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Carlene Stratton – CIRS/DMHS/Aspergillus Diseases

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 Burleigh Waters Queensland after returning to Queensland from Sydney in September 2013.

I was working in Pyrmont when I became ill. I had been employed by Tabcorp to manage the client-side procurement functions for the redevelopment of Star Casino and the building of a new hotel adjacent to the Casino. I started work on 5 January 2009, my office was shared with 4 others, we were located in the corporate offices on Level 4 of the Apartment Tower. I would say within a week of commencing work at the Casino, I started to develop respiratory symptoms, and very soon after was prescribed Asthma inhalers, antibiotics for an infection and a course of prednisone. I could not see nor smell mould. The office was adjacent to the kitchen, if there was a leak, it hadn't come through the wall, I cannot comment on the slab as it was carpeted. The air-conditioning was insufficient, the room was very hot and stuffy with little to no air-flow. Two of the other ladies in the room had a number of days of work, I cannot comment on why they were ill, nor the cause of the other lady in the room who had a flare in eczema. Outside the office I worked in, in the open plan office area, 2 of the ladies later connected that since starting work there, one had had a number of chest infections and the other a number of ear infections – both attributed this to public transport, though when I became ill started to rethink this. From January on over the next 5 months I became extraordinarily unwell: severe weight loss from 55 kg to 42kg, fevers, headaches, upper and lower respiratory infections, I couldn't tolerate being in the room and asked to be moved. This was refused by the then Project Finance Manager (who later had his employment terminated). In April 2009, my then GP, contacted the workplace after I cultured *Aspergillus Fumigatus* on top of pneumonia, and asking what was in the environment. The same Finance Manager asked if I had always been sickly...NO. I was a super-fit long-distance runner and rower, this was not normal for me at all. The workplace was to carry out an OHS assessment of the air quality in the room, although weeks passed and nothing eventuated. I went to the Star Casino OHS Manager and formally requested that the testing be carried out, explaining the severe health problems I was experiencing. He asked if he could have access to my medical records, to which I readily agreed. I also put this into an email confirming my agreement to health records access and them testing the room (an occupational habit). A couple more weeks passed and still no action despite my continued follow-ups both in person and via email. I took a week off work to try and settle down. On June 17th, whilst already being treated for the Aspergillosis (fungus) infection, I tested positive for pneumonia again. On June 18th I submitted my first work cover certificate stating the workplace had to have its air quality tested. *Aspergillus* is one of the most ubiquitous organisms known to mankind, our immune systems protect us against this pathogen, but a contamination can change this. This is a disease usually contracted by severe asthmatics, those with cystic fibrosis or the severely immune-suppressed, not in very

fit and healthy athletes as I was, it didn't make sense. Before moving into project-based procurement roles I was a Facilities Services Manager, OHS was part of my mandate and something I took seriously, this didn't appear to be the case at Star Casino. Within 2 hours of submitting the work-cover certificate I was terminated on the spot.

In December 2009 I had significant sinus surgery, this required a post op hospitalisation for orbital cellulitis, a complication of the surgery. My workers compensation claim was accepted. Although I have never recovered and have ongoing courses of anti-fungal therapy to alleviate the fungal burden, I have constant bacterial infections, which are becoming of real concern as time progresses because the pathogens I am developing infections to are generally found in severely immune-compromised people. In 2011 I was forced to job seek even though I wasn't well, this was part of the workers compensation legislative requirements that I return to work or have my claim cut off. This started a series of 7 jobs, with each environment causing me more and more problems, once sensitive and a host to aspergillus there is no environment I am able to be healthy in. I haven't tried to work for the past 4 years, and as I write this, I am on yet another course of anti-fungal therapy and have/am treating a highly unusual bacterial infection, normally found in neo-nates with meningitis. I can only describe my daily symptoms as if I am being literally poisoned.

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

I have seen so many doctors it is both obscene and disturbing. I have a very unusual illness to a very common pathogen, that most doctors have never even heard of. I have had one specialist, an infectious diseases doctor who has had one other patient with some form of aspergillosis. ABPA is the most known diagnosis of Aspergillus spectrum illnesses, that is what comes up when doctors google aspergillus. Because I don't meet all of the criteria I was then put in the "it's complicated" box. I heard it's complicated so often in my 'doctor shopping', that I started to ask for its treatment, hoping it was more effective and permanent than prednisone, anti-fungal therapy, plaquenil, methotrexate, Imuran, numerous antibiotics including taken as a prophylactic until I developed enormous blisters as a reaction after nearly 4 years, and a host of other asthma-based medication options. Still I am unwell. One respiratory specialist told me to move back to Queensland, as I was from here and didn't have any problems prior to leaving. Mind you I had lived in Sydney for 7 years prior without any problems either. No moving to Queensland hasn't restored my health, in fact the humidity here is a precipitant. For the first 3 years of being back in Queensland I couldn't even get access to the anti-fungal treatment that I need, despite numerous trips to the emergency department. The lack of experience and education in this pathogen is astounding given its ubiquity. I am being treated for Fibromyalgia after concluding that I don't have sero-negative rheumatoid arthritis, I spent 2.5 years taking the highest dose of methotrexate I could with no effect on my joint pain. I have had ongoing gastro issues, with 3 gastroscopies revealing all is ok but have developed a mild dysphagia, one day, financially, I will be able to see a Neurologist the dysphagia may be related to the peripheral neuropathy. There was more focus on the amount of prednisolone I have been on for over 7 years now than looking at why I take so much of it. If I had my own provider number I would manage a damn site better than relying on the medical profession who lack

the motivation, insight or care factor to expand their education and mind set. If I sound angry it is because I am, when something like this changes your life so fundamentally and no one is listening as you watch your whole life slip into oblivion it is distressing beyond words. Doctors wonder why I have problems with depression – not being heard doesn't help. My whole career has been problem solving, finding solutions, I have never felt so constrained. I have a GP now who is listening and I am under the Immunology clinic at the Princess Alexandra Hospital in Brisbane, it isn't ideal but until my financial situation can change it is the best I can do.

I have tried all treatment options available, including treatments that have caused permanent injuries such as peripheral neuropathy.

On a day to day basis I am constantly symptomatic, I cannot continue to take very high doses of prednisone because of the long-term side effects, and I take courses of the anti-fungal therapy when I am so unwell I can barely function. It has not been easy to have this prescribed since moving back to Queensland even though I had this for 5 years in Sydney.

The most difficult aspect is getting a diagnosis, made even more difficult by doctors having absolutely no idea, beyond google. I know more about my illness than any doctor, I had to make contact with a Professor Denning in the UK, the world-renowned expert in Aspergillus and Aspergillus associated diseases for some advice. When I can I intend going to see him in the UK, that is how desperate things are.

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

I have had extensive medical testing done especially immunological. I am skin prick test positive to aspergillus, nasal provocation challenge test positive to a very dilute concentration 1:1000 dilute. I have numerous chest CT scans, again these are not interpreted correctly. For example, 2009 chest CT shows parenchymal bands at both lung bases, reported as possible fibrotic scarring. 2010 same parenchymal bands are larger, this was put down to additional scarring from pneumonia the year before. 2011 no parenchymal bands at all, fibrosis does not disappear, I had been on anti-fungal therapy for 18 months at this stage. Radiologists and doctors are looking for large consolidations, not everyone has large consolidations. 2018 Chest CT shows some scarring on lower left lung and pleural bands, I am sure after long term anti-fungal treatment these will vanish too. I cannot afford private specialist care where I can demonstrate what is going on over time until someone finally gets it. In the public health system I see a different trainee doctor every visit to the same clinic and each has their own opinion on what it is.

I saw a thoracic specialist in Sydney who was more progressive in some areas, over time she believed I had also developed multiple chemical sensitivity syndrome but could not formally diagnose this because of its controversial status. The issue with the medical professions lag time in accepting new medical conditions is that it doesn't change one's symptomology or the eventual outcome (ignorance, or non-acceptance is not a cure or a form of treatment). I can no longer tolerate strong smells, chemicals that are innocuous to others literally burn

my airway passages, I can also demonstrate this over and over and over. I have recently been diagnosed with fibromyalgia instead of sero-negative rheumatoid arthritis, after fibromyalgia being excluded quite a few years ago. It is like being on a merry-go-round and not a fun one at that.

I have had a number of hospital admissions in the past 9 years, and emergency department visits too numerous to count. I had an emergency room visit 2 years ago, was discharged with a 'cough', in reality I had a severe pseudomonas A infection. When the medical profession do not understand what is happening with you, you can be treated quite poorly. I am treated for an aspergillus related disease, but do not have a formal diagnosis which is problematic. I recently came across CIRS and mentioned this at my first Immunology clinic consult in June this year, follow up is at the end of September (not an ideal scenario), I noted Dr Shoemaker's comments on his concerns for people who develop CIRS with Aspergillus as the trigger, and with good reason. Most people with some form of aspergillosis have it to one strand, to date I have had infections to 2 different strands. Even more recently I have come across a paper on Dampness and Mould Hypersensitivity Syndrome (DMHS), and have attached this for your interest and consideration. It is some comfort there is acknowledgement of the very real and serious health issues associated with moulds and funguses.

Before becoming unwell, I was a highly paid career professional, in training for my first ultra-marathon and had recently started training for competitive outrigger rowing. My GP was used to seeing me for sports related injuries not for this.

4. Any intersection with other chronic diseases:

As mentioned previously I have been diagnosed formally and informally with fibromyalgia, multiple chemical sensitivity syndrome, peripheral neuropathy, chronic bacterial infections, sicca syndrome, chronic reactivation of Epstein barr virus, bronchitis, sero-negative spondyloarthropy. All of these have developed post initial illness with Aspergillus, with the exception of bronchitis, I had this as a teenager. All of my symptoms are exacerbated by every-day life exposure. There is no family history of immune, auto-immune or respiratory diseases, I recently even tested myself to see if I was related to my family.

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

I am not familiar with any research carried out in Australia on Aspergillus or any other mould related diseases. I would like to see research into mould and fungal based diseases in Australia, I honestly believe the prevalence here is as at least as high as other parts of the world, especially as Australia has one of the highest rates of asthma in the world. It is time for the government and the medical community to open its mind to what is happening in the environments of our changing world, the day air-conditioning replaced open windows was the day moulds and fungi found a potential home.

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

Again, I am not familiar with any biotoxin-related research into illness caused by water damaged buildings, in Australia, the CDC in the United States is lightyears ahead.

7. Any related matters.

I wrote earlier about my struggles to have the air quality tested when I started having respiratory problems in the workplace, and how I had my employment terminated 2 hours after submitting a work cover certificate stipulating the testing had to be carried out. I always believed it was my responsibility to report known and potential work place hazards, and that it was the work places responsibility and duty of care to investigate these reported hazards. If it had been in my home I could have done the testing myself. At that stage I knew nothing about agar plate and the potential to do the tests myself.

The personal and financial cost to me has been enormous, not only have I lost my health, my career and ability to work, I have lost a relationship, friendships, my running, independence and autonomy, the ability to make plans and be consistent.

I am currently trying to overturn a workers' compensation decision due to the changes in the NSW Workers Compensation System. I have exhausted my Superannuation, savings, assets and am at the end of an out of court settlement for a total permanent disability policy on my superannuation.

Solutions I would like to see implemented to prevent mould related illness in Australia. The most obvious changes needed are legal accountability, in the case of workplace contamination problems, they have to be investigated, WHS legislation is to ensure this. Mandatory testing and remediation of heating and cooling systems monthly, this to be in line with water tower testing; research into developing guidelines for effective mould testing and remediation etc. When a worker or tenant reports an issue, it must be mandatory for testing to be carried out within 7 days, not all moulds and fungi will have a smell or be visible.

There needs to be research and the development of guidelines into effective CIRS/DMHS/Aspergillosis diagnosis & treatment; CIRS/DMHS/Aspergillosis training for the Australian medical profession; public awareness campaign of symptoms of mould related illness etc.

No one should have to live with, or experience what I have, and continue to experience daily for over 9.5 years.