

M.E. AND BIOTOXINS: AN INTRODUCTION

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WRITINGS FROM 2010

Background Information

Mold Toxicity vs. Mold Allergy:

A common reason for ruling mold out as a factor of particular relevance to this disease is that “mold is just an allergy.”

Indeed, mold can cause allergies. However, certain species of mold also contain chemical poisons that can cause severe illness or death in all manner of species, including humans.

These poisons are made by molds as “secondary metabolites” to kill off other fungi and bacteria in an environment, so that they themselves can grow unchecked. Some of these toxins are strong enough that they also cause illness and death in humans.

Trichothecene is a main class of chemicals that are known to be of concern and have been classified by the U.S. government as bioweapons. T-2 toxin is generally considered to have been used as a bioweapon. Satratoxin, the chemical made by *Stachybotrys* (commonly known as “black mold”) is said to be several times stronger than T-2.

An allergy is the misidentification by the body of a benign substance as problematic. Any species of mold can cause allergies.

A toxicity reaction is the poisoning of the body by a particular chemical substance. Examples include rattlesnake and brown recluse spider venom. (The latter substance is particularly relevant here because that poison is similar in chemical structure to ionophore mycotoxins.)

Typical allergic symptoms to mold include sneezing and runny nose, watery or itching eyes, and asthmatic symptoms such as wheezing and coughing.

Toxic mold symptoms are largely neurological, including memory loss, attention deficit/concentration problems, personality changes such as irritability/depression, tremors, tingling or burning of nose and mouth, chronic fatigue, dizziness, nausea/vomiting, bleeding or fluid in the lungs, suppression of the immune system, headache, flu-like symptoms, incoordination, muscle spasms and cramps, and damage to various internal organs (especially the gall bladder and liver). They are cytotoxic,

disrupting various cellular structures such as membranes and interfering with various cellular processes such as protein, RNA and DNA synthesis. Decreased Natural Killer Cell function has been cited as a particularly common effect of mold toxicity.

Many people have mold allergies but have not been poisoned to any significant extent by mold. On the other hand, many victims of mold toxicity (including myself) do not have any mold allergy symptoms at all.

Substantial academic research on the effects of mycotoxins can easily be accessed. Keywords include mycotoxins, satratoxins, T-2, DON, aflatoxin and Stachybotrys.

Mold Susceptible and Multi Susceptible Genes:

The leading clinical researcher in the area of the effects of mycotoxins on humans is Dr. Ritchie Shoemaker. Dr. Shoemaker presented some of his work at the 2009 CFS conference in Reno. He was one of the members of the Ratna Ling/Sonoma Working Group (which also included CFS researchers Paul Cheney, Jose Montoya, Martin Pall, Richard Deth, Jacob Teitelbaum and Rich van Konynenberg). His M.D. is from Duke University.

Dr. Shoemaker's book "Mold Warriors" was published in 2005. He also has published numerous academic papers on the topic. His web site is here:

<http://www.biotoxin.info/>

Dr. Shoemaker has developed a number of laboratory tests measuring the propensity for and presence of mold illness in patients. He states on his web site that this is based on looking at approximately 6000 individuals.

The genetic test is a standard HLA DR test that can be obtained through LabCorp or Quest. Dr. Shoemaker's observation is that specific genetics are correlated with mold illness, with about 24% of the population susceptible. About 2% of the population has at least a multisusceptible gene (causing susceptibility to being affected by various biotoxins such as mycotoxins, Lyme toxins, dinoflagellates and brown recluse spider toxin).

The multisusceptible genes are 4-3-53, 11/12-3-52B and 14-5-52B. The mold susceptible genes are 7-2/3-53, 13-6-52A/B/C, 17-2-52A, and 18-4-52A.

Dr. Shoemaker states that CFS patients are vastly more likely than the population as a whole to have the mold susceptible genotypes and (especially) the multisusceptible genotypes. While correlation is not causation, Dr. Shoemaker speculates that people with mold susceptible and multi susceptible genotypes do not have the antibodies to remove mold toxins from the body through the immune system that the rest of the population does.

Stachybotrys and Satratoxins:

Although a wide variety of mycotoxins can cause damaging symptoms in humans, satratoxins seem to be especially worth consideration with regard to CFS.

Here is a good paper on this topic:

Karunasena E, Larrañaga MD, Simoni JS, Douglas DR, Straus DC. Building-Associated Neurological Damage Modeled in Human Cells: A Mechanism of Neurotoxic Effects by Exposure to Mycotoxins in the Indoor Environment. *Mycopathologia*. 2010 Jun 13. PMID: 20549560.

Damage to human neurological system cells resulting from exposure to mycotoxins confirms a previously controversial public health threat for occupants of water-damaged buildings. Leading scientific organizations disagree about the ability of inhaled mycotoxins in the indoor environment to cause adverse human health effects. Damage to the neurological system can result from exposure to trichothecene mycotoxins in the indoor environment. This study demonstrates that neurological system cell damage can occur from satratoxin H exposure to neurological cells at exposure levels that can be found in water-damaged buildings contaminated with fungal growth. The constant activation of inflammatory and apoptotic pathways at low levels of exposure in human brain capillary endothelial cells, astrocytes, and neural progenitor cells may amplify devastation to neurological tissues and lead to neurological system cell damage from indirect events triggered by the presence of trichothecenes.

The dissertation on which it's based is available here:

<http://etd.lib.ttu.edu/theses/availa...252005-163223/>

David Straus, the committee chair for this Texas A&M doctoral graduate, has been a leading researcher in the study of mycotoxins. Numerous papers by him are readily accessed.

The dissertation has the following conclusion:

“These experiments demonstrate that the macrocyclic trichothecenes produced by *Stachybotrys chartarum* are able to induce apoptotic and inflammatory cascades in endothelial cells, astrocytes, and neurons. These studies suggest that exposure to low

to moderate doses of satratoxin could activate cellular pathways that induce a series of events leading to neurological tissue damage, which may induce the symptoms observed in individuals exposed to *Stachybotrys chartarum*.”

The experiments also demonstrate that *Stachybotrys* is able to induce perforations in the blood-brain barrier, allowing various substances that should not be there to enter. Although other chemicals such as formaldehyde can pass the blood-brain barrier themselves, I have been unable to locate research that suggests that other chemicals are able to create these perforations.

In addition, satratoxin was shown in this study and in others to increase the presence of NF-kappa-beta in cells such as astrocytes.

Substantial research easily accessible demonstrates that Satratoxin H generates reactive oxygen species and lipid peroxidases. Research findings demonstrate that this occurs at least in part due to the decreased presence of reduced glutathione in the cells.

Those who are familiar with recent developments in the field of CFS will immediately understand why these particular findings are of relevance.

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1. Mold is not just an allergen or a pathogen. Some molds also make toxins that serve to poison people.

More than 26 years ago, Erik walked into Dr. Cheney’s office stating that mold was making him sick and, no, it wasn’t just a runny nose or asthma.

At the time, the only literature about mold toxicity was a few studies related to *aspergillus* in animal feed. *Stachybotrys* (“black mold”) wasn’t even on the radar screen.

Today, even the most casual search uncovers ample literature to show easily to even the most doubtful that mold indeed has the potential of making people sick in “non-allergy” ways.

So that’s progress.

A question I have is why it is that such literature didn’t exist prior to the mid-1980s. Was it because such illness did exist but nobody noticed? Or is this a problem that’s worse now than in the past?

Considering my own experience at controlling my own CFS through mold avoidance, I also would like to know whether the emergence of both Sick Building Syndrome and Chronic Fatigue Syndrome (which clearly are not the same thing) in the mid-1980s are in any way connected.



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I'm not saying they are connected, just that I think it would be interesting to explore whether that might be.

2. "Mold" is a term so broad as to be ridiculously useless.

Suggesting that "mold" has anything to do with my illness or anybody's illness is inherently misleading.

Just as there are lots of different kinds of bacteria (some "good," some "bad," some neither), there are lots of different kinds of mold.

My own interest is not related to pathogenic molds that colonize the body, nor to molds that cause only allergic responses. Although people can suffer as a result of those molds, they do not seem to me specifically related to CFS.

The molds that I'm particularly focusing on are a few species of toxin producers. *Stachybotrys*, described earlier in this thread, is foremost.

Often when I mention *Stachybotrys*, people say, "But sometimes *Aspergillus* makes toxins that are just as bad, so you can't leave that out."

Unfortunately, because mixed colonies in buildings are normal, it's sometimes hard to pick out exactly what toxic species is causing a problem even if you send in samples to a laboratory.

However, an initial evaluation makes it seem that *Stachy* tends to be associated with CFS - in terms of the exposures that CFS sufferers have experienced, their subjective impressions of what molds do bother them, and the symptoms of the mold.

3. Dr. Shoemaker holds the belief that certain genotypes are associated with a propensity to be made ill by mold.

The genes that Dr. Shoemaker has identified actually do exist. They can be ascertained from LabCorp tests.

The question is whether Dr. Shoemaker is correct in his assessment of the correlation with mold illness.

Until such time as his work is published, the formal wording should be, “the genes that Dr. Shoemaker believes to be associated with mold susceptibility and/or multi susceptibility.”

4. Mold illness is not equivalent to CFS.

The effects of Sick Building Syndrome have been detailed in the literature. The effects are not the same as have been demonstrated to be present in ME/CFS (according to the Canadian Criteria). They are more similar to the CDC (Fukuda) Criteria for CFS.

This, by the way, is consistent with Erik’s description of what happened to him during the Incline Village epidemic. He says that when he was just being influenced by the mold, his illness was more like “chronic fatigue” (e.g. Fukuda). It only was after getting the “Yuppie Flu” that it turned into classic ME/CFS.

*

There are blood tests to determine the presence of Stachy toxin in the system, but their accuracy has been disputed.

Unlike Aspergillus, Stachybotrys does not live in the body. The negative effects on people are a result of the toxic chemicals that are inhaled or that are otherwise taken into the system, not a result of colonization.

Unfortunately, antifungals, antivirals or antibiotics will have no direct effect on any toxic chemicals already in the system. (I personally am interested in the idea that eliminating pathogens in the body will increase its overall health and thus its ability to deal effectively with toxic exposures, but there is as of yet to my knowledge no scientific evidence to support this concept.)

In some cases, the presence of mold toxicity causes immune system problems that make candida more likely to flourish. If that is the case, antifungal drugs may provide some health benefits. But these have nothing to do with addressing the Stachybotrys problem.

The studies regarding the Cleveland problem (where infants died) and the dose of the toxin required to create illness are generally not thought to be substantive enough to be held to be conclusive scientific "truth."

For example, different Stachybotrys strains make different types of toxins, and molds vary in the amounts of toxins they make depending on factors such as competition with other molds in the environment. It thus is possible that in some circumstances, people are getting much more exposure to particularly problematic toxins than some researchers have assumed.



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In addition, some studies have shown that different mold toxins exercise a synergistic effect, meaning that two or more working together are much more damaging than single ones alone. It thus would be necessary to do lab experiments involving combinations of toxins (plus other "Sick Building Syndrome" components such as the presence of bacteria or various chemicals) to ascertain precisely how much damage may be taking place.

The studies also do not take into consideration what the cumulative effects of a toxin might be if an individual were exposed to it on a continuous basis over many years, as occurs with people who have toxic mold in their homes.

The simultaneous presence in the system of particular pathogens also could lead to a synergistic effect that would increase the damage done by a particular type of toxin.

The "chronic inflammation" mentioned as the method by which Stachy exercises its toxic effects is one reason that it has relevance to a discussion of "control points," since inflammation is thought to have the potential of activating or re-activating XMRV and other pathogens.

The studies citing the 25% genetic susceptibility are consistent with Dr. Shoemaker's statements of 24% having what he calls the "mold susceptible genotype" or "multi susceptible genotype."

*

When I say "Mold" or "Molds," what I mean is, "Toxic molds that have been shown in research studies to cause negative effects in humans."

I am especially concerned about Stachybotrys, but other toxic molds that have been shown to be damaging in peer-reviewed published research studies are also included.

Hopefully folks will accept this as shorthand.

*

Toxic mold has a number of weird characteristics that tend to cause people to inappropriately rule it out as a potential factor in CFS. Here is a summary of some of those.

1. Stachybotrys vs. Other Molds

Stachybotrys, which appears to be the most problematic mold in CFS, rarely grows in places where it can be seen or smelled. Thus, many buildings have severe Stachy problems without any evidence of its being there.

This mold usually grows inside walls, behind shower tile or (as in my house) behind other solid surfaces such as paneling. On those occasions when it can be seen, it usually looks like smears of dirt on the wall rather than mold.

Only if the walls (or whatever) are opened up does it look like mold.

However:

PLEASE DON'T OPEN UP THE WALLS TO LOOK AT THE MOLD! THIS IS VERY DANGEROUS!!!!

(CFS sufferers should never go looking for mold in their homes or try to remediate it themselves. They should be nowhere around when any remediations are done, and should hire a competent professional to do the job. I have seen CFSers experience permanent declines as a result of not following these recommendations, and Erik has seen many people get sick or die as a result of doing this type of do-it-yourself work. Be safe!!!)

Stachy doesn't come up on most tests used by remediators either, as described in one of my posts earlier on this thread. So not being able to see mold, smell it, or find it on conventional tests gives no assurance whatsoever that it's not there.

(Are we having fun yet?)

Stachy can grow synergistically with certain other molds. This is misleading as well. People get various tests done and find out, to their relief, that it's "ONLY" X mold. Meanwhile, the hidden Stachy is ignored.

On the other hand, buildings can be quite moldy and not have any Stachy or other particularly toxic molds growing. This especially tends to be the case in damp climates.

Most non-toxic molds need a good bit of moisture in the air to grow. When moisture is present, these molds can just spring up "spontaneously" as a result of spores being blown in from outside and the water in the air.

Stachy grows under a very different set of circumstances.

First, Stachy usually needs a water sitting for an extended period of time (24 hours or more) to get started. Thus, it is associated with "water events" such as leaks or floods. In some cases, the condensation in ductwork or in between walls (e.g. at the "condensation interface") is enough.



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If Stachy gets some water, it can grow even if the general humidity is low. 60% (which is the “comfort level” in climate controlled buildings) is plenty high enough. (More benign molds usually require more humidity to grow freely.)

Once a colony of Stachy has been established, it does not help to dry it out or kill it (e.g. with Thieves Oil). Dead colonies of Stachy are just as problematic as live ones. All that happens when a colony is dried out is that it releases a whole lot more dormant spores into the environment. (See abstract below.)

Stachy creates its poisons in order to coat all the surfaces of the environment. This is designed to prevent competitive molds from growing, thus allowing Stachy to grow more freely. (The poisoning that it does to people and animals apparently is just a side effect.)

A dwelling that has previously had a big Stachy problem thus will have poison spread throughout. This poison may keep occupants sick even if all the colonies have been properly removed. It also will make it more likely that Stachy (rather than competitive molds) will grow if conditions again become conducive.

Remediated buildings also will have lots of Stachy spores left, just waiting to spring up into live mold if they get some water.

Insofar as a building is remediated correctly and maintained carefully, it may be safe for people who are not already sick. However, it’s my belief that the amounts of mold toxins required to keep CFSers sick are often so low that recovery even in a house that’s been remediated may be extremely difficult.

Just because a house is moldy does not mean that it has Stachy in it. In fact, the presence of competitive molds can keep Stachy at bay. (This is the main reason why Stachy tends not to be found outdoors except under very specific circumstances.)

I don’t think that this means that it’s a good idea to let “benign” molds grow wild! Mold is unsightly, smells bad, damages property/possessions and causes allergies.

However, especially in a humid climate, the presence of obvious mold does not mean that Stachy or other particularly problematic species are present.

And just because it seems that there’s no mold at all is no assurance that that a horrific Stachy problem is not present.

2. New Buildings vs. Old Buildings

Very new buildings MAY be less likely to have mold growth than ones that are a bit older. However, many times they go bad really fast.

Newer buildings tend to be built with characteristics (e.g. drywall, HVAC systems, lots of insulation, cheap construction) that lend themselves to mold growth.

In addition, a lot of building materials are stored in moldy warehouses or otherwise put into place “pre-molded.” The mold toxins on these materials have effects on those of us who are being especially scrupulous in pursuing avoidance. In addition, the spores present are sitting there waiting for a water event so that they can spring into live mold.

It’s hard to predict what buildings are going to be bad just from looking at them. Erik insists, “It is where it is.”

I personally get nervous about entering two specific kinds of buildings: ones with modern construction that look like they’ve been poorly maintained (especially if they have flat roofs), and ones that are sealed off with centralized duct systems.

I’ve never been in a big fancy hotel that felt good to me, for instance. Shopping malls and big office towers usually are problematic.

Buildings that fall into both of these categories (e.g. many schools and government buildings) tend to be the very worst, in my experience.

It’s impossible to know whether an “old mouldy Edwardian terrace house,” a “dry modern house” or an “old mouldy farmhouse” would be especially good or especially bad with regard to toxic mold.

“It is where it is.”

3. Progressive Effects

Another thing to keep in mind about toxic mold is that we’re not talking about an allergy. We’re talking about being poisoned.

If someone had a big exposure to nerve gas, we wouldn’t expect them to recover the moment they got away from it. And the idea that they might be especially susceptible if they got hit with the nerve gas again wouldn’t seem entirely unreasonable.

The same thing applies to toxic mold.

For at least some people, effects are cumulative. Just because you live in a building and aren't being made deathly ill by it doesn't mean that it's not priming you for future serious illness.

Our belief is that once people get CFS, they tend to become much more affected by even small amounts of toxic mold. This means that even if a building isn't that bad with regard to toxic mold, their "extreme reactions" to it may be keeping them much sicker than they would be if they were in a really good building.

These reactions may be so extreme that even moving to a really good building won't make any difference, if people bring along all their contaminated stuff.

A main reason that people rule out mold as a factor in their illness is because "moving didn't help."

Those of us who have substantially improved or gotten well from mold avoidance wouldn't have been helped much just by moving either.

Even moving to a really good building with only good stuff doesn't result in a magic recovery most of the time. Toxic mold in the outside air can be an issue. Also, it can take the system a long time to address all the downstream effects and repair itself.

4. "Humid Days"

One issue that is really related to toxic mold "flares" is barometric pressure changes.

When storms approach, toxic mold colonies release their spores in the hopes of getting water to start a colony. This means that those affected by toxic mold tend to feel worse during those times.

In some cases, a severe storm will wash those released spores out of the air. Usually the outside air (and certainly the inside air) does not recover until the weather improves though.

Even in climates with little rain, spores are released at times of barometric pressure drops. Purchasing a device to measure barometric pressure (available at places like Wal-Mart) or just looking at the extent to which skies are sunny vs. cloudy can allow CFSers to get a sense of whether this phenomenon might be going on for them.

5. "Fresh Air"

Feeling better in fresh air is generally a good hint that toxic mold (or at least some substance present inside buildings) is a problem.

However, in some places, the outside air is severely affected by toxic mold. Pollution can affect outdoor air quality as well.

Therefore, not feeling better outside (especially on days that are not sunny) is not necessarily a good indication that toxic mold is not an issue.

Obviously, all of this makes the questions of whether CFSers are getting toxic mold exposures and whether they are affected by toxic mold really hard to answer.

That's why it took me 12+ years to realize that mold was an issue for me.

I wish I'd understood that the possibility existed upfront. I'd have gotten to a higher level of wellness much more easily and quickly, and not wasted all those years doing nothing but lying in bed staring at the ceiling.

The only way to figure it out for sure is to unmask in the way that Erik (the "Godforsaken Wilderness" sabbatical) and Dr. Myhill ("I'm afraid you'll have to go on holiday") recommend doing.

*

Fog Nielsen K. Mycotoxin production by indoor molds. Fungal Genet Biol. 2003 Jul;39(2):103-17. PMID: 12781669

"The worst-case scenario for homeowners is produced by consecutive episodes of water damage that promote fungal growth and mycotoxin synthesis, followed by drier conditions that facilitate the liberation of spores and hyphal fragments."

*

Here are a couple of comments.

1. For at least some (and possibly all) patients, ME/CFS involves a hyperreactivity to even infinitesimal amounts of toxic mold and other biotoxins.

Certainly, it seems like if you remove all the growing mold from your home and if you don't have any mold growth on your possessions, that should be enough -- within what anyone should be reasonably expected to be able to do -- with regard to getting better.



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That is not the experience of people who have successfully addressed the problem. I've encountered dozens of people in person and on various boards who state that once they get clear, they are made sick by contaminated possessions.

No one says that anybody has to get rid of exposed possessions or that it's reasonable to do so. We're only saying that insofar as severely ill individuals keep those possessions, they should not be surprised if they don't make improvements.

2. Insofar as people cannot remediate contaminated possessions, it is even more unlikely that they will be able to remediate a contaminated house.

The whole reason that toxic mold makes poisons is so that it can coat all the surfaces of the dwelling with it. As a result, other species of mold will be less likely to grow, and the toxic varieties (e.g. *Stachybotrys*) will be able to spread more freely.

Even if you remove all the colonies in the house, the toxins will still be there. They will keep other species of mold from growing, and keep Moldies from being able to live in the house without getting sick.

3. Ritchie Shoemaker is a brilliant man (I would argue a true genius) who has done a great service to the ME/CFS community by providing us information through his research.

His work suggests very strongly that toxic mold plays a role in this illness, and defines some of the ways that it has an effect on us.

However, I have yet to encounter one ME/CFS patient who has gotten anywhere close to well as a result of following his protocols.

Shoemaker has been successful at treating simple mold illness, which is far less complicated than ME/CFS. While he has some ideas about treatments that might be helpful for ME/CFS, I've yet to see any of them succeed.

Erik Johnson's protocols, on the other hand, have allowed a great many people to achieve substantial improvements or get to close to full wellness. Certainly, following them is not a reasonable thing to do. I'm not suggesting that anyone do them. I'm just presenting the information as an option.

On the other hand, I do strongly feel that people who are living in a bad environment should move or remediate even if they choose not to pursue anything more "extreme." This may prevent further declines or allow other treatments more of a chance to work. In this disease, even small declines in functioning can be catastrophic, and small improvements can make a big difference in quality of life.

4. Avoidance does not require camping!

Erik's suggestion with the camping is to get people unmasked from the mold, so that they could prove to themselves that it was having an effect on them and so that they could better find it when they return to civilization. He did not encourage anyone to go camping permanently. I'm not suggesting it either.

If people cannot or do not want to go camping at all, I suggest that they try different environments to see how they feel in them. Many people with ME/CFS tend to be extremely good at discerning the effects that various treatments (supplements, drugs, avoidance of foods, pacing, saunas, etc.) have on their health. It's my observation that they quickly become just as good at evaluating their environments, regardless of whether they do the desert "sabbatical." However, in order to do this, they need to start paying attention and trying out various environments. (And, per above, bringing contaminated possessions along will make the differences between various environments much less obvious.)

5. The presence or absence of odor is not a good predictor of whether toxic mold is present in an environment.

Some of the worst buildings of all have no discernible odors. Some buildings with strong mold odors do not have any of the toxic variety.

6. Shoemaker talks about the connection between gluten and mold in his books.

Mold illness frequently causes people to become reactive to gluten. Even without avoidance of mold toxins, gluten avoidance can give some benefits.

It would be interesting to find out what percentage of the people who go to alternative practitioners with "minor" problems (ADHD, fatigue, mood swings, lack of concentration) and benefit from addressing candida and gluten are living or working in moldy buildings.

Shoemaker suggests that for many of these people, the gluten reactivity fades after an extended time in a good environment.

That's what many people pursuing extreme avoidance have found. Six months tends to be the usual amount.



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Of course, some people have celiac problems and need to avoid gluten for reasons that have nothing to do with mold. And some people may choose to avoid wheat even though successfully practicing avoidance (for instance, to keep a handle on candida).

There is a definite connection though.

7. Deciding who to trust is an important factor in whether people make improvements.

Lots of people have tried to address mold and not gotten better. Others who have tried to address it have gotten better.

My inclination is to follow the lead of those people who have gotten better from addressing it. My early decision was to follow Erik's lead, and I've yet to find anything that he's said that's led me astray.

Erik started talking about the role of toxic mold in the disease that later became known as CFS (ME) in 1980, before there were any articles about either CFS or toxic mold in buildings in the literature. He obtained improvements as a result of avoiding it almost immediately after becoming sick with the illness himself in 1985. In 1998, before toxic mold was recognized widely as a factor in human illness and when only a few papers had been written about it, he developed his extreme avoidance approach and shortly thereafter shared it with other patients on various boards. Since then, large numbers of patients have implemented the techniques to various extents, and gotten various degrees of improvements. It's my observation that people who decline to follow the basic principles (e.g. choosing not to discard objects that are not overtly moldy or continuing to spend part of their time in moldy buildings or trailers even when in the desert) do not achieve very good results with it.

Back when Erik first started talking about mold, everybody denied it could be a problem beyond an allergen. Even ten years ago, the journals were full of articles stating that there was "no evidence" that it was a problem. Now there are hundreds of articles that show that, um, yes, it's a problem after all.

There are still information pieces available that suggest that it's not a problem. That's not consistent with the academic literature though.

Whether scrupulous mold avoidance would help all ME/CFS sufferers, I don't know. We need more study into this. The main reason that I started writing about mold was not to persuade people to try avoidance, but to try to get research into the phenomenon.

I've yet to hear of any treatment for ME/CFS that has helped everyone who's tried it. With this illness, even moderate improvement amongst a fraction of patients is usually considered a big success.

That being said, I've yet to hear of anyone who's tried Erik's approach according to his instructions -- including getting unmasked in a really good place -- who's not experienced substantial improvements.

But again, it only works when you follow the instructions. That's part of why I spent so much time compiling them into a book.

And again, I'm not promising anything or suggesting that anybody do anything. I'm just providing information, because it seems to me that it's the right thing to do.

M.E. Patients and Mold

From what I've seen, a really high percentage of CFSers do have the mold-sensitive or multi-susceptible genes. But some do not.

I know a couple of CFSers who do not have those genes but who are very sensitive to even tiny amounts of mold.

Dr. Ritchie Shoemaker likes the ERMI test, and I'm of the impression that it does a good job of finding really bad buildings. Unfortunately, many CFSers are so reactive to mold that merely having our "stuff" from a previous residence with us can be enough to keep us permanently ill. That would never show up on an ERMI test! And it's the experience of some of us that there are particular kinds of mold that can be harmful even to normal (not-yet-sick) people in amounts that the ERMI doesn't pick up on.

Especially for severe CFS patients, moving generally doesn't reduce mold exposures enough to make much noticeable difference in the illness. Usually they have their stuff with them, which can nullify any benefit. Most buildings have at least a little bit of mold in them. And outdoor mold can (depending on the place) be the biggest problem of all.

Reducing mold to 5% of the original level may not result in any big improvements. It may need to be more like 1%. Or 1/100th of 1%. And that's really hard!

So the question then is, why bother to think about mold at all?

I increasingly believe that lowering the level of mold in an environment can provide a foundation for other treatments to work. People who take antiviral drugs without attending to their living environment seem to me to be shooting themselves in the foot, for instance. It's really hard to take these drugs. Reducing the oxidative stress on the



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system by decreasing mold levels as much as possible may make the drugs easier to take and give them a chance to actually work.

At least, that's what happened to me with Valcyte.

It also can help patients to keep from declining. Considering that people with this illness do seem to slide downward over time, that's not a trivial benefit.

It also may allow them to very gradually improve over time, regardless of whether other treatments are used. I've heard a number of stories like this: that people have moved from a really bad environment to a better one and, a few years later, recovered some of their health. With so many toxins accumulated and so many pathogens in place, we wouldn't expect immediate improvements. It takes the system some time to reset itself.

Because mold is an allergen, people reflexively think that mold toxicity should act like an allergy. It's a poison! If someone had pesticide poisoning, you wouldn't expect him to recover the minute that he wasn't being sprayed with pesticides. It takes the system time to sort out.

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It's interesting to look at people who don't have the mold susceptible or multi susceptible genes but have CFS. I've not encountered many of them so far.

In theory, those people should be able to clear the mold from their systems. So perhaps they do not have the "build up" that CFSers who cannot do it through the immune system seem to have.

That would be in line with the idea that these people might have big reactions to large amounts of mold exposures, but not as much to small ones.

The more I look at the recent research and think about this topic, the more it seems to be that what we have is an "induced reaction" to various substances, including mold. Our systems seem to be primed to go nuts with the inflammation any time we get exposures to "bad stuff."

It also seems like our systems are not very good at detoxifying anything, at least through what Rich calls the "main" (non-immune) channel. Part of it may be the methylation/glutathione issues that Rich has discussed. Part may have to do with detox enzymes, as Dr. Cheney has discussed with the P450 being decoupled.

(I really wonder if our bodies are supposed to be able to detoxify mold at least somewhat through the methylation/glutathione channel as well as the immune system. That would be consistent with my own experience that this stuff is "supposed to" be broken down in some way rather than excreted intact. Normal people do not react to the mold toxins being excreted in their perspiration, for example, Dr. Cheney is no mold expert, but he seems to think that the P450 decoupling is related to mold.)

I would think that if people who are able to detoxify mold through their immune systems get a relatively big hit of mold, it may take them a while to detoxify it. That's what Shoemaker says, actually. That normal people who work in a really bad building may feel effects, but get over them as soon as they get out.

If someone is abnormally affected by any toxins, that big hit might start a huge inflammation response with a downward spiral (of the type that Marty Pall describes) that might take a while to subside. And for CFSers, once that kind of inflammation starts going, just about anything (foods, chemicals, emotional stress) seems to exacerbate it.

So, just following the logic, perhaps people who don't have the mold susceptible genes can quickly process a small hit before the inflammation starts going and not notice or be affected by it. But if they get a big hit, that might trigger the inflammation downward spiral.

My experience is that figuring out how to stop that downward spiral (what Erik calls "break the response") once it starts seems paramount. In my case, because (apparently) I can't detox mold, getting my mold exposures down super-low seems to be the key. But for people who can detox mold, maybe other measures can work better.

Erik's mountain climbing tactic, described in *Mold Warriors*, seems like one "emergency measure" that seems to work for people, for example. I wonder what other measures, in addition to getting viruses under control, would work for those people.

The current thinking on CFS is that viruses and/or other factors cause us to have systems that are primed for inflammation for very little reason and that can't detoxify. So in theory, getting the viruses and/or other factors under control should help us.

Indeed, after eight months on the Valcyte, my mold reactivity is far lower than when I started it. This drug specifically targets just herpes viruses, but I tend to agree with the idea (posited in AIDS) that HHV6a serves as a sort of helper/exacerbator for retroviruses such as XMRV or HIV.

Dr. Guyer's (and Stormy Skye's, if people know her) belief is that if you can get the immune system out from under a chunk of these pathogens, detox and/or avoid a chunk of the toxins, and support the system, it becomes strong enough to keep even the worst bugs in check. That's increasingly starting to seem right to me.



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I also think that even for those of us who are extreme reactors to mold, there is a lot of underlying toxic stuff going on. For instance, now that I've detoxed a whole lot of (apparently) mold with the cholestyramine and am not getting reactions to small amounts of mold (at least on objects or in buildings), other things seem to be coming up.

For instance, I still get big responses to things like ALA, which appears to detox mercury. CSM, which used to be really intense for me, now doesn't seem to give me much of a reaction at all.

Recently I had a terrible reaction to a pot of fresh broccoli soup (repeated vomiting), and it feels to me like that was pesticides rather than mold. All produce was tasting terrible to me for a while, actually. After I started thoroughly washing it with Dr. Bronner's Unscented Magic Soap (mild but thorough), it's all been fine.

I also had a bad experience with something "blowing in the wind" from Mexico while in southern NM. A severe Moldie friend of mine said that she wasn't bothered by it, so I'm wondering if it might be some other kind of bad chemical rather than mold.

Maybe people who are able to detox mold (and Lyme) through their immune systems tend to have problems with other sorts of toxins, like mercury or organophosphates, and would benefit from working on those?

This is all very complex, and no one has all the answers.

It does seem to be very peculiar that a very few of us (with Shoemaker the only medical professional in the bunch) are the only ones even asking the questions yet though.

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A number of people with classic severe CFS have found that "merely" by avoiding toxic mold, they can exercise vigorously without PEM. Whether that would hold for any other CFSers other than ourselves, I cannot say.

The extent to which these individuals have had to attend to the presence of toxic mold in the environment in order to obtain this gain is really large. It's not just a matter of moving to a building where there's no mold growing. Very small amounts of mycotoxins (mold toxins) can set off the response. For instance, at my most reactive, the amount of mold that clung to my hair after a 30-second visit to a moldy building would make me increasingly sick until I washed it out.

This is apparently similar to how people with severe peanut allergies respond when they get exposed to even tiny amounts of peanuts. They don't have to eat a peanut butter sandwich to get affected. Just a tiny bit of peanut oil or a tiny bit of peanut "dust" breathed in can do it. That's why foods now carry labels that say "this product is from a factory that processes peanuts"....so that people with peanut allergies know to avoid it.

Since such tiny amounts of toxin can cause the response, care needs to be taken in terms of all aspects of our lives. Because mycotoxins can be in the outside air (especially in cities where there are a lot of bad buildings or in certain places where it grows outside), that puts a limit on where we can live and remain wholly well. Contaminated objects in the environment (such as bedding) can have an effect. Going briefly into a bad building and then not decontaminating afterwards (washing hair and changing clothing) can be enough. Just living in a building without any mold growing in it is just a start.

Obviously controlling for all these factors is extremely difficult. It's not something that I am encouraging people to jump into lightly.

I'm discussing it for a couple of reasons.

First, I'm increasingly of the belief that the reason that many CFSers don't benefit from the treatments that dedicated doctors and researchers are making available is not because the treatments themselves are useless but because their systems are too overwhelmed with toxic mold exposures to be able to use those treatments effectively.

Toxic mold is not the only factor that contributes to CFSers' illnesses. Our illnesses seem to be a stew of all kinds of bad stuff---viruses, Lyme, other bacteria, candida, mercury, other toxins, hormonal dysfunctions, brain injuries.

Effectively addressing any of these things seems like it has the potential of getting at the core issues of CFS---e.g. getting inflammation under control, increasing system strength, improving mitochondrial function. All of these things are tied together.

The problem is that a high percentage of CFSers are so debilitated that they can't address any of these things effectively. Die-off responses are a major impediment to the effective treatment of Lyme. Jose Montoya, who started off treating CFS patients aggressively with Valcyte, more recently concluded that this is counterproductive and is being much more conservative in the amounts he prescribes. Many CFSers can't treat candida without getting really sick. We've seen already that drugs that could conceivably address XMRV cannot be easily tolerated by at least many CFSers. Many patients starting Rich van K's methylation protocol cannot tolerate even the tiniest doses of those supplements.

So what we have is a bunch of patients who know that they have a huge variety of problems but cannot treat any of them. What's then left to do is the approach that Dr. Cheney is now advocating. In large part, this involves reducing stress on the system.



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Avoid foods that create sensitivities or that are hard to process. Don't take most drugs. Don't do too much. Support the system with proper nutrition and supplements.

I don't have any problem with any of these things. I don't even have any problem with Amygdala Retraining or other ways of helping people to address their emotional stress levels. Certainly, it's stressful to have CFS, stress is not without physical consequence, and we need all the help we can get.

The problem that I have is that many of the very same people who are sitting around worrying about flecks of gluten in their diet and who are attempting to make themselves more serene than Buddhist monks, or who are enduring excruciatingly painful experiences trying to get viruses or Lyme under control, are doing so without having put even one second's worth of thought into the topic of toxic mold.

Even if it weren't for my experiences and the experiences of other CFSers in achieving recovery just from avoiding mold, this would make no sense.

As we've discussed on this thread, there is no doubt in the literature at this point that toxic mold is dangerous. Living in a moldy place has the ability to make well people sick in and of itself. It affects the immune system, causes inflammation, causes decreases in the presence of available reduced glutathione, and causes neurological problems. The idea that CFSers---who clearly have all those problems---would be especially harmed by its presence should not be that hard to accept.

And yet, almost universally, the presence of toxic mold has been overlooked.

Just looking at this logically, it would make sense that one of the first things that a CFS doctor would want to do during a consultation with a new patient is to consider whether toxic mold could be contributing to the problem. A simple ERMI test would be a good start. If all kinds of other "stressors" are being discussed, it doesn't make sense for this one to be left out.

I've yet to hear any CFS doctor propose this as part of an interview though. I'm not sure why. My best guess is that they're afraid that patients won't want to move out of their homes and thus don't want to open up the whole can of worms. "What you're suggesting would lose me all my patients," one doctor (who believes my recovery story and admits that many of his patients appear to be "Moldies") told me at one point.

So here we have doctors who are not suggesting that mold could be an issue because they're afraid that patients are not going to be happy at being told that they should do something about it. And of course, we have patients who don't believe that they need to

do anything about mold because their doctors aren't suggesting it. This makes for less contentious office visits, but if I'm right and mold is an issue, it means that a lot of people are shooting themselves in the foot in terms of their potential to get well.

Here I'm not talking about "extreme avoidance" of the sort that I am doing, and that has restored my exercise ability. I'm just talking about not living in an ordinarily moldy building. If every CFSer got the ERMI done and addressed any problems (by moving or remediation) to the point that the ERMI was okay, that would be a really good first step. The number of people who would get markedly better just from that would be pretty small, but it would be a good stepping stone toward avoiding further declines and maximizing the effects of other treatments.

Certainly, people with peanut allergies don't want to get any exposures. But even if they had to continue to fly on airplanes where peanuts were served, I would guess that they probably would want to minimize the number of peanut butter sandwiches that they consumed.

When I was in my own moldy house, I was unable to tolerate any treatments for this disease. Tiny doses of antibiotics and antivirals made me extremely ill, and I didn't recover from those experiments for months after I stopped the drugs. I got sick enough on Rich's supplements that I was included in the "adverse effects" section of his papers. Candida was out of control no matter what I did to address it. And though I was fanatical in terms of my attention to food sensitivities, rarely did anything other than rest in bed, and took a whole bunch of supportive supplements, my health just kept declining.

Throughout my 12-year illness, I tried every single treatment I could find for this illness. Some of them helped a little, but in general my health just kept going down. It only stopped going down after I got away from the mold.

I didn't have to pursue "extreme avoidance" to experience improvements. Just moving out of my house and putting aside the stuff from the house was enough to allow me to make really big gains.

And after I made those gains, a lot of the treatments that I hadn't been able to use before (like Rich's supplements, antivirals, antibiotics and things to address candida) became tolerable and beneficial to me.

This is what I mean by leverage. Regardless of whether mold is a "cause" of this disease, decreasing exposures is an option for CFSers regardless of how debilitated their bodies are. Many people never are going to be able to attack Lyme, viruses or methylation defects head on, if that's where they begin. Reducing mold exposures is a place where they can at least start.

Obviously, addressing one's environment can be difficult and expensive. Some say that the emotional stress is not worth it. I would encourage those individuals to look at the

literature involving the physical effects of emotional stress vs. the physical effects of toxic mold exposures and make their own conclusions about which is worse.

It's my observation that a very high percentage of people with CFS are hyperreactive to mold and that a bizarrely high percentage of them are living in extraordinarily moldy environments. I don't have peer-reviewed published evidence that this is the case, and (unless either CFS doctors and/or CFS patients start to look into whether mold indeed is a particular issue in this disease) I don't anticipate having them available right away. But even if we take the info that we already know (e.g. the effects that toxic mold has on the system and doctors' insistence that addressing these same issues is important in CFS), looking at the mold seems a sensible and prudent thing to do for those who have any interest whatsoever in maximizing their own health.

My other goal is to try to use the experiences of those who have achieved spectacular and specific improvements in wellness (such as the ability to exercise) as a way of providing information about the nature of this disease to those researchers and doctors who might benefit from knowing more. Not everyone is going to want to pursue mold avoidance to the extent that I have. I understand that. But the information about what does happen if you can avoid this stuff to a large enough amount is informative in terms of the role that it plays, just as knowing that people get sick from the peanut exposures rather than something else is a good first step in allowing researchers to attempt to treat that problem.

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Dr. Paul Cheney recently has mentioned that CFS sufferers can be "mold canaries," but he seems to think that this is equivalent to their relapsing after moving into a particularly moldy house. The fact that people can be really reactive to the tiny amounts of mold that we've been discussing on this thread, and that remissions can be achieved systematically solely by avoiding mold (with wellness continuing if and only mold continues to be successfully avoided), is something that he seems yet to understand.

Making him and other CFS researchers aware of these things so that they will start looking into them is my main goal at this point.

Toxic Mold and Other Treatments

What I'm increasingly interested in is what makes some CFSers benefit from treatments and some not benefit.

Certainly we've seen a scattering of patients improve from various treatments, including the ones that you mention. The question, in my mind, is why so many of them do not make progress or decline over time even with treatments that seem like they make sense and that do indeed help some people.

There are lots of factors why people don't get better from CFS. Mold isn't the only stress on our system. And mold avoidance isn't the answer either.....or at least, it's an impractical answer for most people. And I've added lots of other stuff to my own mold avoidance efforts.

But I feel pretty confident in saying that if CFS sufferers are getting a lot of mold exposure, they're going to be handicapped in terms of making any progress getting well from this disease.

The definition of "a lot of mold exposure" varies across people. I suspect it differs based on how sick people are, how many bugs they have, how many other toxins they have problems with, how long they've been sick, how broken their glutathione/methylation systems are, and other things. Just staying out of really moldy buildings may be enough for some people, even those who start off as pretty sick. And decreasing exposures by however much is always going to be a good thing.

I've discussed this with Mike Dessin on occasion, and I see him as an ideal example of a person who incorporated mold avoidance into his recovery. His health started to decline over time, but the time that things really fell apart was when he got a really severe mold problem in his home. He then moved around a lot. Finally he moved to a place in Ohio that felt good to him with regard to mold and chemicals and (following Erik's advice) got rid of all his old possessions. After that, he started the neural therapy and quickly regained much of his health.

This actually is precisely what I did. I moved out of my bad house and put aside all my stuff. I found a new place. I made a lot of improvements (moving from being bedridden 18-22 hours a day to being up and reasonably functional most of the time) just from that.....even though I realized after really getting clear of mold that the place I was living had somewhat of a mold problem too. And then I worked on detox, including with neural therapy which (recently) I've found to be extremely helpful in pushing me toward the point that my reactivity has gone down to where few buildings and basically no objects have much of an effect on me any more.

Mike had a hell of a time of it. I'd like to think that people can do what he eventually did, but more systematically. If he had chosen a home in Ohio that was moldy, or if he'd had a bunch of contaminated possessions from a previous residence with him, would the neural therapy have been enough to turn it around? I don't know. Neural therapy is powerful. I benefited from it even when I was living in a really moldy house. But I can't believe that mold exposure wouldn't have made it a lot more difficult for him, at the very



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least requiring more treatments and with slower and less permanently stable results. That's what he told me, anyway.

I have a lot of respect for the work that Cheney is doing. I've heard enough good things about the artesunate that I likely will try it myself, when I'm done with the Valcyte course. Are the people who got functional cures living in better environments than the non-cures? Could the people who come back from stem cell treatments make even more progress if they were attending to their living environments and making even small attempts to stay out of moldy buildings?

I don't know. And until researchers start looking at the issue, no one else will know either.

The stem cell therapy is fascinating. I would consider it myself, if my own reactivity weren't going down so much from other means. My initial feeling is that, like neural therapy, it allows people to tolerate a lot more toxic exposures of all sorts than they did in the past. (Insofar as our detox mechanisms are part of what's broken, resetting everything might allow our bodies to excrete the toxins naturally without adding things like CSM or neural therapy, for instance.)

Certainly, lots of people live in Incline Village and don't get sick. There are a fair number of moldy houses there, but a lot of good ones. The scattered outdoor mold can be vicious for those of us who are already sick, but occasional exposures wouldn't drive down someone whose system is working well. The stem cell story is really encouraging all around, that a person could withstand even occasional exposures to this stuff.

But what I'd really hate is for people to go through stem cell treatments, come back to the U.S., feel better, and then get exposed to lots of mold again. Just because our systems are capable of handling increased amounts of whatever kinds of toxins doesn't mean that we shouldn't be at least a little careful.

What I do know is that neither Cheney nor any other leading CFS doctor is actively encouraging patients to look into this issue. Certainly, these doctors are helping some patients with the treatments that they are proposing, and I am grateful to them for that. But I'd like to see them help a higher percentage of patients, and for the patients who are helped not just to reach a functional cure ("normal activity with some difficulty") but actually get to the point where they're living full lives again.

Insofar as mold is weighing people down, that's going to be less likely to happen.

As for the desert.....Erik never encouraged people to live in the desert. He never lived there himself. He lived in the Tahoe area for many years after getting well, and now he lives in Reno. The point of "the desert" was for people to get to somewhere really clear for a while, so that the "masking" recedes and they can avoid mold better back in civilization. ("Masking" is a chemical sensitivity term, similar to what happens when people eat wheat all the time and don't know they're sick from it until they stop.) Once they get unmasked, people can do a better job of finding mold in their environments.....for instance, not unknowingly moving into a moldy home.

I took the whole exercise to extremes by living in a tent for a while, because I concluded that it would allow me to detox more efficiently and take Valcyte without getting sick. This experiment has gone remarkably well. I'm way better than a "functional cure" at this point.

Whether I will ever not have to think about mold at all, I don't know. But my life is a lot less weird than you may think, even now.

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I heard recently that stem cell patients in Cheney's studies had C4a go down. Cheney apparently attributes this to general inflammation going down. Insofar as all his patients are like me, I would attribute it to their being able to "hold their mold" better.

Maybe this seems a small distinction, but I'm not so sure. If their C4a was initially really high because they were in a moldy environment and the stem cell made them more able to handle the moldy environment and all other mold exposures permanently, that would be great.

But our observations and Shoemaker's hypotheses suggest that the longer that normal people stay in moldy environments, the worse their health gets. If that's the case, wouldn't you expect a stem cell patient who went back to a really moldy house to eventually relapse?

In that case, wouldn't it make sense to take a look at the house and at least do some basic remediation so that the place isn't a Sick Building?

Certainly, remediation isn't cheap. It might even cost more than the \$20k stem cell transplant.

But even if the stem cell transplants have the potential of allowing people's systems to withstand this crap, getting multiple transplants done seems like it would have the potential to really add up.

Maybe a stem cell transplant plus moderate avoidance (meaning simply not living in a really moldy place) would equal full wellness, not just the ten or twenty point

improvements on the Karnofsky Performance Status index that Cheney's patients are reporting.

Role in Etiology

Marty Pall has done a wonderful job in laying out some of the ways in which these feedback loops may occur. I think it's clear that what he says has relevance to what's going on in this disease.

The problem that I have with his theory is his speculation that once the cycle gets going, it keeps going on of its own accord for all eternity. While this is possible, it seems to me more likely that there are some trigger mechanisms that are keeping it going. One way of treating this disease is thus to identify what those triggers are and intercede.

One trigger mechanism seems to be XMRV. Still, as the WPI studies suggest, not everyone with XMRV has CFS. And some people with CFS have "spontaneous" remissions or substantial decreases in the severity of the disease. It thus seems worthwhile to look for other trigger mechanisms, especially insofar as we are still in the process of learning to how to address the virus directly through the use of available drugs and waiting for new drugs to be developed.

I agree with the idea that a wide variety of "stressors" might serve as triggering mechanisms to keep the feedback cycles going. The question is whether we can find ones that 1) are especially good at doing that and 2) can be addressed.

Candida seems to me to be a good place to start, and indeed it has gotten plenty of attention in this disease. Interestingly (but not surprisingly), candida produces a toxin that is similar to that produced by toxic molds. This type of toxin seems to be especially good at contributing to oxidative stress. And, as I understand Cheney, this leads to another feedback loop, with the oxidative stress leading to a comparatively anaerobic environment of the system, and the anaerobic environment making it easier for yeast to proliferate.

Certainly, candida is not the cause of CFS. But my goal is not to suggest a "cause." It is to suggest how we can intercede at control points in order to a) make it easier to treat the virus(es) and b) work toward achieving a remission in the context of what researchers now suspect about XMRV.

There are a variety of stressors that have the potential of being relevant here. My focus here is on mold because a) the little research that we have about it suggests that the particular ways in which it exerts its toxicity seems consistent with the problems in CFS, b) it is a toxin to which many “average” people (e.g. not farm or industrial workers) are exposed to (in most cases unknowingly) on a continuous long-term basis, c) I myself and a number of others with classic documented CFS (including Erik Johnson, one of the original Incline Village prototypes for the disease) have achieved close to full remission by systematically addressing mold and doing nothing else, d) my recent experience with Valcyte suggests that addressing mold reduced the die-off and other problematic symptoms associated with the drug to basically nil and allowed me to benefit from it in ways that very few CFS patients have reported doing, and e) unlike just about every other stressor imaginable, mold (apart from Dr. Shoemaker’s and Erik Johnson’s work) has received almost no attention in CFS thus far.

A couple of elaborative comments.

Considering the extent to which toxins are increasingly present in the environment, research into any kinds of toxins has been extremely limited. Part of this is another “feedback loop”: if most medical researchers study viruses, their students also are going to be studying viruses and they are more likely to be receptive to papers from other virologists when deciding what to include in medical journals.

In addition, it’s hard to get funding for toxicity issues. Drug companies are happy to fund work into viruses (e.g. Jose Montoya’s \$1 million grant for the Valcyte study), since this has the potential to lead to profitability for them. Toxicity research seems less likely (at least on the surface) to lead to more drug sales; indeed, insofar as people focus on toxicity, they may be less inclined to consider any drugs at all. This does not mean that we should ignore the need for scientific research in the area; rather, it suggests the idea to develop hypotheses based on the information that we do have so that they can be tested with whatever moneys and researchers can be solicited.

One area in which toxicity actually has been studied is in agriculture, since farmers have the needs to a) keep livestock healthy and b) kill bugs and other pests. I thus spent some time looking into various chemicals to see if I could find ones that might serve as models for what might be going on with the mold.

One that seemed close was phosphine, which is used to kill insects in grain as well as rodents. Unlike most other toxins, phosphine exercises its mechanism primarily through oxidative stress. Interestingly, large doses of phosphine are not particularly effective at killing insects; rather, they actually can induce resistance. The thing that is particularly effective at killing insects is small doses of phosphine administered over very long periods of time.

This seemed relevant to me because it is analogous to the conditions under which people are exposed to toxic mold. Probably it is true that a very large dose of satratoxin is effective at causing damage. But it may also be that a very low level of satratoxin



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administered over a period of years (as would occur if people live or work for a long time in one moldy building or in a series of moldy buildings) may have an equal or greater effect.

It would be terrific to have such actual studies to prove that this hypothesis has merit, but since they would be expensive and would take a long time to be completed (e.g. 20 years of exposure), likely that will not occur soon. The hypothesis does seem consistent with the anecdotal evidence of large numbers of people (most of whom have no financial motivation for doing so) reporting far worse symptoms as a result of exposure to various molds than research studies suggest that they should be.

CFS sufferers do on occasion experience “spontaneous” remissions, and so it is important to consider whether the ones that those of us who are attributing our recoveries to mold avoidance are misguided. The strongest argument is that staying well is contingent upon maintaining a high avoidance level. Insofar as this level of avoidance is not attended to extraordinarily carefully by those using such a strategy, health immediately plummets. Renewing mold avoidance is immediately followed by a restoration in health (with the time period needed for the restoration varying from an hour to several months depending on the extent to which and length of time mold avoidance was not pursued successfully).

This results in a “quasi-experimental design” (see the book of this name by a former professor of mine, Thomas Cook) that those who are pursuing mold avoidance cannot help but repeat over and over again as they encounter small amounts of mold in the environment. For instance, at the time that I was most reactive, the amount of mold spores in my hair as a result of a 30-second visit to a moldy building would cause me to become increasingly sick until I washed them out. Mold toxin (or the toxins on the spores) caused this reaction regardless of whether it was growing in a building, cross-contaminating objects, or present in the outside air.

Clearly, getting to this level of mold avoidance is not something that would occur by chance. This seems to explain why “moving” is not generally successful in allowing CFS sufferers who have mold issues to recover their wellness. It also suggests (at least to me) that this is not a placebo effect: as placebos go, this is the last one I would choose! Neither I nor the others who have achieved partial or full remission as a result of this strategy have anything to gain as a result of pursuing it except for renewed health and the possibility of helping others to achieve the same thing. There are much easier ways to get attention.

Certainly this could be a case of mass hysteria. But that’s what’s said about the entire disease of CFS, so what else is new?

I've put off talking about mold in recent months because I wanted to observe what would happen as a result of my Valcyte trial. Back when I was living unknowingly in my moldy house, I was unable to take even a small dose (250 mg) of Famvir without getting more ill than what most people were reporting on full doses of Valcyte. After an extended period of what Erik calls "extreme mold avoidance," I was able to take a full dose (1000 mg) of Famvir with no symptoms whatsoever. I then added a full dose of Valcyte (900 mg) with few die-off symptoms.

The Famvir caused my mold reactivity (the extent to which mold makes me sick) to go up for three days and then go down below baseline. The Valcyte caused my mold reactivity to go up for about three months and then go down below baseline. At this point it is down to the point that no objects and relatively few buildings have an effect on me, which means that (insofar as this continues) I will be able to move back towards having a much more normal life.

In addition, after just a month or so on Valcyte, my cognitive functioning started to "flicker" on at a level that I had not experienced since getting sick in 1996. This has occurred increasingly frequently since then, and now is at that level the majority of the time. Apart from continuing hangover-like detox symptoms every morning, remaining reactions to mold toxins and (recently, perhaps as a result of increased detox as a result of P450 restoration?) pollution, and an odd recent case of TMJ, I have no symptoms whatsoever of any disease at this time.

My CFS was classic and increasingly severe (low NKC function, low suppressors, high Rnase-L and LMW Rnase-L, high apoptosis, extremely high interferon alpha, HHV6 titres sufficient to qualify for Montoya's study, reactivated EBV, CMV, mycoplasma, chlamydia pneumoniae, post-exertional malaise, cognitive issues described in Osler's Web, exercise intolerance, agitated exhaustion, sleep difficulties, need to stay within an "energy envelope," candida, food sensitivities, gut problems, hormonal dysregulation, extreme die-off to doxycycline as well as Famvir, huge detox reaction to the supplements on Rich's methylation protocol, gradual-then-sudden onset apparently triggered by high stress level, a series of Hepatitis B vaccines, a head injury, a pregnancy and a bad flu, ill for 12 years, bedridden 18-22 hours a day for the last year). As an Incline Village prototype, Erik's illness was even more severe and obviously classic. Others who have recovered as a result of using this strategy report similar histories.

An interesting question to me is the fact that Valcyte had such a positive effect on my health when it targets herpes viruses rather than retroviruses. One conclusion is that HHV6a is established in the body opportunistically, secondarily to the XMRV, but directly caused symptoms such as cognitive problems and inflammation. (That would make XMRV an interesting "cause," if HHV6a were also needed and provoked all the symptoms that weren't addressed fully by getting away from the mold). It also seems possible that HHV6 or one of the other herpes viruses serves as a helper virus to XMRV and that a one-two punch is needed for the XMRV to exert its effects. Or perhaps the



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reduction in overall stress on my system as a result of lowering the mold exposures, pursuing two year's worth of intensive detox, and getting the herpes viruses under control allowed my body to regain enough of its immune system functioning to get the XMRV under control naturally.

The “one-two punch” conceivably could apply to the XMRV and mold combination as well. Judy Mikovits and Paul Cheney have acknowledged that there may be some sort of “terrain” issue that is allowing the virus to lodge itself into the system and/or not be kept in check. Considering how much health I and others have been able to regain just by avoiding the mold, it does not seem to be inconceivable that the mold is a factor (or the factor) causing this terrain issue. It even is conceivable (and to my understanding this has not been disproved) that XMRV is not a new virus at all, and instead is exerting itself as a result of the changed terrain that results as a result of people's increased exposure to more mold (e.g. as a result of the emergence of drywall in the early 1970s) or the emergence of a new particularly damaging “super mold” (similar to the “super bacteria” that are known to have emerged recently). If that's the case, then XMRV would be considered opportunistic, just as (say) toxoplasmosis is in AIDS.

That mold is a “terrain” issue is wholly consistent with Erik's observations that those individuals who were being exposed to large amounts of mold during the Incline Village epidemic were the ones who were more likely to get the “Yuppie Flu” to begin with and then to remain really sick after catching it. Obviously, his is just one observation. However, all science starts with one observation. Neither he nor I is a medical researcher. Our goal in bringing this up is not to prove anything. It is to supply professional medical researchers with our observations and experiences so that they will have a starting point to pursue testing what may be useful channels of inquiry in terms of better understanding and then treating this disease.

In the meantime, regardless of whether researchers decide to pursue this line of research, my own experience that I was able to take and benefit from Valcyte only after addressing the mold seems that it has the potential of having value for people. Taking antiretrovirals seems to have the potential of proving as difficult and unproductive for CFS patients as does taking Valcyte. To the extent that addressing mold can be used as a leverage point to allow people to be more likely to be able to take and benefit from any of these drugs, the topic seems worth discussing in the context of XMRV.

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Many times, we hear reports of things like, “Red dye #2 causes cancer” (according to either prevalence studies in humans or laboratory studies with animals).

Clearly, this substance is not the only cause of cancer. People are still getting cancer even though this stuff was removed from the market. And lots of people consumed this stuff without getting cancer.

That means that there have to be other underlying causes for the disease. For instance, my impression that cancer researchers think that viral issues underlie many or all cancers, even though specific viruses (e.g. Hepatitis B in liver cancer) have been identified in only a few kinds of cancers so far.

People don't seem to hesitate about using the word "causes" with regard to the red dye though.

I ask this because of some comments that Erik made regarding his observations about what was happening during the Incline Village epidemic.

Prior to the epidemic (as I mentioned earlier on this thread), Erik was aware that toxic mold bothered him somewhat. He thus paid attention to where it was in his surroundings.

It is his contention that people who already were living or working in "Sick Buildings" (e.g. the ones that bothered him) were more likely to come down with the "Yuppie Flu" and much more likely not to recover from it after a few weeks than those people who were living in environments that he found to be "good" with regard to the apparent absence of toxic mold.

Obviously we should not trust Erik's observations on this. Any hypotheses that we make about this topic need to be scientifically verified before we can give any credibility to them.

Even if Erik is right and this can be proven, that still wouldn't mean that previous toxic mold exposure is necessary in order for people to come down with CFS. As with the red dye, it only would mean that the toxic mold exposure makes it more likely that people will get the disease.

And obviously, it also wouldn't mean that toxic mold exposure makes people get CFS all by itself. Lots of people work or live in sick buildings and don't get sick at all, much less get CFS. Just like lots of people consumed Red Dye #2 and didn't get any sort of illness (to our knowledge) as a result.

I think that Erik's observation is worth considering as a hypothesis for research. Regardless of how the study came out, I'd like to know the answer.

But I'm having a hard time framing this.

Every time he or I mentions the words "toxic mold" and "CFS" in the same sentence, people respond by saying, "Mold doesn't cause CFS" and then dismiss the whole idea.



Paradigm Change

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1. Rich, here you list a variety of things that can place a demand on glutathione and cause oxidative stress.

> This includes a wide variety of stressors, some of them toxins or pathogens, but also physical stressors such as trauma or extreme overexercise, or psychological/emotional stressors. In studying the histories of many PWCs over the past several years, I have found that in many cases the person was subject to a combination of stressors that were present simultaneously, some of them long-term.

Do you have any sense of the relative extent to which each of these can contribute to this phenomenon? Or do you have any thoughts about how we might be able to figure out which of these are mildly important vs. extremely important?

I believe that I currently have a good understanding of what “oxidative stress” feels like for me. This was part of why I did the phosphine experiment: to know for sure what it felt like to be poisoned by a chemical that kills by oxidative stress, so that I could know what other substances were affecting me in the same way.

(This sounds exceedingly stupid, but I was really careful to get just a little bit of exposure. And in the end, the kind of poisoned feeling that I got from the phosphine was far less problematic, qualitatively and quantitatively, than what happens when I get exposed to the mold that’s present in relatively large amounts in Lake Tahoe. That toxin is in a horrific category all by itself. The phosphine just felt like a regular mold hit of the sort I get every day, if I’m not being super careful.)

Exposures to even tiny amounts of toxic mold (especially when I was at my most reactive) give me strong feelings of oxidative stress. Lyme die-off does that. The Valcyte and Famvir (for the herpes viruses) did that.

Other than the phosphine, I never found any toxic chemicals that have given me that effect. (Plenty of toxins have bothered me, but none of them in that way.)

I have on plenty of occasions during the past year experienced lots of emotional/psychological stress. I’ve also done a lot of exercise. If I already was experiencing the “oxidative stress response,” those additional factors seemed to exacerbate it a bit. If my system was not already in “oxidative stress response,” those additional factors did not create it.

I thus would like to posit that the key factors that cause the oxidative stress response in CFS are toxic mold and certain specific pathogens. Other “stressors” seem to me to have the potential to exacerbate the situation but not to cause it.

Do you have any studies discussing the ability of these various stressors to create oxidative stress? Maybe looking at such studies would make the extent to which they're important more clear from an objective standpoint.

Have you written anything on how you think the various viruses present in CFS (e.g. XMRV, HHV6a, etc.) play into your hypothesis?

2. I agree that oxidative stress is an important link between CFS and toxic mold.

>Based on the above, it seems that a link (or "the" link) between mold toxins and CFS in genetically susceptible people is the promotion of oxidative stress by the toxins, bringing down the glutathione levels.

In addition, there's a good bit of literature detailing the ability of various toxic molds (especially trichothecenes) to compromise the immune system directly.

This would combine with the indirect effects (through the creation of oxidative stress) that you detail, making people even more subject to colonization by various pathogens.

A number of doctors/researchers have focused their attention on the importance of the gut in CFS. Thus, the particular ability of mold toxins to affect the intestinal system (e.g. the abstracts I recently posted) seems of relevance.

This is particularly interesting to me since it seems connected with the idea that mold toxins from *Stachybotrys* tend to be more damaging (especially with regards to creating a whole lot of oxidative stress even when present in small quantities) when bacteria toxins are also present.

In some cases, the bacteria (e.g. *Streptomyces Californicus*) are ones growing alongside the Stachy in sick buildings. However, LPS (an endotoxin made by bacteria) also has that effect.

Insofar as CFS patients' guts are colonized with LPS-producing bacteria, any mold exposures they get will be more damaging. And insofar as this leads to even more gut bugs, a downward spiral will result.

Doctors such as Kenny de Meirleir and Paul Cheney have focused much of their attention on addressing gut problems, which is consistent with addressing this phenomenon. However, if indeed mold exposures are causing the gut problems, it seems to make sense that reducing exposures to the mold would be a particularly good place to start when working towards improving the gut.

Another particularly relevant effect of toxic mold is its ability to create perforations in the blood-brain barrier. Many CFSers have at least moderate MCS, and it seems reasonable to think the perforations are at least partially responsible. It also seems to me that these holes may allow various other toxins (especially mercury and Lyme) to move easily into the brain, thus becoming especially damaging and (perhaps) with the particularly neurological effects observed in CFS.

3. Following, you discuss how CFS can turn into a vicious cycle:

>One of the most important sulfur-containing substances in the body is glutathione, so now you can see how this is starting to look like a dog chasing its tail! The thing that causes chronic fatigue syndrome to be chronic, and keeps people ill for years and years, is this interaction between glutathione, vitamin B12, and the methylation cycle. When glutathione goes too low, the effect on vitamin B12 slows down the methylation cycle too much. The sulfur metabolites are then dumped into the transsulfuration pathway (which is connected to the methylation cycle) too much, are oxidized to form cystine, pass through hydrogen sulfide, and are eventually converted to thiosulfate and sulfate and are excreted in the urine. This lowers the production of glutathione, which requires cysteine rather than cystine, and now there is a vicious circle mechanism that preserves this malfunction and keeps you sick.

Marty Pall also posits a vicious cycle that goes on forever and ever without any particular outside stimuli. Dr. Shoemaker seems to be implying that this can happen too, with his comments about how how C3a goes up and stays up for no apparent reason in CFS patients.

Perhaps I have an over-idealized perception of how the body works, but this does not sound right to me. Any gene that would make us so fragile that a single knock-out blow would keep an unending vicious circle going forever without any further stimuli seems to me that it would have been weeded out of the population long ago.

I thus have to believe that there's something that's contributing to the oxidative stress/inflammation that's keeping the cycle going.

One possibility is that it's one of the pathogens (e.g. viruses or Lyme). But my own experience in being able to get the oxidative stress to mostly or entirely go away just as a result of extreme mold avoidance makes me think that for at least some people, it's tiny bits of mold exposures that are doing it.

The idea that tiny bits of mold could be having such a tremendous effect seems at first a little bizarre. However, agricultural studies suggest that phosphine (which seems similar to mold in terms of all of its effects) is especially toxic in very small doses administered over long periods of time. Insofar as CFSers already have experienced that condition as a result of years or decades of exposures in their homes, each additional bit may be bringing them closer to the “deadly” dose and thus having an unexpectedly severe effect.

This especially seems to be the case when certain viruses are added or reactivated.

4. You periodically have distinguished in your work between the epidemic/cluster cases and the isolated cases.

> To get an isolated case of CFS (I'm not talking here about the epidemics or clusters), you have to have inherited some genetic variations from your parents.... I suspect that the clusters or epidemic occurrences of CFS (such as at Incline Village in the mid-80s) were caused by particularly virulent infectious agents, such as powerful viruses, and the genetic factor is less important in these cases.

I think that you are differentiating here because in the epidemics, a high percentage of the population (e.g. all the teachers who used the teachers' lounge at Truckee High School, half the girls' basketball team) came down with the illness. This suggests that everyone was susceptible, not just a few people with the bad genes.

I agree.

However, as you know, I am positing that the epidemic cases presented with such prevalence and such severity not because of a particularly virulent infectious agent but because of the presence of a particularly problematic toxin.

Clearly, no one should take my word on the potency of the mold that I found in quantity in certain specific places in Lake Tahoe and in other places where CFS sufferers experience particularly vicious forms of the disease. Nor should they take the word of a bunch of us on this, without any systematic scientific research.

However, it seems to me that these observations should at least be a starting point for getting such research to be done.

What Changed?

Shoemaker's books provide a lot of insight into what's going on with the phenomenon of toxic mold, including some speculation on why it's become so much more of a problem in recent years.

Here are several different hypotheses, including ones posed by Shoemaker:

1. Building techniques (such as the use of drywall, insulation and HVAC systems) have caused there to be greater quantities of mold growing in buildings than in the past.
2. The use of chemicals (such as mold resistant paints) have caused some toxic molds to be more able to grow than others. The toxic molds that are able to grow in those conditions may (for whatever reason) create toxins that are more damaging to us than other molds.
3. One or more chemicals may have mutated toxic mold, causing it to create toxins that we are not genetically adapted to resist. Benomyl, a "systemic fungicide" developed by DuPont in the late 1960s, is a prime suspect of this.
4. Our "background levels" of toxins in general (e.g. from other chemicals) is greater now than in the past, and the "toxic terrain" of our bodies may make us more susceptible to mold toxins.
5. Some sort of new pathogen (such as XMRV or Lyme) may cause some people to be more susceptible to toxic mold, or to be vulnerable to tiny amounts of it.
6. EMF's may cause mold to grow more easily or to create more potent toxins.

Note that when Shoemaker says "mold," he's using it as shorthand for biotoxins of all sorts. For instance, toxin-producing bacteria in buildings can be just as dangerous as even the worst molds, and can work in combination with molds to create particularly bad effects, he says.

I tend to think that more than one of the factors above may be responsible for the increases in mold illness. I will be interested to see whether that turns out to be the case.

Virus and Mold Interactions

Even if XMRV is the root cause for all of us (which Cheney now seems to think) doesn't mean that treating it directly is the way to go.

Clearly something (maybe XMRV) is making our bodies unable to eliminate all kinds of toxins. Maybe through P450 (as he suggested to you), maybe some other ways too.

Clearly mold is extremely common in our environments, especially compared to other toxins.

Clearly when the body doesn't eliminate mold, the effects of the mold on our systems are worse.

Clearly mold has a number of strong negative effects on the body that are applicable to this disease, including the creation of oxidative stress, the decrease of reduced glutathione, perforations in the BBB, and destruction of intestinal cells.

Clearly mold also has big effects on the immune system, including Natural Killer Cell function. (That's a big defect in this illness and a primary reason why we have such bad herpes family virus problems.)

Clearly all those things above are "control points" (as Cheney puts it) that not only cause "downstream" problems but that cause the viruses that we have to flourish.

Nothing ever is going to get rid of XMRV, I think. All we're ever going to be able to do is to keep it and the other bugs we have from getting out of control.

Cheney's whole approach (even with the XMRV discovery) is to address various "control points" in order to improve the general system and get the viral activity to go down. He's not using antiviral drugs at all, or at least not yet. It's all indirect. He thinks of artesunate as an antiviral treatment, for instance. It's my impression that he thinks of working on the gut as an antiviral treatment.

So according to this logic, mold avoidance also is an antiviral treatment. And considering the fact that the mold is, as far as I can tell, the only reasonable explanation (other than certain pathogens like viruses and Lyme) for all the oxidative stress that we're getting, eliminating it to the extent that we can is a good foundation for anything else we try to do.

None of these points are arguable. They're just complex. But Cheney is a complex thinker, and the other people working in this field are (by and large) not stupid either. It's just a matter of helping them see it.

One issue that I'm seeing is that as soon as people fasten on the idea of a virus as "the cause" (or a cause) of CFS, they immediately jump to the conclusion that drugs to kill the virus are the solution. That may turn out to be the way to go, but then again it may not be.



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I have no moral objection to drugs. Lamictal has been hugely helpful to me for the past decade (though with the mold avoidance, I've now cut down on the dose without backlash). The Valcyte/Famvir have been essential in the gains I've made recently. I never would have made nearly as much detox progress without the cholestyramine.

But I think that the drugs have to be looked at as part of the whole picture. Part of it is that some people can't take drugs, and part of it is that optimal drugs to treat this virus have (at least according to the researcher working on the virus) not been developed yet.

But it's also that even if the virus is at the bottom of the whole thing and we wouldn't be sick at all if we didn't have it doesn't mean we can get back to pre-illness just by addressing it. It's not just the genetic changes, it's the fact that our bodies (as Cheney suggests) have fallen behind in doing the things that they need to in order to run optimally. Even a normally functioning system without XMRV (or a "re-stemmed" one) would have a hard time getting rid of the garbage that has accumulated and doing backlogged "repair work." So giving our bodies as much support as we can on our way to healing, using whatever tools we have, seems to me a good idea.

What amazes me is just how much we actually know about this disease. There are some really good and committed people working on it. The kind of person attracted to this disease tends to be a "new ideas" type of person, and that has really allowed a lot of progress to be made. But everybody's now defending their own little piece. They're all in their own little cubbyholes.

I think the pieces are there to work with though. I wouldn't be making this much progress otherwise. It's not just the mold, in my case. But I never would have gotten anywhere without addressing the mold first.

And since I've yet to see anyone with confirmed CFS who's been sick for more than two years get anywhere close to being well (meaning as well as Erik or Jonathan or I am) by ANY methods as those of us who have pursued Erik's approach suggests that this is an important piece of the puzzle. (And this includes both Mike Dessin and StormySkye, who both acknowledge that they were following this mold avoidance approach, even if rather inadvertently and without knowing exactly what they were avoiding, as they also did other things.)

I'm not saying that mold is the answer, by any means. I just am saying that leaving it out may not be prudent.

Hopefully if doctors start to understand this, they can factor the mold into the other things that they're doing and, perhaps, see better results.

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Judy Mikovits suggests that certain factors may serve as “triggers” for XMRV to become active:

> Q: If XMRV is present but inactive, are there any suggestions as to what could be a trigger for (re)-activation?

> A: Estrogens, androgens, cortisol (stress) and inflammation.

As I understand this, XMRV may flare like (say) a genital herpes infection. Insofar as those things that Dr. Mikovits mentions are present, the virus may become more problematic.

The interesting thing to me is that both cortisol and inflammation are strongly associated with exposures to certain strains of toxic mold, and in particular to *Stachybotrys* exposures.

When she states “stress,” it may mean “emotional stress.” But it could also mean “stress to the system” through any sort of event (and in particular, an inflammation-inducing event).

It's my hypothesis that one of the reasons that mold avoidance has been successful in promoting my own wellness is because doing so reduces both cortisol levels and inflammation in my system.

Lowering cortisol and inflammation is good for anybody, but it seems that if you have XMRV, it's especially good.

This is what I mean by addressing the virus using a “control point.”

Getting the virus to be inactive is not as good as getting rid of it, but it seems to me that it's still better than letting it be active.

In addition, I suspect (and someone who knows more about virology than I do can correct me if I'm wrong) that a virus that's already partially under control is going to be a lot less stressful for the body to address using antivirals than one that is not under control at all.

If this is true, it would be consistent with my contention that using antivirals in conjunction with even a minimal amount of mold avoidance might be a good strategy.

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Here is an exchange between Dr. Cheney and Dr. Mikovits:

Cheney: A lot of [CFS] patients, if you investigate their immune system, there's evidence of significant activation of the immune system of almost any parameter that you look at, particularly cytokine elevations of various kinds and evidence of TGF beta 1 activations. Suggesting the immune system is really activated and there's kind of a counter response trying to tone it down. Is immune activation, which we almost see universally by cytokine markers, consistent with XMRV infection?

Mikovits: Well yes, and every other retroviral infection, absolutely. Again, it goes unchecked, so the immune system is trying to do it's job, clear the virus, keep the virus down, and when the virus goes unchecked, it causes the kind of things we discussed with elevated T cells as the problem. So in the face of chronic inflammation you develop immune deficiency.

And here is a comment from that same interview that the envelope of XMRV might be serving as a neurotoxin itself:

Cheney: There's a lot of brain involvement in CFS and it comes in the form of neurocognitive complaints; it comes in the form of neuro-behavioral shifts; it comes in the form of abnormal MRI scans that are typically non-specific but abnormal; it comes in the form of subtle neurological findings on exams such as hyper-reflexia and disturbances of the vestibular apparatus. So my question is, do you think XMRV could be causing neurological problems like this?

Mikovits: Oh absolutely, and again we go back to other retroviruses, HTLV-1, in addition to leukemia that it is causative for, has associated with it a disease called HTLV-1 associated myelopathy, where it is a myelopathy type disease. The patients stagger, can't walk, end up in wheelchairs, and it is related directly to viral load but they don't understand all of the mechanisms. Importantly, in XMRV family members in animals the envelope protein actually is a neurotoxin, so parts of the viruses by themselves, without all the infectious replicating virus, can cause neurotoxicity. We are actually investigating the envelope protein of this virus as potentially a neurotoxin.

“Tahoe Toxin”

A number of people practicing Erik's "extreme avoidance" of mold have gotten to the point where we can tell right away if we have been exposed. Unfortunately, the spores and toxins stick to belongings, meaning that avoidance doesn't just mean walking away once we get hit. If we don't wash our clothes and ourselves, and attend to anything that the mold has stuck to, it continues to have an effect on us.

Even more unfortunately, there is one particularly bad kind of mold that causes a variety of especially damaging symptoms. These include heart palpitations/pain, chest pressure, excruciating migraine-like headaches, cognitive dysfunction that goes beyond brain fog (e.g. inability to read or do math, "white-outs" where brain goes blank), burning of skin/throat (sometimes severe burns), emotional responses (panic/anger/depression/suicidal inclinations), organ pain, severe chemical sensitivities, extremely deep skin "dents," seizures, convulsions, extreme sound/light sensitivity, shivering, diarrhea, vomiting, gait problems, and non-specific feelings of agony.

These are symptoms that many CFSers experience in low-grade form or on occasion. Note, however, that they are the "weird" ones that those with particularly severe CFS report. Osler's Web discusses them.

I met the Canadian Criteria, but only occasionally had this group of specific symptoms during my 12-year illness. (I'm from Chicago.)

After I had gotten to a relatively high degree of recovery through mold avoidance, I decided to pay a visit to Lake Tahoe on my own (without Erik's babysitting) to revisit a couple of buildings there. I figured that if I decontaminated (took a shower and changed clothes) afterwards, I would be okay.

The campground that I was at felt terrific for the first two nights. At about midnight on the third night, the barometer dropped. This is when mold of all sorts (toxic and non-toxic) lets loose with its dormant spores, since the possibility that water might follow makes it more likely that the "seeds" will be able to spring up into live mold.

The initial symptoms of the exposure weren't excruciating, so I waited until it was light before packing up my stuff and leaving. This was a mistake.

Over the next few days, my response continued to build to the point that I had all of the "weird" symptoms (above) at a far worse level than I'd ever experienced during my 14 year illness. And it just kept going on and on and on, both because of the big hit itself and then because re-exposure to my stuff brought the symptoms back.

For the first time in my life, I seriously prayed to die. Pain beyond endurance. Pain beyond imagining. And it doesn't seem wholly inconceivable that I actually could have died, based on what I was experiencing.



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I made a big effort to clean all my stuff and to get rid of things that couldn't be cleaned or (like bedding) that I was in particular contact with. I came close to getting rid of the car too.

Toxic mold in general is immunosuppressive, and it seemed reasonable (especially in light of many of Erik's comments) that this particularly bad mold would be even more so. I thus decided to take some Famvir. My response to the items that had been contaminated with this mold got even worse for three days, then fell below baseline. That was a surprise!

So I thus managed to keep the car and most of my stuff. After several months, it all died down. (If it had been exposed for more than six hours, presumably it would have taken longer to die down.)

Other treatments (I give credit to Valcyte, continued detox with cholestyramine and neural therapy) helped me to decrease reactivity to toxic mold even further.

I'm now at the point where moderate amounts of "regular bad mold" (like the Stachy mix I had in my own house) don't have much of an effect on me. This "super mold" (or what I sometimes call "Tahoe mold") does still have an effect when I come into contact with it (I now can recognize it very fast!), but I can tolerate very small amounts without as much harm.

Only after my own experience did Erik share his own experiences with and observations of this particularly bad mold. Others have reported their own experiences. They are consistent with mine in all respects.

One other thing that Erik told me is that he repeatedly has seen people unexpectedly drop dead of heart attacks when exposed to large amounts of this mold. The heart attacks are always blamed on something else. The fact that his own heart goes wild with palpitations at such moments makes him think that this is not just a coincidence.

This "super mold" is not (at least not yet) distributed evenly in the U.S. For instance, there is quite a large amount of it outside in the Tahoe/Truckee area (and to a lesser extent in Reno), but only in scattered places. Main sources include trees that have been treated with fire retardants, sewers and sewer ponds, and a compost farm. Those of us who are able to immediately identify it have found it outdoors in significant amounts in

certain parts of Texas (e.g. Dallas), especially at certain times; in Telluride, Co.; and throughout the Bay Area. (Unfortunately, I don't have any reliable reports yet from most other countries or the eastern half of the U.S.)

Erik encountered it in small amounts in Truckee High School (where he was a student) in the early 1970s, and then in Germany in 1976. He found it in the Bay Area in 1980, and then outdoors in Incline Village immediately prior to the epidemic there in 1984.

It's also present in scattered buildings. This tends to be especially the case in places where it's growing outside (presumably because the spores that the colonies let loose settle on building materials and then spring to life when they get some water), but in other places too.

We believe that it's a particular strain of Stachy, one that is capable of growing in places that have been treated with chemicals and perhaps that uses the chemicals as "food" to create particularly strong toxins.

Just about everything about CFS makes sense to me now. (I'm not saying that I'm right about everything.....just that it fits into a coherent theory.)

I believe that this mold is so damaging that it has the possibility of killing people who are susceptible to it. It thus would be a functional response of the system to do everything that it thinks it has to in order to protect itself from this mold, short of having the protective measures result in death themselves.

A question is why it would be that certain people are so affected by this mold while others are not affected (or affected only to a relatively lower extent even by large quantities). Here are a few possibilities.

1. Dr. Shoemaker is right and the genes that he believes to be "mold susceptible" or "multi susceptible" prevent us from processing and eliminating this super mold from our systems in an efficient and effective way.
2. Insofar as their "toxic tank" is already full, people may be less able to tolerate this mold.

This is not inconsistent with how Dr. Bill Rea and others have described sensitivities to other toxins working. For instance, people who have had a huge exposure to pesticides tend to have big reactions to new exposures of even tiny amounts.

Those who have spent a lot of time exposed to "regular bad molds" in sick buildings conceivably may be especially susceptible to this particularly bad mold. But those with other toxic exposures (e.g. mercury, pesticides) that they have not been able to

effectively eliminate from their systems also may be affected more strongly than the average person.

3. Whatever the pathogen is that "defines" CFS and caused the Tahoe Flu may cause people to be more affected by this mold.

This is consistent with what Erik observed during the epidemic in Incline Village. He reports that he and others showed symptoms to exposures to the "super mold" (even though the other people always blamed it on something else) even before the "flu" went through. After the flu, exposures to it went from having a minor effect in relatively large quantities to a horrific effect in even tiny quantities.

Why it would be that this "funny little flu bug" would cause people to be more susceptible to this mold, I don't know. It seems to me that we're missing a "shield" that's supposed to protect us from it. My initial layman's guess, based on my own experiences with it, is that perhaps it destroys our ability to make a particular enzyme that breaks it down before it gets into the system. It also could be affecting the system's ability to detoxify it, though the effects of it happen so fast (through a few breaths, probably hitting the vanilloid receptors and going right to the brain rather than acting through the bloodstream) that the "protective" mechanism of an enzyme or first level immune system barrier (e.g. macrophages) to keep it out seems more likely to be me to be the problem.

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There's a particular type of outdoor toxin -- apparently a biotoxin -- that is present in certain places.

It produces a specific group of symptoms. These can include:

- * Heart pain (in particular, a feeling of a needle through the heart).
- * Heart palpitations.
- * Chest pressure (a feeling of a dagger through the chest or a marble - sometimes actually swollen - at the sternum).
- * Excruciating headaches (migraine-like but not one-sided).
- * Extreme photophobia (light sensitivity).
- * Extreme noise sensitivity.
- * Cognitive problems that go beyond brain fog (e.g. inability to add numbers or recognize words)

- * Weird memory losses (like the inability to remember the name of one's hometown or to find the way home)
- * Seizures or "white-outs" (where the brain goes 100% blank for extended periods of time, sometimes even when a concerted effort is being made to bring up thoughts)
- * Severe trembling.
- * Organ pain (particularly kidney pain).
- * Strong suicidal feelings.
- * Convulsions.
- * Extreme MCS.
- * Marked gait problems.
- * Inability to sit or stand up.
- * Extremely deep skin "dents."
- * Feeling of skin being burned.
- * Sore throats that make eating difficult or impossible.

If you read the descriptions of the Incline Village illness in "Osler's Web," those are the symptoms you're looking for.

In addition to these specific acute symptoms, even short exposures to this poison seems to cause longer-term effects (including extremely severe immune dysfunction).

These are in addition to the more run-of-the-mill CFS symptoms that (for instance) I suffered when in my moldy house in Chicago. Note that people can be close to death in a moldy house, but not get those symptoms above. They're specific to the outdoor biotoxin.

This stuff is present to a scattered extent in various places, but it's particularly problematic in a few of them.

These include the San Francisco Bay Area (though apparently not so much SF itself) and certain other parts of California; the Lake Tahoe area; Dallas; Ann Arbor, MI; and Telluride/Ridgway, CO.

Very occasionally, it is present inside buildings as well.

Insofar as people are exposed to more than a touch of this outdoor contaminant on even an occasional basis, they will have a very difficult time making progress. I am not able to visit these places even briefly, even though I have recovered to the point of being able to live in Chicago and go into the vast majority of buildings without substantial consequence.

If people are having the sorts of symptoms listed above, a move to a totally different location (e.g. another city or state) might be required to make progress.

Insofar as people can find a reasonably mold-free residence (by normal standards), put aside their contaminated belongings and not live in a place with this particularly bad

outdoor contaminant, they should start to be able to benefit from the other treatments that they are pursuing.

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It is my strong belief that the reason that many people are so ill with ME/CFS is because they are living in an area with problematic outdoor air, related specifically to a certain sort of biotoxin.

This biotoxin, some of us (including Erik) believe, is responsible for the Lake Tahoe epidemic in the mid 1980s, in terms of the weird severe symptoms reported in Osler's Web. It is present in quantity in certain specific places, some of us have found.

Erik has been trying to get people to look into the role of this biotoxin in ME/CFS for the past 30 years (before the epidemic, when he was observing just some scattered cases of the disease -- associated with places where this biotoxin was especially concentrated). It currently is being investigated by the World Health Organization, so perhaps we will finally find out what it is.

However, I currently cannot give you details on what it is. I personally believe that it is a particularly problematic kind of cyanobacteria that grows in certain sewers and certain other places (such as wooded areas that have been treated with fire retardants), but it could be some other form of biotoxin such as a mold.

Regardless of what it is, this substance exerts a tremendous effect on people who have ME/CFS. Like mold, it does not cause us to get sick, I believe. What I do believe is that it causes people who already have this disease to be outrageously, horrendously, life-destroyingly sick.

Unfortunately, many people with CFS suffer from heavy exposures to this substance. Other people are affected by lighter exposures. This is all regardless of whether they are living in a good or even pristine building in terms of mold.

Like indoor mold, this substance is "sticky" enough that contaminated belongings can keep ME/CFS sufferers from making substantial progress toward wellness, I believe. Because its acute effects manifest in symptoms that people feel are "from within" (such as "sensory storms" and suicidal impulses), with chronic effects that are subtle (apparently, we believe, on the heart and immune system), people usually do not believe they are being affected by any toxin even when they are in a place that has horrific amounts. And they certainly don't understand, when they move to another place,

that the small amounts on their belongings from (say) living in a bad place for a month could be having a major effect.

I believe that people can make major progress from this disease "merely" by moving from a bad building to a decent one. This especially is the case if they don't bring along any contaminated possessions. However, even that may not be absolutely necessary in terms of making some improvements. I recently heard from someone who moved from a very moldy home to a better one, discarded some belongings and washed the rest, and experienced a "20% improvement" within four months. This person had had first-rate care from a well-known ME/CFS physician prior to that, but nonetheless got improvements "just" from moving and reducing exposure substantially from belongings, and plans to look at ways to further reduce exposure in the future.

I see no reason why other people cannot follow this path. Certainly, it is impressive that Erik has managed to take charge of his health so much just through committed biotoxin avoidance (including, most especially, absolutely scrupulous avoidance of this outdoor substance). However, this clearly is an unrealistic path for others to follow. It is way too hard for most people, and too life-limiting. And, the previous story suggests to me, people can make substantial improvements (as great or greater than those touted by even the best ME/CFS doctors) just by living in a good building without a lot of contaminated stuff.

Making sure that a building is good is a little tricky, for people who are not yet unmasked from mold. Nonetheless, especially for people who have an instinctive understanding of how various treatments can affect their health, it can be done. Some people manage to get a good feeling for which buildings are good vs. bad, just by experimenting with being in different buildings and watching how their symptoms change, and report substantial health improvements as a result.

Perfection, I believe, is not necessary. Pushing in the right direction can be worthwhile.

The problem here is that if people move into a place with substantial amounts of this particularly problematic substance, they will not get well. Rather, they may experience the most severe of ME/CFS symptoms.

A few people I know appear to have done just that. It is my belief (though I cannot check since I will not go to places that I believe are this bad for fear that I will wholly and possibly permanently jeopardize my own recovery) that although these individuals have been scrupulous about leaving their moldy homes, discarding their mold-contaminated belongings, and choosing a new place that is okay in terms of mold, they have moved into an area that is just as bad or worse than the place that they just left in terms of the outdoor substance that terrifies me most.

I cannot be responsible for this happening. I myself lived in a moldy home, and I was extremely sick as a result. But it was nothing -- nothing! -- compared to the symptoms that I got after a six-hour run-in with this outdoor biotoxin in Lake Tahoe. It was the

difference between having my system shut down to the point of being close to death.....and being in the worst hell I could possibly imagine.

And having people go through the stress of a move, and lose all their belongings, prior to having this happen is the icing on the cake.

I continue to feel guilty about those cases. Part of it is because of the effect it has had on them. In addition, their stories suggest that "I moved and got rid of my stuff, and it didn't help, so mold is not an issue in ME/CFS for all patients." This makes people doubt the phenomenon when -- in my belief -- it actually is something of relevance for all patients rather than just an idiosyncratic irritant that affects some people rather than all of us.

Characteristics of Toxic Mold

Dormant *Stachybotrys* spores are released from the colony into the air. Most of these immediately sink the ground, where they almost immediately fragment and turn into poison "dust." This dust is just as poisonous as the intact spores. Recent research makes it clear the the spores or spore fragments do not have to be inhaled in order to cause damage; the poison gases released from the spores is sufficient. (Erik has been saying this for more than a decade, based on his own experiments with the molds, btw.)

Conceivably, an intact spore could land in the body and turn into live mold. It is extremely rare to have *Stachybotrys* growing in the body, however. *Aspergillus* infections occur much more frequently, but these are mostly in people whose immune systems are already problematic.

(The idea that molds like *Stachybotrys* damage the immune system, allowing molds like *Aspergillus* to colonize, in Sick Building Syndrome environments is one that is worthy of scientific testing, in my view.)

Stachybotrys produces a wide variety of mycotoxins, all of which have different effects. Here's an article:

"Mycotoxins and Other Biologically Active Metabolites," from Eckhardt Johanning and Chin Yang's book on bioaerosols.

>The mycotoxins and other biologically active compounds produced by *S. chartarum* are of concern to human health (23,32,33,57). Mycotoxin poisoning by this fungus is referred to as stachybotryotoxicosis.

>*S. chartarum* produces a variety of macrocyclic trichothecenes and related trichoverroids: roridin E and L-2; satratoxins F, G, and H; isosatratoxins F, G, and H; verrucarins B and J; and the trichoverroids, trichoverrols A and B and trichoverrins A and B. The satratoxins are generally produced in greater amounts than the other trichothecenes, but all compounds are produced in low quantities. They apparently occur in all parts of the fungus (53). The difficulty in obtaining, identifying, and purifying these toxins has slowed extensive studies on their biological activity. Hinkley and Jarvis (23) recently published analytical methods for the identification and quantification of bioactive compounds produced by this fungus. These methods were designed to quantitate individual compounds in culture extracts and detect low levels of trichothecenes in samples.

>Macrocyclic trichothecenes are highly toxic compounds with a potent ability to inhibit protein synthesis (32). Numerous studies have demonstrated the toxicity of toxins from *S. chartarum* on animals and animal and human cells (42,45,49,51). Yang et al. (62) reported that satratoxin G was the most cytotoxic of eight trichothecenes tested on mammalian cells, even more toxic than the well known T-2 toxin associated with alimentary toxic aleukia. Other researchers have also reported the high toxicity of satratoxins compared to other trichothecenes (18). The LD50 in mice for satratoxins is ~1 mg/kg (32).

>In addition, the fungus produces nine phenylspirodrimanes (spirolactones and spirolactams) and cyclosporin, which are potent immunosuppressive agents (33). Jarvis et al. (33) suggested that the combination of trichothecenes and these immunosuppressive agents may be responsible for the observed high toxicity of this fungus. New biologically active compounds are still being discovered in cultures of *S. chartarum*. Hinkley et al. (24,25) recently described the metabolites atranones A-G and two dolabellane diterpenes, but the complete biological activity of these compounds is unknown. Vesper and colleagues (57,59,60) reported some isolates produce Stachylysin, a hemolysin (compounds that lyse erythrocytes), and a hydroxamate siderophore. They suggest these compounds could be pathogenicity factors involved in pulmonary hemorrhage in infants exposed to *S. chartarum*.

>There is considerable variation among isolates of *S. chartarum* in the production of mycotoxins and other metabolites (2,24,27,34,40). Indeed, Hinkley et al. (25) suggest there are two chemotypes of the fungus: the atranone and the macrocyclic trichothecene producers.

<http://www.apsnet.org/online/feature/Stachybotrys/>

Locations and Weather Effects

Of all the questions that I get, the ones from CFSers living in Texas, Louisiana, the San Francisco Bay Area and England are the most frustrating to me.

CFSers living in these places are frequently very sick. Often they express some agreement that mold probably is an issue for them and willingness to try mold avoidance. But I've yet to see anyone living in any of these places make much improvement as a result of addressing mold.

Based on my own experiences, I can see why. I wouldn't be able to live in any of these places without getting really sick myself, even though I'm a lot less reactive than I used to be and have become really good at using Erik's "extreme avoidance tricks" to stay well in most other places.

The problem is that it's not just the insides of buildings that are bad. The outside air in these places is really bad too, meaning that every building is a bad building.

I was impressed that one person from the UK did make some progress through mold avoidance. But this has been accomplished only insofar as he stays inside his home with air purifiers running. If he steps outside, he gets sick again.

It's scary, that entire states or countries can have air that's worse than a lot of bad buildings. That's what I and others who are sensitive to mold are seeing though.

People in these "sick regions" or "sick countries" often move from residence to residence, spend time outside in tents, even get rid of all their stuff....to no avail, because everywhere is bad.

Though sometimes they do feel better when they follow Dr. Myhill's advice to test for mold by going "on holiday" elsewhere, that doesn't always reveal the problem. If they stay in a bad building, or happen upon a patch of bad air, or bring their contaminated stuff with them, it may negate the whole experiment.

And even if it goes well and they get clear, they still may not feel better right away. Sometimes (especially for really sick people) the first thing the body does when it gets to a good place is play "catch up": dump toxins, kill bugs, do repair work. If that's what's going on, people may feel even more tired (though maybe in a less agitated way) than they did when they were back home.

And then even if people feel better when they're on vacation, that's not going to help them much if they go back to a place where all the outside air is bad. Erik's "trip to the desert" is supposed to get people sensitive enough to know when a building (or in some cases, section of a city) is bad, so that a hasty retreat can be made. But if everywhere is bad, people are back to Square One when they get back home.

The topic of mold as it relates to CFS is so complex. I finally decided to compile a bunch of Erik's writings into a "book" so I wouldn't have to keep explaining it to people (a full-time job). People have told me that the compilation finally has made the topic understandable to them, so at least that's a first step.

I think that Dr. Shoemaker's research is pretty convincing that there is a huge CFS/mold connection and that maybe everyone with CFS is a mold reactor. (This does not mean that mold is the cause of CFS, of course. Just that mold exposure makes many or all of us ill.) I'm looking forward to seeing more studies from other researchers on this topic.

So when people who live in a place that I know would make me personally deathly ill tell me that they don't think that mold avoidance is the answer for them, I don't know what to say.

Maybe they're not mold reactors. But then again, maybe they are.

I'm happy to give people the information that I have on this topic. Erik's writings (in compiled form) are remarkably instructive, and I'm putting together some additional materials.

Especially for people in bad places though, they're not a magic solution. They may not help at all, if they can't move to a different region or country.

That's why this needs more attention.

Neither Erik nor I are medical doctors, much less wizards. (My own Ph.D. is in psychology/marketing.) It's nice to help people, but our goal really is for CFS researchers and doctors to start attending to this phenomenon so that better treatments of whatever sort can be developed.

Because if mold really is as important to us as I think it is, we're never going to get anywhere if the leaders in this field don't take it into consideration when attempting to help us.

*

Many of us "Moldies" find that we do much worse in winter than in warmer months.



Paradigm Change

Damp musty environments don't necessarily have substantial amounts of toxic mold in them. We're only concerned with the poisonous species of mold, and perhaps in particular *Stachybotrys*.

My own observations makes me think that if a building doesn't have drywall in it, the likelihood that it will be at least vaguely tolerable for me even if it smells musty is pretty good. This is consistent with the idea that *Stachy* is finicky in its growing conditions, generally needing a lot of water and some easily digestible cellulose. The use of "paper" to cover up plumbing pipes was a disaster waiting to happen, from that perspective.

Buildings without any drywall (in original construction or renovations) are increasingly uncommon in the U.S. Maybe they're more common in England?

In any case, as discussed above, the outside air in England seems to be an issue. The story of people feeling great when they go to places like Greece or the Caribbean and then relapsing when they return to England is absolutely classic.

Not everywhere with damp air is bad, btw. I felt great in Carmel, California, which is right on the ocean. I would suspect that there are certain places in England that are on the sea that might feel okay too (as a result of the fresh breezes and/or negative ions), but I have no concept of where they might be.

Oddly, the only place I felt good in England when I spent a summer there many years ago was in Stratford-upon-Avon. Things may have changed since then though. It may have been that it was more in the countryside. Also, this was an old cob inn from the 1500s, and it may not have had any drywall renovations in it. Anyway, there may be scattered okay places in England, but good luck finding them if you're not already unmasked enough to identify this stuff when you come across it.

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Fusarium makes T-2, a trichothecene that has been documented extensively in the literature to be deadly. It may not be quite as bad as the satratoxin made by some strains of *Stachy*, but it has a lot more studies behind it.

Most of the T-2 studies have been done on ingested toxins. However, some recent studies suggest that inhaled mycotoxins are much more damaging than ingested ones. (Apparently this is partly because inhaled toxins can go right up the olfactory nerve into the brain, skipping the blood-brain barrier entirely.) Insofar as there are high outdoor *Fusarium* air counts, this would suggest that just breathing the outdoor air could make a big difference in how mold responders feel.

I've been back in the Midwest for the past two months. What I've found is that the rural areas of Indiana, Illinois, Ohio, Michigan and Missouri all have felt just awful to me. The cities (with the exception of Ann Arbor) have been substantially better.

On the other hand, the entire state of Kansas was the best place I've been on any of my travels. With the exception of a very few scattered bad pockets, it was absolutely wonderful.

The question is: Why would that be? What is it that's different about Kansas than from all these other farming states?

One thing that I found out in my readings is that Fusarium grows much better when it's in the presence of the herbicide Roundup. And now that genetically modified Roundup Ready Corn and Roundup Ready Soybeans are available, Roundup is sprayed in large quantities on a high percentage of fields in corn/soybean states.

Kansas has a few cornfields, but its primary crop is wheat. And it seems that we "Moldies" have a kindred spirit in wheat. When wheat gets hit with even a bit of Fusarium, it suffers from "Fusarium head blight" and dies. So thus, to my understanding, the farmers in Kansas avoid using Roundup at all, in order to keep the Fusarium from harming their wheat crops.

Of course, agricultural companies have tried all kinds of things to kill off the Fusarium. This seems to work to some extent, but also causes the Fusarium that's there to release even more toxins as a defense mechanism. Too many toxins to be tolerated by the wheat anyway.

This past weekend, I went out to a town called Galena, on the Illinois/Iowa border. Absolutely nothing there but cornfields and a few golf courses.

I've gotten to the point where few buildings (even ones that are overtly moldy!) bother me very much, but the outside air over the weekend (when it was cloudy and muggy) was another story. I kept thinking that I didn't understand why I could be so bothered and everybody else be okay.

But when I looked around, it seemed like all the local people were in very poor health and feeling quite miserable. This contrasted greatly with other places I've been over the past two years (e.g. Arizona, Utah, Colorado, New Mexico, Nevada, Wyoming), where people seemed much healthier regardless of their financial status, exercise habits or customary diet.

Then I had a 25-year-old guy, in apparently good health, complain spontaneously to me about how bad he had been feeling over the weekend. "It's awful," he said. "You can barely stand to be outside."



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Another guy, the same age, said that he felt fine. So I don't think it's everybody. Maybe Shoemaker's right and it's 25% of people.

But it's not just the few of us who have CFS, I don't think.

I'm not absolutely certain that the problem in Galena and the rest of the Midwest is with Fusarium. It could be another toxic mold, or maybe a toxic cyanobacteria. I feel pretty crappy when I drive or walk by ponds or rivers covered with that bright green crap, for sure.

It would be interesting to do some outside air tests in the places that I feel really bad and see how they come up though.

But it's not just this particular town where people seemed in poor health. It's the agricultural areas in the whole Midwest, in all the states I mentioned.

It's even more apparent to me in the Indiana town (Greenfield, 30 miles outside of Indianapolis) where I grew up than in Galena. People there have far more money than in most of the western towns where I've spent the past two years. They're educated, they have what I would consider to be a good take on life, and they care about their health. A lot of them live in the country and then commute to good jobs in Indianapolis.

On the surface, it seems like these folks couldn't possibly care about their health, because they're overweight and don't exercise much. I think this is reversing cause and effect though.

Keep in mind our "guiding force" knowledge that CFSers can't exercise.....unless they're in a low-mold environment. That's how Erik got to the top of Mt Whitney all those times: by subtracting out the mold.

What I now believe is that actually, nobody is capable of exercising safely when in the presence of more biotoxins than their bodies can handle. For CFSers, the amount that we can handle is less than what sticks to our clothing after being run through the dryer in most laundromats. But people who aren't (yet) as sick as we are have their limits too.

Some people who aren't biotoxin responders can exercise almost anywhere. But if people feel bad when they try to exercise (say, in a place with a high Fusarium count), they're going to be less inclined to do it.....even if their doctor says it's a good idea and they objectively want to do it.

Ritchie Shoemaker talks in his books (e.g. Mold Warriors, Ch. 4) about the physiological changes that cause people with biotoxin illness to gain weight. In addition to the ones he describes, I think it may be that since sequestering toxins in fats is "safer" than sequestering them in organs, our bodies may bulk up with some extra fat as a functional defense mechanism when our "toxic tanks" start to get full.

I spent those two days in Galena with a rip-roaring headache, huddled inside with a HEPA filter going full-blast. (This was an inadequate emergency measure, not a solution! Filtration is no substitute for avoidance.) I drank seven cans of Coke over a 24-hour period, since the caffeine and sugar helped some.

Even if I didn't fall into CFS again, merely doing those remediation measures would make me fat and out-of-shape in no time whatsoever. Out in Colorado, I spent at least a few hours every day exercising and never had any desire whatsoever for soft drinks or desserts. My personality didn't change (I would have loved to have been back in Colorado climbing mountains that weekend), but my environment exerted an effect.

It's not just Galena that makes me feel this bad, in this exact same way. All the rural areas of those states are just as bad. Some days are much worse than others, and some even feel fine. But I think over time, it would just add up.

Dr. Guyer, who practices in Indianapolis, suggested to me 2 1/2 years ago that instead of taking off for the Godforsaken wilderness, I create a "clean room" for sleeping using a bunch of air filters and negative ion generators. And of course, if I'd stayed in the Midwest, I could have kept getting IV's and hyperbaric treatments at his clinic. Undoubtedly those things would have been better than staying in Indiana and doing nothing. I'd never have gotten well that way though.

(He told me yesterday that he'd never seen anyone like me - "the sickest of the sick" - get anywhere close to full wellness using any strategy, so it seems he's in agreement with me. And as CFS doctors go, he's absolutely tops. So if he's not getting folks at my level of illness well, I'm not surprised that nobody else is either.)

All in all, the past 2 1/2 years have been a real eye-opener for me.

I started off thinking that I and at least a few other CFSers were weirdly affected by mold, which was not at all an issue for other people.

Now I think that mold is a big issue for a high percentage of people, and that CFSers are just farther along on terms of just how terrible of an issue it is.

I would rather it just be us. But unfortunately, I don't think it is.

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Paradigm Change

Many people with ME/CFS comment that they feel much worse in late fall and winter than in summer. Severe crashes often take place. Doctors and patients all express puzzlement about why that should be, since it often occurs even for patients who live in warm sunny places.

Some patients notice that they feel particularly bad on days when the barometer is dropping fast (e.g. when lots of clouds cover the sky). This sometimes is the case in summer too, but more often in winter. Again, the reasons for given for this are unconvincing. Barometric pressure changes from weather are small compared to changes in altitude, but altitude changes rarely prompt a severe crash in ME/CFS sufferers. When symptoms from altitude changes do occur, they're usually much different than symptoms that happen with the weather.

In some cases, people attribute weather changes to something else (e.g. stress or a pathogen problem). Only when people try to look back at their illness over time does the weather effect become clear.

It's our observation that barometric pressure drops -- especially during winter -- lead to a particular type of outdoor biotoxin getting much worse. Although this biotoxin is present in some places year round, it almost always is worse in the winter.

For whatever reason, the presence of this biotoxin seems to be centered around the winter solstice. It generally starts the first week of November (it was a week or two early in many places this year) and generally eases up toward the beginning of February.

If we get to a "good" place (one that is generally clear), the weather/season effect in terms of the presence of this biotoxin in the outside air goes away. Winters feel the same as summers. Approaching storms feel like they did when i was a child -- refreshing rather than catastrophic.

The worse the symptoms get in winter, the more improvements should be expected if people move to a good place.

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I agree that microclimates are important.

For years, Erik was able to live mostly in Truckee by staying out of the bad areas. Truckee's gotten bad enough in the past year or two that he no longer can even drive through it without experiencing bad effects, but the same principle still applies in other places.

Probably there even are parts of England that are okay. Rumor has it that Sarah Myhill tells some of her patients that they need to move to either the coast or to another country like Spain if they want to get better, but perhaps there are microclimates there that she hasn't found.

The U.S. is a very big place, and fortunately not all of it is bad.

Anecdotal Cases

I went through the Canadian criteria for CFS to give folks an idea of what symptoms had improved for Erik and for me as a result of mold avoidance.

I've also gotten a bunch of questions about Erik: was he really sick with "real CFS" (yes, severely), is he really recovered (yes, except he has to make a ridiculous effort to avoid mold), does he live in the Godforsaken desert by himself (no, he lives in Reno, "The Biggest Little City in the World"), is he working (yes, full-time), what else has he done to get well (absolutely nothing, "avoidance alone"), how long was my visit to see him (a week), what is he like in person (MUCH nicer than he comes across on these boards), why haven't doctors told people about the fact that he got well through avoidance (I don't know).

So here's the info about the Canadian criteria symptoms, along with Erik's description of what it was like when he first got sick in the Incline Village epidemic in 1985.

Canadian Criteria

1-3. Fatigue, PEM, Sleep Dysfunction.

Erik and I had all of these, each with very severe symptoms (mostly in bed, rarely going out) for 1+ years.

4. Pain.

Erik and I both had muscle pain. Mine has been specific to trigger points, though not (usually) as severe as what FM sufferers experience. He had horrific headaches regularly. I almost never had headaches of any sort, except for a once or twice a year when I'd have horrific ones (unlike any I had pre-illness).

5. Neurological/Cognitive: confusion, impairment of concentration and short-term memory consolidation, disorientation, difficulty with information processing, categorizing and word retrieval, and perceptual and sensory disturbances -- e.g. spatial instability and disorientation and inability to focus vision. Ataxia, muscle weakness and



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fasciculations are common. There may be overload phenomena: cognitive, sensory - e.g. photophobia and hypersensitivity to noise - and/or emotional overload, which may lead to “crash” periods and/or anxiety.

I didn't have the ataxia or muscle weakness, at least not to an extent that was noticeable to me. My coordination in general was poor though. I had significant confusion, disorientation, spatial instability/disorientation/inability to focus vision when I took a small dose of doxy late in my illness, but not other than that. I had all the other symptoms.

Erik had all these symptoms.

6a. Orthostatic intolerance - neurally mediated hypotension (NMH), postural orthostatic tachycardia syndrome (POTS), delayed postural hypotension; light-headedness; extreme pallor; nausea and irritable bowel syndrome; urinary frequency and bladder dysfunction; palpitations with or without cardiac arrhythmias; exertional dyspepsia.

My bp was low (e.g. 85/55). It and the resulting lightheadedness was helped by Florinef. I didn't have the nausea or IBS (I was constipated unless I took 10+ g of vitamin C per day) or bladder dysfunction. My skin was pale, but I don't know about the “extreme” characterization. I had extreme thirst and somewhat frequent urination. My digestion was problematic (tested hypochloridia, many abnormalities on stool tests), but I don't know if it was specifically “exertional.” I didn't notice heart symptoms, but never had any tests to rule cardiac issues out.

Erik had all these symptoms except the bladder dysfunction.

6b. Loss of thermostatic stability - subnormal body temperature and marked diurnal fluctuation, sweating episodes, recurrent feelings of feverishness and cold extremities, intolerance of extremes of heat and cold, marked weight change - anorexia or abnormal appetite, loss of adaptability and worsening of symptoms with stress.

T3 mostly resolved my chronic subnormal body temperature, but for a time late in my illness my temperature swung a few times a day between 98 and 100 degrees. My weight varied - I usually was overweight (compared to pre-illness), but I felt unable to eat anything and spontaneously lost 50 pounds (so that I was significantly underweight) over the course of one year. I had the other symptoms.

Erik had all these symptoms.

6c. Tender lymph nodes, recurrent sore throat, recurrent flu-like symptoms, general malaise, new sensitivities to food, medications and/or chemicals.

I periodically had a sore throat that I described as “feeling like I’m getting the flu,” but then it would go away. It wasn’t severe though. “Recurrent flu-like symptoms” were in the area of malaise/cytokines (not vomiting). I had the others.

Erik had all these symptoms.

7. The illness persists for at least six months. It usually has distinct onset, though it may be gradual.

I had some of these symptoms starting in 1994. In early 1996, I got a bad “flu” and developed most of them (plus the usual CFS lab tests) in moderate severity. In early 2007, I got a very bad cold and had much more severe symptoms for the rest of the year (until starting mold avoidance in December).

Erik had some symptoms periodically for a few years, and consulted Dr. Cheney about them in fall 1984. In summer 1985, he got the “Yuppie Flu” that was followed by very severe illness. He partially recovered (he says as a result of moderate mold avoidance) from 1986-1994, relapsed to severe illness, then started “extreme” mold avoidance in 1998 and recovered.

All of these symptoms, except some of the cognitive ones and a few associated with detox (below), has resolved completely for both Erik and me insofar as we pursue toxic mold avoidance scrupulously.

All the symptoms start to come back with re-exposures to mold, and then dissipate quickly when mold avoidance is resumed.

Most of these symptoms improved substantially for each of us within 6-12 months after starting avoidance. The rest resolved in less than two years after starting avoidance.

Except for one time when I made the mistake of visiting Lake Tahoe/Truckee without Erik's guidance (the mold situation there is really bad), my progress has been a straight line up with no relapses.

Except for a short period when he decided to try living with a girlfriend in a house that he already knew was too much for him, Erik's been well with no relapses since 1998.

Even with scrupulous mold avoidance, concentration, short-term memory consolidation, and difficulty with information processing/categorizing have not fully resolved. Erik says that he is unable to do any math at all (he passed the pilot's exam prior to getting sick and so used to be proficient), and my own math abilities have not fully recovered either.



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My remaining cognitive issues (especially with information organization and integration) have improved with Valcyte. Some days, it feels like I'm almost at pre-illness. Others, not so much.

A few other symptoms (sweating episodes, trigger point pain, downturn in energy, grogginess, alcohol intolerance, nausea) can resume when detoxification is aggressively pursued.

A number of other people who met the Canadian criteria have partially or fully recovered as a result of extreme mold avoidance (using Erik's techniques) as well. Their experiences with the symptoms recurring with renewed exposures and (in most cases) the cognitive area remaining a weak point are the same.

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The following is a teaser for an upcoming documentary on CFS, called "What About ME?"

<http://www.whataboutme.biz/>

In the video (U.S. version), Erik Johnson talks at length about how the "Tahoe Flu" (or "Yuppie Flu") moved through the Lake Tahoe area in 1984-1986, causing a substantial number of people to get severely and permanently ill with the "Mystery illness" (later named CFS).

A few people have expressed puzzlement to me about this. It seems that Erik's spent so much time trying to draw attention to the role of mold in this disease that his also having been affected by the "flu" (and whatever pathogen caused it) has been overlooked.

The fact that a pathogen apparently caused/triggered the illness does not mean that other factors were not involved.

Exactly how various toxins (including the mold) and pathogens (such as XMRV, Lyme, HHV6a, etc.) interact with one another in this disease is one of the most interesting questions related to the CFS phenomenon. An answer will bring us much closer to understanding the disease as a whole.

Environmental Testing & Remediation

Here is my own perspective on mold testing. However, please note that this is not scientifically proven to be the optimal approach and also is not what professionals in the remediation industry will tell you to do.

There are several challenges with regard to finding out if a home has a mold problem. This is why most CFSers who are affected by mold don't know it. And insofar as people don't know if mold is an issue for them, it has the potential of undermining any other treatments (including use of antiviral drugs) that they may choose to pursue.

Mold professionals usually recommend air tests. These take photos of the air in the home. Someone then looks at the pictures to see how many of various mold spores are present.

One problem with this is that *Stachybotrys* (which is generally considered a particularly dangerous mold and the one that I think is especially relevant to CFSers) almost never shows up on air tests. It releases a heavy, sticky spore that falls to the ground within at most an hour or two. At that point, the majority of the spores immediately disintegrate into "spore fragments" that look like dust. These fragments (which are just as poisonous as the whole spores) are blown around or are carried around the environment.

In addition, *Stachy* releases its spores in waves. Some observers have found homes showing no *Stachy* problems on air tests for 23 hours per day, but horrific problems during the remaining hour.

Air tests attempt to "control" for the issue of whether a house is moldy by doing a comparison with the outdoor air. Unfortunately, some of us with CFS have found that it doesn't matter if it's the outside air vs. the inside air that's giving us mold exposure. It still makes us sick.

Air tests are expensive. Professionals usually want to test multiple rooms in the house as well as the outside air. The total can run to \$1000 or more.

The ERMI is another test that can be used. It looks at household dust to create an estimation of how likely the home is to have a mold problem compared to other homes. The results are given in quartiles, with the top 25% said to have "the greatest likelihood of having a mold problem."

I have not used the ERMI, and I'm not certain how *Stachy* is weighted compared to other molds. The cost is a bit over \$300.

This is a DNA test, and so does take into consideration mold that has fallen from the air and spore fragments. I suspect that it's fine with regard to identifying buildings that are so bad that they are making ordinary people sick.



Paradigm Change

However, knowing that a home has "passed" the ERMI doesn't mean that CFSers are not being affected by mold. Being in the top 25% of homes is not generally "good enough" for really reactive people to make a lot of progress. Those of us who have partially or fully recovered from CFS just as a result of attending to mold have needed to be looking at mold in the outside air and on our possessions (and on our own hair) in order to maintain that wellness. These sources of exposure will not be measured in an ERMI test.

It's my own belief that getting the ERMI test done is useful as a basic evaluative step for CFSers though. Moving to a home that passes the ERMI won't necessarily improve wellness in itself, but it's my suspicion that living in a home that's very moldy will prevent other treatments from working as well as they could. This hypothesis wouldn't be very hard to test, so hopefully this can be done in conjunction with other CFS treatment studies soon.

Another test looks at a particular obvious mold and gets an identification of it. This type of test is readily available. However, regardless of what comes up on the test, it shouldn't be considered to be useful in providing information on whether an environment is problematic. Stachy grows almost wholly within walls, and most moldy homes have more than one type of mold growing. If Stachy actually can be seen (in many cases, it looks more like smears of dirt than mold), that's a suggestion that the problem is really horrific.

There's a company called MouldWorks that does a nice job of giving a description of what samples of mold include. Regardless of what they say, their analysis shouldn't be thought to be very helpful in CFSers' decision making.

Those CFSers who have realized that mold is a problem for them have mostly done so as a result of leaving their home for a while and then returning. Dr. Sarah Myhill actually recommends this, suggesting that "you'll have to go on holiday" in order to find out whether mold is an issue for you since "mould allergy" does not show up on conventional allergy testing. (That's because it's a toxicity problem rather than an allergy problem, of course.)

This is an excellent suggestion, but it only works if the "holiday" actually reduces toxic mold exposure. If people bring their contaminated clothing and other belongings with them, they may not get to a low enough level to make much difference. If they stay in a moldy building (most hotels are quite moldy) or happen upon a place with a lot of outdoor mold, this also will negate the experiment. I've heard that Dr. Myhill recommends that people in England try going to another country, like Greece, for the experiment.

In addition, this does not work like a mold allergy. Getting away from the mold for a short period of time does not necessarily create much improved wellness. If people are poisoned by pesticides, getting away from new pesticide exposures wouldn't be expected to provide immediate relief. This is the same principle. It takes time for the system to detoxify previous exposures and to repair itself from downstream problems. And since mold is just one part of the equation, other treatments (such as antivirals) may be needed. This is just a stepping stone.

If a person who's getting a lot of mold exposures does go to a clear environment, they do usually feel a bit different. They may be more able to "exercise," whatever that means for them. They may have less agitated exhaustion, more falling into a deep heavy sleep that promotes detox.

Most importantly, they may find that they feel particularly bad when they return to their usual environment. In some cases, the downturn is so dramatic that they have a difficult time remaining in their homes.

Erik has written a lot more extensive information on this kind of "mold test," which I can supply to people if they want it. Please write and ask.

CFSers who try to do their own remediation often get much more ill as a result of the process. In many cases, they do not recover to their previous baseline. Some patients have died or become bedridden as a result of doing this.

Anything to do with windows makes me especially nervous, because Stachy tends to grow in places where it can get lots of water on a regular basis (which happens when a window has a leak).

I strongly urge people with CFS not to go looking for or repairing mold in their own homes. It could prove to be really harmful or deadly.

Please be safe!!!

*

Mold certainly should be removed. I just want to be sure that CFSers don't do it themselves.

The safe way to do this is to have a mold professional take care of it. They should seal the surrounding area off with plastic so that the spores do not disseminate all over the environment when they are exposed. The professionals should be wearing protective clothing and masks for their own health.

Obviously this costs money.



Paradigm Change

I'm reluctant to suggest to people that they have non-professionals help them to remove the mold. Depending on the extent of the problem, they may risk long-term damage to their own health even from one exposure. In addition, if the area is not sealed off properly, the spores may disseminate into the area and make it more problematic long-term for CFS sufferers.

All of this, like everything else about the topic of toxic mold, sounds ridiculous. But people used to think that asbestos, lead paint and mercury fillings/vaccines were perfectly innocuous too.

I wish I had better answers for people.

*

I wish I had a good book on remediation to offer you. There are a few on the market, but I'm not sure how to evaluate them.

What you might consider doing is going to a Yahoo group called SickBuildings. There are a couple of professional remediators on that board that offer information to people. Usually they will offer some basic suggestions for free, and then provide more extensive consultation for a flat fee by telephone.

A lot of the people on that board are pretty sick with CFS or mold illness, so they're accustomed to discussing the matter in the context of people who may need to take special care with the removal process.

*

Here's the Mold Dogs site.

http://www.mold-dog.com/find_a_dog.htm

*

Stachy makes a heavy sticky spore that quickly falls to the ground and disintegrates into spore fragments. Finding even one spore on an air test is indicative of a major problem, therefore. The spore fragments are just as poisonous as the airborne spores.

I'm not sure how easily Fusarium goes airborne, or if it's a problem when no spores are found in the air.

*

Thieves Oil kills mold colonies, causing a lot of spores to be released all at once.

I strongly urge other people with CFS not to follow this approach. Many CFS sufferers are already living at the edge of their tolerance level with regard to the mold, and so any increase in exposure might well push them over the edge into even more serious long-term disability.

I've seen this happen several times as people have tried various ways (including ways they thought should be "safe") to address mold problems themselves. This has included deaths from heart attacks, strokes, and descent from "moderate" CFS to months of being bedridden.

Because the toxic effects of mold are cumulative (especially for those with the mold susceptible or multi susceptible genotypes), recovery from large exposures back to previous levels of CFS may never occur. Insofar as the mold causes people to acquire new infections or activates latent pathogens, this may affect their long-term health as well.

Since mold problems tend to be really hidden, it's impossible to know how bad they are without digging into walls.

My fear and (frankly) guilt over what very frequently happens when CFSers start trying to address mold problems themselves almost makes me not want to talk about this issue with them at all.

I thus implore (please, please, please) CFSers to acquire professional help to address any mold problems they have. These professionals should address the mold by sealing off the area to be addressed with plastic and then carefully removing it under Hazardous Materials protocols. CFS sufferers should be nowhere near while this process is occurring.

Health Impact Testing

Here is some information about various kinds of tests related to whether individuals are being affected by mold illness.

1. One kind of test panel is the one that Dr. Shoemaker has developed. It includes a number of measurements related to inflammation and immune responses. This includes measurements of various cytokines (such as MMP-9 and TNF), since that kind of inflammation seems to be related to toxic mold illness. It also includes measurements of

various hormones (such as MSH, cortisol, leptin and ACTH), since those are thought to be affected by the presence of the inflammation and other negative effects brought about by toxic mold. Measurements of complement elevations (C3a and C4a) also are included, since those are thought to be related to current acute toxic mold exposures. VEGF, which is a chemical signal directing growth of new blood vessels, is also part of the panel. The HLA-DR genetic testing, which Dr. Shoemaker says that he has observed to be strongly correlated with toxic mold illness, also is included on the panel.

These tests still are unfamiliar to many practitioners, but seem to be gaining acceptance. They are described in detail in Dr. Shoemaker's book "Mold Warriors" and on his website at www.biotoxins.info.

2. Also on his website, Dr. Shoemaker makes available a test that he calls variously the VCS (visual contrast sensitivity) and the BIRS (biotoxin illness risk score). This is an eye test of visual contrast, which he states is a good detector of the presence of neurotoxins of whatever sort (not just biotoxins) in the brain. It can be completed online and serves as an initial screening device.

My own personal experience and observations suggest that this is a useful screening device, but that it doesn't necessarily do a good job in ruling out mold illness in CFS sufferers. When I was living in my moldy house, I indeed did terribly on the VCS. At that point, my vision has declined to the point that everything looked dim and I could barely see anything to read inside. This was scary!

During the couple of months after I moved out of my moldy house, my vision improved to the point where I could pass the VCS. I felt a bit better, but was not even close to being well. It only was after I visited Erik for a week and got really clear (and then started this ridiculous "extreme mold avoidance" thing) that my health really recovered.

Most of the time now, I can pass the VCS. Sometimes, especially after I've had a good bit of mold exposure, I fail it.

Dr. Shoemaker says although people who aren't suffering from biotoxin illnesses (which also can include things like chronic Lyme, dinoflagellates and brown recluse spider bites) shouldn't fail the test, those people who are having problems sometimes can pass it.

The idea that I can pass the test even though I'm being affected by small amounts of mold toxin is consistent with one hypothesis about the role that toxic mold plays in this illness. Certainly, significant amounts of the neurotoxin itself (enough to affect the vision) can be present in CFSers who are suffering from mold illness. However, a

hyperreactivity of the complement component (C3a and C4a) seems to be a more fundamental part of the problem, just as it is in people who suffer from peanut "allergies." This is more related to what the body does to itself when it senses the mold toxin than to the direct effects of the toxin. Why the body is going nuts when it senses tiny bits of this stuff is, in my mind, a key question that we need to answer about the disease.

Interestingly, the C4a responses has been mentioned in other research related to CFS. I'm going to post an abstract related to that topic below.

I certainly think that it's a good idea for CFSers to take the VCS. On its own or in combination with the ERMI, it can provide substantial information on whether people are living or working in really moldy buildings.

That's important to know, so that the problem can be addressed if so. No one should be living in a sick building. That's especially the case for anyone with an illness that affects the immune system, regardless of whether we think that mold might be a "cause" of that illness.

However, passing the VCS should not be taken to provide conclusive evidence that mold toxicity is not a factor in an individual's illness. It is only a first step.

3. Another kind of test is an allergy test panel. Here we are talking about allergic reactions to toxins, not to their poisonous effects. Still, I have heard of people using them for cases of mold toxicity illness, so I will discuss them.

One measure is the IgE tests to different species of mold. These measure allergic reactions, which result in symptoms such as watery eyes, runny nose and asthma.

This is not useful for the purpose of measuring mold toxicity, because this is not an allergy. In my case, even though I appear to be suffering from the negative effects of toxic mold, I do not have any allergic symptoms of mold at all.

A second component of this test is the IgG. This apparently measures the extent to which people have been recently exposed to various species of mold.

As it was explained to me, the rationale for the use of this test is to try to determine the extent to which various molds are present in the person's usual environment. If the IgG to *Stachybotrys* comes up high, it is thought to mean that the person's home (or other area where s/he spends time) has a *Stachybotrys* problem.

This does not mean that the person is being affected by the particular mold, though. Some people appear to be able to get a very large amount of exposure to these molds and not suffer from any apparent ill effects at all.

Having a low IgG does not mean that the person is not being affected either. Again, it is our contention that for some of us, even small amounts of exposure (apparently triggering complement to go ballistic) are enough to keep us sick.

The potential usefulness of the IgG is to serve as an environmental test, since the tests that remediators use (air tests, ERMI, tape lists) are so unreliable. I don't have enough data on the accuracy of the IgG for this purpose to say whether it actually provides good information.

4. Another type of test shows whether various molds, including toxic species such as *Aspergillus*, have colonized the body. In this case, the molds are serving as pathogens (like a bacteria would). Insofar as the molds continue to produce toxins while living in the body, this would be contributing to any toxicity problem present.

It's my impression that this sort of test is reliable. However, the colonization of individuals' systems with these pathogens is only one part of the problem. We also are affected by the toxins that we take in just by breathing them in. One toxicologist (Dr. Jack Thrasher) told me recently that these toxins appear to have the ability to go straight up the olfactory nerve and into the brain, totally bypassing the lungs or bloodstream.

Stachybotrys, which is possibly the most problematic toxic mold for CFS sufferers, very rarely can get any sort of a foothold in the body. *Aspergillus* does so more frequently, especially in people who are already immune compromised. It tends to cause sinus infections and lung problems. These types of problems often are attributed in CFS sufferers to infections with candida, bacteria (such as *Chlamydia pneumoniae*) or mycoplasma. Considering the idea that they might be related to *Aspergillosis* or other mold colonization, especially if mold in the home is suspected, may be warranted.

I actually had a lung problem, with mild-ish pneumonia-like coughing, during the couple of months before I found out about the mold in my house. It went away within a couple of weeks after I moved out. One hypothesis is that immune defects resulting from mold toxicity make *Aspergillosis* more likely to occur. Of course, other immune problems from CFS also could contribute to its presence.

5. There also is a panel of tests that measure the presence of various chemicals, including various mycotoxins, in the bloodstream. These tests are used frequently by various environmental specialists, such as Dr. William Rea.

This kind of test was originally designed to assess the presence of manmade chemicals, as might occur from industrial exposures to solvents or pesticides. They then were extended to measure mycotoxins.

A company that does this type of test is RealTime Laboratories.

One issue here is that toxic molds make a whole variety of chemicals. We don't have enough knowledge yet to be able to say for sure which ones are particularly bad.

Another issue is that the body tends to sequester mold toxins and other chemicals in the fat cells rather than in the bloodstream. The amounts in the blood thus may be misleading.

I don't have enough information about these tests to gauge their accuracy. From what I've heard, people who have environmental exposures to most chemicals tend to see their blood levels gradually go down if they get away from the environmental exposures and engage in active detox. The levels of the mycotoxins seem more likely to stay stubbornly elevated.

Everything I run into suggests that there's something weird going on with the mold compared to all other substances. I wish I understood better what it is.

6. The test that Dr. Myhill suggests ("you'll have to go on holiday") and that Erik has long advocated ("the Godforsaken wilderness" sabbatical) discussed above are designed to help individuals determine how much of an impact small amounts of toxic mold are having on them.

The test needs to be done carefully in order to yield a useful result though. Because CFSers are affected by such small amounts of mold, staying in a bad building, a bad region or amidst bad belongings (or other objects) can make it seem that toxic mold is not a problem even when it actually is.

If the test is done right though, it provides much more convincing results than any of the lab tests. Only two weeks after moving out of my moldy house and four days after putting aside my belongings from the house, I found that I couldn't go back into close proximity with those items without feeling ill. Washed clothing made my heart beat fast. Putting my hand inside my purse caused a painful burn that lasted for a week. Putting on my heavy coat made me have to stop by the side of the road to repeatedly vomit.

This is what Dr. Rea calls "unmasking." Interestingly, CFSers talk about it with regard to food allergens all the time---e.g. needing to stop eating wheat in order to figure out that small amounts of it cause a problem. Considering that toxic mold is inherently a "worse" substance for people than is "wheat" (consumed by the majority of the population with only positive results), the idea that the former may be causing problems that are at least as bad as the latter at low levels does not seem that unfathomable of a concept. Just an unfamiliar one.

In general, practitioners seem to be moving more toward using Dr. Shoemaker's panel of tests (including the VCS) to assess mold illness. For CFSers, the "Godforsaken wilderness" one (perhaps in combination with Dr. Shoemaker's panel) seems to work best. The others seem to be more useful for particular situations rather than for the diagnosis and monitoring of mold illness in general.

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Here's an article on the measurement of mycotoxins in tissues and body fluids (as mentioned above in #5).

Int J Mol Sci. 2009 Apr 1;10(4):1465-75.

Mycotoxin detection in human samples from patients exposed to environmental molds.

Hooper DG, Bolton VE, Guilford FT, Straus DC.

RealTime Laboratories, LLC, 13016 Bee Street #203, Dallas, TX 79234, USA.

Abstract

The goal of this study was to determine if selected mycotoxins (trichothecenes, aflatoxins, and ochratoxins) could be extracted and identified in human tissue and body fluids from patients exposed to toxin producing molds in their environment. Human urine and methanol extracted tissues and sputum were examined. Trichothecenes were tested using competitive ELISA techniques. Aflatoxins B1, B2, G1, and G2, and ochratoxin A were tested by using immunoaffinity columns and fluorometry. Test sensitivity and specificity were determined. Levels of detection for the various mycotoxins varied from 0.2 ppb for trichothecenes, 1.0 ppb for aflatoxins, and 2.0 ppb for ochratoxins. Trichothecene levels varied in urine, sputum, and tissue biopsies (lung, liver, brain) from undetectable (<0.2 ppb) to levels up to 18 ppb. Aflatoxin levels from the same types of tissues varied from 1.0 to 5.0 ppb. Ochratoxins isolated in the same type of tissues varied from 2.0 ppb to > 10.0 ppb. Negative control patients had no detectable mycotoxins in their tissues or fluids. These data show that mycotoxins can be detected in body fluids and human tissue from patients exposed to mycotoxin producing molds in the environment, and demonstrate which human tissues or fluids are the most likely to yield positive results.

<http://www.ncbi.nlm.nih.gov/pubmed/19468319>

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>I'm a mom trying to do some self help for my 28-year-old son. He's been sick for eight years. We're not ready to jump into full-on avoidance right now, but I'd like to know how big of a problem it might be for him. The cost of Dr. Shoemaker's panel is way more than we can afford -- more than \$1000! Do you have any suggestions about how else we might start looking into this?

This is a really good question. I think that the "unmasking test" suggested by Dr. Sarah Myhill ("I'm afraid you'll have to go on holiday") and long advocated by Erik (the "Godforsaken wilderness sabbatical") are the best, but that takes a lot of effort and money with a not-certain result. If people go to a bad place, they won't experience any improvements. And if they go to a really good place, they may find that they can't return to their existing dwelling when they return.

Dr. Shoemaker's panel is far too expensive for most CFSers without test insurance to do. In addition, it's more designed to help people figure out if they have a mold problem at all, rather than one that's particularly bad.

My belief is that while "extreme mold avoidance" likely is inappropriate for the majority of CFS sufferers, making sure that they're not living in conditions that are WAY over tolerance level is a smart thing to do. If mold exposures are really high, it seems reasonable to think that they will not benefit as much from other treatments and possibly will continue to decline over time.

So I put some thought into how I would recommend that a friend or relative approach the situation. I think that perhaps it would be best to use a variety of kinds of tests, which approach the problem from different ways.

1. Toxic Mold Screening Questionnaire

It seems to me that the most important question for CFSers to be considering is whether toxic mold is a really serious problem in the place where they're living. I thus put together a questionnaire that looks at various situational factors.

Very few people will respond positively to all these questions. But the more "Yes" answers that are given, the more likely it may be that a serious problem does exist.

This questionnaire also can be used to think back on whether previous residences might have been problematic with regard to toxic mold. However, insofar as the main goal is to take appropriate action now, focusing on the current dwelling seems especially important.

2. VCS test.

This is an eye exam that screens for the presence of neurotoxins in the brain, developed by Dr. Ritchie Shoemaker. It can be taken online and costs \$15.

www.biotoxins.info

Unfortunately, people who have toxic mold problems often pass this test. Also, a variety of neurotoxins (including mercury and Lyme) can give a positive result on the test. Therefore, it's hard to make a conclusion about whether mold is a particular problem regardless of the result.

When I was first considering whether mold might be a problem for me, my vision was so dim that I could barely see. The results on the test were convincing to me. I suspect that this test is pretty good at identifying people who are living in catastrophically moldy environments, but some may still slip through the cracks.

I thus suggest using this as part of an overall evaluation rather than a "Yes/No" answer in itself.

3. Dr. Shoemaker's Lab Tests

The most important test that Dr. Shoemaker has previously suggested to determine current exposures is the C4a. He states that this is particularly useful for mold exposures (as opposed to most other biotoxins).

Occasionally, people with mold illness do come up with a normal C4a on tests even though they're living in bad environments. Again, that's a reason to look at a group of measures. Based on what I've seen, people who are living in environments that are way above their tolerance levels tend to have very high C4a levels, so it seems to me a good clue.

Another test that Dr. Shoemaker now uses to test current exposures is the TGF beta-1 test. I don't have enough information about its accuracy to suggest it though.

4. The "Exercise Test"

It's my belief that CFSers will have a hard time doing any exercise at all while living in a bad environment. In many cases, walking from the bedroom to the bathroom is more "exercise" than an individual can handle.

Insofar as people can exercise (whatever that means for them) more outside their homes than inside it, that suggests to me that the home is a big problem.

Thus, gauging whether exercise seems more doable outside the home may be useful. Nobody should push it though! The idea here is to see what the body is easily able to do, not to force it and then end up back in PEM.

Spending most of a day outside or perhaps overnight in another location will be the best way to do this test, since the body may take time to rest. Trying different locations for comparison purposes may be useful too.

Because many CFSers are affected by the small amounts of mold toxins on their hair or clothing, showering elsewhere and then putting on new clothes that haven't been exposed to the suspect dwelling might be a useful addition to the experiment.

5. The Weather & Activity Journal

CFSers often keep journals of how they are responding to factors such as medications or supplements. Less often do they do so in order to keep track of what's going on in their environment.

This experiment will keep track of a number of factors related to mold exposures including:

- * Barometric pressure drops

These cause mold colonies to release their spores in the hope of having them spring into live mold as a result of rain. A device to keep track of barometric pressure can be purchased at Wal-Mart, or just look to cloud cover.

A web site that provides barometric pressure readings is here:

<http://www.wunderground.com/weathers...p?ID=KNVINCLI5>

- * Wind direction.

Sometimes wind direction and speed will matter. This especially is the case if the wind is blowing from a place that is suspected of being bad.

- * Time spent away from the home.

Keep track of various places visited. Be sure to write down everywhere visited, since even a short time in a really bad place can cause some people a downturn that can go on for days or weeks.

Sometimes people do not feel bad until several hours after an exposure. Thus, if a downturn occurs, think back to what happened over the past day or so to see if anything suspicious can be identified.

Outdoor places as well as inside buildings should be considered.

6. ERMI Test

This is a DNA test of mold in the home. Insofar as a home is really bad, the test might pick up on it. The test costs \$340.

Previously on this thread, I talked about Dr. Mary Beth Short-Ray and environmental mold testing. Here is the site with the test for sale:

<http://www.toxic-black-mold-syndrome...HELPSTORE.html>

I don't suggest any of the other tests on this site except the ERMI.

7. Am I A Moldie?

The response that I usually get when I list various symptoms that are associated with mold reactivity is, "But those are just general CFS symptoms."

Insofar as mold reactivity is an inherent part of CFS, this makes sense. But that doesn't help people who don't know yet if they believe it's an issue for most CFSers.

I thus am including not only symptom descriptions, but a list of situational factors, below.

*

This screening questionnaire is not designed to give CFSers a definitive answer about whether toxic mold in general is a problem for them.

It is only designed to look at whether it seems possible that it's a particular problem in their current residence.

Your Current Home:

- * You are aware of a water event having happened at some point in your home. This could have been even a small amount of flooding (e.g. from a broken air conditioner or toilet overflowing) or a burst/leaking pipe where the water problem was not addressed within 24-48 hours.
- * A water event like this at any time during your illness was followed within a relatively short period of time (e.g. a year) with a decline in your well-being.
- * Your house has a basement or laundry room (especially if below ground) that you don't "monitor" very closely for water problems or wall discolorations.
- * You have/had cracks or water spots on your ceilings or walls and haven't taken steps to make sure that mold is not a problem in those places.
- * Your home has a flat roof.
- * When it rains hard, water outside (e.g. on a sidewalk) runs/ran in the direction of your house.
- * You live in a neighborhood where homes are known to flood easily.
- * You have a sump pump that occasionally or frequently allows some flooding.
- * Your house is very well insulated or sealed, allowing little air circulation from outside.
- * Your house uses an HVAC (ductwork) system rather than radiators.
- * You have older windows in your house and haven't checked to see if they need to be replaced.
- * You have walls made of drywall, fiberboard or other cellulose-based products in your home. (Check especially in rooms where water intrusions might occur, like in basements or laundry rooms.)
- * You have paneling in your home, especially in a room below ground like a recreation room.
- * You have noted design or construction problems in your home that you wish the original builder had handled differently.



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- * In carefully examining your home, you note dark smudges on the wall that look more like dirt than mold.
- * You previously noted dark green or black mold growth (e.g. on a wall or carpet) in your home, but believe you've gotten rid of it all.
- * You've uncovered mold during renovations of your home, but believe that you've gotten it all.
- * You or others have noted the smell of mold in your home.
- * You live in a house that is more than one year old.
- * You suspect that your landlord or your home's previous owners did not take really good care of it.
- * You get a lot of mildew on your shower curtain, window panes, and plants.
- * Onions in your home get moldy before they dry up.
- * Your clothes start to smell mildewed if you leave them in the washer for more than a short while.

Your Neighborhood:

- * You live in a city.
- * It feels like your city doesn't get good air circulation (e.g. has a "haze" that hangs over it).
- * You live in a valley (even if it's just 100 feet below the surrounding area).
- * You live near a lake that's host to a lot of algae.
- * You live in a hot, humid climate where air conditioning is used a lot.
- * You live in a wooded area where fire retardants often are used.
- * You live in a place with strong CFS support groups, a historical CFS epidemic, and/or thriving Fatigue & Fibro Centers (FFCs).

- * You've met at least a few really sick CFS patients from your local area online or in person.
- * You've been able to find local doctors who seem well-versed in CFS and have other patients like you.
- * You live in California (especially the SF Bay Area), Texas (especially Dallas/Ft. Worth or Houston) or England.

Household Members:

- * Someone else previously or currently living with you has unexplained health problems (e.g. CFS, fibro, ADHD, MS, autism, Asperger's, unusual tumors, "liver problems," miscarriages, infertility, SIDS, heart problems, thyroid problems, depression, "just plain tired")
- * Someone else previously or currently living with you has mood issues (anger/rage, depression, bipolar depression, suicidal feelings, lethargy, underachievement, withdrawal, anxiety).
- * You have one or more pets that seem unhealthy for their age (e.g. lethargic, howling, stiff, cancer, "acting up").
- * You are aware of other people in your building or neighborhood who are sick with any sort of odd or unexpected illnesses.

Reactions to Your Home:

- * You or someone else has noted that it seems like there's something wrong with the air in your home or workplace, but have blamed it on something like cigarette smoke, the presence of a pet or poor air circulation.
- * You feel like certain other people's homes feel more comfortable than yours, but you're not sure why.
- * Blow drying your hair makes you feel really exhausted.
- * After a shower, you find that you need to lie down and/or that your heart is beating fast.
- * You feel worse when you or someone else vacuums the house.
- * You feel worse when running the clothes dryer or folding laundry.



Paradigm Change

- * Cleaning closets or straightening up piles of belongings can make you feel a lot worse.
- * You feel better in some parts of your home than others.
- * When you spend time outside, you often feel better in other places than you do in your own backyard.

History:

- * You live in the same home that you got sick in.
- * You've gotten worse while living in your current home.
- * You were spending most of your time in your current home (rather than working outside the home) when you got sick.
- * You still have a lot of your clothes, furniture, books/papers and other belongings from the house you got sick in.
- * When you're at work (or when you were working), you felt as good or better than you do when at home.
- * People at the place where you were working when you got sick seemed generally pretty healthy and in good spirits.

Symptoms:

- * You have a lot of static shocks.
- * You have heart pain/palpitations, horrific headaches, very deep skin dents, suicidal feelings, sensations of skin burning, a tender spot (like a marble) at your sternum, feeling of your brain and spinal cord swelling, trembling even when it's not very cold,
- * You feel more poisoned (or like a fly caught in a web) than fatigued.
- * You often feel a bit better if you can drag yourself out of bed, even if you don't leave the house.

- * You find it necessary to drink a lot of water when at home, but not always so much when you're away from home for a while.
- * You react very poorly to supplements or drugs that are designed to address pathogens (e.g. antivirals, antibiotics, antifungals) or toxins.
- * You have candida problems that are out of control
- * You have a doctor who seems to help other patients, but his/her treatments do not seem to be working very well for you.
- * You have a feeling of pain in your lungs or an ongoing cough.
- * Sometimes you wake up and are covered with clammy sweat.
- * You have chemical sensitivities that are getting worse.
- * You have a hard time reading unless it's in bright sunlight. Everything looks a little dim.
- * You feel much worse prior to or during storms (when the barometer is dropping).
- * Sunny days make you feel considerably better.
- * Your health takes a big downturn when fall comes.
- * Getting ready to go out or getting packed for a trip is really hard.
- * You have a hard time drawing a deep breath.

Getting Out of the House:

- * You feel different (though not necessarily better) when away from the house for several days or more. Or you alternate while you're away between feeling pretty good and being dead tired.
- * You have a very hard time dragging yourself out of the house (e.g. to go out to dinner or for another relaxing activity) but often feel better for a while once you do go out .
- * Swimming or spending time in outdoor pools (but not indoor pools) has appeal for you.
- * You have certain friends or relatives that you like to visit because you just feel good there.
- * Sometimes when you spend a night or two away from the house, you find you "sleep like the dead" in a way you usually don't at home.



Paradigm Change

* Sometimes when you go out, you feel fine until you get back home. Then you just collapse.

* You often feel especially tired and bad when you return home from a trip (possibly attributing it to "crashing" from the accumulated stress or from being depressed that you're no longer on vacation)

* You've had one or more experiences where you've gone on a trip and "come back to life."

* Sometimes you look forward to going out but then feel awful. Other times you don't feel like going out, but feel pretty good.

*

Below are some situational "clues" and symptoms that seem to be associated with toxic mold illness.

They are compiled from observations from a few different doctors specializing in mold illness, as well as my and other CFSers' personal experiences.

This is a long list, but I had just about all of the symptoms on both lists prior to mold avoidance.

Now they're all gone.

Preferences:

* You often feel worse when you stay in big hotels with centralized duct systems.

* You often feel worse in big indoor shopping malls.

* You've felt really bad in schools or government buildings

* Stores like Home Depot and Wal-Mart bother you.

* Starbucks and Panera feel good to you.

- * You sometimes avoid going to certain places or driving certain routes, because doing so makes you feel worse.
- * Air travel takes a real toll on you.
- * You feel especially drawn to the mountains, seashore or desert.
- * Vacations in less “civilized” areas sometimes feel really good to you.
- * There are certain places that you go to that feel really good to you, but you’re not sure why or attribute it to “good chi”/“feng shui.”
- * You’ve had experiences on vacation or travel when you’ve felt absolutely awful.
- * You’ve felt particularly bad on vacations to Dallas/Ft. Worth, Houston, England, or the San Francisco Bay Area.
- * You’ve felt better on a vacation to Greece, the Caribbean or other places with similar climates.
- * If you were feeling up to doing a little exercise, you’d much rather do it outside than inside.
- * Usually when you go to the doctor, you feel worse during and after the visit.

Symptoms:

- * Sometimes when you go shopping or other places, you feel short-tempered or lose your temper with people for no particular reason.
- * Sometimes your moods seem out of control. You can get angry with people or severely depressed, even though there doesn’t seem to be any particular reason why.
- * Sometimes when you go out, you unexpectedly feel so faint that you need to sit down or lie down.
- * Sometimes when you go out, you have a sensation that “I’ve got to get out of here” for no reason.
- * Sometimes for “no reason” you can do more “exercise” (whatever that means to you) than at other times.
- *

TOXIC MOLD ILLNESS HEALTH SYMPTOM LIST

BRAIN:

Headaches
Poor memory
Trouble concentrating
Trouble learnings
Trouble finding words
Trouble handling numbers in head
Confusion
Vertigo
Disorientation
Seizures
Trouble speaking fast
Trouble understanding fast verbal information
Trembling
Vocal or motor tics
Abnormal reflexes
Strokes
Edema or swelling in brain

EMOTIONAL:

Mood swings
Mania
Irritability
Impulsivity
Increased risk taking
Decreased speech smoothness
Poor stress coping
Increased verbal fighting
New lateness
Poor empathy
Poor boundary awareness
Immaturity
Spaciness
Rigidity
Poor insight
Decreased productivity
Unable to process trauma or interpersonal pain
Increased narcissism

Forgetfulness
Poorly organized or obsessively organized
Dead creativity
Depression
Anxiety
Panic attacks
Decreased attention

EYES:

Light sensitivity
Red eyes
Blurred vision
Tearing
Eye pain
Burning eyes
Low visual contrast

HEARING:

Sound sensitivity
Decreased hearing

MOUTH:

Metallic taste
Saliva with blood streaks

NOSE AND SINUSES:

Chronic infections
Sniffing
Tingling nose
Nasal itching
Stuffy nose
Runny nose
Blood streak in saliva or nasal mucous

THROAT AND LUNGS:

Cough
Erosion of membranes
Shortness of Breath
Sore throats
Cold or Flu symptoms
Chest pain
Wheezing
Voice changes

STOMACH AND INTESTINES:

Ulcers

Indigestion
Nausea
Vomiting
Sloughing and death of intestinal villi
New Reaction to wheat or dairy
Diarrhea
Constipation
Belly pain
Bile duct disease

LIVER:
Fatty liver
Liver cancer
Abnormal liver lab tests
Jaundice or yellowing

SKIN & HAIR
Numbness
Tingling
Hair loss
Diverse and severe rashes
Itching
Blisters
Burning skin sensation

MUSCLES AND JOINTS
Cramps
Stiffness
Joint pain
Cartilage damage
Muscle Aches
Delayed Recovery
Sharp Stabbing Pains
Lightning Bolt Pains
Morning Stiffness

HEART AND BLOOD VESSELS
Heart Muscle damage
Heart muscle inflammation
Chest pain
Red or pale skin

REPRODUCTIVE TISSUE & GROWTH

Increased Testicular cancer
Vaginal irritation
Decreased sperm production
Erectile dysfunction
Decreased sex drive
Irregular or stopped menstrual cycle (when not menopause)

HORMONES & HORMONE TISSUE

Low DHEA
Low MSH
Low Free Testosterone
Low Androstenedione
Low Cortisol
Abnormal cortisol regulation
Damage to Adrenal glands (Makes Cortisol, DHEA and ADH)

OVERALL BODY:

Fatigue
Weakness
Malaise
Eccentric weight gain
Low Motivation
Occasionally eccentric thinness
Bizarre pain
Ice pick pain
Lightening bolt pain
New chemical sensitivity
Spinning sensation/Dizziness
Increased thirst
Frequent urination
Shocking sensation (e.g. when touching light switch)
Sweats
Temperature variation
Appetite swings
Easy bleeding or bruising
Swelling
Trouble walking or running easily
Reduced coordination
Rapid pulse
Low temperature
Jerky movements
Abnormal Blood Pressure (low or high)
Fever
Chills

Post Exertional Exhaustion
Increased tumors

PREGNANCY
Fetal abnormalities (birth defects)
Infertility
Miscarriages

Mold Avoidance Tactics

The first experience that I had that convinced me that mold was really a problem for me was when I'd been out of my house for a couple of weeks. That was when I started to feel ill (nausea, heart beating fast) as a result of being around clothing that had been put through the washer and dryer of the relatively okay place that I was staying.

It seems that the poison that these molds make sticks really well to things. It can be really hard to remove even from solid objects. Plastic (which apparently actually has lots of little holes in it) can be especially tough.

Feeling "a little sick" around objects seems like it shouldn't be a big deal. But those acute reactions are the only ones that provide information that the objects are contaminated, and thus that may cause more severe long-term effects.

If objects are transiently contaminated (e.g. in a bad building for a day), they tend to clean up comparatively easily. But if they've been in a bad place for a long time, it's conceivable that no amount of washing may remediate them.

Some people have managed to reclaim all their belongings after they've been in storage for a long time (3+ years). Others have been less fortunate.

My own reactivity has gone down to the point that objects in general don't have much of an effect on me, so I think I will be able to reclaim some stuff. But I'm sure that wouldn't have happened if I'd not been extreme about avoidance upfront.

Keeping clothing (especially shirts) and bedding as pristine as possible is important, since those items are close to the face (where the poisons can be breathed in) for extended periods of time.

Honestly, this is the stupidest way of getting well from CFS that I ever could have imagined. I wish somebody would come up with a better solution.

*

My goal is to increase general awareness of the role of mold toxicity in CFS so that researchers/doctors will be pressured to look into it, and to urge people to consider whether the presence of severe mold problems in their homes or workplaces might be compromising their own health or that of their families.

Encouraging folks to try to use extreme mold avoidance to get really well from CFS is something I hesitate to do. This is a really hard path!

However, I've gotten a lot of questions about how extreme avoidance is pursued.

This isn't a secret. A document summarizing Erik's approach is available to all those who want it, but the information is so complex that I hesitate to thrust it upon people. It's sort of like saying it would be fun to take an airplane ride and having someone hand you a manual on how to build the airplane as well as fly it.

So as a simple starting point, for those who are wondering what doing this might entail, here are some thoughts. I don't have any scientific evidence that what I'm saying has validity though...it's just based on my and others' experiences.

1. Should I be concerned at all about regular mold? What about the "Mold Diet"?

Regular non-toxic mold can cause allergies. Some people suffer a good deal from those. I know almost nothing about mold allergies (I don't have any myself), and so can't help with that. I'm only interested in toxic mold, which is a few species that mostly grow on indoor building materials and in very specific circumstances outside.

The "Mold Diet" was created about 15 years ago, when the role of mold toxins in illness was not very well understood. It includes things like mushrooms, which have no toxicity at all. I don't think many knowledgeable doctors use it these days.

Foods that contain mycotoxins (mostly aspergillus, a somewhat toxic mold) are mostly grains (e.g. corn, wheat, oats, rye) and nuts (e.g. peanuts, cashews). I used to have problems with those. However, inhaled mold toxins are (according to all the people I know who have gotten real improvements from addressing mold) much more important than ingested ones.

I tend to think that focusing on individual food sensitivities, whatever they are, would be more helpful than focusing on mold in foods in particular.



Paradigm Change

2. My house is moldy but I can't move. What should I do?

I hate this question. It seems that there should be something that would be helpful, but I've never heard of anything.

If a house has a real mold problem, air purifiers will soon become the worst items in the house (except for vacuum cleaners and clothes dryers). So that doesn't help much, even if filters are changed frequently.

Using dehumidifiers or otherwise killing the mold (e.g. with Thieves Oil) is totally counterproductive. Drying out mold causes it to release its spores all at once, increasing the amount in the air. The resulting big hit is one that CFSers may not recover from.

Attempting to fix the mold oneself (or getting people who are not trained in doing so) is extremely dangerous for CFSers. Please don't do this! Please, please, please. Please!

Professional remediators and then reconstruction are expensive, and improvements likely will not be enough to help CFSers make much progress.

I can't recommend leaving the mold, but none of those other options is good either.

I don't know of any magic tricks to let CFSers tolerate mold better, other than all the general treatments that are discussed on this board.

Leaving the windows open and spending as much time outside the house as possible may be helpful.

Laundering bed linens frequently and hanging them to dry (preferably outside the house) might be a little helpful as well.

3. I am willing to move. If I don't get rid of all my stuff, should I even bother moving? Why can't I just wash it?

Whether "stuff" turns out to be a deal killer depends on the situation. Some people are more reactive than others. Some types of mold are much more damaging than others. The extent to which stuff has been exposed to mold also matters.

Some CFSers may only need to pursue "moderate avoidance" in order to get clear. It's possible that some are not affected by mold at all. That's one reason we need research: to get a better sense of what's going on.

If people are being affected by mold, any reduction in exposures is a good thing. Even if nothing dramatic seems to happen, it may result in longer term gains, give other treatments a better chance of working, and/or prevent a decline.

On the other hand, even a few really bad objects in a living space can be enough to keep some people scarily sick all by themselves.

So it's hard to know upfront what the best thing is to do. Putting things aside, getting really clear (e.g. with the "Godforsaken wilderness sabbatical"), and then returning to the "stuff" to see if it's a problem is the only way to know for sure how much it matters.

Maybe I can get someone who knows more about physics than I do to explain why the toxins can't be completely washed off hard objects. Metal and glass seem much less problematic than plastic though.

Washing does help a lot in terms of reducing the potency of the toxins. It also keeps them from cross-contaminating other stuff.

Books and papers tend to be especially problematic since they absorb a lot of toxins and can't be washed.

4. I am willing to leave behind much of what I own, but I can't leave everything, if only because of my son. There are beloved stuffed animals and toys I cannot make him give up. He's just still too young. I am fine with leaving behind all soft furniture, rugs, drapes, most clothes, and I can replace some tech items. But there are a few wooden pieces of furniture I'd like to be able to bring, some paintings of my grandmother's, expensive kitchenware, and some tech stuff I can't afford to replace. Is it pointless to leave some stuff behind if you're going to still drag contaminated items with you?

I think that it's only a good thing to get any reduction in mold exposures. Moving from a moldy residence and bringing a minimum amount of possessions is a good start.

But if folks are going to do this, it's nice to get as much benefit as possible. So this is what I suggest.

First, the most important thing is not to cross-contaminate the new residence. Washing everything after it leaves the old place and before it comes into the new place is crucial. If things can't be washed, putting them in storage or getting rid of them is best.

I'd suggest moving into the new place without the old stuff for a while, just to get a sense of how things feel without the stuff. That way, it will be possible to know how much of an effect the stuff from the old place actually is having when it's introduced.

Tech items can't be washed, but they're expensive. The only way to decide whether it's worth keeping them is to get unmasked first and then see what kind of effect they're having.

Having a "safe space" for sleeping in any residence is crucial. Keeping suspect stuff out of that area is really important. This includes newly purchased items as well as anything that's transferred from the old place.

The worst items to bring (other than things that can't be washed) are clothing and bedding. Because these items are in close proximity to the individual for extended periods of time, they have a much greater effect than, say, a painting or a piece of kitchenware that is only approached for shorter periods of time.

5. My ex-husband used to live in this house, so probably his stuff is contaminated. If my son goes to visit him, won't he bring the mold back with him and ruin all my efforts? Maybe I should just give up.....this sounds way too hard.

Yes, this is the kind of thing that I have to be thinking about all the time. It's a different type of hell than having active CFS, but it still really sucks.

I don't think that this particular problem is something that can't be overcome though. Establishing specific protocols regarding what might be called "mold hygiene" (e.g. having the kid change clothes and take a shower as soon as he comes home, washing suspect stuff or leaving it in a box in the garage, etc.) can be done later on, if what's being dragged back home starts to feel problematic.

6. I'm willing to move to another location of the U.S. What factors make some places better in terms of outside mold than others?

This is a hard question because there are so many variables. But after having traveled to a couple of hundred different places during the past two years, here are a few observations.

A high percentage of the mold that's in the outside air comes from the insides of bad buildings. Because cities have more buildings (some of which are going to be bad), they tend to be worse than less populated areas.

Good air circulation in a location can blow the outdoor toxic mold out of the area. Big cities that are surrounded by mountains often are especially bad. Being on the water

(Chicago, New York) is helpful. Places that are higher in elevation compared to the surrounding area tend to be better.

Humidity only matters insofar as it makes buildings more likely to have mold growing. Some dry cities, like Phoenix, have terrible outside air in terms of mold. Carmel, CA, is damp but felt great to me.

Sunny skies tend to be really helpful in nullifying the effects of mold. UV radiation may degrade mold toxins, while clouds may prevent them from being dissipating into the environment.

Bad weather (rainstorms or snowstorms) usually means an increase in mold problems, since colonies release their dormant spores at this time with the goal of getting a new colony started in the water.

Different locations can vary in terms of which season is the worst. Fall tends to be bad in most places, because of all the rain. Winters tend to be especially cloudy, which hurts areas that benefit from sun in other seasons. Summers in really humid climates can cause the easy growth of all kinds of mold, and the heavy use of air conditioners releases a lot of spores from the ductwork.

Some places have more than their fair share of particularly damaging mold growing outside or in buildings. Examples of places that I have been include Texas, Lake Tahoe, the SF Bay Area, and Telluride, CO. As a rule of thumb, I suggest looking for places that have high rates of severe CFS (indicated by the presence of strong support groups, thriving FFC's or historical epidemics) and then avoiding those locations at all costs.

Proximity to a super-good location can be really helpful for taking periodic "sabbaticals." If I spend some time in a place that's really pristine, I can tolerate even a relatively bad location much better the rest of the time.

For instance, one place that I might consider living is Flagstaff, AZ, which feels really good to me. It's a moderate sized city surrounded by great expanses of wilderness on all sides, is pretty sunny year round, is at a high altitude compared to the surrounding area, and is very close to the very best place I've found in my travels (the Four Corners reservation area).

7. If Lake Tahoe is such a bad place, how could Erik have lived there for so long and stayed well?

Lake Tahoe has an unusual dynamic. In general, the air is terrifically great. However, the area has much more than its fair share of a particularly damaging mold that causes CFS sufferers (and to a lesser extent normal people) a great deal of suffering.



Paradigm Change

This super problematic mold is inside certain buildings in the area (e.g. Truckee High School). In addition, plumes of this particular mold waft around on air currents outside, coming from sewers and from trees that have been treated with fire retardants.

After Erik got really unmasked by going to the “Godforsaken desert” for a while, he was able to tell where these plumes were. He thus started decontaminating (taking a shower and changing clothes) every time he passed through them, and shifting locations frequently to get away from them. At one point he was taking up to 10 showers a day and often getting up in the middle of the night to move his camper to another place.

Most people (including me) would just go live somewhere less “challenging” under that circumstance. But he wanted to stay there.

During the past few years, the number of plumes of this really bad mold in the Lake Tahoe area (especially in Truckee) has gotten larger. Finally he got hit one too many times and moved to Reno. Reno has some plumes of this really bad stuff too (mostly coming from some sewer ponds in the area as well as from a few really bad buildings), but the situation there still is not as bad as the one in Truckee.

*

From Rock:

I have been asked how to find a mold free (or a near as possible) home.

From the Colorado perspective where I have concluded that 90% of homes have enough Penicillium/Aspergillus group to sustain symptoms, look for:

1. houses less than 5 years old
2. houses without gutters on their north sides
3. houses with no history of roof or plumbing leaks
4. houses with no subgrade wood materials
5. houses that have not had carpets shampooed in warm humid weather

Then air sample a round or two with Mircro5 or similar cassetes (25 liter samples), maybe 4-12 samples, send samples to EMSL then review report

Then if clean or nearly clean, hire Mark Peltz (Denver CO) and his mold dog to check out the house.

If that passes then strongly consider buying it or rent it.

Sorry to say, all of this is fairly complicated and fairly expensive. We have nearly rented or bought homes, done expensive sampling and have them fail. So it can be risky in that way.

Once you find a clean home work hard to make sure it stays that way no matter what it takes. For us that means being obsessive about keeping 100-200 inches / year snow off the decks and off the lower 3 feet of the roof.

*

A few of weeks ago, Dr. Cheney sent out a note about toxic mold to his patients through their online forum.

The note stated that even though toxic mold is not the cause of CFS, patients should look for toxic mold in their homes and should consider moving if they found it.

Remediation alone might not be enough to provide relief, he suggested.

I agree with all of this, and am really happy to have his acknowledgement that this is an important factor for us.

However, I would like to encourage people who are following Dr. Cheney's advice to consider leaving their possessions behind or putting them aside for a trial period.

Unfortunately, the contamination on items that have been exposed to moldy places for long periods of time can be enough to keep some of us wholly sick indefinitely.

The majority of homes are reasonably okay for CFSers, but a bunch of contaminated belongings is disastrous.

*

Some cyanobacteria toxins are worse than others.

Some cyanobacteria make large amounts of toxins. Some make only small amounts. Many make no toxins at all.

Dr. Shoemaker suggests that toxic cyanobacteria are more likely to be present in places that have been affected by agricultural chemicals or chemicals designed to kill off the cyanobacteria. These wipe out ordinary cyanobacteria, providing an opportunity for mutant strains to take over.



Paradigm Change

Cyanobacteria toxins are similar to mold toxins in terms of their structure and some of their effects. Generally they are recognized by governmental authorities as being more dangerous than mold toxins.

As is the case with toxic mold, many types of cyanobacteria release spores into the air. CFS patients can be affected by the spores even if they don't go in the water.

However, staying out of suspicious water probably is a good idea.

According to Dr. Shoemaker, people who are "multi susceptible" have a difficult time eliminating both cyanobacteria and mold from their systems. (That's part of what's included in the "multi.") However, "mold susceptible" people (and people in general) may be affected by cyanobacteria toxins.

The specific symptoms that I mention above seem to be associated with one particular type of cyanobacteria. It seems to me pretty rare, since I've only encountered it in a few places.

It would be interesting to see if clusters of CFS patients in particular areas suffer from these symptoms. That would suggest that it's something environmental rather than a pathogen that colonizes.

*

I have no idea when Ann Arbor became especially problematic. I just know that I ran into the outdoor biotoxin that affects me the most at the end of June this year, and that at least one other CFS patient from that area reported those same symptoms (and is doing much better now that she's out!).

That's an interesting question about whether people mistake these symptoms for babesia. I think they're very frequently mistaken as being a bad flu, by those people who run into it abruptly (e.g. when visiting a city where it's at).

But even if it is babesia, moving may help you quickly. It's my impression that babesia is fairly easy to get under control, if the immune system is functioning even marginally well.

Erik said that in Incline Village, people who were living/working in moldy places became more susceptible to this outdoor biotoxin. They seem to work synergistically.

*

Note to a Individual Sufferer:

I'm trying to get a sense of what locations seem to be non-starters for any CFSers (or at least ones with the mold or multi genotypes). The ones I mentioned above (England, Bay Area, Texas/Louisiana) seem particularly problematic with regard to mold. I do wonder about Boston too, since a CFS epidemic once was reported there.

But you reminded me that you live in a place that I visited after seeing Erik and starting extreme avoidance, and during a rainy period of time (mold gets worse in bad weather). The outdoors felt good there. So I don't think that the outside air is your problem, at least as far as mold goes.

Out of further curiosity, how severe is your CFS? My increasing belief is that the reason that mold is so problematic for CFSers is because it's the toxin that we come into contact with the most. In small amounts, it's pretty much ubiquitous.

But if someone weren't bothered by small amounts of mold toxins, that would give him/her a real leg up in terms of being able to remain less severely affected, even if XMRV and HHV6a and whatever other bugs were causing inflammation to go nuts whenever other types of irritants were encountered.

Maybe looking at the viral issues indeed would be worthwhile in that case. And for someone without a lot of extreme mold reactivity, perhaps antivirals even (as occurred for me when I was in the Godforsaken Desert) might be relatively tolerable to take.

*

>It may be that until there is a cure or at least any easy method to avoid moulds that pursuing this may not be feasible for some.

Yes, I know that. Especially for people who already are really sick.

Maybe if the information becomes more widely known, people will suspect mold as being an issue as soon as they get any CFS-type symptoms.

It's a lot easier to pursue this earlier on, when mold reactivity isn't as high and resources (physical and financial) aren't as depleted.

Mold and Exercise Intolerance

The reason that Erik was able to climb Mt. Whitney all those times is because he figured out that if he could get his level of mold exposure low enough, his post-exertional malaise and exercise intolerance would go away.



Paradigm Change

Because his mold reactivity was so high, he had to take really extreme measures (doing thorough decontamination and only exercising in really pristine places) for it to work.

This seems to me that it's so thoroughly correlated that it can be taken as a "marker" for whether people are getting more mold exposure than they can tolerate.

People who are really intolerant likely won't be able to exercise anywhere. People who are somewhat intolerant might be able to exercise some places but not in others (e.g. a moldy gym).

If people are less able to "exercise" (whatever that means) in their own home than elsewhere, that may be a good clue that their home is problematic.

It would be interesting to look at those non mold or multi susceptible CFS patients to see if they indeed to have less exercise intolerance than the rest of us.

*

When Erik first got sick during the Incline Village epidemic, he had not just "post-exertional malaise" but what he calls "no-exertional malaise." Just trying to crawl to the bathroom or open a can of soup (to eat cold because heating it was too hard) made him relapse.

What he eventually found was that if he could get free enough of all traces of toxic mold contamination (or, at least, what he identified subjectively as toxic mold contamination), his post-exertional malaise and exercise intolerance went away.

However, this only worked insofar as he made this special effort. He only could exercise in areas with "good" outside air (since, in his subjective opinion, the substance that he identified as toxic mold can be outside as well as inside). And he only could do it insofar as he was thoroughly decontaminated (e.g. after he washed his hair and changed into clothes that hadn't been exposed to toxic mold). Otherwise, both the PEM and exercise inability came back.

Insofar as he made this special effort, he was able to exercise without any problems. His exercise intolerance and PEM went totally away.

If he didn't make this special effort, he stopped being able to exercise. The exercise intolerance and PEM returned at full force.

It's not just that the exercise intolerance and PEM improved. It went totally away, enough so that he was able to climb to the top of Mt. Whitney (14,000 feet; half of all people making the attempt don't finish) every summer for 10 years in a row.

The first time he did it was six months after being approved for Ampligen from Dr. Peterson, so he obviously was pretty sick.

I found the same thing to be true. My own PEM used to be marked. Now, if (and only if) I follow Erik's "protocols," I am able to exercise without negative consequence as well (though I haven't gotten to the top of Mt. Whitney yet....just the "difficult" hikes in the Frommer's books).

Other people with CFS report their exercise intolerance and PEM going away as long as they attend closely enough to mold avoidance as well.

*

Transcriptional Control of Complement Activation in an Exercise Model of Chronic Fatigue Syndrome.

Journal: Mol Med. 2008 Nov 16.

Authors: Sorensen B, Jones JF, Vernon SD, Rajeevan MS.

Affiliation: Division of Viral and Rickettsial Diseases, National Center for Zoonotic, Vector-borne and Enteric Diseases, Centers for Disease Control and Prevention, Atlanta, GA, USA 30333;

NLM Citation: PMID: 19015737

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.

*

And here is a further comment made to Erik and me by Keith Berndtson, M.D.:

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

*

I've been puzzling over the topic of C4a and thought I'd put some comments here.

First, Dr. Shoemaker's beliefs (which, to my understanding, have not been published in a peer-reviewed journal yet).

Dr. S says that C3a and C4a tend to be correlated with acute toxic mold exposures in non-CFS patients. If you can get these patients out of a moldy environment, their C3a and C4a (complement) levels go down to normal.

In CFS patients, that doesn't happen. He states in *Mold Warriors* that C3a remains stubbornly up. (That seems to be the case for C4a, which he doesn't discuss in *MW*. It seems to be much more correlated with toxic mold exposures than C3a though, he says now.)

Dr. S makes it seem in *MW* that C3a (and presumably C4a) are staying elevated for no apparent reason. That would be consistent with the idea that all kinds of things are causing inflammation in the CFS patient, not just mold.

However, this is where my little trip down the rabbit hole has the potential of providing useful testable information.

Some of us pursuing extreme mold avoidance have found that insofar as we keep our exposures low, we are able to get those complement measures down to normal. (What I need to do is to arrange to get a draw before and then after a small exposure, to show that only a small amount of exposure indeed is needed to cause the elevation.)

It thus seems that in our case, C4a is not being driven by "general inflammation" or the system doing things randomly. It's in response to tiny bits of mold exposures.

This is hardly an unprecedented concept. It's exactly what happens in (say) peanut allergies, which is the metaphor that Erik's been using ever since 1998 when he first proposed the "extreme avoidance" concept to Dr. Peterson.

Similarly, those exercise studies (above) make it seem like CFSers are just generally inflamed. They observe C4a going up after exercise and staying up, and attribute the post-exertional malaise to it.

That's not our experience though. We experience the PEM not from exercise alone, but from exercise in combination with toxic mold. We've yet to find any other substance or any other variable that causes PEM, if toxic mold is taken out of the equation.

And as the authors suggest, there doesn't have to be any exercise in order to cause the problem (Erik's "no-exertional malaise" concept). They report C4a being elevated to begin with; it just gets worse with exercise.

I'd like to be able to say, "Yes, there are all kinds of things that cause inflammation in CFS, and mold is just one." That doesn't seem to be what's happening though. Underlying Lyme infections or XMRV infections or herpes virus infections or emotional stress or other sorts of chemicals don't, in our experience, interfere with the ability to exercise without PEM. Just the mold.

Moreover, the ability to exercise without PEM seems to occur almost immediately after getting free of the mold. Most of the improvements from mold avoidance take time. But with the PEM, it happens almost immediately. Based on our experience, if a CFSer can really get clear, it's possible for the ability to exercise to come back within a day or two, sometimes even within a couple of hours. Depending on the overall weakened state of the body and decreased muscle capabilities, exercise ABILITY may still be limited. But in that case, it's not inflammation driven and the PEM concept won't apply.

It's very hard for people to get that free of mold toxicity though. But the fact that some CFSers can engage in a perplexingly large amount of exercise at odd times without negative effects is consistent with this.

*

I just want to note that Ray Stricker and Ritchie Shoemaker have also studied C3a and C4a in Lyme disease. Stricker's paper is about chronic Lyme, and Shoemaker's is about acute Lyme. See below.

Best regards,

Rich

Scand J Immunol. 2009 Jan;69(1):64-9.
Complement split products c3a and c4a in chronic lyme disease.

Stricker RB, Savely VR, Motanya NC, Giclas PC.

International Lyme and Associated Diseases Society, Bethesda, MD, USA.
rstricker@usmamed.com

Abstract

Complement split products C3a and C4a are reportedly elevated in patients with acute Lyme disease. We have now examined these immunologic markers in patients with chronic Lyme disease compared to appropriate disease controls. The study population consisted of 29 healthy controls, 445 patients with chronic Lyme disease, 11 patients with systemic lupus erythematosus (SLE) and six patients with AIDS. The Lyme disease patients were divided according to predominant musculoskeletal symptoms (324 patients) or predominant neurologic symptoms (121 patients). C3a and C4a levels were measured by radioimmunoassay. All patients with chronic Lyme disease and AIDS had normal C3a levels compared to controls, whereas patients with SLE had significantly increased levels of this marker. Patients with predominant musculoskeletal symptoms of Lyme disease and AIDS patients had significantly increased levels of C4a compared to either controls, patients with predominant neurologic symptoms of Lyme disease or SLE patients. Response to antibiotic therapy in chronic Lyme disease was associated with a significant decrease in the C4a level, whereas lack of response was associated with a significant increase in this marker. In contrast, AIDS patients had persistently increased C4a levels despite antiretroviral therapy. Lyme patients with positive single-photon emission computed tomographic (SPECT) scans had significantly lower C4a levels compared to Lyme patients with normal SPECT scan results. Patients with predominant musculoskeletal symptoms of Lyme disease have normal C3a and increased C4a levels. This pattern differs from the increase in both markers seen in acute Lyme disease, and C4a changes correlate with the response to therapy in chronic Lyme disease. C4a appears to be a valuable immunologic marker in patients with persistent symptoms of Lyme disease.

PMID: 19140878 [PubMed - indexed for MEDLINE]

Int Arch Allergy Immunol. 2008;146(3):255-61. Epub 2008 Feb 13.

Complement split products C3a and C4a are early markers of acute lyme disease in tick bite patients in the United States.

Shoemaker RC, Giclas PC, Crowder C, House D, Glovsky MM.

Center for Research on Biotoxin Associated Illnesses, Pocomoke, Md., USA.

Abstract

BACKGROUND: Current laboratory markers do not readily detect acute Lyme disease. We assessed the utility of complement and its split products as markers of Lyme disease in patients shortly after a tick bite. **METHODS:** Thirty-one consecutive acute Lyme disease patients, 14 with and 17 without erythema migrans (EM) skin rash, seen by a physician within 96 h of a tick bite were matched with 24 consecutive tick bite

patients without Lyme disease symptoms and 46 healthy control subjects. Complement and split products measured included factor B, Bb, C4, C3c, C3a(des Arg), C4a(des Arg), C1q- and C3d-containing immune complexes, and C2. RESULTS: C2, C4, C3 and factor B levels were within normal ranges in all groups. C3a and C4a levels were significantly higher in acute Lyme disease patients than in tick bite and healthy control groups (both $p < 0.001$). All acute Lyme disease patients, regardless of EM, had elevated levels of C3a or C4a. Few tick bite controls had elevated levels of C3a (2/20) or C4a (5/24) and only 1 of the healthy control subjects had elevated C3a (0/46) or C4a (1/32). CONCLUSIONS: These findings suggest that C3a and C4a may be useful markers of Lyme disease in patients seen shortly after tick bite, even in those without EM. (c) 2008 S. Karger AG, Basel

PMID: 18270493 [PubMed - indexed for MEDLINE]

*

I'm a little puzzled about something. Maybe if I summarize, someone can fill me in.

The Shoemaker et al study suggests that C4a is highly elevated in patients who have just acquired acute Lyme disease after getting a tick bite. They suggest that (presumably since conventional ELISA/Western Blot testing is so inaccurate), this could be a good diagnostic marker for physicians to use.

The Stricker et al study suggests that C4a is tends to be elevated in chronic Lyme with predominantly "musculoskeletal symptoms" and in AIDS. It is not elevated in chronic Lyme with predominantly "neurological symptoms" or in Lupus.

<http://www3.interscience.wiley.com/c...76238/PDFSTART>

Consistent with that is the finding that Lyme patients with a positive SPECT (showing evidence of changes in the brain apparently due to the Lyme) had lower levels of C4a than those patients with a normal SPECT (showing no evidence that the brain had been changed by the Lyme).

The study also looked at responses to antibiotics. In those subjects who "responded" to antibiotics (apparently with a decrease in symptoms), the C4a did go down. In subjects that did not respond, the C4a did not go down. (Actually what it says is "whereas lack of response was associated with a significant increase in this marker," which almost suggests to me that there was a die-off like effect where the level got higher. I'd have to read the whole paper to check.)

AIDS patients did not have their C4a levels improve as a result of antiretrovirals.

What puzzles me a bit are the findings about musculoskeletal Lyme vs. neurological Lyme. I'm aware that the first cases of Lyme were mostly "physical" (e.g. like arthritis), but was under the impression that it had become much more neurological in most patients in recent years. Certainly that seems to be the case with those Lyme patients who also meet the criteria for CFS (regardless of whether we're using Fukuda or Canadian Criteria definition).

But if CFS patients tend to have elevated C4a (as the exercise studies suggest), and Lyme/CFS patients are primarily neurological (which seems clear), then it's surprising that the neurological ones wouldn't have come up with elevated C4a.

I find it interesting to see that the antiretroviral drugs did not help AIDS patients to get the C4a levels down. Do AIDS patients get PEM?

*

The Stricker study does indeed say that C4a increased as a result of treatment with antibiotics in the Lyme patients who did not improve. I would guess that most LLMD's would say that the patients were not on the drug for long enough, and that if they'd continued to take it for a number of years, the C4a levels eventually would go down.

The summary of the article is below. It's hard to find much info out there about C4a, so it will be good to keep it here for reference.

What I find interesting is the suggestion that C4a is not associated with neurological inflammation. It more seems to be associated with physical inflammation, of the sort experienced by CFSers in post-exertional malaise (or "no-exertional malaise").

What I have found is that overcoming the PEM is a pretty low bar in terms of my efforts to achieve wellness. If I'm not avoiding toxic mold successfully, my ability to exercise is non-existent and my PEM if I force myself to do so is profound. But if I "merely" avoid mold scrupulously for a few days, I have no problems exercising without PEM. I can do so quite consistently and predictably. So can Erik, which is why he was able to make it to the top of Mt Whitney every August for 10 years in a row.

The neurological inflammation is much more difficult for me to get under control. This affects both cognition and emotions, but also just being "present" in the world. I think it's clearly related to the mold, since if I get a big mold hit it gets infinitely worse. But even the most careful mold avoidance doesn't resolve it completely.

The Valcyte actually does seem to have helped that. And not being as reactive to the mold has helped keep the neurological inflammation from flaring as much as I try to navigate a world where toxic mold is ubiquitous. But it feels like the neurological inflammation is still there, underlying everything that I do.

I wonder what "measure" it is that the "neurological" Lyme is causing to be inflamed. Apparently it's something other than C4a.

(Dr. Shoemaker actually has said, to my understanding, that C4a tends to be a more specific marker for chronic mold toxicity than chronic Lyme. So the idea that addressing just mold fixes C4a altogether, and also allows exercise issues to be resolved, makes some sense in that context.)

And I would bet a large amount of money that whatever that inflammatory "thing" is, it needs both Lyme toxin and mold toxin to really go haywire. It's not an additive effect, in my experience. The two toxins seem to work synergistically. I once said, subjectively, that it was like the mold was inflaming my brain and the Lyme was pouring salt into it. Based on what I know of the effects of satratoxin and of Lyme toxin, this might even be almost literally true.

I wonder what that neurological inflammatory marker would be.

I guess I could try antibiotics (on their own or as part of the Marshall Protocol) next. I will say that chipping away at this stuff is becoming a bit tedious, but collecting as much information as I can from the rabbit hole seems to have the potential of being of value anyway.

*

Discussion

C3a, C4a and C5a have been designated as anaphylatoxins. Recent studies, however, have cast doubt on the role of C4a as an anaphylatoxin, and the function of this molecule is presently unclear.

Whereas C4a is generated by the classical or the lectin complement activation pathway, C3a is generated by the classical, alternative and lectin pathways. C5a, which is a product of the terminal pathway of complement activation, has a very short half-life that makes it difficult to measure in routine blood samples.

In contrast, C4a levels are selectively increased in adult insulin-dependent diabetes mellitus, while C3a and C4a are reportedly increased in normal pregnancy, active SLE requiring immunosuppressive therapy and other forms of vasculitis.

C4a was also found to be increased in a model of CFS.

Of note, C3a appears to play a significant role in central nervous system inflammation associated with ischaemic stroke and subarachnoid haemorrhage, while C4a appears to have only a minor role in brain inflammation. The reason for this discrepancy is unclear, but it may reflect decreased constitutive production of the parent C4 compound or a diminished response to cytokines such as interferon gamma in brain tissue.

In contrast to C4a, an increase in C3a was only seen in patients with active SLE. As stated previously, increased C3a correlates with active autoimmunity, and this immunologic marker may help to distinguish chronic autoimmune pathology from persistent tick borne infection. As increased C4a was also found in patients with AIDS and to a variable degree in patients with SLE, this marker by itself would not be sufficient to diagnose chronic Lyme disease. In the absence of a positive AIDS test or autoimmune serology and the presence of significant musculoskeletal symptoms, the pattern of normal C3a and increased C4a appears to correlate with the presence of chronic tick-borne disease.

Sorensen et al demonstrated that C4a is increased in patients with CFS following exertional challenge. Chronic fatigue and fibromyalgia are prominent symptoms of chronic Lyme disease, and there appears to be significant overlap in these clinical syndromes.

It is noteworthy that patients with predominant neurologic symptoms of Lyme disease had normal levels of C4a despite the presence of chronic fatigue in most of these patients. A comparison between chronic fatigue patients who are seronegative for Lyme disease and seropositive Lyme patients would be of interest to help distinguish these disease entities.

It is unclear why C4a but not C3a is increased in patients with predominant musculoskeletal symptoms of chronic Lyme disease. The pattern suggests that chronic infection with *B. burgdorferi* is associated with activation of the classical complement pathway rather than the alternative and lectin pathways.

Support for this hypothesis comes from in vitro studies showing that the Lyme spirochete activates complement via both the classical and alternative pathways, but the spirochetes are capable of inactivating the alternative pathway, thereby allowing the infection to persist. Alternatively, increased C4a with normal C3a may reflect the inhibition of immune precipitation rather than solubilization of immune complexes in chronic Lyme disease. Thus, elevated C4a may be a marker of a failed immune response against the Lyme spirochete. Conversely return of this complement component to normal suggests clearance of the organism by antibiotic therapy.

C4a does not appear to play a significant role in inflammation of the central nervous system. This may explain why patients with predominant neurological symptoms of chronic Lyme disease have relatively normal levels of this complement split product. The difference in C4a levels associated with positive or negative SPECT scan results is



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intriguing. One explanation is that predominant neurological symptoms may reflect generalized inflammation rather than direct brain involvement in some patients with concomitant musculoskeletal symptoms. Alternatively, increased C4a may be associated with inflammation in peripheral nerves rather than the central nervous system in chronic Lyme disease. We have observed elevated levels of C4a in patients with Lyme-associated motor neuron disease that resembles ALS. In this condition, however, the increase in C4a may reflect the involvement of both upper and lower motor neurons. The interaction between nervous system inflammation and complement activation requires further study.

WRITINGS FROM 2011:

CFS Treatments

>There are 100 treatments out there which can and do kill pathogens. The problem is how to tolerate them when you have a non-existent stress response, and when you barely produce enough cellular energy to make it through the day.

My primary focus at this point is to encourage researchers to look at the role of toxic mold in our illness in the hopes that this will help them to understand the etiology better -- not to exhort patients to try extreme mold avoidance. The latter is, unfortunately, really hard.

However, one thing that all patients might consider is making an effort to reduce their toxic mold exposures at least somewhat, in the hope that it will allow other treatments to work more effectively as well as prevent further declines. As you say, there are lots of treatments out there that should work for us, theoretically. The problem is tolerating them.

To this end, reducing the pro-inflammatory stress on our systems in any ways that we can seems like it can only be a good thing. (Based on the interviews I've done of people who have "mostly recovered," avoidance of gluten -- another inflammatory substance -- also can be helpful for some people, as an addition to being in an environment that's at least "okay.")

I recently heard from a patient of Dan Peterson's who moved from a really moldy home to a better one, discarded a lot of possessions, washed the rest -- and got a "20% improvement" within four months. This individual thinks of moderate avoidance as part of an overall treatment approach (including aggressive antivirals) and is considering further ways to reduce mold exposure in the future.

I like that story.

*

It's clear that it's neither realistic nor desirable for any but a very few CFS patients to pursue extreme avoidance, regardless of how well they conceivably could get as a result of it. It is much too hard and often requires giving up far too many things.

Unfortunately, there is no testing that will tell people accurately even whether they're living in a moldy house -- much less whether they're getting exposure from the outside air or from their belongings.

I thus think that a good start may be to do the following.



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1. Look at trends in patients' health situations.

If patients are moderately ill and improving substantially as a result of other treatments, I would tend to guess that they likely are not getting a horrific amount of any kind of biotoxin exposure. Of course, improvements of any sort are always welcome, so looking to the environment may still be worthwhile insofar as they find that thought attractive.

If patients are very ill or do not improve no matter what other treatments they try, that is a clue that perhaps the environment is in some way really problematic and overriding everything else. I thus would consider options that involve avoidance -- for example, moving from a really moldy house in a really bad place to a decent apartment in a less bad place, leaving the contaminated stuff behind.

That kind of change obviously is stressful, expensive and challenging to pull off. Some people ultimately have found the benefits to be worthwhile though.

2. Start considering the idea that symptom changes could be the result of environmental exposures.

Many people with CFS are very good at figuring out the effects that drugs, supplements, foods, stress, exercise and other stimuli have on them.

Doing the same thing with environmental biotoxins is no more difficult. It's just a matter of considering the idea that some kind of "invisible odorless poison gases" could be having effects (and, in particular, acute emotional effects), rather than dismissing it.

Sometimes this is not a matter of just feeling better or worse, but different.

For instance, when I was living in my moldy house, I occasionally would stay overnight at the home of a friend that (I realized later) was exceptionally good in terms of biotoxins.

In my house, I always was in "agitated exhaustion" mode. At my friend's house, I slept like the dead -- 16+ hours a day. Getting out of the bad environment allowed my system to go into repair mode, it seems.

Understanding these kinds of surface weirdnesses seems to me crucial in terms of helping patients to figure out how they use the "locations effect" to help them, especially when nothing else is working.

Figuring out how to incorporate this mindset into a clinical practice is difficult though.

*

My experience is that if I am getting a modest amount of exposure to toxic mold or other environmental biotoxins, Vitamin C IV's are very helpful at letting me tolerate that last bit. At a high level of exposure, the IV's do nothing.

The theory here is that the Vitamin C serves to help to "erase" the oxidative stress created by the biotoxins.

I don't see a mechanism posited in the paper cited here, and so am not sure if the control of oxidative stress is what's helping to keep the virus in check. If it is, that would be consistent with our general theory -- that by decreasing exposure to oxidative-stress producing biotoxins, various sorts of pathogens (including retroviruses) can be better kept under control.

I've found Vitamin C IV's to be far more helpful than glutathione or anything else administered IV (provided that I'm in a reasonably clean environment.....nothing helps with too much exposure).

But people with ME/CFS have to be careful. If the dose of Vitamin C is too high, it will convert to hydrogen peroxide in the cells, thereby killing pathogens such as Lyme. This could be a good thing, but (as with most treatments) it can be very bad for people who are especially ill with this disease.

My impression is that anything higher than 15g will convert to hydrogen peroxide. Starting much more conservatively than this to gauge the extent of die-off issues seems a good idea.

*

My goal in bringing this topic up in public forums is not to encourage anyone to pursue any sort of extreme avoidance. That is, quite frankly, no fun at all.

The only reason that I've pursued extreme avoidance myself is because I've been on a mission to find out information about the phenomenon, in the hope what I learn will allow researchers to develop ways of treating the disease that don't require other people to go through what I have.

Let's say that I'm right and that accumulated toxicity from certain specific exposures is what leads to the activation of XMRV and other pathogens.

In my imagined ideal world, I would have gone to the doctor when I first got sick in 1994 and been diagnosed with the disease. The doctor would have advised me to look for



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and remediate any mold in my environment (something that would have cost me several thousand dollars) and would have prescribed me drugs (developed by pharmaceutical companies) to help me to detoxify effectively the stuff that was already in my system.

That would have been an end to my illness, allowing me to live the life (work, family, personal rewards) that I deserved.

Instead, I've lost 17 years and counting. Even if tomorrow I were magically cured, I can't get that time back.

My hope is that other people who come down with this disease can get a better shake, as a result of a better understanding the overall dynamic.

This is not an implausible scenario, I don't think. But from what I've seen so far, if I stop talking publicly about this phenomenon, it's never going to happen.

*

Some new data on treatments.

Below (for understandability) I reorganized responses from the Cure Together site by the % showing improvement.

<http://curetogether.com/chronic-fatigue-syndrome/treatments/>

About 1600 people with "CFS" responded.

I was surprised that half said that mold avoidance was helpful, since for most people this just means "moving." Biotoxin avoidance was higher (likely because only informed people know that word).

Ampligen and LDN (both immune modulators) scored 50%. It really does seem like those treatments should work on this disease, and it's frustrating that they're not more consistent. My hypothesis is that it's because people are getting so much inflammatory stress that it overwhelms the positive effects, and thus am excited to see this blog from an "extreme avoider" about to start Ampligen:

<http://ampligen4me.wordpress.com/>

I'd like to see more reports on oxytocin, the top-rated hormone. T3 also rated highly.

Antidepressants, CBT and GET helped about 20%. Thus, my guess is that of people diagnosed with CFS, about 1/5 actually have plain depression.

From 9/4/2011

% Reporting Mild/Moderate Improvement

80%+

Low stim environment.

70%+

Frequent rest breaks. Oxytocin (10).

60%+

Rest. Personal development. Mindfulness.

T3. Avoid biotoxins. Wheelchair.

50%+

Ignore people who think ME/CFIDS is not real. Meditation. Change job.

LDN. Ampligen (6).

Stimulants. Ritalin. Klonopin.

Avoid mold. Avoid allergens. Diet changes. Reduce sugar.

Orthomolecular. Sinus treatments. FIR sauna. Invert body position.

Qi Gong. Massage. Lymphatic Massage.

40%+

Go to bed early/sleep longer. Recuperation.

Treat yeast. Probiotics. Treat methylation.

Avoid alcohol. Avoid gluten. Avoid dairy.

Baclofen. Immunovir. Xanax. Antivirals. Ultramadol. Ibuprofen. Guaifenesin.

Oral magnesium. B12 Injections.

Stay well-hydrated. Electrolyte beverages.

Diaphragmatic breathing. Cranial Sacral. Chiropractic. Yoga. Stretching.

HBOT (7).

30%+

ARVs (7). Antibiotics.

Tylenol. Naproxen. Aspirin.

Provigil. Benadryl. Cymbalta. Trazadone. Neurontin. Wellbutrin.

D-Ribose. Myers' Cocktail. Malic acid. Topical magnesium. Vitamin D. 5HTP. Sublingual

B12. Cerefolin. Betaine Hcl. NAC. Liposomal glutathione. Testosterone. Melatonin.

Cortef.

Kinesiology. Reiki. Tai Chi. Orthostatic conditioning. Soak feet in cold water. Cool shower following exertion. EFT. Distract attention from symptoms. Amygdala retraining.

Ayurveda. Eat more produce. Root canal/cavitation removal.

20%+

B Vitamins. Omega 3, 6, 9. ALA. CoQ10. DMG. Carnitine. Iodine. Chinese herbs. Homeopathy.

Xyrem. Altenol. Celexa. SSRIs. Effexor. Amitriptyline. Antihistamines. Caffeine.

Detox foot baths. Chelation. Ionized water. Skin Brushing. Osteopathy.

Neurofeedback. Lightning Process. CBT. Psychotherapy. Exercise. GET.

10%+

Doxycycline. Doxylamine. Zoloft. Prozac. Paroxetine.

Ginkgo Biloba. GABA. Glucosamine/Chondroitin. EPA. NADH. MSM. Monolaurin. Inosine. Undenatured whey. SAM-E. Brainwave CD's. Rolfing. Rebounder.

Less than 10%

Vitamin E. Cat's Claw. Garlic. Alcohol.

*

I'm currently finding myself in the odd position of spending a huge deal of time working to create a solid case to demolish the research of the Wessely School, while at the same time benefiting from exercise myself.

Of course, I'm at the point now where I do not meet any of the ME ICC criteria (I used to be severely affected on every single one except joint pain) unless I go out of my way to expose myself to very large amounts of the toxins that are especially problematic for me. And therein lies the difference.

Insofar as CFS patients could exercise without PEM, it seems that it might be beneficial in ways that go beyond the avoidance of deconditioning and general positive effects that normal people experience from it. Erik Johnson, for instance, stated that if it weren't for exercise (sweating out the toxins), he likely would still be a semi-invalid. Exercise seems to serve to move toxins through the lymph system in the body, causing them to more readily move out rather than sitting there causing pain. And the Japanese researcher who found that CFS patients have small hearts suggested to me that conceivably, exercise could help to address that problem.

Unfortunately, as is clear in the following literature review (62 articles starting on P. 20), exercise has markedly deleterious physiological effects on CFS sufferers' systems.

www.tinyurl.com/CFS-medical-abnormalities

Since mold avoiders actually can exercise vigorously without negative consequence when clear (that's how Erik got to the top of Mt. Whitney), I would posit that somehow the inflammatory stress from the toxins is somehow integral to the negative effects.

Unfortunately, the Cure Together info is not available to people who don't sign up as members and (I believe) get another person to sign up too! But an important point is that for all antidepressants and all types of exercise, the vast majority of patients who did not report getting better said that they got worse as a result of these treatments.

So from that, I derived the conclusion that perhaps the people who got worse vs. better were different subsets (conceivably with some being misdiagnosed).

I certainly wouldn't be surprised if some patients who truly had ME benefited from some antidepressants though. This is a very weird disease, and all kinds of things seem to be possible.

Finally, for those CFS sufferers who suffer from depression (and many do, as a result of either the cytokine problems or the existential condition), it may be that any sort of psychotherapy from an empathetic therapist might be perceived as helpful. I recall one study where university students who talked about their problems once a week to science professors (hardly the most touchy-feely group) demonstrated just as much improvement as those getting counseling from professional therapists -- and far more improvement than controls.

Anecdotes

This week, in Palm Springs, I met another person who (like me) is mostly recovered from ME/CFS.

She got sick in a house with "black mold" (*Stachybotrys*) in San Diego. Now (like all the other mostly-fully recovered ME/CFS'ers I've met in person) she lives in a home that is so good with regard to toxic mold that I could live there myself and be fine.

She's traveled around a bit and says she feels best in Hawaii and Palm Springs. She does poorly in San Diego (in winter), Oregon and San Francisco.

She has focused most of her work in getting well on detox-related treatments, including saunas, colonics, herbs, neural therapy, B12/B6/folic acid (promoting methylation), reiki and ozone. (Some of these also address pathogens.)

Altitude has nothing to do with how she feels, she says. And (after doing in-depth interviews with about 20 people who have mostly/fully recovered from ME/CFS), I've yet to find anybody else who's gotten much better as a result of changes in altitude either.

Insofar as people experience spontaneous "Locations" recoveries, I'd like to hear



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reports of how they do in a variety of locations at the same altitude before making any conclusions.

I suggest starting with Berkeley (183 feet above sea level), as a comparison point.

Obviously it's extremely important to understand what's going on with XMRV. But as Erik Johnson's been saying for 25 years now, until that's figured out, the "Locations Effect" is a good way to feel better in the meantime.

*

Last summer, I spent some time interacting with a severely ill Cheney patient living in a moldy house in Ann Arbor (a town that seems to have become especially problematic for some of us with biotoxin reactivities).

This person spent a couple of weeks in Kansas (living in the very clean Victorian home of a recovered CFSer/mold avoider) and Colorado (staying in a clean hotel accompanied by this same recovered CFSer), in order to get clear and find out whether she benefited from avoidance.

Most of her symptoms went away during this time.

As a result of the experiment, she decided to move to Boulder, CO, because she thought that it was a place where she would feel psychologically comfortable and because other Moldies reported good things about it. She rented an apartment sight unseen, thinking that if she got there and it was bad, she could try somewhere else.

She got her ex-husband to drive her there and settled into the apartment (which turned out to be reasonably okay). She lived there for several months, recovering some of her health. Her son, who remained in Ann Arbor with her ex-husband, visited her twice during this time.

Then she spent some time house hunting (one of us Moldies' least favorite activities) and found a townhouse that felt great to her. My understanding is that her son is moving in with her permanently in a week or two.

She reports that while she is not 100% well, she is doing far better. Her main symptom at this point is POTS -- while she can go out for a number of hours during the day, she feels better if she can remain lying down the majority of the time.

I am keeping my fingers crossed for her.

This person got lucky that a Moldie was willing to take her into a good home and help her choose a good hotel, rather than going tent camping, for her "sabbatical."

But even if she had gone tent camping, the goal would have been the same: Get to a really great place so that you know what "pristine" feels like and see if you make improvements, then use that knowledge to go back and choose a good location in civilization.

If you skip getting to a super-good place upfront, you're wandering blind forever.

Here's a comment that this woman wrote to me a couple of weeks ago. I like it because it's consistent with Erik's conception (learned in the military) that people don't need to know what they're avoiding in order to be successful avoiders.

"I am beginning to realize that I am sensitive to all kinds of ick, including the ick that emanates from the energies of confused people. As I said, I'm not always sure what about a place or location doesn't work for me, but I'm clear that I need to move on."

*

>Funny. My illness went from bad to awful in this very same Boulder, CO, which seems to have a penchant for a higher than normal MS population per capita. I spent a lot of time outdoors too, but never noticed a difference in terms of symptomology. I would imagine mold, VOCs, chemicals, and other pathogens all can evoke "sickness behavior," but perhaps XMRV is the common denominator that allows it to be so.

Yep, it's hard to know.

There could be something in the outside air in Boulder that bothers you, but that doesn't bother some other people with ME/CFS.

You could be living in a small area of Boulder that is particularly bad. (Even Kansas -- a generally great state -- has certain places that are very bad.)

You could be especially reactive, and need a more pristine environment to do well.

You could be living in a bad home.

You could be living with possessions contaminated elsewhere.

You could be not affected by biotoxins at all. (I've yet to find anyone who's concluded they weren't reactive after doing the test according to Erik's instructions, but it's certainly possible that some people with ME/CFS are not reactive since no researchers have yet done any systematic study using the scientific method to see.)



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Until people get clear in a really good place, without contaminated possessions, it's impossible to know which of these might be the case.

And while I have much enjoyed traveling around to different places and scoping out people's dwellings, there's only so much of it that I can do.

If this effect were easy to understand, people would have figured it out long ago.

*

Erik suggests that it takes about five years for contaminated belongings to wholly die down. Thus, even if your possessions were contaminated at a previous residence, they might not present any sort of problem for you or anyone else now.

(BTW, over and over again, I have seen people move from a bad residence/location and then, 5-6 years later, obtain a remarkable recovery that they attribute to whatever treatment they were trying at the time. I'm not sure how that five-year mark corresponds to your starting ARV's though.)

I also am not sure whether heavy exposures to toxic mold or outdoor biotoxins were an initial factor responsible for your own illness. As you know, Ritchie Shoemaker suggests that Lyme creates an ionophore toxin similar to the toxins made by some molds, and that cross-reactivities between Lyme and mold are common (e.g. with people who get a Lyme infection becoming more sensitive to mold).

My own guess is that an inflamed "toxic terrain" is what causes XMRV to activate, but that this terrain could be toxified by exposures to Lyme or to mold or to ciguatera-contaminated fish or to cyanobacteria or to the outdoor "Tahoe toxin." (Mercury is pretty inflammatory too, so I wouldn't be surprised if it's playing a role.) This is very complex and needs to have someone other than the overextended Ritchie Shoemaker studying it.

My observation thus far is that all people with ME/CFS (including those who got sick following a Lyme infection) are very sensitive to biotoxins in their environments but that most have no idea that's the case until they make a systematic effort to investigate the phenomenon. I wish someone would do a study, so that we all would know for sure, one way or the other.

*

For 26 years, doctors have been hinting to ME/CFS patients that a pill to control the many pathogens in their bodies is just on the horizon.

And for 26 years, every single pill offered has been a failure at helping any more than a tiny percentage of ME/CFS patients to feel anything more than slightly better.

Meanwhile, every single ME/CFS patient who has followed Erik's instructions to the letter has improved markedly.

Yesterday, I heard from another person (prominent on ME/CFS boards) who has spent many years doggedly trying every treatment discussed.

Finally, after witnessing improvements of others and reading Ritchie Shoemaker's "Surviving Mold," she got an ERMI test on her house. When it came up as problematic, she bought some new camping gear and tried sleeping in a tent in her backyard. (She lives in a place where I did reasonably okay, when I visited.)

She got a good deal of improvement immediately and so decided to try camping in some spots that I suggested were particularly good. She writes: "I did great in the mountains. Now I'm at a friend's house, in (a big city). Not good here. Didn't like the air at all. Wish we had stayed in the rainy forest but we were tired of being wet! So far I haven't found a building I can tolerate. I'm impatient to get home, in order to take care of everything I have to do before the weather turns too cold."

(Of course, there are buildings out there that extreme responders can tolerate. Sometimes it does take some searching though.)

I've now had dozens of people share with me stories of feeling better or worse in particular locations, and even more ask me for suggestions on good places to go. Paul Beith and I therefore put together a board for people to share their experiences.

<http://locationeffect.proboards.com/index.cgi?>

My own experiences traveling in my RV to hundreds of places in 23 states over the past two and a half years are a start. Especially if folks have different experiences than mine, please share them.

Hopefully this, along with the compilation of Erik's writings on how to do extreme avoidance (along with other topics), will give people the tools they need to get started if they so choose.

Nobody's obliged to do any sort of avoidance, of course. It's certainly not an easy way to go.

It does work though.

Outdoor Toxins and the Locations Effect

Putting causal theory aside, here is what we know.

A high percentage of people with ME/CFS (Canadian Criteria) have a hyperreactivity to a variety of biotoxins, including toxic mold and toxic cyanobacteria. We believe that percentage to be 100%.

The hyperreactivity is like some people have to wheat, except much worse. Even an infinitesimal amount creates a hyper inflammatory response that knocks the whole system off balance. We get the same reactions to these biotoxins as normal people, except that even tiny amounts trigger them.

In 1980, Erik was living in the San Francisco Bay Area. He already knew he was heavily influenced by mold in buildings. This was long before there was even one article about toxic building mold being a problem to humans in the medical literature or in news media.

Erik started to encounter a substance outdoors that was hugely worse than any mold in buildings. He first encountered it at Berkeley, and then in other places throughout the Bay Area. He witnessed people drop dead of heart attacks when exposed.

(Note that shortly after this was about when Carol Jessop started seeing serious cases of this illness in the Bay Area -- read Osler's Web.)

He also got hit with it when hang gliding, above a forest that had been treated with fire retardants.

In mid 1984, Erik found that this same outdoor substance began being present in Incline Village and Truckee. It came mostly out of sewers.

In late 1984, a weird "flu" went through town. Erik observed that those people who were living in moldy buildings or getting a lot of exposure to this outdoor substance were more likely to get the flu and much more likely to stay sick if they did get it.

After getting the flu himself, Erik's reactivity to both toxic mold and this outdoor substance went up tremendously. Even tiny amounts of exposure to the outdoor substance gave him all the horrific symptoms described in Osler's Web. Eventually he found that if he avoided both mold and the outdoor substance -- using the protocols he'd

learned in the military to deal with nuclear radiation -- he could be basically well. If he stopped avoiding, he got sick again. He started climbing Mt. Whitney on an annual basis to prove how well he was.

His observations were that both mold and this outdoor substance affected other people in his cohort (the one used for the WPI "Science" paper) in exactly the same ways that they did him.

In general, toxic mold gives "neurasthenia" type symptoms (fatigue, cognitive slowing, etc). The outdoor substance gives the weird symptoms described in Osler's Web (and that also are associated with the disease Amnesiac Shellfish Poisoning, caused by the cyanobacteria toxin domoic acid).

The outdoor substance is much more present in some places than others. It is still present in extremely concentrated form in scattered places in the Bay Area and the Lake Tahoe area.

People in these locations who have CFS (defined by the Canadian Criteria) generally have extremely severe and weird symptoms. People who have CFS who live in certain other locations (e.g. Wichita, the Caribbean) have milder symptoms or can even have their illness spontaneously disappear -- providing they're staying out of moldy buildings and not dragging around lots of contaminated stuff.

Our suggestion is that it is exposure to this particular outdoor substance that transforms the disease from mild to a just-barely-living hell.

The main reason that CFS doctors give for ignoring both toxic mold and this outdoor substance is that "it's not the cause." The idea that patients could avoid being in horrific agony merely by avoiding it (and there are ways to avoid it that don't involve bioweapons protocols or living in a tent in the desert) seems not to register. As a result, patients continue to suffer infinitely more than they would have to.

*

My understanding from Erik (and he can correct me if I'm wrong) is that the outdoor biotoxin that seems to be particularly problematic to many of us with ME/CFS first appeared in Lake Tahoe in substantial quantity in 1984, just prior to the epidemic reported there by Cheney and Peterson.

He says that he encountered this particular toxin nearer to the coast, in the Bay Area, starting in 1980.

*

It's our observation that anyone with CFS can learn to detect the presence of this outdoor substance or of mold in buildings, and that (when contamination levels are



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great enough) many healthy people can learn to do so as well.

(Another source of biotoxin exposure for some people is the water supply, if it is periodically contaminated by cyanobacteria from Hazardous Algal Blooms. Check the source.)

One reason that people have a hard time identifying these toxins in their environments is because they are masked to them. It's the same principle as gluten exposure: if you eat wheat at every meal, your body doesn't know what it's like to be free of it. As with uncovering a gluten reactivity, a withdrawal-reintroduction trial can be effective.

Another reason is that people always attribute the effects of these toxins to something internal, and don't even consider the idea that something in the environment could be responsible.

Initial exposure symptoms to biotoxins tend to be unlike those experienced with other chemicals, so it's confusing. For instance, especially with the outdoor substance, there can be a sudden inexplicable desire to commit suicide. Or other kinds of inexplicable emotions may emerge -- depression, rage, anxiety, paranoia, loss of self-confidence. Or a "sensory storm" panic-like attack can set in. Or there can be a weird memory loss (like the inability to drive or remember how to get home), or a stabbing sensation in the chest, or heart palpitations, or a need to lie down, or severe trembling, or chills, or a sudden increase in heart beat rate or blood pressure.

There are longer-term effects from exposure to these biotoxins as well. These are just a few warning signs.

Even if people cannot immediately do a trial in a clear location, they often can get pretty far just observing how their symptoms change in different places and considering whether something in the environment might be triggering them.

One tricky factor is that levels of this outdoor biotoxin in particular places can vary a lot from moment to moment. Generally it is more concentrated at times of dropping barometric pressure and during the winter months, for instance. Wind currents can cause it to be a problem in some places only at certain times.

Cyanobacteria (HAB) contamination of the water supply tends to come in pulses as well.

I can only speak with confidence about the situation in the United States, unfortunately. It seems there may be a different sort of an issue going on in the UK, and I don't have

enough reports yet to make any conclusions about it.

Watching for changes in symptoms and then considering whether environmental factors could be playing a part is a good start in moving toward effective avoidance. Because heartbeat rates often spike upon exposure, some people have found the use of a heart rate monitor to be helpful for this purpose.

*

My experience in traveling around the continental U.S. is that altitude has nothing to do with how I feel.

I did terrific hiking at Rocky Mountain National Park (10,000 feet). I also did terrific hiking at Death Valley National Park (-180 feet).

I did terrible in Santa Fe. After a few days there, I recovered by spending time in Pagosa Springs (at the same altitude just over the Colorado border), where I felt great.

And a short trip to Lake Tahoe made me more sick than anyone without this disease could imagine feeling.

People with ME/CFS often do much better in some geographic locations than in others. Provided that they didn't bring along a lot of contaminated belongings and aren't staying in a moldy place, the difference can be dramatic.

The classic "Feel Good" locations are the Caribbean and Greece. But I've heard of some people stating that some parts of Hawaii -- especially outside the metropolitan areas and on the beach -- can be really good too.

Here, Dr. Sarah Myhill talks about the effectiveness of beach locations in improving ME/CFS sufferers' symptoms.

http://www.drmyhill.co.uk/wiki/Mould_Sensitivity

*

As far as I can tell, the Locations Effect has nothing to do with conventional air pollution.

The subsegment of ME/CFS sufferers who have chemical sensitivities (for instance, due to the shutdown of the methylation/glutathione system) may be bothered by conventional air pollution. Conceivably, this will lead to fatigue, amongst other MCS symptoms.

ME/CFS symptoms of the type specific to our disease are something different and, I would like to suggest, related to hyperreactivities to specific sorts of toxins that are not measured on air pollution indexes.

For those interested in the sort of effect I'm discussing, I suggest taking a look at the current print issue of Discover magazine. In it, there is an article on the connection between ALS and the cyanobacteria toxin BMAA. It is my belief that this particular toxin also is related to ME/CFS, and that additional outdoor biotoxins (toxins made by organisms such as mold, cyanobacteria or dinoflagellates) are related to our disease as well.

Those interested in how these sorts of toxins might interact with both XMRV and the herpes family viruses in order to create ME/CFS may want to check out this link.

http://www.imeassoc.com/Cause_of_ME_outbreaks_.html

The Locations Effect is something totally separate than living in a moldy house. People can live in a perfectly mold-free house (or in a tent) and still be really sick from what's going on outside.

The positive effects of a Good Location can be nullified by living in a bad building, however.

If people tell me that they feel much worse when they leave the house (especially if they have panic attacks when they go out), that makes me feel suspect that their residence is likely not the problem.

*

I'm getting a variety of people asking me whether their experiences with the Locations Effect could be due to altitude.

Some, as above, suggest that low altitudes could feel good because of the presence of a lot of oxygen.

Others question whether they felt good on a particular mountain as a result of the lack of oxygen.

A simpler theory is that if people are particularly sensitive to specific kinds of toxins, places without those toxins are going to feel good to them regardless of the altitude.

Certainly, some people are sensitive to altitude and need to factor that into their decisions about where to travel.

However, I've yet to observe anyone state that they get a lot better anytime they're in any place at a low altitude (or at a high altitude or at a medium altitude).

It seems to be only certain places at a low altitude (or a high altitude or a medium altitude) that do the trick.

I've felt equally great in places at 12,000 feet, at -200 feet, on the coast, in the woods, in the desert, on the prairie and even (occasionally) in cities.

As long as a place is not being influenced by the very specific sorts of toxins that bother me, it's a Good Location in my book.

*

During 2009, I spent about 10 days total driving around the area surrounding Santa Fe. I did not encounter any of the particularly problematic outdoor toxin that (we believe) was responsible for the severity of the Lake Tahoe epidemic, and that is present in quantity in places like Berkeley, Dallas and Ann Arbor.

What I found instead was what seemed to me to be a somewhat less problematic outdoor toxin that did not cross-contaminate very much, and that was not nearly as devastating, but that nonetheless made me quite sick after several days' exposure to it. Several other mold avoiders report the same response.

People who are living in a moldy residence or in a place with the "Tahoe toxin" are the ones that need to be concerned about their possessions when trying out the "Locations Effect," I believe.

The possibility that someone would journey a long way to a really good place and then fail to experience any gains because of the "stuff factor" seems unfortunate. Until there's a cure, successful management of the disease is all we can hope for.

*

I looked up some information about Kapaau, Hawaii.

The town is on the big island of Hawaii, which (according to Wikipedia) is a favorite of astronomers because it has little light pollution. Generally when there is not light pollution, there is little toxic pollution either.

The wind direction on Hawaii generally is from the northeast. Mapquest shows Kapaau being located all the way at the northeast tip of the island, putting it in a good position to receive unpolluted winds from sea on a regular basis.

At least once a week recently, I have been hearing from additional CFS patients who have gone into spontaneous remission while in Hawaii, and then relapsed when

returning home. Almost all of them live at sea level. Here is a comment I got yesterday from someone who lives in the Chicago area, for instance.

"I always feel almost normal if I am in the Hawaiian Islands. I have been to the islands 3 times and saw a lot of improvement each time. I am trying to save some money to get to the islands in the fall."

Hawaii has been better for this person than the Caribbean, Tucson or a variety of other places at sea level.

Concluding that the "Hawaii effect" described is due to oxygen levels rather than to clean air seems to me premature. A comparison of Hawaii vs. other places at sea level would be needed in order to draw any conclusions whatsoever, even for individual people experiencing the effect. I suggest a visit to Berkeley/Richmond, as the comparison point.

It will be interesting to hear how CFS patients traveling to Kapaau from places at sea level (and especially from places like the Bay Area or Lake Tahoe) do there.

I would suggest that these folks consider leaving all their (possibly contaminated) belongings at home, and ordering a few new clothes to wear while in Hawaii. LL Bean clothes always have worked well for me, for example.

It's hard to imagine that contaminated possessions alone can be enough to keep people wholly sick, but for people living in particularly problematic places or residences, it can occur.

CFS and Toxins

>These articles do not say that XMRV causes CFS or prostate cancer and there are many theories to be tested before anyone can say this conclusively. For example, one theory could be that the immune system of CFS patients (well-documented) is altered in a way to allow more opportunistic infections. This may prove true considering all of the other viruses that are found in CFS patients.

Do you have any thoughts on what might be causing this alteration of the immune system?

The Cournaud et al commentary in PNAS mentions "environmental agents." Have you

looked at what any of those might be?

I bring this up because there is very clearly an extremely strong toxic mold connection to this illness that goes far beyond sensitivities to other environmental substances.

I'm not saying that CFS is the same thing as Sick Building Syndrome. I'm saying that there's a specific connection to toxic mold as an underlying environmental agent.

Toxic mold creates a large amount of inflammation, and thus logically would put pressure on the retrovirus to activate. This especially would be the case when herpes family viruses and/or Lyme are present, since those also are very inflammatory.

I now have several dozen cases of individuals with classic documented ME/CFS who have demonstrated a severe hyperreactivity to toxic mold, following extended exposures to it. For example, a 30-second exposure to a moldy building is enough to keep them wholly sick for hours or days, unless they immediately shower and change their clothes after exposure.

But insofar as they are able to avoid such exposures (in buildings, on objects and in the outside air) for extended amounts of time, they are able to regain close to full wellness.

The phenomenon is hidden because of the "masking" that takes place, due to the fact that most people never remove themselves from moldy environments (including from their contaminated possessions) long enough to get their systems to settle down. What you will hear if you talk to people is, "Yes, I had an exposure, but I moved and it didn't get any better."

It's only when people make a purposeful effort to get wholly away from the mold contaminations that they start to get better. It generally takes a number of months in a good environment to turn people around, presumably because the infections need time to come under control.

This is not a cure. This is a clue. It's exactly the sort of question that you're asking -- why is it that all of these infections are reactivating?

It's been difficult to get doctors within the traditional CFS community to understand the importance of this -- somehow it always just comes across to them as an oddity. Their response is, "But it's unrealistic for people to avoid mold that scrupulously, so I can't do anything with the information. So what if you can climb to the top of Mt. Whitney -- I have a practice to run."

But your comment about the idea that something about the ME/CFS sufferers' systems may be causing XMRV to activate is right on track.

Thank you for your diligence in considering the complexities of all the factors that may be impacting this illness. That sort of sophisticated thinking is precisely what is needed

if we are to work toward a cure.

*

With small amounts of radiation from the reactors in Japan now being detected in California, Colorado, Hawaii, Washington and Nevada, this seems as good a time as any to discuss the idea of whether toxins are capable of causing disease.

Let me first say here that I am fully aware that neither the worst mold toxins (satratoxin) nor the worst aquatic biotoxins (domoic acid) are capable of causing all the abnormalities in ME/CFS all by themselves.

(Though if you look up their effects, you may find that they seem awfully familiar -- especially if you've just been reading Osler's Web.)

Nor is there any evidence that suggests that the stew of toxins present in "water damaged buildings" are capable of causing the all abnormalities in ME/CFS all by themselves.

However, dismissing toxins as being relevant because they don't cause all the abnormalities themselves may be acting a bit too hastily.

For instance, nuclear radiation does not just cause burns and cancer. Most of its effects are through the destruction of the immune system, causing all kinds of latent infections to go active.

http://en.wikipedia.org/wiki/Walking_ghost_phase#.22Walking_Ghost_phase.22

Not to be morbid, but "Walking Ghost Disease" sounds like about as good a name to replace ME/CFS as I've ever heard.

Could it be that if our immune systems weren't being undermined by the crap in our environments, XMRV would be a harmless commensal pathogen?

Maybe this is a whole new dynamic of illness: different toxins undermine our immune systems in different ways, causing different sorts of pathogens to emerge.

That seems like it would be important to know, if it's what's going on.

*

Even if we accept the premises that a) mold and other biotoxins are no more problematic for CFS sufferers than other chemicals (which I do not believe), and b) mold and other biotoxins are issues only for some CFS sufferers (which I also do not believe), there is another factor to consider.

People who are being affected by manmade chemicals usually know that is the case. Thus, they avoid them spontaneously.

People who are being affected by biotoxins almost never know that it is the case. Even when they are living in horrendously moldy homes (as I was), they don't know. Even when they are carried to hospitals on stretchers, they still don't know.

Thus, just saying, "Avoid what's bad for you" is not enough.

Rather, CFS doctors who want to make certain that their patients are not unknowingly being affected by biotoxins will need to take a particularly proactive stance in bringing them up and suggesting investigation.

It would be interesting to have a discussion on how that might be effectively implemented in a medical practice.

*

In 1984, Erik walked into Paul Cheney's office and told him that he had an "inexorably increasing reactivity to mold that gets progressively worse no matter where I live or how well I take care of myself."

At the time, there was absolutely nothing -- not one paper -- in the literature about the idea that toxic mold in buildings could have an effect on human health. So we perhaps can reasonably choose to forgive Cheney for not knowing what to do with that piece of information, even if his not pursuing it proactively was not exactly in the Oslerian tradition of listening to the patients.

Today, there is abundant information in the literature that toxic mold is a poison.

It's not an allergen or irritant. It is a poison.

It is not a chemical with the sort of toxicity that any sort of manmade chemical that people are likely to encounter in their day-to-day lives has. It is much worse.

Toxic mold, like CFS, has faced a dearth of government research funding. Nonetheless, there is plenty of literature that suggests that it is far more dangerous than any non-biotoxin chemicals that people encounter outside of industrial settings or, for instance, when nuclear reactors melt down.

Even with our pro-business governments, nothing like this stuff ever would get

governmental approval for widespread use. And certainly it would not for domestic home use.

Thus, brushing it off as an allergen or as just another part of MCS is inappropriate.

There are some individuals, such as Ritchie Shoemaker, who have suggested that toxic mold is the whole story in CFS.

I personally do not agree with that. Certainly, toxic mold has been shown conclusively to have the potential of creating CDC (Fukuda) CFS, and it seems to me reasonable to think that a high percentage of people qualifying for that diagnosis may have mold illness (regardless of whether they realize it).

“Real” ME/CFS (Canadian Criteria or Incline Village) is something more specific. I don’t see in the literature enough evidence that toxic mold, in itself, has the potential of creating all the abnormalities of the disease.

What instead seems to have the potential of going on is that the various factors associated with toxic molds such as *Stachybotrys* (inflammation, oxidative stress, cortisol stimulation, glutathione depletion, immune cell problems) are serving to activate various pathogens such as HHV6, EBV and XMRV. Once activated, those pathogens may create large amounts of damage -- especially in combination with additional mold exposures -- that the mold toxins themselves would not create on their own.

Would XMRV or other pathogens activate if it weren’t for the terrain issues caused by the mold? I don’t have speculation on that. What I do think is that it’s unlikely that they would go active as much in someone who was not getting any significant toxic mold exposure, compared to someone who was getting a lot.

And considering that the whole purpose of antiretrovirals is to get the virus to not be as active -- not living in a moldy environment is an antiretroviral treatment.

All of this is just common sense. Mold toxins lead to inflammation. Inflammation leads to viral activation.

The reason Erik keeps bringing this up is because even with the effects of the toxic mold in combination with the effects of various pathogens, there **STILL** is not any particular reason to think that the effects of CFS should be as severe and weird as the ones that his cohort experienced.

Those severe and weird effects that are associated with the outdoor substance present

in Tahoe and other locations to a particular effect have, however, been shown to be caused by various cyanobacteria toxins, such as brevetoxin or domoic acid.

<http://www.ncbi.nlm.nih.gov/pmc/articles/PMC2579735/>

http://en.wikipedia.org/wiki/Amnesic_shellfish_poisoning

That is why I suspect that this outdoor substance may be some sort of particularly problematic aquatic biotoxin that has mutated to be able to grow in certain sewer environments. I can't say that for sure until someone goes looking for it and tests it, though.

The other question here is why at least some of us are so weirdly reactive to even small amounts of these toxins.

At the very least, there should be no argument that living in a moldy home is a very bad thing in general, and particularly for anyone with CFS. That's consistent with the literature as well as with a multitude of "anecdotal" case studies.

*

Mold is not an allergen or a trigger. It is a toxin, one shown in hundreds of studies to create illness all by itself.

If you had a huge pesticide exposure, you would not expect to get better just by moving to a place where you weren't getting hit with more pesticides and doing a bit of detox. This is the same thing.

*

Insofar as ME/CFS is a disease with an etiology that is partly related to toxicity, it makes sense that second (and third) generation sufferers would be particularly affected at an early age.

To my understanding, a mother who is being affected by toxins will pass those on in a disproportionate amount to offspring through blood in the womb and then through breast milk. Here's a layman's book on the phenomenon, as it relates to pesticides:

http://www.amazon.com/Our-Stolen-Future-Threatening-Intelligence/dp/0452274141/ref=sr_1_1?ie=UTF8&qid=1307657310&sr=8-1

Children thus are born with "toxic terrain," without ever even having to come into contact with any environmental toxicity themselves. Insofar as this toxic terrain makes pathogens such as retroviruses more able to easily activate, this thus will occur at a younger age.



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In reading "Our Stolen Future," my main thought was that what we need is for scientists (and pharmaceutical companies!) to focus on how to get our bodies to detoxify better.

I seriously keep thinking about leaches, myself. But surely we can do better than that!

*

No doubt, there now are plenty of public forums focusing on the topic of toxic mold. There are even a good many doctors attempting to treat patients for mold illness.

The problem is that those folks are only looking at the "miasma" aspect -- the direct effects of toxic mold (and to a lesser extent other biotoxins) on the body. They dismiss the pathogens as irrelevant.

I do try to talk to them anyway, but by and large (at least at the moment) it's pretty pointless.

The interesting part of the question is the intersection of pathogens (especially XMRV) and toxic mold. Insofar as the phenomenon of ME/CFS makes sense, it seems to do so only when both components are taken into consideration.

*

Stories about people getting extended remissions as a result of treating candida or Lyme are really frequent amongst CFS sufferers. Sometimes they last indefinitely, often not.

Both candida and Lyme make a toxin that is very similar to the ones made by environmental biotoxins (mold, cyanobacteria, dinoflagellates, brown recluse spiders, etc.). Insofar as people can get those pathogens under control, their toxic exposures to go down, in much the same way that people's toxic exposures go down when moving out of a moldy house.

Apparently, getting total toxic exposures below a certain threshold is good for us.

As the illness progresses, that threshold often becomes higher. Just moving to Hawaii, or just addressing candida or Lyme, is no longer enough. This is where Erik's "extreme avoidance" concept comes in -- where eventually, the tiniest amount of this sort of toxin is enough to prompt a response. That level of avoidance is not much fun!

At the very least, biotoxins seem to be something that our bodies are "reacting to."

Removing the current toxic exposures (generated by internal and/or external microorganisms) has the potential of creating improvements or even wellness. Until a “cure” is found, that seems worthwhile in itself.

The question here is whether the toxins actually are responsible for the progression of the illness. If we can avoid getting sick(er) as a result of just controlling the toxins, that suggests that the toxins are not just a “trigger” but a root cause -- even if the illness would not be present if (say) a retrovirus were not also present.

I don't know the answer to whether the viruses in CFS would be a problem without our having had specific toxic exposures. I don't have enough cases. I do hear awfully frequently from people who trace permanent downslides to toxic exposures.

Unfortunately, most people have no idea that their environment is a problem until they get clear of it and then return to it. Until we can get everyone with CFS to do the exercise, there's no way to know what percentage indeed are affected.

Here's another example of someone whose illness progression seems to have been driven by toxins:

http://www.youtube.com/watch?v=TkUVIQNQGB0&feature=channel_video_title

My tentative belief is that the pathogens in our illness (including XMRV or whatever other retroviruses we have) are being activated by the “toxic terrain” of stored biotoxins (including toxins made by Lyme, mold, etc. etc.). If that's the case, one solution might be to get pharmaceutical companies to help us to figure out how to detoxify our bodies from those biotoxins.

Based on what I know about pharmaceuticals, creating drugs to help the body detox sounds a lot easier than developing ones to kill bugs. Plus I'd rather not be on those bug killers forever, and most people with CFS have a hard time tolerating them or using them effectively.

*

I didn't have any idea that mold was an issue for me for the first 13 years of my illness, including for a year after Erik brought up the topic to me. I didn't have any mold allergies at all and didn't think I was bothered by coming into contact with mold. This stuff works in weird ways.

Mold hides in walls and grows even in very dry climates. There's one building in Death Valley (humidity 0-15%) that knocks the crap out of me.

Whatever the outdoor biotoxin that's responsible for the Tahoe epidemic is, it's capable of growing in dry places. I personally think that it's a diatom or a dinoflagellate, not a mold. But whatever it is, it does not work in the way that we would imagine that a “mold”

to work.

*

Using the AIDS paradigm, it makes sense that a retrovirus would have the potential of reactivating all these other viruses.

However, perhaps in ME/CFS, a particular toxin acts the way that HIV does in AIDS -- causing all kinds of viruses to reactivate.

It doesn't seem inconceivable that a toxin could do that. For instance, from the HHV6 Foundation's site, here is a summary of a recent article.

<http://www.hhv-6foundation.org/>

Arbuckle JH, Medveczky MM, Luka J, Hadley SH, Luegmayr A, Ablashi D, Lund TC, Tolar J, De Meirleir K, Montoya JG, Komaroff AL, Ambros PF, Medveczky PG. The latent human herpesvirus-6A genome specifically integrates in telomeres of human chromosomes in vivo and in vitro. Proc Natl Acad Sci U S A. 2010 Mar 23;107(12):5563-8.

"HHV-6 integrates into the chromosome during latency and reactivates in response to chemical stimulation. Peter Medveczky and colleagues determined that HHV-6 uses a novel form of latency. The virus finds safe harbor inside the human chromosomes to evade the immune system. Medveczky made this surprising finding by studying patients who have a rare form of HHV-6. These patients are actually born with HHV-6 integrated into every cell of their body, and the virus is passed from parent to child. Many scientists believed that this integrated virus could not be reactivated, but Medveczky's group determined that chemical stimulation can cause the integrated virus to reactivate and start producing active virus."

Meanwhile, on its own website, the National CFIDS Foundation has expressed interest in the following paper, which suggests that certain aquatic biotoxins have the potential of reactivating herpes viruses:

Okadaic acid-like toxin in systemic lupus erythematosus patients: hypothesis for toxin-induced pathology, immune dysregulation, and transactivation of herpes viruses; Mitchell TM; Med Hypotheses 1996 Sep;47(3):217-25

This is of specific interest to me because of my own experiences with a particularly potent outdoor toxin having the characteristics of aquatic biotoxins (such as brevetoxin or domoic acid).

I was hit very badly with this poison when camping in the Lake Tahoe area a couple of years ago, and have encountered it (in lesser quantities) in other places as well.

Erik has informed me that this toxin was particularly intense ("like an asteroid strike") in the Lake Tahoe area in 1984-85, during the epidemic, and that it indeed remains problematic there to this day.

I also see in the National CFIDS Foundation's website that Dr. Yoshitsugi Hokama, of the University of Hawaii, received \$5 million from the NIH to study aquatic biotoxins, and that \$1 million of this was related to work he was doing with ME/CFS.

Certainly I think that we need to continue to carry out work into XMRV until we get the answers we deserve.

But I don't think that we should assume that XMRV is the only factor that has the potential of explaining the phenomenon.

There is at least one alternative explanation. Perhaps when the controversy with XMRV is resolved, one way or the other, someone will take a look at it.

*

I never proposed that a retrovirus is not involved in ME/CFS. People who know more about viruses than I do need to figure that out.

My proposal, as always, was that being poisoned by general or specific toxins might cause people to catch various pathogens (such as retroviruses) and/or have them remain perpetually activated.

Perhaps, then, without being poisoned, they conceivably might not be sick at all, or might be much less sick. If indeed that's the dynamic, it seems important to know about.

Epidemiology

>I don't see how one could explain the cluster outbreaks with genetics....that is, unless a very huge aspect of the populace is genetically predisposed.

Outbreaks could be explained by an "environmental agent" though.

Insofar as average cases of an outbreak are much more severe than the average cases of people suffering from the same disease in other places (e.g. as occurred in the Lake



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Tahoe epidemic in the mid 1980s), environmental agents should be the #1 suspect.

An infectious agent should not be expected to present more severely in one geographic cluster area than in others that occur at the same moment in time.

But an environmental agent certainly could (and likely would) be worse in some places than in others.

Insofar as the environmental agent primes people for becoming (especially) sick from the infectious agent, it may look like the difference is the infectious agent (e.g. that Lake Tahoe had some unusual virus or super-strain of a virus).

In that circumstance, a good idea might be: look harder for "background" environmental factors specific to that one geographic area.

Otherwise, you might miss something really important.

>Another point along these lines is the hospital outbreaks involving many of the staff, but not the patients. That couldn't possibly be genetics or infectious disease. What's left?

Again, environmental agents.

For example.... let's say that a hospital is contaminated with a lot of toxic mold. (You'd be surprised at how many are.)

Then let's say that it takes people a long time being exposed to toxic mold before they are much affected by it. (That's true too.)

Thus, the staff (who work there over time) are primed for getting sick. The patients (who are there for only a short period of time) are not.

Now, assume that the mold exerts its toxicity primarily by causing shifts in the immune system, making people more susceptible to certain pathogens.

Thus, when the infectious agent rips through, it settles in the systems of those people who are primed - the hospital staff.

This has the potential of being a bit more complex than most people imagine.

*

Categorization is a challenge.

Groups overlap. Relevant characteristics are not always immediately obvious. Specific cases have anomalies.

Finding a small group where the members look really similar is the easiest way to start. Once you figure out the core characteristics of that group, you can broaden out and see how other cases relate.

All the people in the Tahoe cohort got super sick with a bizarre form of this illness at the same time, in the same relatively isolated place, with a disease that looked remarkably consistent across cases.

Understanding the illness dynamic for these people is a first step. Following that, we can look at other people and figure out why they're different.

But we've got to start somewhere. Otherwise it's just a mess.

It's not a surprise that everyone in the Tahoe cohort came up positive for the same retrovirus. This was not a "CFS is everything and anything" group. It was an extremely discrete, carefully screened subgroup.

The studies that showed no association with the retrovirus did use the "everything and anything" definition. Maybe there was no one at all who would inherently fit into the Tahoe subgroup in those studies. We just don't know.

So, what I'd like to see a comparison (done by a good lab) of the Tahoe cohort vs. (say) the CDC Wichita CFS cohort vs. truly healthy controls (not just random blood donors).

If the Tahoe cohort all came up positive (again) and the other groups all came up negative.....then a good question would be:

What makes the Tahoe group different than the Wichita one? How come the Tahoe group all had XMRV active, whereas nobody in the Wichita sample did?

Figure out that and maybe we'll finally be getting somewhere.

*

>The widespread belief that CFS is comprised of subgroups, a belief derived from thousands of lab studies not showing consistent abnormalities in all patients, the clinical course of disease in separate patients with some having sudden acute onset while others have gradual, progressive onsets, as well as treatment response with it being common knowledge that what helps one patient might do nothing for another and make



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yet another worse, etc. All of these indicate a disease composed of subtypes therefore to find a common pathogen in nearly all cases, as the WPI has claimed it is able to do, doesn't make a whole lot of sense. Plus even the WPI has reported finding distinct cytokine/chemokine profiles which is yet another argument against common causation.

Whenever anybody mentions this “subgroup” concept, my first thought is, “Great, let's figure out what those subgroups are in order to learn more about the disease(s).”

That's usually not why people bring up “subgroups” though. As seems to be the case here, it usually is more like, “CFS can be anything or everything, so let's throw the whole disease in the waste paper basket and go look at some other disease that's more interesting.”

We'll never get anywhere that way.

Let's presume for the moment that it's the case that some people who have what the CDC defines as “CFS” have XMRV, and that some other people who have what the CDC defines as “CFS” don't have XMRV.

And for the sake of argument, let's say that in those people who have XMRV, it actually does something.

Wouldn't we want to know that? Just out of curiosity, if nothing else?

And if that's the case, wouldn't we want to look hard at the subgroups (such as the Incline Village one used in the WPI study) who had it, just to see if there was anything else interesting about them that wasn't present in other populations?

*

From the transcript by XMRV Global Advocacy, here is a comment on CFS by Ian Lipkin:

Q: Do you feel that this is something that you suspect the agent of being viral?

A: The thing is, to the guy who's holding a hammer, everything looks like a nail. So, you know, I'm a virologist. So it looks to me like a virus. But I also like, I mean, I also work with bacteria and fungi too. But it smells more like a viral infection. But it would not at all surprise me if it were a common viral infection to which people had an uncommon response. There are all kinds of models, but what we prefer to do is to see whether or not there's a consistent finding, you know, in some subset of people.

Like Harvey Alter (and just about all the other viral researchers looking at this disease), he seems to be expressing doubts about whether any virus is the underlying cause of the disease regardless of whether it is present in some or all sufferers.

I've yet to read much explicit rationale for these folks' doubts, but here are a couple of possibilities.

The first that generally when an illness is caused by a virus, it's possible with not too much effort to trace how it's spread. With CFS, it doesn't seem to be spread consistently through sex, or casually, or even blood. The vast majority of people who are exposed to CFS sufferers (or their blood) do not get the disease, even decades later.

The only suggestions that this disease might be contagious are family clusters and "town/building clusters" (such as Truckee High School). Conceivably the family clusters could suggest mother-child transmission, except that we also see father-child, spouse-spouse and (I believe) owner-pet concurrencies. This is not the pattern of a contagious pathogen. It's much more consistent with the idea of a shared environmental exposure making people more susceptible to catching pathogens (or having them activate), along with perhaps shared genetic susceptibility.

In certain towns (and especially in certain buildings in those towns), the disease seems to spread like wildfire. In other places, it does not spread much at all. This, again, is not consistent with the idea that a virus is driving the disease. The idea that a toxic exposure in these places is making people susceptible to pathogens (leading to an "uncommon response") makes much more sense.

The other obvious rationale is the diversity of courses that this disease takes. Insofar as viruses cause illness, they tend to have a fairly predictable course. (AIDS certainly does, for instance.) CFS, on the other hand, has a very unpredictable course. Two people with the exact same symptoms/tests during the first year may have very different life experiences thereafter -- some deteriorating rapidly, others remaining stable or almost recovering. Treatment response varies as well.

That's much more consistent with how an environmental toxin works -- with some people being mildly exposed and others being severely exposed. Think Hiroshima, for instance.

It's hard if you're a virologist (or, in our society, any medical researcher or doctor) to seriously consider the idea that the main cause of the illness could be that people are being poisoned, and that this is causing specific pathogens (including some particularly nasty ones) to activate. It's been less than 150 years since we've started really polluting our planet, and idea that the crap in our environments could be causing illness has yet to take root. Paradigm shifts take time.



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http://en.wikipedia.org/wiki/The_Structure_of_Scientific_Revolutions

The idea that this is a toxin-driven rather than pathogen-driven illness seems more epidemiologically consistent with the evidence though.

*

I recently interviewed a woman who came down with ME/CFS during the Lake Tahoe outbreak in 1985. She was working as a teacher's aide in an elementary school nearby, and stated that her illness occurred about six months after getting a mandatory vaccine for Hepatitis B and (possibly) other diseases. She said that this vaccine was required of teachers at all the schools in the area.

Might this be part of why the teachers at Truckee High School were hit so hard during the epidemic? Truckee HS also was a very moldy building at that time, putting stress on the immune systems of people who attended and worked there. A mandatory vaccine for teachers seems to have the potential for explaining why they were so hard hit, even compared to the students in the same building.

Perhaps someone might check on the history of vaccinations in the Tahoe area during that time period?

*

I finished reading "The Ghost Map," which turned out to be really enlightening. For one thing, I had no idea how literal Stephen Sondheim was being in his description of 1850 London, in Sweeney Todd:

There's a hole in the world like a great black pit
And it's filled with people who are filled with sh*t
And the vermin of the world inhabit it.

Cram 5 million people into a small space with no sewers or other effective way of disposing of human waste, and it's unsurprising that people would focus on the smell! That would be offensive enough that it would be hard to believe that no human health hazard was resulting.

As it turns out, inhaling the fumes of human excrement seems not to be that dangerous. The disgust generated seems instead to be a warning, to keep us from picking up various nasty pathogens (such as the one that causes cholera) as a result of eating

human excrement.

Thus, while the miasma (fumes) did not cause the cholera, not addressing the conditions that created the miasma led to situations where people ended up eating one another's feces, through contaminated water sources.

The emergence of cholera thus was a direct result of the changes in living conditions. The solution was not antibiotics (which eventually would create resistant strains) but to change the "background factors" -- creation of sanitary systems that separate human waste from food and water supplies.

Once in a while, perhaps, a "bug from hell" comes about that is a killer regardless of contextual factors. Perhaps HIV is one of those. More often though, pathogens seem to operate like cholera -- emerging as a result of environmental changes.

This, some of us think, is what's happening today. The big contextual change of our age is the large amounts of manmade toxins in our environments. This is problematic not so much because these chemicals cause disease all by themselves, but because (it seems) that they allow the emergence of microbes that we are not evolved to coexist peacefully with and that create toxins that are especially poisonous to us (much more so to us than the manmade chemicals themselves).

This dynamic appears to occur both in our bodies and in our environments. Insofar as our bodies take in more toxins than we can effectively process, our internal terrain is altered. The chemicals dumped in our rivers, lakes, sewers, forests, oceans and fields do the same thing to the environmental terrain.

The idea that only mutated strains of microorganisms might be able to thrive in profoundly altered terrain seems pretty reasonable, in my opinion. It's only when you think through the implications that it starts to sink in how profound of a paradigm change this may be.

A couple of possibly relevant points.

1. Absolutely reliably, if I go to a place that's not been altered with chemicals (even if it's frequently been visited by humans carrying a variety of spores), I have no problems at all. It's only places that have been treated with chemicals (like the fire retardants used so liberally in the Lake Tahoe area) that I encounter microorganisms that are problematic to me.

2. The vast majority of bad buildings have no offensive smell whatsoever. You'd think (according to the miasma theory) that if this were the "same old mold," our bodies would be evolved to find the smell offensive so that everybody would automatically get away.

The solution to the spread of cholera was the addressing of the contextual factors (such as building sewer systems), using drugs only for emergencies. Similarly, it could turn



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out that the best or only solution to the internal and environmental microbes that are problematic in ME/CFS is to fix the context -- by somehow addressing the toxins that are causing those microbes to flourish.

>Exposure to environmental chemicals, toxins and off-gassing products would be stressing the immune systems of all people, but changing those conditions doesn't allow our immune systems to recover and rid itself of the multiple chronic viral infections we have.

Once someone has contracted cholera from drinking bad water, ceasing to drink more of that water may not be enough to resolve the problem.

Similarly, evacuation from a toxic environment may not be enough to resolve whatever problems that toxic environment has already caused.

That doesn't mean that we should ignore the issues of contaminated water or toxic environments though.

Through the understanding of such contextual factors, we can possibly help to prevent others from getting the disease and possibly develop more effective treatments that go to the root causes of it.

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One takeaway from story of the London cholera epidemic is that human disease is caused by pathogens, and that breathed-in toxins are irrelevant to health concerns.

This seems to me an overstatement. Certainly it was the case that breathed-in toxins were not the cause of cholera, but suggesting that this means that we should ignore them in the investigation of every other disease throughout all eternity misses the point.

I think it's more enlightening to look at the story as how John Snow used epidemiology to figure out how the disease was spreading. Once he was able to trace the spread, the "cause" became clear.

That's something that's never been done in the field of ME/CFS. No one in any official role has ever presented even a vaguely plausible theory of how this disease spreads.

To my knowledge, the only person who has proposed any even vaguely plausible theory on this topic is Erik Johnson. His observation was that people who were living or

working in particularly bad environments in Tahoe in the mid 1980s were the ones who came down with the "Yuppie Flu" (later renamed by the CDC as "CFS"). People who were not getting as heavy exposures were much less likely to get the flu and much more likely to recover from it if they did get it, he reports.

At the time, mold was considered not to have the potential of causing anything other than allergies, and other sorts of biotoxins (such as dinoflagellates) had not been recognized as dangerous either. Thus, as was the case with Snow's, Erik's observations and hypothesis were ignored by all officials who were supposed to be studying the disease.

Even though molds and other biotoxins now are recognized as having effects that indeed would lead to the activation of pathogens like XMRV, Erik's hypothesis still has not been studied epidemiologically. I think it's time that that changed.

*

I think we have to be careful with this disease when we use words like "caught." Just because people in close proximity to one another get the same disease does not mean that it is caused by a pathogen.

For instance, people who live in close proximity are exposed to the same toxins, and those who are related by blood share the same genetics (including, conceivably, the ability or inability to eliminate those toxins from the system).

It also may be that toxins are passed from mother to child in the womb, meaning that children can be born with a high toxic load without ever being exposed themselves. If that's the case, then a relatively small amount of additional toxic exposure as they progress in life may be enough to tip them over the edge into disease at an early age.

As I said, I'm not discounting the idea that a retrovirus is playing a role in this illness and actually think that the phenomenon is better explained by including a retrovirus than by leaving it out.

I'm just trying to present as many different plausible hypotheses as possible with regard to what is going on, so that we have a better chance of getting to the truth.

Oxygen

Insofar as people are in a bad environment, it may be that oxygen is a bad thing for them. I certainly wouldn't discard the idea just because oxygen is good for normal folks and because the lack of it has a downside.

As with everything else with CFS patients, different rules apply and biotoxin avoidance

can change everything.

On our bodies not wanting oxygen, this is from a 2009 summary of a presentation by Paul Cheney, written by Sarah Myhill M.D.:

>Oxygen is clearly vital for efficient aerobic metabolism. It allows us as human beings to function at speed and this has massive evolutionary advantages. However, if we cannot handle oxygen this would result in massive pro-oxidant stress and we would quickly collapse and die. So what we actually do when we cannot handle oxygen is that we switch back into safe but slow anaerobic metabolism and hope that our body can repair its antioxidant defences quickly so that we can get back to normal life again. Almost certainly this is the mechanism of fatigue after any exertion whether that be the normal exertion of daily life, an acute illness, acute physical exertion, or whatever. Essentially if we cannot handle oxygen we switch back into safe, but slow anaerobic metabolism and effectively we mimic life as a foetus. As I say we have to do this because if we do not recover our antioxidant defences we die from oxygen toxicity! One example of how toxic oxygen can be – if you give 100% oxygen to a new born baby they will quickly go blind.

Biotoxins create lots of oxidative stress. That's their main mechanism of toxicity.

Perhaps ME/CFS is partly a result of our bodies' ability to operate with less oxygen, as a functional mechanism to produce less damage under conditions of high biotoxin exposure.

What sorts of damage might occur if a person did not have that ability?

Cheney suggested heart damage, such as the kind that he himself experienced (and that forced him to get a heart transplant).

That's the sort of damage that wouldn't necessarily be immediately noticeable, but which could have a long-term effect just the same.

If Biotoxins + Oxygen = Damage, one way to resolve the problem is to decrease the oxygen. This definitely has a downside though.

I would like to suggest that decreasing the biotoxins may be a better choice.

*

As with most things with ME/CFS, the tolerance of oxygen conceivably may depend on how sick people are and how much exposure to particular toxins they are getting.

For people who are only mildly or moderately currently affected, living in a reasonably good environment, oxygen conceivably could be a very good thing.

For someone who is very debilitated, living in a very moldy house in a place with very problematic outdoor air, oxygen conceivably could be a very bad thing.

It doesn't have to be one or the other. Maybe it depends on the circumstances.

Similarly, when I was living in my moldy house, even 250 mg of Famvir (a tiny dose of a mild herpes antiviral) made me scarily weak for many months after discontinuing the drug.

Eighteen months later, living in pristine conditions (good RV/tent in the Godforsaken wilderness), I was able to take a combination of 900 mg of Valcyte (a strong herpes antiviral) and 1000 mg of Famvir with almost no negative effects at all (just a little bit of mild tiredness). I benefited from these drugs substantially, I believe.

Not giving antivirals to anybody with ME/CFS because some people are harmed by them would be a suboptimal approach. But passing them out indiscriminately because I benefited from them while living in a tent in the desert is suboptimal (and -- I think -- dangerous) too.

Most of Cheney's patients are extremely ill. Perhaps that is why so many of them show negative reactions to oxygen (not just in terms of their heart reactions, but in how they feel) when he administers it to them.

Benefiting from relatively anaerobic conditions is counterintuitive, but it's not a concept that Cheney made up himself. For instance, here are a couple of papers from the agricultural literature about how worms react when given phosphine (a chemical that -- like toxic mold -- exerts most of its toxicity through oxidative stress).

Zuryn S, Kuang J, Ebert PR. Mitochondrial Modulation of Phosphine Toxicity and Resistance in *Caenorhabditis elegans*. *Toxicological Sciences* 2008 102(1):179-186. PMID: 17998274

Cheng Q, Valmas N, Reilly N, Collins PJ, Kopittke R, Ebert PR. *Caenorhabditis elegans* Mutants Resistant to Phosphine Toxicity Show Increased Longevity and Cross-Resistance to the Synergistic Action of Oxygen. *Toxicological Sciences* 73, 60-65 (2003) PMID: 12700416

In the studies, worms with a lower rate of respiration were able to withstand phosphine administration really well. Worms that used lots of oxygen died fast from the phosphine. The authors call this phenomenon "oxygen toxicity."



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Here is some basic information on *Caenorhabditis elegans*, including its use as a "model organism" to investigate life processes basic to all kinds of animals (including humans). The use of oxygen -- which is definitional for animals as a whole -- is one of those basic life processes.

http://en.wikipedia.org/wiki/Caenorhabditis_elegans

Conceivably, ME/CFS patients are like the worms with the low rate of respiration -- able to withstand the oxidative-stress causing biotoxins, but with sluggishness and other "side effects."

Insofar as people with ME/CFS can change their environment -- such as removing themselves from conditions of high biotoxin exposure -- so that they can tolerate and benefit from oxygen administration, that seems like it would be a really positive step forward for them.

Insofar as they remain in toxic conditions, sticking to non-stressful supportive treatments (such as the ones that Cheney uses in his practice) conceivably may be preferable.

It would be interesting to do a systematic study on whether ME/CFS patients in good environments indeed can tolerate more interventions than those in bad environments. That would provide insights into the disease in general as well as how to treat it, perhaps.

*

Here is Sarah Myhill's summary of Paul Cheney's work on oxygen toxicity.

http://www.drmyhill.co.uk/wiki/Dr_Cheney_on_heart_function

http://www.drmyhill.co.uk/wiki/Patent_foramen_ovale_as_a_cause_of_fatigue

In her summary, Myhill discusses the apparent role of various toxins in the phenomenon. She brings up pesticides, heavy metals, foods, alcohol and medications.

Unfortunately, there is no mention of toxic mold -- even though toxic mold is well known to induce large amounts of oxidative stress and many ME/CFS patients (especially in England) are living in very moldy homes.

Here is a small selection of the literature showing that *Stachybotrys* exerts a great deal of oxidative stress, for instance.

Rakkestad KE, Skaar I, Ansteinsson VE, Solhaug A, Holme JA, Pestka JJ, Samuelsen JT, Dahlman HJ, Hongslo JK, Becher R. DNA damage and DNA damage responses in THP-1 monocytes after exposure to spores of either *Stachybotrys chartarum* or *Aspergillus versicolor* or to T-2 toxin. *Toxicol Sci.* 2010 May;115(1):140-55. PMID: 20150440

Markkanen Penttinen P, Pelkonen J, Tapanainen M, Mäki-Paakkanen J, Jalava PI, Hirvonen MR. Co-cultivated damp building related microbes *Streptomyces californicus* and *Stachybotrys chartarum* induce immunotoxic and genotoxic responses via oxidative stress. *Inhal Toxicol.* 2009 Aug;21(10):857-67. PMID: 19459771

Shimazu K, Oshima Y, Nakahata N, Yoshida M. Satratoxin H generates reactive oxygen species and lipid peroxides in PC12 cells. *Biol Pharm Bull.* 2008 Jun;31(6):1115-20. PMID: 18520041

Wang H, Yadav JS. Global gene expression changes underlying *Stachybotrys chartarum* toxin-induced apoptosis in murine alveolar macrophages: evidence of multiple signal transduction pathways. *Apoptosis.* 2007 Mar;12(3):535-48. PMID: 17186382

Wang H, Yadav JS. DNA damage, redox changes, and associated stress-inducible signaling events underlying the apoptosis and cytotoxicity in murine alveolar macrophage cell line MH-S by methanol-extracted *Stachybotrys chartarum* toxins. *Toxicol Appl Pharmacol.* 2006 Aug 1;214(3):297-308. PMID: 16476459

Fortunately, at least in part as a result of public discussions on forums like this one, Cheney and Myhill have both started bringing up the role of toxic mold in ME/CFS fairly regularly.

Now, if we can just get some research into the topic, we'll be making some real progress.

Benzodiazepines

There is a good deal of study about the use of benzos to counteract the effects of the cyanobacteria toxins such as domoic acid, which are biotoxins that have effects on the hippocampus.

For instance:



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Debonnel G, Weiss M, de Montigny C. Neurotoxic effect of domoic acid: mediation by kainate receptor electrophysiological studies in the rat. *Can Dis Wkly Rep.* 1990 Sep;16 Suppl 1E:59-68.

Benzos have frequently been used by animal rescuers trying to save sea otters on the coast of California from the seizures that this toxin causes, for instance.

Insofar as people with CFS are particularly affected by such toxins, benzos conceivably may be an especially appropriate treatment, therefore.

Paul Cheney has been suggesting benzos as protective of the brain in CFS for more than a decade. I don't think he knows what the benzos are protecting the brain from, but the theory of using benzos to protect it is quite grounded in the literature.

Conceivably his observations about the oxygen -- which also are consistent with how biotoxins work -- are accurate too. If Oxygen + Toxic Mold = Damage (which indeed is true), then subtracting the oxygen can prevent such damage from occurring when a person is in a bad environment. The downside of having a relatively anaerobic systemic environment certainly is not negligible, but it may be better than the damage that otherwise would be sustained as a result of the toxin/oxygen combination.

I took 1.5 mg of Klonopin (a decent sized dose) every night for 8 years while unknowingly living in my bad house. I got much better sleep and felt less out of it. On a couple of occasions, I experimented with stopping -- just to see -- and got big withdrawal symptoms.

Shortly after moving to a really good place, I again experimented with stopping at the rate the didn't give me symptoms. I tapered off within a week and never needed them again.

This is consistent with Cheney's view that benzos do not cause dependence in CFS, and that they are just protective.

I've heard of lots of other mold avoiders who've had the same experience with benzos. Just this week, in Yucca Valley and Death Valley (both very good places in California), I collected two more such stories. I didn't suggest to either person that they try it -- they figured it out on their own.

I didn't bring it up to either of these people that I'd weaned off benzos with no effects

within a week after moving to a good location. The effect was so noticeable that it just happened for them, as a result of not getting any symptoms when experimenting.

I've gotten reports of it happening for a substantial number of others too.

Certainly I wouldn't encourage anyone else to do anything of any sort though. I'm not a medical doctor and not am encouraging anyone to do anything. I'm just supplying information here about what people have experienced, for the sake of better understanding the phenomenon.

A third person -- classic ME/CFS, XMRV+, huge Valcyte die-off -- came to Death Valley with all new stuff (tent, clothing, supplies) last week on 70 pills a day. While here, she felt so good that she dropped just about all of them, including the beta blockers (which had been essential back at home). She went from just about bedridden (severe POTS, severe PEM) to hiking all day every day, swimming, drinking three beers in one day, eating lots of sugar, feeling wholly normal, all symptoms gone except mild-ish cognitive remnants and cold intolerance). Then she went back home and all of her symptoms immediately came back.

I'm not suggesting that anyone go off benzos cold turkey. If someone were to ask me, I would tell them that I did not think it was a good idea.

I'm not suggesting that people go to the wilderness as a way to more easily get off benzos either.

It's the phenomenon of sufferers getting so much better, in so many different ways, when they get to a good place that the medical professionals should be attending to.

Interactions with XMRV

>I have seen the data, and XMRV can infect rats. Whether it causes CFS in rats unknown and may take years for CFS-like symptoms in rats to develop. Silverman's group is also working on a monkey model but the story is the same: CFS-like symptoms may pop up next week or never. Nobody knows.

Let's say that XMRV only results in CFS in people if they've already been exposed for an extended period of time to certain kinds of environmental agents (like certain strains of toxic mold and toxic cyanobacteria).

If that's the case, there's no particular reason to think that XMRV would result in CFS in monkeys or rats either, unless the environmental agent is present.

Thus, without the environmental agent, you could wait around for decades trying to get the rats and the monkeys to come down with CFS and never get anywhere..... even if



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the model were exactly the same as the human one.

*

>For me, as a doctor, the proof is in the pudding. A simple retroviral etiology explains the pathology perfectly. Antiretrovirals move the illness. Case closed. It's a retrovirus stupid.

Is the paradigm of illness that we want to pursue really so simple?

All we want to look for is main effects?

You either have a retrovirus or you don't? That's it? Nothing else matters?

Nothing whatsoever could possibly be going on with the terrain? We're not even going to consider the possibility?

This is a huge risk and a dangerous game. If the terrain matters, and researchers don't think about the terrain when they try to make the virus go active in the animal studies, then it's possible that it may look like the virus is wholly innocuous.

If that happens, then the idea that the retrovirus is relevant at all to making anybody sick may be dismissed. And then we're back to Square One:

Thus far, I've yet to hear from a single researcher outside this tight little community who does not seem to be leaning toward an interaction effect.

I don't think they're out to get us in some kind of worldwide conspiracy. I think that maybe -- just maybe -- they're seeing something that some folks here don't see and (frankly) don't much want to see.

Why some folks in this community might prefer not to see it, I don't know. As a random guess, perhaps it's because they think that following the AIDS model will allow us to achieve an "easy solution" like the AIDS patients got.

But an easy solution only is easy if it's a solution. And to get to a solution, we've got to figure out what's really going on -- by opening ourselves up to all the possibilities.

Here is what the Courgnaud et al commentary to the 2010 PNAS article says:

"These observations suggest a scenario in which retroviruses, MLV-related agents, and

potentially, other viral agents may cross-complement to promote coinfection and enable pathogenicity. The current data suggest that a variety of xenotropic and polytropic MLV can be found in North Americans with and without disease. To add to this bewilderment, it is likely that more than one environmental agent impacts on the development of both CFS and prostate cancer."

There are a number of obvious pathogens that might be factors here -- the herpes viruses, Lyme and even candida amongst them. And there are environmental agents as well -- biotoxins such as mold perhaps the most likely.

Addressing those factors has produced far more movement in terms of getting large numbers of people much closer to wellness than I've seen in even one person from the antiretrovirals.

I went from just about bedridden to basically fully functional. And look at the photos of Erik Johnson -- an Incline Village cohort member -- on top of Mt. Whitney.

<http://www.facebook.com/album.php?id=631131187&aid=212484>

And we're just the tip of the iceberg.

I'm not saying that people should follow our approach to wellness. I'm saying that this is a clue with regard to the etiology of the illness, and that if people don't pay attention to it, all the money and effort that the WPI has put into this might be lost.

These factors could make the retrovirus go active more quickly or have more severe effects. Conceivably, without the right background factors, you might not be able to get the retrovirus to go active at all -- certainly not enough to create noticeable effects in lab animals.

*

Unless this retrovirus is a total red herring, it does seem like those who have it would be at risk and that taking proactive measures might be something to consider.

I'm not sure that taking antiretroviral drugs would be my choice of measures though.

The more obvious things to do are the other ones we keep mentioning:

- * Avoid environmental biotoxins (e.g. moldy buildings, certain outdoor locations like the Lake Tahoe area)
- * Avoid mercury (e.g. fillings, vaccines, certain seafood)
- * Avoid exposures to biotoxin-producing organisms (e.g. Lyme, brown recluse spiders)
- * Support methylation (e.g. Metafolin, B12)
- * Address oxidative stress and mercury (e.g. ALA, zinc, Vitamin C, other antioxidants)



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- * Address subacute inflammatory infections (e.g. herbs, colloidal silver, HBOT, digestive enzymes to dissolve biofilms, gut health support)
- * Be particularly careful to reduce other pro-activation factors when pregnant, to prevent too much stress on the system at once
- * Proactively detox (e.g. sweating through exercise or saunas, cholestyramine, chelation, etc.)
- * Avoid toxins in general (even if they're not specifically inflammatory, increased toxic load could be a weakening factor)
- * Avoid immunological challenges (vaccines)
- * Avoid gluten and other inflammation-producing foods (when relevant)
- * Avoid medications known to promote activation of the retrovirus (e.g. certain antidepressants, valproic acid)
- * Don't go to extremes in terms of overwork or overexercise

If I'd done all these things upfront, maybe I still would have gotten sick.

I'm pretty sure I wouldn't have gotten SO sick though.

With this disease, it's a lot easier to keep things from falling apart than to put the pieces back together again.

>Sorry to be pessimistic. I wish you were right but I personally don't think so. Here's why: 1) 99.7% of the population don't do any of the things in your long list and are not sick. 2) almost all patients do some or all of the things you suggest. I did get two sick kids away from a house with hidden mold though. They will also get other treatment. But we have determined that, as a symptom reducer, mold avoidance is by far the best bang-for-buck for them.

I guess on my long list above, I should have distinguished the first item from the others to make sure I got across the idea that it is the most important.

Unfortunately, if people do all the others but do not successfully avoid the environmental biotoxins, that very well may not do them any good at all.

*

The WPI study used the original Tahoe cohort and other exceedingly sick individuals. If you read Osler's Web, you will see that their symptoms and markers went far beyond the Canadian Criteria. This was especially the case with immune system abnormalities,

such as extraordinarily bizarre B cells that are not seen in less affected ME/CFS patients.

I believe this was due to those people's disproportionate exposure to a particularly damaging outdoor biotoxin present in high levels in certain geographic areas. Regardless of the reason, though, it seems conceivable that XMRV occasionally can be found in the blood of extremely sick patients, but otherwise is just in tissues. That could explain the disparate results.

*

I don't think that mold should be studied only if XMRV does not pan out. Certainly it would be good if (as in autism) toxins in general gained more attention in ME/CFS, but having viral researchers consider toxins as part of the equation would be even better. If we knew that certain toxins made XMRV go more active, for instance, that would be a good variable to control in studies.

*

No one arguing here for the importance of looking at the role of biotoxins in ME/CFS has suggested that "mold is the cause" of the illness. I myself have stated over and over again that I do not believe that is the case.

What I am suggesting here is that the cytokine abnormalities caused by XMRV make us especially susceptible to the oxidative stress generated by toxic mold and other biotoxins, and that by removing ourselves from exposures to these toxins we can eliminate the negative effects that result.

*

I continue to think that there's some sort of "master controller" pathogen that works the way that people have told me XMRV works operating in this disease. The illness makes more sense to me with that component than it does without it.

But XMRV is not the only possible explanation for the phenomenon of every bug under the sun going active in this disease. Too many people seem to be thinking that if XMRV isn't "it," all is lost for all of us. I don't think that's a good position for us to be in, as patients trying to get well or as scientists trying to find out the truth.

*

Even if XMRV is exactly what its staunchest supporters say it is, maybe it only goes active under very specific conditions.

That would be much more consistent with the epidemiology of the disease than the idea that it's the Killer Bug from Hell.



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Below is Harvey Alter's comment from the State of the Knowledge conference.

The obvious suspects here are the biotoxins and herpes viruses, both of which are very inflammatory.

Here's Gerwyn Morris's nice summary of how the three might tie together.

http://www.imeassoc.com/Cause_of_ME_outbreaks_.html

*

Alter:

And lastly, I want to lay out the other postulate that I had. Whatever the etiology of ME/CFS is, it happens in a subset of patients, not in all patients who get any virus or multiple viruses. There must be something unique in the host that facilitates the syndrome. I don't think that has been sufficiently explored.

Q:

What do you mean by, it happens in some? What's the "it" that you're talking about?

Alter:

The syndrome that we call ME/CFS occurs in only a small minority of people who have a viral infection, whether it's a particular viral infection.

That's classic for viral infections. Some people get sick, some people don't get sick. Some people get over it quickly, some become chronic carriers.

But here, it seems to be a very small pice of the pie who go on to this very full syndrome. What is it about those people that makes that happen?

*

It's my understanding that HIV goes active pretty easily -- for example, that if people get it in a blood transfusion, their likelihood of getting AIDS is quite high without treatment. Certainly factors that screw with the immune system aren't helpful with that disease either, and I'm of the impression that one reason IV drug users are particularly

susceptible to AIDS is not just because of the transmission from the needle but because their bodies are debilitated from the drugs.

The epidemiology of CFS does not suggest a pathogen that robust. As Harvey Alter commented, it's only a "very small piece of the pie" who are exposed to these viruses who get the disease. Few people who have sex with people with CFS appear to get the disease, for instance. (An exception is people living in the same house, which could be related to the environment.) There is some sense that people might be able to get it through a needle stick, but it's far harder to follow the chain than it is with AIDS. I've yet to hear any studies suggesting that people who have gotten blood transfusions are more likely than the average person to have gotten CFS.

So my guess is that any causative virus must be fairly wimpy, activating only under certain circumstances. That seems to be what Alter is saying as well.

*

I think it's hard for anyone to deny that people in the modern world are exposed to a lot more chemicals than humans used to be.

I'm not talking necessarily about chemicals made by biotoxins here (though toxic mold is possibly the one that people routinely get the most exposure to). As it turns out (and this was a shock to me), even Erik's not just talking about biotoxins:

<http://cfsuntied.com/blog2/2011/09/21/the-bleed/>

The question is whether these chemicals have the potential of doing anything bad to us (and especially to subsegments of the population that are worse at detoxifying than others).

The amount of chemical exposure we get has been such a monumental shift in the conditions under which people live that I think it would be surprising if it had no effect at all. But of course, "scientists" usually discard the idea that anything could be bad for us until it's proven.

So the question is, what bad things might the accumulated crap we have in our bodies (as a result of more exposures and finite detox abilities) be causing?

I'm going to float a hypothesis. I don't know if it's true. It's just a hypothesis.

"There are lots of human gamma retroviruses floating around in the population, and there have been for thousands of years. Innately, they don't cause people any harm, because they rarely go active and come back under control fast if they do. However, insofar as people's bodies are filled up with a lot of crap, whichever ones are present -- which is different for different people -- go active and stay active, causing a range of related diseases that can be roughly categorized as CFS."

Is this consistent with what we are seeing in our search for HGRV's? In what ways does or doesn't it fit the facts?

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