

8/2/2018

SUBMISSION

PARLIAMENTARY INQUIRY INTO BIOTOXIN –
RELATED ILLNESS IN AUSTRALIA

NAME WITHELD.
PARLIAMENT OF AUSTRALIA

SUBMISSION - Parliamentary Inquiry into Biotoxin - related illness in Australia.

"Potentially affecting 24% of global population" - Dr Ritchie Shoemaker

"FUNGUS EATS YOU FROM THE INSIDE OUT SLOWLY".

"CANDIDA ALBICANS FUNGUS ATE MY DAUGHTERS HEART VALVES"

"I HAVE NURSED THREE FAMILY MEMBERS THROUGH CANCER, THIS IS WORSE DUE TO LACK OF AWARENESS."

My daughter had a heart operation at three and a half months when she obtained a Candida fungal infection which partially disintegrated her heart valves. The infection entered her blood and travelled to her heart and other organs. Months of high end Anti-fungal treatments followed by natural treatments and three years of rehabilitation my daughter went on to live a full and happy life. She loved life which included swimming, dancing, singing and piano lessons. She loved people and school.

I was very careful with her diet making sure to incorporate all the foods that helped her thrive and take out the foods that she reacted to. These happened to be foods with Wheat, Gluten, and Dairy.

The next 7 years of life were HAPPY! Until 2009!

We bought and moved to an acreage. A lifelong dream. Little did we know it would make us all sick.....

We noticed white mold growing up the walls and over the furniture.

My daughters' weight instantly and slowly started to decline, but I didn't connect the mould. At least not initially.

And so began, the next nightmarish chapter of our lives.....

Here is our summary.

1. The prevalence and geographic distribution of biotoxin-related illnesses in Australia, particularly related to water-damaged buildings:

LOCATION

- Queensland remote
- Higher than average rainfall

WATER DAMAGED BUILDING

- Home Purchased in 2009
- Home was made of timber
- Noticed White mould growing over furniture and up walls.
- All family members fell ill or became chronically tired. (I became autoimmune)

MOULD

- There were various moulds.
- Outside - Black mould
- Inside - White mould and Black mould combination
- Would clean it with vinegar, bleach and water blasting.

OTHER KNOWN Mould or WDB

Four (4) other homes in same postcode.

NOTE: There are other people I know with CIRS (Chronic Inflammatory Response Syndrome). They cannot make a submission because they are too ill or wish to remain anonymous.

2. The prevalence of Chronic Inflammatory Response Syndrome (CIRS) or biotoxin related illness in Australian patients and the treatment available to them.

TREATMENT OPTIONS PRESENTED FOR MY "DAUGHTER" (Severe)

- Cholestyramine
- Laxatives
- Vitamin C
- Anti-Fungal treatment
- NGT feeding
- BEG spray
- Glutathione
- Iodine
- Selenium
- Tyrosine
- Glutamine
- Basica Alkaline Powder

TREATMENT I CHOSE TO TAKE FOR MY DAUGHTER

- All of the above + Biotin

EFFECTIVENESS OF THE TREATMENTS UNDERTAKEN

- All the above were effective
- Treatment may have come too late
- Continual relapsing problem

3. The current medical process of identifying biotoxin-related illness in patients and the medical evaluation of symptom complexes attributed to biotoxins and CIRS.

- The current medical diagnostic process in Australia is inefficient.
- There are not enough GP's and Medical Specialists whom are aware of this illness.
- Repeated visits to GPs and some hospital admissions with no diagnosis costs money.
- My life savings were depleted searching for a Medical Specialist and testing for a diagnosis.
- Traveling extensively to find a Medical Professional during acute illness proved challenging, expensive and disruptive.

- My pleas to Hospital/Specialist staff regarding my concerns for my daughter's fungal illness went ignored and I was taken to an interview room, yelled at, bullied, accused of Munchausen's and DOCS (Department of Community Services) were called to remove my daughter from my care.
- The accusations were unsubstantiated however, I was then refused her life saving anti-fungal drugs and refused the right to see Private Specialists. Left with a dying daughter and no medical help, I spent my life savings engaging Scientific, Biomedical help in Australia and Medical help from America.

THE TIME IT TOOK TO GET A DIAGNOSIS

- It took 7 years to receive an official diagnosis of CIRS. (Chronic Inflammatory Response Syndrome – Mold related biotoxin illness.)
- My daughter was officially diagnosed with CIRS in 2016 by an American Pediatrician.

THE SYMPTOMS BEFORE AND AFTER

- Prior to falling ill my daughter was happy at school and loving life. She had had a previous fungal infection. She would react to foods with gluten.
- Her health decline commenced with an obvious “cognitive decline”. (detailed in school observation letter)
- Current symptoms fluctuate between chronic and acute attacks which are still current today.
 - (a) Full body pins and needles (**very painful**) – Ice pick pain throughout body.
 - (b) Major cognitive decline – (at worst she couldn’t remember that I was her mummy)
 - (c) Daily throat, nasal, ear, eye, joint, shin and chest pain. (**very painful**)
 - (d) Forgetfulness Daily Headaches. (fluctuates between chronic and acute)
 - (e) Low grade intermittent temperatures.
 - (f) Narrowing of stools, compaction, dysmotility. (Cannot defecate without laxatives)
 - (g) CNS Central Nervous system dysfunction. Cannot toilet independently.
 - (h) Minimal taste. Temperature dysregulation. (Cannot feel hot or cold food/water – intermittent) (requires Air-conditioning when cold)
 - (i) Cannot swallow wholefoods. All foods steamed and blended. (Chokes on chunky foods)
 - (j) Malabsorption (It takes two hours to eat a blended meal of Salmon and Vegetables).
 - (k) Low Neutrophils in blood tests.
 - (l) Severe chronic fatigue. Cannot get out of bed some days.
 - (m) Night terrors

- (n) Sleep disturbance
- (o) Severe Gastrointestinal reflux. (have to prop up head of bed 45-degree angle)
- (p) Severe abdominal pain.
- (q) Low blood pressure – fainting episodes.
- (r) Acute sudden weight loss- intermittent. (4kg in 1 week) as seen on weight chart
- (s) Muscle wasting and muscle stiffness
- (t) Yellowing of skin
- (u) Extreme sensitivity in ears and touching her skin hurts.

THE MEDICAL TESTS AND THE RESULTS

Genetic testing

HLA-DR/DQ Genotyping for Coeliac Disease (biotoxin susceptible) - POSITIVE

- (a) **13-3-52A Multi mould-susceptible** **-DR Shoemaker protocol**
- (b) **13-3-52B Multi-mould susceptible**
- (c) **17-2-52A Mold Susceptible**
- (d) **17-2-52B Mold Susceptible**

(e) 17-2-52C Benign

MTHFR C677T - Positive Heterozygous Mutation Detected.

BTD D444H- Positive Heterozygous (rare) (slight biotin deficiency)

T21

Blood Tests – Positive

- (a) White blood cell count – Neutrophils consistently low People who have neutropenia have a higher risk of getting serious Infections.
- (b) Consistently high MCV red blood cell count
- (c) ANA Autoantibodies Positive Speckled 1:160 (Autoimmune unknown)
- (d) Slightly Elevated Liver enzyme tests. (intermittent)
- (e) High Urea and High Urea/Cret. Low Calcium. Low Iodine.(intermittent)
- (f) Infections: Mycoplasma, Cryptosporidium, IgM Positive.
- (g) Diagnosed with Constipation, Malnutrition (BMI 13) Pelvic Dyssynergia
- (h) Diagnosed lymphoid hyperplasia. (White nodules in duodenal cap)?
- (i) SIBO (Small intestinal Bacterial overgrowth) Methane dominant)
- (j) EBV (Epstein Barr Virus) – REACTIVE

THE NON-MEDICAL TESTS AND RESULTS

(1) Mycotoxin test panel ELISA Urine – Results – (dangerously high)

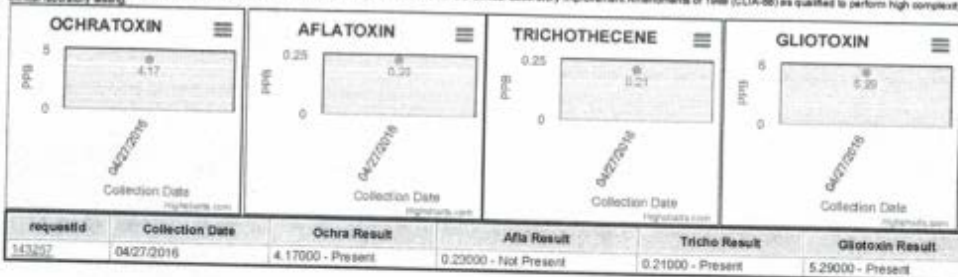
TEST	VALUE	RESULT	PRESENT IF GREATER OR EQUAL
OCHRATOXIN	4.17000ppb	Present	2.0ppb
AFLATOXIN	.023000ppb	Not Present	0.8ppb
TRICHOHECENE	0.21000ppb	Present	0.16ppb
GLIOTOXIN	5.29000ppb	Present	0.2-0.3ppb

Results:

Code	Test	Specimen	Value	Result	Not Present if less than	Equivalocal if between	Present if greater or equal
E8501	Ochratoxin A	Urine	4.17000 ppb	Present	1.8 ppb	1.8-2.0 ppb	2.0 ppb
E8502	Aflatoxin Group (B1, B2, G1, G2)	Urine	0.23000 ppb	Not Present	0.8 ppb	0.8-1.0 ppb	1.0 ppb
E8503	Trichothecene Group (Macrocytic)	Urine	0.21000 ppb	Present	0.16 ppb	0.16-0.2 ppb	0.2 ppb
E8510	Gliotoxin Derivative	Urine	5.29000 ppb	Present	0.2 ppb	0.2-0.3 ppb	0.3 ppb

Director Signature

Tests such as this should be used only in conjunction with other medically established diagnostic elements (e.g. symptoms, history, clinical impressions, results from other tests, etc). Physicians should use all the information available to them to diagnose and determine appropriate treatment for their patients.
Disclaimer: This test was developed and its performance characteristics determined by RealTime Lab. It has not been cleared or approved by the U.S. Food and Drug Administration. The FDA has determined that such clearance or approval is not necessary. This laboratory is certified under the Clinical Laboratory Improvement Amendments of 1988 (CLIA-88) as qualified to perform high complexity clinical laboratory testing.



(2) Marcons Nasal Swab - Dr Shoemaker testing protocol - Positive – Large amount

ENVIRONMENTAL ANALYSIS		
Result	Range	Units
SWAB, NASAL		
MARCoNS SWAB		
OVERALL RESULT: POSITIVE - MARCoNS		
ORGANISM #1: STAPH COAG NEGATIVE - LARGE AMOUNT		
SUSCEPTIBILITY #1:		
CIPROFLOXACIN	S	
CLINDAMYCIN	S	
ERYTHROMYCIN		R
GENTAMICIN	S	
LEVOFLOXACIN	S	
LINEZOLID	S	
MOXIFLOXACIN	S	
OXACILLIN (METHICILLIN)		R
PENICILLIN-G		R
QUINUPRISTIN/DALFO	S	
RIFAMPICIN		R
TETRACYCLINE (DOXYCYCLINE)	S	
TIGECYCLINE	S	
TRIMETHOPRIM/SULFA	S	
VANCOMYCIN	S	

KEY:
S=Sensitive I=Intermediate R=Resistant

COMMENT:
MARCoNS is a multiple antibiotic resistant coag negative staph that resides in the deep nasal passages of most people with no significant health concerns. However, in genetically susceptible patients (identified through HLA DQ-DR testing), these organisms are commonly seen in biotoxin illness, where they lower MSH levels (an anti-inflammatory neuropeptide) and produce biofilms which form a barrier to immune defenses and anti-infection therapy. Biofilm production in bacteria, mould or yeast may account for some cases of chronic nasal and sinus congestion and inflammation. MARCoNS releases exotoxins which lead to increased inflammation (decreased MSH) and hemolysins which disrupt RBCs and endothelial cells. MARCoNS infections can be minimised using BEG (Bactroban, EDTA, Gentamycin) nasal spray.

If test results indicate coag neg staph is present with two or more antibiotics showing Resistant or Intermediate susceptibility, these results are classified as MARCoNS whether Methicillin is resistant or not and whether there is a large amount or small amount.
(Ref: Dr. Ritchie Shoemaker, 05/09/14)

If biotoxins exposure is suspected, biotoxin load may be reduced through removal from the source of exposure and the use of Cholestyramine.

In commencing the treatment process, other baseline assessments include Gliadin and Transglutaminase Antibody levels, anti-Cardiolipin Antibodies, and Androgen studies (DHEAS, SHBG, Testosterone).

- VCS Marker tests - Dr Shoemaker testing protocol – Positive
- 2016 - 2018 test results to monitor progress.

VCS APTitude© Screening Test
www.survivingmold.com

Date: 07/11/2016 Gender: [REDACTED]
 Name: [REDACTED] Age: [REDACTED]
 Birth Date: [REDACTED] Race: White
 Email: [REDACTED]

VCS Left Eye

	A	B	C	D	E
9	✗	✗	✗	✗	✗
8	✗	✗	✗	✗	✗
7	✓	✗	✗	✗	✗
6	✓	✓	✗	✗	✗
5	✗	✓	✗	✗	✗
4	✓	✗	✓	✗	✗
3	✓	✓	✓	✗	✗
2	✓	✓	✓	✗	✗
1	✓	✓	✗	✓	✗

VCS Right Eye

	A	B	C	D	E
9	✗	✗	✗	✗	✗
8	✗	✗	✗	✗	✗
7	✗	✗	✗	✗	✗
6	✗	✗	✗	✗	✗
5	✓	✗	✗	✗	✗
4	✓	✓	✓	✗	✗
3	✓	✓	✓	✗	✗
2	✓	✓	✓	✗	✗
1	✗	✓	✗	✓	✗

Result: Fail

VCS APTitude© Screening Test
www.survivingmold.com

Date: 05/14/2018 Gender: [REDACTED]
 Name: [REDACTED] Age: [REDACTED]
 Birth Date: [REDACTED] Race: White
 Email: [REDACTED]

VCS Left Eye

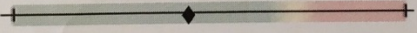
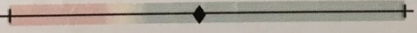
	A	B	C	D	E
9	✗	✗	✗	✗	✗
8	✗	✗	✗	✗	✗
7	✗	✗	✗	✗	✗
6	✗	✓	✗	✗	✗
5	✗	✓	✗	✗	✗
4	✓	✓	✗	✓	✗
3	✗	✓	✓	✓	✗
2	✓	✓	✓	✓	✗
1	✓	✓	✗	✓	✗

VCS Right Eye

	A	B	C	D	E
9	✗	✗	✗	✗	✗
8	✓	✗	✗	✗	✗
7	✓	✗	✗	✗	✗
6	✓	✓	✗	✗	✗
5	✓	✓	✗	✗	✗
4	✓	✓	✓	✗	✓
3	✓	✓	✓	✓	✓
2	✓	✓	✓	✓	✗
1	✓	✓	✓	✓	✗

Result: Fail

(4)DNA Analysis Stool Profile - USA - Positive Yeast/Fungi, Cryptosporidium spp, Parasite unknown

Pathogenic Bacteria		Expected Value	
Helicobacter pylori - Molecular Probe	Negative	Negative	
Campylobacter spp. - Molecular Probe	Negative	Negative	
Shiga toxin E. coli*	Negative	Negative	
Clostridium difficile*	Negative	Negative	
*Positive results are confirmed by EIA			
Yeast/Fungi		Expected Value	
Yeast/Fungi; taxonomy unavailable	+2 => 1000 pg DNA/g specimen	Negative	Yeast/Fungi Yeast overgrowth has been linked to many chronic conditions, in part because of antigenic responses in some patients to even low rates of yeast growth. Potential symptoms include diarrhea, headache, bloating, atopic dermatitis and fatigue. Positives are reported as +1, +2, +3 or +4 indicating >100, >1000, >10000 or >100000 pg DNA/g.
Parasites		Expected Value	
Cryptosporidium spp.	Positive	Negative	Parasites Parasite infections are a major cause of non-viral diarrhea. Symptoms may include constipation, gas, bloating, increased allergy response, colitis, nausea and distention.
Parasite present; taxonomy unavailable	Positive	Negative	
Adiposity Index		Expected Value	
Firmicutes %	60	 <= 80 %	The Adiposity Index is derived by using DNA probes that detect multiple genera of the phyla Firmicutes and Bacteroidetes. Abnormalities of these phyla may be associated with increased caloric extraction from food.
Bacteroidetes %	40	 >= 20 %	
Drug Resistance Genes			
aacA, aphD	Pos		Drug Resistance Genes aacA, aphD - Gentamycin, Kanamycin, and Tobramycin mecA - Methicillin
mecA	Neg		

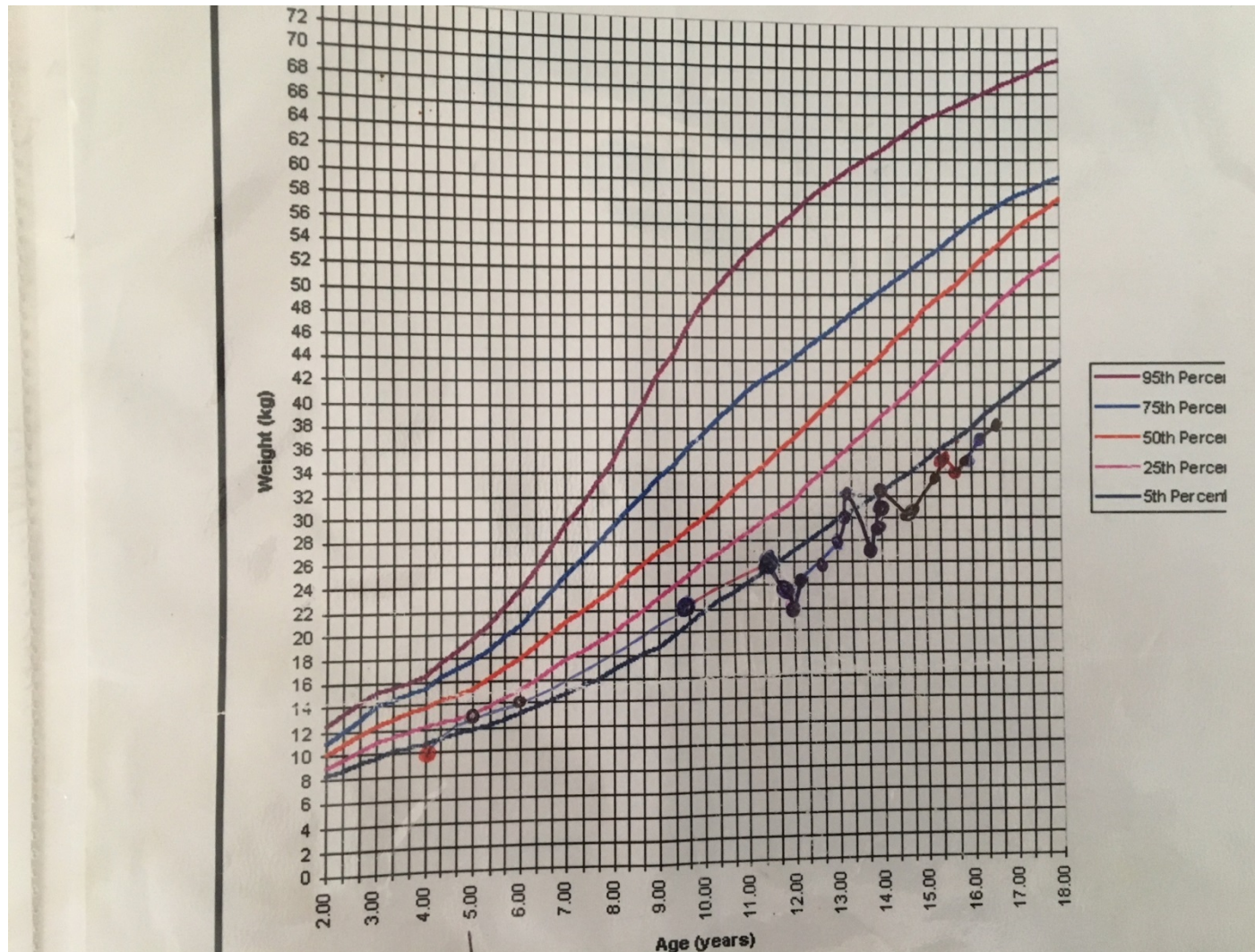
- **Allergy test - Food Testing (Full) Positive Allergy response**

- (a) Bakers Yeast, Brewer's Yeast, Barley, Cows Milk, Malt, Wheat, Potato, Pork, Tartrazine, Erythrosine
Lactulose, Glucose. Cannot eat anything with Sugar including any fruit, Red Meat - (Neu5Gc sugar
in red meat - not found in poultry or fish)

Date of Test: 29-Jul-18

1 Apple	32 Celery	63 Coca-Cola
2 Baker's Yeast 3	33 Capsicum	64 Crab
3 Brewer's Yeast 4	34 Cashew Nut	65 Flounder
4 Banana	35 Gelatine	66 Grape
5 Barley 1	36 Garlic	67 Goat Milk
6 Bran	37 Honey	68 Meta-Bi-Sulphite
7 Cocoa	38 Lentil	69 Lobster
8 Corn	39 Mandarin	70 Lettuce
9 Coffee	40 Mushroom	71 Mint
10 Cane Sugar	41 Parsley	72 Mustard
11 Cow's Milk 2	42 Pea	73 Pumpkin
12 Whole Egg	43 Pear	74 Peach
13 Lamb	44 Potato 3	75 Pork 3
14 Malt 4	45 Salmon	76 Sardine
15 Onion	46 Shrimp	77 M.S.G.
16 Orange	47 Cauliflower	78 Turkey
17 Pineapple	48 Walnut	79 Tuna
18 Peanut	49 Nutmeg	80 Almond
19 Rice	50 Oyster	81 Tea
20 Rye	51 Plum (Prune)	82 Black Pepper
21 Oat	52 Lemon	83 Licorice
22 Strawberry	53 Ginger	84 Spinach
23 String Bean	54 Date	85 Olive
24 Soy Bean	55 Cabbage	86 Mango
25 Tomato	56 Cucumber	87 Tartrazine 2
26 Safflower	57 Avocado	88 Carmosine
27 Vanilla	58 Asparagus	89 Sunset Yellow
28 Wheat 2	59 Apricot	90 Erythrosine 3
29 Beef	60 Carrot	91 Sorbate
30 Chicken	61 Cinnamon	92 Benzoate
31 Coconut	62 Curry Powder	93 Spice

WEIGHT CHART – CONSTANT BATTLE TO KEEP WEIGHT ON WITH EXTREME DIPS.



4. Any intersection with other chronic diseases:

My daughter has other chronic diseases that came after the mold exposure. These include

- SIBO – Intestinal bacterial overgrowth (have test results)
- EBV – Epstein barr virus – Reactive
- Many other infectious bacterial microbiome (can discuss further if required)
- Plus Genetic MTHFR Heterozygous C677T,
- HLA – Multi mold genetic susceptibility – Dr Shoemaker Protocol.

5. Investment in contemporary Australian research to discover and provide evidence of CIRS as a chronic, multisystem disease.

- Much research is required in Australia. There are 3 GP's whom specialize in this field in Australia that I am aware of.
- America can provide much insight. (Dr Ritchie Shoemaker)
- Further testing be made available to Health Practitioners for diagnostic purposes.
- A publication to Australian Health Practitioners to increase awareness of genetic profile susceptibility

6. Research into biotoxin – related illness caused from water damaged buildings.

- Research into High temperate areas with high humidity and rainfall. (Sydney-Cape York)
- A publication in potentially affected areas to create awareness to the genetically susceptible consumers about health hazards of mold and testing process .e.g. (ERMI or HERTSMI-2 test. Or agar plate test)
- Research into the types of molds affecting health consumers and relevant specific treatments

WDB

We have lived in three homes in the same postcode that have been WDB or had visible mould growing.

THE WDB TEST

An ERMI and HERTSMI-2 test was undertaken, with surprising results.

The test results came back with **ERMI very high** relative moldiness and **HERTSMI-2** of **14**. (see results – following page)

HERTSMI-2 scores between **11 and 15** have been associated with **re-occurrence of CIRS-WDB symptoms**.

4.1 The ERMI was found to be:-

Sample No:	Sample Location	Environmental Mouldiness Index (ERMI)	Relative Mouldiness Index (ERMI)	Interpretation
[REDACTED]	Not stated	20.4		Q4

4.2 Interpretation was made with reference to the following table:-

Level	ERMI Value	Interpretation	Comment
Q1	Less than -4	Low Relative Mouldiness	Further investigation is not needed to determine the sources of the mould.
Q2	-4 to 0	Low- Medium Relative Mouldiness	Further investigation may be needed to determine the sources of the mould if occupants have been reactive, sensitised, genetically predisposed or otherwise immuno-compromised
Q3	0 to 5	Medium- High Relative Mouldiness	
Q4	>5 to 20 >20	High Relative Mouldiness Very High Relative Mouldiness	Source and cause of mould should be determined and remediation undertaken, reducing the ERMI to levels below Q2

4.3 According to Vesper⁹ ERMI Scores have a SD of +/-3 and should be assessed with this in mind.

4.4 Further assessment was performed by calculating the HERTSMI-2 score from this data, it was found to be:-

Site Address: Not stated	Sample Location	
Sample ID: [REDACTED]	Not stated	
Sample type: Cloth	Spore E./mg	Weighting
<i>Aspergillus penicillioides</i>	0	0
<i>Aspergillus versicolor</i>	16	4
<i>Chaetomium globosum</i>	391	10
<i>Stachybotrys chartarum</i>	0	0
<i>Walleimia sebi</i>	94	0
HERTSMI-2 SCORE		1.4

4.5 HERTSMI-2 scores between 11 and 15 have been associated with re-occurrence of CIRS-WDB symptoms. Further assessment is suggested to determine the cause and

4.6 A spore equivalent may reflect the presence of any other fungal structures (i.e. mycelia) containing the same number of target genes as a spore.

INVESTIGATION

- Investigations were carried out to determine the cause of high HERSMI-2 as no visible mould was showing inside the house.
- A slow leak from a pin sized hole in the shower tiles into the wall was found to be the cause.

REMEDICATION

- A builder was sourced, and the shower tiles and walls taken off.
- All new timber, walls, tiling and waterproofing was carried out.
- An air filter/purifier was purchased and ran 24/7.
- All rooms were treated with Hydrogen Peroxide and vacuumed with a Hepa filter.

7. Other related matters.

- I have experienced seven (7) years of lost income and superannuation due to my role as a full time carer.
- I have had my social life become nonexistent due to caring 24/7.
- I have lost independence as I rely on other care for my daughter to purchase necessities like groceries, postage etc
- I have lost contact with most friends and family. (who wants to be around morbidity)
- I have lost confidence in Healthcare.
- I have had my character slandered and my integrity questioned.
- I nearly lost my daughter but never gave up
- Worst of all I have seen my daughter suffer for so long.

"I do not wish for any parent or human being to experience such devastating illness and not receive help."

"If I can help just one person, then this submission has been worthwhile".

