8/2/2018

SUBMSSION

PARLIAMENTARY INQUIRY INTO BIOTOXIN – RELATED ILLNESS IN AUSTRALIA



PARLIAMENT OF AUSTRALIA

Inquiry into Biotoxin-related Illnesses in Australia
Submission 12

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!

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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 Airconditioning 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.
 - (I) 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
AFLOTOXIN	.023000ppb	Not Present	0.8ppb
TRICHOTHECENE	0.21000ppb	Present	0.16ppb
GLIOTOXIN	5.29000ppb	Present	0.2-0.3ppb

Code Not Present if less than Equivocal if between Present if greater or equal E8501 Ochratoxin A 4.17000 ppb Present 1.8-2.0 ppb E8502 Affatoxin Group (B1.B2.G1.G2) Urine 0.23000 ppb Not Present 0.8 ppb 1.0 ppb E8503 Trichothecene Group (Macrocyclic) Urine 0.8-1.0 ppb 0.21000 ppb Present 0.18 ppb 0.18-0.2 ppb 0.2 ppb 0.2-0.3 ppb 0.3 ppb Tests such as this should be used only in conjunction with other medically established diagnostic elements (a.g., symptoms, history, clinical impressions, neutra, from other tests, etc). Physicians should use at the information evaluate to them to diagnose and describes expensive to their patients. This level as developed and by performance characteristics determined by RealTime Lab. If then not been cleared or approved by the U.S. Food and Drug Administration. The FDA has determined that such determined that discovers or approved in not necessary. This laboratory is certified under the Cinical Laboratory Improvement Americansis of 1988 (CLIA-08) as qualified to perform high complexity clinical laboratory leading. **OCHRATOXIN AFLATOXIN** TRICHOTHECENE GLIOTOXIN Collection Date Ochra Result Afla Result Tricho Result Gliotoxin Result 4.17000 - Present 0.23000 - Not Present 0.21000 - Present 5.29000 - Present

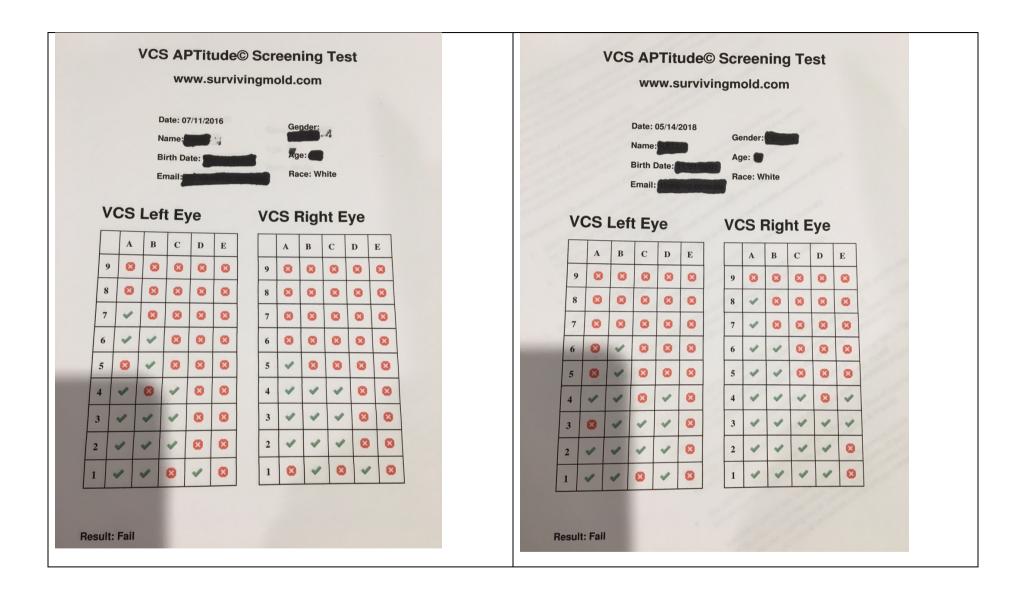
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Results:

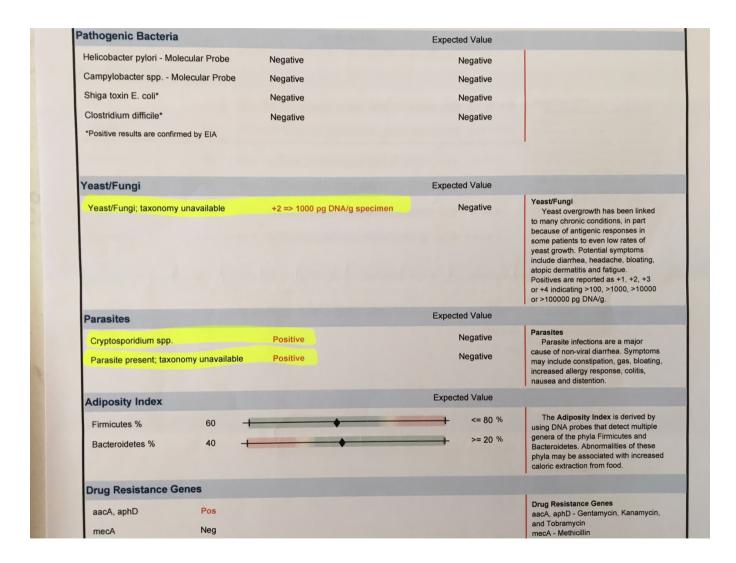
(2) Marcons Nasal Swab - Dr Shoemaker testing protocol - Positive - Large amount

SWAB, NASAL MARCONS SWAB		NVIRONMENTAL ANALYS
- WOONS SWAB	Resu	It Range Units
OVERALL RESULT:	POSITIVE - MA	Oliks .
ORGANISM #1:		
	STAPH COAG NEC	CATIVE - LARGE AMOUNT
SUSCEPTIBILITY #1	:	LARGE AMOUNT
CIPROFLOXACIN		
CLINDAMYCTM	S	
ERYTHROMYCIN	S	
GENTAMICTN		R
LEVOFLOXACIN	S	
LINEZOLID	S	
MOXIFLOXACTN	S	
OXACILLIN (MEMURA)		
	LLIN)	R
QUINUPRISTIN /DATE		R
	S	
TETRACYCL THE (DOWN		R
TIGECYCLINE (DOXYCY	CLINE) S	
TRIMETHOPRIM/CITY TO	S	
VANCOMYCIN	S	
2000000	S	
KEY:		
S=Sensitive T=T-		
	ntermediate	R=Resistant
COMMENT: MARCONS is a multipl		
MARCONS is a multipl deep nasal passages flowever, in genetical these organisms are canti-inflammatory net defenses and anti-inf may account for some MARCONS releases exothemolysins which disr MARCONS infections call spray. If test results indical showing Resistant or 1 MARCONS whether Methic small accounts for same and services for small accounts for same and services for same and same and services for same and same a	e antibiotic resort most people willy susceptible commonly seen in irropeptide) and fection therapy. cases of chronic wins which lead out the most people will be minimised to the minimised to the most people will be minimised to the	sistant coag negative staph that resides in the rith no significant health concerns. patients (identified through HLA DQ-DR testing), biotoxin illness, where they lower MSH levels (an Biofilm production in bacteria, mould or yeast c nasal and sinus congestion and inflammation. it o increased inflammation (decreased MSH) and it is in the sinus congestion and inflammation. It is in the sinus congestion and inflammation in the sinus congestion and inflammation. It is in the sinus because in the sin
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- VCS Marker tests Dr Shoemaker testing protocol Positive
- 2016 2018 test results to monitor progress.



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

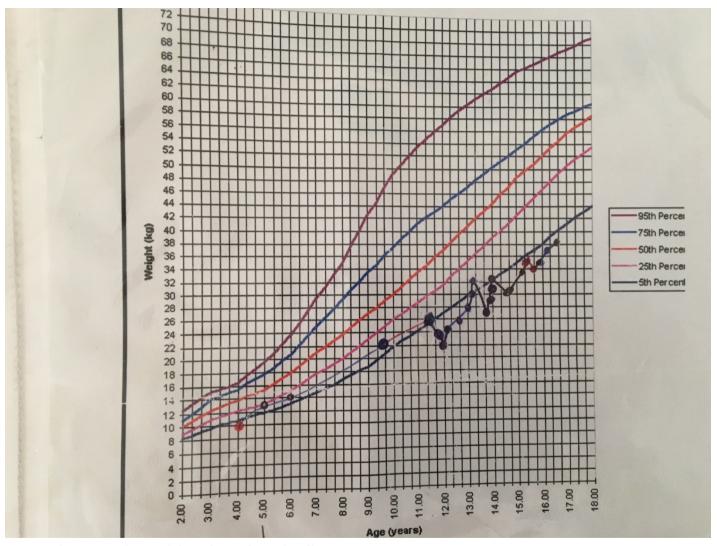


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- Allergy test Food Testing (Full) Positive Allergy response
- (a) Bakers Yeast, Brewer's Yeast, Barley, Cows Milk, Malt, Wheat, Potato, Pork, Tartrazine, Erythrosine Lactulose, Glucose. Cannot eat anything with Sugar including any fruit, Red Meat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



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 an 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 susceptibly

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

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WDB

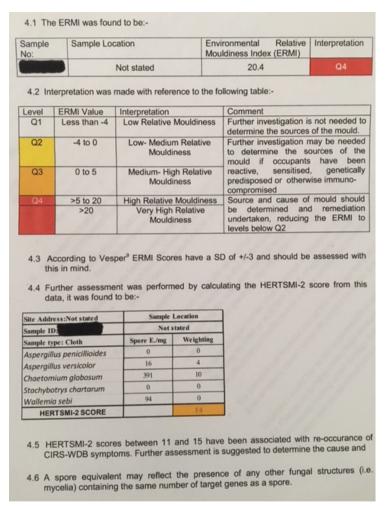
We have lived in three homes in the same postcode that have been WDB or had visible mould growing.

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.



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.

REMEDIATION

- 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."

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

V