

PARLIAMENT OF THE COMMONWEALTH OF AUSTRALIA

# **Report on the Inquiry into Biotoxin-related Illnesses in Australia**

House of Representatives Standing Committee on Health, Aged Care and  
Sport

October 2018  
CANBERRA

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ISBN 978-1-74366-850-4 (Printed Version)

ISBN 978-1-74366-851-1 (HTML Version)

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# Chair's Foreword

Indoor mould growth is a common problem in homes and workplaces which is usually easy to treat, and generally does not impact on human health. In some cases, human contact with mould can cause health issues, such as worsening asthma symptoms, an allergic response, and (in rare cases) an infection.

In addition to these health effects, the Committee received evidence that buildings that have been exposed to water damage (and subsequently experienced high levels of mould and dampness) may contribute to ill health in susceptible individuals. Health effects described by inquiry participants were varied, often debilitating, and included cognitive and physical symptoms.

The link between water damaged buildings and a range of health effects has been termed *Chronic Inflammatory Response Syndrome* (CIRS). There is consensus that there are people who suffer from a range of complex symptoms that are debilitating, difficult to diagnose and treat effectively. For these people, being unable to obtain a definitive diagnosis and consequently recover from conditions often ascribed to CIRS can have a significant and ongoing impact on their quality of life.

The Committee has put forward recommendations aimed at supporting medical professionals to identify, diagnose, treat, and/or support patients with complex and/or unexplained conditions such as CIRS. Clinical guidelines, outlining a clear path for medical practitioners to follow, could assist in this regard. Guidelines may also ensure patients receive adequate support from the first medical professional they encounter, and reduce the incidence of 'doctor shopping' and the potential for possible exploitation of vulnerable individuals.

In addition to investigating the medical process of identifying and treating CIRS-like syndromes, the Committee received information about the mould testing and remediation industries. In particular, the Committee found that greater

oversight of these industries and the methods used for testing and remediation is needed to ensure consistency of standard and advice.

The Committee also considered that tenants of rental properties should be provided with information regarding any history of mould or water damage to a property before signing a tenancy agreement. This would serve to ensure potential renters can make an informed decision about where they choose to live.

I would like to extend the Committee's thanks to the organisations, agencies, and individuals who participated in this inquiry by providing submissions and attending public hearings. In particular, I would like to thank the many individuals who provided personal accounts of their symptoms and experiences, or those of a friend or family member. I would also like to thank my Committee colleagues for their contribution to this inquiry.

**Mr Trent Zimmerman MP**  
**Chair**

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# Members

## *Chair*

Mr Trent Zimmerman MP

## *Deputy Chair*

Mr Steve Georganas MP

## *Members*

Hon Damian Drum MP (from 10.09.18)

Dr Mike Freeland MP

Mr Andrew Laming MP

Ms Michelle Landry MP (until 26.08.18)

Mrs Lucy Wicks MP

Mr Tim Wilson MP

Mr Tony Zappia MP





# Committee Secretariat

Ms Stephanie Mikac, Secretary

Ms Caitlin Cahill, Inquiry Secretary (from 18.08.18)

Ms Aleshia Westgate, Inquiry Secretary (until 17.08.18)

Ms Emma Knezevic, Senior Research Officer (from 13.08.18)

Mr Raqeeb Bhuyan, Research Officer (from 21.08.18)

Ms Carissa Skinner, Office Manager



# Terms of Reference

The Standing Committee on Health, Aged Care and Sport will inquire into and report by 21 October 2018 on:

1. The prevalence and geographic distribution of biotoxin-related illnesses in Australia, particularly related to water-damaged buildings;
2. The prevalence of Chronic Inflammatory Response Syndrome (CIRS) or biotoxin-related illness in Australian patients and 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;
4. Any intersection with other chronic diseases;
5. Investment in contemporary Australian research to discover and provide evidence of CIRS as a chronic, multisystem disease;
6. Research into biotoxin-related illness caused from water damaged buildings; and
7. Any related matters.



# Abbreviations

ABCB	Australian Building Codes Board
ACIIDS	Australian Chronic Infectious and Inflammatory Disease Society
ACNEM	Australasian College of Nutritional and Environmental Medicine
ACT	Australian Capital Territory
AIMA	Australasian Integrative Medicine Association
AIOH	Australian Institute of Occupational Hygienists
ASBB	Australasian Society of Building Biologists
CFS	Chronic Fatigue Syndrome
CIRS	Chronic Inflammatory Response Syndrome
DAS	Ducted Air Solutions
EPA	Environmental Protection Agency
ERMI	Environmental Relative Mouldiness Index
GP	General Practitioner
HERTSMI-2	Health Effects Roster of Type of Specific Formers of Mycotoxins and Inflammagens – 2 <sup>nd</sup> Version
IAQA	Indoor Air Quality Association
MARCoNS	Multiple Antibiotic Resistant Coagulate Negative Staphylococci
ME	Myalgic Encephalomyelitis
MRI	Magnetic Resonance Imaging
NATO	National Association of Tenant Organisations

NSW	New South Wales
NT	Northern Territory
PBS	Pharmaceutical Benefits Scheme
RACP	Royal Australasian College of Physicians
REINSW	Real Estate Institute of New South Wales
SA	South Australia
TMSA	Toxic Mould Support Australia
USA	United States of America
WA	Western Australia
WHO	World Health Organization

# List of Recommendations

## **Recommendation 1**

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2.91 The Committee recommends that the Department of Health produce and publish in the short term a fact sheet, and in the medium term undertake further research on:

- the potential health effects of exposure to damp and mould;
- the prevalence of dampness and mould in the built environment; and
- advice on the prevention and removal of mould.

## **Recommendation 2**

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2.92 The Committee recommends that the Australian Government work with the states and territories to conduct further research into, and develop standards and/or accreditation requirements for the mould testing and remediation industries, which should include consideration of:

- the most effective methods of testing and remediation of buildings affected by mould and/or moisture;
- appropriate accreditation requirements for professionals working in these fields; and
- options for greater regulatory oversight of these industries.

### **Recommendation 3**

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2.93 The Committee recommends that the Australian Government work with the states and territories to ensure that tenants in rental properties, aged care facilities, and community, social and public housing are provided with timely information about disclosure and rectification of any previous or existing mould and/or water damage issues in a property before entering into a residential leasing agreement.

### **Recommendation 4**

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2.94 The Committee recommends that the Australian Government work with states and territories to conduct further research into the adequacy of current building codes and standards related to the prevention and remediation of dampness and mould in buildings.

### **Recommendation 5**

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3.95 The Committee recommends the Department of Health conduct a review into the treatment of patients presenting with complex illnesses that are difficult to diagnose such as those with CIRS-like symptoms. This review should consider:

- methods to ensure patients with complex conditions, such as individuals reporting to have CIRS, are provided with effective and timely treatment and support (with the aim of reducing 'doctor shopping'); and
- whether doctors require further support in order to: identify environmental impacts on health; manage complex conditions; and provide appropriate treatment.

### **Recommendation 6**

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3.96 The Committee recommends that the Australian Government commission the National Health and Medical Research Council to conduct research into CIRS-like syndromes with a view to assisting in the diagnosis, treatment and management of patients. Research should also examine any links between mould and biotoxins and complex symptoms most commonly reported as typifying CIRS.



## **Recommendation 7**

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- 3.97 The Committee recommends that the Department of Health, in consultation with patient groups, medical practitioners, and health bodies, develop clinical guidelines for general practitioners for the diagnosis, treatment and management of CIRS-like conditions.



# 1. Introduction

## Overview

- 1.1 Mould is a naturally occurring type of fungi that can be found throughout the environment, both indoors and outdoors. Mould produces airborne particles called spores, which have the potential to cause health issues if inhaled by susceptible individuals.<sup>1</sup> In particular, mould may impact the health of people with allergies, asthma, weakened immune systems and/or other health conditions.<sup>2</sup>
- 1.2 In addition to these established health impacts of mould, the prevalence of a condition referred to as *Chronic Inflammatory Response Syndrome* (CIRS) has been described in Australia and internationally as a biotoxin-related illness.
- 1.3 In some instances, CIRS and biotoxin-related illnesses have been reported to be associated with exposure to biotoxins such as mould in buildings arising from excessive moisture build-up from water damage. Buildings can become water-damaged after events such as leaks, heavy rain and flooding, and moisture can also enter a building through incoming air or through a

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<sup>1</sup> Department of Health, *Submission 56*, p. 2.

<sup>2</sup> Government of Victoria, *Mould and Your Health*, [www.betterhealth.vic.gov.au/health/conditionsandtreatments/mould-and-your-health](http://www.betterhealth.vic.gov.au/health/conditionsandtreatments/mould-and-your-health), Accessed 23 August 2018.

build-up of condensation.<sup>3</sup> Certain building and construction practices may also increase the amount of condensation within a building. While water damage can occur in any building, tenants in rental properties and public housing may face particular challenges related to having water damage issues resolved.

- 1.4 A variety of methods can be used for the assessment and remediation of a property for mould and/or water damage. The effectiveness of different methods is contested<sup>4</sup>, and there is limited guidance in the form of agreed standards or regulation.<sup>5</sup>
- 1.5 Biotoxin-related illnesses and CIRS are not widely recognised medical conditions among the Australian medical profession. The Department of Health stated that ‘biotoxin-related illnesses are not captured within the National Notifiable Diseases Surveillance System’ and that data is not retained on their frequency or distribution.<sup>6</sup> Further, there are no clinical guidelines for the diagnosis and treatment of CIRS.<sup>7</sup>
- 1.6 A number of inquiry participants described symptoms of biotoxin-related illnesses and the effect these symptoms had on their daily lives, and also linked these symptoms with the presence of mould in their homes or workplaces. The symptoms described ranged from mild to severe, with commonly described symptoms including fatigue, pain, memory and concentration problems, disorientation, insomnia, gastrointestinal issues, sinus issues, fever, headaches, and respiratory issues.
- 1.7 The Department of Health stated that, at this stage, ‘the scientific evidence is not sufficient ... to accept the assertion that exposure to environmental biotoxins is causing [CIRS].’<sup>8</sup> The Department of Health also emphasised the importance of providing patients who present with multiple unexplained symptoms with a comprehensive and multidisciplinary clinical evaluation.<sup>9</sup>

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<sup>3</sup> World Health Organization, *Guidelines for Indoor Air Quality: Dampness and Mould*, 2009, p. xiv.

<sup>4</sup> Australian Institute of Occupational Hygienists, *Submission 50*, p. 6.

<sup>5</sup> Greencap, *Submission 138*, p. 9.

<sup>6</sup> Department of Health, *Submission 56*, p. 2.

<sup>7</sup> Royal Australasian College of Physicians, *Submission 142*, p. 3.

<sup>8</sup> Professor Brendan Murphy, Chief Medical Officer, Department of Health, *Official Committee Hansard*, Canberra, 12 September 2018, p. 1.

<sup>9</sup> Professor Brendan Murphy, Department of Health, *Official Committee Hansard*, Canberra, 12 September 2018, p. 1.

## Terminology

- 1.8 Inquiry participants used a variety of terms to describe and discuss the effects of biotoxin-related illness and CIRS. In many instances, terms were used interchangeably, such as:
- CIRS;
  - CIRS-Water Damaged Building;
  - biotoxin-related illness; and
  - mould illness.
- 1.9 The Royal Australasian College of Physicians preferred to use the phrase ‘people with *multiple not-readily-explained symptoms*’.<sup>10</sup>

## About the Inquiry

### Objectives and Scope

- 1.10 On 21 June 2018, the Minister for Health, the Hon Greg Hunt MP, referred the *Inquiry into Biotoxin-related Illnesses in Australia* (the inquiry) to the Standing Committee on Health, Aged Care and Sport (the Committee).
- 1.11 As part of the inquiry, the Committee reviewed the prevalence, diagnosis and treatment of biotoxin-related illnesses such as CIRS. The Committee, in particular, focused on:
- the potential health impacts of exposure to dampness and/or mould, particularly in indoor environments;
  - the prevalence of CIRS and biotoxin-related illnesses in inquiry participants; and
  - the current medical process of identifying CIRS and biotoxin-related illnesses and available treatments.
- 1.12 The Committee received a number of personal accounts from people who identified as having CIRS or a biotoxin-related illness and also outlined the symptoms associated with these illnesses and the effect they had on daily life.
- 1.13 While the Committee does not have the power to intervene in, or investigate, personal circumstances, Members appreciate the time and effort taken by individuals experiencing CIRS, as well as their friends and family, to

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<sup>10</sup> Royal Australasian College of Physicians, *Submission 142*, p. 2.

participate in the inquiry. These personal accounts provided the Committee with a valuable insight into the health, financial and wellbeing impacts associated with this condition.

- 1.14 The Committee also received personal accounts from inquiry participants who suffer from Chronic Fatigue Syndrome and tick-bite related conditions (Lyme Disease). The Committee considered that these illnesses were comprehensively examined by the Committee's predecessor in 2016, and that further investigation in this area was not warranted for this inquiry. The Committee's predecessor in the 44<sup>th</sup> Parliament, the Standing Committee on Health, conducted the *Inquiry Into Chronic Disease Prevention and Management in Primary Health Care*, which included an examination of Myalgic Encephalomyelitis (Chronic Fatigue Syndrome) and Tick-Borne and Lyme-Like Diseases.<sup>11</sup>

## Inquiry Conduct

- 1.15 On 21 June 2018, the Committee issued a media release announcing the inquiry, calling for submissions to be received by 2 August 2018. The Committee also invited submissions from: government agencies, advocacy groups, medical bodies and academics.
- 1.16 The inquiry received 142 submissions and 39 exhibits, which are listed at Appendix A and B respectively. The Committee also received a form letter from six participants, which used an identical structure.
- 1.17 The Committee subsequently held two public hearings as outlined in the table below. A list of witnesses and organisations who attended these public hearings is at Appendix C.

**Table 1.1 Public Hearings Held**

Date	Place
9 August 2018	Canberra, ACT
12 September 2018	Canberra, ACT

<sup>11</sup> Standing Committee on Health, *Inquiry into Chronic Disease Prevention and Management in Primary Health Care*, [www.aph.gov.au/Parliamentary Business/Committees/House/Health/Chronic Disease](http://www.aph.gov.au/Parliamentary_Business/Committees/House/Health/Chronic_Disease), Accessed 29 August 2018.

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## Report Structure

- 1.18 Chapter 2 discusses mould and its potential health effects, including an outline of biotoxin-related illnesses. The prevalence and possible sources of indoor mould growth is also discussed, as well as methods for testing and remediation of buildings with mould issues.
- 1.19 Chapter 3 outlines diagnostic and treatment options that have been put forward for CIRS. Chapter 3 also presents personal accounts of individuals who have reported as experiencing CIRS, or CIRS-attributed symptoms.





## 2. Possible Health and Social Impacts of Exposure to Mould

### Background

- 2.1 Mould is naturally occurring in our environment and is commonly regarded as harmless to humans and animals. In some cases, however, exposure to mould can have an adverse impact on health. Health effects associated with mould exposure tend to be temporary reactions including headaches, sinus and nasal congestion and skin and eye irritation. Some people may have an allergy to mould, or may be more susceptible to the health effects of mould due to their immune system being compromised.
- 2.2 In addition, some have linked a range of symptoms with exposure to mould, which has been referred to as a biotoxin-related illness named *Chronic Inflammatory Response Syndrome* (CIRS). There are a range of views within the medical profession regarding the relationship between mould and the range of physical and cognitive symptoms identified as related to CIRS.
- 2.3 Factors that can lead to a building developing mould or damp include: climate; natural weather events (such as floods); building and structural issues; or occupant behaviour. In rental properties, mould remediation may be the responsibility of a tenant (if their actions have led to the mould growth) or landlord (if it is a structural issue), although it can sometimes be challenging to determine the exact cause of mould growth.

- 2.4 A range of professionals offer services to test and remediate a building or dwelling suspected of having mould and/or water damage. There are limited legislative and regulatory guidelines pertaining to this industry, including how testing is undertaken.

## What is Mould?

- 2.5 Mould is a type of fungi, and is present in the natural environment. Mould produces tiny particles called spores which are carried in the air, and help it to grow and spread.<sup>1</sup> These spores are not visible to the naked eye.<sup>2</sup>
- 2.6 Mould can be found in both indoor and outdoor environments<sup>3</sup>, and can be black, grey, green or white.<sup>4</sup> Mould may also have a musty odour.<sup>5</sup> Naturally occurring mould in outdoor environments has a part in helping to breakdown organic matter.<sup>6</sup>
- 2.7 While mould spores can also be commonly found indoors, higher concentrations of indoor mould may appear in areas of a building which are poorly ventilated and become wet or damp.<sup>7</sup> This type of environment may increase the amount of mould spores, which could potentially lead to health problems.<sup>8</sup>

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<sup>1</sup> New South Wales (NSW) Health, *Mould*, [www.health.nsw.gov.au/environment/factsheets/Pages/mould.aspx](http://www.health.nsw.gov.au/environment/factsheets/Pages/mould.aspx), Accessed 23 August 2018.

<sup>2</sup> Tenants Victoria, *Submission 125*, p. 8.

<sup>3</sup> NSW Health, *Mould*, <http://www.health.nsw.gov.au/environment/factsheets/Pages/mould.aspx>, Accessed 23 August 2018.

<sup>4</sup> South Australia (SA) Health, *Household mould*, [www.sahealth.sa.gov.au/wps/wcm/connect/public+content/sa+health+internet/protecting+public+health/living+conditions+and+sanitation/household+mould](http://www.sahealth.sa.gov.au/wps/wcm/connect/public+content/sa+health+internet/protecting+public+health/living+conditions+and+sanitation/household+mould), Accessed 4 September 2018.

<sup>5</sup> Northern Territory (NT) Government, *Mould growth and your health*, <https://nt.gov.au/wellbeing/healthy-living/mould-growth>, Accessed 23 August 2018.

<sup>6</sup> United States of America (USA) Environmental Protection Agency (EPA), Exhibit 7F: *A Brief Guide to Mould, Moisture and Your Home*, p. 2.

<sup>7</sup> Victorian State Government, *Mould and your health*, [www.betterhealth.vic.gov.au/health/conditionsandtreatments/mould-and-your-health](http://www.betterhealth.vic.gov.au/health/conditionsandtreatments/mould-and-your-health), Accessed 23 July 2018.

<sup>8</sup> USA EPA, Exhibit 7F: *A Brief Guide to Mould, Moisture and Your Home*, p. 2.

2.8 Human contact with mould primarily occurs through inhalation of airborne spores, skin contact with mould affected surfaces or by ingesting mould affected food.<sup>9</sup>

## Potential Health Effects of Mould

2.9 The Department of Health advised that the World Health Organization (WHO) has ‘concluded that there is an association between exposure to dampness or mould and conditions such as asthma, allergic alveolitis and mould infections in susceptible individuals.’<sup>10</sup>

2.10 Australian state and territory governments set out the health effects of mould and provide advice on dealing with dampness and mould in the home. This advice is detailed in Table 2.1.

**Table 2.1 State and Territory Governments' Advice on Mould**

Government	Health Effects	Advice on Mould Removal
Australian Capital Territory	<ul style="list-style-type: none"> <li>▪ Nasal congestion;</li> <li>▪ Sneezing, coughing, and/or wheezing;</li> <li>▪ respiratory infections; and</li> <li>▪ worsening of asthma and allergic conditions.</li> <li>▪ People with certain pre-existing conditions may be more susceptible to mould.<sup>11</sup></li> </ul>	Wash area with water and vinegar solution, wipe with a cloth and dispose of cloth. <sup>12</sup>
New South Wales	<ul style="list-style-type: none"> <li>▪ If sensitive or allergic:               <ul style="list-style-type: none"> <li>– running or blocked nose;</li> <li>– irritation of the eyes and skin; and/or</li> <li>– wheezing.</li> </ul> </li> <li>▪ For people with asthma,</li> </ul>	Use diluted mild detergent or vinegar solution and dry the affected area. Use diluted bleach solution if mould is difficult to remove. Absorbent materials may

<sup>9</sup> NT Government, *Mould growth and your health*, <https://nt.gov.au/wellbeing/healthy-living/mould-growth>, Accessed 23 August 2018.

<sup>10</sup> Department of Health, *Submission 56*, p. 2.

<sup>11</sup> Australian Capital Territory (ACT) Health, *Mould fact sheet*, <https://www.health.act.gov.au/sites/default/files/Fact%20sheets/Mould%20fact%20sheet%20%28June%202011%29.pdf>, Accessed 23 July 2018.

<sup>12</sup> ACT Community Services, *Mould and Condensation*, [http://www.communityservices.act.gov.au/hcs/publications/fact\\_sheets/mould-and-condensation](http://www.communityservices.act.gov.au/hcs/publications/fact_sheets/mould-and-condensation), Accessed 23 July 2018.

	<p>inhaling mould spores may cause an asthma attack.</p> <ul style="list-style-type: none"> <li>▪ People with weakened immune systems are more at risk of severe reaction such as infection.</li> </ul>	need to be professionally cleaned or replaced. <sup>13</sup>
Northern Territory	<ul style="list-style-type: none"> <li>▪ If sensitive to mould: <ul style="list-style-type: none"> <li>– stuffy nose;</li> <li>– irritated eyes;</li> <li>– wheezing; and/or</li> <li>– skin irritation.</li> </ul> </li> <li>▪ If allergic to mould: <ul style="list-style-type: none"> <li>– shortness of breath; and/or</li> <li>– mould infections (if you have a weak immune system or chronic lung condition).</li> </ul> </li> </ul>	Clean using household products, disinfect surfaces, dry area. <sup>14</sup>
Queensland	'Health problems, especially for people with asthma, sensitivities or allergies.'	Use household cleaning agents, detergents or vinegar on area. Wash soft fabric articles, or take them to a professional cleaner or discard if necessary. Have air conditioning or ventilation unit serviced. <sup>15</sup>
South Australia	<ul style="list-style-type: none"> <li>▪ Allergic reactions;</li> <li>▪ coughs; congestion; and/or runny nose;</li> <li>▪ eye and skin irritation; and</li> <li>▪ headaches.</li> <li>▪ If immuno-compromised or suffering from a respiratory disease: <ul style="list-style-type: none"> <li>– fever; and/or</li> <li>– breathing problems.</li> </ul> </li> </ul>	Clean small areas of mould using bleach or commercial product; consult professional cleaner if mould is extensive. <sup>16</sup>
Tasmania	'Damp, condensation and mould can make you sick, especially in winter when colds	Spray area with tea tree oil or grapefruit seed extract mixed with

<sup>13</sup> NSW Health, *Mould*, <http://www.health.nsw.gov.au/environment/factsheets/Pages/mould.aspx>, Accessed 23 July 2018.

<sup>14</sup> NT Government, *Mould growth and your health*, <https://nt.gov.au/wellbeing/healthy-living/mould-growth>, Accessed 19 July 2018.

<sup>15</sup> Queensland Government, *Mould*, <https://www.qld.gov.au/community/disasters-emergencies/mould>, Accessed 23 July 2018.

<sup>16</sup> SA Health, *Household mould*, [www.sahealth.sa.gov.au/wps/wcm/connect/public+content/sa+health+internet/protecting+public+health/living+conditions+and+sanitation/household+mould](http://www.sahealth.sa.gov.au/wps/wcm/connect/public+content/sa+health+internet/protecting+public+health/living+conditions+and+sanitation/household+mould), Accessed 19 July 2018.

	and flus are common.’	water, or white vinegar; or wipe bleach and water solution onto area. <sup>17</sup>
Victoria	<ul style="list-style-type: none"> <li>▪ Nasal congestion;</li> <li>▪ sneezing, coughing, and/or wheezing;</li> <li>▪ respiratory infections; and/or</li> <li>▪ worsening of asthma and allergic conditions.</li> <li>▪ People with allergies, asthma, lung disease or weakened immune systems are more susceptible.<sup>18</sup></li> </ul>	Use household detergent on area, wipe area with sponge, use antibacterial disinfectant spray afterwards. Wash soft fabric articles (such as bedding). A vinegar, tea tree oil, or hydrogen peroxide solution can be used to treat small areas of mould regrowth. <sup>19</sup>
Western Australia (WA)	<ul style="list-style-type: none"> <li>▪ Asthma attacks;</li> <li>▪ watery, itchy and red eyes;</li> <li>▪ respiratory infections;</li> <li>▪ rashes (dermatitis);</li> <li>▪ sinus problems; and/or</li> <li>▪ blocked nose.</li> </ul>	Scrub mould using soapy water, wipe with damp cloth, dry area. <sup>20</sup>

2.11 Professor Matthew Cook provided further information regarding allergies, hypersensitivity disorders and mould and stated:

... [there are] immunological disorders that arise ... from either an excessive or an abnormal immune response. We can think about allergies as such an example – hay fever, asthma, eczema – where the immune response occurs to what is an otherwise innocuous environmental antigen, a substance, that might be derived from a microbe. That microbe doesn't really pose any immediate threat of infection to the individual, and yet they become unwell as a result of the wrong sort, or an excessive magnitude, of immune response. We call these hypersensitivity disorders.<sup>21</sup>

<sup>17</sup> Tasmanian Department of Health and Human Services, *Fact Sheet - Damp, Condensation and Mould*, [https://www.dhhs.tas.gov.au/housing/about/tenants/tenancy\\_facts\\_and\\_policies/living\\_conditions/damp\\_condensation\\_and\\_mould](https://www.dhhs.tas.gov.au/housing/about/tenants/tenancy_facts_and_policies/living_conditions/damp_condensation_and_mould), Accessed 23 July 2018.

<sup>18</sup> Victorian State Government, *Mould and your health*, [www.betterhealth.vic.gov.au/health/conditionsandtreatments/mould-and-your-health](http://www.betterhealth.vic.gov.au/health/conditionsandtreatments/mould-and-your-health), Accessed 23 July 2018.

<sup>19</sup> Victorian State Government, *Removing Mould at Home – Community Fact Sheet*, <https://www2.health.vic.gov.au/about/publications/policiesandguidelines/Removing-mould-at-home>, Accessed 23 August 2018.

<sup>20</sup> WA Department of Health, *Mould and dampness*, [http://healthywa.wa.gov.au/Articles/I\\_M/Mould-and-dampness](http://healthywa.wa.gov.au/Articles/I_M/Mould-and-dampness), Accessed 11 July 2018.

<sup>21</sup> Professor Matthew Cook, Professor of Medicine, Australian National University (ANU); and Head of Immunology, Canberra Hospital, *Official Committee Hansard*, Canberra, 9 August 2018, p. 7.

- 2.12 Tenants Victoria stated that allergic reactions associated with mould or mould spores include ‘hay fever-type symptoms such as sneezing, runny nose, red eyes and skin rash’.<sup>22</sup>
- 2.13 Professor Cook also outlined the role of the immune system in responding to microorganisms including mould, and that some people with suppressed immunity may contract an infection from microorganisms. Professor Cook stated:
- ... [there are] rare disorders where people who have deficiencies of their immune system get unusual infections because their immune response is somehow defective ... Amongst those ... are individuals who suffer infections from moulds, yeasts and fungi. This is an extremely rare situation, and in many cases we understand the molecular basis of that – the precise abnormality that occurs in someone's immune system to develop that illness.<sup>23</sup>
- 2.14 The Real Estate Institute of New South Wales (REINSW) was of the view that in most cases, mould is not dangerous and that there is ‘a general unwarranted fear surrounding the identification and presence of mould with little medical or scientific evidence to support such fear.’<sup>24</sup> The REINSW further stated that there are often ‘common sense solutions’ regarding the removal of mould.<sup>25</sup>

## Mould and Biotoxins

### What is a Biotoxin-related Illness?

- 2.15 The Royal Australasian College of Physicians (RACP) stated that “‘biotoxins” is an umbrella term for substances of biological origin, some of which can produce toxic effects in humans.’<sup>26</sup> Greencap stated that ‘biotoxin is defined as toxins from any biological source’, including animals and plants.<sup>27</sup> MouldLab defined biotoxins as including ‘toxic chemicals found on

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<sup>22</sup> Tenants Victoria, *Submission 125*, p. 8.

<sup>23</sup> Professor Matthew Cook, ANU and Canberra Hospital, *Official Committee Hansard*, Canberra, 9 August 2018, p. 7.

<sup>24</sup> Real Estate Institute of NSW (REINSW), *Submission 17*, p. 2.

<sup>25</sup> Mr Stephen Burke, External Advisor, REINSW, *Official Committee Hansard*, Canberra, 9 August 2018, p. 4.

<sup>26</sup> Royal Australasian College of Physicians, *Submission 142*, p. 2.

<sup>27</sup> Greencap, *Submission 138*, p. 2.

spores, fine or ultrafine fragments of mould or fungus ... that are able to be released into the air'.<sup>28</sup>

- 2.16 Dr Sandeep Gupta stated that 'biotoxins can be of various different origins, but the most common is related to water-damaged buildings.'<sup>29</sup> In addition, MouldLab put forward that human contact with biotoxins occurs 'mostly by inhalation', but can also occur through tick and spider bites, and contaminated water.<sup>30</sup>
- 2.17 MouldLab stated that there are a group of 'genetically susceptible' people who may develop inflammation and chronic illness after coming into contact with biotoxins, often within a building that has had water damage.<sup>31</sup> This illness has been termed by some as CIRS.<sup>32</sup>
- 2.18 Dr Mark Donohoe described his experience of seeing patients who reported being exposed to mould and also presenting with a range of symptoms:
- ... I have had a large number of patients with mould exposure and ongoing persistent unexplained illnesses ... There are acute respiratory tract illnesses that the patients I've seen from interstate around Australia and overseas get from being in mould affected buildings. After the initial illness they get persistent ongoing inflammatory responses that result in severe illness and fatigue.<sup>33</sup>
- 2.19 Dr Gupta stated that in addition to mould, other substances found in buildings that have been impacted by water damage may also contribute to ill-health. Dr Gupta listed these substances as including: bacteria, volatile organic compounds, parasites, and dust-mites. Dr Gupta considered that

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<sup>28</sup> MouldLab, *Submission 26*, p. 19.

<sup>29</sup> Dr Sandeep Gupta, Board Member, Australian Chronic Infectious and Inflammatory Disease Society (ACIIDS) and Australasian College of Nutritional and Environmental Medicine (ACNEM), *Official Committee Hansard*, Canberra, 9 August 2018, p. 16.

<sup>30</sup> MouldLab, *Submission 26*, p. 20.

<sup>31</sup> MouldLab, *Submission 26*, p. 20.

<sup>32</sup> MouldLab, *Submission 26*, p. 20; ACIIDS, *Submission 129*, p. 1; Toxic Mould Support Australia (TMSA), *Submission 105*, p. 3; Name Withheld, *Submission 1*, p. 1; Mrs Annette Dwyer, *Submission 6*, pp 1-2; Mr Caleb Rudd, *Submission 65*, p. 2; Name Withheld, *Submission 79*, p. 4.

<sup>33</sup> Dr Mark Donohoe, Private Capacity, *Official Committee Hansard*, Canberra, 9 August 2018, p. 3.

health effects associated with CIRS are the result of the 'sum total of all the different constituents of a water-damaged building.'<sup>34</sup>

2.20 Dr Tim Law similarly stated:

... mycotoxins<sup>35</sup> are only a part of the entire biotoxin load an occupant [of a water damaged building] is exposed to. Moreover mould is not the only problem, but an indicator of excessive moisture that permits the occurrence and continuation of an entire microbiological ecology that contributes to the total biotoxin load of a [water damaged building].<sup>36</sup>

2.21 In contrast, the RACP stated that while 'there is relatively good consensus that there is some form of association' between mould and a range of health effects, there is contention as to whether 'mould exposure causes all these other consequences'.<sup>37</sup>

2.22 The Department of Health similarly stated that there is insufficient evidence supporting a causal link between mould and the chronic symptoms associated with CIRS:

The department understands that some people suffer from a collection of chronic debilitating symptom complexes that have been attributed to exposure to mould ... At this stage, there is insufficient evidence to support a direct link between these symptoms and mould exposure.<sup>38</sup>

2.23 Grencap stated that awareness of CIRS and biotoxin-related illnesses has been driven by online communities of individuals who have had difficulty obtaining a medical diagnosis for their often debilitating symptoms. Grencap stated:

Much of the interest around "biotoxin-related illness" and "CIRS" has stemmed from health issues faced by thousands of Australians, many of whom are part of online self-help forums ... Many individuals have not been

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<sup>34</sup> Dr Sandeep Gupta, ACIIDS and ACNEM, *Official Committee Hansard*, Canberra, 9 August 2018, p. 17.

<sup>35</sup> The World Health Organization (WHO) defined mycotoxins as 'low-relative-molecular-mass biomolecules produced by fungi, some of which are toxic to animals and human beings.' WHO, *WHO Guidelines for Indoor Air Quality: Dampness and Mould*, 2009, p. 18.

<sup>36</sup> Dr Tim Law, *Submission 75*, p. 5.

<sup>37</sup> Dr Graeme Edwards, Fellow and Regional Councillor (Queensland), Faculty of Occupational and Environmental Medicine, Royal Australasian College of Physicians, *Official Committee Hansard*, Canberra, 9 August 2018, p. 11.

<sup>38</sup> Department of Health, *Submission 56*, p. 2.



able to resolve their issues with chronic illness through mainstream medicine and are therefore seeking a better understanding and cure for their condition and advice on how to manage their living situations.<sup>39</sup>

2.24 The REINSW stated that ‘there is limited evidence suggesting that biotoxin-related illnesses are directly the result of water-damaged buildings.’ The REINSW further stated that mould is an ‘easy scapegoat’, and is ‘often identified as the cause of diseases, many of which cannot be properly diagnosed or proven to be related to toxic mould.’<sup>40</sup>

### ***Reported Prevalence in Australia***

2.25 While a number of individuals have relayed their experiences with biotoxin-related illnesses<sup>41</sup>, the Department of Health advised that ‘as biotoxin-related illnesses are not captured within the National Notifiable Diseases Surveillance system, the department does not retain data on their frequency or distribution.’<sup>42</sup>

2.26 Toxic Mould Support Australia (TMSA) similarly stated that the prevalence of CIRS among Australians is ‘unknown at present.’<sup>43</sup>

2.27 In the absence of Australian estimates, both the TMSA and MouldLab cited estimates from the United States of America (USA). The TMSA drew attention to a USA study which had ‘estimated the prevalence of CIRS as being seven per cent.’<sup>44</sup> MouldLab stated that millions of people in the USA could be predisposed to developing CIRS:

Given the finding ... that 50 per cent of buildings in the US are water-damaged, and the finding that 24 per cent of exposed patients are at risk to develop CIRS, up to 40 000 000 people in the US are at risk of developing CIRS.<sup>45</sup>

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<sup>39</sup> Greencap, *Submission 138*, p. 1.

<sup>40</sup> REINSW, *Submission 17*, p. 2.

<sup>41</sup> Name Withheld, *Submission 24*, p. 2; Name Withheld, *Submission 1*, p. 1; Name Withheld, *Submission 61*, p. 1; Ms Jodie Donnelly, *Submission 135*, p. 4; Name Withheld, *Submission 134*, p. 3; Name Withheld, *Submission 97*, p. 1.

<sup>42</sup> Department of Health, *Submission 56*, p. 2.

<sup>43</sup> TMSA, *Submission 105*, p. 1.

<sup>44</sup> TMSA, *Submission 105*, p. 1.

<sup>45</sup> MouldLab, *Submission 26*, p. 13.

## Mould Exposure and Testing

### Prevalence of Indoor Mould

- 2.28 The WHO estimated that the prevalence of indoor dampness may affect between 10 and 50 per cent of indoor environments in Australia, particularly in settings such as river valleys and coastal areas.<sup>46</sup>
- 2.29 Dr Law put forward an estimate that one third of new buildings in Australia may be affected by condensation problems.<sup>47</sup> Dr Law stated that this estimate indicates that ‘condensation is a very common problem to encounter in residential buildings’.<sup>48</sup>
- 2.30 The Australasian Society of Building Biologists (ASBB) stated that ‘mould is frequently found in pre-purchase house assessments particularly in older houses, as well as new apartments that lacked adequate ventilation in wet areas.’<sup>49</sup>
- 2.31 The ASBB further stated that the true prevalence and geographic distribution of dampness in Australian buildings is yet to be quantified. The ASBB stated:

We definitely need to quantify the prevalence of dampness—it’s been done in many countries, not in Australia—to see if there are at least correlations to things like asthma allergies, which is well documented in literature, and, potentially, to chronic fatiguing illness.<sup>50</sup>

### Possible Sources of Indoor Mould

- 2.32 The TMSA put forward three main causes of mould and/or indoor moisture in buildings:
- Design or construction flaws and inadequate maintenance, which the TMSA stated was ‘the leading cause of water damage’;
  - Natural events such as floods, storms, hail and/or cyclones; and

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<sup>46</sup> WHO, *WHO Guidelines for Indoor Air Quality: Dampness and Mould*, 2009, p. xiv.

<sup>47</sup> Dr Tim Law, *Submission 75*, p. 6.

<sup>48</sup> Dr Tim Law, *Submission 75*, p. 7.

<sup>49</sup> Australasian Society of Building Biologists (ASBB), *Submission 45*, p. 5.

<sup>50</sup> Mrs Nicole Bijlsma, ASBB, *Official Committee Hansard*, Canberra, 9 August 2018, p. 10.

- Occupant behaviour, such as keeping windows shut at all times or flooding of sinks and baths.<sup>51</sup>

### ***Building and Construction Practices***

- 2.33 Building Biology Sydney stated that there is a 'lack of understanding' that dampness and mould in houses may have health effects. Building Biology Sydney stated that this lack of awareness has 'resulted in the continuance of poor building practices, poor building design [and] insufficient building maintenance'.<sup>52</sup>
- 2.34 Building practices that were put forward as potentially increasing dampness and/or mould levels included: exposing building materials to moisture during construction;<sup>53</sup> inadequate ventilation (such as buildings that are air-conditioned at all times);<sup>54</sup> practices that enable a build-up of condensation (such as the use of foil to wrap buildings);<sup>55</sup> the use of timber framing and/or gypsum board which may encourage mould growth;<sup>56</sup> or inadequate and/or incorrectly installed waterproofing.<sup>57</sup> The ASBB also put forward concerns that the uncovering of 'hidden mould' in wall cavities during renovation works could expose occupants to biotoxins.<sup>58</sup>
- 2.35 Dr Law was of the view that the creation of highly energy-efficient and fireproof homes over recent years may have had the unintended consequence of increasing the incidence of condensation, and consequently increasing the risk of dampness and mould build-up. Dr Law further stated that 'the persistent damp from condensation has led to other problems with mould and its deleterious effects on human health.'<sup>59</sup>

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<sup>51</sup> TMSA, *Submission 105*, p. 10.

<sup>52</sup> Mrs Jeanette Williams, Building Biologist, Building Biology Sydney, *Official Committee Hansard*, Canberra, 9 August 2018, p. 3.

<sup>53</sup> ASBB, *Submission 45*, p. 9.

<sup>54</sup> Dr Tim Law, Private Capacity, *Official Committee Hansard*, Canberra, 9 August 2018, p. 25.

<sup>55</sup> Dr Tim Law, Private Capacity, *Official Committee Hansard*, Canberra, 9 August 2018, p. 13.

<sup>56</sup> Dr Tim Law, Private Capacity, *Official Committee Hansard*, Canberra, 9 August 2018, p. 25.

<sup>57</sup> ASBB, *Submission 45*, p. 9.

<sup>58</sup> Mrs Nicole Bijlsma, ASBB, *Official Committee Hansard*, Canberra, 9 August 2018, p. 5.

<sup>59</sup> Dr Tim Law, *Submission 75*, p. 10.

- 2.36 The TMSA pointed to the Australian Building Codes Board's (ABCB) non-mandatory guide for condensation in buildings and an ABCB scoping study regarding condensation, and recommended both these items be incorporated into Australia's Building Code. The TMSA also recommended 'a remediation program be instigated for buildings already built to the current building code to mitigate condensation issues.'<sup>60</sup>
- 2.37 Dr Law stated that Australia's codes 'are decades behind international best practices in managing and responding to condensation problems'.<sup>61</sup> Countries Dr Law considered to be best practice included Canada and Ireland, while the United Kingdom of Great Britain, the USA and New Zealand are also 'way ahead' of Australia.<sup>62</sup>

### *Air Conditioning Systems*

- 2.38 Ducted Air Solutions (DAS) stated that in recent decades 'buildings have become "sealed", relying on mechanical air processes to provide breathable air over natural ventilation.'<sup>63</sup>
- 2.39 HydroKleen advised that air conditioning systems that are not properly maintained can become clogged with mould and dust, and can subsequently spread airborne mould spores throughout a building.<sup>64</sup> The DAS similarly stated that mould spores within air conditioning systems that are then dispersed become 'a major contaminant of indoor air.'<sup>65</sup> The ASBB added that 'heating, ventilation and air conditioning systems that are not properly maintained are frequently a source of biotoxins, especially in commercial buildings'.<sup>66</sup>
- 2.40 HydroKleen stated that inhaling mould spores may potentially cause lung and respiratory issues, virus and bacteria reactions, and/or allergic

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<sup>60</sup> TMSA, *Submission 105*, p. 10.

<sup>61</sup> Dr Tim Law, *Submission 75*, p. 7.

<sup>62</sup> Dr Tim Law, *Private Capacity, Official Committee Hansard*, Canberra, 9 August 2018, p. 13.

<sup>63</sup> Ducted Air Solutions (DAS), *Submission 70*, p. 2.

<sup>64</sup> HydroKleen, *Submission 31*, p. 3.

<sup>65</sup> DAS, *Submission 70*, p. 2.

<sup>66</sup> Mrs Nicole Bijlsma, ASBB, *Official Committee Hansard*, Canberra, 9 August 2018, p. 25.

reactions.<sup>67</sup> As such, HydroKleen recommended greater public awareness on the cleaning and maintaining of air conditioning units.<sup>68</sup>

### *Rental Homes*

2.41 Whilst tenancy legislation across the states and territories varies, the National Association of Tenant Organisations (NATO) stated that:

Across Australia the experience of dealing with mould and other biotoxins while renting a home is similar ... In all states, the enforcement of the applicable standards of repair and habitability are primarily left to the tenant through the enforcement of contractual obligations.<sup>69</sup>

2.42 The Tenants' Union of NSW stated that some tenants it surveyed who had mould in their dwellings described 'being dismissed by real estate agents and landlords' when raising the problem, being evicted, or staying silent due to a fear of being evicted.<sup>70</sup> The NATO recommended that the Australian Government work with state governments to end 'evictions where the landlord does not have to give a reason.'<sup>71</sup>

2.43 Tenants Victoria stated mould in rental properties can take a long time to be addressed as it is generally treated as a non-urgent repair.<sup>72</sup> As such, Tenants Victoria recommended that mould-related issues be listed as an urgent repair under tenancy statutes and regulations.<sup>73</sup>

2.44 In contrast, the REINSW stated that it sees:

... a lot of leases that are broken because people see mould and have what industry believes at the moment to be unwarranted fear. While people may be susceptible to related illnesses, we're finding that they're getting a doctor's certificate from doctors who are told "there's mould on the property," and

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<sup>67</sup> HydroKleen, *Submission 31*, p. 4.

<sup>68</sup> HydroKleen, *Submission 31*, p. 5.

<sup>69</sup> National Association of Tenant Organisations (NATO), *Submission 115*, p. 2.

<sup>70</sup> Mr Leo Patterson Ross, Senior Policy Officer, Tenants' Union of NSW, *Official Committee Hansard*, Canberra, 9 August 2018, p. 4.

<sup>71</sup> NATO, *Submission 115*, p. 2.

<sup>72</sup> Tenants Victoria, *Submission 125*, p. 19.

<sup>73</sup> Tenants Victoria, *Submission 125*, pp 30-31.

that's a reason to break lease when that mould might not actually be dangerous.<sup>74</sup>

- 2.45 The NATO stated that 'the issue of who deals with the mould depends on the cause of the mould.'<sup>75</sup> Mr Stephen Burke, external advisor to REINSW, stated that tenant behaviour can affect mould levels, and that there 'are a lot of lifestyle issues that contribute to this problem.'<sup>76</sup> In contrast, the TMSA stated that occupant behaviour is 'overemphasised by the insurance and real estate industries, when the underlying fault is due to the design, construction or maintenance flaws.'<sup>77</sup>
- 2.46 The ASBB and Biological Health Services both stated that the damage and repair history of a home may not be available to a tenant.<sup>78</sup> The ASBB commented that this information is necessary for prospective tenants 'to make an informed choice prior to signing a lease'.<sup>79</sup> To address this, Tenants Victoria recommended that the Australian Government 'facilitate [the] creation of mandatory uniform disclosures about health and safety matters including ... previous flood damage or mould occurrence and repairs.'<sup>80</sup>
- 2.47 In contrast, the REINSW stated that tenants already have the opportunity to inspect the premises and ask questions prior to entering a tenancy agreement.<sup>81</sup>

#### *Guidelines and Regulations for Rental Homes*

- 2.48 The REINSW stated that there is a 'lack of standardised plans or guides for property managers and strata managers in how to deal with mould.'<sup>82</sup> To address this, Biological Health Services recommended 'the development of

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<sup>74</sup> Ms Nicole Unger, General Counsel, REINSW, *Official Committee Hansard*, Canberra, 9 August 2018, p. 4.

<sup>75</sup> NATO, *Submission 115*, p. 4.

<sup>76</sup> Mr Stephen Burke, External Advisor, REINSW, *Official Committee Hansard*, Canberra, 9 August 2018, p. 4.

<sup>77</sup> TMSA, *Submission 105*, p. 10.

<sup>78</sup> ASBB, *Submission 45*, p. 3; Biological Health Services, *Submission 33*, p. 16.

<sup>79</sup> ASBB, *Submission 45*, p. 3.

<sup>80</sup> Tenants Victoria, *Submission 125*, p. 32.

<sup>81</sup> REINSW, *Submission 17*, p. 3.

<sup>82</sup> REINSW, *Submission 17*, p. 4.

checklists, assessment protocols, [and] advice and advocacy options for all stakeholders.’<sup>83</sup>

2.49 The NATO stated that tenancy legislation across Australia sets obligations for landlords to ‘provide and maintain premises at a certain level of repair’. Despite this, the NATO stated that most states and territories do not ‘adequately provide a level of standard which the landlord must comply with’ in their legislation.<sup>84</sup>

2.50 The Tenants’ Union of NSW put forward that ‘every state currently has no effective minimum standard system that allows a tenant to know what the minimum acceptable standard [is].’<sup>85</sup> The Tenants’ Union of NSW further advised that whilst we ‘are seeing some advancement in some states’, all states need to improve.<sup>86</sup> In this vein, the NATO recommended that:

The Federal Government work with state governments to ensure each state implement standards for tenanted residential premises ... including identifying particular standards concerning building quality; such as dampness, drainage, insulation, and adequate cooling and heating facilities.<sup>87</sup>

2.51 The TMSA also supported more explicit definitions of standards for rental accommodation, and recommended that Australia follow the Californian (USA) example of adding ‘visible mould growth to the list of dangerous health conditions which define substandard housing’.<sup>88</sup>

## **Mould Testing and Remediation**

### *Mould Testing Methods*

2.52 The Australian Institute of Occupational Hygienists (AIOH) outlined a process of testing for mould, which begins with a physical inspection for mould, moisture damage, humidity, condensation and/or a musty odour.

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<sup>83</sup> Biological Health Services, *Submission 33*, pp 27-28.

<sup>84</sup> NATO, *Submission 115*, p. 2.

<sup>85</sup> Mr Leo Patterson Ross, Tenants’ Union of NSW, *Official Committee Hansard*, Canberra, 9 August 2018, p. 4.

<sup>86</sup> Mr Leo Patterson Ross, Tenants’ Union of NSW, *Official Committee Hansard*, Canberra, 9 August 2018, p. 4.

<sup>87</sup> NATO, *Submission 115*, p. 2.

<sup>88</sup> TMSA, *Submission 105*, p. 11.

Inspection of ventilation systems may also be undertaken. Following this, air, surface, or bulk sampling may be required.<sup>89</sup>

- 2.53 If any mould is sighted, the AIOH stated that it should be remediated. If mould is suspected but not sighted, air sampling may be used to test for 'hidden mould – behind walls or structures.' Bulk sampling and moisture readings may assist in determining how far mould extends into an area.<sup>90</sup>
- 2.54 Dr Law stated that there is no consistent mould sampling method or the minimum level at which mould starts to effect human health.<sup>91</sup> The AIOH further advised that 'there is an absence of consensus on mould testing methods.' To address this, the AIOH supported 'quality public health research into this area.'<sup>92</sup>
- 2.55 Mr Jeremy Stamkos stated that 'there is no consensus anywhere in the world as to what level of mould exposure for certain individuals is tolerable or allowable.'<sup>93</sup> Mr Stamkos further stated that when assessing a house for mould, 'it's not so much about particular levels of particular moulds; it's in relation to the amount of moisture and dampness in a building', and in addition, the 'odour is a big factor.'<sup>94</sup>

#### *ERMI and HERTSMI-2*

- 2.56 The ACIIDS stated that '[CIRS] patients are commonly advised to organise testing of their home and work/study environments', to determine whether a building is 'safe to reoccupy'.<sup>95</sup> The testing methodologies that were put forward for this purpose are: the Environmental Relative Mouldiness Index (ERMI) and the HERTSMI-2<sup>96</sup> (which was described as 'a derivative of

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<sup>89</sup> Australian Institute of Occupational Hygienists (AIOH), *Submission 50*, p. 6.

<sup>90</sup> AIOH, *Submission 50*, p. 6.

<sup>91</sup> Dr Tim Law, *Submission 75*, p. 23.

<sup>92</sup> AIOH, *Submission 50*, p. 6.

<sup>93</sup> Mr Jeremy Stamkos, Private Capacity, *Official Committee Hansard*, Canberra, 9 August 2018, p. 21.

<sup>94</sup> Mr Jeremy Stamkos, Private Capacity, *Official Committee Hansard*, Canberra, 9 August 2018, p. 20.

<sup>95</sup> ACIIDS, *Submission 129*, pp 10-11.

<sup>96</sup> HERTSMI-2 stands for Health Effects Roster of Type of Specific formers of Mycotoxins and Inflammagens – 2<sup>ND</sup> Version. Robert Goldsworthy, *Submission 72*, p. 19.



ERMI<sup>97</sup>).<sup>98</sup> The ACIIDS advised that these can cost between \$188 and \$466 in Australia.<sup>99</sup>

2.57 The ACIIDS further stated that:

Those with a high ERMI/HERTSMI-2 and a firm diagnosis of CIRS may need to consider remediation of their home or work environment or face the onerous task of relocating their home or work premises before formal treatment can be undergone. This step can lead to some degree of emotional trauma for the patient and experience has shown that a great deal of psychological support is required by patients during this stage.<sup>100</sup>

2.58 The ERMI was developed by the USA Environmental Protection Agency (EPA). The ERMI is an 'index or scale', against which dust samples can be compared. This analysis can then 'be used by researchers to estimate the amount of mould in a home as well as indicate some of the types of mould that are present.'<sup>101</sup>

2.59 The USA EPA advice states that 'at this point in its development, the ERMI should be used only for research.'<sup>102</sup> Greencap agreed and stated that it 'could not identify sufficient research to be basing decisions around chronic systemic inflammation treatment, building occupancy or diagnostic decisions based on ERMI.'<sup>103</sup>

2.60 MouldLab also stated that ERMI 'could not be confirmed to give reliable information about safety of re-occupancy of a building by a CIRS patient.' As such, MouldLab stated that HERTSMI-2 has 'come to broad, international clinical use.'<sup>104</sup>

2.61 Mr Goldsworthy stated that HERTSMI-2 analyses five types of moulds, and the results are 'used to complete a scorecard which is designed to help

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<sup>97</sup> MouldLab, *Submission 26*, p. 10.

<sup>98</sup> ACIIDS, *Submission 129*, p. 10.

<sup>99</sup> ACIIDS, *Submission 129*, p. 10.

<sup>100</sup> ACIIDS, *Submission 129*, p. 11.

<sup>101</sup> USA EPA, Exhibit 7G: *The Environmental Relative Moldiness Index: a Research Tool*, p. 1.

<sup>102</sup> USA EPA, Exhibit 7G: *The Environmental Relative Moldiness Index: a Research Tool*, p. 1.

<sup>103</sup> Greencap, *Submission 138*, p. 4.

<sup>104</sup> MouldLab, *Submission 26*, p. 10.

patients who were previously sickened by water damaged buildings understand if a building is safe for them to occupy.’<sup>105</sup>

2.62 The TMSA stated that the testing of a building for people who identify as having CIRS should include a HERTSMI-2 score.<sup>106</sup>

2.63 In contrast, Mr Goldsworthy stated that the ‘HERTSMI-2 system’s dependency on ERMI means it encounters the same controversies and limitations’.<sup>107</sup> Further, Biological Health Services stated that HERTSMI-2 allows for ‘selective reporting and interpretations’, which ‘leads to misleading interpretations and extrapolations.’<sup>108</sup>

### ***Mould Testing Industry***

2.64 The TMSA stated that testing of buildings for water damage and/or mould can be undertaken by a range of professionals. These include: indoor environmental professionals, certified occupational hygienists, mycologists, building biologists and/or remediators. Building occupants can also use self-test kits, which are then mailed to mycologists to be analysed.<sup>109</sup>

2.65 Mr Stamkos stated that there is ‘no uniform approach’ across these professions for assessing buildings for mould. Consequently, there is wide variation in accuracy of advice. Mr Stamkos stated:

Consumers will pay several thousands of dollars to have an indoor environmental professional, building biologist or people who are self-proclaimed experts in mould investigations, come in and give very different results, from the way they do their sampling to giving different scope of works. They provide incorrect advice on buildings [by] saying that they either don't have contamination issues where they clearly have mould growing ... to other people going in and over analysing a building and giving misinformation about the levels of contamination saying the whole building has to be condemned because of certain types of mould present.<sup>110</sup>

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<sup>105</sup> Mr Robert Goldsworthy, *Submission 72*, p. 19.

<sup>106</sup> TMSA, *Submission 105*, p. 11.

<sup>107</sup> Mr Robert Goldsworthy, *Submission 72*, p. 19.

<sup>108</sup> Biological Health Services, *Submission 33*, p. 24.

<sup>109</sup> TMSA, *Submission 105*, p. 10.

<sup>110</sup> Mr Jeremy Stamkos, Private Capacity, *Official Committee Hansard*, Canberra, 9 August 2018, p. 26.

- 2.66 The REINSW stated that anxiety around indoor mould has ‘created the development of an industry with inexperienced mould inspectors capitalising on the fear factor.’<sup>111</sup> The REINSW recommended that the mould testing industry be regulated to ensure methods of testing that are used are ‘approved and verified.’<sup>112</sup>
- 2.67 Greencap stated that many individuals have self-tested their house for evidence of dampness and mould, using ‘off the shelf mould testing kits and expensive analyses.’ Greencap advised that self-testing by someone who is unqualified may lead to incorrect conclusions about the level of mould or water damage in a building.<sup>113</sup>
- 2.68 The Indoor Air Quality Association (IAQA) Australia considered that there is a need for education, training and the development of guidelines to assist the mould testing and remediation industries and commented:
- Currently, in Australia, there are limited avenues for accessing education and training in accurately assessing the potential health effects of mould damaged buildings. IAQA Australia supports intersectoral collaboration in developing and delivering consistent, evidence-based guidelines for mould assessment and remediation; and education and training programs to the remediation industry, housing associations and the public, as appropriate.<sup>114</sup>
- 2.69 Biological Health Services recommended that training for mould remediation and assessment should be moved to the Vocational Education and Training framework, in order to ‘enhance the calibre and delivery of quality educational content’.<sup>115</sup>

## ***Remediation***

- 2.70 The TMSA was of the view that ‘the Australian mould remediation industry is currently one without regulation, recourse, or accountability.’ The TMSA further stated that some commonly used mould remediation methods may have negative health impacts for individuals experiencing CIRS-attributed symptoms:

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<sup>111</sup> REINSW, *Submission 17*, p. 2.

<sup>112</sup> REINSW, *Submission 17*, p. 3.

<sup>113</sup> Greencap, *Submission 138*, p. 4.

<sup>114</sup> Indoor Air Quality Association (IAQA) Australia, *Submission 71*, p. 3.

<sup>115</sup> Biological Health Services, *Submission 33*, p. 3.

A major trend in this country is to remediate water damage and fungal growth by using gassing, fogging or spraying of biocides to kill microbes in place of source removal. This practice is dangerous for those with CIRS-[water damaged buildings] as fungi and their fragments are even more toxic when dead than when living.<sup>116</sup>

- 2.71 The ASBB also made the point that ‘the use of fogging, spraying and gassing of water-damaged buildings ... only provides a band-aid approach to this complex issue.’<sup>117</sup>
- 2.72 To address this, the TMSA recommended the implementation of an accreditation or regulation program for the mould remediation industry. Remediators used by insurance companies, assessors, real estate agencies and landlords would be required to comply with relevant international standards.<sup>118</sup>
- 2.73 The TMSA further recommended that the ability of remediators to test their own work should be disallowed, as ‘this is an obvious conflict of interest.’<sup>119</sup>

### ***Regulations and Standards***

- 2.74 Greencap was concerned that there is no regulatory framework for assessment and remediation of damp and mould-affected buildings. In regard to the risk to human health, Greencap stated:

There is no standardised framework in Australia for the assessment, remediation or independent works certification of damp and fungal contaminated buildings despite their impacts on health being significant. There remains no Australian certification for operatives in the remediation or building/health assessment space, with some practitioners providing services that ultimately have potential to put health at risk. Lack of accepted standards and regulation is leaving occupants at significant risk and causing confusion in the industry.<sup>120</sup>

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<sup>116</sup> TMSA, *Submission 105*, p. 11.

<sup>117</sup> ASBB, *Submission 45*, p. 3.

<sup>118</sup> TMSA, *Submission 105*, p. 11.

<sup>119</sup> TMSA, *Submission 105*, p. 11.

<sup>120</sup> Greencap, *Submission 138*, p. 9.

- 2.75 MouldLab recommended that the development of nationally consistent guidelines for mould identification and remediation in buildings be ‘a major consideration’.<sup>121</sup>
- 2.76 Biological Health Services similarly called for minimum testing standards and guidelines for the inspection, assessment and remediation of buildings with water damage and/or mould. Biological Health Services further stated that these standards and guidelines should be:
- ... based on existing and established indoor air quality testing methods that provide evidence-based whole-of-home results to guide both occupants and clinicians in terms of managing risk. Priority should be given to quantitative over qualitative metrics that allow for statistical significance testing.<sup>122</sup>
- 2.77 The DAS stated that there is a lack of legislation to regulate indoor air quality in Australia. In particular, the DAS considered regulation was needed in relation to ‘manufactured/mechanical air’ in air-conditioned buildings.<sup>123</sup>
- 2.78 Mr Stamkos stated that ‘compliance with the existing Australian standard ... needs to be regulated to help prevent exposure.’<sup>124</sup> In addition, Mr Stamkos recommended the development of:
- ‘Australian standards for conducting assessments of water-damaged buildings, as well as drying and remediation of water-damaged and contaminated buildings’;
  - ‘Australian training and certification for individuals conducting assessments/investigations of water-damaged buildings and microbial contamination, as well as for those conducting drying and remediation of such buildings’; and
  - ‘an Australian standard for indoor air quality.’<sup>125</sup>

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<sup>121</sup> Mr David Lark, Principal Mycologist, MouldLab, *Official Committee Hansard*, Canberra, 9 August 2018, p. 19.

<sup>122</sup> Biological Health Services, *Submission 33*, pp 4-5.

<sup>123</sup> DAS, *Submission 70*, p. 5.

<sup>124</sup> Mr Stamkos referenced the Australian/New Zealand Standard 3666.2: ‘air handling and water systems of buildings — microbial control — operation and maintenance’. Mr Jeremy Stamkos, Private Capacity, *Official Committee Hansard*, Canberra, 9 August 2018, p. 6.

<sup>125</sup> Mr Jeremy Stamkos, Private Capacity, *Official Committee Hansard*, Canberra, 9 August 2018, pp 6-7.

### *Further Research*

2.79 A range of recommendations for further research were put forward in order to create a stronger evidence base and consensus regarding mould, its effects, and testing and remediation methods.

2.80 The REINSW was of the view that a scientific study on mould and its potential effects is needed to determine at what levels mould may become a danger to human health. The REINSW stated:

We encourage a scientific study on mould—its levels of toxicity and what level is dangerous. We find that, whilst mould might exist in properties, more often than not it is not dangerous. The tests used to determine the extent of toxicity are not scientifically proven. A lot of the inspectors don't have qualifications. They use a lot of common sense and the experience they've had in the industry ... we need to work out the problems we actually have before we start solving issues.<sup>126</sup>

2.81 Mr Stamkos called for 'research to better understand the mechanisms causing illness resultant from water-damaged buildings and how to better identify the risks'.<sup>127</sup>

2.82 Tenants Victoria recommended a research centre be established to undertake:

- 'building standards research into the precursors for and conditions to promote mould, and those that prevent mould and biotoxin formation (with a view to revision of the [National Construction Code]),
- building research into structural requirements, building techniques and materials to avoid growth of moulds and development of biotoxins, the best methods to treat mould in commercial and domestic situations (including methods to avoid spreading fungal spores), and
- medical research into respiratory and other conditions caused by biotoxins.'<sup>128</sup>

2.83 The Myalgic Encephalomyelitis/Chronic Fatigue Syndrome and Lyme Association of WA recommended research into 'the efficacy of numerous

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<sup>126</sup> Ms Nicole Unger, REINSW, *Official Committee Hansard*, Canberra, 9 August 2018, p. 4.

<sup>127</sup> Mr Jeremy Stamkos, Private Capacity, *Official Committee Hansard*, Canberra, 9 August 2018, p. 6.

<sup>128</sup> Tenants Victoria, *Submission 125*, p. 33.

mould remediation techniques'.<sup>129</sup> Greencap similarly advised that research is needed to develop a stronger understanding 'of the impact of testing, analysis and methodology on the reliability of findings in [water damaged building] investigations'.<sup>130</sup> In addition, the AIOH and IAQA Australia both supported public health research into mould health effects and mould testing methods.<sup>131</sup>

2.84 The ASBB recommended research in relation to water damaged buildings and stated:

Future research needs to focus on patients with chronic fatiguing illnesses brought on by [water damaged buildings] and to establish predictive tools to test and effectively remediate [water damaged buildings]. This needs to include epidemiological research, economic modelling, collection of anecdotes, observational studies, before and after clinical studies, randomized control trials and targeted clinical research to determine the causes, implications and treatment for patients with chronic fatiguing illnesses brought on by [water damaged buildings].<sup>132</sup>

*Increasing the Availability of Information*

2.85 The AIOH considered that the Australian Government could provide information and advice regarding mould, particularly for 'building owners/managers, health professionals, environmental health professionals and building professionals.' The AIOH recommended that the Australian Government develop:

- a 'national mould and health monograph', which 'would be important for public health, and could play a significant role in the health, construction and insurance sectors of the economy'; and
- a 'national mould portal', to ensure ready access to government advice and factual information.<sup>133</sup>

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<sup>129</sup> Myalgic Encephalomyelitis/Chronic Fatigue Syndrome and Lyme Association of WA, *Submission 44*, p. 3.

<sup>130</sup> Greencap, *Submission 138*, p. 5.

<sup>131</sup> AIOH, *Submission 50*, p. 3; IAQA Australia, *Submission 71*, p. 1.

<sup>132</sup> ASBB, *Submission 45*, p. 9.

<sup>133</sup> AIOH, *Submission 50*, p. 5.

- 2.86 Biological Health Services also saw a need for information related to mould that reflects ‘consensus scientific opinion’ and is ‘independent of internet-era medical misinformation’.<sup>134</sup>

## Concluding Comment

- 2.87 Mould is naturally occurring and so can be found almost everywhere in the environment, and it seems may not be possible to avoid. While mould is generally harmless and will not cause health issues for the majority of the population, a small number of people however may experience allergic reactions or more serious effects through exposure to mould.
- 2.88 The Committee received evidence that there is no general consensus on the potential health impact of biotoxins associated with mould and water damaged buildings. Further, the Committee heard there is some uncertainty regarding the level at which mould may begin to pose a health risk, as well as the most effective method to test and remediate mould issues in buildings.
- 2.89 As such, the Australian Government could have a role in the provision of scientific information regarding mould, any associated health risks, and reliable mould testing and remediation methods. This may assist in creating a consensus across mould testing and remediation industries as to the most effective and scientifically supported method to address mould issues.
- 2.90 The Committee was concerned to hear that some tenants of rental properties, social and public housing have faced challenges in having mould-related issues resolved. Providing potential tenants with timely information regarding any mould and/or water damage incident that has occurred in a property will ensure all parties are in receipt of previous damp and mould related issues before entering into a residential leasing arrangement.

## Recommendation 1

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- 2.91 **The Committee recommends that the Department of Health produce and publish in the short term a fact sheet, and in the medium term undertake further research on:**
- **the potential health effects of exposure to damp and mould;**

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<sup>134</sup> Biological Health Services, *Submission 33*, p. 5.



- the prevalence of dampness and mould in the built environment; and
- advice on the prevention and removal of mould.

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## **Recommendation 2**

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2.92 The Committee recommends that the Australian Government work with the states and territories to conduct further research into, and develop standards and/or accreditation requirements for the mould testing and remediation industries, which should include consideration of:

- the most effective methods of testing and remediation of buildings affected by mould and/or moisture;
- appropriate accreditation requirements for professionals working in these fields; and
- options for greater regulatory oversight of these industries.

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## **Recommendation 3**

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2.93 The Committee recommends that the Australian Government work with the states and territories to ensure that tenants in rental properties, aged care facilities, and community, social and public housing are provided with timely information about disclosure and rectification of any previous or existing mould and/or water damage issues in a property before entering into a residential leasing agreement.

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## **Recommendation 4**

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2.94 The Committee recommends that the Australian Government work with states and territories to conduct further research into the adequacy of current building codes and standards related to the prevention and remediation of dampness and mould in buildings.



# 3. Chronic Inflammatory Response Syndrome (CIRS)

## Overview

- 3.1 Dr Sandeep Gupta outlined four factors that have been used to define and identify CIRS:
- it is a multisystem and multi-symptom illness;
  - the patient has had 'documented exposure to biotoxins, usually in the form of a water damaged building';
  - testing indicates the patient has a number of 'abnormal biomarkers'<sup>1</sup>; and
  - the illness responds to therapy, 'the main one being cholestyramine.'<sup>2</sup>
- 3.2 MouldLab put forward an estimate that '25 per cent of people are genetically predisposed to biotoxin illnesses, and are more likely to develop the disease

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<sup>1</sup> Biomarker has been defined as 'a characteristic that is objectively measured and evaluated as an indicator of normal biologic or pathogenic processes or pharmacological responses to a therapeutic intervention.' Australian Government National Measurement Institute, *Reference Materials and Methods for Global Biomarker Profiling – Case Studies in Cancer Diagnosis and Cell Culture Systems*, 2008, p. 4.

<sup>2</sup> Dr Sandeep Gupta, Board Member, Australian Chronic Infectious and Inflammatory Disease Society (ACIIDS) and Australasian College of Nutritional and Environmental Medicine (ACNEM), *Official Committee Hansard*, Canberra, 9 August 2018, p. 20.

and have much stronger symptoms.<sup>3</sup> Other potential types of predisposition put forward included ‘hypermobility’ in the joints, a prior infection of some kind<sup>4</sup>, and/or allergy<sup>5</sup>.

3.3 Additional features of CIRS that were described included that it is a chronic condition (lasting more than six months) and that it is ‘inflammatory involving multiple elements of immune response’.<sup>6</sup>

3.4 Dr Mark Donohoe highlighted that CIRS is considered a syndrome, rather than a disease. Dr Donohoe explained the difference between syndrome and disease and stated:

A syndrome is an observational gathering of symptoms that are in common between different patients. [For example] in Chronic Fatigue Syndrome we have a particular group of people with six months fatigue and five of the eight criteria in addition to it. Do we know cause? No. Do we know treatment? No. There's no one common thing ... You don't have a disease until the consensus of medicine is that you have a disease, and it moves from syndrome to disease at that point, but that's because you have testing or treatment that is widely accepted to work.<sup>7</sup>

3.5 The Department of Health stated that ‘some people suffer from a collection of chronic debilitating symptom complexes that have been attributed to exposure to mould’, which included symptoms of ‘skin sensitivity, chronic sinus inflammation, photophobia, night sweats, light headedness, chronic fatigue, chronic headaches, muscle and joint pains, cognitive impairment, and malaise’.<sup>8</sup>

3.6 The Department of Health further stated that there is no evidence to suggest a causal relationship exists between exposure to biotoxins and unexplained complex symptoms.<sup>9</sup> In a separate statement the Department of Health commented:

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<sup>3</sup> MouldLab, *Submission 26*, p. 21.

<sup>4</sup> Dr Sandeep Gupta, ACIIDS and ACNEM, *Official Committee Hansard*, Canberra, 9 August 2018, p. 27.

<sup>5</sup> Dr Mark Donohoe, Private Capacity, *Official Committee Hansard*, Canberra, 9 August 2018, p. 27.

<sup>6</sup> MouldLab, *Submission 26*, p. 5.

<sup>7</sup> Dr Mark Donohoe, Private Capacity, *Official Committee Hansard*, Canberra, 9 August 2018, p. 19.

<sup>8</sup> Department of Health, *Submission 56*, p. 2.

<sup>9</sup> Professor Brendan Murphy, Chief Medical Officer, Department of Health, *Official Committee Hansard*, Canberra, 12 September 2018, p. 1.

... the evidence ... at this stage [is] lacking that there is a causal relationship between exposure to environmental biotoxins and the nature of these essentially unexplained symptom complexes.<sup>10</sup>

- 3.7 Biological Health Services stated that the term CIRS 'is neither recognised nor has been made legitimate within medicine or the wider academic community.'<sup>11</sup>
- 3.8 The Royal Australasian College of Physicians (RACP) agreed and stated:  
... sufficient research has not been conducted nor consensus reached for the terms 'biotoxin-related illnesses' or 'Chronic Inflammatory Response Syndrome (CIRS)' to be used as valid diagnostic labels.<sup>12</sup>
- 3.9 The RACP further stated that 'inappropriate labels can mislead efforts to improve the health and wellbeing of people with symptoms.' As such, the RACP preferred to refer to these patients as people with 'multiple not-readily-explained symptoms'.<sup>13</sup>

## Identification and Treatment of CIRS

### Reaching a diagnosis

- 3.10 The Department of Health outlined the steps a person could take if they are concerned about health impacts that may be associated with mould exposure. This involves first consulting a general practitioner (GP), who may refer a patient to a clinical immunologist or allergist if necessary.<sup>14</sup>
- 3.11 The Department of Health stated that these specialists 'have available specific diagnostic approaches including bedside allergen testing as well as referral to pathologists for in-vitro laboratory-based testing.'<sup>15</sup> The Department of Health further advised that respiratory physicians may also

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<sup>10</sup> Professor Brendan Murphy, Department of Health, *Official Committee Hansard*, Canberra, 12 September 2018, p. 1.

<sup>11</sup> Biological Health Services, *Submission 33*, p. 21.

<sup>12</sup> Royal Australasian College of Physicians (RACP), *Submission 142*, p. 2.

<sup>13</sup> RACP, *Submission 142*, p. 2.

<sup>14</sup> Department of Health, *Submission 56*, p. 4.

<sup>15</sup> Department of Health, *Submission 56*, p. 4.

be consulted to investigate hypersensitivity illness or other respiratory illnesses.<sup>16</sup>

3.12 In relation to people who describe having a multitude of chronic symptoms, the Department of Health stated that it noted:

... the importance of a multidisciplinary approach to patient care, involving general practitioners as well as specialists such as general physicians, infectious diseases physicians, clinical allergists, clinical immunologists and psychiatrists. A number of potential causes of these debilitating symptoms may be relevant and, as a result, each patient should undergo a thorough clinical assessment that considers the patient's complete history as well as appropriate referral for diagnostic investigations.<sup>17</sup>

3.13 The Department of Health further explained that a comprehensive assessment is necessary to ensure any undiagnosed illnesses and underlying conditions are identified and treated.<sup>18</sup>

3.14 The Department of Health stated that:

... the symptom complexes are so similar between people with this condition, the tick-bite associated group and the chronic fatigue group, we're very concerned to make sure that the first thing we do is have everybody properly assessed in a sympathetic and comprehensive way by physicians. In the tick-bite group in Melbourne, we found 40 per cent of them had otherwise undiagnosed illnesses, including brain tumours, musculoskeletal rheumatic disorders, and a small number had diagnosable psychiatric illnesses. So our very first priority is to make sure that people don't latch on to a diagnosis because their symptom complexes match what's on a website or a list and that they have a proper comprehensive assessment.<sup>19</sup>

3.15 Toxic Mould Support Australia (TMSA) stated that 'there are relatively few general practitioners in Australia who are aware of CIRS and who can diagnose and treat the condition.'<sup>20</sup> The Australian Chronic Infectious and Inflammatory Disease Society (ACIIDS) agreed and added that there are less

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<sup>16</sup> Department of Health, *Submission 56*, p. 4.

<sup>17</sup> Department of Health, *Submission 56*, p. 4.

<sup>18</sup> Professor Brendan Murphy, Department of Health, *Official Committee Hansard*, Canberra, 12 September 2018, p. 2.

<sup>19</sup> Professor Brendan Murphy, Department of Health, *Official Committee Hansard*, Canberra, 12 September 2018, p. 2.

<sup>20</sup> Toxic Mould Support Australia, *Submission 105*, p. 1.

than 30 medical practitioners in Australia with any training related to CIRS.<sup>21</sup>

- 3.16 Dr Gupta similarly stated that one of the 'barriers to being diagnosed and treated for CIRS in Australia' was that:

There is a vast shortage of general and specialist practitioners who are knowledgeable in the screening, diagnosis and treatment of the condition. Most health practitioners are only aware of common severe mould-related diagnoses, such as allergy or invasive aspergillosis, a severe condition often treated in a hospital setting.<sup>22</sup>

- 3.17 To address this, Dr Gupta recommended that CIRS become 'a recognised medical illness' and that 'training for medical practitioners in CIRS needs to be endorsed and funded as a priority.'<sup>23</sup> The TMSA similarly recommended that 'CIRS diagnosis and treatment information be included in the medical curriculum at universities.'<sup>24</sup>

- 3.18 Further, Dr Gupta recommended that 'specialist practitioners who are knowledgeable about CIRS' be given access to Medicare Benefit Schedule video consultation item numbers in order to treat bedridden and distance patients.<sup>25</sup>

- 3.19 MouldLab stated that due to the wide variety of symptoms that have been associated with CIRS, 'patients are often misdiagnosed and eventually mistreated, due to the wrong diagnostic.'<sup>26</sup> MouldLab further stated that misdiagnoses include: allergies, fibromyalgia, anxiety and depression, attention deficit disorders, post-traumatic stress disorder, irritable bowel syndrome, Chronic Fatigue Syndrome (CFS), stress and somatisation.<sup>27</sup>

- 3.20 The RACP advised that 'there is no consensus' related to diagnosing CIRS.<sup>28</sup> The RACP further stated:

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<sup>21</sup> ACIIDS, *Submission 129*, p. 19.

<sup>22</sup> Dr Sandeep Gupta, *Submission 124*, p. 2.

<sup>23</sup> Dr Sandeep Gupta, *Submission 124*, p. 3.

<sup>24</sup> Toxic Mould Support Australia, *Submission 105*, p. 7.

<sup>25</sup> Dr Sandeep Gupta, *Submission 124*, p. 3.

<sup>26</sup> MouldLab, *Submission 26*, p. 22.

<sup>27</sup> MouldLab, *Submission 26*, p. 21.

<sup>28</sup> Dr Graeme Edwards, Fellow and Regional Councillor (Queensland) Faculty of Occupational and Environmental Medicine, RACP, *Official Committee Hansard*, Canberra, 9 August 2018, p. 18.

... where we're looking in this setting when we're talking about CIRS is how we're starting to see the gelling together of what should be considered and what shouldn't be considered. We're in a very embryonic state of defining what it is. There are still out there in the marketplace people who are naive, and [think] it basically doesn't exist full stop.<sup>29</sup>

- 3.21 The RACP also stated that it would 'express caution' in using the phrase 'diagnostic' when describing a connection between mould and CIRS-attributed symptoms. The RACP stated:

... [the] phrase 'diagnostic' implies that there is a strong connection that is causative. When we have someone reporting the sense of odour, the sense of moisture or whatever it is that they're reporting—the visual or the olfactory sense being stimulated—it raises the level of suspicion but it's not diagnostic. That's the problem. It's because people assert diagnostic connectivity when the evidence isn't there to actually say that that level of mould in that particular premise is causative. It's an implied association.<sup>30</sup>

- 3.22 Dr Donohoe similarly expressed that:

... you have diagnosis of a disease but you have a contribution to a syndrome. What I'm really saying is there's no diagnostic certainty [in relation to CIRS], because there's no disease certainty yet.<sup>31</sup>

- 3.23 Dr Edwards from the RACP stated that he does not use the term CIRS in his clinical practice, as he considers there are 'a multitude of potential triggers', and that 'mould is but one of the potential triggers of the immunological system.'<sup>32</sup>

- 3.24 The Department of Health explained that establishing causality would involve identifying the specific toxin that may be causing various symptoms. The Department of Health stated:

In a clinical situation to establish a causality between environmental exposure, you would need to establish what agent is causing it. That is very difficult in this context because the postulated agents that might be in the environment are many ... Without some sort of proof of association between a potentially

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<sup>29</sup> Dr Graeme Edwards, RACP, *Official Committee Hansard*, Canberra, 9 August 2018, p. 18.

<sup>30</sup> Dr Graeme Edwards, RACP, *Official Committee Hansard*, Canberra, 9 August 2018, p. 21.

<sup>31</sup> Dr Mark Donohoe, Private Capacity, *Official Committee Hansard*, Canberra, 9 August 2018, p. 19.

<sup>32</sup> Dr Graeme Edwards, RACP, *Official Committee Hansard*, Canberra, 9 August 2018, pp 11-12.



toxic entity and the symptoms, it's very hard to take this matter significantly further.<sup>33</sup>

## Identifying CIRS

- 3.25 Dr Gupta stated that he has seen 'many hundreds of patients who appeared to meet the diagnostic criteria for either "provisionally diagnosed" or "confirmed cases" of CIRS.'<sup>34</sup> Dr Gupta described the diagnosis process he uses for CIRS as involving 'history and examination, bedside tests and formal investigations'.<sup>35</sup>
- 3.26 Of these steps, Dr Gupta stated that environmental history is the 'most important part of the assessment' and involves questioning what possible mould exposures a patient may have had.<sup>36</sup> Another aspect for diagnosis raised by Dr Gupta is to determine whether the person is experiencing a 'multisystem illness', affecting more than two body systems.<sup>37</sup>
- 3.27 Further steps that may be taken to identify CIRS include:
- Symptoms cluster analysis: MouldLab stated that the described symptoms of CIRS (outlined in Box 3.1) can be separated into 13 different groups or 'clusters', and if a patient presents with symptoms from eight or more clusters, 'this may indicate a positive CIRS diagnosis'.<sup>38</sup>
  - Visual Contrast Sensitivity testing to determine if a patient has an impaired ability to detect visual patterns;<sup>39</sup>
  - Genetic testing 'to determine if a patient is genetically susceptible to biotoxin illness';<sup>40</sup>

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<sup>33</sup> Professor Brendan Murphy, Department of Health, *Official Committee Hansard*, Canberra, 12 September 2018, p. 2.

<sup>34</sup> Dr Sandeep Gupta, *Submission 124*, p. 1.

<sup>35</sup> Dr Sandeep Gupta, ACIIDS and ACNEM, *Official Committee Hansard*, Canberra, 9 August 2018, p. 16.

<sup>36</sup> Dr Sandeep Gupta, ACIIDS and ACNEM, *Official Committee Hansard*, Canberra, 9 August 2018, pp 16-17.

<sup>37</sup> Dr Sandeep Gupta, ACIIDS and ACNEM, *Official Committee Hansard*, Canberra, 9 August 2018, p. 17.

<sup>38</sup> MouldLab, *Submission 26*, p. 22.

<sup>39</sup> MouldLab, *Submission 26*, pp 22-23.

<sup>40</sup> MouldLab, *Submission 26*, p. 23.

- Biomarker testing;<sup>41</sup>
- A range of blood tests;<sup>42</sup>
- MRI testing using a software program to examine a standard MRI scan for ‘any abnormalities in the brain’s structure of brain atrophy’;<sup>43</sup> and
- A deep nasal swab to test for ‘Multiple Antibiotic Resistant Coagulate Negative Staphylococci’ (MARCoNS).<sup>44</sup>

3.28 The ACIIDS commented that some tests that are used for CIRS are not available in Australia and are undertaken in the United States of America. The ACIIDS explained:

... in Australia medical practitioners are limited in their ability to order the biomarkers specific for CIRS as most of these biomarkers are not available by any [National Association of Testing Authorities] accredited Australian laboratories. Hence diagnostic blood tests need to be forwarded to ... [the] United States.<sup>45</sup>

3.29 Dr Gupta agreed and stated that this presents logistical difficulties for patients, as there is only one lab in Australia (located in Queensland) that ‘is willing to forward the blood to America.’ In addition, the testing comes at considerable expense and no Medicare rebate is available.<sup>46</sup>

3.30 MouldLab recommended the ‘establishment of competent biomarker analysis and sampling locally.’<sup>47</sup> Dr Gupta also recommended that Medicare rebates be made available for biomarker testing in Australia.<sup>48</sup>

### Box 3.1 Described Symptoms of CIRS

Reported symptoms<sup>49</sup> associated with CIRS include combinations of:

<sup>41</sup> MouldLab, *Submission 26*, pp 24-26.

<sup>42</sup> ACIIDS, *Submission 129*, p. 10.

<sup>43</sup> MouldLab, *Submission 26*, p. 26.

<sup>44</sup> ACIIDS, *Submission 129*, p. 10.

<sup>45</sup> ACIIDS, *Submission 129*, p. 9.

<sup>46</sup> Dr Sandeep Gupta, ACIIDS and ACNEM, *Official Committee Hansard*, Canberra, 9 August 2018, p. 18.

<sup>47</sup> MouldLab, *Submission 26*, p. 28.

<sup>48</sup> Dr Sandeep Gupta, *Submission 124*, p. 3.

<sup>49</sup> Unless referenced otherwise, listed symptoms were reported by ACIIDS, *Submission 129*, pp 7-8; MouldLab, *Submission 26*, p. 22; Dr Tim Law, *Submission 75*, p. 4.

- Fatigue
- Weakness
- Aches
- Muscle cramps
- Sharp pain
- Headache
- Light sensitivity
- Red eyes
- Blurred vision
- Tearing
- Sinus problems
- Cough
- Shortness of breath
- Joint pain
- Morning stiffness
- Memory issues
- Difficulty with focus/concentration
- Word finding difficulties
- Decreased assimilation of new knowledge
- Confusion
- Disorientation
- Skin sensitivity
- Mood swings
- Sweats (especially night sweats)
- Temperature regulation or dysregulation problems
- Excessive thirst despite frequent water intake
- Static shocks
- Numbness
- Tingling
- Vertigo/Dizziness
- Metallic taste
- Abdominal pain
- Diarrhoea
- Tremors<sup>50</sup>
- Unusual pain<sup>51</sup>
- Migraine/ facial pain<sup>52</sup>

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<sup>50</sup> ACIIDS, *Submission 129*, pp 7-8.

<sup>51</sup> ACIIDS, *Submission 129*, pp 7-8.

- Appetite swings<sup>53</sup>
- Increased urination<sup>54</sup>/nocturia<sup>55</sup>

The Department of Health observed commonalities between many of these symptoms and those associated with CFS and Lyme disease.<sup>56</sup>

The Myalgic Encephalomyelitis (ME)/CFS and Lyme Association of Western Australia (WA) agreed and further stated that some of its members with ME/CFS and/or Lyme reported: mould in their living environment; a mould exposure at the time of becoming ill; and/or recovering after moving out of a mouldy environment.<sup>57</sup>

In addition, the ACIIDS stated that there are a number of conditions that are 'known to commonly intersect with CIRS', or that are 'likely to be worsened by co-existent CIRS.'<sup>58</sup>

### *Diagnosis and Treatment of Complex Illnesses*

- 3.31 Professor Matthew Cook stated that 'one of the challenges of clinical practice is that many people have symptoms that can't be adequately explained' and that as a result, people 'pursue various avenues to get an explanation.'<sup>59</sup>
- 3.32 The RACP similarly stated that these individuals may explore different options, including 'doctor-shopping', undertaking internet research and/or finding a support network or organisation.<sup>60</sup> The Department of Health

<sup>52</sup> ACIIDS, *Submission 129*, pp 7-8.

<sup>53</sup> ACIIDS, *Submission 129*, pp 7-8; Dr Tim Law, *Submission 75*, p. 4.

<sup>54</sup> ACIIDS, *Submission 129*, pp 7-8; MouldLab, *Submission 26*, p. 22; Dr Tim Law, *Submission 75*, p. 4; Dr Scott McMahon, *Submission 85*, p. 3.

<sup>55</sup> ACIIDS, *Submission 129*, pp 7-8; Dr Scott McMahon, *Submission 85*, p. 3.

<sup>56</sup> Professor Brendan Murphy, Department of Health, *Official Committee Hansard*, Canberra, 12 September 2018, p. 1.

<sup>57</sup> Myalgic Encephalomyelitis/Chronic Fatigue Syndrome (ME/CFS) and Lyme Association of Western Australia (WA), *Submission 44*, pp 1-2.

<sup>58</sup> ACIIDS, *Submission 129*, p. 17.

<sup>59</sup> Professor Matthew Cook, Professor of Medicine, Australian National University; and Head of Immunology, Canberra Hospital, *Official Committee Hansard*, Canberra, 9 August 2018, p. 8.

<sup>60</sup> Dr Graeme Edwards, RACP, *Official Committee Hansard*, Canberra, 9 August 2018, p. 12.

added that these individuals are vulnerable to 'exploitation' and 'being sold quackery' in their search for a diagnosis and treatment.<sup>61</sup>

- 3.33 The Department of Health stated that parts of the medical profession have been unsympathetic to people presenting with a range of unexplained symptoms:

... the medical profession hasn't always been very sympathetic. They've tended to say, 'This disease doesn't exist' and therefore they've downplayed or belittled the symptoms. [The Department of Health is] very strongly of the view that these symptoms are absolutely genuine, serious and debilitating, and need to be taken seriously.<sup>62</sup>

- 3.34 The RACP stated that the education system for doctors is 'deficient' in relation to recognising and treating complex, multisystem and/or unexplained illnesses.<sup>63</sup> The RACP stated that this is due to aspects of medical training having a 'compartmentalised' approach to considering body systems, and that it is not until doctors get 'into a general practice setting that we start looking at a more comprehensive overview of multisystem experience again, in terms of what our patients actually suffer.'<sup>64</sup>

- 3.35 The RACP further stated that, while it is not possible to change the system of educating doctors, 'we can make it more patient centred as we delve into the multidimensional nature of the patient's suffering'.<sup>65</sup>

- 3.36 Dr Donohoe stated that a barrier to effective treatment of complex illnesses is a 'lack of appropriate funding for prolonged consultations' under Medicare. Further, Dr Donohoe stated a difficulty in treating complex illness was where to 'draw the line with testing'. Dr Donohoe stated that 'diagnostic testing is not cheap, so Medicare is never ... thrilled about something which would escalate diagnostic testing.'<sup>66</sup>

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<sup>61</sup> Professor Brendan Murphy, Department of Health, *Official Committee Hansard*, Canberra, 12 September 2018, p. 5.

<sup>62</sup> Professor Brendan Murphy, Department of Health, *Official Committee Hansard*, Canberra, 12 September 2018, p. 2.

<sup>63</sup> Dr Graeme Edwards, RACP, *Official Committee Hansard*, Canberra, 9 August 2018, p. 15.

<sup>64</sup> Dr Graeme Edwards, RACP, *Official Committee Hansard*, Canberra, 9 August 2018, p. 15.

<sup>65</sup> Dr Graeme Edwards, RACP, *Official Committee Hansard*, Canberra, 9 August 2018, p. 15.

<sup>66</sup> Dr Mark Donohoe, Private Capacity, *Official Committee Hansard*, Canberra, 9 August 2018, p. 23.

- 3.37 The ME/CFS and Lyme Association of WA stated that there is a need for ‘government-funded specialist chronic illness diagnostic and treatment clinics.’<sup>67</sup>

## Treatment

- 3.38 The *Shoemaker Protocol* was put forward as being a treatment plan for CIRS.<sup>68</sup> MouldLab described the *Shoemaker Protocol* as a ‘step-by-step protocol that requires compliance, careful supervision and follow-through.’<sup>69</sup>
- 3.39 Dr Gupta advised that the *Shoemaker Protocol* involves a number of treatment steps which are ‘designed to bring the biomarkers back to normal.’<sup>70</sup> These steps include: people removing themselves from exposure to the biotoxins (which may involve moving house and replacing possessions);<sup>71</sup> giving patients ‘binder medications to help remove mycotoxins and other compounds from the system;’<sup>72</sup> administering a vasoactive intestinal polypeptide nasal spray;<sup>73</sup> ‘correction of inflammatory and hormonal dysregulation’<sup>74</sup> and ‘treating of MARCoNS if present.’<sup>75</sup>
- 3.40 The Department of Health stated that ‘there isn’t established scientific evidence ... that it has been proven to the extent that [the Department] would regard a treatment [for CIRS] as established.’<sup>76</sup>
- 3.41 Dr Gupta advised that two doctors in Australia have been certified in the *Shoemaker Protocol*, but in 2017 both ‘decided to decertify’, as they found

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<sup>67</sup> ME/CFS and Lyme Association of WA, *Submission 44*, p. 2.

<sup>68</sup> MouldLab, *Submission 26*, p. 11; Toxic Mould Support Australia, *Submission 105*, p. 5; Dr Sandeep Gupta, *Submission 124*, p. 1.

<sup>69</sup> MouldLab, *Submission 26*, p. 11, 2.

<sup>70</sup> Dr Sandeep Gupta, ACIIDS and ACNEM, *Official Committee Hansard*, Canberra, 9 August 2018, p. 21.

<sup>71</sup> Toxic Mould Support Australia, *Submission 105*, p. 5.

<sup>72</sup> Dr Sandeep Gupta, ACIIDS and ACNEM, *Official Committee Hansard*, Canberra, 9 August 2018, p. 21.

<sup>73</sup> Dr Sandeep Gupta, ACIIDS and ACNEM, *Official Committee Hansard*, Canberra, 9 August 2018, p. 21.

<sup>74</sup> Toxic Mould Support Australia, *Submission 105*, p. 5.

<sup>75</sup> Toxic Mould Support Australia, *Submission 105*, p. 5.

<sup>76</sup> Professor Brendan Murphy, Department of Health, *Official Committee Hansard*, Canberra, 12 September 2018, p. 5.

some patients were 'unable to tolerate the various treatments due to their sensitivities.' In particular, Dr Gupta advised that cholestyramine, which is used as a 'binder medication' in the *Shoemaker Protocol*, was not tolerated by some patients, while natural binders may be tolerated (but are not included in the *Shoemaker Protocol*).<sup>77</sup>

3.42 Dr Gupta outlined the impediments to the diagnosis and treatment of CIRS as including:

- 'a vast shortage of general and specialist practitioners who are knowledgeable in the screening, diagnosis and treatment' of CIRS;
- 'the general practitioners trained in this condition are generally limited to the major cities on the east coast of Australia';
- 'the financial costs of undertaking remediation and medical treatment are very high';
- 'the testing is very difficult to access'; and
- 'the treatment is arduous, and often patients experience difficulties in tolerating the medical treatments, which requires high levels of experience to manage.'<sup>78</sup>

3.43 In addition, Dr Gupta listed costs associated with developing and recovering from CIRS as including:

- 'the cost of remediation of one's property', which Dr Gupta stated can be 'tens of thousands of dollars';
- 'the cost of seeing doctors', which can involve 'private fees in addition to the Medicare rebate due to the long and complex nature of consultations';
- 'the cost of medications', which can include a 'compounded form of cholestyramine' at a cost of \$200 per month, other medications which 'are generally private prescriptions, and are not on the Pharmaceutical Benefits Scheme', and two nasal sprays which can each cost approximately \$180 per month; and
- 'the costs of investigations' to confirm the presence of CIRS.<sup>79</sup>

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<sup>77</sup> Dr Sandeep Gupta, *Submission 124*, pp 1-2.

<sup>78</sup> Dr Sandeep Gupta, *Submission 124*, p. 2.

<sup>79</sup> Dr Sandeep Gupta, *Submission 124*, pp 2-3.

## Clinical Guidelines

- 3.44 The RACP stated that ‘there is a severe lack of any useful guidelines that are consistent and accepted across the different jurisdictions of the populations of Australia’.<sup>80</sup>
- 3.45 The Australasian Integrative Medicine Association (AIMA) stated that ‘the lack of standardised guidelines for the identification, testing and treating of these patients has the potential to compromise patient care and contribute to significant ongoing morbidity.’<sup>81</sup>
- 3.46 The AIMA also stated that ‘currently, many doctors do not feel competent in either recognising or treating environmentally acquired illnesses’, and further training for doctors is required.<sup>82</sup> As such, the AIMA called for the establishment of diagnostic and treatment protocols and education in this area for doctors.<sup>83</sup>
- 3.47 Dr Gupta stated that the development of clinical guidelines would assist GPs to correctly identify the source(s) of symptoms and provide effective treatment. This would also have the effect of ensuring patients ‘don’t continue to doctor-shop’ which can be ‘a huge strain on the health system if [people] are just going from doctor to doctor without a correct diagnosis.’<sup>84</sup>
- 3.48 Professor Cook cautioned that any development of guidelines should include consideration of established medical reactions to exposure to mould, and also avoid medical investigations that are not needed and/or widely accepted. Professor Cook stated:

... it's very difficult to come up with guidelines in a state of such massive uncertainty, but two things that guidelines can be useful for are to ensure that we don't miss things that we do know about. We do know about asthma, and we do know about some rare fungal induced hypersensitivity syndromes ... We need to be clear that we don't miss those. The second element ... is to avoid unnecessary and unvalidated investigations. We know an enormous amount about the immune system and it's very easy to measure lots of

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<sup>80</sup> Dr Graeme Edwards, RACP, *Official Committee Hansard*, Canberra, 9 August 2018, p. 4.

<sup>81</sup> Australasian Integrative Medicine Association (AIMA), *Submission 51*, p. 1.

<sup>82</sup> AIMA, *Submission 51*, p. 3.

<sup>83</sup> AIMA, *Submission 51*, p. 8.

<sup>84</sup> Dr Sandeep Gupta, ACIIDS and ACNEM, *Official Committee Hansard*, Canberra, 9 August 2018, pp 12-13.



analytes, but, until we have an understanding of a causal mechanism, simply measuring those will not necessarily be a fruitful line of investigation.<sup>85</sup>

- 3.49 The RACP explained that 'clinical guidelines will stop excessive over-investigation. They will stop unnecessary investigation in the vast majority of cases.'<sup>86</sup>
- 3.50 The RACP also recommended the 'adequate resourcing of the processes necessary to get clinical guidelines that are consensus based and accepted across the different vested stakeholder interests.'<sup>87</sup> The RACP put forward the USA Department of Veterans' Affairs guidelines that related to the Gulf War Syndrome as a possible model for guidelines.<sup>88</sup>
- 3.51 The Department of Health stated that it would:
- ... certainly support guidelines for evaluating [and] managing people with these chronic symptom complexes, whether they are believed to be biotoxin associated, tick bite associated, chronic fatigue, electromagnetic – whatever association ... there is enough commonality in them that guidelines [for] that initial evaluation are valuable. We certainly have committed to do that work with the Lyme support group. I've suggested to them that they might want to broaden and interact with the other patient support groups so that we can get some comprehensive guidelines. It may not take us to the specific end point of the disease, but at least we can get the GPs and other health professionals to reset their approach, which is: 'This disease doesn't exist; go away,' rather than: 'You have a serious debilitating set of complex symptoms that we need to properly evaluate and manage and support you.' So definitely we support guidelines in that broader context.<sup>89</sup>
- 3.52 The RACP supported the development of a clinical pathway or a 'clinical guideline' for patients that present with 'multiple not-readily explained symptoms'. The pathway or guideline should address the following key issues:

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<sup>85</sup> Professor Matthew Cook, Professor of Medicine, Australian National University; and Head of Immunology, Canberra Hospital, *Official Committee Hansard*, Canberra, 9 August 2018, p. 14.

<sup>86</sup> Dr Graeme Edwards, RACP, *Official Committee Hansard*, Canberra, 9 August 2018, p. 15.

<sup>87</sup> Dr Graeme Edwards, RACP, *Official Committee Hansard*, Canberra, 9 August 2018, p. 15.

<sup>88</sup> Dr Graeme Edwards, RACP, *Official Committee Hansard*, Canberra, 9 August 2018, p. 22.

<sup>89</sup> Professor Brendan Murphy, Department of Health, *Official Committee Hansard*, Canberra, 12 September 2018, p. 4.

- 1 'The formulation of clear working diagnostic criteria and an agreed minimum dataset to enable better case-definition, case management and cohort identification for research purposes.
- 2 Development of standardised indices of exposure of damp or mould-contaminated environments on which research and clinical judgement and management can be reliably founded.
- 3 The development of well-designed longitudinal studies to understand the relative contribution of genetics, epigenetics and the range of biopsychosocial factors impacting on those suffering from multiple not-readily explained symptoms.
- 4 Research into the role of various biomarkers which have been championed by some authors in the broader and general literature.
- 5 Research to improve ways of preventing, reducing and removing damp and mould in homes in order to prevent / reduce childhood asthma, especially among children in socio-economically disadvantaged families and communities.
- 6 The development of clinical guidelines based on the evolving evidence derived from the management and treatment of people who suffer from multiple not-readily explainable symptoms; and
- 7 Access to co-ordinated biopsychosocial supports for those people who meet agreed criteria.'<sup>90</sup>

## Research

3.53 A range of recommendations for further research were put forward that related to CIRS. Determining the potential prevalence of CIRS among the population and the most effective method for the identification and treatment of CIRS were particular areas of focus.

3.54 The ACIIDS and the TMSA both recommended that research be undertaken to determine the prevalence of CIRS.<sup>91</sup> Dr Donohoe similarly expressed that research was needed to determine the incidence of mould-related illness among the population and whether predictive testing could be used. Dr Donohoe stated:

... when we look back through complex illnesses, mould exposure is a very commonly reported thing in a well-taken history. And, more importantly,

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<sup>90</sup> RACP, *Submission 142*, p. 3.

<sup>91</sup> ACIIDS, *Submission 129*, p. 5; and Toxic Mould Support Australia, *Submission 105*, p. 9.

when people leave those environments, they recover. But I can't come to incidence yet, and I'd propose that the research actually is the most important thing to find out how many and who are affected and whether we have predictive testing that we could possibly employ to say not just 10 per cent but this 10 per cent.<sup>92</sup>

3.55 The AIMA recommended 'clinical research into the nature of biotoxin/mycotoxin illness' be undertaken.<sup>93</sup> In a similar vein, Greencap stated that:

... the Government needs to develop a platform with the help of industry bodies and stakeholders and provide funding for research into the complex nature of exposure to environmental toxins and inflammation.<sup>94</sup>

3.56 Further, the ME/CFS and Lyme Association of WA recommended funding for research in relation to:

- 'the health effects of exposure to mould and biotoxins'; and
- 'how [this exposure] may trigger or be connected to ME/CFS and Lyme-like symptoms.'<sup>95</sup>

3.57 In addition, the ME/CFS and Lyme Association of WA recommended an investigation into testing and diagnosis options for CIRS, including options for them to be made more affordable.<sup>96</sup>

3.58 The Australian Institute of Occupational Hygienists stated that it would 'support a scientific review of non-asthma, non-allergy mould research.'<sup>97</sup>

3.59 Dr Law stated that funding for research into CIRS will be difficult to obtain without CIRS first becoming more widely accepted in the medical profession. Dr Law stated:

... the medical community has had doubts whether biotoxin illness, or CIRS, [is] a medical entity. There is a gap between a condition occurring, and a condition being recognised. Where there is no recognition, research funding is

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<sup>92</sup> Dr Mark Donohoe, Private Capacity, *Official Committee Hansard*, Canberra, 9 August 2018, p. 9.

<sup>93</sup> AIMA, Submission 51, p. 1.

<sup>94</sup> Greencap, *Submission 138*, p. 2.

<sup>95</sup> ME/CFS and Lyme Association of WA, *Submission 44*, p. 2.

<sup>96</sup> ME/CFS and Lyme Association of WA, *Submission 44*, p. 2.

<sup>97</sup> Australian Institute of Occupational Hygienists, *Submission 50*, p. 3.

unattainable, and data will remain scant, if any. We would all like to have answers, but answers need research, and research needs funding.<sup>98</sup>

3.60 Research into treatment for CIRS was recommended by the TMSA, which stated that ‘studies are needed to determine the most efficacious clinical treatments for patients.’<sup>99</sup> Greencap similarly stated that ‘the approach to treatment following exposure to [water damaged buildings] requires deeper investigation.’<sup>100</sup>

3.61 Dr Gupta recommended the Australian Government endorse and fund research into the following areas:

- ‘the prevalence of CIRS;
- the prevalence of water-damaged buildings in Australia;
- the prevalence of susceptible gene types; and
- the effectiveness of treatment protocols’.<sup>101</sup>

3.62 The Department of Health was of the view that broader research into the range of unexplained symptom complexes experienced by individuals (such as those associated with CIRS, Lyme Disease, and/or CFS) may be of use. The Department of Health stated that:

... there might be some value in broadening research to look at the overlap between these groups of patients who do have very similar symptoms, and there may well be some common background in the biology of people so that different triggers might produce the symptoms. That's where I think a targeted call for research in these multiple debilitating symptom complexes that are otherwise not fully explained scientifically in a broader sense might be possible.<sup>102</sup>

3.63 This was emphasised by a large number of witnesses who supported the need for both Australian based medical research and the development of consistent clinical guidelines for medical practitioners.

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<sup>98</sup> Dr Tim Law, *Submission 75*, p. 25.

<sup>99</sup> Toxic Mould Support Australia, *Submission 105*, p. 9.

<sup>100</sup> Greencap, *Submission 138*, p. 9.

<sup>101</sup> Dr Sandeep Gupta, *Submission 124*, p. 3.

<sup>102</sup> Professor Brendan Murphy, Department of Health, *Official Committee Hansard*, Canberra, 12 September 2018, p. 3.

## Personal Accounts of CIRS

### Introduction

- 3.64 The Committee received a large number of submissions from individuals detailing their, or their family member's, experience of living with symptoms associated with CIRS. Most accounts detailed individual experiences of being exposed to mould, often in the home or workplace, which individuals have linked to the onset of symptoms they attributed to CIRS. A wide range of physical and cognitive symptoms were reported, which had significant health, wellbeing and financial impacts.
- 3.65 Many inquiry participants stated that they had faced difficulties in obtaining a medical diagnosis for their symptoms and finding effective treatment.<sup>103</sup> Of particular concern to a number of individuals was a sense of not being believed by doctors<sup>104</sup>, and that they often consulted numerous GPs and specialists before finding effective treatment.<sup>105</sup> Some inquiry participants pieced-together their own treatment regime,<sup>106</sup> or sought medical advice from interstate or overseas doctors who offered an understanding of mould-related disease.<sup>107</sup>
- 3.66 Some personal accounts also described being diagnosed with psychological symptoms,<sup>108</sup> referrals to psychologists or psychiatrists, or being prescribed anti-depressants, rather than treatment for physical symptoms.<sup>109</sup>
- 3.67 An additional concern was the significant financial expense associated with CIRS arising from numerous treatments and tests, relocation costs, and the cost of replacing suspected mould affected property.<sup>110</sup>

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<sup>103</sup> Ms Vanessa Lee, *Submission 108*, p. 1; Name Withheld, *Submission 99*, p. 1; Name Withheld, *Submission 106*, p. 8; Ms Maree Kratzer, *Submission 101*, p. 4.

<sup>104</sup> Name Withheld, *Submission 116*, p. 4; Ms Monica Clonda, *Submission 42*, p. 1; Name Withheld, *Submission 34*, p. 1; Name Withheld, *Submission 106*, pp 9-10; Name Withheld, *Submission 52*, p. 3.

<sup>105</sup> Name Withheld, *Submission 24*, p. 1; Name Withheld, *Submission 37*, p. 1; Name Withheld, *Submission 99*, p. 1; Name Withheld, *Submission 108*, p. 6.

<sup>106</sup> Name Withheld, *Submission 99*, p. 1; Name Withheld, *Submission 28*, p. 1; Name Withheld, *Submission 11*, p. 1.

<sup>107</sup> Mr Ted Donnelly, *Submission 89*, p. 1; Name Withheld, *Submission 12*, p. 6; Name Withheld, *Submission 36*, p. 2.

<sup>108</sup> Name Withheld, *Submission 7*, p. 1.

<sup>109</sup> Name Withheld, *Submission 24*, pp 1-2; Name Withheld, *Submission 36*, p. 2.

## Mould in the Home and Workplace

- 3.68 Inquiry participants, who identified as having CIRS, or CIRS-symptoms, frequently described an incident of exposure to mould.<sup>111</sup> Some inquiry participants also stated that they believed they were genetically susceptible to CIRS.<sup>112</sup>
- 3.69 Exposure to mould was commonly reported to have occurred at inquiry participants' place of residence (or series of residences)<sup>113</sup> while others described exposure to mould in their workplace.<sup>114</sup> Submissions were received concerning mould affected buildings from across Australia, including Queensland<sup>115</sup>, New South Wales<sup>116</sup>, Victoria<sup>117</sup>, Western Australia<sup>118</sup>, South Australia<sup>119</sup> and Tasmania.<sup>120</sup>
- 3.70 Mould-affected buildings included newly built<sup>121</sup> and older houses<sup>122</sup> and also workplaces.<sup>123</sup> A common feature was that buildings had been affected

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<sup>110</sup> Name Withheld, *Submission 59*, p. 10; Name Withheld, *Submission 11*, p. 2; Ms Janice Foster, *Submission 18*, p. 7.

<sup>111</sup> Name Withheld, *Submission 1*, p. 1; Name Withheld, *Submission 9*, p. 1; Name Withheld, *Submission 11*, p. 2; Name Withheld, *Submission 13*, p. 1; Name Withheld, *Submission 22*, pp 2-3; Name Withheld, *Submission 37*, p. 1; Ms Barbara Olive, *Submission 74*, pp 3-4.

<sup>112</sup> Name Withheld, *Submission 62*, p. 1; Ms Jodie Donnelly, *Submission 135*, p. 2; Name Withheld, *Submission 59*, p. 5; Name Withheld, *Submission 1*, p. 1; Name Withheld, *Submission 60*, p. 1; Name Withheld, *Submission 80*, p. 3.

<sup>113</sup> Name Withheld, *Submission 1*, p. 1; Name Withheld, *Submission 34*, p. 3; Name Withheld, *Submission 63*, pp 1-2; Name Withheld, *Submission 67*, p. 1; Ms Robyn Knight, *Submission 139*, p. 1; Name Withheld, *Submission 83*, p. 1; Name Withheld, *Submission 97*, p. 1.

<sup>114</sup> Ms Carlene Stratton, *Submission 3*, p. 1; Mrs Annette Dwyer, *Submission 6*, p. 1; Ms Jodie Donnelly, *Submission 135*, p. 1.

<sup>115</sup> Name Withheld, *Submission 112*, p. 1; Name Withheld, *Submission 83*, p. 1.

<sup>116</sup> Ms Vanessa Lee, *Submission 108*, p. 2; Name Withheld, *Submission 104*, p. 1; Name Withheld, *Submission 106*, p. 1.

<sup>117</sup> Mr Dennis Smith, *Submission 109*, p. 1; Ms Maree Kratzer, *Submission 101*, p. 2; Name Withheld, *Submission 80*, p. 1.

<sup>118</sup> Name Withheld, *Submission 141*, p. 1; Name Withheld, *Submission 134*, p. 1.

<sup>119</sup> Name Withheld, *Submission 37*, p. 1.

<sup>120</sup> Name Withheld, *Submission 46*, p. 1.

<sup>121</sup> Name Withheld, *Submission 30*, p. 1.

<sup>122</sup> Name Withheld, *Submission 67*, p. 1; Name Withheld, *Submission 34*, p. 3.

by water (flooding incident, or ongoing problems) or internal leaks.<sup>124</sup>  
Concerns raised included:

- 'I have lived at my residence ... since circa 2000. I and my family have been experiencing health issues as a result of mould growth (including spores, biotoxins and bacteria). The growth of the mould and bacteria is largely due to a long term water leak ... as a result of a burst pipe in the foundations of the house.'<sup>125</sup>
- 'In 2017, I was exposed to mould in a commercial office space. Mould was found in the air conditioner and in the ceiling tile adjacent [to] the [air conditioning] unit and the mould growth was due to a leak in the roof. I fell ill immediately upon my first exposure.'<sup>126</sup>

## Health and Wellbeing Impacts

3.71 Inquiry participants shared personal accounts of living with CIRS-attributed symptoms, including experiencing multiple symptoms over a long period of time.<sup>127</sup> Ms Monica Clonda described experiencing 'a myriad of symptoms including, but not limited to fatigue, brain fog, headaches, muscle pain and weakness, weight gain and joint pain'.<sup>128</sup>

3.72 The most commonly reported symptoms included fatigue<sup>129</sup>; pain and joint pain<sup>130</sup>; memory and concentration problems and disorientation<sup>131</sup>;

<sup>123</sup> Mrs Karen Gallaty, *Submission 32*, p. 1; Ms Carlene Stratton, *Private Capacity, Official Committee Hansard*, Canberra, 9 August 2018, p. 28.

<sup>124</sup> Name Withheld, *Submission 12*, p. 3; Name Withheld, *Submission 27*, p. 1; Name Withheld, *Submission 88*, p. 1; Name Withheld, *Submission 104*, p. 1; Mr Dennis Smith, *Submission 109*, p. 2; Name Withheld, *Submission 112*, p. 1; Ms Carolyn Frohmader, *Submission 111*, p. 7; Ms Vanessa Lee, *Submission 108*, p. 2; Name Withheld, *Submission 83*, p. 1.

<sup>125</sup> Name Withheld, *Submission 37*, p. 1.

<sup>126</sup> Mrs Karen Gallaty, *Submission 32*, p. 1.

<sup>127</sup> Ms Carlene Stratton, *Private Capacity, Official Committee Hansard*, Canberra, 9 August 2018, p. 29; Mrs Annette Dwyer, *Private Capacity, Official Committee Hansard*, Canberra, 9 August 2018, p. 29; Name Withheld, *Submission 36*, p. 3; Name Withheld, *Submission 34*, p. 6; Name Withheld, *Submission 83*, p. 1.

<sup>128</sup> Ms Monica Clonda, *Submission 42*, p. 1.

<sup>129</sup> Name Withheld, *Submission 7*, p. 1; Name Withheld, *Submission 11*, p. 1; Name Withheld, *Submission 12*, p. 7; Name Withheld, *Submission 22*, p. 3; Name Withheld, *Submission 27*, p. 2.

<sup>130</sup> Name Withheld, *Submission 88*, p. 2; Ms Lynne McCarty, *Submission 43*, p. 1; Name Withheld, *Submission 62*, p. 1; Name Withheld, *Submission 24*, p. 1; Name Withheld, *Submission 38*, p. 1.

insomnia<sup>132</sup>; gastrointestinal issues<sup>133</sup>; sinus issues<sup>134</sup>; fever<sup>135</sup>; headaches<sup>136</sup>; and respiratory issues.<sup>137</sup>

3.73 Inquiry participants reported impacts on their physical, social and mental health and overall wellbeing. In particular:

- 'I have been stripped of who I am/was: almost all of my tastes, preferences, activities, delights, interests etc. can no longer be accommodated.'<sup>138</sup>
- 'I can't do much anymore. I am mostly housebound, but I make sure I go out once each day for an hour or two. Our nanny takes our children on all outings ... I never take our children anywhere by myself anymore.'<sup>139</sup>
- 'I have gone from an extremely fit, healthy individual to a much skinnier, struggling individual ... [I] have so much pain and various problems that are not visible.'<sup>140</sup>
- 'Both my daughter and I have experienced profound trauma and distress from this whole experience, which is still ongoing with no clear outcome in sight. The effects and impacts on myself and my young daughter –

<sup>131</sup> Name Withheld, *Submission 2*, p. 1; Name Withheld, *Submission 46*, p. 3; Mr Caleb Rudd, *Submission 65*, p. 1; Ms Barbara Olive, *Submission 74*, p. 6; Name Withheld, *Submission 106*, p. 10; Name Withheld, *Submission 116*, p. 2.

<sup>132</sup> Mr Caleb Rudd, *Submission 65*, p. 1; Miss Zara D'Cotta, *Submission 68*, p. 7; Name Withheld, *Submission 88*, p. 2; Ms Maree Kratzer, *Submission 101*, p. 3; Name Withheld, *Submission 116*, p. 2.

<sup>133</sup> Ms Liz Martin, *Submission 14*, p. 1; Ms Carlene Stratton, *Submission 3*, p. 2; Ms Janice Foster, *Submission 18*, p. 3; Name Withheld, *Submission 24*, p. 1; Name Withheld, *Submission 81*, p. 1; Name Withheld, *Submission 99*, p. 1; Name Withheld, *Submission 103*, p. 1.

<sup>134</sup> Ms Janice Foster, *Submission 18*, p. 3; Name Withheld, *Submission 22*, p. 3; Name Withheld, *Submission 59*, p. 6; Name Withheld, *Submission 82*, p. 5; Ms Carolyn Frohmader, *Submission 111*, p. 9.

<sup>135</sup> Ms Carlene Stratton, *Submission 3*, p. 1; Name Withheld, *Submission 81*, p. 1.

<sup>136</sup> Name Withheld, *Submission 7*, p. 1; Ms Liz Martin, *Submission 14*, p. 1; Name Withheld, *Submission 27*, p. 3; Name Withheld, *Submission 30*, p. 3; Name Withheld, *Submission 47*, p. 1; Ms Barbara Olive, *Submission 74*, p. 3; Name Withheld, *Submission 130*, p. 2.

<sup>137</sup> Ms Diana Eastment, *Submission 4*, p. 1; Name Withheld, *Submission 24*, p. 1; Name Withheld, *Submission 79*, p. 4; Ms Lynne McCarty, *Submission 43*, pp 2-3; Ms Nicole A, *Submission 120*, p. 12; Name Withheld, *Submission 113*, p. 1.

<sup>138</sup> Name Withheld, *Submission 59*, p. 10.

<sup>139</sup> Name Withheld, *Submission 79*, p. 6.

<sup>140</sup> Mr Mark Stuart, *Submission 114*, p. 1.



including on our physical, psychological, emotional, mental health and well-being – have been severe and cumulative ... as a result of a flood event that was not of our making.’<sup>141</sup>

- ‘I have had little social interaction since 2012 ... This has resulted in moderate to extreme loneliness ... It is not realistic to expect that patients have family members to fall back on during CIRS recovery ... Numerous friends abandoned their friendships with me because I was not able to initiate contact or organise or participate in gatherings. It tested the levels of compassion and empathy and generosity of the people in my life and sadly the result was that most of them moved on with their lives without me in it.’<sup>142</sup>

3.74 The intersection of CIRS-attributed symptoms with other complex medical conditions was described in a number of personal accounts.<sup>143</sup> Ms Janice Foster described her experience, and stated:

I primarily identify as having a condition similar to Lyme disease, but I also have a probable diagnosis of CIRS. I've been debilitatingly ill for the last 17 years and unable to work the last six. Although I have the mould exposure genetic predisposition and MRI results commonly used to diagnose CIRS, some of my other ... results were unexpected, ruling out a definitive diagnosis ... It might seem particularly unlucky that I've ended up with two controversial illnesses, but it's actually quite common.<sup>144</sup>

## Finding Effective Treatment

3.75 Despite presenting with a range of symptoms, CIRS-affected individuals described having difficulty in gaining a diagnosis and treatment.<sup>145</sup> Some individuals found there was a limited knowledge among GPs and specialists in relation to mould exposure and illness.<sup>146</sup> As a consequence individuals did not always feel they were believed or understood by medical

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<sup>141</sup> Ms Carolyn Frohmader, *Submission 111*, p. 11.

<sup>142</sup> Name Withheld, *Submission 134*, p. 8.

<sup>143</sup> Name Withheld, *Submission 27*, p. 2; Name Withheld, *Submission 110*, pp 3-4; Name Withheld, *Submission 133*, p. 3.

<sup>144</sup> Ms Janice Foster, Private Capacity, *Official Committee Hansard*, Canberra, 9 August 2018, p. 30.

<sup>145</sup> Name Withheld, *Submission 30*, p. 1; Mr Mark Stuart, *Submission 114*, p. 1; Name Withheld, *Submission 7*, p. 1; Dr Kate Barry, *Submission 93*, p. 1.

<sup>146</sup> Ms Liz Martin, *Submission 14*, p. 1; Ms Vanessa Lee, *Submission 108*, p. 6; Name Withheld, *Submission 102*, p. 6.

practitioners.<sup>147</sup> Personal accounts of the difficulties that arose while seeking effective treatment included:

- 'No practitioner in Australia was able to diagnose or treat me, or offer anything that gave me any relief until I undertook careful avoidance of all mould and found the doctor who treated me for CIRS in 2014. I suffered nine years of steadily deteriorating health and functionality despite consulting over 40 practitioners. Not one of them was aware that mould could have been the precipitating cause, or the factor that was keeping me ill.'<sup>148</sup>
- 'The attitude of doctors towards me when I told them I had a mould-related illness was very unhelpful and sceptical. I was ostracised and the lack of consensus, understanding and support was extremely distressing, added to my expenses, exposed me to additional radiation unnecessarily, and prolonged my recovery time as I started to think maybe I had lost the plot ... at a time in my life when I so desperately needed to be understood, nurtured and supported I felt completely alone.'<sup>149</sup>
- '... I began suffering from a range of severe medical symptoms and spent many years seeing doctors, medical specialists (immunology, otolaryngology, toxicology, gastroenterology, psychiatry, etc.), going into hospital ... but never resolving my conditions'.<sup>150</sup>
- 'I have been ignored; belittled, laughed at and dismissed ... [some medical practitioners] are not aware of what this illness does so therefore [assume] I must be mentally ill. The ignorance and arrogance has prolonged my suffering and pain'.<sup>151</sup>

3.76 Concerns were raised that the medical profession has been reluctant to acknowledge mould-related illness.<sup>152</sup> Further to this, Dr Liz Stringer stated that 'formal recognition will assist patients with CIRS to access the help they so dearly need and for medical practitioners ... to access the resources needed to treat these patients.'<sup>153</sup> There was consensus that it would be

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<sup>147</sup> Name Withheld, *Submission 112*, p. 3; Name Withheld, *Submission 61*, p. 3; Ms Monica Clonda, *Submission 42*, p. 1; Name Withheld, *Submission 116*, p. 4.

<sup>148</sup> Ms Maree Kratzer, *Submission 101*, p. 3.

<sup>149</sup> Miss Zara D'Cotta, *Submission 68*, p. 8.

<sup>150</sup> Name Withheld, *Submission 30*, p. 1.

<sup>151</sup> Ms Nicole A., *Submission 120*, p. 4.

<sup>152</sup> Ms Monica Clonda, *Submission 42*, p. 1.

<sup>153</sup> Dr Liz Stringer, *Submission 90*, p. 3.

beneficial to CIRS patients for doctors to recognise CIRS<sup>154</sup>, or as one inquiry participant suggested ‘to see this medical issue being recognised in the “medical world”’.<sup>155</sup>

3.77 Recommendations included initiatives to increase awareness of the need for mould prevention and management<sup>156</sup> and mould-related illness<sup>157</sup> for the medical community, architects, builders and other trades, the public, hotels and accommodation providers, schools and day-care centres.<sup>158</sup> Mrs Nicole A. raised similar concerns and stated that she ‘had no idea how dangerous mould could be and people need to be educated and alerted to the dangers’.<sup>159</sup>

## Financial Impacts

3.78 The financial impact of living with CIRS was reported to include costs of: medical consultations, testing and health treatments<sup>160</sup> which were often not covered by Medicare<sup>161</sup>, supplements and dietary changes<sup>162</sup>, moving house<sup>163</sup>, and replacing household contents.<sup>164</sup> Having a reduced capacity to work due to CIRS-attributed symptoms was another significant financial cost commonly reported.<sup>165</sup> Some individual concerns were:

- ‘We have now spent literally thousands of dollars (over \$200 000) including moving house, remediation, buying all new furnishings and belongings, repairs to [our] new house to make suitable for me, medications and medical visits. I have used up much of my

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<sup>154</sup> Name Withheld, *Submission 103*, pp 3-4; Ms Vanessa Lee, *Submission 108*, p. 13.

<sup>155</sup> Name Withheld, *Submission 112*, p. 3.

<sup>156</sup> Ms Diana Eastment, *Submission 4*, p. 5; Name Withheld, *Submission 59*, p. 11.

<sup>157</sup> Name Withheld, *Submission 30*, p. 5; Name Withheld, *Submission 1*, p. 2.

<sup>158</sup> Miss Zara D’Cotta, *Submission 68*, p. 15.

<sup>159</sup> Ms Nicole A., *Submission 120*, p. 5.

<sup>160</sup> Name Withheld, *Submission 34*, p. 5.

<sup>161</sup> Name Withheld, *Submission 80*, p. 6; Ms Angela Eisenhauer, *Submission 49*, p. 1.

<sup>162</sup> Name Withheld, *Submission 11*, p. 2.

<sup>163</sup> Ms Janice Foster, *Submission 18*, p. 7.

<sup>164</sup> Name Withheld, *Submission 36*, p. 4.

<sup>165</sup> Ms Dianne Nolan, *Submission 127*, p. 1; Mr Mark Stuart, *Submission 114*, p. 2; Name Withheld, *Submission 110*, p. 3.

superannuation and my partner is paying a mortgage that is over 40 per cent of his pay. I am unable to work as I am so reactive to places.<sup>166</sup>

- 'The personal financial loss has also been immense, due to direct health costs, such as out of pocket testing, medications, supplements and doctor visits that I estimate as \$75 000 - \$100 000. Other financial costs include loss of income due to inability to work for many years. I can only work part-time at present. I estimate an indirect financial loss of \$750 000 - \$1 000 000 over the 18 years.'<sup>167</sup>
- 'I earned a six-figure salary, and now I have been living off an income that doesn't even cover basic living costs, and I'm not even including rent in this. I'm unable to seek proper specialist medical treatment, because I can't financially. It is crippling. For example, one medication I take is \$700 for a bottle. A bottle lasts five days.'<sup>168</sup>
- '... I haven't been able to work. Once WorkCover payments ceased at the end of last year, our household lost a total income. That's difficult because we've been a two-income family ... It's difficult to go back to being a one-income family. Of course, there are the medical expenses on top of that, so it's reduced income and extra medical expenses.'<sup>169</sup>

## Managing Mould in Buildings

3.79 Strengthening regulations and obligations of real estate agents and landlords to remediate and manage mould was put forward as a way to reduce indoor mould exposure for tenants.<sup>170</sup> This was also supported by an inquiry participant who suggested the development of 'guidelines or regulations ... particularly for commercial and rental properties to ensure air quality does not impact human health'.<sup>171</sup> Another concern raised was that mould-related issues are not always identified in building inspection reports, which may limit the ability of prospective occupants to make informed decisions.<sup>172</sup>

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<sup>166</sup> Ms Lynne McCarty, *Submission 43*, p. 6.

<sup>167</sup> Mr Caleb Rudd, *Submission 65*, p. 1.

<sup>168</sup> Ms Carlene Stratton, Private Capacity, *Official Committee Hansard*, Canberra, 9 August 2018, p. 33.

<sup>169</sup> Mrs Annette Dwyer, Private Capacity, *Official Committee Hansard*, Canberra, 9 August 2018, pp 33-34.

<sup>170</sup> Name Withheld, *Submission 27*, p. 7.

<sup>171</sup> Name Withheld, *Submission 36*, p. 5.

<sup>172</sup> Name Withheld, *Submission 2*, p. 2.

3.80 Gutter installation methods that leave a gap for overflow during significant rain events was identified as a way of avoiding water damage to buildings.<sup>173</sup> One inquiry participant reported being advised by their local council that compliance regarding this issue is a 'grey area'.<sup>174</sup> Similar concerns that were raised included:

- '... compliant installation provides a 10 millimetre gap between the back of the gutter and the front of the fascia ... Our gutters have been installed flush against the fascia, leaving no overflow gap. Overtopping storm water will flood over the eaves lining and into the house.'<sup>175</sup>
- '... I know there are a few building companies of integrity who use the 10 millimetre gap method, but most ... don't comply with gutter installation requirements and are not brought to notice.'<sup>176</sup>

3.81 Inadequate building ventilation resulting in moisture build up was also recognised as a contributor to mould problems.<sup>177</sup>

3.82 Adding to the financial burden of mould-affected properties, insurance did not always cover the cost of mould-related damage to property and/or belongings.<sup>178</sup> One inquiry participant outlined their experience and stated:

'... I disposed of over two-thirds of my belongings as they were contaminated by the biotoxins from the water damaged house and could not be guaranteed to be treated and free from biotoxins in the future ... as the leak in the shower did not meet my contents insurance policy terms of reference I was not able to claim any insurance on my damaged belongings'.<sup>179</sup>

3.83 Current and former tenants had been affected by mould in residential<sup>180</sup> and commercial rental properties.<sup>181</sup> Some recounted protracted dealings with real estate agents and landlords who did not respond satisfactorily or comprehensively to mould in dwellings. One inquiry participant stated:

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<sup>173</sup> Name Withheld, *Submission 10*, p. 1; Mr Manning Clarke, *Submission 15*, p. 1.

<sup>174</sup> Name Withheld, *Submission 21*, p. 1.

<sup>175</sup> Name Withheld, *Submission 10*, p. 2.

<sup>176</sup> Mr Manning Clarke, *Submission 15*, p. 1.

<sup>177</sup> Name Withheld, *Submission 9*, p. 1.

<sup>178</sup> Name Withheld, *Submission 103*, p. 4; Name Withheld, *Submission 19*, p. 3.

<sup>179</sup> Name Withheld, *Submission 36*, p. 4.

<sup>180</sup> Name Withheld, *Submission 13*, p. 1.

<sup>181</sup> Name Withheld, *Submission 141*, p. 1.

'There were many leaks over the years that were either dealt with very leisurely, carelessly or never, despite being reported to the estate agent or landlord ... We often had to wash mould off the walls and ceiling of the lounge, dining room, kitchen, little back room, bathroom and all the internal doors.'<sup>182</sup>

3.84 In addition, a number of individuals with CIRS reported difficulty in finding a mould-free home.<sup>183</sup> Personal experiences included:

- 'The first step of my treatment program was to find a mould free home to live in. With the prevalence of [water damaged buildings] being approximately 40 per cent of new build homes along with the issue of not being able to detect hidden mould in wall cavities, in roof spaces and under floor boards. This was by far the hardest challenge.'<sup>184</sup>
- '... it took over 12 weeks to find an appropriate property to recover in ... I looked at over 30 rentals many of which appeared to be affected by water damage'.<sup>185</sup>

## Concluding Comment

3.85 The illness that has been termed by some as *Chronic Inflammatory Response Syndrome* (CIRS) has been associated with a range of physical and cognitive symptoms, which can affect multiple systems within the body. Commonly reported symptoms by individuals experiencing CIRS included: fatigue, pain, memory and concentration difficulties, disorientation, insomnia, gastrointestinal issues, sinus issues, fever, headaches and respiratory issues.

3.86 The Committee received evidence from individuals who say their exposure to biotoxins is associated with the onset of CIRS. Further, it was put forward that a common cause of biotoxin exposure is through working or living in a building with significant mould growth or water damage.

3.87 CIRS has been defined as a syndrome, which is different from a disease. In particular, the Committee heard that a syndrome may not be supported by a consensus medical view regarding cause, testing and/or treatment and that there are no clinical guidelines pertaining to CIRS or CIRS-like symptoms.

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<sup>182</sup> Name Withheld, *Submission 59*, p. 1.

<sup>183</sup> Name Withheld, *Submission 83*, p. 2; Ms Pamela Connellan, *Submission 84*, p. 1; Name Withheld, *Submission 110*, p. 3; Name Withheld, *Submission 132*, p. 3.

<sup>184</sup> Mrs Lisa Coulburn, *Submission 117*, p. 16.

<sup>185</sup> Name Withheld, *Submission 36*, p. 4.

- 3.88 A range of tests were put forward as being used in combination to determine whether a patient was experiencing CIRS. These included blood and biomarker testing, MRI testing, genetic testing and testing of visual abilities. Treatment that has been used for CIRS also involves a number of steps which can include remediation of a dwelling and/or belongings, and a range of medications. The Committee received evidence that elements of this diagnosis and treatment regime are costly, not widely available in Australia, and may be lengthy.
- 3.89 Many inquiry participants who provided personal accounts of living with CIRS-attributed symptoms stated that they had experienced difficulty in identifying CIRS and then finding effective treatment, and that they had often visited multiple doctors in the interim.
- 3.90 Individuals who provided the Committee with personal accounts of experiencing CIRS also described difficulty in finding a dwelling or workplace that was mould free and did not impact on their health.
- 3.91 Throughout this inquiry, the Committee was presented with a range of views regarding CIRS. The Committee heard from the Department of Health and some medical practitioners that CIRS is not widely recognised in the medical profession, and that there is insufficient medical evidence regarding the identification of a common cause of the symptoms that have been associated with CIRS.
- 3.92 The Committee also heard from other medical practitioners in Australia who have identified and treated CIRS in many patients. In addition, the Committee received personal accounts from individuals who identified as having CIRS or having experienced symptoms associated with CIRS. These individuals outlined the significant financial, health, and social impacts of living with a multi-symptom illness, often for many years.
- 3.93 The Committee was concerned to hear that often desperate individuals experiencing ongoing debilitating symptoms are turned away from mainstream medical practitioners and may be exploited in 'being sold quackery.'
- 3.94 Complex illnesses such as CIRS and other biotoxin-related illnesses can be difficult to diagnose and treat. Consideration of options to improve the diagnosis and treatment of complex illness and unexplained symptoms may help to reduce the social and financial burden for individuals, ensure doctors are provided with adequate support and training, and reduce the resulting impact on the health system.

## **Recommendation 5**

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**3.95 The Committee recommends the Department of Health conduct a review into the treatment of patients presenting with complex illnesses that are difficult to diagnose such as those with CIRS-like symptoms. This review should consider:**

- **methods to ensure patients with complex conditions, such as individuals reporting to have CIRS, are provided with effective and timely treatment and support (with the aim of reducing ‘doctor shopping’); and**
- **whether doctors require further support in order to: identify environmental impacts on health; manage complex conditions; and provide appropriate treatment.**

## **Recommendation 6**

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**3.96 The Committee recommends that the Australian Government commission the National Health and Medical Research Council to conduct research into CIRS-like syndromes with a view to assisting in the diagnosis, treatment and management of patients. Research should also examine any links between mould and biotoxins and complex symptoms most commonly reported as typifying CIRS.**

## **Recommendation 7**

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**3.97 The Committee recommends that the Department of Health, in consultation with patient groups, medical practitioners, and health bodies, develop clinical guidelines for general practitioners for the diagnosis, treatment and management of CIRS-like conditions.**



**Mr Trent Zimmerman MP**  
**Chair**

**8 October 2018**



## A. Submissions

- 1 *Name Withheld*
- 2 *Name Withheld*
- 3 Ms Carlene Stratton
- 4 Ms Diana Eastment
- 5 Ms Teresa Crisp
- 6 Mrs Annette Dwyer
- 7 *Name Withheld*
- 8 Mr Vyvyan Stott
- 9 *Name Withheld*
- 10 *Name Withheld*
- 11 *Name Withheld*
- 12 *Name Withheld*
- 13 *Name Withheld*
- 14 Ms Liz Martin
- 15 Mr Manning Clarke
- 16 *Confidential*
- 17 The Real Estate Institute of New South Wales Limited
- 18 Ms Janice Foster
- 19 Ms Helen Cahill
- 20 Ms Deborah Lee

- 21 *Name Withheld*
- 22 *Name Withheld*
- 23 *Name Withheld*
- 24 *Name Withheld*
- 25 Dr Mary Ackerley
- 26 MouldLab
- 27 *Name Withheld*
- 28 *Name Withheld*
- 29 *Confidential*
- 30 *Name Withheld*
- 31 HydroKleen
- 32 Mrs Karen Gallaty
- 33 Biological Health Services
- 34 *Name Withheld*
- 35 *Name Withheld*
- 36 *Name Withheld*
- 37 *Name Withheld*
- 38 *Name Withheld*
- 39 *Confidential*
- 40 *Confidential*
- 41 *Confidential*
- 42 Ms Monica Clonda
- 43 Ms Lynne McCarty
- 44 ME/CFS and Lyme Association of WA Inc
- 45 Australasian Society of Building Biologists
- 46 *Name Withheld*
- 47 *Name Withheld*
- 48 *Name Withheld*
- 49 Ms Angela Eisenhauer

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- 50 Australian Institute of Occupational Hygienists
- 51 Australasian Integrative Medicine Association
- 52 *Name Withheld*
- 53 Ms Christine Martin
- 54 Stop Smart Meters Australia Inc
- 55 Dr Kenneth Moroney
- 56 Department of Health
- 57 *Name Withheld*
- 58 *Confidential*
- 59 *Name Withheld*
- 60 *Name Withheld*
- 61 *Name Withheld*
- 62 *Name Withheld*
- 63 *Name Withheld*
- 64 *Name Withheld*
- 65 Mr Caleb Rudd
- 66 *Name Withheld*
- 67 *Name Withheld*
- 68 Miss Zara D'Cotta
- 69 Ms Margaret Clarke
- 70 Ducted Air Solutions
- 71 Indoor Air Quality Association Australian Chapter
- 72 Mr Robert Goldsworthy
- 73 Aeris Environmental
- 74 Ms Barbara Olive
- 75 Dr Tim Law
- 76 *Confidential*
- 77 *Confidential*
- 78 *Name Withheld*

- 79 *Name Withheld*
- 80 *Name Withheld*
- 81 *Name Withheld*
- 82 *Name Withheld*
- 83 *Name Withheld*
- 84 Ms Pamela Connellan
- 85 Dr Scott McMahon
- 86 Mr Vince Neil
- 87 *Name Withheld*
- 88 *Name Withheld*
- 89 Mr Ted Donnelly
- 90 Dr Liz Stringer
- 91 Dr Graeme Stringer
- 92 *Name Withheld*
- 93 Dr Kate Barry
- 94 MouldSquad
- 95 *Confidential*
- 96 *Confidential*
- 97 *Name Withheld*
- 98 Mr Don Want
- 99 *Name Withheld*
- 100 *Confidential*
- 101 Ms Maree Kratzer
- 102 *Name Withheld*
- 103 *Name Withheld*
- 104 *Name Withheld*
- 105 Toxic Mould Support Australia
- 106 *Name Withheld*
- 107 *Name Withheld*

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- 108 Ms Vanessa Lee
- 109 Mr Dennis Smith
- 110 *Name Withheld*
- 111 Ms Carolyn Frohmader
- 112 *Name Withheld*
- 113 *Name Withheld*
- 114 Mr Mark Stuart
- 115 National Association of Tenant Organisations
- 116 *Name Withheld*
- 117 Mrs Lisa Coulburn
- 118 *Confidential*
- 119 *Confidential*
- 120 Ms Nicole A
- 121 *Confidential*
- 122 *Confidential*
- 123 *Confidential*
- 124 Dr Sandeep Gupta
- 125 Tenants Victoria
- 126 *Confidential*
- 127 Ms Dianne Nolan
- 128 *Confidential*
- 129 Australian Chronic Infectious & Inflammatory Disease Society
- 130 *Name Withheld*
- 131 *Confidential*
- 132 *Name Withheld*
- 133 Ms Nicole Griffin
- 134 *Name Withheld*
- 135 Ms Jodie Donnelly
- 136 *Confidential*

- 137 *Confidential*
- 138 Greencap Pty Ltd
- 139 Ms Robyn Knight
- 140 *Confidential*
- 141 *Name Withheld*
- 142 The Royal Australasian College of Physicians

## **Form Letters**

A form letter was received from 6 individuals.



## B. Exhibits

- 1 Ms Carlene Stratton  
Article: V Valtonen, *Clinical Diagnosis of the Dampness and Mold Hypersensitivity Syndrome: Review of the Literature and Suggested Diagnostic Criteria*, *Frontiers in Immunology*, vol. 8, August 2017
- 2 Confidential
- 3 Mr David Lark, Mouldlab  
Various articles
- 4 Dr Graeme Edwards, Royal Australasian College of Physicians  
Brochure: *Chronic Multisymptom Illness: summary of clinical guidelines*
  - a) Article: J Jankovic, *Etiology and pathogenesis of Parkinson disease*, UpToDate, August 2018
  - b) Article: K L Chou, *Diagnosis and differential diagnosis of Parkinson disease*, UpToDate, July 2017
- 5 Ms Patricia Greenway, Australasian Integrative Medicine Association  
Brochure: *Information on Australasian Integrative Medicine Association*
- 6 Ms Dianne Nolan  
Article: V Valtonen, *Clinical Diagnosis of the Dampness and Mold Hypersensitivity Syndrome: Review of the Literature and Suggested Diagnostic Criteria*, *Frontiers in Immunology*, vol. 8, August 2017
- 7 Mr Robert Goldsworthy  
Thesis: E Bloom, *Mycotoxins in Indoor Environments*, Lund University, 2008

- a) Article: J Brewer et al., *Detection of Mycotoxins in Patients with Chronic Fatigue Syndrome*, *Toxins*, vol. 5, 2013
- b) Article: R Bush et al., *The Medical Effects of Mold Exposure*, *Journal of Allergy and Clinical Immunology*, vol. 117, no. 2, 2006
- c) Article: A Campbell et al., *Mold and Mycotoxins: Effects on the Neurological and Immune Systems in Humans*, *Advances in Applied Microbiology*, vol. 55, 2004
- d) EM Lab P&K, *ERMI Testing Lab Services Guide*, 2018
- e) EMSL Analytical, *Mold Tape Lift, Bulk, Swab and Wipe Sampling Guide & Mold Air-O-Cell Sampling Guide*, 2018
- f) USA Environmental Protection Agency, *A Brief Guide to Mold, Moisture and Your Home*, 2012
- g) USA Environmental Protection Agency, *The Environmental Relative Moldiness Index: A Research Tool*, 2017
- h) N Gromicko and E Ward, *Tape Sampling for Mold Inspections*, 2018
- i) InspectAPedia, *Validity of Mold Culture Tests*, 2018
- j) Article: G T Kleinheinz et al., *Characterization of Airborne Fungal Levels after Mold Remediation*, *Microbiological Research*, vol. 161, 2006
- k) MouldLab (NSJ EnviroSciences Pty Ltd) *Swab Sampling Guide & Zefon Air-O-Cell Mould Sampling Cassettes*, 2018
- l) Omicsonline, *Biotoxins*, *Journal of Biochemical and Microbial Toxicology*, 2018
- m) Article: S Parkhurst, *Beyond ERMI: Can ERMI be improved*, *The Synergist*, 2009
- n) M A Pinto, *A Quick Primer on the Perils of using ERMI Samples for Post-Remediation Verification for Mold Projects*, 2014
- o) G Rosen, *Is ERMI Testing Being Used for Its Intended Purposes?*, 2015
- p) Article: M Taubel et al., *Application of the Environmental Relative Moldiness Index in Finland*, *Applied and Environmental Microbiology*, vol. 82, 2015
- q) Article: S Vesper, *Correlation between ERMI Values & Other Moisture and Mold Assessment of Homes in the American Healthy Homes Survey*, *Journal of Urban Health: Bulletin of the New York Academy of Medicine*, vol. 86, 2009

- r) Article: J Pitt, *A Bulletin for the Australian Food Industry*, Food Safety & Hygiene, February 1998
- s) Queensland Government, *Aflatoxin Poisoning and Contaminant Issues in Production Animals*, 2017
- t) Aflasafe, *Aflatoxin Standards for Food, Building an Aflatoxin Safe East African Community*, 2015
- u) Grains Research and Development Corporation, *Mycotoxins, Stored Grain*, 2009
- v) Centers for Disease Control and Prevention, *Information for Clinicians Helping Patients with Asthma, Other Respiratory Conditions, and/or Allergies to Mold After a Hurricane or Other Tropical Storm*, 2017
- w) Division of Environmental Hazards and Health Effects, USA National Center of Environmental Health, *Allergy Testing for Persons with Asthma, FAQ*, 2018
- x) Florida Solar Energy Center, *Mold Growth*, 2018
- y) Centers for Disease Control and Prevention, *Facts about Mold and Dampness*, 2017
- z) Article: U Mu et al., *An Overview of Mycotoxin Contamination of Foods and Feeds*, *Journal of Biochemical and Microbial Toxicology*, vol. 1, no. 1, 2017
- 8 TGC APAC Pty Ltd  
*Research analysis leading to predictive based preventative measures*
- a) L Terret, RapidMap Global, *Public Health Mould and Biotoxin Detection, Response and Control Submission*, July 2018
- 9 Dr Ailis O'Carroll  
*Report on Biotoxin-related illnesses in Australia*
- 10 Ms Margaret Clarke  
*FENG SHUI 101: Environments, Moulds and Human Health, A Short Digest of Current Scientific Literature and Summary of Mitigation and Healing Modalities*, July 2013



# C. Hearings and Witnesses

## Thursday, 9 August 2018 – Canberra

*Australasian Society of Building Biologists*

- Mrs Nicole Bijlsma, Vice President

*Australasian Integrative Medicine Association*

- Ms Patricia Greenway, Consumer Board Member

*Australian Chronic Infectious and Inflammatory Disease Society and Australasian College of Nutritional and Environmental Medicine*

- Dr Sandeep Gupta, Board Member

*Building Biology Sydney*

- Mrs Jeanette Williams, Building Biologist

*Dr Mark Donohoe, Private Capacity*

*Dr Tim Law, Private Capacity*

*MouldLab*

- Mr David Lark, Principal Mycologist

*Mr Jeremy Stamkos, Private Capacity*

*Professor Matthew Cook, Professor of Medicine, Australian National University; and Head of Immunology, Canberra Hospital*

*Real Estate Institute of New South Wales (NSW)*

- Ms Nicole Unger, General Counsel

- Mr Stephen Burke, External Advisor

*Royal Australasian College of Physicians*

- Dr Graeme Edwards, Fellow and Regional Councillor (Queensland),  
Faculty of Occupational and Environmental Medicine

*Tenants' Union ACT*

- Ms Deborah Pippen, Executive Officer

*Tenants' Union of NSW*

- Mr Leo Patterson Ross, Senior Policy Officer

*Toxic Mould Support Australia*

- Mr Caleb Rudd, Administrator

*Mrs Anette Dwyer, Private Capacity*

*Ms Carlene Stratton, Private Capacity*

*Ms Diana Eastment, Private Capacity*

*Ms Janice Foster, Private Capacity*

*Ms Pamela Connellan, Private Capacity*

## **Wednesday, 12 September 2018 – Canberra**

*Department of Health*

- Professor Brendan Murphy, Chief Medical Officer
- Dr Gary Lum, Principal Medical Adviser, Office of Health Protection
- Ms Gillian Shaw, Acting First Assistant Secretary, Office of Health Protection
- Mr Michael Ryan, Acting Assistant Secretary, Medical Benefits Schedule (MBS) Policy and Specialist Services Branch, Medical Benefits Division
- Dr Tony Willis, Executive Director, Research Quality & Priorities, National Health and Medical Research Council