



Appendix A - Case Study on Tick-Borne and Lyme-Like Diseases

Background

Lyme disease or Lyme borreliosis is a tick-borne illness caused by the bacterium *Borrelia burgdorferi*. The condition causes a wide range of symptoms, including fever, headache, fatigue, sore muscles and joints, and a characteristic skin rash known as *erythema migrans*.¹ Later symptoms of untreated Lyme disease can include severe joint pain, facial palsy, heart palpitations, dizziness or shortness of breath, and short-term memory problems, among others.² According to the Lyme Disease Association of Australia (LDAA), the disease 'can degenerate to a chronic state and can be fatal if left untreated'.³

Lyme disease is carried by ticks belonging to the *Ixodes* genus. Although several *Ixodes* species do exist in Eastern Australia, there has been no recognised evidence of these carrying *Borrelia burgdorferi*.⁴ The Australian *Ixodes holocyclus* is known to cause tick paralysis, tick typhus, and allergic reactions.⁵ Research being conducted by Professor Peter Irwin at Murdoch University has found one case of *Borrelia* 'of

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- 1 NSW Health, 'Lyme Disease', http://www.health.nsw.gov.au/Infectious/factsheets/Pages/Lyme_disease.aspx, viewed 16 March 2016.
 - 2 Centers for Disease Control and Prevention, 'Lyme disease - Signs and Symptoms of Untreated Lyme Disease', http://www.cdc.gov/lyme/signs_symptoms/index.html/, viewed 16 March 2016.
 - 3 Lyme Disease Association of Australia, *Submission 85*, introductory letter, p. 1.
 - 4 NSW Health, 'Lyme Disease', http://www.health.nsw.gov.au/Infectious/factsheets/Pages/Lyme_disease.aspx, viewed 16 March 2016.
 - 5 NSW Health, 'Lyme Disease', http://www.health.nsw.gov.au/Infectious/factsheets/Pages/Lyme_disease.aspx, viewed 16 March 2016. The *Ixodes holocyclus* is known to cause tick paralysis, tick typhus, and allergic reactions.

the relapsing fever group' in an *Ixodes halocyclus* tick, but has not found *Borrelia burgdorferi*.⁶

A growing number of Australians are being diagnosed with tick-borne or Lyme-like illnesses and showing symptoms consistent with Lyme disease, including many who have never left Australia.⁷ The LDAA has been notified of 1 494 cases of individual Australian residents with tick-borne or Lyme-like disease, from 625 tick bite locations across Australia.⁸

Defining Tick-Borne or Lyme-Like Diseases

The LDAA, the Country Women's Association of New South Wales (CWA of NSW), and Dr Richard Schloeffel commented that the term 'Lyme disease' is inappropriate.

The Lyme Disease Association of Australia (LDAA) stated 'Lyme' is too narrow and that 'Lyme-like illness' is appropriate in the absence of some other name.

Ms Alex Patson commented that the term 'Lyme disease' is more appropriate in the American context.⁹ Dr Richard Schloeffel commented that it is only properly called Lyme disease if contracted in America, and suggested the term 'Borreliosis and Co-Infection with Multi System Disorder' or something similar would be more appropriate.¹⁰

The view that a name other than Lyme disease should be adopted was supported by the CWA of NSW,¹¹ Sarcoidosis Lyme Australia,¹² and the Karl McManus Foundation (KMF).¹³

The KMF also stated that 'the other borreliosis infection which is endemic in the world is relapsing fever', stating:

6 Professor Peter Irwin, *Official Committee Hansard*, Sydney, 18 September 2015, p. 4. See also Murdoch University, 'Researchers closer to ending debate around Lyme disease and ticks in Australia', <http://media.murdoch.edu.au/researchers-closer-to-ending-debate-around-lyme-disease-and-ticks-in-australia>, viewed 16 March 2016.

7 Dr Richard Schloeffel, *Submission 162*, p. [2].

8 Lyme Disease Association of Australia, 'The Stats', <<http://www.lymedisease.org.au/stats/>>, viewed 16 March 2016.

9 Ms Alex Patson, Lyme Disease Association of Australia, *Official Committee Hansard*, Sydney, 18 September 2015, p. 30.

10 Dr Richard Schloeffel, *Submission 162*, p. 2.

11 Ms Annie Kiefer, Country Women's Association of New South Wales, *Official Committee Hansard*, Sydney, 18 September 2015, p. 19.

12 Sarcoidosis Lyme Australia, *Submission 166*, p. 5.

13 Dr Mualla McManus, Karl McManus Foundation, *Official Committee Hansard*, Sydney, 18 September 2015, p. 2.

Given that Peter Irwin's work has shown that there is a relapsing fever *Borrelia* in Australian ticks, it is even more important for us to focus on that rather than on Lyme.¹⁴

For the sake of consistency and clarity, this report uses the term 'tick-borne or Lyme-like disease'.

Current Australian Research

The Department of Health established the Clinical Advisory Committee on Lyme Disease (CACLD) in 2013 to advise the Chief Medical Officer on the evidence for tick-borne or Lyme-like disease in Australia, diagnostic testing, treatment, and research requirements. In regard to these diseases, the Department of Health stated:

Through regular communication and correspondence, the department has gained a deeper appreciation and real concern for those Australians experiencing these chronic, debilitating symptoms, which they associate with a tick bite. We wish to remain engaged with the patient and medical community to continue to find, share and understand the evidence associated with this medical conundrum.¹⁵

Professor Peter Irwin, who was part of the CACLD, has been leading a team at Murdoch University which has developed a new method of detecting the DNA of bacteria inside ticks. They have recently found *Borrelia* DNA on a tick taken from a wild echidna. Professor Irwin emphasised that this was found only in one tick out of 196, and that '*Borrelia burgdorferi* has never been found [in Australia].'¹⁶ Professor Irwin suggested that it is likely Australia has something unique.¹⁷

There is broad agreement that further research into the causes of tick-borne illnesses in Australia is essential. The Royal Australian College of General Practitioners (RACGP) stated:

We recognise that in Australia there is a Lyme-like illness with no consistent causative organism, very little epidemiology, unstructured treatment and poor evidence about outcomes of current management. There is a great need for further research into what can be a very

14 Dr Mualla McManus, Karl McManus Foundation, *Official Committee Hansard*, Sydney, 18 September 2015, p. 2.

15 Dr Gary Lum, Department of Health, *Official Committee Hansard*, Sydney, 18 September 2015, p. 3.

16 Professor Peter Irwin, *Official Committee Hansard*, Sydney, 18 September 2015, p. 4.

17 Professor Peter Irwin, *Official Committee Hansard*, Sydney, 18 September 2015, p. 4.

disabling condition for patients. The college would support anything in that direction.¹⁸

Dr Richard Schloeffel 'strongly support[s]' the view that further research and 'rigorous science' is needed.¹⁹

Incidence

The incidence of tick-borne or Lyme-like diseases in Australia is difficult to determine. Dr Richard Schloeffel identified as a 'tentative projection of 102 000 [people] in Australia with chronic borrelial infection'.²⁰ Dr Schloeffel also stated that 'we have no idea how many people may have symptoms that fit this category', emphasising that tick-borne or Lyme-like disease is not a notifiable condition,²¹ but stated that he currently has '400 patients with borreliosis or related illnesses'.²²

The Department of Health (DoH) stated that tick-borne or Lyme-like disease has previously been assessed and was not added to the list of nationally notifiable diseases. The Department of Health explained this was due to a lack of a good case definition and consensus about the cause of the disease.²³ The DoH also suggested that a case definition would need to be developed.²⁴

The KMF stated that part of the difficulty of determining incidence of tick-borne or Lyme-like diseases is due to the non-specific symptoms and unreliable diagnostics of these diseases.²⁵

The RACGP indicated it could not know how widespread tick-borne or Lyme-like disease is as no research has been undertaken into the disease in the Australian context.²⁶

18 Professor Nigel Stocks, Royal Australian College of General Practitioners, *Committee Hansard*, Sydney, 18 September 2015, p. 5.

19 Dr Richard Schloeffel, *Submission 162*, p. 4.

20 Dr Richard Schloeffel, *Submission 162*, Attachment B, p. 4.

21 Dr Richard Schloeffel, *Submission 162*, p. 2.

22 Dr Richard Schloeffel, *Official Committee Hansard*, Sydney, 18 September 2015, p. 6.

23 Dr Gary Lum, Department of Health, *Official Committee Hansard*, Sydney, 18 September 2015, p. 19.

24 Dr Gary Lum, Department of Health, *Official Committee Hansard*, Sydney, 18 September 2015, p. 19.

25 Dr Mualla McManus, Karl McManus Foundation, *Official Committee Hansard*, Sydney, 18 September 2015, p. 2.

26 Professor Nigel Stocks, Royal Australian College of General Practitioners, *Official Committee Hansard*, Sydney, 18 September 2015, p. 7.

Diagnosis

Tick-borne or Lyme-like disease can be diagnosed based on symptoms, physical signs such as the *erythema migrans* or 'bulls-eye' rash, and the possibility of exposure to ticks infected with *Borrelia*. Laboratory testing is undertaken in later stages of the illness. In Australia, a common method of diagnosis of tick-borne illnesses involves an 'ELISA' screening test²⁷ which, if positive, is confirmed by a 'western blot' or 'immunoblot' test.²⁸

Dr Richard Schloeffel suggested the current use of the ELISA test is 'inadequate to assess whether the patients have Borreliosis', and that a better guide is the western blot test or a Polymerase Chain Reaction (PCR) test.²⁹ Dr Schloeffel described the diagnosis process for some of his patients who have acquired and were diagnosed with Lyme disease overseas. This typically involves 'appropriate testing with approved labs' in Germany or America, using immunoblot or PCR testing but not ELISA testing.³⁰

Australian Biologics, a commercial laboratory, stated that it undertakes tests for tick-borne illness which return positives for the *Borrelia* bacteria. Australian Biologics stated that, using immunoblot and EliSpot testing,³¹ it gets positives from patients, including from patients who have never left the country.³²

Australian Biologics has found 'probably five to six types of *Borrelia*' bacteria. Ms Jennie Burke from Australian Biologics stated that they have found 'close to - not quite a perfect match; close to' *Borrelia burgdorferi* in Australian ticks.³³

One of the symptoms of Lyme disease is a characteristic 'bulls-eye' rash called *erythema migrans*. The LDAA indicated that in other countries the presence of this rash is a 'pathognomonic' sign warranting an immediate diagnosis of Lyme disease, but that this advice is not generally followed in Australia. The LDAA stated:

In other countries Lyme disease is diagnosed on clinical signs alone if a 'bullseye' (EM) rash is present. The bullseye rash is known as a 'pathognomonic' sign that warrants an immediate diagnosis of Lyme disease as it is unique to Lyme disease; this is a CDC-agreed diagnostic

27 Enzyme-linked immunosorbent assay.

28 NSW Health, 'Lyme Disease', <http://www.health.nsw.gov.au/Infectious/factsheets/Pages/Lyme_disease.aspx>, viewed 16 March 2016.

29 Dr Richard Schloeffel, *Submission 162*, p. 3.

30 Dr Richard Schloeffel, *Official Committee Hansard*, Sydney, 18 September 2015, pp 6-7.

31 An ELISPOT (enzyme-linked immunospot) assay is a modification of the ELISA test.

32 Ms Jennie Burke, *Official Committee Hansard*, Sydney, 18 September 2015, pp 1-2.

33 Ms Jennie Burke, *Official Committee Hansard*, Sydney, 18 September 2015, p. 6.

position, negating the need for any diagnostic test. In Australia we don't educate doctors about this sign.³⁴

Co-infections

The LDAA stated that tick-borne or Lyme-like disease is often contracted with co-infections, as ticks are able to transmit more than one pathogen. According to the LDAA, 55 per cent of patients with tick-borne or Lyme-like disease reported being diagnosed with at least one co-infection. This is a much higher rate than that reported in the USA.³⁵

Dr Schloeffel lists ten groups of co-infections associated with tick-borne or Lyme-like disease, including: relapsing fever,³⁶ *rickettsias*,³⁷ and chronic viral infections including HIV.³⁸

Treatment

Antibiotics

In cases where patients do test positively for tick-borne or Lyme-like disease, a common experience is for patients to be treated with a short course of antibiotics. The LDAA stated that infectious diseases specialists commonly follow the Infectious Diseases Society of America (IDSA) practice guidelines. However, the LDAA stated that this is 'seen as vastly inadequate by any medical professional that is educated and experienced in treating Lyme-like disease'.³⁹

The LDAA stated that longer term treatment is required in cases where patients have co-infections.⁴⁰ The LDAA also identified the complexity of treatment

34 Lyme Disease Association of Australia, *Submission 85*, p. 2.

35 Lyme Disease Association of Australia, *Submission 85*, p. 2.

36 Dr Schloeffel described his experience with relapsing fever working in Papua New Guinea: 'I think this picture of evolving *Borrelia* relapsing fever would fit the pattern, because it fits the symptom of the patient. When I trained originally I worked in Papua New Guinea in malaria and TB and leprosy... I would look at some of these patients, and they were like they had malaria because they had these relapsing fevers and these funny chronic symptoms where every day, or every third day, they had a massive night sweat where they would completely saturate the bed.' Dr Richard Schloeffel, *Official Committee Hansard*, Sydney, 18 September 2015, p. 7.

37 Rickettsial infections are transmitted to humans by ticks and fleas and fall into one of three groups: spotted fever, typhus, and scrub typhus. Dr Richard Schloeffel, *Submission 162*, Attachment B, pp 3-4.

38 Dr Richard Schloeffel, *Submission 162*, Attachment B, pp 2-4. See also Dr Richard Schloeffel, *Submission 162*, Attachment A, pp 1-2.

39 Lyme Disease Association of Australia, *Submission 85*, p. 2.

40 Lyme Disease Association of Australia, *Submission 85*, p. 2.

pathways due to the 'different infections and different manifestations' patients in Australia present with.⁴¹

The complexity of treating tick-borne or Lyme-like diseases was articulated by Dr Richard Schloeffel, who has treated patients with these illnesses. Dr Schloeffel stated:

The type of treatment that we do is not just about throwing antibiotics at patients.... It is about management and giving the patient an understanding of their illness, making a proper diagnosis, sorting out their mental state and making sure they have carers and community support. It is about providing them with advice about how they should change their diet or improve their eating patterns, providing adequate supplementation for foods and for things that they may require as part of the treatment but also as a result of the treatment. So they will be on vitamins and supplements and other things, which they have often already started because they have already seen six or seven naturopaths before they see you. Then depending on their diagnosis, very gently and slowly, there is an antibiotic protocol. I have many antibiotic protocols, because every patient is different.⁴²

Dr Schloeffel emphasised the importance of not 'bombarding' with doses of antibiotics that are too high.⁴³ This view was shared by the Australasian Society for Infectious Diseases (ASID), which stated:

...it is of no benefit to the patients to treat them long term with antibiotics, which can be potentially harmful and certainly will not help chronic symptoms that are not due to bacterial infection. In the absence of a specific diagnosis, this, I would suggest, is malpractice, if it is not supported by any laboratory diagnosis.⁴⁴

The ASID also stated that most professional bodies in endemic areas have guidelines advising 'short-term antibiotic therapy usually for two weeks', in which time the 'vast majority of patients' will improve.⁴⁵

The RACGP highlighted its concern about antimicrobial resistance to prolonged use of antibiotics and stated:

...we have to be concerned about antimicrobial resistance, as already mentioned, in conditions which may be related to the overuse of antibiotics. Although people are seemingly getting some benefit from

41 Lyme Disease Association of Australia, *Submission 85*, p. 3.

42 Dr Richard Schloeffel, *Official Committee Hansard*, Sydney, 18 September 2015, p. 13.

43 Dr Richard Schloeffel, *Official Committee Hansard*, Sydney, 18 September 2015, p. 17.

44 Professor Lyn Gilbert, *Official Committee Hansard*, Sydney, 18 September 2015, p. 4.

45 Professor Lyn Gilbert, *Official Committee Hansard*, Sydney, 18 September 2015, p. 15.

this anecdotally, we also have to be aware that some patients will be having adverse effects because of long-term antibiotic use.⁴⁶

The KMF commented that in some cases 'the patient has prolonged antibiotic treatment and they can end up with adverse effects from the antibiotics'.⁴⁷

The KMF and LDAA stated, however, that antibiotic treatment would be inadequate if it was not long enough. The KMF stated:

...a short-term treatment [of antibiotics] will not be adequate to actually decrease the bacterial load so that the immune system can take over defeating the infection.⁴⁸

The LDAA stated that international Lyme experts and Lyme-treating doctors in Australia agree that 'four weeks is simply not long enough'.⁴⁹

Dr Schloeffel stated that there are two approaches in the USA to treating Lyme disease: the Centers for Disease Control (CDC) recommends a short course of treatment while the International Lyme and Associated Diseases Society (ILADS) recommends a longer period of therapy.⁵⁰

Other Treatments

Dr Schloeffel, in addition to antibiotic treatment, is also involved in treatment using hyperthermia, a method used in Germany in which the body is heated for nine hours to 41.7 degrees in an intensive care unit. Dr Schloeffel stated that over 1 000 Australians have travelled to Germany to receive this particular treatment, which 'seems to be very effective'.⁵¹

The RACGP stated that as it advocates for evidence based practice it 'cannot support many of the treatments currently being used or advocated', regardless of 'whatever success individual doctors have with their patients'.⁵²

46 Professor Nigel Stocks, Royal Australian College of General Practitioners, *Official Committee Hansard*, Sydney, 18 September 2015, p. 16.

47 Dr Mualla McManus, Karl McManus Foundation, *Official Committee Hansard*, Sydney, 18 September 2015, p. 14.

48 Dr Mualla McManus, Karl McManus Foundation, *Official Committee Hansard*, Sydney, 18 September 2015, p. 14.

49 Ms Sharon Whiteman, Lyme Disease Association of Australia, *Official Committee Hansard*, 18 September 2015, p. 3.

50 Dr Richard Schloeffel, *Submission 162*, p. 3.

51 Dr Richard Schloeffel, *Official Committee Hansard*, Sydney, 18 September 2015, p. 17.

52 Professor Nigel Stocks, Royal Australian College of General Practitioners, *Official Committee Hansard*, Sydney, 18 September 2015, p. 16.

Living With Tick-Borne or Lyme-Like Disease

Several first-hand accounts of Australians living with tick-borne or Lyme-like disease symptoms outlined the debilitating effects their condition has on their lives. Common to all those affected is the long-term nature of their conditions.

Comments from Ms Lynn Rees are a typical representation of the effects of tick-borne or Lyme-like disease on sufferers. Ms Rees recounted her ongoing treatment for the disease and the personal cost:

...even after nearly four years of active treatment, I continue to be ill, though with appropriate treatment I am recovering slowly. My two children, now teenagers, can barely remember when I was an intelligent, healthy and fit mother, and my marriage of 18 years recently collapsed due to the impacts of this disease. The personal cost to my life and career and the impacts Lyme disease has had on my family have been profound.⁵³

Ms Elaine Kelly also related a long-term illness, having been sick for 15 years since travelling to endemic areas.⁵⁴

Mrs Michelle Wheeler outlined how debilitating tick-borne or Lyme-like disease is, speaking of her inability to function and care for her family, and of being bedridden most days.⁵⁵

Mr Christopher Walker described how he was diagnosed with a range of different illnesses over a decade before receiving a clinical diagnosis of borreliosis. Mr Walker, similarly to Mrs Wheeler,⁵⁶ spends \$5000 a month on treatment.⁵⁷

Mr Walker's experience of visiting multiple doctors and receiving various diagnoses was shared by other witnesses. Dr Schloeffel stated that many patients 'often seen multiple specialists and have multiple tests'.⁵⁸ Ms Rees stated that she received 'numerous diagnoses' over four years, including:

...chronic fatigue, systemic lupus erythematosus, post-traumatic stress disorder, anxiety, depression and perimenopause.⁵⁹

Ms Alex Patson and her two children contracted the condition at the same time after bushwalking in Newcastle.⁶⁰ Ms Patson described symptoms including word-block, neurological issues, Parkinson's shakes, arthritic pain, muscle and

53 Ms Lynn Rees, *Official Committee Hansard*, Sydney, 18 September 2015, p. 27.

54 Ms Elaine Kelly, *Official Committee Hansard*, Sydney, 18 September 2015, p. 28.

55 Mrs Michelle Wheeler, *Official Committee Hansard*, Sydney, 18 September 2015, p. 26.

56 Mrs Michelle Wheeler, *Official Committee Hansard*, Sydney, 18 September 2015, p. 26.

57 Mr Christopher Walker, *Official Committee Hansard*, Sydney, 18 September 2015, p. 28.

58 Dr Richard Schloeffel, *Official Committee Hansard*, Sydney, 18 September 2015, p. 17.

59 Ms Lynn Rees, *Official Committee Hansard*, Sydney, 18 September 2015, p. 27.

60 Ms Alex Patson, *Official Committee Hansard*, Sydney, 18 September 2015, pp 29-30.

bone pain and stiffness. At one point Ms Patson also recounted how at one point she lost the use of one arm, could not lift a cup or brush her teeth, could not walk, talk, or get changed.⁶¹

Ms Patson also related her experience of having to visit multiple specialists before being diagnosed with a tick-borne disease.⁶²

Ms Gabrielle Stevens' two daughters developed a tick-borne or Lyme-like illness, and as a consequence they have missed much of their schooling.⁶³ This was also the case for Ms Patson's children.⁶⁴

Another experience some people described was the necessity of travelling to Europe to receive treatment. Ms Stevens lived in Europe for over a year with her children, who underwent treatment in the Netherlands, Germany, and the Czech Republic.⁶⁵

Mr Walker was advised to travel to Germany for treatment but was too sick. He began receiving treatment in Australia and recovered to a point where he no longer needed to travel to Germany for treatment.⁶⁶

The need for many patients to travel to Europe is a great financial burden in addition to the cost of the treatment itself. Dr Schloeffel estimated that overseas blood tests cost between \$1000 and \$2000 per patient.⁶⁷ Additionally, Dr Schloeffel stated that patients who use supplements have an additional cost of \$600 a month for a minor treatment to several thousand a month. Dr Schloeffel estimated treatment costs 'between \$20 000 and \$50 000 a year per patient'.⁶⁸

Ms Rees stated her costs after four years of treatment are nearly \$80 000.⁶⁹ Mrs Wheeler stated the cost of her illness is about \$5000 a month on average and has cost her family their life savings.⁷⁰

Mrs Wheeler also explained the social burdens in addition to the financial costs that people with tick-borne or Lyme-like disease can face, sharing her experience of stress, anger, sadness, guilt, and depression.⁷¹

61 Ms Alex Patson, *Official Committee Hansard*, Sydney, 18 September 2015, p. 30.

62 Ms Alex Patson, *Official Committee Hansard*, Sydney, 18 September 2015, pp 29-30.

63 Ms Gabrielle Stevens, *Official Committee Hansard*, Sydney, 18 September 2015, p. 31.

64 Ms Alex Patson, *Official Committee Hansard*, Sydney, 18 September 2015, p. 30.

65 Ms Gabrielle Stevens, *Official Committee Hansard*, Sydney, 18 September 2015, p. 30.

66 Mr Christopher Walker, *Official Committee Hansard*, Sydney, 18 September 2015, p. 28.

67 Dr Richard Schloeffel, *Official Committee Hansard*, Sydney, 18 September 2015, p. 13.

68 Dr Richard Schloeffel, *Official Committee Hansard*, Sydney, 18 September 2015, p. 18.

69 Ms Lynn Rees, *Official Committee Hansard*, Sydney, 18 September 2015, p. 27.

70 Mrs Michelle Wheeler, *Official Committee Hansard*, Sydney, 18 September 2015, p. 26.

71 Mrs Michelle Wheeler, *Official Committee Hansard*, Sydney, 18 September 2015, p. 26.

Ms Stevens related a similarly exhaustive experience and a 'huge emotional impact', saying her family 'often are afraid' and how they 'hate to see the children suffer'.⁷²

Another recurring experience among Australians living with tick-borne or Lyme-like disease is stigma, including a lack of recognition of their condition in the medical profession.

Ms Rees stated her concern about the lack of acceptance of this disease in Australia, contrasting that with her experience with her employer, who accepts her condition and has 'taken a proactive role' in supporting her.⁷³

Mr Walker also expressed concerns about lack of recognition among the medical profession. Referring to the controversy around the contraction within Australia, he said:

Whether it is contracted here or overseas is irrelevant as to whether the individual is deserving and entitled to being properly treated.⁷⁴

This broad lack of recognition was also discussed by Mrs Wheeler⁷⁵ and Ms Stevens,⁷⁶ and Ms Kelly stated that 'treating GPs have no peer support and no back-up medical support services'.⁷⁷

Concluding Comment

As outlined in this case study, the Committee has received evidence from individuals, advocacy groups, and doctors demonstrating the extent of the difficulties presented by tick-borne or Lyme-like diseases.

The Committee acknowledges the suffering endured by many Australians living with these conditions. They can be debilitating and last for many years. Due to the uncertainty in the medical community about the existence and type of tick-borne or Lyme-like disease and associated conditions in Australia, many patients face a frustrating process before being diagnosed and treated appropriately, if at all. This often involves visiting multiple doctors and sometimes requires travelling to America or Europe. These costs as well as the ongoing costs of treatment and the resulting loss of employment create a significant financial burden on those with the condition. There is also significant cost to a patient's family members.

72 Ms Gabrielle Stevens, *Official Committee Hansard*, Sydney, 18 September 2015, p. 31.

73 Ms Lynn Rees, *Official Committee Hansard*, Sydney, 18 September 2015, pp 27-28.

74 Mr Christopher Walker, *Official Committee Hansard*, Sydney, 18 September 2015, p. 28.

75 Mrs Michelle Wheeler, *Official Committee Hansard*, Sydney, 18 September 2015, p. 26.

76 Ms Gabrielle Stevens, *Official Committee Hansard*, Sydney, 18 September 2015, p. 31.

77 Ms Elaine Kelly, *Official Committee Hansard*, Sydney, 18 September 2015, pp 28-29.

The Committee is aware of the ongoing discussion about the definition of 'Lyme disease' and whether Lyme disease is something that can be contracted within Australia. The Committee acknowledges the concerns about misdiagnosis,⁷⁸ and the possibility of overuse of antibiotics.⁷⁹

The Committee acknowledges the lack of recognition of tick-borne or Lyme-like diseases within the medical community. This was highlighted in the evidence from people living with tick-borne or Lyme-like diseases, who experience a lack of recognition and stigma from much of the medical profession until they find a 'Lyme-literate'⁸⁰ doctor.

One of the consequences of the lack of attention tick-borne or Lyme-like disease has received in the medical community is that very little is known about the incidence of these diseases throughout Australia. The fact that tick-borne or Lyme-like disease is not a notifiable disease was raised in the evidence as a hindrance to knowing more about the disease in this country and the scale of the disease as a social problem. The lack of consensus about the definition was cited as a main reason for tick-borne or Lyme-like disease not being a notifiable disease.

The Committee acknowledges the research efforts of the CACLD and the work being done by Professor Irwin and his team at Murdoch University. Professor Irwin's recent discovery of *Borrelia* DNA on a tick taken from an echidna may yet prove to have significance for further research into Lyme-like and other tick-borne illnesses in humans.

However, there is wide agreement on the need for further research. The CACLD's 'five research priorities', mentioned in the case study, should continue to generate further research activity. The Committee recommends that the Australian Government continue to pursue advances in relevant policy and relevant research areas as per the following recommendation.

78 Dr Stephen Graves, Royal College of Pathologists of Australasia, *Official Committee Hansard*, Sydney, 18 September 2015, p. 4; Professor Lyn Gilbert, Australasian Society for Infectious Diseases, *Official Committee Hansard*, Sydney, 18 September 2015, p. 4.

79 Professor Nigel Stocks, Royal Australian College of General Practitioners, *Official Committee Hansard*, Sydney, 18 September 2015, p. 16; Professor Lyn Gilbert, Australasian Society for Infectious Diseases, *Official Committee Hansard*, Sydney, 18 September 2015, p. 4.

80 Ms Lynn Rees, *Official Committee Hansard*, Sydney, 18 September 2015, p. 27; Ms Alex Patson, *Official Committee Hansard*, Sydney, 18 September 2015, p. 30.

Recommendation

Recommendation 14

The Committee recommends that the Australian Government consider:

- developing a case definition for tick-borne and Lyme-like illnesses for addition to the national notifiable disease register;
- developing protocols of diagnosis and treatment for tick-borne and Lyme-like diseases; and
- continuing to prioritise the research areas identified by the Clinical Advisory Committee on Lyme Disease.

Steve Irons MP
Chair

3 May 2016