Senate submission

Inquiry into Biotoxin-related Illnesses in Australia

Introduction

I am writing this submission as a probable patient of Chronic Inflammatory Response Syndrome (CIRS).

I have been chronically ill for 17 years, with the primary diagnosis of Lyme-like illness.[1] It may seem significantly (suspiciously?!) unlucky to the reader that I suffer from two controversial and relatively obscure illnesses, but there is an explanation for that.

America's Dr Richard Horowitz, who has treated over 12 000 Lyme patients and provided expertise to multiple governments internationally,[2] observed that the impact of the disease can cause, exacerbate, or make patients more susceptible to other conditions.

He therefore suggested replacing 'Lyme disease' with the term 'Multi-Systemic Infectious Disease Syndrome'(MSIDS), which he describes as

"...a symptom complex of Lyme disease and multiple associated tick-borne co-infections that encompasses not only infections with Borrelia burgdorferi*… but also other bacterial infections, viral infections, parasitic infections and fungal infections.*

It also includes: immune dysfunction; inflammation; environmental toxicity; allergies; nutritional and enzyme deficiencies, with functional medicine abnormalities in biochemical pathways; mitochondrial dysfunction; neuropsychological issues, autonomic nervous system dysfunction, endocrine abnormalities, sleep disorders; gastrointestinal abnormalities, with abnormal liver functions; and issues with pain, drug use and physical deconditioning.

By using this definition, I can treat my patients more effectively, because these patients are unable to recover their prior state of health unless all of these factors are addressed, simultaneously."[3]

Dr Horowitz classifies mould and its neurotoxins as environmental toxins.[4]

I know of many other patients of Lyme-like illness who have been also diagnosed with CIRS, however I note that at time of writing this submission (late July 2018), only one patient submission has been published. I speculate the reason for this may be that these patients were so disillusioned by the outcome of the 2016 Senate inquiry into Lyme-like illness that they cannot justify investing their limited energy in contributing to this inquiry.

Symptoms

I cannot clarify which symptoms were caused by probable CIRS as opposed to Lyme-like illness or any of the other conditions I've been diagnosed with (hypothyroidism, Chronic Fatigue Syndrome, Leaky Gut.)

I have therefore listed below all of the symptoms I've experienced.

Neurological	
Brain fog - memory loss, difficulty in concentration and comprehension, spelling difficulties, word block, confusion	Hypoperfusion to bilateral temporal and posterior parietal lobes
Mood swings	Suicidal ideation
Reduced spatial awareness	Headaches
Frequent accidental biting of tongue and lips	Reduced coordination
Sense of impending doom	Baseless feeling of rage
Sensitivity to touch	Temperature dysregulation
Noise sensitivity	Light sensitivity
Difficulty swallowing	Temporary facial paralysis
Slurred speech	Repetitive quality to speech
Robotic sounding speech patterns	Tremors
Involuntary twitches	Presence of 'flashing lights' when closing eyes
Mental hyperstimulation	
Gastrointestinal	
Severe abdominal cramping	Chronic vomiting
Alternating diarrhoea and constipation	Bladder and bowel urgency
Bladder and bowel incontinence	Gut distention
Blood in stool	Pruritis ani
Increased motion sickness (when driving self, scrolling too quickly on a webpage)	Nausea
Hypochlorhydria	
General	
Severe fatigue	Weight loss ("very underweight" on BMI scale)
Extensive food intolerances	Menorrhagia
Frequent bruising	Pain behind eyes
Reduced vision (Note: may be coincidental timing)	Pain in ears
Tinnitus	Tachycardia
Salivary hypofunction	Xerostomia
Severe menstrual pain	Tingling feet
Teeth chattering	Low blood pressure
Severe cystic acne	Inability to walk due to fatigue and/or dizziness
Breast pain	Decreased sex drive
Insomnia	Fevers
‘Cold patches' on body	Crawling' sensation that travels across body
Muscle cramps	Air hunger
Dizziness	Dental pain
Genital pain	Early morning waking
Drawn/grey complexion	Puffy 'dead' eyes
No appetite	Voracious appetite
Pins and needles feeling	Blocked nose and phlegmy throat
Night sweats	Low thyroid function

My diagnosis

I was diagnosed with Lyme-like illness in 2012, and although I experienced the Jarisch-Herxheimer reactions commonly experienced when treating a bacterial infection, my progress was unstable.

Through my own research and discussion with my doctor, I began to consider CIRS as a possibility. In late 2014, I was referred to a doctor trained by Dr Ritchie Shoemaker, the American doctor responsible for much of the medical profession's knowledge of CIRS.

The following factors were considerations in my diagnosis:

History of mould exposure

The first indication was my history of mould exposure. When I first became ill in 2002, I was living in a new townhouse in Sydney with a couple. Over time, we realised that the shower in their ensuite was leaking downstairs into the lounge room ceiling, and eventually through the ceiling into the area where I usually sat. This was reported to our landlord.

During this time, a situation developed in which the couple decided not to clean their shower. A film of white mould grew over all the shower's glass surfaces. It almost looked like the shower was created using frosted glass.

Despite this, they continued to use the shower. I became worried for their health, and eventually, when I was particularly bored on an RDO, I decided to clean it myself. I briefly considered popping down to Bunnings for a face mask but dismissed this thought as overly-cautious. I took my clothes off, and armed with just gloves, a scrubbing brush, a bottle of Domestos and the questionable benefits of an ineffective exhaust fan, I climbed into the shower, set the water flow to warm and began to scrub.

I can't confidently say what the timeframe was after which I became debilitatingly ill, but it was a matter of weeks or months. I don't know whether the Lyme-like illness exacerbated the effects, or vice versa. All I know is that I became very ill, and doctors were unable to offer me any form of diagnosis or treatment.

Within a year, we all moved out of the townhouse for unrelated reasons, and I bought a 1970s house in a flat, coastal area. Like many of the houses in this region, it contained a small amount of mould.

Physical examination

My new doctor assessed the (poor) condition of my nails and skin, my (low) blood pressure and my (normal) temperature. He also identified the abdominal sensitivity commonly found in CIRS patients.

Symptom analysis

I completed a symptom checklist to ascertain the compatibility of my symptoms with those of CIRS.

Personal testing

There is currently no single test used to diagnose CIRS; a combination of different investigative serology is used.

<u>HLA DR genes</u>

These genes, related to immune response, are supposed to deal with mould exposure. In people

with faulty HLA DR genes, the process of identifying mould antigens and producing antibodies to bind them fails. The mould just stays inside the patients, causing an ongoing inflammatory response.

The HLA DR genes are assessed via a blood test called 'Coeliac DQ/DR gene studies.' Mine were found to be faulty.

Transforming Growth Factor (TGF) Beta 1

TGF Beta 1 is a cytokine that can cause damage to the body when produced in excess. It can be a significant influence in gastrointestinal dysfunction, which I was experiencing. The normal range in a healthy person is 344-2382 pg/mL. My result was 7440.

Vascular Endothelial Growth Factor (VEGF)

VEGF promotes blood flow throughout the body and is found at reduced levels in CIRS patients. I didn't get an exact figure for my VEGF levels; my pathology results just say it was below the normal range of 31-86 pg/mL.

Vascoactive Intestinal Peptide (VIP)

VIP can cause hormonal issues and is generally found to be low in CIRS patients. My result, however, was 49pmol/L, which is at the high end of the normal scale of 0-50. My doctor speculated there were three possible reasons for this:

1. I don't have CIRS – this theory was to be viewed in the context of the other test results
2. The VIP test, which was analysed in Australia, was not of a gold standard. (Some of my other tests were analysed in America.)
3. My body was overcompensating by providing high levels of VIP.

Multi-Antibiotic Resistant Coagulase-Negative Staphylococci (MARCoNs)

MARCoNS is a nasal infection common in CIRS patients. I tested positive for this.

NeuroQuant MRI

NeuroQuants MRIs are generally used to clarify whether symptoms are caused by Lyme disease or mould exposure.

My MRI was examined by both my doctor and Dr Shoemaker. They determined that there was evidence of prior Lyme damage, but that impacts of mould exposure appeared to be current and significant.

Visual Contrast Sensitivity Test (VCS)

The VCS test is used to measure the patient's ability to recognise contrast. I passed a 'handheld' version in my doctor's office, but later repeatedly failed additional tests conducted at home on my computer.

Other tests

I was also tested for Osmolality/Anti-Diuretic Hormone (ADH) and MMP-9. Both were within normal

ranges.

I'm pretty sure I was also tested for ACTH, cortisol, DHEA, testosterone, antigliadin antibodies and Melanocyte Stimulating Hormone (MSH) but I seem to have lost the results.

Based on my results, my doctor was not 100% certain I had CIRS. He uses three criteria for diagnosis; genetics, Neuroquant MRI and at least three additional serology markers, primarily TGF Beta, VIP and ADH.

My genetic results and Neuroquant supported a CIRS diagnosis. However although my TFG Beta results were high (as anticipated), my VIP was unexpectedly high and my ADH was normal.

My doctor told me I was "not classic CIRS, but pretty close" and that overall I was "a very complex case" with "a mixed bag of problems."

Environmental testing

In addition to personal pathology, my home also needed to be tested. In August 2014, a sample of the dust from my house underwent an Environmental Relative Mouldiness Index (ERMI) test to identify mould DNA. The results are represented from a scale of -10 to 20; the higher the score, the greater the mould presence.

My house scored 6.52; not terrible, but certainly not great. I sought advice from a recommended mould remediator who had previously worked with both Dr Shoemaker and the doctor treating me. He thought the mould issue could be easily fixed by wiping the house and furniture down with a vinegar solution. Given the weakened state of my immune system though and a condensation problem in my house, he also highly recommended the installation of a ducted air purifying system, particularly in case there were any microbes present.

However, there was no way to do this; the house had cathedral ceilings, and the floor was a cement slab, so there was no access.

My husband Ryan and I cleaned the house the best we could and hoped for the best. It was exhausting, but preferable to moving house – we didn't have the money for that, given I had been unable to work for over two years and our savings had been eaten up by my costly treatment.

A second test in 2015 showed a reduction in harmful mould, with a score of 4.86, but it was not enough. We made the decision to move house.

Treatment

Removal from mould exposure is key to mould treatment. As noted above, Ryan and I cleaned the house ourselves before I underwent treatment in late 2014.

I was given antibiotics for the MARCoNS, and it cleared up within weeks. For the first time in approximately 12 years, I was breathing through my nose (not my mouth) and did not have a 'gluggy phlegm-y' feeling at the top of my throat. A follow up test was negative, and I have remained free of those symptoms ever since.

I was also prescribed cholestyramine to bind to the mould antigens and allow their effective removal from my body. Within a very short period of time, this appeared to stabilise my weight. I had weighed around 45kg for the last decade, but within a year of starting treatment for Lyme-like illness in 2012, I was back at my pre-illness weight of 48-51kg. However, I was unable to exceed the 50kg threshold consistently. In a startlingly short amount of time after commencing the cholestyramine, I consistently exceeded the 50kg threshold, and at time of writing, I weigh 53kg.

Ryan and I then moved to a new house assessed by the mould remediator and had an air purifying ducted system installed.

My VCS scores reduced, demonstrating an improved ability to identify contrast.

My doctor prescribed VIP spray, in an effort to confirm whether my body had been overcompensating by producing so much of its own VIP. Unfortunately I was unable to tolerate the spray– it gave me severe headaches.

A second TGF Beta 1 test less than a year after commencing treatment showed a reduction from 7440 to 5700.

Despite these improvements, my doctor was still reluctant to formally diagnose me with CIRS due to my VIP and ADH results. Both of these tests were conducted in Australia (unlike the TGF Beta 1 and VEGF tests which were interpreted by an American lab), where CIRS is virtually unknown.

As a number of other patients had unexpected or inconsistent results, my doctor began liaising with different Australian labs to seek clarity and ensure 'gold standard' testing. In the meantime, my doctor also approached labs to request that they collect blood to be sent to America for testing. Unfortunately, this fell through in New South Wales.

At time of writing, I still don't know for sure whether I had/have CIRS. I hope that my submission is still of use, though, as it highlights the difficulty in obtaining testing and diagnosis, and my objective improvements under treatment.

Current situation

It is no exaggeration to say that my chronic illness has absolutely devastated the last 16 years of my life.

It has significantly affected my quality of life and ability to build a future physically, financially, socially and professionally.

The easiest area to measure is my financial situation. As you can imagine, the cost of having American testing is daunting. Treatment was nowhere near as costly as it is for Lyme-like illness, but it was still considerable. Both pale into significance compared to the cost of selling a house, buying a new one and having appropriate modifications made. This easily exceeded $100 000.

Although I'm still not as well as I'd like to be, I've now reached the stage where I have started looking for part time work. I don't have the health to cope with the challenges of my old career, but after a six year absence from the paid workforce, I am looking forward to being able to being able to contribute financially via a lesser-paid role.

Concerns

I hope the following concerns will be addressed by the inquiry:

- The Terms of Reference include "*The prevalence and geographic distribution of biotoxin-related illnesses in Australia."* I hope the Committee acknowledges that the data required to investigate these issues is simply not available.

  These illnesses have a very low profile in Australia, and anecdotally, it seems few doctors are able to recognise and treat them – let alone report them, assuming a reporting mechanism is even available.

- Education of healthcare staff, pathologists and those in related professions about biotoxin-related illness needs to be a priority. Prompt diagnosis and treatment could improve the lives of thousands of Australians.

- Having appropriate 'gold standard' testing readily available would reduce patient costs, lead to prompt diagnosis and support Australia's efforts to provide a world class medical system. As mould can often grow in concealed areas, and patients' memories may be impacted, some patients may not even know they've had exposure, so accurate testing is vital.

- Due to the current real estate boom, developers are building housing estates, unit blocks and 'McMansions' very quickly. It is possible that additional building codes/requirements and landlord responsibilities need to be updated to minimise the risk of mould exposure incidents.

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[1] I provided submission 695 to the 2016 Senate inquiry into '*Growing evidence of an emerging tick-borne disease that causes a Lyme-like illness for many Australian patients.'* It can be located here: https://www.aph.gov.au/Parliamentary_Business/Committees/Senate/Community_Affairs/Lymelikeillness45/Submissions

[2] Horowitz, *Growing Evidence of an Emerging Tick-borne Disease that causes a Lyme-Like Illness for many Australian Patients, Senate Submission 936*, p22-27, http://www.aph.gov.au/Parliamentary_Business/Committees/Senate/Community_Affairs/Lyme-like_Illness/Submissions

[3] Horowitz, *Why Can't I Get Better? Solving the Mystery of Lyme & Chronic Disease*, St Martin's Press, 2013, p58

[4] Horowitz, *Why Can't I Get Better? Solving the Mystery of Lyme & Chronic Disease*, St Martin's Press, 2013, p215, 471-472