To: The Standing Committee on Health, Aged Care and Sports

Inquiry into Biotoxin-related illnesses in Australia Submission

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Background

In 2000, I worked as an IT professional in London, and lived in a damp, water-damaged flat. During this time, I contracted a flu-like illness that progressed into a chronic illness, which included bouts of recurrent upper respiratory events, and a decrease in functioning. In 2002 I was formally diagnosed with Myalgic Encephalomyelitis (ME)/Chronic Fatigue Syndrome (CFS). I had constant flu-like symptoms, rhinitis, blurred vision, irritable bowel syndrome, cognitive difficulties, insomnia, unrefreshing sleep, extreme fatigue and exercise intolerance/PENE (post-exercise neuroimmune exhaustion) among other symptoms. Standard pathology markers were, and remain, within normal ranges.

Having regained some improvement in health after leaving that water-damaged abode I returned to my parent's home in Australia. Soon after cleaning their mouldy atrium, I again suffered from a flu-like illness, and became even sicker. I have never reached the level of health that I enjoyed prior to these events of mould exposure.

In 2006 I researched the work of Dr. Ritchie Shoemaker and read his book Mold Warriors (Shoemaker, 2005). I took the book and Dr. Shoemaker's biotoxin pathway (Shoemaker, 2011) to my physician, and asked for testing and treatment. As neither were available, or accessible, at that time I moved onto other therapies.

After thirteen years, and visiting 20 doctors, I was diagnosed with Chronic Inflammatory Response Syndrome (CIRS) in 2014. Despite treatment I remain significantly disabled. I believe if I was diagnosed with CIRS earlier, and avoided water-damaged buildings, I would now have greater functionality, and a greatly superior quality of life.

I am mostly housebound due to the exacerbation of symptoms (PENE) that happens when I leave my home for any social, medical or business activity. There has been considerable social stigmatisation, loss of friends and significantly reduced time with friends and family. In addition to the symptoms of ME/CFS above I have also developed Fibromyalgia since my initial diagnosis. This means I am in constant bodily pain, and I experience migraines 2-3 times per week. One explanation that I give to people is that it feels like I've had influenza for 18 years.

The personal financial loss has also been immense, due to direct health costs, such as out of pocket testing, medications, supplements and doctor visits that I estimate as $75,000-$100,000. Other financial costs include loss of income due to inability to work for many years. I can only work part-time at present. I estimate an indirect financial loss of $750,000-$1,000,000 over the 18 years.

I volunteer as an administrator of the community group Toxic Mould Support Australia (Toxic Mould Support Australia Facebook Group, n.d.). I am also the web editor and main contributor to the associated website (Toxic Mould Support Australia, n.d.). I have prepared a separate submission on behalf of Toxic Mould Support Australia.

Response to Terms of Reference

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

I currently live in Brisbane (4030 postcode), Australia. I have noted water damage in 5 of the last 8 abodes that I have lived in. Seven (4 water-damaged) were in south east Queensland and 1 (that was water-damaged) was in Melbourne. This 62% rate of water-damaged buildings that I have encountered is over the World Health Organization estimate of 10-50% of Australian buildings being affected by dampness (World Health Organization Europe, 2009, p93) but is consistent with fellow rates among TMSA members.

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

After being diagnosed with CIRS in 2015 I undertook therapy that included using a binding agent, cholestryramine, and eventually vasoactive intestinal polypeptide (VIP) replacement therapy. In late 2016 I moved to a newly built social housing apartment that tested low for mould via HERTSMI-2 scoring (Shoemaker, Lark, 2016).

While I have had improvement in certain CIRS laboratory biomarkers and some symptoms, including gastrointestinal and cognition, my other symptoms and overall functionality have remain largely unchanged. I believe this is due to the gap between initial CIRS onset and diagnosis and treatment. There is also the possibility that CIRS may be a co-factor or comorbidity, and not the underlying factor, for some patients with ME/CFS and similar multi-symptom, multisystem illnesses.

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

At the time of my initial CIRS diagnosis I was positive for all screening/diagnostic tests (Shoemaker et al, 2018).

These included:

- Symptom cluster analysis – 10 out of 13 clusters, 17 out of 37 symptoms.
- Visual contrast sensitivity (VCS) – failed in 2006 and 2014.
- HLA DR/DQ genetic susceptibility. One of my HLA haplotype's is 4-3-53 which is known as multi-susceptible. This set of genes that are susceptible to all biotoxins, and associated with Chronic Fatigue Syndrome (Shoemaker, 2010; HLA-DR Haplotype Definitions – 4-3-53, n.d.).

From 2014 to 2018 I have also tested positive for other CIRS diagnostic markers:

- alpha-melanocyte stimulating hormone (MSH) – low.
- VIP – low.
- complement 4a (C4a) – high.
- Leptin – high.
- Volumetric MRI (NeuroQuant) analysis – hypertrophy and atrophy consistent with CIRS-WDB (Shoemaker, House, Ryan, 2014).
- Multiple antibiotic resistant coagulase negative staphylococci (MARCoNS) in the deep nasal passages.

I have tested normal for traditional markers of inflammation such as ESR, CRP, and IgE mould allergy on multiple occasions.

Conclusion

There is an urgent need for timely diagnosis and treatment interventions for those patients with CIRS in Australia. This will prevent suffering, disability, and reduction in quality of life for many people. Intrinsically linked to the CIRS medical side is the need for safe housing for those suffering or susceptible to CIRS, and the building of future housing that will not be prone to condensation, damp, and water damage.

References

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APPENDIX 1. CIRS Biomarker Results 2014-2018

	14/11/2014	14//01/2015	23/12/2015	3/03/2016	8/01/2016	10/11/2016	1/03/2017	1/09/2017	24/03/2018	8/05/2018	units	RANGE
ADH	2.9										pg/ml	< 7
Osmolality	295										mosmol	280-300
C3a						38					ng/ml	55-486
C4a				**5,897**		**10,355**					ng/ml	< 2830
TGF-b1				1,900		1,292					pg/ml	< 2380
Leptin	**13.8**		**10.1**				**7.7**			**18.1**	ng/mL	0.8-6.1
VEGF				37							pg/mL	31-86
VIP	**17.5**		45.3				**12.0**				pg/mL	23-63
MSH						**9.8**					pg/mL	35-81
Lipase			38									< 70
MARCoNS		Negative			Negative			**Postive**	**Postive**			
								Penicillin	Penicillin			
								Levofloxcin	Levofloxcin			
									Oxacillin			
Biofilm								Low (+1)				
Coag Pos Staph		Pos			Pos							
Bacillis sp.		Pos										
HLA 1	**4-3-53**	(Multi/CFS)										
HLA 2	**17-2-52A/B/C**	(Mold)										

Other biomarkers (available on request)

VCS testing (2006, 2014) - Fail
Volumetric MRI (NeuroQuant) (2014, 2015, 2017) - shows hypertrophy and atrophy consistent with CIRS-WDB.

Pathology laboratories:

C3a, C4a, TGF-b1, VEGF – Quest diagnostics
ADH, Leptin, VIP – Sydney Southwest Pathology
Osmolality, HLA – Sullivan Nicolaides Pathology/Sonic Health Care Ltd.
Lipase – QML
MARCoNS – Microbiology Dx