoms.

Perhaps infection does not necessarily mean CFS.

-Erik (2005, CFSResearch)

*

The Lyme vaccine did an amazing thing. It gave people what appeared to be Chronic Lyme without the bacteria.

This artifact opened up the door to a whole new way of looking at an illness. Dr. Shoemaker describes this as priming the immune system for an aberrant reaction.

The weirdness of having Lyme antibodies and a hyper reactivity to ionophore toxins leads people to believe they MUST have an active infection. But the Lymerix phenomenon was a pretty graphic illustration that there can be a situation where there really is no active infection.

The Lyme doctors are just barely learning about this. They didn't want to face the possibility that this is why some people utterly fail to respond to all those hundreds of thousands of dollars of antibiotics.

The bacterial component of the illness was already knocked down... and from here on, it's become a biotoxin illness.

-Erik (2008, CFSU)

**OPPORTUNIST**

In order for the Lyme epidemic to be taking place, something must have changed. Either an increase in pathogenesis or environmental factors, or both. If these have not changed, then the only reason that makes sense to me is that it was "allowed" by immune suppression.
The EBV reactivation in CFS looked causative because it was clearly present. But it had the exclusionary factors of not infecting everybody with CFS symptoms and the EBV was apparently still the same old virus that it had always been - not known to cause this type of chronic illness.

Lyme is in the same boat, no matter how hard you try to stretch it. If all CFS victims don't have it, and it's the same old collection of organisms that have not increased their pathogenesis, then it seems more likely that the Lyme epidemic is another secondary pathogen that has only apparently increased in power.

All infections in AIDS give the appearance of being supercharged mutant bugs from hell. But they're not. They only appear that way.

When someone with AIDS is being destroyed by candida or Molluscum Contagiosum, it's hard to look at the infection as non causative, but if you present these same organisms to someone with a normal immune system, it is clear that there is something else that is allowing these organisms to get out of control.

It looks to me like every time someone identifies a "subgroup" that consists of a seemingly causative mechanism, they ignore any evidence that the mechanism isn't pathogenic to most people and emerged suddenly for no apparent reason. Then they throw out anybody who doesn't have the factors involved in their pet theory as a fluke or not having "true CFS."

That's why I advocate an inclusionary approach to CFS rather than subgroups. If you apply this separation and subgrouping approach to AIDS, you'd would wind up idiopathic groupings and fewer clues that point to a mysterious factor that connects the idiosyncrasies.

If there are cases of CFS without Lyme, we have to keep looking.

But if you do have Lyme, might as well get it treated while we look.

-Erik (2003, CFSExp)

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No question about it. Lyme has gone nuts. But can we say that ME/CFS is definitely Lyme because we definitely find Lyme in ME/CFS?

How about candida? Know anyone with ME/CFS who doesn't have some fungal overgrowth?

In fact, if one were looking for universality in a pathogen, at this point candida seems to transcend Bb. If every animal on the planet exploded with candida, could you say that candida was the cause?
Even if every single human and animal on the planet were found to have Bb, would it still be safe to say that Bb is the cause if Bb has existed for a long time without causing animals with Bb to suffer this way?

Is a viral or toxic co-factor required to get the Full Monty?

If Bb could cause such co-factors to rise up and cause ME/CFS in people who had such co-factors, why did it fail to manifest in a noticeable way until recently?

Historic lab specimens have Bb so we know the opportunity must have existed. What changed?


Was Bb potentiated?

All of these?

About the only thing we do know is that Bb existed before this epidemic without causing this same type of epidemic.

-Erik (2006, Locations)

**PREVALENCE**

At the current rate of progression, Planet Earth will soon be considered a hot spot for Lyme disease.

Researchers in Santa Cruz find Lyme in ticks on their front lawns without the difficulty that the CDC seems to have.

The cluster effect of the Incline Village epidemic has long struck me as being markedly similar to the manner in which Yellow Fever spread - and confused everyone.

Apparently contagious, but not quite.

The salivary glands of mosquitos have been identified as a vector for transmission of spirochetes.

This finding matches brings the manner in which the illness spread into concurrency with the characteristics of Lyme-unveiled biotoxin associated illness.
A few moments ago, I witnessed the response of medical workers to the Alert. It was, "We have known about Lyme disease for some time now and know several people with the illness."

I asked where these Lyme sufferers received their diagnosis since the local doctors are still not acting in a manner consistent with "Lyme Cognizance," and generally respond with a blank stare.

Interestingly enough and in perfect accord with "doctor oblivion," where the Lyme patients found an LLMD is unknown.

-Erik (2005, CFSExp)

CAVITATIONS

I know of an Lyme Literate doctor who has seen so many cavitations in the area of the jaw between bicuspids and molars that he is convinced that this particular area is a niche for spirochetes, which he observes with his darkfield.

He says he has seen dramatic improvements after this niche is cleared up and that this location should be a special focus for investigation whenever osteonecrosis is suspected.

I saw an acquaintance experience a good level of recovery after such treatment.

-Erik (2006, CFSExp)
Chapter 52 - Other Treatments

MOLD AVOIDANCE VS. OTHER TREATMENTS

Prior to mold avoidance, no digestive enzymes, supplements or anything else I did seemed to help.

After six months, none of them seemed necessary.

I've taken no medications at all since 2001, when I was knowingly in a mycotoxin zone and was trying to compensate with CSM.

I finally got tired of fighting to stay alive in a moldy area and got out.

Since then I take nothing, not even aspirin.

-Erik (2006, CFSExp)

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I remember in 1997 getting so fed up about reacting to foods that I started screaming, "What is left that I can possibly eat? Mung beans?"

This was all so complicated, so overwhelming. And I wasn't getting any help from doctors. Indeed, virtually all of them told me that what I was describing was impossible.

The tendency is for people to throw a lot of effort and money into trying the least troublesome remedies. This just makes sense, except that as far as I can tell, they don't seem to do a fraction of what just avoidance does.

As I watch people try to "chemicalize" their way out of this, or normalize their immune response by endless attempts at antifungals, various supplements, and subtracting more and more "mycotoxin laden foods," I realize just how lucky I was to have undertaken this path.

The stuff I see other people trying just doesn't seem to be working, and some are eventually forced into more concerted efforts anyway.

-Erik (2008, CFSU)

AMALGAM REMOVALS
Dr. Cheney traces the inception of his heart disease to an improper amalgam removal procedure.

All it takes is once, and it's like the worst thimerosal laden vaccination in the world. The lungs have little protection against this kind of neurotoxic assault.

-Erik (2010, CAA)

AMPLICEN

If anybody is getting well on Ampligen, that's great. I want nothing more than effective treatment for this DD.

Dr. Peterson told me that Ampligen would be a cure for me but there was no way I could afford it. It may as well have been on the moon.

The people I contacted to find out about their results said that it took many months before they saw any improvement, that the results were nothing like a return to a normal lifestyle, and that if they went off it they faced the prospect of a relapse that left them worse off than before. All this after breaking your bank account. One person had to stop because it was too toxic.

This was around five years ago so my information isn't current, but Ampligen was nowhere near a viable option for me.

-Erik (2003, CFSExp)

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> If Ampligen hikes up the TNF, as they admit in their own patent, that drug would be a bad thing.

Are we certain of this?

Or might it be that restoration of NK function would allow a sufficiently targeted immune response that any elevated TNF becomes negligible, or at least, a lesser risk than an unabated illness process?

I'd put my bets on improved immune function being the better way to go.

-Erik (2009, CFSResearch)

ANTIFUNGALS
I asked Dr. Joseph Heitman and Dr. John Perfect at Duke University, who were conducting the clearance trials for voriconazole, about fungal treatment.

They explained that strong antifungals tend to wipe out the weaker strains, opening up a niche for more aggressive species.

People often have a recurrence of fungal infection, find it is a different strain, and say, "It mutated."

No, it didn't mutate into a different species. It was replaced by a dominant different strain.

If the basic reason for the immune dysfunction is not resolved, one can almost count on fungal recurrence, only this time with stronger species that have replaced the weaker ones wiped out by the treatment.

I asked if they saw signs of someone progressing toward severe fungal infection, they would preemptively treat with the strongest antifungals.

Dr. Heitman replied, "No. Never. The risks are too great."

-Erik (2010, SevereReactor)

ANTIVIRALS

People are so wildly fired up about XMRV that they've completely blinded themselves to the distance between identifying a virus and developing an effective treatment.

It seems like people who were right on the edge of considering pursuing the locations effect just suddenly lost interest and said, "But Erik, that's no cure."

Obviously they feel they have the leisure to wait for a miracle pill.

Perhaps I should change the name of Mobile Environmental Control Unit (MECU) to Xcape Moldule Recreational Vehicle (XMRV), so that people won't be so swift to trash the concept.

-Erik (2009, Locations)

CHEMOTHERAPIES

This reminds me of my military training in biological warfare. I guess that my Army experience helped shape my response to a situation.
During an artillery barrage, at least one-third of all rounds were expected to be chemical/biological, with heavy emphasis on nerve agent.

During a barrage, flying shrapnel reduces odds of survival to near zero unless one is in a foxhole.

But nerve agent settles in foxholes. At high concentrations, it doesn't matter if you have a M17A1 face mask, as it will go through your skin.

So if your foxhole fills with wafting mist that doesn't look quite like smoke, and if the chemical alarms are going off, what choice do you make? Which is the lesser risk?

If you cannot exit the foxhole due to the barrage, you pop yourself with your Atropine Auto Injector, try to stay out of the deepest part of the hole, but bail at the first opportunity.

Of course, if the barrage has already lifted, since the Nerve Agent Atropine Auto Injector has fairly serious consequences, try to avoid using it and evacuate immediately.

That's how I've always felt about various chemotherapies. Never resort to them, if bailing out can make it unnecessary.

-Erik (2008, CFSU)

DIET

How does one discount the importance of eating “right,” when it sounds so right?

I can't recall that I've ever seen any CFSers fail to try to influence their health by making changes in their diet. Everything from "just vitamins" to all-out "caveman diet."

And over time, it seems that each and every dietary regimen just gets progressively more strict. Every time a fellow "EatRighter" falls apart, it was "because their diet wasn’t the right one."

It seems to me that humans could not have evolved if their health were so dependent upon getting hold of a specific vitamin, mineral, or plant substance in exactly the right amount, each and every day. If those daily needs were truly necessary, people would have dropped into illness and death as soon as they couldn't get the right stuff every day.

But if you examine the entire history of deprivation, that is never what happens. Humans have done remarkably well on amazingly restricted food selections and short rations.
It's not easy to suggest that people de-emphasize something that is just about written in stone as the right thing to do.

But I've seen people "sensible" themselves to death, and not get much out of the deal.

I did "crazy mold avoidance" and got more out it than the sensible types can imagine, so they don't believe it.

I eat bad, drink bad, and do bad, by their standards, yet I'm still doing better than they are. I don't see any of them out climbing mountains.

So I put my priorities accordingly.

-Erik (2008, CFSU)

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Dr. Marinkovich gave his patients a handout on mycotoxin laden foods to avoid. Wine, cheese, nuts, a bunch more.

I told him that my experience had been that although I had become reactive to these things and had to give up eating them while in a moldy environment, once I started actively avoiding inhaled mold, I had no further problems with these foods.

I can eat all of them all I want now, with zilcho reaction.

Giving them up while in the mold zone had done almost nothing to reduce my illness. So I considered the edible factor to be paltry by comparison.

But if you see the way people glom onto that handout, you can tell the gleam in their eye that they think avoiding moldy food is going to haul them out of a jam all by itself, without the unpleasantness of moving, abandoning their stuff, decontaminating, etc. etc.

So that's what they do.

-Erik (2008, CFSU)

EPD

Dr. Marinkovich warned me against Enzymed Potentiated Desensitization ten years ago.

I expressed an interest in it, but he said that it had proven to be counterproductive in his patients. It seemed to upregulate rather than damp down.
He had been enthusiastic about its potential until he saw the adverse effects.

-Erik (2008, CFSU)

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Many patients with biotoxin illness are also highly allergic.

Remember, by "allergic" I am speaking of the classical concept of a programmed antibody response.

One might expect that EPD could reduce allergies. But biotoxin illness involves a different arm of immune response.

What Dr. Marinkovich anecdotally observed was that his patients actually got worse.

It might be assumed that due to Dr. Marinkovich's reputation, his patients were self-selecting for biotoxin illness, as conventional allergy shots do seem to work for people with mold allergy.

Biotoxin illness is a different animal.

-Erik (2010, SevereReactor)

FOOT BATHS

Of all the weird therapies I've heard, the ionic foot baths seem to "speak" better than the rest. I haven't tried it, but the reports I've heard have been very impressive.

-Erik (2008, CFSU)

STATINS

Careful about those statins, unless you supplement heavily with CoQ10.

We've had some extremely adverse results in statin usage in patients who didn't know about this CoQ10 connection.

Some people can tolerate statins with no problem if they know about the CoQ10 connection and supplement properly.

-Erik (2010, CAA)
SUPPLEMENTS

I knew a biochemist in Incline who designed vitamins and I asked him what he recommended. This was in 1986.

He told me about CoQ10 and L-Carnitine. I couldn't tell if the CoQ10 was doing anything but the L-Carnitine really did seem to help a bit. Not a lot by most people's standards, but I guessed that I was crawling to the bathroom at least 10% faster than usual and that meant a lot to me.

I told everyone that I had a small but significant improvement. Some had similar results, others didn't. But for those who did, it was well worth knowing about.

Years later, Dr. Peterson released an abstract describing an Acetyl L-Carnitine deficiency in CFS. Since it didn't help everyone, it's semi-ignored but it really helped me get through some hard times.

I know a CFS specialist who charges triple a normal doctor's rate to tell people that L-Carnitine is damn near curative, and he just happens to have some in his office he'll sell you for a slight markup over store price for the convenience.

-Erik (2003, CFSExp)

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I guess the reason people feel they are locked in battle with me is that, in a really weird way, we are.

You see, at the beginning of CFS, I saw a whole bunch of people fall apart from various things, but there was one small commonality that seemed worthy of note.

I tried to get researchers to look at this one small thing, but they would say, "That's just one small thing" and "Don't forget about this other thing..." and in so doing, they completely forgot about that one small thing that I was talking about.

I would say, "What about this strange burning sensation here..." and they would come back, "Yes, but don't forget about Vitamin C."

It almost seems inadvertent, like they aren't trying to do it on purpose. It just kind of happens.

They think I'm putting too much emphasis on mold, and I think they aren't putting enough on it. It's an impasse that we just can't break, until one of us tries the other's concepts on for size.
Well, a whole bunch of us did try all kinds of nutritional interventions. Pretty much everything in the book, I'd say. Most of the recommendations are well known to us, and have been repeatedly recommended for twenty years. We've got a pretty good track record of seeing how they work out.

I'm doing something different. Yes, it's not easy, and it's certainly not something we can all do. It's not something that will save the world. But it is a clue, and it's one that is just lost, buried deep under the "But don't forget about..." innumerable other things.

This pure mold avoidance is just spectacular. And I don't quite know how to bring attention to it without comparatively stomping on other concepts which didn't quite pan out so well.

It's not that I want to interfere with supplementalism. It's just that every time I see people given a choice, they absolutely leap to the supplements and interminably put off trying the other thing.

I don't think you'll find a single mold extremist who doesn't look wistfully back at an earlier point in which they could have made plans and changed the whole course of what happened.

But they just didn't think it was going to go so far... and the supplements seemed to help a bit.

-Erik (2008, CFSU)

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You get to a point in which you suddenly ask yourself, "What the hell am I doing? This stuff is killing me" and your desire to have it, be around it, deal with it disappears.

When people start talking about herbs, supplements and therapies as an alternative to just getting rid of things you are reacting to, you kind of look at them and think to yourself, "Even if I could improve my immune system's ability to withstand this crap, how would I ever feel truly safe around it anymore? How would I know it's not dragging me down? How would I ever know just how good I could I would feel if I weren't around this stuff, unless I get away from it and find out?"

When you finally decide that you've had enough of toxic possessions, the shift in behavior is amazing to others. People who aren't there yet wouldn't dream of abandoning everything.

People who find out how much better they can feel wouldn't dream of doing anything less.
I was taking Sodium Ascorbate to bowel tolerance in 1986 and definitely got some benefit, most notably with digestion.

Dr. Robert Cathcart was "the quack in Incline" before Dr. Cheney and Dr. Peterson became "the two quacks in Incline."

Dr. Cathcart got an oblique mention in Osler's Web in the section about "Not Normal Americans" where the health department official was disparaging all the crazies up here with their weird theories - and used the wacko doctor with the Vitamin C theory as an example of what kind of nonsense went on in Incline Village.

Dr. Cathcart proposes a mechanism of the Vitamin C as an electron transport modulator, but the naysayers derided and trivialized the concept on the basis that it is just a nutrient from a fruit.

Yes, it is a nutrient from a fruit, but by ignoring what Dr. Cathcart was saying, they could portray the effect in such a minor way that it is removed from consideration.

This is what happened with mold. Even though people could feel the effects, attempts to focus attention on it are met with, "But there are many molds" and "Mold is just an allergen."

They completely ignore the fact that despite their ignorance of a possible mechanism, the effect still exists.
Chapter 53 - Lake Tahoe Illness

THE BEGINNING

I was a patient of Dr. Cheney’s in 1984, before the Truckee teacher cohort and the Incline Village girls’ basketball team became ill with “Tahoe Mystery Illness.”

It was the viral illness that I came down with on August 5, 1985, that constituted my "sudden onset" of what came to be called CFS.

In addition to the Truckee Crud, which corresponded to the infection identified by Dr. Peterson as HHV6a, there was a simultaneous manifestation of a precursor CFS state in which people started succumbing to stresses or exposures which had never bothered anybody before.

There also was a striking increase in sinus infections, depression and chemical sensitivities, even though these people didn't develop Ramsay-style ME.

Prior to the weird flu, my problems would have been adequately described as inexplicable fatigue, but after the "?" happened, the sensation turned into life-destroying godawful drop-dead neurological living death illness that was nothing like fatigue.


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I had seen about ten doctors, and Dr. Cheney was virtually the only one who didn’t tell me, “It’s all in your head.”

He had no idea what was wrong with me and told me he had never seen anything like this before, but unlike all other doctors, he always made it very clear that he was taking my illness extremely seriously and was determined to find out what it was.

-Erik Johnson (2009, Phoenix)

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Although Dr. Cheney and Dr. Peterson didn't recognize that our illnesses were anything but purely individual flukes until Dr. Peterson read the Straus/Jones "Chronic Mononucleosis" paper in the medical "Annals" in 1985, we began getting ill in the late summer of 1984.

The epidemic didn't spike until mid 1985.
I was one of those early patients who almost got away.

In September 1984, three months before the girls’ basketball team in Incline became ill, Dr. Cheney told me that he had never seen any illness like mine, was completely stymied, had no further ideas on what to do - and that we were at an impasse.

Ironically, this was the same month that Dr. Peterson noticed that three of his patients had an eerily similar illness description, although he didn't connect them to "Chronic Mono" until December when he read the Straus/Jones Annals paper.

But they didn't really realize how much trouble we were in until the Truckee teachers became ill, when they started to view this as an epidemic.

I saw about ten more doctors before there was a front page headline in the local newspaper describing "Tahoe Mystery Illness." Dr. Cheney and Dr. Peterson gave an interview about what they were seeing in patients. I showed it to the doctor I was at and asked, "Have you seen this?"

He said, "Yes, I heard about that, but those two doctors are quacks and should be run out of town."

"But this describes all my symptoms, and you weren't even going to tell me?!

I was out the door within a minute and on my way back to Dr. Cheney.

- Erik (2006, CFSExp)

**LESS SEVERE CASES**

All of us in the Incline Village epidemic were sudden onset cases.

We later saw gradualls, but they don't describe the illness in the same terms. They seem almost comfortable in describing this as a tiring sort of illness.

What we experienced that was described in Osler’s Web was nothing like the gradualls. It was so different that we cannot compare symptoms in a meaningful way.

We Incliners would meet in a group and say things like, "You know? The fluorescent lights?"
Another would nod, knowing that words cannot describe the awfulness of so much as a flickering light turning you into a quivering lump of flesh lying prostrate on the floor in agony that leaves you wondering how an illness can torture you to such an extreme without the mercy of killing you - as if designed by the devil for torture without respite.

When people talk about fatigue and post-exertional malaise without mentioning that this is nothing like fatigue, and that there was no exertion whatsoever to be malaised about, I figure these must be similar to the gradual onsets that we saw later.

But not like the CFS that got the ball rolling.

-Erik (2006, CFSExp)

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—I have extreme weakness and fatigue often unrelieved by rest after exercise, but no muscle pains or mental confusion. Basically it just seems if my energy system has collapsed. Does this sound like CFS or possibly something else?

Sounds like a possible precursor, but without the neuro-paralysis, cognitive defects, myasthenia gravis, exercise intolerance, post-exertional malaise, Raynaud’s, killer sore throat, heart pain, circulatory disorders, dyscalculia, photophobia, tinnitus, rashes, bloody stools, muscle and joint pain, extreme confusion and mind-boggling memory loss, it doesn’t quite sound like you’ve descended into the darkest pit of CFS hell (yet).

But we did have people complain in this manner prior to the Full Monty.

-Erik (2007, CFSResearch)

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I saw a precursor phenomenon sweep through Incline Village before the "Yuppie Flu" hit.

This "Before CFS" condition caused people a lot of problems, but it wasn't anything like what happened when "The Flu From Hell" went through.

Nobody called the CDC for the tiredness, swollen glands and general fatigue that seemed to be hitting people, not even Dr. Cheney or Dr. Peterson.

Then that "flu" slammed into us and everything changed. This was not something that could be ignored.

People couldn't walk, were paralyzed. Barely able to feed themselves with the greatest of effort. Couldn't sit up in a chair. If people helped us to a standing position, we would pass out.
Marathon runners, champion swimmers, tennis pro and a hang glider Instructor, all unable to walk to the corner.

You couldn't miss this aftermath. Nobody had ever seen anything like it.

Nobody had ever seen anything like it.

Nobody had ever seen anything like it.

I repeat that because somehow people try to say that this was known and had been around. But this cannot be true.

We had people crossing the country and no doctor could even give them a name for their illness. When we tried to express it, doctors would say, "Stop, stop, you cannot have all of that."

So let me repeat that. Nobody had seen anything like that.

If they now claim that they did, they must explain why they didn't say so, knew no name, could point us nowhere, and failed to step forward.

Look at Hyde’s story about the Holmes proceedings. The people who could pin the name ME on our illness at that time were less than half a dozen doctors, and most of them were overseas.

Dr. Peterson called the CDC for help with that illness, not for the precursor.

What happened is that the CDC gave the term "CFS" to our illness, and then it was reverse engineered back upon everyone who has that precursor state even if they don't collapse with that horrible paralytic neurological life-destroying illness that the CDC was supposed to be investigating.

You can see this in Osler's Web. The lawyer from Zephyr Cove would not have received a CFS diagnosis until after falling apart. But it looks like a lot of people are in this semi-CFS state without quite having this incredible paralytic phenomenon.

It is not so difficult to separate the people who view their illness in the same way I do. In fact, the CFS term lends itself to it.

If you suggest that a patient is fatigued and they fail to vehemently reject the notion that this is any kind of tiredness and is more like paralysis, they either did not experience that paralysis or they are limited by a poor vocabulary.

But at the very least, they will try to say how their illness is beyond fatigue.
We did see a wide range of disability, all happening at the same time.

But all the people at a lesser level endlessly circulated among doctors and got pushed around through a continual variety of vitamins, supplements and half measures.

The purveyors made money from a captive patient population which had too few doctors who see this illness for what it was.

Most doctors still completely refuse to act as if this were a life-destroying thing, no matter what level a CFSer is at.

They fit CFS into their box as if it were some form of excessive tiredness problem, despite all the indications that it is far more wrong than that.

I consider myself unbelievably fortunate because I recovered to the extent that I did.

It seemed like a responsibility to use my experience to point back at those who are still totally immobilized: "Yes, I was lucky because I got better, maybe I am an anomaly, but listen to what I saw, because that is what this illness can really do."

As a result of the way people want to see a "moved on" picture of CFS, the portrayal is watered down to one that I scarcely recognize.

There were cases like the lawyer from Zephyr Cove who didn't have the Full Monty until after Dr. Cheney had already detected precursor immunological signs such as the undifferentiated B cell anomaly.

Nor was he pathogen ridden.

So Dr. Cheney didn't rule people out just because they hadn't taken the full CFS plunge yet. No worries on qualifying for CFS if one isn't the sickest of the sick.

After CFS was coined, Dr. Robert Cathcart, who left Incline Village in 1980, believed he saw people who matched that description beginning in 1978.
Which makes people say, "Oh, then CFS really started there in 1978."

But did it? Were these early cases the same?

These people did not inspire anyone to call the CDC.

Even Dr. Cheney and Dr. Peterson weren't impressed by these early cases, when they moved into town and saw some of them.

Then something strange happened.

Clusters of illness broke out.

This was new. This was different. Nobody had seen anything like this before.

You can't have groups of teachers and half a girls' basketball team be completely debilitated without vaguely noticing that this never happened before.

This weird flu-like illness from hell killed people.

The survivors of this horrible flu were so devastated that, as Dr. Cheney reported, it was not something that anyone could overlook. The 1985 Annals paper on "Chronic Mononucleosis" didn't cover a situation like this.

That was the illness Dr. Peterson called for help with.

Not Dr. Cathcart's fatigue condition, even though Dr. Cathcart later thought it was CFS.

This weird flu scared the crap out of the entire nation and made front-page headlines. It devastated the Tahoe economy. It made the community threaten Dr. Cheney, Dr. Peterson and all the survivors to leave town.

Since that was the illness Kaplan and Holmes came to investigate, that is the one Dr. Peterson is talking about when he refers to his original cohort.

Dr. Peterson calls it "The Tahoe Flu," to keep it from being subsumed into the amorphous morass that "CFS" has become.

-Erik (2009, CAA)

CONTAGION
We were used to the yearly influenza routine, which always seemed concentrate on the I-80 corridor and Truckee and then would move quickly through the schools and casinos.

Being in an isolated area, we had a clearer view of spread than most communities.

At first, that's what we thought Yuppie Flu was.

But it didn't follow the same pattern. It moved far more slowly and didn't go from person to person.

It almost seemed to slowly creep from Truckee, then through North Tahoe across Kings’ Beach, and then into Incline, like something physically spreading across the landscape.

Dr. Cheney had a map of sudden onsets who can often pinpoint the precise hour they hit the wall.

As I recall, he had colored pins representing the sudden onsets’ reported time periods. Even though this was just a rough outline, it was very suggestive that Yuppie Flu had moved across the U.S. in a pattern reminiscent of influenza, from east to west, but much, much more slowly than a flu virus moves.

Now that we’ve seen West Nile Virus creep across the country, it was a lot more like that.

-Erik (2006, CFSExp)

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Even those of us who were in the Lake Tahoe outbreak, especially the Truckee teachers where the phenomenon looked most like contagion, were strikingly surrounded by close associates, spouses and family members who didn't get CFS.

My closest known physical association to coming into contact with other "Yuppie Flu" patients was that I lived directly behind Dr. Cheney’s office and passed within twenty feet of his door every time I left my house.

Yet people who worked in the same building didn't all become sick.

There were just a few who did.

-Erik (2006, CFSExp)

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The way the "Yuppie Flu" spread through our community was exactly like "Yellow Fever," which had people totally confused in precisely the same way about how it sometimes appeared to be contagious in groups yet non-transmissible from person to person.

Not only that, but the "YF" started in Truckee and gradually spread eastward, moving across the north shore in a geographic progression.

-Erik (2008, CFSU)

**VICTIMS**

We didn't see any difference between the Tahoe girls’ basketball team and the Truckee teachers due to the age difference.

If you look at the Truckee High School incident, the Kennedys who shared that teachers lounge where nine teachers became ill had different onsets. As I recall, Gerald Kennedy had sudden onset and Janice took ill gradually over many months.

-Erik (2006, CFSResearch)

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Once upon a time, there was a weird "Yuppie Flu" that raged through a small community. It hit athletes, children, some old folks and a whole lot of plain old working class citizens.

It didn't hit the diabetics, the drug addicts, the heavy smokers, the alcoholics, the people in hospitals with broken limbs and surgeries, or those with AIDS or compromised immune systems.

No, it just slammed teachers, kids who were out mountain biking or playing basketball, hikers, kayakers, tennis players, swimmers, skiers... outdoorsy types.

We often wished we had really been the drug addicts, junk food eaters and alcoholics that "immune overload” conceptualists keep saying we must have been - because none of them caught the illness.

-Erik (2007, CFSResearch)

**TAHOE VISITORS**

I've heard quite a number of stories of people who were at Tahoe for a vacation at this particular time, and this seemed to be a turning point in their lives.
ALMOST RECOVEREDS

Of the people in Incline who caught that weird flu but seemed to recover, many of them now have precarious health issues.

Their issues are so different from anyone with classic CFS that you would swear they are unrelated in any manner.

But there's one small thing that you had to be there in order to see.

It was the simultaneous timing that their ability to maintain good health took a plunge and never came back to what it had been before.

- Erik (2007, CFSExp)

* 

While a great many people seemed to catch that weird flu-like illness that blazed through town, about eighty percent passed it off within four weeks without overt lingering effects.

Although that may be open to question, as many later developed strange illnesses which weren't identical to CFS, such as lymphomas and chemical sensitivities.

If people think of "Yuppie Flu" as the subset who didn't make that apparent four-week recovery and, strangely, got worse as time went along, quite a few seemed to get back to a fairly normal looking life after a year or so.

But they still complain and doctors won't listen to them at all.

They are a completely invisible phenomenon until they succumb to an illness, which doctors almost never connect to that "flu-like" one that they apparently recovered from years before.

- Erik (2008, CFSResearch)

* 

There seemed to be a cut-off point.
If people recovered within two weeks, they seemed to have beaten it. But if this “weird flu” went on for longer, for three weeks or more, the illness seemed to actually get worse.

We had never heard of anything like this. That's not how any normal flu acts. It scared us all to death.

And some of the people who seemed to have beaten it weren't quite out of the woods. They have gone on to have all kinds of horrible health problems.

Not like CFS. Other stuff.

Various cancers and mold illness.

- Erik (2009, CFSResearch)

* Many people had their flu-like illness die down after three weeks. They were seen as "recovered" and not included as part of the CFS epidemic.

But as we have seen, many people who thought they had recovered after that initial onslaught didn't really recover at all. They just didn't know it until the relapse hit.

- Erik (2010, CAA)
Chapter 54 - Cohorts

PREVIOUS EPIDEMICS

There were certainly clusters of this illness that had various names at various times in the past, but it was unknown, unrecognized, and unfamiliar to everyone around us.

All doctors, relatives, everybody that we asked.

People crossed the country trying to get help, to get a diagnosis.

They didn't find doctors who said, "Of course you have ME, we know all about that," no matter how hard they searched.

So the concept of "ME was known" doesn't match our experience of people who utterly failed to get an ME diagnosis from the largest medical institutions in the country - and they tried their butts off to get some help from anywhere.

I know about the L.A. Hospital 1937 epidemic and other clusters such as Dr. Ryll's 1975 "Epidemic Phlebodynia."

Dr. Ryll didn't know about ME either.

I met the first person who described exactly what later happened to me in 1980. Her illness was absolutely unforgettable and unmistakeable. I saw nobody like her anywhere until our epidemic - and I was looking.

After 1985 there were hundreds of us, all in one small town.

After so many years of hearing people say that this illness couldn't exist because it is unrecognizable as anything that could possibly happen to a human, it is psychotically bizarre to hear people say that this illness is nothing special because it is and always has been common.

Not in my neck of the woods - until 1985.

-Erik (2006, CFSResearch)

* 

The signs and symptoms that were collated to form the description of CFS were lifted directly from the individuals in the Holmes study group, as Byron Hyde and the "ME
aware" doctors could clearly see when they said, "You are dooming the patients" by applying the term CFS.

That is a clear indication that CFS was applied to a specific group that had symptoms consistent with ME.

Their dire prediction was accurate, but it also means that one cannot claim that CFS was applied to just fatigue.

If the individuals in this group have the same illness as ME, then CFS was applied directly to ME sufferers.

That means "CFS" was not constructed on the basis of a fatigue cohort.

And even after all this time, there are survivors of the Royal Free ME cohort and the original group which CFS was based on.

If we have the same illness, then CFS is ME.

-Erik (2006, CFSResearch)

* By self limiting, I mean that the pre-1975 outbreaks didn't continue on into the millions of sufferers.

Dr. Ryll's Mercy Hospital cohort seemed to be about the last hurrah for the "old style" clusters before something changed - when an illness which previously had only hit groups and somehow was self-limited now just kept spreading and affecting more and more people without restraint.

His description of his 1975 Mercy Hospital outbreak matches Royal Free pretty closely.

In 1984, the CDC started getting thousands of calls for inexplicable "chronic mononucleosis."

Doctors were well able to diagnose EBV, so this shift in the clinical course of an illness they were familiar with signals the time when the epidemic assumed a horrifying new level of pathogenesis.

-Erik (2008, CFSResearch)

* The illness itself certainly did not originate in Incline.
Dr. Komaroff noted it years earlier on the East Coast.

Dr. Cheney had a map which showed people’s remembered "sudden onsets" progress across the country from east to west.

The only reason Incline Village became Ground Zero is because Dr. Cheney and Dr. Peterson were the first to get their foot in the door with the evidence that the illness was nothing like the CDC thought it was.

-Erik (2009, CFSKnowledge)

OTHER CLUSTERS

Just in 1986, we knew of clusters in Boston, Silicon Valley, Yerington, Zephyr Cove, Carson City, Berkeley, and, of course, Truckee, Incline Village and Lyndonville.

-Erik (2009, CAA)

COHORT SELECTION

The reason that Dr. Cheney and Dr. Peterson chose me to be in the CDC study group to refine the parameters for the syndrome was that even though I wasn’t the sickest, I was EBV negative and had the fewest co-morbid pathogens of the cohort.

They told me it was because I was the "purest and most pristine case of CFS" they knew of.

-Erik (2005, CFSExp)

*

I was negative for just about everything.

The only virus they found was the "HBLV," as Gallo's lab called it at the time.

The "HHV6A" strain, which as Dr. Peterson told me, is a totally different animal than the Roseola children's disease.

Dr. Cheney asked me to participate in the Holmes CFS definition study group for the very reason that I had such a paucity of pathogens.

Some theorists talk about allostatic load and seem to believe that the best cases for study would be the ones with the most infections.
But CFS was originally based on the principle of an illness which consisted of an utter lack of allostatic load.

-Erik (2009, WPI)

ORIGINAL COHORT MEMBERS

I asked other members of the original CFS cohort why they don't lend their voices to defending the history of their experience.

They found an equilibrium of the least amount of pain they can attain by living in this prison, and they won't leave it.

The pain that is your reward for raising your voice to even say that you are still in that prison is too much to be worth it.

It seems completely pointless when people from all sides just try to deny or distort everything you say when all you are doing is describing what happened, exactly as it happened.

-Erik (2006, CFSResearch)

*

The "Original CFS Cohort" that Dr. Peterson speaks of is all of us who were in his practice during the 1984-85 outbreak and who were intensively studied for presentation to the CDC.

They even paid for some of the exotic and expensive tests that were so leading edge that they weren't even available to the medical community yet.

Dr. Peterson has a research associate who kept track of us over the years and occasionally sent us questionnaires.

We weren't your normal patients who happened to wind up having a crazy name applied to our illness.

We were a cohort just like Royal Free.

-Erik (2006, CFSExp)

*

There is a very informal group, scarcely even what you could call a support group. Just some folks who get together now and then.
Nobody has completely recovered, although the waxing and waning of illness in a few people is so striking that the good times can give the false appearance that they beat the illness.

But the lymphoma rate in the "Tahoe Flu" group that Dr. Peterson managed to keep track of is running at a rate of one out of three people.

-Erik (2009, CAA)
Chapter 55 - Lake Tahoe Events

CDC AND NIH

It doesn't make sense to think that "many of the residents were not even aware that the same experts had made reports about the outbreak."

What do they think the "experts" were there for?

"Experts sent from government agencies" identifies Kaplan and Holmes, and of course everyone knew that they were present to investigate the outbreak. Their mere presence implies that they were making reports to the CDC. One would have had to be completely isolated from the media and virtually anyone who was out and about to be unaware that they were sent to investigate the outbreak.

When they reported their views that it was a combination of mass hysteria and suggestible doctors who are swayed by their patients, everybody in town certainly knew about the content of the report.

The reaction of the community was swift and decisive.

All the doctors who had quietly been calling Dr. Cheney and Dr. Peterson incompetent quacks now did so quite publicly with official sanction.

The ill people who had made public comments on the illness were now "officially crazy."

People who had been helpful and supportive literally shut off their brains and their sympathy and said, "Well, if the CDC says..."

Anyone who still believed we were really ill was forced to keep their mouth shut and dared not say a word in our defense, except for Dr. Cheney and Dr. Peterson who were already committed and had their professional lives at stake.

I don't think any of the other clusters were thrown into the convulsions that Incline Village was, thanks to the type of location and the fact that it was a resort town that depended so heavily upon the tourist trade.

The backlash against "hysterical hypochondriacs with an agenda" was enormous.

-Erik (2006, CFSResearch)

*
The reason Straus went ballistic is that Dr. Cheney went to great lengths to locate 19 people who had all the concurrent immune anomalies but were entirely EBV negative.

Straus, Jones and the CDC were quite pleased with their "CEBV Syndrome" concept and were not particularly amenable to changing it.

They wanted nothing to do with us. Even as the Holmes committee was convened, they were trying to exclude our illness from being included because we had too many things wrong with us to fit into "CEBV Syndrome."

Then Dr. Cheney unleashed with "The Tahoe Study."

It slamdunked the Straus/Jones "CEBV Syndrome" concept right out of the ballpark.

The CDC couldn’t back down because the Incline Village connection had already made national news.

They were forced to include us.

That’s why Holmes deftly omitted all the critical elements when he put together the criteria - the “CFS chimera,” as Dr. Hyde calls it, that the ME doctors refused to sign off on.

Before the ink was dry, they were trying to force the Incline cohort out of being "CFS."

I thought that anybody could instantly see the insanity of trying to tell the prototypes for a syndrome that they couldn’t have their own syndrome.

We felt pretty betrayed, but after all, they said CFS was going to be a research tool, and so we thought everything would soon be cleared up.

-Erik (2008, CFSU)

* 

Try to put yourself back in time, long before "CFS" turned into the mega-monster that it has become, when it was thought to be no more than a few dozen people.

The CDC had seen such illness clusters before, but they had all been self-limiting. The mystery illness would hit a few locals, get a "local name," and fade away as mysteriously as it appeared.

Read about Dr. Erich Ryll’s "1975 Mercy Hospital" cohort. This was the customary pattern. Even if no answers were found, the problem tended to go away on its own. You can see that Dr. Ryll’s cohort was simply ignored to death.
When the "Tahoe Malady" threatened the lucrative tourist economy, great pressure was exerted to minimize the situation.

Frankly, even to the sufferers, this didn't seem like a bad idea at the time. It was really getting scary. People were paralyzed with fear.

But this trivialization turned into official policy and got a life of its own. It just snowballed and got larger - totally out of control.

We thought that at some point the CDC would see that their cover-up of a situation they believed to be self-resolving, which may have started out as a fairly reasonable strategy, would backfire at some point and they would seriously work to understand the illness before this happened.

Instead they put all their effort into covering up the cover-up. "CFS" was chosen as an ambiguous term to avoid according the illness any real credibility until proven otherwise, although the very immune abnormalities that caused the convening of the Holmes committee were compelling enough.

If you look at all the local epidemics that received this treatment - Punta Gorda, Silicon Valley, Yerington, Tapanui, Akureyri - it is apparent that this strategy has been consistently applied.

Thanks to a series of flukes, Dr. Peterson’s personal connections, the very public response of Kaplan and Holmes, the derision of "Yuppie Flu," and the national headlines, the phenomenon finally snaked its way through all the suppressive mechanisms that made this illness disappear in the past.

In Dr. Hyde's "Irreverent History of CFS," when he says, "Business comes first," he was not exaggerating. This is how it really happened.

-Erik (2008, CFSU)

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In 1999, Reeves said that the epidemiological team sent to Incline found no evidence of a fatiguing illness.

-Erik (2008, CFSResearch)

*  

While 1984-85 had been a very good year for snow up at Lake Tahoe, the snow levels thereafter were very poor. The ski economy was suffering greatly, which put intense financial pressure upon the locals.
This was before the ski resorts had acquired snow making equipment, and the lack of
snow hit us all very hard. Businesses were laying off workers and closing. The entire
North Shore was rolling up the sidewalks and shuttering the windows of businesses.

Then what was later called the "Yuppie Flu" swept through our little town and scared us
all to death.

At the very beginning, the fact that nobody official was responding made the epidemic
seem as if it must not be important, for if it were, surely the government would have
jumped right on it... wouldn't they?

That all changed when CDC epidemiologists Jon Kaplan and Gary Holmes finally
arrived, to investigate the "Tahoe Mystery Illness."

Their very presence gave the illness an assumed authenticity and the whole community
was holding its breath, waiting in dread for whatever the pronouncement from the CDC
turned out to be.

And then, whatever vestiges of the slight interest the CDC had in getting to the bottom
of things seemed to vanish with a shocking suddenness that took us all by surprise.

Instead of a thorough investigation, all the CDC's efforts turned to debating Dr. Cheney
and Dr. Peterson on every point. Every bit of evidence was disputed or discounted as if
it meant nothing.

It was a shocking kind of reversal. Rumors went around Incline Village that the local
business leaders had approached the CDC and told them that any further bad publicity
would be utterly devastating to the Tahoe tourist economy and they could take no more. There might even have been violent confrontation between townspeople, and the "sick
people who had an agenda to destroy the economy"... as they constantly told us.

And while it was true about the economic damage, we were torn between wanting help
for our illness and the horrible unwanted national attention which the epidemic had
created.

This bad publicity was destroying the economy, but was it our fault? For committing the
crime of becoming ill when others had somehow got through it?

The CDC solved the problem for us by announcing there was "no evidence for any
fatiguing illness" (although there was) and dismissing the entire incident as some kind of
mass hysteria that had been created by inadvertent collusion between "weird Tahoe
people and two suggestible doctors who were overly influenced by listening to their
hysterical patients."

It seemed inconceivable that the CDC could truly be doing this to us.
We tried to convince ourselves that they had deliberately tried to do us a favor of covering up the extent of the epidemic... but that they were going to quietly look into it later.

This would help restore the economy and calm the public's fears. It seemed that this would have been a good plan.

So the ridiculously benign "CFS" nomenclature that was later devised did not trouble us much at first, and seemed to be part of a good plan.

If this had been true, it would have been an excellent way to quell the societal and financial problems created by the epidemic and create leeway for a subdued scientific investigation.

Instead, what started as a kind of innocent suppression of information about the phenomenon built momentum, and the CDC's efforts turned more to covering up the cover up more than resolving the real problem. Ultimately, the CDC disengaged itself from doing any research into the original flu-like illness which had first brought them out to Lake Tahoe.

In really good winters, when ski tourism is great and the economy booms, Lake Tahoe would have been far better able to absorb the unpleasantness of a strange local illness. I cannot swear that this strange CDC reversal wouldn't have taken place anyway, but it appears that concerted effort by local business interests might have been placed upon the CDC to do something to keep the "hysteria" under control.

Crazy as it sounds, it may very well be that the pathway to "CFS" and its intentionally trivializing syndromic nomenclature and description might have originally been set in motion by lack of snow.

-Erik Johnson (2009, CFSKnowledge)

DENIERS

A weird "Flu from Hell" was circulating around Tahoe in 1984-85.

We were all talking about it and hoping to avoid it by staying away from people and by spending more time out in the woods doing Tahoe type outdoors stuff. We called it "The Truckee Crud" because reports started there first.

The doctors could all see that people were having an extraordinary flu, but only Dr. Cheney and Dr. Peterson made the observation that it wasn't going away.

The rest of the doctors went into total extended denial of reality. They got to a point where they would stand and fight with you and deny your symptoms.
After two months, if you were still ill, the doctors would start talking about mental problems and recommend "hug therapy" and motivational seminars.

And you should have seen what those other doctors tried to do to Dr. Cheney and Dr. Peterson in attempting to destroy their credibility and run them out of town.

Half the girls' basketball team got sick and people started talking about "stress" and "lack of motivation" and "nutritional deficiencies."

One group of deniers said that it was nothing more than laziness. Another group said that it was burnout from Type A personality "overachieving Yuppies."

So we've got diametrically opposed concepts but instead of directing their abuse and arguments against those people who held irreconcilable views, both groups ignored each other and heaped their concepts up sick people who just wanted to find out why they weren't getting better.

Athlete or sedentary, junkfoodist or health nut, young or old, this illness didn't care. It just didn't matter. It hit all types.

No matter what ridiculous grasping denier theory is proposed, there were always plenty of sick people present who simply didn't fit the hypothesis.

-Erik (2005, CFSExp)

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When Dr. Cheney and Dr. Peterson described "Tahoe Mystery Illness" in the North Lake Tahoe Bonanza, it was as a "mysterious fatiguing illness" and included the other symptoms that all of us were complaining of - and which every other doctor said they had never heard before no matter how many of us they saw.

Everyone who saw the newspaper article recognized their symptoms immediately and knew this was exactly it.

All of us fought with doctors and went though a dozen or more until finding our way to Dr. Cheney and Dr. Peterson, thanks to that front page headline.

We took that paper back to our various obstinate doctors and said, "Look, see this?" and asked why they were so blind to something that everyone in Incline was talking about.

That's all it took. Just a simple description and a stupid name.

See it once, and there was no doubt. Of course we knew we were sick.
Being unable to walk does that to you, but at least we finally knew that two doctors were acting like we thought all doctors should act in a crisis like this.

-Erik (2006, CFSResearch)

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It started out with everyone thinking it was just a normal flu, but then we noticed that it wasn't acting normally.

People weren't getting better. That's when doctors began declaring war on patients. They would accuse you of all kinds of reasons for creating your own illness. And we were forced to argue back that we weren't drug addicts, junk food eaters, alcoholics or secret manic-depressives who managed to hide having mental illness until after getting that weird flu.

The harder that patients fought back, the more doctors began to stonewall us: "If you are still ill, then you MUST have done something to yourself"

-Erik (2010, CAA)

NAMES

Just like CFS itself, "Incline Village" epidemic is a term of derision.

In 1984 there was an outbreak of an unidentified illness that hit people scattered around Lake Tahoe.

As long as it was just individuals, it was of some concern, but when a cluster of schoolchildren and teachers got sick at Truckee High School, Dr. Peterson decided that this was sure looking like an epidemic and called the CDC.

Amazingly enough, the CDC didn't want to respond.

But the mystery illness had made national newspaper headlines and couldn't be conveniently ignored. So they sent two investigators who investigated nothing, called it "mass hysteria" and left.

Well, the problem just didn't go away and news continued to spread.

A local paper called it "Tahoe Mystery Illness." But then, because Dr. Cheney and Dr. Peterson were located in Incline Village, the name was changed in pure contempt and scorn to "Incline Village Disease."
This was a direct derisive poke at Dr. Cheney and Peterson and had nothing to do with Incline really being the center of the cluster.

This was similar to “Yuppie Flu.” There were no Yuppies. Scorners just used any means they could to belittle sufferers.

But all this publicity made Dr. Cheney and Dr. Peterson’s evidence harder to shove under the table. Dr. Cheney had found Dr. Bell's Lyndonville cluster, which was also being ignored. Up until then, it was thought that we were totally alone.

So the CDC came back, put together a phony EBV study, did a partial description of our illness, and called it CFS.

Yes, the illness certainly existed before, but under different names and not recognized in any form whatsoever by the CDC.

Dr. Erich Ryll's 1975 Infectious Venulitis should have been the epicenter of the emerging awareness of this illness - but it wasn't.

Dr. Ryll did all the right stuff, but there was a major difference. He didn't have all the publicity that the scorn of the whiny Yuppies and crazy Incline Village Quacks created.

Without all the scorn and derision, it is very likely that the Incline Village cohort would have been buried, consigned to oblivion, and just as deliberately forgotten as Dr. Ryll's cluster was.

And since the CDC is only now recognizing the convergence of evidence that says CFS is real, without the early CFS doctors we'd have almost no research into this illness at all.

-Erik (2006, CFSExp)

**TOWN RESPONSE**

Unless you've read Osler's Web, you can't believe how vicious people were, toward Dr. Cheney and Dr. Peterson, and toward us.

Some people came to support groups under an assumed name or didn't come at all for fear that others would find out.

All the other doctors and community leaders accused us of having some bizarre agenda of trying to destroy the economy at Incline Village and wanted us all to leave.

This illness unveils a savage, merciless, evil side of humanity that none of us ever wanted to find out about.
It was Living Hell.

Until Dr. Cheney and Dr. Peterson noticed the concurrency of the complaints, not one other damn doctor believed us.

My family watched me turn literally overnight from a windsurfer and hang gliding instructor into someone who couldn't walk, read, watch a movie, stand open sunlight or stay warm and decided that it was some sort of weird personal choice.

The community made threats against us and warned us to leave town. They attacked Dr. Cheney and Dr. Peterson and called them quacks.

People even talked about rounding us all up and having us arrested and deported for "crimes against the community" for "trying to destroy the tourist economy."

Some people would only go to a support group outside of their own town and only came under assumed names. Others were too scared to go or have anyone find out they had CFS.

We were treated worse than AIDS patients.

Virtually everybody called us crazy and mental cases.

It's unbelievable to be fighting for your life and have "friends," family, doctors, your community, the CDC, and humans in general abandon and attack you, calling you a liar and a criminal for being guilty of getting sick.

It gives one a whole new perspective on the human race.

-Erik (2004, Locations)

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When our wonderful little community tried to have us all arrested and deported for "crimes against the community for creating an epidemic in order to destroy the economy," Dr. Cheney pointed out that similar illness clusters were happening around the country, like Lyndonville - and used various other arguments against our noble neighbors and former friends.

-Erik (2005, CFSExp)
I guess it shouldn't surprise me that the history of CFS isn't better known than it is.

Just a few minutes ago I was in the Incline Village Library with Osler's Web in my hand, giving a speech on what happened in Dr. Cheney and Dr. Peterson’s Alder Street office twenty years before - right next door to the library.

And even though people vaguely know that "something happened here,” there is a sort of unreal aspect to it that makes it seem disconnected and far away, like this couldn't possibly be where such a horrible thing happened.

People look shocked when I point up at Dr. Cheney’s window and tell of the events that transpired there.

It seems that even Incline has done its best to forget. But it's all written down, the old CFS Chronicle collection is there, and not all of us are gone.

On a bright note, Santa Claus showed up and entertained the kids.

The "real" Santa Claus! This local guy is so into it, he had his name legally changed to Santa Claus - and boy! Does he look the part!

Nicest library I've ever seen. It has a fireplace, and it's a great setting for Santa to do his thing.

The place is bustling with life and CFS seems long ago and far away. As if it couldn't touch a place like this.

-Erik (2006, CFSResearch)

Amazingly enough, when the "Yuppie Flu" swept through in 1985, few people had any real doubts or denials.

It was slamming people right out of their hobbies, jobs, marriages, etc. You couldn't ignore this thing.

There was a window of about a year when the fear and resentment of this illness grew and grew but the hardcore doubt and denialism really hadn't developed yet.

I can just about give you the exact date when screaming denial hit us like a sledgehammer.
When Kaplan and Holmes first came out, their very presence from the mighty CDC was like a validation. Even the few who had lingering questions were silenced, simply because the CDC had involved itself.

It was a very hopeful time for all of us. It seemed like real answers were finally at hand.

And then the hammer blow fell. They suddenly left, saying, "I don't think we have an epidemic here."

That's all it took. The rumor swept through town that the CDC didn't believe there was any substance to our claims.

All the sickness, the disability, the suffering, the loss... all that people had gone through suddenly vanished as though it had never been witnessed by family, "friends," doctors, neighbors.

They fell upon us in full fury, attacking us for "destroying the economy," for faking, for making false claims, for malingering, for fooling good people into helping us, for being useless slackers who had wasted the time of all involved.

It was like day and night. Just those simple parting words from the CDC and we were plunged into black despair of the darkest kind.

All those who still supported or believed us were under attack, especially Cheney and Peterson who were considered the ringleaders of falsely creating "mass hysteria."

The community leaders openly called for Cheney and Peterson to be run out of town on a rail, tarred and feathered...or that at the very least, to lose their licenses and be forced to leave.

Sufferers went into hiding, used phony names, moved out of town, tried to pretend they had never been ill. People were even scared to go out in the light of day, because the dark circles under the eyes and the weird staggering gait we all had would give us away and make us a target for hatred, contempt and scorn.

People told us, "If you gave a damn about anybody but yourself, you would leave town for the good of us all. You're not wanted here. Why don't you leave? What kind of evil person are you, to cause all this trouble?"

The day before the CDC left, we were all infused with a sense of hope that maybe we were running down the home stretch to real therapies, that something was finally being done.

Literally overnight, like the sudden onset of the disease itself, we were hit by an asteroid, blindsided out of nowhere, smashed from a direction that we never expected.
By the time of the 1987 convening of the Holmes committee to grudgingly give Dr. Cheney and Dr. Peterson's evidence its undeniable belated dues, the forces of the medical establishment had already arrayed themselves against us.

The CFS definition did not come about because they wanted to help us. It was because the CDC could not develop any reasonable excuse to ignore the evidence any more.

-Erik (2008, CFSU)

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I asked around the Incline Village library if anybody remembered something funny happening in the medical office next door about twenty years ago.

It was astonishing how little people remembered.

And for those who did, it was almost like a repressed memory, something distasteful that had long been pushed into the depths of unwanted information.

-Erik (2009, CFSResearch)

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Look what happened to pigs both times swine flu has erupted.

When hantavirus was in the news, sales of mousetraps exploded.

Remember what happened to pets in Asia when SARS was thought to be transmitted zoonotically?

I've seen what happens to beloved cats when the doctor says, "Probably just a cat allergy," even without testing to find out.

Well, when "Tahoe Mystery Illness" went through Incline Village, our neighbors didn't stop to think that we were no different from them.

None of us wanted to become ill or had any idea how this had happened to us.

But this didn't stop our neighbors from reacting to us exactly the same way that humans react to the mere possibility that the creatures around them might (even when the scientists say not) have a transmissible illness.

We become the creatures.

-Erik (2009, WPI)
It was a flu like illness.

It moved into town much as we had seen other seasonal type flus make their way through the community before... starting at the schools and casinos before spreading to the more isolated individuals.

We all tried to avoid catching it by staying as far away from people as we could and doing the normal anti-flu tactics, such as minimizing time in stores, cutting down on social activities, washing hands, etc.

The resort community came to a screeching halt, and the economy was suffering.

The grumbling started. Jobs were lost. Casino employees were laid off. Business cut back their hours. Some just closed up shop.

There was no doubt in anyone’s minds who was responsible.

Even as the illness claimed new victims, they were thrown into the blame pit even if they had only been sick for weeks.

We were threatened. Told to leave town. Accused of having some weird agenda of deliberately trying to ruin the economy, devastate the town, destroy our neighbors and eradicate Incline Village from the map as a ski resort destination.

We became the enemy. They attacked us.

"Don't you even care about your families? About what you are doing by spreading this? If you cared about anybody but yourselves, you would all leave town... for the good of us all."

-Erik (2010, WPI)
Chapter 56 - Lake Tahoe Illness Description

SYMPTOMS

As far as an induced response to prevent exercise goes, the nature of the fatigue would be extremely counterproductive to survival at the level of exercise intolerance experienced during the Incline Village epidemic.

It was almost impossible to feed yourself. People who didn't have help resorted to canned food, often eaten cold, or things that required virtually no preparation. Many people expressed how difficult it was to maintain proper nutrition without the ability to prepare it.

As is so often described, the fatigue didn't feel like an energy saving strategy. It was literally as if the mental commands failed to elicit a response.

People generally do not have to will a response for simple things like reaching for a glass. In this instance it felt like you were operating a mechanical arm had to literally concentrate on directing the action. The mental effort required to force the body to respond was so great it was as if you had to perform a complex mathematical calculation to be rewarded by enough function to crawl to the bathroom.

Trying to follow the plot of a movie or read a book was impossible.

Long term memory was fairly intact but short term was almost nonexistent. Most people I knew could not remember their own phone number unless they had it a long time. Learning a new one was out of the question.

Looking out of your eyes was like watching a movie. It took a great deal of effort to try to connect with reality. If you had enough energy to drive, it often seemed that you could drive off a cliff and it wouldn't affect you personally.

It took a hat and dark glasses to go outside. The light from a single LED from an alarm clock would fill the room with a glare that was unbearable at night.

People despise the "F" word because it doesn't describe the sensation in CFS, but the problem is that there is simply no word for this.

It probably seems appropriate that the best attempt at conveying this would come from the drug culture. "Zonked" is about the only word I can think of that seems to more adequately express the concept.

Somehow I can't see people agreeing to call this "Chronic Zonked Syndrome" though.
It always blows me away when someone says that "CFS is not ME," using the rationale that we were less ill.

We had all the symptoms of Ramsay-defined Myalgic Encephalomyelitis - plus a few obvious ones that he didn't even mention.

I was able to stand up for most of the time, but was unable to predict exactly when those times would be when I could not. Very frustrating.

Even though the severity had quite a range, the commonality is that we were all afflicted in the same way regarding those symptoms chosen to define the illness.

We weren't much different from each other. We were pretty much all the same in possessing these particular signs and symptoms peculiar to the syndrome.

When the public lashed out at us after Dr. Cheney and Dr. Peterson published a description of the complaints of "Tahoe Mystery Illness" and we tried to keep ourselves hidden to avoid the wrath and hatred of our community, our eyes gave us away.

People said they could spot us at a distance because of a peculiar gait that resembled an old person with a bad back.

Once they got close enough to see the "myasthenia gravis" appearance of the eyelids, the pale skin and the dark "heroin addict" eye sockets, it was quite clear that something was seriously wrong.

We were often asked if we had AIDS.

Doctors saw it too, and you can imagine our disbelief when their concern over our obviously sickly and haggard appearance changed to accusations of overwork and stress when the tests came back negative.

"What about this killer sore throat that you can see? What about these swollen lymph glands?"
And in their efforts to dismiss the illness, doctors would say that these could be from virtually anything and didn't prove that we were sick - especially without confirmation from the test results.

So doctors could not be induced to believe us from these visible signs, yet people who wanted to force us out of Incline could readily use those same signs to spot us.

It was just as well that the painful photophobia forced CFSers to hide during the day, because that was when the need to hide was greatest anyway.

-Erik (2006, CFSResearch)

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I have to stick to what I know, what I saw.

I can't say if what happened to us is precisely like everyone else.

But if you want to know what is was like for the "Yuppie Flu" cohort that was instrumental in getting CFS started - that I can tell you.

The Incline Village cohort did not have anything resembling fatigue.

Our pallor made us recognizable to people at a distance. We all looked like heroin addicts.

We also had a peculiar gait that was like lifting a leg and falling forward until it touched. Almost like catching yourself from a fall at every step. It was very distinctive and could also give a person away at a distance.

We had virtually every symptom described for ME plus a few more really distinctive ones, like the loss of fingerprints.

That really blew people away. I don't know if ME describers didn't have it or just didn't notice.

When you demonstrated that you could do a blank ink blot, you could see the shock in people’s faces as the realization finally hit home that this was no ordinary situation.

I had absolutely the worst sore throat I've ever experienced, as did we all.

Made eating incredibly painful for years. I've never recovered from it completely.

I didn't have a fever, and I personally didn't see many people with both CFS and FM.
Saw a group of ladies from Carson City with FM and it was certainly a much different appearing illness than CFS.

Devastating, but different.

-Erik (2006, CFSResearch)

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Why did Dr. Peterson call the CDC?

Marathon runners, overnight, could not climb a flight of stairs.

People who set out in the morning for work had to be carried home.

Those who could still drive got lost trying to find their way home.

A math teacher could not do addition.

An English teacher could not conjugate a verb.

Throats looked like people had gargled with battery acid.

We could barely stand without leaning against something and were forced to stagger from place to place where we could lean. Walking was more like lurching: aim for a door, and those with this illness only made it through fifty percent of the time. People who closed their eyes dropped instantly.

Nobody could remember what they did five minutes ago.

If you ate bread and you put it away at all, it was more than likely to be in the freezer. If you ate ice cream to try to kill the pain in your throat, it rarely made it back to the freezer.

People suffered from malnutrition in the midst of a fully stocked kitchen because they couldn’t stand long enough or think well enough to prepare food.

We ate cold canned food, because that was the best we could do.

Reading was out of the question. If you tried, you’d find that you had been reading the same paragraph, over and over.

The glare from normal light book pages was too much.

No TV: seizures.
No lights in the room: they burned your eyes.

No music: it hurt your head.

And that's not the half of it.

There was nothing but pain and disbelief in our lives.

Kaplan and Holmes left? They left? They LEFT?

Saying they saw no evidence?

I swear to God!....

-Erik (2009, CAA)

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I am an Incline Village survivor, and this is how Dr. Cheney described us... like "soldiers coming out of a war zone."

We lay comatose, but it wasn't sleep.

When we dragged ourselves back to consciousness, we were kind of awake, in a groggy, toxic, Twilight Zone fashion, but felt no better than when we lapsed into that wretched torture that doctors mistake for sleep.... no matter how hard we try to tell them it is more like being hit with a brick.

The way some people not only fail to describe the illness that I saw and even argue in favor of fatigue and weakness makes me wonder if they ever experienced anything like we did.

At the 2009 Reno Conference, I met with other survivors of the Tahoe cohort to compare descriptions, and they were the same as mine.

-Erik (2009, CAA)

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All of our descriptions to Dr. Cheney and Dr. Peterson were how much this illness was not like fatigue.

Beyond any fatigue we had ever felt, like nothing that was within the range of what a human could feel even right after running a marathon... of which a number of Incline survivors had experience, being marathon runners.
It has been incredible to watch things change until the current day, when so many people talking about CFS seem strangely comfortable with the word and feel perfectly free to use it.

This is totally contrary. It doesn't make sense.

Did people forget what fatigue means? Did it change definitions?

Or are the people who describe it as fatigue feeling something different than the illness that we were describing?

The other thing is that the claim is often made that there were no outward signs of illness.

The "good people" of Incline could spot a mystery illness sufferer at a distance.

Not only because of the hollow eye sockets, heroin-addict appearing dark circles under the eyes, skin pallor... but because our gait gave us away.

It was like nothing anyone had ever seen.

Almost like falling forward and catching yourself at every step.

Even an old man who staggers didn't look quite this ungainly.

Yet, when you try to explain it to doctors, they act like they have no idea what you are talking about.

We would look at doctors in shock.

Our neighbors had no problem seeing the illness, when they wanted to.

What is happening in the minds of those who say they can't?

-Erik (2009, CAA)

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It felt like we were in a nightmare that wouldn't end.

-Erik (2010, CFSKnowledge)

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People just fell apart, as if their immune systems had been turned off.
CANCER

The type of cancer was extremely relevant as an integral part of the Tahoe outbreak.

There was a time when the undifferentiated B-cell phenomenon was so striking that it appeared "Tahoe Mystery Illness" might be a cancer death sentence.

The rate of lymphoma was so extraordinarily high in this illness that Dr. Peterson ordered special Kappa Lambda tests for all of us.

The insurance companies refused to cover the tests, which they considered to be irrelevant to a mere fatiguing condition.

When Dr. Peterson tried to relate the extraordinary significance of this finding to the CDC, Gary Holmes wrote back to say that B-cell lymphoma would move the patient out of the CFS category.

Marc Iverson's research grant paid for my test. Much to my relief, it was in the favorable range and my sentence was lifted.

- Erik (2008, CFSResearch)

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Long before Ampligen was tried, Dr. Peterson's "Tahoe Flu" patients were developing lymphoma.

As one can see by the current one in three lymphoma rate in survivors of the original Incline Village cohort who never got the drug, Ampligen had nothing to do with the rate of cancer.

It's the "Tahoe Flu" that is responsible.

- Erik (2009, CFSResearch)

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During the Incline epidemic, after Dr. Peterson and Dr. Cheney saw the profound loss of B cell immunity, and after we heard about the woman from South Africa that came to visit and left a swath of destruction in her family of Burkitt’s lymphoma, it appeared that all of us would be dead of cancer within a short time.

We didn't expect any survivors.
This lady from South Africa went on a tour of visits to family in the US. Shortly after, she died of a very aggressive Burkitt's lymphoma. Then the people she visited started getting the same thing.

For a while, that was the top contender for what had happened in Incline.

I asked Dr. Cheney how we could possibly deal with the loss of a major component of immune function, and he said, "I don't know. We've never seen this before."

Dr. Peterson ordered Kappa Lambda light-chain ratio tests, to gain a sense of the risk. The CDC protested that the tests were not officially approved for this purpose, and insurance didn't cover them.

My results showed that I was not in the high risk group.

This was most likely because I was completely EBV negative, and it is the reactivated EBV which seems to be associated with the lymphomas.

-Erik (2009, WPI)

DEATHS

"CFS doesn't kill anyone."

How often have you heard that?

Always said in the sort of tone that is meant to convince you that CFS is just a trivial illness.

But when the "mystery illness" went through town, a bunch of people died of heart failure, and whether they had that "weird flu thing" was completely ignored.

The only reason doctors say "no deaths" is because these instantly dead victims don't live long enough to become "chronic" and fit the criteria.

-Erik (2005, CFSResearch)

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When the "Yuppie Flu" hit Incline Village, I was working part time as a snow shoveler saving houses that were collapsing from heavy winter snows at Tahoe.
"Sierra cement," we called it. There was so much snow that in order to save houses, we were using double-handed crosscut saws with one handle removed to saw the snow into huge blocks that we rolled off the roofs.

People would come up to our teams with tears in their eyes, pleading with us to save their house next, saying that they could hear the roof beams cracking under the weight of the snow. It was hard work and we did what we could, managing to keep a lot of houses from collapsing.

We were working 10-12 hours a day, and you couldn't do this kind of work unless you were in reasonably good shape.

One of our team got the same damned weird flu that I did. He just disappeared.

Somebody went to check on him and he was dead.

The official report was that he died of heart failure.

You'd think he would have died on the job if his heart was that weak. But no, he died at home, coughing his lungs out.

I asked, "What about the weird flu - he had that too. Doesn't that mean anything?"

I was told, "That flu doesn't kill, so that is ruled out. It didn't kill you, did it?"

Damn near!

And it was a bit of a shock when Dr. August Stemmer, the oral surgeon in the same building with Dr. Cheney and Dr. Peterson, suddenly dropped dead of heart failure while the epidemic was underway.

He was older, so this time it was blamed on his age.

All along, every time someone died who had the "flu-like illness," the fact that they died was used as "evidence" because of the fixed notion that the illness creates "survivors."

-Erik (2006, CFSResearch)

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What lack of deaths?

People are dropping like flies.

But every time we lose another one, it is "not due to CFS" because CFS is defined as something that doesn't kill.
So it's always "something else," such as cancer or heart failure.

A million people with CFS could die early deaths, and not one of them will ever be caused by CFS, by definition.

-Erik (2010, CAA)

FATIGUE

It's kind of an odd coincidence for me, how the Nijmegen School of Psychiatry leads the charge on saying that CFS is fatigue.

I have a medal from the Nijmegen Ministry of Physical Culture for completing the famous Volksmarch in the Netherlands.

I was part of a volunteer military contingent sent to participate. Naturally, even though it is not a competition, it simply wouldn't do to send a group of soldiers who didn't make it look easy - so we trained.

A lot.

Almost a thousand miles carrying a 40 lb. ALICE pack.

I can remember the fatigue after each day’s march.

Sink down on your bunk with a cold German beer and soak up the rest and relaxation after a hard day’s trudging.

It was glorious. The feeling of rest and recovery was enlivening and empowering, and one of the best times of my life.

Now we have this "flu-like illness" that leaves me unable to climb a single flight of stairs. The doctors say I am deconditioned and lack motivation. The strange inability to exercise and post-exertion malaise which follow no exertion at all is strangely referred to as "fatigue," and people seem to accept this.

How can one of the best, most recuperative sensations I ever experienced and the most horrific devastating paralysis be called by the very same word?

I have felt fatigue, and it is nothing like CFS.

Yes, there is also fatigue in CFS, but fatigue is a normal part of the human experience and should not be construed as part of the illness any more than the normal sadness
and grief after a loved one dies can be thought of as a medical disease of clinical depression.

It is normal to feel sad under such circumstances.

It is normal to feel fatigue after exertion.

That CFS sensation which doctors confuse with fatigue is anything but normal.

-Erik (2006, CFSExp)

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I should send you a picture I have of Dr. Cheney’s office.

My house is directly behind, and you can see the short flight of stairs leading up to the door.

Literally overnight, I went from being a hang glider instructor who ran wind sprints all day long - holding onto students flying wires to control the glider in the initial "launch and land" learning phase - to not even being able to climb those stairs without clinging to the handrail and resting halfway.

This was a hallmark of the Incline Village epidemic.

"Post-exertional malaise"?

What "exertion" are they talking about? Standing up? Trying to feed yourself? Crawling to the bathroom?

I would wake up after "resting" feeling worse and more destroyed than when I lost consciousness and fell into the catatonic collapse that doctors think is just "sleeping."

I only got the joy of experiencing post-exertional malaise after a couple of years when I recovered enough to walk the length of the driveway.

And the doctors call this "deconditioning."

Dr. Cheney knows this full well but I believe that he is just trying to avoid excluding other types of CFS by not saying, "no-exertional malaise."

-Erik (2006, CFSExp)

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While CFS may result in symptoms that mimic old age and may even share some of the downstream immunological results, CFS is absolutely nothing like that.

Torturing mice into tiredness and calling it suitable for comparison with CFS is like comparing encephalitis with a concussion. Knocking people over the heads until they assume the same prone position isn't quite the same - although the head bashing might give that appearance.

Old people do not have remissions in which the instigating factor can lift for periods and leave them feeling almost like a normal person.

We were not worn out by time. We were beaten half to death by some induced inflammatory response, and whatever was doing it happened literally overnight.

If an old person had CFS and the two were roughly the same, an old person wouldn't really know the difference. I've seen old farts with CFS and believe me, they know.

Aside from sharing the recumbent position, whatever happened in Incline Village was absolutely nothing like old age.

-Erik (2006, CFSExp)

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One conceptual framework puts CFS on a scale of tiredness - combining "CFS and CFS-like conditions."

But are those "CFS-like conditions" really like CFS?

Seems to me that's about like putting "concussion" at one end of "sleep disorders."

-Erik (2008, CFSResearch)

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The Type A concept was developed by people who refused to listen to the facts and were trying to fit CFS into their "overly tired" box.

They came up with the notion that if the illness consisted of excessive fatigue, people who already had a sedentary lifestyle wouldn't see much difference... so it would be the active personalities who would complain the most about how much CFS had changed their lives.

From this perspective, "Sedentary personalities pretty much all have CFS."
So by not seeing their lives changed by more fatigue, they “don’t have CFS... that’s just how they are.”

But when a couch potato can no longer watch TV or read a book because the glare from the screen is burning holes in his eyes, and short-term memory is so poor that he winds up reading the same paragraph over and over, not even realizing it until it has been read, ten... maybe twenty times.... and then he can't remember anything prior to that paragraph....

And the couch potato can barely crawl to the refrigerator to get some chips and dip, and even if he did, it is so agonizingly painful to force food down the worst sore throat he ever had in his life, so eating anything feels like swallowing broken glass with a lighter fluid chaser...

Believe you me, the couch potato notices a big difference in his life!

-Erik (2008, CFSU)

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There was no such thing as "CFS" until the Holmes committee applied it to our illness. We had never heard the words put together before. Until that moment we were calling it "Chronic Epstein-Barr Virus Syndrome," even though we already knew that it wasn't.

I looked at Dr. Cheney in shock when he told me what the Holmes Committee was going to call the illness. Dr. Cheney immediately told me that it was just a provisional term that probably wouldn’t last more than a month or two, now that the CDC was finally looking into this.

We weren't really classified as anything except anomalies. Dr. Cheney just had to put something on paper. That description was just there to satisfy people that they were using some kind of classification.

If you read the comments from Peterson, Cheney, Komaroff, Bell, Klimas and others, it was the shocking nature of our descriptions that grabbed them.

"Debilitating fatigue" is an unbelievably paltry way to try to express this. It was impossible to put this into words. You had to see it to believe it.

Marathon runner who can't stand up. Teachers who can't remember their subjects. People getting lost on their way home. Remember Chris Guthrie, the meter reader who couldn't even make it home? People who could actually stand up and walk to the bathroom instead crawling were the lucky ones.

Having to be told a phone number in two parts, because with pen already on paper we couldn’t remember that many numbers long enough to write it down. And when trying to
write, somebody who had perfect penmanship was now writing an almost completely illegible scrawl in huge letters.

When you go try to hold a fork, your fingers refuse to respond. And when you try and you try... and with your utmost concentration...sweating with the effort, you manage to lift a fork to your mouth... and MISS.... "fatigue" is not how you describe your illness.

Thinking that it is just shows that they don't know the illness.

That's why I say that CFS is actually a good diagnostic. Anyone who is comfortable in describing their illness as fatigue cannot possibly have the illness that the CDC named "CFS."

Anyone who described their illness as fatigue would not have been in this study. Although it may not be written down, they had to have the whole shebang.

-Erik (2008, CFSU)

FIBROMYALGIA

We saw very few people with FM during the Incline epidemic.

I was amazed when I first heard someone describe it - and they were from out of town.

Just like with our complaints, it seemed almost impossible.

Nobody had ever heard of anything like this - and you bet we asked, all over the country.

Seemed like the FM people didn't have anything like our illness, but it sure was strange.

Not really like rheumatism at all, but doctors tried to ram it into their "We already know about this" box.

Just as they did with "Everybody gets fatigued sometimes" with CFS, even when what we described was nothing like fatigue.

-Erik (2007, CFSResearch)

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During the Incline epidemic, we had no shortage of muscle pain.

But people started coming up from Carson City with those "trigger points."
Frankly, this was astonishing to us.

The term fibromyalgia had been coined many years before to apply to a condition with muscle pain, but had fallen out of usage.

FM was resurrected to use for the "trigger point" condition.

If it hadn't been for the astonishingly bizarre trigger points, most people could have easily fit into the "mystery illness" phenomenon.

So the way I see it, if someone doesn't have the trigger points but has everything else, including the normal muscle pain in CFS... they probably have CFS and should not have received an FM diagnosis.

-Erik (2009, WPI)

GAIT

The implication that the gait disturbance is due to self-selected velocity reveals a total lack of understanding or cognizance of the "foot drop" phenomenon.

Anyone who has experienced the "foot drop" knows velocity has nothing to do with it.

The abnormal gait represents ataxia: a loss of proprioception.

This is verified by a positive Romberg test.

After the CDC concluded its investigation in Incline Village with the parting words that they found nothing of interest and no evidence of a fatiguing illness, the community lashed out at us for "trying to ruin the economy" with a phony epidemic that was now "proven to be false by the CDC."

Angry residents could easily identify "Mystery Illness" sufferers at great distances by the distinctive gait which gave us away.

We tried to hide it, to walk normally in an attempt to disguise our disability, but the harder we tried to assume normal walking patterns, the more ungainly our motion became.

It was not under our control.

People were afraid to go out during the day, not just for the photophobia, but for this very obvious "foot drop" manifestation that openly betrayed our illness.

This was a very distinctive characteristic of the mystery illness.
The gait was a distinctive neurological motor control dysregulation just as surely as the loss of writing skills and strangeness of reaching for an object... and missing.

There is certainly some fatigue in CFS, but that is not what made this illness distinctive.

There are balance problems too, but if researchers believe these are what define this illness and are the basis of the descriptions of not being able to lift a coffee cup or tripping over a pebble, they do not understand CFS.

- Erik (2008, CFSResearch)

PARALYSIS

I went through many sleep deprivation exercises in the Army.

One lasted for five days before I hit my limit during Operation Reфорger (Return of Forces to Germany) in 1975. This was an exercise that simulated a NATO invasion of Europe in response to a Soviet incursion.

I would often refer to that exercise and say, "I've been set on fire, had broken bones, had hangovers from drinking Ouzo all night in Crete and been kept awake for five days on military missions, and if you put them all together it still wouldn't feel as bad as CFS."

The military often pushed people to the limit, just to weed out the ones who broke down first. I got to see what happened, and it was absolutely nothing like CFS.

It is infuriating that you can explain the neuro-paralytic dysfunction in very clear terms, and yet people will still say, "So you mean, very, very tired."


Looks more to me like a stroke victim who struggles, but cannot find the words to speak and cannot move.

- Erik (2006, CFSExp)
The vertigo was worse than the worst drunken spree hangover I ever had. The leg pain and burn were so severe that I went from being a runner to virtually unable to climb a half flight of stairs without a very long agonizing pause, stopping at each step.

But the worst part was this thing that doctors keep calling "fatigue."

Unless one has felt it, there is no way to explain or comprehend what it is like. No matter how many times you try to convey it, the doctor inevitably starts making statements back to you that indicate the mental model that he has is one of "extreme exhaustion."

Not only did this "exhaustion" fail to correspond to any activity, often even being exacerbated by rest, it really consisted of an "unwillingness" of the body to respond to your neural commands.

Doctors will see you sweating with the effort of raising your hand, and they conclude that this is similar to being so darned tired that your muscles aren't working - but the muscles are rested.

What is happening is that your brain is working overtime trying to force the nerves to respond. It feels more like trying to work some kind of complex math problem in order to get the banana.

Imagine if one had to do a calculus problem every time they wanted to move, eat, pick their nose or whatever - and if the solution isn't done correctly, they can't move or even think any more.

-Erik (2006, CFSResearch)

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Anyone who has seen an Autistic tantrum and is familiar with the neurological paralysis that besets CFSers has to be a bit confused at the Autism/CFS comparison.

Such a burst of physical energy would be impossible for a CFSer.

The merest attempt to emulate such energy would be devastating.

-Erik (2007, CFSResearch)

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Patients with "Tahoe Mystery Illness" were carried into Dr. Cheney and Dr. Peterson’s office by relatives, because we couldn't walk, drive, or care for ourselves.
The primary sensation that scared Dr. Peterson into calling the CDC was not fatigue of any type, description, range or level.

It was like the blood was drained out of you and bricks piled on top of you.

Not unreasonable for low circulating red cell mass and encephalitic inflammation.

It was literally a physical unwillingness of the body to respond to mental commands. Tiredness at any extreme, even running a marathon, is nothing like this.

It was scary as hell and we all thought we were going to die.

-Erik (2008, CFSResearch)

* This is how one of our teachers at Truckee HS described it:

Unable to move, like having bricks piled on you.

This wasn't a description of being tired after exercise, as no exercise has happened yet.

The nerves don’t work to control the muscles.

This comes so unconsciously and naturally to everyone else that they cannot even conceive of the sensation.

Virtually every motion is like trying to solve a geometry problem in your head.

And if you successfully solve the problem, you can crawl to the bathroom as your reward.

-Erik (2009, CAA)

* Instead of "fatigue," I call it "neurotransmitter enervation."

It fits the facts.

It sounds medically impressive.

Trouble is, doctors don't know what that means and don't have a dictionary... so you’ve got no choice but to say,
"Uh, like beyond the worst fatigue or exhaustion I ever felt, death-drop disabling, bone crushing, wipe-out, life-smashing paralysis."

Usual response: "Oh, you mean like really really tired?"  

-Erik (2009, CAA)

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I can still remember the sense of panic, the first time I "told" my arm to reach for something, and nothing happened.

To have that sense of paralysis, to realize that your brain is no longer in full communication with your limbs... it just flattens you.

Until it happens, it's just not even imaginable.

My grandfather had a stroke, and we talked about how horrible it was when he realized that although he could understand speech was being spoken, he could not understand it, as if it were a foreign language.

Nor could he articulate his own thoughts, and could only make garbled sounds.

I remember the look in his eyes, as he relived the way his world was shattered by this experience.

Well, I remember saying things, and having everyone in the room tell me that it was like I was "speaking in tongues"... utter nonsense, and I could have sworn that it was perfect English.

Other times, I told people to speak clearly, because it seemed to me that THEY were talking Greek, and everyone would look at me: "No, he wasn't, I understood every word."

I'm sure that my eyes looked a lot like my grandfather’s.

Now, my grandfather never said that having a stroke was like being tired, although that was certainly some part of what he went through.

That is just not the description he would have used.

When something like this happens, you certainly wouldn't emphasize the only part of it that doesn't scare the crap out of you.

-Erik (2010, CAA)
PHOTOSENSITIVE EPILEPSY

Doctors fixated on the electrical pulse rate as causative.

But if you were driving next to the lake in the afternoon, and the setting sun deflected off ripples from boats, and when the flashes hit a certain frequency, the same thing would happen.

I remember having my mom drive me along Lakeshore Blvd. and having to tell her to speed up or slow down to avoid the speed that put exactly the right frequency of flashes between the trees.

Even hunching down in the car and closing my eyes just barely worked.

I had to keep my closed eyes covered.

And don't even get me started about the lights at the casinos!

-Erik (2010, WPI)

SORE THROATS

The crimson crescents are also called "Inflamed Anterior Pharyngeal Pillars" and were discovered by Dr. Burke Cunha to be an artifact common in CFS.

He made the observation that when the tonsils are removed, the placement of the reddening moves slightly down the esophagus, just inside the pharyngeal pillars.

We had the worst sore throats that anyone had ever seen.

It looked like gargling with battery acid.

Eating was staggeringly painful. Some people used ice or ice cream to deaden the pain long enough to try to choke down something soft, mushy, that could be swallowed easily with minimal abrasion.

Some people’s tonsils literally eroded.

This was something that was undeniably visible, so to even hint that this illness was anything other than some kind of horrible infection was a blazing leap of utter insanity.

You couldn't really call this a "sore throat" any more than it makes sense to say "post exertional malaise."
It was so far outside the range of anything that anybody had experienced that words don't quite seem to get there.

You try to describe, describe, describe it. But somehow, when what you said gets repeated back, only the merest fraction seemed to make it through to comprehension, and about eighty percent is completely lost in translation.

-Erik (2010, WPI)

**STANDING UP**

I just saw the latest Cheney Research letter about the combination of diastolic heart failure making someone unable to stand, and systolic, which leaves you unable to lay down flat.

That was my situation. If I lay down, I got shrieking brain pressure and the spins. If I tried to stand up, I got lightheaded and passed out.

As he said, there was a window of standing position that lasted about fifteen seconds, not nearly enough to make it to the bathroom.

That's why we all wound up crawling on our hands and knees.

We knew that if we stood up, we were just going to pass out.

Since I couldn't lay flat, there was no comfortable position, only one that was a combination of the least of these combined evils.

I found a reclining chair that allowed me to precisely control a body angle that gave me the least of these opposing forces, rather than trying to lie down flat.

I had to try to conduct what others call sleep in that chair.

-Erik (2010, CAA)
Chapter 57 - Lake Tahoe Illness Abnormalities

TESTING

One of the weirdnesses that caused Dr. Peterson to call the CDC was a zero ESR. This struck him as extremely odd.

Not one, two or three, but zero.

We had activated RNase-L / RNA ribosomal destruction - unlike anything Cheney or Suhadolnik had ever seen before.

Unbelievably high IL-2 - only seen in things like hairy T cell lymphoma and AIDS.

Inexplicable viral reactivations of unrestrained Nuclear Antigen.

Blown up B-cells by a huge herpetic virus that nobody had ever seen before - which was called HBLV, then HHV6, then HHV6a.

Low NKC function.

Low red cell mass and morphology - similar only to things like Sickle Cell Anemia.

Autonomic dysfunction.

The crimson crescents.

Loss of fingerprints.

Low red cell mass.

Cardiological abnormalities strangely similar to Osler Weber Rendu - telangiectasis.

UBO's on MRI.

Opening pressure for spinal taps - indicating inflammation.

Oral lesions - roughly following the curve of Spee.

Candidiasis - indicative of immune failure.
White spots and swelling of the ruggae.

Swollen spleens.

Swollen lymph nodes.

Rashes.

Myasthenia Gravis - Raynaud’s - CMT syndrome and Guillian Barre similarities.

Left ventricular enlargement.

Orthostatic intolerance.

And of course, a skewed suppressor/helper ratio that was virtually unknown to virologists - the mirror image of AIDS.

Just to name a few off the top of my head.

These were things that people could observe on scans, palpation, and testing.

The strange pattern of the cognitive difficulties, with the loss of short term memory and IQ/dyscalculia - along with the photophobia and photo epileptic seizures - were something that doctors could see if they knew what to ask.

We figured the list was more than sufficient to show that even if we didn’t know precisely what it was, things were clearly not okay.

Who gives a darn about fatigue when you "tell" your hand to grasp a fork so you can try to force some food past the worst sore throat you ever had in your life - and you watch in amazement as nothing happens until you concentrate with all your will to make your fingers move?

If someone talks about CFS as if they think fatigue is the sensation people are complaining about, they don’t know jack about this damned disease.

-Erik (2008, CFSResearch)

**BLOOD PRESSURE**

During the Incline epidemic, I sat with Dr. Cheney and discussed the way this illness mimics Osler's Disease: hereditary hemorrhagic telangiectasia (HHT), which consists of a peculiar internalized high blood pressure that is not detected by a sphygmomanometer.
Imagine our surprise to find out later that the same type of illness had occurred in Sacramento, only two hours’ drive away, just ten years before.

And Dr. Ryll had not only made the same observations, but he had given the illness a much better name:

"Infectious Venulitis."

But just as had happened with so many other outbreaks in the past, this critical information had been forgotten and lost, at a time when we needed it the most.

-Erik (2009, WPI)

**EBV**

What happened in Incline Village was a reactivated EBV infection that only occurred in people who already had EBV.

Those who didn't, like me, just went on to become CFS despite being EBV negative.

That's why Dr. Cheney asked me to volunteer to be in the Holmes et al CDC study to define what they came to call "Chronic Fatigue Syndrome" - because I was one of the exclusions that demonstrated that CFS caused reactivated EBV instead of EBV causing CFS.

He scoured the country and found nineteen of us who were EBV negative, but as he told me, "It is important that you participate because you are the only one of the original Incline Village cohort who is EBV negative."

It was strange that for a while, I was forced to tell people that our "Mystery Illness" of "CEBV" existed, except that it wasn't from EBV.

Dr. Peterson retested me in 1998 and said, "Once again, just as during the original epidemic, you are the perfect case of CFS and are still EBV negative. You need more of a social life."

Funny joke.

-Erik (2006, CFSResearch)

*  

When the "Yuppie Flu" went through Incline, it reactivated EBV in those that had it or made people (even people in middle age) susceptible to a first time EBV infection...
OR....

It reactivated whatever virus a person had or was exposed to, even if it was CMV, coxsackie, HSV1 or 2...

OR....

Sometimes a person developed CFS with NONE of these!

How important is EBV as a "trigger" when you watch the damned illness happen EBV or no EBV?

-Erik (2008, CFSU)

*

The way the "mystery illness" moved through already told us that "Agent X" (yes, Dr. Cheney even called it that) was causing reactivated EBV, new adult-onset EBV and the most important thing of all - the same illness and immune parameters even when EBV was not involved at all.

That means, first and foremost, to look for a process that is independent of EBV.

And yes, I have heard Dr. Peterson speak of CFS following an "A" variant of EBV, but whether or not EBV has the capacity to create CFS is not the point.

"CFS" was coined on the direct evidence that EBV was not involved.

If researchers had looked at the reasons why CFS was created, their mindset should have been "Agent X without EBV" instead of "EBV plus a contribution from agent X."

But to this day, people still express their conceptual framework that the fatigue in CFS is undoubtedly due to the input from EBV/chronic mononucleosis.

"CFS" was intended to show that the neuro-immune properties were not from "mono" at all.

Gary Holmes, to his credit, wrote the proposal to create the chronic fatigue syndrome with the warning that doctors were likely to disregard the evidence which called for the name change and elevate EBV to a role it did not merit.

And that is exactly what happened, despite the new name and clearly stated reasons for changing it.
Yet, although they were successful in pushing through a new syndrome in response to that evidence, the CDC allowed the perspective to revert right back to CEBV Syndrome, as if almost nothing had changed.

-Erik (2009, CFSKnowledge)

* 

In terms of mononucleosis, the very word refers to the abundance of "monocytes" - the proliferation of abnormal B cells.

Part of the evidence which demolished CEBV Syndrome was that although we did have giant, blown-up B cells, there were so few of them that it appeared we had no B cell immunity at all.

-Erik (2009, WPI)

* 

Back in CEBV Syndrome days, I was in the same weird position that CFS puts us in: "CFS is a serious and disabling illness, but it isn't fatigue."

It wasn't much different to have to say, "CEBV Syndrome is a serious and disabling illness, except that EBV isn't the cause."

-Erik (2010, CFSKnowledge)

ENVIRONMENTAL

When Dr. Cheney first found out about Dr. Bell's Lyndonville cohort and the unpasteurized goats’ milk incident, word spread like wildfire through Incline.

Suddenly, everyone was saying, "When did you eat goat cheese or drink goats’ milk? You must have had some goats’ milk products, to have this illness."

We had to swear that we never touched the stuff or had never eaten in any exotic restaurant that might have used goat cheese as a secret ingredient.

(Dr. Bell eventually concluded that this was probably just a trigger, so it didn't seem particularly critical.)

And then there was the tung oil.
People thought that just like that, out of the blue, everyone in Lake Tahoe had decided to simultaneously refinish their furniture and use tung oil.

-Erik (2009, WPI)

**HHV6A**

The "Tahoe Flu" was the first discrete illness entity that the newly discovered virus was found in, other than AIDS patients.

It was provisionally called Human B-Cell Lymphotropic Virus (HBVL) then renamed HHV6, and then again renamed HHV6a to differentiate it from the HHV6b Roseola strain that was discovered later.

The HHV6b is the one everyone thinks of as a common childhood disease. HHV6a is actually pretty rare.

Dr. Peterson made it very clear to me that the A variant was so much more savagely pathogenic than the B that they shouldn't have the same classification, as this just misleads people.

Just like everything else about this crazy illness.

-Erik (2009, CFSResearch)

*

Dr. Peterson believes there are substrains of HHV6a, and the Tahoe cohort got nailed by a particularly nasty one that came straight out of the San Francisco AIDS population.

And he told me that the difference between the A and B variants is so great that they shouldn't have the same name.

The B variant causes a childhood disease of Roseola and is extremely common.

The A variant is only found in 4 percent of the population (strikingly similar to XMRV in the normal population) and is associated with neurological illnesses like multiple sclerosis.

-Erik (2009, CFSKnowledge)

**PLATELET DEBRIS**
I was one of the patients that had the flow cytometry done and had the messed up platelet debris.

Look at Dr. Cheney's description of what this means. Scary stuff. Kind of important to me.

This wasn't something “found in CFS.”

It was something found in people that Dr. Cheney and Dr. Peterson tried to diagnose with CEBV syndrome, but could not. And their evidence caused the CDC to whip up a new syndrome as an "operational concept" to figure this bizarreness out.

-Erik (2009, CFSKnowledge)

PURELY PHYSICAL

CFS - or at least the original illness which received that term - is a purely physical post viral neurological disease.

It was just a killer flu from hell that left people ill.

There was no "mindbody" about it.

We just got sick and that was that.

This is what Seymour Grufferman said at the time:

"There is need for multidisciplinary approaches. We are talking about a disease, the investigation of which requires epidemiologists, virologists, psychologists."

Why the psychologists?

"To prove you're not all crazy."

-Erik (2010, CAA)

SED RATE

When Dr. Cheney ran standard work-ups on survivors of "Tahoe Flu" who just didn't seem to be improving, nothing much of any significance showed up.

This is why he and Dr. Peterson began looking around for different tests to run on people who were obviously not making this up.
Only one thing stood out in some of us on the standard panel.

Our erythrocyte sedimentation rate was zero.

Since most doctors think of high ESR is bad, they never bothered to consider the possibility that too low might be an abnormality as well.

-Erik (2009)
Chapter 58 - Developing a Test

CONFIRMATORY TESTING

As was intended all along by Dr. Cheney and Dr. Peterson, the 1988 criteria were something that doctors could use as an indicator that their patient might have the same illness we were observing and do confirmatory tests.

Dr. Cheney reported the new CFS name back to us and was clearly disappointed with the CDC (again), but the definition was open enough that a doctor who wanted to help his patients could use the description and do additional testing to see the illness.

It wouldn't have taken all the doctors to manifest scientific curiosity and a willingness to have a little faith in their patients. Just a few and the phenomenon would surely have been uncovered in undeniable numbers - as per Dr. Cheney's map of outbreaks.

We never dreamed that the vast majority of doctors would use the definition as a dumping ground and even a limitation by saying that if you had a more serious illness than persistent fatigue, it couldn't be CFS which was only fatigue.

And even more, we never dreamed that future CFSers would turn on each other and express words of agreement with denialists.

-Erik (2006, CFSResearch)

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I was in Dr. Cheney's office with a condition that I described as bouts of intermittent overwhelming fatigue.

Then I got "The Yuppie Flu," a totally different animal.

It was that damned "flu" that brought out Kaplan and Holmes and was named CFS.

It is that which I think of as "CFS," because that is the illness which was given that term.

If you saw the story in Osler's Web about the lawyer from Zephyr Cove who had no overt symptoms but still had the immune abnormalities, and who was then triggered into full-blown CFS, it was always pretty clear that there was a smoldering subclinical precursor state.

Trouble is, there are no symptoms which would approximate CFS in this early stage and it wasn't weird enough to get any research.
So the idea was to use the extreme cases to draw attention to this situation, find out what it is and develop a test.

Then using that test, people who suspected that they had something more than normal fatigue could get tested.

This was the plan of all the "CFS pioneers" who were involved.

It didn't seem possible that even one immune abnormality would fail to be enough for the medical profession to instantly understand that common fatigue shouldn't have immune aberrations and shouldn't be mixed up with CFS.

It didn't seem possible that research could be completely derailed by the CDC’s saying, "There is no test for CFS," and having everyone misinterpret this to mean there are no abnormalities in CFS.

There couldn't possibly be a test for “CFS.” The reason a syndrome is developed is that the etiology is not yet known.

The 1988 Holmes proposal to create "the chronic fatigue syndrome” clearly states that CFS is an operational concept for the purpose of studying the condition, so tests could be developed.

- Erik (2009, SevereReactor)

"NO BIOMARKERS"

How can a biomarker ever be found, if one functionally believes that CFS is an illness which has no biomarkers?

Every time one was brought up, Holmes said that this would move people out of the CFS category.

This refrain has been repeated ever since, flying in the face of the constellation of abnormalities that were identified.

- Erik (2008, CFSResearch)

*

Those of us in the Tahoe cohort had opposite immune function of what happens in chronic EBV.

Instead of a proliferation of B cells, we had almost no B cell function at all.
To top it off, Dr. Cheney found nineteen of us who had no EBV at all to put in the study group to define the new syndrome.

This is the evidence that forced the CDC to change their paradigm and invent a new name.

For twenty years, they have been saying that there are no tests for CFS, when it was these specific tests which revealed the abnormalities which forced them to coin a new term for the phenomenon.

-Erik (2009, CFSKnowledge)

**CONDUCTING RESEARCH**

At the very moment Dr. Peterson and Cheney called the CDC to Incline, they had already identified biomarkers that were so extremely unusual that they were not congruent with any known illness.

That is why they called the CDC - not because they saw a bunch of tired people with sore throats.

Among a multitude of others, a pathologically low ESR, only known in things like sickle cell anemia; extremely high IL2, which was only seen in a few other illnesses like Myalgic Encephalomyelitis, hairy T cell lymphoma and AIDS; and of course the deformed B cells, which led to the discovery of HBLV (later called HHV6 and then HHV6a).

These were presented to the Holmes committee, which created a loose "working definition" for "research purposes."

We didn't think this definition was going to be written in stone.

We thought that it was going to be used in they way they said it was going to be used: to research these anomalies.

But that's not what they did. They just found some tired people who had nothing to do with our illness, snuck them in under the loose research definition, called them "CFS," started studying those fatigue patients, and completely abandoned the very people that the CFS definition was ostensibly created to study.

-Erik (2008, CFSResearch)

*
The CDC capitalized on the lesser cases to shift attention away from the immune abnormalities to the symptoms, in order to keep eyes focused in the wrong place.

Not even Dr. Cheney or Peterson called the CDC about anything less than the cases that were truly extraordinary.

Asking for research into a phenomenon that has nothing particularly unusual about it is like asking why people who eat too much fast food get fat.

That leaves out all the "interesting" stuff that made this phenomenon new, different, and scary.

Yes, I was concerned that everyone was going to confuse the very prevalent fatigue phenomenon with the Tahoe Flu illness.

But I thought to myself, "People aren't stupid. They will read about the origins of the syndrome, come to Incline and ask, and we can tell them."

-Erik (2009, SevereReactor)
Chapter 59 - Medical Science

IMPOSSIBLE

After twenty years of being told that science and research has proven that CFS does not exist and that mold is harmless, I'm not so sure that the words "science and research" mean what doctors think they mean.

Since I started with all doctors saying that mold illness is impossible, I tested every concept myself and trusted my perceptions rather than trying to act like everything that was happening was impossible.

-Erik (2006, SickBuildings)

*

"Impossible! If what you say were true, everyone would know it already - Stupid!"

(That's Erik’s Razor)

-Erik (2008, IAQ)

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In a weird kind of way, it was easier 25 years ago.

Doctors were so utterly wrong about this that they didn't even offer partial or flawed advice.

They just said it was flat out impossible.

Knowing that they were clueless made it easier to mistrust everything they said.

I think it is much more difficult nowadays, because when people stay feeling absolutely beat to hell, they are convinced that it must be something else because they've already done what the doctor said to do about mold.

-Erik (2010, CAA)

PEER-REVIEWED EVIDENCE
I was so concerned about the emergence of this specific phenomenon that I even went to famous CFS doctors and paid them to listen to my story about the mold clues.

I regret the wasted money and the misspent time. Perhaps even more than that, I wish I had never found out that their desire to help patients must be based more on maintaining appearances rather than possession of an authentic spirit of scientific enquiry.

How many other people are tripping over this effect and try to tell their doctors? Only to be shut down with, "If other physicians don't think so, then you have no peer reviewed evidence supporting your claim. Therefore you cannot prove it."

There is a virtual brick wall of medical denial created by the fundamental philosophy that, "If we don't already know it, then it cannot be worth investigating."

-Erik (2006, Locations)

*

The situation is that we have a special circumstance of an association between water damaged buildings and an illness that is unrecognized and unexplained by the scientific literature.

The "experts" are using lack of peer reviewed evidence as "evidence of lack..." meaning that the phenomenon is not likely to exist.

We know that it does! But until science gets off its butt and finds out why, it won't be in the scientific literature.

-Erik (2008, CFSU)

**NEED FOR CAUSAL EXPLANATION**

Back before Dr. Cheney or Dr. Peterson had a clue that there was anything wrong in Incline Village, I talked to an Incline Village doctor who said that my mold complaints were out of normal human range.

I asked him, "Since antibiotics are originally constituted from mold, did it ever occur to you that if I have a reaction that is completely out of line with a normal human response, that it might not be my reaction to mold, but rather, my immune reaction to whatever an infective bacteria is doing when it senses mold?"

Well, he got that glazed over look that I have come to know so well in doctors. Without a definite reason and a definite solution, he was paralyzed and went into utter brainlock.
So due to the lack of any reasonable "causality theory," I didn't bother to make any. It wasn't necessary to know whether my mold reactivity was a cause... or an effect.

Kind of like the Semmelweis thing. You don't have to know why the hand washing works in order to just do it and get the benefit even without knowing why.

As long as it works, they can always work out the details later. But even if you don't, you still get as much benefit as the people who came along later, found a reason and then started doing it.

So I just started avoiding mold and feeling better, watching the suffering of all the people who looked pretty ill in the same places that made me ill and saying to myself, "Someday they'll want to know about this. I can see that they are hurting. It's just a matter of time. How much of this can they take before they decide to do something about it?"

Well, it was a lot more suffering than I ever thought. That was nearly twenty-five years ago.

-Erik (2008, CFSU)

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Put yourself in Dr. John Snow's place.

Back during the Great London Cholera epidemic, the mainstream didn't know about germs. Oh, they had their suspicions, but it wasn't "proven."

But John Snow could see the effect.

People who clustered around a certain public water source were dropping like flies.

He didn't need to nail down the precise etiology to make that connection. He didn't have to prove anything to take advantage of the phenomenon which he could clearly observe.

By acting in accordance with the reality that sick people obtained water from that well, and persuading the city officials to put a lock on the pump handle, he interceded in the effect and stopped the chain of cholera transmission.

He wasn't validated until later, after science caught up with what was, after all, a very simple observation.

At the beginning of the CFS epidemic, I saw that people who were in the presence of mold were dropping like flies. I told everyone about it, but they said that mold had been around forever, so this couldn't be right.
While they stayed in the presence of mold and continued to manifest symptoms, I simply acted in accordance with the effect and asked doctors to find out why.

They refused, for exactly the same reasons that the mainstream doctors argued with John Snow.

"If we don't already know it, then you can't prove it - and we aren't going to do anything until you can prove it."

-Erik (2008, CFSU)

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People wouldn't believe Pliny the Younger's description of pyroclastic flow as Herculaneum was engulfed by the eruption of Vesuvius.

They couldn't conceive of any mechanism for how his words could make sense. Some translations even leave out Pliny's description to spare his posthumous embarrassment.

Oops! Turns out his description was right.

So now volcanic eruptions which contain pyroclastic flow are called "Plinian Eruptions." Couple thousand years too late for him to enjoy being validated, but better late than never.

-Erik (2008, CFSU)

*

It is a peculiarity of human epistemology that a "cause" often has to be conceived before a strategy based purely on "effect" is put into action.

The "Semmelweis Situation" illustrates this clearly.

Even after Dr. Semmelweis demonstrated the clear effects of medical prophylaxis, his hand washing program was still rejected by the medical profession since the direct relationship of bacterial infection to infant mortality had not yet been established.

During the Incline Village CFS debacle, some of us took evasive action based on what we could feel, while others argued that our tactics had no basis... and refused to even try.

Knowledge of XMRV or any other pathogen was not necessary to exploit this effect. It existed, and for some of us, that was enough.
Trouble is, when people cannot conceive of a logical explanation for the effect, they tend to act in defiance of all the clues which show that this is not a good idea.

-Erik (2010, CAA)

A FLAWED PARADIGM

I used the Whitcomb’s Area Rule of supersonic flight as one example of how "helpful people" become the enemy of the real paradigm.

Everyone who thought it made sense to improve aerodynamics by making an aircraft sleeker were actually adding to the problem. There was no convincing them that this had already been tried. Their answer was to try harder.

Whitcomb went the other way and broke all the rules by reshaping the aircraft in a manner that would never occur to the people who kept reinforcing the wrong concept.

They keep trying to jam a square peg into a round hole.... and to just "try harder.." doing the same thing.

That is the danger of being educated into a flawed paradigm.

They are much too entrenched to see when the entire basis needs to be reexamined.

-Erik (2009, CAA)

SERENDIPITOUS CLUES

I am completely aware that I am lacking in diplomacy and skills of persuasion.

All things considered, is this a matter where patients should be forced to resort to this kind of appeal?

What happened to scientific investigation of serendipitous clues?

-Erik (2008, CFSU)

*
You never know who is going to have that incredible mindset that can see things that nobody else can and understand that there is more to the equation.

All one can do is put out clues and try to attract such people, because they are the ones who really move things forward.

-Erik (2008, CFSU)

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I realize that doctors can simply walk away from any number of patients who repeat the same clues, over and over.

This is why I agreed to become a prototype for a new syndrome, later called Chronic Fatigue Syndrome.

The instant that I said yes to Dr. Cheney, my mind was thinking, "Now they will have to look into the mold. They cannot very well have a prototype for a syndrome running around with an unexplained complaint like this."

Much to my surprise, they not only could but did.

And that is when I began collecting rejection slips.

Twenty-five years worth of them!

I hit just about all the “name” researchers.

Lost count after about three hundred.

Just for the heck of it, and so I could say I did so, I even contacted Prof. Simon Wessely and Peter D. White.

And I do have records of their unresponsiveness.

-Erik (2009, SevereReactor)

*

A crime investigator will take clues from wherever clues are to be found.

If a murder victims scrawls the name of his murderer in his own blood, a detective would probably consider it significant.

A doctor would say this is not fit evidence, because it hasn't been peer reviewed and wasn't written on fancy stationary.
I should have been able to write this clue on a rock with a piece of charcoal and still have had it penetrate their minds, for in the end it is the meaning that counts.

-Erik (2010, SevereReactor)

A SIMPLE STATEMENT

People often go into attack mode before stopping to consider whether it might just be a simple statement of what happened.

A really good example is the Wright Brothers.

The director of the Smithsonian Institution, Samuel Langley, who was working on his own flying machine, was so jealous that using the clout behind the institution, he tried to convince the world that his machine would have flown if it hadn't crashed.

And it was his "Aerodrome" that was hanging up in the Smithsonian.

Orville Wright was not allowed to present his side of the case, as he was "obviously biased" by his own claims.

You would think that with something as straightforward as "Fly / No Fly," it would be impossible to slam down the Wright brothers for several years. But it happened.

It just blows you away, that scientists are not quite like you believed they were.

-Erik (2010, SevereReactor)

ON THE FRINGE

Scientific progress always starts with an individual who makes an observation, creates a new hypothesis, and constructs a test that was heretofore untried and untested.

When a phenomenon is unknown, that new hypothesis is always on the fringe.

While chasing down every hypothesis that anyone constructs may often be a waste of time, there is historically always that one time when it was not.

The fact that most theories are a waste of time is not a scientific argument that can be used to dismiss the necessity of examining "fringe" theories. The criteria that determines follow-up is whether the hypothesis fits the facts and is not contradictory to the body of knowledge in the field.
As long is this principle is upheld, breakthroughs will always be found on the fringe.

There is probably no single human who has enough of a grasp to embody all the known factors and variables so it is unlikely that any hypothesis can begin from a position of total congruency.

It is necessary to progressively compare the hypothesis against the known facts to make sure it fits what is known until it either addresses the phenomenon or can be ruled out.

Most researchers have a tendency to confirm their hypotheses by simply ruling out anything that doesn't fit as meaningless or a separate phenomenon. This has even led to the bizarre situation of the very people who were used as prototypes for ME and CFS being discounted or dismissed if their experiences do not fit the proposed hypothesis of the particular researcher.

Dr. Cheney gave me a good lesson in the scientific method and relevance of statistical analysis. When the scientific community seized upon Chronic Epstein-Barr Virus as the cause of CFS, Dr. Cheney was "on the fringe" because he recognized that CEBV did not fit the facts. So he tested this hypothesis by searching for individuals who had the concurrent signs and symptoms peculiar to the illness who did not have EBV, until he found nineteen of us to demonstrate his hypothesis that EBV was not necessary to development of the illness.

Dr. Cheney's observations were that EBV did not have the known pathogenesis to cause CFS and he set out to prove it. Even though this was accomplished by statistical exclusionary evidence, this was only a compelling demonstration. The mere fact that EBV did not fit the facts should have conveyed to researchers who were not on the fringe that the EBV model was flawed - but it did not.

To them, the simple fact that it was present satisfied their statistical model. Not so for Dr. Cheney. He did not even require any EBV negative individuals to reach his conclusions. Indeed, even if every single person with CFS had EBV, it would have made no difference to Dr. Cheney since he know that EBV lacked the known pathogenesis to fit the facts. Dr. Cheney's methods opt out of the rigors of statistical analysis under those circumstances when statistics do not apply.

The conclusion is the EBV is not the cause nor even complicit as a significant factor in CFS. Dr. Cheney knew this before "CFS" was created and yet others who do not understand his methods still debate EBV as causative for CFS.

Instead of adopting the expedient of ruling out individuals who do not fit the known facts, Dr. Cheney continually searches for a unifying phenomenon that does not require the presence of factors which are known to be absent in some illness sufferers - and is also in agreement with the manner in which the phenomenon is known to spread.
He taught me that statistical analysis is meaningless in the face of hypotheses that do not fit the facts - and he proved his point.

I suppose that is why Dr. Cheney remains on the fringe.

Because that is where the answers will be found.

-Erik (2005, CFSExp)

LISTENING TO PATIENTS

All of us think back: "Could I even describe this to the person I was, before it happened? Would I believe it?"

Hard to say, this is so far out of the normal human range of experience.

But we can see that even good doctors are struggling to wrap their heads around it.

The problem is that when it goes through their filters to another doctor, it loses something each time it is re-translated.

We need to have "parties of the first part" describing this to medical students, researchers, and the public.

And when the helpful doctor sitting next to them has an opinion, it is the patients’ description which should carry more weight.

-Erik (2010, CAA)

ENVIRONMENTAL IMPACT

The rash arrogance with which gene-altering environmental experiments have been unleashed upon our eco-environment is not dissimilar to the cavalier negligence of giving a small child a hand grenade to play with.

-Erik (2009, WPI)

*Methicillin Resistant Staphylococcus Aureus (MRSA) didn't come from nowhere.

It came from people who were treated with Methicillin that didn't get all of the bad bugs.

The strong survived, and now all of humanity has to deal with them.
If the prime cause of the immune dysfunction is not being addressed, therapies which just target opportunistic infections tend to wipe out the most susceptible organisms. This opens up a niche for the resistant and more aggressive strains.

Short term gain.... for long term pain.

-Erik (2010, CAA)
Chapter 60 - Doctors and Mold

BRAINWASHED

In 1999, a coworker I educated about mold had put a truck for sale.

A guy showed up to look at it with a Hazmat suit in a bag, which he put on before test driving the truck.

He said, "I have to get a new vehicle because something in my house is making me sick. It's gotten in my truck and is on my clothing too, so when I get a new vehicle, I don't want it to ruin it."

My friend said, "I know just what you are talking about. You really, really need to talk to my friend Erik about his experience with mold."

Amazingly, the answer was, "I thought it must be mold, but my doctor tells me this is impossible, so it must be formaldehyde or some chemical."

My friend said, "That's what all the doctors are saying, but it really is mold despite what they believe. You really ought to contact Erik. I can give you his number."

But the guy said, "No. That was the first thing I checked into, and it absolutely cannot be mold."

I have a bunch of stories about people who pointed at mold first, but the doctors brainwashed them out of it.

-Erik (2006, SickBuildings)

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Doctors cannot help but treat what they know as fairly definitive. The information they were taught is supposed to have been the state of the science. Anything that challenges their paradigm is rendered suspect.

Amazingly enough, the less one knows about mold science, the easier it is to act in accordance with one’s animal instincts.

When doctors told me unequivocally that my mold complaints were unheard of, unknown, and physically impossible, they did me the favor of demonstrating that this type of reactivity is so far removed from their base of knowledge that nothing they said about it could be trusted.
As more people become aware of mold reactivity, they tend to develop concepts which almost-but-not-quite seem to fit the facts. Many of these "truths" are so compelling that people will incorporate them into their "reality" and try to force their experience to fit their beliefs.... rather than the other way around.

Even when they feel terrible in a place, if a doctor's test comes back negative, they tend to act in denial of their own senses.

When Dr. Shoemaker saw that my mold avoidance strategy was far beyond what one would expect from someone who wasn't wildly reactive, he demanded that I be tested for HLA susceptibility. He even paid for it.

But I told him that I didn't give a damn what the results were. If his test told me that I didn't have the double dreaded gene, this wouldn't change the intensity with which I am forced to avoid mold and would just prove to me that the test wasn't addressing the correct paradigm.

-Erik (2008, CFSU)

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All doctors tried to talk me out of mold by pointing out that I had moved many times. It's a good argument, and works on most people.

I did a couple of things differently. I trained myself to perceive mold on a moment-to-moment basis and made a concerted effort to get the stuff off me before I was upregulated.

This wasn't a quick "Shazzam! POOF, CURED!" deal. It was just a direction to "push" in, because it seemed promising.

The harder I "pushed," the better I got. (And the more doctors pushed back.)

I thought that pictures of myself on Whitney would bring pause to their stubborn denials, and yet this launched them into the strongest frenzy of denial imaginable.

So I wouldn't count on doctors. Even as they claim to be mold experts, the context in which they place it actually creates a mindset where, "If you moved, and that didn't help, then your problem cannot be mold, because moving would have helped."

I already told Dr. Cheney at the beginning of CFS that I was far beyond that stage.

-Erik (2008, CFSU)
DOCTORS WITH MOLD ILLNESS

One of the interesting and somewhat disappointing facets of this shift of reported effects from mold exposure is that sick physicians place themselves at much higher risk than patients by coming out of the closet.

It is a sorry testament to the dysfunctional process of medical discovery that those who dare to speak up about unfamiliar paradigms make themselves a target.

Their own colleagues and fellows find it far easier to simply discredit the evidence than to make attempts to verify it.

The physicians and medical professionals who have contacted me always begin their conversations with the request that they remain anonymous.

Considering the response I've had to my story, I can't blame them.

-Erik (2007, IAQ)

MOLD DISMISSAL

Mold survivors speak of "mold toxicity" and those who have never experienced it answer from their underlying conceptual framework of "allergy."

You say, "My house is killing me" and people respond as they would to "My job is killing me" or "My curtains and drapes don't match my furniture, it's just killing me."

The more you try to explain that you are serious and this is not an exaggeration, the more they protest that it is an exaggeration because "mold doesn't hurt anyone in the way you describe."

For whatever reason, mold is doing precisely that these days. The denial response I refer to is the stunning incapacity to reshape that view and respond with words commensurate with the severe characteristics that mold is now manifesting.

What's worse is that in some kind of attempt to humor sufferers, many doctors say that they do understand. It takes examination of their words, therapies, and actions to show that they don't.

-Erik (2007, IAQ)

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It seems to me the real problem is that a great many people who are being made ill in the presence of mold point at specific species which are known producers of mycotoxins, ask for help in finding out why this horrible thing is happening, and instead of receiving assistance are being told, "You aren't saying it right."

People often lead into their quest for help with the simple straightforward phrase, "My house is killing me."

And the response is usually something like, "That's impossible. Houses don't 'kill' anyone. You can't say that. You're not saying it right."

The rejoinder is, "Okay, then it's something in my house, but it is killing me, and I think it might be mold."

And the debate rages: "Houses don't kill, and mold is just an allergen, so you are wrong on both counts. You're not making any sense."

"Yes, I am. My house is killing me, killing me, killing me. Why won't you listen?"

"I will certainly listen when you begin to make sense. If you want to say that you intensely dislike your house and that your allergies are bothersome to you, then we can begin to talk. But as long as you make nonsense remarks, there is nothing to discuss."

"If I were to say that this was just bothersome, then you would believe me, but that wouldn't describe what is really happening. I am saying it right.

"It is killing me, as in death, dead, corpse, mortality, pushing up daisies, passed on, fatal, terminal, dead! Is this not clear enough?"

"You're just being hysterical."

Everyone who has been through the toxic mold experience recognizes this kind of conversation.

I reckon that's why somebody chose that phrase for the title of his book.

-Erik (2008, IAQ)

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I totally agree that Koch's postulates have been found inadequate to address many etiological entities.

Regardless, it still doesn't make sense to most people when a doctor or IAQ specialist who subscribes to Koch's as a standard attempts to use lack of fulfillment of Koch's postulates as a reason to dispute mold illness.
From a layman’s perspective, the repetitive demonstrations of illness exacerbation in response to an identifiable substance inherent to a microorganism would still meet Koch’s litmus test of scientific reproducibility.

The mold sufferer is left wondering why any person who resorts to this argument mysteriously appears to be grasping at semantic straws as an excuse to avoid coming to grips with reality.

-Erik (2008, IAQ)

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A friend who was working as a receptionist in a local doctor’s office was made ill by mold and wound up in the hospital coming apart at the seams. The hospital doctors could find nothing wrong with her.

After a short time of being away from the bad place she recovered enough to start going to allergists and immunologists, who similarly couldn't find any reason for her level of illness.

I gave her a copy of Mold Warriors, laid out the whole thing, reminded her that she had been a witness to my entire story, and had her take a copy of the book to her doctors.

They gave it back to her, pumped her full of prednisone and told her to rest for a couple of weeks.

She did, was feeling somewhat better and tried to return to work.

I said, “Probably make it about one week and that will be it.”

She lasted almost two weeks, fell apart again, and was forced to retire.

So we have a patient who has witnessed the entire phenomenon in another person, had been told that the reason she became ill whenever she was at work was from mold, physically had the book Mold Warriors in her hands...and still couldn't get due consideration brought to bear upon her biotoxin illness from the medical profession.

-Erik (2008, IAQ)

TREATING MOLDIES

Recovery took a long time and a lot of avoidance. If I gave people the complete rundown on everything I've done, it would sound so daunting that they probably wouldn't feel able to try it.
This is a very difficult strategy to attempt on your own. That's why I was trying to get doctors interested.

They could set up the right conditions for a patient, somewhat the same as what Dr. Rea has done in his Dallas Clinic.

Unfortunately, this takes a much longer than most people can afford to stay under his environmental control.

You would think that doctors would be taking note that there are more and more of us who are forced into avoidance lifestyles.

They can't just keep dismissing this forever, at the incredible rate this problem keeps increasing.

It's strange that they would even try.

It's as if they don't dare admit to themselves that this is really happening.

That's a luxury that sufferers don't have.

-Erik (2006, Locations)

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Years ago I was trying to interest the director of a CFS clinic in Reno in the mold connection to CFS and wound up diagnosing him and his wife with mold illness.

They had it in their office and had noticed that everyone who spent too much time in one certain room would fall apart.

The doctor turned that room into a storage area and forbade anyone to spend any longer in there than was necessary.

Yet the doctor found that the difficulty in conveying the importance of mold avoidance to people was insurmountable and pretty much sticks to selling his remedies.

Even if doctors know about mold avoidance, they are very reluctant to point to this as a therapeutic intervention.

I can see their point. It opens up a huge can of worms.

So it looks like it is left up to the "Extremies" who are doing it to talk to others who might be thinking of going this route.
PRACTITIONER CONVERSION

Considering that the medical literature in the US doesn't even have any record of trichothecene "mold illness" until Croft et al 1986, and that now mold hysteria is running rampant, you'd think that doctors would be concerned about the increasing prevalence and perhaps try to find out what is going on.

Since more and more doctors who never gave it a thought before are gradually bringing hints and mentions of mold into their lexicon, perhaps some day they'll get serious about investigating it.

What is really funny is to find that doctors who formerly charged you for their advice that mold is harmless are now charging for their "expertise" in dealing with harmful mold.

If their former viewpoint is listed in your medical records, do you think there is the slightest chance you might get an apology... or a refund?

DOCTOR VISITS

In 1998, I had pretty much given up on mainstream doctors and was going to alternative practitioners.

I described that I could feel cross contamination of mold on my clothing after just walking through a spore plume and said, "I can feel it on my jacket right now. I take off my jacket and my exposure is reduced. I can even feel my heart settling down a bit from just taking off my jacket."

The practitioner said, "What is really happening is that by taking off your jacket, you are symbolically freeing yourself from the burdens you have taken on during the day. You need to take deep breaths and learn to free yourself of stress without relying on symbols."

I said, "What? What are you TALKING about? It's mold, damn it. It's on my jacket. I can feel it. I take off the jacket and I get away from some of the mold that I am reacting to. Is that so difficult to understand?"
But of course, like everybody else, he thought that mold reactivity was impossible.

-Erik (2005, SickBuildings)
Chapter 61 - Dealing with Doctors

CFS PATIENTS

Three years ago, I overheard a doctor joking to another about an attractive lady with CFS and how it would be easy to get her in bed because, “That's where she likes to be.”

When the second doctor asked about symptoms, the first said, "There's nothing wrong with her. She just has chronic EBV."

I wish there were a website where everyone could list these experiences, so you could click on a doctor’s name and find out what to expect.

-Erik (2001, CFSExp)

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I've seen doctors and dentists go into brainlock disbelief at their "crazy" CFS patients’ over response to anesthesia.

No matter how many times CFSers warn them in advance to cut down on the dose because they cannot tolerate normal levels, the doctors are equally amazed and treat every instance as a fluke - and keep right on using the normal dose on the next CFSer.

This reminds me of a support group meeting where we were all discussing a certain doctor and discovered that he had told each one of us that he had never seen any other patients who had our complaints.

Can he say that to all of us when we were all in agreement on our description?

-Erik (2008, CFSU)

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I heard so many times in support groups, "I didn't say anything to the doctor, he can keep his opinions. I just left and found a new one."

And heard later from doctors, "Well, they just stopped making appointments, so my treatments must have helped or they would have kept coming."

-Erik (2010, CAA)

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Twenty years ago, I proposed that whenever someone tries out a new doctor, as many members of the local support group as possible should go and pack the reception room, all armed with stacks of evidence.

The patient who made the appointment should carry a tape recorder and tell the doctor that due to short-term memory loss, he needs this device so as not to lose a second of his precious medical advice.

Let's see how determined they are to push you out with a psychiatric diagnosis when there are witnesses and a record of the proceedings.

Naturally, my proposal was rejected. "We don't want to anger the doctors."

But we see what the results have been of playing nice, so what is there to lose?

-Erik (2010, CAA)

**GAINING ACCEPTANCE**

With all the millions of words that have been put into asking people to consider the medical evidence and believe that CFS exists, how many times did you ever see someone go, "Oh, yes, now I understand" and start really acting like it?

I can't recall that I ever have. Not even once.

The only way that effective belief seems to be instilled is when someone watches a close personal friend or relation get smashed down by this illness, and it finally starts to sink in that all those millions of words really do mean something.

If anyone can find so much as a single doubtful person who was persuaded into CFS belief by "advocacy" and not by witnessing personal destruction of a shattered life, I'd be glad to hear about it... for this is something I've never seen.

-Erik (2009, CFSKnowledge)

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I did see a doctor who changed his mind after many years of laying out CFS abuse to many local people.

So I just had to ask, what was it, after all the many years of CFS groups, magazines, evidence, Congressional testimony, etc, etc.?  

What was the key thing in finally turning his head around?
His response was, "There are just too many people with this. Something is wrong."
Like voting an entity into existence through sheer numbers, evidence be damned.

-Erik (2009, CFSKnowledge)

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I work in a doctors’ world and have watched how they respond to advertisements on new technology.

Their behavior is a real eye opener.

Do they weigh the merits of the new technology and make up their own minds like the individual thinkers they claim to be?

They like to say they do, but this is not how it works at all.

They look around to see if some doctor they respect is using it.

Whatever they may have suspected about the new material is not what motivates them to make the actual purchase and use it.

It is finding out that some fearless leader has made up his mind that makes up their minds for them.

No matter how much they admire the new stuff, 99 doctors out of a hundred will not act until they see one of two situations.

1. A doctor is using it whose brilliance they do not doubt.

2. The other 99 doctors are already using the new stuff.

That is why manufacturers pay such high retainers to get a name doctor to act as spokesmen. His word is more than persuasive... it is the clincher.

Once the product has reached critical mass, it takes on a life of its own.

But getting there is the hard part.

-Erik (2010, CAA)

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Doctors like to bask in the reflected glow of science and technology, but they are no more likely to research a new paradigm than a car salesman is likely to design you a new type of car.

Doctors are following the manual, and any deviation from the status quo earns them the derision and censure of their colleagues.

We have seen time and again that any doctor who is the first to identify anything is the first to be crucified by his own peers.

For the first dentists to reject mercury, taking a public stand to protect their patients was a major stumble in their career path as both their fellow dentists and the ADA threatened them with loss of their licenses if they didn't retract their statements and adhere to official policy.

With this in mind, consider that the qualities of mycotoxins are known to those researchers who are in pure research, which is not applied to the medical field yet.

The scientific disconnect occurs at the bottleneck where it becomes time to interface this knowledge with the political and economic consequences.

For example:

> Retired Gen. Tommy Franks is warring these days against mold. The former commander of U.S. Central Command at MacDill Air Force Base has partnered with Tampa's Innovative Decon Solutions to pitch a cure for "sick building syndrome," that is, structures infested with mold and other contaminants. A nontoxic decontamination chemical developed by the military to neutralize chemical warfare agents in the Gulf War is now licensed for civilian use.

Now, it is fairly obvious that the military, for a long time, has possessed a great deal of knowledge regarding mold toxins. It must have, in order to license a product for civilian use to treat a problem that doctors don't even believe is a problem yet.

Why wasn't this knowledge imparted to the medical community or to the public before?

Apparently it wasn't until now that they believed that the economic benefit outweighs the political and social ramifications

-Erik (2006, SickBuildings)

“SERIOUS-SOUNDING” NAME

Professor Leonard Jason’s De Paul University study of medical students’ attributions of illness severity corresponding to different illness names for the same symptom set
indicates that selection of illness names does indeed influence the perceptions of practitioners.

http://www.cfids.org/archives/1999/1999-4-article04.asp

This is taken as evidence of the necessity to abandon the trivializing "CFS" in order to induce a serious response from physicians.

Many CFS patients in the USA had hoped that the medical name of Myalgic Encephalomyelitis would inspire the appropriate response from doctors, as it had induced a more serious illness attribution in Prof. Jason’s study.

The difficulties ME patients are having indicates that even this "serious sounding medical name" has not had the desired effect.

The variability in the medical students’ response to the same illness presentation described in Prof. Jason’s study and the general practitioners’ psychological misperceptions of IBS, which are only now being corrected, point to the source of the more fundamental problem.

General Practitioners are influenced more by belief systems than symptoms.

If the medical students in Prof. Jason’s study assessed severity according to the illness presentation rather than correlating the severity to the name, the symptoms presented under the different names should have resulted in the same diagnosis.

While I agree that changing to a more "serious sounding medical name" may indeed influence suggestible doctors, I would like to point out that people seeking the cause of their pain don’t bring medical names along to convince the doctors of the illness severity.

They bring their symptoms.

If the physicians were responding in an objective manner to the illness presentation, the name should not have made a difference.

-Erik Johnson (2004, BMJ)

PROGRESSIVE PRACTITIONERS

Prior to the Incline Village debacle, I got to witness a slight precursor of the medical mentality that protects and prolongs status quo "statistical thinking."

It was a dentist who saw the implicit contradiction between declaring mercury to be a completely safe substance for use in amalgams and the fact that the handling
procedures were for a toxic waste hazard. He refused to use mercury amalgams and started advertising "mercury-free dentistry."

Naturally, this represented a stark philosophical break from all other local dentists, some of whom felt this cast their use of mercury in a negative light. He was threatened, was reported to the dental boards for not operating within the "accepted standard of care," and was even threatened with loss of his license.

Politely explaining that the toxicity of mercury is self-evident had no effect. In fact, it didn’t even matter, for this was not the real problem.

This was all done by "good doctors" whose actions were considered perfectly acceptable and correct. Whether mercury was toxic or not had little to do with the matter.

His crime was for doing something that made sense, but was different. He was making the others look bad. And for that, he had to be punished.

Over the years, what was wrong became right. Now the very same doctors who did the suppressing are avoiding the use of mercury. Yet they feel no qualms, not even a twinge of remorse for what they did.

I started looking over the history of how the medical profession responds to paradigm shifts, and found that this is not the exception. It is the rule.

And in all cases, the shift in paradigms was never successfully prosecuted by asking people to respond to the evidence. It was by making them look stupid by for failing to do so.

-Erik (2008, CFSU)

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The stress theory kept doctors from discovering the connection between H Pylori and ulcers for over a century.

The funny thing is that back in the early 1960s, some doctors in hospitals had noticed that some patients who were receiving antibiotics for various infections had their ulcers go away. They started treating ulcers with amazing results until the word spread and they were forced to quit this "inappropriate misuse of antibiotics, since everyone knows that stress is the cause of ulcers."

The powers that be figured that these doctors were just exploiting the placebo effect. They were so certain about the stress theory that they never bothered to test the patients to find out if a bacteria present in the ulcers had mysteriously vanished after antibiotics.
In retrospect, it's pretty easy to see that elevated inflammation from bacteria boring holes in your intestines might reduce your stress tolerance. But they had the relationship exactly backwards.

-Erik (2008, CFSU)

REPORTING FROM THE FRONT LINES

I don't need any doctor to tell me to reduce stress or how to pace myself or how to eat better. I want answers why normal life has become abnormally difficult.

If doctors are consistently unable to provide those answers to people whose inability to tolerate normal life was acquired simultaneously or in groups, these doctors need to be made aware that they are observing a phenomenon that is beyond their capacity and should pass on this information to suitable agencies.

Usually they deal with obvious abnormalities by denying their existence or relevance and by stretching pathogenesis of many "stresses and stressors" out of proportion.

-Erik (2005, CFSExp)

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I used to work in a restaurant where the catsup was left permanently on the tables. It wasn't a problem in the winter, but in the summer the catsup would start to go bad. When a customer opened a new bottle, the internal pressure would spray catsup all over the place... which is a sign of some pretty darned unsafe catsup, even if it looks okay after the pressure has been released.

Whose responsibility is it to recognize and address the problem?

If the waitresses, who were the ones who saw it all the time, don't report it to the manager, how would he know - except by happenstance or if enough customers complain? The front line of people interfacing with the phenomenon are the ones most likely to see it.

Wouldn't it be reasonable that if the manager had any suspicions that this might be happening because a customer reported it, the waitresses would be the ones who would see it routinely and be the appropriate ones to ask? Wouldn't you expect it of them to observe that something was abnormal... and say so?

In our restaurant, the waitresses did see, they did report, and the manager took remedial action of storing all catsup in the walk-in at night.
Would it be excusable for them to have said, "I just deliver the food. It's not my job to notice anything out of the ordinary"?

If we trust the people who prescribe drugs to safely monitor their use, shouldn't we also have an expectation that they would be the first ones to go to, if there were suspicions that there might be some risks or unexpected effects? Who else would be at the top of the list?

-Erik (2008, CFSU)

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If all mechanics are baffled about a certain type of electronic ignition that they can't fix, what do they do?

Take all those cars to the junkyard?

No, they apply to the manufacturer for a fix.

They take the problem up to the next echelon.

That's how these recalls get started. Customer complains to mechanic, mechanic goes to dealer, dealer tells manufacturer, and manufacturer decides if this problem is bad enough to do something about it.

So, if a GP has a bunch of people that he can't fix, does he just say, "Not my problem, go elsewhere" and leave it at that?

Is that how doctors show their sense of responsibility for something that is beyond them?

That's not what Dr. Cheney and Dr. Peterson did. They called "the next echelon" for help.

So how many MD's called up the CDC and said, "I can't fix these people and could really use some more help with this type of problem"?

Are they "good MD's" if they are "do nothing MD's"?

-Erik (2010, CAA)

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Where would a person who was environmentally ill go first, but to their doctor?
If the spewers of environmental contaminants claim their actions are harmless, who is to challenge them, if not the doctors who have the ability to measure these effects in their patients?

During the Incline epidemic, I said to doctors, “You know something is happening. How can you do nothing?”

They said, "But I'm just a simple doctor. It's not my job to uncover an epidemic. That's for someone higher above to find out, and let us know.”

So I called the CDC who told me, "We only respond to requests made by doctors through proper channels"

Both sides, waiting on the other. Each one, using the inaction of the other as an excuse.

That is where our environment sits, as well. Polluters say that without evidence of doctors, there is no proof that they are doing harm.

And doctors say it is not their job to respond to evidence of environmental pollutants... "We just treat patients.”

They say "All that is necessary for the triumph of evil is that good men do nothing.”

But if they do nothing, are they good men?

-Erik (2009, WPI)

AN INHERENT CONFLICT

Let me tell you a true story about my blue Ford half-ton pickup.

It started overheating, so I took it to the mechanic and said, "My Crappy Ford is Steaming.”

So the mechanic hooked it up to his diagnostic gizmo's and goodyhoppers. Soon he came back and said, "Well, the spark plugs are okay. The oil is clean. The timing is good. There are no leaks in the intake manifold and the injectors are clean, the fuel mixture is correct. The cylinder head and exhaust manifold temps are within range, so there's only one thing left. It must be in the cooling system.”

You don't have to be a master mechanic and know all this stuff to get the gist of my story. I just wanted to let you know that the mechanic was really up to snuff and had thoroughly checked things out.
In fact, if you aren't very mechanical, the first thing you might think after hearing the mechanics diagnosis would be "Well, du-uh." When the radiator cap starts blasting steam from the pressure relief valve, most people immediately leap to the conclusion that the problem might be in the cooling system.

So anyway, he checked the water pump and put in fresh coolant and made sure everything was circulating properly and sent me on down the road.

It made no difference at all. I'm just cruising along with no particular heavy load or going up any steep hill and the damn thing overheats again. Dagsnabbit! My truck has CFS, Crappy Ford Steaming syndrome.

So now what do I do? (I swear to God I am not making this up.) That first mechanic was really thorough but he still didn't fix the problem. Seemed like he was as good as any mechanic, but hey, if the fix didn't work - I better try elsewhere.

So I went to a different mechanic and this one seems pretty competent. He repeats all the same tests and comes to the same conclusion about the cooling system.

"But the cooling system was checked out and everything worked."

The mechanic responds, "You can see for yourself. It ain't workin' now."

So I grudgingly allow him to rebuild the whole thing. New hoses, radiator flush, new water pump, new coolant - the works.

As I hit the road again, I sincerely hoped that this would end my problems, but something just didn't set right. Why would replacing all this stuff make a difference if the last mechanic had checked it and found everything to be in working order? Something is just not right.

Sure enough, it wasn't. I wasn't even driving up a hill. It was just cruising along with nothing in the back of the truck, no load, no headwind, not a hot day, no excuse for this crap.

Damn these crappy Fords. Why didn't I listen to my brother and buy a Chevy? (I had no choice, he had one. So I had to buy something else.)

I couldn't believe this truck was doing it again. I paid particular attention to the gauges hoping to see some pattern, some warning, some clue that would tell me what was going on.

One thing jumped out at me. As the engine started to overheat, I could hear the oil lose viscosity and the rods would start to knock and the valves would rattle. I looked at the water temperature gauge and it wasn't even hot.
What the heck? How can this be?

With my faith in mechanics draining away as fast as my radiator coolant, but with no other choice, I searched the phone book looking for an advertisement that might suggest that a certain mechanic might have some special proficiency that the others lacked.

Selecting one, probably by giving up on trying to find a specialist and just flipping a coin, I tried again. But this time I was armed with that special clue that my gauges had given me. I told the mechanic all the work that had been done and that it had made no difference in my truck's CFS. (Really! True Story).

I told him that the water had only overheated after the engine had started to show signs of being too hot. He looked at me, startled that I had dared make an attempt at self diagnosis. But he seemed to have heard me. At least his brow had furrowed when I gave him that clue so I know his ears must have been working.

But after repeating virtually all the tests that the others had done, he reached the same conclusion. "It has to be the cooling system, but since you've already replaced all the other components, you need a bigger radiator."

"What? Why would I need a bigger radiator? The one that was in there worked for 75,000 miles. Now you're telling me that even though it checks out just fine, it just doesn't work anymore?"

He replied, "You just said it yourself. The truck is getting old and the one that worked before just isn't good enough now. Ford trucks always had a radiator that was too small, in my opinion."

"But what about the gauges telling me that the water only heated up after I heard the valves and rods rattling?"

Okay, are you ready for this? Here it comes.

He told me, "That's impossible. It must just be what you thought you saw."

OMIGOD, is there no escape from this?

So I said, "We can just go for a drive and you can see it for yourself." And so we did.

Sure enough, the engine started making "hot" noises and the water temperature hadn't gone up. We stopped and opened the hood and felt the engine. Sure enough, it was hot to the touch.

"That settles it," he said. "Not only do you need a bigger radiator, but your water temperature sensor is defective too."
"But it works whenever the engine gets hot enough to make the water hot. It goes up every time. It must be working."

"Look! Who's the mechanic here! You or me? Do you want my help or not?!"

Gawd. Now what do I do? You know what I did. I did what I had to do because I had no other choice. I let him replace the radiator and water temperature sensor. But this time I was pretty damn certain that it wouldn't make any difference. What would you have done in my place?

My "mental state" as I paid for the latest attempt and repair wasn't good. I had been telling some of my friends how I was fighting with my truck and mechanics and I had been warned, "Well, don't expect a bad outcome or you will create it yourself."

Yes, I am surrounded by people who believe in the "Awesome Power of the Human Mind to Create Your Own Destiny."

I've had some pretty good arguments about whether a mind can shape reality through sheer determination. I tell them, "If the power of total focus and concentration could create reality, then that steak you just barbecued would magically levitate off your plate and right into your dog's mouth. Just look at that! Did you ever see such total focus and concentration? I think in your dog's mind, the destiny of that steak is already predetermined!"

But that argument doesn't work. "Manifest your Destinyites" always just add the caveat "It's the power of the HUMAN mind."

Oh, right, of course. Now I get it. How silly of me.

But I digress.

My mental attitude and I picked up the newly re-repaired enhanced cooling capacity truck and took it out for a test drive.

I tried really hard not to think negative thoughts though.

But I guess my overwhelming negativity was just too much for my poor old truck because the "fix" didn't fix a damn thing.

I took my Crappy Steaming Ford right back to the mechanic and said, "Listen. I'm telling you that the damn coolant is overheating after the engine gets hot. I can hear the valves rattle before the gauge moves. Everything has been ruled out except loss of lubrication. Isn't it obvious? The insufficient oil flow is causing increased friction. The increased friction is overheating the engine. The engine then and only then goes on to transfer its
heat to the coolant. Everything else has been ruled out. I want you to replace the oil pump."

The mechanic damn near went into shock. He responded, "The oil pressure is good. We checked it, of course. You're not listening to me. I'm a mechanic and you're not. Who do you think you are to tell me my job?"

I said, "You only checked it with the engine in a static run, not under load. All I know is that the progression of indicators lead to the opposite conclusion of Bad Cooling System Overheating the Engine. The gauges and the rattling I hear tell me it's exactly the other way around."

And then I told him, "I'm paying for it, just do what I say and replace the oil pump."

"You don't know what you're doing and I'm telling you it won't work. But if you're stupid enough to pay me for it, I'll do it."

When the job was done, I really had confidence in the concept because it was the only thing that made sense to me. Nonetheless, my negativity was at peak intensity when I drove the truck out for a test.

Somehow, despite my worst fears that the mechanic might have been right and that my incredibly bad attitude was going to jinx the truck - it ran perfectly.

It was only later when I told the story of my CFS truck to somebody who ran a shipping business that I learned, "We had a whole fleet of those trucks with that engine. They were legendary for doing that, and yes, that's what it was, though most mechanics just never seem to figure it out."

It might seem a little odd for me to tell a story about my experience with Crappy Ford Steaming syndrome, but I see a parallel here.

The point of my story is that this is exactly the same situation we face with CFS. The doctors aren't paying attention to the clues that absolutely rule out and contradict the way they are looking at the illness. You can go to doctor after doctor after doctor, and they all respond to their training and have few original thoughts. Maybe you'll get lucky and find one who is a true diagnostician but it's statistically unlikely. Most are just like mechanics who only take there information from a manual and if it isn't in there, it's "impossible and doesn't exist."

Though doctors like to drape themselves in the mantle of research and technology, most of them are nothing more than instruction manual followers who couldn't diagnose a stalled car with the gas gauge on "empty." If they can't find the right page in their owner's manual that tells them what the problem is, they call for help. Ask any tow truck driver how many doctors he's had to bring gas to.
Most doctors cannot recognize or elucidate the nature of a new paradigm any more than the average mechanic can design you a new car. The mechanics who never heard of Ford trucks with CFS are never going to change their attitude unless people who recognize the syndrome and the contradiction in their approach force them to do so.

Despite the inadequacy and inappropriate nature of “Chronic Fatigue Syndrome,” the public awareness that has been generated of complaints attached to that name allow people to connect their symptoms to the epidemic. Every person who "self diagnoses" because they have no other choice will see the discrepancy between the way most professionals regard this illness and their own "clues."

Calling it "CFS" literally forces people into conflict with doctors. "Why are you telling me this is ‘fatigue’? This is like no fatigue I ever felt before."

If the attitudes of professionals who interface with the first echelon of CFS can't be changed by information from the leading edge of medical technology trickling down, I propose that we start at the patient and work our way up by pointing out to everyone who seeks information on CFS that if a doctor seems to regard it as "tired," then this doctor doesn’t understand the problem and his conclusions are in total opposition to the facts.

The doctors who are trying to attach CFS to mental illness and "fatigue" haven't realized yet that this sets up an inherent conflict that they cannot win and can actually lead to greater numbers of the kind of confrontation that forces people to reassess their views.

When someone gives you a theory that contradicts your observations, you must refuse it.

- Erik (2004, CFSResearch)

FEELING POISONED

I was trying to describe my symptoms to a doctor in Truckee and made the distinction that I felt more poisoned than fatigued.

She said, "How would you know what it's like to be poisoned? Have you ever been poisoned?"

I said, "No, but I have drunk a little too much alcohol, and I'd say the sick way I felt was more like..."

Suddenly she cut me off with, "So who do you think is trying to poison you?"

I couldn't believe it. I said that I was trying to describe how I felt the best I could, and that I didn't believe that anyone was trying to poison me.
Experiences like this also convince me that you can try to describe the fatigue of CFS until you're dead and all doctors can hear is "very tired."

-Erik (2003, CFSResearch)

A PAST LIFE

I had a practitioner in Incline tell me that I needed to "look within yourself to find the cause of why you drew this into your life."

I said, "What? Who am I, Hitler? Jeffrey Dahmer? If all the evil that bad guys do isn't enough to draw CFS into their lives, what could I have done that is more horrific?"

He replied, "Maybe it was something you did in a past life."

What can you say to that?

-Erik (2009, WPI)

A BASIC PANEL

Years after the CFS debacle, I told a doctor in Truckee that I was part of the Incline Village deal so I had all kinds of evidence of immune abnormalities, but that I was looking for help with one small detail that had gone overlooked.

She ran a basic panel and, of course, found nothing notable.

She tried to tell me that this was proof that there was nothing wrong with me.

I began to explain to her about the B cell cytometry, Kappa Lambda light chain ratio, Gallo’s HBLV results and all the other stuff that Dr. Peterson and Dr. Cheney had found.... and she cut me off:

"We can run the test again if it makes you happy, but it won't show anything different."

-Erik (2009, WPI)
Chapter 62 - Fellow Sufferers

ADVOCACY

Let me tell you a funny thing about the first "CFS" meeting.

I mean, of course, the first meeting of Cheney/Peterson patients after "CFS" was unveiled.

A doctor came up to the hospital to explain our illness.

We were overjoyed, thinking that someone with specialist knowledge had been attracted by the publicity and had come to our rescue. Turns out that it was an idiot psychologizer who was only trying to promote his "You Brought This On Yourself By Bad Behaviors" b.s.

Some of us rose to smite this flapdoodle down.

We could have done it too, because he had nothing more than a lame theory and we had tons of evidence, fresh out of Dr. Cheney and Dr. Peterson’s extensive testing.

But the strangest thing happened.

There were more patients anxious to avoid confrontation than there were activist types who were ready, willing and eager to debate this doctor.

They wouldn't speak one harsh word to a doctor, but they would yell at us to sit down and shut up.

Those of us who stood to protest looked back in confusion. "Aren't you people on our side?" we thought.

"We have the evidence, why shouldn't we use it?"

This is where the divide started: the divergence between CFSers who said, "This is real and we can prove it" and other CFSers who would echo the unbelievable words, "There is no test for CFS."

One group is advocating the reality of the illness, while the other says we may as well abandon "CFS" because it is nothing more than a description.

Same room full of patients. Totally different conclusions.
The two sides use the name CFS, but are pushing in totally opposite directions.

The "Evidence CFSers" have a tough time joining ranks with the "Description CFSers," because thinking of CFS as being nothing more than the description is taking the teeth right out of the dog.

He can growl, he can snarl, he can put on quite a show... but without that evidence, he can't bite.

Put the evidence back in, and now you've got a pit bull.

If the majority hadn't thrown a leash on us, we could have chased that doctor right out of there.

-Erik (2009, CFSKnowledge)

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Dictionary: 
"Advocacy"  
–noun, plural -cies. 
the act of pleading for, supporting, or recommending; active espousal: 
He was known for his advocacy of states' rights.

Advocacy is an irrelevant concept for CFS.

It does not apply here.

It's like trying to sail around the world with a crew of Flat Earthers and prevent them from turning the ship around.

No amount of asking, pleading, supporting, recommending or active espousal of the fact that it's okay to keep going is going to change anyone's mind.

You can ask a Flat Earther a million times, and each time is just as ridiculous to them as the last.

Unless you can pin them down, teach them geometry, astrophysics and planetary motion, then show them Eratosthenes’ little trick with measuring the angle of the sun at two different points during the summer solstice.... the evidence of their eyes is not overruled and they have no mental means to even try to believe you.

It even seems anti-scientific, to a Flat Earther, to suggest that sticks, shadows, and the rays of the sun can tell you that the earth is round and the circumference can even be measured.
Very few people have actually bothered to reproduce this experiment. Even now, most of us couldn't.

The way "Round Earthness" seems to have been accepted is not because every single person learned how.

It's because "Flat Earth" became a token of provincial ignorance.

Nobody likes to be a provincial pinheaded fool who subscribes to outdated information.

This is the key to unlocking doctor brains.

CFSers need to approach doctors as a Round Earther would talk to a Flattie.

This is the mindset CFSers need to adopt:

"The evidence is out there, smart physicians have demonstrated the existence of this phenomenon, and it is not up to you to doubt it."

Think about it for a second.

Asking a doctor to believe is like asking for his opinion.

Telling the doctor that his opinion has been rendered obsolete is the best way to kick start him into finding out if "smart doctors" really know something that he doesn't.

No paradigm shift was ever successfully prosecuted by nicely asking people to believe it.

It was by making them look like fools if they didn't.

-Erik (2009, CFSKnowledge)

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By politely allowing these wrong-headed theorists to enter right into the heart of CFS groups and promote their nonsense with total impunity, the lack of resistance makes it appear that CFSers are not in substantial disagreement with these concepts.

It would be like giving a Flat Earther a place at the table in a cartographer's convention. Or letting a person who believes the earth is the center of the solar system "help" direct the Hubble space telescope.

Anyone who thinks about the situation for a second must realize that the wrong thinkers will certainly never leave, as long as they are allowed to remain.
One would think that there would come a point that CFSers would have finally had enough and tell these theorists, "You have no place here. Get out!"

-Erik (2009, CFSKnowledge)
Chapter 63 - Loved Ones

BLAMING THE PATIENTS

Has there been any illness in history that wasn't completely or partially ascribed to personality defects or psychological disorders until identification of a precise etiology silenced such speculations forever?

Psychotheorists seem to have little compunction about waiting for physical evidence before they try on their theories to see if they fit. This has caused each emerging illness to go through a "blame the patient" phase in which victims of illness are guilty until proven innocent of mental defects or behaviors that caused or contributed to the illness.

People who are guilty of nothing except being sick cannot change their attitude and get better, and they then have the charge of “obstinate” laid onto those of “hypochondria and malingering.”

This almost inevitable phase virtually guarantees that support from family and "friends" will be withdrawn in the same way that people are told to help an alcoholic by withdrawing all help so they can “hit rock bottom and be forced to recognize and deal with their dysfunctional behavior.” Sick people are abandoned with official sanction!

This climate of psychologizer induced patient destruction is only ended when the etiology of the so-called mental illness has been unquestionably established. Yet for all the damage this has caused, those responsible have never been called to account for their abuse and the process repeats itself for the next emerging unexplained illness.

When will promoters of psychological concepts learn from history and be given pause by their legacy of damage?

When will society see the injustice and hold the perpetrators responsible?

-Erik Johnson (2004, BMJ)

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My family wrote me a letter in which they said that my absolute unwavering insistence that this was a real illness was a sign that the best way they could help me was by withdrawing any further support that would enable my negative behaviors and plunge me deeper into my illness delusions.
They proposed that the best thing they could do would be to toss me out, allowing me to hit bottom and live or die by my own decisions.

And so they did.

-Erik (2005, CFSExp)

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The first person I saw who described this illness to me perfectly was in 1980 down in the South Bay Area, not too far from Silicon Valley.

Five years before I saw it sweep through Incline.

It wasn't the illness that was unbelievable, it was the response of people around her. I saw people choose what to believe and completely ignore her physical appearance and everything she said.

She obviously had no name for this, but different people could look at her and the reaction ranged from "obviously ill" to "can't prove it."

But I was there the day she hopefully went to a doctor who had seemed sympathetic and returned home in tears, totally devastated.

She told us that the doctor had diagnosed her with "Doctor Seeking Behavior," a mental illness in which people wander endlessly from doctor to doctor trying to obtain validation for their imaginary complaints.

The doctor said, "She believes her illness is real and the worst thing you can do is feed into it by validating her."

And then a peculiar thing happened. Those who had been believers and said the illness was "obvious" showed no backbone to their beliefs and went mentally limp, while those who tended to the "can't prove it" went wild in their righteous condemnation and denial - totally confirmed by the Godhood of Doctordom.

I just about lost it and yelled, "Look at her. Look at her."

Here's where it got interesting. The few who had initially supported her stood silent while the denialists showed the greater fortitude and focused all their "if the doctor says" BS on me.

Nothing less than a baseball bat was going to alter their opinions, and since I didn't want to go to jail, there was nothing much I could do.
But a silent rage built up in me, and I said to myself, "If such a thing should ever happen to me, they wouldn't do that to me. I wouldn't let them! For there must be a lower threshold to stupidity that even these people cannot descend below. It would be impossible to watch an athlete be overcome in such a way and reach that ridiculous conclusion. To apply something like that to someone like myself would be too far beyond the pale, even for idiots like these."

And then it happened to me!

-Erik (2006, CFSExp)

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I have encountered a few cases of "SBS" over the years. Sick Boat Syndrome!

Seven years ago I stepped on board a classic wooden yacht in Santa Cruz and got slammed - so I stepped off just as quick.

With all the severe condensation problems and difficulty cleaning the hold, boats can be pretty scary.

When I started asking the owner about any peculiar health complaints, he told me that he did have a strange problem that somehow seemed to be associated with the boat.

He said that he had married the most terrific gal. They had been friends for years and she had a terrific personality.

She was everything he could have asked for in a sailing mate... until right after she moved on board.


Not only that, but she physically fell apart too.

Strange illnesses and infections, weakness, fatigue, photophobia, migraines, rashes, temperature intolerance....

"She turned from my dream girl into my worst nightmare, and it started after she moved on this boat."

Finally she became so ill that she could no longer work.

She was diagnosed with Chronic Fatigue Syndrome. The doctors could do nothing at all to help.
Even beyond that, her complaining had become incessant and intolerable.

"Just a constant witch."

The doctors had told him that her problems were mental illness.

He said that it must be true and that somehow the "closeness" of the boat had keyed into a weird form of emotional instability.

The upshot was that they realized that their life together was over and done - no longer survivable. He was really torn up and confused about it.

"I thought that I had found the perfect person to have great sailing adventures with, yet it seemed that being on a boat turned her into the total bitch from hell. We could have had such great adventures. Why would she do this to us?"

And so she was moved out - almost carried - to some relatives who took care of her in her semi-invalid condition.

After a time, her problems started to slowly go away.

The yacht owner said, "At first, I didn't even want to have any contact with her, after what she put us through. But it was strange, as if her old self started to emerge. But how can I trust it? What is to keep her from doing this again?"

Then, "This confirms that the doctors must have been right. This is proof that was the boat and that she had mental problems brought on by the small living space on board. I guess some people aren't emotionally suited to this lifestyle."

Here was another perfect example of how toxigenic mold breaks up relationships and destroys lives - and how the process is obliviously exacerbated by doctors who unwittingly put the total blame for the problem upon the sufferer.

In so doing, they cause any support or sympathy to be dismissed.

I explained that I am a "mold responder" and that the problems his wife had were exactly what would have happened to me if I stayed on that boat for any length of time.

It was amazing to watch the lights go on as I recounted example after example of what this illness does and why people act the way they do.

He was also amazed that all the doctors knew absolutely nothing about this.

He felt ashamed and remorseful for the way he had blamed his wife as a "mental case," when she had just been describing a physical reality of mycotoxin induced illness.
Everything I said resonated with this man. I could see the comprehension growing of the full burden of the injustice that had been done as he realized that everything she had described is exactly how mold illness really is.

I said, "If she manages to recover and can avoid mycotoxin exposure, there is a good possibility that she could be the person that you used to know."

But he said, "No. This was hell beyond belief. I couldn't take that chance. It's all over."

More dreams destroyed. What a senseless waste.

-Erik (2006, SickBuildings)

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When I was so sick that I was stuck in bed, my family told me that I just needed to "think positive" and brought me motivational books and tapes,

I threw the tapes across the room and said, "I'm absolutely positive that this garbage has nothing to do with my illness. Is that 'positive' enough for you?"

-Erik (2009, CAA)

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You know how in a terminal illness, there is a grieving process of "letting go" of a loved one?

There comes a point in an orderly "letting go" phase when people begin to shut down their emotional connection to the person they know is leaving them. Like there is an emotional self-protection circuit breaker in the brain.

When the grieving process works like it is supposed to, this circuit clicks off so the survivors are not horribly devastated by their loss.

I think this protective mechanism is genetic, controlled by mental neurological pathways that we have not yet identified but know probably exist, judging by the human constancy of how survivors mentally distance themselves during the grieving process.

At a certain point in our illness, our descriptions must be close enough to a terminal illness that our presence is triggering that self-protection circuit, and the compassion/sympathy centers begin to shut down.

To them, it is as if we are already dead.

-Erik (2010, CAA)
Chapter 64 - Erik: Family and Youth

MOLDE

My grandmother’s name was Marka Myklebust.

She was from Molde, Norway.

I figure that's how I must have got the mold gene.

-Erik (2006, SickBuildings)

GENETICS

When I look at my parents - who have been separated since I was a small child, but both of whom have lived in moldy places which slammed the snot out of me - I see two halves of the genetic equation.

My mother is a good detoxer, full of static zaps, but gets nosebleeds and headaches.

My father does not get zaps or nosebleeds or headaches, but does get depressed and fatigued.

Lucky me. I got all the bad stuff from both of them.

-Erik (2008, CFSU)

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I come from a farming family which used to supply hay for the US cavalry.

My granduncle, Gottleb, eschewed the newfangled methods of baling hay, as he said it this technique results in moldy hay and sickly horses.

He resisted using new farming methods, right up until World War II, much to the dismay of his brothers. But being the oldest, he was in charge and was obstinate.

From economic necessity, Gottleb went to the new methods for the cavalry. But he used the old rakes and haystacks for his own horses, which everyone said were noticeably healthier for it.

My grandmother complained bitterly about living right next to the hay barn and forced my grandfather to build her a new house.
I thought this was a bit odd, since the new house was scarcely a mile away. What was the point of going to so much trouble, yet moving such a short distance away?

I had my father take me to both places a couple of years ago, and then I got a clue.

The new one was out in the fields, and the area felt pretty good to me.

The old one was surrounded by the sensation I recognize as being from the bad mold.

I told my Dad, "No wonder. Now it makes sense why she did that."

-Erik (2009, IAQ)

CHILDHOOD

I grew up in an old hotel that had green wallpaper that was old enough to be a trimethylarsine Gosio's gas producer.

-Erik (2006, SickBuildings)

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The hotel, which was an old stagecoach stop on Sonora Pass, had this gorgeous green wallpaper whose color was absolutely mesmerizing.

Everyone commented that they had never seen such amazing color.

When I read the description of the vivid hues of the "Killer Wallpaper," I was absolutely floored.

That is exactly how the arsenic pigments are described, but the place burnt down and I cannot have it tested.

There is a bronze historic marker on the spot now.

-Erik (2009, SevereReactor)

TRUCKEE HIGH SCHOOL

I couldn't learn a damn thing when I was at Truckee H.S., other than how much I really wanted to be somewhere else.

-Erik (2008, CFSU)
My interest in "The Human Element" started when I confronted a teacher who walked out into the hallway from this conference room at Truckee High School.

She was holding her head in agony, and we all knew she had been to at least eight doctors, all of whom were unable to help her.

None of these doctors had the slightest idea why she was so fatigued, had pounding headaches, rashes, joint pain and was generally falling to pieces... and getting worse.

I felt sorry for her, as some of us knew that the building was having this effect, and tried to intervene.

I told her how many of us felt much better by getting outside for fresh air as often as possible, and that the moldy inside air was having this effect.

At first, she seemed interested in hearing our experience.

But then the strangest thing happened. She became almost angry at the concept, and at me for telling her about it.

Her initial interest suddenly switched to a haughty attitude, as she retorted, "Thank you very much, but I think I will just follow my doctors’ advice."

What advice? All they were doing was telling her to pound down more aspirin. They were utterly clueless to what this building was doing to us.

She turned and walked back into her office across the hallway. Her hand, which had dropped to her side while we spoke, clearly in an effort to hide her migraine headache, involuntarily returned to her temple as she forgot why she had lowered it.

I turned and walked out the front door for some fresh air.

-Erik (2009, SevereReactor)

This building made me sick: Truckee High School.

I stood in the hallway directly in front of the conference room and argued with a sick teacher about it.

She didn't believe me when I said how much better I felt by getting outside as much as possible.
-Erik (2010, SevereReactor)
Chapter 65 - Erik: Army

A PEANUT ALLERGY

I was fortunate enough to have had a weird experience with my commanding officer which completely reshaped my view of allergies and gave me a powerful advantage.

My captain was a peanut responder who dropped in his tracks while yelling in my face during disciplinary action - just by inhaling a few peanut molecules from a sandwich I had just eaten. It was incredible. Peanuts were harmless to me, yet the slightest exposure could drop him in his tracks.

Whoops! He got too close and it smacked him right down on the ground. And it taught me something that turned out to be very useful.

When I applied this hyper-reactive conceptual model to my own circumstances, it fit much better than the classical toxicology concepts which doctors were trying to impress upon the situation.

And when I acted in accordance with that extreme reactor model, I had demonstrably better results than the people around me, who had all the signs of dealing with a similar problem.

-Erik (2008, IAQ)

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My first thought when my commanding officer hit the floor after yelling in my face for disobeying orders was that I had made him so enraged that he'd had a heart attack.

As if that wasn't surreal enough, to have your CO suddenly drop and start writhing around, turning colors, the sergeant asked me, "What did you have for lunch?"

What? The poor guy is dying and this crazy sergeant wants to indulge in idle conversation? "A sandwich," I replied.

This seemed to make the sergeant mad, for he yelled loudly, "What kind of sandwich?"

"Peanut butter."

"That's it then," he said as he turned to help the captain, who was curled up on the floor, gasping for breath.
This was an impressive demonstration of peanut allergy.

Just a few molecules was enough to knock him out, and he never saw it coming. There was no way this could be any kind of fear-based response.

This incident shaped my view of mold reactivity.

As soon as I realized that my "allergy" wasn't acting like anything like an allergy, I remembered my captain and said, "That's it then."

-Erik (2008, IAQ)

*Many years ago, before the rash of peanut allergy problems, I was allowed to sit in, as an observer, when the industry asked to have the amount of mold material that is deemed acceptable to be raised by a factor of 10, as they were experiencing profitability problems. That increase was ultimately granted.

> I had a government scientist tell me at the time that we normally had poorer immune response to toxins than to proteins and that the first responses to too much moldy material may be an allergic response to peanut protein. He had suggested that this increase was not a good idea to the industry representatives, but was told to butt out.

> Several years later, we started to hear about peanut "allergy" and even anaphylactic shock.

> I still wonder if the triggering event for many people who react to peanuts is one of a hit from some very moldy peanut material (not all standards are met in all instances) that is then displayed as an overreaction in an allergic response.

A perfect question!

That incident I described took place in Hitler's Bunker, as we jokingly called it.

Perhaps that was why my CO had such a severe reaction.

-Erik (2009, IAQ)

**HITLER’S MOLDY BUNKER**

I got my first killer mold slam in an interesting place.

It was in Hitler’s Bunker in Giessen, Germany.
In 1975 I was in the Army, stationed in the bunker that Hitler ordered built for his command and control structure for Operation Sea Lion, the invasion of Britain.

This was a reinforced bunker with five levels below ground that were flooded at the end of World War Two. We used the buildings above the bunker.

The Germans called it Verdun Kaserne, but it was renamed Rivers Barracks in honor of Sgt. Rubin Rivers. We called it the Zoo.

I have pictures of myself trying to prepare a lance tactical battlefield nuclear missile for launch with toilet paper plugging up my inexplicable constant bloody nose.

At the time I could never understand the fatigue and inability to tolerate cold that was progressively getting worse.

Now I know.

I also know that this isn't just an indoor air problem.

I was doing my daily two-mile run around the Kaserne when I would run into a spore plume and get knocked flat. I would suddenly become unable to continue with a run that normally wouldn't even raise a sweat. I didn't know what it was that stopped me in my tracks then.

Now I know.

-Erik (2002, SickBuildings)

*  

This is why the “testing can give reliable information” concept doesn't apply to me.

I got slammed in Hitler's Moldy Bunker. Not the Berlin one, of course.

This is Verdun Kaserne - built by the Wehrmacht as forward HQ for Operation Sea Lion, the invasion of Britain.

My building can be seen to the left of the Winkelturme in the "Rivers Barracks" photos on the Third Reich in Ruins website.

http://www.thirdreichruins.com/misc_sites3.htm#giessen

When I got back to the U.S. and unpacked my stereo and belongings, I was laid out. They knocked me flat.
I was fresh out of the military as a veteran Nijmegen marcher in the best shape of my life. Suddenly I couldn't keep up with my brother on a hiking trip, and he'd never backpacked or been a runner at all!

It was just my stuff.

It was more than enough to do a number on me.

I had an intensification reaction after leaving that moldy bunker. I was only surviving there until my ACTH ran out. It was just a matter of time. The supply sergeant down in the basement was Med Evac'd back to the states with an illness no one could identify.

I didn't know what it was then, but now I do.

-Erik (2005, SickBuildings)

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In 1976 we had some of the worst rain in Germany for over a hundred years, and the basement armory flooded.

I was part of a group detailed to go down weeks after and clean out the cardboard boxes that were covered in black mold.

There was nobody down in the armory to tell us where to get rid of this shit, and I asked "Where's the supply sergeant? Shouldn't he be down here helping us?"

"Oh, he got really sick with a brain tumor or something. They think he's going to die. They med-evac'd him back to the States."

Within an hour or so, I could barely stand up. The others finally told me to get lost, since I was just about useless and just getting in the way. Looked like I was ready to collapse.

I never recovered from that.

I told the Captain (the same one with the peanut allergy) that something down below the bunker was killing me.

I speculated that perhaps some chemical agent or pesticide left behind by the Nazis was leaching out of some hidden storage area and feeding the weird mold that was growing all over the place.

He actually listened to me. He was worried. Others were sick too, but nobody was able to figure out what was going on.
People said from that point on, that I looked like I had the Vietnam "Thousand Yard Stare" and was totally burned out.

I went to see a number of doctors over the years, and nobody payed any attention to the black mold. All said, "Impossible."

After the "Yuppie Flu" hit Incline, and I saw how others were falling apart in mold zones, I figured that this was my ticket to finally get someone to listen to me about strange things happening with mold.

-Erik (2009, Email)

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The first concept I proposed to my CO was that deteriorating drums of pesticides or delousing powder were feeding the black mold in sealed subterranean storage areas beneath the bunker and releasing toxic plumes from vents that were scattered around periphery of the bunker complex.

(The bunker had several levels that were flooded by the Nazis when they abandoned the Kaserne.)

He actually took me seriously.

There were too many sick soldiers in my unit to be a coincidence. One guy down the hall died of a brain tumor.

The chem/bio unit checked the premises but found nothing.

My CO said that all we could do is wait to see if more people become ill before deciding on further action.

More soldiers did become ill, but the numbers were too few and the illness was too "random" to get any further investigation.

The qualities of this agent appeared to be neurologically disabling, and after finding that emissions could act independently of spores, I began referring to it as a kind of "nerve gas."

-Erik (2009, SevereReactor)

A STRANGE FLU-LIKE ILLNESS

I think I may have the European strain of Lyme, because of a peculiar incident that happened to me in Giessen, Germany.
I was in the Army out on field maneuvers and got the strangest "flu" I ever felt. Raging sinus infections, neuro symptoms - you know, "the works." It was really bad, but it wasn't CFS.

But when I went on sick call, they wouldn't let me go to the dispensary (hospital) because I had no temperature to go along with the "flu."

They accused me of malingering and said, "You don't have any elevated temperature at all! In fact, your temperature is below normal by a few degrees."

I asked, "Doesn't a low temperature mean that something is wrong?"

"No, we only send people in for a checkup if their temperature is high."

So I spent the next week out in the back of a leaky five ton truck in the pouring "Giessen" rain, so sick I couldn't even get up to eat. The only action the military took was to occasionally yell at me how I was going to be disciplined when we got back to garrison.

After a few days, my own sergeant could tell I wasn't faking and at least checked to see if I was still alive.

I consider this incident to be the beginning of my total descent into hell, which didn't culminate in the CFS illness until the strange flu-like Truckee Crud swept through Incline Village in 1985.

So you can understand my questions about whether Lyme requires a co-morbid infection to result in the full-on CFS/ME, drop dead, unbelievable, killer clusters of people so sick that even the stoutest denials of doctors can't bury this type of phenomenon.

-Erik (2004, EuroLyme)

**BIOWARFARE DRILLS**

The ironic thing is that I got out of the Army because I hated the constant biowarfare drills.

Being woken up multiple times in the middle of the night to don my M17A1 gas mask when the chemical alarms went off.

Having to take immediate evasive action and decontaminate.
Over and over and over.

Hated it. Hated it. Hated it.

Who’d have thought it would have turned out to be the best thing that could have happened?

When I finally figured out that low-level, almost “insignificant” seeming exposures were still having a very bad effect, my training just kicked in.

So I guess that I sort of cheated, because I didn't really have to figure it out. It was just my training.

Still, this corrected my exercise intolerance when nothing else did, so I thought that people who were studying exercise intolerance and post exertion malaise might find it to be of some interest.

-Erik (2009, Facebook)

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I sure hope that I was never exposed to nerve agent.

Our biowarfare training was with CS gas - the military equivalent of tear gas. I'm told it is just a bit stronger.

If your M17A1 gas mask has a leak, I guarantee, you'll know it, and so will everyone else.

-Erik (2009, SevereReactor)

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> This article makes tear gas sound not totally innocuous.

I heard a rumor that the military no longer conducts training with it.

Don't know if that is true or not.

I had experienced cross contamination with CS, and so when I had lingering effects from moldy buildings on possessions and clothing, I could see that it was the same situation.

The sensation was not the same, but the action of cross contamination is strikingly similar.
ARMY BUDDIES

>Have you stayed in touch with your old Army buddies?

Yes, I am in contact with some of them.

None of the ones I know are aware of any peculiar illness that might have been associated with their service.

(Although some are very ill.)

But then, I saw CFS literally disappear in Incline Village.

You can literally ask people at random about the history of CFS and most will tell you they have no idea what you are talking about... as if humans have universally agreed to mentally "oblivionize" such phenomena.

-Erik (2009, SevereReactor)
Chapter 66 - Erik: Post Army

THE BAY AREA

I met my first person with all the signs of this illness in 1980 down in the South Bay Area, not too far from Silicon Valley.

This was five years before I saw it sweep through Incline.

One look at this person convinced me that absolutely no one would make this up. I wound up arguing with virtually everyone around me that the doctors (who diagnosed her with "doctor attention seeking behavior") were out of their minds.

So I guess it's easily possible that this illness could have destroyed millions of lives right under the oblivious noses of non-comprehenders.

-Erik (2003, CFSExp)

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> You stated that the first time you met someone with the disease that later was named CFS was in 1980. Where did she live?

It was in an apartment complex, south of San Francisco Bay, that was full of people complaining of mysterious rashes, illness, and sudden deaths.

Doctors couldn't find anything wrong, and as far as I know, the concept of sick building was never even brought up, as if all of this was some kind of bizarre coincidence.

I was visiting, and the place just beat the crap out of me.

I didn't know her at all, just that her complaints had a familiar ring. When she related how badly the doctor treated her, it made me angry, because this place surely had the capacity to put me in the same position.... given enough time.

All I later heard was that she moved out and got better.

-Erik (2009, SevereReactor)

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I got slammed while on a construction project in Berkeley in 1980. It was on the UCB campus, right next door to the School of Law.
While I was feeling so lousy, a guy that I was going to meet for lunch to hear his WW2 stories walked in the front door, downstairs, apparently very chipper and feeling just fine.

Not a sign of what was about to happen.

Poured himself a cup of coffee, sat down, had a massive heart attack and died on the spot.

Since I felt bad and my heart was pounding after walking in the door, I didn't think it was a coincidence, but nobody believed me.

After all, "Mold is just an allergy, and even if his heart attack was triggered by a mold allergy, that just shows that it was his time to go because allergies don't kill anyone.”

Two other people on our crew became ill and started going to doctors.

One was a plumber, who suddenly acquired a reactivity to poison oak that he hadn't had before. The other was an electrician who started feeling tired all the time and became so reactive to wheat that his doctor told him that he had to give up all sources of wheat... including beer, which sounded to me like a fate worse than death.

I just couldn't seem to shake that slam.

I started going to doctors. They had never heard of anything like this.

Seemed like every time I went into a bad building after that, not only would I get knocked for a loop, it was a guaranteed nosebleed.

-Erik (2009, SevereReactor)

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> I found a couple interesting articles about the Berkeley area. It was shocking to learn that there are so many toxic problems in that area, especially the one they call their "dirty little secret" (the Pacific Steel Company).


This one was especially interesting to me, as I was repeatedly knocked flat by "something" that went across Hwy. 80 just south of Gilman Street.

-Erik (2009, SevereReactor)

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I remember later hearing about the outbreak in Silicon Valley and wondering if that might have been where I was exposed to "whatever," because I used to spend a lot of time down there hang gliding at Mission Ridge/Ed Levin Park near Milpitas.

-Erik (2006, CFSExp)

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I taught hang gliding for years out at Dillon Beach.

On crappy days when we'd get rained out, we would retreat to a bar in Petaluma for a hot brandy before heading back south.

The place was a slammer and I soon learned to stay away.

Nobody understood why I just refused to go in and be sociable.

Why I took a sudden dislike to the place.

This is the lifestyle I've been forced to practice.

Moment to moment, paying attention and never ignoring those particular places that have taught me through years of experience that the long term effects of these "So what?" exposures have effects on me that go far beyond what anyone believes can be possible.

-Erik (2006, CFSExp)
Chapter 67 - Erik: Epidemic

A BLAST OF MOLD

My "sudden onset" actually started when I inhaled a blast of mold, so I knew for sure that mold was a significant factor.

It was August 1984. I can't remember the exact date, but I was out in some sand dunes on the coast and suddenly the whole world turned sideways.

This was such a strange sight to see that I didn't even realize that it wasn't the world turning sideways until the side of my head hit the ground.

I went, "Whoa! That's never happened before."

That was the first utterly neurological sign that something was wrong. I just suddenly totally lost all perception of balance.

I did not have any head injury at all. This was soft sand.

I had plenty of mold slams before that, but this was like nothing I had ever felt.

That's when I went to see Dr. Cheney.

When you read Dr. Hyde's description of ME progression, he talks about these precursor episodes before fully descending into illness.

I didn't get the full sore throat and all other CFS symptoms until a year later. Since no one was listening to me about these precursor problems or about the mold, I thought that eventually when CFS researchers began to research CFS, I could tell them about it.

-Erik (2010, SevereReactor)

SITTING IN THE CAMPER

In 1984, I was having health problems, and didn't have to go very far to find a doctor in this quiet little town at Lake Tahoe. I happened to live right next to one.

I went a few hundred feet to his office. He did a bunch of tests, but said he had never seen anyone like me and had no idea what was wrong.
After a while, I gave up on him and left. I went wandering through about ten other doctors, who weren't nearly as nice as the first one.

Unlike the very first doctor, the rest didn't believe a word I said and diagnosed me with "hysterical hyperventilation," "depression," and a whole bunch of other nonsense. It was pretty clear they were never going to try to help, and just fought me all the way.

So eventually I wound up going back to the very first doctor I saw, the one who was right next door. Nice guy, but just had no familiarity with this kind of illness and try as he might, he just didn't come up with any answers.

I had wild spins at night as if I were on the worst drunk of my life. Killer sore throat that looked like I had gargled with battery acid. I was bleeding from damn near every orifice. Rashes, veins looked all weird, heart palpitations. The list goes on.

I found mold in the north wall of the house, and there was another bit under the kitchen sink. If I went outside, then I could just about stand up - but if I tried to wash or do dishes at that sink, my eyes would go dim and I would collapse. I would literally have to hold my breath at that sink or suffer the consequences.

It just so happened that I had a camper, which I used when I was teaching hang gliding at Dillon beach. I got sick and tired of feeling like crap in that moldy house, so I'd go out and sit in the camper. For hours at a time.

The camper was just a basic shell and didn't have a heater. Somehow sitting out there gave me a slight reserve of function that I could use for a short time. I used that energy to find and install a heater so I could spend even more time in the camper.

It really helped, when nothing else did. That was about the only thing that gave me any significant relief from this Living Hell of a weird illness.

While I was sitting in the camper, I would look at the back side of that doctor's office and furiously ask myself, "This is really important! Why won't Dr. Cheney look into the strange effect mold has on me?"

-Erik (2006, SickBuildings)

**PROTOTYPE**

The reason that Dr. Cheney and Dr. Peterson chose me to be in the CDC study group to refine the parameters for the syndrome was that even though I wasn't the sickest, I was EBV negative and had the fewest co-morbid pathogens of the cohort.
It may have been the paucity of pathogens that gave me a better chance at recovering to the level I have, but I have to stay away from neurotoxic exposures or I quickly become nonfunctional again.

-Erik (2005, CFSExp)

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When Dr. Cheney asked me to volunteer to participate in the Holmes et al, CDC study group to identify and re-name what we were then calling "CEBV Syndrome," I tried to refuse because I had already told him that mold was making me sick.

I desperately wanted our Incline Village "Mystery Illness" to be investigated, and I didn't want to interfere with Dr. Cheney and Dr. Peterson's retroviral concepts by inserting my weird mold illness.

But Dr. Cheney thought that the mold wouldn't matter, and since I was a member of the original cohort and EBV negative, he particularly wanted my cooperation. When I initially refused, he gave me a long lecture upon how important it was that someone in my peculiar situation should step up and do the right thing - as my experience of location, timing of onset, signs and symptoms and lack of EBV could not be found in anyone else.

And then it occurred to me that as a prototypical case of illness, the CDC authorities would be forced to examine my abnormal mold complaints in particular.

They would simply have no other choice, I thought, as any complicating factor in someone used as an example of the purest form of a new syndrome would have to be researched to find out where this abnormality fit into the picture.

As an inducement to persuade me to volunteer, after my initial refusal, Dr. Cheney told me that my case would receive special attention, access to leading edge research and the newest therapies.

I always had tried some primitive efforts at mold avoidance and had a fair degree of success - at least enough that it was well worth doing. It surprised me all along that no one was interested, even in this slight improvement.

It wasn't until I understood that cross contaminated items could be a driving force in my symptoms, and trained myself to perceive this type of contamination and take appropriate measures, that I really managed to take significant control of the situation.

-Erik (2006, Locations)

**THE MOLD AND THE VIRUS**
I asked Dr. Cheney and Dr. Peterson to look into it, but they said the virus was the main thing.

So I said, "Fine, I'll just stay away from the mold while you guys work on the virus."

-Erik (2010, SevereReactor)

**THE UPPER END OF VILLAGE BLVD.**

I was living at the upper end of Village Blvd. in Incline Village during the epidemic. I found that when I got clear enough to start to feel better and tried to exercise, whenever I’d go down into Incline I would literally fall apart, barely make it home and crash for days. Yet if I went up towards Mt. Rose, for some very strange reason, I somehow failed to fall apart in the customary manner.

You can bet your ass which direction I went! So I was getting clear for a while each day - and at the same time increasing altitude to cause EPO release.

The place where I first consistently perceived that "Here's a spot I cannot pass without suffering like crazy" was right on a corner - the very corner that the "marathon runner who can't walk to the corner" mentioned in Osler's Web used to live.

So I know which specific corner it was that the marathon runner couldn't walk to - and why.

I also know that she moved away and started to mysteriously recover, which, of course, is always dismissed as a fluke no matter how many times people lucky enough to lower their exposure make the correlation to a location change.

The converse is also true. You can move to a worse place and slowly "lose it" again.

That's how I wound up relapsing.

-Erik (2006, Locations)

**SHOWER**

I lived in a house that only had a shower, so my only real option was to sit on the floor of the shower because I couldn't stand up long enough to take one.

-Erik (2010, CAA)
GETTING OUTSIDE

By the fall of 1986, I realized that staying inside was slowly tearing me to pieces and I had to get outside as much as possible.

I had an old camper, and I would just go out and sit in it and look at the back of Dr. Cheney's office, recover a bit, and then try to survive the night inside.

Over the years, I just gradually kept pushing in the same direction, better and more avoidance, more time outside, and the more I controlled mold exposure, the better I got, and the more amazed I was that no one wanted to hear about this weirdness.

-Erik (2006, SickBuildings)
Chapter 68 - Erik: Post Epidemic

A PARTIAL RECOVERY

I eventually recovered enough to start driving again, and it was a tradition for us Bay Area hang glider pilots to congregate and celebrate Thanksgiving at Big Sur every year.

I really wanted to go along even though there was no way I could even think about flying and felt so ill that I wasn't sure if I could make it. But I had been sick so long that if I dropped dead, it would be a relief - so I went.

Much to my amazement, I had more energy and less pain while I was out camping than I had experienced in two years. It was incredible!

So I concentrated upon learning the specifics of this effect.

-Erik (2005, CFSExp)

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I recovered to the point of doing a bicycle tour of Crete.

I rode all the way around the island and up to places like the Arkady Monastery, the "Greek Alamo." I hiked the Samarian Gorge with no problem.

I felt good for a fair amount of the trip, but then stayed in a moldy hotel in Hania and completely lost it.

People on the tour were amazed, since I had kicked ass and been such a dynamo over the course of the tour but then suddenly, overnight, could scarcely stand up.

That's why I needed a reliable RV option. I just can't take too many hits like that before I slide down into CFS hell again.

-Erik (2006, Locations)

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I am not mentioned in Osler's Web. By the time Hillary came around in the early 1990s, I was busy hiking up Mt. Rose and building an experimental aircraft to replace the hang gliding that I was still too ill to do.... and trying to figure out how to get people to look into the weird mold connection.
I don't tell people that, or they would never take my story seriously.

They would have to see the mold effect in action before hearing why I was able to do these things, or they wouldn't believe it.

The reason I "lost it" in 1997 was because I bought a house in a mold zone for the specific purpose of building my second aircraft. I thought that my system was tough enough to handle it, but I got beaten worse than a redheaded stepchild.

-Erik (2008, Email)
Chapter 69 - Relapse

LOSING IT

After I started paying more attention to the mold in 1985, I kind of stayed the same, moving from house to house. Nothing really changed for years.

Then I moved into a really bad house in 1994 and relapsed down to 1985 levels.

I was in a bad place prior to buying "the bad place" in 1994. At the time, I just wanted to move and didn't know how to perceptify a place. I could feel that it was bad after I moved in, but it had been bad where I had come from so I felt like I was caught in my own personal problems more than attributing it to the environment.

So I kept going on with supplements and all the rest until September 1997, when I was literally on the floor, right back to crawling to the bathroom.

My symptoms were vastly different when I relapsed than they were in the mid-1980s. But then nothing about the illness had ever stayed the same for more than a few months. It was as if the disease was determined to hit every major organ system, and just kept jumping around until it hit all of them.

In 1994, I had an episode where I was just lying on the floor, unable to move. It was like my brain couldn’t move my muscles and nothing made sense.

I remember lying there, realizing that if anyone found me, I would be taken to a hospital and pumped full of drugs and not one person would believe me about the mold.

I would probably wind up unable to move, with tubes down my throat and no one would believe me. I managed to crawl out to my camper, where I felt somewhat better.

-Erik (2008, CFSU)

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The vertigo was coming back.

I was reacting to all types of chemicals. I couldn’t stand just about everything. Dr. Peterson said I was a universal reactor. I remember having problems with trees, diesel, new cars, paint, carpet, outgassing plastics, perfume, stores, EMF’s.
I also was reacting to all kinds of foods. I had to give up drinking wine, eating cheese, bread, nuts. It seemed like everything was making me sick. I remember thinking, “What is left that I can still eat, mung beans?”

It was overwhelming.

It seemed like everything was out to kill me and closing in on me

Which way to go? What to do next? No therapy I ever tried had really made much difference before.

- Erik (2005/2006, CFSExp)

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Testing and medical bills broke me.

- Erik (2006, SickBuildings)

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When I was at my worst, I told my parents that if I had a million dollars, it would do me no good with this illness.

I'd just give every penny to doctors.

I'd already seen that they haven't been able to help others with my illness, so it felt pretty useless. No way out.

- Erik (2008, CFSU)

AMPLIGEN PROGRAM

Eleven years after Dr. Cheney asked me to serve as a prototype in the Holmes study to define CFS, Dr. Peterson reexamined me and pronounced me to be, "Once again, as during the Incline epidemic, the perfect case of CFS, with all the right markers for a response to Ampligen" and "still EBV negative after all these years."

- Erik (2007, CFSExp)

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I was approved for the Ampligen study but did not qualify for the Hemispherx funded portion.
I could have had Ampligen under the cost recovery program, but I couldn't afford it.

Insurance companies had cut me off long ago, and I had none. Imagine trying to get insurance in my circumstances.

Dr. Peterson wanted to include me in the funded study because I was a member of the original cohort, but the cut-off was that I was still ambulatory. I was capable of walking, while the funded study was for strictly bedridden patients.

And the irony is that what made me capable of walking was that I was already doing a level of mold avoidance that helped me considerably.

I had nothing left to try except pursuance of this weird effect that mold seemed to have on me. So that's what I pursued.

I told Dr. Peterson that if I couldn't have Ampligen, I wanted to improve my efforts at something that was already paying off.

I asked if he would assist me in studying the characteristics of mold and devising a strategy of extreme avoidance. He said that mold was just an irritant and that he didn't think it would work.

I did see some people improve on Ampligen, but for me it might as well have been on the moon.

So it is ironic that many Ampligen success stories have relapsed and I am out mountain climbing.

I would say that I am the luckiest CFSer in the world for not being able to afford Ampligen. Otherwise I surely would have gone for it and probably not done extreme avoidance.

-Erik (2008, CFSU)

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I can assure you that when I was this close, approved for the trial, and couldn't get it for lack of money....

Well, it was a real low point.

But in an illness where virtually everything you do, you have and you are gets taken away, you almost get to a point where you learn that there is absolutely nothing you can count on.

-Erik (2010, CFSKnowledge)
Chapter 70 - Early Avoidance

DECISION

With nothing else left to try, I went ahead with the mycotoxin avoidance strategy. I was only trying to stay alive until Dr. Peterson figured out a cheaper way to treat CFS.

-Erik (2005, SickBuildings)

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Dr. Peterson proposes that the Yuppie Flu was HHV6a, and that Ampligen could knock it down. But so far, it’s been disappointing that such a costly and toxic drug that theoretically should knock the crap out of HHV6 isn’t having better and more predictable results.

I couldn’t afford the Ampligen anyway, since Hemispherx rejected me for the funded study, as they only wanted people who could barely stand up.

By the time I had done the treadmill test, I was already practicing a strategy of “Extreme Mycotoxin Avoidance.”

So at the time I disqualified myself for doing too well on the oxygen uptake test, I had already started to enjoy recovery from an alternate strategy.

My "sudden onset" actually started when I inhaled a blast of mold, so I knew for sure that mold was a significant factor.

I had become so reactive to chemicals that I could pick out differences in my response, and one exposure that really stood out was to a particular mold. I took a sample of that mold out to the desert and trained myself to recognize subtle signs of exposure and treat those as if I had been in the presence of nerve gas.

By consistently practicing the procedures I was taught in the military for biological warfare nerve agent exposure, I started to improve.

The surprise was that with my heightened awareness of that specific mold, I found that other CFSers were responding to slight exposures in a similar way. Absolutely none of them were aware that this strange emanation of wafting brain fog was actually spore plumes of toxigenic particulates that create a lasting response - which makes it difficult to identify for what it is.

-Erik (2006, CFSExp)
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In a weird sort of way, the fact that all the top doctors across the U.S. discounted mold made me realize they were missing the boat.

They were so outrageously wrong that I realized that there was nothing about their opinions that I could trust.

This actually made it much easier for me to step out on my own.

-Erik (2009, Facebook)

EXTREME REACTOR

When I started thinking about how my health gradually shifted in places and according to seasons, it made me wonder how much further I might be able to control the problem if I learned to sense subclinical exposures to this substance, which was concentrated in certain places, and treat lesser exposures as though they were having a long term effect - in the same theoretical way as peanut anaphylaxis might wear someone down.

-Erik (2006, Locations)

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I went all-out concentrating on doing my own testing to determine just how much how mycotoxins were affecting me.

It wasn't until I performed my own simple tests and acted in accordance with the results that I finally managed to crawl out of what appeared to be an impossibly deep hole.

-Erik (2006, SickBuildings)

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It turned out to be incredibly slight amounts of a specific mold: Stachybotrys.

I was so reactive to the stuff that to me, it was just like the unbelievably small amounts of peanut product or residue upon someone with severe peanut allergy.

Even the slightest cross contamination upon various possessions would set up the inflammatory response that was wearing me down. So I used my Army training in biological warfare to devise an avoidance strategy very similar to battlefield Nerve Agent protocols.
I recovered beyond anything I dared hope for and have been out leading an active lifestyle ever since.

-Erik (2005, CFSExp)

LETTING GO

I have no health insurance. I lost my business, house, insurance, hobbies and became homeless for a while.

Thankfully a friend gave me a place to sleep on the floor of his office.

-Erik (2004, CFSResearch)

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That's what it took for me! Thinking that I was going to die.

I sure wish I had had access to someone who could have told me what I was facing by not getting out in time - instead of being surrounded by people that told me my inclination to bail out was crazy and unfounded.

I fought for everything I had and by trying to keep it, I lost even more. I lost my world when I became so reactive that standing next to a person with Stachy on their clothing is too much for me.

And it could have been avoided if someone like me had been around to say just how rotten it can be.

I was ready to hear it. But there was no one.

-Erik (2006, SickBuildings)

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I went nuts trying to remediate the house, which turned out not even to be the source of the problem. I wasted thousands, only to find out that the mold was coming from a sewer vent outside.

I didn’t really switch my thinking until I went camping, and then hung out for a while in front of the vent without even going in the house. Then it finally sunk in that nothing I did inside the house was ever going to make that area safe for me.

So I spent every penny I had before I crawled out on my hands and knees.
Back in those days, I was still being misled that not only was this only an allergy and that if one had any kind of problem with mold, it could be easily cleaned up.

I must have been completely out of it. Because I believed them and tried to clean up the house for the next four years, even though I wasn't sleeping in it.

I wish there had been someone who could have told me to just cut and run. Virtually everyone told me that even thinking that I needed to was a sign of insanity.

-Erik (2008, CFSU)

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I pushed it too far, relying on doctors who told me that this was impossible and that mold could be cleaned up with a little bleach. At the time, there was no mention of toxic mold in the media, and virtually none of the dozens of doctors I contacted in Tahoe, Reno, Grass Valley and Sacramento had ever heard of such a thing.

I finally realized that I didn't have to go in my house to get sick. One time, there was three feet of fresh snow and it was snowing like crazy. I thought that any spores must surely be buried under snow and scrubbed out of the air by the intense snowfall. I was completely wrong and got horribly slammed.

Just passing through the neighborhood was enough. I didn't even have to stop at the house. That's when I realized that all my efforts were wasted.

I sold the house and used the money to buy an RV. Then I started running for my life from the moldy neighborhoods and scattered spore plumes that are everywhere, no matter whether it is Las Vegas, San Francisco or Tampa.

And that's what I'm still doing.

The downside is not having a home. The upside is that I don't have to worry about being trapped in a sick region, can escape horrible mold symptoms and can go hiking or mountain climbing whenever I choose.

-Erik (2006, SickBuildings)

**BIOWARFARE TECHNIQUES**

At the beginning of CFS, my mold complaints were seemingly overruled by the fact that I had moved many times and it made no significant difference. It was just enough of a difference to let me know that there was a difference.
It didn’t make sense.

Moving only gave me enough of an indication of a shift in symptoms to let me know that there was an "effect" which might be exploited.

The complications and logistics of cross contamination are absolutely formidable.

It wasn't until I adapted my training in biological warfare protocols from the Army that I really started to get a handle on direct intervention and control of my illness.

That is what it took. I was forced into a more concerted method because doing less simply wasn't helping me control my symptoms or recover.

It's not like I wanted to do this, but I had nothing else in the way of viable options.

-Erik (2008, CFSU)

**MYCOLOGIST**

My primary irritant was disputed by all doctors even though I could clearly feel that it was mold, so I adopted the expedient of hiring a mycologist to accompany me while I disturbed various mold colonies. When we found one that such disturbance released a cloud of spores and I collapsed on the floor, I said, "That's the one!"

It was Stachybotrys - and that was the first time I heard the name.

I knew that I had felt this Stachy hit in many locations and that testing by conventional means was expensive, time consuming and would not give me a real time indicator of exposure. So I took a sample of a Stachy-contaminated object to a pristine location and trained myself to recognize the most subtle sensations of exposure that I could perceive.

In this way, I don't require a major slam to recognize that I have been exposed, and I conduct avoidance before my immune system is upregulated to the point of being painfully disabled.

-Erik (2002, SickBuildings)

**TRIP TO THE DESERT**

When I proposed this I had turned into a universal reactor and was being tortured by almost everything except when I was in the desert. But I remembered that my illness had started with mold reactivity and chose a leap of faith that this response had a specificity to it which was more important than the responses that followed later.
I got a sample of a Stachy contaminated item and wrapped it up in a Hepa filter. I laid it on the floor, covered it with six layers of blankets and tried to sleep on it.

I did this to familiarize myself with the mycotoxin response so that I could learn to recognize extremely subtle exposures.

Naturally I would get up after various periods of time absolutely fighting for my life. It is not a technique I can recommend, but since no doctors would help me and everybody told me that mold reactivity was impossible, I was forced to find my own way.

By learning to recognize mold hits before they turned into an immune devastating mold slams, I was able to consistently perceive, avoid and decontaminate from exposures before my immune response was forced into a damaging upregulated state.

I made no special effort to avoid anything except that feeling of exposure to mold. The response was a miracle beyond anything I dared hope for.

-Erik (2008, CFSU)

*

I identified a sample of the mold that was most bothersome and took a bit out to the desert. After getting myself as clear as possible, I did proximity testing to see at what distance this tiny amount would still have a discernible effect.

It was astounding. Just like the peanut allergy in my commanding officer. Infinitesimal amounts were still creating sensations which were only discernible by the fact that there was a shift in symptoms.

For example, if I was slightly depressed, it would get slightly worse. If I had difficulty sleeping, the problem would turn into full on insomnia. If I felt slightly anxious, it would turn into a sense of desperation.

What I felt wasn't "mold" per se, like an allergy. It was the shift in symptomology. And because I had taken the mold to a place free of other variables, I concluded that this was the factor responsible.

-Erik (2006, Locations)

STARTING OUT

Instead just going to the woods, I tested out some used campers until I found that I could tolerate.
It was a bitch trying to talk dealers into letting me sleep in them, but I was lucky and found a few.

I got myself a camper. I started dropping my clothes at the door and taking a shower as soon as I got inside, to keep the nasties out.

It was more comfy than the tent in the woods that people were kind of misled into thinking I was doing.

-Erik (2009, Email)

*

The green binocular epiphany was the turning point when I finally started to get a handle on why this stuff could slam me from out of nowhere, for no apparent reason.

I had washed those binoculars, but they still slammed me.

I thought, "If these can do this to me after dunking them in a sink, the whole notion of mold testing and remediation is totally out the window. None of it applies to me."

So I acquired all new stuff and got rid of everything that I could feel the badness on.

I learned to "perceptify" stuff before it come in, to get rid of anything that slips through perceptification... and the most important thing of all, stay out of mold plumes.

I finally started to turn my reactivity around and decrease it.

-Erik (2009, SevereReactor)

**BIOWARFARE PROTOCOLS**

Wouldn't it be great if someone with mold sensitivity identified a safe place and just said, "Go here?"

I did this in one shot, because I knew that when I went out to the desert and got clear, there was such a relative shift when I was re-exposed that it took a major part of guessing out of the equation.

I would go out and spend time in the boondocks and then go directly to the proposed place. A lot of "potentials" that I thought might have been okay were instantly revealed as not.
When I did find a place, I knew that dragging spores back in my hair would be too much.

I scrubbed an area of linoleum in a place that was already good and made that my safe zone.

I would not even sit in that area until I had taken a shower and washed my hair thoroughly.

I slept on an inflatable and washable backpacking sleeping pad, which I washed every day.

No pillow. Only a rolled up towel. Washed in a good place. I would change to a different towel every time I woke up.

I found a laundromat that felt good. I laid myself flat on the floor to perceive any accumulations of mold to see if it was safe enough to do laundry. There were so many that I couldn't tolerate, but I kept looking until I found one.

I washed a half dozen sleeping bags and as many towels. Wrapped them up in plastic bags and when I was ready to try to survive another night from hell, got them out and stacked them up. I rolled up the towels similarly in a stack. It took anywhere from a few minutes to a few hours for each new fresh surface to become contaminated.

When it did, I would throw it to one side and keep a fresh surface for a respite, as long as it would last.

If nothing else helped, I would prop myself up against a wall to keep my face as high up from the most intense area of spore accumulations where they occur on horizontal surfaces.

I spent every moment outdoors but even that wasn't enough. I had to learn to perceive mold plumes and avoid those areas.

There is a killer plume in Incline Village. It took me many times of passing through before I realized that just going through it momentarily would keep me ill for days.

Once I started decontaminating right away after passing through plumes and not waiting for symptoms to start up, I can hardly express how many CFS symptoms were simply washed right out of my life.

I can't believe any of this crap myself. How can I expect anyone else to?

But I did whatever it took to drag myself away from what I could so clearly perceive.

-Erik (2006, SickBuildings)
I was way beyond the point of being able to tolerate anything that was contaminated, porous or not.

I couldn't even stand next to someone who had been in a moldy place. Nor downwind of them.... for at least thirty feet.

Nobody knew the rules to this game, so I had to make up my own.

It was months before I was absolutely certain that I was doing the right thing. At about the four month mark, I seemed crawl up on the right side of the power curve and my improvement accelerated like crazy after that.

-Erik (2008, CFSU)

I was fortunate to have a part time job, some friends, a camper, and a family that was supportive of whatever I was doing even though they didn't believe a word of it. Without so many resources, yes - it's really tough.

But if I could get out to a really decent pristine area for a couple of weeks, this would help give me more ability to do more.

It took several months of acting on faith before I was absolutely certain that I was getting better. The symptoms would swing wildly, but every month the low point was a bit less low and the high would get geometrically higher.

At first I wasn't sure about what was happening, because I could feel badness virtually everywhere. My sensitivity shot through the roof.

But what finally sank in was that there is huge difference between "sensitivity, the ability to perceive" and "reactivity, the profundness of adverse effect."

Over time, I could feel it more, but it slammed me less. And the senses become so acute that instead of a curse, they turn out to be the best guide one could possibly ask for.

But only if you act in accordance with what you sense.

-Erik (2008, CFSU)
For a couple of months after my worst mold nightmare, I would make the area under my head "hot" when I tried to sleep.

Each place I lay would become intolerable after about fifteen minutes.

That's a lot of moving during the night.

Although I was covering the bed with plastic and using fresh blankets, every night I would run out of places on the bed to put my head.

Then I'd have to start using up floor space.

-Erik (2009, SevereReactor)

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I despised the trancelike sensation that induces inertia.

The more intense it was, the more it inspired me to crawl outside.

Yes, it took all my willpower to drag myself out. Sometimes it seemed easier to just lapse into a somnolent state.

But I desperately wanted my life back, and this seemed like the only option I had.

And painful experience had shown that the longer I lingered in toxic torpor, the less the likelihood I had of ever getting that life.

-Erik (2008, CFSU)
Chapter 71 - Recovery

DR. D

My girlfriend, Dr. D, bought a house without perceptifying it first in 2001, saying it was too good of a deal to pass up.

We spent one night and I told her, "It is here."

I didn't want to abandon our relationship, but I knew that I was literally making the decision to plunge myself back into Mold Hell if I made this move with her.

I figured that since Dr. D is also a mold responder, it was my responsibility to go and suffer with her. When we both fell apart - as I knew we surely would by living there - I would have my escape module ready to evacuate us both when the time came.

That is exactly what happened.

She spent all her money trying to remediate the house, even though I told her that the entire neighborhood was bad and this would not make enough of a difference.

In the meantime, she was mad at me for being unhelpful because I "wasted time" remediating the RV.

At the very last, we were so sick that we could take it no longer, not one more moment in Living Hell.

When finally we hit the wall, I had my Plan B ready. We escaped to the woods, where we were able to recover.

I had been through this before, and I knew what to do. We made it out, decontaminated - and left the mold behind.

-Erik (2006, SickBuildings)

*

Heck no, you don't have to wash in lakes if you don't want to. We didn't. We just bought a new RV.

After mold avoidance, my ex and I climbed Whitney together.

She was amazed because just a few weeks prior to this photo, she had been so achy and tired that a short half mile walk to Devil’s Postpile had knocked her on her ass.
She didn't think she had a chance to make Whitney.

And I kept saying, "Just wait. You'll see."

A few days later, she felt great and climbed Whitney with no problems.

The shift in symptomology is just incredible. That really convinced her.

Unfortunately the RV got moldy, and that really finished off our relationship.

She said, "I can't believe this shit. Mold is following you around. I think you are cursed to have this hanging over your head for the rest of your life. I have never seen anyone with such bad luck. You are mold cursed and I'll never have a chance at a normal life unless I get away from you."

Sometimes I have to agree that she must be right.

I still keep tripping over this damned mold wherever I go, as if this curse is really attached to me.

Almost like the gods have singled me out for this fate.

-Erik (2008, Email)

*

Dr. D had a particularly severe case of mononucleosis, but described it very much like Dr. Teitelbaum.

Like a very bad case of mononucleosis and nothing more.

These people are very comfortable about using the word "fatigue."

The illness that hit Incline was not like that. This was pure murder.

We didn't wonder why we were so tired.

We wondered why we weren't already dead, which would have been one hell of a relief.

Our cohort screamed at the insult of fatigue. So much that the word is actually a good diagnostic.

People who had the Incline illness consistently rejected that term, never embracing it or considering it adequate.
But our reaction to mold was strikingly similar.

During the mold tour, she actually tested me. "I feel hit. Do you feel that too?"

"No, I don't."

"Neither do I. I just wanted to make sure you weren't going to agree when there was nothing there."

-Erik (2009, SevereReactor)

LOOKING BACK

I wanted to live, to breathe, to be able to predict when I could stand up, to have one moment free of shrieking pain, and I did it!

I can't tell you how difficult it was. It was a totally wild leap at this weird concept, like a vague feeling that mold was affecting me more than it felt like it was.

-Erik (2006, CFSExp)

*

I guess that I went beyond scared.

I remember once losing control of an airplane at 800 feet. I was so certain that I wasn't going to survive that I simply stopped caring about whether I did or not and put my total focus into action - and it worked.

And when I reached a point in this illness where I felt that there was no chance for survival, I made one last attempt at a promising concept - and it worked.

So much so that I went from the most aggressive experimental antiviral program of a novel immune modulator Ampligen treatment for severe ME/CFS back to mountain climbing within six months.

People should be scared because if they are anything like me, conventional medicine is not currently helping them much or even demonstrating interest in pursuing relevant clues when they are presented.

But at the same time, my story offers hope to people who recognize their illness in my story, because if they are like me, then they too might benefit from extreme avoidance in the same way I have.

It's been a miracle.
It all seems like a crazy dream now.

I am doing so much better that sometimes I think, "Did all that really happen?"

Then I look around at my “act of desperation” custom-built RV, my bedraggled possessions that remain, all the stuff for decontamination.... and I'm shocked back into reality.

Yes, it sure enough did.

-Erik (2009, SevereReactor)
AVOIDANCE ALONE

The mold was such a paramount factor that I lost interest in taking any drugs, when they did not appear to be doing much in the way of eradicating this horrible reactivity.

There was another reason why I stopped doing all other therapies.

I wanted to make sure it was really avoidance that was doing it, so that people couldn’t point at something else I was doing as an excuse to talk themselves out of undertaking avoidance.

-Erik (2008, CFSU)

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I tried Garth Nicolson’s pulsed doxycycline therapy for about nine months. It was fairly low dose.

This was for Mycoplasma Fermentans, on the theory that if this were the problem, maybe it would help break this wild mold reactivity.

It didn’t really seem to help all that much.

People try to tell me that it must have and that I’m in denial about it. All I know is that it didn’t reduce my mold reactivity, and that my day-to-day perception of how I was doing corresponded to how well I managed to avoid mold.

This is why, when I did finally try CSM a couple of years later, after a very short time of seeing results that were far less than just staying away from mold and getting completely blocked up, I said, "To heck with this."

And just went back to the only thing that seems to really do the trick.

Pure, all-out mold avoidance.

-Erik (2009, SevereReactor)

ANTIBIOTICS
In 1999, when I realized that no doctors were going to listen to me or try to develop a therapy consistent with the illness, I managed to get enough doxy using surreptitious means to try Garth Nicolson’s pulsed protocol.

The doxy was an attempt to break out of this reactivity and return to a normal life.

I herxed so badly that I thought that the therapy was going to kill me faster than the illness, but I knew that my condition had been deteriorating steadily and that "doing nothing accomplishes nothing" so I stuck it out, not knowing if this would finish me off or not.

While it did seem to help a bit, it was so minimal that whatever benefit I got was utterly overwhelmed by re-exposure to mold.

I stopped because as I became more concerted in my avoidance, the decreased duration of inflammation was restoring the anti-inflammatory cytokines.

-Erik (2004, EuroLyme)

MYCOPLASMA

Dr. Cheney departed Incline before we became aware of mycoplasma.

I asked Dr. Peterson for a panel, but he reiterated his views of HHV6a and declined to test or treat mycoplasma.

I printed out a requisition form from Garth’s old lab "International Molecular Diagnostics," put my own name as the proxy and took it to Sierra Nevada Lab, where I was well known to the test vampires.

SNL accepted it and did the draw and sent off the blood. IMD sent the result directly to me.

Positive: M. Fermentans.

As virtually all doctors within my sphere had refused to test or treat myco, they forced me to obtain doxy by "alternate means" in order to do Garth’s pulsed protocol.

While others have continued with the pulsed protocol, I eventually abandoned it in favor of mycotoxin avoidance.

The greatest challenge for all CFSers has been trying to find ways to get around doctors.
LYME

I don't know if I have Lyme or not, but I wouldn't be surprised.

-Erik (2005, CFSResearch)

ANTIVIRALS

I have HHV6a, and it is surely a problem.

This desperate mold avoidance strategy was just a wild leap at trying to stay alive until Ampligen became affordable or some other therapy was developed.

I guess it still is.

-Erik (2006, Locations)

*

The antiviral therapies that I saw did not reduce the recipients' mold reactivity.

My reactivity appeared to be paramount, so that is the direction I took.

-Erik (2008, CFSU)
Chapter 73 - GETTING WELL

A BUBBLE

It is like living in a bubble. I would like nothing better than to have my old life back.

Maybe someone will discover a Magic Bullet someday. Until then, this is the best bubble I could come up with - and it could be a heck of a lot worse.

I know, because it was!

-Erik (2006, CFSExp)

A ROTTEN SOLUTION

>Shall we assume that your mold avoidance is a permanent solution?

No, it's a rotten solution and if it made me permanently well, I'd be off living a normal life. I'm not totally satisfied with the lifestyle constraints of practicing extreme mycotoxin avoidance although it sure beats the alternative.

It's the equivalent of a person with life threatening peanut allergies discovering that as long as he avoids every form of peanuts - fragments, oils and fumes - in all kinds of hidden sources, he can avoid the immunological response and feel fairly normal.

It's feeling like the gears are stripped and the immune response is out of control.

This hasn't fixed the problem. It has allowed me to drive along looking fairly normal and avoid a lot of gnashing.

-Erik (2005, Locations)

*

> Don’t you want to be really well without having to do mold avoidance?

That's why I still haunt these lists. Despite a spectacular amount of control over the illness, I don't know how to get there.


-Erik (2007, CFSExp)
LUCK

I just climbed Mt. Whitney for the ninth consecutive year, to celebrate leaving the Ampligen program to try something else, so I reckon I can't complain.

What would be really nice is not having to conduct avoidance.

But I gotta tell you, after looking at the pathetic results that all these other somewhat expensive and semi-toxic therapies are having, I consider myself the luckiest guy in the world to have pursued this one instead.

It's gonna have to be some kinda whup-ass miracle pill to equal the effect this strategy has had.

-Erik (2007, CFSExp)

HYSTERIA

It would be terrific to find out that the main problem was primarily mental.

I'm sure that almost anyone would gladly swap an intractable physical illness for an easily treatable mental one.

I'd much rather have hysteria than an immune dysfunction. I'd be glad to call it a mental problem, if that would make it so, but testing indicates otherwise.

-Erik (2009, CAA)

WASTEBASKET CASES

Dr. Bell's follow up study of the children involved in the Lyndonville CFS cluster finds that many improve but never quite completely recover.

Those who recovered met the criteria for a clinical diagnosis at time of onset but no longer have enough symptoms to qualify as cases of CFS.

CFS survivors who improve would still like to know what causes their illness and would prefer to recover completely.

CFS survivors who recover beyond the parameters of a clinical diagnosis fall within the range of impairment that psychologizers and "Strict Criteria Proponents" alike are calling "CFS Wastebasket" cases.
I submit to you that it is painful and disappointing for partially recovered people to have their persistent life limiting symptoms dismissed by those with the severest form of the illness as "likely to be wastebasket cases of CFS."

People who partially recover are truly ill and deserving of medical attention even though they no longer meet the criteria for "clinical CFS."

I believe that cases of such partial recovery constitute a great portion of the epidemic and it is not in the best interests of the sickest patients to dismiss and alienate such people.

I propose the possibility that the vast majority of "CFS wastebasket" cases have no more reason to exaggerate their complaints than those who meet the strictest criteria for CFS/ME.

I am a "CFS wastebasket case" and "psychologizing" from other sick people is no different to me than psychologizing from doctors.

-Erik (2004, OneClick)
I really don't remember me anymore. My memories of the person I was before this happened are as disconnected as if from a movie of someone else's life.

I clearly remember telling Dr. Cheney what carnage there would be if this horrific illness spreads around the world as easily as it did in Incline and being extremely concerned about my responsibility for spreading it. I was a patient of Dr. Cheney’s in 1984 before he knew about this mess so for all I knew, I was the person who brought it to Incline.

I remember that my concern for my fellow humans was at the very top of my priority list.

-Erik (2004, CFSExp)

*

I grieve a little for my lost life every day. I think you have to grieve in small increments to avoid having it hit you all at once, when you just can't keep it stuffed anymore.

-Erik (2008, CFSU)

*

That's how it feels to me too, like my old life is so distant that I have to look at these events as if they happened to another person.

It is so bizarre, to have watched this phenomenon induce the "CFS epidemic,” and then spent decades trying to warn the most famous doctors and researchers in the world - with all of them literally turning and running, saying this is impossible, and then... the excrement really does hit the impeller blades!

This is surreal beyond anything I could have imagined.

-Erik (2008, CFSU)
Chapter 75 - Reflections

BORROWED TIME

I spent today going through the old historical Donner Lake snow sheds where the Chinese bored the tunnels for the transcontinental railroad, and then up the PCT from Donner Lake to Boreal Ridge.

And to think that there was a time that I couldn't predict when I could stand up or not.

I thought that my life was completely over, and so did the doctors.

When all my medical treatment options were gone, I was forced to try something else. I only wish I had done it sooner.

Mycotoxin avoidance has been a miracle.

-Erik (2006, SickBuildings)

*

If the ship is headed in a bad direction, and the ship does not have sufficient mechanisms to stop the progressing situation, the outcome is "extrapolatable."
You don't need to wait for the event to happen to predict that it is unavoidable. If plumes continue to spread, and no mechanism develops to control my situation, what will happen to me is completely predictable.

But I remember thinking when I couldn’t afford the Ampligen that I would do just about anything to feel like a semi-normal person again, before I headed off to the last roundup to pitch the last inning.

I have managed to pull off an incredible number of great adventures while living on borrowed time. Adventures that a lot of people will never be so lucky to have.

So I consider myself to be the luckiest guy on the face of the Earth.

-Erik (2008, CFSU)

*

Deprivation takes on a whole new meaning, when it means giving up agony in living hell for feeling fairly human in a natural environment.
This is hard for even me to believe.

Most people will read this and think that I must not have ever been really fighting for my life out in the desert.

But if you ever saw what I had to do to build my MECU, you can see an artifact that represents an act of total desperation that nobody in their right mind would ever do unless under extreme duress.

I now routinely go back into places where I never dreamed that I would ever be able to go again.

I didn't expect this.

It took lots of time to work up the courage.

I didn't expect any of this to happen, so what else is new?

-CRAZY DEAL

Man, what a crazy life this turned out to be.

Anybody less reactive just insults and abuses what you have to do to stay alive.

People who are more reactive are either dead already or in such a sorry state that they are consigned to the twilight of mortality.

-There is nothing fair about this illness.

-Crazy deal to be going through. Like a nightmare that you can't wake up from.
I'm thankful for a lot of things, but nothing about getting this illness is one of them.

I can't think of anything this disease has brought me that could be better done without.

I very much enjoyed my life as a hang glider pilot and instructor and only wished to go on as I had been.

People tell me that this is the wrong attitude, that I should be happy no matter what, yet these are the same people who scream bloody murder if their vacation plans are so much as disturbed.

I wonder if they would say this to themselves if they had this illness rip the guts out of their life?

Judging by the way they howl at mere trifles, I think not.

-I've been working on accepting this illness for 25 years, and I haven't quite got there yet.

In fact, I think that I'm going the other way.

-IMAGINARY PROBLEMS

If anybody thinks I have nothing better to do than imagine all this nonsense instead of having fun...

I can show them pictures of the things I've chosen to "obsess about" ever since I survived this living hell, like backpacking the Evolution Basin and climbing Half Dome in Yosemite.

-Erik (2008, CFSU)

*  

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-Erik (2008, CFSU)

*
It is asking too much of a human, to have to try to live with this, figure it all out, and be virtually surrounded by people who think that you have nothing better to do with your time than make up imaginary problems.

- Erik (2008, CFSU)

This is unfair beyond belief. And to be disbelieved is intolerable beyond belief.

- Erik (2008, CFSU)

VALIDATION

To go from universal disbelief, denial and condemnation to achieving validation is something I thought would never happen in my lifetime. It's been quite an amazing journey that I have been privileged to travel.

- Erik (2008, CFSU)

FRIENDS

I'm so lucky that I still have my cat, though sometimes I apologize to her that she hitched her wagon to such a lame horse.

After I lost almost everything and my family withdrew any further help, I learned to go to the desert and recover.

This is so important and the doctors won't look at it.

The good thing about this illness is that you find out who your true friends are.

The bad part is...

- Erik (2004, Locations)

HANG GLIDER PILOTS

> What is it that you find so appealing about hang gliding?

Success at defying death or disaster using a finely crafted technique that only the highest degree of practice and skill makes possible.

Like a stunt pilot who deliberately drags a wingtip, or does a snap-roll on takeoff.
You know that you can do it, because you understand how it is done and have worked hard on refining your expertise.

If others want to do such things, just launching into it without years of intense knowledge gathering and training is not likely to succeed.

Novices have to watch what the successful pilots do very carefully.

I think it'd be really neat to climb El Cap. I know a lot of rock climbers who have, but I wouldn't try it without a lot of time bouldering on Donner Pass - and watching what the skilled guys do.

Hang glider pilots do it for the thrill alone. The only higher goal is to go higher.

-Erik (2008, CFSU)

PARABLE

>Once upon a time there was a man that lived by the river. He heard a radio report that the river was going to rush up and flood the town. The report said that the whole town should evacuate immediately. But the man said, "I'm religious, I pray. God loves me. God will save me." But the waters began to rise. A man in a rowing boat came along and he shouted, "Hey! Hey you! You up there. The town is flooding. I can take you to safety." But the man shouted back: "I'm religious, I pray. God loves me. God will save me." A helicopter came hovering overhead. A guy with a megaphone shouted. "Hey! You there! The town is fully flooded. Let me drop down a ladder and I will help you to safety." But the men shouted back that he was religious, that he prayed, that God loved him and that God would take him to safety. The man then drowned. When he got to the pearly gates of St. Peter, he demanded an audience with God. "Lord," he said, "I'm a religious man, I pray. I thought you loved me. Why did this happen?" God said, "I sent you a radio report, a helicopter, and a guy in a rowing boat. What on earth are you doing here?"

I'll tell you why this parable means so much to me.

At a time when everyone was saying to sit back and trust that things would work out, a little voice in my head kept telling me,

"Do something now. Don't lie down. Fight this thing."

I listened to that voice and crawled outside.

-Erik (2010, CAA)

IT'S A WONDERFUL LIFE
Can't live like this? I've done it for a quarter century.

Being bedridden and constantly miserable? That's not my choice.

-Erik (2008, CFSU)

*

At a friend’s request, I checked out a million dollar mansion this morning.

It was a whup job. I mean, after two hours I was really hating life.

Thank God I know what to do about it. And thank goodness I have the tools to do it.

But it sure made me pause to think about all the people who would be stuck - in the hellish agony that I would have been stuck in, if I didn't have my MECU and the knowledge of decontamination techniques.

So every day, every hour, every minute that people spend ignoring this information are minutes, hours, and days of agony that could have been spent without it.

Why?

-Erik (2008, CFSU)

*

Yes, it's incredible that a brain so badly battered could recover to this extent. Sure made me happy.

Fortunately, unlike MS, our illness seems to more inflammation than demyelination, so a lot of the cognitive problems can be reversed if the inflammatory response is brought down.

-Erik (2009, CAA)

*

I'm celebrating a very pleasant Christmas with relatives (instead of huddling in the Godforsaken Desert as the anti-extreme avoidance crowd likes to misportray Erik's strategy).

I'm getting some pretty good mold hits from various family members that I know are carrying the badness on them, for I feel the same badness in their houses.
But rather than feeling sick for “no reason,” I know exactly what is happening and can control how much of this I want to take.

I can step away from some of them, go to another part of the room.

Check the direction of wind drafts and stand upwind.

Not sit where they sat.

Go outside for a break.

(To my nice, warm MECU.)

And spend quality time with my very good friend, the cat.

This beats the crap out of how it used to be, so many years ago, when all I could do is wonder what the heck was happening to me and suffer through it all in confusion and doubt.... feeling very depressed, since everyone told me that what I felt was "all in your head."

People tell me, "I couldn't do that," in reference to mold avoidance?

What the heck do they think they are accomplishing by not doing it?

They need Clarence the Christmas Angel to swoop down and show them how life would have been.... just like Walter Bailey got to see how dramatically different things might have been, just because of all the things that didn’t happen if he had never been born.

-Erik (2009, SevereReactor)

A LIFEBOAT

I am honestly confused, to the point of feeling bludgeoned with something that is almost incomprehensible. If I were someone else, I would have thought that a person with a story like mine would have been something that no one could ignore.

I was present at different sources of illness clusters that scared Dr. Peterson into calling the CDC and led up to this CFS phenomenon. I felt this effect at all of them. I don't know what is going on, I just wanted help finding out.

I ran from this effect, I sat in my car, I hid in my camper, I tried to wash it off, I did everything within my power to find out what this thing is, and it paid off.

I never got that help with learning more. What I know, I had to learn on my own the hard way.
I only know that by staying away from this mysterious phenomenon, I can have a life that is far better than the people who complain bitterly about feeling affected in these bad places but do not run from it in a timely fashion.

I have taken samples of this substance out to the desert and learned more about its characteristics. I have wrapped my entire life around dealing with this effect.

I cannot say for certain what this dynamic is, but it is spreading fast.

I know this much. I made provisions for survival. I built a bubble: a Mobile Environmental Control Unit. Without it, I would have had no decent life, probably not even survival.

I see others rapidly progressing toward them same level of reactivity.

If they have no Plan B or means of escape, they will not survive. They will suffer. They will beg for a merciful death. They will commit suicide, and I cannot blame them for doing it. If I hadn't planned for this eventuality, that is the way I would have gone.

In my environmental bubble, I am quite comfortable, I can have adventures, but it is a false life.

I wanted to make my way back to a real life, but instead of getting real medical attention for this problem, all I see is thousands of people getting no meaningful help and winding up in my situation, except they have no lifeboat to swim to.

I feel like I am sitting in a lifeboat watching everybody drown, and there is nothing I can do about it.

-Erik (2008, CFSU)

**DISCOVERY**

I'm not going to lay claim to discovering anything, as we all pointed at it.

Some even mentioned mold.

The nature of this emerging paradigm makes it inevitable that lots of people are going to discover it independently and without prior knowledge from media, doctors or mold experts.

There's nothing very interesting about who was the first to notice that a ship is sinking, when in short order, it becomes obvious to all.
I don't know any magic cures.

-Erik (2010, SevereReactor)

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OPENING DOORS

The uncanny way that I've been hurled up against critical people, places, and times makes me feel almost like I had some kind of destiny.

Every time I tried to run from it, doors slammed shut in my face.

But it seems that when I embrace it, almost every time it seems that all is hopeless, another door opens up.

And so I keep on going through them.

-Erik (2009, Email)
Chapter 76 - Shoemaker

Dr. Shoemaker pestered me for years to have the HLA tests done.

I told him that my experience indicated that I possess the extreme susceptibility and that my words have inherent value.

My personal experience, while suggestive as an example of what might be a factor in other CFSers’ symptoms, should not be the deciding factor in whether to apply protocols of avoidance.

Just as people are being forced to make the self-determination if they have CFS over the obstinacy and disbelief of doctors, one should also be able to look at my story of being a prototype for CFS, hear my description of the mycotoxin connection, and make the decision whether to see if this is a factor in their case as well.

After all the years of fighting with doctors, I trust my perceptions over any tests. No matter what my HLA is, if I test myself against molds and have this response, I must act in accordance with that level of reactivity. I believed that others would look at this the same way.

Dr. Shoemaker had never seen anyone with the dreaded double mold gene recover to the extent that I described, and so he wrote in Mold Warriors that I probably had the genetic makeup that allows recovery through avoidance. But people inexplicably used that element of uncertainty as an excuse to avoid looking at my approach to "Just test yourself and find out."

So Dr. Shoemaker insisted that I have my HLA done.

HLA DR by PCR 4-3-53 and 7-2-53. Mold susceptible and highly increased risk of CFS.

Dr. Shoemaker has confirmed that I am an anomaly in managing to take control over my illness by mold avoidance. It is as I have always said, that conventional views of mycotoxin exposure do not apply to someone at my level of reactivity and I was forced to adopt a lifestyle of extreme avoidance. The simple fact is that this is an anomaly because no one had tried it before.

We are now finding that others who are extreme responders are also able to take advantage of extreme avoidance once they are taught how.

-Erik (2006, CFSExp)

*
Dr. Shoemaker finally demanded that I quit putting it off and have the HLA done:

HLA Dr. by PCR 4-3-53 and 7-2-53.

I do indeed have the double dreaded mold gene.

It turns out that despite being an extreme mold responder, I have taken better control of my illness simply because I make a more concerted effort than others with similar genetic susceptibility.

-Erik (2006, SickBuildings)

* 

If you read Mold Warriors, Dr. Shoemaker thought that I probably didn't have both dreaded mold genes because of the very fact that I was able to take control of the situation. So he wrote that for those who do, my strategy would never work.

But after hearing about just how determined my avoidance strategy is, he began to reconsider and demanded that I have my HLA done. Turns out that I am, indeed, a Double Dreaded Mold Genie.

People underestimated just how serious I am about avoiding the Bad Mold.

-Erik (2008, CFSU)

* 

After Dr. S. realized that I did indeed have the double dreaded mold genes, I asked him if he knew of anyone else had managed to crawl back from my level of illness.

He said, "No. Not one."

So I figured it would be a good thing to make my story available for those who were in a really rough spot, and wanted to go all out because they have no other options left.

I didn't plan on advising this for anyone who isn't fighting for their life. Just though it beats the hell out of agony and death, while we wait for doctors to...

A. Figure out that we aren't kidding.

B. Do something about it.

-Erik (2008, CFSU)
Chapter 77 - Suicide

I wish there as a euthanasia center like the one in the movie "Soylent Green" where you could go and be treated with one last gesture of respect. (Okay, we can skip the part about being turned into people food.)

It is horrible to fight this illness so hard only to have to resort to such uncivilized methods and lonely measures to end one’s life.

I remember when Dr. Kevorkian helped a PWC commit suicide and everybody was appalled because they believed that what she was suffering from was some sort of depression.

This is one strange illness when you can't even get your own family to believe you, even when they see you go from being an athlete to bedridden.

I remember the professor in the Nazi propaganda film Dasein Ohne Leben (Existence Without Life) who was supporting the "mercy killing" of mentally retarded and insane people. He said that if by some mischance, he himself were reduced to such a state, he would wish for someone motivated by kindness to help him end his pain.

This illness is truly Existence Without Life.

This is one strange illness when it forces you to think that even Nazis may have a point.

-Erik (2001, CFSResearch)

*I remember Jim Leroy, a support group leader who wrote articles on the success he had in controlling symptoms by avoidance of chemicals that triggered his MCS. He grew increasingly reactive until he finally committed suicide, saying that he "could not longer interface in a meaningful way" with people.

That was his choice, and I respect it. I finally got to a point with MCS where I could no longer interface with much of anything.

Then at my lowest point I discovered that Stachybotrys was my primary trigger and started avoiding it like the plague. I've felt free of my severest symptoms ever since.
I don't have a quality of life that I consider to be acceptable though, and I use all of my new energy to try to get out of this mess and fight with people who say CFS doesn't exist.

I just think it is unfair that people don't have an option for death with dignity. Death is inevitable for everyone, but dragging it out until you are artificially sustained in a hospital with no hope of recovery does no good for anyone.

This is really off-topic for "research," except the part where I say that Stachybotrys really has a devastating effect on me.

I don't believe that Stachy causes CFS, but it sure can make it worse.

-Erik (2001, CFSResearch)

*

When I was in the Ampligen program and just desperately wanted out, I wished many times for a euthanasia center like the one in the movie Soylent Green (only without the postmortem sequelae).

One last reflective moment of the wonders of this world, a comfortable room where you can face the next step with serenity instead of a death hospital where you lay in shrieking agony with tubes down your throat and the inexplicable actions of health professionals who will try to keep you alive when you are almost dead, but not support research to seek a decent quality of life for CFS victims.

Suicide is a viable and preferable option to the perpetual living death of CFS.

Sufferers with the courage to step beyond the bedraggled remnants of a ruined life should be counseled and then assisted to die with dignity.

Society should view their choice with respect.

-Erik (2005, Locations)

*

If it hadn't been for the locations effect, I would have had no life at all or committed suicide long ago.

This effect has meant everything to me. It's not a cure since, as far as I know, nobody has found one, but in the absence of any effective treatment, this is the best I could do.

It beats the heck out of lying in bed waiting to die - and having death put you on a very long waiting list.
The lack of interest from CFSers is even more amazing than the lack of interest from doctors and researchers.

-Erik (2005, Locations)

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I was horribly worried about giving my illness to others.

I told Dr. Cheney that I would rather shoot myself than pass this on to my family and friends.

He empathized, but explained that killing myself probably wouldn't do any good.

Regardless of whether I was contagious or not, this stuff has gone around the world, transmitting itself by casual contact, and we are all taking our chances.

So committing suicide would be a noble but probably useless gesture.

-Erik (2009, CFSResearch)

*

I don't know how I survived. I tried to give up, many times.

Trouble is, you lay down to die, and it just doesn't work. So you stagger back up again and keep moving.

-Erik (2009, Email)

*

The number one thing that kept me from dropping the hammer was that I knew for damn sure that my family would have written on my headstone:

"Died of a Bad Attitude."

And I just couldn't let that happen.

I know not what course others may choose, but as for me, I say.... give me validation or give me death.

Preferably the former.

-Erik (2010, WPI)
Chapter 78 - Telling My Story

STANDING ON MT. WHITNEY

I am the only refugee from the Ampligen program who is getting ready to climb Whitney for the tenth annual time since leaving.

How amazing that I could go from such a low point to such a high one. And by a deliberate and concerted strategy that I proposed even as doctors were telling me that what I was doing wouldn't work.

This is why I thought that a mere picture of myself in "high places" with the words "Incline Village survivor - Ampligen refugee" would be more than enough to get some researcher to say to himself, "Wait, that can't be right" and try to find out how it can be right.

My story is selective in the sense that if one viewed CFS as some kind of fatigue illness, they would see nothing unusual in someone exercising their way out of it.

The only people who would understand that it means something are the people who have a very good knowledge of the history of CFS.

The first thing they should say is, "But that's impossible. He must not have real CFS."

Then they would be confronted by the peculiarity that if I had been an Incline Village survivor and in Dr. Peterson's Ampligen program, I couldn't possibly be faking.

So if a "real CFSer" who is not of the CDC's phony fatigue persuasion managed to do something like that, how did he do it?

-Erik (2008, CFSU)

MORAL DUTY

I remember being in support groups, hearing vague rumors of people who had recovered.

But if so, they never seemed to come back to tell us what they had done - or even if the rumor was true.

We all promised that if any of us found something that really made a difference, it would be our duty to come back.
"Mycotoxin Avoidance."

-Erik (2006, CFSExp)

MENTAL TOOLS

I've been public about this all along.

I can speak the words, and have done so a zillion times, and people attach no importance to them.

People just don't have the “mental tools” to perceive mold.

It's like saying, "I got better by staying away from butterscotch pudding." People find no meaning in the words, so it just disappears as if nothing had ever been said.

People literally have to be knocked to the ground by butterscotch pudding before they go, "Oh my God... so that is what Erik was talking about."

Now, substitute "black mold" for "butterscotch pudding."

-Erik (2009, CAA)

SELF-SELECTIVE

If I tell people how sick I was, it seems to make them recoil as if I were exaggerating in order to make a point. They seem to want to hear it from another source before they can accept it.

That's where I thought that being an Incline Village survivor would be useful. I can just point to Osler's Web and say, "I'm one of those people."

Even that doesn't seem to be enough, as there are varying levels of illness. So I try again.

"I was approved for the experimental Ampligen trials."

I don't know. It just seems that people try so hard to find excuses to not listen that once somebody has their mind set to dismiss this, it's not worth trying to persuade them.

My story is self selective, for only those who are ready to hear it.

-Erik (2008, CFSU)
It's weird to watch the way people approach this paradigm. We like to think that someone can simply explain it, and "That is that."

The reality is that people have to slowly accumulate bits and pieces, a gradual awareness from multiple sources over a long time, until one day, they are finally ready to hear about it.

Like... it just clicks.

But before that day, it sounds like somebody is trying to sell you snake oil.

-Erik (2008, CFSU)

DISBELIEF

I've spent many years controlling my symptoms by avoiding the chemical that mediated the immunological response to the viral trigger which swept though our community.

The chemical was mycotoxins.

I told everyone about it too. Nobody believed me until Shoemaker came along.

-Erik (2005, Locations)

I wouldn't dream of calling what I'm doing a cure, but it sure beats the heck out of the life I had before.

As I told an NIH CFS researcher in 1999, "I have permits to climb Mt. Whitney next month, and that's not too damned shabby for someone with Chronic Fatigue Syndrome."

This illness has nothing to do with fatigue. It's an out of control inflammatory response for reasons unknown.

But of course, for many people, the mere fact of finding something that helps is proof to them that "You never had True CFS," which means that anything you find is irrelevant to them.

-Erik (2006, CFSExp)
And some of the people who criticized you at the time now are so arrogant, as if they knew all along!

Yeah, even though you have posts preserving their words when they fought with you about it.

Schopenhauer was right!

"Stages of Truth":

"Mold illness is ridiculous, Stupid."

"Mold illness is impossible, Stupid."

"Mold illness? Why everyone knows about that! What are you? Stupid?"

-Erikenhauer (2006, SickBuildings)

What would you took a wild leap at something crazy, clawed your way out of this hell hole, went back to tell others of what you had seen....

And nobody believed you?

-Erik (2009, CAA)

People steadfastly cannot believe that my degree of improvement was due to avoidance of this effect, so I have no effective means to communicate it to them.

Denial is as simple as, "I don't think so."

It’s been 25 years since this happened, and all doctors and researchers still refuse to research this phenomenon.

In a weird kind of way, the disinterest has been more phenomenal than the phenomenon itself.

-Erik (2010, CAA)
THE DIVIDE

I traipsed around to various support groups and attempted to see if pictures of a prototype for a syndrome on top of Mt. Whitney were enough to get curiosity going. But it's hard to get people to give this any consideration.

As far back as Truckee High School, there were those of us who tried to get out of there. Others fought with us, saying the doctors said there was no need and the place was perfectly fine.

People like to believe that everyone responds to information as if it were the information itself which dictates how people will act. It turns out that people respond according to their own conceptual framework. If they don't have that framework, they simply will not respond.

Kind of like floods or volcanic eruptions. Same phenomenon. Everyone sees it, but some run and some stay.

-Erik (2008, CFSU)

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Given the belief that people have of "If someone found anything that helps, everyone would jump on it," I was worried about going into groups and saying how much this helps.

I was afraid of an unmanageable overload of interested people.

Imagine my surprise to see what actually happens when I say that I'm an Incline Village survivor and prototype for CFS who found something that seems to help.

Most people turn and flee. Others fight to demolish the concept.

Makes me wonder.... if anyone found a cure for cancer, the backlash would probably be so enormous that they'd kill the poor sap to shut him up.

Hey, maybe it's happened. There might be cures for cancer all over the place, but we never hear about it because the suppressive force to dispute these things prevents it from going very far.

-Erik (2008, CFSU)

*
People who are being pushed toward the wall are scared and trying to hang onto their stuff. Their life and everything they’ve worked for are slipping away, and they’re in fight mode to keep things the way they are.

They defend the concepts of filters, oils, remedies, and "hang in there at all costs."

After one hits the wall, everything changes.

A person at a lesser stage wouldn't dream of just abandoning everything and pursuing extreme avoidance strategies...

(This is what they are fighting to keep from doing.)

But a person who has been driven to the extreme wouldn’t dream of doing anything less.

That’s what I call “The Divide.”

Although I make a really good target because I am pretty outspoken about avoidance, the lesser stage mold responders see what happened to all severe mold responders, and everything we stand for, as a threat, the enemy, and exactly what they don’t want to become.

This is testable.

Just propose some extreme tactics in a group of lesser responders and watch what they do.

-Erik (2009, SevereReactor)

*

I remember working in a restaurant in Mill Valley when a flood happened.

I pointed out that we should prepare, as the creeks were still rising, the forecast was for more rain, and the water kept creeping higher and higher. People said I was just being negative, and that the water would probably stop rising.... hopefully.

"What gives you reason to think so?" I asked. "Is there anything that leads you to think that it won't keep rising, so long as the rain keeps falling?"

I was universally condemned as being pessimistic and having a gloomy outlook.

I thought it was just an objective assessment of the very real and "in your face" facts.
They actually got angry at me for making dire predictions and told me to just keep on doing my job as if nothing was wrong.

I said, "If it is still raining when the water hits the front door, I'm getting ready to have this place be flooded out."

It did and I did. I got everything damageable up off the floor that I could.

I got sandbags and plywood. Started boarding up exterior vents, placed the sandbags to deflect the water, and shoved towels under doors to stop the mud. Cut power to the outlets.

Nobody made a move to help me until the water was four inches deep, running right in the front door.

When it was all over, although the water came right in through the walls, it was so finely filtered that all we had to do was sweep up the dust and go back to work. We had done one heckuva job of sandbagging every crack.

I have pictures of what happened to all the surrounding businesses. They were mopping slimy mud and gooey silt out of their places for a week. Nobody else had thought to do more than throw a sandbag in front of the door. Their damage was enormous.

My boss said that I had saved her a week’s work of cleanup and a whole lot of stuff by putting it up high. She called the San Francisco Chronicle about the cook who refused to listen to naysayers, and they did a write-up on me.

As long as my boss owned that restaurant, I never had to pay for another meal there when visiting.

When it is all said and done, there are times when one person’s so-called "negativity" is actually a straightforward attitude of proactive planning... which is about as positive as anyone can be, under the circumstances.

-Erik (2009, CFSKnowledge)

THE PROPER CREDENTIALS

In 2000 I was visiting a friend who had a pipe burst at the water heater. The mold was knocking me flat and she had all the symptoms of reactivity. I kept trying to convince her that mold was causing an exacerbation of symptoms but didn't make much progress until her ears turned bright red, her ankles swelled up and the top of her feet became swollen, and she collapsed.
I literally carried her out of that house and took her out to the desert, where she recovered.

After persistent self testing in which we repeatedly came into contact with mold, she was finally convinced that this response was mold and not other chemicals.

When she tried to get help with this mold reactivity, all the doctors told her this was impossible.

Her own family, which has several doctors, insisted that mold was harmless. When she persisted in saying that simple experimentation of contact reaction had convinced her that she really was reactive to mold, her family contacted doctor friends at Stanford who assured them that such a reaction to mold was impossible and suggested that she see a psychiatrist.

Despite several home town incidents of a hospital and courthouse that required remediation and resulted in cases of chronic illness, the family continues to disbelieve her.

They maintained that she had been duped by the power of my Svengalian personality and that anyone who complains of mold illness are suggestible people who have been influenced by media hype.

They say that only supreme arrogance on my part could cause a layman to contradict the word of a doctor.

-Erik the Supremely Arrogant (2004, CFSResearch)

Imagine you are a Cessna pilot on a jet. The pilot and copilot got food poisoning and collapsed, and the stewardess steps into the cabin.

"Can anyone here fly a plane?"

You've never flown a "heavy," just small stuff.

Nobody else puts up their hand. What do you do?

I guess that I felt like I had a responsibility that no ethical person could duck, so I stepped up.
But it was amazing to have the passengers decide that my credentials weren't good enough, when that leaves nobody that even looks like they know how to land the damn thing at all.

So I just strapped on my MECU parachute and said, "Are you sure this is how you want it?"

I'm so stunned that this is indeed what they wanted that I just don't even know what to think any more of how the human mind operates.

-Erik (2008, Email)

* 

As hang glider design changed in the late 1970s, the control bar configuration became too large to use the same hand positions as for an old standard.

I was a new instructor at the largest hang gliding school in northern California, and as I had only recently struggled with the increasingly difficult old position, I saw how this was actually contributing to crashes during launch. We all agreed that "something should be done," but nothing was.

Finally, fed up with watching my students pound, I just went ahead and instituted a new hand position that matched the larger control bars. It was an instant success, and the pound rate went down to near zero.

I was naive enough to think that my superiors would be happy with me.

And when I was called into a general meeting of all instructors, I didn't see it coming.

They were furious and most demanded that I be fired.

The owner of the school just ripped me open even as he commended me for the success of the new teaching method.

In confusion at how angry they were, I said, "But we discussed how the old position needed to be changed. It was just a matter of time..."

That's when the fullness of my crime was hurled at me:

"Yes, but as a junior instructor it wasn't your place to do it."

Well... I liked my job, so I kept my mouth shut and didn't say what I was thinking:

"You're right. YOU should have done it."
-Erik (2010, CFSKnowledge)

**TOO “SOMETHING”**

I believe you're right. My story is too "something" for people to handle.

I tried everything else in terms of persuasive techniques, and it seems that nothing less than being outrageous gets people to sit up and take notice.

People who take partial notice jump into this, "But Erik, everyone knows to stay away from mold" and then, boom, onto the next goji berry juice discussion - as if the matter had been satisfactorily addressed.

Then they fail to describe doing much of anything in the way of real avoidance.

What I am doing is almost ungodly in its difficulty and complexity. Requires specialized tools, like the MECU.

But it does seem to me that if someone really, really wanted to stay alive, they could do as I did.

The very essence of how I present myself is a challenge test of whether someone has the type of attitude to pursue this course.

We could really be onto something big, here.

Thanks for putting up with my annoying ways.

-Erik (2008, Email)

**REGRETS**

Judging by the way my story is generally received, it looks like revealing it may have been the second worst mistake of my life.

The first, of course, being that I wish to God that I had never moved to Incline Village.

-Erik (2009, Locations)

**COMMUNICATIONS TECHNIQUES**
I have wasted a book’s worth of words trying to explain this without successfully conveying the significance of the mycotoxin connection.

I have taken people into moldy places and turned them into believers in minutes.

Once we determine if mold really is a factor in their symptoms, it takes me several hours to explain my avoidance strategy.

-Erik (2003, CFSResearch)

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I identify myself as an Incline Village CFS survivor or ExCFSer, since it is the phenomenon that I am trying to draw attention to... and it’s a butt kicker in its severe form.

-Erik (2008, CFSU)

* 

"Mountain Pilots" had a kind of mystique that put novices off.

We were viewed as arrogant, gruff and argumentative... not nice and willing to discuss like coastal soaring pilots.

But that was the very attribute which made for a successful mountain pilot.

Some coastal pilots were almost scared to ask mountain pilots anything.

Since my origins were among the coastals, I got to see both sides.

It was like a clash of subcultures within hang gliding.

And it was true that coastals had it easy.

They would just about shit a brick when they saw the increase in launch and stall speeds above 6,000 feet. Not to mention going from smooth ocean breezes to updrafts which rip wings off airplanes.

It's a whole different sport up in the mountains.

I think that it was a good proving ground for creating a kind of philosophical response that helped me get through this mold thing.

-Erik (2008, CFSU)
I figure that the best way I can honor the memory of those who have gone before is to stick to the facts and describe exactly what I saw, as straightforwardly as I possibly can.

-Erik (2009, CAA)

**ONE HELL OF A CLUE**

When Dr. Cheney asked me to volunteer to be in the 1988 study group to define the parameters of CFS, he said that this would be providing a valuable service in the cause of CFS, that I would have access to the leading edge diagnostic tools and technology that was being brought to bear upon CFS, and that special attention would be given to my case of illness.

I believed that by volunteering, this would compel examination of my complaints about mold.

The opposite happened. Instead of taking an interest, doctors, researchers and PWC's took this complaint as evidence that, "You must not have had CFS at all and are just allergic to mold.”

The very fact that I found something that helped was taken as evidence that I didn't have CFS: "Everyone knows that nothing helps, so if you found something that did, it just proves you never had CFS."

I don't claim to have a cure or even a viable therapy that can be applied to all cases of CFS.

What I have is one hell of a clue.

-Erik (2006, CFSExp)

* When I found that this same darn mold that was kicking my butt was also at Truckee High School and various other clusters of sudden CFS onset, it seemed to me that my status as a prototypical case of CFS and the association of this same mold with famous clusters of illness should have given this particular toxin a high priority - even if only as an exacerbating factor that can help alleviate suffering.

Much to my ever increasing amazement, nobody was interested.

-Erik (2006, CFSExp)
It has been a hell of a life. I've been living this way for nearly a quarter century, and I don't see how most people will ever be capable of doing it.

That's why I wasn't really thinking of offering this as a strategy, except to those people who desperately want to stay alive and are willing to undergo this level of deprivation.

My major goal was to get a doctor to listen to this and to believe it.

-Erik (2008, CFSU)

I didn't want to spend the rest of my life debating this concept, one on one, with skeptical people who tend to view my lack of credentials as an automatic lack of credibility.

The breadcrumbs were something I kept scattering about, thinking that eventually a serious researcher would encounter them and would respond as researchers were rumored to do under such circumstances.

-Erik (2009, SevereReactor)

I had thought that I could use "Stachybotrys/toxic mold" as my foot in the door, since it was found in several clusters of CFS.

It had seemed logical that a prototype for a syndrome should not need to lay out an entire theory or provide full scientific explanations to get attention to this clue.

I was just going to lead them to some of this "supersubstance" and say, "There it is."

-Erik (2009, Email)

In this case, it's because what I have to say is so contrary to anything we care to conceive that people do not care to conceive of it.

I can say the words clearly enough, but people will spend years insisting that my words make no sense.
As I've said so many times before, an effect moved into town. I've seen it knock people with no apparent health problems for a loop, but it is particularly devastating to people with CFS.

I learned to treat that effect as if it were plutonium.

What could be plainer than that?

I really don't care to “quander” what it is, as I do not have a research lab in my pocket.

But people really shouldn't have any difficulty with the concept that when you don't know what something is, and only have an idea of what it does, that's when you call it an effect.

-Erik (2010, CAA)

*

The thing that stuns me is that I could sail right on through the virtual ground zero for the creation of a syndrome that has gone on to be all the rage lately... and not one person agreed with me about the mold, acted on it, researched it, or recognized what was happening in these places, even after it was described to them.

-Erik (2010, SevereReactor)

*

From the very outset of CFS when I walked into Dr. Cheney's office, I was very careful to avoid expressing the problem in terms of "mold can do this"... because mold is very well known not to have such effects.

So I just kept repeating "an effect from mold," hoping that eventually, the sheer force of more people with complaints of this type would induce them to change their minds, and look into the mycotoxin "connection" to CFS.

It should have been obvious. They tested the heck out of various environments, and found nothing in common between them except a few species of mold that kept cropping up.

In an attempt to get the future "CFS researchers" that I knew would eventually be investigating the new syndrome to look into this specificity, I told them that perhaps some kind of pathogen interaction was involved: "Then it must be a bacteria, because whatever's got ahold of me seems to care a great deal about mold.”
But there was nothing I could do, nothing I could say, and no amount of more people collapsing in the presence of mold that prevented 25 years’ worth of researchers saying over and over...

"But mold doesn't do that, so there is nothing to investigate."

As I said a long time ago, "What does one do, when words do not suffice?"

I don't care what this is. I just know it is happening.

-Erik (2009, SevereReactor)
Part 5

Discussions
Chapter 79 - A Conversation with Keith Berndtson, M.D.

Following are some excerpts from a discussion between Dr. Keith Berndtson, a physician specializing in Chronic Fatigue Syndrome and related illnesses, and several CFS patients with experience or interest in pursuing extreme mold avoidance.

One of the problems with setting somebody up with "If your home...." is that if there is nothing wrong with your home, "home" is established as baseline for how much exposure one would need to have in order to become ill and the notion of having a mold problem tends to go out the window.

It doesn't really occur to people that they could pick up an illness-causing toxin load from various other sources which all accumulate over time.

-Erik

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Erik makes an important point. Brief introductions to the topic cannot do justice to the many nuances that must be understood and acted upon if sufferers are to get well.

As a doc who's trying to get a handle on what's known about toxic mold related illnesses, I find that every door I pass through leads to several others where one route is probably better than the rest but I'm not sure which to choose.

Are thought leaders in this area nearing the point where they can draft a reality-based algorithm for navigating from toxic mold illness to wellness?

A best-practice algorithm that considers history, exam, labs, environmental testing, other forms of testing, remediation, avoidance, detoxification and related matters would be a big help to docs like me who are trying to make this monster submit to a clinical protocol.

-Keith

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Dr. Shoemaker is probably furthest along in developing a concatenated dialectic to address those patients who recognize and pursue biotoxin illness.
The huge problem we Moldies see in various groups is that neither doctors or patients think this is really a problem as of yet.

We are sailing in uncharted waters here.

-Erik

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Regarding toxic mold in general, I keep thinking about potential ways to treat it. Since it's a toxin, the most reasonable strategy is extreme avoidance. Erik's had a lot of success once he figured out for himself how to do that. And besides, it's not like you can treat poisons like anthrax with a drug.

But other facts hint at potential drug treatments. Many people have different sensitization to mold, which vary depending on their genes and their past exposure to mold. At the extremes, enough exposure will do anyone in. But in between the extremes, there might be ways to alter sensitivity. High sensitivity is thought to partly be a failure of the immune system to detect the toxins in your system. So maybe sensitivity could be altered in some manner.

-Josh

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I've been mostly symptom free for several years with only occasional bouts of illness, mostly related to an immune system that doesn't appear to be quite up to snuff but is still vastly better than it was five years ago.

I cannot prove mold issues and it's too late for me to go back and check that, but I remain sensitive to mold. I believe I have repaired my body to a point where I'm no longer susceptible to illness from light exposure. I don't think anyone can live in an actively moldy building.

There are a multitude of "pests" that come into play and those seem different for everyone. It's just whatever one has been exposed to in their state of illness. Those can also be addressed effectively without causing additional damage to an already stressed body.

-Stormy

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Dr. Berndtson mentioned the need for a multi-pronged treatment algorithm involving many approaches, including remediation, avoidance and detoxification.
Could I ask for advice on doing one without the others? Avoidance is currently impossible for me. I’m caring for my mother, living in her moldy house. Given that I can’t avoid the mold for now, would you recommend that I try detoxing?

I live in England and call my disease ME, though I know that many people with the same disease are diagnosed as suffering from CFS. The name is a vexed question that I won’t go into here.

-Lesley

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It is strange that the CDC has managed to create a situation where people believe that there is confusion about the relationship between ME and CFS, when there really is none.

We had a diagnosis of ME even as the CDC ignored it and "provisionally" called the illness “CFS" as a temporary research tool.

But if one thinks of CFS as being the actual illness that was named CFS instead of just words on paper, then it is ME.

-Erik

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Lesley, rather than trying to detox, I suggest that you and your mother get out of the house as much as possible.

Preferably you would spend your time somewhere really clear. But it sounds like anywhere outside your house would be better than being there. Try to find a place where you get more energy even if you still feel bad.

In terms of supplements, I'd think about Vitamin C to bowel tolerance or in IV form, and working on candida.

-Lisa

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Lesley, my own situation is that I cannot persist in a place where I am gradually losing ground.

No matter what I've tried, I just keep losing more, and options just keep getting fewer as more money and health disappear.
It would be great if someone comes up with a miracle "something" that would change that, but I just haven't seen it yet.

Mostly, all I've seen are people that are fooling themselves into thinking that whatever it is that they are doing is really paying off. But if you ask them about it later, you nearly always find that they aren't doing "it" anymore because it wasn't really working.

-Erik

*

Thanks for the welcome and the thoughtful responses. So many nuances, so little time. Where to begin?

Erik and Lisa's experience with mold toxin sensitivity suggests a "when in doubt, get out" policy, which we know is easier said than done. However, it is probably not too much to ask for most sufferers to arrange a two week-long mold holiday while maintaining a symptom log about what improves and whether re-exposure triggers a heightened reaction. This alone might seal the deal for those whose doubts kept them from making what is admittedly a very difficult decision.

Also at the starting line is a need for careful self-assessment. We need a series of questions whose answers generate rough guesses as to the presence of mold and/or Lyme susceptibility. This would be a useful first sort for cases that qualify or have already qualified for a CFS/ME diagnosis.

We should then run the Shoemaker panel to see whether the self-assessment aligns well with Shoemaker's interpretation of susceptibility based on genetic and metabolic markers. We also need the clearest possible descriptions of how mold and Lyme toxins are alike and how they are different in terms of mechanisms of action and immune responses.

Superimposed on this understanding, we have to factor in TH1-TH2 immune system imbalances produced by viral peptides that overactivate TH2 pathways (neutrophils, eosinophils, and antibody-producing cells) when TH1 pathways (NK and cytotoxic T cells) are what's needed to contain viral damage.

With or without mold avoidance, the question remains open as to whether there can be a safe, reliable, and comprehensive detox regimen to support a path toward better health.

Please keep this discussion going. You folks are onto something that could figure hugely in a new paradigm for the prevention and care of chronic illness.

Keith
At least in some patients, the "chronic fatigue" of mold illness is a precursor to what eventually becomes CFS.

Mycotoxin problems seem extremely common these days, resulting in all kinds of vaguely sick people. Maybe some of these people currently are mild or moderate mold responders who (with continued exposure) will turn into extreme responders.

Erik showed signs of hyperreactivity and “chronic fatigue” long before the “Truckee Crud” flu-like outbreak in Incline Village, when he got full-blown ME-style CFS.

I tend to think of it as people who have acquired the HIV virus but have not yet become sick. Waiting to treat them until they’re in the throes of serious illness does not seem to be the best plan. Heading it off at the pass before things get too out-of-control seems a better idea.

I think this is of especial concern for physicians like Dr. Berndtson. He has a wide variety of patients with chronic fatigue issues. To the extent that some of these patients show signs of being "pre-ME," he may decide to treat them in the same way that he would treat CFS/ME sufferers.

-Lisa

Yes. Since 1980, I had been going to doctors and complaining about intermittent fatigue.

I kept pointing at mold, but doctors all assured me this was impossible.

Because I had the growing awareness of "bad places," I was amazed that when the Truckee Crud went through, it was people in these very environments who appeared to fare the worst with this flu-like illness.

I started asking the other members of the original CFS cohort about this connection, and it just kept cropping up again and again.

These people seemed to be just like me... especially susceptible to mold, perhaps even prior to the Truckee Crud.

One might vaguely remember "the tennis pro" from Osler's Web.

He had been in a helicopter crash and was pretty beat up, so he had a preexisting reason for falling apart. It wasn’t until I checked out the apartment he was living in that I made the connection that he was another person who had been in the presence of mold.
I read Osler's Web 10 years ago. I don't remember it well and I don't have time to read it again. It would help me think about this if you refreshed me by clarifying the distinction between CDC CFS (research purposes) and the ME described in Osler's Web (the Incline cohort).

The idea of mold toxicity setting people up for a fall into a combo platter of concurrent stealth infections seems to have the power to explain a quantum leap in gruesomeness.

A simple chemistry panel might pick up markers for increased systemic acidity and protein metabolism imbalances. For example, a low phosphorus, low Na:Cl ratio, low albumin, and low carbon dioxide levels (all being low but still within the reference range) indicate a low pH buffering capacity and elevated acidity. Total protein and albumin levels in the upper reference range indicate problems recycling protein and refreshing the amino acid pool.

The work of Sam Queen (Institute for Health Realities) documents the usefulness of these and other markers of metabolic imbalance that you'd predict would exist in people this sick.

We go crazy fishing for THE infectious or toxic agent when it may well be all of the above, in any possible permutation.

In this context, identifying who is in a mold toxic precursor stage would prevent tons of morbidity assuming compliance with mold avoidance and helpful detox support protocols (to be determined).

My next question is, how can we relate the CNS effects of toxic mold exposure to Dr. Hyde's description of a classic ME case vs. a classic CFS case? Where does toxic mold exposure come in, and how might it account for these presentations?

-Keith

Dr. B... that's the thing. There IS no discernible difference between classic ME and classic CFS.

Drs. Hyde, Parish and Shelokov diagnosed us with ME... and then our illness was named "CFS," so it had to be the same illness. That is why they walked out of the Holmes committee in protest.
Dr. Hyde used "ME/CFS" for a while, since he considered them the same thing.

But when the aftermarket distortions started kicking in, instead of looking to the originals, people started quoting the CDC's "CFS criteria" as if it were more definitive than our own experience.

Dr. Hyde, to protect ME, started saying that ME and CFS are not the same thing, but what he meant was the ME illness was not the same as the CFS definition: apples and oranges.

If you look elsewhere in Dr. Hyde's writings, it's clear that he knows that classic ME and classic CFS are the same thing. If they weren't, it would have been totally wrong for the ME literate doctors to have made that walkout protest about the renaming of ME.

-Erik

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Thanks to all for the clarification.

I see now that ME (the diffuse brain injury whose characteristics had been meticulously documented by respected physician-researchers over multiple epidemics, only to be swept aside by a pair of unethical opportunists and a complicit medical journal) is highly similar to the Lake Tahoe prototype, and that the CDC definition for CFS is a wobbly piece of fiction. Dr. Hyde seems to be one of the old school generalists who care less about labels than about what's really going on. He nails it when describing why the mainstream "name the disease, name the drug for the disease" paradigm is no match for chronic illness in general, let alone controversial chronic illness.

Chester and Levine found evidence that something besides an infectious agent and genetics is involved in these outbreaks and clusters, Shoemaker (with little outside help) has amassed a convincing case series indicating that biotoxins fit that bill, Erik makes a convincing case that mycotoxin avoidance can ameliorate and even totally resolve the diffuse brain and nervous system complications that arise in these cases, and Shoemaker finds that an adsorption agent (cholestyramine) helps in many cases and reasons that it might do so by driving an electrochemical or chemotactic gradient that pulls biotoxins (and perhaps other toxin types) from their cell membrane or intracellular locations into the bloodstream, hepatocytes, the bile, and out.

This is rich with possibility. If I understand Shoemaker, mold susceptible and multi-susceptible people are genetically unable to mount an effective acquired immune response to biotoxin exposure. They depend on innate immunity - the complement system. If I understand Cheney, acquired immunity relies on TH1 pathways to combat viruses, yeasts, cancer cells, and cell wall deficient forms; TH2 pathways to combat bacteria, parasites, toxins, and allergens. I also understand that some of the TH1
targets release IL-10 like peptides to ramp up TH2 and ramp down TH1, and that some of the TH2 targets release IL-12 like peptides to ramp up TH1 and ramp down TH2.

In this mix, we have trichothecene toxins that act like ionophores, disrupting cell membrane function in multiple ways including the activity of phospholipids and other ion channels, the behavior of various membrane receptors, G protein coupling, protein kinase signaling, ribosomal function, and so on.

Affected cells would send out their cytokine alarms, and as first, second, and third responders make their way to the brain they'd met with chaos and heavy traffic, making it hard for detection, elimination, and restoration systems to get a leg up.

As the cascade grows out of control (perhaps within 4 to 7 days of exposure to infectious and/or environmental triggers), cold-preserved brain specimens in such patients (like the Newcastle-upon-Tyne patient whose brain was studied by Dr. Mowbray) might be expected to reveal separations between brain capillaries and their adjacent basement membranes. This finding could be interpreted as a vasculitis or encephalitis, but these labels are not nuanced enough to capture the multiple pathway failures involved, a phenomenon better caught by the term diffuse brain injury.

This process might involve one cortex, both, or become a more global brain/spinal cord problem. In any case, if myalgias develop there would be plentiful hypotheses as to why. SPECT and other scans might prove to be a reliable way to document the abnormal brain function, but they'd remain expensive and poorly accessible without incontrovertible research to back them up, perhaps including treatment studies documenting what can done about it, which takes forever.

Then there is mold toxicity - such a Pandora's Box that insurance and real estate ownership lobbies would just as soon shoot legislators who'd propose funding for independent research on the matter before language makes it into a bill - and it appears they'd have the CDC riding shotgun.

That said, the best way to proceed is to keep building on what Hyde, Cheney, Shoemaker, and other key observers, including yourselves, have painstakingly laid out thus far. The goal would be to develop an algorithm for assessment and treatment that calls for certain inputs into the ME black box that yield reliably positive outcomes, a process that would be shared by the new great leveler of politics as usual in our time - a growing online community.

-Keith

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As time goes along and you see how consistently people are affected in sick buildings, you lose the "It's just me" mindset that doctors create by treating this as being "your individual illness," as if this was nothing more than your personal problem...
And tend to see the situation more as, "We are in a war zone, and it's hitting everyone to some degree, but they don't know it yet."

-Erik

*

> If I understand Shoemaker, mold susceptible and multi-susceptible people are genetically unable to mount an effective acquired immune response to biotoxin exposure. They depend on innate immunity - the complement system.

The interesting thing to me here is the implication that the complement system actually might be useful in clearing mycotoxins from the bodies of mold-susceptible or multi-susceptible people.

Dr. Shoemaker suggests in “Mold Warriors” (pp. 66-68) that the persistent elevation of complement (measured by C3a and, now, C4a) is wholly dysfunctional. He makes it seem like complement just has gone nuts.

We believe that it is elevated as a result of the tiny bits of mold toxin encountered, and that extreme avoidance can bring it down.

That being the case, is it possible that the complement activation actually has some functional activity with regard to eliminating the toxin? If so, what is the benefit?

-Lisa

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The body has had some 4 billion years to program itself to win, and we should not underestimate what is can do to compensate when its back is against the wall. Dr. Cheney's observation that the body dials down circulation and energy throughput in order to prevent oxygen toxicity is a compelling example. Are huge blasts of C3a compensatory?

The C3a response could reflect a functional mechanism, but despite its high voltage it's apparently not functional enough in those genetically susceptible to mold toxins.

Can Dr. Shoemaker or anyone else with expertise in immune system genetics specifically draw the pathway/mediator connections between the mold susceptible HLA pattern and a C3a response that appears overamplified compared to people without the HLA susceptibility?
Are there experts at National Jewish or elsewhere who might enlighten us as to what other conditions (autoimmune, toxic exposures, infections of various types, cancers, etc.) are associated with similar spikes or elevations in complement pathway activity?

If there are similarities with other conditions, do they extend to small patches of ischemic gliosis on brain CT or MRI?

If so, are the signs and symptoms in such cases similar to ME?

Is chronic Lyme a species of chronic ME?

How does brain pathology in chronic Lyme match up with brain pathology in non-Lyme chronic ME, and do we know how the immune response affects the brains of chronic Lyme patients compared to the the brains of non-Lyme chronic ME patients?

What are the signs and symptoms that might reliably differentiate chronic Lyme from non-Lyme chronic ME?

By looking elsewhere for a mechanism, where should we start? Additional genetic susceptibilities? Concurrent toxic and/or infectious exposures? Other? All of the above?

-Keith

*  

Lyme is not a species of ME. They are two separate illnesses.

It's a good question, though, because both Lyme and ME are typically chronic conditions. Both are often diagnosed as “CFS” as both can cause fatigue. There is some overlap of symptoms, but they can be distinguished.

ME causes neurological damage, cardiac dysfunction, post-exertional muscle weakness, and orthostatic stress intolerance, which Lyme typically does not. Lyme can cause emotional symptoms and very occasionally delusions or psychosis.

-Lesley

*

Lyme does cause neurological damage, cardiac dysfunction, post-exertional muscle weakness, and orthostatic stress intolerance.

It's a part of my theory that Lyme, mold, candida, and a multitude of other things can cause similar damage. The underlying cause is different, but it manifests similarly. If it goes on long enough, the other factors come into play. There is a domino effect. And a which came first, the chicken or the egg?
What is the real cause of some being extreme mold responders? Or susceptible to Lyme infection? Or riddled with candida?

If you have any of the above you should address the possibilities of all of them, not just one.

-Stormy

*

I've seen everyone around me addressing all these things you mention as hard as they can. I'm glad they are doing it, so I can see what works, and what doesn't. They discuss therapies endlessly and recommend all of them to me, which I appreciate. When one of these therapies works well enough that they accompany me out mountain climbing, I'll be happy to try it.

-Erik

*

From what I can tell, of all human assertions, the one closest to the truth is that reality is always more complex than we think it is. Uncertainty always remains, but lessens over time as the current paradigm of best fit gives way to a new paradigm of best fit.

So what is the most accurate case definition for CFS, and the most accurate and precise explanation so far for the etiology, pathophysiology, diagnosis, and treatment of it? Let that explanation be the platform from which the community builds the next paradigm upgrade.

Out of curiosity, have any of you had first or secondhand experience with, or otherwise formed opinions about, the Marshall Protocol?

-Keith

*

Professor Marshall is earnestly trying to figure out why some people simply cannot tolerate the MP, and get steadily worse instead of better.

Wouldn't it be something if the difference was found to be compensated for by biotoxin avoidance?

-Erik

*
Erik, that's a valid hypothesis. It would be nice if Dr. Marshall could poll his non/worse-responders about mold just to see if it raises an index of suspicion that you're right.

A proper test of the hypothesis would require an airtight mold avoidance trial. It's probably worth describing what bases absolutely must be covered for a mold avoidance trial to provide an airtight answer to the question, "Am I a mold toxin reactor?" Also, what's on the list of non-mold biotoxins that Marshall non/worse-responders should worry about, and how can they conduct a trial to find out if they're an issue?

Processing the views posted on this board keeps pressing me to think about CFS in new ways, which is a credit to your group.

-Keith

*I've been bugging Dr. Marshall to do that very thing, but we just wind up swapping our emphases and they cancel each other out.

I ask why he wouldn't be interested in pursuing the mold connection and he just replies that this is just a consequence of TH1 illness, and when I'm sick and tired of playing hooky from civilization and ready to do something about my reactivities, to quit futzing around and start his protocol. My point was that I am doing far too well to take unnecessary chances at this point, and am letting others be the guinea pigs.

I have been monitoring stories on his website, and I do indeed see that some people on his protocol are screaming mold clues, although they don't know it. I've been slowly sneaking more mold info into the equation in various groups, and I see a gradual movement toward acceptance of the possibility.

It's weird to watch the way people approach this paradigm. We like to think that someone can simply explain it, and, "That is that." The reality is that people have to slowly accumulate bits and pieces; a gradual awareness from multiple sources over a long time, until one day they are finally ready to hear about it. Like, it just clicks.

But before that day, it sounds like somebody is trying to sell you snake oil.

-Erik

*We have a need to define, analyze, and break things down. However, many of the promising theories about CFS (such as Shoemaker’s, Pall’s, Marshall’s and Rich van Konynenberg’s) were formed by keeping such classifications at an arm’s length.
A key assumption in all of these approaches is that some underlying mechanism may be manifesting itself differently across distinct disease groups. This is something that a narrow approach simply can't pick up on.

But this works from a more concrete perspective as well. For instance, post-exertional malaise and orthostatic intolerance are studied in COPD, exercise physiology, and altitude sickness.

Anyway, I guess that's the glass half-full perspective.

-Josh

* It's the fine print of what makes the illness different from others that tells us the most about it.

Remember, the CDC was willing to consign the whole lot of us to a vague and amorphous "CEBV Syndrome" simply because 99% really did have elevated EBV. It took Dr. Cheney to utterly bring down the CDC's paradigm, by showing that so much as a single exception can disprove the rule.

It was because his approach came from the completely opposite direction. It was focusing on dissimilarities that gave us "CFS."

-Erik

* The Baltimore sessions posted on Scivee make your point, Josh. A lot of solid information came from the mainstream researchers who presented that day.

But how is that information getting integrated into a bigger, more coherent picture? It's a generic problem in mainstream medical research and practice. Research specialists operate in their silos, clinicians operate their silos, and once a careerist finds his or her way into franchise mode, there's little reason anymore to think outside of the box, where reality is, being more complex than we think it is. With a gold mine of information in these fragmented silos, nobody seems to be in charge of integrating the pieces together.

Dr. Marshall discovered an important piece if stealth pathogens have indeed evolved a way to hijack vitamin D's ability to express genes that make proteins that lymphocytes use to shoot holes into the membranes those pathogens. It's even more impressive if it turns out that olmesartan can block this ability. Minocycline plays a role in Phase One of his protocol, but what role? Antibiotic? Antiviral? IMPACS? What about azithromycin and clindamycin in Phase Two?
From Erik's perch on the mountaintop we can look out on the sea of people with CFS/ME, Lyme, Sarcoid, autoimmune disease, and the host of chronic illnesses that share systemic similarities yet include processes that pick on the brain here, the lungs there, the muscle over there, and so on.

The only problem-solving mindset that can possibly match this puzzle form is an integrative one, but an integrative clinical problem-solving mindset has yet to establish itself in mainstream clinical practice or research. Reasons include close-mindedness, lack of time, lack of funding, lack of effective PR, cultural bias, franchise mode, turf issues, and whatever threats a new paradigm poses to established ways of thinking and doing business.

Society should at least understand what's at stake. If it were to support an all-out effort to integrate the data and experience that's already available on CFS, the benefits would apply to the prevention and care of chronic illness in general.

With the coming aging boom there will be an acute shortage of dead people in the senior ranks - people who'll be dropping their chronic health complaints onto Medicare in the US and the universal health systems in other industrialized countries. Can these countries afford not to take into account the effects of industrial chemicals and toxic mold on chronic illness?

Shouldn't the public understand that stealth pathogens and resistant strains are waging tough competition with the human immune system, and that our industrial exposures may be helping them win?

CFS research is documenting how fuzzy forms of severe debilitation can come about, and how genetics makes some people more vulnerable than others. This information should not be flying under the radar of mainstream thought and opinion - it should be front and center, being filtered first into knowledge and then into wisdom as fast and as well as possible by people and organizations whose job is to use an integrative, wide-angle lens needed to defragment what's already known.

-Keith

*

Yes, society should make some effort to understand what is at stake: an almost indefinable degradation of the quality of life is clearly discernible to anyone over fifty years old.

When I began my mold journey, the very "experts" that are being cited as evidence that mold is a “known factor” told me they had never heard of complaints like mine. That is how fast this mold paradigm shift has overtaken us, and it shows no signs of slowing down.
Opponents of "mold hysteria" are pointing to a very recent subsidence of mold legal claims as proof that the problem is not increasing. The factor they conveniently leave out is the frantic rush by insurance companies to write all-encompassing exclusions for anything related to water damage and mold in the last decade.

This is a similar phenomenon to what happened immediately after "CFS" was coined. We were in the peculiar position of being denied benefits for an illness which the entire medical profession said was nonexistent.

In just a few short years, mold evacuations have gone from unheard of to a commonality of such magnitude that it is becoming difficult to find anyone who doesn’t have a mold story.

Society had better take notice. This is happening quickly.

-Erik

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I try to think in terms of which root dynamics are shared by various illnesses, and then which downstream dynamics constitute the fine print differences. For example, how many chronic diseases and illness syndromes are preceded by inflammation?

Well, what is inflammation? It's not a black or white phenomenon, it manifests in multiple shades of gray. Yet every shade begins with the expression of genes that code for pro-inflammatory cytokines. So atherosclerosis, metabolic syndrome, inflammatory osteoarthritis, osteoporosis, Alzheimer's, COPD, and autoimmune diseases are all preceded, usually for some years, by increased cytokine chatter.

CFS/ME, toxic mold syndromes, Lyme, post-infectious fatigue syndromes, and so on are preceded by cytokine chatter as well, but what may be for mere days.

The fine print distinctions begin with the individual's Hap Map - the genetic variations they've inherited - and how these would affect gene regulation and the proteomics of immune system function, hormonal function, detoxification systems, methylation pathways, etc. Thus the various manifestations of insidious routes to chronic disease as well as the acute to chronic disease shift would show distinct patterns of abnormality and dysfunction in biochemical pathway based on genetic differences.

These fine print differences branch out as early as the transcription, translation, and protein synthesis phases, but clearly carry down to HLA markers, TH1/TH2 balance, dopamine/folate balance, sympathetic/parasympathetic balance, and so on to involve dozens of "early branch point" ways of distinguishing one disease process from another.
The wide-angle clinician in the trenches starts with a detailed, mission-oriented history and tries to reason his or her way to making sense of what's going on. The mission is to understand when the person last felt perfectly well, how significant health turns for the worse unfolded over time, and thinking what could have caused each bad turn. Ideally, this process generates a few solid working hypotheses that are able to get at the reality of what's going on. Snap diagnostic judgments have little place in the chronic illness care arena).

What laboratory findings would help such clinicians derive the best working hypothesis to explain what's going on with patients in these chronic illness categories?

What can we infer about someone's illness based on their response or non-response to empirical trials of therapy?

What then can we learn about which chronic illnesses share the same "early branch point" abnormalities? The answers to such questions can help us determine which "age-related chronic diseases" share fundamental similarities with "post-infectious chronic diseases."

From 30,000 feet up, it stands to reason that industrial chemical and biotoxin effects are playing significant roles in both age-related chronic disease and the appearance of new post-infectious/post-exposure syndromes like CFS/ME.

Let us be humble about the subtlety and complexity of what we're up against as patients and doctors concerned about these debilitating forms of chronic illness. But let us also work to change the mindset within our health system to more doctors and researchers are willing and able to address the reality of our situation.

I'd like to know more about what other poisons emanate from toxic molds beyond the ionophores. What forms do they take and what do we know about their biological effects?

-Keith

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Dr. B, you've gone straight to the point.

What we do know is that the studies on these toxins per se do not appear to explain the scope of the observed phenomenon. That would make it highly counterproductive to view any of them as causative.

They seem to be more of an especially critical component of a process that occurs under certain conditions.

As Dr. Cheney said, so long ago, "A New Dynamic."
There exist a number of different mycotoxins for which we have no data about their toxicity. Trichothecenes have been the object of more thorough laboratory testing. We know that they exhibit their toxicity through DNA and RNA synthesis inhibition. The brain and immunological systems are therefore sensitive organs to these poisons (Feuerstein G., et al 1989).

A considerable number of other fungal metabolites exist from which we have gathered few data. Preliminary results seem to unravel general and neurological toxics effects in many of them (Watson D. H., 1982). In Table III, it is possible to compare the acute neurotoxics effects of well-known agents compared to the only trichothecene studied in human (DAS).

Table III. Comparative Scale of Solvents and Mycotoxins Associated With Human Neurotoxicity.

<table>
<thead>
<tr>
<th>Known Human Neurotoxics</th>
</tr>
</thead>
<tbody>
<tr>
<td>Toluene: 65 mg/kilos (Inh-8hrs man)</td>
</tr>
<tr>
<td>Xylene: 74 mg/kilos (Inh-8hrs man)</td>
</tr>
<tr>
<td>Stryrene: 37 mg/kilos (Inh-8hrs man)</td>
</tr>
<tr>
<td>Trichothecene In Man DAS; 0.09mg/kilo (i.v. -rapid-70 kilos man) 0.26mg/kilo</td>
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</tbody>
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Two other publications seem to entertain a similar hypothesis (Leving P.H., et al 1992, Chester A.C. et al, 1994). They described cases of chronic fatigue syndrome in
buildings with indoor air problems. Also a few epidemiological studies of other symptoms than respiratory have shown significant relative risks of exposure to molds and humidity giving rise to symptoms like depression, aching joints, nausea, tiredness (Waegermaekers M., et al 1989, Platt, et al 1989). Finally Gordon et al (1993) reported a neurological syndrome in a young man consisting of dementia and tremor possibly related to the presence of different toxicogenic Aspergillus and Penicillium in a moldy silage.

* 

Other component of "The New Dynamic."

-Erik

Daniel Peterson, MD, Medical Director of the Whittemore Peterson Institute and past president of the International Association for Chronic Fatigue Syndrome (CFS) will lecture on the role of viruses such as parvovirus B-19, enterovirus, Human Herpesvirus-6 (HHV-6) and Epstein Barr virus (EBV) in patients with CFS.

* 

Erik, thanks for digging up that chapter on mycotoxins. Looking at the neurotoxicity of toluene, xylene, and styrene and seeing that a trichothecene-derived toxin (DAS) is 1,000 times more toxic gives new meaning to the word gruesome.

Trichothecene-derived toxins are considered biological weapons-grade material. They were in the Khmer's yellow rain attacks on the Laotian people in the mid-seventies. Their CNS effects are striking, but they can also effect GI, respiratory, cardiovascular, eye, skin, immune, and bone marrow systems. Onset from acute exposure seems to be a few hours, lasting up to 9 days (described as stage 1). Later stages are described.

http://www.iaqm.com/trichothecene.html

Do you think the Tahoe, or other ME/CFS epidemics, involved a viral-mycotoxin double whammy?

Is there any evidence collected to support this?

Do Dr. Peterson's HHV-6a cases suggest that this virus acting alone is enough?

Erik, did you have high HHV-6 titers? If so, would you have considered a spinal tap and Vistide therapy if mold avoidance wasn't already a sufficient treatment?

What are Dr. Shoemaker's latest thoughts on biomarkers of toxic mold exposure?
I know the test exists, but has anybody obtained IgM testing against satratoxin?

Would antibody responses against satratoxin identify those less susceptible (because mold susceptibles don't mount effective Ig responses to exposure)? If so, then we should look for a sick building outbreak and screen samples of exposed sufferers and non-sufferers. If the non-sufferers are positive and the sufferers are negative for anti-satratoxin IgM but positive on a Shoemaker panel, then we've got some good evidence to support Shoemaker's work so far.

Sorry about spraying folks with questions but I'm kinda bent on seeing what kind of integrative CFS algorithm can emerge out of this discussion.

-Keith

* Everybody from Dr. Croft in 1986 to Eckhardt Johanning in the Lopate radio show have referenced mycotoxins as "a toxin in search of a syndrome," and have even speculatively wondered what connection these molds may have to CFS.

So it is surprising to me that they take no interest when I tell them that I was a prototype for the syndrome who implicated mold at the time I was made a prototype.

Yes, I had high HHV6A, and was approved for the Ampligen trials. However, I was unimpressed with the results, knew from experience that mold was a huge factor for me, and decided to try an experimental strategy of extreme avoidance.

Although people back in those days had heard of folks who moved out of mold infested buildings, they had no idea of doing anything more extended, such as quick decontamination after momentary exposures and paying attention to plumes where ever they may be.

It was basically impossible to get people to act upon my information before the mold epidemic made itself apparent.

At this point, I am now asking for research into the incredible "Disinterest Response" from the medical profession, as this is about the scariest antiscientific behavior that I could have ever imagined.

Yes, I saw other member of the original cohort who were having the same reactions Lisa had when I took her to places that are critical to the early history of CFS, so I do believe that we were hit with a double whammy.

In 1999, I asked Dr. Marinkovich about Ig testing to satratoxin, and he said it was unavailable. I asked how he was determining the degree of reactivity people had to
Stachy, and his reply was that he was extrapolating it by the reaction people had to other measurable mold responses.

That's when I said that this wouldn't work, because, "Compared to Stachy, these other molds are less than a mosquito bite on my ass."

Of course, I wouldn't have known this if I hadn't done my own proximity testing to find out. So other patients, who had no way of knowing how fierce Stachy can be, may have been misled.

-Erik

*


Do we know how transfer factors would help against viruses?

Herpes viruses only, or parvo-, borna- entero-, and echo too?

On what basis would one transfer factor be selected over another?

What do we know about Dr. Cheney's buffalo heart preparation?

-Keith

*

Looks like what the CDC read in Mold Warriors is finally starting to make sense to them.

-Erik

Transcriptional Control of Complement Activation in an Exercise Model of Chronic Fatigue Syndrome.


Authors: Sorensen B, Jones JF, Vernon SD, Rajeevan MS.
Complement activation resulting in significant increase of C4a split product may be a marker of post-exertional malaise in chronic fatigue syndrome (CFS) subjects. This study was focused to identify the transcriptional control that may contribute to the increased C4a in CFS subjects post-exercise.

Differential expression of genes in the classical and lectin pathways were evaluated in peripheral blood mononuclear cells (PBMCs) using quantitative reverse transcription PCR. Calibrated expression values were normalized to internal (peptidylpropyl isomerase B [PPIB]) or external (ribulose-1,5-bisphosphate carboxylase/oxygenase large subunit [rbcL]) reference genes or geometric mean (GM) of genes ribosomal protein, large, P0 (RPLP0) and phosphoglycerate kinase 1 (PGK1).

All nine genes tested, except mannose-binding lectin 2 (MBL2), were expressed in PBMCs. At 1 hr post-exercise, C4, mannan-binding lectin serine protease 2 (MASP2) and ficolin 1 (FCN1) transcripts were detected at higher levels (>\(\geq\) 2-fold) in at least 50% (4 out of 8) of CFS subjects that increased to 88% (7 out of 8) CFS subjects when subjects with over-expression of either C4 or MASP2 were combined.

Only increase in MASP2 transcript was statistically significant [PPIB, \(p=0.001\); GM, \(p=0.047\); rbcL, \(p=0.045\)]. This may be due to the significant but transient down-regulation of MASP2 in control subjects (PPIB, \(p = 0.023\); rbcL, \(p = 0.027\)). By 6 hrs post-exercise, MASP2 expression was similar in both groups.

In conclusion, lectin pathway responded to exercise differentially between CFS and controls subjects. MASP2 down-regulation may act as an anti-inflammatory acute-phase response in healthy subjects, whereas its elevated level may account for increased C4a and inflammation mediated post-exertional malaise in CFS subjects.

* The conclusion to the study whose abstract Erik provided above:

“In conclusion, this study detected expression of both classical and lectin pathways in PBMCs of normal healthy and CFS subjects, but transcripts for components of the lectin pathway (C4 and MASP2) were observed at higher level in CFS subjects 1 hr post-exercise. Higher expression of C4 and MASP2 may contribute to the increased C4a split product in CFS subjects 6 hr post exercise. MASP2 expression was significantly down-regulated in control subjects 1 hr post-exercise, and this down-regulation may be mediated by the anti-inflammatory effect of cortisol in response to exercise. Further
studies are needed to replicate the differential expression of complement genes and its potential link with inflammation and cortisol secretion in response to exercise.”

Notice the possible connection with hypocortisolism, in which decreased cortisol release post-exercise may be what allows transcription of C4a splitters to proceed at a higher rate than in healthy controls, who produce enough cortisol within 1 hour after exertion to contain the complement system.

Such a dynamic could apply to toxic mold responses where high C4a levels are also seen. Perhaps the same CDC group would be interested enough to compare the time vs. C4a level curves in post-exertional CFS with post-acute toxic mold exposure CFS, and then correlate any differences with HLA typing.

This might allow subtyping of CFS patients using HLA typing and post-challenge C4a levels as biomarkers.

More of this kind of research could make the disinterest response too conspicuous to ignore. Then again, it may be the kind of bias that only fades one funeral at a time.

-Keith

* Dr. Berndtson. You have just put me in shock.

I've spent twenty years trying to describe this effect to doctors, ever since I helped launch the “CFS epidemic,” and you are only the second physician, in all this time, who didn't just walk away, or go all-out to shoot it down.

That's all I have: an effect that needs to be matched with an explanation.

I am basically like one of those people who are severely affected by peanuts that didn't die, because they figured it out in time to take special precautions. As Dr. Peterson said to me ten years ago, people like me generally don't get this far. So they literally are not around to make the types of observations that the survivors can.

Minutes ago, I was in a bank, which was acting up so badly that I was getting overt signs of a slam, and I heard the most amazing conversation.

One teller remarked that he was too hot, and others started saying they were too cold. They all thought that it was odd how differently they were responding to this area, and started comparing notes.

One said that her fingers were numb as if it were colder than it really were. Another said that he was sweating profusely as if it were hotter than it really were. Yet another said
that he was only comfortable at 78 degrees, and was intolerant of more than a few degrees either way.

It was really amazing to hear this discussion, since this is one that is common to CFS groups, and it is also exactly what happened to me in a mold zone. And this loss of thermoregulation was restored when I adopted extreme avoidance.

Boy, wouldn't I love to measure their C4A at that bank, and compare to when they are on vacation.

Everybody knows that canaries, the "susceptible" ones, will be the first to start showing signs of an impending catastrophe.

Society had better start listening to us, because when their security blanket belief that "It's just you" changes to "Oh my God, this is happening to everyone" occurs, things are bound to become a lot more interesting.

-Erik

*

Seems that a doc who doesn't show signs of the disinterest response can trigger a C4a-like response in you, Erik.

I just skimmed Dr. Shoemaker's National Toxicology Panel remarks, and this is all starting to make a large amount of sense.

To think that toxicology studies once led researchers to conclude that toxic mold spores place on rat trachea resulted in a linear dose-response type of pathological response, and that the mold field has run with this concept for years without thinking about the pathological response as a more complex equation, puts me in shock.

The Shoemaker post also shows how much thought his team has put into this phenomenon. This is a ripe time to try to create a new synthesis of ideas on CFS and water damaged building syndromes.

-Keith

*

One way to assess CFS/biotoxin illness is to look for orthostatic intolerance (OI) using what's called an Ansar machine, which painlessly measures HR & BP over 10 minutes as you stand, sit, and do a few breathing exercises.
Within one patient, OI can vary day-to-day and week-to-week. This makes sense as in the context of biotoxins, as OI may be some people's inflammatory responses to biotoxins.

-Josh

A patient's LabCorp Shoemaker panel shows a mold and multisusceptible HLA pattern, her C4a was 3447, MMP-9 was 1857, leptin was 33.8, and MSH was 10. VEGF was 456 and C3a was 2479. She worked in a water damaged building. The employer remediated by replacing affected walls, and had a mold testing company measure the remediated work environment (methods not known), with results showing "less mold in the space than outdoors," according to the patient's account of what the testing company told the employer.

This patient's home does not appear to be a problem. She had test looking at WBC volume changes in whole blood after exposure to antigens/inciting agents. This test (ALCAT) claims that any significant WBC volume changes following exposure are a cytokine-mediated phenomenon. She showed two severe reactions to molds: trichoderma, and curvularia.

She started on Valcyte 2 weeks ago (prescribed by an out of state doc knowledgeable about CFIDS), and she reports more brain fog as a result.

Interesting case. The patient and I are both looking for any insights.

-Keith

Any test that compared indoor vs. outdoor mold levels would be an air test. Unfortunately, those tests are a) the standard in the industry and b) useless with regard to measuring the presence of Stachy, which seems to be the most problematic mold for us.

I have serious doubts about the use of Valcyte or other antivirals in patients with mycotoxin illness, if they're still getting mold exposure. I've seen an awfully lot of sick people take Valcyte and end up far sicker than they started after they stopped the drug.

Before I found out about the mold, I was taking a small dose of a mild antiviral (Famvir). It depleted my system strength and, apparently, my HGH levels My suspicion is that my MSH level might have decreased also. This is the last thing that people with biotoxin illness need.

-Lisa
Dr. B. As best I understand it, the chronic inflammation from innate activation complexes derails the very programming necessary for the WBC response that doctors are looking to as an indicator of illness.

The lack of response misleads them. The illness is the indicator, not the tests which fail to detect it.

I remember a gal who had become ill in a moldy shipyard, became reactive to mold in her house, had moved multiple times, and was being plagued in a place why, by her own description, she felt better inside than outside by virtue of having six Hepa filters on at all times.

That tells the story right there. She is in an ambient mold zone, and the only relief she is getting is from the amount that her Hepa filters are removing indoors.

I suppose that if the Hepa system were so effective that she felt quite recovered in her house that over time, the chronic inflammation might damp down enough to allow her to recover, but this is not what she described.

She was still sick in that house, but slightly LESS so.

From what I have seen in people, that's not good enough to hope for a recovery.

-Erik

Lisa, the patient whose home you visited had an MSH of 9. In Mold Warriors there is a comment to the effect that if want to know if you're getting better and will be all right, the first question is, "What's your MSH?"

My question is, what's the best combination of ways to get the MSH headed up?

Avoidance, adsorbers (CSM, what others?), PPAR agonists (Actos, what others?), fresh air, what else?

How often does Dr. Shoemaker repeat the MSH level?

Does he target for monitoring whatever was abnormal or suspiciously high or low within its reference range at baseline, or does he choose his markers in another way?

Do VCS improvements correlate with increasing MSH?
Does he order API-Staph kits and perform the MARcoNS tests in his office? Would I need CLIA certification to bill this test to insurance?

Also, the ANSAR machine sells for 48K, and the equipment lease is $895 per month. I wonder if Shoemaker sees it as potentially useful beyond disability cases.

Keith

*

It’s my impression that this patient’s current living place is bad enough that merely moving out and maybe putting possessions aside (without doing extreme avoidance) could help her a lot.

She says that she tends to start to feel better cognitively after a few hours away and hates to come home from trips away. That suggests to me that just getting away could help her.

I wouldn’t expect MSH to go up insofar as someone was living in a bad environment.

Here is a comment that Rich van Konynenberg made about MSH.

Lisa

MSH is made from part of the molecule called POMC (proopiomelanocortin), which is formed in the pituitary. Other parts of this same molecule are used to form ACTH (which signals the adrenals to secrete cortisol) and an endorphin (which makes us feel better).

If the cells in the pituitary that make POMC are low in glutathione, they will not be able to make as much POMC as normal, and they will not be able to route it to the so-called regulated secretory pathway.

The reason is that there is normally a hook on the POMC molecule that contains four cysteine residues that have to be connected together properly to form the hook, which is used to route the molecule to the right pathway. If there isn't enough glutathione present when amino acids are strung together to make the protein, this hook will not be formed properly, because the cysteines will bind together with each other too soon, forming cystine molecules with the wrong partners, and this will mess up the process. A lot of the bogus molecules will be sent to the recycling bin (the proteosome), and others will be routed to the unregulated secretory pathway.

The human growth hormone molecule has two cystine disulfide bridges in it. If those are not formed properly, the molecule won't do its job properly. Glutathione depletion is the problem here, too.
By the way, this same argument holds for antidiuretic hormone, oxytocin, ACTH, and perforin in NK cells. It may apply to some other secretory proteins in CFS also, but I haven't checked them all out.

The reason I'm fond of this part of the hypothesis is that it can explain the oddball collection of several symptoms and several corresponding known biochemical abnormalities in CFS.

* 

Below find excerpts from a PhD dissertation by Enusha Karunasena that came up on a mold toxicity search I did a few months back. It's dense text. I only included the list of figures so you can get a feel for the scope of cellular biomarkers examined in human brain capillary endothelial cells (HBCEC) and astrocytes (AC), along with the section and overall conclusions.

I share this because it dovetails with:

1. Sorenson's study on lectin pathway transcriptional and cortisol regulation abnormalities in CFS patients post-exercise;

2. Rich van K's comments on VEGF, EPO, POMC cysteine groups and glutathione in people who have cleared inflammatory responses vs. those who still suffer from active inflammation (accounting for why "cleared" CFS patients respond to gradual exercise training and higher elevations, and "non-cleared" patients get toxic instead;

3. Dr. Hyde's descriptions of ME patients with signs of capillary endothelial damage;

4. Dr. Shoemaker's unraveling of the biotoxin pathway; and

5. Various studies implicating cytokine upregulation and hormonal dysregulation in CFS.

THE MECHANISMS OF NEUROTOXICITY INDUCED BY A STACHYBOTRYS CHARTARUM TRICHOTHECENE MYCOTOXIN IN AN IN VITRO MODEL

ENUSHA KARUNASENA, M.S.

A Dissertation in Microbiology and Immunology submitted to the Graduate Faculty of Texas Tech University Health Sciences Center in Partial Fulfillment of the Requirements for the Degree of Doctor of Philosophy

Advisory Committee, David C. Straus, Chairperson

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SECTION 1 CONCLUSIONS (Satratoxin H effects on human brain capillary endothelial cells)

Results from the adhesion molecule receptor expression on HBCEC demonstrate that satratoxin H levels of 100ng/ml and 1000ng/ml are able to induce inflammatory pathway activation alone. Additive effects are demonstrated with very low concentrations of SH, such as 10ng/ml in the presence of inflammatory agents such as LPS and H202. Similar concentrations of the mycotoxin are able to induce apoptotic pathways leading to the activation of early stages of apoptosis in the presence of 100ng/ml SH, however evidence of late stages of apoptosis are observed with 1000ng/ml and 10ng/ml + LPS or 10ng/ml + H202. These results demonstrate the ability of satratoxins to induce apoptotic pathways at the same concentrations that inflammatory pathways are being activated. This suggests that low levels of inflammation and apoptotic events can be induced in the presence of moderate levels of SH, and low levels of SH are able to induce similar events in the presence of other inflammatory agents and oxidative stress conditions, as demonstrated by the levels of GSH and cytochrome C in cell extracts. In addition, the ability of the mycotoxins to induce cell shrinkage at moderate to low levels of SH demonstrate the potential ability of these agents to compromise the integrity of the BBB.
which could lead to further neurological damage from mycotoxins or other harmful agents. The presence of lipid peroxidation in cells exposed to moderate concentrations of SH and additive conditions, further demonstrates the ability of the mycotoxins to amplify cellular damage through the indirect production of lipid radicals and other ROS. The results further suggest that low to moderate levels of SH are able to induce inflammatory and apoptotic pathways that amplify the cellular damage by the continuous activation of these biological pathways.

SECTION 2 CONCLUSIONS (Satratoxin H effects on astrocytes)
These studies demonstrate that mycotoxins at moderate concentrations and under additive conditions are able to produce cytotoxic events. These results demonstrate that direct exposure of astrocytes to satratoxin H at low to moderate concentrations alone do not produce a strong inflammatory response as evidenced by no significant increase in ICAM, VCAM, and P/E selectin as well as NF-κB expression. However, these results do demonstrate an additive effect in the expression of inflammatory events with a moderate dose (100ng/ml) of satratoxin H in the presence of other inflammatory compounds (LPS) or under oxidative stress conditions. Early and late apoptotic events are evidenced with moderate levels of satratoxin H (100ng/ml and 1000ng/ml), as demonstrated by the Annexin V assay for apoptosis. In addition, the evaluation of cytochrome C and GSH levels demonstrate that moderate concentrations of SH alone and under additive conditions of pro-inflammatory compounds and oxidative stress, produce significantly higher levels (P>0.05) of apoptosis in astrocytes. These results demonstrate that moderate levels of mycotoxins are able to activate inflammatory pathways in astrocytes under additive conditions, which could lead to increased expression of inflammatory compounds by astrocytes. This would increase the production of ROS, such as lipid radicals through lipid peroxidation, under oxidative stress conditions, which would lead to cell damage. Further evaluation of these data also demonstrates that astrocytes significantly increase (P>0.05) the expression of apoptotic events, alone and under additive conditions. The production of ROS can further cause cell damage under conditions of continuous inflammatory and apoptotic pathway activation. These results further suggest that the production of pro-inflammatory and apoptotic compounds by astrocytes, when released in the environment of neural tissues, could activate HBCEC and neurons leading to inflammation and apoptosis. These studies propose that under SBS conditions, individuals exposed to satratoxin H and microbial organisms in the environment over a prolonged period could have increased sensitivity to these agents, leading to neural damage.

OVERALL CONCLUSIONS
Several conclusions can be drawn from the overall study of each of these cell lines. The experiments conducted on the HBCEC demonstrate that in the event of exposure to trichothecene mycotoxins such as satratoxin H, low to moderate doses of these compounds are able to activate immunological pathways in these cells. Under additive events, these compounds can further stimulate the production of significant pro-inflammatory pathways and apoptotic pathways at low levels on a continuous basis. The activation of these pathways on a constant basis can shift the homeostasis of these...
cells, leading to changes in the integrity of the BBB. These results have demonstrated that low to moderate levels of satratoxin can cause cell shrinkage in HBCECs leading to the compromise of the BBB. The loss of activity of the BBB due to satratoxin exposure could potentially amplify the damage to the neural tissue in multiple ways. The BBB prevents other toxic substances and microorganisms from invading the neural tissues. If an individual is exposed to low to moderate levels of satratoxin on a regular basis under SBS conditions, this could increase the potential risk of neurological damage due to the constant activation of cellular pathways in the body, however other harmful agents would also be able to pass through a damaged BBB. In the event that HBCECs are damaged by trichothecenes such as satratoxin H, these mycotoxins and other agents would then come in contact with astrocytes. Since astrocytes behave as macrophages, the production of reactive oxygen species, cytokines, chemokines, and other pro-inflammatory agents released into the environment of these tissues due to the additive effects of moderate doses of satratoxin in the presence of other agents or oxidative stress, could overwhelm the astrocytes themselves leading to programmed cell death. In addition, the release of these agents into the neural tissues could further activate HBCECs and neurons leading these cells to enter programmed cell death or produce increase inflammatory events. This could lead to devastating effects especially in neurons, since astrocytes initiate protective mechanisms to prevent neurons from going into apoptosis. However, under SBS conditions, if individuals were constantly being exposed to satratoxins that overwhelmed the astrocytes, the protective compounds produced by astrocytes for neurons, such as erythropoietin, which prevents neurons from going into apoptosis, would be compromised. These events could then lead to programmed cell death in neurons. In the event of programmed cell death in neurons, these cells are not regenerated in adult neural tissues, which could lead to the permanent neurological damage witnessed in individuals exposed to S. chartarum in SBS conditions. This study demonstrates that tissue damage can occur from satratoxin H exposure to neurological tissues. This study suggests that it is the constant activation of inflammatory and apoptotic pathways at low levels in these tissues, that amplifies the devastation in these tissues, and leads to neurological damage due to indirect events triggered by the presence of trichothecenes.

I feel like I'm watching a Star Trek episode. They're visiting a planet whose dominant species is suffering from an epidemic of brain rot called the "Malaise Monster." Ten percent of the crew are affected. Investigation finds a broad range of abnormalities that show up in a few basic permutations. Puzzlement finally gives way to insight when Bones and his team find that the common denominator is a mix of genetic traits and exposure to the toxic molds growing in water damaged buildings. The species realizes that it needs to use different building materials and methods, and that sufferers who avoid affected buildings and plumes can partially or fully recover. The crew leaves the planet. Years later, Star Trek's next generation returns for a checkup visit.

They are shocked to find that the suffering is worse and that little else has changed. Bones files a report: "The Tragic Effects of the Disinterest Response and its Relationship to the Endangered Oslerian Tradition in Medicine."
What will the next episode in CFS Trek reveal?

-Keith

*

"Engineering!..... Snotty, I need more speed!"

"Ahhh, but Kiptain, th' toilet has backed up int'a the antimatter warp drive... and somebody has snorted up all the dilithium crystals. I canna do it."

"Dammit Snotty, more speed!"

"Aye Kiptain. but if she blows all to hell, dun be blamin' me"

Basically, this journey started when I noticed the amazing difference between going down into Incline Village...and what didn't happen when I headed up toward Mt Rose.

You see, my experience has to be placed in context of having the toilet backed up into the antimatter drive... with no dilithium cystals in reserve.

What people failed to notice is that I was pushing the engines to warp speed without blowing up.

-Erik

*

Can susceptibles be exposed to, say, Stachy's satratoxin H at one point in life and not notice, and then at another point be exposed and start a long wrestling match with the malaise monster?

Does this happen, and what accounts for the change?

This seems related to the question about why some CFS patients get better with exercise, while some get toxic, which appears related to whether a given person's cytokine storms, hormonal, and transcriptional problem's remain active and uncontrolled or have faded and became clinically insignificant due to corrective measures. Which corrective measures?

-Keith

*
I keep going back and forth in my mind as to whether the thing to correct is the mold exposure itself or the changes caused by the mold exposure.

On the one hand, the mold is acting like a toxin and the obvious thing to do is to avoid it.

At the same time, exposure to toxic mold seems to flip on some sort of switch that makes people way too sensitive to any mold. Maybe it's an epigenetic switch. Or perhaps it's something tied to immune activation.

It's analogous to allergies (particularly severe peanut ones) but not the same. A similar thing happens in response to anti-nerve gas pills in cases of Gulf War Syndrome.

We were once able to function without extreme sensitivity and then something switched inside. Theoretically it seems like it must be possible to switch that back.

-Josh

*

As a nuclear missile launcher specialist for the neutron bomb...

(Honestly. Sounds like a joke, but totally true.)

I was trained that the zone of radiation would be indicated by the increased pathology in humans and various animals as one approached ground zero for an airburst which would leave buildings essentially undamaged but for the radiation.

The animals that are developing cancers and being generally unwell in mold zones tells me that what is going on is far more than just a flipping switch in a few genetically susceptible individuals.

Maybe turning off our mold perceptions would be akin to switching off the Geiger counter in my old job.

-Erik

*

People can trace the onset to several different triggers. The obvious moldy house, an extended "flu," an accident, a surgery, gradual onset, or a dozen other things.

It appears to be the straw that broke the camel's back. Whether it was gradual accumulation or massive exposure, the body simply can't keep up with the toxic load. When the defense system starts to fail, suddenly one is opened up to all kinds of additional pests and problems. Toxins build up in the system.
So the trick is to find a way to ditch the exposure, reduce the toxins that have built up, and put a stop to whatever else has found a happy home in the damaged body. Then rebuild the body.

I think a person’s sensitivity will also go down, to light exposure. A well running body will remove the toxins quickly enough to handle light exposure. But heavy exposure sets off alarm bells. Their onset is telling you to run.

-Stormy

* 

>Can susceptibles be exposed to, say, Stachy's satratoxin H at one point in life and not notice, and then at another point be exposed and start a long wrestling match with the malaise monster?

"Not notice" seems a lot different than "ascribe to the right cause."

As an example: I have a friend whose home is better than just about anywhere I've been in terms of absence of toxic mold. He chose the house because it “felt good.” Every single day all winter, I get a report of whether the day is sunny (good) or grey (bad). He bought a vacation home in Taos, which he likes because it's sunny in the winter and he can be outside skiing.

Apart from perceptifying objects as they came in the door, he really couldn't be doing a better job of avoiding toxic mold. He doesn't want to hear about the mold though. He’s just doing what feels good.

Maybe that will keep him from being hurt by it.

-Lisa

* 

Did you see my stories about David Jameson, who wrote the "MindBody" book about CFS? And Thomas Oates Jr., who put all his possessions in storage and went the mountains for "healing peace"?

They are terrific examples of unconscious avoidance.

Yet they are so eager to attribute their enhanced well being to control of their emotional state that they completely overlook the fact that those of us who go through the same motions to physically remove ourselves from places that are "depressing" to us can get the same results.

No healing peace required. Just get your ass out of the mold.
It seems to me that the fact that the problems with methylation/glutathione in CFS has to be related in some way to the devastating effect of toxic mold, which also is common/universal in CFS.

Here are three possibilities.

1. Dr. Shoemaker makes it sound like all mycotoxins are removed through the immune system, but it’s possible that some of the chemicals in it go through the glutathione pathway.

2. If the body’s toxin stores are all filled up with other guck, there’s no good place to sequester mycotoxins (meaning that they continue to do active damage).

3. Studies suggest that increased levels of mycotoxins can lead to decreased levels of glutathione, e.g.

http://cat.inist.fr/?aModele=afficheN&cpsidt=18469887

It’s possible that all three of these things are true, thus creating a downward spiral.

-Lisa

That's an interesting find on mycotoxins and glutathione. Recall Rich van K's insight on glutathione's crucial effect on the cysteine residues on POMC and the broken ACTH/cortisol loop in exercise toxic CFS.

Glutathione reduces free radical, but can also sacrifice itself "US Marshal" style by escorting toxins all the way out via the bile. Perhaps this has something to do with the detox response when using methylfolate or methyl B12.

Also, it does seem that Stachy is the evil mastermind.

As long as we're swimming in the information deep end, see what you make of this excerpt from Dr. Shoemaker's biotoxin.info.org that links biotoxin exposure and/or solvent and/or volatile organic exposure to subtle visual deficits in CFS, Alzheimer's, Parkinson's, diabetes, and cancer

-Keith
It is suspected that many clinical diseases involve both genetic and environmental risk factors, and many are known to involve deficits in visual perception, although little research has sought to relate toxic exposures to modes of action which may produce measurable alterations in visual function prior to progression of disease to a diagnostic level. VCS deficits are present at diagnosis in diseases better known for effects on other body systems, such as Type 1 diabetes mellitus (deficiency in insulin release), in which there is little or no observable retinopathy. Multiple sclerosis patients display VCS deficits which are orientation specific, suggesting cortical rather than retinal or optic nerve damage. A primarily low spatial-frequency VCS deficit is present in Alzheimer's disease, a classical "cognitive" illness, and in Parkinson's disease, a classical "motor" illness. A number of recent papers present evidence that VCS and other vision impairment in Alzheimer's disease may be responsible for behavioral and functional outcomes previously attributed to cognitive impairment. The report that the extent of cognitive impairment in Alzheimer's disease can be predicted by VCS scores supports the hypothesis of a common mode of action for the cognitive and visual dysfunction. If Alzheimer disease etiology in at least some patients involves toxic exposure, and if visual disturbances are present well in advance of diagnosis, measures of visual function in prospective studies of exposed populations could help link exposure to risk for Alzheimer's disease. Recent research on exposure to airborne manganese and risk for a Parkinson-like disease provided support for this approach. Only measures of VCS significantly predicted the risk for development of Parkinsonism 5 years later in a study of workers at a ferro-manganese alloy plant. In studies of oncologic conditions associated with toxic exposures, no studies have been found which sought to identify early, neurobehavioral indicators of risk for tumor development. This is somewhat surprising since many studies on volatile organic compounds, for example, have reported symptom complexes and neurobehavioral deficits in exposed populations, while other studies have reported an increased incidence of carcinoma in similarly exposed populations. Whether or not a common mode of action underlies the earlier developing non-cancer, and later developing cancer, outcomes of exposure is unknown. The mode(s) of action of solvent-induced deficits and illness undoubtedly differs from that of biotoxins, as evidenced by reports that biotoxin-induced VCS deficits are reversible (7,8), whereas solvent-induced VCS deficits are irreversible (12-14). Yet the potential for common modes of action in visual dysfunction, multi-system symptoms and cancer is shown by the relationships between these endpoint and the proinflammatory cytokine, TNFa, in biotoxicity. Prospective or follow-up study designs which include biochemical measures and clinical outcomes are needed to characterize and link together early, sub-clinical effects, modes of action and clinical outcomes resulting from environmental exposures to toxins.

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>Can susceptibles be exposed to, say, Stachy's satratoxin H at one point in life and not notice, and then at another point be exposed and start a long wrestling match with the malaise monster?"
I want to say the answer is yes. At least, this is what's observed clinically.

My impression from reading Mold Warriors was that people who are exposed to toxic mold reach a threshold where suddenly all their symptoms explode. People with certain HLA-genotypes are likely to reach this threshold sooner, although theoretically anyone exposed to enough mold will reach the threshold. Moreover, even before you reach the threshold, toxic mold is likely to cause some symptoms.

So the story's often like, “Well there were some symptoms, but then winter came and everything just got crazy, I had the flu and never got better.”

After a patient reaches the threshold, there are two overlapping perspectives: (1) The body is overloaded with toxins it can't get rid of. (2) The body is reacting to toxins in a categorically different manner than before. In all likelihood, both of these are going at once, and to correct one, you probably have to correct the other.

It's in the overreaction where a bunch of recent CFS theories apply. Maybe somehow the toxins easily trigger some cascade of events probably involving a few of their own self-reinforcing cycles, like Pall's NO upregulation, hypercoagulation, inflammation, orthostatic intolerance, and sleep problems.

As to whether the latter processes are CFS itself, epiphenomena from mold sensitivity, or both, I'm not sure.

-Josh

*

From that dissertation:

> If it triggers cell destruction, and if adult neural cells do not regenerate, then cognitive losses may be permanent."

I believe that adult neural cells do regenerate but I don't know where I read theory on this.

From my own experience, the long term cognitive losses do not appear to be permanent. I've regained some memories that I thought I wouldn't. Some memories that I think I should regain, I haven't. Those are often things that happened at the worst times of my illness. I don't know if it's memory loss or more that I simply didn't hang onto them or note them into memory then. Short term memory is good now.

-Stormy

*
At one point I read a lot about traumatic brain injuries, and it seemed clear that the neural cells do re-grow pretty well. It can take years though. And the brain does restructure itself to use cells that haven't been destroyed, though that can take time too.

I'm thinking now about the "moldy whiff" study, where one sniff of mycotoxin caused destruction of the olfactory nerves in rodents' brains. (Just the ones that detect odors though. Perhaps the mold does this "on purpose," since people who can't smell mold will be less likely to clean it up.)

The researchers stated with slight amazement that those cells had not grown back a month after the study, but still suggested that they should do so eventually.

-Lisa

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Lisa - If glutathione helps with the POMC cysteine residue conformation problem that Rich van K described, then it's reasonable to think it would help raise MSH. The moldy whiff study involved in vitro work on rat olfactory neurons. My guess is that olfactory neurons are more apoptosis-resistant than that in vivo. Not sure whether its an adaptation strategy by molds to kill olfactory nerves and sense of smell, or that olfactory nerve irritation helps trigger a cascade of its own.

Josh - Thanks for the lucid description. I can imagine a gradual accumulation of toxins, a sort of gradual increase of toxic noise in the system, so that the system as a whole becomes primed. When the bad mold hits, there's a cascade and the system undergoes a phase transition to the Malaise Monster category, and it is going to be difficult to rewind without mold avoidance. The door remains open for supportive roles for things like methylated folate and B12, methyl donors, glutathione, high dose vitamin C, air purifiers, and so on.

-Keith

* 

This is from the Incline Village epidemic.

> The 259 patients enrolled in the study were asked to complete a detailed questionnaire, and data from each patient's medical record were abstracted. To be included in our study, a patient had to have chronic, debilitating fatigue of at least 3 months duration that was associated with at least two of the following symptoms (also of at least 3 months duration): fever, headache, sore throat, earache, rhinorrhea, cough, diarrhea, or myalgias.
Erik, were you one of the patients in this study? In any event, what do you make of its inclusion criteria? Might mold toxic patients with at least 3 months of debilitating fatigue have failed to qualify because their symptoms (such as cognitive dysfunction, malaise, worse when lying down, worse with exercise, worse in certain places, etc.) didn't include at least two of the associated symptom criteria? Are earache and rhinorrhea common CFS symptoms? Mold symptoms? Between 1984 and 1987, were Dr. P and Dr. C classifying people like you as CFS or something else?

-Keith

* 

Yes, I was part of this study.

There was no such thing as "CFS" until the Holmes committee applied it to our illness. We weren't really classified as anything except anomalies.

If you read the comments from Peterson, Cheney, Komaroff, Bell, Klimas and others, it was the shocking nature of our descriptions that grabbed them. "debilitating fatigue" is an unbelievably paltry way to try to express this.

Marathon runner who can't stand up. Teachers who can't remember their subjects. People getting lost on their way home. Remember Chris Guthrie, the meter reader who couldn't even make it home? People who could actually stand up and walk to the bathroom instead crawling were the lucky ones.

Having to be told a phone number in two parts, because with pen already on paper we couldn't remember that many numbers long enough to write it down. And when trying to write, somebody who had perfect penmanship was now writing an almost completely illegible scrawl in huge letters.

When you go try to hold a fork, and your fingers refuse to respond. And you try, and you try, and with your utmost concentration, sweating with the effort, you manage to lift a fork to your mouth... and miss...., "fatigue" is not how you describe your illness.

Dr. Cheney wasn't concerned with the patients’ description or complaints nearly as much as things like this.

>One of the most striking immunological aberrations Wormsley observed, however, was abnormal ration of T-cell subsets. T-cells are a major category of immune system cell; they regulate production of disease-fighting antibodies. Two primary T-cell subsets are "helper" and "suppressor" T-cells, which boost and suppress antibody production respectively. In AIDS the normal ratio tends to be dramatically skewed in favor of suppressors. Since this finding is virtually diagnostic for AIDS, Cheney and Peterson were curious to know the T-cell subset production in the Tahoe malady.
Anyone who described their illness as fatigue would certainly not have been in this study. Although it may not be written down, they had to have the whole shebang.

-Erik

*

So is the best guess that Incline Village cases had a double whammy of HHV-6a and toxic mold, and that the severe symptoms Erik described were a previously unseen form of encephalitis (with or without myalgias)?

Did the toxic mold hit first and "prime" their systems, making them HHV-6a susceptible and encephalitis prone?

Or was it vice versa? Or was it something else again?

-Keith

*

Since the mold came first, it appeared to me that this type of exposure paved the way for creating extra severity when the HHV6A went through.

-Erik

*

What do you think of the idea that different types of mold (or in some cases mold potentiated by chemicals) is responsible for the "type" of CFS that people get?

-Lisa

*

I think we probably won't know until researchers are scared enough to get off their butts and start researching.

-Erik

*

Glad to hear you think it’s a possibility anyway. Based on my own experience, "super mold" seems much more plausible than "super virus."

-Lisa
"Delicious dessert topping...or a floor wax?"

"Hey, you two... It's both."

-Erik

This is how I'm currently seeing it.

What we on this board seem to have is a hyperreactivity to mycotoxins that disables the immune system, thus allowing the colonization of various pathogens. It's possible that some of those pathogens might cause mycotoxin hyperreactivity to increase, though that seems less clear.

I don't think that the exact type of toxic mold is relevant in terms of the general disease category. Nor do I think that the exact pathogens that colonize are relevant to that classification.

The people who got sick in Incline Village in the 1980s fall into this category. A lot of other people who have somewhat or different symptoms than the ones from Incline Village fall into this category too.

Getting professionals to focus their attention on the couple hundred people who got sick in Incline Village does nothing to make them aware of the extent to which toxic mold hyperreactivity and ensuing immune system problems are important in the world today. It just gives them an excuse to marginalize the problem as related only to the few individuals in that one town who got sick back in the 1980s....i.e., a blip in history with which we no longer need to be concerned.

-Lisa

Why does it matter if it's exactly the same or not? If I understand correctly, it began as a major mold issue, then a bug triggered a collective downfall. This is a similar scenario that is happening all over the world. It's no longer a few hundred people, it's millions. Each person may have slightly differing symptoms and levels of exposure, different pests. But the general issues are the same.

We need to pull everyone who might be at risk into the circle and help them all. Not exclude anyone. Some of those diagnosed with CFS don't have mold issues at all at this point, but they will, because it looks to be nearly unavoidable. But their systems have been compromised by something and this puts them at risk for being sensitive to mold.
-Stormy

*

The mold is just a clue to something much bigger.

The EBV onsets go on to describe their illness as a really bad fatigue - horrible, grinding, crushing fatigue.

Ours was a little different. The illness was neurologically paralytic. Notably so. When you are silently screaming at your limbs to respond and they refuse, you just don't settle for it when a doctor conveys his belief that your problem is "really bad fatigue."

Listen to Dr. Peterson’s video description of that carpenter from the original cohort that was lost for many years and found in a nursing home with intractable seizures. If you have HHV6A and lose it by falling under the power curve, you want the doctor to understand that you aren't heading for worse fatigue. You are headed for seizures.

I'm not trying to intentionally diminish other people's illness. After all, dead is dead. If you can't work and lose your life to crushing fatigue, you are still destroyed. But it is the manner of the destruction that speaks to the etiology.

Back to the carpenter, again. In the nursing home, the doctors noted that his illness strangely "waxed and wane." Where have we heard that before?

So if that person knew that his worst times correlated to a certain environmental substance whose concentrations wax and wane, what do you think? Could he do what I did?

Dunno. And neither will he, or anybody else, unless they try.

-Erik

*

>When you are silently screaming at your limbs to respond, and they refuse, you just don't settle for it, when a doctor conveys his belief that your problem is "really bad fatigue."

I had this too. I didn't think of it as seizures so much as a major disconnect someplace between the brain and the body. As in I couldn't get up. The signals to the body didn't happen and I felt almost as if I was watching somebody else's body. Disconnect. It was those types of moments that I have to thank for many a wipe out. I'd find myself on the floor. Sometimes I'd recall the fall, sometimes not.
-Stormy
*

Stormy, you described the disconnect perfectly. Nothing like fatigue, is it?

We had one heck of a time trying to get the CDC to pay attention to stuff like this. They kept trying to twist it back into their "tiredness" charts.

Whatever it is they're thinking of when they say "CFS," somehow it doesn't seem to include your problem.

- Erik
*

There are reasons to split and categorize, and reasons to lump and synthesize. Doctors need better preparation to handle the coming waves of people whose conditions fall somewhere along this spectrum. We need better case definitions. We need a better understanding of which treatments are generally helpful for people all along the spectrum, and which are helpful to those whose history and biomarkers place them in a specific category along the spectrum.

It will take more than published studies to guide patients and physicians as to what we should do by way of metabolic rehabilitation in the fatigue/myalgia/seizure/pathogen/mold/neurotoxin spectrum of chronic illness -- it will take forums like this, where a community works hard to factor in what's noteworthy about the personal experience of trying to cope with life lived on this spectrum, and where a community guards what is noteworthy about the outbreaks of the past.

- Keith
*

There is a symptom that really doesn't get talked about much and while one is experiencing it, there's no looking at it objectively.

It's a matter of becoming stuck in one's thinking (or lack of). It's an exaggerated response to a word, idea, or whatever. And it's always accompanied by anger. Unrealistic anger.

There appears to be a sort of disconnect that goes with it. Like one part of the brain is at odds with the other. But the whole mess gets stuck.
Quite frankly, those moments made me wonder if I had completely lost my mind. But as with other symptoms, it wanes. And when you look back on it, you're just confused by it. This sort of thing has caused more than one battle in my home.

I tend to think we don't talk about this sort of thing much because of the stigma of "it's all in your head." The closest thing I can think of is OCD. But even that isn't quite right.

-Stormy

*

Stormy is dead on, it's a topic we really need to address. I've lived with this phenomenon myself.

It goes beyond not being able to think. It feels like a stuck cycle in the brain. It's not just inability to reach a conclusion through channels of logic, though it's partly that. It's reaching the wrongest conclusion possible on a consistent basis.

And, it's getting stuck on a faulty thought and not being able to break free of it.

I seem to think in pictures rather than words, and the picture-to-words translator in my brain is broken. When really sick with this stuff, I can't even convey my smallest thoughts. When clear, I can, but the translation mechanism takes effort where it used to be seamless.

-Khaly

*

Remember the elevated pressure on lumbar spinal taps that Dr. Peterson was using as evidence of possible CNS inflammation?

Well, Dr. Baraniuk and Dr. Ravindram at Georgetown University have been testing proteins in spinal fluid, and they noticed an amazing thing:

After a draw of fluid, the patients’ cognitive symptoms would dramatically improve. But this only lasted for several hours, and then they were back to being messed up again.

A clue!

-Erik

*
I wrote this a couple of years ago:

Another one of the symptoms that wasn't considered important was patients pointing to the base of their skulls and complaining of pressure and pain. To the extent that some people resorted to surgical stenosis to relieve "Chiari Malformation."

It always struck me as rather odd that doctors were quick to consider that the brainstem "outgrew the cranial aperture" and caused pressure, instead of looking for some inflammatory process that might have caused spinal cord swelling.

But since people pointing at the top of their spines and complaining about a specific area that disturbs them looks like nothing more than a headache, it's not considered to be relevant.

No matter how many people point and try to call attention to it.

-Erik (2006)

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With the increased spinal fluid pressures, the temporary relief after spinal tap, the questions raised about whether Chiari malformations are causative or merely associated chronic recurrent severe headaches, the progression from an initial stage (depression, short fuse, cognitive dysfunction, etc.) to "migraine" headache make you wonder whether brain capillary endothelial membranes can become leaky from mold exposure.

Daniel Amen, MD, has documented regional brain blood flow patterns in patients with various diagnoses (though not CFS). Certain symptoms correlate with reduced flow in certain brain regions. For example, if you experience decreased blood flow in your dominant-side temporal lobe, you may experience aggression (directed externally or internally), reading difficulties, word-finding problems, or increased sensitivity to slights, or emotional instability.

We know that mold toxins create a leaky blood brain barrier. We also know that the choroid plexus of the brain filters brain blood and lymph into CSF. It also makes beta-2-microglobulin, a protein whose grab free toxins in this filtrate and escort them out of the CSF compartment.

Let's say a biotoxin exposure creates a sequence of cytokine release, MMP-9 release, and a patch of leaky blood brain barrier. The cytokine response moves into the brain. Depending on which part of an individual's brain is affected, and depending on the relative state of neurochemical balance or imbalance in various parts of that person's brain, you might experience a sudden quickness to anger, reversible paralysis, brain fog, depression, or something else.
Meanwhile, the choroid plexus is receiving more toxic shipments, so it is to crank up the
volume of CSF production. The intracranial and/or spinal CSF pressure builds, creating
deep pain at the base of the neck, top of the head, above the eyes, spine swelling, etc.
You have what almost everyone would agree is a migraine headache, but it's really
driven by the increased CSF pressure that occurs when the choroid plexus is trying to
mop up after another toxic spill type of exposure to brain tissue. We do a spinal tap and
the pressure is abnormally high, but tapping 30 cc of fluid out of the CSF space relieves
the pressure on your brain and spinal cord and you feel better - until the pressure builds
up again.

You learn that mold is a trigger, so you avoid it as best you can. The avoidance slides
you toward the part of the CFS spectrum where cytokine activity is quiet enough for you
to tolerate exercise well. You exercise regularly at high altitudes and the EPO effect
does wonders for your system.

There may be "priming" triggers - or antecedent changes exposures to (reactivated
HHV-6a, leaky gut-derived toxicities, parvovirus, Lyme, toxic fat stores, heavy metals,
solvents, pesticides, etc.), and there may be "cascade triggers" (biotoxins, chemical
exposures, food sensitivities, etc.).

We should get the idea that there would be dozens of biomarker abnormalities floating
through the bloodstream and CSF of CFS patients. The question is, is there a set
pattern of abnormal biomarkers that a) place people on the CFS spectrum of illness,
and b) sort them into specific types somewhere on the spectrum.

We shall see. But if CFS patients remain something like a black box (or a dark gray
box), as long as we can devise inputs (care plans) that produce reliably good outputs
(clinical outcomes), then the pathways and mediators can unfold at the pace of
academic research.

-Keith

*  

Would this cause a feeling like acid in your cervical spine? Many of us have this
sensation just prior to or accompanying the neck pain and headache.

-Sammy

*  

A couple of thoughts.
1. I believe that the mold in my house was garden-variety stachy without any particular chemical reinforcement. It never gave me any headaches. I did get bad ones when I went to certain places away from the house though.

2. The type of headaches you're describing seem to be coming on a lot since I've been in the Southwest, but only during weather changes. That makes me think there’s a particular mold or some other type of “ick” here that I wasn't being exposed to back in Chicago.

3. The only thing that I have found that has helped these sorts of headaches is very strong peppermint tea. I wonder why that would be.

-Lisa

*

With the weather, watch the barometer. When pressure drops, things that aren't normally airborne become airborne.

We used to fish a lot growing up on the Gulf of Mexico. When the pressure drops it's a good time to fish. Fish that are normally bottom feeders start to feed on the top. That's because when the pressure drops, food particles that are normally tenuously anchored to the bottom by pressure will start to rise.

Same thing happens with mold spores. And it doesn't take much of a drop.

-Khaly

*

I'm just spitting out hypotheses. Anything I know stands on the shoulders of Peterson, Cheney, Shoemaker, Teitelbaum, and the other doctors who've made this illness spectrum a major part of their focus as doctor/researchers, not to mention the shoulders of the contributors to this thread who've lived it and have important clues as to what's going on.

If the toxicity being filtered by the choroid plexus is more than it can handle, then we would expect oxidative stress to spill into the CSF. That is, the CSF produced by the choroid would not be filtered and pristine, as usual, but contaminated with excess protons. To test the hypothesis, we might tap CFS patients who feel that "acid spine" at times when they feel it and times when they don't, predicting that at times when they're feeling it, the CSF pH is lower, and that "acid spinal fluid" is exactly what they're experiencing. As Osler said, "Listen to the patient. 90% of the time they'll tell you what's going on."
Barometric swings have their own role to play. When there is a fast change (typically the drop of an approaching low pressure front), the air pressure on our bodies decreases. This allows more filling of surface lymph channels, creating a subtle pulling of fluid volume out of circulation compartments (blood, CSF). The consequence is reduced perfusion pressures, which will be noticed first in the tissue beds that are hosting inflammatory processes, with increased cytokine and protein traffic, and reactive spasm of skeletal or smooth muscle. In CFS these stressed tissue beds, or low perfusion pressure/low oxygen tension/low pH zones, are parts of the brain and central nervous system compartment. In fibro, arthritis, and other chronic illnesses, they tend to be the muscles and joints in the periphery. There is plenty of overlap between conditions.

I believe the barometric sensitivity is a sign of blood pressure dysregulation in CFS (Neurally Mediated Hypotension, Postural Orthostatic Tachycardia Syndrome, Orthostatic Intolerance, Hypovolemia, or whatever else you want to call it.

One countermeasure is to use something like celtic sea salt, 1/4 tsp in water, juice, or soup in the morning, as the long tail of minerals in the circulation will help retain fluid volume in the circulation compartment, rather than have it seep into the third space (between your cells), resulting in decreased perfusion pressures. Florinef and Midodrine are not perfect solutions, but they can help in the more severely affected subpopulation.

Sometimes dry high pressure fronts are simply mold plumes. When the flood waters receded in Western Illinois and Iowa this past September, field mold counts jumped to 50,000, and when the westerlies came we experienced an "outbreak" of asthma, headache, sinusitis, brain fog, and fatigue.

Peppermint has been in the US Pharmacopoeia for 200 years as a smooth muscle relaxer. If it relaxes arteriolar smooth muscle spasm (that has gone into spasm as part of the arteriolar endothelial cell-mediated neurovascular reflex arc whose job is to regulate flow at the gateway into your tissue beds - remember the law of hydraulics and garden hoses which states if you need to increase perfusion pressure, narrow the outlet of the tube), then you will increase perfusion pressure and quite possibly feel better.

Keith

* 

Dr. Teitelbaum is misrepresenting CFS. He portrays CFS the way the CDC does.

"Fatigued to Fantastic"? He's got to be kidding. Don't people remember that "fatigue" was the insult?

- Erik

*
The fatigue is also a part of the equation. In fact, that was what I complained about first for all those years. I didn't focus on the off-and-on seizure like stuff. I would guess that between the sleep issues and an assortment of pests, plain and simple exhaustion took over.

-Stormy

* 

What I've found recently is that on good days, when I'm not getting mold exposure, I am absolutely exhausted.

Not pseudo-exhausted (aka poisoned). Just plain tired, like a normal person who'd been ill for a long time or had a major operation would be expected to be.

-Lisa

* 

I agree, there is a massive fatigue on top of that other-thing-that-isn't-fatigue. It's grinding to be sick all the time, and the body, I'm sure, gets fatigued in its nonstop effort to combat illness.

Unfortunately, I think the science entities latched onto that fatigue and didn't dig further, and the word "fatigue" has effectively put a stop to real investigative work in CFS. That leaves us with a neural paralysis problem that is a crucial clue to the mechanisms of this illness - and nobody has taken it seriously to date.

-Khaly

* 

I agree that there is a great deal of the sensation one could describe as fatigue, but that is not the primary complaint as doctors keep repeating. This shows us they don't understand that while losing your ability to do math, getting lost on your way home and not being able to write legibly may seem like trivial things... they are the important things.

-Erik

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The reason I mention Teitelbaum as an influence is because of an experience I had back in 1996. I had just left an academic post to joint a holistic practice in Chicago. My goal was to take a year or two to figure out which alternative therapies were valid, and which were from another galaxy. On a guaranteed salary, I'd close my knowledge gaps
in two years and go back to the medical center with the Dean's blessings to start an integrative medicine program.

Close my knowledge gaps? What a moron. The more you know, the wider the gaps become.

On my first day seeing patients, I see that I have a CFS patient on my schedule. Oh my God! What was I gonna do? I'd been crossing the hall to avoid these people, and now, all of a sudden, I'm supposed to help them?

I asked the colleague who'd recruited me what to do, and he tossed me Teitelbaum's Fatigued to Fantastic. I power-skimmed it. After taking the patient's history (classic POTS), I suggested we try Florinef. She came back in 3 weeks and said she thought it was helping. I'd never had a CFS patient say that. Teitelbaum's perspective first opened my eyes to the world of integrative thinking, so I'm grateful to him for that.

But for cases of "real" "ME-style" CFS, all of the diagnosis and treatment models still fall short, for all the reasons that Erik cites, not the least of which is the subtlety and complexity of the illness. The models aren't granular enough, and yet their scopes are too narrow as well. Even the deepest thinkers on the subject rarely stray from the silos of their own expertise to venture toward a larger synthesis, but that's the mainstream bias: all zoom, no wide-angle.

But in my experience, it's only in the bigger picture where reality comes into clear enough view.

It's not unusual to feel exhausted in a "good tired" way when you've somehow managed to dial your way out of a pattern of frequent or severe cytokine responses. When the defensive is finally off the field and the restoration team gets some playing time, total rest and sleep are part of the body's way of cleaning up and building strength. It's as if you're an animal that's been sick or wounded. The instinct is to find a quiet rut and lay still, sipping from a puddle now and then, and let the restoration team get something done without distractions.

-Keith

*I suppose Dr. Teitelbaum wants to instill hope in patients, but he portrays CFS as an illness that can be successfully managed with supplements, with a 90% improvement rate in his patients. This really hurts people who don't recover so easily and want society to believe them.

Contrast Dr. Teitelbaum’s "success rate" with Dr. Peterson and Dr. Cheney, who have barely been able to help anyone using everything in the book.
I suppose if people were to vote on what CFS is, Dr. Teitelbaum’s portrayal would far outnumber Dr. Peterson’s and win the election.

But it was Dr. Peterson’s illness which received the term. And that was the illness which the CDC was supposed to be researching but didn't.

-Erik

*

Dr. B, let me see if you can make heads or tails of this symptom of mine.

PVC is caused by a different part of the heart doing the "beat" than what is normal. Some people have this going on all the time and just can't feel it.

Why does a different part of the heart do the beat than the normal part? What's the causal mechanism for that?

Is it because the normal part is broken? Or is it just an additional beat trigger caused by an electromagnetic sort of misfire? Or the little Lyme creepies causing a muck?

-Stormy

*

Yes, heart palpitations. I get them with mold toxin exposure. They don't seem to go away until I've been clear for quite a long time, sometimes months.

I wonder about this, from page 12 of the Karunasena dissertation we've been reading:

"Stachylysin is a recently identified compound produced by Stachybotrys that has been implicated in inducing hemorrhaging in people exposed to S.chartarum [51]. This compound was suggested as being able to produce vascular leakage [51].”

-Khay

*

Like Dr. Teitelbaum, I saw the less severe 80 or 90% of people who qualify for the loose diagnosis of CFS (and still do, for the most part). In the late 1990s when I saw the CFS patients of the Peterson-Cheney variety, among the 10 or 20% more severely affected, I didn't help them much. It's a different species of hell.

The cardiac dysrhythmias are poorly understood. Dr. Lerner found CMV in myocardial biopsies in some of his patients, so there may be stealth pathogens involved in CFS cases with dysrhythmias. Patients on the Marshall Protocol often experience
dysrhythmias as part of their Herxheimer reactions on Benicar with or without minocycline.

Cardiac tissue is very dense with mitochondria, which concentrate magnesium at a seven times higher rate than other mitochondria (can't remember where I ran across this factoid), and apparently the amino acid L-taurine assists in this process. In addition to magnesium glycinate and B vitamins nutritional approaches to dysrhythmia include Co-Q-10 (ubiquinol probably the best form), acetyl-L-carnitine, and alpha-lipoic acid (all considered mitochondrial resuscitants).

If mold exposure trigger palpitations, perhaps the cytokine response is triggering viral reactivation in cardiac tissue. An antiviral (Valtrex, L-Lysine) might help block that. Supplementing with magnesium and taurine, B's, and/or mitochondrial resuscitants might raise the threshold to cardiac irritability over time.

-Keith

* 

I was having a Lyme episodes (as a result of a high dose of doxy) last week and was trying to find a way to put into words what it felt like. Finally I came across the thought that it felt like salt was being rubbed into a wound.

Maybe the toxin that Lyme makes is an irritating one, but is only problematic if the inflammation is there to begin with.

No inflammation from the mold (or other sources) and the Lyme isn't bothersome. No Lyme and the inflammation is only a moderately bad problem. Even a little of both and you've got a really hellish situation going on.

If that's the case, maybe the reason that I stopped having a hard time with the doxy once I got to a high level of mold avoidance had nothing to do with my immune system getting stronger. Maybe it's instead that my brain got less inflamed.

-Lisa

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Lisa, here's a somewhat primitive way to account for what you're describing with your "if mold, then Lyme flare" scenario.

It seems that Lyme and cell wall deficient forms, once they find a stable intracellular environment (in the brain, a monocyte, an endothelial cell, or a synovial cell), they are happy to morph into a dormant cyst form and wait for kingdom come.
When the metabolic environment inside their host cell is shifting to a less friendly state as a result of, say, changes in cell signaling brought about by a local cytokine downpour or a wave of doxycycline, resulting in their detection of a heightened level of oxidative stress, these intracellular pathogens morph back into their active, replicating form because, well, it's closing time and they can't stay where they are.

If Lyme makes its way past an inflamed, leaky blood-brain barrier to find refuge in a glial cell, it'll morph into dormant mode until something disturbs the peace, say a toxic mold reaction.

-Keith

*

During the epidemic, I told Dr. Cheney and Dr. Peterson that I had a progressive and inexorably increasing reactivity to mold. I theorized that the reactivity was "infection induced."

I wondered why a virus would care about mold. When they told me that it wouldn't, I replied, "Then whatever's got me must be a bacteria, because it seems to care a great deal about mold."

I asked another doctor, "Since antibiotics are originally constituted from mold, did it ever occur to you that if I have a reaction that is completely out of line with a normal human response, it might not be my reaction to mold, but rather, my immune reaction to whatever an infective bacteria is doing when it senses mold?"

He got that glazed over look that I have come to know so well in doctors and went into utter brainlock.

-Erik

*

Every time the weather changes here and I feel worse, I go back to thinking about what's going on.

What do you all think of these different explanations?

1. Erik (from a while back):

Mold spores are primed to release their toxins at times of weather change when conditions of wind and potential water give spores their best chance for dispersion and survival.
2. Keith:

I believe the barometric sensitivity is a sign of blood pressure dysregulation in CFS (Neurally Mediated Hypotension, Postural Orthostatic Tachycardia Syndrome, Orthostatic Intolerance, Hypovolemia, or whatever else you want to call it.

3. Khaly:

Watch the barometer. When pressure drops, things that aren't normally airborne become airborne.

4. Something nebulous having to do with the sun and/or electrical charge.

My experience is that I do feel bad as soon as the barometer drops, even before the skies get cloudy. But it’s only when the clouds clear and the sun comes out that everything magically rights itself. And it happens in about five minutes when that occurs.

Might the sun have some kind of effect on the electromagnetic charge of the particles or in some other way degrade the toxins?

-Lisa

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If sun is helpful, I wonder if the benefits that people get from those lights they sell for seasonal affective disorder are related.

-Sammy

*

Everybody, including me, got those lights to correct SAD. Whatever benefits they gave could easily be overwhelmed by mold.

The only people they helped are those who were just barely falling under the power curve. For those who were further down, it was a pathetic drop in a leaky bucket.

Lights = "Geez, I think maybe I'm not quite so depressed but I'm still crawling to the bathroom."

Extreme Avoidance = "Sure is nice to feel human while I effortlessly climb mountains."

When I'm out in a good place, the barometric pressure can do whatever it wants and I don't feel a thing.
I climb mountains, more than a mile’s worth of barometric pressure drop, and I feel
great. I go back down from these mountains, more than a mile’s worth of pressure gain,
and I feel great.

If it was baro change per se, people would complain equally about all the times that
pressure changes, like driving up and down hills or being in elevators in tall buildings,
but they don't. These are just pressure changes on them, but not the environment.

The only type of pressure change that everyone constantly points to is the one which
exerts pressure on environment. So it is something in the environment which is subject
to pressure change which must be the culprit.

-Erik

*I'm not quite so depressed but I'm still crawling to the bathroom" sums up the
psychiatric model for CFS.

Most of my patients who note flares with barometric shifts do not indicate that there is a
threshold above which they're fine and below which they're not, but then again, I haven't
courage them to track it. I think that people with low blood volumes, especially if
they're venous baroreceptor reflexes aren't properly regulating venous pressure,
experience delayed effects from BP shifts that range from a couple of hours to a day. It
would be influenced by hydration, mineral status, and whether they're immune systems
are kicked up by toxins, infections, and so on.

I don't know enough about differences in oxygen tension and air pressure at 15,000 feet
vs. sea level to guess whether folks with low blood volumes should expect fast changes
for better or worse, or whether the changes are enough to produce delayed effects, but I
do think that what's going on in the venous and lymph compartments is a variable in the
equation for most sufferers of chronic inflammatory and degenerative illnesses who
notice effects from BP shifts.

Erik's observation that BP changes can trigger toxin release has to be taken into
account, especially if the effect is one of being slammed down as opposed to, say,
knees stiffening up a bit.

-Keith

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Not to be obstreperous (God, I love that word), but the way I see it, If one undertakes
the desert experiment - gets clear and then experiences no symptomology during
periods of barometric pressure change - the effects of barometric pressure on internal organs have been entirely ruled out.

Those people who have accompanied me marvel that I have to point out that baroshift has indeed occurred because they can no longer perceive it, so what didn’t happen totally failed to cross their minds.

-Erik

*

Better to be obstreperous than obstinate, or heaven forbid, mulish, like the CFS as mood disorder crowd.

Erik, I get your point that if someone with CFS does a sufficient job of avoiding mold that they will no longer notice baroshifts. If they do, it’s because they haven't sufficiently avoided mold exposure, or because they have a chronic inflammatory or degenerative disease that was hard to label and got lumped in as CDC-type CFS, but they're not ME/ Incline Village type CFS.

The truth is, mold sensitive patients are a detection system for mold zones, assuming they know that they're sensitive to mold in the first place. Lisa proved it when she visited the home of one of my patients when we were suspicious but not sure about mold there. Then there is the problem that frustrates not just Erik, but progress in the field, and that's people who know they're mold sensitive but refuse to accept it and take the necessary avoidance steps. In the middle are those who accept that mold toxins are slamming their brains but who are trapped by the pragmatics of life, unwilling or unable to take radical steps back to health that offer no guarantees.

What would be on our list of Top Ten ways to help these people in the middle either take the radical avoidance steps, or best minimize and cope with exposures they "can't, for practical reasons" move away from?

-Keith

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>What would be on our list of Top Ten ways to help these people in the middle either take the radical avoidance steps, or best minimize and cope with exposures they "can't, for practical reasons" move away from?

Well, that was easy! That's what I've been trying to find out for over a year.

-Sammy

*
Boy, good question.

Could you suggest that a person who is stuck in the middle try to spend as much time as possible outdoors or away from their home? Or would that also lead to increased reactivity to the toxins, meaning that they would be more sick when they’re re-exposed?

Here are some things that doctors could do for patients who DO want to try avoidance.

They can give them validation that this is a legitimate way to heal from mold illness/ CFS.

They could hand them a book or pamphlet on how to do it, if there were one.

They could refer new patients to people who are farther down the road to healing using avoidance.

I have preferred to do additional things, like CSM and soluble fiber, seaweed, chlorophyll, phytosterols, methylation supplements, hormones, etc. And of course a doctor could help with all of those things.

And I preferred to do Dr. Shoemaker's tests, which a doctor is necessary for.

-Forebearance

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Here's the trick with advising someone to spend more time outside, for instance. That's going to be situational. Some areas are lethal outside. You may possibly have no mold in your house and still have a mold problem if there are plumes in your neighborhood.

And this harkens back to the need of each individual responder to learn to perceptify. How else do you learn to do that without getting clear?

Not trying to squash ideas, just trying to point out the insane difficulty of this.

-Khaly

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It's crazy. But you have to establish a tabula rasa of baseline wellness before you can do this.

A person who has gone extreme can then make educated choices about dipping into places that are pushing their threshold. They develop the senses that allow them to move around in this environment.
But a person who hasn't done it is unaware of what they are shooting for.

It's like trying to teach someone all the movements of hang gliding without having a hang glider, so that if they need to jump in and fly, they'll be able to.

And yes, I've seen people do a trial by going to the Godforsaken desert and find to their horror that they cannot reenter a place that just seemed troublesome when they left.

Holy crap, now you're stuck between a rock and a hard place. It's motel city for sure.

So people who are steadily moving down the path of moldiness aren't going to act until they are forced. Why would they? If you don't feel a serious need, who would do it?

But if you do feel the need, you are already there. Once people have no choice, intensification reaction puts them in a terrible position that they didn't plan for.

Really, the only solution I see is for somebody out there who recognizes the need to establish Plan B for the people who don't see this coming.

-Erik

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So maybe what people need in order to try extreme mold avoidance is someone who will feed and clothe them while they are in the wilderness.

-Forebearance

*

Yes, and to try to convince them that the vague feelings of unease, depression, heart palpitations and skin hypoperfusion that they feel when they are around contaminated objects is not just in their imagination.

-Erik

*

If anyone knows an angel investor who wants to build a mold-free retreat facility in the desert, where confused sufferers can go for a glimpse of normal, some basic training, and an integrative care plan, I'd like to work the winter shift. Winters in Chicago can be a real pain in the gluteals.

-Keith
I don't think anybody is going to make any moves in this direction until some really rich person is fighting for his own life and realizes that doctors cannot save him and this is his only way out, but wants to take advantage of the experience of those who have gone before.

-Erik

Although I keep hankering after the dream of a mold-unfriendly building in pristine location, I keep being told by experienced mold warriors that no building can be guaranteed to remain mold-free. Plumes drift. Mold avoiders need to be mobile.

When you say "a facility," are you envisaging a dwelling or a medical facility or both? Is it the sort of thing that would require permanent buildings or could it be housed in RVs?

-Lesley

There are plenty of places where I wouldn't need to be mobile if I could stay there all the time. But if I want to go into civili-devastation with relative impunity, I need to have my decontamination unit with me.

-Erik

Oh? There are places where you could stay and not be at risk from drifting mold plumes?

I'm guessing that such places would be far enough from civili-devastation that mold plumes could not reach you. Does that mean that all dangerous mold originates in man-made environments, and the mold found in nature is not dangerous to you?

If so, I'm puzzled. The recipe for stachy growth is cellulose + moisture, right? Surely the the conditions are right in damp woods? I must be missing some vital element.

-Lesley

I read somewhere that the relatively few indoor molds do well on cellulose and moisture alone, but they're in a habitat that doesn't compete with the universe of outdoor molds.
For all we know, Stachbotrys can't survive the competition outside, and does well only in buildings that have had water intrusion or are weapons labs.

Does stachy grow in the wild? If so, is it as nasty bad as the indoor type?

I agree with Erik - there's seems to be only one remote chance scenario for getting a mold avoidance retreat off the ground, and that's a rich person fighting against toxic mold for his or her life.

-Keith

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Most people don't quite hear me when I tell them not to get all fired up about putting all their attention into studying into normal mycotoxins and to keep this in mind as kind of an unexplained effect until we know more.

That's why I've been telling the story of Gosio's Gas killer wallpaper and Dr. Sprott's SIDS intervention based on the Richardson hypothesis.

It doesn't do a darn bit of good to equate toxicity with a species of mold, if the toxin potential isn't inherent to the mold but is dependent on what that mold is eating and then spewing out.

Remember my story of hang gliding over an area that had been firebombed with flame retardant, This is one of the few times that an area out in the woods - or shall I say, "flying 3,000 feet over the woods" - really got to me.

Surely mold is all over the place. So what makes this different?

It struck me that the difference was that the mold out there must have been feasting on the flame retardant.

-Erik

*

I think this paper by Gray addresses my last question:

"Mycotoxins produced by structural molds-meaning molds imported into the residences, workplaces, and public buildings on the paper covering the drywall, and other wood based composite materials-- often represent some of the most toxic substances known to humankind. The molds imported on building materials are not the same as molds commonly encountered in outdoor environments. The wood chips, and wood pulp imported from the Amazon rain forests bring with them their own varieties of mold spores."
Toxic is toxic. Indoors or out.

If we can stumble over potentiated mycotoxins out in the woods, but only in association with flame retardants, the possibilities postulated by Dr. Gray do not apply.

Really, it narrows down the field considerably to what might be happening.

The mold was there. It's the same mold. But it wasn't whuppin' ass until it got ahold of something special to spew out.

-Erik

Erik, your hang gliding experience is saying that mold toxins can be potentiated by flame retardants. Is there a biochemical understanding of this to support the face validity of the concept based on the experience of a trustworthy historian? How would a flame retardant change the toxicity of a mold, by binding to it and becoming a vector?

-Keith

Dr. Sprott’s experience with the Babe Safe system tells us that for all practical purposes, avoiding the combination of moldy mattresses and flame retardants yields real results.

-Erik

http://www.purdeyenvironment.com/cotdeath.htm

The Guardian Weekend : Saturday, April 1st 1995

Inside Story: Bob Woffinden

Seven years ago Barry Richardson came up with what remains the most persuasive explanation of cot death. It makes far more sense than the latest theory - that the syndrome is caused by smoking. So why is his work ignored or condemned?

Cot death had not always been an inherent danger of parental life. It was first described as a medical phenomenon by Dr A M Barrett in 1953. He estimated that unexplained
infant deaths then were three to four times what they had been a few years earlier, and that the additional numbers occurred mainly in sleep.

Pathologists in Britain had previously been reluctant to diagnose cot death. They felt it implied some inadequacy on their own behalf, and also compounded the distress and bewilderment of parents. But by the late Sixties coroners started to record SIDS with confidence, and the figures had become reasonably accurate by 1980. From 1986-88, as cot death peaked, approximately 1,500 babies were dying annually in England and Wales, all in the same mysterious way. They showed no symptoms of illness, just suddenly capitulated, displaying no outstanding pathological features. No one could doubt that it was a medical issue of critical importance.

Though especially acute in Britain, the problem was not confined to this country. There were cot deaths in the US, Australia and New Zealand and throughout Western Europe. However, there appeared to be none in China, India, parts of Africa or Japan. Yet Japanese families in America suffered cot death at the same rate as the rest of the population. A number of international conferences were held, and a variety of academic projects set up. But the research seemed to be getting nowhere, and the deaths were increasing.

The wedding in Winchester of Barry Richardson's daughter Sue on September 17, 1988 did not, at the time, seem a significant turning-point in the investigation of cot death; nor is it currently perceived as such. But history may exercise a more prudent judgment.

For the occasion of his daughter's wedding, Richardson hired a marquee from a Rotarian friend, Peter Mitchell. The latter took the opportunity to ask Richardson's advice. He explained that the manufacturers were having problems with the biodeterioration of the reinforced PVC fabric used in marquees. Although designed to last for years, they often looked unsightly after a short period. Richardson was the ideal man to consult. He had spent most of his professional life working on the deterioration of materials and associated health risks. It was work on which his father had been engaged in the Thirties, and Richardson had taken a general science degree (embracing physics, zoology, biochemistry and physiology) to enable him to pursue it further. He had set up his own practice as a consulting scientist in 1965.

He was able to provide the answer. He explained that the degeneration of the marquee fabric was due to fungi. At a later meeting, one of the Austrian manufacturers commented that if the problem was really that straightforward, he'd simply increase the amount of fungicide.

"The deterioration was so severe that it hadn't occurred to me that a fungicide was present," recalled Richardson. "But I warned against increasing the amount. This particular fungicide, OBPA, is an arsenical compound. I knew that when you have active fungal deterioration there is a danger that the fungus can convert the fungicide into toxic arsine gas."
The PVC manufacturers listened politely, but seemed to consider this cautionary warning little short of loopy. Peter Mitchell didn't know who to believe. He decided to try to reconcile the situation by telephoning the fungicide manufacturers. They returned his call the same day. They told him that his friend was talking absolute nonsense. OBPA was perfectly safe. Indeed, it was so innocuous that it was even approved for use in cot-mattress PVC.

Mitchell spent a sleepless night, and telephoned Richardson at breakfast-time. He asked whether there was any possibility that fungal deterioration and the production of toxic gases could conceivably be linked to cot death. Richardson replied that it was a possibility. He even knew which fungus could be involved.

The notion that deaths might be caused in this way was not new. In the 19th century, a number of fatalities occurred because of arsine gas generated by a fungus, now known as Scopulariopsis brevicaulis, growing on wallpaper containing arsenical pigments. It is now generally considered that Napoleon died on St Helena in this way. The mycological mechanism was ultimately identified by an Italian chemist. The syndrome was named after him: Gosio's Disease. At the turn of the century, a number of infant deaths in England were attributed to this. Lord Salisbury's Conservative administration set up the Royal Commission on Arsenical Poisoning, which in 1904 reported that arsine poisoning was difficult to diagnose and was probably undetected in many cases. As late as 1932 however it killed two children in the Forest of Dean.

Richardson's hypothesis fitted in with one observation. At the start of the Eighties, parents were warned not to overwrap their children. This had some success in reducing the death-rate; but overwrapping itself was obviously not the cause, otherwise Inuit people would have suffered an abnormally high rate of cot death. However, overwrapping could simultaneously trap the toxic gases and cause overheating, thereby generating more gases more quickly.

Would the theory be borne out in practice? Richardson resolved to examine the issue. No one was paying him to do the work, but the urgent need to save lives overrode other priorities.

Mitchell wrote to all coroners in England and Wales, asking if he and Richardson could be supplied with actual, cot-death mattresses. Hampshire and other police forces lent generous support, and more than 200 mattresses were delivered to Winchester for analysis at Richardson's laboratory in Guernsey.

The first part of the experimental work was easy. All the mattresses were contaminated with scopulariopsis brevicaulis, particularly in the areas exposed to the warmth and perspiration of the baby. Yet, no one could detect the arsine gas that Richardson had anticipated finding.

'We did notice that those of us doing the lab work were suffering headaches," explained Richardson. ",I was teasing my chemist, saying he obviously wasn't competent. He
replied, 'Well, you will give me these complicated jobs, looking for arsenic in the presence of so much phosphorus and antimony.' And then it all clicked. This fungus was working on phosphorus and antimony compounds. We immediately repeated the tests, looking instead for phosphine (from phosphorous) and stibine (from antimony) gases - and we found them straightaway."

In fact, arsenic - with one important exception - was not used in British mattresses. But arsenic, phosphorus and antimony are adjacent Group Five elements in the periodic table, and react similarly. Phosphine, stibine and arsine are exceedingly dangerous trihydride gases (stibine is 1000 times more toxic than carbon monoxide) which act as anti cholinesterases - like organo-phosphorus insecticides - and to which infants are very sensitive. Anticholinesterases in the blood cause cardiac inhibition. The heart beats slower and slower until it stops altogether. It was a wholly logical explanation for SIDS.

The poisoning action would leave no visible signs, but was consistent with the recorded observations. If this was really the solution then, 36 years on, Barrett's original observation in 1953 made perfect sense: PVC cot mattress coverings were introduced in 1948-49, and fire retardants were first put into them in 1951.

From 1953 onwards, the deaths appeared to rise steadily until they significantly increased in the mid-Eighties. To enhance fire safety precautions, the Department of Trade and Industry (DTI) brought in the Furniture and Furnishings (Fire Safety) Regulations in 1988, but had given industry four years' advance warning of their implementation. Under DTI pressure, all companies had put increased amounts of fire retardants into furnishing materials, cot mattresses included, over the previous four years.

Richardson's finding explained virtually, all of the cot-death mysteries. In two cases, families had decided at the last minute to stay overnight with friends. In each case, their baby was placed in the cot of the hosts' older child. The latter, by using the mattress daily, had activated the fungus which liberated the gases. The child had been strong enough to withstand the toxic effects; the baby had not.

It also explained why lower-income and single parent families were especially vulnerable, as they were more likely to use older mattresses on which the invisible fungus was more highly developed; and why there was no cot death in Japan, where cotton futons were impregnated with boric acid, a safe fire retardant.

Richardson and Mitchell had first outlined the theory to the Department of Health on January 11, 1989. They received a reply on February 22 from Dr. Lister Cheese, senior medical officer, who politely explained that the hypothesis did "not stand up to scientific scrutiny."

"This was astonishing," said Richardson. "The process that I was describing was in all the industrial mycology handbooks. Had they even bothered to look?"
On October 31, 1991, the Back to sleep recommendations were announced. The campaign had a clear message: if babies were put to sleep on their backs, they would be safer. Yet it was evident it that the sleeping position could only be a secondary factor; after all, babies had been sleeping every which way for centuries. When the cot-death statistics could be analysed, some time later, it could be seen that this initiative had reduced the cot-death rate by about 40 per cent. This is something for which the Department of health, suddenly overlooking the years through which it had been offering totally contrary advice, claimed great credit.

There was soon a third factor at work. Richardson completed his research and, before moving on to other work, published his report, Cot Death: Must Babies Still Die? in November 1991.

By this and other means, manufacturers had been alerted to the risks. They changed the composition of the fire-retardant materials, leaving out antimony.

This has never been publicised. If a company openly stated that it had changed the composition of the chemicals to make mattresses safer, there would be automatic inference that they hadn't previously been safe - and thus the company would be vulnerable to legal actions. One of the leading companies did, in fact, put together a major advertising campaign stressing the newly-enhanced safety of its mattresses - but aborted it, presumably on legal advice.

Fresh research compared antimony levels in the hair of children and their mothers, and discovered that the children were exposed to much higher levels. Since the mothers were inhabiting the same general environment, the most plausible explanation for the disparity was whatever babies had been exposed to in their cots; and that had been established by analysis of the mattresses.

The Scottish Cot Death Trust had commissioned work on antimony levels found in the livers of cot-death victims and a control group of babies who had died of other causes. No significant difference was perceived between the two groups.

However, there seemed to be confusion between chronic poisoning, which could be measured by deposits in the liver, and acute poisoning - which would cause SIDS, and would not be measured in the liver but in serum or lung tissue.

We are now all asked to believe the fresh theory: that SIDS can be attributed to parental smoking. Here, at last, is a perfect theory for the government, one which absolves it of all responsibility and blame.

It is axiomatic that no parent should smoke in the same house as any child, let alone a newborn baby; but to suggest that smoking is a significant cause of SIDS is questionable. If there were bona fide epidemiological evidence to support this, it would have been discovered long ago. In fact, anecdotal evidence tends to undermine it. Julie
Oakley, who helps to organise a cot-death support-group in Plymouth, told me that "we're in close contact with nine cot-death families, of which four are non-smoking."

If smoking were linked to cot-death, then one would have expected to see high cot-death rates in Britain in the Thirties and Forties, when smoking was fashionable and widespread. There was, however, no cot-death at that period.

Similarly, one would expect to see particularly high levels today in southern European countries like Spain and Italy. This is not the case. In Russia, smoking is prevalent but cot-death non-existent; conversely, in America, fewer and fewer households are smoking, yet cot-death remains a serious problem.

Although Richardson's work continues to be repudiated by scientists in Britain and, especially, the United States, it is clear both that the death-rate has been falling since his theory was first propounded, and that current research - with the figures thankfully way below the 1988 peak - can shed only limited light on the situation then.

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Thanks, answer man. That's interesting, in a haunting kind of way.

It makes me wonder if, in some cases of ME/Incline-type CFS, there's a third accomplice to go with toxic mold and HHV-6a, and that's chemicals containing chemicals and/or elements (arsenic, phosphorus, antimony, etc.) that, when mixed with certain indoor molds, are metabolized by those molds into gas poisonous enough to cause sudden death in infants, and but only abject misery and sometimes death in adults.

In this analysis, a linen mold called scopulariopsis brevicaulis would metabolize the phosphorus or antimony found in the deteriorating PVC material used to reinforce a mattress into dangerous trihydride gases, which, like organophosphates, act like anticholinesterases. This chance combination of mold and chemical created a sufficient personal dose of nerve gas to result in crib death.

Do you think the flame retardants used to douse forest fires can mix with molds, and that it was a gaseous metabolic byproduct produced by this mix that set you off while hang gliding?

Are you aware of any research linking ME/Inclince-type CFS to firefighters?

Are you aware of other industrial chemicals that would have the potential to be metabolized by molds into neurotoxic gases? Which chemicals? Which molds?

-Keith
Evidence for more instances in which the Richardson hypothesis comes into play is all anecdotal. But when you develop an ear for it, the number of repetitions makes it compelling.

I've heard several stories of firefighters, doing mop up operations in forest fires that were fought from the air with fire retardant, who turned over a smoldering stump and the whole crew winds up in the hospital.

To me, this says they had just the mycotoxin connection part of the equation, but without the viral co-factor present in clusters of CFS.

The firefighters recovered. That's the difference from not having the virus.

And when you see the same thing happen in cases of C Pneumonia, where someone becomes more or less chronically ill, but you know the mold is there because you can feel it, then you begin to wonder why the medical profession is so obstinate about refusing to examine this sensation as a possible common denominator.

-Erik

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From Erik's excerpt of Brian Martin's, "Confronting the Experts" above:

"In every case, the establishment has a comprehensive world view to which leading figures are intensely committed...No, the secret of every successful critic is good arguments, based on collecting information, carrying out careful analyses, preparing well thought-out written and verbal presentations...All of this requires a lot of hard work."

You're fighting the good fight. Keep amassing and collating the facts. Mold, mold-viral interactions, and mold-chemical interactions, are not just an issue for CFS research. They're environmental and public health issues. Maybe individuals or groups within the environmental movement, or members of the media that cover environmental issues, would find these issues interesting enough to be worth a story.

What would a press release on "mold as a health and environmental concern" look like? Who should the spokespeople be? Which facts and sources best support the argument? How can they best be used to sharpen the contrast between paradigms? Which mold stories really hit emotional notes (frustration, sadness, anger, recovery, etc.) that would resonate?

If a small group of critics armed with facts and cogent arguments can't generate enough heat to change the mainstream medical approach to CFS, maybe the environmental movement can.
I've only now begun exploring postings on other threads from this board. Their postings, combined with the discussion on this thread so far, have me virtually convinced that ME/Incline-type CFS is a spectrum of toxic encephalitis disorders. For sure, toxic encephalopathy is too vague (and too kind).

The "Why is Alex Paralyzed?" posting on green wallpaper poisonings in the Victorian era raise the questions of chemicals (that seem to contain heavy metals or toxic elements) that can form poisonous gases. Juxtaposed with the mold/flame retardant/trihydride gas hypothesis, it made me wonder if certain chemicals alone or only mold-activated chemicals can produce such instant brain slams because a toxic gas is involved.

A toxic gas would quickly pass through human brain capillary endothelial cells (HBCECs) -- quickly enough, perhaps, to account for the "flipping of a switch" suddenness of the hypersensitized moldies. A first wave of toxic gas would be followed by the ionophoric tactics of, say, satratoxins on HBCECs.

This allows peripheral blood plasma elements that are ordinarily kept out of the brain to get in. This would put the glial network on the front lines, trying to manage cytokine storms. Various brain functions would start showing signs of dysfunction.

As the blood-brain barrier's dysfunction has the HBCECs and glial cells pointing fingers at each other, a cytokine-peppered toxic soup makes its way to the choroid plexus. It responds by unleashing its trappers, alpha- and beta-2 microglobulins, but they're not enough in this unusual situation.

As cytokine-mediated inflammatory responses proceed, the spillover into the cerebrospinal fluid will include an interesting assortment of proteins. The post of Dr. Baraniuk's lumbar puncture study (also on the "Alex" thread, I think) seems to indicate that this is exactly what's happening. His proteomic analysis of CSF is CFS patients is documenting the traces of a toxic encephalitis.

There is no mention by Dr. Baraniuk of pressure abnormalities, but with this much inflammatory spillover into the CSF there may be irritation of the arachnoid and/or pia mater layers to produce headaches. We don't have to postulate pressure abnormalities. He did find an unusually high frequency of post-spinal tap headaches.

Based on the population of Gulf War Illness and CFS patients he tapped in this study, somewhere around 70 to 80% reported migraine headaches. In practice, if someone's severe headache is not clearly caused by muscle tension or sinus inflammation, it's likely to be called a migraine. The diagnosis of a migraine headaches syndrome is still non-specific because migraine researchers still don't know how to explain them. The
new ICD-9 codes for 2009 include 54 different codes for cluster and migraine headache syndromes.

How many of these cluster or migraine headaches are mediated by the pathways just outlined?

I'd speculate that if we knew enough about the interactions of molds, viruses, spirochetes, cell wall deficient forms, bacteria, dinoflagellates-chemicals, and gases, that we'd be able to predict which pattern of migraine an exposed, genetically susceptible person would develop. We might also be able to predict which pattern of toxic encephalitis exists based on exposure, susceptibility, and CSF protein analysis. Perhaps for any CFS patient undergoing a spinal tap, there should be an epidural blood patch tray at the ready to prevent the post-tap headache.

The toxic encephalitis-inducing mold-virus-spirochete-CWDF-bacteria-dinoflagellate-chemical-gas interactions could involve every possible permutation, and this is an abbreviated list of suspects. With the interaction hypothesis, no particular advocacy group would have to lose its sacred cow, they'd just have to give toxic mold sufferers a little credit for moving the chains down the field. The interesting thing is how far out in front of the inductive reasoning process you folks in the toxic mold realm seem to be in figuring this thing out.

-Keith

*  

It seems clear to me that there needs to be a way to identify the toxic soup being breathed in. If you can detect strep with a throat swab, surely there must be a way to swab the sinus/throat/lungs and identify mold toxins. Such a test should also be able to identify assorted chemicals that are mixing with the mold ick. Since this seems the likely entry point into the body, identifying it there, before there is a body response to break it down, seems like a good step.

Sinus issues seem to be an across the board issue. Those mucous membranes are working overtime to encapsulate the ick we breathe in. I think it should be tested.

-Stormy

*

The manner of description of this burning sensation accompanied by the utter failure of scientific testing to ascribe a suitable level of pathogenesis to that specific exposure, tells us the the diagnostic tools to detect this type response have yet to be developed.
The medical profession appears scarcely even aware that the numerous reports of this phenomenon might actually be true. This alone is testament to their inability to measure it.

Those of us who pursue the effect of "Feel Good Locations" have experienced a near miraculous level of recovery, but only in these locations.

This led to my speculation that someone like Alex remains in a stated of perpetual neurotoxic-feedback inflammation which is unlikely to be successfully neutralized without moving her to such a location.

-Erik

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Erik, how sick were you before you started to feel the burn? Was that one of the first symptoms, or did that come later after an accumulation of exposure?

What I've noticed is that, even though I've had burning sensations pretty much forever with exposure, the ones I get now with the Texass effect are much, much hotter. If I close my eyes, I would not be surprised to open them and find my hands and face coated in acid.

-Khaly

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It was so vague prior to 1985 as to be almost imperceptible to me.

All that changed when the "Yuppie Flu" went through. After that, it was like inhaling hot coals and gargling with battery acid.

The Truckee HS teachers described it perfectly, but air quality professionals found nothing, so it was forgotten.

That is, forgotten by all except a couple of people who knew just how much it paid to stay out of rooms like that.

But because we aren't paralyzed, those who are don't want to hear about it.

-Erik

* 

I'm not sure spinal taps for the masses is a good idea. Lest we forget, Dr. Shoemaker is blazing a trail as well that not only has identified reliable biomarkers (VCS, C4a, MMP-9,
MSH, etc), but a method of treatment that involves avoidance, PPAR agonists, and CSM. Swab technology would be interesting to explore. What would it look for?

-Keith

*

Not to ignore the individual issues, but a mere ten years ago I asked Eckhardt Johanning's office about the effects of Stachy - remember, this is the guy who identified the Cleveland infant pulmonary hemosiderosis phenomenon and brought Stachybotrys into mainstream medical culture - and they had never heard of anyone with complaints as extreme as mine. Now, within a decade, we have slew of people who sound just like me.

Many of these people don't stop to ask why we didn't hear about this kind of thing before. They just quote Dr. Johanning and others in saying that this is happening, but without much attention to just how much it didn't used to happen.

This inadvertently creates the "It must be just me" conceptual framework, which places more emphasis on the person than on the vast scope of an emerging phenomenon.

It's scary to have a substance rolling around out there that can take us to pieces so quickly. Some of these zones are acquiring such an incredible potency that even though we Moldies are the first to be affected, it is clear to us by the way others are changing behaviors, getting depressed and tired, and complain of vague problems that they aren't quite as immune as they had hoped.

But I suppose this illness will have to become statistically significant before doctors wake up to what is going on.

How many "just me's" do we need before society goes, "Holy shit, it isn't just them and I could be next"?

-Erik

*

"Safe exposure thresholds" is a way of providing false reassurance to the public. Toxic molds and chemicals can have additive toxic effects that have never even been studied. Some people are genetically weak at clearing toxins. Some are weakened by concurrent medical conditions or unhealthy habits.

The science needed by expert witnesses isn't developed yet. Laws lean toward protecting the interests of the equity holders. Precedents for or against the public health interest pop up every few years, but nothing definitive happens. Here's a nice summary
of cases that offers equity holders the refuge they need, arguing that judgments against equity holders would need definitive scientific evidence, which in Daubert v. Merrel Dow is defined as proven toxicity within 95% confidence intervals.

www.thefederation.org/documents/Hanekampe-Su03.htm#_edn81

As for interaction effects between molds and chemicals, this site digs into the Richardson hypothesis regarding mold, flame retardants, toxic gas, and cot death and comes away unconvinced.


The emergent complexity of toxicity effects on living systems make it easy for the courts to dodge the issue because the "junk science" defense creates a vast refuge for property owners. But the growing controversy is telling us that the problems are real, if not well understood, and that public health and environmental action is warranted. Such action should be aimed at funding the kind of research that will help us better understand the health and environmental threats, so we can lay a more definitive foundation for being smart and playing it safe.

-Keith

*  

Yes, "junk science" has been successfully used to suppress investigation into this phenomenon countless times.

This is why I tell people not to get all worked up about reading about studying mycotoxins. Thousands of repetitions of stories tell us the tools to measure it have not been developed yet.

-Erik

http://www.environmentalhealth.ca/Jan98report.html

*  

Thanks for the great posts again, Erik.

From Patricia Beresford's response to the Langley Committee's Report:

Quote:
The Langley “working definition” is extremely limiting in the symptoms listed and their timing: “at least six months duration, ...fatigue, sensitivity to odours and confusion”, and a further list of 10 symptoms which were based on a survey done over ten years ago on
a very small sample of 50 patients whom, I believe, are not representative of the over eight hundred patients who have now been seen. Dr. Miller suggests that “...restricting thinking about chemical sensitivity to any immutable set of symptoms or number of organ systems could prematurely constrict the field of view”.

Comment:
It could similarly be said that the CDC prematurely restricted its field of view with the Holmes and Fukuda case definitions. The same "at least six months duration" concept pulls attention away from the manner in which these syndrome-disease entities unfold, and completely ignores genetic and environmental variables at play during the pre-trigger "induction" phase.

I'm troubled that when expert panels can't pigeonhole a syndrome as an infectious, allergic, or autoimmune disease, it decides that the symptoms are therefore non-specific, the people whose lives are disabled by these non-specific symptoms warrant our "support," and that will just have to wait a few decades and see what science makes of the problem.

ME/CFS and MCS are in the spectrum of toxicity syndromes. The nature of these toxicity syndromes is so complex that purely reductionistic, top-down, zoom lens scientific approaches are too restricted in their perspectives. It's only when we pan back to a wide enough view that we see how biotoxins and synthetic chemical toxins interact with things like genes and viral exposures to produce the characteristic patterns of ME/CFS and MCS.

Who is the "Dr. Miller" she quotes here? What do we know about the Langley Committee?

Quote:
The Langley definition goes on to state that “various inhaled or injected substances are used in the diagnosis, but reactions to these do not exclude the diagnosis nor do positive reactions necessarily substantiate the diagnosis.” On the contrary, if, under properly designed testing, in a controlled environment, symptoms are incited by low level substance exposure, and then resolved by clearance of the substance, then this, by definition, establishes the diagnosis of chemical sensitivity. Numerous researchers have now carried out these trials.

A more universally accepted definition of multiple chemical sensitivity is that presented by Mark Cullen:

“Multiple Chemical Sensitivity can be defined as an acquired disorder characterized by recurrent symptoms, referable to multiple organ systems, occurring in response to demonstrable exposure to many chemically unrelated compounds at doses far below those established in the general population to cause harmful effects. No single widely accepted test of physiologic function can be shown to correlate with symptoms.”
This definition would be a better alternative to use, although not ideal. This definition can also be applied to the Chronic Fatigue Syndrome patient who experiences “the spreading phenomenon” leading to multiple sensitivities.

Another major problem with the Langley definition is the omission of the critical factor that the triggering exposures, in the syndrome, “multiple chemical sensitivity” are to chemicals or other substance, i.e. drugs, at doses far below those established in the general population to cause harmful effects. Specialists in the field universally accept this factor.

Comment:
How many ME/CFS patients would say they experienced, at any point after illness onset, the "spreading phenomenon" mentioned above in MCS patients, where sensitivity comes to involve an ever-longer list of substances?

-Keith

*"Hippocrates: Burning Winds"

-Erik


*"Sounds like Hippocrates was describing a flesh-eating bacteria as on of the wet weather afflictions, but some of those descriptions fit a mold-virus whammy pretty well.

Dr. Myhill's group has found a way to document mitochondrial dysfunction that is easily reproducible by other labs. Their results are striking. The worse the ME/CFS, the lower the aerobic output from their neutrophil mitochondria. At the end of this paper, she acknowledges that this study cannot distinguish between primary mitochondriopathy and secondary mitochondrial dysfunction related to decreased redox balance in cells, etc.

My guess is that it is an effect that's secondary to the changes created by cytokine upregulation, toxins, viruses, spirochetes, and other intracellular pathogens. In such clinical situations, regulation neurohormonal systems are disrupted, and metabolic parameters start drifting away from normal. As acidity increases, pH dependent processes suffer. The amino acid pool may shrink. The HP axis with thyroid and the adrenals drifts off kilter. Mitochondria default to their anaerobic mode. The body, being programmed to win, decides to keep it that way, knowing that if hemoglobin were to release oxygen in cells this dysfunctional they'd turn into radicals and oxidize anything
in their path. In some of these folks, you'll find biotoxin pathway abnormalities (Shoemaker cases). In others you'll find low blood volumes (Cheney cases). In others, you'll find characteristic HHV-6a findings (Peterson cases). In some, if you look, you'll find CSF abnormalities (Baraniuk cases). In others, you'll find methylation and glutathione pathway abnormalities (van Konynenberg cases). In others, you'll find evidence of microvasculitis in the brain (Hyde cases). In still others, you may find evidence of chemical sensitivity to multiple substances (Rea cases).

As group, you'll find plenty of overlap between sub-types, and perhaps genomic ways to account for the differences.

The picture emerging for me is one of Multifactorial Toxic Encephalitis (MuTE), resulting in Widespread Metabolic Dysfunction (WMD). The weapons of mass destruction include biotoxins, viral DNA or RNA code sequences, autoimmune friendly fire, and the full registry chemical toxins. Some combinations unleash a shock and awe campaign. Others bog the system down using sleeper cells and guerilla tactics. The permutations are endless. The postings on this thread and elsewhere on this Board have me thinking that ME/CFS should be the flagship disease puzzle for the new era of systems biology, with implications that extend to age-related chronic disease as a category.

We'll see, I guess.

But if this is a somewhat accurate portrayal of what's going on in people who found their way onto the ME/CFS spectrum of illness, I'd like to learn more about how low-level energy neurofeedback or transcranial stimulation provided a way for such patients to climb back to normal, as I have not heard of this before and need to understand the proposed mechanisms of action.

-Keith

* * *

The unappreciated spectacularity of Hippocrates’ observations were that all the other illnesses were subordinate to the wind and weather. Regardless of what they had, their afflictions waxed and waned according the some mediating influence whose clues were to be found in the change of the weather.

And the other amazing thing about this weather and seasonal connection is the way it is made so repetitively that the association remains embedded as an iconic cultural artifact, yet not in a direct manner where people can point at the exact source.

It remains vague and almost indefinable.

That means if people are looking for an identifiable symptom or feature of that they can easily perceive and use as an indication of exposure, as one would expect with an allergy, they’re not likely to find it.
This is from a researcher in Iran that I corresponded with, a few years ago.

I told him that CFS research in Iran appeared to be years ahead of CFS research in Incline Village, at least in terms of exploring the mycotoxin connection.

Is there any relation between moldy building exposure and chronic fatigue syndrome?

Journal: Med Hypotheses. 2006 Mar 7

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It is reported that workers who are employed in moldy buildings show different symptoms like respiratory difficulties, fatigue, fever and headache. Hirvonen et al. have reported elevated cytokines (interleukin-1, interleukin-6 and tumor necrosis factor a) and nitric oxide (NO) levels in nasal lavage of workers in exposure to moldy buildings. Due to laboratory tests, Aspergillus fumigatus, Trichoderma, Actinomycetes, etc. were detected in indoor air [1].

On the other hand, chronic fatigue syndrome (CFS) is the current name for a disorder characterized by debilitating fatigue and several associated complaints including headache, sleep disorder, low grade fever and concentration difficulties [2]. It is mentioned that post-infectious, immunological, and psychological factors are involved in the syndrome [3].

Researches in patients with CFS have shown a significant elevation in serum levels of interleukin-1 and tumor necrosis factors a and ß [4], which can result in the appearance of CFS symptoms. Small amounts of circulating cytokines can enter the cerebrospinal fluid and the parenchyma of the brain [5]. Cytokines administered systemically or directly into the central nervous system have shown to alter the activity of hypothalamus, hippocampus, and prefrontal cortex [6].

In addition, elevated nitric oxide levels have been documented in CFS patients. It is hypothesized that NO plays a significant role in pain sensitization, which is seen in
these patients [7]. Moreover, excessive NO production is an important factor in pulmonary manifestations including vasodilation, edema and cytotoxicity [1].

It seems from the above mentioned points that, in accordance with the post-infectious theory of CFS, the exposure to moldy conditions may be a trigger for the onset of CFS. Moreover, the working of persons with CFS in moldy conditions may aggravate their symptoms including pulmonary pain and psychoneurological manifestations. Surely, our hypothesis needs to be validated by experimental evaluation.

*  

It doesn't hurt to have CFS researchers in Iran hypothesizing about the link between mold toxicity and CFS. To me, the evidence of Lisa's experience (which first brought my attention to the mold-CFS link and to Shoemaker's work), and of your well-documented experience, combined with so many links that span the decades and the globe, the case is already made.

The question is when will thought leaders in the field make room for the mold factor? Just give mold toxicity a seat at the CFS table and let it compete for some funding. Looking at the biomarkers, a good team of systems biologists would settle the matter in a year or two and there would be no question that mold is playing a key role.

-Keith
Chapter 80 - A Conversation with Branislav

Following is a conversation about “super molds” with Branislav, an extreme mold reactor from Belgrade, Serbia.

> About a week ago I was going into my bank by public bus. A young man came into the bus about three stations before I reached the destination. He carried a large suitcase. I guess he was probably returning from a vacation from a foreign country. His suitcase emitted huge amounts of extremely powerful mycotoxins, and I got contaminated. All I carried with me (personal ID, bank documents and a lot more) became contaminated too. I thought the contamination would drop off by itself but it didn't. Of course, the bank is now contaminated as well.

> Apparently it was not living mold but mainly mycotoxins. Even my plastic bank card got contaminated.

> How do you handle your personal documents when you must take them with you to a place where mold hits are possible? Do you enclose them in something to prevent contamination?

I don't believe that your materials became contaminated by that specific exposure. I think they were already contaminated at the bank by adsorbed mycotoxins, and the powerful mycotoxins from the man with the suitcase upregulated your immune response and made the pre-contamination of your materials apparent to you.

This is why I keep referring to going to a pristine place to get clear. It is because when you return, you will find that objects and locations which you thought were safe, aren't all that safe at all. It was just lower of the relative scale of response, and the blocking effect common in MCS was in play and made you unable to perceive it.

Extreme avoidance means that you must go out of your way to identify areas that are masked by blocking and treat them as though they were perceptible hits and a driving force in a chronic immune response which wears you down over time.

The discussion on buying a house and having to sleep in it goes right to the point. It might not be possible to feel an intolerable level of badness right away, and if you aren't educated in unmasking subclinical intolerances hidden by blocking, you'll walk right into another trap.
So, to try to answer your question. I make no provisions for protecting my documents from this type of momentary exposure, because I do not believe that casual exposure causes this type of contamination. My experience is that under the circumstances that you describe, mycotoxin pre-contamination was only unmasked by a potentiating upregulation of inflammatory response.

-Erik (2006, SickBuildings)

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> I have tons of papers from that bank accumulated over the years. Mostly bank receipts, contracts, and paper money. I just looked at them. I even have several papers I got on the same day the contamination occurred, but from my morning visit to the bank. (I went twice to the bank on that unlucky day, in the morning when nothing happened and in the afternoon when I got slammed with the mycotoxin cloud.)

> None of these papers cause me any adverse reactions except those that I carried with me when the man with the suitcase passed by me.

> According to your theory, the bank already had substantial amount of mycotoxins on their papers but I wasn’t aware of it until the powerful mycotoxin cloud slammed me. The corollary would be that all the papers from that bank should be causing me problems now when my immune system was upregulated. But that’s just not the case.

> In 2004 and 2005 during summer I went to pristine places. I went to a beautiful mountain and to the country, respectively. Both places are completely clean and very mold-free. I can tell that because I didn’t have any symptoms typical for mold exposure. I felt completely refreshed upon return.

> When I got back to my flat, there were no surprises you are talking about. The objects that I had previously considered to be clean were clean after I came back, causing me no surprise reactions. Those objects that I knew that had been contaminated were still contaminated after I came back. How does this fit into your theory?

If papers are carried in layers, one would assume that only the outer layers have the potential to be become the most contaminated.

If the bank was the source, a top sheet would have been contaminated far more than the contents underneath. I would expect whatever documents that were placed at risk had more exposure.

So I do not agree that all documents from the bank can be used for ruling out the concept, since cannot all be considered equal in terms of exposure.
If you were carrying your paperwork in layers, I don’t see how the momentary exposure could have done much more than contaminate exterior layers. Interior ones were not at risk.

Where did their contamination come from if they were not at risk during that briefcase event?

I shop at a local store that feels perfectly fine to me when I return from the wilderness. But when I leave my moderately contaminated workplace, this same store is not only slams me, but I feel hits from people in the store on a regular basis.

This happens so consistently that I do not believe that when I fail to perceive it, this store and these people just happen to be totally lacking in contamination that day. I believe that the amount of exposure unveiled my reactivity above and beyond the level that a pristine environment would.

Conversely, when I’ve had a major slam from somewhere other than my workplace, going there feels like a major relief, even though I know from years of experience that long duration of exposure to that place would take me apart.

I cannot look at this as reaction vs. no reaction because it always changes according to where I am on the power curve of exposure.

Everything has to be placed in context according to where it stands on the relative shift of variable response.

-Erik (2006, SickBuildings)

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> You have your theory which is based on your experience, and thus far it seems it has served you well. However, based on your descriptions and your understanding of how mycotoxins work or behave, I can only conclude that you either a) have much, much higher resistance to mycotoxins than me, or b) you have never experienced such powerful mycotoxin clouds as I have.

> That is because you say:

> > If papers are carried in layers, one would assume that only the outer layers have the potential to be become the most contaminated.

> No! Mycotoxins that I’m talking about here are so powerful that they can penetrate many layers of paper. Why is it so hard to imagine? Trichothecene mycotoxins have very small molecules, thus they can penetrate deep into objects, especially porous ones. If a pile of papers is sprayed with a concentrated form of trichothecene
mycotoxins, they will penetrate at least 10 cm, especially if they are given about an hour to do their job and if it the temperature is high.

>Here you say:

> >If the bank was the source, a top sheet would have been contaminated far more than the contents underneath. I would expect whatever documents that were placed at risk to have had more exposure. So I do not agree that all documents from the bank can be used for ruling out the concept since all cannot be considered equal in terms of exposure.

> In all honesty I don't understand what you're talking about now. You are starting to contradict yourself.

I can only work from my own experience, because I have had no one to even discuss these details with.

The only books that I have had a response from the interior pages that was comparably strong to the exterior of the book were ones that had an extended duration of exposure. I have never experienced a momentary exposure that penetrated equally throughout a porous object without dilution of intensity corresponding to depth.

The surface contamination was always stronger than the interior unless the exposure was for days or weeks.

And certainly I have never had a lingering contamination from a source such as a person carrying a briefcase.

While I have had reactions to objects such as a television and a box of dishes at two meters, I have never had a comparable reaction to a book or document at that distance. Nor have I had a noticeable reaction to insects, so I believe your reactivity must far exceed mine or the toxins are far stronger.

I differentiate between mycotoxin clouds and spore plumes in that if I don't carry the response with me, I assume that it has been a toxin cloud and don't hurry so much to decontaminate after leaving the area, because the effect seems to dissipate on its own and lacks permanence.

So your toxin cloud is unlike ones I am familiar with, although I remember encountering some that seemed more consistent with your description in the San Francisco Bay area. However these also seemed to die down within a week and did not, to my perception, have the ability to transfer a powerful response to other objects.
The strength of the toxins you describe in having the ability to cross contaminate every paper it touches is beyond my experience, but I would be interested in understanding this paradigm. Can you contaminate a document, seal it and mail it to me?

-Erik (2006, SickBuildings)

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Controlling contamination was the basis for the protocol I proposed to Dr. Peterson when he told me that Ampligen was my last hope:

To avoid mycotoxins carried on contaminated clothing and in the hair.

I created a mobile bubble and trained myself to detect subtle exposures instead of waiting for overt slams before conducting avoidance and decontamination.

When hit, I would take a shower and isolate my clothing in a special compartment, consistently doing this as a preemptive resolution of future upregulation instead of toughing it out as the inflammatory response really gets going.

It was nothing less than acting in advance of immune upregulation that allowed my MCS responses to abate.

I cannot park my mobile decon module in a spore plume, but I can pass through them without lasting effects.

In all the years that I have been doing this, my experience has been that clothing which was only momentarily exposed can be isolated and cleaned by conventional means, with no special treatment.

It was only long term exposure that made objects and clothing acquire sufficient toxin load to be uncleanable.

I have lived a successful life for quite a while by relying on mold hits as indicators of a toxic exposure which sets up a remediatable scenario that can be resolved if action is taken quickly and preemptively.

That is why Branislav’s description of locating toxins in which momentary exposure creates enduring contamination and cannot be cleaned is so disturbing.

Toxins that are stable enough and toxic enough to have the capacity to create bad zones of permanence with such ease changes the scenario entirely, and introduces an almost impossibly complex and expensive variable to a lifestyle of avoidance.

If one encounters toxins of such potency, then clothing would have to be automatically abandoned every time.
> Does anyone have any idea what I might try in order to deactivate this toxin?

The possessions I had which somehow developed permanent toxic potential had to be abandoned, but fortunately, these were few.

I had to develop a safe zone and test virtually everything that is brought in, before I could really start to damp down my reactivity.

As long as I was in an area of continued exposure - that is, being plumed from an outside source - no amount of concentrating on individual items was sufficient to alter the progressive course of my reactivity.

Your contaminated possessions apparently do not have objective toxicity in that they fail to affect others, such as your relatives or the guy with the briefcase. So even though these toxins you've located are extremely durable and can cross contaminate other items, I believe that your reactivity is so extreme that we are talking about transfer of a few scant molecules, which is triggering an inflammatory self-perpetuating release of cytokines which is not being countered by an appropriate release of anti-inflammatory cytokines.

No anti-inflammatory cytokines are released because the continued exposure is still sufficient to signal the necessity for an immune upregulation. Theoretically, in the lack of a proper damping of immune response, a single triggering molecule could set the entire chain of events in motion. So your description is entirely reasonable and has a logical explanation that can even be consistent with conventional mold toxins, but, as far as I know, this occurs only when the immune system is so continually upregulated that normal mechanisms to stage over-expression of cytokines is overwhelmed and semi-nonexistent.

I managed to catch my progression at a level in which a tent in the desert was pristine enough to signal a stop and give me the break I needed.

It sounds like you probably require both an extremely pristine environment and Actos to shut down the response and give your immune system a chance to repair the damage.

I never had much success with bleach. Leaving things out in the sun seemed to work better for me.

-Erik (2006, SickBuildings)

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> This goes on to show that although I am more sensitive than other people, I merely
react to an existing and really problematic contaminations. The fact that other people
don't react to smaller amounts of toxins (which can make me ill for months) does not
mean that these contaminations do not exist.

But it does mean that you feel them due to your overloaded immune system, at a level
which others cannot perceive.

That is why you perceive it when they cannot.

*

> The contamination on these objects is unbelievably durable. I guess the mycotoxins
were absorbed into plastic, and that's why they are so hard to remove.

> As for the man with the suitcase and why he seemed not to be affected, why is that
given as an argument in this story at all? As Dr. Shoemaker said, many people can
literally swim in mycotoxins and not be affected at all.

That was the point of saying that in the lack of anti-inflammatory cytokine response, a
single triggering molecule can start a response that isn't held in check.

The point about the guy with the suitcase is that he didn't apparently leave a trail of
people lying on the ground with rashes and difficulty breathing while holding their heads
in pain.

So I'm assuming that the toxins, while devastating to you, were not objectively toxic to
others.

I have a number of stories from people who were slam dunked by a single exposure
that was so powerful that the toxins appeared to have the capacity to affect anyone and
everyone instantly. But even those ferocious toxins died down after six weeks.

If the toxins from the briefcase guy had demonstrable effects on others, it would be fairly
safe to conclude that they were massively potent. Without that evidence, it still leaves
the door open to speculation that they may be of normal toxicity but that these
molecules lock into your toll receptors in a particularly individual way. So it would be
your level on the power curve of exposure that dictates their effect.

That's what makes me keep coming back to assigning a relative toxicity which is
suggested by your response balanced against the presumed lack of response in others.

The difference has to be made up in individual susceptibility.
If the long-chain polystyrene backbone of CSM has a particular affinity to adsorb mycotoxins by its electron charge, why wouldn't similarly constituted plastics of electrostatic potential also have a peculiar binding affinity that might make an otherwise normal contamination excessively durable?

That's why I focused on the plastic laminate as being a possible myco-magnet. Speculation, of course, but if there is an effect to be explained, we have to seek out the possibilities.

I do have a few areas that have become contaminated in a durable way, but haven't been able to witness a single exposure that can do it. At least not yet.

I just got blasted night before last outside of Spanish Springs.

I woke up at 3 a.m. with the usual sensations and can scarcely express how terrific it is to be able to just start up my RV and drive out of the area. I went out towards Pyramid Lake and parked in the sagebrush, and the relief was immediate after I got out my backup bedding.

Not quite like some plumes in Santa Cruz where momentary exposure took four days to die down, even though I left just as quickly.

If those plumes had possessed the capacity to create endless torment from a single hit, that would certainly "complexificate" things enormously and I would have to change my entire strategy. I certainly couldn't afford to drive my RV into such a place even for an instant.

So far, because my RV has always died down within a few days at most, that would appear to mean that I am either not at your level of response or that, just as you say, the toxins you are identifying have longevity far beyond the ones I am encountering.

There is a peculiarity to the VCS in that people who have been through cycles of inflammatory response and are in ACTH correction can have a negative VCS but still have a hyper C4a.

We know from your description that despite the negative VCS, you are certainly hyper C4a.

-Erik (2006, SickBuildings)

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> I think there is a much simpler explanation. My genetic makeup is such that I can feel very small amounts of toxins. I believe that the HLA-DR genetic test will prove this beyond any doubt.
In a way you are right too. My immune system gets overloaded during exposures. The blood tests will say the final word.

The HLA DR can indicate whether you have the genetic makeup for susceptibility, but does not determine whether those genes have been expressed by a biotoxin exposure or cytokine challenge/cascade from ionophore toxins.

That is what the five step exposure assessment protocol is for. Dr. Shoemaker’s methods provide a medical context for an explanation rather than a definitive simple diagnostic test.

The final word reads more like a textbook.

I’m assuming that briefcase guy wouldn’t have made it far if he were affected by what he was carrying in the same way you were.

We are like two peanut allergy sufferers who are discussing our methods for avoiding the slightest trace of peanut residue while surrounded by people who range from nonreactive all the way to deathly affected, all viewing a single trigger from different perspectives.

To speak of peanut butter as toxic wouldn’t sound reasonable to those who have no reactivity at all.

To be scared to death of getting on a plane that serves peanuts sounds more than reasonable to someone whose very life depends on it.

And we both know that there were periods in our lives when we were far less reactive, so this aberration is just like peanuts in that the range of reactivity can vary from nil to annihilation.

So to my way of thinking, if the toxin does not elicit a consistent response from Normies, then I consider that the difference between their minimal or lesser response and mine is due to where I am on the power curve of exposure that dictates my personal reactivity.

Carl’s Personal Impact Rating is a good start for creating a basis of communication between people of varying reactivity to the same toxin, because it is our own reactivity that determines what toxic means to us and what actions are appropriate.

And if you’ve encountered a more potent toxin or have such a reactivity that it includes sensing contaminated insects and remains upregulated by exposures that do not have the capacity to create the same effect on other HLA susceptible people, we might just have to create a “PIR 7” to describe your level of response.

-Erik (2006, SickBuildings)
Branislav’s description of the briefcase incident is special in that the toxicity did not die down and that he could not air out or decontaminate the materials which were exposed. Not only that, but cross contamination after that brief exposure spread to other items with little loss of effect.

If anyone has had a similar experience of cross contamination potential of toxins which do not die down or diminish after a few days, I'd like to hear about it.

The strategy I have been relying on depends upon the toxins denaturing over time. Toxins which do not would force a reassessment of my entire situation.

-Erik (2006, SickBuildings)

The most powerful mold toxins I encountered in Europe were just outside the Forward HQ built for the proposed invasion of Britain during WW2. That was the only one I remember strong enough to absolutely stop me in my tracks. The possessions I had when I was stationed in that bunker were still incredibly strong a year later.

I also encountered strong plumes near the SchwimBad in Giessen, the Patton Hotel in Garmisch Partenkirchen, and King Ludwig’s Linderhof castle, just outside the Wagnerian Grotto.

But none of these had nearly the effect on me that you describe from the Turkish cross contamination.

-Erik (2006, SickBuildings)
Glossary

**Above Tolerance.** An environment (particularly a home or work environment) that is host to a larger amount of mycotoxins than a particular individual can bear without becoming ill.

**ACTH.** Adrenocorticotropic hormone, which stimulates release of cortisol; serves as a masking device allowing individuals being affected by mold to function without observable symptoms.

**Adsorbed.** The process by which mycotoxins (or other gases or liquids) bond permanently to the surface of a solid item.

**Agitated Exhaustion.** A state experienced by CFS sufferers as a result of their being unable to sleep deeply or restfully; may be caused by the presence of mold toxins.

**Air Test.** Environmental test looking for the presence of mold spores in the air; not helpful in gauging the presence of Stachybotrys or determining effects of an environment on severe reactors.

**Ambiently Bad.** A place that causes a mold reactor to suffer a decline in mood.

**Anaphylaxis (or Anaphylactic Response).** A complement spike accompanied by a variety of possibly severe symptoms that can occur in individuals that are hyperreactive to certain substances (such as peanuts, latex, strawberries or mycotoxins).

**Aspergillosis.** A disease characterized by the colonization in the human body of the mold aspergillus; generally present only in individuals with compromised immune systems.

**Aspergillus.** A toxic mold that is easily airborne, contaminates food and sometimes colonizes the human body.

**Avoidance.** Staying away from areas or objects contaminated with toxic mold spores, spore fragments or mycotoxins.

**Bad Building.** A building with a problematic level of mold toxicity.

**Badness.** An area or object that has a negative effect on a mold responder.

**Bad Zone.** An area problematic for mold responders.

**Balance the Books.** Spend time in a low-mold area in order to mitigate the effects of previous mold exposures.
**Benign Mold.** Fungi that do not manufacture mycotoxins.

**Beta Glucans.** Pre-sensitizer compounds made by toxic molds.

**Biotoxin.** Toxin made by certain organisms, including certain types of mold, certain strains of Lyme bacteria, brown recluse spiders, certain types of algae, certain dinoflagellates and certain other bacteria.

**Biowarfare Protocols.** Methods used to combat the effects of biological, chemical and radiological weapons, using the principles of “detect, evacuate, avoid and decontaminate.”

**Black Mold.** Stachybotrys.

**Blood-Brain Barrier (BBB).** A boundary surrounding the central nervous system that prevents the penetration of certain substances such as commonly used chemicals; satratoxins can increase its permeability.

**Blue-Sky Day.** A clear sunny day with a low level of outdoor toxic mold.

**Brain Fog.** Decreased cognitive abilities experienced by Chronic Fatigue Syndrome and mycotoxin illness sufferers.

**Breaking the Response.** Spending an extended amount of time in an environment with a low level of toxic mold, in order to bring down a complement spike.

**C3a.** A form of complement (anaphylatoxin) that tends to be elevated in patients with biotoxin illnesses.

**C4a.** A form of complement (anaphylatoxin) that tends to be very highly elevated in patients with mold toxicity and certain other biotoxin illnesses.

**Carrying the Response.** Having hair or clothing contaminated by previous exposures to toxic mold spores or spore fragments.

**Chaetomium Globosum.** A toxic mold that is particularly difficult to remediate.

**Cholestyramine (CSM).** A medication that was originally used to lower cholesterol and that is effective at removing mycotoxins and other biotoxins from the body.

**Chronic Fatigue Syndrome (CFS).** The disease identified in the Incline Village patient cohort in the mid-1980s, characterized by specific and persistent immune system, hormonal, neurological and other systemic abnormalities.

**Ciguatera.** A biotoxin illness obtained as a result of eating fish that are predators of dinoflagellates.
**Clear.** A system that is free enough of toxic mold for complement to decrease to normal levels, or an area that is low enough in toxic mold for this to occur in a particular individual.

**Colony.** A growth of mold.

**Compensation.** Spending time in areas low in toxic mold in order to be able to tolerate greater toxic mold exposure at other times.

**Complement.** Proteins in the blood that identify and remove molecules identified as foreign; these molecules can include mycotoxins, allergens, and pathogens.

**Complement Spike.** An sudden increase in complement caused by an exposure to toxic mold or other substance.

**Contamination.** The exposure of an item to toxic mold spores or spore fragments, causing it to carry mycotoxins on it.

** Crash.** Extended abnormal physical exhaustion after a period of activity exhibited in CFS sufferers.

**Cross Contamination.** The process by which toxic mold spores or spore fragments dislodge themselves from one item and attach themselves to another item.

**Cyclosporins.** Immune suppressor compounds made by toxic molds.

**Cytokine.** Proteins that control inflammation; overproduction of pro-inflammatory cytokines and/or lack of anti-inflammatory cytokines are characteristic of mycotoxin illness.

**Damp Down.** The decrease in complement to a normal level as a result of decreases in toxic mold exposures.

**Decontaminate (Decon).** Wash one’s hair, take a shower and change clothes after being exposed to toxic mold spores or spore fragments.

**Delayed Response.** Negative reactions experienced hours or days after mycotoxin exposures occur.

**Denature.** The process by which items contaminated with mycotoxins become more tolerable to mold responders; occurs as a function of time or very high heat (500 degrees or higher); exposure to sunlight, high altitudes or alcohol also may contribute.
**Dent Test.** Observing the extent to which skin indentations as a result of pressure occur and persist as a way in which to measure the extent to which mycotoxins have created hypoperfusion or edema, and thus affected the system as a whole.

**Depression Response (also Anger/Anxiety/Panic/Suicide Response).** A negative change in mood resulting from exposure to mycotoxins.

“A Desert.” A wilderness area with a low level of toxic mold.

**Detoxification.** The process by which toxic chemicals of any sort are expelled from the body.

**Die Down.** The process by which items contaminated by toxic mold lose their ability to negatively affect mold responders.

**Disinterest Response.** Common unwillingness of medical professionals to attend to or examine the issue of mold illness and its connection to CFS.

**Down-regulate.** A decrease in complement to a normal level, accomplished as a result of decreased exposure to toxic mold or other problematic substances.

**Dose Related.** An effect determined by the total amount of toxic mold to which a person has been exposed.

**Dr. B.** Dr. Keith Berndtson, a medical doctor with an interest in mycotoxins.

**Dr. Mary.** Dr. Mary Beth Short-Ray (a.k.a. Dr. Mary Short or Dr. S-R), a doctor of osteopathic medicine with an interest in mycotoxins.

**Dr. S.** Dr. Ritchie Shoemaker, a medical doctor with an interest in mycotoxins and other biotoxins.

**Duration Related.** An effect determined by the length of time that a person has been exposed to toxic mold.

**Effect.** The changes that occur in the systems of sufferers of CFS or mold illness as a result of environmental exposures to toxic mold and/or related substances.

**EMF’s.** Electromagnetic fields such as those emitted by satellites, cellular phones, power lines, CD players and computers; have the potential to cause molds to release more toxins or more potent toxins.

**EMF Sensitivity.** Being negatively affected by electromagnetic fields such as those emitted by satellites, cellular phones, power lines, CD players and computers.

**ERMI.** Environmental test looking at the presence of genetic material from molds.
**Erythropoietin (Epo).** An anti-cytokine protein that can improve VEGF problems in CFS and mycotoxin illness sufferers; may be increased by temporarily spending time at high altitudes or through administration of the drug Procrit.

**Exposure.** Coming into contact with toxic mold spores, spore fragments or poisons.

**Extreme Avoidance.** A technique using avoidance and decontamination techniques in order to limit exposure to even very small amounts of mycotoxins.

**Extreme Responder (or Extreme Reactor).** An individual who experiences negative symptoms as a result of exposure to very small amounts of mycotoxins.

**Fusarium.** A common indoor and outdoor mold that often can be toxic.

**Getting Clear.** Going to a low-mold area in order to reduce the symptoms of previous mycotoxin exposures.

**Gluten Intolerance.** Negative reactions to consuming protein found in wheat, barley, rye and oats; may dissipate when mycotoxin reactivity is successfully addressed through avoidance or other means.

**Godforsaken Desert (or Godforsaken Wilderness).** Any area far from civilization and with a very low level of toxic mold.

**Good Day/Bad Day Phenomenon.** A common tendency of CFS sufferers to feel better on some days than others, related in at least some cases to the total amount of toxic mold in the air.

**Good Laundromat.** A laundromat with a toxic mold level low enough to permit clothing or bedding put through the dryer to be safe for extreme mold responders.

**HEPA Filter.** An air filter that removes mold spores from the air, but that does not provide protection from small spore fragments or the mycotoxins manufactured by toxic mold.

**High Spore Count Day.** A day with a high level of outdoor toxic mold.

**Hit.** Contact with mycotoxin.

**Hitting the Wall.** Reaching a level of toxic mold exposure that causes the individual to suffer debilitating effects lasting for an extended length of time, and that cannot be quickly reversed by subsequent exposure to pristine areas.
**HLA DR.** A genetic test that can be used to assess an individual’s ability to effectively eliminate from the body mycotoxins, Lyme toxins and other biotoxins, as well as tendency toward low MSH production.

**Herxheimer.** An exacerbation of symptoms due to increased cytokine effects in Lyme patients taking antibiotics or cholestyramine.

**House in the Desert.** A home in any secluded area with a very low outdoor mold level.

**Hyperreactivity.** Being affected by very small amounts of toxic mold to a much more dramatic extent than the average person, due to complement activation.

**Hypoperfusion.** Decreased blood flow through an organ (including the skin), a problem common amongst CFS and mycotoxin poisoning sufferers and caused by low levels of VEGF.

**Hypothalamus.** The master gland of the endocrine system; produces MSH and other hormones.

**Intensification Reaction (or Intensification Response).** Phenomenon in which an individual’s reactivity to toxic mold increases dramatically after spending time in a place with a relatively low level of toxic mold.

**Intracranial Pressure.** Pressure in the brain and spinal cord; tends to be elevated in CFS patients, possibly as a result of inflammation from exposures to toxic mold.

**Ionophore Toxins.** A lipid-soluble molecule (including those made by toxic mold) that transports materials across cell membranes and thus distributes them evenly throughout the body.

**Irritable Bowel Syndrome.** Condition consisting of abdominal pain and alternating constipation/diarrhea; may resolve when mycotoxin poisoning is successfully addressed.

**It.** A substance prompting specific symptoms in a mold responder; may be comprised of Stachybotrys, other toxic molds, and/or a combination of toxic molds and other chemicals.

**Leptin.** Cytokine made by fat cells that regulates body mass; high leptin and low MSH levels tend to be present in biotoxin patients and lead to obesity.

**Locations Effect.** The tendency of CFS sufferers to feel better in some places than others; may be related to outdoor toxic mold levels.

**Low MSH Genotype.** HLA DR category that indicates an individual who tends to have a low amount of MSH, especially when suffering from biotoxin illness.
Low Spore Count Day. A day with a low level of outdoor toxic mold.

Lyme Disease. An acute or chronic illness caused by several species of bacteria belonging to the genus Borrelia and characterized by a wide variety of physical, cognitive and emotional symptoms (some similar to those attributable to mycotoxins).

Lyme Susceptible Genotype. HLA DR category that indicates an individual who is unable to easily detoxify Lyme toxins from the system.

Lymie. Individual suffering from Lyme disease, especially chronic Lyme disease.

Macrophage. A type of white blood cell that collects cell debris and serves as a first-line defense against the infiltration of toxins and pathogens.

Masking. Compensations made by the system in order to continue to function despite toxic exposures; can prevent the recognition that an overload is occurring.

MCS. Multiple Chemical Sensitivity, a condition in which sufferers respond negatively to a wide variety of chemicals that do not affect most people; may abate with successful avoidance of toxic mold.

Melatonin. Hormone regulating restorative restful sleep.

MELTDOWN Syndrome. “Malingering Exaggerating Lying Troubled Over Worked Neurotic Syndrome.” Joking name for CFS, based on various causes for the disease postulated by uninformed professionals and laymen.

Microbial Volatile Organic Compounds (MVOC’s). Organic compounds that evaporate easily; these account for the mustiness of molds but not their most toxic characteristics.

Mildew. Superficial growth of fungi on organic surfaces.

MMP9. A pro-inflammatory cytokine that tends to be elevated in mycotoxin illness.

Mobile Environmental Containment Unit (MECU). Recreational vehicle or other vehicle that can be used for showering after mold contamination and for flexibility in being able to travel to areas that are low in toxic mold at a particular time.

Mold. Any of various fungi that often cause disintegration of organic matter; may be used as shorthand for “toxic mold” or “mycotoxins.”

Mold Advocate. Individual who attempts to make the dangers of toxic mold more widely known.
**Mold Allergy.** The body’s reaction to the misidentification of benign mold as problematic; characterized by symptoms such as sneezing, watery eyes, stuffy nose, itching or asthma.

**Mold Avoider.** An individual who makes an effort to obtain wellness by avoiding toxic mold.

**Mold Castle.** A home (especially an expensive home) characterized by a high level of toxic mold growth.

**Mold Facies.** A red rash on the face caused by exposure to toxic mold.

**Moldie.** An individual who suffers from negative effects of toxic mold, especially from very small amounts of toxic mold.

**Moldie Mobile.** An MECU.

**Mold Responder.** An individual who suffers from negative effects of toxic mold.

**Mold Sabbatical.** A finite period of time spent in a wilderness area very low in toxic mold, in order to gauge mold reactivity, increase mold sensitivity and/or promote healing.

**Mold Susceptible Genotype.** HLA DR category that indicates an individual who is unable to easily detoxify mycotoxins from the system.

**Mold Swing.** A rapid change in mood due to a toxic mold exposure.

**Mold Toxicity.** Poisoning resulting from toxic mold exposures.

**Mold Unfriendly Environment.** A building or vehicle designed to prevent the growth of toxic mold.

**Mold Warrior.** Individual who is aware of negative responses to toxic mold and makes an attempt to avoid it, or individual who fights for the welfare of toxic mold sufferers.

**Mold Zone.** An area that constantly or frequently is hit with a large amount of airborne toxic mold.

**Mother Colony.** A growth of Stachybotrys or other toxic mold that feeds on a substantial amount of cellulose and a constant water source; often hidden from view inside walls or in other areas.

**MSH (Alpha Melanocyte Stimulating Hormone).** A hormone that regulates most aspects of innate immune response; often low in patients affected by toxic mold.
Multiple Chemical Sensitivity (MCS). A condition in which sufferers respond negatively to a wide variety of chemicals that do not affect most people; may abate with successful avoidance of toxic mold.

Multiple Susceptible (or Multisusceptible) Genotype. HLA DR category that indicates an individual who is unable to easily detoxify a variety of biotoxins from the system.

Multiply Antibiotic Resistant Coagulase Negative Staphlococci (MARCoNS). A bacteria that colonizes the skin and nose of MSH-deficient patients, making their recovery from mold illness more difficult.

Myalgic Encephalomyelitis (ME). Another name for the disease identified in the Incline Village patient cohort in the mid-1980s, characterized by specific and persistent immune system, hormonal, neurological and other systemic abnormalities.

Mycotoxicosis. Disease caused by exposure to toxic mold.

Mycotoxin. Poison made by toxic mold.

Mycotoxin Gradient. The mixed air/toxin distance from spore accumulations that gives hits.

Mycotoxin Release. Period of time when toxic mold and mycotoxins increase in the outside air; often occurs during weather changes.

Neurotoxin. Any chemical that has a destructive effect on the brain.

Normie. An individual who is not unusually influenced by small amounts of toxic mold.

Overreactivity. Being affected by very small amounts of toxic mold to a much more dramatic extent than the average person, due to complement activation.

Penicillium. A toxic mold that easily goes airborne.

Perceptify. Determine the presence of toxic mold in an environment or on an object by paying attention to physical, cognitive or emotional responses.

Personal Impact Rating (PIR). The extent to which an individual must make accommodation by avoidance with regard to the presence of toxic mold in order to be well.

Pfisteria. A dinoflagellate that carries a biotoxin.

Plume. A moving cloud of toxic mold spores, spore fragments and/or mycotoxins that causes an inside or outside area to be problematic for mold responders.
Plumed. Hit with a plume.

Poison Dust. Substance present in contaminated homes, comprised of toxic mold spore fragments and household dust carrying mycotoxins.

Potentiated Mycotoxins. Substance made or distributed by toxic mold and incorporating chemicals from the environment.

Power Curve. Extent to which a reactive individual can tolerate additional mycotoxin exposures; being “on top of the curve” provides more resilience.

Pre-contaminated (or pre-molded). A building or item contaminated with toxic mold during the construction, manufacturing or distribution process.

Pristine. Free of a level of mycotoxins or other substances having a negative effect on a particular mold responder.

Psychologize. The act of misattributing symptoms of mold illness or CFS to psychological causes.

Rainy Weather Response. The tendency of mold responders to experience negative symptoms just before and during rainy periods.

Raking. Tendency of mold spores to move through the air in search of a location providing the conditions in which growth can occur.

Reactivity. The extent to which an individual suffers negative effects that are more than transitory as a result of exposures to toxic mold.

Regular Bad Mold (or Regular Bad Stuff). Toxic molds previously studied by researchers.

Regular Mold. Fungi that do not manufacture mycotoxins.

Relative Shift. The extent to which one environment is found to be significantly better or worse than another; can only be ascertained insofar as the mold responder is not carrying the response from the previous environment on hair or clothing.

Remediation. The process by which toxic mold is carefully removed from a building, thus making it comparatively safe for the majority of the population; generally is not sufficient for tolerance by extreme mold reactors.

Safe Space (or Safe Zone). An area in a living space that is kept as clear of toxic mold as possible.
**Satellite Colony.** A superficial growth of a toxic mold on an observable surface; suggests the presence of a problematic hidden growth.

**Satratoxin.** A trichothecene mycotoxin made by Stachybotrys.

**Secondary Contamination.** The transfer of mold spores and spore fragments from an item that has been exposed to toxic mold to another item.

**Secondary Metabolites.** The poisons released by toxic molds.

**Sensitivity.** The extent to which an individual can detect the presence of toxic mold based on physical reactions.

**Severe Responder (or Severe Reactor).** An individual who experiences negative symptoms as a result of exposure to very small amounts of mycotoxins.

**Shrieking Dream Response.** The tendency of mold responders to experience nightmares when sleeping in environments contaminated with mycotoxins or toxic mold.

**Sick Building.** A building that has a high level of toxic mold, often accompanied by other problematic chemicals.

**Sick Building Design.** A building design conducive to the growth of toxic molds and chemical toxicity, characterized by centralized duct systems, sealed windows and high levels of insulation.

**Sick Building Syndrome.** An environmental illness apparently set off by exposure to toxic mold (often along with toxic bacteria and/or toxic chemicals) in a work or home environment.

**Sick Region Syndrome.** Area of the country that has high levels of outdoor toxic mold; Lake Tahoe-Truckee and post-hurricane Texas and New Orleans are examples.

**Slam.** A negative effect of a mold exposure that does not dissipate immediately upon obtaining distance from the item or area and the use of decontamination techniques.

**Sourcepoint.** A colony of mold that is emitting toxic spores.

**Spore.** The reproductive component of mold; toxic mold releases dormant spores that carry deadly poisons and that can remain viable for a very long time.

**Spore Cloud.** A clump of toxic mold spores and spore fragments existing in the air outdoors.

**Spore Fragment.** A piece of a dormant mold spore, especially one carrying mold toxin.
**Sporulate.** The release of dormant spores from a mold colony.

**Spot Plume.** The presence of toxic mold (or particularly problematic toxic mold) in just part of a building.

**Stachybotrys chartarum.** A damaging species of toxic mold.

**Stachybotrys.** A genus of mold that includes the species Stachybotrys chartarum and Stachybotrys atra; also known as “Stachy.”

**Stressologizer.** An individual who insists that mold illness or CFS is at least in part caused by psychological stress.

**Suicide Response.** A brief but intense desire to kill oneself after experiencing a mold slam; may occur in extreme mold avoiders who otherwise have no suicidal inclinations or ideations.

**Suicide Season.** The period of time between November and February, when outdoor toxic mold often exerts particularly negative effects on mold responders.

**Super Bad Stuff.** A particular substance, yet to be studied, that has particularly problematic effects on mold responders.

**Super mold.** A particularly damaging toxic mold.

**Supertoxins.** An alternative name for potentiated mycotoxins.

**T-2 Mycotoxin.** A tricothecene mycotoxin made by the toxic mold Fusarium and present in moldy grains; has been used as a biological weapon.

**Tape Lift.** A sample of toxic mold used to identify the species that are present.

**Texass Effect.** Phenomenon by which toxic mold and other chemicals in a particular geographic area cause problems in other places due to wind currents; in particular, the result of post-flooding problems in Texas in 2007-2010.

**Thermalling.** In hang gliding, seeking out pockets of air that have the potential of lifting the individual higher above the ground.

**Threshold of Discernment.** The level at which a particular individual can sense that toxic mold is present in the environment.

**Toxic Mold.** Certain species of mold that produce poisons that have a negative effect on people, animals, bacteria and/or other molds.

**Toxin.** A chemical substance that has a damaging effect on the body.
**Toxin Release.** The phenomenon by which adsorbed mycotoxins are released from objects; often occurs to an accelerated extent as a result of barometric pressure drops from weather changes or altitude increases.

**Trichothecenes.** Poisonous chemicals made by a variety of toxic molds.

**Trigger.** A chemical substance that has an effect on a sensitive individual.

**Tumor Necrosis Factor Alpha (TNF).** A pro-inflammatory “killer” cytokine; tends to be elevated in patients with Lyme disease rather than those with toxic mold illness.

**Ulocladium.** A common mold often found on wet sheetrock; rarely is a toxin former.

**Universal Reactor.** Individual with especially severe Multiple Chemical Sensitivity, exhibiting negative reactions to a very wide variety of chemical substances.

**Unmasking.** Spending time in a relatively pristine area, so that the chronic negative effects of toxic mold (or other toxic substances) will begin to manifest themselves in acute symptoms upon exposure.

**Upregulate.** Physical reaction to exposure to toxic mold (or other substance), by which complement becomes elevated.

**Vacuum Exacerbation Response.** The negative response of mold responders to the stirring up of spores as a result of vacuuming, cleaning or straightening up of an environment contaminated with toxic mold spores or dust.

**Van Der Waals Forces.** The possible action by which mycotoxins permanently bond with solid or porous objects, thus preventing them from being washed off or otherwise removed by forces other than denaturing.

**Vascular Endothelial Growth Factor (VEGF).** Substance responsible for blood flow in capillaries; often low in biotoxin and CFS patients.

**Visual Contrast Sensitivity Test (VCS Test).** An eye exam that detects the presence of toxins (such as mycotoxins and Lyme toxins) in the brain.

**Water Damaged Building (WDB).** A building that has had a water event such as a flood or leak, and thus may have been subject to mold growth.

**Water Event.** A flood, leak or other water intrusion into a building; should be addressed within 24 hours so that stachy and other toxic mold does not begin to grow.

**Wilderness.** An area without man-made buildings; often but not always characterized by low levels of toxic mold.