

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

Currently I live in Parkes, NSW. I moved to Parkes from the Newcastle area in May 2012 and lived with family until 10 weeks later I found a rental for my partner and myself.

The rental was a semi-detached very old double brick construction with plastered internal walls, very high ceilings, with very rusty roof. It had what appeared timber panelled ceilings, plaster walls and tiled floors throughout. It seemed quite plentiful for my partner and I. It also had a single window in each room with the floor plan of a single hallway, running the full length of the property with 2 bedrooms from front of the home, bathroom and toilet combined, another bedroom used by us as an office, then lounge, through to kitchen and straight out back door onto a rear patio from which where was an outside toilet and also an added room attached to patio with laundry facilities. It was a very cold house in winter and extreme in summer having no insulation. My estimation would be that the home was approximately 100 years old. All wiring ran around the outside of the building if not in the roof cavity.

We moved into the premises on Friday 13<sup>th</sup> July 2012. The exterior areas were very overgrown and no gardens or lawn existed. I set about creating massive gardens and establishing lawns on both the front street verge and rear yard areas. I prided myself in keeping a clean home and loved the fact that it was tiled throughout, making for easy cleaning. The very front room of the house, being a bedroom, facing due south had a single opening window to the street. When we first moved in about ¼ of the ceiling on the south/eastern corner had black mold on it. As it was winter I noticed that in that bedroom the window would become wet with moisture and you could place your hand on the eastern wall and it would come away wet. In spite of the fact that this room was never closed and had 2 high ventilation vents which were not covered over it always seemed damp. I used this room as a guest bedroom, with a portable cot, double bed, double wardrobe, and toy box.

At this stage of moving in I had commenced creating all of these gardens as I was unemployed and aged 56 at that time (soon to be 58). I was a very fit and strong woman who in creating these gardens moved 2 trailer loads (8ft x 5ft) of bush rock, single handed from the back yard to the side garden. The majority of these rocks weights 30kg, some even weighing 50kg. I am 5ft ½' or 155cm and at that time weight a spritely 85kg. So I was already 30kg overweight but still very fit. I had no illness apart from kidney stones in 2012, gall bladder removal in around 2006, and an umbilical hernia repair in 1995. I was on no medications and as I had worked in the health industry with the previous 20 years I regularly had a medical done as well as flu vaccinations each year.

So shortly after moving into these premises, I began babysitting my newborn granddaughter, the joy of my life. I also travelled each Friday afternoon from Parkes to Orange (1hr 15mins) to look after my elderly mother (mid 80yo) and stayed with her on Friday and Saturday nights. I paid her bills, cleaned, cooked, did shopping for her as well as her gardening as she was immobile. She had carers come in 3 times a day as well as 2 cleaners, so my time with her was purely for pleasure, and I love doing her gardening as that was her joy.

So by August 2012 I was babysitting a newborn full-time, keeping my own house, lots of physical gardening, and caring for my elderly mum. Life was great. I loved the township and starting making new friends and meeting people. I had lovely elderly neighbours who would often pop in for a chat and to check out my gardens, sharing advice and plants. These 2 ladies were at the time 87 and 92 and very fit. They went walking every day and would stop in for a chat on their walk.

Fast forward from August 2012 to March 2013. I gained employment as a medical receptionist in our local Imaging Centre. It was 3 days per week. So I worked Monday, Tuesday, Wednesday. Babysat my granddaughter Thursday 7am-5.30pm and Friday 7am-7pm(who was 1yo by this time). Travelled to my mums for Friday and Saturday and returned home Sunday to do my regular housecleaning, gardening, washing etc. I lived a busy lifestyle and was loving it.

Work was busy for the next 9 months or so and I relished it. I was in a role of temp Practice Manager and we had many locums until towards the end of 2013, when a permanent Radiographer was appointed who took over this role. One week before Christmas 2013 I developed a rash on my chest and took myself straight to the doctors, who confirmed it was shingles and treatment me with antiviral medications. I had 2 weeks off work due to closure as well as being contagious, and didn't have my granddaughter to prevent her from getting chicken pox at such a young age. By this stage the mold in the front bedroom (next to the master bedroom) had spread to  $\frac{3}{4}$  of the ceiling and was also appearing in the south-eastern corner of our bedroom.

In March 2014 I got my able-bodied 28yo daughter to clean it all for me with Selley Rid Mold. No protective clothing was worn (except a scarf tied around her face for fumes) and I was in the room with she cleaned advising her if she missed any spots. We simply covered the furniture with sheets to protect from any dropage. We opened up doors and windows to clear the air of the fumes. The ceilings came up beautifully. No mold to be seen. I believe that was the beginning of the end of my health.

Some weeks later, I remember the day so well, it was Easter Monday in 2014 and I was out in my back garden weeding. I felt like something had bitten the palm of my left hand (on the right base). 3 small pimple-like eruptions occurred. I didn't think much of it at the time (I was renowned for gardening minus gloves and shoes). Tuesday morning I got up late with a headache (rare for me. Am lucky if I have had

4 headaches in my life-time), my palm is red and itchy, I had nausea,(similar to morning sickness nausea when you cant stand the smell of rotten food, or raw meat and anything that smells strange) and a very tinny taste in my mouth. I couldn't stand that smell or taste of coffee (equally unusual for me). And an overwhelming feeling of tiredness, so tired, felt exhausted.

I gained an appointment to see my GP, my thinking was that I was bitten on the hand by something poisonous, namely a white-tail spider, but he assured me that he didn't believe it was. He ran blood tests and they come back with abnormal results for the following (keeping in mind that I always had regular tests due to working in the health industry and they were always normal)

1 Underactive thyroid

2 Anaemic

3 High blood sugar levels

4 High cholesterol

5 My BP went from (normal 135/85) to 165/92.

6 Enlarged lymph nodes on left side of neck.

His advice was to treat it as viral and we would check the result in 4 weeks. 4 weeks later my results were all normal, with fluctuations in my BP. BUT my symptoms were all there and increasing. I was feeling fatigued, very fatigued. I kept going back to my GP every 2-3 weeks showing him my hand which had now increased in these bite marks to about 4 times the area and they looked infected. He gave me antibiotics which didn't help, then cortisone creams, then antifungal creams. In frustration after some 8 months of repeatedly going back I asked for a referral to a specialist who may be able to give me some answers as to why I was feeling so unwell all the time.

Within 4 weeks of that initial outbreak on my hand I became very fatigued. So much so that I had to stop my visit to my mum and go only once a month and be driven there by my partner as I was concerned about falling ill whilst driving. I obtained a Glucose tester and my blood sugars would drop to 2.9 and I would develop the shakes, thirst and need an urgent sugar hit. This started happening from the start as well and I requested an appointment with the Diabetes Educator who advised (along with the GP) due to all of the blood tests, that it was not diabetes, and yet this happened at least twice a week.

I went to see a Rheumatologist in Dubbo toward the end of 2014 to get answers. He informed me that at some state I had had glandular fever, that my thyroid was underactive and that I had some form of Auto-Immune disease that could not be diagnosed at that stage. He said that my inflammation markers were hugely

elevated and that my blood T-cells panel was abnormal. I went back to my GP to be told "There is nothing wrong with you. You simply have depression". My response to his remark was "It's no wonder I have depression. I am sick and you are not listening to me". With that I left his office, and practice never to return there. The sad fact was that you could see that I was unwell as he and his offsider often worked with me in the imaging clinic where they would perform the injections of contrast for CTs.

With each week I became sicker with loss of strength and new symptoms, such as intolerance to heat and bright light. By the beginning of 2015, some 10 months after the initial symptoms I could tolerate it no more. So on 24 January 2014 I left my job. I was just too sick to even drag myself out of bed. They knew I had been sick for months and so let me leave without working my notice. I finished at 3.30 on the Friday afternoon and went home to bed. I SLEPT from 4pm Friday to 2pm Sunday, early 48 hours solid. I was exhausted. From then on it was a downhill slide. I became bedridden. Could not do any housework at all, my gardens pretty much died and I couldn't even bring myself out to water. I eventually only showered every 3 to 4 days as the simple task was exhausting. I never left the house unless to go to the doctors. My elderly neighbours both in their late 80s and 90s would come to check on me. I was a 60yo woman in a 90 year olds body. I couldn't wait until they put me in a nursing home. And I still had no idea what was making me sick.

I stayed in bed for almost 2 years in that room with the mold infested ceiling which was infiltrating my body. I didn't know, that the worst thing you can do with mold is clean it. That was until I was on facebook and happened upon a story about a woman who had very similar symptoms to me and she suggested it was mold. So I spend about 3 months researching everything from within my bed about mold.

By this time we are looking at towards to end of 2016. I have been off work nearly 2 years, in bed most of it, and making a decision to move out of this moldy house. The rash on my left hand had moved to my right hand as well and both hands were greatly inflamed. So were the soles of both of my feet. It starts with 3 pimples, they burst, then skin dies and they peel. 2 weeks later a new outbreak with 3 more pimples, they burst, then the skin dies. That process repeated itself for 3 years at this stage. My feet were so bad that I could hardly walk. My once very bright brain was craving information, but even if you ready something 4 times only a few key words stuck.

My the time I moved house on 26<sup>th</sup> January 2017 I had been living in that moldy environment from July 2012. So lets even it out to say 4 ½ years. 2 of those years bedridden. Not able to work, not able to clean, no money as on the dole you only get about \$580/fortnight of which half goes to rent/electricity. So tried all sort of supplements and more specialists but still no answers. The closest I even got to a formal diagnosis was "oh you have an allergy to mold". This same GP was

convinced that the rash on the soles of my feet was fungal, so more expense of creams. But nothing worked.

AMAZING 2 weeks after I moved out of the moldy premises the rash was completely gone!!!! After having it on 2 hands and 2 feet for 3 years and no treatment helping, it was GONE. That was enough to convince me that it was mold definitely that caused my illness. Doctors have no idea about toxic mold or CIRS. They treat it like it's all in your head.

Do you honestly think I would live my life this way when life was so great. I was living in a small country town, friendly people, close to family, with a brand new granddaughter, making new friends, had a brilliant job and enjoying my hobbies

AND EXCHANGE IT FOR

A gain of 40kg

Loss of employment

Max out a credit card

Go from earning \$1200/wk to \$270/wk

No more housekeeping

No cooking

No cleaning

No self-pride

Feeling nauseated all the time

Cant tolerate heat or bright light

No being able to drink coffee anymore (just try that one on if you were like me and loved your coffee)

Having to be badgered by doctors who literally have NO IDEA.

Suffering depression as you cant get answers

People not wanting to see you because you've becoming a boring full-of-it moldy person who simply is no fun to be around.

Always sleeping, or too tired to venture anywhere.

Now the incontinence from the excessive 70kg that my poor body carries around.

I reckon when you read the part about no cleaning or cooking or housework, you thought (be it all so briefly) that I could live with that. Well when you are like me, 62 about to turn 63 and all in your life that you get excited for is to go into a nursing home at aged 67, when I can get the Age Pension, so that somebody can provide me with 3 meals a day, shower me, and wash my clothes. Wouldn't that be wonderful!!! Isn't it sad that to think 4 short years ago I had everything to live for and life was exciting and exhilarating. My health was wonderful and life was good. Yes I would love to be able to wash up and clean like I used to and not spend 2 days in bed as a result of a little exertion.

My whole journey I have not asked for any sympathy but understanding. I do believe that CIRS today will be like Asbestos was in the 70s. It just takes some good people out there to take it seriously and do something about it.

Many thanks for taking the time to read my submission