

Dear Sir or Madam:

Thank you for undertaking this much-needed inquiry. I would be most grateful for the opportunity to give evidence.

I wanted to put in a submission in my capacity as someone who has largely recovered from biotoxin-related illness, and who does not have a vested financial interest.

Background

I first became ill with biotoxin-related illness when I moved into a house in the Northern Rivers of New South Wales.

The day I moved into the house, I recall thinking "I am not sure I can live here" and I felt overwhelmingly sick sitting in my own living room.

I could not identify what the cause was at that time. It did not occur to me that it could be water damage and I knew little if anything about CIRS or mould's affect on health.

On the day I moved in my symptoms included chronic insomnia (waking every few hours), chronic fatigue (inability to carry shopping bags, complete basic tasks such as vacuum), impaired short-term memory (could not read as I could not remember what I had just read, could not add numbers, could not speak easily in a full sentence), and chronic gastro-intestinal and sinus issue.

I found myself not only unable to work but unable to take care of myself. My energy consisted of no more than about 5 minutes of energy an hour. I would have to sit down and rest after for example cleaning my teeth. The effect of this illness has been to rob me of three years of my life.

Problem 1: Poorly Maintained Rental Properties

The building I moved into had been rented out for over 10 years and not maintained properly. The house has never been flooded (it is on a top of a hill) but simply due to poor maintenance which I believe to be a common theme in this area.

Fortunately, the house is owned by my parents, so I could remediate it. Others who lease houses are not so fortunate.

Whilst there are other causes of CIRS (including polluted water) I would like to emphasize that CIRS is primarily an illness due to poor building or maintenance practices.

Whilst medical interventions are important, it is my view, that quicker more effective interventions can be obtained through addressing building and leasing standards.

Problem 2: Poor Building Inspection Standards

I did not know the building had extensive water damage when I moved in because the building inspection was not worth the paper it was written on.

Specifically, holes in the tin roof had not been repaired, and the internal gutters had rotted some of the roof. Had the building inspector actually inspected the roof this would have been self-evident.

As a result, the insulation bats were moldy which I now believe was the primary issue. On the day the roof was removed I felt significantly better.

In addition, as a result of poor maintenance of the roof (a non-roof non-water proof silicone had been used to repair the seal around a pipe) when it rained (as it tends to do in the sub-tropics) water ran down the inside wall of the kitchen and there was bubbling with an obvious previous poor repair. Once again not identified by the building inspector.

Furthermore, in one of the bathrooms, there was no shower membrane, there was a cracked tile, and extensive black mold on the abutting wall. The previous owner had shut off the tap with silicone (so there was no running water) but the leak was actually coming from the shower not the tap.

The smell in the adjoining room of mould was severe. If I went into the room I would break out in a rash so I kept the door shut until it could be repaired.

All of this should have been very evident to a building inspector but none of it was mentioned on the building inspection report. I actually wonder if he event got out of this car.

We would not have purchased this house had we have known the extent of the damage. Indeed, we purchased this house, over another, believing it needed little work.

In my opinion, building inspections should expressly cover water damage and this should not be able to be opted out.

Problem 3: Poor Building Standards

On moving in we did some minor planned building works.

At the time we believed the only mold issue was with the bathroom and we sought to address this with the building renovations.

I made it clear to the builder that I was sensitive to mould and when repairing the bathroom that I wanted it done properly.

He called in a waterproofing expert who concluded that the water was coming from the cracked tile and that it would be sufficient just to seal the tile. The conclusion was reached on a "gut feel" rather than using a water meter to identify the leak.

After identifying I had CIRS, I hired a building biologist who identified that the leak was not coming from the tile and identified the source. They used a water meter to identify the source of the leak something I now would have expected the builder to do.

As the building works were under a contract, and the builder refused to remediate the fault, fair-trading became involved, and sent out a building inspector. I had the building biologist at the site meeting.

The building inspector concluded that the builder had not done the right thing by me as he had not done sufficient investigation and the solution he identified was only temporary at best, which the builder had failed to notify me.

He ruled that the builder would have to pay for all labor and we would have to pay for all materials to gut the bathroom, remove all walls with mold on them, redo the water membrane, and ensure that the work was signed off by a mold remediator.

Although this was a good outcome, had the builder done the job right, I would have been in a mold-free house six to nine months earlier.

Problem 4: Non-regulation of Remediators

From there, the next problem was identifying a mold remediator, who could help remediate the house.

Most of the remediator had their start in commercial cleaning and have done little if any training. They are not licensed. Most are cowboys. None can do the job from beginning to end.

They all recommend different ways of remediating the house, the amounts involved are extremely large numbers, and few if any are prepared to give guarantees.

One provider refused to accept my building biologist report and wanted \$1,000 to redo it themselves.

Another provider wanted to install a \$10,000 extraction unit in the room with mould but could not tell me how to remediate the house.

Another provider, who had not seen the house, wanted to install an air-filtration system, at the cost of around \$10,000. This appeared to be a pet project and there were no studies. He also wanted to drill holes in the wall and send it off to a lab for testing when it was simply cheaper to remove the wall.

All of these providers would also not guarantee their work.

In the end, I called Mould Lab (who do the testing in Australia) and spoke to the owner. I asked him who was getting the lowest scores on retesting and he gave me a name of a company.

That company employs ozone treatment with cleaning. They also guarantee their work, and provide an ERMI afterwards. It cost \$7,000 to clean the house.

In my opinion, like asbestos, there should be clear standards for dealing with water-damaged buildings, the provider should be licensed, the work guaranteed, and if the provider fails to repeatedly provide a clean ERMI on completion, they should lose their license.

I conservatively estimate that we spent close to \$50,000 remediating the house. If this was done by a builder, this would require a contract administered by fair trading. In contrast, anyone can remediate a house, with little to no protection for the consumer. Furthermore, consumers are sick, and vulnerable.

I will now address the specific terms of reference:

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

My water-damaged buildings were located in the Northern Rivers NSW where there is a sub-tropical climate with periods of torrential rains and local flooding. I believe that the damage to my building was due to poor maintenance standards when leased out.

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

I cannot speak to the prevalence of CIRS other than to say that many consumers even those with chronic illnesses are simply unaware of the effect that mold has on their health or perceive it as something too overwhelming to deal with.

The treatment available to me in Australia has been limited. I have had to turn to America for testing and treatment.

Doctors and immunologists are poorly trained in this area.

My immunologist, who is well regarded, and who has been most helpful in other matters, was unaware of the research out of the USA, and simply wanted to do an allergy test to see if I was allergic to mold. This was pointless.

I also previously saw an immunologist involved with the chronic fatigue trials at Griffiths University. This research is based on a certain gene cluster being switched on by environmental factors.

I have that gene cluster, and after I had improved with treatment for CIRS, he refused to look at the American studies, and told me "it was not that easy". I stopped seeing him, as it was apparent to me that he had a vested interest in me having CFS and was not open to me being better.

I believe the CIRS research enhances (rather than detracts) from the CIRS work at Griffiths University.

Fortunately, I identified the ONE doctor in Australia at that time (Dr. Sandeep Gupta) that had been trained in chronic inflammatory response. I had to travel to the Sunshine Coast to see him. His costs are largely not covered by Medicare.

I could not tolerate the medication used by Dr. Gupta and the Shoemaker protocol and had to identify other alternatives.

Twelve months ago, I consulted an American doctor, who provided me with an alternative (non-medication) protocol to detoxify the mold. I easily tolerated this treatment and my health dramatically improved.

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

Accessing some of the blood panels to diagnose and monitor my treatment has had to be done via Quest labs from America.

This involves me to travel to the Sunshine Coast and the cost of the testing is around \$1,500 inclusive of pathology fees.

I understand that these panels can also be performed privately via Nutripath in Australia but the reliability of this testing is inconsistent with the American Lab.

We need reliable testing (that is consistent with Quest labs) available to us on Medicare via a reputable Australian lab. Without it, we have no way of easily monitoring our progress, and what if anything is working.

4. **Any intersection with other chronic diseases.**

I was diagnosed with chronic fatigue syndrome and acquired brain impairment at the time that I was diagnosed with CIRS. Treatment for CIRS has reversed my CFS symptoms.

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

Others are better suited to answer this question.

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

Others are better suited to answer this question.

7. **Any related matters.**

It is tempting to see this as a medical problem.

I would simply state that this problem, like asbestos, is primarily a building standards problem.

It is well recognized that due to political interests it can take a generation for the medical profession to recognize new concepts.

One would hope that the building industry would be more responsive. In my opinion, there is an urgent need to develop standard around the building including:

- Rental/leasing standards,
- Buildings inspections reports,
- Standards for mediating water-damaged buildings, and
- Registration of those remediating mold in buildings.

I would welcome the opportunity to give further evidence.

with thanks