Part 1: Introduction to TMSA & Mould Illness/CIRS

1.1 - What is the Toxic Mould Support Australia (TMSA) Website and Facebook group?
TMSA is a website and Facebook group which provides information and support for Australians who have health issues associated with toxins from a biological source, otherwise known as biotoxins specifically from mould and bacteria due to water-damaged buildings and/or Lyme disease/stealth infections, Ciguatera, toxic blue-green algae and more. We discuss the health effects of these biotoxins on our health and also the impact of water damage to our buildings where we live and work and public buildings.
1.2 - How do I search the Facebook group for past posts?
TBA
1.3 - What is mould?
Mould is a microorganism, omnipresent in nature, which breaks down organic matter. It is nature's great decomposer. Mould has been a cause of health problems for thousands of years even being referenced in the Old Testament (Leviticus 14:43). It is theorised that it has become an issue in modern times due to building practices and materials which have provided conditions for toxigenic mould and bacteria to flourish in buildings after they have experienced water damage. Mould are multi-celled fungi, while yeast such as candida

albicans are single celled fungi.
1.4 - Is it spelt mould or mold?
The British English spelling is mould and is the one used throughout this FAQ. American English spelling omits the u.
1.5 - What is CIRS-WDB / mould illness?
Chronic Inflammatory Response Syndrome (acquired following exposure to the interior environment of) Water-Damaged Buildings (CIRS-WDB).

Mould illness (mold illness, USA spelling) is the common name for CIRS-WDB. The two terms will be used interchangeably throughout this FAQ. CIRS-WDB is a condition caused by biotoxins and inflammagens produced by microorganisms such as mould, bacteria and actinomyces found in water-damaged buildings. Tick-borne infections such as Borrelia (Lyme disease) and Babesia, toxic blue-green algae and ciguatera found in reef fish can also produce biotoxins and cause CIRS.

These conditions are called biotoxin illnesses.

1.6 - Is CIRS-WDB just due to mould?
No! CIRS is caused by the toxigenic microbial soup found in water damaged buildings and includes mould fragments, mycotoxins, mannans and beta-glucans from mould, endotoxins and exotoxins from bacteria (including gram positive and gram negative bacteria, mycobacteria and actinomycetes) microbial volatile organic compounds (mVOCs) from bacteria and mould, VOCs from building materials that are broken down through microbial activity and many more compounds. Mould is just the most visible, most researched and easiest microbe to test for.
1.7 - What are the main theories about mould causing health problems?

There are three main schools of thought about mould causing health problems.

1. The traditional viewpoint is known as the **allergy theory**. This theory views mould as causing an allergic response that results in upper respiratory symptoms, such as asthma and rhinitis. The typical medical practitioner generally views mould as a minor ailment only. Doctors will usually test for mould allergy via IgE RAST blood tests or skin prick tests. Treatment is centred on exposure reduction and/or immunotherapy. In CIRS, IgE responses to mould will usually be normal, although it’s possible to have mould allergy and CIRS. CIRS treatment should also work for mould allergy.
2. The second viewpoint is the **colonisation/infection theory**. This theory views mould as mostly a problem when found growing in the body, either in the gastrointestinal tract (yeast overgrowth), nasal and sinus cavities, skin and/or bloodstream. Stool tests,

culture of sinus/nasal cavity or urine mycotoxin testing are usually the way this is diagnosed. This is treated with anti-fungal medications and/or supplements and diet. Binders and other supplements such as glutathione are often used by proponents of this philosophy. Detoxification methods such as far infrared saunas and coffee enemas can be recommended as well.

3. The third viewpoint is the **Chronic Inflammatory Response theory**. This theory views mould and other microbes in water damaged buildings as being able to cause a chronic inflammatory response and a host of symptoms that can persist for years and decades even if removed from exposure, especially in a genetically predisposed subset of the population. This is because those with impaired HLA genetics are not able to mount an effective antibody response to biotoxins and inflammagens found in water-damaged buildings (including, but not limited, to those from mould). As a result, a chaotic and ineffective inflammatory cascade occurs which includes lowering of the regulatory hormones and increase in inflammatory cytokines, dysregulation of gene expression, and atrophy and inflammation in the brain.

***Note**: One or a combination of the three may be an issue for a patient. TMSA and this document primarily focuses on the CIRS theory.*

1.8 - Who are the leading doctors and researchers in the field of mould illness/CIRS?

Dr. Ritchie Shoemaker, MD, from Pocomoke, Maryland, USA is the leading physician and researcher in regards to the CIRS theory. He has published over 20 peer-reviewed papers, on the mechanism, diagnosis and treatment of CIRS. A new organisation, International Society for Environmentally Acquired Illness (ISEAI), formed by several former Shoemaker certified physicians, aims to continue research and education into CIRS, that they term EAI-WDB (Environmentally Acquired Illness due to Water-damaged Buildings), and other environmentally acquired illnesses.

For the colonization theory Dr. Joseph Brewer, Dr. Neil Nathan, Dr. Janette Hope are the leading proponents. See references section for papers.

1.9 - I heard Dr. Shoemaker lost his license etc
Dr. Shoemaker did *not* lose his medical license. However in March 2013, the Maryland State Board of Physicians issued a reprimand and placed him on probation for 2 years. He could have continued being a licensed physician if he employed a practice monitor. Due to his age (early sixties) and suffering from pulmonary hypertension he decided to retire from clinical practice and devote his time to research and physician certification.

Why was he reprimanded? Primarily for using several pharmaceutical drugs off-label that were then part of the CIRS/Shoemaker protocol.

– Actos (then used for reducing the intensification reaction)
– Rifampin (then used an an antibiotic for eliminating MARCoNS)
– Procrit (then used for decreasing C4a)

Note: none of these drugs are part of the current protocol.

Remember as CIRS is a relatively new concept and not embraced by mainstream medicine all medications for CIRS are off-label, from cholestyramine and Welchol to vasoactive intestinal polypeptide (VIP). Many Lyme literate doctors have also had reprimands, or worse, due to prescribing of antibiotics and other medications off-label. This is the price of being cutting edge and not accepting current "standard of care" or typical diagnoses for complex chronic illnesses such as CIRS.

1.10 - Are there other forms of CIRS apart from mould/water-damaged buildings?

Yes. Borrelia species (Lyme disease) and the parasite Babesia (Babesiosis) transmitted through tick bites also produce biotoxins and can cause CIRS even after the infection is eradicated. CIRS can also be caused by eating reef fish contaminated with toxins causing cigutera, or exposure to bodies of water with toxic blue-green algae or dinoflagellates.

Viruses and, probably, other stealth infections can also contribute to lowered MSH and VIP and may cause, or at least contribute to CIRS. Similarly traumatic brain injury can lower MSH and cause, or contribute to, CIRS. (Shoemaker et al, 2014, [0061])

- Shoemaker, R., & Ryan, J. (2014). US Patent No. 20,140,046,143 A. Washington, DC: U.S. Patent and Trademark Office. Google patents

1.11 - How does Lyme disease/Babesia figure into CIRS?

In two ways

1. Borrelia and Babseia produce biotoxins that may cause CIRS and account for some cases of Post Treatment Lyme Disease/Chronic Lyme disease; that is continuing symptoms of Lyme disease/Babesiosis even if the bacteria/parasite have been eradicated.
2. Borrelia and Babseia infection can cause an inflammatory cascade that can be the priming event that prime the HLA genes and cause susceptibility to mould/water-

damaged buildings that could be tolerated before (see 2.4 – HLA DR/DQ gene testing)

Reference: Shoemaker, R.C., Giclas, P, Crowder, C, House, D.E., & Glovsky, M. (2008). Complement split products C3a and C4a are early markers of acute lyme disease in tick bite patients in the United States. *International archives of allergy and immunology, 146*(3), 255-61. doi: 10.1159/000116362 | PMID 18270493 | Full text

Part 2: Screening and diagnosing Mould Illness/CIRS

2.1 - Screening based on symptoms

CIRS is a multisystem, multi-symptom condition, meaning patients will have multiple symptoms across more than one body system.

In research Dr. Shoemaker found that 35 health symptoms could be categorised into 13 clusters. If a patient is confirmed to have 8 or more clusters of symptoms the likelihood of presence of CIRS exceeds 95%. A cluster is positive if you have one or more symptoms in each group. When combined with VCS deficits, symptom clusters can yield an accuracy of 98.5%, with false negatives < 2%. (Shoemaker et al, 2017). [Note clusters and VCS cannot differentiate CIRS-WDB from other CIRS causes such as CIRS Lyme].

You can see the CIRS clusters on the symptom page.

2.2 - Conditions associated with CIRS

Common conditions that are CIRS is the causal factor of, a co-factor of, or co-morbid with, include

- Lyme disease (Borrelia), Babesiosis (Babesia) and other stealth infections (watch this webinar)
- Myalgic Encephalomyelitis/Chronic Fatigue Syndrome (ME/CFS)
- Fibromyalgia
- Multiple Chemical Sensitivity (MCS)
- Inflammatory Bowel Disease (IBD), Irritable Bowel Syndrome (IBS), SIBO, Leaky Gut (watch this webinar)
- Alzheimer’s Disease (watch this webinar)
- Mast Cell Activation Syndrome (MCAS) (watch this webinar)
- Multiple Sclerosis (MS)
- Depression
- Post Traumatic Stress Disorder
- Allergies

(cf: common misdiagnoses at Surviving Mold).

2.3 - Visual Contrast Sensitivity (VCS) testing
The VCS is a simple online visual test as a handheld version (the gold standard) at a doctor's office or at the Surviving Mold website. It can be used to screen patients to see if they are affected by biotoxins and also used to track treatment progress. It works because biotoxins cause inflammation that causes hypoperfusion (lack of blood flow) throughout the optic nerve.

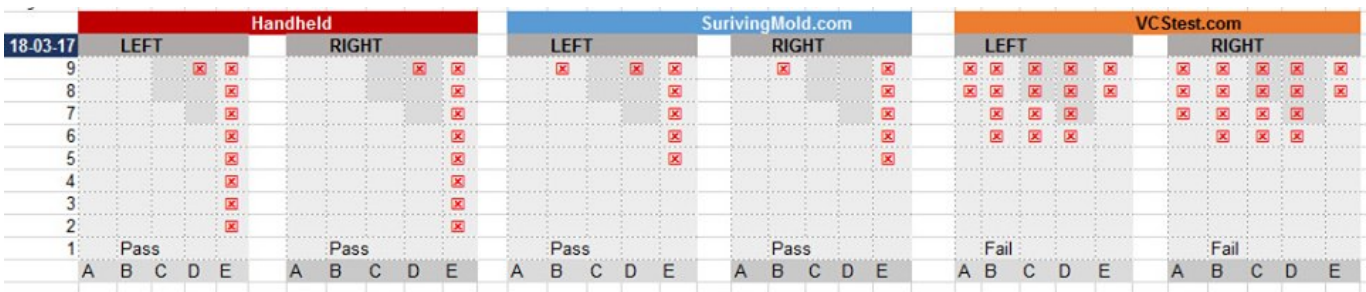
The cost is $15 USD although there are discounts for bulk purchasing which are handy if continue with the CIRS protocol.

Dr. Shoemaker's original research showed a sensitivity of 92.5% with only 7.5% false negative results, although this was done with a handheld device. False positive were even less (2.5%) and mainly seen in those who had been exposed to occupational solvents, heavy metals, hydrocarbons and petrochemicals. In layman's terms if you are positive via the Surviving Mold test it is very likely you have a biotoxin illness; VCS can also be used to track your treatment.

If you are negative you should go onto other screening and diagnostic testing to confirm or rule CIRS out but you may still be able to rely on VCS to track treatment.

Is there a free one available? (VCSTest.com)

Yes, there is a free test available at VCSTest.com however the results don't seem to correlate with the handheld or Surviving Mold versions. It's strongly suggested to do the Surviving Mold test, in addition, if you do the free one first. See the following table for a sequential comparison done by the author in March 2017, comparing the handheld to the Surviving Mold test, to the VCSTest.com one (following instructions given).



2.4 - HLA DR/DQ gene testing

2.4.1 What are the HLA genes?

In unpublished research conducted by Dr. Shoemaker of his 10,000 size patient population approximately 25% of the general population have Human Leukocyte Antigen (HLA) genes that are mould, Lyme or multi-susceptible (i.e. susceptible to biotoxins from mould/WDB, and Lyme, and dinoflagellates). When these genes are primed (see 2.4.5 below) and a person is exposed to biotoxins the immune system does not make the appropriate antibodies to clear them due to a defect in antigen presentation. These people will not excrete biotoxins, they instead recirculate in the body for years, if not indefinitely, unless binding compounds are used.

The HLA genes merely indicate genetic susceptibility to biotoxin illness – having them does not automatically mean you have CIRS.

2.4.2 Getting the HLA gene test in Australia

Any GP can request "HLA DR/DQ for Coeliac Disease" or "HLA Panel Screen (DR and DQ)" but it must be performed at a Sonic Healthcare laboratory for the results to be formatted correctly. See the Resources page ("HLA DR/DQ Gene Test" section) for the Sonic Healthcare division in your state.

It *can* be if your doctor checks the bulk bill box. The MBS schedule number is 71151.

2.4.3 Interpreting the results

If your doctor is unable to interpret you can put your numbers into the Australian HLA-DR calculator and/or post in the TMSA Facebook group.

2.4.4 Does 23andme show these HLA genes?

No. 23andme does not show all the HLA haplotypes and not in a format that correlates to Dr. Shoemaker's table.

2.4.5 My friend/partner/child has HLA susceptible genes but they don't get sick with exposure to water-damaged buildings, how come?

Dr. Shoemaker found that HLA genes generally need to be primed by an inflammatory illness, or event, that causes a cytokine storm such as influenza, Coxsackie virus, Lyme disease, mononucleosis (Epstein Barr Virus/glandular fever) or ECHO virus infections, intense inflammatory lung responses and unusual conditions such as Kawasaki disease.

(Berry, 2014, p14)

Following that logic, other events like surgery, accidents, stressful events/trauma and other infections or illness could also be priming events.

However, if there is a great deal of inflammagens and biotoxins in a water-damaged building that can be enough to prime the genes and cause CIRS by itself. (Shoemaker et al, 2006).

References:

- Berry, Y. (2014). A physician's guide to understanding & treating biotoxin illness. *Surviving Mold*.
- Shoemaker R, Lipsey R. (2006). Results of health screening and visual contrast testing. St. Bernard's Parish, Louisiana. *Surviving Mold*. Full-text

2.5 - Blood biomarker testing available in Australia

The following tests are available in Australia. See the Screening and Diagnostic testing page for more information.

Medicare rebateable (no out of pocket)

- **Vasoactive Intestinal Peptide (VIP**) – A hormone which has far reaching effects throughout the body especially in the brain, gut and lungs. It is often low. Every MCS patient that Dr. Shoemaker has seen has had low VIP. Can be covered Medicare (schedule 66695). Special EDTA/trasylol tube needs to be ordered by the pathology lab. Also note that the range (0-50 pmol/L) is too broad and should be 8-21 pmol/L as per Shoemaker's research. ***Fasting test.***
- **Osmolality (serum) –** Tends to be high but interpret with ADH level (see below).
- **ACTH** & **Cortisol AM –** Hormones which are affected by low MSH. ACTH is often low while cortisol is often high, although this can be reversed.
- **DHEA-S** & **Testosterone –** Androgen hormones often low.
- **Estradiol –** The main form of estrogen in the body. Often high, especially in males.
- **Anti-gliadin antibodies –** Can be present either due to coeliac disease or low MSH.

Non-Medicare rebateable (out of pocket)

- **Leptin** – A hormone and cytokine which is most well-known for fat storage but has more profound effects. Tends to be high especially in overweight CIRS patients. ***Fasting test***.

- **Anti-Diuretic Hormone (aka Vasopressin)** – ADH is a hormone which retains water in the body and constricts blood vessels. Often low but interpret with osmolality.

Note 1*: VIP, Leptin and ADH can be collected at any pathology centre but must be forwarded to Sydney Southwest Pathology/Royal Prince Alfred Hospital Sydney.*
Note 2: *Costs can vary form one pathology lab to another, so check costs before draw.*

2.6 - Blood biomarker tests unavailable in Australia

- **alpha-Melanocyte Stimulating Hormone (MSH**) – A master hormone secreted by the pituitary gland which is involved in regulating inflammatory responses throughout the body. Low levels allow MARCoNS to flourish which then reduce MSH further.
- **Transforming growth factor beta 1 (TGF-b1) –** A multifunctional cytokine and marker of inflammation which has both pro and anti-inflammatory effects depending on level and tissue. Usually elevated.
- **C3a –** An inflammatory protein used in the complementary arm of the immune system. complement immune system component. Can be high in active Lyme but usually normal or low in mould illness. *NOT the same as C3 routinely performed by Australian laboratories.*
- **C4a** – Another complement protein. Usually elevated in CIRS. *NOT the same as C4 routinely performed by Australian laboratories.*
- **Matrix metallopeptidase 9 (MMP-9) –** An enzyme which serves as a proxy for inflammatory cytokines. Often high in CIRS. Can rise with intensification.
- **Vascular endothelial growth factor (VEGF)** – Low levels cause capillary hypoperfusion which results in cells and organs not getting sufficient blood flow. Often low, although occasionally high early in the illness. Contributes to exercise intolerance/PENE symptoms.

See Surviving Mold for ranges and more information.

Dr. Gupta and Dr. Hale (Sunshine Coast) are sending bloods to Quest Diagnostics in the USA in batches, 3-4 times per year. Dr. Gupta is in the process of organising Quest blood draws in other states.

2.7 - NutriPATH testing

NutriPATH's biotoxin/mould blood tests and panels (apart from HLA DR/DQ and MARCoNS) cannot be recommended at this time due to inaccuracies compared to Quest Diagnostics.

Reference: Mold Illness in Children webinar (35m) and Low Tox Life podcast episode 55.

No other Australian diagnostic testing for TGF-b1, VEGF, C3a, C4a, MMP-9, MSH currently available.

Part 3: Other biomarker testing

3.1 - NeuroQuant (Volumetric MRI)

NeuroQuant (NQ) is an FDA cleared software program from Cortechs Labs that measures microscopic volumetric changes in defined areas of the brain from a magnetic resonance imaging (MRI) scan. Dr. Shoemaker found edema (inflammation) and atrophy (shrinkage) in brain areas in two small studies (2014, 2017) of CIRS patients.

It is still an experimental test at present and therefore should not be used for diagnosis. However, it can be a tool to track inflammatory and atrophy changes at baseline and throughout treatment. Dr. Ackerley believes the triage brain atrophy report, that takes into account normal ranges for patient sex and age, is more accurate than the general morphology report alone, and the spreadsheet that was previously used.

Dr. Gupta is currently discussing with Cortechs to get the triage report for Australian patients, and with consultation with Dr. Ackerley, plans to train CIRS doctors in how to interpret these in 2018.

3.2 - MARCoNS testing

Multiple Antibiotic Resistant Coagulase Negative Staphylococci (MARCoNS) are bacteria that colonise in the nasopharynx area forming biofilms and creating exotoxins. These form due to low levels of MSH which protects mucus membranes, such as the nose and stomach, from microbes that can themselves lower MSH further. Dr. Shoemaker sees MARCoNS colonisation in 80% of CIRS patients. See the Biotoxin pathway diagram to see how hormones and immunity are affected in CIRS.

- **Obtaining the collection tube**
    1. *Direct from Microbiology Dx*
       Order swab kit from Microbiology Dx free of charge. Go to the 'Order Collection Kits' page and fill in the details. You'll need to put Australia onto the 'City, State, Zip' field. You will need to include your doctor's details on the web form. Ideally email them and ask for the Remel® BactiSwab™ wire shaft transport swab – although the default swab will suffice.

Alternatively you can use an aerobic nasal swab from your doctor and get your doctor to fill out the requisition form.

2. *NutriPATH*
   Order a kit via NutriPATH, who send it on to Microbiology Dx.

- **Performing swab**
  - This can be done by a doctor or patient. The swab needs to go through the nose right up to the back of the throat, about 3 inches. Swivel the swab for 3-5 seconds when you reach the throat. It is unpleasant but not painful. Read the Microbiology Dx instructions or read the blog post on Biotoxin Journey for directions.
- **Sending swab to Microbiology Dx**
  - When used with the correct swab, the sample is viable for up to 30 days. There are several options for sending it to Microbiology Dx. Write "non-infectious sample" on the customs form.
    1. Australia Post air mail letter ($2.75). The cheapest option.
    2. Australia Post's EMS Courier (approx $57-58).
    3. FedEx. Supplied with the kit from Microbiology Dx (approx $80).
- **Sending swab to NutriPATH**
  - Follow the instructions in the NutriPATH kit.
- **Cost**
  - Currently the cost for MARCoNS and other bacteria with sensitivities is $85 USD. The results will be emailed to your doctor. NutriPATH is more expensive ($150 AUD).
- **Fungal culture testing**
  - Dr. Shoemaker strongly disagrees with treating fungal colonies (see 4.3.3 – Nasal fungal colonisation and anti-fungals, below) while some other doctors do. This is an additional cost ($80 USD) and takes longer to report than MARCoNS.
- **Biofilm testing**
  - This is optional ($100 USD) but can be useful as it tells you if any biofilm is present and at what strength. Dr. Shoemaker originally deduced that MARCoNS produced biofilm when they were resistant to 2 or more antibiotic classes but this may not always be the case.
- **Interpretation**
  - If the culture reveals coagulase negative staph which are resistant to two or more antibiotics then you are positive for MARCoNS and should be treated with a suitable nasal spray (see 4.3.2 MARCoNS Treatment). The amount ("large amount" etc.) is not important. If the culture is methicillin resistant you may herx more when using anti-microbials. Staph coag positive (golden staph), staph coag

neg with only one antibiotic resistance, non-staph bacteria, as well as fungus (if requested) are common findings and do *not* need to be treated generally.

3.3 - What about urine mycotoxin testing?
Two laboratories, Realtime (available via NutriPATH) and Great Plains (available via RN Labs) currently offer urine mycotoxin testing in Australia.

Dr. Shoemaker does not recommend this test for a number of reasons.

1. Mycotoxins make up < 1% of the burden of inflammagens in a WDB.
2. These tests only look for several mycotoxins (aflatoxin, ochratoxin, gliotoxin, trichothecenes in the main) when there have been four hundred discovered so far.
3. These tests are polyclonal and have never had specificity of their antibodies confirmed (Realtime test).
4. Urine mycotoxins are generally confounded by mycotoxin ingestion from food.

See Dr. Shoemaker 2015's Hopkinton Lecture (2:24:53. Thoughts on Realtime Labs) and Dr. Joseph Brewer: Nasal fungi, anti-fungals and junk science.

Another group of doctors, including Dr. Neil Nathan, Dr. Joseph Brewer and many of the ISEAI practitioners, have found mycotoxin testing to be useful. While there may be some value to these tests they shouldn't be used as the sole diagnostic test for CIRS. There needs to be more studies done on the association between environmental moulds/water-damaged buildings and mycotoxins in human urine or blood.

Part 4: CIRS treatment protocol (Shoemaker protocol)

4.0 - What is the recommended CIRS treatment protocol

The Shoemaker protocol is a systematic treatment plan consisting of several steps that need to be followed in order. The full protocol consists of 11 steps, however depending on biomarkers and symptoms not all steps may have to be followed. Only the main steps are outlined here.

4.1.1 - Removal from WDB exposure

This is of paramount importance but is often the most difficult step. One must live, work and otherwise spend time in/visit buildings with a HERTSMI of < 11 at a minimum. Otherwise you'll continue to be exposed to inflammation causing biotoxins and inflammgens. If re-exposed to another water-damaged building you may need to re-start the protocol from this step.

4.1.2 - Mold Avoidance
Some CRS patients, especially those with low or undetectable levels of MSH and VIP, and extremely high C4a, will react to even tiny amounts of biotoxins in water-damaged buildings. These extreme reactors often resort to camping in dry locations such as deserts in tents or caravans and converted trailers.

The most well-known mould avoider is Erik Johnson, who was the prototype for CFS in Lake Tahoe, Nevada in the mid-1980s. He was effectively symptom free with extreme mould avoidance only, and did not follow the rest of the Shoemaker protocol. For more on Erik's story and mould avoidance techniques read the book *Back from the edge* by Lisa Petrison (see resources).

4.2.1 - Binding of toxins (CSM and Welchol)

Ideally the use of binding medication is done once clear of water-damaged buildings, although binders can be initiated if still exposed.

Dr. Shoemaker's preferred binder – Cholestyramine

Cholestyramine (CSM) is a sixty year old cholesterol lowering medication which has been extensively studied and has an excellent safety profile. This negatively charged binding resin attracts positively charged biotoxins from bile and excretes them in the feces. It is not absorbed systemically. It is available in Australia either as Questran Lite, which contains aspartame or as a pure compounded version. The compounded version may contain stevia and various forms of cellulose, which are harmless excipients in the vast majority of people. See resources for compounding pharmacies. The full dosage is four grams four times per day (QID), thirty minutes before meals/medications or one hour after meals/medications. It is suggested you start with a small dose (1-4 grams) and work your way up to the full dose.

Are there any side-effects?

CSM can have some gastrointestinal (GI) side-effects such as constipation, gas and acid reflux. Constipation can usually be ameliorated with magnesium citrate/ vitamin C/ soluble fibre (chia seeds, flax seeds and psyllium). Long term use can deplete fat soluble vitamins (A, E, D, K, Co Q10) so it is suggested to supplement those, away from CSM dosing. It is also advised to increase healthy fats in the diet such as eggs, butter/ghee, coconut oil, avocados and olive oil.

Dr. Shoemaker's second binder of choice – Welchol

Welchol (colesevelam) is a medication similar to CSM. It generally causes less GI side effects, and can be taken with food. It is the binder recommended by Dr. Shoemaker for sensitive patients who can't tolerate CSM. One caveat is that it only has 25% of the binding capacity of CSM. Also it can only be obtained at a select number of compounding pharmacies in Australia. Dosage is two tablets (625mg) two to three times per day.

How long do I stay on binders?

A minimum of one month with the average time being six-twelve months, although some people stay on it for longer. Duration is dependent on the VCS being passed, symptom reduction and absence of exposure to further water-damaged buildings. Some people stay on a lower maintenance dose (4 grams, twice a day) on a continual basis or prophylactically, taking it short term when re-exposed to WDBs (full dose, 3-7 days after exposure).

4.2.2 - Binding of toxins (other)

Non-systemic binders (stay in the GI tract)

- Activated charcoal – A broad spectrum binder, that has been used in animal mycotoxin and endotoxin (bacterial toxin) studies. Can also bind pesticides and VOCs. May bind with nutrients, so, as with CSM it is best taken away from supplements and medications. Suggested dose: 500-1000mg, 2-4 times per day. Suggested brands: Bulletproof, Blants (powder form) and Nature's Way. Caveat: it will cause darkening of stools.
- Chitosan – Similar in structure to CSM and Welchol and has a similar lowering of cholesterol of those medications but may also have anti-microbial and anti-cancer properties. Caveat: Derived from shellfish. (1, 2, 3). Suggested dose: 500-1000mg, 2-4 times per day. Suggested brands: Now, Nutricology, and Natural Balance.
- Bentonite clay (aka montmorilonite). Binds to mycotoxins (1, 2), bacterial toxins (1, 3), pesticides (1), and heavy metals (1). Suggested dose: 1-3 grams, 2-4 times per day. Suggested brands: Blants, also widely found on eBay (make sure it is marked for human consumption/internal use).
- Zeolite clay (aka clinoptilolite) – Similar to bentonite clay. Established as a mycotoxin binder in animal studies (1, 2, 3). Suggested dose: as per bentonite. Suggested brands: Vita Pure (LavaeVitae), Zeolith MED, Toxaprevent, ZeoBind (BioPure)
- Chlorella – TBA

Note: Dr. Shoemaker didn't find that any of these were of benefit statistically speaking but your results may vary and some may be helpful adjunctive therapies.

Systemic (is absorbed into blood stream)

- Nanoised zeolite – e.g. TRS, ACT. These are zeolite that are small enough to be absorbed into the blood stream and cells from the gut. As with normal zeolite mainly thought of as a heavy metal chelator. (No peer reviewed studies found for nanoised zeolite and chelation or binding, refer to zeolite research above).
- Modified citrus pectin – A fibre from citrus peel that is known to bind to heavy metals, especially lead, and environmental toxins. Also has anti-cancer effects. Brands include Pectasol-C, Now. (1, 2, 3, 4).
- Glutathione – The body's master antioxidant. Can also add in detoxification of toxins, including mycotoxins, and heavy metals. Can be in various forms including liposomal, intravenous, intranasal, N-acetyl-cysteine (a precursor) and L-glutathione.

Binders specific for heavy metals

- EDTA, DMSA, DMPS – Tried and tested compounds used in heavy metal chelation.
- Silica – Mainly known to bind to metals especially aluminium, but also thallium and tin. Brands include Biosil and Jarrosil.
- Thiol-functionalized silica – Quicksilver Scientific have a proprietary product, Intestinal Metals Detox (IMD) that is purported to bind to many heavy metals. (1).

Combination formulas

- Ultra Binder (Quicksilver) – Bentonite clay, activated charcoal, chitosan, aloe vera, IMD, arabic gum. Available from ProHealth.

References

- Shade et al. (2018). A Push-Catch System That Enables Effective Detoxification. The townsend letter, February/march 2018. Link.
- Huwig, A., Freimund, S., Käppeli, O., & Dutler, H. (2001). Mycotoxin detoxication of animal feed by different adsorbents. *Toxicol Lett,* 122(2):179-88. PMID 11439224
- Wilson, T. (2017). Are you detoxing with the correct binders. Sophia Health Institute. Link.

4.2.3 - Intensification reaction

CSM and nasal sprays can cause intensification reactions commonly but incorrectly referred to as herxing, or a herx, especially in Lyme patients. This is because as biotoxins enter the bloodstream, instead of cell receptors, they cause a rise in inflammatory cytokines.

Symptoms will generally exacerbate along with worsening of VCS, in columns D and E, and MMP-9 will increase.

Start these interventions from 30 to 10 days before you start CSM. If intensification gets too much either lower the CSM dose or stop and then follow the intervention(s) below for 5-10 days before restarting CSM.

- **No amylose diet**
  - A no amylose diet enhances the effectiveness of Actos or fish oil by a factor of 500.
    Amylose is found in most grains, vegetables grown below the ground (root vegetables) and bananas. Read Dr. Shoemaker's book *Lose the weight you hate* for in-depth advice. Similar diets include low carbohydrate, grain free, paleo diets such as the Bulletproof diet, Wahls Diet or Doug Kaufman's Phase I diet for at least the duration of CSM treatment.
- **High dose fish oil**
  - High dose fish oil can lower inflammatory cytokines and other inflammatory markers. Dr. Shoemaker suggests a dose of fish oil where the daily total of EPA at least 2.4 grams per day and DHA is 1.8 grams for 10 days, with CSM started on day 6. Many people stay on this high dose fish oil for longer.

Overweight patients with leptin levels above 8 may have more success with Actos (pioglitazone) a medication for diabetics at 45mg for 10 days (CSM started on day 6) although this is being used less by CIRS doctors due to its black box warning.

4.3.2 - MARCoNS treatment

- **Current Recommended Treatment – EDTA plus colloidal silver nasal spray**
  - If positive for MARCoNS the usual treatment is at least 30 days, but in reality it can take months, of EDTA/colloidal silver nasal. EDTA helps break down the biofilm and the colloidal silver is an effective antimicrobial with some anti-biofilm activity as well.
- **Past Treatments**
  - Previously BEG nasal spray was used which contained **B**actroban, **E**DTA and **G**entamicin. With the increase of antibiotic resistant MARCoNS strains, and studies done by Dr. Joseph Musto of Microbiology DX showing the effectiveness of colloidal silver, the protocol has been changed.
- **Alternative treatments**
  - Neti pot or nasal spray of water with iodine / salt / xylitol (xyclear)

    - Colloidal silver nasal spray by itself may help
    - nebulised PVP-iodine is very effective according to Greg Muske of Biotoxin Journey. Read his detailed MARCoNS, More MARCoNS and Even more MARCoNS blog posts for more details.
- **Follow up testing**
    - After several months of treatment it is recommended to repeat the MARCoNS test. If still positive, consult with your health practitioner for treatment options.

4.3.3 - Nasal fungal colonisation and anti-fungals

Dr. Shoemaker vehemently discourages the use of nasal anti-fungals. For two main reasons:

1. The rates of fungal colonisation in the nasal passages in CIRS patients is the same as healthy controls
2. Anti-fungal use can cause anti-biotic resistance to nasal bacteria such as MARCoNS as fungus and bacteria can transfer genes to one another.

See Dr. Joseph Brewer: Nasal fungi, anti-fungals and junk science.

Some other doctors such as Dr. Brewer and Dr. Neil Nathan have been advocating, and publishing studies, on the use of nasal anti-fungals in ME/CFS.

4.4 - Correcting gluten intolerence, hormones and inflammatory markers

Dr. Shoemaker advocates a gluten free diet, especially if positive for anti-gliadin antibodies. Other steps to balance hormones and reduce inflammatory markers may be required and treated for, please consult with your health care practitioner.

4.5 - VIP nasal spray

Vasoactive Intestinal Polypeptide (VIP) is a neuropeptide hormone that is predominately made in the hypothalamus and along with MSH is critical in controlling inflammation and the immune system. In a 2013 study, and in clinical practice, Dr. Shoemaker found that VIP:

- Increased plasma VIP levels
- Reduced symptoms to the level of healthy controls
- Reduced inflammatory cytokines (TGF-b1, C4a, MMP-9)
- Increased VEGF
- Balanced Treg immunity
- Increased 25-Vitamin D levels

- Normalised low testosterone levels in Males
- Normalised high estradiol (estrogen) levels in Males
- Increased tolerance to water-damaged buildings

However the caveat to VIP therapy is that if you're still being exposed to biotoxins from water damaged buildings or MARCoNS then instead of reducing inflammation VIP can increase it (TGF-b1, C4a). It is therefore imperative then that the following conditions must be met before using VIP spray.

- You live, work, study in buildings with a HERTSMI-2 score of < 11
- You pass the VCS test
- You test negative for MARCoNS
- You have normal lipase levels

My VIP level is normal, can I still benefit from VIP spray?

Yes. VIP has wide ranging effects apart from repleting VIP plasma levels. If you still have symptoms even with a normal VIP level, VIP may help.

Part 5: Building testing

5.1 - How do I test my home/workplace?

While your sense of sight, smell and touch are useful tools for identifying mould and feeling dampness much of the time mould overgrowth is not visible or odorous.

1. Professional inspection by an Indoor Environmental Professional (IEP), mycologist or building biologist with ERMI testing.
2. Self testing via ERMI
    - The current standard for determining mould levels in a building which will impact the health of CIRS patients is by doing an ERMI.
3. Professional inspection by an Indoor Environmental Professional (IEP), mycologist or building biologist without ERMI testing.

5.2 - What is ERMI testing?

ERMI stands for Environmental Relative Moldiness Index and was developed in conjunction with the EPA to determine the mould burden of a building using quantified PCR (DNA) testing of settled dust. The ERMI is able to detect full spores and spore fragments which can be 500 times more numerous than intact spores and which most of the biotoxins and inflammagens are attached to.

ERMI is a QPCR mould test *and* a score calculated from the test. ERMI tests for 36 species of indoor (21) and outdoor mould (14). The ERMI score is derived from subtracting the latter from the former.

5.2 - What is the HERTSMI-2 score?

HERTSMI-2 is a score, which focuses on five of the most toxigenic mould species, derived from the ERMI. However you can get a stand alone HERTSMI test which only tests for those 5 species.

It is generally recommended to do an ERMI first as it provides you with much more information and calculate the HERTSMI from that. If repeat tests are required, after remediation, or if you are screening properties to rent, then just a HERTSMI may suffice.

5.3 - What is a safe HERTSMI-2 score?

- HERTSMI-2 Total > 15: This building is permanently off-limits to those with CIRS.
- HERTSMI-2 Total 11 – 15: This building must be remediated before those with CIRS can enter.
- If HERTSMI-2 Points < 11: This building is most likely safe for CIRS people.

Use the HERTSMI calculator to determine the HERSTMI from the ERMI report.

Note: *Some particularly sensitive people may need a lower HERTSMI than 10.*

5.4 - What is a safe ERMI score?

The ERMI score has been depreciated as Dr. Shoemaker and mycologist David Lark determined HERTSMI-2 is more accurate than ERMI to determine if CIRS patients will relapse in a building. Previously, however, an ERMI score of 2 or below was considered safe for those with CIRS for re-entry. However if your MSH is less than 35 and your C4a is higher than 20,000 then the safe level reduced to -1 or below.

5.5 - My HERTSMI-2 is good but my ERMI is high, what should I do?
tba
5.6 - How do I do the ERMI test myself?

MouldLab is currently the only company doing ERMI testing in Australia. MouldLab will give you a kit with either a vacuum attachment or a Swiffer cloth (similar to a pledge cloth). Most people use the Swiffer cloth method. If using the Swiffer method you will wipe down

dusty surfaces in one direction, don't wipe back and forth, in the room(s) you want to test. Generally these are the master bedroom and living room. You should aim to have both sides of the cloth covered with approximately 80% of visible dust. Good surfaces to dust are the topside of ceiling fans, desktop fans, light fittings, top of cupboards, bookshelves, fridges, painting and poster frames, underneath the fridge, fridge coils and underneath furniture.

Avoid window and door areas and floor or skirting boards and do not dust visible mould as this may skew the results. Use latex/plastic cloves when performing dusting so no cross contamination occurs. Put the cloth in a plastic zip lock bag and mail to MouldLab with the completed forms.

6. Building remediation and mould prevention

6.1 - What is mould remediation?

Mould remediation is the technique of stopping moisture intrusion to a building, removing water-damaged building materials and removing mould spores, mould fragments, bacteria and biotoxins so a building is safe enough for those with CIRS to enter without relapsing.

6.2 - Do you need professional remediation?

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6.3 - Can you do mould remediation yourself (DIY)?

The answer is "it depends". It depends on how much water damage there is and how high the ERMI or HERTSMI-2 score is. It may be possible to do remediation either partly or fully with the caveat that it should not be done by the CIRS patient personally, they should ideally not be in the home at the time of cleaning, as it can cause mould to become airborne. See the article Remove, Don't Kill Mould – Part 1 for details.

This is primarily going to have benefit when your ERMI report shows moderate water saturation moulds such as Aspergillis penicilloides, Aspergillis versicolor and Wallemia sebi. If there is an excess of other species, particularly Stachybotrys and Chaematomium which indicate higher water saturation and possible ongoing water ingress in the house, the services of a professional remediator may be needed. In uncertain cases it is recommended to consult experts such as mycologists, indoor environmental professionals or building biologists on the best way to proceed with remediating a property.

6.3 - What about professional remediation?

If there is major water damage, the source of a leak is difficult to find or there are structural problems you will most likely need a professional remediator. See the resources section for possible remediators.

6.4 - How do you know if remediation has been successful?
Whatever method you use the ERMI/HERTSMI is again your best tool to check to see if the remediation was successful. You will need to wait four weeks after remediation to repeat an ERMI to allow time for mould DNA to settle in the dust.
6.5 - Areas of concern for water damage
Outside – The best location for a house is on the top of a hill so water drains away and doesn't pool. Consider the drainage of the block and placement of plants and trees. Check guttering and drains. Make sure weatherproofing (flashing) of windows and chimneys is adequate.
Basement/Garage – Basements are notorious for damp. Look for rising damp**.** Some have a dehumidifier on 24/7 in these areas.
Roof – Flat roof buildings will develop water leaks sooner or later, avoid. Look for leaks in all roofs, especially in old roofs and cement tile roofs which can be porous in little as 9 years (David Lark). USB data loggers can be used to detect high humidity levels in crawlspaces under roofs.
Attic/crawlspaces – Check for leaks coming from the roof and walls. Also for humidity and condensation in these areas.
Airflow – Draughty buildings are often mould free. Consider ceiling fans and desktop fans, good exhaust fans in bathroom and kitchen and opening of windows as much as possible.
Air conditioners – Due to condensation can be mould havens. Check inside also piping.
Kitchen – Around and under sink for water leaks and water splashing. Sinks are often not properly attached to bench allowing leaks to the particleboard below. Piping can develop pin hole leaks, especially plastic piping, in less than a decade from new. Check dishwasher inside (use vinegar in a wash) and pipes for leaks.
Bathroom – Dehumidifiers and fans are useful tools here. Squidgy showers after use. Mould growth in grouting is a common problem. Aim for good ventilation.
Bedroom – Try to make clutter free with nothing under the bed, that is slatted, to help airflow. Open wardrobe doors for airflow.
Furniture – Non-porous (leather, vinyl) can usually be cleaned and HEPA vacuumed. Porous furniture usually needs to be trashed after water damage.
Books/paper/photos – Photos can be cleaned. Scan and throw away books and paper documents or put in storage.
Carpets – These act as reservoirs for mould, bacteria and dust mites. If water damaged they generally need to be thrown out. If cleaned use a fast drying steam cleaning (e.g. Chemdry).
Clothes – Can be washed with normal washing powder and then dried in sun. Some people have used borax and/or vinegar or clove oil.
Bedding – Mattresses, pillows and quilts are notorious for mould, bacteria and dust mites.

Use a whole mattress protector around mattresses. Wash and air in sun blankets, sheets and quilts.

Fridges/washing machines – Notorious for low-level leaks. Should be moved and the underside and back areas thoroughly inspected. In one particularly bad case of water damage in Australia, the culprit was a water pipe to a fridge which had been gnawed by a rodent of some kind.

6.6 - Dehumidifiers

Mould and dust mites grow in relative humidity of 60% and over. Coastal Australia is renowned for having very high humidity levels so dehumidifiers can be a tool in keep household humidity at low levels, especially in damp areas such as the basement and bathroom. See Choice for a review of dehumidifiers from 2015.

6.7 - Air purifiers

The role of air purifiers in cleaning air of mould spores and mycotoxins is controversial. At the minimum a filter should be HEPA rated to filter spores with the addition of generous amounts of activated carbon to filter toxins. However it is possible for the air purifiers themselves to be become reservoirs for mould and bacterial growth. If you decide to implement air purifiers regular HEPA vacuuming and regular replacement of filters is recommended. Dr. Shoemaker recommends two small purifiers in a room that are moved daily rather than one large for optimal airflow. Brands some of members have used include IQAir (USA), InnovaAir (Aus) and Blueair(Sweden).

Dr. Shoemaker is currently testing a specific brand of photocatalytic air purifier while monitoring inflammatory blood markers in a patient cohort.

Part 7: Conclusion

While CIRS, biotoxins and Dr. Shoemaker's protocol are a relatively new concept in healthcare and may initially seem daunting the science is extremely solid and growing each year. It is backed by over 30 papers and Shoemaker's own clinical practice of 10,000 CIRS patients, four books over almost twenty years. Feel free to ask any remaining questions you might have on the facebook group and join in the discussion. Australian mould warriors unite!

Disclaimer

The author of the FAQ is written by a patient who is not a medical or mould industry professional. Any screening, diagnosis, treatment or building testing/remediation advice is for personal research purposes. Please consult with trained professionals before embarking on any of the protocols mentioned.