

SURVIVINGMOLD.COM FREQUENTLY ASKED QUESTIONS

VOLUME 5



*“Surviving mold begins with knowing what’s wrong
...and developing a plan to beat it.”*

A COLLECTION OF QUESTIONS FROM
PATIENTS AND PHYSICIANS WITH ANSWERS
BY RITCHIE C. SHOEMAKER, M.D.

Surviving Mold F.A.Q. ANSWERS VOLUME V

1. ACTH, suppression by use of oral cortisone

I know cortisone can suppress immune system as well as suppress the adrenal output but generally those rebound after cortisone is stopped. How does CIRS change this?

I am uncertain what you mean when you say cortisone can “suppress the immune system,” but please recall that both ACTH and MSH are members of a hormone system called melanocortins. There is interaction between ACTH and MSH in the production pathway involving proopiomelanocortin in the hypothalamus.

For those with MSH deficiency, persistent suppression of ACTH following exogenously administered cortisol (or any of the related adrenal steroid compounds) is common and can be an ominous finding. Steroids have an important role in medicine; if the use will bring about needed physiologic parameters, then the risk of suppressed ACTH is not too great. But optional use of prednisone for dermatitis, a mild flare of lung disease or sinus problems, for example, is best avoided.

2. Air conditioners, window units

I found mold on the outside window sill and cover of my window air conditioner. Are window air conditioners safe for those with biotoxin illness?

Any air conditioning unit can create problems with condensation and possible microbial growth. Window air conditioners are designed to deliver condensation to the outside world with such delivery enhanced by having a slight angle of the air conditioner with a down hill side directed to the outside world. If there is evidence of microbial growth on the inside of your home related to the extra moisture created by the dehumidifier effect of the air conditioner, I would suggest that you have that looked at with a tape lift sample. This procedure costs approximately \$35 in a mycology lab. In my experience the normal organisms found around condensation areas from air conditioners are *Cladosporium* and *Alternaria*. These organisms can create some problems with allergy but are not toxin formers.

3. Amylose diet

Does a no-amylose diet need to be followed when taking Welchol?

No. The only time I use a no-amylose diet is when I am using either interventions with Actos (almost never anymore) or Omega 3 to either 1) lower leptin; 2) lower PAI-1; or 3) lower MMP-9. Once those tasks are completed there is no need to continue the no-amylose diet.

Having said that, many patients feel a lot better on the no-amylose diet, as without high glycemic index foods, and thereby bringing extra insulin into their bloodstream, patients avoid the slings and arrows of insulin, a hormone well known pro-inflammatory.

4. Animals with mold illness

Do dogs or other animals have mold illness?

There is no question that humans are not the only animals with inflammatory response syndromes. I have collaborated with veterinarians in the past looking at creatures as diverse as hawksbill turtles and green turtles; race horses and riding mares; horses with Sarcocystis and Lyme; dogs, cats, pelicans; and many more. The difficulty a veterinarian faces is use of laboratory studies to confirm the diagnosis.

5. Aromatase

How do aromatase and low MSH fit into fertility issues?

If we have up regulated aromatase due to inflammatory responses in CIRS, and this is incredibly common, we will see enhanced conversion of testosterone to estrone and then to estradiol. Such disruption of normal androgens can have fertility effects both on men and women.

MSH has a significant role in regulation of LH and FSH, the gonadotrophins that regulate production of sex steroids. If there is evidence of abnormalities of FSH or LH, correction of MSH is a desired part of treatment.

6. Bartonella

With 27 different known species of Bartonella and with only the ability to test for 2, how can one be certain whether Bartonella is present or absent?

This is an excellent question. To my knowledge, there are 28 species of Bartonella that Dr. Breischwert has identified as causing disease in dogs. It is not clear that these veterinary organisms will also create a zoonosis.

Galaxy Laboratories has been working for at least 4 years to develop sophisticated testing for Bartonella as even the available tests for Bartonella are confounded with false positives and false negatives.

Short of a tissue biopsy showing the organism with a silver stain, this diagnosis is usually made by guess in the US.

7. C3a

A physician writes, will C3a levels be elevated in other organisms of interest in tick born disease such as Mycoplasma, Anaplasma, Bartonella and Babesia?

Because Mycoplasma and Babesia are intracellular dwelling organisms, it is unlikely that they will present a significant bacterial membrane as a platform to provide for cleavage of C3 thereby raising C3a. We have no data on C3a levels in Anaplasma. The difficulty with confirmation of Bartonella is still a problem. In my mind the absence of reliable markers for the illness creates terrible problems for those trying to avoid assumptions. We are faced with using IgG and IgM studies from commercial laboratories with unknown reliability. It is possible that Galaxy Labs will be bringing reliable tests to commercial use in the future.

What these comments mean is that I can not tell you that Bartonella causes elevated C3a.

8. Cholestyramine, long term

I am a 4-3-53. I become ill rapidly will re-exposure to contaminated environments. Is it possible for me to take cholestyramine on a regular basis for a long time?

Given your reactivity and your genetic susceptibility, it will be necessary for you to observe your responses to additional environments besides your home carefully. I would make sure your home was shown (by HERTSMI-2) testing to be safe for you. If your home is not safe then you can not conclude that other areas are also not safe. Having a home fixed is the first step.

Cholestyramine (CSM) was used before for years to lower cholesterol (basically ending in 1987, the first year of the statin treatments!). People stayed on CSM year after year, putting up with the expected gastrointestinal side effects. For people who have been on cholestyramine for more than six months I do recommend use of a one a day multiple vitamins that will prevent depletion of vitamins A, D, E and K.

9. Cholestyramine and mag citrate

I don't like the taste of CSM or its texture; it's like trying to swallow sand. My physician has given me the product called Natural Vitality Calm, which is ionic magnesium citrate, citric acid, organic raspberry and lemon flavorings and stevia. Now the CSM mixture has a pleasant texture and is very easy to swallow.

My question is, is the cholestyramine still as good as before?

Years ago I used to ask patients to save stool specimens in their freezer before and after use of cholestyramine so that at some time in the future I would have been able assay for cholestyramine bound to a biotoxin in stool. That assay never developed. Needless to say I didn't advertise that one of my freezers was full of stool specimens. An attorney in a deposition remarked that my compulsion about measurements in stool certainly would make for interesting cocktail party conversation.

If we did have a stool assay we could say whether the Natural Vitality was creating a problem for absorption of biotoxins by cholestyramine. But we don't so you are "flying blind," a bit here.

There is nothing in what you have written, however, that sounds like there would be a problem as the positive charge of magnesium and citrate will each not bind to the positive charges of cholestyramine (see FAQ on Zeolite). Stevia does not bind to cholestyramine. I see no basis for the organic raspberry flavors either to bind to CSM but here you may need to ask your physician what the structures of the chemicals are in the flavoring. In the meantime, by having cholestyramine that you can tolerate I am sure that will be facilitating use of cholestyramine four times a day and not hating every dose thereby impacting on compliance.

10. Cholestyramine, mixing

Are there problems mixing cholestyramine with maple syrup?

To date, we have had no one show reduced benefit of cholestyramine by mixing it with liquid medications that did not have a large preponderance of negatively charged ions (one person took CSM with bicarbonate and complained of no benefit). Maple syrup was the preferred method of use of cholestyramine by one of our patients from Canada. I know of no differences in the light, medium or extra dark syrup and CSM.

11. Cholestyramine, used with fatty meals.

My physician has recommended small amounts of avocado or coconut oil to be used 15 minutes following a dose of cholestyramine. The idea is to stimulate bile flow. If this is reasonable should I wait longer than 15 minutes before using the oil based materials?

In my initial cholestyramine protocol I included an attempt to stimulate bile flow into the duodenum as cholestyramine was making its way through the stomach. The initial approach to use alternating doses of olive oil and milk of magnesia. This protocol worked very nicely but as time went by we found there was no difference in rate of healing whether a patient used a compound that was a cholecystagogue (stimulating gallbladder contraction) or was a fat-containing liquid.

I have no objection to you using fatty materials 30 minutes after cholestyramine but I would wait that long. Any presumed benefit of stimulating bile flow diminishes beyond 60 minutes after CSM.

12. Cholestyramine, used with non-sweetened almond milk.

Can I use cholestyramine with almond milk and water?

I have no experience with use of almond milk mixed with cholestyramine. Because we frequently will use cholestyramine with ice cream in children, I see no contraindication to almond milk.

13. CIRS and elective surgery

A physician writes, I have a 56 year old patient who is facing a repeat total hip replacement. Her mobility continues to decline despite multiple attempts at improving her quality of life. She has a TGF beta-1 of 12,000. Is the elevated TGF beta-1 associated with her ongoing bone problems?

TGF beta-1 plays a dual role in just about every organ system in the body including bone. We would like to know whether or not there are elevated levels of retinoic acid orphan receptor in bone to assess more carefully the role of TGF beta-1 in this case. As that assay is not even available on a research basis, all I can suggest is to treat the TGF beta-1 aggressively using the 11 step treatment protocol and then assess changes in bone density.

We know that osteoporosis remains an inflammatory illness with multiple variables contributing to increased activity of osteoclast activating factor. There is also evidence of suppression of osteoblast activity. This combination of increased bone resorption and decreased bone formation is a prescription for loss of bone density.

The literature is scanty but I suspect what we are looking at here is series of abnormalities of Th17/T reg imbalance promoting tissue based inflammatory responses.

The T reg assay performed by Quest Nichols in Chantilly, Virginia is researching performance of the test using an upgraded national code to make it easier to obtain. This decision will be forth coming over the next several weeks.

14. CIRS in organ transplant patient

A physician writes, I have a renal transplant patient who may have CIRS. What special precautions do I have to take?

The same diagnostic protocol for CIRS that is done in people without renal transplants is done in those with immune suppression. Cholestyramine is not absorbed and such will have no adverse affect on medicines given to renal transplant patients provided the drugs are not dosed at the same time. Please see the cholestyramine treatment module on this website.

There are a variety of inflammatory mediators that can be accentuated in patients who have had renal transplants. Before jumping into treatment before cholestyramine it would be reasonable to discuss the issue with the renal transplant physician, particularly if elevated TGF beta-1 is found.

15. Cleaning

Can electronics with ventilation holes be cleaned? How about framed art paper on a frame? Do dishes washed in a dishwasher need to be washed with quaternary ammonium compounds? Can non porous items be washed in hot soup?

All these questions are answered in Frequently Asked Questions as well as in remediation sections in the Surviving Mold book. I would urge that you take a look at the extensive materials on remediation since your questions are multiple.

The principals remain the same. Non porous materials can be cleaned with quaternary ammoniums compounds, porous materials usually can not.

As far as oil paintings go they can be safely cleaned by a restoration expert.

16. Climate and CIRS

Would finding safe housing be easier in the dry Southwest or does it make any difference?

The problem with illness acquired following exposure to the interior environment of a water damaged buildings is not dictated by location. The outdoor fungi may be important for a remarkably small number of people but the overwhelming majority of people are sickened only by indoor environments. Many people have moved to Arizona and New Mexico hoping to avoid excessive humidity. That approach is fine as long as there are no swamp coolers or plumbing indoors that could leak; or no roof changes that would permit water intrusion. A bad roof in Phoenix is not different that a bad roof in Boston.

Having said that, if you are one of the few that can't live in any constructed building and have to live in a tent or in a yurt, for example, then I would put the dry Southwest higher on my list of destinations.

17. Communication with other physicians

I am looking for a preprinted message from your site that would make it easy to give to my physician to assist in management of my illness.

I would suggest that you begin with the visual contrast sensitivity test on the site that includes a registry of symptoms. I would further suggest that you print a copy of the paper published in March, 2013 on use of VIP in that it has the lab abnormalities found in 1,829 patients compared to nearly 500 controls. It further outlines the treatment protocol. The site cannot diagnose people: that will be the job you take to your physician.

18. Cross contamination

In an effort to avoid re-exposure I have moved several times with each sequential HERTSMI-2 score showing increasing levels of *Aspergillus penicillioides*. Should I simply discard my belongings?

Aspergillus penicillioides is routinely observed in indoor environments with water saturation between 80% and 90% in areas of reduced ventilation. What this means is that the areas of greatest concern will be leaks in closets, in cabinets and underneath as well as rooms that are not well ventilated. It is more likely to me that the contamination that you are experiencing is due to the home as opposed to simple cross contamination where we would expect a greater diversity of organisms in addition to *Aspergillus penicillioides*. Fortunately, if the moisture leak is identified and corrected, remediation and improved ventilation will provide the least expensive “fix” that is seen in wet buildings.

19. CSM simultaneously with Bio Identical Hormones

If I take Bio Identical Hormones is that an issue with taking CSM?

Taking cholestyramine on an empty stomach, waiting 30 minutes (at least) before taking other medicines will not create an issue with other medications, including Bio Identical Hormones. If you are uncomfortable with just the 30 minute window of time after cholestyramine, there is no reason you couldn't wait two hours to have an additional confirmation that your stomach truly is empty.

20. Daughter with 4-3-53 going to college

I was hoping you could give me some insight on how I can protect my daughter from contaminated housing and unsafe school environments during her college years? My daughter has one of the dreaded haplotypes with ill health. Do I need to get a 504? Is there anything else you would recommend?

I will share some comments made by a patient's family as it is from the heart.

“We made site visits to numerous college campuses across the country and chose one that was continually upgrading their facilities. Texas Christian University (TCU) in Ft Worth, Texas seemed to be a good fit for our daughter since they were constantly building new dorms and classrooms. New construction was a major selection issue. Fortunately, she had options so we were able to be selective.

“Although she did the best she could with her choice, no campus is 100 percent clean. She immediately knew that some of the frat/sorority houses, dorms and other such places were not healthy environments and made the choice to stay away. Avoidance of certain activities seemed to be the best strategy for her as she attempted to participate in college life. We had already experienced the removal from classroom environment throughout high school and that was a horrible experience. Further isolation in college

was not an option. It was a must for her to get a full college experience. So she had to pick her spots. Nothing was perfect by any means. Some classrooms at school give her problems and she struggles with that continuously. Whenever she finds herself in that position, she deals with it the best she knows how. She knows the treatment protocol and does her best to stay on top of the treatment regimen. She has her CSM, VIP and whatever she needs to get her back on track when setbacks occur.

“The good news is that three years have zipped by. Our pride and joy is studying for finals this week and will complete her junior year as marketing major. She will be a graduating senior on time next year and has been accepted into the Neely School of Business. She leaves for her business school study abroad program at the end of this month where she will be in Barcelona, Cologne and Dijon, France with her classmates. Since she has been in college she has traveled to Germany over Christmas her sophomore year and toured Ireland last summer as well as side trips to London and Paris. I am so proud of this little girl who couldn’t get out of bed her freshman year in high school. Her entire high school experience was incredibly stressful and I know she suffered immensely. Fortunately, she followed Dr. Shoemaker’s specific protocol and he got her well. She is forever changed by her illness, but only for the good. I am proud to say that she is well and thriving.

“Everybody is different, but once college rolled around, I found it better to let her deal with her illness and manage it the best she could on her own. Rather than run interference for her and receive accommodations, we chose to deal with the issues privately and make adjustments on our own. It wasn't easy to take that route, but we had gone the adversarial route for many years in high school and found that it only created an environment of stress and discontent. That strategy seemed almost as unhealthy as a water damaged building. So we remained in the background providing whatever support we could possible give this young adult. Each year seemed to get a little easier.

21. Diagnosis

A healthcare provider writes, how can I determine that the illness I have is an allergy to mold versus a chronic inflammatory response syndrome (CIRS)? I took a mold collection test with airborne sampling and grew common molds.

This question remains fundamental to the basic concept of an acquired immune response illness (allergy) versus an innate immune response illness (CIRS). For those with an allergy to mold, removal of exposure will result in self healing and resolution of symptoms. For those with a CIRS, removal from exposure does not result in improvement. Acquired immune problems will have normal levels of C4a and TGF beta-1; CIRS will have abnormalities. Acquired immune responses will have elevated IgE but CIRS patients will usually have an IgE that is normal.

The labs that are listed in the March, 2013 paper on VIP provide an index of what is wrong with a CIRS patient. These abnormalities are not caused by allergy but by innate immune activation.

22. Diagnosis, minimum number of laboratory studies.

Our adult son has multiple complex health issues possibly related to his HLA DR and a mold exposure. His IgE is quite high and he has extreme eczema. What is the fewest number of test needed to confirm presence of CIRS?

Understanding that diagnosis of CIRS is a process involving much more than just laboratory testing, for those who have the potential for exposure and a multisystem, multisymptom illness, what we look for in laboratory studies includes HLA, MSH, TGF beta-1, C4a, MMP-9, VEGF and a T regulatory cell assay. I further will add ACTH/cortisol and ADH/osmolality if MSH is less than 35pg/ml. Use of this testing should be done in close collaboration with your attending physician. Skipping steps in a complex case is never a good idea.

23. Diagnosis, prolonged symptoms after exposure

I moved out of a house that had major water damaged 6 years ago. I was ill then as was my son, but we have not improved with removal from exposure. The house was brand new. Could this long term mold exposure be contributing to my illness?

For those with HLA-based susceptibility, and in the rest of the question you wondered if you had one of the haplotypes that confer such susceptibility, there will not be resolution of illness with removal from exposure. Chronic inflammatory response syndromes are initiated by response to antigens, which certainly would have been the case with your exposure several years ago, but are perpetuated by differential gene activation.

I would suggest you take a few minutes to review Frequently Asked Questions, Volumes I-IV on diagnosis as there is a wealth of material for you to review there. As I see your case now, however, it will be necessary to approach you as an unknown. We would need to make sure that you have no other exposures to water-damaged buildings that were ongoing; we would need symptom rosters; together with visual contrast sensitivity testing (the VCS on this site is adequate to help you get started); and if you have exposure, symptoms and positive VCS test results I would recommend the battery of tests that are listed in the diagnosis section of this website. You may have to open the main block that says symptoms to find diagnosis or you can enter diagnosis in the search bar.

For those with longer duration illness without treatment, such as yours possibly could be, the approach to therapy must include consideration long term of correcting the genomic abnormalities that you are likely to have.

A word about new buildings. Water intrusion has nothing to do with age. Newer structures can be put up quickly (and that can mean skipping steps or using shoddy methods), have not had passed the test of time to show absence of construction defects. There is a developing series of data that also show that older structures, build before 1970, are less likely to be contaminated by some of the many species of mutated fungi that we see since that time that are major sources of inflammagens in an interior environment

24. Diagnosis; some family members ill, some not.

Can some members of the same household develop CIRS while others do not?

Of course. The mechanism by which patients lose regulation of inflammation begins with genetic susceptibility and exposure. There is no guarantee that siblings will have the same genetic makeup in that they have one copy of the immune response genes (out of two), with one from Mom and one from Dad. It is quite possible that one child will have two copies of a gene that increases susceptibility for CIRS while others will have none.

There is no guarantee that using proteomic evaluations that we can tell when an individual is developing a CIRS before the full syndrome develops.

Genomics, however, is a different story. Here we feel strongly that our genomic data will give us an indication of who is developing CIRS *even before* the syndrome is full blown. What this would mean is that treatment could be instituted effectively early on when there are less complicating factors from longer duration illness.

25. CIRS

I note that in medical conditions such as type 2 diabetes and hypertension there is discussion of an abnormal presentation that appears before the full expression of the disease. We hear terms like pre-diabetic and borderline hypertension often. Is there a pre-CIRS state?

As in my practice, there are patients with multiple system, multiple symptom illnesses and mold exposure who still are able to pass the VCS test and do not have a full blown group of abnormalities and labs.

Over the years establishing what is the time course of conversion from HLA-based susceptibility and exposure to mold to presence of a CIRS has been a complex research effort. For those with less than the full syndrome, such as what you described, it is likely that HLA will not be mold susceptible. Secondly, there is clear evidence that as long as MSH and VIP levels are both normal the full blown syndrome does not develop despite exposure. In these patients, while we don't use "pre-CIRS," frequent (every three months would be fine) testing of C4a and TGF beta-2 makes sense.

26. CIRS, testing

I am looking for information about accuracy of testing for CIRS and HIV.

CIRS is readily diagnosed according to a standard protocol that includes potential for exposure, symptoms and laboratory findings. Visual contrast is an additional aid to assist in accuracy of diagnosis. False positives are incredibly rare when this protocol is used properly.

To my knowledge, HIV testing has been evaluated extensively over the last 30 years with an incidence of false negatives and false positives that approaches zero.

27. Depression

I have major depression. Can you tell whether it is inflammation or depressant episode?

NeuroQuant will help very quickly sort out if this is a mold problem versus an inflammatory problem. Similarly, having lab tests done including C4a, MMP-9, VEGF and TGF beta-1 can quickly show you if you inflammatory problems. Often times correction of inflammation must occur before adequate response to anti-depressants begins. Frequently seen as well is resolution of so-called depression when the inflammatory changes are fixed.

28. Diagnosis

My condition has worsened since our home was flooded in 2011. I failed the VCS test. What do I do next?

Please review the extensive discussions of diagnosis and treatment found in Frequently Asked Questions. We must begin by establishing whether or not you meet the criteria provided by the case definition. If your home was flooded in 2011, what does sampling for fungal DNA show now? If you are worse, do you have a multisystem, multisymptom illness? Does differential diagnosis show anything else to account for your symptoms and VCS other than the exposure to the wet building? You should have laboratory testing done to establish a basis for treatment and confirmation of the preliminary diagnosis of a CIRS. There are many FAQ on this topic; Surviving Mold is a must-read for you.

29. Diagnosis Lyme, coinfections

I was recently diagnosed with having Babesia and Bartonella though with not Lyme disease. Does cholestyramine have the same effect on the coinfections as Lyme?

I wish you had provided the documentation by which the diagnoses of Babesia and Bartonella were made in you. I see these diagnoses made on these “clinical grounds,” but there is no basis in my mind for such specific diagnoses without specific confirmation. If you have evidence of inclusion bodies in red blood cells shown on a thick smear; low haptoglobins; and free hemoglobin in urine, I think we would all agree that Babesia or other apicomplexans are likely to be present.

Testing for Bartonella remains in primitive stages. I am aware that Galaxy Labs is working very hard to bring these tests to clinical medicine. Having a reliable test for any of the 28 species of Bartonella known to cause illness in dogs would be welcome.

30. Dietary restrictions, carrots

I am fond of carrots but read that carrots are foods that should not be consumed while being treated for a biotoxin illness.

Carrots are full of amylose hence the sweet taste. For those people who are requiring use of Actos or high dose Omega 3, usually for 30 days, I will restrict carrots as I will restrict potatoes and other root vegetables. Once the target has been corrected by Actos or Omega 3 if there is no indication for the no-amylose diet.

31. Differential Diagnosis

I am not a medical person but I am trying to look at the blood tests to be done in performance of a differential diagnosis.

Differential diagnosis begins with assessment of what could be wrong with testing targeted to those abnormalities. For example; if uncontrolled diabetes is considered a blood sugar and A1C hemoglobin would be done. If liver disease or renal disease is considered (and they should be) then a Chem-12 will be helpful. Similarly, if lupus is considered on the list of concerns then a sedimentation rate and a ANA are helpful, understanding that false positive ANA's are disproportionately found in people who have high levels of TGF beta-1.

The problem with your question is that the differential diagnosis of a chronic fatiguing illness is one that essentially includes all elements, all illnesses reported over the history of medicine. Here is where your physician's attention to detail will be most important.

If the testing listed on the SM website has not been done, then please proceed to have the needed lab tests drawn. Please don't omit tests that we use (see the three new videos on You Tube). I remain concerned as to the "short cut approach" to diagnosis. There is no room to skip on details in illnesses as complex as these.

32. ERMI, use in litigation

We have a complicated situation here in Michigan. We had a leaky drain pipe that somehow was multiplied into a major mold contamination in part due to shoddy workmanship by a representative of our insurance company. We are facing a need for remediation of our entire house but the insurance company is balking at coverage for this expense. Our daughter is in ongoing treatment for Lyme disease.

How can I show that mold found elsewhere in the house is due to the kitchen pipe leak as opposed to another source? Would ERMI be of benefit?

The daughter's health must be protected with use of sequential C4a and TGF beta-1 testing now required urgently. You should follow visual contrast sensitivity testing to

look for a change in her, as exposure is not guaranteed to bring about illness in someone with Lyme disease.

Having said that, the likelihood is high that HLA testing would be of benefit. If she has mold susceptible genes, or low MSH (from her Lyme), then the likelihood of exposure not creating illness is quite low.

ERMI can show changes in fungal equilibrium from location to location in a home which would have been established by any leaks or areas of water intrusion that pre-existed the kitchen leak. I do not know how long the kitchen leak has gone on; minor leaks can contribute to prolonged disturbances in fungal populations that can be contributing to the fungal equilibrium.

I would suggest you contact Mycometrics to develop a sampling plan that would include upstairs versus downstairs; kitchen versus living room; bedroom versus bedroom in an effort to identify source not just of *Stachybotrys* but also of other important organisms, especially *Aspergillus penicillioides* and *Aspergillus versicolor*.

33. Exposure, living on a boat

I am becoming frustrated by my inability to find a residence that is safe for me now that I know what 4-3-53 means to people with chronic illness. I am considering living on a fiber glass boat. Please comment.

Living in a boat will not cause adverse health affects just by being outdoors. Given your susceptibility based on your HLA, please be as diligent as possible looking for evidence of cellulose based materials within the structure of the boat that could grow mold. Many boats will have compartments with reduced air flow below decks which create an ideal environment for *Aspergillus penicillioides*. Be sure to assess ventilation of compartments in your boat before purchasing the craft. People of the Chesapeake Bay area often refer to boats as “a giant hole in the water into which they through money.” I would suggest that you read the chapters about extreme avoidance by Erik Johnson (in *Mold Warriors* and *Surviving Mold*) to see how seemingly trivial amounts of mold in his converted camper made him ill.

34. Extreme avoidance

Regarding the use of pure avoidance as employed by Erik Johnson and others, what do you think is the mechanism for his improvement?

While I certainly have no basis to disagree with what Erik has repeatedly documented and his story remains compelling as to the true source of chronic fatigue syndrome in Incline Village, Nevada, I do not have the benefit of laboratory testing on Erik to clarify mechanisms of his improvement.

Given his extreme sensitivity and his multiple relapses over the years, I suspect you will find that there are elements, particularly in genomics, of his illness that are yet untreated.

35. Gallbladder

Does cholestyramine treatment have any relationship to presence or absence of a gallbladder?

The gallbladder simply stores bile and reduces the fluid content of bile. If there is no gallbladder, bile will not be stored in the liver but will be secreted in an ongoing basis into the duodenum. Having no gallbladder has no relationship in benefit of cholestyramine binding bile in the duodenum.

36. HLA

I have heard that the people who have the 4-3-53 HLA DR gene can not take cholestyramine. Is this true?

Intolerance to cholestyramine is not impacted by genetic disposition. Aldous Huxley told us the key to understanding is casting out false knowledge. I suggest you cast out knowledge that 4-3-53 means you can't take cholestyramine.

37. HLA

Does the 11-5-52B genotype cause immune system to not clear toxigenic mold spores in addition to toxins? Or do genotypes kill spores?

The HLA is neither involved in killing spores nor clearing mycotoxins. The HLA is simply associated with processing of antigens. We have seen repeatedly in multiple cohorts that the 11-3-52B shows up disproportionately in those who have the worst outcomes and the greatest elevations (statistically) of TGF beta-1.

The killing of mold spores is accomplished by alveolar macrophages. The illness is not related to spores themselves as a general rule only as there will be 500 fragments of spores for every single spore with each fragment able to set off inflammatory responses.

38. HLA

Are there published text book references for use on HLA?

Yes. Academic Press has two books of interest. The first by Lechler and Warrens is entitled HLA in Health and Disease, 2nd edition. The other book from Academic Press is the HLA Facts Book by authors, Marsh, Parham and Barber.

Given the fact that the field of HLA is moving so rapidly, comments in published books will often be out of date by the time that the book is in print. Pay careful attention to

detail. References found in the bibliographies found on the Surviving Mold website will be of benefit.

39. HLA

What are the mechanisms immune systems that cause mold illness in mold susceptible genotypes?

The HLA haplotype 4-3-53 is the best studied showing the presence of seven separate amino acids that are “permissive,” in that a variety of chemical structures, call epitopes, are not recognized by this series of seven amino acids. What this means is that if these epitopes are antigens, presentation to an HLA will no result in antibody formation.

40. HLA basis for susceptibility

Has there been any progress in research to determine the mechanisms by which antigen presentation will fail?

There are HLA papers published each month with recent discussion of 4-3-53 in Lyme disease. I have not seen any new HLA papers regarding clearance of mycotoxins. I continue to look however as it is just a matter of time.

41. HLA DR

I believe I read that you wrote that the genetic HLA haplotype 15-6-51 is one of the “better ones” to have. Why is that?

There is no better or worse on HLA; we are what we are. For patients with exposure to the interior environment of water-damaged buildings there is no increased incidence of illness in cases compared to controls for 15-6-51. In patients with Post Lyme Syndrome, 15-6-51 is one of the dominant haplotypes that appears disproportionately in cases compared to controls.

42. HLA, susceptibility

My wife does not have HLA-based susceptibility to mold. She wants to clean out our moldy basement. Can she, as part of the 75% without such susceptibility, get sick?

Over 95% of confirmed cases of CIRS due to exposure to water-damaged buildings will have one of the six HLA-based susceptible genotypes. That means that 5% do not. There is no guarantee that your wife will not get ill with significant exposure to a moldy environment. If she were to begin cleaning I would recommend monitoring inflammatory studies at baseline and then sequentially. Here is where VCS testing makes a big difference. If she has abnormal VCS before beginning exposure I would want her to get evaluated before cleaning the moldy basement. If her VCS is normal, and hopefully that

will be the case, then you can use VCS to monitor any changes inexpensively, quickly and reliably.

43. HLA DR testing by buccal swab

I am trying to have the diagnostic test HLA DR in Canada. My doctor sent a buccal swab. Is this the same test as a blood test?

Unfortunately, I have no experience with accuracy of a buccal swab showing individual HLA DR haplotypes. If indeed this swab is as accurate as a blood test then that would be a significant advance. I know that buccal swabs can be used to obtain DNA typing but looking for the genomics for HLA DR would be quite expensive.

44. Hypothyroidism

My physician says my symptoms from hypothyroidism are caused by mold. I have an “infection taste” in my mouth that is not improved by penicillin. I have had three rounds of antibiotics consecutively. Now one of my molars is protruding.

To date, properly corrected hypothyroidism is not a confounder for chronic inflammatory response syndrome. Autoimmune problems, such as Hashimoto's, are not caused by exposure to mold.

I am uncertain by what you mean as far as “infection taste” in your mouth. If this is post nasal drip from sinuses surely some imaging study will confirm.

Receding gums can be due to localized infection and inflammation. A periodontist's opinion would be valuable in this case to sort out whether this is a primary dental reason for your protruding tooth or something else.

45. Infection from mold

I have been ill for many years. I am wondering if my exposure to moldy hay could be making me ill from an infection. My home is also moldy.

The chronic inflammatory response syndrome acquired following exposure to interior environments of water-damaged buildings is not an infection. There is a peer-reviewed published protocol that establishes diagnosis and then treatment. These steps are covered in multiple issues of frequently asked questions (FAQ). Please take a minute to review diagnosis and treatment.

Simply stated, there must be confirmation of the potential exposure, with documentation of water intrusion and microbial growth. Secondly there must be presence of a multisystem, multisymptom illness followed by performance of differential diagnosis to establish what are the possible sources of making you feel bad for so long. Testing with visual contrast sensitivity (which can be done on this site) is extremely helpful looking

for inflammatory responses from biotoxins. If symptoms and VCS deficits are present then it is reasonable to obtain the labs listed in the diagnosis section of this website.

46. Interstitial cystitis

I am taking cholestyramine but can not tolerate that medication when mixed with cranberry juice due to my interstitial cystitis. Does this intolerance provide a clue to inflammatory responses?

Patients with IC (interstitial cystitis) will often have intolerances of particular liquids. Many people feel that cranberry juice has benefit because of its acid content when in fact there is far less acid in cranberry juice (from hippuric acid) than one might think. Similarly, the high potassium levels of cranberry juice are an item to be investigated further regarding your IC.

Any liquid can be used to dissolve CSM. There are pharmacies that will compound capsules containing CSM that may be of benefit. Also, use of Welchol tablets provides benefit in treatment as well.

Most patients mix up CSM with water and while this is not an appetizing drink it will accomplish the job.

47. Labs in pregnancy

Are the blood parameters of CIRS affected by pregnancy?

To date, the number of pregnant woman who have had labs done throughout their pregnancy is limited. We do see a rise in C4a and a fall in T regulatory cells in late third trimester but these are simply anecdotal data. We have no data on lab values found in amniotic fluid.

48. Labs in very young patients

Are children who are very young known to have lab abnormalities similar to adults?

Because of the wording on use of cholestyramine in the FDA-approved packet insert we do not routinely check laboratory findings in children less than 3 years. In a smaller group of patients, again on an anecdotal basis, we do see similar kinds of lab abnormalities of C4a and MMP-9 but TGF beta-1 has wild fluctuations. We have not seen MSH deficiency in children less than 2 years old.

49. Laboratory testing

Our local LabCorp has informed me that the HLA DR by PCR is non orderable. Please ask your physician to contact our office to make that we are both using the same

HLA DR codes. As we get multiple patients sending us copies of the correct HLA DR, I suspect there is a simple answer to your problem.

50. Legal representation

I am wondering if your website has a section for patients to use to locate attorneys who are well versed in Workman's Compensation claims.

To date, we initially established a section of our website for mold literate attorneys but found this created significant legal concern suggesting that we were referring patients to attorneys. I am sorry but we can not help you with such a list.

51. MARCoNS

I have just been prescribed BEG spray for markers. I wonder, can MARCoNS disseminate throughout the body? I am taking charcoal and bentonite clay.

Treatment of MARCoNS is the second intervention step in the Shoemaker protocol once you have been removed from exposure. You will need to have one month of Welchol or cholestyramine as a run up to taking BEG spray for MARCoNS. I have seen many people use charcoal and bentonite clay, trying to substitute for cholestyramine but have never seen any data showing efficacy either in correction visual contrast deficits or in reduction of inflammatory burdens. Please make sure your physician is following your case carefully and not making an assumption that clay is a proven substitute for cholestyramine. If it works for you that is fine. If so, please document.

We have no evidence that MARCoNS in its biofilm state will leave its mucous membrane colonization in the deep aerobic space of the nose. In years gone by I worked with a dentist in West Chester, New York who had an opinion that MARCoNS at the base of diseased teeth was a significant problem. We did a small series in which I would culture the deep aerobic space of the nose on one day and he would then pull a tooth and culture the bone socket the next day. We found marked consistency of isolation of the same MARCoNS as evidenced by antibiotic resistance patterns of the organisms found in the nose and the jaw. So it is my understanding that there is no reason to think MARCoNS could not be elsewhere; the fact that we have never isolated them from anywhere else doesn't mean it's not possible.

Please be sure to follow inflammatory parameters after your one month of BEG spray to verify improvement. Also, it would be of benefit for you to review the BEG spray/MARCoNS module available on the website. There is a tremendous amount of information there.

52. MARCoNS

I have received a nasal culture result from Diagnostic Laboratory Medicine that showed coag negative staph although a small amount. Antibiotic resistance to

penicillin and intermediated resistance to Clindamycin were listed. Is this a MARCoNS?

Yes. The intermediate resistance is considered to not be sensitive therefore it meets criteria for MARCoNS.

53. MARCoNS

I am in a home with a low ERMI. What is the dose of BEG spray for me?

The dose of BEG spray is two sprays put into each side of your nose each a total of 3 times a day. This means 12 total sprays daily.

54. Medication, antidepressants

Does cholestyramine have any effect on the antidepressants I am taking?

Cholestyramine will bind any kind of medication if taken within 30 minutes of a dose of CSM. Be sure to take your antidepressant after 30 minutes following CSM.

A greater question has to be, is the depression that you have been diagnosed and treated for been confirmed to be clearly due to psychiatric issue and not due to inflammatory changes in the central nervous system. I see depression diagnosed incredibly commonly in patients with CIRS with such diagnosis not supported when adequate treatment ensues. Here is where use of NeuroQuant testing will help you. In 10 minutes of MRI time, without contrast, and a cost of \$96 we can look for the distinctive fingerprint of mold illness in the brain which is quite separate from that caused by depression.

55. Mold, systemic

Where can I get blood levels to check to verify I have mold in my system?

The problem with illness acquired from exposure to the interior environment of water-damaged building has nothing to do with presence of mold in blood. For people who have illness 99% of the inflammatory burden that they face is due to inhalation of fragments of fungi, bacteria and actinomycetes. These elements set off inflammatory responses. Of the individuals that inhale intact spores, half of which will be nonviable, the human body is remarkably effective at internalizing engulfing living fungi and killing them. The incidence of Aspergillus infections is enhanced in immune compromised patients and is quite rare in people with such immune compromise.

To determine presence of living fungi in sinuses an aspiration of sinus fluid needs to be obtained. This is not done routinely in a primary care office but will require cooperation of an ear, nose and throat physician to put a catheter (tube) in the sinus openings to draw out sinus fluid. As there are multiple sinus openings on both sides of the nose, this process is involved and is not particularly comfortable.

We know that there are people who have carriage of fungi in their sinuses that do not have infection but instead have an inflammatory illness called chronic rhinosinusitis. For these patients the fluid should be aspirated for a culture and in addition should be analyzed for particular inflammatory markers including interleukin 13 and interleukin 17 as per the exemplary done by Dr. Sherris, Dr. Ponikau, Dr. Kern and colleagues at the Mayo. Of note is that these researchers relocated to SUNY Buffalo some years ago.

56. Mold testing

I have been treated for Post Lyme Syndrome but I remain ill. My physicians have suggested I look into mold exposure. What do I do? Do I do settle plates? Do I do blood cultures? Do I do mold urine screenings? Do I do antibody tests?

Use of fungal DNA testing in a building with HERTSMI-2 or ERMI remains the proper and cost effective approach to answering the question, “do I satisfy the requirement that there be the potential for exposure,” as the first step. Assessment of visual contrast and symptoms are next. Finally, use of laboratory testing, together (hopefully!) with NeuroQuant and stress echo measurement of pulmonary arterial pressure before and after exercise are all incredibly useful.

I am aware that other physicians approach diagnosis using some of the methods that you have asked about. I do not use them for anyone at any time. I am always happy to receive additional information/data to support use of these alternative diagnostic tests.

57. MTHFR

If someone is MTHFR positive will mold remediation and treatment protocol remain the same?

Yes. This is commonly observed finding, seen in about 80% of our patients. The vast majority of patients are heterozygous. There is no need to adjust treatment for this common genetic change.

58. Multisystem, multisymptom illness

I don't know if I have a mold problem or not. I did the 23andme gene test and I am positive for the HLDA mold gene. I took my VCS test and that is normal. My antidiuretic hormone level is elevated and I have a high urine osmolality test. I drink one glass of water a day. I have no mold exposure that I know of but I had a skin allergy test that showed environmental allergies. My serum iron and ferritin are both normal but are at the bottom of the normal range. Could this be due to mold exposure?

You have raised many significant issues that are best answered in a consultation and not just a short answer for frequently asked questions. I will try, however.

I am unfamiliar with the documentation from 23andme regarding adverse effects of the HLDA mold gene. I am happy to read such information. Please forward at your earliest convenience.

We do not look at urine osmolality; we look at plasma osmolality. The relationship of antidiuretic hormone to simultaneously measured osmolality is often disrupted in CIRS, independent of whether an exposure to a water-damaged building is the cause or not.

Allergy testing will look at acquired immune responses and not innate immune responses. The skin allergy test has no relationship to the CIRS from water-damaged buildings.

With normal serum iron and ferritin, even though those numbers might be low normal, there is no diagnosis that can be made. If there were problems with hemoglobin, hemolysins, transferrins, or intestinal malabsorption of iron, those would be important elements to know to assist you with your concerns about iron.

59. Muscle twitching

I have an annoying symptom of muscle twitching in my legs that creates a problem 24/7. Sleep certainly is disrupted. Do you have an opinion as to what could be the cause of these muscle twitching problems? My TGF beta-1 is 10750 and MMP-9 is 667. C4a is fortunately now in the normal range, down from 6800.

Even though MMP-9 is twice what it should be I would be more worried about TGF beta-1 and unusual neurologic problems, including muscle twitching, compared to any other parameter.

We have seen patients with facial muscle twitching and we routinely will use the term “tic,” for such twitching that is associated with abnormalities in the caudate nucleus. Peripheral twitching which can be very fine (fibrillations) or coarse (fasciculations). The profound muscle jerking seen in some classical seizure disorders is unlikely to be related to TGF beta-1.

Muscle contraction is a complex issue with possible contributions from magnesium, sodium and potassium. Lets make the assumption that your electrolytes are under stable control (sounds like). Some authors rely on doing red blood cell magnesium testing; but I am not convinced that this test is available in a reliable fashion. I know others disagree with me.

Please make a concerted effort to correct any visual contrast sensitivity abnormalities; be sure that you are out of exposure; be sure that coagulase negative staphs have been eradicated. I would then approach treatment of your high TGF beta-1 after the MMP-9 was normalized. Use of a sequential intervention process can help you determine the likely mechanism for a problem that is likely to be multi-factorial.

60. Mycology labs

Is there any lab in the country that can take an article from an old house and determine the causative agent? We have had air samples done.

A number of mycology laboratories can assess individual pieces taken from a contaminated environment. That singly selected item could bring in the possibility of what is called selection bias in that one item is not necessarily going to provide a full picture of what went on the whole house. If you had a vacuum cleaner from the old house that had a bag saved that would be the best way to look retrospectively at what could have been a problem when you are in that home.

Having said all of this, any mycology lab can tell you what is on the article that you want. I have relied on Mycometrics in the past and know that they will speak to you on the telephone and assist in further evaluation.

61. Mycotoxins

Do I feel that testing mycotoxins in urine makes sense and if so does using amphotericin nasal spray follow?

If a clinician has proven colonization of sinus cavities with fungi by using a culture, a variety of antifungals are available in nasal sprays that make a difference. Almost never, however, is a mixture of fungi in sinus lavage indicative of colonization. We usually see a monoculture. I do not see routine benefit from use of amphotericin in such case of chronic rhinosinusitis.

As far as mycotoxins testing in urine go, I look forward to the day when we will see a monoclonal antibody, not a polyclonal antibody, such that we can actually make clear differentiation of individual breakdown products of toxins and similar epitopes. For example, it is clinically important to see if ochratoxin A, ochratoxin B and ochratoxin ester levels are. I don't see anyone's urine test doing that. Without a monoclonal antibody, we can't really say what the urine test is telling us except that something is triggering an antibody. Does that mean the person is ill? No ill? Exposed? Not exposed?

62. NeuroQuant

A physician writes, I have ordered my first NeuroQuant study. Patient has a history of Lyme disease as well as a mold exposure. How do I interpret the findings?

I would suggest that you send the formal report, deidentified of course, to me so that I can go over the findings with you as well as share with you the mold scoring system and the Lyme scoring system presented in October 2013.

63. NeuroQuant

Please discuss NeuroQuant/MRI Spectroscopy. Is this widely available in New England? Do insurances cover these tests?

These are two separate tests done in a brain MRI. Spectroscopy (MRS) records six different chemicals in four areas of the brain (frontal lobes and hippocampus on left and right). Most important are lactate and the ratio of glutamate to glutamine. Insurers rarely cover MRS. NeuroQuant is an FDA-cleared software program that has an insurance code providing for third party coverage. The Cortechs website has additional information in getting the NeuroQuant paid for. Most MRI facilities will do NeuroQuant as part of an MRI of the brain such that billing for the MRI of the brain is separate from the NeuroQuant charge. Costs to have NeuroQuant run by Cortechs (we don't ask radiologists to replace the automated system that Cortechs has) are \$96. You also asked questions regarding coding. We have found that use of terms for diagnosis including microscopic interstitial edema and gray matter atrophy are used successfully by treating physicians.

64. Nose bleeds

I have had a few bloody noses this year that seem to appear out of the blue. Could that be related to exposure to indoor environments with mold growth?

Many people will have nose bleeds due to a variety of "benign" nasal conditions. Differential diagnosis can range from excessive nose picking to air that is too dry, deviated septum and sometimes sinus problems as well. Unusual inflammatory illnesses like Wegener's granulomatosis can also be added for the very unusual case. As far as wet buildings go, it is not uncommon to find acquired von Willebrands deficiency in those with CIRS. Two large studies, from Italy, each showed approximately 20 people out of 100,000 had this unusual condition of low ristocetin associated cofactor, low multimer formation and low von Willebrand's antigen. This abnormality was found in nearly 3% of mold patients!

We have been measuring the Quest von Willebrands profile (VWF; note the profile from LabCorp is not worth using) with data in over 4,000 patients. We see abnormalities in one or more components of the von Willebrands profile in nearly 66% of patients. Excessive clotting due to high von Willebrands antigen and high ristocetin associated cofactor (and also high factor 8) are additional problems that go along with this coagulation disorder.

Coagulation problems are commonly seen in inflammatory response syndromes as part of the over all innate immune activation that CIRS involves. If nose bleeds are associated with low levels of von Willebrands factors then treatment is disarmingly simple using DDAVP to mobilize endothelial reservoirs of monomers of vWF antigen.

We look for changes in vWF with re-exposure to wet buildings. On Day one of re-exposure, also called SAIIE (Sequential Activation of Innate Immune Elements), we see Factor VIII fall rapidly with recovery starting on Day 2. This doesn't result in bleeding. On Day 2 and then Day 3, we see a fall in ristocetin-associated co-factor. If bleeding is going to occur, it happened on Day 4.

65. Outdoor illness

How do I know if I am one of the few sickened by outdoor exposures?

The first approach is identify if you truly have a CIRS. If so, we need to look at interior exposures and verify that ERMI/HERTSMI-2 is normal for buildings you inhabit. Then once we have established that a given building does not make you ill then what we would do is re-expose you prospectively to defined areas outdoors using the 3 day SAIIE protocol. Please see the two PowerPoint's on SAIIE on this website.

Confirmation of outdoor acquisition is extraordinarily hard. Use of symptoms has been espoused by many including my friend, Eric Johnson. I certainly have no basis to argue with these observations, as they have been reproduced by others on multiple occasions. What I would strongly hope for you is that you would do some of the academic testing to show the presence of an inflammatory response syndrome as the basis for your illness symptoms should those symptoms be acquired following the outdoor exposure.

66. Panchakarma

Are you familiar with the treatment from Ayurvedic medicine called panchakarma which uses heated steam, oil massages, purging and oil based enemas? I have seen studies showing that it helps reduce cholesterol and increase VIP.

I would love to see the studies showing an effect on VIP. This is exciting news.

I do acknowledge that I have no understanding of Ayurvedic medicine and would welcome the additional information that you might share about practices that provide benefit from CIRS without adverse affects.

Please direct me to the study on panchakarma and VIP. This is an exciting bit of information and I would hope to follow up quickly.

Thank you for your contribution.

67. Pediatric low VEGF

A physician writes, I have a patient now age 12 who had exposure to the water-damaged building at age 2.5 and then had Lyme disease found at age 5. Patient has normal labs and C4a, TGF beta-1 but has persistently low VEGF. ERMI is 0. Patient is not in a school. How do I treat low VEGF?

A course of Omega-3 would be reasonable. The pediatric dosages are less than adults but we still are looking at dosing approximately 2.4grams a day. Persistent low VEGF despite Omega-3s in adults (but not in children) often responds to a graded exercise protocol.

Persistent low VEGF is a rare but significant problem in pediatric age group.

68. Pediatric mold

My story is long and somewhat complicated; I guess it sounds like many that are discussed in the book, Surviving Mold. At any rate, we moved from the Golf Coast to Massachusetts; my daughter remains ill. She has respiratory problems and now vocal cord polyps. How do I have her evaluated?

The role of pediatric mold testing is discussed in some detail in the frequently asked questions. We would want to know her HLA; MSH (do not do at Quest, use LabCorp); TGF beta-1; C4a (do not do at LabCorp, use Quest); antigliadin antibodies; anticardiolipin antibodies; and MMP-9. If you were able to find the Quest Nichols Lab for the T regulatory cell assay that would help, but as that lab is still reassessing their national codes, it might not be available as I write this in May of 2014. In any event, the possibility that TGF beta-1 is important is quite high.

Vocal cord polyps and nasal polyps are linked to high TGF beta-1 but high levels are not sufficient to be certain that polyp formation will begin.

69. Porous materials

I have an extensive collection of baskets made from sea grass. This collection was in a water-damaged environment. Can I clean them?

Until such time as we have protocols that are proven to remove particulates from porous materials like baskets, I would suggest you store your collection in sealed plastic containers. I am aware that some sea grass baskets made by isolated cultures along the coast of South Carolina are of museum quality. I wish that there were some way to make them safe for you. Perhaps when you have completed your treatment protocol and have taken VIP for 6 months, your reactivity will be reduced such that you can go back to including your sea grass baskets in your life.

70. Re-exposure

In people who have symptoms immediately after exposure, what symptoms do they have?

Each individual will have a stereotyped grouping of symptoms. There is no basis to diagnose particular inflammatory markers based on one symptom that appears early after

exposure compared to another. Many patients will notice headache, mild shortness of breath, cognitive impairment and blurred vision as their dominant symptoms but others will have numbness, tingling, unusual hot metallic taste and cough. The fact that these symptoms occur as grouping is the important feature and not the specific symptoms within the grouping.

71. Remediation, chlorine dioxide

We are faced with trying to remediate a very large home with extensive collections of antiques, paintings, oriental rugs and first edition books. How shall we proceed? We have been told that chlorine dioxide gas is useful. We note it was used to decontaminate anthrax in the Senate office building.

Historically there is no way to decontaminate porous materials such as carpets (whether they are expensive antiques or not is irrelevant regarding cleaning) or cellulose based books. Non porous surfaces in furniture can be readily cleaned but upholstery can not. Oil based paintings can be cleaned professionally.

I do not agree that chlorine dioxide gas is a reasonable choice in that less than 0.1% of elements that make people sick in water-damaged buildings are viable spores. Killing (by use of chlorine dioxide) organic chemicals makes no sense as the chemicals are not alive.

I don't object to using chloride dioxide gas if done by a person with experience but you still will need the cleaning as detailed in multiple places on this website.

72. Remediation, dry cleaning.

Does dry cleaning get rid of mold?

To date, none of the particulates found in the interior environment of water-damaged buildings including fragments of mold, bacteria and actinomycetes, have given persistent inflammatory results when contaminated clothes were dry cleaned. One might ask why clothing can be dry cleaned successfully but drapes can not. There is paucity of literature in this regard but since the fabric is used for clothing are usually not the same as draperies (with the exception of Scarlet O'Hara), I think that the different makeup of porous fabrics is important. Having said all that, I tell people to simply wash their clothes or dry clean and remove from exposure to prevent cross-contamination.

73. Remediation, steam cleaning

Is steam cleaning safe to use? It certainly is easier for the heavy cleaning that I need to finish.

Steam cleaning is satisfactory, especially for carpets provided the dry out will be accomplished in several hours. Some people have used steam cleaning to a point that a

clean rug stays wet for several days. This will only add to mold growth. Steam cleaning has not been needed for tile floors or hardwood floors in my experience.

74. Remediation, microwaving books

I have a variety of old master books that have been kept on a shelf in my mold contaminated residence. How can I decontaminate these books? Is microwaving satisfactory?

I am not a book conservator but would strongly suggest that you speak to an expert in rare books regarding the mechanism of decontamination of cellulose-based materials. Certainly books have been saved from a variety of water-damaged buildings by experts in the past!

I am unfamiliar with use of microwaving alone to assist with management of decontamination of books as killing organisms will only help for the one actually viable spore for each of 500 particulates. Microwaving does not curdle or coagulate toxins and inflammagens. If microwaving is used, I would strongly recommend that adequate cleaning be followed.

76. Remediation issues

I am working hard to avoid cross contamination. I have a collection of candles and wonder if they are safe to clean or do I need to discard them?

Candles may be washed in lukewarm water and then wiped down with a quaternary ammonium compound.

77. Remediation issues, indoor plants

Do I need to re-pot my indoor plants to avoid cross contamination?

No. To date, the ecological community of organisms found in soils of potted plants has not been a reservoir of inflammagens or toxigens. I have not restricted use of indoor plants in any patients although I am aware that some people are so sensitive that they most avoid plants. This number of people is quite small.

78. “Sicker-quicker”

What is the biological mechanism involved with acceleration of CIRS to which you have given the jargon term “sicker, quicker?”

The enzyme that makes C4a is abbreviated as MASP2. This particular receptor-based enzyme is important in activation of the complement cascade. There is a variety of sugar compounds that will activate this receptor provided the particular sugar moiety can be detected by the receptor.

Both mannose and ficolins sugars will activate this receptor and particular toxins too. Importantly, in mutations of fungal species acquired during the time in which benomyl was widely used as a fungicide there is good reason to suspect that the particular mutants are now ones that activate MASP2 but the parents did not. Whether benomyl is the problem or not however, has never been proven. The chapter in Surviving Mold on benomyl has a lot of information on this topic.

Nonetheless, the marker for a mutant created by benomyl exposure is found in the beta tubulin-1 compound. The genes for beta tubulin-1 are linked to the genes that move a methyl- or acetyl-group from inside the hydrophobic area of a mycotoxin to outside the hydrophobic area such that now this structure will be recognized by ficolins.

This movement of structures provides for fascinating speculation as to the emergence of inflammation related to exposure to mycotoxins following a man-made intervention and not a long term function of mycotoxins themselves.

Once there is activation of ficolins, the MASP2 develops the ability to autoactivate. We don't see autoactivation in most people but those who have it will suffer from rapidly rising C4a after trivial exposures.

79. Sicker-quicker, measurement

How can sicker-quicker be measured?

Repetitive re-exposure trials are the only way to show heightened production of C4a following controlled duration exposures to the interior environment of water-damaged buildings. I don't think this kind of experimentation will be viewed as ethical by an IRB review board.

80. Sicker-quicker, treatment

What can be done to down regulate MASP2?

Ongoing removal from exposure is critical to accomplish this task. The use of VIP for extended periods of time certainly down regulates MASP2. Whether that benefit is on a genomic basis or not is not clear at this time. Also treatment with erythropoietin in doses that require significant informed consent will be effective.

81. Skin changes

What sort of skin changes do you see in patients with CIRS? Does that include loosening of skin?

We see laxity of skin frequently in patients with CIRS who have wing span greater than height. Some of these patients will meet criteria for Ehlers-Danlos Syndrome. Other

patients who have significantly increased capillary permeability due to inflammatory responses will have noticed that as inflammatory recedes and permeability is reduced that the interstitial edema also resolves. This will result in loosening of previously stretched skin.

83. Thyroid cancer

I have been diagnosed with papillary thyroid cancer. There is also mold in my basement. Does mold exposure contribute to risk of thyroid cancer?

We only have data on 10,000 patients who have been affected by mold exposure. There is no increased risk that we can tell statistically in cases of CIRS from mold compared to a normal population as far as thyroid cancer goes.

84. T regulatory cell assay

Please clarify the Quest order for the CD4+CD25++CD127-/low.

The code used by Quest in Chantilly Virginia is 56880. Please note that these codes do not cover presence or absence of FoxP3. In your note you mentioned that specific nomenclature. The direct phone number for Quest Chantilly is 703-802-6900.

85. Toxins, storage in fat

What is the mechanism for fat cells to store and release toxins?

All of the fungal toxins are ionophores which mean they travel from cell to cell. In my early work it appeared that there was an additional reservoir in fatty tissue but as yet data to confirm this theory remains scanty. As there is movement of toxins from cell to cell, this necessarily means is that binding toxins to receptors (such as what we see especially with ciguatoxin) will occur. When the toxin is dissociated (breaks free) from its receptor, there is going to be a time that these toxins make their way to cells that line bile ducts. There the organic anion transport system will secrete these toxins against a gradient into bile. Bile then traverses through the bile duct system into the duodenum where constituents in bile can be bound by cholestyramine. Such binding disrupts enterohepatic recirculation preventing ongoing accumulation of toxins in the body.

86. Treatment approach

A patient from Iceland writes that he is ill with his beginning following exposure to a water-damaged building. He has been removed from exposure but is still trying to regain his health. He is starting to take cholestyramine and wants to know what more he can do? He also wants to know about his diet.

There is no special diet that I recommend for people taking cholestyramine with the exception that I do recommend increasing the amounts of soluble fiber as a reasonable

mechanism to avoid constipation. Soluble fiber (not insoluble) is found in a variety of fruits and nuts with soluble oat bran fiber possibly being the best.

You do not need to avoid mushrooms, bread, cheeses, wine or beer in my opinion understanding that some people are quite sensitive to those items when they have a CIRS from mold. We are in the process of looking to see if genomics are altered by these foods and if so would probiotics correct that abnormality.

87. Treatment protocol results

What can I expect as far as an improvement rate after use of your protocol?

We have looked carefully at people who did not have successful improvement with the 11 step treatment protocol. The two main sources of problems have arisen from ongoing exposure to the interior environment of water-damaged buildings and incorrect diagnosis. As long as the labs are drawn you will have guidelines to help you follow your illness parameters as you go from one step to another. If you truly have the CIRS you absolutely must pay proper attention to detail about additional exposures in day to day life. While NIOSH says 50% of the buildings in the U.S. are water-damaged, there are times that I think that is an underestimate.

Now that we have VIP and can show improvement in genomics as well as improvement in volumes of structures of the brain by using NeuroQuant, we are in an era where the fundamental mechanisms that underlie this disorder can be identified and treated.

88. Treatment resources

I have had multiple health symptoms since I was sickened following Hurricane Irene. My home developed very high levels of Aspergillus and Penicillium. I moved out and still remain ill. I have multiple lab abnormalities but as I am on disability this time, I do not have resources needed to assess care.

The treatment protocols that I use are not expensive once you have been confirmed to be removed from exposure. Most insurance companies will cover costs of cholestyramine or Welchol. I would suggest that you discuss your lab abnormalities with one of the physicians certified by this site (see home page). I do not agree that avoiding treatment because of financial terms at this time is justified as your disability is bad enough; you do not need ongoing progression of CIRS to add more injury.

89. Unknown mold

I am living in a home that has a truly obnoxious smell that affects my daughter and me. Curiously, my husband can not detect the odor. How can I identify if a fungus is responsible for the smell?

A mycology laboratory will be able to take bulk samples (or dust) and identify molds that are present. I know of no mechanism available in the U.S. to confirm that something that creates an odor, possibly a volatile organic compound, is reliably causing your health affects. In Australia, Vince Neil and his colleagues are working on a repetitive protocol to identify VOCs that create adverse health affects. That work is in the manuscript preparation phase. I hope that Vince will be done with his work within the next several months as this is an area without good data from U.S. labs.

I would welcome input from U.S. based labs regarding their ability to identify VOC creating adverse health affects in or adverse smells.

90. VCS

I just took the VCS test, failing in both eyes. Does this mean I have a good chance of having mold exposure?

The incidence of false positives in VCS is quite low. If you have a multisymptom, multisymptom illness and a VCS deficit, the likelihood that you have a chronic inflammatory response syndrome is 98.5%. This means there are 1.5% of patients who will be normal despite a bad outcome on VCS. In this group we find some known confounders as people with occupational exposure to heavy metals, hydrocarbons and solvents can acquire a VCS deficit that never corrects. VCS will not tell us which chronic inflammatory response syndrome you have, if indeed you have it. It will give clear direction that you need to be evaluated for entities such as cyanobacteria, dinoflagellates, Lyme and mold. Please review the diagnosis sections in Frequently Asked Questions Volume 1-IV.

91. VCS testing

I took the VCS test at home at the end of the weekend and I plan on taking it again after the work week. I suspect my workplace is contributing to my illness.

VCS will show changes that occur with treatment and with relapse. If the test is positive at baseline, from an unknown location, it is rarely possible to use VCS to analyze where the exposure is coming from without having had treatment first.

Said another way, if we can show your abnormal VCS has been converted to normal, then we can use your exposure prospectively, monitored carefully, to look to see where you were when VCS relapsed. You will have to be limited in what areas you are exposed to!

Simply seeing a change hyperacutely in Column E helps us to understand intensification seen in Post-Lyme syndrome patients but is not as reliable to show additional complications of additional exposures.

92. VCS

My daughter and I have had significant illness symptoms since we were exposed to moldy environments in 2010. My VCS test and that of my daughter was positive in 2012. I am trying to decide what should I do?

If you have a multisystem, multisymptom illness together with a positive VCS, the likelihood that the illness that you have is going to be a chronic inflammatory response syndrome is over 98.5%. I do urge you to have testing done before initiating treatment. The labs are listed in the diagnosis section of the Surviving Mold website underneath laboratory orders.

93. VCS

I took the VCS test and passed in one eye and failed in one eye. What does this mean? Could Bell's palsy cause a false positive?

In order to pass the VCS test (which means not showing a deficit), each eye must meet criteria. If you fail with one eye then the entire test is graded as a fail.

Possible confounders include occupational exposure to hydrocarbons, solvents and petrochemicals. If visual acuity is not better than 20/50 for one eye, that eye can not be tested. If visual acuity is better than 20/50 then that eye can be tested. Bell's palsy should not affect visual acuity although a dry cornea could affect visual acuity.

94. VCS, passing score

How many people will have CIRS and yet still pass the VCS test?

Using data that consistently show presence of 8% false negatives seen in VCS testing over the years, we have looked to see who those people are. There is a disproportionate increase in teenagers, especially teenage woman, in those that have normal VCS but abnormal laboratory studies in the presence of multiple symptoms.

The other groups of people that have routinely preserved contrast vision show a significant increase in particular occupations such as artists, photographers, interior designers, baseball players and tennis players. These individuals might have a physiologic basis for their "good eye."

95. VCS testing

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Simply seeing a change hyperacutely in Column E helps us to understand intensification seen in Post-Lyme syndrome patients but is not as reliable to show additional complications of additional exposures.

96. VCS, treatment

97. Visual contrast sensitivity, validity

I have performed a VCS screening test but would request references to validate use of visual contrast sensitivity.

There are multiple papers showing the benefits of visual contrast sensitivity in assessment of functional vision. In my last count there were over 4,000 references in PubMed. Please see the early papers on Pfiesteria and mold discussing visual contrast sensitivity in the resources list under published papers.

98. VIP, lipase

What is the incidence of increase in lipase while on VIP?

To date, the rise in lipase associated with use of VIP is uncommon, with less than 1% of patients having problems. I do recommend that a fasting lipase be drawn before beginning VIP and if that level is elevated then one should not start VIP. Common sources of elevated lipase include occult gall bladder disease (sometimes HIDA scans are needed) as well as measurement of lipase after a fatty meal.

If there is no evidence of biliary tract disease and lipase rises, I do not recommend continuing VIP as the rise of lipase is not dose related. If there is an asymptomatic rise in lipase (no evidence of pancreatitis) I have seen benefit from use of cholecystagogues taken frequently. Some of these modalities are old fashioned, including 5 cc of milk of magnesia or 15 cc of olive oil, with each consumed on alternate days first thing in AM (yuck!).

Laurie Rossi (San Luis Obispo, California) showed me some years ago that a “liver cleanse,” a procedure for which I was quite skeptical, actually does work quite nicely. This liver cleanse is based on use of apple juice and a variety of diet interventions.

99. VIP, tapering off

I have been on VIP for 5 months with great benefit. I am interested to know what the protocol is to reduce VIP.

Many people have simply stopped. If you have great benefit, and no more exposures, the next step is to see if the benefit is durable off meds. Stop and observe for relapse of symptoms. If none occurs then stat accepting your new life! If you start to relapse, look for exposures and re-check TGF beta-1 and C4a.

In our VIP titration study we started at 4 does a day and reduced the dose monthly by half until relapse occurred. We now know that the duration of treatment with VIP probably needs to be at least four months so our taper was technically too rapid

For individuals with multiple exposures and ongoing reactivity, I do not recommend that the VIP be stopped. Even at doses as low as one a day, VIP will provide some benefit for those that need the medication.

The reason that VIP is not required has to do with the binding of VIP to cellular receptors that create a reservoir of VIP when used over time.

It is this reservoir phenomenon that also assists individuals in determining their maximum daily required dose of VIP. Once the reservoir is saturated (with more time needed with worse VIP deficiency, or pulmonary hypertension, or dysregulation), raising the dose does not provide enhanced benefit.

100. Welchol

Will Welchol bind my supplements, thyroid, cymbalta and singulair?

Welchol is FDA approved to be taken with food and with other medications. We have not seen a rise in TSH in patients who have been taking Welchol and thyroid replacement but it is theoretically possible. If your Armour thyroid were bound by Welchol then a rise in TSH would say to not take thyroid with Welchol. This is not a minor issue; following TSH will help you.

With psychiatric drugs like Cymbalta even when the FDA says there is no problem, I tend to wait two hours after a Welchol dose before taking meds like Cymbalta.

Singulair is a medicine to date has had no evidence of reduced benefit when taken with Welchol.

When you say you take supplements, I am wondering about binding with Welchol. perhaps if you sent a list it would be easier to answer you with some certainty

What is The Surviving Mold Membership Program?

A Surviving Mold membership is your gateway to a more interactive Surviving Mold experience!

Your membership grants you access to the world's leading expert on biotoxin related illness.

Your membership allows you to submit any and all questions to Dr. Shoemaker and each week, he will answer the most pertinent questions (at most 4 per day) and they will be distributed via our exclusive email blast.

Your membership also gives you access to member's only special offers and other free materials!

About the Membership Section

Please be informed that participants may not discuss individuals.

Respect and courtesy must be used without fail. These submissions are not a forum to vent personal grievances and are not intended to review any topic under the sun, just mold illnesses and remediation.

Membership will automatically renew and charge your card each cycle depending on the membership package chosen (monthly, biannually, or annually). If you wish to change membership term or cancel, you must notify us in writing at member@survivingmold.com.

Don't miss out on this exciting opportunity to share your questions with Dr. Shoemaker as well as be part of a network of individuals that have similar questions and concerns!

Due to the number of questions received and the questions answered; this program is not designed to provide an immediate response to inquiries. If you require an immediate response to your question, please contact us about a [phone consult](#) with Dr. Shoemaker.

[Click Here for More Information.](#)



Ritchie Shoemaker, M. D.

Ritchie Shoemaker, M. D., is a recognized leader in patient care, research and education pioneer in the field of biotoxin related illness. While illness acquired following exposure to the interior environment of water-damaged buildings (WDB) comprises the bulk of Shoemaker's daily practice, other illnesses caused by exposure to biologically produced toxins are quite similar in their "final common pathway." What this means is that while the illness might begin acutely with exposure to fungi, spirochetes, apicomplexans, dinoflagellates and cyanobacteria, for example, in its chronic form, each of these illnesses has similar symptoms, lab findings and Visual Contrast Sensitivity findings. Taken together the inflammatory illness from each of these diverse sources is known as a Chronic Inflammatory Response Syndrome.

The few sentences above might make one think that the path of discovery of the complex abnormalities of innate immune physiology now confirmed to be present was simple. Frankly, none of the "players," as one might call C4a, TGF beta-1 and MMP9 or the genetic susceptibility from the immune response genes HLA DR, was known in 1997, the first year of Shoemaker's odyssey into the world of unusual diseases. Beginning with Pfiesteria, a dinoflagellate that killed fish and sickened over 300 people along the estuaries of the Chesapeake Bay from 1997-2001, Shoemaker has looked at multisystem, multisymptom illness with an environmental source as his "Holy Grail."

Indeed, finding the answers to countless questions raised by biotoxin illnesses has provided help, and for some, cure, with illnesses defined by symptoms alone such as fibromyalgia and Chronic Fatigue Syndrome.

Shoemaker says, "I suspect that the next textbook of autoimmunity and rheumatology will be one dedicated to treating high TGF beta-1 and restoring control of T-regulatory cells. Similarly, no one will be seen for neurological deficits and pulmonary problems without consideration of nerves and lungs as targets of innate immune responses gone haywire. As it is now we see unusual cases of multiple sclerosis, idiopathic juvenile arthritis, interstitial lung disease and many others unveiled as treatable conditions where the therapeutic target is lack of regulation of innate immune inflammation.

Physician Certification Process

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"In the future, we will be offering an exam, open for docs to take, that will show their competence in the basic sciences and clinical management of illnesses associated with exposure to biotoxins. We will be allowed, I am told, to publish a list of those physicians who have passed the test. We won't be allowed to show who didn't pass the test or how many times they needed to take the test. Naturally, we can't publish the test contents or scores either. We won't be allowed to call this test a "Board" exam, as that might imply we had applied for and received approval to provide certification as Specialty Board. We haven't and (likely) won't."

–Ritchie Shoemaker, MD

The Future is Now!!!!

We are pleased to report that the process to certify physicians in the "Shoemaker Protocol" is complete. In fact, the test bank of questions for the exam has been built.

Shoemaker Protocol Certification

The Certification Examination Process will be conducted in three stages:

1. Screening Exam–Multiple Choice
2. Essay Questions–Protocol and Practice Related
3. Oral Exam–Patient Integration

Screening Exam–The examination includes multiple choice and true/false questions designed to illustrate the strengths and weaknesses the doctor may have in the subject of Biotoxin related illness. It is simply step one in the process. The test questions have been categorized by topic to identify areas that need further study and give a specific direction to those attempting to be certified.

Essay Questions–The essay question are designed to illustrate the doctor’s level of understanding of the Shoemaker Protocol and evidenced based medicine. It is simply another step in the learning process.

Oral Exam–In this third and final stage of Certification, the physician will be asked to demonstrate his competence in case management through use of one of the most time honored forms of testing in medicine. One on one, using several cases the diplomate “to be” will be challenged to bring all his skills and knowledge to bear quickly and accurately. At the completion of certification, Dr. Shoemaker will guide you through the entire Protocol using one of your selected patients.

It is important to understand that this is not an on line study course. The material, training and testing described will be administered directly by Dr. Shoemaker. You will obtain your certification directly from the physician that developed the protocol. It is a tremendous opportunity that fewer and fewer will have going forward. Dr. Shoemaker’s time constraints are still enormous and ever increasing. We strongly recommend that if you have a desire to become certified in the Shoemaker Protocol that you begin today. We believe that in the very near future, you will be glad that you certified as we will be able to respond accurately and confidently to the number one question submitted to the Surviving Mold website: “Is there a doctor in my area that practices the Shoemaker Protocol?”

For more information about the program; [click here](#).

Please feel free to email any questions you might have to: info@survivingmold.com