

I was discussing how difficult it was to get patient's suffering from Biotoxin Illness to grasp the importance of some of the first steps of treatment with a retired teacher. She told me I was hitting people with way too much information and I needed to make it simpler. I don't recall if "Quick Start Guide" was her idea or mine so I'll give her the credit. But what I pictured when she explained this was how you buy a lawn mower and you can read the long directions in 5 different languages or go to the Quick Start Guide so you can mow your lawn that's over a foot high now and figure out the nitty gritty later.

The Quick Starts will be inserted into this long guide so you can get started and learn more about the whole process later.

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Glossary of acronyms/abbreviations

ACLA anticardiolipin antibodies

ACTH adrenocorticotrophic hormone (compare to simultaneous cortisol)

ADH antidiuretic hormone (compare to simultaneous osmolality)

AGA antigliadin antibodies

ANA anti-nuclear antibody

API-STAPH special culture for MARCoNS

APUD amine precursor uptake and deamination

ATP adenosine triphosphate

BBB blood brain barrier

BEG spray Bactroban, EDTA and gentamicin nasal spray

BP (Biotoxin Pathway) schematic designed to represent various components of innate immune responses in CIRS

BNP brain natriuretic peptide

cAMP cyclic AMP

C3a split product of activation of complement component 3

C4a split product of activation of complement component 4

CIRS chronic inflammatory response syndrome

CBC complete blood count

CDC Centers for Disease Control and Prevention

CFS chronic fatigue syndrome

CIH certified industrial hygienist (see IEP same thing)

CIRS-BB chronic inflammatory response syndrome caused by exposure to *Borrelia burgdorferi*

CIRS-DF chronic inflammatory response syndrome caused by exposure to Dinoflagellates

CIRS-CTX chronic inflammatory response syndrome caused by exposure to Ciguarra toxin

CIRS-WDB chronic inflammatory response syndrome caused by exposure to the interior environment of water-damaged buildings

CMP comprehensive metabolic profile

CN caudate nucleus

CNS central nervous system

CoNS not more than one class of antibiotic resistance-coagulase neg staph
CRBAI Center for Research on Biotoxin Associated Illnesses. 501-c-3; Pocomoke, Md.
CRP C-reactive protein
CRS chronic rhinosinusitis, inflammatory response to fungi in sinuses
CSM cholestyramine
DDAVP synthetic arginine vasopressin
DJD degenerative joint disease
DHEA-S stable precursor of the androgen testosterone
EPA Environmental Protection Agency
Epo erythropoietin
ERMI Environmental Relative Moldiness Index
ESR sedimentation rate (sed rate)
FACT Functional Acuity Contrast Test
Factor VIII clotting factor included in vWF
FSH follicle stimulating hormone
GAO US Government Accountability Office (Federal report on mold 2008)
GFAP glial fibrillary acidic protein
GGTP gamma glutamyl transpeptidase (bile canalicular marker)
G/g ratio glutamate to glutamine ratio measured on MRS
HEPA High efficiency particulate air filtration
HERTSMI-2 Health effects roster of type specific (formers) of mycotoxins and inflammagens, second version
HIDA scan nuclear scan looking for reduced gallbladder ejection of bile
HIV human immunodeficiency virus
HLA DR human leukocyte antigen Class II, DR locus
HVAC heating, air conditioning and ventilation
IEP Indoor Environmental Professional
IgE immune globulin E
LH luteinizing hormone
Lyme WB Lyme Western blot

MARCoNS multiply antibiotic resistant coagulase negative staphylococci

MRCoNS Methicillin resistant coagulase negative staph

MASP-2 mannose binding lectin associated serine protease 2

microRNA small, non-coding regulatory RNA

MMP-9 matrix metalloproteinase 9

MNQI mold NeuroQuant Index

MRI magnetic resonance imaging

mRNA messenger RNA

MRS magnetic resonance spectroscopy

MSH alpha melanocyte stimulating hormone

NAA N-acetyl aspartate a measure of white matter

NIOSH National Institute of Occupational Health

NQ NeuroQuant

OATP Organic anion transport system cellular based pump that secretes anions into bile and CSF

OspA Antigen produced by Borrelia after stimulated by animal blood: agonist of Toll

PAI-1 plasminogen activating inhibitor

PASP pulmonary artery systolic pressure

POA Policy Holders of America 2010 Report of Expert Mold Treating Physicians Consensus Statement

POTS postural orthostatic tachycardia syndrome. Often misdiagnosed usually includes ADH depletion, volume depletion and rapidly rising PASP with positional changes

RAP pressure right atrial pressure

SNP single nucleotide polymorphism

TGF beta-1 transforming growth factor beta-1

Th 17/T reg imbalance high TGF beta-1 and low T regs

T reg T regulatory lymphocytes, with two kinds noted

acquired CD4+CD25++

thymus derived CD4+CD25++CD127 lo/-

T3 triiodothyronine

TIMP tissue inhibitor of metalloproteinase
TMJ temporo-mandibular joint arthritis
TSH thyroid stimulating hormone
TR tricuspid regurgitation, or tricuspid valve insufficiency
vWF von Willebrand's profile
VCS visual contrast sensitivity
VEGF vascular endothelial growth factor
VIP vasoactive intestinal polypeptide
WDB water-damaged building
WHO World Health Organization (report on mold 2009)

Stay tuned more added daily...

Quick Start Guide

I realized that when people have mold, Lyme or other toxin issues they aren't in their right mind. Thus, the cautionary advice I give is often executed in the exact opposite fashion of how it was described or forgotten all together. This is common and not on purpose by the pitiful person suddenly aware of what toxins are doing to their life and health. To avoid that I've compiled this QUICK START guide that summarizes what you need to do and what you need to avoid simply. You can read the full guide after to understand why.

No matter what toxin I think you have we have to eliminate mold as a suspect. Many hear the word mold and panic and grab a bottle of bleach. Bleach is not the answer and makes the problem worse. It does nothing about mold toxins and can hurt you. Stop, put the spray bottle down and back away. Let me say this again. **DO NOT USE BLEACH UNDER ANY CIRCUMSTANCE!**

Many in the mold remediation businesses are out to make a quick dollar off this panic. Don't do anything until you read this quick start guide at least twice and have a friend or family member also read it and explain to them what you understand so far, so they can see if you got it right.

When and Why to TEST?

1. We test to find proof of exposure. I can't treat you for mold illness until I have proof you're being exposed. Sure, if you just moved from a house that smelled musty we aren't going to test the prior house, BUT we still must test the current house to make sure you're not STILL being exposed.
2. I don't want to treat Chronic Lyme Disease anymore without mold testing. Of course, if you present with acute Lyme Disease we treat first, ask questions later. Time is of the essence then but if you think you need ongoing antibiotic treatment past 6-12 weeks then you will have to prove you're mold free first.
3. Musty smell does equal mold. But lack of musty smell doesn't equal no mold. There are mold species of concern that do not smell. So, telling me your house smells fine is not sufficient. Plus, you've all seen the commercials, you could be nose blind. Very interesting trend, those most resistant to testing are scoring the worst for mold. Don't be fooled and do molds bidding. It can make you it's minion if you let it.
4. After remediation, I will need a HERTSMI2 score again to be sure the house is now safe. I understand now why most Mold doctors don't want to start treatment until the patient can prove their home is safe. For one thing, it doesn't work until the house is safe. So why spin your wheels. Just focus on getting through remediation and when the house tests < 10 after remediation or if pre-remediation was <8 then we can start.
5. When you're ready for VIP we test again to make sure it's still good. Trust me you don't want to waste money on VIP only to have it not work because your mold exposure hasn't stopped.

Test kits

We now have the kits here in the office. We have mostly the "Swiffer" kind because it's the easiest and cheapest. It's \$105. We have one vacuum type and they're \$125. We are now

going through Envirobiomics, the company most recently endorsed by Dr. Shoemaker and with much better customer service than Mycometrics. You pay for the kit and send it when you've collected your sample. They email us the report and they may email you at same time. If not, we'll send it to you.

For the Swiffer test you simply wipe 10 horizontal surfaces or backs of computer monitors or computers anywhere you can find a decent amount of dust. If you clean weekly, you may need to not dust a couple weeks then dust with this Swiffer. You do NOT want to wipe mold up directly or go in especially grimy places like behind toilets or under sinks. The point is to capture dust that's settled over the past 2-3 weeks. Tops of door frames are often a great place to find dust. OK my house any surface is a place to sample! Except I should have avoided areas that had 10 years of dust. That's not accurate either.

Another sampling method that is especially useful for **post-remediation** testing is to take black garbage bags and slice open and hang the black plastic on the wall. It will cling with electrostatic charge and then after 2-3 weeks you simply Swiffer that garbage bag hanging there. This is helpful in homes with pets that track in stuff or kids. A video to demonstrate how to hang it and swiffing it is located here:

<https://www.youtube.com/watch?v=jPF0Z7wOBYY&list=PL70JCLZ7QeFw9T5R0HHQrAdDjSuzilCwv>

or try this <https://youtu.be/jPF0Z7wOBYY>

Inspectors

Martine Davis is an amazing inspector and was doing mold before Shoemaker even knew about mold. She trained in Europe because the USA was so behind in building science. However, she is travelling less and has trained an inspector now here in Peoria for Central Illinois patients. His name is Ben Kunze and he can be reached at 919-402-7670. Ideally you will test your house before having an inspection because that helps direct the inspector of what mold we're concerned about. *The test has limitations especially with respect to Stachybotrys. Stachybotrys is very sticky and doesn't typically show up in the HERTSMI test and just should be ruled out by visual inspection. So even though the HERTSMI reports a score for Stachy we assume it's erring on the low side.*

Inspector **Martine Davis**, BBEC, Certified Building Biologist, Indoor Environmental Testing Inc.

1.800.MY.AIR.TEST

(608) 241-9883

www.AirInspector.com

samsaramadison@gmail.com

Ben Kunze

919-402-7670

Benjamin.j.kunze@gmail.com

Remediation Companies

Remediation Company in Peoria and Bloomington, Mike Lanius, Indoor Environmental Professionals Inc. 309-670-6653 will work with you and use an approach guided by Martine or Ben that will do you the least harm and reduce your exposure to mold toxins. Many companies will remediate so poorly they increase the exposure of mold toxins to the inhabitants. I can't tell you how many times people come back and tell me well it can't be a mold problem we had someone out to clean it up and it didn't help at all, in fact, she's sicker now than before. Oh, that's a mold problem and now a bigger mold problem. I'm not saying Mike is the only one to use out there. He's just the only one I'd recommend so far based on patient experiences. If you have a great experience with another company, please let me know. The HERTSMI2 before and after will prove they were effective.

I can't emphasize enough to not cut corners and skip the inspector if you hire a remediator. The remediator will not test properly to show proof of a complete job. Even Mike Lanius that I recommend does air sampling afterwards. Air samples are insufficient to prove the home is safe. They are useful but don't rely on only them. You should still ALWAYS have an independent inspector to check on the work performed by the company and make sure they did it right and adequately. They can take their air samples and if you're moving and they say clear that's good enough to sell the house. It is not good enough to live in and remember that when you move as well.

I hope in the future we'll be able to support other companies. I have patients that have used other companies, but they still had to have Lanius come in and finish up because of an inadequate job in one case. Another patient, used ServiceMaster but has yet to do a post-remediation test to show if it was successful.

Environmental Illnesses

Per Dr. Joseph Burrascano, anyone with the classic triad of symptoms for (*insert environmental illness here*) will present with the following symptoms present for more than three months and not explained by any other illness; profound fatigue (tiredness, exhaustion), musculoskeletal pain (joints, muscle, back, neck, headache), and cognitive problems (memory loss, trouble concentrating, difficulty remembering what you read, depression, disorientation, getting lost). I call them chronic fatigue, widespread, migratory pain and brain fog for short. Dr. Burrascano was describing Lyme Disease. Substitute Dr. Ritchie Shoemaker for him and insert Mold Illness for Lyme Disease and it's the same thing. Dr. Shoemaker also demonstrated similar findings in people exposed to Pfiesteria, a dinoflagellate from rivers in Maryland. In fact, that was where he started and it's a good place to start our discussion.

In 1980, Dr. Shoemaker, a graduate of Duke University Medical School, launched his medical practice in Pocomoke City, Maryland. He loved the idyllic small town along the shores of the Pocomoke that flowed South from Delaware in route to Chesapeake Bay.

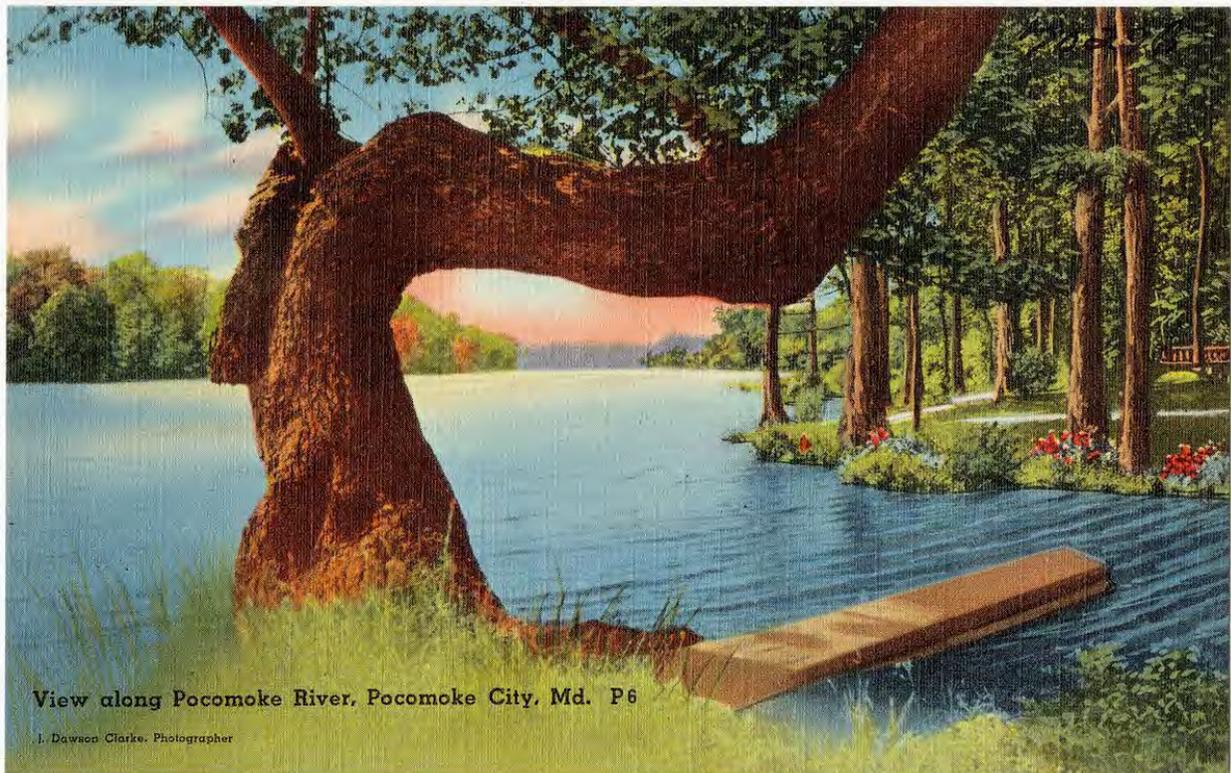


Figure 1 Title: *View along Pocomoke River, Pocomoke City, Md.* Subjects: Rivers Places: Maryland > Worcester (county) > Pocomoke City Notes: Title from item. Extent: 1 print (postcard): linen texture, color; 3 1/2 x 5 1/2 in. Accession #: 06_10_014547

It's idyllic small town living with a population of 4,168 but not that far from many large cities. He worked many volunteer hours in those first 20 years of practice to get funds for a "nature trail" that flanks the river. It was completed in 1994. The summer of 1997, a fisherman brought him a fish for an autopsy. Scores of dead fish were floating in the river covered with ugly sores and no one knew why. Then the people began to report a mysterious

illness of nasty headaches, secretory diarrhea, rash, cough, persistent muscle aches and increasing problems with short term memory. Reports that the river had been invaded by a toxin-producing, one-celled dinoflagellate: Pfiesteria emerged. His pursuit of the truth with respect to this illness and the CDC denials and eventual connection to use of pesticides is well documented in his book, "Desperation Medicine." Pfiesteria is a fascinating creature that can change its form depending on the availability of its food choices. When there is plenty of nutrient-rich, chloroplast-bearing microorganisms—including blue green algae—living at the edge of the river water and sediment it's in the amoeba form. But if that food source becomes scarce it changes into a zoospore armed with toxins for sedating fish and eating them instead. It switches from an herbivore to omnivore. If there are no fish it sheds most of its cell and forms a cyst and drops to the bottom of the river. It lives a long time in that state until food becomes available again.

The main complaint of Pfiesteria illness was secretory diarrhea. That's copious watery, bilious diarrhea that won't stop. This lead to Shoemaker giving a patient cholestyramine to try and stop her diarrhea. Shockingly she called him back on day 3 and said all her symptoms were gone. He only thought it would help the diarrhea and didn't expect all of it to resolve. That made him think that this toxin had to be fat soluble and liked tissues that were fatty like brain, lung surfactant, and intestines.

Then Dr. Shoemaker met Dr. Kenneth Hudnell. Dr. Hudnell's area of research was contrast sensitivity and the neurotoxicology of vision. The eye, more specifically the retina was a "microcosm" of the brain. I was told in medical school that when we look at the back of the eye we are catching a glimpse of the brain. Dr. Arthur Ginsburg designed a test called the "Functional Acuity Contrast Test" (FACT) that tests the limited outputs of neurons in the visual system by presenting them with sinusoidal wave patterns among lines printed on cards. This ability to detect low contrast patterns is measured and gives a more accurate representation of the eye's visual performance. Poor contrast sensitivity is associated with poorer night vision, difficulty seeing pedestrians on poorly lit streets, eye fatigue watching television or reading and increased risk of falling from failing to see a step down from a curb onto similarly colored pavement. Reminds me of my face plant in July 2010 before I'd ever heard of this test but that's another story. It

BIOTOXIN TIMELINE

Otzi the Iceman (5,300-year-old mummy) had *Borrelia burgdorferi* DNA in him.

5,265 yrs.

1975 Lyme Disease based on a cluster of cases in 3 towns, in Southeastern, Connecticut

1982 Willy Burgdorferi, researcher at Rocky Mtn. Biological Laboratory, confirms spirochete that causes Lyme Disease

1987 *Borrelia burgdorferi* discovered in tick saliva

1988 Pfiesteria discovered by NC State researchers

1997 Pfiesteria Outbreak in Pocomoke MD

1998 Shoemaker investigates different algae in Destin FL



BIOTOXIN TIMELINE CONTINUED

Late 1998, a series of patients come to his office with illnesses like Pfiesteria and Cyclindrospermopsis but from mold exposure and positive Visual Contrast Sensitivity deficits.

1999 researchers Dr. Sam Donta and Dr. Mark Cartwright find a biotoxin made by *Borrelia burgdorferi*.

In May 1999, he researches Cholestyramine for Lyme Disease patient cohort of 112 patients with refractory symptoms after antibiotics. But half of the LD patients got worse and half better.

Data presented supporting Lyme Disease involves a biotoxin at Regional Meeting, American Society of Microbiology, May 2000.

2006 After Katrina the CDC reports 3 ways mold is hazardous to health

can occur in patients with cataracts, glaucoma, diabetic retinopathy and post refractive surgery. It's also associated with neurotoxins. You can improve your contrast sensitivity by wearing lens with yellow tint. I used to wear them mountain-biking and they helped so I would recommend them especially for driving or walking.

Dr. Hudnell's FACT was the only test that picked up the deficit in neurological function in the Pfiesteria patients. They developed it into a handheld device that holds the card the perfect 18 inches from the patient and is very easily administered. We have one in our office now. Your vision does need to be better than 20/50 at 16 inches of the Snellen to take the VCS test.

Shoemaker realized that Pfiesteria mutated because of loss of food from run off into the river of copper laden fungicides from nearby tomato farms. This model continues to work for many biotoxin illness. Nature is disrupted and an organism takes advantage of a new "habitat" and without balancing forces causes human illness. People keep building homes in wooded locations not thinking about how close they are to the ticks and deer. The nymph that gives you Lyme disease hasn't even been on a deer yet when it infects you but it has been on the ears of a mouse. Guess what determines how bad a year it'll be for Lyme disease? Acorn density. The lack of food source drives the mice to our houses and brings Lyme disease to us. There will be more of these in the future, mark my words. The following steps from Shoemaker should be a road map to help any of us find these toxins in our own area of the country when they arise.

Steps in discovering Biotoxin Illnesses:

First step: Look for a common "exposure" affecting the patients with the neurotoxic illness.

Second step: Test their neurologic function using VCS.

Third step: Those that can't pass are then a cohort.

When reading the official government reports about possible new outbreaks, he also warns, beware of the Appearance of Good Science and always read the methods section of any study before you think it's worth of reading. When facing public outcry, and trying to hide a piss poor job of investigation be wary if these elements are used.

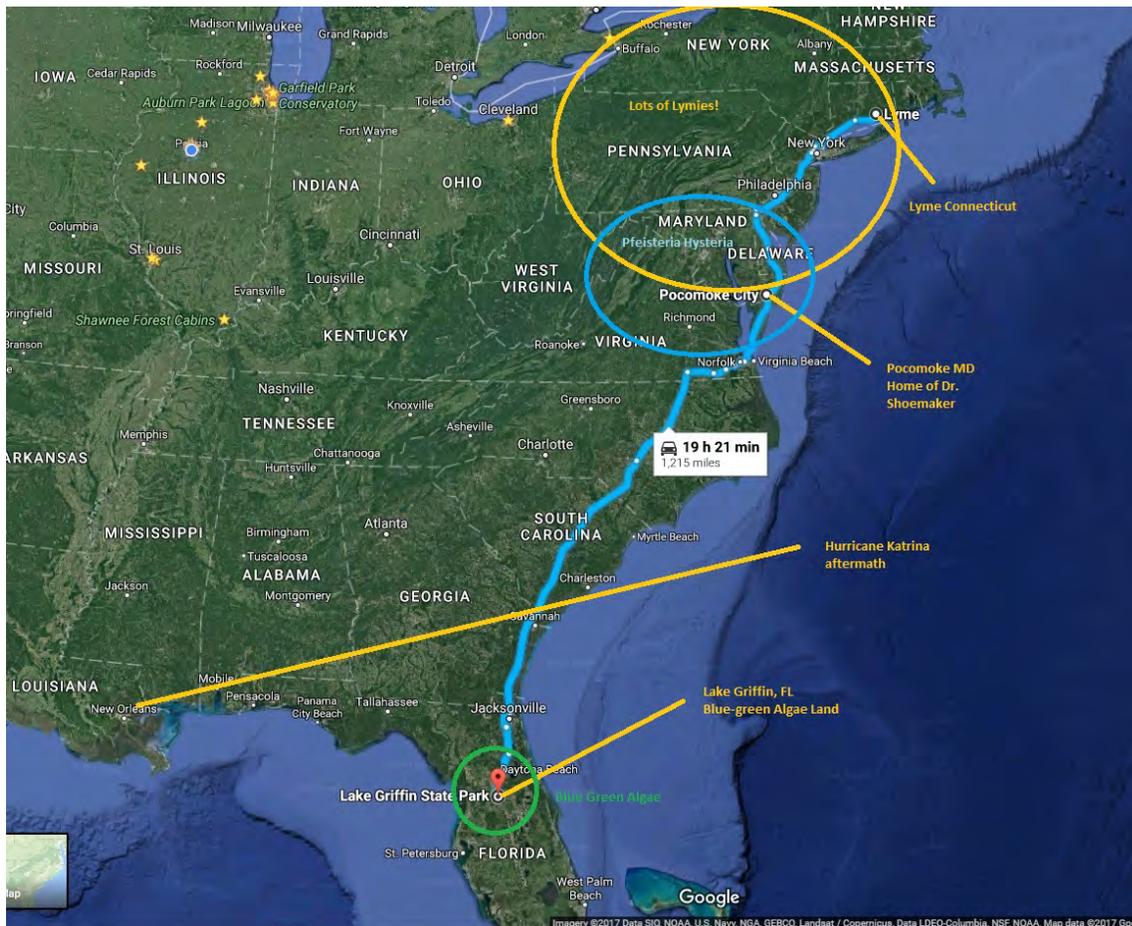
1. A consensus panel or committee of Experts...
2. They'll praise it for being impartial.

3. They won't make it public until AFTER their investigation is done because they aren't truly interested in fact finding.
4. They'll quote their study over and over since the more we say it the more people will believe it.

All the biotoxin illnesses mentioned also have in common that they have been handled poorly with government denial and cover up. This is well documented in Shoemaker's books with respect to Pfiesteria, Cylindrospermopsis, and mold. You would have to be a hermit to now know the same can be said for Lyme disease. You will also face this if you fight for a mold free work place. Progress is slow and thanks to Dr. Shoemaker for sharing his victories and how he fights this battle.

Right time, right place, right person

I made this map to show that Shoemaker was the right man, in the right locations at the right time. When all three line up... SHIT happens! (pardon my French)



He obviously isn't the typical doctor either. We are lucky he didn't like golfing.

Moldies, Lymies and other biotoxin illnesses

Just when I thought I was getting better at treating chronic borreliosis (Lyme Disease) I met a patient that was working in a water damaged building. Christina Hunt* reminds me of the "Lymies" as I affectionately call us. But there are differences as well as she looks sicker than I would expect. She looks severely dehydrated, she is clearly distressed and confused, and her fatigue is evident. She appears thin but if she told me she gained 20 lbs. in a week I wouldn't be surprised. I heard mold could do that. She gets short of breath just talking to me and has big dark circles under her eyes. But just like the Lymies, she has brain fog, overwhelming fatigue and pain everywhere. She went to University of Iowa and was told she might have farmer's lung. When her boss heard that they closed the building and moved the business. But they also moved all the contaminated furniture to the new place. Then her employer sent her to an occupational health physician that told her to her face he believed her and tested her for mold allergies but then reported her as healthy and able to return to work. She tried to return but suffered an immediate splitting icepick pain in her head that had her running for the door. She vomited as soon as she got outside. She realized then, she couldn't enter that building ever again.

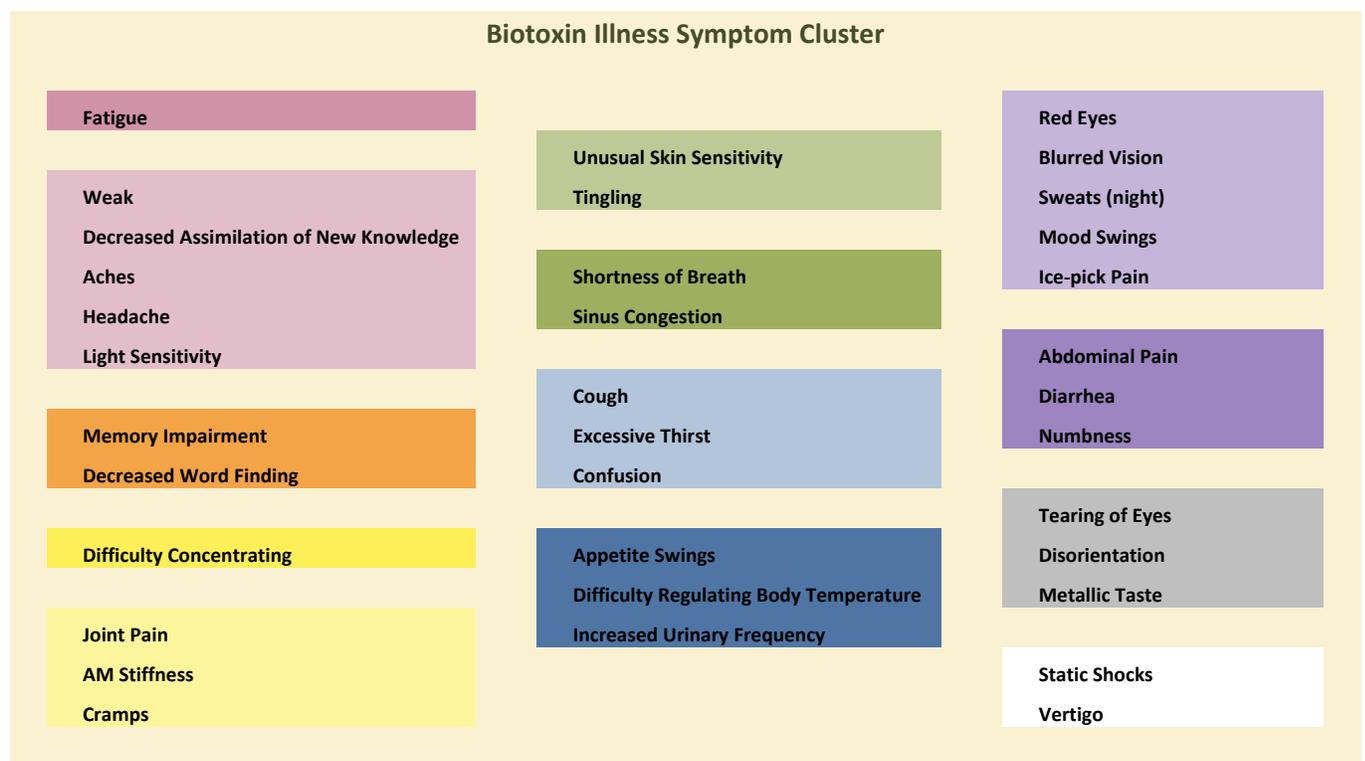
She came to me because she heard that I would treat her for Lyme disease. I said "Lyme?" Why not mold? She said that they told her she wasn't allergic to mold and so it can't be the cause of my illness. I said, "Who told you that?" "The occupational health doctor." I replied, "And this doctor is paid by who? That's who they work for and they're not your doctor." (I'd really like to know how these occupational health doctors keep their licenses. They clearly do not follow the Hippocratic oath once they take this job. In theory, there must be one out there that isn't biased in favor of the employer but I've yet to hear of one.) I told her, I've been reading books by Dr. Ritchie Shoemaker and I think mold really is your problem. I told her I'd do my tests for Lyme, but I also wanted to do the tests from his book for mold and then the adventure began! Unlike Lyme Disease diagnosis and treatment, Dr. Shoemaker laid out all the testing and explained the results. Many were labs I had not heard of and took me a couple times to order them correctly. But once I figured that out, I was amazed as they all came back abnormal just as he predicted. Finally, useful labs that would correlate with the illness and show improvement as the patient recovered.

Water damaged building are breeding grounds for indoor mold, bacteria and other inflammagens that are very dangerous. Those that recognize the danger have been fighting a hard battle to get this recognized. Then if the remediation isn't done carefully the biotoxin stew is spread throughout the building and makes the susceptible even sicker than they already were. But it's not the amount of toxins that make a person sick per se but the response of the immune system. This gets

complicated so we're going to back up and start at the beginning with the symptoms. The science of the diagnosis and treatment of mold illness has started and is growing. I used to say that much of it could be wrong but lately even more evidence has come to light and so far, it continues to support the work Shoemaker has already done.

Symptoms of Biotoxin Illness

Many of these are the same symptoms that make me think of Lyme Disease and there is a good reason for that. Both are biotoxins and they illicit the same immune response in susceptible people. However, it appears if there is a mold problem, it needs to be dealt with first before the rest will respond normally. If a Lymie has a moldy house, they're not going to recover and get off their antibiotics.



If you have 6 of the symptom clusters listed above, then that's grounds for a thorough diagnostic work up. To tally if you have at least one symptom in a box that's a positive cluster. If you have 8 then you have biotoxin illness unless proven otherwise. Many patients are dealing with both mold and Lyme and multiple chemical sensitivity! Dr. Shoemaker even states that he's not saying it can't exist but he's never had a multiple chemical sensitivity patient that didn't also have mold as the inciting event.

Dr. Shoemaker, a family practice physician in Pocomoke, Maryland, has studied environmental illness for more than 40 years and like those of us that see a lot of patients with chronic borreliosis (Lyme Disease) the stories all shared common threads. He also stumbled on to the fact that cholestyramine a binder for bile salts (fats) would help bind up toxins from mold and other biological toxins. So, he believes that these illnesses are caused by exposure to biologically produced neurotoxins, also known as biotoxins. Exposure to toxins isn't that unusual anymore as chemicals have entered the picture in agriculture and food production that impact our environment leading to an upset in the balance of habitat. Mold is everywhere but it doesn't hurt anybody until it takes up habitat inside buildings where it's not meant to be. The tick nymph that transmits Lyme Disease is so small that I'm sure most people living in an endemic area or visiting May through July quite possibly have been bit and never know it because not everyone gets ill. Dr. Shoemaker found a reason for why some people are treated for an acute Lyme Disease infection and never have a bit of trouble and others can't get well. He also showed this same system selects for who succumbs to *Pfiesteria* in water ways and mold in buildings. He showed that 25% of the population has genetic susceptibility to biotoxin illness. They are unable to process the biotoxin and that leads to a series of biochemical alterations called the Biotoxin Pathway. Finally, a good explanation for why everyone isn't as sick as some.

Why am I sicker than everyone else at work?

People often ask me isn't mold bad for everybody? Yes, and no. The difference is the level of mold toxicity that most people can cohabit with and not be ill and the level acceptable for genetically susceptible individuals. If the mold is only at work and everyone goes home every night 75% of the workers will recover when they're away and not develop a chronic illness. But 25% of the workers can't recover because they can't clear the toxins. However, you could encounter a small office with only 5 people working and only one is ill or 4 out of 5 are ill. Statistically it is about 25% but chance allows for many variations. If you're the only one ill it tends to lead to disbelief that the person is ill from their environment. Dr. Richie Shoemaker was a pioneer in demonstrating that there was a logical reason for why the level of illness would be different among the people that were exposed in a water damaged building. He linked the human leukocyte antigens (HLAs) to different environmental toxins.

Lyme Disease is the same idea. I would bet scores more people than what are reflected even by CDC tracking are bitten in the spring and have a flu like illness and go on their merry way and never know they had it but about 25% of them never get better. I remember having a flu like illness my first summer in Wisconsin distinctly. I was in great shape. I ran Chicago Marathon a year earlier, first time, and only missed qualifying for Boston by 4 minutes. So, I was planning on doing it again until I got this flu. I went for a run and only made it or block or two before I was doubled over with abdominal cramping. The muscle cramping in the abdomen was something I'd never experienced before even with gastroenteritis. But even more crazy was I couldn't run.

I went from fantastic to no stamina in a month. Guess what that must have been? I never thought it could be Lyme because I had jumped at the chance to get the Lyme vaccine right before I moved there. Yeah that sure didn't work out.

One of these HLAs is also associated with post Lyme syndrome or I call it Chronic Lyme. Borreliosis like it's cousin Treponema can go dormant for a while and then the next phase is usually much worse and doesn't have the EM rash and may just be joint pain. These HLA markers are there so when we're exposed to foreign substances are immune system tags this substance as "not self" and removes it from our system. Most often it is removed or detoxified in the liver. The problem is if your HLA DR tags that mark your own cells as self are like the tags of these toxins then your body can't label as non-self and remove them.

Another way to look at it, the T cells are supposed to see the toxin and label it, so they can present it to the B cells that make antibodies against it. But people with the susceptible HLA types can't do this so we can't make antibodies against them and clear them the normal way. When that happens, our system has a plan B. But plan B is to trigger the innate immune system. The innate immune system is version 1.0 of our immune system and what we used before we acquired the ability to make antibodies. It's our factory installed version at birth. But after we're born we acquire antibodies through exposure to the environment. Children born without the ability to make any antibodies must live in a bubble. We can make antibodies to most things just not these toxins.

[More on HLA DR at <http://en.wikipedia.org/wiki/HLA-DR>]

This plan B system gets involved when the antibody system fails, and the complement system triggers a cascade response. When I say cascade picture one domino knocking over three lines of dominoes then nine lines of dominoes and so on. The ensuing chain reaction once started is difficult to stop. This overkill nearly kills us in the process and is why so many systems of the body are not working. That's why there are typically more than a few symptoms, try 37 core symptoms. It's also why once you've been exposed, if it gets above a certain level then you will get sicker, quicker.

Since the susceptible can't make antibodies against these biotoxins, the antigens (foreign substance) stick around and continue to trigger release of our own cytokines. (Cytokines are two of the labs we'll use to show mold illness and recovery, TGF-Beta 1 is any biotoxin illness, C4a is mold, C3a is acute biotoxin and if remains up is an indicator of Lyme). Cytokines are chemical signals secreted by certain cells of the immune system to influence other cells. They're basically directions. In response, our next defense is secretion of small hormones made by our

Dr. Shoemaker has all his prospective patients write a detailed timeline of their important medical events and a complete medical history BEFORE their first visit. Consider writing your medical event history on a timeline if you haven't yet. In the future, we will need it if we must go to court or if you need to apply for disability. I've written mine if you want to see a sample for the level of detail needed.

brain called regulatory neuropeptides. The neuropeptides that are abnormal with biotoxin illness are alpha melanocyte stimulating hormone (MSH) and vasoactive intestinal peptide (VIP) and ADH (anti diuretic hormone) and ACTH (adrenocorticotrophic hormone). When they're low then TGF-Beta 1, C4a, MMP-9 rise even higher. This continues the illness I'm referring to as Biotoxin Illness. Pfiesteria and Tick-borne infections cause very similar signs and symptoms and the labs are mostly similar with a few nuances.

Microbial Toxins Known So Far

Mold: Stachybotrys, Aspergillus, Penicillium, Chaetomium, Fusarium, Wallemia (Chlamydia pneumoniae, Mycoplasma pneumoniae suggested by some not sure of)
Lyme disease and co-infections: Borrelia, Babesia, Bartonella
Pfiesteria: Dinoflagellate in algae
Ciguatera: Red snapper, Grouper, Barracuda
Brown-recluse spider bites
Cylindrospermopsis: blue-green algae (FL)

Case Definition for Chronic Inflammatory Response Syndrome (also called Systemic Inflammatory Response Syndrome)

Ritchie Shoemaker, MD as I've already gone on and on about is a pioneer in environmental medicine and has written two excellent books on mold that you should read. The first is Mold Warrior and the second is Surviving Mold. He writes in a style that is unusual for medical books but very entertaining. I think it's because I love to solve puzzles and he presents most chapters as short stories and you can't wait to see how they play out. He's a genius in my estimation and this next excerpt from Surviving Mold is so important I had to share it. I have no doubt that I'll find myself eventually on the witness stand in court defending my diagnosis and treatment of patients with mold and he's laid a ground work in his books for my argument. I appreciate the help as you can imagine.

"We have a case definition for mold illness that our group published in 2003. The earlier case definition contains two tiers as follows below. Given the September 2008 case definition of mold illness from the General Accountability Office following (in time) that from our group, I certainly defer to that body's panel regarding causation and what isn't. Basically, they say the illness is caused by mold if all the epidemiologic findings of the individual are consistent with that of others reported; that the physiology has been shown to be present in laboratory animals and/or people previously; and that treatment is successful. Until September 2008, however, according to our data gathered in thousands of cases any diagnosis of environmentally acquired biotoxin illness, including that from mold, must also include:

- 2) *The potential for exposure;*
- 3) *The presence of a distinctive grouping of symptoms; and*
- 4) *The absence of confounding diagnoses and exposures.*

This first tier of the case definition is adopted from the initial CDC case definition of Pfiesteria cases from 1998.

The second tier of objective factors demands presence of (at least) three of six of the following:

- 1) HLA DR by PCR showing susceptibility;
- 2) Reduced levels of melanocyte stimulating hormone (MSH) in a properly performed/prepared specimen;
- 3) Elevated levels of matrix metalloproteinase-9 (MMP-9) in a properly prepared serum specimen;
- 4) Deficits in visual contrast sensitivity (VCS);
- 5) Dysregulation of ACTH/cortisol in simultaneously obtained specimens;
- 6) Dysregulation of ADH/osmolality in simultaneously obtained specimens.

...The second tier is adapted from similar use of different parameters in illnesses such as systemic lupus erythematosus and rheumatic fever, among others. The case definition is derived from looking at what thousands of mold illness patients demonstrated that none of the control patients demonstrated."

This passage from Surviving Mold Life in the Era of Dangerous Buildings by Ritchie C. Shoemaker, MD published by Otter Bay Books, Baltimore, MD 2010.

There is a third tier and that is response to treatment. This works well when we find ourselves in court. However, we realized we needed a case definition that worked in the setting of are we on the right track before we even know the response to treatment.

Recently I found a series of videos on Keith Berndtson's website that showed 8 lectures done by Shoemaker and a few other certified Shoemaker physicians and they presented a new Case definition more practical for a physician's purposes in the clinic. However, the above still is the best approach for a legal case.

New Case Definition of Mold Illness

The new case definition is such that you can make your diagnosis before seeing a response to treatment. The adult patient (>18) needs to have at least 5 abnormal labs from the following list:

1. ≥ 6 Biotoxin Illness Symptoms Clusters and failed VCS or ≥ 8 if passed VCS.
2. ≥ 5 positive Biomarkers from this list:
 - a. Genetics: HLA (DRB1, DQ, DRB3, DRB4, DRB5)
 - b. Anti-inflammatory cytokines: VIP*, MSH
 - c. Hypothalamic-pituitary-end organ function: ADH/OSM, ACTH/Cortisol
 - d. Innate pro-inflammatory cytokines: MMP9, TGF-Beta 1, C3a, C4a
 - e. Auto-antibodies: Antigliadin Antibodies (AGA), Anticardiolipin Antibodies (ACLA)
 - f. Abnormal Mucosal Membrane defenses: MARCoNS
3. Weakness of dominant side compared to non-dominant side in Right handed patients. Either side weaker in Left handed patients.
*Currently unable to measure accurately.

Multiple Chemical Sensitivity Syndrome

I also have mentioned chemical sensitivity syndrome. This problem plagues me as well although much less severely than in the past but I still can't tolerate perfumes, fabric softener and candles. People with Multiple Chemical Sensitivity are sensitive to volatile organic compounds. Shoemaker claims all MCS has started with mold that he's seen so far.

What are volatile organic compounds (VOCs)?

Organic compounds are chemicals that contain carbon and are found in all living things. Volatile organic compounds, sometimes referred to as VOCs, are organic compounds that easily become vapors or gases. They can be released from burning fuel, such as gasoline, wood, coal, or natural gas. They are also emitted from oil and gas fields and diesel exhaust. They are also released from solvents, paints, glues, and other products that are used and stored at home and at work.

Many VOC's are also hazardous air pollutants. When combined with nitrogen oxides, they react to form ground-level ozone, or smog, which contributes to climate change. Further examples of volatile organic compounds are gasoline, benzene, formaldehyde, solvents such as toluene and xylene, styrene, and perchloroethylene (or tetrachloroethylene), the main solvent used in dry cleaning. They are commonly used in paint thinners, lacquer thinners, moth repellents, air fresheners, hobby supplies, wood preservatives, aerosol sprays, degreasers, automotive products, and dry-cleaning fluids.

Some strains of mold ALSO release VOC's. So, there is overlap in these two conditions. There is overlap of several conditions and here's where it gets confusing. For billing purposes or for other reasons, I may at times label you Fibromyalgia or Chronic Fatigue but it's usually when having one of those diagnoses confers some benefit. Fibromyalgia Syndrome will qualify you for cannabis in the state of Illinois is one reason. Chronic Fatigue and Fibromyalgia have been now accepted as causes of disability when documented to be severe. Not so 10 years ago but they are now. Mold Illness, Lyme Disease and Multiple Chemical Sensitivity are possible causes of either FMS or CFS but not as widely accepted yet. To demonstrate how I currently understand these issues in my own head I try to depict how these are all related in a diagram. It would look like this today and yet could probably change tomorrow:

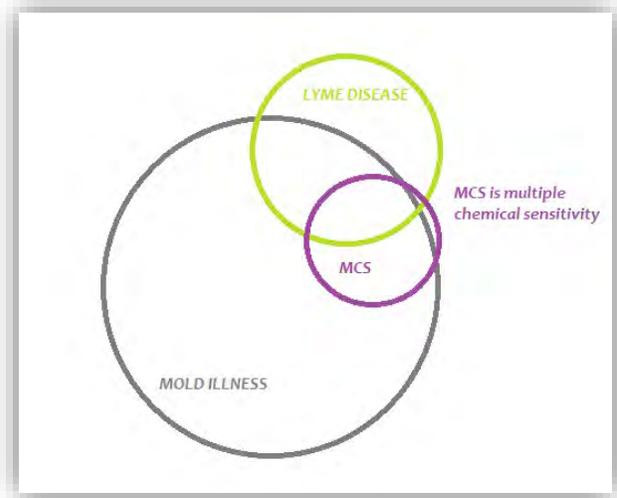


Figure 1 Biotoxin Illnesses

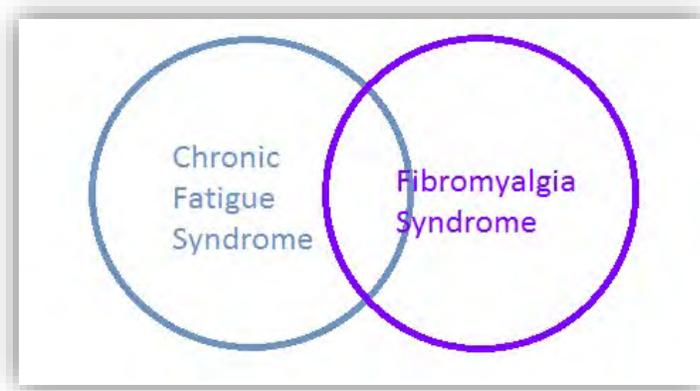


Figure 2. Overlap of Chronic Fatigue Syndrome and Fibromyalgia Syndrome

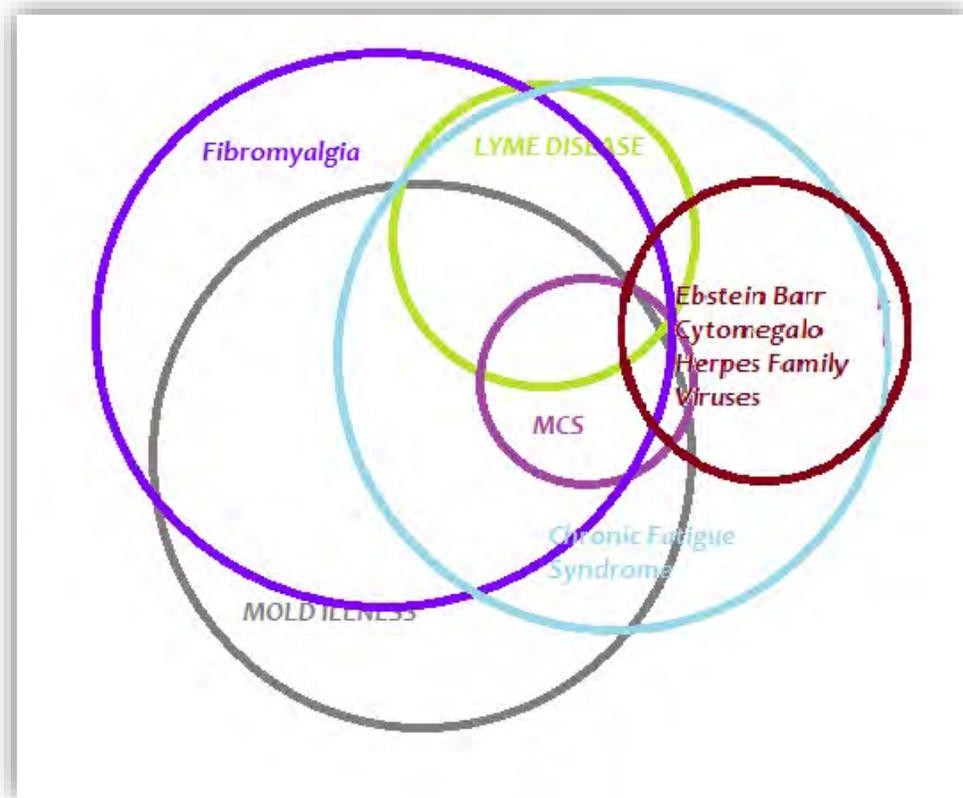


Figure 3. The possible complex interrelationship of all the above plus some herpesvirus family!

More about the HLA DR test

If you have Lyme disease, chemical sensitivity syndrome or unexplained chronic fatigue and/or Fibromyalgia then we should check your HLA Dr types. That will show if you are biotoxin sensitive. Here are the significant HLA DR haplotypes per Dr. Shoemaker's research:



	DRB1	DQ	DRB3	DRB4	DRB5	
Multisusceptible	4	3		53		
	11/12	3	52B			
	14	5	53B			
Mold	7	2/3		53		
	13	6	52A,B,C			
	17	2	52A			
	18*	4	52A			
Borrelia, post Lyme Syndrome	15	6			51	
	16	5			51	
Dinoflagellates	4	7/8		53		
Multiple Antibiotic Resistant Staph epidermidis (MARCoNS)	11	7	52B			
Low MSH	1	5				
No recognized significance	8	3,4,6				
Low-risk Mold	7	9		53		
	12	7	52B			
	9	9		53		

Explanation of how you determine your haplotype from what you will see in your lab results is further explained in Appendix 2.

Interesting, I have always believed that Fibromyalgia (FMS) is a sleep disorder. Chronic Fatigue on the other hand always seemed to me to be related to infections. Well there is also a gene on here that is linked to narcolepsy. Narcolepsy is interesting to me because I have it and the medicine that works best for Narcolepsy can cure, yes CURE Fibromyalgia. But the FDA won't approve for it for FMS because it can be used as a date rape drug and was used with other street drugs in the past to enhance them. For everyone with Fibromyalgia it may be worth testing for the narcolepsy haplotype and then doing an appropriately ordered sleep study that is geared toward picking up narcolepsy. If they don't know you're considering it and do just a regular sleep study they will miss it. Nothing is easy!

I've been compiling these on most of my patient with chronic tick-borne infections, Mold illness and chemical sensitivity. Some of you already knew you were suffering from mold illness. But many were just as many are seeing me for fibromyalgia or chronic fatigue or were just one my "super sensitive" patients. I even tested a person that has Gulf War Syndrome.

The results have been fascinating so now I'm starting to test "normal" people. For our purposes by normal I mean people with no complaints of long term fatigue or widespread pain or people with recent fatigue that's not chronic yet. I also tested people with autoimmune problems. So how many CFS/FMS/Lyme/Mold... has at least one? ALL OF THEM SO FAR! I kid you not. I've tested over 200 now. Problem is in my practice? There are almost no normal people to test. Plus, Shoemaker claims we tend to attract people with similar sensitivities. Of course, my husband is multisusceptible and post-Lyme susceptible. Guess that was part of the attraction! Shoemaker claims all the Gulf War Syndrome he saw was 4-3-53 and 11-3-52B. But the GWS person I tested returned 13-3-52B which is another multisusceptible type. I suspect his pool of GWS isn't huge and obviously, mine isn't.

The BIOTOXIN MAP

Ian has been my medical assistant for almost 9 years, when he makes a suggestion, I better follow it. Because it usually means he's speaking up based on a common request or he's identified a common need. He requested I make a "mold map". A map of the process so patients understand where they are, where they are going, and how they will get there. Since many will have more than just mold, I'm calling it the Biotoxin Map. Not as catchy but I hope just as helpful. For that information see Appendix 1.

Visual Contrast Sensitivity

The visual contrast sensitivity test is useful for diagnosing biotoxin illness. One issue that can give false positive on VCS testing is refractory surgery and since I had that and had problems since the surgery there was a possibility that I had a false positive VCS test. However, I flunked the test completely and was eventually able to pass it despite the surgery so I know now that most of my visual problems were biotoxins and not the Lasik procedure.

This is the test Dr. Charles Christ had me do when I asked how to know if I had chronic Lyme or a similar illness. It's a simple test using a card you read at 18 inches from your face. But it took forever for me to find the test for our office. Briefly I could have people do a screening test online but then it disappeared. I did find another one <https://www.vctest.com/> If you want to test yourself every month this would be a good one to use because the test automatically changes where our card test is obviously the same test every time. This online test tracks your performance and maybe a great way to see if you're making progress.

This test was originally made for eye doctors but wasn't used much anymore and I believe the original company went out of business. Dr. Richie Shoemaker started using it with all his mold illness patients and bought the patent for the hand-held card model for in office testing. It was his research project that made it available online for a while free as part of research he was doing. Now he produces the in-office equipment and I could buy one for the office. It was very reasonable compared to a testing device that is now sold to optometrists and ophthalmologists. That was one of those machines you put your head in and I couldn't afford that at several thousands of dollars. I'm thankful that he made this much cheaper and just as accurate technology available again.

Biotoxins directly affect nerve cell function, which is one of the reasons the Visual Contrast Sensitivity (VCS) test is useful in supporting a diagnosis.

The first step

Is to test your home and workplace if you work outside of your home for mold. Because you need to determine where your exposure is coming from and get away from it. If it's your home, you'll need remediation and I've given you the name of an excellent inspector and the company in Peoria that was willing to follow her guidelines to avoid further exposure. (See Quick Start Guide at the front).

Next Step for the MOLD SENSITIVE and Multisusceptible

Don't be surprised if you talk to an "expert" in the mold remediation business on the contractor side if they've never heard of an ERMI or HERTSMI test. Builders have relied on air sampling forever and it's notoriously poor at picking up mold. It has never been found to correlate with human illness. But the ERMI (Environmental Relative Moldiness Index) was designed by the Environmental Protection Agency (EPA) using a standardized DNA-based method that will identify and quantify molds. This method was used by the Department of Housing and Urban development to complete the American Healthy Homes Survey. This method was tested on homes across the entire US and analysis of the dust collected was used to develop a national Environmental Relative Moldiness Index. Basically, a way of categorizing a home on a scale to compare it to other homes. How moldy is this home compared to the average home? Mold isn't the only concern in water damaged buildings but further research showed that this index correlated with the degree of water damage the building has had historically which correlates with how the health is of the occupants. Air sampling tells what is happening today for this 10-minute sample but has little to do with how little Jimmy's asthma will do if he lives here. The ERMI tells us if it's safe for Jimmy or not.

Side note: It takes the government to do this type of survey and it's very helpful. So later when I bash the government, remember we can at least thank them for the

ERMI. Our government isn't all bad or all good, but the CDC and NIH tend to favor academic centers and big business over the individual when it comes to health policies. They are quick to try and point at a doctor or patient and say they're biased when EVERYTHING they do is often biased and developed by doctors with big undisclosed conflicts of interest.

If you are mold susceptible or multisusceptible then you need to prove exposure. You must test your home and work for mold and mycotoxins. The best test for your home was the ERMI but now we have an even more affordable option that will suffice called the HERTSMI-2. It will return a score. Everyone is susceptible to mold at a certain level but if you're sensitive you will suffer unless your score is < 2. See Appendix 2 for sample ERMI report. The ERMI sampling method is vacuuming a square of carpet or flooring of a set size. The kit tells you how to do it. You can obtain a test kit at this link:

<http://assuredbio.com/product/the-environmental-relative-moldiness-index-ermi/>

For the office, people often use the Mold Investigator or similar tests. Here you may have a cloth you wipe down a surface with or some other type of sampling device. See Appendix 3 for sample report. Here's a link to order the Mold investigator:

<http://assuredbio.com/product/diy-mold-test-w-dna-analysis/>

I can tell you that you want surface testing not air testing. Contractor prefer air testing because it's the most likely to tell you that you DON'T have a mold problem. Skip the air test. If you talk with a mold remediation company or inspector that only uses air tests don't use them. RUN AWAY!!!! Martine uses both and because she is independent from remediation as any ethical inspector must be so she will find mold if it's there.

Your ERMI Results

Once you obtained the ERMI test results email them to me and then we apply a scoring method called the HERTSMI-2. See appendix 4. This will tell you if you home or work is safe for you to remain there. DON'T PANIC!!! If you haven't talked to Martine yet and your results are higher than acceptable now would be a good time. But don't just randomly call companies to remediate. Already patients have done this and told me stories that were very alarming to me. One family it was done while the affected family member was at home the whole time. Does that seem like a good idea? It sure doesn't to me. Then they claimed it couldn't be the problem because she wasn't any better. She kept a diary and it showed she got worse after the remediation. As I would expect her to when done by people using air samples. PLEASE talk to Martine before hiring a company to remediate or talk to me if you don't get a hold of her.

Dr. Richie Shoemaker developed a protocol for eliminating mold illness. He claims you must go through the protocol steps in order and it won't work if you jump around or skip a step. Other experts in mold claim that it's not quite that essential BUT they all agree that the first step is

mandatory. The important first step is you must remove yourself from the moldy environment or remove the mold. The mold must be removed very carefully or you will get sicker and worse exposure than before you messed with it. DO NOT ATTEMPT TO REMEDIATE YOUR OWN HOME WITHOUT READING THE REST OF THIS DOCUMENT.

Keeping Records

As I stated earlier it would be in your best interest to prepare a detailed timeline of your important medical events and a complete medical history. Next start a daily journal or diary and it can be very simple. I like using 4 measures daily 0 to 10 with 0 being none and 10 being unbearable and for 4 categories:

P pain scale with 0 none and 10 unbearable

F fatigue scale with 0 lots of energy and 10 unable to lift head off bed

M mental fog with 0 genius and 10 I couldn't remember my own name today

O is Other symptom and should be the same symptoms for the entire time between appointments.

I have put a copy of the symptom calendars in the Facebook group.

<https://www.facebook.com/groups/693182417520774/files/>

Or you can email me for one if you haven't been given one in the office.
drknight@theknightcenter.com

Binding Agents

You can start this next step even while determining if you're still being exposed. Most people start taking either Questran or Welchol to bind the mycotoxins in their system. Even though it's a binder it can as it pulls toxins out of the tissue cause your immune system to see those toxins again and react. You can effectively "herx" just like the Lymies. If you don't know what a Jarish-Herxheimer reaction is see appendix 5. I also treat Moldies with weekly IV or IM glutathione if they can get to the office that often. Obviously, that would be difficult for some people if they live far away. You can also get benefits from oral liposomal glutathione per several mold experts in the American Academy of Environmental Medicine that I attend and am a member. (Dr. Shoemaker is also a member but there are several "mold" experts.) I ordered ours from Pure Encapsulation and it is available at our office or I'm sure you can find it online. Another brand mentioned at the last meeting was from ReadiSorb.

I can send off Questran (cholestyramine) for you but here's a kicker it may have gluten and for sure has aspartame in the Light version and sugar in the regular version I prefer the sugar version and would avoid the aspartame version.

QUESTRAN (Cholestyramine for Oral Suspension USP) contains the following inactive ingredients: acacia, citric acid, D&C Yellow No. 10, FD&C Yellow No. 6,

flavor (natural and artificial Orange), polysorbate 80, propylene glycol alginate and **sucrose**. *

QUESTRAN LIGHT (Cholestyramine for Oral Suspension USP, Light) contains the following inactive ingredients: **aspartame**, citric acid, colloidal silicon dioxide, D&C Yellow No. 10, FD&C Red No. 40, flavor (natural and artificial Orange), **maltodextrin**, propylene glycol alginate and xanthan gum. MALTODEXTRIN MAY CONTAIN GLUTEN. *

You can get compounded cholestyramine without gluten, sugar or aspartame made with just stevia. I found a great informational sheet all about cholestyramine (abbreviated CSM) on survivingmold.com and will attach it to this document in the appendix. However, I also follow a list maintained at www.glutenfreedrugs.com and they claim Questran and Questran light are gluten free as well as Welchol. They claim if you've been told by a drug company that something contains gluten on their list that when they investigated was due to it containing sugar alcohol as excipient. They can be extracted from many sources including wheat BUT during the manufacturing process are completely refined leaving behind NO GLUTEN. One person called and was told the xanthan gum in Questran Light contains gluten. Xanthan is fermented from sugar so again like sugar alcohol issue it doesn't include gluten. Typically, maltodextrin can be from corn, rice or potato in the US, but it's made from wheat starch in Europe so be careful over there. But here all three are considered acceptable for patients with celiac and if it's ok for celiac it's ok for me.

It also interacts with other medications especially thyroid hormone and other hormones. It will lower their effectiveness by binding them and preventing their full absorption if taken too close to them. It should be taken 2 hours away from thyroid or oral contraceptives. But not necessary for other medications.

Another option is Welchol and it doesn't contain gluten. Most Lymies need to avoid gluten and same goes for Moldies. But you won't be on this medication for life hopefully just months. Only reason people would take more than months is they failed the first step and are still being exposed to mold or they have a biofilm containing MARCoNS in their deep nasal passages.

Yes, that's what we're calling everyone now Lymies and Moldies. I recently heard of people that get messed up from fluoroquinolones and get neuropathy, now you and I know they may have a tick-borne infection. BUT anyway, they call themselves Floxies.

This is as far as we can go in treatment without further testing and there is no reason to do that until you know what your home and work place mold scores are or to prove how sick you are. That's probably worth doing if you suspect it's in your work place. Or you simply don't believe that you have a mold illness then we could also do the next set of tests and if they're all normal then I agree.

For many reasons people often drag their feet with testing their home. I realize it may be the cost. But an ERMI is usually \$250 which isn't much when you consider the money you've already lost being sick. I suspect it's due to the fear that it is their home making them sick and dread of what that will cost them. BUT it may be a small problem and you still could be very sick. But you continue to let it go and it can become a big problem. Do the test!!!!

Many people voice concerns about outdoors mold getting in somehow. You will feel worse on days that the mold is higher outside BUT I've now read and heard in several places what matters the most is your indoor air. Also, don't block all air from outside from getting in. That may be the worst thing you can do as we need to be able to flush our houses and get rid of the stale air. Mold doesn't creep in. It happens naturally in buildings with water damage, leaky basements, leaky roofs, and broken pipes.

Problems on BINDERS

If you are taking the binders and feel you are getting steadily worse. You **must stop** the binders for two weeks, but if you worsen when you go off, then the problem is poor detoxification and you need more glutathione. If you improve then restart at lower dose and go slower, but most of the time it will be the former. Either way if you should restart and go slower then start with 1/8 or 1/4 of scoop. 1 scoop equals 1 3/4 tsp. You can also take pioglitazone 15-45 mg for 5 days prior then restart and that can help with tolerating but that only works in those with high leptin. The very thin do better with high dose omega 3 fatty acids (fish oil).

You can mix the CSM with water or juice (pomegranate has been suggested as good) one half an hour before a meal (usually lunch) and have some fat in that meal. You want to have bile salts empty from gallbladder because that's where the toxin is hanging out. Wait 90 minutes before taking any other supplements or medications, except probiotics you don't need to wait. You want to wait 120 minutes before taking hormones such as thyroid or oral contraceptives.

If you still can't tolerate the CSM, you can try WelChol (colesevelam) 2 caps three times a day but again start slowly and work your way up.

Remediation is Dangerous!

You need to be very careful. This is not the time to grab a bottle of bleach spray and go to town. Bleach does not stop mold from releasing mycotoxins and the toxins release are far worse than the mildew you just cleaned up. **First go to the Quick Start Guide.** You would be much better off talking to Martine Davis before attempting remediation. On her website, she recommends obtaining a copy of the EPA publication entitled Mold, Moisture and Your Home or go to the New York City Health Dept. website and read the Mold Remediation guidelines. They both offer detailed mold cleanup guidelines. Visit www.epa.gov/iaq/molds/moldguide.html to print a copy of the guidelines. The phone

number for the EPA Indoor Air Quality Clearinghouse is 800-438-4318. But she advised against clean up unless it's a very small, contained area.

On Martine's website www.airinspector.com I saw this and had to post it here as it explains the problem when you rush to fix this situation and get taken advantage of:

Promises of a quick fix are tempting and attractive. Homeowners don't like to hear that all their drywall has to be ripped out; that their house has to be subjected to noisy air-scrubbing machines, large vacuums and plastic containment, so when someone comes in with the promise of a much easier solution, like a spray, enzyme or encapsulant, it's tempting. The only caveat is that when it comes to mold, no spraying method has consistently been proven to work. Worse, many homeowners were made ill by sprays. Even enzyme formulas can cause allergies/reactions in occupants, in the same manner as some people may react to enzymes in laundry soap.

Ask yourself this: If you had a cancerous tumor inside of your body, would you prefer to have it cut out and removed or just sprayed with something and left there? REMOVAL is the word when it comes to mold.

There are several facts about mold that should help you when selecting a method for mold remediation.

1. Dead mold is still toxic and allergenic.

Dead mold is quite capable of producing and emitting mycotoxins and numerous other allergenic and poisonous vapors and by-products. A case in point is the ancient Egyptian tombs, in which scientists recovered deadly molds dating back thousands of years.

"Killing the mold" is a precaution one might take to make the mold less infectious, but it does not eliminate the allergenic and toxic substances emitted by the mold.

2. Sprays rarely kill the underlayer and roots.

When mold is sprayed, only the top layer is affected. More layers and roots underneath are unaffected and will continue to thrive, given the proper ambient temperature and humidity. As a matter of fact, given an adequate amount of moisture and food such as wood, mold will grow right through paints and other encapsulants.

3. Most fungicide sprays are toxic.

Finally, unless the agent being sprayed is botanical, there is a likelihood the spray itself is toxic and can make occupants ill. Several homeowners in the Madison area were forced to evacuate their home after a mold-remediation product was used to spray either in their duct work or in their basement.

www.airinspector.com

While spraying bleach on mold seems at first to be effective, it rarely solves the problem, and most people find that the mold eventually returns plus bleach does nothing against mycotoxins and VOC's. The latest scientific research has clearly shown that, not only is

bleach not effective in killing mold, but the spores that are dead are still toxigenic and allergenic (capable of producing mycotoxins and causing allergies). Additionally, bleach itself is toxic, environmentally unsound and can be a strong lung and eye irritant. Many people drag out damaged drywall and drop mold spores throughout the entire house and if the heat or cooling is running disperse the spores throughout the entire house. This must be done very carefully.

I would highly recommend reading *Surviving Mold* by Ritchie Shoemaker if you have any intention of remediating your own home. Chapter 24 Testing and Remediation by Greg Weatherman. He is principal owner of Aerobiological, Inc. Arlington, Virginia and discuss how to go about it but most of it is way over my head. Especially read it if you can't go with Ms. Davis or Mr. Lanius in Appendix 1. Because there is a lot of bad remediation going on that will **make you worse** not better. If they are only sampling the air, then they're not doing it right. There are guidelines for mold remediation assuming the home owners have normal or average mold sensitivity. That doesn't work if you have a susceptibility to mold and susceptibility to chemicals on top of that. Air sampling CAN be a part of the testing but there also needs to be trapping and DNA identification of molds.

Another great guide now available to help with both your own treatment and remediation is called MOLD ILLNESS Surviving and Thriving by Paula Vetter, RN, MSN, FNP-C, Laurie Rossi, RN, Cindy Edwards, CBA and Introduction by Ritchie Shoemaker, MD. You can find it on Amazon of course or at SurvivingandThrivingBook.com. I'm thrilled with this book but considering that was going to be a title of a book I plan to write someday... That's ok I have another variation of it.

You've Got Mold and You Tested Your Home

So, you obtain testing of your home what now? We look at the result of the test and determine if it's low enough for your health. See appendix 4 and calculate your HERTSMI2. If you have a mold susceptibility gene, then you need the ERMI result to determine if your home is safe for you. You have a level then you can aim for in your remediation and then if you adhere to the Shoemaker protocol you should get better. The most important element in the mold story is the active of water. Martine Davis can tell you from what species show up on your test where the mold is at. I'm far from experience but can list some of that information as I learned from Shoemaker's book that the mold species can be predicted from the available water on the surface of the substrate.

A piece of wood with 0.5 Aw	No mold growth
0.65-0.82 Xerophilic (dry loving) penicillium, and	Eurotium, Eupenicillium, Aspergillus, Wallemia
0.84 to 0.95 Mesophilic (moderate moisture) Epicoccum and Staphylococcus	Cladosporium, Alternaria, Curvularia and are more typically outside molds bacteria
Above 0.9 Hydrophilic (water-loving) Bacillus and	Stachybotrys and Chaetomium molds, other gram-negative bacteria

You'll see publications recommending relative humidity should not exceed 60% (allowing for a 5% error rate). But that's the relative humidity in the air rather than on a surface. You look at the colder base of walls in humid environments and the moisture on the surface goes up.

Most of you can smell. I unfortunately suffer from anosmia. (lack of smell) BUT then why no perfumes. That's the funny thing. I still can taste them and they still give me migraines. My sense of smell is not completely gone; I can smell coffee if I put it right under my nose but not otherwise unless it's brewing a few feet away from me. However, I used to be able to smell so I remember I could smell yeast in the past. Yeast has no odor or very little in the package. But when you warm the milk to 105 degrees and add a pinch of sugar and then pour your baker's yeast on top of that milk. Suddenly you smell the strong smell of those spores waking up and growing. That odor comes from them metabolizing the sugar and producing ethyl alcohols and carbon dioxide. This is an example of a microbial volatile organic compound (MVOCs). In a building, especially in the basement or crawlspace when you smell the dirty sock smell or in a library the smell of old books, you are smelling VOC's. If you are Multisusceptible then you are also sensitive to VOCs. I can't help but want to sing her you know VOCs yeah you know me. Sorry. I can't tell you all the information you will get from that chapter in Shoemaker's book. But humidity in a room should be maintained between 40% and 55% relative humidity.

A person or company engaged in microbial remediation should NEVER be doing the post-remediation verification testing that is a conflict of interest.

You've Got Mold and You Tested Your Work

If your source of mold exposure is your work building, you are also in a difficult situation. Now you need your employer to agree to remediation and that can be tough. If you work at a school or government building, well that's an uphill battle. Two places where you would think it should be easiest since don't we have an obligation to protect our children? Don't even go there.

If they won't remediate and you recover, then you may have to return to work for 5 days and get sick again to prove your case. Yes, I know that sounds horrible but you should demonstrate that you recovered but that exposure to the building made you ill again. Don't do this without first working with me to put testing in place because when you do that we have blood drawn daily. (It should be done right so if you live far from our office we will do a test run with a lab near you before you enter the building). If you don't do that it may be very difficult to prove or much harder your case in court.

Obviously, this hinges on recovery. It can take some very sensitive patients years to recover and then the place they worked could be gone by then. The first patient's place of employment got nervous when she went to U. of Iowa and closed the building they were working in. However, they moved the furniture and equipment into the new building without proper decontamination of it. So, when she entered she was immediately sick again and felt so bad she left and never went back. You may be too sick to make it 5 days. You can only do what you can do. But I'm outline the "ideal" approach for legal reasons.

Ideally your employer would say you are worth it and we want to remediate so that you can work here safely. Then what would you do? Just like your home you would start with having

them test the building and working with an inspector that knows about mold. They should talk to at least two different remediation companies. If the companies rely on air samples run away. Again, remember the inspector should be separate financially from the remediator. You will want to run an ERMI and then plug the scores into a worksheet to get the HERTSMI2 score. Appendix 4. If the score is <11 congratulations your home or office or both is safe for you.

The Shoemaker Protocol and The Biotoxin Pathway

Basically, the Shoemaker protocol involves testing your labs for markers of your immune system and signaling system of the body and finding areas that are out of whack and applying his recommended corrections to remediate these imbalances. Sounds easy, right? Nothing is easy. Because these toxins have set off a system that triggers widespread inflammation we must help the body remove them. We also must try and reset the system. I've appended a graphical depiction of the Biotoxin Pathway from Shoemaker's website in Appendix 6. Sorry I made it as big as I could which meant it had to be landscape orientation.

Some patients will be started on a binding agent and will return in a month doing enormously better and that's before they even remediate their home. BUT don't get your hopes up, that is rare. Also, you must remove the mold from your environment OR remove yourself from the moldy environment. Without that most will not improve. But at the same time, it is very difficult for the moldy, sick person to accomplish this because of the brain fog making it hard to think through simple things not to mention the complexities of home remediation or evacuation. There are also the huge financial implications of property loss and how to overcome that issue. I understand that this is extremely difficult. But you only have your health and if your home is making you sick then you'll have to face that but there is help to be had. Talk with Martine Davis, she suffered this as well and has been there and got better. She can point you towards guidelines for picking the right professionals and she's likely worked with professionals in our area. She has worked for sure in the Peoria area. She is based in Wisconsin but travels to Illinois, Minnesota and Tennessee as well and has been highly recommended by two patients so far.

We will run a panel of tests on you on two separate days if you're local but we can do same day if you travel far we just had to put aside more time. But we also need to do a set that includes a nasal swab for MARCoNS and other basic labs. Antibiotic-resistant coagulase negative staphylococcus colonizes the nose of many individuals. If you are one of those it will cause reactions from your immune system that interfere with the treatment of your mold illness so it must be addressed. I will also measure the following:

- ADH/Osmolality
- ACTH/cortisol/DHEA
- MSH (melanocytic stimulating hormone) #
- VIP (Vasoactive Intestinal Polypeptide) *
- TGF beta-1
- C3a and C4a^
- VEGF
- MMP9

I also monitor thyroid and adrenal hormones and other lab tests in patients with biotoxin illnesses as indicated. #Dr. Shoemaker recommends MSH only from LabCorp and that's who does ours. *Dr. Neil Nathan now recommended getting VIP from Arup Laboratories and stated that neither LabCorp or Quest were doing it right. Our lab VIP was done at Mayo and when it comes to markers for endocrine tumors Mayo is top notch. The problem is not that they don't run it right but they don't report lower than 50 value. They just say less than 50. ^Dr. Shoemaker recommends Quest only for C4a and not LabCorp. We get this one from ADVANCED DIAGNOSTIC LABORATORIES AT NATIONAL JEWISH HEALTH in Denver, CO but when I investigated it National Jewish is where the complement test was developed and most experts recommend only using them. The ability to just get labs from one specific lab isn't easy and from my experience with Health Lab they will change if there is a problem. For instance, we measure the "CD57" test frequently in our Lyme patients. That test at first was being done by Quest or LabCorp. But then Quest had issues so for a while Health Lab switched to LabCorp. Then LabCorp was reported to have problems and they switched back to Quest. They've been using Quest now consistently for a couple years. They appear to have their ear to the ground and no one when to switch tracks. (Sorry if that euphemism confuses you.)

Shoemaker recommends monthly testing but I can't see doing that on tests that take 3 weeks to come back. I retest ADH/osm, ACTH/cortisol, C4a, TGF beta-1 every 3 months but I'm willing to do it every 4-6 weeks along with the vision contrast sensitivity test to guide the treatment protocol when people are getting close to the end. Shoemaker's protocol then addresses the following issues in this order.

1. Proper Evaluation
2. Visual contrast testing
3. HLA susceptibility, CIRS labs
4. ERMI testing of home, other testing of work place or outside home
5. Remove from exposure
6. Preload with Fish Oil or Actos if high MMP9 or Leptin
7. CSM/Welchol. May need a low amylose diet.
8. Avoid constipation at all costs
9. Check for MARCoNS if hypothalamic illness suspected (High leptin, mismatched ADH/osm, low MSH, low VIP and/or mismatched ACTH/cortisol all = hypothalamic illness)
 - a. Correct androgens
 - b. Correct ADH/osmolality
10. Correct TGF-Beta-1 may require:
 - a. Correct antigliadin
 - b. R/O acquired von Willebrand (nosebleeds) from elevated C4a
 - c. If post exertional malaise check PFT if show restrictive do Pulm Stress Test
 - d. Normalize CD4+CD25+ t helper cells
11. If VCS is normal, an ERMI<2 at home and work (or a HERTSMI-2 < 10), fully cleared MARCoNS, and persistently low VIP or persistently elevated C4a, try compounded VIP.

Dr. Nathan also was advocating using Real Time Labs for mycotoxin testing in the urine so I ordered kits and handed a few out. I think one patient may have taken the test but I'm not sure as I haven't seen any results yet. However, since that time I read more about this lab and have some concerns. There are claims on the internet that every test ever sent there has

come back positive. If this is true, then there is a problem. I've halted doing this test until I can confirm its validity with another source.

Treat MARCoNS

We also will check your nasal passages for colonization by MRSA or MARCoNS as Shoemaker calls them. To eradicate them it is recommended to take Rifampin 300 mg 2 tabs daily for 30 days for adults. (I don't treat kids but their dose is 10-20 mg/kg/day.) In addition, the recommend BEG spray, it's an acronym for Bactroban (mupirocin), EDTA and gentamicin. I've used mupirocin alone as recommended by the standard protocol and it's not been successful in previous patients that had recurrent boils due to MRSA so I imagine it won't work alone in this group either. The dose of this is two sprays 2-3 times a day for 30 days. Start together with Rifampin to avoid resistance.

If you want a less harsh approach you can try a recommendation from Stephen Buhner, the herbalist lead for Lyme treatment. 30 days of a cryptolepis/aida actua/alchornea tincture regimen (from woodlandessence.com) will clear it up quite nicely. Or its use as a nasal spray. Terminalia is a good herb and it is active against staph, so use it as well if you want to. I also read a story online (there are many and they can freak you out so I don't advise looking for them) but when the BEG spray didn't work for one girl they found a nebulized concoction of itraconazole and clindamycin did the trick. That's big guns but it didn't sting. That's a plus. BEG spray is very stingy. You can get any of these nasal sprays from Woodland Hills Pharmacy. <http://www.woodlandhillsparmacy.com/compounds/biotoxin/beg-nasal-spray/> I imagine you could try asking your local compounding pharmacist for BEG spray and they have the formula on their website and they may be able to compound for you. I can't speak to that since I haven't had anyone try that YET! They also have other sprays that add more ingredients probably for those resistant and for those that are found to have more than just MARCoNS in their nose. This pharmacy is also a source for pure CSM without sugar, artificial sweetener or gluten in powder or capsule form or with methylcellulose and Stevia.

Correct Anti-gliadin or Avoid Gluten

If that means a gluten free diet, then I'm not surprised. Most of the Lymies that go gluten-free see a big improvement and I'm one of them. I suspect that most people with mold or Lyme related illness would benefit from going gluten free. You don't have to do it forever but it's probably worth doing while you're also doing this treatment. I suspect the biggest reason going off gluten and sugar are because of their avoidance helping improve the gut biome. Shoemaker's protocol tests one antibody if it's positive then the other antibody. Well they come together in a panel so we test both and we test the HLA DQ types to see if you're susceptible to Celiac just like you were tested to see if you susceptible to Mold. I feel more comfortable with those that test neg to either antibody and not genetically susceptible being able to eat gluten. BUT I think if you show the genetic susceptibility it doesn't sense to further contribute to leaky gut by not avoiding gluten. It's not easy to give up bread. But if you feel so much better off of it then you won't miss it.

Correct Androgens

This is interesting as well. The amount of DHEA recommended by Shoemaker's protocol is high and I'm not comfortable with giving most women that dose. I prefer to measure cortisol and

DHEA and aim to get their DHEA 150-300 range. But we also address if the ACTH/cortisol is mismatched.

Correct ADH/Osmolality

Often ADH is reported as high or low. Same with osmolality. But the important thing to note is what are they with respect to each other. If the osmolality is high normal 305. Then the ADH should also be high normal or higher than normal. If it's low, then that's a problem. If this is off treatment is with desmopressin taken as a pill or a nasal spray and then the ADH, osmolality and electrolytes need to also be followed monthly. This issue when corrects the polydipsia, polyuria, orthostatic hypotension and tachycardia and static shocks. It also helps the recurrent headaches.

Correct MMP-9

This involves the pioglitazone or fish oil we already mentioned as being needed if patients aren't tolerating the binders. Then this is taken for 30 days along with the low amylose diet. The low amylose diet will be in appendix 7. This one also depends on the patient's weight, history of diabetes, and levels of leptin. Thin patients with low leptin should go the fish oil route. But heavier patients especially with higher leptin levels will need the pioglitazone to lower leptin. If you don't lower leptin, the fat cells keep signaling the biotoxin pathway. Leptin resistance increases fat cells and increases fat storage instead of utilizing fat by muscles for energy.

Correct high C3a

Dr. Nathan claims this step is skipped but I still see it on Shoemaker's physicians' protocols. It's probably because the treatment is statins and CoQ10. I've never seen CoQ10 work to reduce myalgia's from statins so the fact that Nathan does say if C3a high he pretreats with Coq10 then high dose statins makes me think he doesn't follow through on how that works very much. But Shoemaker's people say the same thing. 150 mg of CoQ10 10 days prior then simvastatin 80 mg. I would recommend 50 mg of Coq10 and rosuvastatin 10 or 20 mg daily or every other day and I bet it would work as well if not better.

Correct high C4a

The recommendation here is Procrit. I've never used Procrit and have big concerns that it would not be covered by insurance even if I did write for it. It's an injection used typically in cancer patients and renal patients to increase their red blood cells. You must watch very closely that you don't cause polycythemia. Five shots of 8000 units are given twice a week over a 15-day period. If it works and the C4a drops significantly a second trial can be started to find the best dosing to keep it lower. If Procrit doesn't work you can try VIP therapy. 4 vials of Procrit 20000 units are \$1918.19 at Kroger. Athletes have gone to jail for using this to dope for races. If you buy it from China wholesale one site listed the cost for 10 vials or 30000IU at \$430. I'm hoping no one needs this step.

Correct TGF-B1

Transforming growth factor beta 1 or TGF-B1 is a cytokine and impairs normal T-regulatory cell function. Normal T-regulatory cell function prevents autoimmunity. Reduction of an

elevated level of TGF- β 1 is done by giving losartan up to 25 mg twice a day. This medication is usually for blood pressure and has been shown to have positive effects in Lyme patients as well. Lyme or mold patients that need blood pressure medicine I put on this or Benicar. Benicar has been shown to work similarly. High TGF- β 1 is also an issue in connective tissue disorders like Marfan's syndrome and losartan was found to be uniquely adept at preventing aneurysm formation. High TGF- β 1 is far worse in the "dreaded" genotypes especially 11-3-52B

Finally, VIP

Patients should be much better with resolution of 75% of their symptoms. Then they say some will need this last push to get back to their old self. Tadalafil 20mg 3x week is an alternative. VIP nasal spray can only be obtained through Hopkinton Drug in Massachusetts. The dosage is 1 spray 50 mcg 4 times a day alternating nares. It's done for at least 2-3 months then titrated down. It won't work if you aren't completely away from mold, have MARCONs and a normalized VCS screen. If all the steps are followed (and not all are needed in everyone) then Shoemaker's protocol claims 90% success rate.

The two steps that concern me are the Procrit and the VIP spray. I don't have anyone on this protocol close to those two steps yet. But when I do I will be signed up with Shoemaker before that happens. He certifies physicians in his protocol and I need to learn a lot more about those two steps before I would be comfortable starting patients on those therapies. But so far, I've had a few that haven't needed to go that route.

15 Things All Mold Illness Patients Need to Know from Richie Shoemaker's Surviving Mold Book:

Before you read this list. Note that I don't agree with it. Because it violates one of my own principles, which is this, there are no always or never's in medicine. He uses a lot of "always" and "never's" which should raise a red flag. BUT I'm sharing it anyway, because these are areas of concern for Moldies. I just don't agree with all of them or how he words them.

1. Always have a plan. (If you are reading this for the first time then consider this our plan or our starting point but be prepared plans change.)
2. Be careful extending your ankles in bed, as the muscle spasm, the wrenching, twisting, knotting cramps caused by capillary hypoperfusion, which in turn, is caused by inflammatory compounds seen in some CIRS-WDB.
3. NEVER take steroid meds by mouth unless threatened with death. Yes, I capitalized the NEVER but it's almost never. If you do happen to have near completely adrenal fatigue you're going to need steroids or you will possibly die. There is no NEVER.
4. Trust your new-onset symptoms to tell you to get out of exposure.
5. Ask for objective data from anyone who says you have Chronic Fatigue Syndrome or Fibromyalgia. (I disagree on this one with Richie. We may have to label you with one of those or both if you fit even though we know they don't tell why you're sick at least they are now recognized as disabling and that may be helpful.) But I do agree with Richie because I know he's saying find the cause of these syndromes. It's likely environmental illness.
6. Never do two new interventions at once. If you do, you will have little hope of using scientific approach to getting better. You must test everything and can only do this by testing one thing at a time.
7. It is a good bet your crawl space or basement is moldy.
8. The diagnosis you had last year doesn't necessarily make sense this year. Or I like to say, if you don't like what I tell you today, don't worry just come back next year and I'll tell you I had it all wrong.
9. If a healthcare provider says adrenal fatigue or androgen deficiency or reverse T3 run away. Hah! I don't agree with this one either. Those issues I think are more common thankfully than mold. BUT hey in a year I may change my tune. Ask me again in a year.
10. Demand peer reviewed publications to support the basis of new therapies. This one is interesting because yes Dr. Shoemaker has published. But the reviews of his articles haven't always been favorable. Don't get me wrong I think he's approached the issue more scientifically than anyone else and deserves a prize for that for sure. But his approach STILL might fall apart under scrutiny. It's a very complex, difficult task to test mold illness scientifically and I'm always wary of anyone that claims to have the ONLY cure.
11. Never use cash-only labs unless you need new liners for canary cages? OK but he now says only Arup labs can be used for VIP and they fall in this category. So, see Richie, there's no always or never.
12. Never trust negative air samples or those who rely on them.
13. Administrators are known to lie. And they do. Trust rarely.
14. Don't believe for a minute you need virus killers, anti-depressants, fibromyalgia pills or bizarre therapies. You need a plan based on hard science. But if you truly have

major depressive episode or meet the criteria for Fibromyalgia, then there are BETTER studies than Dr. Shoemaker's with proven treatments so he is not following his own rules here. BUT I understand he's saying don't stop and settle for I'm depressed or I have fibromyalgia. I have both of those things but I still looked until I found other illnesses that when treated cured me of fibromyalgia. But I still need sertraline for my depression. I've had that I was a teen so I don't know if I'll ever cure it.

15. Always evaluate action taken carefully thoroughly. Never make assumptions without checking.
16. From Dr. Knight and always remember there is no always and never forget there is no never.

Approaches to Mold from practitioners other than Shoemaker

Dr. Richie Shoemaker is the pioneer in this area and did us all a great service by so carefully documenting all his methods and testing them as well. I tend to think we should follow his lead. However, other physicians have criticized the protocol as being too much for some sensitive patients. My take on this is you try to follow the protocol as best as you can. If you just can't tolerate something he recommends we will try to find a substitute. Yes, it's less researched and less proof of success but doing something is better than nothing.

Supplements and Herbal Formulas

If someone is just not tolerating either binder but it's not due to a true allergy or intolerance, then we have offered Glutathione IV or IM to help tolerate the intensification.

Glutathione Rescue

We started doing this for Lymies but it helped the Moldies as well to stay on the binders. Glutathione is our most potent anti-oxidant. Genova Diagnostics Nutreval uses the Glutathione level as an overall predictor of how you handle everything. After Glutathione is oxidized, it is recharged by using NADPH as an electron donor. The ratio of reduced glutathione to oxidized glutathione within cells is often used a measure of cellular oxidative stress. It is one of the major endogenous antioxidant produced by the cells, participating directly in the neutralization of free radicals and reactive oxygen compounds, as well as maintaining exogenous antioxidants such as vitamins C and E in their reduced (active) forms. It regulates the nitric oxide cycle which is critical for life. It has a vital function in iron metabolism. It's necessary to repair DNA and RNA. It can't be taken orally unless attached to a carrier protein. Thus, why there is now liposomal glutathione or intranasal glutathione. To start however, naturopaths often give it IV or IM and we've started doing that as well. You can also boost your own production by taking N-Acetyl Cysteine. However, we must stress that we want to record baseline labs and VCS and then post treatment VCS and then labs and VCS again in 1-3 months times depending on where you are in the protocol. You should not be adding or subtracting medications or supplements without our knowledge and without a plan for testing to see if it's of benefit. Plus, we want to see how you respond first to following the protocol before you change anything.

I believe that Dr. Shoemaker's protocol can be done without the expense of IV nutrients and fancy supplements and be successful. I also know that some people don't believe in a protocol unless they pay a lot of money for it. In fact, I think the more some alternative practitioners

charge for their “treatments” the bigger the draw. Be smart. Try it out without any added bells or whistles. Later if you want to add something do ONE thing at a time. Record your progress and make sure it’s helping or if of no use then move on.

Post Lyme Susceptible and Unsure Why III?

Most of my Lyme Disease patients came to me declaring themselves to have Borreliosis. I believe they all have biotoxin illnesses but I realize now they could have Borrelia, co-infections, but also could be suffering from mold. It doesn’t matter what the biotoxin illness is that caused it all because they’re all variations of the same process. The key to take note of is if your MSH level is below 35 then you will become susceptible to other biotoxins just like a multisusceptible patient.

My new biotoxin illness algorithm:

Patient complaining of the Biotoxin Trinity: Fatigue, Pain, and Mental Fog over 6 months.

If you’re sitting in front of me when we decide to investigate this possibility.

1st step would be to test your Visual Contrast Sensitivity.

2nd step is to review the Biotoxin Symptoms Clusters and remember it’s not just what you are currently reporting as symptoms, it’s all the symptoms you’ve had since you became chronically fatigued and they count even if you think you know why you have them and blame something else.

If you are an adult and have failed the VCS and have at least 6 symptoms clusters we will draw the labs. If you have passed the VCS but have at least 8 symptom clusters we will draw the labs. If you are younger than 20 years old it can be the source of problems with far fewer symptoms but I’m not prepared to discuss kids yet. I’m an internist and that means a doctor for adults. I realize in the future I very likely will have to learn how to treat children but I’m concentrating on figuring out those over 14 years of age for now.

3rd step review your labs. If your HLA shows susceptibility that’s clearly a strong biomarker for CIRS and counts as one. From there we count from the following:

CIRS 1 Panel*

ACTH/cortisol (evaluate as with respect to each other and the pair can only count as 1 biomarker)

ADH/osmolality (evaluate as with respect to each other and the pair can only count as 1 biomarker)

C4a if over 2830 is positive. C4a is generated from

*I often draw only these on a patient first since their relatively cheap to see how likely it is we’ll need the rest.

Appendix 1 Biotoxin Map

When you wonder where am I on this journey? This is the steps you are taking.

1. Differential Diagnosis begins with a compulsively obtained data base - answering questions like what could be wrong? The labs needed to show inflammatory abnormalities are collected, and the labs that are always normal in biotoxin illness are also collected.

You've been to many doctors besides me. You have heard that they don't know what is wrong with you. Your usual labs CBC, CMP, lipids, even sed rate, ANA, other markers have not lead to a diagnosis. Or perhaps you've been my patient awhile and I've worked up you for various things, but we were left with Fibromyalgia or Chronic Fatigue. I've done all I can to optimize your thyroid and adrenal function and you're still tired. So, we started this journey to see if you could have Chronic Inflammatory Response Syndrome or CIRS.

- A. We found you are genetically susceptible.
 - B. You have either 6 to 7 symptom clusters and failed the VCS (vision test) or you have more than 8 symptoms clusters and most of you have also failed the VCS test.
 - C. You have 5 or more abnormal biomarkers. (The Biomarkers are MARCoNS, ADH/osmolality abnormal, ACTH/cortisol abnormal, elevated C4a, elevated TGF Beta-1, elevated MMP9, low MSH, low VIP*, and anti-gliadin antibody (Deamidated Gliadin IgA Ab). *VIP, we need to find different lab to get accurate measure.
 - D. You have had exposure to a water-damaged building, a tick bite, blue green algae or ate reef fish. If we don't know where the exposure(s) came from you can bet on mold for most and Lyme Disease for some.
2. Performing ERMI testing to ensure there is no exposure to a building with an ERMI greater than 2 if the patient's MSH is less than 35 and C4a is less than 20,000; or no exposure to ERMI greater than negative 1 if MSH is less than 35 and C4a is greater than 20,000.
 - E. If a patient has higher markers than most, I'll tell them to do the ERMI over the HERTSMI2. You perform a HERTSMI2 or ERMI on your home. If your HERTSMI2 score is 8 or higher I recommend an inspection because the test standard measurement error is +/- 3 so your 8 could be an 11 and 10 or higher needs an inspection. If your home is good and you work outside the home or you spend a lot of time at someone else's home, then consider testing there as well. We also may check you for Lyme Disease now or later if you're not responding to mold treatment appropriately.
 3. Removal from prior exposure (this means no more working, schooling, or living in a moldy environment for WDB illness patients).
 - F. Your testing showed presence of mold in your environment at a level of concern, so you remediated and then you test again. This time if the score is <10 I am satisfied that it should be safe for you to be there. If it's 11 to 15 you don't have to evacuate but there is still more work to be done but if it's over 15 and you don't get it lower soon your C4a may climb over 20,000 and then you'll be come sensitized and get sicker, quicker. Some have already developed that before I ever did labs to warn them. Those of us that are susceptible need to understand it's not

really the amount of mold that matters. A little can still make someone sick especially if they've become primed to react. A score of 15 is half of what the average home scores. The average home in the US scores a 30. If a mold remediator says oh your mold isn't so bad they don't have a clue about susceptibility. Ignore them. NOTE: Sometimes we'll do step 7 first to reduce symptom intensification to the CSM. This can be done if your MMP9 is over 900 or if your leptin is over 25 in women or over 13 in men.

4. Correcting toxin carriage in the body with CSM (Cholestyramine) or Welchol, using VCS monitoring to assess progress.
 - G. You start cholestyramine. Work up very slowly because you do not want to get constipated. Cholestyramine (CSM) works by binding your bile salts that the liver makes daily. They are high in fat and these toxins like to hide in our fat so by pulling the fat out of your system, we're trapping the toxins. If you get constipated your body will reabsorb them so your liver worked hard for nothing.
5. Eradicating biofilm-forming MARCoNS.
 - H. Shoemaker painstakingly tested every step of this protocol and in different orders and this is the order that had the highest degree of success. He found much higher rate of eradication of MARCoNS when the patients were on daily CSM for at least a month before starting treatment for the MARCoNS. If you tested positive you must get rid of these before you can move on. Those that drag this step out just take that much longer to get better. Get the nasal spray done in a month and you won't be sorry. CONTINUE CSM while treating nose and continue until step N. If you must lower dose or temporarily stop due to constipation that's fine but don't stop completely without discussing with Dr. Knight. You stay on CSM until you go on VIP! If you can't do CSM, then you can do Welchol. Clay or Charcoal didn't show statistical significance when tested. If you're not on Welchol or CSM then you're not following the protocol.
6. Eliminating gluten for those with anti-gliadin positivity as shown by a positive blood test, with celiac disease ruled out.
 - I. We check if we haven't already for antibodies to gluten. If you have them, you will need to abstain from gluten until you are better. If you have high Deamidated Gliadin IgA Ab or IgG Ab but normal tTg IgA Ab this is a typical pattern for a mold toxic patient that will not have a gluten problem once they get through this protocol. Celiac patients will have both antibodies elevated.
7. Correcting elevated MMP9
 - J. If your MMP9 at this point is still close to or over 900 then if you are still holding down a full-time job you are amazing. For those with a level over 900 in this marker we need to lower it with Actos or high dose fish oil and the no Amylose diet. For some we should do this before even taking the CSM if they have symptom intensification from taking the CSM. So, this can move to in front of step G for some. It's also the same treatment for high Leptin levels (over 25 for women and over 13 for men)
8. Correcting ADH/osmolality
 - K. Those that have the very low ADH with high osmolality combination may be so dehydrated they can't keep from getting constipated. If this happens then this will also move to before G. Usually after its correct it is supposed to stay corrected

without having to stay on desmopressin the medication used to fix it. But those with POTS may have to stay on it. Are you getting a feel yet for why it's been so hard to learn this protocol?

9. Correcting low VEGF

L. Usually by the time we get to this point this is already improved. If it's high, we don't need to treat that but if it's super low then we can improve with graded exercise. You start with just 5 minutes or less a day and go up gradually.

10. Correcting elevated C3a

M. C3a is only elevated in CIRS patients that have Lyme Disease as cause of their CIRS. If it's staying elevated despite antibiotic treatment it can be lowered with a statin.

11. Correcting elevated C4a

N. Ideally the C4a should be much lower now especially if the patient is diligent in avoiding re-exposure and their home is safe. If it's still high but MARCoNS are absent, they are passing the VCS now and have done so at least 2 times in a row, their home HERTSMI2 is < 10. We can bring it down with VIP. Must also have normal lipase because VIP can cause it to rise. We also want a baseline NeuroQuant MRI before starting VIP to document the extent of brain inflammation and see the recovery. It's also helpful for being sure that Lyme isn't a part of the picture since Lyme has a distinctly different pattern on the NQ MRI from mold.

O. VIP trial is done before you start daily VIP. We order it, but you can't start taking it until you've done the VIP trial (first dose) in the office. On VIP you can go to 2 Welchol capsules daily or 1 scoop of CSM daily. If you are re-exposed you will want to take 3-4 scoops for 3 days then return to lower dose.

P. Typically, VIP is used 4-6 months and tapered off and with diligence to avoid any further exposure the patient should return to normal. Labs and VCS should be normal. For those unfortunately unable to use VIP we can lower C4a and TGF Beta-1 with erythropoietin. It's expensive and you will have to sign an informed consent to use it as it is not FDA approved for this use.

12. Reducing elevated TGF beta-1

Q. No longer separate step if can do VIP, it'll take care of this.

13. Replacing low VIP

R. VIP to replace VIP.

14. Final check to verify stability off meds

S. Recheck VCS, labs and NeuroQuant MRI to see that everything is returned to normal.

Appendix 2 HLA DR test

I order the HLA DR test through HealthLab but they are done at Labcorp. If you checked your results through our portal they aren't easy to read but when you come to the office, we give you the report as it prints from our lab computer and it looks like this. These are mine by the way.

```
HLA DRB1,3,4,5, DQB1 (IR)                09/08/2016 09:19
PERFORMED AT: 2Q
LabCorp Burlington DNA
1440 York Court
Burlington, NC 272153361
LAB DIRECTOR: George C Maha, PhD   PHONE: 800-742-3944
HLA Methodology                     See comments

HLA results were obtained using sequence based typing (SBT),
sequence specific oligonucleotide probes (SSOP), and/or sequence
specific primers (SSP) as needed to obtain the required resolution.
Please contact HLA Customer Service at 1-800-533-1037 if you have any
questions.

Director of HLA Laboratory
Dr George C Maha, PhD

DRB1                                     See comments
DRB1*04:ZX                               DRB1*04:ZX
DRB1                                     See comments
DRB1*13:KMCH                             DRB1*13:KMCH

Code Translation:
ZX                                       04/23
KMCH                                    02/109

DRB3                                     See comments
DRB3*03:AC                               DRB3*03:AC
DRB3                                     See comments
DRB3*-                                   DRB3*-

Code Translation:
AC                                       01/03

DRB4                                     See comments
DRB4*01:AHXJA                           DRB4*01:AHXJA
DRB4                                     See comments
DRB4*-                                   DRB4*-

Code Translation:
AHXJA                                  01:01/01:02/01:03/01:03N/01:04/01:05/01:06
/01:07/01:08/01:09/01:10/02:01N/03:01N

DRB5                                     See comments
DRB5*-                                   DRB5*-
DRB5                                     See comments
DRB5*-                                   DRB5*-

DQB1 Allele 1                           See comments
DQB1*03:AHUZP                            DQB1*03:AHUZP
DQB1 Allele 2                           See comments
DQB1*06:AHUTP                            DQB1*06:AHUTP

Code Translation:
AHUZP                                  03:02/03:04/03:07/03:08/03:14/03:32/03:37
/03:45/03:62/03:63/03:64/03:66N/03:67
/03:68/03:70/03:80/03:81/03:85/03:106
/03:107/03:125/03:138/03:146/03:153/03:161
/03:174/03:175/03:178/03:179/03:185/03:190

AHUTP                                  04/08/21/27/34/36/38/39/52/58/69/85/86/89
/93/135/155/160/164/171

HLA allele interpretation for all loci based on IMGT/HLA
database version 3.21
HLA Lab CLIA ID Number 34D0954530
```

Shoemaker figured out how to read these and has the decoder in the appendix of his Surviving Mold book.

1. Look at the report there are five categories of line entries: DRB1, DRB3, DRB4, DRB5 and DQB1. I circled the first DRB1 in yellow. My DRB1 first allele is 04 and I circled it in red. Each of us has 2 sets of three alleles so from this you will have 3 possible haplotypes, unless the DRB1 is 1, 8 or 10. Those patients will only have a DQB1 and will not have DRB3, DRB4, or DRB5. Every individual with a DRB1 other than those will have one other allele from DRB 3, 4, or 5. If you are

expecting to find two entries in DRB 3, 4, or 5 and only find one it means you are homozygous for that allele and only one is reported but you have 2 copies. Yes, this sounds crazy and don't stress over it because at the end I'll give you a cheat.

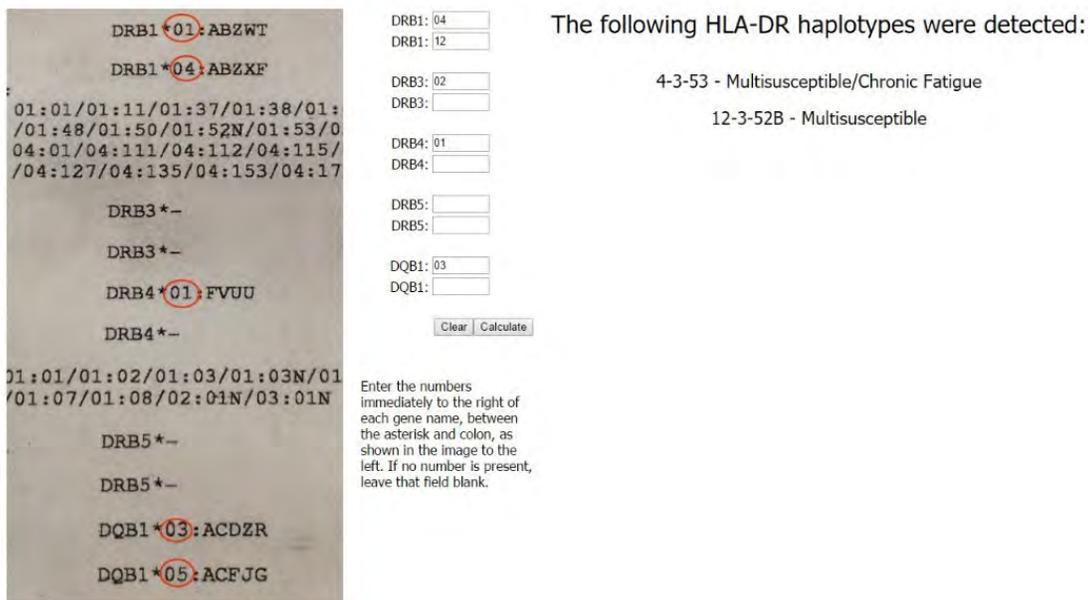
2. You will translate these categories into a HLA DR Haplotype that is listed first by the DRB1, then the DQB1, then the DRB3 if you have an allele there can be 52 (A, B, C), 53 and 51 respectively.
3. You only need the first two numbers before the colon. Ignore the rest of the letters and numbers. Just the red circle. Write down those first two numbers in each line 04. Next one is 13.
4. If you see 03 as one of the two genes, an allele, for DRB1, REWRITE is as 17. (Don't ask just do it.)
5. Record the entries for DRB3 next by converting 01 to A, the 02 to B and the 03 to C. So, see how mine at DRB3 is *03:AC so that's a 03 and I write down C and further it's 52C. 01 would be 52A and 02 would be 52B.
6. DRB4 is 53 if there's a 01 as an allele.
7. DRB5 is 51 if there's a 01 as an allele.
8. That's how you used to have to translate this test BUT thankfully someone devised an online calculator you can use that makes it much easier. It's listed below. I have written them and thanked them personally already.

<http://www.myhousemakesmesick.com/hlacalc/>

I love it when people work together!

Here's when I put my numbers in to this calculator and get this result. Likely I gave you your results on a similar screen shot. Now you just put the numbers in as they are from the report no need to decode and it'll decode for you. The circled numbers are just an example.

HLA-DR Calculator



The following HLA-DR haplotypes were detected:

4-3-53 - Multisusceptible/Chronic Fatigue

12-3-52B - Multisusceptible

I have 4-3-53 the Multisusceptible/Chronic Fatigue and 12-3-52B Multisusceptible haplotypes. Yes, I have the DREADED 4-3-53. Don't let the word dreaded get you down. I don't feel

dreaded so there. I have TWO multisusceptibility haplotypes meaning I can become chronically fatigued after Borrelia infection, mold illness, Pfiesteria infection or even a brown recluse spider bite.

Another HLA DR test is done to look for susceptibility to Celiac Disease and involves DQB1 and DQA1. This results also contains half of the celiac test. But you still need DQA1 to decipher it. Just like Celiac, you can have these genes and NOT develop the problem depends on toxin exposure and other factors. But if you know you're susceptible it makes sense to avoid these toxins to prevent chronic fatigue especially when they estimate 50% of buildings have some water damage.

Appendix 3 ERM Test

EMLabP&K
 1150 Bayhill Drive, Suite 100
 San Bruno, CA 94066

12/16/13
 999999

Results:

Group 1 Water Damage Indicators Fungal ID	Sample ID Dust Weight	
	01 5.0 mg	
	SE*	SE/mg
<i>Aspergillus flavus</i>	ND	<1
<i>Aspergillus fumigatus</i>	4	1
<i>Aspergillus niger</i>	7	1
<i>Aspergillus ochraceus</i>	ND	<1
<i>Aspergillus penicillioides</i>	1	1
<i>Aspergillus restrictus</i>	ND	<1
<i>Aspergillus sclerotiorum</i>	ND	<1
<i>Aspergillus sydowii</i>	ND	<3
<i>Aspergillus unguis</i>	ND	<1
<i>Aspergillus versicolor</i>	1	1
<i>Aureobasidium pullulans</i>	360	72
<i>Chaetomium globosum</i>	1	1
<i>Cladosporium sphaerospermum</i>	1	1
<i>Eurotium (Asp.) amstelodami</i>	260	51
<i>Paecilomyces variotii</i>	1	1
<i>Penicillium brevicompactum</i>	12	2
<i>Penicillium coryophilum</i>	ND	<1
<i>Penicillium crustosum (Group 2)</i>	ND	<2
<i>Penicillium purpurogenum</i>	ND	<1
<i>Penicillium spinulosum</i>	ND	<4
<i>Penicillium variable</i>	ND	<2
<i>Scopulariopsis brevicaulis</i>	ND	<1
<i>Scopulariopsis chartarum</i>	1	1
<i>Stachybotrys chartarum</i>	1	1
<i>Trichoderma viride</i>	1	1
<i>Wallenia sebi</i>	1	1
Sums of the logs	4.1	

Group 2 Common Indoor Molds Fungal ID	Sample ID Dust Weight	
	01 5.0 mg	
	SE*	SE/mg
<i>Acremonium strictum</i>	5	1
<i>Alternaria alternata</i>	ND	<1
<i>Aspergillus ustus</i>	ND	<1
<i>Cladosporium cladosporioides -1</i>	530	110
<i>Cladosporium cladosporioides -2</i>	2	1
<i>Cladosporium herbarum</i>	22	4
<i>Epicoecum nigrum</i>	1	1
<i>Mucor/Rhizopus</i>	4	1
<i>Penicillium chrysogenum -2</i>	7	1
<i>Rhizopus stolonifer</i>	ND	<1
Sums of the logs	2.8	

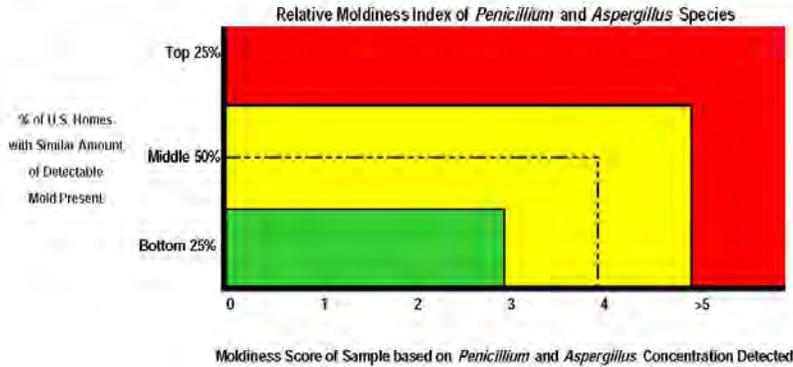
* SE = Spore Equivalents, ND = Not Detected

Sample	01
ERMI Calculation	4.1 — 2.8
ERMI Result	1

Appendix 3 Mold Investigator Test

The chart below is to help interpret results:

1. *Penicillium* and *Aspergillus* values/scores are based on the EPA's Environmental Moldiness Index for these molds.
2. *Stachybotrys chartarum* is considered a highly toxic and allergenic mold. If found in your sample locating the source should be considered.



Sample ID:	MM050511-1-1
Description:	Master Bedroom
	<u>Assay</u> <u>Spores / Sample</u>
	PenAsp* 61,729
	Stach* 1
Moldiness Score of <i>Penicillium</i> and <i>Aspergillus</i> :	4.79
<i>Stachybotrys chartarum</i> Detected:	YES

Sample ID:	MM050511-1-2
Description:	Living Room
	<u>Assay</u> <u>Spores / Sample</u>
	PenAsp* 1,302
	Stach* Below Detectable Limits
Moldiness Score of <i>Penicillium</i> and <i>Aspergillus</i> :	3.11
<i>Stachybotrys chartarum</i> Detected:	NO

Appendix 4 HERTSMI-2 Score Sheet

HERTSMI-2 Score Sheet 10_29_14

Patient name _____ Date _____

Date of testing _____ Location _____

	Spore E/mg	Points	Concern
Aspergillus penicilloides			
Aspergillus versicolor			
Chaetomium globosum			
Stachybotrys chartarum			
Wallemia sebi			
HERTSMI-2 Score = Total Points awarded =			

We use a point system. Units are Spore E/mg.

10 points are assigned for

Aspergillus penicilloides	≥500
Aspergillus versicolor	≥500
Chaetomium globosum	≥125
Stachybotrys chartarum	≥125
Wallemia sebi	≥2500

6 points are assigned for

Aspergillus penicilloides	100-499
Aspergillus versicolor	100-499
Chaetomium globosum	25-124
Stachybotrys chartarum	25-124
Wallemia sebi	500-2499

4 points are assigned for

Aspergillus penicilloides	10-99
Aspergillus versicolor	10-99
Chaetomium globosum	5-24
Stachybotrys chartarum	5-24
Wallemia sebi	100-499

Interpretation of HERTSMI-2 Score

- <11 Statistically safe for re-entry for those with CIRS
- 11-15 Borderline; clean first and re-test before re-entry
- >15 Dangerous for those with CIRS. Do not enter.

Disclaimer:

HERTSMI-2 is a building index. No one HERTSMI-2 can possibly show all areas of a given building.
HERTSMI-2 does not replace careful observation of symptoms and lab results obtained following re-exposure

Appendix 5 What to Expect from Cholestyramine (CSM) from survivingmold.com

Cholestyramine (CSM) is an FDA-approved medication used to lower elevated levels of cholesterol. It has been used safely for over forty years in millions of patients who have taken the medication for extended periods of time. You have been given a prescription for CSM to be used for only a short period to treat your chronic, biotoxin-associated illness. The FDA (6/28/99) ruled that there was no reason to expect an increased risk to health from use of CSM in a group of patients who have biotoxin illnesses (such as Pfiesteria, ciguatera, mold, Post-Lyme) and blue green algae syndromes compared to those who don't. Therefore, such use is exempt from repeating FDA clinical trials to show safety. Your prescription is given to you under this FDA exemption.

This use of CSM is called "off-label." Off-label use is completely legal, ethical and is part of standard medical practice. There might be a few physicians somewhere in the US who don't use drugs off-label but I haven't met any yet. You need to know that your prescription is for CSM being used off-label.

Cholestyramine is not absorbed. It helps you get better but it adds nothing to you. All it does is take things away. If CSM is not taken with food, it binds cholesterol, bile salts and biotoxins in the small intestine. Because it binds biotoxins tightly, the biotoxins cannot be reabsorbed; the CSM-biotoxin complex is excreted harmlessly in the stool. Provided there is no re-exposure to sources of biotoxin or reacquisition of biotoxin, the CSM treatment will remove the biotoxin from tissues over time, providing the first step needed to resolve the chronic, biotoxin-associated illness. The illnesses of some patients can be resolved in two weeks, but depending on the amount of biotoxin in your body, and the inflammatory problems initiated by exposure to biotoxins and inflammagens, the time to regaining health may be longer. CSM will not correct presence of MARCoNS, low VEGF, high TGF beta-1 or low levels of CD4CD25 cells, for example.

Used at the FDA approved dose of 9 grams of CSM, or 4 grams of Questran Light (note this product contains aspartame), taken 4 times a day, there are gastrointestinal side effects that are potentially annoying but are usually not dangerous and should not interfere with your treatment program. Some people who are sensitive to chemicals might want to have compounded form of CSM ("MCS-CSM") that has nothing other than Stevia in it. Some people who tend to be constipated even before using CSM will need to be very careful to prevent CSM making their stools become too hard, as such brick-like stools can cause bleeding from the rectum when they pass out of the body. Our treatment protocol attempts to anticipate the possible troublesome side effects; you will be given additional medications to keep on hand "just in case."

Reflux of stomach acid, also called heartburn or indigestion, is commonly experienced early on in treatment. The symptom abates spontaneously in most patients within a few days. A medication to stop over-production of stomach acid, taken before beginning the CSM doses, can prevent heartburn. Mixing the CSM in apple juice, www.survivingmold.com cranberry juice or dissolving CSM, first in luke-warm water and then adding ice, helps reduce heartburn. Bloating and belching can also be cause initially by CSM. Fortunately, those side effects are

rarely a major problem. As mentioned, constipation is commonly seen. Many patients simply increase their consumption of fruit or fiber products, such as psyllium (Metamucil), to avoid this problem. A non-absorbable, sweet tasting liquid, Miralax, available without a prescription, can hold water in stools, making bowel movements soft, thereby preventing constipation. Even though Miralax tastes sweet, it will not make your blood sugar rise or make you gain weight.

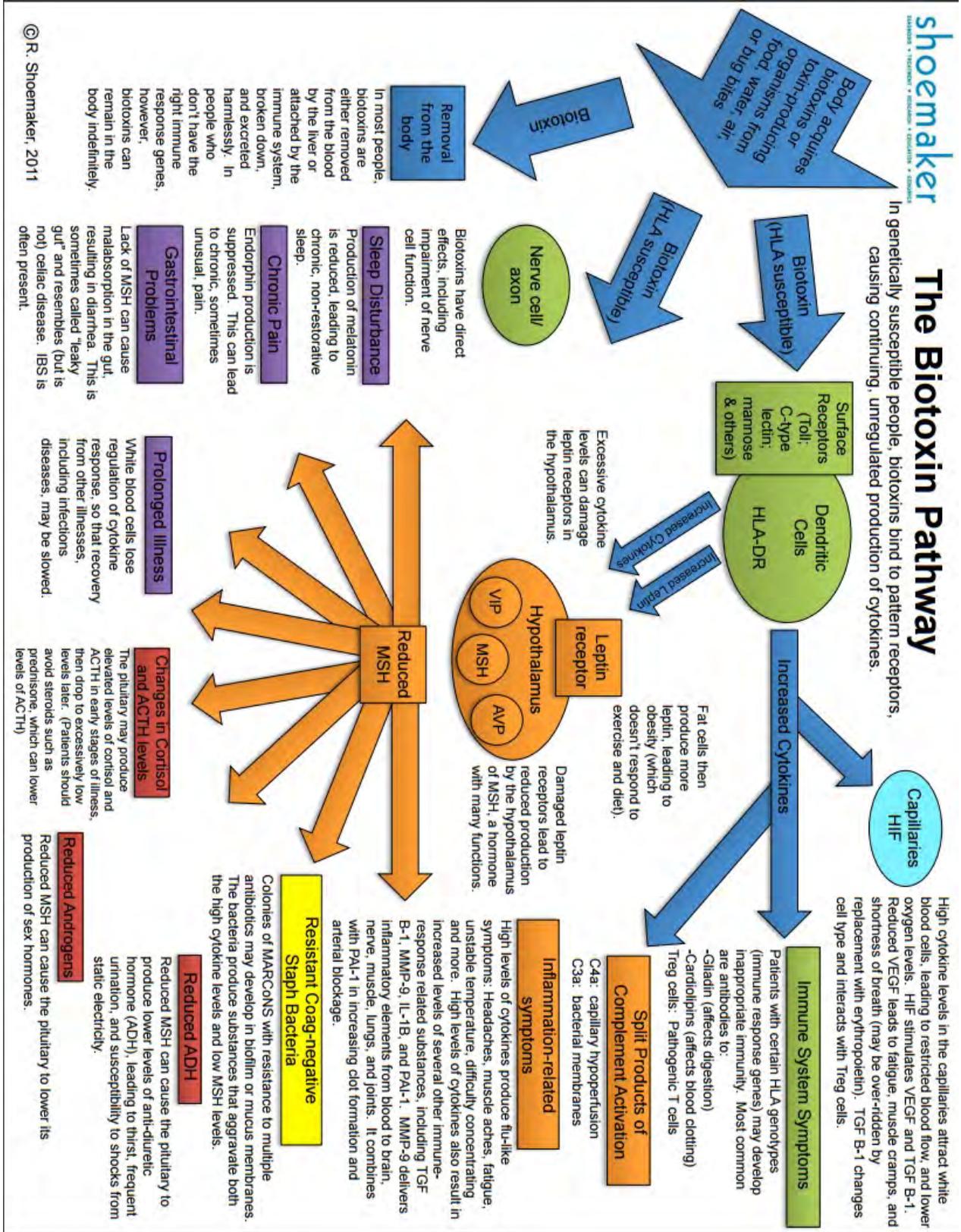
Because many patients with chronic biotoxin associated illnesses have diarrhea or more frequent, softer stools, the constipating side effect of CSM can become a welcome, early benefit. CSM has been extensively tested in multiple clinical trials involving patients with chronic, biotoxin associated illnesses. The benefit of use of CSM has been confirmed by two double-blinded, placebo-controlled crossover studies. To date we have looked for, but not found benefit from CSM substitutes such as charcoal, chitosan, clay in several forms or any herbal remedy. We will use Welchol as a CSM substitute for those unable to take CSM. It is taken with food in a pill form. It is far easier to take but it is only 25% as effective as CSM.

Your physician will be following your case carefully. If you have questions regarding any phase of your treatment, please notify your doctor's office promptly. You will be given special tests of visual contrast sensitivity (VCS) on a regular basis. Your treatment will continue until your symptoms have resolved and your VCS is normal. Your physician will review your case in detail as your treatment progresses.

CSM Protocol

1. On an empty stomach, take one scoop of CSM (9 grams), mix with water, or juice, 4-6 oz.
2. Stir well and swallow. Add more liquid, repeat 1 above until done.
3. Drink an extra 4-6 oz. of liquid.
4. After 30 minutes, you may eat or take meds (wait at least 2 hours before taking thyroxine, digitalis, theophylline, Coumadin and others; ask your doctor for information).
5. Take CSM 4 times a day! (Unless you weigh less than 120 lbs. then 3 times a day adequate)
6. If you eat first, wait at least 60 minutes before taking your next CSM.
7. Reflux, constipation, bloating and bowel distress are not unusual.
8. Use acid blocking medications as needed.
9. Use Miralax to relieve constipation.

Appendix 6 Dr. Shoemaker's Biotoxin Pathway



Appendix 7 The Low Amylose Diet

From Ritchie Shoemaker's Mold Warriors

This diet is not the "anti-mold" diet and is only if you have high leptin or high MMP-9 still after correcting the previous steps. (MMP-9 is step 7) If you don't need this extreme than you're better off I believe on gluten-free, no white stuff diet OR paleo type diet or better yet gluten free Cook Well, Eat Well, Live Well diet to follow. CIRS-Lyme because they're so often on antibiotics do best gluten-free, sugar avoid but only sugar substitute would be stevia. I wouldn't worry about the sugar that is naturally found in fruit and veggies but avoid added sucrose and high fructose corn syrup while on antibiotics to help reduce risk of yeast infections. I find that works well with doxycycline and often people won't need an anti-yeast medication until they move from doxy to cephalosporin's or penicillin's. But regardless of your susceptibility to Celiac Disease it is worth going gluten-free for 2-3 months and seeing if it helps. If you're a moldy (CIRS-WDB) it's very common to see antibodies to Gliadin even in individuals not susceptible to Celiac Disease (CD). Gluten is often a key element in seeing a big change in the response to treatment. Anyone that's been getting any treatment more than a year or two and hasn't gone gluten-free is in denial and must face their addiction to food. Because it often works so try it. When you're finally out of the woods and rid of all your symptoms you can always add it back. You'll know quickly if it's still a problem or not.

The Low Amylose Diet is high protein and high carbs but cuts out some fat that I think is a mistake. But here's the basic diet:

No Skipping Meals. The starvation response burns protein. (Agree)

Adequate protein. 6-8 oz. Final Cooked Weight. (I'm assuming he means meat/fish so vegetarians?)

Lactose (milk) and fructose (fruit) ok. (I know very few adults with CIRS that can drink milk with their leaky guts. But most can do yogurt and cheese. However, he says careful with those so probably small amount ok.)

He says artificial sweeteners are ok. I disagree and he might now as well. This diet was before we knew about aspartame. Only artificial sweetener that's ok is Stevia. In fact, Stevia kills *Borrelia* in biofilms.

Avoid: Glucose, Amylose

Easier way is to avoid all foods which grow underground except onions and garlic.

No potatoes, sweet potatoes, beets, ... not sure about kohlrabi. The beet is a root so stores a lot of sugar. Kohlrabi not so much.

Avoid grains wheat, rice, oats, barley and rye. (I would only do this for step 7 if I had to get MMP-9 and leptin normalized because I think it's too hard to get enough fiber if you don't eat oats at least.)

Corn is ok because it has a natural inhibitor of amylose.

Popcorn and baked corn chip ok, tortilla chips ok, watch out Fritos may have sugar added.

No cereal, no chocolate (cacao powder ok), no fast foods, he says no regular soda but diet ok. I completely disagree with that. Diet soda raises Insulin levels as well as regular soda. No commercial fruit juices fine but ok to squeeze your own.

Caffeinated beverages other than soda ok.

Otherwise he says eating in moderation includes eating good food, prepared well, presented pleasingly and eaten with gusto, not gluttony.

Taken from Appendix 11 of Mold Warriors.

I disagree with diet and regular soda. Soda is the one thing that whenever someone that drinks a lot of it cuts out you see an amazing transformation in their health. It doesn't matter if it's diet or regular. I think diet might even be worse especially if it contains aspartame. I have no problem with someone drinking one soda a week as a treat. But I do feel that it should not be consumed daily because people drink that instead of water. You would be much better off drinking water. If you can't drink water without some flavoring, then get little packets of crystal light with stevia.

Insulin increases appetite and stores carbs as fat. Diet soda makes you hungrier and now your rising insulin level doesn't have sugar to store so you're going to soon feel shaky if you don't eat something like candy. Diet soda delivers the promise of sweetness and falls short and then your body still demands it. Why bother. If you must have one soda, then make it count and get regular but avoid sodium benzoate the preservative in most soda. You can get Izze which is sparkling water and juice no added sugar or preservatives and quite delightful. BUT I would advise NO SODA containing sodium benzoate while fighting biotoxins.

Now for the better diet!

The Cook Well, Eat Well, Live Well Diet

This diet is plant based and focuses on eating a wide variety of food in very pleasing ways and eating seasonally. People who love food will love this diet. You want to obtain as much organic, pesticide free food as you can so go to farmer's markets, start a garden and/or make friends with a gardener. Gardening is good therapy in my mind and how I worked on regaining my physical strength after my own biotoxin illness. I'm also a master gardener now and love to help people learn to grow so don't hesitate to ask me how to start a garden. I'd love to help!

You also need to learn and even the dieticians that participated in this program apparently didn't listen because fat is not the enemy. Don't avoid oil and fat anymore. Here's a shocker for most people eating higher fat isn't why your cholesterol is high. It's eating junk! There are however three different genotypes that affect how we should eat. I'm going to briefly explain them here but eventually this will be a different guide or another chapter if you will.

APO E Lipoprotein and You