



COMMONWEALTH OF AUSTRALIA

Proof Committee Hansard

SENATE

COMMUNITY AFFAIRS REFERENCES COMMITTEE

Emerging tick-borne disease

(Public)

THURSDAY, 14 APRIL 2016

PERTH

CONDITIONS OF DISTRIBUTION

This is an uncorrected proof of evidence taken before the committee.
It is made available under the condition that it is recognised as such.

BY AUTHORITY OF THE SENATE

[PROOF COPY]

INTERNET

Hansard transcripts of public hearings are made available on the internet when authorised by the committee.

To search the parliamentary database, go to:

<http://parlinfo.aph.gov.au>

SENATE

COMMUNITY AFFAIRS REFERENCES COMMITTEE

Thursday, 14 April 2016

Members in attendance: Senators Ludlam, Madigan, Moore, Reynolds, Siewert, Wang.

Terms of Reference for the Inquiry:

To inquire into and report on:

The growing evidence of an emerging tick-borne disease that causes a Lyme-like illness for many Australian patients, with particular reference to:

- 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 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.

WITNESSES

ADAMS, Ms Carol, Private capacity	47
ASH, Ms Judith, Private capacity	24
BOWER, Ms Joanne, Private capacity	24
BROWN, Ms Natalie, Private capacity	24
BULL, Ms Rebecca, Private capacity.....	24
COLLIGNON, Professor Peter, Private capacity	31
DANIELS, Ms Kathryn Mary (Kate), Chairperson, Multiple Systemic Infectious Disease Syndrome Inc. ...	9
DERHAM, Dr Hugh, Private capacity.....	40
DOWNIE, Mrs Leanne, Private capacity	24
EBDEN, Ms Linda, Private capacity.....	24
ERSEK, Ms Nikki, Private capacity.....	50
FORBES, Professor David Alan, Senior Clinical Adviser, Office of the Chief Medical Officer, Department of Health, Western Australia	1
GUERINI, Ms Nicole, Private capacity.....	50
HAMERSLEY, Ms Stephanie, Private capacity	24
HUTTLEY-JACKSON, Ms Marie, Representative, Lyme Disease Association of Australia.....	50
KELLY, Ms Elaine, Secretary, Sarcoidosis Lyme Australia	9
KENT, Ms Jan, Private capacity	50
KURET, Ms Gabrielle, Private capacity.....	50
LE PAGE, Mr Stephen George, Committee Member, ME/CFS and Lyme Association of WA Inc.....	17
LIDDELL, Ms Carol, Private capacity	50
LIM, Mr Nick, Private capacity	50
MACKENZIE, Professor John Sheppard, Private capacity	55
MAK, Dr Donna, Public Health Physician, Communicable Disease Control Directorate, Department of Health, Western Australia	1
MONKS, Ms Sue, Private capacity	24
NETTLE, Ms Michelle, Private capacity	47
NUTTALL, Dr Adam, Private capacity	40
OSKAM, Dr Charlotte, Lecturer, Murdoch University	55
RYAN, Professor Una, Professor, Vector and Waterborne Pathogens Group, Murdoch University.....	55
SHEPHERD, Ms Val, Private capacity	50
STEPHEN, Ms Melinda, Private capacity	24
STEVEN, Mrs Meg, Private capacity	24
VARY, Ms Rebecca Ellen, Volunteer, Lyme Disease Association of Australia.....	17
WEBB, Ms Leanne, Private capacity	24
WHITE, Ms Vicki, Private capacity.....	24
WILLIAMS, Ms Amy, Private capacity	50
ZAGARELLA, Associate Professor Samuel, Fellow, Australasian College of Dermatologists	31

FORBES, Professor David Alan, Senior Clinical Adviser, Office of the Chief Medical Officer, Department of Health, Western Australia

MAK, Dr Donna, Public Health Physician, Communicable Disease Control Directorate, Department of Health, Western Australia

Committee met at 08:01

CHAIR (Senator Siewert): I declare open this public hearing and welcome everyone here today. We acknowledge the traditional owners of the land on which we meet, the Wajuk Nyungar people, and pay our respects to elders, past and present. This is the first public hearing for the committee's inquiry into the growing evidence of an emerging tick-borne disease that causes a Lyme-like illness for many Australian patients. I thank everybody who has made a submission to this inquiry. This is a public hearing and a *Hansard* transcript of the proceedings is being made. The audio of this public hearing is also being broadcast via the internet.

The committee has scheduled two sessions at 10.25 am and at 1.35 pm today for individuals who are not listed on the program to make a short statement to the committee. These statements will be broadcast and will be included in the *Hansard* transcript of today's hearing, together with your name. The *Hansard* transcript will be published on the inquiry website. The secretariat will provide you with a copy of the information on parliamentary privilege and the protection of witnesses and evidence and will ask you to complete a *Hansard* witness form.

Before the committee starts taking evidence, I remind all present here today that in giving evidence to the committee witnesses are protected by parliamentary privilege. It is unlawful for anyone to threaten or disadvantage a witness on account of evidence given to the committee and such action may be treated by the Senate as a contempt. It is also a contempt to give false or misleading evidence to the committee. The committee prefers all evidence to be given in public but, under the Senate's resolutions, witnesses have the right to request to be heard in private session. It is important that witnesses give notice if they intend to ask to give evidence in private.

We will endeavour to have as many short statements as possible. I welcome officers of the Western Australian Department of Health. I understand that information on parliamentary privilege and the protection of witnesses and evidence has been given to you. Do you have any comments to make about the capacity in which you appear?

Prof. Forbes: I am a paediatrician and I am employed by both the University of Western Australia and the Western Australian Department of Health as a senior clinical adviser.

CHAIR: We have your submission, thank you very much. I would also like to thank you for coming. Sometimes government agencies do not appear, so it is much appreciated. I invite you to make an opening statement, and then we will ask you some questions.

Prof. Forbes: WA Health appreciates the opportunity to provide a submission to this inquiry. The department notes that there is no widely published or accepted definition of Lyme-like illness. It is not possible, therefore, to determine the prevalence or geographical distribution of Lyme-like illness in Australia or even to be certain that different groups discussing Lyme-like disease are referring to the same concept. The term is used to describe a variety of symptoms and clinical features ranging from well-defined illnesses to non-specific chronic symptoms. However, there is no evidence to indicate that infection with *Borrelia burgdorferi* sensu lato, resulting in Lyme disease, has been acquired within Australia. In addition, there is no convincing scientific evidence to date that tick bites from native Australian ticks result in Lyme-like disease.

However, the ability of the Australian healthcare system to detect and respond appropriately to new infections has been shown by the recent discovery of two cases of tularaemia in Australia, the second and third cases of this infection reported in the southern hemisphere, indicating that we have a high-quality health diagnostic service. There are well-established diagnostic processes and criteria for the confirmation of Lyme disease. To the best of our knowledge these have not been fulfilled in Australia in individuals with so-called Lyme-like disease.

The features of the clinical syndrome labelled Lyme-like disease are non-specific and associated with a range of other chronic illnesses and problems, including mental health problems. Insistence that these features represent Lyme-like disease precludes appropriate diagnosis and management, missing opportunities for effective medical care and running the risk of side-effects from inappropriate treatments and of misusing public resources. WA Health is of the view that individuals experiencing symptoms labelled Lyme-like disease need acknowledgement of their suffering—ideally in the context of medically unexplained symptoms—until a definitive cause is identified, as this would be more likely to facilitate empathic support and rehabilitation. A more appropriate name than Lyme-like disease for this syndrome should be sought as a first step.

CHAIR: Dr Mak, did you want to add anything?

Dr Mak: We prepared that together.

Senator MADIGAN: In your submission to the inquiry, you have said that Lyme disease may occur in those who have been exposed in endemic areas overseas. You have also said that you cannot acquire it in Australia. I have got a little bit perplexed here. I have spoken to doctors and that who have said to me that people can acquire Lyme-like disease—a child could acquire it through the womb, from a mother who has been exposed overseas in an endemic area, acknowledging what you say there. How then could you not acquire Lyme-like disease if you have been in a relationship, or you have had a blood transfusion, or you have been born to a mother who has contracted Lyme disease overseas?

Dr Mak: The scientific evidence so far shows that there is no evidence of transmission from mother to child through the placenta, or through blood transfusions. It is a tick-borne disease. We are aware that there are many doctors who say that it can be acquired through these alternative ways, but after looking at the scientific publications we do not actually believe that that is the case. We cannot find any evidence to support that.

Senator MADIGAN: For the benefit of the committee, Dr Mak, are you saying that there is no evidence of Lyme disease being transmitted from the mother to the child or through a blood transfusion or through sexual contact?

Dr Mak: No. To the best of our knowledge there is no evidence of that.

Senator WANG: You mentioned a number of times the lack of evidence. What is your department doing to try to collect the evidence and do research into Lyme-like disease, in the department itself?

Dr Mak: The WA health department's view is that the research into Lyme-like illness should be done collaboratively at the national level. WA Health certainly has been keeping abreast of all the developments that are happening at the national level. In particular, we are very well aware of the research that is going on at Murdoch University into looking for organisms that might cause Lyme-like illness in Australian ticks. In our submission we have made reference to those recent publications. Again, to the best of our knowledge, based on these very recently published studies, there is no evidence that there is the presence of organisms that would cause Lyme-like illness in Australian ticks, either in WA or in other parts of Australia where they have been sampled.

Senator WANG: To the best of your knowledge what are we doing at the national level?

Dr Mak: At the national level a lot of work has been done by Communicable Diseases Network Australia and Public Health Laboratory Network. The Chief Medical Officer of Australia, Dr Chris Baggeley, has actually convened a group of people to look at Lyme disease. They came out with a scoping paper about the research that needed to be done. To the best of our knowledge those recommendations are actually being followed through. Some of these research studies have been funded and have been progressing. Also, the Communicable Diseases Network Australia did consider a submission from Lyme-like illness advocacy groups about making Lyme disease a notifiable condition. That was considered by Communicable Diseases Network Australia using the criteria that it always uses when it considers whether or not a disease should be made nationally notifiable. Based on a careful assessment against those criteria, and the benefits versus the downsides of making it a notifiable condition, it was decided that it would not be made of notifiable condition. That occurred in 2008. That was considered carefully.

So there is actually a lot happening at the national level with the Australian Department of Health to collect more evidence about what is going on. WA Health is very well aware of that and we keep abreast of it.

Senator WANG: When you said 'collect more evidence' were you referring to the fact that you are going out actively seeking researchers to do certain jobs, or are they just sitting in their office waiting for researchers to finally show some interest and do some research into Lyme-like illness and then publish a paper?

Dr Mak: There are mechanisms in Australia for funding research into important public health problems. That is mainly through the National Health and Medical Research Council. Any research that is done should be meeting those very strict criteria and scientific rigor. Applications for research have been funded through these bodies. Some of that represents the research that has been done at Murdoch University.

Senator WANG: How much funding are we talking about nationally? Do you have a figure?

Dr Mak: We would not be able to answer that. We are in WA Health, so we do not have control over that sort of funding or those decisions.

Senator WANG: For collaboration your department does not get any funding to do any research into Lyme-like illness?

Prof. Forbes: The department's primary focus is not research; it is management of the healthcare service, but it does provide some funding for research initiatives. This would be available for people contemplating research in this area.

Senator WANG: Did you provide any funding for the work that Murdoch University did? My understanding is that this particular professor is in the process of seeking another research grant. Are you going to help him with that process?

Prof. Forbes: I do not believe that the department of health has provided any funding for the Murdoch University unit. The sort of work that is being done there is not translational research, which is a type of research that the department tends to support. So, we would expect that he would seek funding through the conventional pathways: the National Health and Medical Research Council and the Australian Research Council.

Senator WANG: I would like to think that there are many people in this room who would probably disagree with you that there is no evidence of Lyme-like illness in Australia and who probably want to see very urgent action on them, on their lives and on their families. If we go down the normal path of waiting for research to show up and go through probably years or even decades of have an argument over the research and finally arriving at a conclusion, what would you say to the people in this room who are actually sufferers of Lyme-like illness or who know someone who is suffering from it?

Prof. Forbes: I would clarify one point. We did not say that there is no evidence of Lyme-like illness. He said there was no evidence of infection that is known to cause Lyme disease or infection from Australian ticks. We acknowledge, and did acknowledge in the submission, that people do suffer. At present, we do not have an acceptable definition for Lyme-like disease, so that you know and I know that we are talking about the same thing. That I think is a really important starting point. Then, I think what is needed is that groups within the Australian medical and social societies come together in ways of finding agreement—what can we agree upon; there are these symptoms; there are potential pathways to treat the symptoms—while we await the scientific evidence that defines the cause.

Senator MOORE: I presume you have both read some of these submissions that have come from Western Australians? I know you are very busy. We have a number of submissions and people giving evidence today that you may or may not hear. They talk about their concerns about the way they were treated in the Western Australian health system. Your submission says that people should be treated with respect. Considering the information we have had about people feeling that they have not been treated with respect in the Western Australian health system, what kind of advice can you give them about their genuine belief that as soon as they have mentioned the L-word—I think that is used a few times in these submissions—they are treated quite negatively by practitioners at every level? That is in their evidence.

Prof. Forbes: I feel uncomfortable hearing that, because I would like to think I could be proud of the graduates of our medical schools and the service provided. Dealing with unexplained symptoms is challenging for health practitioners everywhere in the world. Dealing with uncertainty poses a problem to doctors and to patients. As I said to Senator Wang, I think we need to step back and look at ways of dealing with that sort of problem. We need to provide more education in our training programs so that as health professionals we can acknowledge what we do not know and also help patients acknowledge that at the end of the process they may not know all the answers that they want to know

Dr Mak: The point that you have raised really reiterates why it is important to find a better name for this condition. I think giving it a name implies a causation which has not been scientifically proven and for which there is not complete evidence. It makes it very difficult for health practitioners and doctors to treat the patients and perhaps sets up false expectations in people's minds as to what their disease is caused by and therefore what treatment there is. That is why we wrote in our submission that one of the first steps would be to find a better, more appropriate name for this constellation of signs and symptoms and from there to progress to finding evidence based approaches to dealing with people who have these symptoms. I too am very concerned that people feel that they have been treated not in a respectful way, because that certainly is not the way that I would like to think about the medical profession in Western Australia.

Senator MOORE: Are there any programs within the department to inform practitioners about some of the issues that have been raised by people who have given evidence, in particular the immediate inference that people are mentally ill and the large dosages of tranquillisers and medicines within that category that people say they have been treated with. They have been told to their faces that they were mentally ill and should just pull themselves together and get on with life. I am trying not to verbal what has been said, but there are inches of evidence in these papers. I know that is very difficult since this is a case where some people have that and if you were not there as a witness to see it, it is hard to—all those things. As there seems to be such a significant number

of those, is there anything that the Western Australian health department has done to put something out to the practitioners who work in Western Australia to say there are people who are concerned about this issue and this is the kind of treatment they say they had—giving people in the service some awareness that perhaps there is a particular issue about people being treated as mental health patients?

Prof. Forbes: I do not believe there is a program that has undertaken that role. I am aware of individual training programs for individual doctors in hospitals that do focus on dealing with people with complex, multisymptom presentations, the issue of lack of certainty of diagnosis and the need for respect.

Senator MOORE: Is any of that available for the committee to see? Are there notes, guidance programs or anything that we could see?

Prof. Forbes: I believe I can make some material available to you.

Senator MOORE: That would be very useful. Thank you.

CHAIR: Before I go back to you, Senator Madigan, I have a couple questions as well. I understand the point you made earlier about the issues around prevalence. However, I would like to know if the department has any way of collecting the data or understanding how many people in Western Australia have—I will come back to the issue of the name in a minute—Lyme-like illness or the range of symptoms that are currently talked about or recognised around Lyme-like illness. Because the disease is not recognised, it is hard to say 'recognised', but I will use it colloquially.

Dr Mak: It is not a notifiable condition. Because what one person would describe as Lyme-like illness is often very different from what another person would describe as Lyme-like illness, it is very difficult to collect that information. We are not comparing like with like and we are not necessarily all counting apples. Some people might be counting apples and others are counting oranges. So no, the WA health department does not have a way of collecting that information because the illness is so poorly defined. We need to work to get a far better definition and a more appropriate name. When we have done that we might actually start being able to measure the prevalence and do some counting of disease frequency in a scientifically rigorous way.

Prof. Forbes: If I could just add to that, you will be aware that most of these individuals with these symptoms would be managed in the primary care setting in general practice. There is not any comprehensive data collection process in Western Australia—or elsewhere in Australia that I am aware—that counts the range of diseases. There may be opportunities in the future with the primary health alliances that have recently been formed, but to date we do not get too far into that.

CHAIR: So there is no process if we needed to find out fairly quickly the prevalence of any disease, whether it is Lyme-like illness or something else? What would you normally do to find out? If you started seeing particular symptoms of something, what would you normally do? Who would take the lead?

Dr Mak: It would depend very much on what sort of illness it is and how it presents. If it is the kind of illness that would mainly present to emergency departments in hospitals, there are surveillance systems in emergency departments where you can count how many people present with, say, injuries or certain things like that. If it is an infectious disease and it is one of the notifiable infectious diseases—notifiable under law—there are reporting structures that require doctors and pathology laboratories to report. So for things like influenza or whooping cough it is very easy to count the number of cases. There are some surveillance systems that go on in primary healthcare—for example, the BEACH study, which is an Australia-wide research study. Are you aware of that?

CHAIR: We are aware of that, yes.

Dr Mak: That could be one possible way, but it would be difficult for a condition such as Lyme-like illness to be picked up in that study because it presents with a variety of signs and symptoms. It would not have an automatic label put onto it in the way that you could perhaps count the number of people with diabetes or high blood pressure through the BEACH study. Because Lyme-like illness is not well defined it would be hard to count it that way. But there are mechanisms like that as well.

CHAIR: We have had a number of submissions talk about people having taken their own lives as a result of this illness. Do you know how many people may have taken their own lives? This committee has previously undertaken an inquiry into suicide and prevention of suicide, so we know that often suicide is recorded differently on death certificates. I will be asking this around Australia. Are you collecting any evidence or are you aware of any evidence of this being recorded on people's death certificates other than if someone has taken their own lives? Are they recording the cause? Do we have an understanding or any idea of how many people have taken their own life because of this?

Prof. Forbes: I am not aware of any process for recording that data. Again, for the reasons that have been discussed, it would be very difficult to be certain of contributing factors. If the person who signs the death certificate has only limited knowledge of an individual they may not be aware of other symptoms. So although the coroner could possibly tell us about some other factors, I doubt very much that this will be recorded.

Senator MADIGAN: For clarity, Dr Mak and Professor Forbes, in your submission you spoke about areas in Europe where there is endemic Lyme disease. Does the Western Australian Department of Health acknowledge that there are people in Western Australia who have been overseas or have come from overseas who have Lyme disease?

Dr Mak: Yes. The Department of Health certainly does acknowledge that Lyme disease can be acquired in overseas countries—for example, in Europe and North America—and people may well have acquired it there and come to live in Australia, yes.

Senator MADIGAN: Has the department got any idea of how many people who have come from overseas or acquired Lyme disease when overseas are in Western Australia?

Dr Mak: No, we do not have a mechanism to determine that, because Lyme disease is not a notifiable disease.

Senator MADIGAN: It is not a notifiable disease in Western Australia. Is the department aware of how many people claim to have contracted Lyme disease when overseas or to have come from overseas with Lyme disease?

Dr Mak: No, we would not necessarily have that.

Senator MADIGAN: Has the department received correspondence from members of the public who believe that they have Lyme disease or have contracted Lyme disease overseas?

Dr Mak: Yes, we have received some letters from members of the public.

Senator MADIGAN: Could you furnish the committee with the numbers of people who have contacted the department?

Dr Mak: That is quite difficult to do, because when we receive letters they do not always state the patient's full name and details, so it is hard to know, if you receive one letter. Sometimes the letter will be about more than one person. Sometimes several letters will be received which might be describing illness in the same person. So it is not an easy way to measure the number of unique individuals that we have been told about.

Senator MADIGAN: So you do not collate any figures on people who write to you claiming they have got a disease or an illness—and in this case Lyme disease or a Lyme-like illness? The department has done nothing in this space. Is the department aware of the public concern around this issue here in Western Australia?

Dr Mak: The department certainly is aware of the public concern.

Senator MADIGAN: So the department is aware of the concern of people in Western Australia pertaining to Lyme disease, Lyme-like illness, but you have no figures to talk about? You have no idea of how many people have contacted the department—is that right?

Dr Mak: That information has not been collected in a systematic way. We collect notifiable diseases data because there is a health act that supports it.

Senator MADIGAN: I understand that you collect evidence of notifiable diseases, but how does a disease ever become notifiable if we do not look into it?

Prof. Forbes: It becomes notifiable if clusters of cases or an increase in numbers are seen by practitioners who notify us. The issue here I think comes back to what we are talking about. We are talking about collection of symptoms usually, which will be interpreted in different ways. Virtually all the information about notifiable diseases comes from health practitioners of one sort or another, and if a practitioner does not believe this is an infectious disease they are probably not going to tell us.

Senator MADIGAN: Has the Western Australian Department of Health done anything proactive to represent Western Australian citizens in their pursuit of answers as to why they are sick and said to the NHMRC or the ARC, 'We've got people across the state who claim they've got this disease or this disease-like illness' to make those federal departments, which you say are charged with looking into research, aware?

Prof. Forbes: Those agencies are charged with funding research, not initiating research, by and large. I am not aware of any efforts by the department to elevate the issue with those agencies. But, as Dr Mak pointed out, the CDNA, which is made up of health department representatives from around Australia and others, has looked at this issue and made the decision in 2008 that this did not warrant being made a notifiable disease.

Senator MADIGAN: So it is not a notifiable disease. How often does the department review notifiable diseases?

Dr Mak: To my knowledge, there is not a set time, but we do know that it is responsive. For example, when SARS came along, that infection became a notifiable disease very quickly after it was clear that it was a worldwide problem. While there is not a set time interval by which these diseases get reviewed, the Communicable Diseases Network Australia is actually responsive to what is happening with infectious disease patterns globally and in Australia.

Prof. Forbes: If we could confirm that this is an infectious disease, I have no doubt that it would be made a notifiable disease very quickly, because it is of the public interest. One of the limiting factors is the lack of credible scientific evidence that it is an infectious disease.

Senator REYNOLDS: Thank you very much for your submission and your testimony this morning. Listening to the questions and the answers this morning, it seems to me to be a very circular logic—almost a catch 22 situation. On the one hand, even if you do not believe that there is evidence that people here can catch it from tick bites or anything else, you have acknowledged that people can get it overseas, for example. So, on the one hand, you have affirmed that people here could have it, but if there is no testing—and you are not even keeping records of people who are making complaints or raising issues that they have got some sort of illness—how can it ever be listed? It seems to me to be this completely circular logic: you do not record it, you do not test it and you do not investigate it, even when you have had a substantial number of complaints. I am struggling to find a way out of this circular logic argument.

Dr Mak: I do not think that there has been no testing.

Senator REYNOLDS: What testing has been done? When you get complaints to your department about this—and you have said that you have had a number of complaints; I am not sure how many—what testing do you do?

Dr Mak: Patients have gone to doctors and they have been referred to infectious disease specialists. The Western Australian public health laboratory, PathWest, is an accredited laboratory for Lyme disease testing, so individual patients have certainly been tested through that mechanism. Often, when they are tested in an accredited Western Australian laboratory, they find that they do not have Lyme disease, based on those tests. However, many of these individuals say that they have been tested by overseas laboratories, many of which would not meet the criteria that the Australian laboratories need to meet.

Senator REYNOLDS: Just on that point, you have had a number of people who believe that they have a range of symptoms that you would rather find a better definition for. So the Australian tests have not identified Lyme disease, but overseas laboratories have. How detailed are your assessments of particular overseas laboratories? Would the fact that another laboratory might be correct and that possibly we have got it wrong here necessarily discredit it? Talk us through that process.

Dr Mak: The laboratories in Australia that are accredited for Lyme disease testing have proved their ability to detect Lyme disease, because, as part of the accreditation, they have to run tests on samples where they do not know whether there is Lyme disease or not, but the accreditation body knows whether this sample has or does not have Lyme disease. The lab will be given these unlabelled samples to test to see whether the laboratory is good enough to detect it. These Australian laboratories that we are talking about have been through these accreditation processes. I think the other thing that is—

Senator REYNOLDS: Are you aware of any of these tests in Australian laboratories ever coming up positive?

Prof. Forbes: Testing is multilevel—

Senator REYNOLDS: It is a very simple question: are you aware? You have also said that it is not reportable yet, for all the technical reasons. Are you aware of any positive test here in Western Australia, or in Australia, from these accredited Australian labs?

Dr Mak: I am not aware, but I have not done the asking to find out. I think the other thing that is really important to understand is that, just because a particular blood test may be positive or may be negative, the interpretation of that, as we have written in our submission, is far more complicated than just looking at the result of the test.

Senator REYNOLDS: The state Department of Health has done a very comprehensive submission. You are saying you have written this submission and you do not know whether anybody in Western Australia has ever been diagnosed with Lyme disease?

Prof. Forbes: We do know that no-one has been diagnosed with locally acquired Lyme disease—

Senator REYNOLDS: No, that is verbal tautology. Whether it has been found to be from overseas or here, are you aware of any cases of Western Australians being formally diagnosed with Lyme disease?

Prof. Forbes: No, and a recent publication as of this month failed to identify any people in Western Australia.

Senator REYNOLDS: If there is no mandatory reporting, how would you know? If you have not gone out and sought this information from the labs, and they do not have to mandatorily report it to you, how would you know?

Prof. Forbes: It will be reported in the scientific literature if a case is confirmed in Australia. This is a public interest.

Senator REYNOLDS: You are basing all of your evidence on scientific reports?

Prof. Forbes: We are scientists.

Senator REYNOLDS: So you have never actually rung one of the laboratories?

Prof. Forbes: I have not, but—

Senator MOORE: Is there any reason that the Western Australian department would contact a laboratory directly? It would be highly unusual, I would think.

Prof. Forbes: If we saw a cluster of some problem, yes, we would talk to the laboratory.

Senator MOORE: But it is not standard practice?

Prof. Forbes: It does not happen every week.

Senator MADIGAN: In summation, the Western Australian Department of Health says that there is not Lyme disease in Australia—correct?

Dr Mak: No, we are saying that there is no evidence of locally acquired Lyme disease in Australia. We accept that there would be people who have returned from endemic countries to Australia with Lyme disease—that is very possible.

Senator MADIGAN: You are saying it is possible that people have contracted Lyme disease outside of Australia, but you say there is no person in Western Australia who has tested positive for Lyme disease to the Western Australian health department standard. You have said that, if they had a test from, say, IGeneX—I think it is—and Infectolab, their test is not as good as the Australian test. When they are in an area that is endemic—to use your words in your submission—their test is not as good as the Western Australian test, where the official line is that we do not have Lyme disease in Australia?

Dr Mak: This very recent publication, which only came out on 7 April—I am not sure if you have read it—has a very detailed and informative section on Lyme disease testing, and it questions the appropriateness of overseas testing for Lyme disease and how relevant that is to patients who believe they have acquired the disease in Australia, because there are subtle differences in the different organisms between different countries. So, depending on which country you are in, you may need to modify the Lyme disease test that you are using.

CHAIR: That paper was circulated this morning, I understand, so we obviously have not had time to read that one properly, so I think that we will have some questions on notice following that. I know that Senator Wang has one more question.

Senator WANG: I have one quick one. What we understand is that our blood-testing criteria are different from the ones in Europe and possibly the USA. We know, from my discussions with a lot of Lyme-like-disease sufferers, that it is often very difficult for them to find a doctor who is brave enough to refer them for blood tests for Lyme. So I think the problem comes from the bottom. We do not have all the possible Lyme disease sufferers being tested for Lyme actively, so there is no reporting, obviously, for those cases, and also they are probably not talking to the department, and the department is not often talking to the labs.

Medical professionals can be obsessed with finding a name for the problem. I do not think anyone in this room cares about a name. I do not think anyone cares about what we call diseases. We just want a solution. These people sitting in this room have been suffering from the problem for years and, in cases, decades. They want a solution. Are we going to wait until after the normal process of finding a name first and go through the research et cetera? They might be gone when we finally land a name on this issue.

I think we have identified that there is a lot of work that the department needs to do, and I would welcome some effort into doing some more work in that.

Prof. Forbes: I am not sure if you want a response to that. Was it a question?

Senator WANG: Just say yes, you want to do more work!

Prof. Forbes: We seek more evidence to help us understand this, and we seek it in lots of levels.

Senator MOORE: My question remains, Professor and Doctor. This is clearly a national issue, and I am struggling to see what the role of the Western Australian government would be except as part of a national response. I take the issues that the senators have been asking about, but for the Western Australian government alone to have much input in this process, for me, is a difficult thing. I would be keen, though, to see whether the Western Australian government was going to take it up at the national level with the national health ministers and the various bodies that do work there. That would be a response, I think, that I would be seeking to have from the Western Australian government.

Dr Mak: It absolutely has been our approach that this is a national issue. It is not an issue that is confined to Western Australia, so the Western Australian health department has certainly been approaching it as a national issue and has been keeping abreast of what is happening at a national level and supporting that national issue. We have a Western Australian representative on the Communicable Diseases Network Australia and the Public Health Laboratory Network. They are working on this.

CHAIR: Unfortunately, we have run out of time. I think there will be some questions on notice, particularly arising from the previous discussion we had around the new paper. If that is okay, we will get you some questions on notice. Thank you very much for your time today. It is much appreciated, thank you.

Prof. Forbes: Thank you.

DANIELS, Ms Kathryn Mary (Kate), Chairperson, Multiple Systemic Infectious Disease Syndrome Inc.

KELLY, Ms Elaine, Secretary, Sarcoidosis Lyme Australia

[08:49]

Evidence from Ms Kelly was taken via teleconference—

CHAIR: I have some preliminaries. Ms Kelly, I do not know; you may have been listening to the broadcast. I have to do some formalities at the beginning. I would just like to check with both of you that you have had information on parliamentary privilege and the protection of witnesses and evidence.

Ms Kelly: Yes, I have.

CHAIR: And, for the record, Ms Daniels was nodding as well. Thank you. Do you have anything to say about the capacity in which you appear today?

Ms Daniels: The Multiple Systemic Infectious Disease Syndrome Inc. is formally the WA Lyme Association.

CHAIR: Welcome, both of you. I would like to invite both of you to make an opening statement, and then we will ask you some questions. Perhaps, Ms Kelly, we will kick off with you.

Ms Kelly: Thank you for the opportunity to participate today. I have a neuromuscular component to my illness which makes it a bit difficult for me to articulate, so apologies for whatever my voice might happen to do along the way. I am sincerely grateful to the senators who have recognised the enormity of the plight of Australian patients suffering from Lyme-like illness and who have used their position to raise concerns. I found the exercise of reading the 800-plus submissions to be an immensely distressing experience that served to highlight the polarised viewpoints. I would go so far as to say that the submissions from official and scientific bodies, especially those published just before and after the closing date, brought me to the verge of mild hysteria from the wave of brutal negativity. 'God help us,' I thought, 'because those organisations certainly don't intend to.'

It is three years since the CACLD was formed. While it is now closed, the situation for patients is worse than before the CACLD ever formed. There are fewer doctors, more patients, doctors being disciplined and medications out of prescription reach. Why? Why are we all still here today talking around the problem, resolving absolutely nothing? It is because we are having different conversations. I was listening to the broadcast and listening to Professor Forbes and Dr Mak speak, and I think that was a very good example of the different conversations we are having.

Scientific folk want evidence of causative agents to enable disease; patients want focus on their symptoms, their illness, while science works on the details. Both groups make equally valid points, but lives are at risk and people are suffering. Humanity and human rights decree that adequate medical assistance be given to these patients. If the science faction are unhappy about this, they should push the government for funding and resources to expedite research to obtain the answers they are wanting.

The statement that the Department of Health is not a funding body, which we continually hear, is a roadblock, an excuse. Lack of funding translates into lack of recognition of urgency, lack of commitment to the many Australians who are ill. Ticks did not go knocking on the door of the Department of Health; patients did. Dr McManus did because Karl could not. Let us be done with the official complacency. Patients do not have the time to wait a decade until research on ticks and other vectors is complete. It is time to remember the sick humans.

I am just going to talk about prevalence and geographic distribution a little. Who is counting? Absolutely no-one. I think that was clearly evident from earlier. I am not sure where the 2008 review figure came from, because there was a reassessment in 2013, and Lyme-like illness was still considered not to meet the criteria for notification and surveillance, so no official government body is gathering statistics. Sarcoidosis Lyme Australia wrote to the CDNA and queried what 'monitoring' meant, and what it meant was a bit ridiculous. So we wrote to Gary Lum, at the Office of Health Protection, in November last year, querying this. We wrote to Gary, and we said: 'The CDNA May 2013 decision that Lyme disease does not meet the criteria for notification and surveillance is 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. November 2015 brings a need for reassessment with all advocacy groups being allowed to contribute to the process.'

We asked for several things in that email. The third point was that the Department of Health apply for a reassessment with the CDNA on the matter of monitoring and surveillance. Dr Lum replied: 'I will discuss your email with colleagues in the department as well as colleagues in states and territories.' So, the lack of monitoring and surveillance has been a very, very big issue for patient communities and I think, as earlier discussion demonstrated, it is the fundamental catch 22 of the entire debate.

Submission 531, from the CDNA, cites a lack of definition of symptoms included in the spectrum of Lyme-like illness and the absence of a published and widely accepted definition for Lyme-like illness as reasons that it is not possible to determine the prevalence or geographical distribution of people with this constellation of symptoms in Australia. Obviously—and this is really hard because my face is semiparalysed and I cannot say the word I want to say—epidemiological and clinical studies are required as a matter of urgency to be inclusive of patients' symptomatology and general pathology. Current research is focusing on the causative agents and the disease, but an epidemiological study would focus on the patients and the illness.

Treating GPs cannot be expected to be the sole and main source of information about patients. They are too few in number and many have completely closed books. How are they supposed to take time to deliver data to the government? The government needs to dedicate funding and resources for this purpose. Funding and resources were found for the National Serological Reference Laboratory's comparative study, so it is possible to find funding and it is possible to find resources. The issue is that the government is not committed to the idea that Australia has a serious public health issue. No matter what the cause of the illness of these many Australians, infectious or otherwise, the government needs statistics to address the issue. In the unlikely event that infection proves not to be the cause, how is the government planning to address the fact that there are thousands of seriously ill Australians that no medical professional can diagnose? Unlike Stephen Graves, I do not believe that that is just life—somewhere along the way he said, 'That's life.'

Chronic illness is a costly burden to the health budget in Australia and the subject of a current House of Representatives inquiry. The causative agent is one aspect of the investigated need; a road to wellness for ill Australians is the other. Unfortunately, labels are being prioritised over lives, and patients are being sidelined while ticks have been given centre stage. Ticks have been quantified in research studies, but ill patients do not exist in data at all apart from LDAA figures from their patient surveys and a figure from an obscure Westmead Hospital conference paper, which tells us that there were 24,000 occasions when a doctor's clinical suspicions led them to request *Borrelia* testing over an 18-year period from 1994 to 2012. Labs must have data on *Borrelia* and co-infection testing from recent years. Where is that? Why isn't it quantified, qualified and here in front of us on the table today?

The Department of Health's website states:

The Australian government is monitoring Lyme disease, in consultation with the states and territories, through the Communicable Diseases Network Australia.

This implies an active monitoring by the CDNA. Either this statement should be removed or monitoring should be clearly defined.

Submission 495, from the Department of Health, completely omits addressing term of reference (a) on prevalence. Submission 457, from NSW Health, states it is not clear what particular range of clinical manifestations the term 'Lyme-like illness' is being used to describe.

CHAIR: Ms Kelly, I am sorry to interrupt but we are going to run out of time. I apologise. We usually start with short statements and then ask lots of questions.

Ms Kelly: Sorry.

CHAIR: That is perfectly okay. Could you sum up your opening comments, taking about a minute. Then we will go to Ms Daniels and then open up to questions. You will get an opportunity to continue commenting on the issues that the senators are particularly keen on pursuing.

Ms Kelly: Okay. Basically, I was going through the submissions of all the health departments. They are all very negative and they all state that lack of definition is the reason that there is no surveillance, but then the CDNA is going back and—I am sorry; I have lost my train of thought now.

CHAIR: Sorry.

Ms Kelly: Because the Western Australia health people are there I will just make a comment about the Western Australian health department. I hope Professor Forbes and Dr Mak feel embarrassed to hear again that they not only cite lack of definition of cause and impossibility of determining prevalence but then have the audacity to advise the parliamentarians that patients with Lyme-like illness are overrepresented because one person can write multiple letters and their friends, families and peer support groups also write letters about the same person. More correctly, Lyme-like illness patients are underrepresented.

I will finish with the Victorian health department. They also cite lack of definition, but they go on to say that we are a relatively small number of people and it would not be advisable to dedicate funding towards Lyme-like illness. I think that probably sums up the situation of where the health departments are at. The health departments

are sitting back, waiting for the federal government to do something, and the federal government is not committed to the cause at all.

CHAIR: Thank you. Ms Daniels, I invite you to make an opening statement, and then we will ask questions.

Ms Daniels: Thank you. You threw us a little bit by starting with Elaine, because she has gone on to address our recommendation 4. We thought that I would start, but I will just go on. This might throw my introduction a little, but I would like to start by clarifying some of the questions to the earlier speakers.

One of the things I would like to make really clear as the first speaker on behalf of patients is that, though we discuss this in terms of patients who believe they have Lyme disease—we hear this in the media, and I have heard it a couple of times today—it is not a belief system. It is not a religion. The people who are identifying themselves as having Lyme disease have not totally sacrificed their own lives to join some popular cult in order to describe themselves as Lyme patients.

The reality of the situation is that those of us who are here who call ourselves Lyme patients have in fact been through an extensive clinical examination by a doctor who has begun to specialise in Lyme disease. That can take at least an hour or so of eliminating and identifying that we have a range of matching symptoms that meet the criteria for overseas case definitions. Then the doctors put us through a differential diagnosis to eliminate the other potential diagnoses that are there. This includes extensive blood tests. I also should note that, based on the LDAA's figures, these patients have spent an average of 6½ years before they even get to a Lyme doctor, and they have had multiple diagnoses in that time—diagnoses from which they have not seen any recovery, and that is why they are still seeking answers.

The third area which we use to define ourselves as Lyme patients is that we have all had serology obtained in overseas labs that are accredited. Despite all the incredibly defamatory and derogatory comments that have been passed off by Australia's xenophobic NATA—the private company that manages the business of pathology—accredited organisations, Australia is now having to begrudgingly acknowledge that those laboratories are actually on par with Australian laboratories and have been accredited overseas at the same ISO standard and always have been. So we wonder whether or not those results that we have all had will retrospectively now be recognised. I wanted to start the proceedings today by asking for the committee to please be aware of this use of 'people who believe they have Lyme disease'.

So that is Lyme disease. The next thing I probably need to do is clarify this terminology. A lot of the problems arise because the parties involved in this discussion are speaking at cross-purposes when they use term 'Lyme disease'. Dr Lum has used a scientific definition, which I will go into in a moment. He refers to the term 'classical Lyme disease'. Classical Lyme disease was actually discovered in 1973. There were two mums who raised the alarm about 280 cases of juvenile arthritis. Then in 1975 Dr Allen Steere called it Lyme arthritis. In 1976 they came up with a treatment protocol of two weeks of tetracyclines, which are like the doxycycline still used. It is worth noting that because it was not until six years later than Alan Barbour developed a medium that enabled him to grow the bacteria of Willy Burgdorfer's ticks from Long Island in New York. Please note in those six years from when Steere described it and seven years from the time that the alarm was raised they already had treatment in place. They had not discovered the tick—that did not happen until a new tick was discovered—and they had not been able to isolate it.

One of the things about the *Borrelia* bacteria is that it is very difficult to grow in the laboratory. It is called *Borrelia burgdorferi* after Willy Burgdorfer, but it was not until the following year that Alan Barbour was able to develop a medium called the BSK medium that enabled them to grow it in the laboratory under glass in vitro. Right from the start in that test tube there were hundreds of thousands of spirochetes. One of those spirochetes was cloned. They were able to clone it, grow it out and continue to grow it out. So there is a single ancestor for that clone that is called B31. It is hardly surprising that we might not completely align because what happened with those other spirochetes is that they all got tipped down the drain. There is actually quite a lot of genetic diversity that was not even represented when they named those strains. I just wanted to give you that little bit of history and to note that where we are up to in Australia is back at 1973 or 1974. The alarm has been raised, but as opposed to the United States we cannot even get treatment here and we cannot even get a test. I do not want to go too much into that because that was not my main point, but I just wanted to raised that.

The problem we have here is the name. We are speaking at cross-purposes because when the patient community talks about Lyme disease—not just here, but in America as well—patients and doctors are talking in a broad sense where Lyme disease is inclusive of not just an infection arising from *Borrelia burgdorferi*, but also a range of coinfections that occur. The primary ones of those that are experienced by Australian patients are *Bartonella* and *Babesia*. There are a whole range of other coinfections. All of those are here in Australia. The only bacteria that we are battling about is this one that is called Lyme disease. We know that the rest of them exist

here and we know that most of them have been found in ticks. So when patients are talking about Lyme disease they are talking in a broad umbrella.

So we came to the Clinical Advisory Committee on Lyme Disease that the Chief Medical Officer convened. Patients submitted comment on the terms of reference and asked for those terms of reference to be broadened out to include the broader factors, to look also at public health issues and how it might have an impact. The Clinical Advisory Committee on Lyme Disease did adopt some. One of the things was that we asked for a change in the first term of reference, which originally asked whether Lyme disease exists here in Australia. We asked for that to be changed to 'the extent to which' Lyme disease is here in Australia, which changes the context and addresses some of what has been discussed by the previous speaker. 'The extent to which' changes the context of the exploration. Even though they did change that first term of reference, that was not reflected in terms of where the investigation went, because we never saw anything in the scoping study or in the discussions to do with the extent to which the disease actually does exist. It was all desktop research focused on how Lyme disease presents overseas. There was certainly no attempt to collect data about how many patients are affected here. The only source of that data is the LDAA's patient survey.

The narrow definition that has been applied to investigations into Lyme disease in Australia is classical Lyme disease, and by that, Dr Lum and his colleagues mean *Borrelia burgdorferi* sensu stricto—so, the one that was found in Lyme, America—and usually when they say *Borrelia burgdorferi* sensu lato they also are including the European strains that have been found from the same family. Now, our testing only tests for these three strains. Until 2015, the main testing laboratory only tested for two strains—one European and one North American—but they have now changed over. One of the best ways to ignore a problem is to define the terms of reference and the definitions for that problem in such a way that it excludes the majority of people who are affected by that problem. We have seen this. If we translate that to an emerging epidemic, the way you do that—that is, ignore the problem—is to define the case definition so narrowly that the majority of people are excluded. When we are talking about defining the problem in Australia as classical Lyme disease—meaning the North American strain of Lyme disease—then it does exclude a lot of us, because our symptoms are not necessarily the same. We are also talking about people who are affected by co-infections. We do not know whether the *Borrelia* component of Australian Lyme-like illness may actually be a minor co-infection in terms of the symptoms we experience. But nobody is looking at these things, and the attempts by patients to have those issues considered were pretty much sidelined by the process that has gone on to date.

CHAIR: Ms Daniels, we are going to have to ask you to wind up shortly in order to ask some questions.

Ms Daniels: I have made a couple of notes in terms of the questions you asked the previous speaker for the situation in WA. Would you like me to answer a couple of those?

CHAIR: That would probably pre-empt questions from here, so that is fine.

Ms Daniels: I will just leave it there, but I would just like to make the point, to sum up, that we have had an extremely narrow investigation into this disease. It has been focused on Lyme disease overseas. It has made scientific assumptions about the potential vector. It has been based on a rationale that, 'If we can't find North American *Borrelia* in Australian ticks then you're not sick,' and that is certainly how it has been translated by the medical profession. It is a very flawed, unscientific logic, but that is how it has been translated down. The other main thrust of our recommendations is that the department has not taken a lead role in this and it has been other agencies who have taken leadership by default. If you would like to ask me some questions about that I will elaborate further.

Senator MADIGAN: Thank you, Ms Daniels and Ms Kelly. Am I reading your testimony right, Ms Daniels? You are saying that the rationale that has been put forward by some people in the medical profession is that we could not possibly have our own indigenous sort of Lyme disease—that there is no entertainment of the idea that we may have our own version of it?

Ms Daniels: I do not know whether that is what is being said. In fact, we now have a statement on the overseas case guidelines, the first sentence in the first stanza, which I wanted to raise for your attention even though it is guidelines for overseas acquired Lyme disease and treatment guidance, says, 'While it is not possible to acquire classical Lyme disease in Australia'. They did not need to bring in a case definition for what it might be here, because they knock it on the head in that first sentence.

I need to point out to you, as our parliamentary members and senators, the legal liability that that opens you up for. That may have been a decision that was reached in part by Australian government employees, largely based on conclusions reached by non-government agencies and companies with an interest in perpetuating their testing. But that statement, 'Whilst it is not possible to acquire classical Lyme disease in Australia,' opens up the

Australian taxpayer to a massive potential for legal liability and class actions if that bacteria is ever discovered here—as it has been in Brazil, even though they could not find it for years. Recently they have found evidence of *Borrelia burgdorferi*—the American one—and *Borrelia garinii* from Europe. So you need to be cautious about that.

Sorry, I went off on a tangent there from your original question. I do not think that they are saying that there is not any possibility of an indigenous form of *Borrelia* or another causative agent; they are saying that classical Lyme disease cannot be acquired here. That is translated down at the coalface where people walk in the door to a doctor and come in with a tick bite and nothing is done in terms of investigating or treating that. There is no early intervention treatment. The doctors are too terrified to test for it because the Royal College of Pathologists has sent out an advisory to say that they should not test for Lyme disease. They are not testing for any of the co-infections and people are becoming really ill as a consequence, because they are all too scared of Lyme disease because Lyme disease 'cannot be acquired' here. That is how it is coming down. The stigma is coming from that.

Senator MADIGAN: In MSIDS's paper to the committee, you have spoken in your recommendations here about process and you have mentioned the Department of Health and the RCPA. Could you briefly elaborate there about your recommendations and what you suggest could be done to improve—

Ms Daniels: I missed something in my introduction and if I may go back, because Senator Madigan struggled with our name. One of the issues is this name. We have people speaking at cross purposes. At the end of 2014, we changed our name from WA Lyme Association to Multiple Systemic Infectious Disease Syndrome Incorporated in order to break the semantic deadlock that was occurring and all of the confusion and to use a name that described the actual condition that patients have, that is not dependent on naming a particular bacteria that comes from somewhere else, that is not reliant on it being a particular vector, so that it does not necessarily have to come from ticks, and that describes the condition that patients have. The pronunciation for it—it is a new term—is M-SIDS. I will go on to Senator Madigan's question, which was in relation to the process—the first three recommendations. Thank you for the question, Senator Madigan. I started to touch on that, in terms of the process that has gotten us to here. I mentioned that it has been based on flawed scientific logic—that the entire investigation has been looking at the problem through a scientific perspective and looking at the problem in a narrow, filtered approach.

If we zoom out on this issue and look at why we have a problem here. We have two camps, one of which is the people who are affected by the disease and have direct experience of it, and the people who look them in the eye: their doctors, the people who care for them, and the politicians who have taken note. They look at the direct experience of those people and say, 'I believe this. I can see this. I can see this is really happening.' Then, in the other camp, you have the people who approach it from a theoretical perspective and look to a large extent to it being a microbiological problem or a pathology problem. They see it in the laboratory and they are not directly affected. The investigation that has been done within Australia has been along the lines of that second camp. It has been done as a clinical issue, and that is obviously the case. But it has not addressed any of the issues that affect it as a public health issue. We would assume that if we called up the Office of Health Protection they would be interested in things that are to do with protecting the Australian health.

So, things were left out of that process, like the Australian patients. Who is looking at the Australian patients? We know about what is happening in the United States. It missed out on the co-infections. It had one round table for the treating doctors but largely missed out on taking an interest in the experience of the local doctors and what was actually happening here.

The other side of it is what was brought in, and what was brought in with the Lyme disease name—that being the primary focus and that bacteria being the primary focus—were a whole lot of imported controversies coming in from the United States. Lyme disease in America, if we are importing that package, has been plagued with controversy from the outset. There has been controversy regarding the treatment, the testing and case definitions, back to 1994, when these tests were introduced and there were early case definitions. They have been serious enough that in 2006 the Attorney-General of Connecticut, Richard Blumenthal, who is now a senator, instigated and anti-trust investigation into the Infectious Diseases Society members who drafted those guidelines that now apply and that have now been imported into Australia. They found that the committee had failed to screen for conflicts of interests. There were six individuals who held patents, or their universities held patents, on Lyme and its co-infections; four had received funding from Lyme or co-infection test kit manufacturers; four were paid by insurance companies to write Lyme disease policy guidelines; and nine had received money from Lyme disease vaccine manufacturers. These are the people whose guidelines we are relying on in America. When we import that product it is actually quite flawed. The guidelines we have been recommended to use in Australia actually have been removed from the National Guideline Clearinghouse, for noncompliance. The guidelines that are

approved by the National Guideline Clearinghouse are those of the International Lyme and Associated Diseases Society, which is the doctors who specialise, and are similar to the treatment protocols for which our doctors are currently being sanctioned. Sorry, it is a big subject and it is very difficult to wrap it up.

To wrap that up, what is happening in America in the medico-politics is very relevant because what has happened here is that in importing the name we have imported the controversy, and in the way that this has played out here we have replicated the same tactics and the same process, where a private organisation representing part of an industry that stands to benefit from the way guidelines are set up is actually having a greater amount of leadership and influence in how this has occurred than the Australian government has.

Senator WANG: Would it be possible to have the patients come up with a better name? With the definition you have come up with, would it be possible for the patients to gather in a room together and come up with a name and be done with it?

Ms Daniels: That conversation has been debated endlessly for years. There are people who say we should call it borreliosis, but we discovered that because that defines it to a single bacteria. There are people who want to call it tick-borne illness. That confines it to a single vector, when we know that these infections can be carried by mosquitoes and lice. So, for our organisation we just stopped arguing and used Dr Horowitz's term: Multiple Systemic Infectious Diseases Syndrome, or MSIDS. It is a little bit of a mouthful and it takes a while for people to get used to it, but we are happy with that. In terms of getting the patient community to agree on anything at all, good luck with that!

Senator WANG: How is the new term accepted around the community, especially in the health departments and in the medical profession?

Ms Daniels: I have actually found that the professionals have said, 'Wow, that it is a good idea. Very good.' It is just a little bit more difficult within the patient community. Different factions have spent a lot in branding and they are attached to this sort of thing. But when we have that discussion it always causes a fight, so we just went ahead and found something that suited our organisation. We also broadened out nationally and we have tended to attract more members nationally.

Senator WANG: So here is a term, but it seems to me that the department of health, the previous witness, is still struggling to have a name that is agreeable to them. How can we solve that problem?

Ms Daniels: I think the WA department of health is actually so far behind the eight ball that they have not even woken up. Everybody is relying on the federal government to take the lead. The only thing I have seen from the WA health department was where the health minister, Kim Hames—I do not recall exactly when but it was some time last year—when asked a question about Lyme disease, essentially implied that any recovery that patients experienced after their treatment protocols was a placebo effect. At one point I attempted to respond to that but never quite finished it.

Ms Kelly: Could I make a point about the Western Australian department of health. Between 1994 and 2001 there are a couple of official documents available on the internet where Western Australia has relapsing fever listed as a notifiable disease. Could the Western Australian health department be asked to supply to the Senate details of the disease or the pathogen that was associated with that relapsing fever, the process that got it listed as a notifiable disease, and then the process that had it dropped from the list?

CHAIR: That is a very good question. We have taken it down and we will put it on notice to the department.

Senator WANG: We do love to travel with our pets. Some Australians bring their dogs to the USA and to Europe. It is possible that the dogs, or even pets in general, catch Lyme disease overseas. When we come back home we bring our pets home. Is it possible for our local ticks, mosquitoes et cetera to contract Lyme disease from pets we have brought back from overseas, and then pass it on to humans?

Ms Daniels: I do not think that dogs are so much of a problem, because they do have to go through a lengthy quarantine period.

Ms Kelly: Humans do not have to go through a quarantine period when they travel.

Ms Daniels: Humans do not have to, and, also, our migratory birds do not stop off at Christmas Island and shake off their ticks! The other thing I discovered when I was doing the supplementary submission for the Chief Medical Officer's scoping study responses was that I looked into the biosecurity issues in terms of imports and, while we do not have live imports of cattle, the only thing stopping a horse breeder is a voluntary declaration prior to exporting the horse from the United States. The other fascinating thing is that *Borrelia* is capable of surviving at more than minus 112 degrees for up to 12 weeks in frozen semen sample. The viability of semen

sample is maybe a round 60-something per cent and the viability of the Borrelia virus is between 80 and 95 per cent after being frozen for that period. So it does have implications for our imported semen.

Senator WANG: How can the community help you so that we can really get down to treating patients as Lyme or Lyme-like again—whatever name we can finally arrive at?

Ms Daniels: Referring to No. 5 on our recommendations: conduct an independent review of Australian pathology accreditation processes, policies, practices and the interpretation criteria with respect to Lyme disease and co-infections. There has just been such an incredible campaign that has come out of the Royal College of Pathologists. It is astonishing. We have pages of evidence—for example, the spokesperson was interviewed on a radio station in Albany and was asked whether the tests that are used currently would pick up if there were an indigenous form of Lyme disease—whether the currently used overseas tests would pick it up. That is a really good question. The RCPA spokesperson, after quite a lot of scientific jargon that would have confused most of the punters, actually said, 'But we have never ever picked up anything that would indicate it.' That is totally contradicted by the obscure little bit of research that Elaine mentioned earlier, which is a report from Westmead Laboratory that was presented at a conference. It showed the data from 1994 to 2012. As Elaine mentioned, 24,000 tests were done by Westmead, which was the main lab, plus one of the lab. That indicates that 24,000 times a doctor looked at the patient and said, 'That person's clinical examination justifies getting a test.' Of that, 900 samples showed some antibody reaction. Then, there is a chart measured in bands of antibodies. To be a positive test on the surveillance criteria you have to have five of 10 bands positive. So there was a whole range of people who had what would classify as a diagnostic positive—three or above bands positive. I think there were about 270 or more. There were 88 cases that met the Centre for Disease Control's highest criteria which is used for surveillance of five bands positive. They gave the breakdown. Of those, two had never travelled outside of Australia. In most counties in America, to declare endemicity they only need two cases of people who have not travelled outside of their area. So by 2012 we had this and this information has never been brought forward.

What we would like to see is some kind of reporting and surveillance that starts to make that data transparent. What are the figures since then? How much has it changed since all the labs changed over to the European test criteria that only need two or three bands positive? Based on that, we should have been seeing at least eight times more positive tests since those tests were introduced in 2015. Why are we not? We have done a survey of laboratories and they have given us that. One of the laboratories actually admitted that what they do is add a new criteria to that which says, 'Plus a relevant travel history'. So even if you can meet the highest CDC surveillance criteria of five bands positive, which is not needed for a diagnosis in any other country, you have to also meet this criteria of a relevant travel history.

The same thing is happening at the first stage tests. They do not use the test kit guidelines that say that either an equivocal or positive test should be referred to the second stage test. We have test results from people in WA who have had two positives and an equivocal and have never been sent for the second stage test. Send their blood to Germany and they come back positive. How many are being missed when that first stage test is probably only as good as a coin toss in terms of its reliability anyway? They have raised the bar up so high. This is a way of suppressing evidence. There is no evidence because they have raised the bar so high that the majority of the people who have the problem cannot meet the criteria.

Senator WANG: I have a quick question, Chair.

CHAIR: I have heard 'Just a quick one before' already. We are seven minutes over.

Ms Daniels: I am so sorry.

Ms Kelly: Can I throw in a quick two-line answer to that question, too?

CHAIR: Yes.

Ms Kelly: Doctors are expecting us to meet algorithms and we do not. I have so many accompanying things wrong with my illness. I have hypothyroidism for reasons that do not fit the algorithm, and I could list seven or eight other things. I am literally untreatable within a mainstream doctor's surgery and anything that my treating doctor could do for me would have that doctor pulled before AHPRA. He may as well take me outside and shoot me because I am not fixable within the system. That is a problem. You need to scrap the algorithms. I did not have time to listen to the news for the last two weeks because I was too busy reading 800 submissions, but I heard mutterings about one doctor managing the patient system. That is not even a conceivable option for us. One doctor could not do anything with any of us. So you need to scrap the algorithms for us; they do not work.

CHAIR: Senator Wang, I am wondering if you could put your question on notice now.

Senator WANG: All right.

CHAIR: Ms Daniels, would you mind taking this question on notice and just sending us an answer? We are not expecting you to do a whole lot of extra work. I am just conscious of making sure everyone gets a go.

Senator WANG: Thank you, Chair. Ms Daniels, to your knowledge, what caused the laboratories to raise the bar?

CHAIR: Could you take that on notice?

Ms Daniels: I can do that. Can I just add to a response to an earlier question? There are over 1,000 diagnosed patients in WA and there were five suicides in the last three years.

CHAIR: I have a question. Perhaps you could take it on notice too. I do not see the point in raising the bar when people are sick. If we are raising the bar, and it is not this particular illness, people are still sick. Then the question is: why do they raise the bar? Perhaps I could leave that with you and you could also take that on notice.

Ms Daniels: I would like to thank you because that is the obvious question.

CHAIR: Thank you.

LE PAGE, Mr Stephen George, Committee Member, ME/CFS and Lyme Association of WA Inc.

VARY, Ms Rebecca Ellen, Volunteer, Lyme Disease Association of Australia

[9:40]

CHAIR: You have both heard me ask the questions and things, so I am going to ask straight up: have you had information on parliamentary privilege and protection of witnesses and evidence?

Mr Le Page: Yes.

Ms Vary: Yes.

CHAIR: Welcome both of you. We have your submission—thank you very much. I would like to ask you both to make a short statement and then we can go to some questions.

Mr Le Page: I would like to share with you a perspective on Australia's Lyme-like illness from the point of view of chronic fatigue syndrome. CFS is a debilitating illness with symptoms that may include persisting or relapsing fatigue; post exertional malaise; muscle weakness; cognitive dysfunction; muscle and joint pain, sleep dysfunction; memory loss; flu-like symptoms; cardiovascular problems; thermostatic issues; and sensitivities to food, odours and chemicals. We estimate the prevalence of CFS to be somewhere between 0.2 per cent and 1 per cent of the population, so the number of Australians with CFS would be between 48,000 and 240,000.

A major problem with the diagnosis of CFS is that it does not say anything about the underlying pathophysiology of the illness. There is no diagnostic test for chronic fatigue syndrome currently, which sometimes leads to the terrible assumption that the illness is all in the patient's head.

The discovery of Lyme-like illness in Australia has proven to be a significant finding for the CFS community as it has opened up an important new avenue for investigation. A handful of doctors around Australia have discovered that a high proportion of CFS patients return positive test results either to Lyme disease, or a variety of Lyme-like infections or co-infections.

Dr Adam Nuttall writes in his Senate submission:

A number of LLI doctors believe that 95% of those with CFS could be suffering from a LLI.

Dr Hugh Derham writes in his Senate submission:

I have diagnosed over 1200 patients with ME/CFS and over 900 of these patients with the diagnosis of Lyme Disease/Borreliosis and usually several co-infections.

In a survey of Lyme disease patients run by the Lyme Disease Association of Australia patients were asked what other diagnoses they had received, and out of the 715 respondents 630—or 88 per cent—indicated that they had also been diagnosed with CFS. We have seen this firsthand with many people who first contact the association with a diagnosis of CFS subsequently receiving positive lab results for Lyme disease or Lyme-like infection. If we make a conservative hypothesis that perhaps 85 per cent of cases of CFS are contributed to by a Lyme-like infection then it is feasible that Lyme-like illness could be a factor in between 40,000 and 204,000 Australians who have been diagnosed with CFS.

We call upon the healthcare system to provide government funded specialist clinics for dealing with the chronically ill patient and the complexities of the testing and the treatments which they require.

A good model to follow is the Nightingale Research Foundation of Canada, run by expert diagnostician and author, Dr Byron Hyde. He typically spends between Can\$5,000 and Can\$8,000 thoroughly investigating each patient, funded by the Canadian healthcare system. His advanced investigation and testing methods reveal pathologies which would likely have gone undetected. Once pathologies have been identified, many can be treated, and this is often enough to bring patients back from the brink of disability, enabling them to function again and to return to the workforce as contributing members of society no longer needing financial support from the government but instead earning an income and paying income tax. This has a far better outcome for the government, with the Can\$8,000 investment per patient seeming trivial. This also has a far better outcome for the patient than leaving them in a state of chronic illness, dependent on a pension in order to survive.

I would like to leave you with a quote from one of our members: 'To sum up my current life situation in one word, I would say that I am surviving. I simply exist. I know there is something wrong with me. Something has changed. I have gone from pillar to post in an attempt to diagnose and define. I want to be a productive, hardworking member of society and return to a state where I can work hard and contribute back to society. This is very difficult to achieve when I do not have the backing of the government and the broader medical community to help overcome this issue. I yearn to be able to return back to my former self. I do not want to be a burden on the system. Please help me to help you.' Thank you for your time.

CHAIR: Thank you. Ms Vary, would you like to make a short statement as well?

Ms Vary: Yes, my short statement goes for about eight minutes, just to pre-warn you. Would you like me to try to make it shorter?

CHAIR: If you could, that would be great. As you can see, we have a number of senators who really want to ask questions.

Ms Vary: I represent the Lyme Disease Association of Australia in Western Australia, and I am also a patient. Firstly, I would like to thank each of the senators and those who support them for their interest in this topic. We know that you have been inundated with submissions, especially from patients who wanted you to hear their stories. For many patients, the telling of their story was particularly painful. Most had never written it down before and, in doing so, many people found it extremely challenging to reflect on what their lives have become due to their debilitating illness. We trust that you have had time to read each of these stories.

We are here today because four successive health ministers from both sides of government have failed to address this dire situation. We are here to talk to you to bring you the story of what is currently happening and to ask you to provide us the help to find a solution.

To address the terms of reference, I would like to talk for a minute about incidence. Our submission points out that no-one but us, the LDAA, is collecting statistics of patients. We have a detailed patient survey that explores the situation for patients. There were 1,051 respondents, and 161 of those are from Western Australia—that is, 15.3 per cent. We have a mapping survey that plots geographically where these people live. There are 2,126 of them and 362 are in WA—that is, 17 per cent. We also plot where they suffered a tick bite. There are 910 individual locations, and 152 of those locations are in WA—that is, 16 per cent. It is in every state in Australia. For Western Australians, the incidence rate is higher than what our 10 per cent of the population distribution would quite reasonably expect.

There are a handful of doctors who treat Lyme patients, and they tell us that they have treated about 4,000. That is just the tip of the iceberg. Sadly, we expect that the incidence is much higher. This means that, if we compare it to the American statistics with population, there would be 22,000 new cases of Lyme-like illness per year and up to 450,000 cases from the past 22 years, due to stubborn and entrenched denial. There is no official data that may help to quantify the size of the Lyme problem in Australia. I should say that, as an organisation, we are not attached to the name, but it is traditionally not the patient's job to name a disease; that is usually somebody else's job—the scientists or the government.

There is no monitoring of the disease. We asked this as a question on notice—Senator Madigan asked that question—and were told that they were not monitoring it. As far as the definition goes: frankly, no-one can agree on it. Our submission details the many problems with the culture around the name and how it is an impediment to moving forward. The committee has received many submissions from medical and scientific organisations that all have their own trouble detailing what this actually is. As demonstrated by the many submissions, each silo of medicine seems to have its own definition, and none of them agree. This ignores the point that there are many patients who are likely to have acquired Lyme disease, borreliosis. This is not something that we think we have; we have test results that show we have it. We have been clinically diagnosed after we have ruled out everything else. The narrow definition, however you wish to define it, is a problem, as Kate explained.

For us, the Lyme-like illness is caused by a constellation of different organisms: bugs, viruses and protozoans—a cocktail of pathogens that are making people sick. They are typically acquired through the bite of a tick but they are not always acquired through the bite of a tick. Our data shows that not all people are actually bitten by a tick and that there are other vectors and other ways of acquiring Lyme-like illness. They need to be examined. 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.

When sick people need help they see a doctor. The majority of doctors do not help them because they are not trained to ask for a tick bite history or even to recognise the signs and symptoms of Lyme. If they are open-minded enough to test for it then it is not unusual for the Australian testing to come back negative. Compounding this, most doctors have not kept up with the geography of emerging infectious diseases when they go to the website and it says we can only get it in endemic areas. On the rare occasion that a patient encounters an open-minded doctor, the doctor may order a pathology test to check for Lyme. That returns a negative, as they invariably do; this reinforces the doctor's view that Lyme is not here. If the test is returned positive, the doctor will look up advice from the health department and tell the patient that it is a false positive because there is no Lyme here. Without treatment, any opportunity the patient has to stop the dissemination of the disease through

their body is gone. Sadly, it is all too common. Early treatment is affordable. If a doctor were Lyme educated and knew enough, they could prescribe six weeks of doxycycline. The patient might overcome what was ailing them and their story would be completely different.

CHAIR: While you are looking at how you will summarise, I will point out that it is possible for you to table your opening statement if you want to.

Ms Vary: That would be great. I can do that. What I will say is that the WA Department of Health, in their submission, state that the illness should be appropriately categorised not to imply causation by *Borrelia* species. However, patients who are using the term 'Lyme-like' are testing positive and being diagnosed with borreliosis, and they are doing that through labs accredited to ISO 15189, which is an international standard that is recognised here.

Senator MADIGAN: Before you both believed you were suffering from Lyme disease, how many doctors—specialists—did you attend?

Ms Vary: Stephen and I have a very similar history. We were both infected for decades before we were diagnosed. For me, the number of doctors was about 10 to 15. And for you, Stephen?

Mr Le Page: Closer to 20.

Senator MADIGAN: So, somewhere between 15 and 20 doctors—17½ is the average. And you had no joy? Is it correct that your health did not improve after seeing various specialists—I am assuming they were specialists—and GPs in those numbers?

Ms Vary: Yes.

Senator MADIGAN: In evidence earlier this morning I asked the WA health department about something people have said to me, which is that it can be spread by a blood transfusion, through the womb or through sexual contact. The department said that there was no evidence to suggest that. Can the LDAA point the committee to any papers or evidence that refutes that claim?

Ms Vary: We may be able to. I would have to check. That is not something that I have off the top of my head. I would have to check with my office, but certainly, as far as blood transfusion goes, there is some information that we can definitely send you.

Senator MADIGAN: I have personally heard a lot of cases of people who present at hospitals or to doctors saying that they believe they have Lyme disease or a Lyme-like illness. We are told by departments that patients are supposed to be treated with respect. Is the LDAA able to give the committee—take it on notice if you like—figures of how many of your members have presented at hospitals or GPs and have not actually been treated with respect; they have been told they have a few kangaroos loose in the top paddock? Of people who I have met, a number of people have had it suggested that they be scheduled. Can the LDAA furnish the committee with some numbers of people, members, who have been subjected to this sort of thing?

Ms Vary: I do not think we have got it in our current data. It may be something that we would have to pull or something we could question patients on. Anecdotally, we are told stories like that every single day, so, even if I just went back over the emails from the last six months, I could pull up a number of those kinds of stories. But that is not statistically gathered; that is just me going through the emails. So, yes, we can look at that.

Senator MADIGAN: In evidence earlier today, we were trying to thrash out people who have come overseas from Lyme-endemic areas, as identified in the WA health department's submission to us. Has the LDAA got any figures on how many people in Australia currently have got a positive test from overseas—people who have contracted Lyme overseas with a positive result from any of the laboratories?

Ms Vary: Our statistics from our surveys and our mapping surveys would have that sort of information in them, so we could also get you that.

CHAIR: You can take that on notice?

Ms Vary: Yes.

Senator MADIGAN: Is the LDAA aware if IGeneX or Infectolab have NATA approval?

Ms Vary: Infectolab, which are the lab in Germany, are also known as the BCA-Lab. They went through a name change. Infectolab were accredited with ISO 15189, and they have been accredited to that standard for quite a while. What happened in January was that NATA became a member of that accreditation as well, so NATA now has the right to recognise the other labs in ISO 15189, so it can therefore recognise the Infectolab results.

Senator MADIGAN: That ISO accreditation that you have mentioned is an internationally recognised accreditation?

Ms Vary: Yes.

Senator MADIGAN: NATA recognises that now—

Ms Vary: Yes.

Senator MADIGAN: and the German laboratory you mentioned is accredited to that level?

Ms Vary: Yes.

Senator MADIGAN: And that is recognised by NATA, the National Association of Testing Authorities, in Australia?

Ms Vary: It should be, yes.

CHAIR: We can check on that.

Senator WANG: You mentioned that you have seen over a dozen GPs in your history. What did they normally tell you about the problem you had?

Ms Vary: They told me for many years that I had depression and that I should take antidepressant tablets, which clearly made no difference because I was not depressed. And, if I was, it was because I was sick and I was not getting any help. They also then later diagnosed me as having chronic fatigue syndrome. But, yes, the depression was the first one that they waved at me, and they continued to jam those antidepressant tablets at me for decades.

Senator WANG: So you took decades of medications for problems which you do not really have?

Ms Vary: No.

Senator WANG: Do you consider that a serious burden on your personal finance and the taxpayer as well?

Ms Vary: It is a considerable burden on the taxpayer's finance because they were trying to give me drugs which were not going to address my illness, and the taxpayer was paying for that through the public health system.

Senator WANG: Is that a common story shared by Lyme disease sufferers?

Mr Le Page: I think so.

Senator WANG: As far as I know, if you go to a blood donation centre, if you tell the nurses you have Lyme, they will not take your blood; is that correct?

Mr Le Page: I think that is correct.

Ms Vary: It depends. A number of patients have reported to us that they have inquired or said that, and they have been told, 'No, no, that'll be fine,' and then, for other patients, the vast majority are being told no, they cannot. They are not allowed to donate, and they are being sent letters from the Red Cross to say no, they will not be able to donate.

Senator WANG: That is a direct contradiction to the notion that we do not have Lyme in Australia.

Ms Vary: Yes, and it also directly contradicts what they are saying about, 'We don't believe that it is transmissible by blood transfusion.'

Senator WANG: Yes. A lot of patients were professionals working in different areas, earning a healthy income and paying tax, but because of the illness you cannot work normal hours and in some cases you cannot work at all, so some of the patients had to go to Centrelink, and they are living on welfare. I am told that, if you go to Centrelink and you fill out the form, if you put 'Lyme' on the form you will be rejected.

Mr Le Page: Yes. Chronic fatigue syndrome is an illness recognised by Centrelink, so, if a person is disabled, they are more likely to be able to get disability support pension with a diagnosis of chronic fatigue syndrome than with Lyme disease. This is ironic because chronic fatigue syndrome as a diagnosis does not actually say anything about the pathophysiology of what is going on, whereas with Lyme disease you know a lot more about the pathology.

Senator WANG: I think there are a lot of contradictions in this country about whether Lyme exists or not, how we treat it and blah blah. I believe that is a parliamentary term! How can we help the sufferers? How can we help to change the minds of the department and the medical profession? How can we help the sufferers—really get the whole country to think that maybe we should put the name aside; maybe we should put the diagnostic process aside? We know that people are suffering from Lyme already. How can we prioritise those people first?

Mr Le Page: I would like to make a carbon copy of the Nightingale Research Foundation, from Canada, in Australia. I think their model is sound. It helps patients. They have access to a lot more government funding. They have time to research the pathologies in the patient much more thoroughly, and they get results. That model

applies to Lyme disease, Lyme-like illness, chronic fatigue syndrome, myalgic encephalomyelitis—probably many more chronic illnesses could be treated much more effectively through that model.

Ms Vary: I think the establishment of a special multidisciplinary Lyme treatment clinic with services for patients could also be done in conjunction with research, so they could research the patients at the same time and find out the answers as to why they are fatigued or why they are in pain—why they are sick.

Senator WANG: The clinic in a way can be the data collection centre as well?

Ms Vary: Yes.

Mr Le Page: Absolutely.

Ms Vary: On page 8 of our submission we have made a list of recommendations which I will not go into now, because we are running short of time. But there are a lot of things that need to be done, and we have recommended them. We think that some senators and some MPs just need to stand up and get it done.

Senator WANG: Yes, I am aware of the recommendations. Even though we have had conversations before, I am asking the questions so we can put it in the *Hansard*.

Ms Vary: Yes.

Senator WANG: Thank you.

Senator MOORE: One of the troubling aspects of this whole inquiry has been that we could have two separate inquiries and the evidence is straight down the middle. Even in today's hearing we have heard from you, we will hear the two-minute statements and then we will have a segment later with a whole group of medical experts who will all have a completely different position. And we will just be able to draw the line down there, which worries me.

I was very grateful for the evidence of the previous witnesses who started the evidence by saying, 'We are not a cult.' I think that was a really valuable statement, because there are views around that there is a group that has been formed now that is gathering around this issue. Can both of you answer a question for me about a view that people are desperately seeking a diagnosis, so that the very fact of getting a diagnosis in itself provides an outcome? That has been used by some people to claim that a fostering of enthusiasm around issues of Lyme and Lyme-like symptoms has been a desperate seeking by ill people to find a label and a diagnosis for what they have.

Mr Le Page: If you have a chronic illness and you are looking for answers, a diagnosis of Lyme disease is bittersweet. It is bitter because many of us here today know just how difficult it is to get support for Lyme disease. But it is sweet because with Lyme disease you have evidence of pathology, and that gives you a new avenue to investigate the treatment.

Senator MOORE: Ms Vary, I would very much like to get from your organisation a response to that question, because it is something that has been said about the whole area of Lyme disease and Lyme-like symptoms and all the other titles that go into that box. That is, that there is a view being put forward that people who are unwell—and they would be many of the people who are your members—are in the group because they then have a diagnosis; that that is what they are seeking. My understanding is that not every single person who is in your group has had a positive diagnosis—many have, but not all of them have.

Ms Vary: Many have been clinically diagnosed.

Senator MOORE: Not all?

Ms Vary: I do not know. Are you trying to understand why people would be thinking that this is some sort of cult organisation where we are all trying to seek out a diagnosis?

Senator MOORE: I am putting forward a view that has been put in evidence and has been put in discussions around this particular inquiry: that one of the elements, not all, is that people who are genuinely unwell—and people have been falling over themselves in the evidence that we will hear for the next two days to say that people are unwell, they are being very careful to make sure that people who are unwell do not feel as though they are being dismissed by that claim—but within that process, because there is so much evidence being put forward by some clinical and medical groups that there is not Lyme's disease in Australia that has been caused in Australia, there is the view that one of the reasons that so many people have got involved is that they have seen that this could be the answer for the symptoms that they have—that they have been caught up with being so unwell for so long that now that this could be a way of giving them a diagnosis for the various extraordinarily difficult and painful conditions that they have.

Ms Vary: Like Stephen says, it is a bittersweet diagnosis, so it is not something that people seek out. We do have patients that are clinically diagnosed, we do have patients that are tested positive. Those patients were not

dying to find out that they had Lyme—it is a very bittersweet realisation that you are infected. It is not something that was—

Senator MOORE: That allegation? The one that—

Ms Vary: I have heard that it is the latest—'trendy' is the word they are using—it is the trendy disease to have. That is not the case. People have normally gone through ruling out every other diagnosis before they even get to the point where they are looking at Lyme.

Senator MOORE: The other element, Chair, is the amazing amount of evidence we have had about the stigma associated not just with the people who have the condition, but with the physicians who treat them. I am wanting to find out from your organisations a response to the medical evidence we have had that raises questions about the doctors who are considered to be Lyme-aware that they could be harming patients by the treatment regime that they actually describe. Also, I am wanting a response to the allegations that the medications and the testings which are in place are taking advantage of vulnerable people. From the point of view of your association, I would like to get something on record about how you feel about those statements.

Mr Le Page: Perhaps I can make a comment about our patron, Dr Hugh Derham, who is here today. He will be speaking in an hour's time. He is considered a hero to our organisation because he has helped so many people who have been chronically ill for such a long time to discover the pathology that is causing their illness. It is not just Lyme disease; it is not just co-infections. There are a number of other pathologies that can account for chronic fatigue syndrome-type illnesses. It is important that we consider the whole pot. Dr Adam Nuttall is also of the view that we need to stop focusing on *Borrelia burgdorferi sensu stricto*. There is a lot more going on, and we need to consider everything.

Ms Vary: Of the doctors who are treating Lyme-like illness patients, I would say that they have years of experience, they are medically trained and qualified and they are often medically trained and qualified in several different areas of medicine. They are very thorough in ruling out all of the other illnesses which may be affecting us before they arrive at a Lyme diagnosis. These are not young doctors out of university who just think, 'I'm going to grab a bunch of patients and diagnose them with Lyme.' These are doctors who have worked 20, 30, 40, 50 years in medicine and who have seen patients for decades. They have chosen, for whatever reason, to work with the most difficult patients and to treat them, learn about them and find out what is affecting them.

Senator WANG: So these are the doctors who really put the patients ahead of everything else?

Ms Vary: Yes.

Senator LUDLAM: Thanks both for the effort that you have gone to to bring the evidence forward and also for your advocacy. I am interested in if you can help us distinguish between the symptom cloud around Lyme disease and Lyme-like illnesses, and ME/CFS. On the Lyme side, you are having to persuade the medical fraternity that the pathogen exists in an Australia context whereas for ME/CFS there has actually been a complete absence of any kind of diagnostic criteria for years and years. Can you help distinguish the two for us? Maybe, Mr Le Page—if you want to kick off—why is even the association incorporating both conditions?

Mr Le Page: As far as your first question with the symptom cloud, there are an awful lot of symptoms in common between chronic fatigue syndrome and Lyme-like illness. I do not think that you could look at a patient clinically and know the difference. Pathology is required to determine the underlying pathologies. With chronic fatigue syndrome, there is no diagnostic test. There is no specific pathology for chronic fatigue syndrome. Can you remind me of the second part of your question, please.

Senator LUDLAM: I was just trying to get a sense of whether you can distinguish the two conditions for us, because part of the complexity of this is the sort of cloud of symptoms—that we are possibly lumping in three, four or five quite distinct conditions. The second part of the question was on if you could just tease out for us the reason your association, for example, includes both.

Mr Le Page: With patient pathology, this really is the realm of the qualified healthcare professional. I think they would do a better job of answering. As far as the chronic fatigue syndrome society is concerned, we found that Lyme disease, or Lyme-like illness, was such a significant factor in so many of our members that we found ourselves obligated to also provide support for Lyme disease. We formalised that two years ago by changing our name to include Lyme.

Senator LUDLAM: Does your association receive any support at all from state or federal governments in terms of advocacy or patient support work that you do?

Mr Le Page: Nothing.

Senator LUDLAM: Is there anything available—doors to knock on—for that kind of advocacy work?

Mr Le Page: I am open to suggestions.

Senator LUDLAM: Feel free to fire some suggestions back at us as well, because I think a really important part of it is that you folks are performing an incredibly important public service both for the patient cohort and for the researchers and the government agencies on no support at all. How do you folks maintain yourselves?

Ms Vary: I was going to go back to your original question, which was symptoms of Lyme and chronic fatigue syndrome. For me there is no difference. I was diagnosed with chronic fatigue syndrome and later I was diagnosed with Lyme. Some really good statistics from my doctor, Dr Derham, who made a submission, was that 90 per cent of his chronic fatigue patients tested Lyme-positive when their bloods were sent off. I would also like to point out that I am one of the few lucky patients who has been able to treat and is in remission for borreliosis. My chronic fatigue improved by 80 per cent once I treated that condition.

As for what the government can do for us or how they can help us: one of the jobs we do is educate people. If they could help us with mass education funding, pamphlets, posters or education in schools about ticks and the diseases that they carry, that would be one thing that they could help with.

Senator LUDLAM: In answer to an earlier question you mentioned the Canadian model. I presume that you are aware of the work on ME/CFS that the NCNED is doing at Griffith University on the Gold Coast. They are kind of combining the globally significant research effort on diagnostic criteria with a huge patient cohort—data, blood samples, MRI scans and so on. Is that a valuable model that we could maybe extend to larger numbers of people?

Mr Le Page: I understand Griffith University has in development a test kit for chronic fatigue syndrome and is looking to find a market partner. I am very much looking forward to the results of that effort.

Senator LUDLAM: It is absolutely world-leading research. Given both of the conditions and the degree of division and dissent within the medical community, do you folks maintain a list of GPs and specialists who are literate in these issues? Where can we find that?

Ms Vary: The Lyme Disease Association works on a referral system, so patients refer doctors to us. They say, 'This is a doctor who has been able to help,' or, 'This is a doctor who at least is open to testing; he may not be able to help but he can at least do the testing.' We have that list, which is slowly shrinking, because fewer and fewer doctors are happy with us giving our their names, because they are worried about repercussions from AHPRA or any of those organisations.

Senator LUDLAM: I really hope this committee can be part of the work of turning that around. Thanks all of you for bringing it forward today.

CHAIR: We have run out of time. I will also let you know that I have asked the secretariat to look at following up the earlier question about blood banks by writing to the various ones around Australia and asking what their exclusion procedures or criteria guidelines are.

Ms Vary: Also, can we look at whether that is done officially from the top? That is not getting to the girl who takes the blood on the ground. There seems to be a gap where they may have decided one thing in the head office but are not telling the girl who takes the blood, so she is telling patients something different.

CHAIR: That is a good point. We should also ask about how it is implemented. Thank you.

Proceedings suspended from 10:19 to 10:40

ASH, Ms Judith, Private capacity

BOWER, Ms Joanne, Private capacity

BROWN, Ms Natalie, Private capacity

BULL, Ms Rebecca, Private capacity

DOWNIE, Mrs Leanne, Private capacity

EBDEN, Ms Linda, Private capacity

HAMERSLEY, Ms Stephanie, Private capacity

MONKS, Ms Sue, Private capacity

STEPHEN, Ms Melinda, Private capacity

STEVEN, Mrs Meg, Private capacity

WEBB, Ms Leanne, Private capacity

WHITE, Ms Vicki, Private capacity

CHAIR: Welcome. Each of you will have two minutes to make a statement, before we will move on. I know it sounds like a very short space of time, but we have done this before. Because this committee does a lot of sensitive, important issues like this, we want to facilitate as many people as possible making a short statement. If you have not already made a submission and you want to table something, or if you run out of time but still have things to say and so you want to send in something else, you are more than welcome to do that.

Ms Hamersley: I am 43 years old and I am an occupational therapist. I have positive test results for *Borrelia burgdorferi*, meeting the centre for disease control's criteria. I have been sick for six years, having had to wait four years for a diagnosis of Lyme. In all likelihood, I contracted Lyme disease overseas, probably sexually from my Egyptian husband—I do not recall a tick bite. I also have positive test results for Epstein-Barr virus, cytomegalovirus, human herpesvirus 6, chlamydia, pneumonia, toxoplasma and Ross River virus.

If I contracted Ebola or malaria overseas, I would get acknowledgement and treatment. Why not with Lyme disease? A medico-legal occupational physician acknowledged that I was unwell and said, 'The difficulties faced by people in her situation are significant,' and, 'Chronic fatigue has been a controversial diagnosis, avoiding the issue of Lyme disease altogether.' She then recommended a psychiatric review, which had also been arranged—apparently as a matter of course. The psychiatrist indicated I have a somatic disorder and that, without weekly psychiatric intervention, I would not recover.

I have worked in the medico-legal industry for 15 years and even I found this process extremely stressful, insulting and disempowering, resulting in suicidal ideation. I had my own company and I was earning \$200,000-plus per year. I was contributing \$40,000 to \$50,000 per year in taxes. I am now on Newstart and I am rapidly running out of my superannuation money. I cannot get specialist support for claiming the disability pension. This is common amongst us 'Lymeys'. I am dependent on my elderly mother, who travels from Busselton regularly to do chores, food shopping and meal preparation. I have spent over \$200,000 on treatment. Even if it cost the government \$50,000 to fix me, it would have been paid back, and I would be a contributing member of society within one year.

What happened to our fundamental human right to adequate health and medical care? Whether our symptoms are caused by *Borrelia burgdorferi* or other agents, whether transmitted by vectors or other avenues, whether we call it Lyme disease or something else, whether we got it overseas or here, we are sick, we are dying and we are being ignored. We need specialised clinics for treatment and research and we need legal protection for doctors. The medical industry and Australian governments are complicit in this by their lack of action. The government must take the lead, as they did with AIDS. We are facing a national epidemic with far-reaching financial and social implications.

Ms Ebden: From 2000 to 2013, I was subject to hundreds and hundreds of tick bites. In 2006, I went to a local GP, after being bitten by a tick. The bite turned into what I call a volcano, which is an eschar. I was quite ill. A week later I developed a rash. I do not know if you can see it there.

CHAIR: Actually it will be in your submission.

Ms Ebden: Anyway I went to the GP. I was covered in tick bites. He said to me: 'You have an allergy. Go home and take some Phenergan.' I said to him, 'Is it possible that it is something from the ticks?' He said, 'No, we

do not have tick bite diseases in Australia.' So I never learnt to protect myself. I thought being bitten by ticks was just part and parcel of living in the hills. A week later I was still very ill—chills and headaches and it had gone to my chest. I went to the RPH and it was the same thing: 'You have an allergy. Go home and take Phenergan.' A couple of weeks later I was so sick that I went to another GP who finally treated me with antibiotics for the massive chest infection I eventually had.

I had several health problems after that. In 2009 I had my first stent inserted in my left renal artery due to the inflammation of all of my arteries. In the beginning of 2011 one of the tick bites turned into a dart board, which was unfortunately diagnosed as ringworm at the time. The ringworm did not clear up. I became sicker and sicker with all of the signs and symptoms that you are going to see with everybody else. Eventually, to cut a long story short, I went to India. I stayed at an Ayurvedic hospital in the hills of southern India. It was the Indian doctors there who told me that I was suffering from rickettsia and other tick-borne illnesses. I came back to Perth and told my GP. I had blood tests taken and they came back positive for rickettsia. It had already done its damage.

Some months later I was then diagnosed with having borreliosis. My journey had gone from bad to worse. Prior to getting sick, like most other sufferers, I was very active, I was a very educated woman, I had a good and happy life, I was an active member of my community doing volunteer work and I was a respected yoga teacher. I spent over \$20,000 and 10 years training and now I cannot work. I would like doctors to be educated in recognising the signs and symptoms of tick-borne diseases.

Ms Stephen: I would like to preface what I am about to say by saying that I have a first-class honours degree in biochemistry and biotechnology. I would like to point out some gaps I see in what is needed for research and training of doctors, naturopaths and other allied health professionals. Having caught Lyme disease infections 18 years ago from ticks in Tyalgum, New South Wales, it has taken two years and eight months of antimicrobial treatment for me to reach a stage where they cannot find any evidence of any infections remaining of Lyme disease in my body. Now I have what is called post-Lyme syndrome.

There are many people like me who have needed to use natural products instead of antibiotics because long-term illness has made our bodies extremely hypersensitive. It is very hard to find good practitioners who know how to distribute and use natural products to treat Lyme infections. There needs to be a lot more research and training of both Lyme treating doctors and naturopaths on using natural products for killing Lyme infections, such as the Byron White Formulas, herbs, essential oils et cetera.

Also Lyme disease treatment is not just about killing the infections; holistic treatment methods are essential to simultaneously support our extremely beleaguered body systems, such as hormonal gland function, digestion, detoxification et cetera. I and many patients also have been found to have pre-existing conditions that predisposed us to developing chronic Lyme disease in the first place, such as Pyroluria, genetically based methylation and sulphur intolerance issues. Lyme treatment can be exacerbated if these are not screened for and treated, so it is essential that more training is done of Lyme-treating doctors and naturopaths about these conditions and how to better holistically support body systems during Lyme treatment. It is essential that naturopaths collaborate much better with doctors in order to do this because doctors often cannot prescribe herbal medications.

Finally, I just want to point out that there are even fewer doctors in Australia who know how to treat post-Lyme syndrome than active Lyme. Dr Ritchie Shoemaker in the USA has done extensive research and had very good success in the treatment of post-Lyme syndrome, which he refers to as chronic inflammatory response syndrome. His post-Lyme treatment methods simultaneously treat the effects of toxic mould exposure, which also affects the health of many Lyme patients, including me. So a lot more training is needed for doctors in treating post-Lyme using Dr Shoemaker's effective methods. Thank you.

Ms Bull: I am 31 years old. I was bitten by a tick in Kalbarri on 23 December 2014. Previous to this, I worked and studied. I was hospitalised two days later with severe flu symptoms and gastro. Three hospitalisations later, I was transferred to Geraldton Hospital and then Armadale, where I was discharged a week later with an unknown virus. One day later, I was rushed to Royal Perth, where I had two lumbar punctures and another week's admission. Once again, I was discharged with an unknown illness. Not once did they look at my tick bite.

Finally, one month after I got bitten I had a doctor closely look at my tick bite site, and, sure enough, the head was still intact and needed removing. My symptoms continued and I continued to be sent away and ignored and told it's all in my head. This took its toll. In July last year, I took an overdose. I had 12 electric convulsive therapies, shock therapy, that did not help. It just flared my physical symptoms and affected my memory. I have confirmed diagnoses from different labs, including one within Australia, of *Borrelia*, *Bartonellai*, Queensland tick typhus and African tick typhus.

My symptoms vary every day, but I have fatigue, nerve damage, severe pain, vomiting, severe weight loss, rashes, migraines, loss of balance, dizziness, numbness. Every step feels like I am walking on broken glass. I get noise sensitivity and much, much more.

Unfortunately, my story is not unique. We are all in the same boat. 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. I now rely on in-home services to help with my kids, meal preparation and cleaning. I miss my old life before I got sick. I miss playing with my kids. I miss singing. I miss important events with my family and friends. I miss the old me. I miss contributing to society and do not want to feel like this day after day. I am not living; I am existing.

Whether it is labelled as Lyme disease or not, names are not important to us. Tick-borne illnesses, including the many other co-infections and relapsing fever from tick bite, need to be treated and managed appropriately before any more lives are lost to complications or suicides from this awful disease. I would like to thank Dr Hugh Derham for his care and support. I believe that, without his help, I may not have been possibly alive to tell my story today. Good luck to all of you. Thank you very much.

CHAIR: Thank you. The media is now here. I am just double-checking, as many of you were not here this morning when I checked this, particularly our witnesses. Are you okay to be filmed—and everybody else? Okay, thank you.

Ms Brown: I have been suffering from chronic Lyme for almost five years. My story is very similar to that of others at the table. I believe that I caught it on the North Shore of Sydney years ago. The truth is that many people are suffering from chronic Lyme or borreliosis and co-infections in Australia, many undiagnosed. To the trained and experienced medical physician, the Lyme literate MD, the cluster of systems do give a clear and proper basis of diagnosis. Even the US CDC states it is a clinical diagnosis. This should be enough. But, because Australian medical authorities—who are not experienced, by their own admission, nor trained in either recognising or treating chronic Lyme—do not want chronic Lyme to exist, nor be treated by long-term antibiotics, they are behaving in an unconscionable, passive-aggressive manner by pushing the burden of proof onto the patient. Yet, when we do show proof—symptoms, positive test results, EM rash, spirochetes under the microscope in our blood—it is still not enough. It is this attitude that needs to change for the situation to resolve in an ethical manner.

No-one wants chronic Lyme to exist, especially us sufferers. It is truly a horror story of epic proportions. But just wanting something not to exist does not make it so, so it is time to get real. The reality is that it is possible that we are getting sick from local tick bites, it is possible that it is from a pathogenic *Borrelia* species and it is possible that it is treatable with antibiotics, like all the other borreliosis around the world. If the medical community works on this basis that all this is indeed a possibility and allows our truly dedicated and knowledgeable, caring doctors to continue to treat us, then this will minimise the risk to the community. It can reduce suffering, prevent people from developing chronic Lyme and reduce health and welfare costs. By doing nothing and preventing doctors from treating us, there is a risk of creating more unnecessary suffering and severe suffering and increasing their health and welfare costs.

It is unethical to deny patients potentially life-saving treatment while waiting for the research and attitudes and politics to catch up. When the truth eventually comes out, as it always does, we Australians can say, 'At least myGov had my back, and my life mattered.' It would be a shame for all of us if at that time it showed a government of inadequacy and inaction. The only downside is using antibiotics but, since chronic acne is treated with long-term antibiotics, there is no reason why chronic Lyme cannot be. If you are worried about antibiotic resistance, then not treating a relatively small group of Lyme sufferers in Australia is not going to stop that ship from sailing. Maybe focusing on the development of the new antibiotic should be given a priority, rather than locking away the Australian stash of antibiotics while everyone else in the world has the key.

Ms Ash: Good morning. Thank you for allowing me to speak. In January 2002 I was bitten by a tick whilst camping in Murwillumbah, New South Wales. Three weeks later I collapsed at work and fell terribly ill. Numerous tests showed nothing; doctor after doctor that I saw could not tell me what was wrong with me. I have never recovered. In 2003—12 months after falling ill—a doctor diagnosed me with post-viral fatigue syndrome. The doctor explained that there was nothing that he could do to help me, and to just live within my limitations. I was devastated. In 2013—10 years after I was first diagnosed with post-viral fatigue syndrome—I met a Lyme-literate doctor who ran a number of tests in NATA-accredited labs. My results detected six different strains of a *Rickettsia*-Typhus-tick-borne bacterial infections. Based on clinical symptoms and a history of tick bite, I was diagnosed with Lyme disease and Bartonella. I would like to state that I have never left Australia. This experience

leads me to ask: how is it that mainstream doctors are allowed to diagnose me without pathology evidence, but my treating doctor is not allowed the same privilege in terms of Lyme disease?

In the past 14 years since I have first fallen ill my health has deteriorated. I am unable to walk most mornings, and I need help simply to dress myself. My 11-year-old son and eight-year-old daughter often help to care for me and cook meals while I am struggling to manage. Day-to-day tasks like driving a car, grocery shopping and cleaning are a struggle. I have not been able to work for 13 years, leaving my husband to support a family of five on a single wage. I worry that I will become a further burden to my family. My hope is that the Australian government invests more funds into research to find the evidence required so that people receive treatment in the early stages of Lyme disease. I hope that the Australian government recognises the dangers of tick-borne infections and takes the steps to educate doctors and the wider community to recognise the signs so that they can prevent this horrific disease.

Senator SIEWERT: Thank you very much. That, obviously, is on Hansard, and you all raise really important points. Thank you.

Mrs Steven: I am currently being treated for, what I like to call, the WTF disease, plus four co-infections. I was clinically diagnosed in July 2013. I am on treatment via long-term antibiotics, and that is actually working. I want you to note that my Infectolab test for *Borrelia burgdorferi* came back negative, so that is just a side issue. The supposed professionals that we heard talk earlier have talked about expert opinions, scientific evidence, stats and time lines, but I just want to talk about what I know absolutely, for sure, without having a PhD.

When I first became unwell in July 1984, I had not left the state, let alone the country. I was a straight A student at that point. I was very active in athletics and netball, had a very active social life and worked part time. I have been seeing, and I still do, the same GP since I was six years of age. He is very progressive, and he did not mention to me once about the possibility of Lyme disease, despite him taking a biopsy from a rash on my foot, which I do not remember as a tick, but the result of that was inconclusive.

I have seen more doctors, and had more procedures and tests done than I even want to think about—it is completely ridiculous. I have had an increase in symptoms quite regularly with major events—good and bad—including wedding, anniversaries, children, moving and things like that. I did have to change my work, so becoming unwell at 16 changed it at the age of 25, because I could not handle full-time work. I get sick from flying.

I have sons that I believe also have the infections. They are nearly 19 and both of them have multiple anomalies and one is significantly disabled. They both had epilepsy. One had a rash similar to the one on my foot, and one had a lung lavage that showed a bacteria that is very common for Lyme disease. My partner, who is here today, is no longer a blood donor and was a regular one, because he is afraid, or I am afraid, that I might have transmitted it to him. I would also just like to say that last winter I had no chest, throat or sinus infection for the first time in three decades.

Mrs Downie: I just want to make five points. The first one is that I was bitten by a tick in a Lyme endemic area in the USA in 2009. I had the classic bull's-eye rash and all the classic symptoms. I tested positive to *Borrelia burgdorferi* in 2012. I have the classic Lyme disease, not just the Lyme-like illness that we are discussing today, yet I still could not receive treatment in Australia. People who get malaria overseas can be treated here. People who get the Ebola virus can be treated here. People who get HIV overseas can be treated here. My first point is that people who are infected by Lyme disease overseas should be treated in Australia with no delay, no politics and no problems.

My second point, just because something is not written, does not mean that it does not exist. HIV-AIDS infected heterosexual white females when it was only written that it could be found in monkeys and homosexual black males. I have met people who have passed on Lyme-like illness to their children. I personally have passed it onto my husband, and my point there is that transition can occur without it being written.

My next point is that basic scientific principles would show that if there was a group of 50,000 people who have similar signs and symptoms and all got treated with hypothermia and/or antibiotics—which I am suggesting we could probably get 50,000 people together—then this treatment could be a way forward whilst the politicians, the bureaucrats and the AMA catch up with naming the illness, writing the required papers and getting laws changed. The treatment needs to be now. People are dying now. We cannot necessarily wait for the evidence.

Senator Wang was talking about how to help patients. Every Australian has the basic right of access to the medical system and financial support via Medicare. This illness is extremely expensive—I have personally spent \$84,000 in the last financial year—yet it does not fit into the current medical model or the Medicare model. Financial support is imperative to the survival of people with this illness. Treatments can include alternative types of treatment, Rife machines, FIR infrared saunas, supplements, Byron White formula, essential oils and consultations with international doctors.

Ms Monks: I think I am the first healthy person here. I am here on behalf of my son Lachlan Monks, who was diagnosed with borreliosis in February 2014. From 2009, I watched my son progressively get sick. By 2013, his symptoms were so severe he had to be removed from boarding school. Prior to seeing a Lyme literate doctor, Lachlan had seen three GPs on many occasions and a specialist physician. He had countless blood tests, two endoscopies and a two-week stay at Princess Margaret Hospital. Each doctor was unable to find the cause of, or treat, Lachlan's symptoms. Despite Lachlan's emphatic denial, each doctor suggested he was depressed. One doctor and the specialist person had seen Lachlan naked and neither were concerned about the horizontal purple welts across his back. Latterly, we found out that these were symptomatic of *Bartonella*—a common co-infection of Lyme disease.

In November 2014, I took Lachlan to Germany for hypothermia treatment and he has not looked back, despite the fact that his Australian doctor was not permitted to treat him upon our return. Lachlan is now in remission and

getting on with his life. However, while my six-foot three son should have been with his peers playing sport, attending school balls, graduating, having relationships and getting his licence, Lachlan was isolated in pain in a darkened room wasting away to 56 kilograms. I cannot help but think that if Lyme was considered in a differential diagnosis, and treatment options were available to Lachlan when he first fell ill, he would not have lost five years of his life to pain and utter misery.

The effect of Lachlan's illness on my family was considerable. We own a farm 250 kilometres from our treating doctor. From 2011, my husband started work at the Pilbara to make ends meet. Whilst he was away, I cared for Lachlan as best I could while looking after 2,000 sheep and my autistic daughter, who is being home schooled. I also held down part-time jobs. We were all very stretched.

Finally, it goes without saying that while we are waiting for evidence based medicine to catch up with the rest of us, and no data is being collected about the prevalence of this disease, people are suffering and being treated with outrageous condescension and ignorance. We must do better than this.

Ms Bower: Part of a doctor's hippocratic oath is to treat one's patient to the best of your ability. Not to dismiss a patient's symptoms, treat them with contempt, misdiagnose them and fill them up with anti-depressants to keep them numb and quiet. I have Lyme disease. All the above and more happened to me. It was so much easier to tell a mother, who had just had her second baby, that my symptoms stemmed from postnatal depression, even when I said my pain began any before any depression ever set in. I was bounced between doctors and specialists. I was told it was in my head, that I needed to be put in a mother and babies unit at the hospital and that I needed to stop being so stubborn in insisting something else was wrong with me. I gave up hope that anyone would believe I was sick along with any hope that I would get better.

Then I was fortunate enough to find a doctor who would help me. Following this, I received positive results for Lyme and *Bartonella* from both Australian Biologics and Infectolab in Germany. Within seven months of these positive results, I flew to a Lyme clinic in Germany for hypothermia treatment. I was treated as a patient with a real illness and I was treated with respect and dignity. My husband also travelled to Germany for treatment after testing positive for Lyme disease. I live with the guilt every day that I unknowingly infected him with this disease.

One of the hardest parts of this disease was not only being robbed of my health but also having my children robbed of their mother and my husband, his wife. I was so sick I had to get my parents to care for my children, as I was physically unable to.

I am recovering now, but I have an overwhelming dread that I may have passed this on to my son in utero and via breastfeeding. My son has presented with one band showing that he was exposed to a bacteria in utero; however, this is dismissed by our medical society. At the moment, he is happy and healthy, but if that should change I do not want him to suffer as I have. I want him to be able to see a doctor, be tested, treated and most importantly believed.

Ms Webb: I am here representing my son, who is too ill to be here. Where do I start? Braden was a perfectly normal, healthy, six-foot four, 17½-year-old doing the things that 17-year-olds do. He was doing a pre-apprenticeship in bricklaying and looking to get an apprenticeship. Things were all to change. The dates are not exact, but I will do my best. He was laying bricks on a Friday in March 2010 and got a gastro bug over the weekend. The gastro was gone by Monday, but he was left with severe vertigo. He went to the local GP who said to come back if it did not pass. Three weeks later he still had it, so he went back to the GP and did an MRI, but nothing was found. This was the start of our journey.

Over time symptoms have become worse. He has severe head pain day and night, the most debilitating of the symptoms. He has no temperature control and is always hot. Aircon in his bedroom is on 24/7. He is supersensitive to noise and also has a horrible rash on his arms that varies from pink to bright red when he is burning up. He is unable to get his own medication. I have to label everything. He cannot get a meal for himself. He has severe brain fog and muscle waste and cannot sit in a chair as it feels like he is falling off all the time. Travelling in a car is a nightmare. He cannot be left for any length of time or have a shower unless we are home. He has pretty well spent the last six years in his bedroom. It is hard to believe that our fun-loving, energetic son has gone.

We had different specialist appointments. We went to a cardiologist because his heart rate was between 140 and 160 beats a minute. As we walked through the door, the cardiologist said to me, 'I think you should take your son for psychiatric help.' When we got out, Braden said to me, 'Mum, you know that I am not putting this on.' What 18-year-old is going to be putting that on?

Four years ago a friend mentioned Lyme. I went to the GP and asked him. He put his hand up and said, 'No, definitely not in Australia.' Then we got referred to a Lyme doctor, and blood tests, which are absolutely positive were through PathWest, came back positive. We have been to Germany and tried many things. He has been up and down and slightly better. I am grateful to have him still with us, but all I want to see is everybody here and others suffering to get some kind of recognition.

Ms White: I am speaking on behalf of myself and my sons Damian and Ryan. We all suffer from Lyme disease. I wish to address our treatment following admission to Royal Perth Hospital for Damian with an infected PICC for administering follow-up treatment on returning from Germany for Lyme treatment. The infectious disease doctor was only interested in finding out which doctors had been treating Damian and who had arranged the PICC. He insisted that we do not have Lyme as it does not exist in Australia. He discounted our treatment in Germany and told Damian that all of his physical symptoms were, for want of better words, in his head. I asked him to offer a different explanation as to why my son was so ill, said that we were happy to investigate and that, if he could offer us something, we would be willing to try. He did not do this. He insisted that Damian was depressed. He was not. He is a very sick young man who was very well adjusted to his illness, the impact it was having on his life and the fight ahead of him.

Within a week of Damian's admission, both his treating doctors advised us they were no longer allowed to treat him or any Lyme patient. It was not difficult to see the link between Damian's admission and these events. So we were left without a doctor to monitor and provide our follow-up treatment and we were filled with guilt that an event involving our family caused so many other people to lose their doctor and that our doctors were having to go through the awful process of clearing their names. As I said to him in Damian's hospital room and I hope to say to the medical experts that were here this morning but have not stayed to listen, 'Would you take a blood transfusion from one of us?' I doubt they would. But that is exactly what happened to me. My symptoms began after receiving blood transfusions.

The more they deny this disease, the more people they are going to get sick. I wish they would put their egos aside, do their research, do their investigations and in the mean time treat us. Treat us with dignity and respect and as the genuinely ill people that we are. Do not treat us as if it is all in our heads, because it is not. My son is now dying. It did not have to be like this.

CHAIR: Thank you for giving us just a small insight into what you have all been going through. To our previous witnesses: thank you also for sharing your experiences. We know it is very difficult to talk about personal experiences in front of a Senate committee and in front of so many people.

COLLIGNON, Professor Peter, Private capacity**ZAGARELLA, Associate Professor Samuel, Fellow, Australasian College of Dermatologists**

Evidence was taken via teleconference—

[11:17]

CHAIR: Welcome. Have you been given information on the protection of witnesses and evidence?

Prof. Collignon: Yes.

Prof. Zagarella: Yes, we have. I signed the *Hansard* agreement.

CHAIR: Thank you. Is there anything you wish to add about the capacity in which you appear today?

Prof. Collignon: I am representing myself as an infectious diseases physician and pathologist.

CHAIR: Thank you very much. We have your submissions; thank you. I invite you both to make a short opening statement, and then I will throw to the committee members to ask some questions. Professor Collignon, could you start first?

Prof. Collignon: The reason I made my submission is that Lyme disease in Australia is obviously a contentious issue. My own view is that I do not think we have convincing evidence that *Borrelia burgdorferi* is present in Australia in any of our animals or insects and has infected people. Therefore, I am concerned, particularly when people want to give prolonged antibiotics, either orally or intravenously, because I think it will do a lot more harm than good. I think we need to establish what is here and, if any therapy is warranted, what is the appropriate therapy.

In my background as a pathologist, I think there are issues with tests and how they are interpreted, particularly what we call the serology test—the antibody test. A lot of those will be what we call false positive results, because none of the tests are perfect. The definitive tests are what we call PCR and culture. I think they are the ones that we need to concentrate on in animals, insects or people if we want to establish what is going on in Australia.

Having said that, I think ticks are problem. Ticks can cause lots of diseases, not only in Australia but overseas. I think there are probably lots of organisms in ticks—bacteria and even viruses—that we do not know of yet, so I think we have to keep an open mind about what diseases may be transmitted by ticks and what therapy is available or should be used for them. At the moment, in my view I have not seen convincing evidence that Lyme disease caused by the particular bacteria in question, *Borrelia burgdorferi*, does exist in Australia and is transmitted within Australia.

Prof. Zagarella: I am a professor of dermatology and I am representing the Australasian College of Dermatologists. I was asked to provide a submission. From the point of view of the Australasian College of Dermatologists, we have no evidence that Lyme disease exists in Australia, caused by *Borrelia burgdorferi*. The concern here is that there are people out there, such as people who are giving you submissions, who do suffer from disabling diseases. This is not to say that we are not sympathetic or compassionate to these people who are suffering. That is not the issue here.

When doctors say that Lyme disease does not exist in Australia I think that a lot of people misinterpret that as being non-caring. The question is whether these people are suffering from Lyme disease for a different disease. We believe that at the moment there is no evidence to say that they are suffering from Lyme disease caused by ticks, and caused by *Borrelia burgdorferi* specifically. These people may be suffering from other conditions. There are a lot of non-specific symptoms that these people suffer from, such as arthritis, arthralgia, weakness, lethargy, pain and depression. They certainly have some issues, but there is no evidence that Lyme disease as such exists in Australia.

The problem is that these people are really at risk of being treated by long-term antibiotics, as Professor Collignon has mentioned, and these cause side-effects and have absolutely no benefit for these people with these chronic diseases. The other problem is that they are at risk of being seen by certain alternative practitioners, shall we say—I can give you some anecdotes of that if you like—where they expend large amounts of money for non-proven treatments that do not help their diseases, either. These people are at risk of being labelled as being chronic Lyme sufferers, for example, with poor evidence of that diagnosis, and then they get treated with questionable therapies that probably cause more harm than good.

It is important that we understand that the term 'chronic Lyme disease' problem should not be used. In fact, since I gave you my submission, an article was published in the *New England Journal of Medicine*, on 31 March, titled 'Randomised trial of longer-term therapy for symptoms attributed to Lyme disease,' and, to cut a long story

short, this article spoke of people who had presumably been given a diagnosis of—question mark—chronic Lyme disease and were treated with long-term antibiotics. There was no benefit in their symptoms and 68 per cent of them got side-effects from the antibiotics. This is a new study that has just come out. We need to keep all of these points in mind when people are given antibiotics, which are now shown to be not helpful for these chronic symptoms.

Senator MADIGAN: I have met countless people who presented at countless doctors, countless specialists, trying to ascertain what is wrong with them. Some of these patients have been treated to overseas protocols, as I understand it, with the use of antibiotics and have found their symptoms to have improved to varying degrees, some markedly—far better than they were prior to receiving any treatment. I note that you said the use of antibiotics can be, for some people, not to their benefit, but the patients whom I have seen and met say that they have improved markedly. What you say to that?

Prof. Collignon: The problem with any disease is that if you give any drug some people will benefit, and that may well be what we call a placebo effect, or the natural course of the disease. It is particularly a problem if we do not know what the cause is. The study from the *New England Journal of Medicine* that was just mentioned exactly showed that. It is not that nobody got any benefit; it is just that there was no benefit compared to the other arm of therapy, and some people got harmed. So the real problem is knowing if we will do more good than harm. If we could take 100 people with Lyme-like disease and we found, even if we did not know the cause, that 90 per cent of them got better on antibiotics, we may argue that we do not know the cause but obviously there is a benefit.

But the real problem is that while there may be some people who benefit there are a lot more who are likely to come to harm, particularly if you give intravenous antibiotics for a year. We give antibiotics to people with lots of things—infected joints and infected bones—and we know a proportion of those will get other complications from that. They get clots in the veins and they get secondary infections with the thrush germ, for instance, or golden staph. We know a proportion of them—the numbers vary, but it is at least a few per cent—get bugs in their blood and some of them will die. You have to weigh the known harm from doing these things—with antibodies on top of it, and side-effects—with what proportion if any are likely to get better. To my mind, while we can never deny that some people may get better with this, on the available evidence a lot more people will come to harm from doing that than there will be who benefit from it.

Senator MADIGAN: I note your response, but earlier today we heard evidence from the Western Australian department of health saying that they keep no statistics, and I am very interested, and I am sure the rest of the committee is, to know where are the statistics that you and your colleagues have that supports your evidence, because there seems to be a great lack of evidence? This is what we were told earlier today. Could you point the committee to where the evidence is that you rely on?

Prof. Collignon: The evidence I rely on—and I submitted—is a number of peer reviewed articles in Australian and international literature on the complications of antibiotics and intravenous infections. So you actually have the evidence. I have given you—

Senator MADIGAN: Does this evidence you are referring to specifically refer to people who believe they have Lyme or Lyme-like illness? Is this specifically targeted to people in this sector?

Prof. Collignon: No, it is not, but there is no reason to believe people who believe they have Lyme disease will have any more protection from the complications of intravenous antibiotics than somebody with, for instance—

Senator MADIGAN: But the assertion today we are dealing with—

Prof. Collignon: There is absolutely no reason that they will not have the same rate of complications from medical procedures we do to them as everybody else in society. I think that to say to the contrary is really clutching at straws and it is really a fairy tale.

Prof. Zagarella: There are a couple of points I would like to make, but to answer your question specifically there is saying a lot of evidence now that antibiotics do not help people who believe they have Lyme disease. One of the highest forms of evidence that we have in medicine is the randomised trial—a randomised controlled trial with a placebo arm. You now have that—I have just mention that article and you are welcome to have a look at that in the 31 March *New England Journal of Medicine*. This specifically addressed the actual question that you just asked, which was that people who believed they had Lyme disease, which was confirmed on a blood test with antibody positives, were given antibiotics and it made no difference to their symptoms. So we have actual concrete evidence now.

The second piece of evidence I would like to give you concerns what you mentioned before about people who have told you stories about taking antibiotics and getting better. We have evidence now—there has been a good trial done that follows patients who believe they have chronic Lyme disease, and what happens to them over the long term, over the months and years. That trial was published in *Clinical Infectious Diseases*, in 2015. The name of the trial was 'Long-term assessment of health-related quality of life in patients with culture-confirmed early Lyme disease'. The trial showed that with time these patients get better—that people with Lyme disease do get better. So nearly everyone these days with a true diagnosis, or even a suspected diagnosis, of Lyme disease goes to a general practitioner and gets given a course of antibiotics. If you have true Lyme disease the antibiotics kill the *Borrelia burgdorferi* and that would cure your disease. And this is what happens with people's Lyme disease. So we now have lots of evidence for both of the questions you asked.

Senator MADIGAN: How many patients have you gentlemen examined or had come before you who have believe that they are suffering from Lyme disease are Lyme-like illness?

Prof. Collignon: I cannot give you the exact numbers, but over the years, and I have been practising for over 30 years, I have treated quite a number of people who have had Lyme disease, which they have acquired overseas. I have been involved in their therapy, with successful resolution, although some can be a bit fatigued later. I have also treated quite a number of people who have come to me with tick bites, or after tick bites. Because I believe ticks have a lot of bugs in them—*Rickettsia* and a whole lot of things that we cannot readily diagnose—my practice is that, if somebody comes to me with a tick bite and is feeling unwell and has any medical symptoms, I give them two weeks of a tetracycline antibiotic. I believe that that is sufficient, whether you have a *Borrelia* or a *Rickettsia* or a Lyme-like related bacteria, if it is in Australia. What I do not believe is that giving prolonged antibiotics has any more benefit than what I do—and that was just quoted from the literature—in other words, the appropriate short course of an appropriate acting antibiotic, such as a tetracycline-like antibiotic. If they do have a bacteria such as *Borrelia* that should be enough to eradicate it, and that is the evidence from the places that do have Lyme disease—North America and Europe. So my view is that doing anything more than that is unreasonable and you are going to do a lot more harm both to the individual and to society than you will do good.

Senator MADIGAN: When those patients have presented to you and you have given them a course of antibiotics, have you had a blood test done on these patients prior to prescribing an antibiotic for them?

Prof. Collignon: The ones who definitely have Lyme disease and have acquired the infection near the [inaudible] and they have had blood tests that are positive and have a history of a tick bite and they have been in the right area, have got better after giving them the appropriate antibiotic.

Senator MADIGAN: You say that the patients who presented to you that you have treated have contracted Lyme disease from overseas. When they have come to you and said they have Lyme disease, do they give you a copy of their blood tests from overseas to confirm this, or do you send them to have further testing here in Australia?

Prof. Collignon: I always send them to further testing in Australia—where they have tests that are positive in laboratories in Australia. Mostly, it has been tests done in Australia. What happens is that they have come back from the US or from Europe and have become unwell. There has been a question of what they have had, and then Lyme disease has come up and we have diagnosed that and treated it.

Senator MADIGAN: So you do not accept an overseas test—like which is done to the ISO appropriate certification? Do you always get an Australian test?

Prof. Collignon: I would normally get an Australian test, because I would expect that if the overseas one is positive then it would be positive here as well. But if somebody goes to a major hospital in the US—one associated with Yale, Boston or something like that; one of the major hospitals there—and one of the laboratories there give a positive test, I am likely to accept that one because they are a major established laboratory with a major institution. The real problem, which you are getting at, is: what about these tests that are not from laboratories, either overseas or in Australia, associated with major hospitals or major private laboratory networks. I think the problem there is that it is very easy to get false positive results, be it PCR or, particularly, the antibody test. One has to be very careful about interpreting them if you are in what we call a low-prevalence population. In other words, we do not really have evidence the disease is here because you will get a lot more false positive results than true positive results in that situation.

Senator MADIGAN: For the hundreds and thousands of people in Australia that believe they have Lyme disease, or a Lyme-like illness, if they do not have Lyme disease, have you given any thought to what it is they are actually suffering from?

Prof. Collignon: I have. To some degree, this is not too dissimilar to something called a chronic fatigue syndrome, where you see people who have ongoing symptoms that can be disabling, including, sometimes, joint symptoms and neurological symptoms where there have been a whole lot of possibilities of what that might be. Again, 10 or 20 years ago, there was a whole lot of argument that these were due to mycoplasmas and ureaplasmas. Again, I see positive tests from laboratories where, in fact, they could not be confirmed by other laboratories within Australia. For whatever reason, that has now fallen off and something else has come. The problem is: these people are unwell. I fully acknowledge that. They do need support and therapy. My real worry is: because we are trying to help them—and there is a belief that, 'Here's a bacteria than responds to antibiotics; if we give you really prolonged antibiotics you will get better'—I think all of the available evidence is: if we give them any antibiotics at all, it ought to be a short course with something we know works in proper studies done in the US or Europe that show two weeks or four weeks is enough. Where they start wanting two months, three months or one year, I think we will do more harm to those people than we do good. That does not mean that we should not still be supportive of it. I personally agree that we should be looking for more bugs because I think there are more bugs in ticks that we do not know about. This is where we should do research. But I think it is also a mistake to treat them on a presumption that they have something when we do not have the evidence for that, and, more particularly, when we give them antibiotics for six months or a year where there is no very good evidence, even in the places where there is no doubt these diseases exist. All of the recommendation say: don't do that, because you are much more likely to do more harm than good.

Senator MADIGAN: Finally, if a person presents to you tomorrow and they had been bitten by a tick today—and I acknowledge what you are saying in that, if it is Lyme disease in the classical sense that is diagnosed overseas, you give them a course of antibiotics and that that, for the most part, should eradicate the disease. But what I would like to know is: if you have a person that has been bitten by a tick and has not gone to a doctor, but then, two years later when they are chronically ill, they present to a doctor, can you point us to where a short course of antibiotics can help these people? Or, do they have to have a more intensive long-term treatment of antibiotics?

Prof. Collignon: I am not sure that there is enough data to specifically answer the question. What I can say is if somebody is sent to me who has been bitten by a ticks—it would usually be a few days before—and he were unwell with fevers and a rash, I would give them doxycycline for two weeks, because there are a number of possibilities that they could have—rickettsia or another usual bacteria that we may not know about—and that is likely the antibiotic that they will respond to while we are waiting for the tests to come back. If somebody comes to me two years after they have been bitten by a tick—and it is a question of how good their history is on whether they were bitten by a tick, because if you are living in these areas you are bitten by ticks all the time so what symptoms you get may or may not be due to the tick—whether you give them a course of therapy at all is something you would have to judge on what you see in front of you, what signs they have and whether they have some evidence of inflammation. I think if they have some evidence that they have inflammation you might be inclined, even at that late stage, to potentially give them a course of two weeks of doxycycline. But, again, I know of no evidence that giving them more than a couple of weeks of doxycycline will do them any good, while we do know that long-term antibiotics can do harm, more so when they are intravenous. We have lots of evidence of that in Australia and overseas. Again, one of the things we always have to do is make sure that we do not do more harm than good. Particularly where there is no evidence to say six months of antibiotics is going to work in any proper study, which I do not think there is, I think it is actually unethical to give those people those prolonged antibiotics, because, in all conscience, we are likely to do more harm to say 100 people like that than we will do good. That is not to say that one person may not get a benefit, but for that one person getting a benefit you may be harming another 90. In my view, that is not good as a risk to the individual or to society.

Senator MADIGAN: Finally, Professor, say I lived on the northern beaches of Sydney and I were to get a tick bite and if I presented at a local chemist and said, 'I've been bitten by a tick,' as something proactive rather than reactive, would you say that there would be benefit in educating the public, GPs, chemists et cetera, to tell people to present to their local doctor to get a short course of doxycycline as a preventative measure?

Prof. Collignon: Whether everybody with a tick bite should get doxycycline is I think a different argument to people with a tick bite who then get sick a few days later. I do think that if people are sick a few days after a tick bite, they need to see a doctor with a view to whether they need a course of antibiotics if they meet certain criteria. So yes I think an education program is a good idea. We should avoid people being bitten by ticks. Ticks are bad for lots of reasons, the same as mosquitos are really bad for people with, in Australia, Ross River virus, Barmah Forest virus and a lot of things. So the two insects that I think we should avoid being bitten by are ticks and mosquitoes. I think we need to have a program to say what to do and, particularly, how you remove a tick without causing more damage by squirting more toxins or whatever into the person. So, yes, I think we need a

tick education program. I do not think everybody with a tick bite should get antibiotics, but I think anybody who is sick within a few days of getting a tick bite are the ones we should have an education program for.

Prof. Zagarella: If I could make a comment about that question: I think that would be a bad idea. We already have a massive worldwide crisis with overuse of antibiotics, which is causing a massive crisis in antibiotic resistance. So if what you say came about and everybody who was bitten by a tick immediately rushed off and got a course of antibiotics, we would be giving tetracyclines and doxycycline to many, many people who do not need them. These are not safe drugs necessarily. In pregnancy they have side effects. They can cause all sorts of reactions and side effects. So it would just compound the problem of antibiotic overuse, which is already, as I said, a massive worldwide crisis. You need to treat people when they have the disease that needs to be treated and not be proactive as you say to treat people without disease. That is the first thing.

The other point I would like to make on your previous question as to what these people have is: yes these people are suffering; these people with chronic illness have something. Just remember that in the eighties the diagnosis that they would have been given was chronic fatigue syndrome, fibromyalgia or something non-specific like that, or even depression. A lot of people with depression suffer similar symptoms to what you are describing. With chronic fatigue syndrome we went through the same thing where doctors, immunologists, were investigating to find a disease, a bug or bacteria that caused it and nothing was found. It is just that today it seems to be Lyme disease that is the preferred diagnosis for what people believe they have. The fact that some false positive blood tests confirm these false diagnoses is also a big problem for us.

I hope that answers your questions.

Senator WANG: I think some things are very clear: no-one wants to be bitten by a tick or a mosquito, no-one wants have Lyme disease and no-one prefers to be on antibiotics. So, let's put the antibiotics argument aside. Are you aware of any alternative treatment that can help Lyme patients?

Prof. Zagarella: No, I am not aware of any alternative treatment. If you have proven Lyme disease, true Lyme disease, then you should have a two-week course of antibiotics, as has been mentioned. That is entirely appropriate. What are not appropriate, as Professor Collignon mentioned, are questionable diagnoses, which are probably false diagnoses, with people who have these chronic symptoms being given months and years of antibiotics. That is not appropriate. We need to treat when appropriate and with the right treatment.

Senator WANG: I appreciate that you cannot see how packed the room is today. What would you tell the sufferers in this room today? What sort of treatment should they get?

Prof. Zagarella: I think the sufferers in this room have real symptoms. No-one is denying that they are suffering from real symptoms—there is no question of that—and I think they should be helped. First of all a proper diagnosis needs to be made: what are they actually suffering from? They need to have all the investigations done to look for a disease that is causing their symptoms. That may be an arthritis, and autoimmune condition. I will not speculate, because there are lots of possibilities here. They need to have an investigation to find a diagnosis. Sometimes we are not able to find a diagnosis, and in those cases where we cannot find a true diagnosis we should not be calling it Lyme disease and we should not be calling it chronic Lyme disease. We should just accept that they have symptoms which perhaps we cannot diagnose at the moment and we need to support them and give them treatment. It needs to be appropriate treatment.

Senator WANG: Again, what sort of treatment? We have numerous people in this room who went to a number of GPs, who went through decades of treatment for all sorts of things—chronic fatigue, depression—and they were given medications during all that time. None of the medications fixed their problem. Some of them went to Europe; some of them went to the USA. They got diagnosed with Lyme and treated accordingly. They came back feeling much, much better.

Prof. Zagarella: As we said before, that does not prove anything. All it proves is that some people with chronic diseases and chronic symptoms do improve over time. You cannot say that the antibiotics are what made them better, because we now have proper medical evidence that that is not the case.

People with chronic symptoms do get better over time. If you have known anybody in your family, or a friend, with a lower back problem, with a sore back, with arthralgia you will know they often, over years, do a bit of exercise, a bit of physiotherapy and they improve. These sorts of anecdotes do not really help. What really helps is doing a proper randomised control trial. Now that has been done and it has shown that long-term antibiotics do not help.

Senator WANG: It is often cited that there is a lack of evidence, which probably comes from a lack of research. In Australia are we doing enough research on Lyme-like illness?

Prof. Zagarella: There is ongoing research all the time. Some very good experts in Australia have done studies on ticks, examining what bacteria these ticks carry. I have included some of that evidence in my submission. Good research has been done. Unfortunately—or maybe fortunately—the *Borrelia burgdorferi* bacterium, which has been found overseas, has not been located in Australian ticks.

Yes, people are looking at ticks. They are looking at all sorts of different infectious agents that are present in ticks, mosquitoes and so on. So research is being done. The research has to be not just looking at the bugs that are present in ticks; the research has to be also done on improving the sensitivity and specificity of the investigations for Lyme disease. That is being carried out. In fact, in America now there is a new test that has just been approved by the FDA called the C6 antibody test for Lyme disease. That looks like it is going to take over in future the current antibody testing in Australia as well. There are new things happening all the time, which is good.

Senator WANG: We had the WA state health department here this morning and it occurred to me that they are not doing a lot at all. It seems to me that they are very reactive and they are waiting for evidence to come to them rather than going out there actively collecting evidence.

Prof. Collignon: Research in Australia is usually funded by the NHMRC or other grants. It is often university associated people or people in hospitals who do that. State public health departments tend to collate data about certain things but they tend not to do that level of research. They might contract it out to a university. They usually do not have the infrastructure to do it.

I personally believe that there is a lot more we can learn from looking at ticks. If you look at viral diseases, like Ross River virus or Barmah Forest virus, there were Australian observations that have a lot of implications for a lot of things around the world with mosquito-borne viral infections. I am sure there is a lot more we do not know. I think funding research on mosquitoes and ticks is worthwhile because we are likely to find things we do not know about. That is a different issue from now.

Our current knowledge is we have people who are unwell. Even with a disease like glandular fever virus we know some people get it and they can be unwell even 12 months later. We also know that there really is not anything we can do to, if you like, fix that up other than to support the person as best we can. If we did give them drugs, if we gave them traditional, herbal or even non-traditional, there is no good evidence that any of that would make any difference to their recovery. Some will get better anyway and some will not. We need proper studies done—usually randomised, what we call double-blind, placebo-controlled trials—if we are going to do any interventions.

Where we do not know what the cause is—and even when we do know what the cause is—my view is that we need to do those studies because we do not want to do more harm than good. If we give unproven therapy to people, maybe we will be lucky and we will do some good but it is much more likely that we will do harm, including financially to them because the cost of some of these things can be debilitating financially. Royal jelly from queen bees, for instance, was very popular for a number of things about 10 years ago. That was hugely expensive. There was very little evidence that it gave any benefit. It probably did not do any harm, but really it was financially disabling. We have a whole lot of drugs, including herbal drugs, and yes, they may have some active drugs in them but it is much more likely they will have harmful things as well. We have to do these studies properly because at the end of the day we want to make sure we are doing more good than harm from both a health perspective and a financial perspective for the people involved.

Senator MOORE: I have read both of your submissions. Thank you very much. Have you worked with people from the Lyme Disease Association of Australia, which is the group that works with people who have identified as having this condition?

Prof. Zagarella: I personally have not worked with anyone from the Lyme Disease Association of Australia. Of course the problem here is you are dealing with many people who have already made up their minds that they have Lyme disease. They are firmly convinced that that is what they have and it is difficult to have a rational conversation with people who already have firm beliefs in one direction or another.

Senator MOORE: Professor Collignon, in the work you have done have you had an opportunity to work with the quite significant Lyme Disease Association of Australia, which has been working in this field for a while? Have you had a chance to meet with them?

Prof. Collignon: I think at various meetings I have met certain individuals associated with it, including some researchers, but I have not had any formal association. And I have had some email discussions with some people, but that is the extent of my association.

Senator MOORE: Certainly from my reading of the several hundred submissions, many hundreds of submissions, there does not seem to be a lot of communication between the people who have differing views. I

think, Professor Zagarella, you more or less established that with your response to my question—that the people who we are meeting in this inquiry even at the early stages have views, but they do not seem to be sharing them with each other. I find that difficult in terms of where we move forward.

But, Professor Collignon, I did read all the attached papers to your submission, and the focus of your submission is the problems associated with long-term IV antibiotic use and the different dangers that can cause. I totally accept that in terms of the data we have. I think also one of you talked about chronic fatigue syndrome being another condition that may well have been diagnosed earlier. Can either of you tell me whether there is a test for chronic fatigue syndrome?

Prof. Collignon: Unfortunately, the answer is no. The real problem there is also that there are probably a number of different things that contribute to chronic fatigue, so that is a diagnosis of exclusion. I have actually had people come to me over the years who have been labelled as chronic fatigue, one of whom had chronic syphilis; another person had HIV; another person had thyroid disease. I think what is important with any chronic fatigue or any chronic condition is that the first thing you have to do is to make sure that there is not something else going on. That means doing a series of tests, if it is appropriate, for their symptoms to make sure that they have not got something that we know is treatable, such as those examples I have just given you.

The trouble is that after that there is no diagnosis for it, because we do not know what causes it. We know there are a number of possible triggers or maybe causes like glandular fever viruses, for instance, and CMV, but, at the end of the day, for a lot of them we do not know what caused it. It may be virus X that we have not found yet, and we have to keep an open mind about that. We need more research to try to unravel that.

But that is the problem with a lot of these things. People are sick, and, because we do not truly know what is causing it, we haven't got a test to say, 'You've got this,' or even, 'You haven't got it.' That is very unsatisfying for, I think, the patient in particular but also for doctors because if people are unwell we would like to say, 'Hey, here's the test and here's the result,' but, when you do not know what you are looking for, because you may have a condition and we do not know what is causing it, then that is a problem.

One of the issues with this is that, if viruses cause ongoing diseases, there is no real therapy for most viruses still, so that is a problem even if we know what it is, although the big advantage of then knowing is that you may be able to come up with a vaccine or something to prevent people getting it in the first place. But this is why we need ongoing research, particularly into ticks and mosquitoes, to see what is there and then do the research to say, 'Well, are people getting this?' Ross River virus is a good example. Lots of people are infected with Ross River. Luckily, only a minority of people get really sick with it. We need to unravel all these things, including for the viruses and bacteria we do not know about yet.

But, until we know more, I still believe we do more harm than good if we, if you like, go out and give therapy, particularly prolonged therapy, whether it is alternate therapy or antibiotics, because, while some people might benefit, there is a much higher probability that it will do harm than good.

Senator MOORE: Are there any other illnesses or conditions for which long-term antibiotic treatment is prescribed?

Prof. Collignon: I can tell you that the longest antibiotics I would ever give people is when they have infected artificial joints after surgery. For instance, if people have a golden staph infection in an artificial hip, and particularly if they are elderly and for whatever reason you cannot take out that artificial hip and put in a new one—because it is two major operations with a risk of death—I have a number of those people who have been on antibiotics for years. The other people I have actually had on antibiotics for long periods of time are people who have had, for instance, a rupture of an aortic aneurysm, and they have had an artificial graft in there and it has got infected. Because basically the infection is not controlled, they have a major problem.

So, yes, I treat some people for prolonged periods of time with antibiotics—oral antibiotics, I might say; I never give IV antibiotics for that period of time but oral ones. Some get side effects. A lot do not. But then there is no doubt of the diagnosis that they have, because we have proven it with blood tests, and we know what the consequence of not giving them antibiotics is.

This is different for something, first of all, where we cannot even prove it is due to a bacteria such as *Borrelia* causing it and where all the available evidence is that, because they do not have artificial material in their body where the bugs latch to and can never be got rid of, anything more than two weeks of antibiotics does not really make much difference anyway. This is a balancing act with every patient. How much harm are we likely to do you and society with antibiotics, with antibiotic resistance versus what good you are going to get? I think all the available evidence in Australia so far on what we know currently is that we will do more harm than good if we

give prolonged antibiotics, and by that I mean more than a couple of weeks of antibiotics, for a Lyme-like condition.

CHAIR: Professor, I have one question on notice, and Senator Madigan wants a clarification—just a clarification.

Senator MADIGAN: Professor Zagarella, your discipline is dermatology; is that correct?

Prof. Zagarella: That is correct.

Senator MADIGAN: Professor Collignon, yours is in microbiology?

Prof. Collignon: Yes, and also clinical infectious diseases. I did two specialties. I am a specialist physician, and I am a specialist pathologist.

Senator MADIGAN: One of you gentlemen talked about having rational discussions with patients. Have I missed something? Is either one of you qualified as a psychologist or psychiatrist?

Prof. Zagarella: Why do you need to be qualified as a psychiatrist to have a rational discussion?

Senator MADIGAN: Gentlemen, one of you passed an opinion on the mental state of people to have a rational discussion. Have I missed something? Is either of you a qualified psychologist or a qualified psychiatrist, yes or no?

Prof. Zagarella: I think you may have misunderstood what I meant by a rational discussion—

Senator MADIGAN: People in the room did not misunderstand.

CHAIR: Do not start an argument, please.

Prof. Zagarella: Sorry? Answering the question—

Senator MADIGAN: Is either of you a qualified psychologist or a qualified psychiatrist?

Prof. Collignon: No, I am neither, but I do have a lot of experience talking to patients with conditions that we may not be able to cure, including some of the ones I mentioned, such as infected joints, so I would actually think that I am empathetic to the people that come to me. But, by the same token, I think the problem, Senator Madigan, with your suggestion is that you are suggesting that everybody with Lyme-like disease needs to go and see a psychiatrist, which I would not agree with either.

CHAIR: No, hang on. That is not what he was suggesting at all, sorry. I have one question on notice that Senator Reynolds was asking about treatment. Some of our witnesses this morning have been talking about getting successful hyperthermia treatment in Germany. Could I ask both of you on notice whether you have ever had any experience with that particular treatment.

Senator WANG: They have probably never heard of it.

Prof. Zagarella: What was the treatment again?

CHAIR: Hyperthermia.

Prof. Zagarella: The answer is no, and there is no evidence that that therapy is beneficial. But I will say that one of my patients—I have a couple whose son, in his 30s, has long-term disability problems and went to a doctor in South Australia who I believe has since been deregistered from South Australia. This doctor set up a clinic in Bali which gives oxygen therapy to putative Lyme disease sufferers. This couple flew their son to Bali. He was given weeks and weeks of oxygen therapy, which cost them \$30,000. The patient returned, did not get better and then, after a year, went back for another \$30,000 treatment of oxygen therapy.

You need to be careful when you are discussing these kinds of treatments, these alternative therapies. This is the sort of thing that happens to people, and they are really victims of this kind of rip-off, if you like.

CHAIR: I have to say that I have had multiple feedback from senators now, in that, in response to one of the questions Senator Wang asked about alternative therapies, you said you did not know of any. Can I just clarify. When you gave that answer, was there an assumption that you were answering in terms of what you considered successful treatments or therapies?

Prof. Zagarella: The answer I gave was not what I considered successful but what has been shown by evidence and studies to be successful therapy. The answer was that there have been no successful alternative therapies.

CHAIR: It was clear that senators at the table here needed to clarify that. Thank you for your evidence today. We have run over time. I understand that one of you needed to leave at 12 o'clock; I apologise that we have not met that deadline. If you would like to provide the committee with any further information, that would be

welcomed. Are you able to send us a copy of the 31 March study so that we can clarify whether it is the same one that we were talking about this morning?

Prof. Zagarella: Yes, certainly. Would you like me to email that to you?

CHAIR: Yes, if you could email that to the secretariat. We were talking about another study this morning, and I just want to clarify whether it is a separate study to the one we were talking about with the Department of Health.

Prof. Zagarella: Certainly, I would be happy to email it to you.

CHAIR: That would be appreciated, thank you.

DERHAM, Dr Hugh, Private capacity

NUTTALL, Dr Adam, Private capacity

[12:06]

CHAIR: Welcome. Can I ask as we get started whether information on parliamentary privilege and the protection of witnesses and evidence has been provided to you both?

Dr Nuttall: Probably in an email, but I probably have not read it—but I understand it, so that is fine.

Dr Derham: The same for me—I understand the general principles, but I have not been read my rights, so to speak.

CHAIR: We do not read you your rights; we just send you some information about that. I presume you have signed the witness form. Yes. Thank you. Do you have any comments to make on the capacity in which you appear?

Dr Nuttall: I am a GP working in Perth.

Dr Derham: I am a GP in Perth. I am a fellow of the Royal Australian College of General Practitioners and a fellow of the Australian College of Rural and Remote Medicine. I formerly had a diploma of obstetrics.

CHAIR: We have your submissions; thank you for those. I invite you both to make a short opening statement. Then you have seen what we have been doing—we have been asking lots of questions.

Dr Nuttall: This is an area that I drifted into basically because, from my teaching as a student, one of the major things about making a diagnosis is to listen to the patient. I was hearing, time and again, similar stories—and you have heard them; I will not reiterate it. But there is something going on and it is of vast proportions in this country. This is not a small problem. To ignore it is absolutely sinful. There are a couple of other points I will make. I will not harp on about that.

It is very interesting to note that if you say to the Red Cross here, 'I have a diagnosis of Lyme disease,' they will refuse to take your blood. I have had one client turn around and say, 'But I've never left the country. It's not supposed to be here.' They have still said, 'We will not accept your donation.' The bone and tissue bank make a clinical diagnosis; if they have any hint of any form of fatiguing illness, they will refuse to take your tissue. Apparently they laugh at the denial of Lyme disease in this country.

Going back to the 31 March paper that was mentioned time and time again, that paper involved 280 people. Prior to being treated they were all given two weeks of IV ceftriaxone—standard treatment—but only two weeks. They were then split into three arms: there was a placebo group, there was a group that had doxycycline and there was a group that had clarithromycin and hydroxychloroquine. They were only treated for 12 weeks. The side effects that they talked about only occurred in four people in the two-week period where they were receiving antibiotics. The doses that they received were not what we would normally treat people with anyway—they were standard medical doses that I believe, and I suspect Hugh does as well, undertreat people. As for the trial itself, I do not know if it has been cited, but three months of antibiotic treatment is basically pissing in the wind with chronic Lyme sufferers. If you are treating TB and leprosy you are treating them for a lot longer. Those times—six, 12, 18 months—are acknowledged times that you treat people with those conditions for. Why not something like this? As an adjunct to that, antibiotics are extensively used in the farming industry—we are exposed to them all the time. It is there. It is not something that clinicians are doing, and this idea of antibiotic resistance has been and gone. We have destroyed that.

Also, I would like to mention something about autoimmune diseases. There is a lot of evidence that just about all autoimmune diseases are caused by some form of trigger in a genetically susceptible individual. These post-Lyme people have been shown to have markers that suggest an autoimmune process has been started in that individual. So this whole issue, as I have said in my submission, is far bigger than just Lyme-like illnesses and just *Borrelia*. This issue touches most areas of medicine. *Borrelia* is here, from the evidence from various labs—particularly Australian Biologics, who are not NATA accredited, but their accreditation process is overseen by overseas labs and they have returned a false positive rate of zero over the past three years and have had 40 per cent of the samples that are sent in return positive for *Borrelia*. They have also found *Borrelia* in lice flybot in this country, so to have this discussion about whether it is here or not is, I think, immaterial. We should be looking at the whole area of medicine, not just all these people who are suffering with these Lyme-like illnesses and fatiguing illnesses. It affects a whole heap of other areas. That is enough from me.

Dr Derham: Most of my evidence is in the appendices that I added to my submission. The first one, which is essentially the basis of a scientific paper, involved five people who had never left Australia, two people who had never left Western Australia and one who was bitten by a tick in Western Australia. The tick bite, skin and all of

for instance, one day and then the following week it finds another area of your system that is weak. Have I read that right?

Dr Derham: There are several papers pointing out that it has the ability to change its outer protein coat so this week it presents you with antigen A and next week it presents you with antigen B, so the immune system is busy making antibodies against antigen A and two weeks later that it cannot find any antigen A so the antibodies die off and then it has to start making antibodies against antigen B. It can also change its complement system to appear like you, like self, so the body thinks, 'That is just another part of me.'

Senator MADIGAN: So it can blend in—

Dr Derham: It can blend into your system and it can change its antigen characteristics so the antibodies get confused and it can decrease the antibody response.

Senator MADIGAN: We have heard mention on numerous occasions spirochaetes. Dr Derham, can you in layman's terms explain that?

Dr Derham: A spirochaete is a bacterium with a cell wall, usually gram negative like syphilis, leptospirosis and yaws. So they are corkscrew shaped organisms that have a cell wall. The *Borrelia* organism not only can exist as that but it can exist as so-called L-forms, so named because they were first discovered at the Lister Institute in London, where a bacterium with its DNA can exist without its cell wall in little blobs, granules, sheets or mycelia. So the DNA is still there but it does not look like what it looked like yesterday. It can also exist in a large round bodied form commonly referred to as a cystic form but by the definition of 'cyst' it probably is not because it does not have a thick wall, it has a thin wall. This thing sits around, resistant to most normal antibiotics and when the conditions are right it spits out some more fresh young spirochaetes at you.

Senator MADIGAN: You have had patients present to you who believe they have Lyme disease or a Lyme-like illness. We heard earlier from the two professors that you cannot have a rational conversation with those people. Have you experienced this with your patients?

Dr Nuttall: Not once. Basically every single person who comes in with a story of a fatiguing illness gives a very clear history. You have to sit down and work your way through it. The vast majority—not all—have been well and then they are unwell and they are getting worse. Something has happened. They cannot all say it is down to a tick bite because there are studies that show that 60 per cent of people who have been bitten by ticks do not remember the tick bite. As I said, you listen to what the patient has to say—every single one of them. We have heard today people who have been active members in the community suddenly being not active members, and they are not making it up.

The other issue they face is the scorn from the medical profession. I have had people come back from infectious disease consultants in tears. People go to emergency departments and as soon as some form of Lyme-like illness or borreliosis is mentioned they are treated with scorn or told, 'Here's your dose of antidepressants.' That happens across the board at every single hospital. Again if you talk to people here they will tell you those sorts of stories. They are rational.

Senator MADIGAN: Dr Nuttall, how common is it for the people who present to you to have presented to numerous other doctors?

Dr Nuttall: Every single one of them.

Senator MADIGAN: So they have presented to GPs in an attempt to find out what is wrong with them. As far as them presenting to specialists—

Dr Nuttall: The majority have run the gamut of rheumatologists, neurologists, psychiatrists, psychologists as well, haematologists and any combination thereof. I do not think any have seen a politician!

Dr Derham: One of the problems is that medicine is divided up into general practice and specialists. A GP reaches the end of their diagnostic repertoire and they say: 'It must be this. Go off and see such and such specialist.' The specialist has a good look at them and says: 'Well, it doesn't seem to be in my bag. Go back to the GP.' And then they are sent off to another, perhaps different, specialist, who says: 'I can't really make my mind about this one. Go back and see your GP.' The patient is left in limbo because everybody they have seen has exhausted their repertoire of diagnoses.

Funnily enough, the more medicine I learn, the less psychiatry I see. I am not saying that there is nobody out there who is crazy; I have seen a few of them, too—I will not say in which profession! Anyway, I think the majority of people with psychiatric problems that I see have chronic infections. I particularly remember a young engineer, who had never been an anxious person in his life, who was particularly anxious and having panic attacks. Interestingly, he had frank paranoid psychosis. He was hearing voices talking about him in derogatory

ways. In the fourth month of antibiotics against *Bartonella*, 80 per cent of the anxiety and all of the paranoia disappeared. But, of course, it was just a placebo effect!

Senator MADIGAN: Syphilis was mentioned earlier, and I have heard that on a number of occasions. What are the parallels between people suffering syphilis at later stages and mental illnesses?

Dr Derham: Syphilis is known to affect most of the organs in the body, including the brain. *Borrelia* is like a super-duper grand-uncle syphilis. It is more adaptable. It can get everywhere. It can affect your skin, your joints, your liver, your blood vessels, your brain, your nerves—you name it, *Borrelia* can affect it. Syphilis used to be known as the great imitator because advanced stages of syphilis could look like almost any disease. *Borrelia* is even better at doing that.

Senator MADIGAN: So it is like syphilis on steroids, for want of a better term?

Dr Derham: Yes: syphilis without kryptonite.

Dr Nuttall: And it is sexually transmitted as well.

Dr Derham: Sexual transmission has recently been proven quite well. Interestingly, in 2004 the spokesman for the Infectious Diseases Society of America, Eugene Shapiro, published an answer to a question in the *New England Journal of Medicine*. He was asked how he would advise a woman who was pregnant who had proven Lyme disease. He said, 'I would assure her that there has never been a case recorded of a mother giving Lyme disease to her baby.' The critic wrote back saying: 'Here are 28 peer-reviewed published papers. Think again!' Was this man telling lies, or was he the spokesman for the Infectious Diseases Society of America and singularly uninformed? I cannot think of a third possibility.

Senator MADIGAN: Earlier I mentioned that I have heard people say on numerous occasions that you can contract Lyme disease through the placenta at birth, through blood or through sexual contact. Is it right that syphilis can be contracted in those three ways?

Dr Derham: Yes.

Senator MADIGAN: If *Borrelia* is similar to syphilis in the way it attacks your system, is there any evidence to suggest that *Borrelia* can be passed to people that way?

Dr Derham: The evidence is that *Borrelia* can be passed from mother to foetus and between sexual partners. It has been shown that it survives in blood transfusion products, but nobody has ever shown that it has been given to somebody via blood transfusion. It is often suspected to have been incurred from a sandfly bite, mosquito bite or bedbug bite, but that has never been proven. I know of one case where a march fly bite in New South Wales resulted in a bullseye rash and illness and, subsequently, tests showed it was *Borrelia*. The march fly bite bit of skin also proved DNA-positive for *Borrelia*.

Senator WANG: Both of you have treated many patients over the decades. Have you ever got into trouble because you were treating patients with Lyme illness?

Dr Nuttall: Not yet. Both of us feel as though we have got targets painted on us. It would take only one complaint. Despite the Chief Medical Officer saying in one of the magazines last year that doctors were not being targeted, it occurred two months after the incident that we have already heard about, where two doctors were being hammered for it. Already there is another doctor in Victoria, in Melbourne, who has been told that he can only be overseen by somebody else, because he was treating people with Lyme disease.

Senator WANG: Could you speculate for the benefit of the committee. What resulted in the mainstream medical professionals targeting specific GPs who are treating Lyme as Lyme?

Dr Nuttall: One guy wrote in the journal—as part of the answer—that 'these people are quacks'. So we are, by his definition, quacks. Unfortunately, as you have probably seen, Dr Derham in particular is far from it. He bases a lot of his decisions—most of his decisions—on scientific evidence. There is no quackery involved.

Dr Derham: There is medical fashion involved. I have a patient in a large country town. She has had some mental problems in the past. She has definitely got borreliosis, proven by testing. She became ill with abdominal pain, nausea and vomiting. She vomited so much that she became dehydrated. Her tongue was dry. Her lips were cracked. She had not passed urine for 12 hours. She turned up at the local hospital, and, as soon as she uttered the words 'Lyme disease', she was told, 'Get out of my department.' She was not assessed for hydration. She was not treated. She was not medically assessed. She was told to piss off.

Senator WANG: She could have died, actually?

Dr Derham: She did not die, fortunately. In that same hospital, I am referred to as a charlatan by the medical staff.

Senator WANG: Thank you.

Senator MOORE: Dr Derham, every skerrick of evidence we have from professional groups in this country and people in research clearly states that we do not have Lyme disease in Australia—every single one. And you have seen the submissions we have got. Can you—what was the word you used, Senator—speculate for our committee on why?

Dr Derham: There is an old Sufi story. The mullah Nasruddin was seen scrabbling around at midday in the dust of the street, and his students came along. They said, 'Teacher, what are you looking for?' He said, 'I'm looking for my house keys.' They said, 'Where did you lose them?' 'Oh, in my house.' And they said, 'Why are you looking here?' 'Oh, because there's more light here.' Everybody is looking in the wrong direction. There is an entrenched fashionable belief that A is B, and nobody is prepared to look at the small amounts of evidence that B is actually B. And, when somebody comes up with it, they go: 'Oh, they're beyond the pale. They're a crank. They do things differently from us. They're not part of the club'—et cetera et cetera.

Dr Nuttall: And this is not new. We have already heard about the HIV. When Dr Barry Marshall postulated that *Helicobacter* caused duodenal ulcers, for 15 years he was told he was an idiot.

Dr Derham: His critics have gone strangely quiet recently.

Senator MOORE: Can you just clarify on record: what is the difference between a clinical diagnosis and getting the testing done? You used them as two different things in your evidence. As a non-medical person, I thought a clinical diagnosis came after you had the testing, but what is the difference?

Dr Derham: If I want to clinically diagnose pneumonia: if a patient comes in with a painful cough and a fever, I listen to their chest and I hear some crackles and it sounds as if this part of the lung is not open, that is a clinical diagnosis of pneumonia. If I then take an X-ray and I see a white patch on the X-ray, that is a laboratory- or test-supported diagnosis of pneumonia.

Lyme disease patients or chronic *Borrelia* patients—I have seen so many now that I can just about smell them when they walk in the door! And I have seen a couple who were coming to see me thinking that they might have Lyme disease, and their stories just did not add up. I said: 'Look, you're really out of the pattern that I usually see. I'm happy to test you if you want to, but it's like a \$1,500 fishing trip.' So far, two or three of those patients have simply declined to be tested. Prolonged unexplained fatigue was numerous—normal tests. Every single neurological patient that I have seen, fibromyalgia, unexplained prolonged illness—they all test positive.

In the general practice, I do Saturday mornings, seeing people who want to see a GP, and we have tried our best to exclude people who want to see me from those Saturday mornings. In my first 14 months in this practice, I saw 103 patients. Three of them certainly had a borreliosis, and five of them probably had borreliosis. If borreliosis really is five to eight per cent of Australian general practice presentations, this country is in trouble, because a significant proportion of these people are disabled and draining either their families or the public purse.

Senator MOORE: Dr Nuttall, thank you for giving your commentary on the trial that we were told about by the last witness, because, as you would have heard, it was presented as proof positive that we now had a random trial. This committee is very used to hearing the term 'random trial' as being the gold test. The way it was presented was that there was a random trial now; the evidence was in; close your books. So we really appreciated having that explanation because otherwise we would not have had that follow-up.

Dr Nuttall: There are lots of medical papers from about 1990 to 2013. Sixty to 70 per cent of them are discredited later, so the whole issue of papers is—you need to be very, very careful about taking away meaningful messages from them all the time.

Senator MOORE: But you have to have evidence. We live in a place where 'evidence based' is used in every second sentence, so in terms of doing it—

Dr Nuttall: A lot of what is done in medicine is not evidence based. If you want to go down that pathway, a lot of what is performed is not evidence based. It is done because, 'Oh, well, we used to do it, so we'd better carry on doing it.'

Senator MOORE: So it is more standard practice, as opposed to evidence based?

Dr Nuttall: Yes.

Senator MOORE: I have one last question. It is around Professor Collignon's evidence about extensive use of antibiotics, and it has come up in a number of cases. It is certainly one of the things that we have heard through the AHPRA process. It is one of the things that has been used against practitioners. You heard that evidence about the dangerous impact of extended usage of IV antibiotics and his quite passionate arguments as to why he finds that to do no harm is part of what we should do. My understanding, Dr Derham, and I am not sure—Dr Nuttall, I

have read your evidence, but I am not quite sure—is that one of the modes of treatment that you use is extended use of antibiotics to respond to the diagnosis. Can you tell us, in response to the evidence we have just heard, about your assessment of that argument about the dangers of doing that and the fact that it would cause more harm? I do not want to verbal evidence, but I am trying to get it right. The argument is that, for the smaller number of people who may actually get benefit from this process, a much larger group would be endangered by it, and therefore this would be the wrong practice to do.

Dr Derham: This is partly based on experience with acute illnesses. For instance, in tonsillitis, I believe the strep bugs double every half an hour or hour or something like that. Every time bugs replicate, they have a chance to produce a mutation and become resistant. In the chronic intracellular infections that we are dealing with, the bugs replicate once every three or four weeks or when they feel like it, so the potential for developing resistance is much, much less.

I have heard—after treating hundreds of people with these long-term antibiotics—of one patient who developed a multiresistant-bug urinary tract infection, and I do not think the risk for that is high. Most of the so-called side effects that I see are actually Jarisch-Herxheimer reactions, which means that the bug die-off effect is giving the patient symptoms. As long as that is not too severe, that is a good sign that we are on the right track; we just need a lower dose for the time being.

It is very difficult to test a multifactorial treatment regimen with a double blind trial. Double blind trials were designed by drug companies to test one substance against one condition. So, if you have a multifactorial condition, it is almost impossible to have a valid double blind trial, and you certainly cannot have it if you are varying the doses of what you are giving according to patient response and patient tolerability.

Senator MOORE: Dr Nuttall, is there the same or a similar response from you?

Dr Nuttall: Definitely. Hugh is actually far more experienced than I am in this area.

Senator MOORE: But you also treat your patients with extended use of antibiotics?

Dr Nuttall: But not all the time. I, as it happens, get people who have had extended courses of antibiotics and have not necessarily improved, so you start going for other reasons, and those are multifactorial. We have touched on the genetics. You start looking at doing genetic testing. Are the bugs hiding behind biofilms? That has not been touched on. They do actually hide and share information with other bugs hiding behind them. Are there environmental factors? Are they eating badly?

There is a whole raft, which is why one or two people cannot do this. This is why clinics are required, with a multidisciplinary team to assess the situation. This is not a one-man show. It is far too complex for that, particularly when it becomes chronic. The acute cases are simple. The chronic cases—again, as you have seen—are not, and the manifestation varies. We are also, as I said, looking at disease processes that we already recognise as autoimmune processes that may be caused by these infections.

Senator MOORE: Thank you.

Senator REYNOLDS: The main area I would like to focus on is this. Before this inquiry, I knew very little. I had heard about it, but I knew very little about this issue. Reading the submissions and listening to the testimony today, I think it is literally like the tale of two planets. You have the people who are here today who are clearly suffering, their families, and medical practitioners like you who treat them. And then we have had other evidence from the state department of health and other doctors. I am just wondering if you can account for why it seems that the medical profession more generally denies that it exists here—and, we have heard today, in very contradictory ways—and almost vilifies those such as yourselves who dare to say, 'We think it exists.' How has it got to this point? It has been called denial. I have raised it with a few doctors I know, and there are snorts of derision when they hear the words 'Lyme disease' or 'Lyme-like disease'. What do you think has caused this? How have we got to this point?

Dr Derham: These people are believing what they have been told, and the people that are telling them are very important. They have gold braid and gold stars and they are in very high positions, and they have not actually looked at the evidence. We doctors at the coalface are believing what the experts tell us, and some of the ones further up the food chain are also believing what the experts tell us. Very, very few people are actually looking into it, and the people who do look into it are professionally marginalised.

Senator REYNOLDS: Why do you think that is the case? The people up the food chain who are perpetuating this—I am not saying whether I think they are right or wrong, but there is such a gulf. Why are they—the ones with the gold braid that you are talking about—perpetuating it?

Dr Derham: I think it starts in the USA, where the health insurance companies are protecting themselves and feeding the CDC with funds and incentives, so the CDC then spread the word. They are supposed to be the worldwide experts on infectious disease, and it all filters down from there.

Senator REYNOLDS: Dr Nuttall?

Dr Nuttall: I tend to agree with what Hugh said. Basically, it becomes too difficult to actually look at the issue and far easier to say: 'Yes, here's a label of chronic fatigue or fibromyalgia—whatever label you want to give. Sod off.' And, if you start investigating it, you are obviously a quack!

Senator REYNOLDS: Just on chronic fatigue syndrome: we heard testimony this morning that now a diagnosis of chronic fatigue syndrome triggers health support and welfare support, but it does not have a pathology. There is no test, no blood test; there is no pathology for it, whereas for Lyme disease there is, yet it is not treated in the same way. Are you able to comment on that? Have I interpreted the evidence I heard this morning correctly?

Dr Nuttall: Yes, you have, but it does seem to depend on who you actually face up to in Centrelink—literally that. There will be some people in some offices that will actually recognise the diagnosis of Lyme, but they are not very common. Most will recognise the diagnosis of chronic fatigue. So, for those people to get some sort of funding for themselves—and, as you have again heard, most of them have spent a lot of money supporting themselves—to get any sort of funding, the label of 'chronic fatigue' is appended to them.

Senator REYNOLDS: We heard evidence from a number of people this morning that the Red Cross will not take blood from anybody who has a diagnosis or believes they have a diagnosis of Lyme-like disease. Do you know why that is? Are you familiar with that?

Dr Nuttall: Yes. I told you of an example of that, where one of my clients said, 'I've got *Borrelia*. I've never left the country,' and was told, 'Well, we don't accept your blood.'

Senator REYNOLDS: We might chase that up with the Red Cross.

CHAIR: We have already flagged that we are going to write to all of them and ask them about guidelines. We will add the tissue bank to the list. I have one final question. In terms of your patient caseload, you are obviously recognised in the community as having expertise on Lyme disease or Lyme-like disease. Do either of you have waiting lists?

Members of the audience interjecting—

CHAIR: I wanted to get this on the record, folks.

Dr Derham: I think my next available first patient appointment is in April next year. One of the places I work at has simply said, 'Sorry, we don't book that far ahead. We'll put you on the waiting list.' So I have got a waiting list of 20 or 30 people beyond that.

Dr Nuttall: I have actually limited my waiting list to the point where I only see one new Lyme case a day. I try and make up for that on a Friday, when I have just started seeing them for half an hour. We are just trying to point people in the right direction. I think I am booked out for two or three months.

CHAIR: Thank you. I just wanted to get a feel for that.

Senator MOORE: I will put this question on notice. I do not want to have names mentioned, because I know the sensitivities. Is there a network of Lyme-aware doctors that talk to each other and is there any way that people can know who Lyme-aware doctors are? I am using the term 'Lyme-aware', which is the term the Lyme Association have used. Your two names are here because you have given evidence. I know of at least two other doctors who did not wish to give evidence because of their concerns about what would happen.

CHAIR: If you could take that on notice, if that is okay.

Dr Derham: I communicate with about eight or 10 different doctors in ACID, the Australian Chronic Infectious Disease Society. I am not aware of everybody in Australia who treats it. I have just taken on a new patient from New South Wales, who is going to fly over, because none of the Lyme doctors in New South Wales is taking any new patients at all.

CHAIR: Thank you very much. We will shortly break for lunch. After lunch we have an in camera session, which means that nobody else can be in the room. People are welcome to stay here during the lunch break, but we will need the room empty when we resume. We will let you know as soon as we come out of the in camera session, and, of course, you are more than welcome to come back in.

Proceedings suspended from 12:48 to 13:38

ADAMS, Ms Carol, Private capacity**NETTLE, Ms Michelle, Private capacity**

Ms Nettle: [Audio unavailable] I am Bryce's mum. I am here to tell his story.

CHAIR: Have you decided between the two of you who is going to go first?

Ms Adams: I have not thought about what I am going to say. Since Theda euthanised herself three years ago, I have remained in the Lyme support groups because I want to do everything I can to change what happened to her so that more people do not suffer. Theda was a very intelligent and courageous woman. All of her life, she fought for whatever she wanted to do. Her private doctor that she saw, her GP, and some of the others were fine, but when she had to go hospital she was physically and mentally abused. At one stage, she was covered in bruises and she was locked in a room. She had the brain Lyme and, so, she would get psychosis. She was locked in a room in a thin nighty. Theda's body temperature could not adjust, and she was freezing. They would not give her a blanket. Then she asked to go to the toilet, and they refused to let her out, so she had to do a wee in the corner of the room. This was just so awful for her, so distressing.

Then, on another occasion—I do not know if you people have read the submissions—she was mentally and physically abused in a public hospital at Fremantle. It was the hospitals and the way they treat people. When Theda was getting a lot of this abuse, we thought she had chronic fatigue syndrome, so she was being abused at that stage because she had fibromyalgia and chronic fatigue. It was just dreadful. I would be with her and she would be in agony. She was a person who had no fear. Theda would do anything. She would go out at the back of all the waves, jump off 30-foot rocks into the ocean, stand up and talk in public—she was a very brave woman and she believed in getting things out there. She wanted to be an investigative reporter and was well on the way to doing that. It made me cross to hear people say: 'You're too scared to face life—that's why you're like this. There's nothing wrong with you.' I used to think, 'They don't know my daughter. They don't know who this person is.'

So Theda and I went public. It took a lot of courage on her part, because by then she could only lie in bed. She was in a dark room, and the reporters could only just go very quietly into her room and ask a few questions. On one occasion when she went to hospital and she could not tolerate light and sound, they put her in a corridor that was very noisy, lots of light and sound, and I had taken special food in for her. When I went to visit her the next morning, they were refusing to admit her, even though she was in dreadful pain. She was sitting with a bowl of hot water and a cube in it and she said, 'Mum, I can't eat this, and they won't give me the food you've brought in.' So I asked a nurse if she could get Theda's food for me, and she said, 'No, I'm too busy.' So I approached another senior nurse, and he went and got it. They still refused to admit Theda.

So I went to Channel 7 and got Channel 7 involved. They had always supported us a lot. I had to take a hidden camera in to speak to Theda because they would not let the reporters in. Theda was used to talking to camera and very articulate. As soon as that went to air that night, they admitted Theda. They refused for her to see a pain specialist, and that was what it was all about. So they went to air again and said that Theda was not being seen by a pain specialist, and immediately a brought one in. I always had to go to the media to get anything done. It was a hard fight. Kim Hames, the Minister for Health here, just said once, when they interviewed him, 'I know Theda can die, but there's nothing we can do about it.' I had been asking him to give treatment that had been recognised by a top chronic fatigue specialist from Belgium, who had been in Perth and had been to see Theda and recommended treatments. And he said, 'No, she doesn't fit the boxes.' That was our fight—she didn't fit the boxes.

CHAIR: She did not fit the boxes because—

Ms Adams: Because she did not have cancer; she did not have a recognised disease. All it was was to get someone from Silver Chain to come out and give Theda a saline drip, because that helped her headaches, and they refused it. Even though Dr Derham, who she was seeing, asked for that, they said, 'No, he is only a GP. We don't take any notice.'

Senator MOORE: I have not heard that before.

Ms Adams: We all fought very hard and could not get anything done.

CHAIR: Thank you. Ms Nettle.

Ms Nettle: Although it is me who is standing here before you, it is the voice of my son, Bryce, that I want you to hear. I want to give each of you a bookmark that his sister, Kim, and I had made—and I think Josh will hand them out to you. These are quotes that are taken from a personal journal that he wrote in the months leading up to his death. The picture of Bryce is taken before he was sick. He is full of life and promise and is physically very fit. I trust each and every one of you have read my submission, which details Bryce's six-year courageous battle to heal himself. I choose those words 'heal himself' very carefully, because it was he who was alone in this battle to

find this answer to this invisible disease that was consuming his body. It is one thing to take responsibility for your health; it is another thing to have to seek treatment from all over the world. Everything that actually helped Bryce he found himself. He would research, find a treatment or a service and then find a medical practitioner who could provide it.

Before Bryce was ill he was an active teenager with a passion for bodyboarding. In pursuing his *raison d'être* Bryce was exposed to numerous tick bites. I took a number of ticks off him over the years. At the age of 19 he collapsed and he never recovered. Life was never the same. He never bodyboarded again. He never went to a party. He never dated a girl. He never travelled or enjoyed a social life like he had before his illness. What followed was his and our family's nightmare—a revolving door of visits to doctors, health professionals and hospitals and countless tests and re-examinations that did not reveal a satisfaction explanation or a remedy to the excruciating nerve pain that was mainly in the upper part of his body that he continued to experience.

Bryce was determined to find the source of this problem and fix it, so it was about two years of me dragging him to doctors. It was me who was the driving force in those early years. From doctors to specialists and on and on we went. He got so disillusioned with the medical fraternity that he took the healing of his body onto himself and food became his medicine. He did everything possible to ensure that his immune system was in the best shape it could be. His insatiable quest for knowledge, exploring nutrition and various diets and following up on every lead to trial possible treatments was legendary. He left an enduring legacy for family and friends. It took five years for him to find out that he had Lyme disease and by then it was chronic Lyme disease.

I would like to draw the committee's attention to the article at the end of my submission, which is 'Lyme disease and the brain with psychiatrist Dr Robert Bransfield'. It was only once I had written my submission to the Senate inquiry that listed Bryce's systems in chronological order and read this article that I came to realise that Bryce's deteriorating mental condition was the onset of Lyme. Dr Bransfield writes, 'the main impact of late-stage disease is on the nervous system'. I implore this committee to consult with Dr Bransfield and others in his field to better understand the effects of Lyme-like disease on the brain. His research goes a long way in explaining the suicidal tendencies of Lyme-like disease victims.

The other issue I would like to amplify today that seriously undermined Bryce's resilience—and I am sure that of other Lyme sufferers—is the loneliness and the isolation. Bryce received a lack of compassion and respect from a number of people in his life. When suffering from an invisible illness that is denied by the Australian fraternity it is like they are forced to prove they are ill constantly. He often said to me: 'Mum, I wish I had cancer. Then people would believe I was ill and be more supportive.' This dismissive attitude that it must be in his head or he was making it up was extremely heartbreaking to witness and I saw the demoralising effect that it had on Bryce. Recognition by the Australian medical community that this Lyme-like disease exists will facilitate the public's education and enable them to better understand how individuals struggle to cope and live with this debilitating disease.

Living with Bryce I saw what he endured for years and I witnessed his passionate fight to be well again. I am compelled to tell his story so his passing can be a catalyst in this appalling situation. A medical practitioner once told me that Lyme is the abandonment disease, as patients and their families are ignored and left to suffer in virtual silence. This must stop. Finally, another excerpt from Bryce's personal journal: 'Einstein wrote that an unthinkable respect for authority is the enemy of truth.' Sorry, that is it. I had to get that out there.

CHAIR: Thank you. We are running short on time. We do have your submissions. We have read your submissions.

Senator MOORE: What do you want to happen? You have both come to us today because of the strength that your children showed, and you certainly do not want that forgotten. I know that in both of your families' cases you are doing things like the walk for your daughter and the bookmarks and things for your son.

Ms Adams: The reason for the walk is that the international Lyme community started the Red Shoe Day.

Senator MOORE: The Red Shoe Day?

Ms Adams: Yes—for Theda. It is now to remember everybody. Theda loved red shoes.

Senator MOORE: I read your submission, and it just seemed so like her—that red shoes would be her thing. You have kept her alive with you through that day.

Ms Adams: My thing is: if people with Lyme—I do not care whether they call it Lyme or whatever—go to hospital because they are in massive pain, I want that pain to be treated. That is not happening. Theda, in the week she died, would not go to hospital because she had become too scared of doctors. They would just abuse her and not treat her.

Senator MOORE: Ms Nettle?

Ms Nettle: I applaud you for having this inquiry today because it is about education. It is about gathering as much information, because information will change this situation. I would like research to embrace this whole disease and to find out everything about it. Whether that means going overseas, can't we all just come together and figure this out? It is not just here in Australia. Something is going on. I think that is properly enough from me.

CHAIR: Thank you very much. We know that it can be very painful and stressful to appear before a Senate committee, but to also talk about your most personal experiences. But it really does help us to hear people's personal experiences and to hear of what actually happens to real human beings. Thank you for your submissions and for your time today.

ERSEK, Ms Nikki, Private capacity

GUERINI, Ms Nicole, Private capacity

HUTTLEY-JACKSON, Ms Marie, Representative, Lyme Disease Association of Australia

KENT, Ms Jan, Private capacity

KURET, Ms Gabrielle, Private capacity

LIDDELL, Ms Carol, Private capacity

LIM, Mr Nick, Private capacity

SHEPHERD, Ms Val, Private capacity

WILLIAMS, Ms Amy, Private capacity

[13:53]

CHAIR: Welcome. If we could keep your statements to two minutes, so that we can make sure that we hear all of our evidence today, that would be great. Also, you can table things, as well. If you want to table something, just let us know.

Ms Liddell: I am a nurse. I have been nursing for 43 years. I first became unwell in 1992. For 24 years, I have been selecting doctors who did not ridicule me for my illness. In the 1990s, I had chronic fatigue syndrome eventually diagnosed after being told that I had 'that yuppie syndrome'. That is what it was called then. My doctor who has known me for over five years suggested 15 months ago that I might have Lyme disease. I said, 'I don't think so.' I had worked in hospitals and had heard doctors that I worked alongside saying that Lyme disease did not exist. I did not want this diagnosis. It took me six weeks to eventually agree to testing in Germany. That cost me over \$1,000. I do not care where I acquired it; I have travelled all around the world. I had a positive *Borrelia*, a high titre for *Bartonella* and mycobacterium. I began my research because I had already learnt not to trust doctors. I bought books from Amazon and I read them.

Bartonella seems to be my biggest problem. I have gathered that antibiotics do not kill *Bartonella*, that it just encapsulates itself and hides until your immune system breaks down, and then suddenly you have got *Bartonella* full-on again. So I chose to use herbal remedies, and I feel brilliant now. I occasionally use doxycycline. I have used it four times for five weeks at a time, which is more than the dose that the doctors will normally let you take. I have used many complementary herbal medicines, which I will put in my submission that I will add to my previous submission.

It has been really interesting today. Thank you very much for this opportunity to be here. I think the co-infections need to be addressed as well—for example, that *Bartonella* enters your heart. So right now I have got palpitations, and I have been to the emergency department four times for palpitations and have been told that it is okay.

CHAIR: Thank you.

Ms Shepherd: I have never professed to have contracted my Lyme disease here in Australia and, even yet, I am still coming up against all sorts of roadblocks. My doctor, one of then three doctors in Perth who had any knowledge of Lyme, has been forced to stop treating me due to being investigated and harassed by the medical board. My treatment was coming along nicely, and I had gone through a year of struggling with the awful side-effects one gets from the treatment. When our doctor was informed she could not treat us anymore, we were left helpless. We could either get into the long queue to see the other two knowledgeable doctors, which can be up to 12 months, or else go out on our own and try alternative treatment. We chose the latter, and this I have done for about a year now, and I can feel myself sliding backwards and undoing all the hard-earned progress I had made on antibiotics.

It is wonderful that Lyme disease is getting some interest from the media, but often the patients that are highlighted are very bad ones, who have convulsions or are almost paralysed. While this is excellent for the Lyme fraternity, it does not tell all our story. There are thousands of us that are diagnosed with Lyme-like symptoms, either diagnostically or from a laboratory, who are not bed-bound but can function to a certain degree. We are the ones that are not newsworthy but are still affected terribly by this tick-borne disease.

Life is a struggle as we cannot get medicine at an affordable price. Our medical appointments cost more than a normal appointment and we are all using up our savings and every cent we can get. People are selling houses, taking out loans and in general are having to put our lives on hold. I am lost. I have no doctor to turn to to try and

help me with my illness. I have been to numerous GPs since my doctor ceased treating us, and no-one can help. They either tell me that there is no Lyme here or say, 'Sorry, don't know much about Lyme.' No offer to do a bit of research has been forthcoming, and I am sure that if I had a disease that the medical fraternity would not just wave off—they have been given an out.

We know that long-term antibiotics are frowned upon, but at this present time, with the lack of funding and research, and with that being all that is open to us, we are happy to grab any chance of a normal life with both hands. More funding and research is desperately needed by a very large community of Australians. Doctors and medical centres need to be given guidance on where to go for advice, and the doctors need to know that there will be no investigation or risk.

All we ask for is a fair go. I do not think there is anything more Australian than that way of thinking. We beg the government to take us all seriously.

CHAIR: Thank you.

Ms Huttley-Jackson: I am representing the Lyme Disease Association of Australia. I just wanted to follow up on a couple of things that we did not quite have time to finish in our initial session. I wanted to make the point that the Lyme Disease Association statistics that we presented to the inquiry are based on medically diagnosed patients. So, in relation to the statistics, where we have presented evidence of the number of people with this condition, those people have been medically diagnosed by a doctor.

I also wanted to follow up on Senator Ludlam's point about funding for these charities. Our charity work is done entirely by volunteers who are sacrificing the opportunity to earn income by putting time and energy and resources into this important issue. We think it warrants some government support, because that is not sustainable in the long run, when the medication is so expensive and people need to pay their bills. So we would certainly encourage the government to look at finding a way to help the charity work to continue.

Another point—I hope this is not news to you—is that the AMA apparently is holding a press conference to say they think the Senate inquiry is a waste of money. I would just like to make the point that I find that offensive and very upsetting. We obviously do not agree with that position. It is indicative of the dogmatic response that the medical authorities are taking, when there are people here who are suffering who can make the case, doctors who can make the case, when there are international experts presenting their submissions to this inquiry to say that, yes, there is certainly a problem and it needs to be addressed.

I would just like to make the point that 700 articles have been published that show that the use of antibiotics for Lyme disease is effective. To cherry-pick one research paper that says it is not seems rather superficial given they cannot accept that Lyme disease is here in the first place. It just seems like a very poorly thought-out argument. I would like to make the point that there is ample evidence when the evidence is looked at without the coloured glasses of dogma.

CHAIR: Thank you.

Ms Kuret: Thank you for the opportunity to speak to this inquiry. I first became ill 13 years ago. I was diagnosed with chronic fatigue syndrome. Since, I have been forced out of full-time work and on to an invalidity superannuation pension, which I was very lucky to get. My health fluctuated as symptoms came and went. They were not vague symptoms, as I read the President of the WA AMA, Michael Gannon, characterise such symptoms. They were and they are multisystemic. When I first became ill, I read a long list of the symptoms of multiple sclerosis. I had all of them except one—incontinence—but I do not have multiple sclerosis, nor Alzheimer's, nor depression; I had and still have chronic fatigue syndrome. Then, four years ago, still with the same symptoms, I was referred to another doctor who diagnosed a Lyme-like illness. In August 2012, my test results from Infectolab in Germany were positive for *Borrelia burgdorferi* and several co-infections. In October 2012, Australian Biologics Testing Services' results were positive for *Borrelia*, and real-time PCR, endpoint PCR positive. I commenced a regime of antibiotics. I continued for 2½ years. The side-effects and/or Herxheimer reactions were too devastating, so I gave that up after 2½ years.

With regard to the stigmata against Lyme-like illness, I believe this only exists because of the non-acceptance by the mainstream medical profession of Lyme-like illness possibly being endemic to Australia and the media being fed the official 'It doesn't exist here' line. If the medical profession were to allow that the results of research conducted in 1994 are not only dated but that research methods have since advanced and they were to stop calling Lyme-like disease 'imaginary', there would be no stigma. There are catch 22s in the WA Department of Health requirements for agreeing with a diagnosis. It requires that, before a diagnosis can be made, 'epidemiological evidence'—that is, having travelled to an area with endemic Lyme disease. That is a requirement. Catch 22—borreliosis has been detected in Australia, but the WA Department of Health still does not accept the evidence.

CHAIR: I need to ask you to finish. You have gone for nearly double the time. Sorry.

Ms Kent: This is a photo of my children. It was taken in 1987 when they were aged just six and four. This is the year that we all contracted Lyme disease. I was then aged 32—the same age that my son is now. My daughter is now aged 34. I have spent the last three decades searching for answers as to why both of my children were plagued with ill-health and crippling anxiety, and I believe it is only because of my tenacity that we are here today, and we are barely functioning. We have sought out every doctor and specialist and alternative health professional in our quest for wellness. The cost financially and emotionally has been immense. We were all finally diagnosed with *Borrelia*, rickettsia and other co-infections in 2013. My grief at finally having a diagnosis and yet it being denied by our government and most doctors is profound. It spiralled me into a deep depression. To finally have an answer yet be denied treatment and to be told that, yes, we are sick, but there is no Lyme-like illness in Australia, is devastating.

Lyme disease has robbed my daughter of her childhood, a career and the ability to work full time. It has also robbed her of her future. My son was born with an intellectual impairment but was doing quite well until contracting Lyme disease, when he then developed severe anxiety and autistic-type behaviours which made daily life a struggle. Lyme disease has robbed him of reaching his full potential—whatever that may have been. My son will be dependent on me for his care for all of his life. I worry that, as I age, Lyme disease will seriously impact on my ability to care for him.

My daughter, I believe, has paid the highest price. As a small child she was extremely bright, confident and intelligent. Her choices in life were limitless until we went on that fateful holiday in Bateman's Bay, New South Wales. She does not know what it is like to be well, having been sick virtually her entire life. To find out that *Borrelia* was discovered on the South Coast of New South Wales in 1986, just one year before we were infected, and yet no warning or advice was out there for the public to seek immediate treatment is heartbreaking. How different our lives would be if the right advice had been given at the crucial time after discovering the ticks on my children's bodies.

My daughter and I are both limited quite significantly with what we can do physically. We struggle to achieve just a simple act of preparing a meal and it will always leave us in pain. We both have restricted use of our hands and arms and are plagued with nerve pain after doing simple, everyday tasks. Lyme disease is slowly destroying the joints in my body. I move like someone of advanced age, not a woman barely in my 60s. My 86-year-old mother moves with more agility than I do. I worry about what the future will hold for us and the impact of having lived with Lyme disease for 30 years. Will we ever be well or has too much damage been done to our bodies for us ever to heal?

CHAIR: Thank you very much for telling us your life experience. You heard me say before it is invaluable for us to hear people's lived experience.

Ms Williams: Thank you for the opportunity to speak today. I am 40 years old and I have been bitten by more insects and ticks that I am able to remember, in many locations. I grew up on a farm on the mid-North Coast of New South Wales and I have travelled to over 18 countries. Regardless of where I have picked up the infections, I am an Australian citizen living in Australia and I need medical help.

I have been having Lyme symptoms for at least 20 years, not that I knew that they were at the time. The worst symptoms for me have been ongoing massive headaches and chronic fatigue. The biggest trouble has been seeking to get the diagnosis. I have seen at least seven doctors and even more alternative healthcare practitioners in search of the cause of my symptoms. Over 10 years, my health has just been getting worse.

Three years ago I was talking to a sufferer of Lyme who noticed many of my symptoms were like hers and suggested I look into it. But, until I sought out my Lyme-literate doctor, no doctor ever mentioned the possibility of Lyme. I feel lucky to have found my current doctor. If they were forced to close, I do not know who I would see and I would be very afraid for my future.

I have paid thousands of dollars for testing and medication and I was only diagnosed in December last year. I was treated by oral antibiotics when I was a teenager for at least two years—I think more like three—for acne. It seems that it was okay to have ongoing antibiotics when I was a teenager wanting to look prettier, but now, when I actually have a very severe illness, I cannot have it. It just seems crazy.

I was actually very hesitant to come today and speak because of the stigma, because of the risk to my practitioner and because of the possible risk in the future of an employer saying, 'You've said you've got a chronic illness, so we're not going to put you on.' All of these reasons made me really reluctant to come and speak, which I think in itself is an indication of the stigma. You should not have to consider your future and other people's future professions in order to come along and say, 'I've got an illness like this.'

I would really like to see a concerted effort to treat people while finding out what is wrong. Of course we need to find out definitively what is wrong, but we are all sick in the meantime and desperate for some help. Also, my partner is in the Army. Every time he comes back from deployment, he is given doxycycline as a preventative measure. There is also the concern about him bringing his pack and his uniforms into our home, which I then clean; the bugs could be in the house. Just because I might not have gone out to Puckapunyal, he has and so there is still that risk.

Mr Lim: I have a background in organisational psychology. I speak on behalf of my wife, who is unable to make it today. When I left her this morning she was bedridden. It makes me extremely sad that we have had to suffer through this illness for the last five years. Only recently we discovered that Lyme might be the cause.

I want to take you back a couple of years, to September 2009. Anna and I got married. She was a vivacious, energetic and extremely sociable person. We had a great outlook for our future, and a positive start to our life. Two years later, we went to Vietnam. When we returned home, Anna had flu-like symptoms and we visited our local GP on the recommendation of my mum, who noticed something bizarre was happening. We saw my GP, and he said that she had myalgic encephalomyelitis or, as he loosely put it, 'just a post viral infection'. He sent us to a haematologist, who said that she had non-specific symptoms and that the symptoms would resolve.

Since then we have been to haematologists, acupuncturists, naturopaths, iridologists, physios, rheumatologists, chiropractors, psychs and kinesiologists. We have used energy medicine. We have seen many varieties of witch doctors and all sorts of other people with the aim to resolve this illness. Anna had full-time work before we started, but now she can only work a maximum of five hours a week. She had many friends, and she is now on her own every day. I have lost my wife. I am an Australian citizen, and I should deserve better.

I have met many people today, many who have suffered with the illness for a lot longer than we have, but I fear for our future. We want to start a family. We would love to own a home. We want to have a full life. This is not the life that we desired when we first met each other, and not the life any Australian should live through. The only thing that keeps us going is our conviction in God. As we have experienced, no medical practitioner will be able to provide us a solution for this illness. We only trust in God to resolve this health condition. Anna is suffering in silence, and I fear for the many others in this country who are in the same position. We are trapped in a dark corridor. Lights are flashing once every three weeks, to give us an indication of where to go. Every step we take, we tumble. No-one shows us direction. We have to investigate this ourselves, with absolutely no medical training or experience.

Ms Guerini: Never in my wildest dreams would I have thought a group people could be so badly treated. Everyone you talk to has a similar story of mistreatment, having met with the same ignorance. The so-called specialists have no understanding of the basic facts of this disease. Regardless of whether you have developed it here or overseas makes no difference: they do not understand simple, bare basic facts, so how can they ever help anyone?

As a parent, you take what someone in the medical profession tells you as truth, because it seems inconceivable they would do anything other than that. Going through this experience has been a real eye-opener. Doctors and specialists would rather interpret positive borrelia results and co-infection results to suit their 'it's not here' agenda and keep you on the 'I can't help you, but he is sick with something; go and see someone else' merry-go-round than see the problem and treat it for what it is.

As a mother, I have done nothing but help my children reach their potential, achieve their goals and dream big. To have a specialist question if maybe I am making my son believe he is sick when he is not is one of the most hurtful things to come out of this whole experience. I am the one who is up with him all hours of the night when he is not well, telling him everything will be okay. I am the one who encourages him to try to push past it, to push it all aside, because there is really no other option and he just needs to keep going.

This will not stop his life from being what it is destined to be. It is lazy doctoring to fall back on the excuse 'It must be the mother' instead of looking at the evidence in front of you. I am the one who is keeping him together; you are the ones breaking him. For the last six years he has dedicated his life to helping the sick kids and babies of Western Australia, and it is devastating that the doctors within the facility that he has helped have turned their backs on him. There is no magical bubble around Australia. With the amount of travel that goes on around the world and the birds that migrate here, it is ludicrous to think that it cannot be here. I do not need a degree to tell me that; I just have to have my head out of the sand, not be worried about my ego and use my common sense. The only silver lining to come from this treatment, or lack thereof, is that he is determined that when he is a doctor he will never treat his patients or their caregivers in the manner that he has been treated. He will rise above and be better than them. This was about my son, and this photo shows the bullseye rash he presented with that has been ignored.

CHAIR: Are you tabling the photo?

Ms Guerini: Yes.

Ms Ersek: I believe I acquired Lyme disease while living overseas. I am not aware if I contracted my Lyme disease in utero from my mother or from the multiple tick bites that I received through my childhood. My mother, my two siblings and I have all been tested positive through labs overseas and in Australia. We lost our lifeline in 2015 when our doctor was investigated and had the threat of losing her licence. She was told to stop treating Lyme patients and we were referred to two other doctors, but the waiting period was too lengthy. We have now sought and turned to alternative natural therapies. I have been sick on and off my whole life, in which I would go through good periods and stuff like that. I also donated blood for eight years. After disclosing this to the Red Cross, I received a letter and multiple phone calls stating that I am unable to continue donating. I am unaware of the ramifications of this. I do not know who received my blood. Despite our positive testing and a notifiable infectious disease notice from the health department, our doctor still cannot treat me. It is a huge financial burden. We have four members of the family with this. The medication is outrageous. It costs \$1,000 for 20 days worth of some of the medication. We need help and we need support.

Unidentified speaker: Good afternoon, Senators. Thank you very much for coming over here to the west. We have been feeling rather neglected about this for a long time and it is really good to see you starting this off over here. I just trust that all the work you are doing is not lost in the upcoming federal election and you get to carry this right through, because for the people who have gathered here today to put this information in front of you it is extremely hard. We hope that it can be carried through and something is seen at the end of it.

From our point of view—and I am speaking on behalf of Wendy, my wife, and myself—we have been through all the same things that we have heard here today. She has been sick for seven years and was diagnosed three years after the initial sickness. She got crook in Bali, and it possibly came from there—it is hard to know. Now, down the track, I have contracted it too. There are two of us in the household with it now. She seems to have coped with it far less than what I have been able to. To get something positive out of this, wouldn't it be great if from all the things we have heard today we could get a centre of excellence or a place where all the information could be put together and some real good could come out of all these things. I am aware of the Karl McManus Foundation at Sydney university and the work that has been done here at Murdoch, but it seems to be ad hoc and all over the country. If we could have a centre where all the good information came together and we got some answers around it, it would be fantastic for all of us.

I also was a blood donor up until I was diagnosed. During the last seven years we could relate to all the sorts of things that other people have said here today. I am just keen that we get information so that we cannot pass this on to our children and our grandchildren in any way, but there is just nothing out there. I just crave information about it all. I guess collecting data and stats around it all would be the other thing that we need to do because, really and truly, there is nothing currently. Thanks very much.

CHAIR: Thank you to all of you for sharing your experiences.

MACKENZIE, Professor John Sheppard, Private capacity

OSKAM, Dr Charlotte, Lecturer, Murdoch University

RYAN, Professor Una, Professor, Vector and Waterborne Pathogens Group, Murdoch University

[14:21]

CHAIR: Welcome. Can I check before we start that information on parliamentary privilege and the protection of witnesses and evidence has been provided to you?

Prof. Ryan: Yes.

Dr Oskam: Yes.

Prof. Mackenzie: Yes.

CHAIR: Do you have any comments to make about the capacity in which you appear today?

Prof. Mackenzie: I am retired but I am still associated with Curtin University.

Dr Oskam: I am a researcher in the Vector and Waterborne Pathogens Research Group.

CHAIR: Thank you for coming. Can I please ask each of you if you want to make a short opening statement. I invite you to make an opening statement and then we will ask you some questions.

Prof. Ryan: I have just got a very brief statement. Our research uses metagenomics to identify and characterise all microorganisms in Australian ticks and is not biased by screening for one particular organism. Ticks harbour many organisms, some of which are naturally occurring and are not thought to be pathogenic and some of which, like the *Borrelia burgdorferi* group found in ticks overseas, can cause Lyme disease.

Ticks in Australia evolved in isolation and, like our wildlife, are unique. Therefore it is likely that they will harbour unique microorganisms. We used metagenomics to screen large numbers of ticks, including ticks removed from people in areas of Sydney and Perth, where patients have been diagnosed with a Lyme-like illness. Analysis shows that Australian ticks are full of microorganisms. We found no evidence of *Borrelia burgdorferi* in Australian ticks but did identify it in European control ticks and hence are confident that our methodology can detect this particular bacterial group.

We did identify novel bacteria, including two new species of Australian *Neoehrlichia*. This is important, as *Neoehrlichia* species overseas can cause similar symptoms to Australian Lyme-like disease. We are also screening ticks from wildlife, because evidence from overseas has shown that they are most likely to vector potential pathogens. We have identified a novel *Borrelia* species in ticks from echidnas that is not related to the Lyme disease group.

We continue to search for and describe the types and species of bacteria, protozoa and viruses in Australian ticks as this is an essential scientific foundation for the current debate. The next logical step for our research is to screen the blood of and perform biopsies on Australian humans who have been bitten by ticks in Australia and have presented with and without Lyme-like illness. This will require careful epidemiological studies and case selection in collaboration with medical infectious disease specialists, but clearly further research is required.

Dr Oskam: I have no further comment.

Prof. Mackenzie: I will give a brief comment. I was asked to do a scoping study by the Chief Medical Officer some three years ago. I am not a Lyme expert; I am an expert on vector-borne diseases, including ticks and mosquitoes, but mainly viruses rather than bacteria. I think the actual mechanisms of how you do research do not really differ from one to the other. I had to immerse myself, if you like, with the Lyme literature. In that time, I spoke to a number of people, both on the Chief Medical Officer's Lyme panel, but also other people working in the Lyme area, both here and overseas [inaudible] and also to a number of Lyme sufferers and also to people at the McManus Foundation.

My initial finding really was that there is certainly something out there that causes disease. Whether it is always linked to ticks is another matter; I think in some instances maybe not. Nevertheless, there is something which, if you like, we can call a Lyme-like disease. However, the evidence also suggested very strongly that it is not a normal Lyme organism; it is not *burgdorferi* in this instance. If it were, almost certainly ticks would be found to be positive in the areas where there is evidence of this type of disease, as is shown by people in the US and in Europe very clearly, where there is a very high incidence of ticks in areas where there is endemic disease, a very high incidence of ticks which are infected, and also those ticks have very high numbers of organism within them. Yet everyone who has looked so far has found no evidence whatsoever, really, of anything to point towards *Borrelia burgdorferi*.

In my view, from all the information I have been able to gather, I do not believe we have it here in Australia in the classical sense. That does not mean to say we do not have—as Professor Ryan has just said—some other organism which is not *Borrelia burgdorferi* but which can cause similar types of symptoms. I think it is very important to make that distinction.

Having been involved in this for quite a while now, for the last two or three years, I am really quite convinced there are some things that need to be done fairly urgently in terms of research. Unfortunately, Lyme does not fit into that category that is easy to find research money for. It is not a high-priority research when it comes to NHMRC or other research organisations. Yet we do not know very much about what happens in Australia at all in terms of these types of diseases. We do not know, for instance, whether what we are diagnosing in some laboratories is positive or negative, because those laboratories are not necessarily accredited; nor do we know much about them, particularly the ones overseas. So really what we do need to have is a much better quality assurance, quality control, process.

I believe what we need is probably, for a start, a large panel of specimens from Europe, from America, from Asia and probably from South America and Brazil, which we know are Lyme disease positive. We need to have other types of *Borrelia* like relapsing fever *Borrelia* and other control specimens from people who have had similar types of Lyme symptoms but have been negative for *Borrelia*. These then need to be looked at. Laboratories then have to go through the quality control process to make quite sure what they are doing is correct.

I have no doubts about the major laboratories in Australia being able to detect and diagnose Lyme disease in people who acquire that disease overseas. When they come back, our laboratories can very readily and very easily detect it. However, no similar cases in Australia which are acquired in Australia have ever been proved positive by any of our major laboratories, despite being able to do it for all the overseas specimens. Again, this point is very clearly to some other organism altogether. I will leave you with that.

The various suggested research aspects in the scoping study still stand, I believe. There are many aspects which are quite easy to do, not expensive to do—for instance, going back to people with chronic Lyme-like symptoms to find out whether they do or do not have IgG antibodies to *burgdorferi*, a simple thing to do. But these are all issues which have yet to be funded. I would hope this committee might find some way to be able to suggest that some other resources are put together to be able to undertake some of these research areas.

Senator MADIGAN: Thank you, Dr Oskam, Professor Ryan and Professor Mackenzie. Professor Mackenzie, you are saying the classic Lyme symptoms as overseas have not been detected in Australian ticks, but you are not ruling out that we have a different form of infection, of disease, here—

Prof. Mackenzie: I am not ruling anything out at this stage. I do not think it is the classical *Borrelia burgdorferi*—I doubt it is even a *Borrelia* species because I think that, had it been, that would have been picked up by now. But there is something, nevertheless, I believe that probably is involved.

Senator MADIGAN: Do you believe that there is enough emphasis being placed on getting to the bottom of what people are suffering from here?

Prof. Mackenzie: No.

Senator MADIGAN: Have you any idea of what sort of finances would have to be directed to start the ball rolling to get some—

Prof. Mackenzie: The money has to be substantial.

Senator MADIGAN: Right.

Prof. Mackenzie: I would not like to put a figure on it, but I think there are many areas which I do not think everything has to be done at once, obviously. I think there are the various issues which can be taken one after the other, in a sense. But we really do need to know if there is some other organism that does cause Lyme-like symptoms in Australia. I think we also need to distinguish between Lyme disease per se and some of the chronic conditions, which are somewhat different. I do not know exactly where we go with those, but there certainly is some problem which needs to be addressed and needs to be addressed quite rapidly.

Senator MADIGAN: So we would have to have multidisciplinary research running parallel for CDNA to try and get to the bottom of what is happening?

Prof. Mackenzie: Yes.

Senator MOORE: I have to admit that my head aches when I am looking at the various testing processes, and I will keep those questions for some witnesses tomorrow. We had evidence earlier today from a local practitioner, on record, that he has positive diagnosis and testing for people who have never left Australia but do have positive testing for the one particular form of tick which has been linked to Lyme disease overseas. He says that is clearly

on record in different places. What I find difficult is that that evidence contradicts other highly detailed evidence from other sources, and I cannot get my head around that. One person says that they have this clear information that it is here, but from the work you have done in your testing and in the scoping study there has not been any evidence put forward to say that that particular type of tick is in Australia. The doctor involved was quite clear with the sources he provided, so it is all on public record. Are you aware of any studies which prove that that particular form of tick is in Australia?

Prof. Mackenzie: As far as I am concerned, no. I do not know of any evidence whatsoever that the species of tick that has been linked to *Borrelia* transmission in Europe and in the States have been found in Australia, but I am convinced they are not. There is one, however, which occasionally does come through with sea birds—that is *Ixodes uriae*, which can transmit, but that is not one that bites people. None of the other ones, the *ricinus* subcomplex, exists in Australia.

Senator MOORE: I read your scoping study very clearly and I also read the evidence from Murdoch, which talked about making it absolutely clear that there could be other awful things and that we needed to keep looking for it. But there was complete disagreement on this issue, and I wanted to have it on record again that your tests have not proven this.

Prof. Mackenzie: I do not know where that information came from, and I would certainly doubt it enormously.

Senator MOORE: I am sorry, I get people's titles wrong all the time—the Lyme association of Western Australia, a very well organised group which has evidence, did quite a detailed response to your scoping study.

Prof. Mackenzie: I have not seen all the responses to it.

Senator MOORE: You did not see that one? They have done quite a detailed response to the scoping study that you did, to Professor Baggoley's group. We have copies of that in our papers. You have not seen that?

Prof. Mackenzie: I have not seen that particular one, no.

CHAIR: It might be very useful for us if you did have a look at their comments on your study and gave us any feedback about your thoughts on that. Would you have time to do that?

Prof. Mackenzie: If you have it there, yes.

CHAIR: Can you take it on notice to have a look at it?

Senator MOORE: We do not expect you to do it straight away.

Prof. Mackenzie: I am very happy to.

CHAIR: Thank you.

Senator MOORE: Can I go to the funding process. Your scoping study, Professor Mackenzie, was through the Baggoley process, so you were funded for a specific purpose and that funding has ended—is that right?

Prof. Mackenzie: It has given some money to undertake that particular—yes.

Senator MOORE: That was a one-off task?

Prof. Mackenzie: It was a one-off task.

Senator MOORE: You have no further research money in this area?

Prof. Mackenzie: No. I have not been involved in research in Lyme disease at all. All the research that we have been involved in has been mosquito-borne diseases and also zoonotic diseases that run through animals. But that was before I retired.

Senator MOORE: Professor Ryan and Dr Oskam, are you receiving any funding from the Commonwealth for research in this area?

Prof. Ryan: We have been funded through an ARC Linkage grant, but that money runs out at the end of this year.

Senator MOORE: Can you put on the record the basis on which you received your grant? What was the formal title?

Prof. Ryan: It was a grant with a veterinary industry partner, Bayer, who were interested in identifying all the tick species in Australia.

Senator MOORE: Tick by tick. The idea was to get a full record of every tick species in Australia—is that right?

Dr Oskam: The ARC Linkage grant was titled 'Troublesome ticks: molecular characterisation of bacteria and protozoan in ticks'. Our funder, Bayer, contacted a number of veterinary clinics around Australia. The purpose of the study was mainly to screen companion animal ticks. That is why it was funded by the ARC. We have a manuscript that has just been accepted that did look at and survey the ticks that were collected from companion animals. From that, we can confirm from Professor Mackenzie that no European group from *Ixodes ricinus* was identified.

Senator WANG: I find it very surprising, and I am not having a go at you guys at all, that we have done some work on ticks for animals and we have not done any work on ticks for humans. I am not seeking a response, but if you would like to respond please go ahead.

Prof. Mackenzie: I just point out that all the ticks we have anywhere in the world are ticks off animals. Humans are usually just by-products of the transmission cycle. If you are looking for ticks, you are looking at ticks on animals more often than not. Occasionally, you can pick them off humans when they are bitten, but they are not really ticks off humans; they are ticks off animals.

Dr Oskam: In a recent study that came out at the end of December from our research group, and that was also included in our submission, we screened 460 ticks that came from people and around Sydney, and also in Perth. As with our original study, we could not identify *Borrelia burgdorferi sensu stricto* in those specimens or any other *Borrelia*.

Senator WANG: So while work is needed urgently and your funding is going to run out by the end of this year, are you in the process of applying for another grant?

Prof. Ryan: We have applied for another ARC Linkage grant, but that is not to do research on humans.

Senator WANG: What about NHMRC? Have you ever tried NHMRC?

Prof. Ryan: We are planning to apply for NHMRC funding.

Senator WANG: I think the success rate at NHMRC is about 13 per cent or thereabouts. Does that concern you?

Dr Oskam: Absolutely. I think it is even less in WA. I think it is about seven per cent. That is obviously alarming. Also, to apply for NHMRC, you need medical backing and medical professionals on your team as well.

Senator WANG: So you do not have a large chunk of medical professionals on your side already?

Dr Oskam: We are in the process.

Senator WANG: Okay. Thank you.

Senator REYNOLDS: Thank you for your testimony today. I want to follow-up on some of the inconsistencies—in fact, gulfs—in some of the testimony we have heard today. One of the things that struck me—and you may or may not have raised this with other people who have given evidence today—is there just seems to be such a stigma attached now to a diagnosis of Lyme disease. We have heard a lot of stories from people where and in some of the written evidence that it seems to be a mixed blessing, because, after many years of searching for a name or a diagnosis, while, on the one hand they are happy to receive a diagnosis—as any of us would be—they then seem to fall into a pit of hell with all the stigma and vilification that seems to go with that from large sections of the medical sector. What do you attribute—obviously, you have got very different studies—this reaction by the medical profession here to whether it is Lyme disease, or whatever it is called? Professor Mackenzie, you have acknowledged that there is something there—not sure if it is actually Lyme disease or not in the classical sense—but what do you attribute this response from the medical profession to be?

Prof. Mackenzie: I am not a clinician so I guess it is particularly difficult for me to answer that perhaps the way I should. My view really is that at this stage I think most clinicians now—certainly pathologists—would agree that there is a Lyme-like syndrome. I think most of us would also agree that burgdorferi does not exist in Australia. Where a lot of their problems come from is a diagnosis by one or two private laboratories of positive specimens which cannot be confirmed by normal laboratories—nor reference laboratories, I might add.

So I think there is a problem that the three laboratories, which have been utilised to send many specimens to—one in Germany, one in the US and one in Sydney. I have to give some doubt to the veracity of some of those findings, because they cannot be confirmed by normal laboratories. This is a bit of a worry. This is really why it goes back to a comment I made in my opening statement that we really to need to have a panel of good specimens that we know the details of and which can then be used in QA/QC programs.

The trouble is that, once you have lots of different laboratories using different tests and using some which have not been accredited, we are always going to be in difficulty unless there is some system whereby we can assure ourselves that those laboratories are all doing the same thing.

Senator REYNOLDS: In light of what you have said—that is, that we need more research—given that the Red Cross will not accept blood from someone who has a confirmed, suspected or disputed diagnosis, would you take a transfusion at this point in time from one of those people?

Prof. Mackenzie: I do not think it would worry me particularly, no.

Senator REYNOLDS: Really?

Prof. Mackenzie: Truly. I really believe there is something out there but, if we cannot find out what it is, it is one of those issues that you—I will put it another way: I have also been refused to give blood, because I had malaria and I very occasionally get regresses of that malaria.

Senator REYNOLDS: If I can just summarise your testimony to date: you do not believe there is a classical form of Lyme disease as they have seen in North America but you are convinced that there is something there that needs to be reviewed.

Prof. Mackenzie: I think there is something, obviously, people are getting from either from ticks or certainly from countries areas, shall we say, in Australia. Some of the people who have a Lyme-like disease do not live in areas where the holocyclus tick is, the most likely cause of transmission in Australia, if it should exist. So therefore this suggests that it is not always ticks that are transmitting it.

Senator REYNOLDS: But there is something there that needs further—

Prof. Mackenzie: Absolutely—of that I am convinced.

Senator REYNOLDS: Thank you.

CHAIR: Professor, Ryan, could I go to the issue of the novel varieties of *Borrelia* that you just mentioned in your opening statement. When you mentioned them, I think I am right in saying that you said that you do not think they are not related to the other species. Could you expand on that please. What makes you so sure, if they are novel, that they are not involved?

Prof. Ryan: I will pass you to Charlotte, because that is some work that Charlotte has done.

Dr Oskam: Our first study, which came out in the middle of last year, identified one *Borrelia* strain from a single tick removed from an echidna. The *Borrelia* that was identified was very dissimilar to *Borrelia burgdorferi* and clustered more closely with the relapsing fever group. It presents quite different symptoms. We have since done additional work on ticks from echidnas, and that is currently in peer review in a high-profile journal. We have identified that the *Borrelia* is, again, very dissimilar to the *Borrelia burgdorferi*. We have now sequenced multiple genes and we are confident that it is definitely not *Borrelia burgdorferi* and is a unique *Borrelia*.

CHAIR: But, having said that and given the comments that Professor Mackenzie made—I think they were in response to Senator Moore's questions—it is not impossible that that particular strain could actually be associated with some Lyme-like illness?

Dr Oskam: At the moment we do not know. We have identified this *Borrelia*, and I failed to mention that the ticks we have been looking at were from echidnas and known to bite just echidnas. They are called *Bothriocroton concolor* ticks. They are not known to bite humans, so at this stage we are not sure whether the *Borrelia* is actually in the echidna itself or whether there is a cycle going with the tick. At the moment that is unknown. We do not know the pathogenicity of this *Borrelia*.

CHAIR: How many different types of *Borrelia* have you identified in Australia?

Dr Oskam: The *Borrelia* that we identified in the echidna ticks is very similar to the one they originally found in the *Ixodes holocyclus* tick from the echidna. So, to answer your question: one.

Prof. Mackenzie: There is another bacterium, called *Borrelia anserina*, which is found in Australia in birds. So, there are other *Borrelias* in Australia but none of them in the area, as far as we know, that causes Lyme-like disease.

Senator MADIGAN: Professor Mackenzie, are they native birds that it has been identified in or are they migratory birds?

Prof. Mackenzie: It has been mainly chickens and, I think, also doves of some species. I think they are all local birds. I do not think there are any migratory birds.

CHAIR: Are those ticks known to bite humans?

Prof. Mackenzie: No, they do not.

CHAIR: Do I understand that you have not found any that are on ticks that are known to bite humans?

Dr Oskam: We found *Borrelia* that was in an *Ixodes holocyclus* tick, but that was a bite in an echidna. We do not know—

CHAIR: Okay, so of the two different types of ticks that you have found, one has never been known to bite a human and one you do not know—is that right? Sorry, but I am getting very confused between the different *Borrelia* and the different ticks.

Dr Oskam: *Ixodes holocyclus*, the paralysis tick, is—

CHAIR: Right. That is the word that I missed. Okay, that has cleared it up. Thank you.

Senator WANG: What can state and federal governments do to help you speed up your research?

Prof. Ryan: I think there needs to be funding for Lyme disease research. It needs to be cross-institutional. What Professor Mackenzie has said about establishing a panel of known positives and negatives and getting labs to test it would be a good start, but there needs to be research on human patients, and that is something that has not been done.

Senator WANG: You mentioned that you were in the process of looking for suitable medical professionals to be part of the team so that you could apply for NHMRC funding. Would you like the government to take a leading role in that, in pointing you to certain people or a group of people?

Prof. Ryan: That would be very helpful.

CHAIR: Do all *Borrelia* act in the same manner in terms of the way they go into cysts? We heard this morning some quite technical detail about the way they go into cysts—but they are thin-walled cysts—and the way they form spirochaetes. Do all species of *Borrelia* act in the same manner?

Dr Oskam: I cannot comment on that. I am a molecular biologist, so I can only talk on the genetics.

CHAIR: Do either of you know?

Prof. Mackenzie: I am not a specialist in that area either, sorry.

CHAIR: Professor Ryan?

Prof. Ryan: They certainly seem to be very pleomorphic in their presentation, but I am not an expert in that area.

CHAIR: We will pursue that, thank you. I am trying to find out whether the different species of *Borrelia* act in the same way, in terms of potential impact and potentially causing Lyme-like illness in the same manner.

Prof. Mackenzie: I can comment very quickly. I think that the way they cause disease is the same. Whichever species of *Borrelia* causes Lyme disease, for instance, the classical ones, there are about 14 different strains of *B. burgdorferi* sensu lato. I think that you will find that they all cause the disease in the same way.

CHAIR: Thank you, that is very helpful. Are there any other questions? Senator Madigan has one more.

Senator MADIGAN: Thanks, Professor Mackenzie. Has any research been done on whether mosquitos can transmit *Borrelia*?

Prof. Mackenzie: Not to my knowledge, no. Almost certainly no, because what happens in a mosquito is: it has to go from where it is ingested in the blood meal, then it goes into the gut and it has to grow in various cells until it finally gets up into the salivary glands. Viruses can do this very readily and so can *Rickettsia*. Bacteria are much less able to do that, I think.

Senator MADIGAN: So you can get *Rickettsia* from a mosquito bite?

Prof. Mackenzie: Yes, you can—certain *Rickettsias*, yes. But they are intracellular bacteria, generally, so they can go from cell to cell that way.

Senator MADIGAN: Thank you.

Prof. Mackenzie: We have been talking about research and research requirements and so on. It really is a multidisciplinary thing which we are looking at. It cannot be just looking at the ticks; it is also looking at the diagnostic tests that we can use. Newer tests are coming through all the time, and some of the PCR ones coming through are much more accurate than the older ones. A lot of the serology has now been changed by having special antigens which are genetically acquired, if you like. Things do change rapidly, but, nevertheless, we do need that. We also need much more clinical evidence and clinical information. People are suffering from some form of disease, which I think is almost certain now, but we also say that it is almost certainly not Lyme disease but it is 'Lyme-like.' We really do need to find out more about this. That really does require money, skills and commitment. I think this is something that is very important.

CHAIR: Thank you for your time today and for your submissions. It is really appreciated. We will contact you with a link to the comment on the scoping study and if you could provide us with some feedback on that that would be appreciated.

Prof. Mackenzie: It might actually be in the Department of Health's submission; I do not know. I will check with that, in which case it will be easier.

CHAIR: Thank you very much. We are now going in camera and, after that, we are adjourning here.

Evidence was then taken in camera—

Committee adjourned at 14:54