

Submission to Parliamentary Inquiry into CIRS

Term of Reference 1

The prevalence & geographic distribution of biotoxin-related illnesses in Australia, particularly related to water-damaged buildings

The following is an account of 2 residents of a retirement village who discovered they were living in a water-damaged villa, with high levels of mould contamination which caused a variety of health problems.

1. The water-damaged building

- Location: Tranquil Waters Retirement Village, Villa 55 (waterfront), Victoria Point, Queensland (apparently built on reclaimed land)
- The water problem: At the residents' request and expense, the company Australian Leak Detection conducted thermal imaging which revealed moisture in the walls of the study (other walls of the villa were not tested, so the full extent of the problem was not known). Further investigation by the technician revealed that the windows were not sealed on the outside of the villa (in his view, probably from the time of construction), allowing entry of water into the wall cavity every time it rained. This was true of all the windows in the villa (seemingly a building defect).
- The mould problem: At the residents' request and expense, the company New Life Restorations took air samples which were sent to MouldLab in NSW for analysis. The result for the air sample taken from the kitchen was 16213/m³ of airborne mould spores, rated as 'Very High', with the recommendation that "all occupants should be excluded". The main mould detected was 'Aspergillus/Penicillium'. [Refer to mould result Appendix A]
- Dealing with the mould problem: There was severe mould contamination – mould growing on items of furniture, clothing, rugs, kitchen utensils, pantry items & food, clothing & shoes, books & photos, vertical blinds, etc. A lot of these items could not be cleaned, so had to be discarded. The residents vacated the property after 10 months (residence May 2014 – March 2015). Some belongings could be kept after a 3-week remediation process involving an industrial dehumidifier and a HEPA filtration unit in a closed-off section of the villa.

(The above residents believe that Villa 55 was not the only mould-affected residence in the retirement village, as the source of the problem seemed to be a building defect.)

2. Health experience of residents

* The 2 residents started to experience health problems after a few months living in the above property. (These 2 residents will be termed as "Resident 1" and "Resident 2" throughout this submission). These health problems (not pre-existent) were:-

Resident 1: Development of Ground Glass Opacities in lungs, high aspergillus level in blood

Resident 2: Extensive fungal infection in throat and mouth with symptoms of throat irritation, coughing, respiratory problems and tearing which continue today (3+ years later)

Terms of Reference 2 and 3

2 The prevalence of CIRS or biotoxin related illness in Australian patients & the treatment available to them

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

The 2 residents (of the previously mentioned villa) believed they had health problems as a result of living in mould contamination (CIRS), but were unable to find medical help that could provide an accurate diagnosis, or appropriate treatment. The following were the steps taken in seeking medical help:-

- 1 Online research to learn about 'mould illness', CIRS & treatment - the findings were:-
 - a. Dr Ritchie Shoemaker in US has done extensive research into CIRS, published the book 'Surviving Mold', and treated hundreds of patients over many years. He trains medical practitioners in his protocol/treatment process for victims of mould.
 - b. 2 of those trainees (of Dr Shoemaker above) were Queensland medical practitioners (referred to as Doctor A and Doctor B in this submission).
 - c. In Australia there seems to be very little knowledge amongst the medical community of CIRS, biotoxin illness and the dangers to health of mould exposure.
- 2 Consultation with local GP's – results were :- requesting of blood tests; referral to a respiratory physician for residents 1 and 2; referral to an ENT specialist for resident 2.
- 3 Consultation with specialists:

Resident 1 Consultations with a respiratory physician at Greenslopes Private Hospital:

- This physician seemed to acknowledge originally that the Ground Glass Opacities (GGO's) in the lungs were associated with exposure to aspergillus, but later said there was no definite connection.
- Process followed of monitoring the lung nodules through CT chest scan annually to note any changes and monitoring aspergillus level in blood with S-Aspergillus serol test (IgG) annually
- Outcome: the nature and cause of the GGO's were not ascertained, and no treatment was given.

Resident 2

- a. Consultation with the same respiratory physician at Greenslopes Private Hospital
A bronchoscopy revealed areas of oropharyngeal candida which was treated with Diflucan (fluconazole) of very high strength for a period of 6+ months. There was no further investigation or treatment after this.
- b. Consultation with an ENT specialist at Greenslopes Private Hospital yielded no adequate investigation and no diagnosis.

4 Contact with the only 2 (as far as is known) Queensland GP's with training in, and knowledge of, CIRS:-

* Doctor A

- After the residents applied to this doctor for assessment, he refused to treat them as they would not agree to extra lifestyle activities (e.g. "Learn and practise relaxation, emotional release or stress release techniques if required"; "Perform regular detox techniques e.g. saunas, enemas ... "; "Take multiple nutritional supplements each day") as part of the treatment process. (These examples are quoted from the questionnaire that formed part of the New Patient Enquiry document sent by Doctor A)

- Doctor A sent an email stating that the residents were not compatible with him and his treatment, and inviting them to come back to him when they were prepared to undertake all activities required

* Doctor B

The residents contacted this doctor who advised he could help them with suspected biotoxin illness after mould exposure. The process was as follows:-

- nutritional supplements and large quantities of Vitamin D were recommended, but this proved to be very expensive, with no obvious benefits

- nasal swabs were sent to the States, testing for MARCoNS (cost per person \$220); Resident 1 & Resident 2 tested positive for MARCoNS; treatment of 3 courses of BEG nasal spray, of some help, was given

("MARCoNS (Multiple Antibiotic Resistant Coagulase Negative Staphylococci) is an antibiotic resistant staph that resides deep in the nasal passage of 80% of people with low MSH (Melanocyte-Stimulating Hormone), those suffering from Biotoxin Illness and other chronic inflammatory illnesses CIRS (Chronic Inflammatory Response Syndrome) ... "

-quoted from Microbiology Dx website: www.dlmcharlie.wixsite.com/dlmmicro/marcons-testing)

- a vast number of pathology tests with S&N were ordered (cost per person \$700+)

- specialised blood tests were ordered (through QML Sunshine Coast), with specimens sent to Quest Diagnostics in the United States (cost per person \$980 + \$90 carrier)

Specialised blood
tests requested of
Quest Diagnostics US

- * Human Transforming Growth Factor Beta 1
- * Vascular Endothelial Growth Factor (VEGF)
- * C3A Desarg Fragment
- * C4A level
- * Alpha Melanocyte Stimulating Hormone (Alpha MSH)

The results of the blood tests were:-

Resident 1 - Beta 1 in range; VEGF, C3A, C4A, Alpha MSH all out of range results (C4A very high)

Resident 2 - C4A very high result; all other results in normal range

Summary of experience in seeking diagnosis and treatment

*It was found that GP's and specialists had very little comprehension of how mould can affect health, what pathology tests can be conducted to ascertain the presence and extent of biotoxin illness, and what steps need to be taken to treat it. The reaction to the problem seemed to be that it was 'too hard'.

* Although the residents had contact with 2 doctors who had some knowledge of CIRS, it was found that:- in one case, assessment and treatment were withheld on the basis of the patients' reluctance to be involved in alternative, non-medical activities; in the other case, although the doctor ordered a huge range of expensive blood tests, there was no follow up re the results of those tests, and no treatment/treatment plan offered.

* The residents were unable to get a concrete diagnosis with regard to CIRS, and therefore, continue to experience the same symptoms now, over 3 years later.

Term of Reference 6

Research into biotoxin-related illness caused from water-damaged buildings

The aforementioned residents would like to submit the following opinions and suggestions:-

1. Concerted **scientific research** into this health issue needs to be carried out in Australia; in the process a lot can be learned from Dr Ritchie Shoemaker's research and practice in the States.
2. At the moment, it seems that knowledge of, and interest in, biotoxin-related illness from mould exposure, seems to be mainly in the realm of alternative/holistic medicine. It also needs to be taken up by **mainstream medicine**, with medical practitioners specialising in this area.
3. Relevant **pathology tests need to be done in Australia**, instead of having specimens sent to the US for testing (huge costs involved in this, and a longer time process).
4. Water-damaged buildings are a common problem, whether caused by a rain event, flooding, leaking pipes or building defects. Humidity also contributes to mould growth in Queensland and other tropical areas. **Building regulations** should ensure that buildings are as 'weather-proof' as possible to prevent water ingress during rain events.
5. There needs to be **community education** on the health problems that can be caused by mould, how to prevent mould growth in homes and other buildings, how to deal with existing mould problems, and how to effectively eradicate mould.
6. The Public Housing Departments of State Governments, and the Real Estate Industry, already recognise the problem of water-damaged buildings and mould, and have strict regulations preventing the sale of, or lease of, affected buildings. The same regulations should apply to **Retirement Villages**. The residents' experience of a water-damaged building, and exposure to mould, was in a retirement village.