

Chapter 1

Introduction

My brother, Scott Chant, had a tick bite at a northern New South Wales property while doing some work there. He found out he had Lyme after seeing a Lyme-literate doctor. That was after probably 12 months of just not knowing. He gave up his fight on 8 February this year. I think every day about what led him to make that decision but, from reading these stories, it is obvious. Being so debilitated, he had to spend his days in bed or on his fold-out chair. It was not the life he envisaged or wanted to live.

I do blame the medical system in Australia. Yes, there were those who were doing their best to help, and I think of those people every day. Without them, he would not have lasted three years. But when the time came that we needed that next step of help, it was not there. Hospital admissions often ended with Scott being sent home and us, the family, being told it was all in his head and we should stop encouraging it. There were really rough nights. I do believe that, if those experiences had been different, Scott would be here right now speaking to you all and telling you his story.¹

1.1 During the course of this inquiry, the Senate Community Affairs References Committee (committee) has heard many personal accounts of Australians suffering from chronic debilitating symptoms who have struggled to access appropriate medical treatment. The committee is deeply concerned to hear that frustration and dismay with the lack of treatment options has contributed to some patients, like Mr Scott Chant, taking their own lives.

1.2 Patients, advocacy groups and medical authorities all recognise that patients are suffering, that their symptoms are real, and that they deserve access to medical treatment.

Terms of reference

1.3 On 12 November 2015, the Senate referred the following matter to the committee for inquiry and report by 20 June 2015: 'the growing evidence of an emerging tick-borne disease that causes a Lyme-like illness for many Australian patients'.

1.4 The terms of reference for this inquiry are:

- (a) the prevalence and geographic distribution of Lyme-like illness in Australia;
- (b) methods to reduce the stigma associated with Lyme-like illness for patients, doctors and researchers;
- (c) the process for diagnosis of patients with a Lyme-like illness, with a specific focus on the laboratory testing procedures and associated quality

1 Mr Matt Chant, *Committee Hansard*, Brisbane, 15 April 2016, p. 15.

assurance processes, including recognition of accredited international laboratory testing;

- (d) evidence of investments in contemporary research into Australian pathogens specifically acquired through the bite of a tick and including other potential vectors;
- (e) potential investment into research to discover unique local causative agents causing a growing number of Australians debilitating illness;
- (f) the signs and symptoms Australians with Lyme-like illness are enduring, and the treatment they receive from medical professionals; and
- (g) any other related matters.²

Conduct of inquiry

1.5 The committee invited submissions by 31 March 2015. As of 3 May 2016, the committee had accepted and published 1171 submissions. An overview of these submissions is provided below.

1.6 As of 3 May 2016, the committee had held three public hearings in Perth (14 April 2016), Brisbane (15 April 2016) and Canberra (20 April 2016).

1.7 The committee agreed to table an interim report for this inquiry on 4 May 2016. Due to the likelihood of the Federal election being called prior to the tabling date for the committee's final report, the committee agreed to table a summary of the evidence it has collected to date. It is the committee's intention that this inquiry will continue into the new parliament, and the committee table its final report later in 2016. The committee will continue to accept submissions to the inquiry following the tabling of this interim report.

Structure of interim report

1.8 This interim report provides a summary of the evidence heard by the committee as of 3 May 2016.

1.9 This interim report consists of four chapters:

- **Chapter 1** provides an outline of the key concepts and an overview of the submissions received to date;
- **Chapter 2** examines the experience of patients suffering chronic debilitating symptoms and the accessibility of treatment;
- **Chapter 3** examines how patients are diagnosed with Lyme-like illness and the available diagnostic testing procedures; and
- **Chapter 4** examines current and future opportunities for further research to assist patients suffering from chronic debilitating symptoms.

Key concepts

1.10 There is considerable debate in Australia and internationally about the terms 'Lyme disease' and 'Lyme-like illness'. The following section outlines the differing views on the following key terms used throughout this report:

- classical Lyme disease;
- chronic Lyme disease; and
- Lyme-like illness.

Classical Lyme disease

1.11 *Lyme borreliosis* (known as Lyme disease) is a tick-borne disease caused by various closely related species of *Borrelia* bacteria. Lyme disease is recognised as one of the most common tick-borne diseases in humans, and is found in parts of the United States of America (US), Europe and Asia. Lyme disease is named after the town of Lyme in Connecticut where it was first recognised in the early 1970s.³

1.12 One of the common species of *Borrelia* known to cause Lyme disease in the US is *Borrelia burgdorferi*. Other *Borrelia* species known to cause Lyme disease have been identified in parts of Europe and Northern Asia (such as *Borrelia afzelii* and *Borrelia garinii*).⁴ These related species of *Borrelia* are referred to as the *Borrelia burgdorferi* sensu lato complex (shortened in this report to '*Borrelia*').⁵

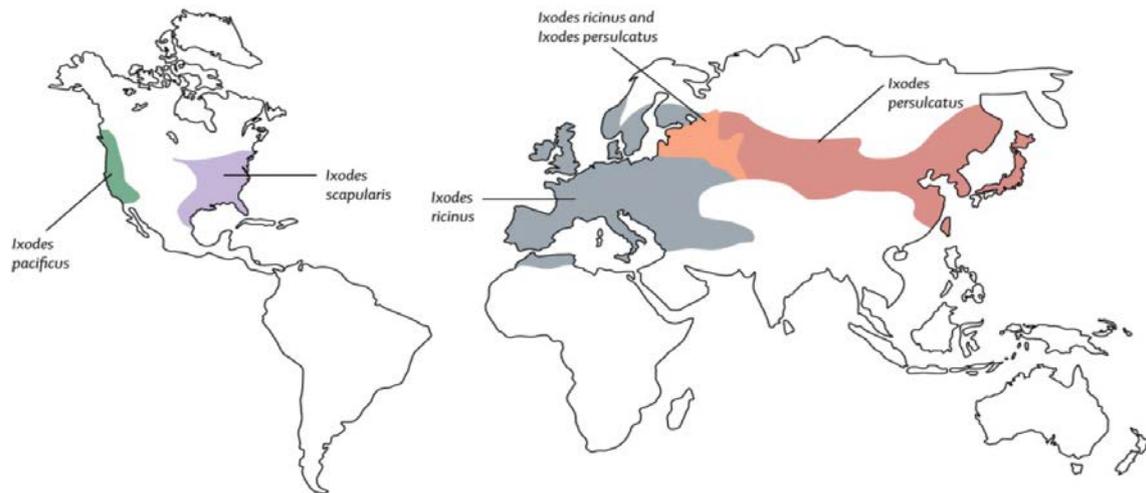
1.13 The most common vectors of the *Borrelia* bacteria known to cause Lyme disease are the *Ixodes* species of ticks. Figure 1.1 shows the global distribution of *Ixodes* ticks known to transmit *Borrelia* bacteria to humans. Lyme disease is considered to be endemic in areas where these vectors carrying *Borrelia* bacteria have been identified.

3 Department of Health, *Submission 495*, p. 2.

4 Professor John Mackenzie, *Scoping study to develop a research project(s) to investigate the presence or absence of Lyme disease in Australia*, 30 September 2013, p. 6, <http://www.health.gov.au/lyme-disease> (accessed 19 November 2015).

5 The committee notes that a number of other *Borrelia* species (not associated with Lyme disease) may cause a range of different diseases in humans and animals, such as *B. recurrentis*, *B. duttonii*, *B. hermsii* and *B. turicatae* (causes relapsing fever and transmitted to humans by lice and ticks in parts of Africa, Asia, southern Europe, North and South America); *B. theileri* (causes bovine borreliosis in cattle and transmitted by cattle ticks); *B. lonestari* (causes STARI – southern tick-associated rash illness – in the US); *B. miyamotoi* (found throughout Eurasia and the US and its role in human disease only recently demonstrated in Russia). See: Mackenzie, *Scoping study*, pp 12–13.

Figure 1.1 – Global distribution of the common vectors of *Borrelia* bacteria known to cause Lyme disease



Source: Professor John Mackenzie, *Scoping study to develop a research project(s) to investigate the presence or absence of Lyme disease in Australia*, 30 September 2013, p. 7.

1.14 Patients with classical Lyme disease commonly display the following key symptoms, depending on the stage of illness:

- **early disease:** erythema migrans (EM – a rash, sometimes in a bulls-eye shape) and an influenza-like illness;
- **early disseminated disease:** multiple EMs, meningitis (acute inflammation of the brain or spinal cord membrane), cranial nerve palsies and carditis (inflammation of the heart); or
- **late stage:** primarily arthritis.⁶

1.15 Lyme disease is regarded as an 'emerging disease', with increasing numbers of cases identified worldwide since the discovery of *B. burgdorferi* 1981 in the US. Estimates suggest there are over 65 000 cases in Europe and over 20 000 cases in the US annually. Professor John Mackenzie's 2013 scoping study on Lyme disease notes that these figures:

...may be a significant underestimate with many cases unreported, and compounded by the small number of countries in Europe to make Lyme disease notifiable, and the actual total may be closer to 255,000 cases annually.⁷

1.16 The US Centers for Disease Control and Prevention (CDC) reports that approximately 30 000 cases of Lyme disease are reported each year in the US but

⁶ Mackenzie, *Scoping study*, p. 5.

⁷ Mackenzie, *Scoping study*, p. 5.

notes that this number does not reflect every case of Lyme disease diagnosed.⁸ In 2013, the CDC suggested that as many as 300 000 people may be diagnosed with Lyme disease in the US each year.⁹

1.17 According to the Communicable Diseases Network Australia (CDNA), a standing committee of the Australian Health Protection Principal Committee (AHPPC), classical Lyme disease is a 'well-defined clinical entity', with a 'clear case definition' that can be confirmed by laboratory, clinical and epidemiological evidence.¹⁰

1.18 The Australian Department of Health's (department) guidelines for treating a confirmed case of classical Lyme disease acquired overseas in an endemic area, consistent with the Infectious Disease Society of America's (IDSA) guidelines,¹¹ recommend a short course of antibiotic treatment of two to four weeks.¹²

Chronic Lyme disease

1.19 Whereas 'classical' Lyme disease is clearly defined, there is considerable debate about the definition of what some practitioners refer to as 'chronic' Lyme disease. The committee recognises that this debate is not unique to Australia and is part of a global debate about 'chronic' Lyme disease.¹³

1.20 The controversy about 'chronic' Lyme disease centres on whether or not an ongoing, active *Borrelia* bacterial infection can result in chronic, debilitating symptoms. The debate is divided on two key questions:

- whether the symptoms described as 'chronic' Lyme disease are caused by an ongoing infection with *Borrelia* bacteria; or

8 US Centers for Disease Control and Prevention (CDC), 'How many people get Lyme disease?' <http://www.cdc.gov/lyme/stats/humancases.html> (accessed 9 December 2015).

9 US CDC, 'CDC provides estimate of Americans diagnosed with Lyme disease each year', 19 August 2013, <http://www.cdc.gov/media/releases/2013/p0819-lyme-disease.html> (accessed 21 April 2016).

10 CDNA, *Submission 531*, pp 1–2.

11 Infectious Disease Society of America, 'Lyme Disease', <http://www.idsociety.org/Lyme/> (accessed 8 December 2015). See: Gary Wormer et al, 'The Clinical Assessment, Treatment, and Prevention of Lyme Disease, Human Granulocytic Anaplasmosis, and Babesiosis: Clinical Practice Guidelines by the Infectious Diseases Society of America', *Clinical Infectious Diseases*, vol. 43, no. 9, pp 1089–1134, <http://cid.oxfordjournals.org/content/43/9/1089.full> (accessed 8 December 2015).

12 Department of Health, 'An Australian guideline on the diagnosis of overseas acquired Lyme Disease/Borreliosis', August 2015, <http://www.health.gov.au/lyme-disease> (accessed 27 April 2016). See: *Submission 495*, Attachment K.

13 See for example: HM Feder et. al, 'A critical appraisal of "chronic Lyme disease"', *New England Journal of Medicine*, v. 357, 2007, pp 1422–1430, <http://www.nejm.org/doi/full/10.1056/NEJMra072023> (accessed 21 April 2016); Adriana Marques, 'Chronic Lyme Disease: An appraisal', *Infectious Disease Clinics of North America*, v. 22, n. 2, June 2008, pp 341–360, <http://www.ncbi.nlm.nih.gov/pmc/articles/PMC2430045/> (accessed 21 April 2016).

- whether these symptoms are the result of a separate condition, or range of conditions, with a different underlying cause (such as residual damage from a previous infection).¹⁴

1.21 Patient advocacy groups and some medical practitioners in Australia and overseas argue that chronic Lyme disease is caused by an active ongoing infection with *Borrelia* bacteria, often with a number of other 'co-infections'.¹⁵ For example, the International Lyme and Associated Diseases Society (ILADS) argues that these chronic symptoms are a direct result of *Borrelia* infection and advocate for greater acceptance and recognition of 'chronic' Lyme disease in the US and internationally.¹⁶

1.22 In Australia, the Lyme Disease Association of Australia (LDAA), representing patients diagnosed with Lyme disease, states that most patients are suffering from 'chronic' stage symptoms of Lyme disease:

The later stage of Lyme disease is referred to as chronic or late stage and is usually marked by a progressive set of debilitating symptoms. Given the time it takes for Australian patients to reach a diagnosis for their Lyme-like illness ... this means that the majority of patients are in the chronic / late stage disease.¹⁷

1.23 Some Australian medical practitioners, such as those associated with the Australian Chronic Infectious and Inflammatory Disease Society (ACIIDS), argue that if classical, or acute, Lyme disease is not treated, it can become chronic:

If the disease is left untreated patients often develop chronic Lyme-like Illness. Chronic Lyme-like Illness can cause a wide variety of symptoms, and in some cases profound disability.

The most common symptoms of chronic Lyme disease are fatigue, headache, muscle and joint pains and cognitive impairment ('brain fog') with poor memory and concentration.

Other symptoms of chronic Lyme-like Illness can include sharp pains, numbness or pins and needles in the limbs, sensitivity to light and sound, sore throat, swollen glands, sleep disturbance, palpitations, limb weakness, muscle twitching, non-epileptic seizures, anxiety, depression, panic attacks, constipation, dizziness, vertigo, fainting episodes, double vision and tinnitus (ringing in the ears).¹⁸

14 Department of Health, *Submission 495*, p. 2.

15 See: Lyme Disease Association of Australia (LDAA) *Submission 528*, Australian Chronic Infectious and Inflammatory Disease Society (ACIIDS) *Submission 370*, Dr Richard Schloeffel *Submission 2*, and Dr Hugh Derham *Submission 453*.

16 International Lyme and Associated Diseases Society, 'About Us', <http://www.ilads.org/ilads/about-ilads.php> (accessed 8 December 2015).

17 LDAA, *Submission 528*, p. 57.

18 ACIIDS, *Submission 370*, p. [11].

1.24 These practitioners argue that treatment for 'chronic' Lyme disease is different to classical Lyme disease and recommend the use of long-term antibiotics and other treatments. These treatments are discussed in detail in **Chapter 2**.

1.25 In the US, the National Institute of Allergy and Infectious Diseases (NIAID) notes that most medical experts in the US do not support the use of the term 'chronic' Lyme disease as it may be used to describe a wide range of illnesses that are not related to infection with the *Borrelia* bacteria known to cause Lyme disease:

The term 'chronic Lyme disease' (CLD) has been used to describe people with different illnesses. While the term is sometimes used to describe illness in patients with Lyme disease, in many occasions it has been used to describe symptoms in people who have no evidence of a current or past infection with *B. burgdorferi*...Because of the confusion in how the term CLD is employed, experts in this field do not support its use...¹⁹

1.26 The US CDC suggests that 'chronic Lyme disease' is better defined as Post-Treatment Lyme Disease Syndrome (PTLDS). The CDC notes that there is significant controversy about the diagnosis and treatment of PTLDS:

The exact cause of PTLDS is not yet known. Most medical experts believe that the lingering symptoms are the result of residual damage to tissues and the immune system that occurred during the infection...In contrast, some health care providers tell patients that these symptoms reflect persistent infection with *Borrelia burgdorferi*.²⁰

1.27 Dr Gary Lum, Principal Medical Adviser in the Department of Health's Office of Health Protection, told the committee that Australian medical authorities, like their counterparts in the US, do not support the use of the term 'chronic' Lyme disease, and do not accept that the cause is an active, ongoing *Borrelia* infection:

The issue of chronic Lyme disease assumes that there is persistent, active infection. That is what is so contentious. The mainstream conventional position is that the sequelae that we see after an infection is post-infectious and not active infection ... So, in Australia, like in many other countries that we would be like-minded with in terms of medicine, the experts in microbiology and infectious disease will not readily accept that there is chronic Lyme disease or chronic persistent active infection. So, for that reason, and because of the association between what is happening in Australia with chronic Lyme disease, most of the medical profession expert in this field do not accept that it is Lyme disease.²¹

1.28 The committee received a number of submissions from Australian medical authorities that do not support the use of the term 'chronic' Lyme disease and do not agree that the chronic debilitating symptoms described by Australian patients are

19 National Institute of Allergy and Infectious Diseases, 'Chronic Lyme Disease', <http://www.niaid.nih.gov/topics/lymeDisease/Pages/chronic.aspx> (accessed 1 December 2015).

20 'Post-Treatment Lyme Disease Syndrome', US Centers for Disease Control and Prevention, <http://www.cdc.gov/lyme/postlds/index.html> (accessed 1 December 2015).

21 Dr Gary Lum, Department of Health, *Committee Hansard*, Canberra, 20 April 2016, p. 10.

caused by an ongoing infection of *Borrelia* bacteria.²² For example, NSW Health submitted that 'chronic' Lyme disease is used to describe a wide range of non-specific symptoms that may not be linked to infection with *Borrelia* bacteria:

The word 'chronic' has also been applied to Lyme disease in a wide variety of contexts and is sometimes used interchangeably with the preferred term 'late Lyme disease.' The chronic Lyme disease term is used by a small number of doctors (often described as 'Lyme-literate physicians') and patient advocacy groups to describe patients whom they believe have persistent *B. burgdorferi* infection, a condition they suggest requires long-term antibiotic treatment and/or a range of other treatments with little evidence of clinical benefit but with a significant risk of harm.

Although chronic Lyme disease can encompass post-Lyme disease syndrome in regions with endemic *B. burgdorferi* disease, it also includes a broad array of illnesses or symptom complexes for which there is no reproducible or convincing scientific evidence of any relationship to *B. burgdorferi* infection. Chronic Lyme disease is increasingly used as a diagnosis for patients with persistent pain, neurocognitive symptoms, fatigue, or all of these symptoms, with or without clinical or laboratory evidence of previous early or late Lyme disease.²³

Lyme-like illness

1.29 The committee heard that patient advocacy groups use the term 'Lyme-like illness' to describe the diagnosis by 'Lyme literate' practitioners of a range of infections that include *Borrelia* and co-infections such as *Babesia*, *Bartonella*, *Ehrlichia*, *Anaplasma* and *Mycoplasma pneumoniae*. For example, the terms 'Lyme disease', 'Lyme-like illness' or simply 'Lyme' are used interchangeably by the LDAA to describe this diagnosis.²⁴ Ms Rebecca Vary from the LDAA told the committee:

Lyme-like illness is caused by a constellation of different organisms: bugs, viruses and protozoans—a cocktail of pathogens that are making people sick ... What we can say is that, whatever you want to call it, there are commonalities in the symptoms experienced by patients. In many Australians sick for months, years and decades it is already chronic, it is debilitating, it is lifelong and it is sometimes deadly.²⁵

1.30 However, this definition of 'Lyme-like illness' (i.e. *Borreliosis* with a range of co-infections) is not recognised by Australian Commonwealth, state or territory

22 See: NSW Health, *Submission 457*; Australasian Society for Infectious Diseases Inc, *Submission 496*; Royal Australasian College of Physicians, *Submission 754*; Royal College of Pathologists Australasia, *Submission 532*.

23 NSW Health, *Submission 457*, p. 1.

24 Lyme Disease Association of Australia, *Submission 528*, p. 5.

25 Ms Rebecca Vary, *Committee Hansard*, Perth, 14 April 2016, p. 18.

governments, or Australian medical authorities.²⁶ The CDNA noted in its submission that the term may be used to describe a range of conditions:

The term 'Lyme-like illness' is used by some patients and health practitioners to describe constellations of symptoms, but what is included and what is not included within the spectrum of 'Lyme-like illness' has not been defined. Unlike most other diseases or conditions for which there are published, widely accepted definitions of the criteria required to be met in order to make a diagnosis of that disease or condition, the term 'Lyme-like illness' is applied to a variety of illnesses which may include an acute illness with headache, fever and fatigue which lasts weeks or months and a non-specific chronic illness with symptoms such as headache, myalgia, and arthralgia.²⁷

1.31 Evidence from submissions suggests that 'Lyme-like illness' may be used to describe a range of conditions, beyond those diagnosed by 'Lyme literate' practitioners, including:

- classical Lyme disease, caused by an acute infection caused by *Borrelia* bacteria transmitted to humans by ticks;
- 'chronic' Lyme disease and a range of 'co-infections' from bacteria;
- an infection of unknown cause transmitted by ticks or other vectors (such as mosquitoes or lice); or
- an illness of unknown cause and exhibiting a range of non-specific symptoms similar to chronic fatigue syndrome, fibromyalgia or multiple sclerosis.

1.32 The committee heard that 'Lyme-like illness' may be used to describe a range of different 'chronic debilitating illness that manifests as a constellation of chronic debilitating symptoms', not necessarily an acute or chronic infection of *Borrelia* bacteria and co-infections.²⁸ The Chief Medical Officer, Professor Chris Baggoley, told the Community Affairs Legislation Committee that there is unlikely to be a single cause for the range of conditions described by patients as 'Lyme-like illness':

There is no doubt there is quite a division and certainly a weight of opinion on the side of the infectious disease specialists and pathologists in this country who say there is not likely to be a unitary cause for their condition.²⁹

1.33 Similarly, the Australian Medical Association (AMA) submitted that it is not clear whether 'Lyme-like illness' is a single condition, or a range of conditions:

It is currently not clear if the 'Lyme-like illness' is one single condition or a collection of different illnesses that have overlapping clinical symptoms.

26 See: WA Department of Health, Submission 529; Victorian Department of Health and Human Services, *Submission 547*; NSW Health, *Submission 457*.

27 Communicable Diseases Network Australia, *Submission 531*, p. 1.

28 Dr Gary Lum, *Committee Hansard*, Canberra, 20 April 2016, p. 5.

29 Professor Chris Baggoley, *Estimates Hansard*, 10 February 2016, p. 19.

This is a significant issue for treating practitioners as many patients present with symptoms that are similar to other chronic conditions.³⁰

Related and concurrent inquiries

Department of Health

1.34 In 2013, the Chief Medical Officer convened a Clinical Advisory Committee on Lyme Disease (CACLD) to provide advice on 'the evidence for Lyme disease in Australia, diagnostic testing, treatment and research requirements'.³¹ The CACLD met five times and held its final meeting on 15 July 2014. Although the CACLD formally ceased in 2014, it continues to consult with the department on research developments related to Lyme disease.³² In consultation with the CACLD, the department has undertaken a number of projects including:

- commissioning Professor John Mackenzie to complete a scoping study in 2013 to identify 'research needs for an investigation into whether a causative tick-borne microorganism (*Borrelia*) for Lyme disease exists in Australia';³³
- hosting the Lyme Disease Treatment Round Table Meeting on 27 May 2014 with members of the CACLD, general practitioners and other medical professionals to identify research projects;³⁴
- contracting the National Serology Reference Laboratory to undertake an evaluation of the serology assays currently used for the diagnosis of Lyme disease (currently in progress);
- developing the *Australian guideline on the diagnosis of overseas acquired Lyme disease/borreliosis* together with the Diagnostic Pathway Working Group, state and territory governments, the Public Health Laboratory Network and the Communicable Diseases Network Australia;³⁵ and

30 Australian Medical Association (AMA), *Submission 456*, p. 4.

31 For terms of reference, see: Department of Health, Clinical Advisory Committee on Lyme Disease (CACLD), <http://www.health.gov.au/internet/main/publishing.nsf/Content/ohp-cacl-d-lyme-disease.htm> (accessed 18 November 2015).

32 Professor Chris Baggoley AO, Chief Medical Officer, *Progress Report on Lyme Disease in Australia*, 31 July 2014, <http://www.health.gov.au/lyme-disease> (accessed 18 November 2015).

33 Professor John Mackenzie, *Scoping study to develop a research project(s) to investigate the presence or absence of Lyme disease in Australia*, 30 September 2013, p. 4, <http://www.health.gov.au/lyme-disease> (accessed 19 November 2015).

34 Department of Health, *Lyme Disease Treatment Round Table Meeting*, 27 May 2014, <http://www.health.gov.au/lyme-disease> (accessed 19 November 2015).

35 See: Department of Health, *An Australian guideline on the diagnosis of overseas acquired Lyme Disease/Borreliosis*, August 2015, <http://www.health.gov.au/lyme-disease> (accessed 7 January 2015).

- developing a revised tick bite education product together with the National Arbovirus and Malaria Advisory Committee and state and territory governments.³⁶

1.35 The department has previously advised the Community Affairs Legislation Committee during 2015-16 Supplementary Estimates that it is currently developing a 'national strategic framework for chronic diseases that will move away from a disease specific approach and address a broader range of chronic diseases'.³⁷

1.36 The committee notes that in March 2016, the Minister for Health, the Hon Sussan Ley MP announced the *Healthier Medicare* package to provide tailored care plans for patients with chronic diseases and complex conditions.³⁸ As part of the package, the department will trial the 'Health Care Homes' measure over two years to coordinate, manage and support care for approximately 65 000 patients with chronic diseases and complex conditions.³⁹

Department of Veterans' Affairs

1.37 In May 2015, the Repatriation Medical Authority (RMA) established an inquiry into whether Lyme disease could be related to eligible military service, including:

...whether there is information available about how Lyme disease may be suffered or contracted, or death from Lyme disease may occur, and the extent to which Lyme disease or death from Lyme disease may be war-caused, defence-caused, a service injury, a service disease or a service death.⁴⁰

1.38 The RMA presented its Statement of Principles concerning Lyme disease on 4 April 2016.⁴¹ The RMA found that 'that there is sound medical-scientific evidence that indicates that Lyme disease and death from Lyme disease can be related to

36 Professor Chris Baggoley AO, Chief Medical Officer, *Progress Report on Lyme Disease in Australia*, 20 August 2015, <http://www.health.gov.au/lyme-disease> (accessed 18 November 2015).

37 Department of Health, Response to question on notice SQ15-000771, Supplementary Estimates, 21 October 2015 (received 11 December 2015).

38 The *Healthier Medicare* package is a core part of the Australian Government's response to the recommendations of the Department of Health's Primary Health Care Advisory Group Report, *Better Outcomes for people with Chronic and Complex Health Conditions*, December 2015. See: <http://www.health.gov.au/internet/main/publishing.nsf/Content/primary-phcag-report> (accessed 22 April 2016).

39 Department of Health, 'A Healthier Medicare for chronically-ill patients', Joint Media Release, 31 March 2016, <https://www.health.gov.au/internet/ministers/publishing.nsf/Content/health-mediarel-yr2016-ley021.htm> (accessed 22 April 2016).

40 Repatriation Medical Authority, Notice of Investigation: Section 196G of the *Veterans' Entitlements Act 1986*, 12 May 2015, <http://www.rma.gov.au/investigations/year/2015> (accessed 4 December 2015).

41 Repatriation Medical Authority, Lyme Disease, 4 April 2016, <http://www.rma.gov.au/sops/condition/lyme-disease> (accessed 21 April 2016).

particular kinds of service', where Lyme disease was acquired overseas in an endemic area.⁴²

Parliamentary inquiries

1.39 As part of its inquiry into chronic disease prevention and management in primary health care, the House of Representatives Standing Committee on Health held a public hearing on Lyme disease on 18 September 2015 in Sydney. The hearing included a roundtable discussion on the diagnosis, treatment and lived experience of Lyme-like illness with key stakeholders including Lyme disease support groups, medical practitioners and researchers. This inquiry is ongoing.⁴³ The committee notes the evidence provided to the House of Representatives Standing Committee on Health as part of this inquiry.

1.40 Notices of motion calling on the Government to support further research into Lyme disease have been raised in both the House of Representatives and Senate throughout 2015.⁴⁴

Overview of submissions

1.41 The committee has received over 1100 submissions to this inquiry to date. A small proportion of submissions were from medical practitioners, medical authorities and Commonwealth, state and territory governments.

1.42 The majority of submissions to the inquiry were from or on behalf of Australians who are suffering from chronic debilitating symptoms. In addition to submissions, the committee received over 250 short statements from the families and friends of patients expressing their support for the inquiry and urging changes to better assist patients to access appropriate treatment.

1.43 The majority of submissions from patients who are experiencing chronic debilitating symptoms came from NSW, Queensland, Victoria and Western Australia. Table 1.1 outlines the distribution by jurisdiction of 1017 submitters to this inquiry.⁴⁵

42 Explanatory Statement, Statement of Principles concerning Lyme disease (Reasonable Hypothesis) (no. 25 of 2016), 4 April 2016, <http://www.rma.gov.au/sops/condition/lyme-disease> (accessed 21 April 2016).

43 House of Representatives Standing Committee on Health, *Inquiry into Chronic Disease Prevention and Management in Primary Health Care*, http://www.aph.gov.au/Parliamentary_Business/Committees/House/Health/Chronic_Disease (accessed 7 December 2015).

44 See: Senator Claire Moore, *Senate Hansard*, No. 9–20 August 2015, p. 5885; Mr Ken Wyatt MP, *House of Representatives Hansard*, Federation Chamber, 20 August 2015, p. 9114; Ms Gai Brodtmann MP, *House of Representatives Hansard*, Federation Chamber, 17 August 2015, p. 8614; Ms Jill Hall MP, *House of Representatives Hansard*, Federation Chamber, 17 August 2015, pp 8586–8589; Mr Stephen Jones MP, *House of Representatives Hansard*, Federation Chamber, 17 August 2015, pp 8586–8587; Ms Jill Hall MP, *House of Representatives Hansard*, Federation Chamber, 28 May 2015, p. 5137; Mr John Murphy MP, *House of Representatives Hansard*, 15 May 2015, p. 3346.

Table 1.1 – Geographical distribution of submissions by jurisdiction at 30 April 2016

Jurisdiction	Number of submissions
NSW	344
Queensland	201
Victoria	200
Western Australia	193
Other (SA, ACT, NT, Tasmania)	71

1.44 A common theme throughout the submissions was of patients presenting to their local GP or medical practitioner with chronic and debilitating symptoms. In some cases they received a diagnosis for a range of non-specific conditions including chronic fatigue syndrome (CFS), fibromyalgia, Epstein-Barr virus or a mental health related condition such as depression. In other cases, they were referred on to multiple specialists and other practitioners who were not able to determine the cause of their illness. In some cases, submitters reported having visited over 20 or more medical practitioners and specialists to seek a diagnosis.⁴⁶

1.45 Submitters highlighted that the impact of these long-term, chronic debilitating symptoms are devastating. The committee heard countless accounts of how the lives of patients and their families have been adversely affected. Some submitters have been unable to work due to their illness or due to taking on carer responsibilities for an ill partner, relative or friend. The significant costs involved in managing a long-term illness have also pushed many submitters into significant financial hardship, often reliant on welfare payments or family members for support.⁴⁷

1.46 Submitters expressed significant frustrations that some medical practitioners were not able to diagnose or treat their symptoms. In cases where submitters did receive a diagnosis, they reported that the prescribed treatments were not effective and their condition continued to worsen. These submitters expressed feelings of being 'let down' by Australia's healthcare system.⁴⁸

45 This indicates those submitters who provided their postal address and whose submissions were accepted and published by 30 April 2016. This includes all submissions from each jurisdiction, including over 900 personal submissions, 28 submissions from organisations and a number of submissions from medical practitioners.

46 See, for example: *Submission 121, Submission 178, Submission 202, and Submission 614.*

47 See, for example: *Submission 1014, Submission 277, Submission 548, Submission 700, Submission 615, Submission 262, and Submission 184.*

48 See, for example: *Submission 606, Submission 164, Submission 324, and Submission 595.*

1.47 Submitters expressed particular concern that their descriptions of their symptoms have not been taken seriously by medical practitioners. Many submitters have been told that their symptoms were psychological, and that 'it's all in your head'. These submitters reported feeling humiliated and disrespected by individual medical practitioners, practices and hospitals and expressed significant anger and disappointment at the way they have been treated.⁴⁹

1.48 The committee is deeply concerned by evidence that suggests that this frustration at the lack of diagnosis and treatment has contributed to some Australians taking their own lives. At its public hearings in Perth and Brisbane, the committee heard from the families of individuals who had taken their own lives.⁵⁰ Mrs Meaghan Sullivan, whose brother Mr Scott Chant took his own life in early 2016, told the committee:

These people are being turned away, and they are sick. They are fighting for their lives, and they are having to find treatment on their own as well as battling each day just trying to get through. I do not blame him at all for doing what he did. I would do the same if I was in his shoes. Something needs to change because it is just going to keep happening.⁵¹

1.49 The committee is also particularly concerned by the impact of these symptoms on children. The committee received a number of submissions from parents on behalf of children suffering chronic debilitating symptoms, and from children themselves.⁵² Like adult patients, the committee heard that children experienced particular challenges in seeking a diagnosis and treatment. Ms Marie Huttley-Jackson, whose child suffers from chronic debilitating symptoms, noted in her submission that doctors blamed her parenting for the symptoms, rather than addressing the illness:

On discharge we were told her condition was the result of my bad parenting as I was letting her fake her symptoms. It is very difficult to understand why doctors would treat an unwell child so dismissively and with impunity.⁵³

1.50 Following their frustrations with some medical services, a large proportion of submitters reported seeking out 'Lyme literate' practitioners for assistance. Unlike other medical services, 'Lyme literate' practitioners diagnose the cause of these symptoms as 'Lyme disease' or 'Lyme-like illness'. Those submitters diagnosed with

49 Due to the large amount of criticism of medical practitioners made in submissions, the committee decided to redact the names of all practitioners, practices and hospitals from submissions.

50 At its hearings in Perth, the committee heard from Ms Michelle Nettle and Ms Carol Adams whose children had taken their own lives following a long battle with chronic debilitating symptoms. See: *Committee Hansard*, Perth, 14 April 2016, pp 47–49.

51 Mrs Meaghan Sullivan, *Committee Hansard*, Brisbane, 15 April 2016, p. 18.

52 To protect the privacy of children, the committee decided to redact the names of all children named in submissions. The committee also decided to accept any submission from children as unpublished correspondence.

53 Ms Marie Huttley-Jackson, *Submission 415*, p. 3.

Lyme-like illness by these practitioners expressed significant relief and hope at having finally received a diagnosis and options for treatment. One submitter noted:

What a relief to know that my symptoms had a name and I got my mind set on what to do next.⁵⁴

1.51 However, due to the controversy in Australia and overseas about 'Lyme disease' and 'Lyme-like illness' submitters reported that they experienced significant challenges in having their diagnosis recognised and accessing treatment. These challenges are examined in detail in **Chapter 2**.

Prevalence of Lyme-like illness

1.52 As Lyme-like illness is not clearly defined and not formally reported on, available statistics on its incidence across Australia are limited. The committee notes that there is no official data on the number of classical Lyme disease cases acquired overseas or Lyme-like illness acquired in Australia.⁵⁵

1.53 The committee heard that in 2013 the CDNA reviewed whether Lyme disease should be added to the National Notifiable Diseases List. The Joint Criteria Assessment Group, using the standard set of endorsed criteria developed by CDNA in 2008, concluded that:

... inclusion was not warranted as Lyme disease did not satisfy a majority of the endorsed criteria and there was no definitive evidence of Lyme disease being acquired in Australia.⁵⁶

1.54 Medical authorities state that without a clear and agreed definition, the prevalence of Lyme-like illness cannot be accurately estimated. For example, the Victorian Department of Health and Human Services submitted that:

It is not possible to describe the prevalence and geographic distribution of Lyme-like illness in Australia, as there is no agreed definition of 'Lyme-like illness'. A clear definition is required to diagnose a person with a particular condition, as is required for any medical condition irrespective of its cause. Without being able to definitively diagnose a person with a condition, it is not possible to count the number of people who have the condition, and therefore describe how frequent it is or where it occurs.⁵⁷

1.55 However, patient advocacy groups state that Lyme-like illness should be made a notifiable disease, and that the CDNA decision should be reviewed in light of

54 *Submission 519*, p. [1].

55 The committee heard that in Western Australia, relapsing fever (caused by a different species of *Borrelia*) was removed from the list of notifiable diseases in 2007 as no cases had been reported. The WA Department of Health advised that the removal of relapsing fever from the list of notifiable diseases was in accordance with the CDNA's guidelines and criteria for assessing whether an infectious disease should be notifiable. See WA Department of Health, Response to question on notice, received 22 April 2016.

56 CDNA, *Submission 531*, p. 7.

57 Victorian Department of Health and Human Services (DHHS), *Submission 547*, p. 1.

the increasing number of patients being diagnosed with the condition.⁵⁸ Ms Elaine Kelly for Sarcoidosis Lyme Australia told the committee that the decision by the CDNA was:

... based on a situation which is already changing and on rationale comments which are fundamentally flawed and frequently based on semantics and bureaucratic subjective opinions.⁵⁹

1.56 In its submission, the LDAA stated that based on data it had collected through online patient surveys, 1051 Australians have been diagnosed with Lyme-like illness since 2012. The LDAA estimates that these figures are the 'tip of the iceberg when it comes to the real incidence of Lyme-like illness in Australia'.⁶⁰ Ms Sharon Whiteman, President of the LDAA, told the committee that the LDAA estimates that:

... based on US figures, we expect there to be about 22 000 new cases of Lyme-like illness in Australia per year, and up to 450 000 cases from the past 22 years of stubborn and entrenched denial by our health officials.⁶¹

1.57 However, some state and territory governments challenged the notion that there is an 'epidemic' of Lyme-like illness in Australia. The Western Australian Department of Health noted in its submission that incidence of Lyme-like illness is probably overstated and reflects instead frustration with the Australian health system:

Lyme-like illness probably appears far more common than it actually is because one person with Lyme-like illness can write multiple letters to the Health Minister, their local Parliamentarian and other Parliamentarians. Their friends, families and peer support groups also write letters about the same person to multiple Parliamentarians. This probably reflects their frustration with the Australian health system, which they perceive as not meeting their needs and expectations, rather than an 'epidemic' of Lyme disease in Australia.⁶²

Definition of Lyme-like illness

1.58 Submitters to the inquiry highlighted that they are not concerned with finding an appropriate name for the debilitating symptoms that they suffer from; what they want is recognition of their illness and access to treatment. Ms Sharon Whiteman from the LDAA told the committee:

...to be honest, as patients we do not really care what it is called. That is not our area. We have progressed to 'Lyme-like' to try and embrace the Lyme

58 See, for example: Global Lyme and Invisible Illness Organisation / Lyme Australia Recognition and Awareness, *Submission 822*, p. 8.

59 Ms Elaine Kelly, *Committee Hansard*, Perth, 14 April 2016, p. 9.

60 According to these surveys, Lyme-like illness disproportionately affects women (73 per cent of respondents were female compared to 27 per cent male). See: LDAA, *Submission 528*, p. 13.

61 Ms Sharon Whiteman, *Committee Hansard*, Brisbane, 15 April 2016, p. 2.

62 WA Department of Health, *Submission 529*, p. 1.

deniers and the single-bug focus, because we are not trying to challenge what it is called; we would just like patients treated.⁶³

1.59 Similarly, Ms Rebecca Bool told the committee in Perth that patients want to be treated with respect by medical practitioners and offered treatment to get better:

We need to be treated with compassion. We need recognition. Ultimately, it does not matter what you name this awful disease; we need you to please help us. We need you to help us feel well. We want to feel well. We do not want to feel like a burden financially and physically on our families, friends and everyone around us in society.⁶⁴

Committee view

1.60 The committee is concerned by evidence from a large number of submitters experiencing a range of chronic debilitating symptoms. The committee recognises the effect of these symptoms on the lives of many Australians and their families.

1.61 The committee acknowledges that for many submitters it does not matter what the illness is called, or what it is caused by; their main concerns are recognising that people are ill and on securing treatment for patients.

1.62 The committee recognises that using the terms classical Lyme disease or chronic Lyme disease risks limiting the scope of the committee's inquiry. For the purposes of this inquiry, the committee prefers the use of the term 'Lyme-like illness' to describe the range of chronic debilitating symptoms experienced by submitters. The committee recognises that this is not a formal acknowledgement of 'Lyme-like illness' as a single entity, but as a broad descriptor for the possible condition or conditions that manifest in chronic debilitating symptoms.

63 Ms Sharon Whiteman, *Committee Hansard*, Brisbane, 15 April 2016, p. 5.

64 Ms Rebecca Bool, *Committee Hansard*, Perth, 14 April 2016, p. 26.

