

The following form letter was received from six individuals with minor variation to content.

## **Submission Guide - Parliamentary Inquiry into Biotoxin-related Illnesses in Australia**

**Note:** Family members assisting mould illness patients can simply write a submission based on what they witnessed the patient going through based on this guide. Children can write a more simple submission on the answers that parents feel are most relevant for them.

**Due Date:** Submissions must be uploaded by **Thursday 2<sup>nd</sup> August 2018**. To upload your submission, go to this

webpage: [https://www.aph.gov.au/Parliamentary\\_Business/Committees/House/Health\\_Aged\\_Care\\_and\\_Sport/BiotoxinIllnesses](https://www.aph.gov.au/Parliamentary_Business/Committees/House/Health_Aged_Care_and_Sport/BiotoxinIllnesses)

**Submission Public or Private:** You will be given the opportunity to make your submission either public (with your name either published, name confidential, name and other parts of your submission confidential), or to make your submission private. If you make important information in your submission public, it will enable the public to read your story & better understand mould illness, plus also enable us all to gather some statistics on various aspects of the mould issue.

### **Terms of Reference - please respond to these in your submission:**

- 1. The prevalence and geographic distribution of biotoxin-related illnesses in Australia, particularly related to water-damaged buildings:**
  - Which suburb and state you currently live
  - Which suburb and state the water damaged building that initially affected your health is located.
  - Was the water damaged building a home, workplace, school, community centre, hospital etc.?
  - What was the nature of the water damage, and was the mould visible or not visible?
  - Was your health initially affected by a contaminated heating or cooling system in the building?
  - How many additional family members, colleagues, or friends were affected by this water damaged building, that you are aware of?
  - Please list the suburb and state of any other water damaged buildings (or contaminated heating & cooling systems) that also affect your health eg. shops, community centres, hospitals, offices etc.
- 2. The prevalence of Chronic Inflammatory Response Syndrome (CIRS) or biotoxin related illness in Australian patients and the treatment available to them:**
  - The Treatment options presented to me by Doctors or other Health Professionals
  - The Treatments I chose to undertake
  - Effectiveness of the treatments undertaken
- 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 Medical Tests I had done and the results of those tests.
- Other non medical tests I had done - Eg. the Visual Contrast Sensitivity (VCS) test etc. - and the results of those tests.
- My symptoms, health condition and abilities after I developed biotoxin related illness, compared with my symptoms, health condition and abilities before I became unwell.
- How many Doctors or Health Professionals I consulted trying to ascertain the cause of my symptoms
- Number of hospital admissions if applicable.
- The attitude of the Doctors, Health Professionals, hospital staff towards me when I told them I had mould related illness (helpful/unhelpful/sceptical/abusive).
- How long it took me to get a diagnosis of Chronic Inflammatory Response Syndrome (Mould related biotoxin illness).

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

- Other chronic illnesses I was diagnosed with in addition to Mould related illness, eg. Tick borne infections (Borrelia, Bartonella etc.), genetic Methylation issues, cancer, other chronic infections, eg. Epstein Barr Virus etc.
- Were these illnesses already present before you developed mould related illness or did they develop afterwards? (if known)
- Are the symptoms of these other illnesses exacerbated by mould exposure?

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

- Research (and publications) that you know of that has occurred in Australia
- Research that you would like to see occur in Australia

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

- Research that you know of that has occurred in Australia
- Research that you would like to see occur in Australia

**7. Any related matters.**

- Actions I took to get the cause of the water damage in the property fixed, and the mould tested and remediated in the contaminated home/workplace/school.  
Eg. Contacting the real estate agent, builder, tradesperson, lawyer, Tenancy Tribunal, supervisor at workplace etc. The difficulty/ease of getting effective action.  
  
Eg. Contacting an Indoor Environmental Professional Inspector or Mould Remediator.  
Eg. Doing an ERMI or HERTSMI-2 test, or agar plate test etc. myself  
The effectiveness/ineffectiveness of the testing and remediation process.
- The personal and financial cost of this illness for me (loss of income, superannuation, independence, career, social life, impact on family & friends)
- Solutions I would like to see implemented to prevent mould related illness in Australia.  
Eg. Changes in building codes; legal accountability of poor construction & building maintenance causing water damage & mould illness; regulation of water damage restoration and mould remediation in buildings; mandatory remediation of heating and

cooling systems a certain number of times per year; research into developing guidelines for effective mould testing and remediation etc.

- Solutions I would like to see implemented to ensure effective treatment of mould related illness in Australia.  
Eg. Research into effective CIRS diagnosis & treatment; CIRS training for the Australian medical profession; public awareness campaign of symptoms of mould related illness etc.