COMMONWEALTH OF AUSTRALIA

Proof Committee Hansard

HOUSE OF REPRESENTATIVES

STANDING COMMITTEE ON HEALTH

Chronic disease prevention and management in primary health care

(Public)

FRIDAY, 18 SEPTEMBER 2015

SYDNEY

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HOUSE OF REPRESENTATIVES

STANDING COMMITTEE ON HEALTH

Friday, 18 September 2015

Members in attendance: Ms Hall, Mr Irons, Mr Stephen Jones, Dr Southcott, Mr Watts, Mr Wyatt.

Terms of Reference for the Inquiry:

To inquire into and report on:

Best practice in chronic disease prevention and management in primary health care, specifically:

1. Examples of best practice in chronic disease prevention and management, both in Australia and internationally;

2. Opportunities for the Medicare payment system to reward and encourage best practice and quality improvement in chronic disease prevention and management;

3. Opportunities for the Primary Health Networks to coordinate and support chronic disease prevention and management in primary health care;

4. The role of private health insurers in chronic disease prevention and management;

5. The role of State and Territory Governments in chronic disease prevention and management;

6. Innovative models which incentivise access, quality and efficiency in chronic disease prevention and management.

7. Best practice of Multidisciplinary teams chronic disease management in primary health care and Hospitals; and

8. Models of chronic disease prevention and management in primary health care which improve outcomes for high end frequent users of medical and health services.

WITNESSES

BURKE, Ms Jennie, Director, Australian Biologics

GILBERT, Professor Lyn, Australasian Society for Infectious Diseases

GRAVES, Dr Stephen, Royal College of Pathologists of Australasia

IRWIN, Professor Peter, Murdoch University

KIEFER, Ms Annie, Country Women's Association of New South Wales

LUM, Dr Gary, Department of Health

McMANUS, Dr Mualla, Karl McManus Foundation

SCHLOEFFEL, Dr Richard, Physician

STOCKS, Professor Nigel, Royal Australian College of General Practitioners

WHITEMAN, Ms Sharon, Lyme Disease Association of Australia

Committee met at 09:01

Evidence from Professor Stocks was taken via teleconference—

CHAIR (Mr Irons): Welcome. I declare open this public hearing of the House of Representatives Standing Committee on Health. Before we commence, I ask a committee member to move that the media be allowed to film the proceedings today in accordance with the rules set down for committees, which includes not interfering with committee proceedings and not taking footage or still images of members, committee staff, witnesses, papers or laptop screens.

Mr WATTS: It is so moved.

CHAIR: The committee is holding a round table hearing today with a focus on Lyme disease under the auspices of its inquiry into chronic disease prevention and management in primary health care. The aim of holding this round table is to hear from organisations and individuals affected by Lyme disease and to gain an understanding of the issues associated with diagnosis and treatment of the disease. The committee will use the information it receives through its round table hearing today as well as the formal submissions it receives to inform its findings and recommendations to the parliament.

The morning will consist of three sessions. During the first session we will discuss the incidence and diagnosis of Lyme disease in Australia, during the second session we will discuss the treatment of Lyme disease in Australia, and the third session will be a discussion with people living with Lyme disease. I thank the individuals who have agreed to share their personal experience with the committee today in the third session. At the start of each session organisations will have the opportunity to give a brief opening statement. I can only stress, as time is limited today, that I would appreciate it if only one opening statement is made per organisation or individual per session. I will then ask committee members whether they wish to ask questions.

Today's proceedings are being recorded by Hansard, and the audio is being broadcast live via a webcast. I believe we are also on national radio. I thank all participants for making time to speak with the committee. Do you as witnesses appearing before the committee have any objection to being recorded by the media during participation in this round table hearing? No? Okay.

Although the committee does not require you to give evidence under oath, I advise you that these hearings are formal proceedings of the parliament and warrant the same respect as proceedings of the respective houses. The giving of false or misleading evidence is a serious matter and may be regarded as a contempt of the parliament. The evidence given today will be recorded by Hansard and attracts parliamentary privilege. The committee will now commence the first discussion session on the diagnosis and incidence of Lyme disease in Australia. I now invite each organisation or individual to make a short opening statement of no more than two minutes—and I do stress two minutes, because if we go any longer we will run out of time. I know how passionate you are, but you will be able to get more information out during the questions and the discussion.

Ms Kiefer: I am the state secretary for the Country Women's Association. Every year we choose a medical research project, and this year we have chosen Lyme disease to give all our fundraising to. I am interested in hearing what research is being done into it so that we can know where our dollars are going.

Ms Burke: I set up our molecular biology section at the laboratory in around 2002. *Borrelia* was one of the first bugs we started testing, because it was an interesting bug. We absolutely get positives. We get positives in

PCR from patients, we get positives in immunoblot and EliSpot, and many of the patients have never left the country. We have had positives from remote rural areas in Western Australia.

Dr Schloeffel: I am a GP with 38 years experience and for the past 20 years I have been treating complex and chronic disorders. That includes 3½ thousand patients with chronic fatigue syndrome and hundreds of patients with borreliosis and co-infections. I am also affiliated with a Sydney University study on tick-borne illnesses and am the founding member of the Australian chronic infectious diseases unit set up by GPs who are concerned about this evolving illness of borreliosis and co-infections. Currently I have over 400 patients in my clinic whom I treat every day. Some of them have acquired this illness overseas. Many of them have acquired it here and had never left Australia. Some of them are extremely ill, and I lose two or three a year who die from borreliosis and co-infections. This is a very serious illness. I am also seeing sexual transmission of this illness, and I am seeing transmission through pregnancies. I have a number of families in which there are three or four generations with these illnesses. I am setting up protocols and paradigms of treatment for this condition and also liaising with American and German practitioners who treat this disorder.

Dr McManus: It was the death of my husband, Karl McManus, that started all this in 2010. In his name I formed the Karl McManus Foundation to investigate it because I could see him dying in front of my eyes when I knew what was wrong with him. Because of my background I was not happy to accept whatever the physicians had told me. I then went ahead and did a lot of investigations and set up the tick-borne disease unit at the University of Sydney and have been funding that research unit for the past three years. We have been aiming to find something in Australian ticks that is making people ill. Presently we do not know what it is. This is a common ground that we can move on. We need to investigate that further. Okay, the terminology 'Lyme' has been used, because a lot of patients who do not get a proper diagnosis then google their symptoms and the first disease that comes up is Lyme disease. That links them up with the Lyme disease sufferers in the USA, and of course that then propagates the idea that this is Lyme disease that people are suffering from.

The problem we have is that tick-borne diseases present with non-specific symptoms and diagnostics are unreliable. In a situation like that it is very hard to determine the incidence of the disease in any place, and we need to work on understanding how to diagnose it properly. A tick bite does not deliver just one pathogen but multiple pathogens, so we really need to investigate not just *Borrelia* but other pathogens that come along with a tick bite. And people need to know that we have to identify it early, because if this disease is detected early and treated, the patient recovers fully. It is only when it becomes chronic that it becomes a really serious disease that can actually lead to morbidity. That is really significant because we need to train our GPs at the front line so that they are able to understand and detect this disease so that they can then liaise with the infectious disease specialists and get a proper treatment for the patient.

This is our aim. We just want to avoid having more people become chronically ill in Australia. That is the aim of the foundation. We want to develop a test that is sensitive enough so that Australians can, after a tick bite, go to their GP, get a proper diagnosis, get treatment and not develop chronic disease. Also, people in Australia are not aware of the dangers of tick bites, and we need to raise community awareness about the dangers of tick bites. The biggest problem with tick bites is that you do not get sick straight after a tick bite; it may be five or six months down the track, so you lose the connection between the tick bite and your infection. We need to give that information out to all the physicians and to the public so that everyone is aware of what is happening.

We have overseas-acquired Lyme disease in Australia, but we may not have Lyme disease as *Borrelia,* in the strict definition of Lyme disease which is common on the east coast of the USA, in Australian ticks. We need to be aware of that, because the equation of the whole situation is that we have Lyme disease, but the other part of the equation is that the other borreliosis that is endemic in the world is relapsing fever, and that is not being addressed in Australia. We do not have appropriate testing for patients with relapsing fever. Patients who have been to Asia or Africa, when they return to Australia, do not get a diagnosis of relapsing fever. Most of those patients are missed, and that is the missing bit of the equation that needs to be addressed by all parties. I think that is very significant. Given that Peter Irwin's work has shown that there is a relapsing fever *Borrelia* in Australian ticks, it is even more important for us to focus on that rather than on Lyme.

Ms Whiteman: The Lyme Disease Association is a small team of people who have Lyme disease or are carers of patients with Lyme disease. We agree with the speakers so far. What they have stated has been our experience as well, and we are living that experience every single day—every second of every day for some of us. That is the reality of the experience. We are representing thousands of people who are devastatingly unwell and who have been misdiagnosed by the medical system in Australia. Many of these sick Australians have tested positive for a number of tick-borne pathogens through accredited special laboratories overseas and a private laboratory here in

Australia. Many of these Australians have lost everything—their health, their careers, their retirement funds, their families and ultimately the quality of their life as they knew it before.

We represent thousands of Australians who are still misdiagnosed in the Australian medical system while pathogens continue to ravage their bodies. We represent thousands who return negative results through the Australian medical testing system for *Borrelia, Babesia, Bartonella, Rickettsia* and a host of other pathogens and who would exhibit the symptoms of infections and be told either that it is something else or that they have a psychiatric problem. Because of this we would like to highlight and query the major discrepancy between thousands of positive tests through specialist accredited international laboratories and one private Australian laboratory versus the relatively few positive tests coming from within Australian. The German vector-borne disease laboratory Infectolab complies with the same accreditation standard used in Australia, but its specialist tests are disregarded by the Australian medical system. So, we need to query that. Overnight we had initial stats coming from Infectolab saying that out of only 400 that they have had time to analyse, 30 to 50 per cent are showing positive for *Borrelia*—different strains and testings, but they are showing positive.

We represent the people who have had four weeks of antibiotics for treatment of these pathogens and still are severely unwell. International Lyme experts unanimously agree, and so do Lyme-treating doctors here in Australia, that four weeks is simply not long enough to treat this illness and support a patient's return to wellness. Australians are paying tens of thousands of dollars to get better because there is no help through Australian mainstream medicine. We challenge anyone listening today as to how you would react should you be in our shoes.

CHAIR: Ms Whiteman, I would just ask you to keep the opening statement brief, and we will get into the detail, as I requested at the opening of the hearing.

Ms Whiteman: Absolutely. I guess what I would like to say in closing is that it is not the responsibility of the sick people to be finding out what is wrong with them. We call on the medical establishment and the government to find a solution for Australians who are sick with Lyme disease.

Dr Lum: Thank you very much for asking the Australian government Department of Health to participate in today's hearing. The department began engaging with patients and advocacy groups in early 2013 to discuss the concerns about *Borreliosis*, also known as Lyme disease. The Chief Medical Officer, Professor Chris Baggoley, established a short-term advisory committee to consider the evidence for a *Borrelia* species causing illness in Australians, looking at diagnostic algorithms for *Borreliosis* in Australians and treatments for *Borreliosis*, awareness-raising and education, plus research into *Borreliosis*. Through regular communication and correspondence, the department has gained a deeper appreciation and real concern for those Australians experiencing these chronic, debilitating symptoms, which they associate with a tick bite. We wish to remain engaged with the patient and medical community to continue to find, share and understand the evidence associated with this medical conundrum. We hope our work with diagnostic pathology and research communities will result in answers and relief for patients and their families.

The department recognises that classical Lyme disease exists endemically in parts of the USA, Europe—including the UK—and Asia as a tick-borne infection that is usually short-lived but can last untreated for days to months, and that the majority of cases respond to a few weeks of oral antimicrobial therapy. In some patients, a post-treatment late Lyme disease syndrome occurs, with patients experiencing non-specific symptoms like headache, fatigue, and muscle and joint pain. These symptoms are generally not regarded as persistence of active infection but more as postinfectious problems. The department is aware of the controversy in endemic areas overseas about the diagnosis of chronic Lyme disease. Since 2013, the department has embarked on multiple projects to assist Australians experiencing these chronic, debilitating symptoms. We acknowledge that the cause of these tick-bite-associated, chronic debilitating symptoms may not be limited to a single bacterial species; parasitic viral causes as well as environmental toxins should also be investigated.

As part of the department's work in communicable diseases in states and territories, we are developing an awareness of newer genomic technology that has the potential to use specimens from patients to look for microbial nucleic acid, in an attempt to find commonality in patient specimens. It may reveal a common pathogen or pathogens which can be further investigated. We welcome the research that is going on, and I know that that will be discussed today. Later in the hearing, I hope to describe some of the activities that the department is working on. The department would like to reiterate just how concerned it is for these patients displaying these chronic debilitating symptoms.

Prof. Irwin: Thank you very much for inviting me to speak to this hearing. My expertise and that of my research group is in tick identification and the application of advanced molecular techniques to detect the DNA of organisms inside ticks. Just very briefly, I would like to summarise some of our recent research. In 2013, my

research group was awarded an ARC Linkage grant. The main aims of this work were to, first of all, investigate the ticks that were here in Australia to see whether any new ticks had arrived, any ticks that are not known about, for example; to develop a molecular tool kit to systematically characterise the microorganisms in these ticks; and then to use this information to try and map areas where there might be hotspots of infection around Australia. We are just over halfway through this study and, with the help of the Australian public, veterinarians, doctors and other researchers, we have collected over 20,000 ticks from many different hosts. We have adapted and developed a meta-genomic approach to detecting the DNA of bacteria and protozoa in ticks. We have not done any work yet with viruses.

A recent publication, which we published a couple of months ago, showed that we took 196 ticks from New South Wales, and 30 ticks from Germany as a control group, if you like. We used a next-generation sequencing technique that allowed us to simultaneously detect the DNA of different bacteria inside these ticks. We found 199 different bacterial groups in the *ixodes holocyclus* paralysis tick here in New South Wales, and the German ticks had 95 different types of bacteria in them. Many of these bacteria were environmental contaminants, as you might expect from ticks living in the bush, in the undergrowth. Six that we identified were of no medical importance. In German ticks, but not in Australian ticks, we found *Borrelia burgdorferi*, which is the cause of Lyme disease. In one Australian tick—and I stress that it was just one—we found *Borrelia* of the relapsing fever group. Importantly, I think, 15 of the Australian ticks, the paralysis ticks, contain the bacterium called *Neoehrlichia*—this is related to a known pathogen overseas—and we found *Rickettsia* in some of these ticks as well.

CHAIR: Can we get into the detail of what you are finding in the discussion?

Prof. Irwin: Sure, absolutely.

CHAIR: The opening statements are just designed to give us your idea of how Lyme disease affects Australia, not to go into the statistics and reports and things like that.

Prof. Irwin: Okay, fair enough. Just very briefly then: ticks are very good at transmitting disease. They have been extensively studied overseas, but the Australian ticks are unique. We have about 80 ticks here that are not found anywhere else, so I guess it is quite likely that whatever we have in the ticks in Australia is different to other parts of the world. *Borrelia burgdorferi* has never been found here, though.

CHAIR: We are just going to have to move on. We have limited time and we cannot be taking time away from other people.

Dr Graves: On behalf of the Royal College of Pathologists of Australasia, thank you for inviting us along. I would just like to make four brief points. The first one is that we recognise that ticks, and ticks in Australia, do transmit infections—there is no question about that—and several of them are well known. We do not have any evidence yet that they transmit Lyme disease in Australia. Point No. 2: Australian NATA-accredited laboratories can diagnose Lyme disease by serology and other means. It is not true to say that they are unable to do it; they do do it—they do it for returned travellers that have got Lyme disease from endemic countries. The third point, and Peter has already mentioned it, is that so far, and from our own research as well, we have not found any Australian ticks that contain *Borrelia burgdorferi* or the other related Lyme disease *Borrelia*. So, if it is not in the ticks, you wonder how people are getting Lyme disease. Certainly Peter has been able to find it in overseas ticks.

The last point I would like to make is that I would like to emphasise that we do feel concern for the patients with these chronic debilitating conditions. We would like to find out what is wrong with them. At this particular point in time, we do not think it is Lyme disease. We do not know what it is. I would leave you with a question: if you misdiagnose a patient and give them the wrong diagnosis, does that really help them?

Prof. Gilbert: On behalf of the Australasian Society for Infectious Diseases, I can endorse particularly what Dr Graves has said about the diagnosis of Lyme disease in Australia. I think Australian infectious diseases physicians are frequently referred patients with symptoms that are suspected of being chronic Lyme disease, and a small minority of patients who have a history of travel to endemic areas, and a tick bite, can be confidently diagnosed with Lyme disease—if that is what they have, based on laboratory tests, including the tests from a laboratory of which I was the director until quite recently at Westmead Hospital.

Infectious diseases physicians also see many patients with chronic symptoms for which no definite cause can be found and feel very strongly—and I would reiterate what Dr Graves just said—that it is of no benefit to the patients to treat them long term with antibiotics, which can be potentially harmful and certainly will not help chronic symptoms that are not due to bacterial infection. In the absence of a specific diagnosis, this, I would suggest, is malpractice, if it is not supported by any laboratory diagnosis.

Prof. Stocks: I represent the Royal Australian College of General Practitioners. Lyme disease is a common clinical problem across North America, Europe and Central Asia. There is a known causative organism,

established epidemiology, clinical presentation and evidence based treatment. We recognise that in Australia there is a Lyme-like illness with no consistent causative organism, very little epidemiology, unstructured treatment and poor evidence about outcomes of current management. There is a great need for further research into what can be a very disabling condition for patients. The college would support anything in that direction.

CHAIR: Thank you.

Dr SOUTHCOTT: Just for clarification, Chair: the idea is session 1 is incidents and diagnosis and then session 2 is treatment?

CHAIR: Yes.

Dr SOUTHCOTT: I would like to ask a question on the research of the committee that was established by the Chief Medical Officer. There were a number of research topics that were identified by the committee as expanding the knowledge of the Lyme-like disease. Are any of those research projects proceeding?

Dr Lum: The scoping study that was commissioned in 2013—and a report was made public in November 2013—had roughly five research priorities that it identified. Those research priorities spanned from investigation of a potential causative organism in potential vectors, so in this situation ticks, through to investigations into patient series or case studies. So far we are aware of the work of Professor Peter Irwin, who I hope will be able to speak about his research shortly, and we have been particularly encouraging the general practitioners who have been looking after the patients who present with these chronic debilitating symptoms to work with academic general practitioners in medical schools to start investigating and looking at commonalities within those patients. I am not aware of any funded research along those lines. Although I know that Dr Schloeffel is working with the University of Sydney and the Karl McManus Foundation funded tick-borne diseases unit there.

The other aspect of this is that the department has recently contracted with the National Serology Reference Laboratory, which is an independent laboratory with expertise in the evaluation of in-vitro diagnostic assays to look at, in the first instance, serological assays used for the diagnosis of Lyme disease. We are involving laboratories in the United States, Germany, the UK and Australia. It includes those specialised and private laboratories that look particularly at Lyme disease as well as Australian laboratories that are accredited in medical testing. From that evaluation of those assays, we will try to ascertain some of the reasons for the discordance in the results that are seen in Australia. We hope to also look at what difference prevalence and the other variability in terms of interpretation of assays might make.

It is exciting to know that the National Serology Reference Laboratory is also looking at a potential study to look at next generation sequencing techniques and it hopes to do something prospectively with patients presenting with these chronic debilitating symptoms, trying to use these techniques, using metagenomic techniques, to find commonalities and potentially, if they exist, pathogen or pathogens associated with these symptoms.

Dr SOUTHCOTT: Thank you. Professor Irwin, I want to go back to your opening statement. Could you give the committee some more information about your discovery of *Borrelia* DNA in an Australian tick? What is the difference between the *Borrelia* species that you have found here and the *Borrelia* that you have found in German ticks, and the diseases they carry?

Prof. Irwin: The DNA of the ticks from Germany was clearly *Borrelia burgdorferi*—the cause of Lyme disease. The DNA of the *Borrelia* in the Australian tick, which was actually taken off an echidna, aligned most closely to a related group of *Borrelia* referred to as 'relapsing fever'. These cause a different type of disease in people. So they are quite different but related to *Borrelia* of the Lyme disease group.

Mr STEPHEN JONES: I am not a medical practitioner. What can we infer from the fact that we have one tick on one echidna with a *Borrelia*-like bacteria?

Prof. Irwin: At this stage, very little. I think we need to confirm this by more testing, and we would need to find it in many more ticks, I think, before we could say that it is a plausible cause of disease.

Dr Graves: Mr Chair, could I just add to that. There are two known *Borrelia* that already exist in Australia that are associated with animal ticks. So it may well be one of those.

CHAIR: As it is a round table, if you feel you want to contribute, just do.

Ms Burke: We have had multiple positives from Australian ticks. We have had a paper published on positive *Borrelia* in *Ixodes holocyclus*. We have had positives in kangaroo ticks. We have actually had positives in bush lice taken from feral animals from a farm in Queensland. And we have sequenced probably five to six types of *Borrelia*, often in patients who have travelled overseas. So we know that our tests will pull up different types of *Borrelia*. We have picked up things like *B. crocidurae* from a patient who had been to Africa and *B. valaisiana*

from a patient who had been to Russia. But we do not tend to have too much of a problem sequencing and getting positives in Australian ticks.

Dr SOUTHCOTT: Have you found *Borrelia burgdorferi* in your sequencing?

Ms Burke: Close to—not quite a perfect match; close to.

Dr SOUTHCOTT: Professor Irwin, do you want to make any comment on that?

Prof. Irwin: No, not at this stage.

Dr Graves: Could I just add to this discussion: my own research group, the Australian Rickettsial Reference Laboratory—which is nothing to do with the college of pathologists, I might add—is investigating this as well. We have actually now looked at just over 300 ticks—10 different species from all over Australia—and not one of them have we found *Borrelia* in.

Mr STEPHEN JONES: But you do not dispute the fact that there has been one tick that did have it? Is that in contest?

Dr Graves: We would not have picked up that tick, I imagine, because the technique that Peter is using is much more sensitive and can pick up much smaller amounts of DNA. We are using a grosser test that picks up the ones that we know are human pathogens.

Ms Whiteman: I can speak to that as well. I got a tick bite in the Queensland hinterland and tested positive on DNA for *Borrelia burgdorferi* in 2006. So my perspective is that we need to broaden this discussion beyond just *B. burgdorferi*, because I say—like most speakers to my left here—this is a cocktail of pathogens; that is what is being seen in world's best practice globally. So to limit the discussion to whether we can find *B. burgdorferi* in a tick is leaving patients in Australia high and dry, really, without help.

CHAIR: Ms Whiteman, can I just ask you to detail what would happen if someone suspected they had Lyme disease? What would be the process in Australia to establish that? How would they go about getting a diagnosis, and is there a path that will take them to—

Dr Schloeffel: Can I answer that?

CHAIR: I want to get to the association's perspective and then you can add to that.

Ms Whiteman: From a patient's perspective and the reports to us: right now we have got just under 1,500 medically diagnosed cases of Lyme disease, or co-infections. It is much broader; 'Lyme' is too narrow a name, but there is not a name right now, so it is 'Lyme-like illness' in Australia. Right now the overwhelming story of patients presenting to doctors is that doctors either feel undereducated to support them or are not inquiring about symptoms. For instance, if it had been inquired of me, when I was presenting to 17 different doctors, whether I had a history of a tick bite, I could have gone, 'Oh yeah, I did, and I felt really sick after, and I got this bull's-eye rash,' and that would have changed the course of the next 13 years of my life. So, right now, overwhelmingly, doctors are feeling underresourced and undereducated or just following what they are told—that there is no *B. burgdorferi* here, which is limiting the picture. Right now in Canada and the US they are finding all kinds of pathogens in migrating birds. So I think what we need to realise is that we are not really looking here in Australia, compared to the gravity of the situation.

Dr Schloeffel: I have currently 400 patients with borreliosis or related illnesses. Some of these patients definitely have acquired this illness overseas, and have been diagnosed overseas. So they may go to America or Germany, and they have appropriate testing with approved labs. In America, it is Galaxy Lab or IGeneX. Quite a number of labs over there will diagnose these conditions. These patients come back here. Or they go to Infectolab or to Armin Schwarzbach's lab in Germany, and they will have, usually, immunoblot testing, and sometimes PCR testing. The ELISA testing that we do here, they do not do over there because they find it is a very non-sensitive test.

The majority of patients I see are referred to me having been diagnosed by other doctors already. I am at the top of the pile—or the bottom of the pile, depending on how you want to look at it. So I get all the very difficult, the very sick and, sometimes, dying patients who have this diagnosis of borreliosis and co-infection. Like my colleagues over here, I am very cautious. I am a physician. The first principle in medicine is 'Do no harm'. But if you actually do not take on this evolving illness and think more broadly about it, we are going to miss a whole lot of people who are very sick, who may die. And we have to develop systems of diagnosis. That is what I have been working on for 20 years.

I started my work with an infectious diseases specialist, who sent me a few patients—Dr Bernie Hudson. He sent me those patients because they seemed to have chronic fatigue syndrome. We were diagnosing those patients with PaLMS Laboratory, a Sydney-based pathology doing an ELISA and western blot in the 1990s and up to

2005. Then, for some reason, those ELISA tests were changed and they became very insensitive to picking it up in these patients. I stopped getting diagnoses from there, so I started to search the world. Fortunately, I had Jennie Burke eventually coming on and doing some testing here in Australia. I started using IGeneX, Infectolab and various other labs because I saw these people who had a chronic fatiguing illness, or they had neuroborreliosis—that looks like motor neurone disease, MS, psychosis or Parkinson's disease. But they see the neurologist and they are atypical in their pattern of symptoms or they are atypical in the disease structure when they are investigated. It is physicians, neurologists, cardiologists, surgeons and professors of all sorts of medicine who send me these patients. They are not just coming off the street, like Sharon getting a tick bite and seeing the GP. The GPs ring me and say, 'What do we do?' Five GPs a week will ring me and say: 'I've got a patient who is really sick after a tick bite. What do I do, Richard?' I am not an infectious diseases specialist. I am a GP interested in chronic and complex disorders. What I am seeing is that the testing and the science have not caught up with the reality of this evolving illness.

I do have Australian patients and I have got positive serology from Australian labs—IGeneX, Infectolab, Jennie Burke—and I have treated these patients, and they have recovered. Seventy per cent of my patients fully recover from this illness. Some of them have it for six to 10 to 20 years. They have a chronic-fatiguing illness, seronegative rheumatoid arthritis, these neurological conditions, and I treat them. I have to monitor them every month. They have long-term antibiotics, in some cases—not always. Often the GPs are managing them in the field.

The science of this is evolving, but we have not got anywhere near the science to catch up with the gravity of the disease that we are seeing evolving in Australia. I go to conferences in America and Germany and I speak with lots of colleagues—hundreds of doctors—treating this all over the world. We are talking different talk to what we have in Australia from our infectious diseases colleagues. I would love them to come on board, like Bernie Hudson has, to give us some idea of what we need to do as GPs.

This is a GP illness; these people go to the GP. They go to the infectious diseases specialist, and then they have contacted the psychiatrist because they have got conversion disorder. Now, that has got to stop! I am so sick of hearing people say they have seen 30 doctors, and then they get to me and they have borreliosis. I diagnose it, I treat them and they recover. So there is something wrong with the system in the diagnostics. The diagnostics are not adequate. I think of the ELISA testing from our Sydney uni work. We have taken 180 patients—180 blood samples times five. We have analysed all those samples, and not a single ELISA was positive. But 66 per cent of the western blot and immunoblot studies were positive for *B. garinii*, which is an Asian-type *Borrelia*. We have also found *B. afzelii* from Europe and some *B. burgdorferi*, but some of them are mixed. I think this picture of evolving *Borrelia* relapsing fever would fit the pattern, because it fits the symptom of the patient. When I trained originally I worked in Papua New Guinea in malaria and TB and leprosy—that was my original work when I was 23 years of age. I would look at some of these patients, and they were like they had malaria because they had these relapsing fevers and these funny chronic symptoms where every day, or every third day, they had a massive night sweat where they would completely saturate the bed. Patients are bedridden, being cared for by families if they are children—and I am seeing children and I am seeing old people and everyone in between. I think that diagnostics is the problem, and the diagnostics we have in Australia conventionally are inadequate for the degree of illness and the evolution of the illness. We have not seen this illness en masse before.

Dr SOUTHCOTT: Professor Stocks, what do we know about the incidence of Lyme-like disease, or the constellation of symptoms that is being described here?

Prof. Stocks: To the best of my knowledge there have been no published papers on that here in Australia, mainly because the work has not been done—it has not been funded. Many people would potentially be diagnosed as having chronic fatigue or would have some other diagnosis attached to them, if I can term it that way. So I cannot give you that estimate.

Dr SOUTHCOTT: Dr Schloeffel, how do you make the diagnosis of Lyme disease?

Dr Schloeffel: The most important thing is that, if someone comes in with an unexplained illness, often it is a plethora of symptoms. I have developed a research tool for them to fill in that contains about a hundred different questions about symptoms from headaches, seizures, sore throat, swollen glands, lung problems, all sorts of bodily problems: fatigue, post-exertional fatigue, sleep disorders, gut problems, weight gain or weight loss—all sorts of things; a whole lot of unrelated symptoms. They have often had it for a long period of time. The patients I see are not acute tick-bite patients—they are seen by GPs, and most GPs that I speak to are now giving three weeks of antibiotics straight away to anyone who gets a tick bite. I will talk about that later, but that is what I think we have probably got to do.

I take a full history. I spend an hour-and-a-half with these patients, then I set about doing pathology. I will always do Australian pathology testing and—rarely, but sometimes—we will have a positive ELISA test, especially if the patient has been to America or Europe, and they will have a positive western blot, confirming the diagnosis. I will use Australian Biologics because they do very good ELISPOT and immunoblot and PCR testing, particularly on serum and urine, if patients can afford it. This is the biggest difficulty we have in Australia—patients are funding an enormous amount of pathology with IGeneX or Infectolab or ArminLabs in Germany to get their diagnosis. In some patients I have four labs, including Australian tests, positive for Australian patients who have never left Australia, so I also use something called a CD57, which is a screening test. It is a vague natural killer cell that is reduced in the presence of chronic infective illness that is stealth, that is not being teched up. These people are not like someone who has got tonsillitis, or who you give an antibiotic to for a week and they get better; they have come in and they have often seen 20 or 30 other doctors already, so I am at the end of the chain. I am not that person who is seeing these people raw—they have often seen 30 other doctors and have been to every other specialist, and they are getting worse. They are bedridden—they come in in their wheelchairs, they are seizuring and are very unwell. Often they are children, and young children as well. Then I set about the process of: 'How can I treat this without making them worse? What is the safest way of treating them?' Often when you start treating them and you give them a series of what I call rotational therapy, rotational antibiotics, if they have just got *Borrelia*, these patients will respond to that and you see changes in some of the pathology.

What often happens at the end of their treatment is that their Australian tests—their ELISA testing—will become positive because these organisms are not recognised by the body's immune response. A *Borrelia* is a spirochaete—a thin little organism related to syphilis in its shape. They are inside your cells. When you attack that spirochaete they convert in the cell to a cyst. They also produce a little DNA bump so that if you kill this organism with an antibiotic they will more than likely morph into another form and will move through whatever tissue they are in—they particularly like brain and muscle and other places—and they will keep growing. And if you chase them around with one antibiotic you will not get this better. So I use triple therapy to try and get all stages: intracellular, extracellular and cystic forms of this illness. As the illness is treated—and I watch people getting better, the joy of this is—the symptom list diminishes. So this is not only how I treat it but how I diagnose it. Somewhere down the track we will get a positive ELISA test, which is what the physicians and the pathologists are asking for as the first test. Generally, I do not see that. I see that as a late changing test, because the body's immune system did not recognise the organism in the first place. That is why someone can be sick for so long.

These are not infections that you suddenly recognise like, 'I've got a disease; I've got to get rid of it.' These are stealth infections within our systems that are disrupting our body functions and making us sick, and our immune systems do not recognise it. The thing that we measure with a pathology test is our immune response. The immune response is not adequate and therefore the tests are negative. I am not questioning the quality of the pathologists; I think that they do a great job but they are not testing the right thing. I think that we should abandon ELISA as a first-right test. It is a waste of time. It is always negative in the first instance. We should be doing western blot, immunoblot and PCR standard testing on every patient that comes in—the tests are available.

Jennie Burke's work is remarkable. There are lots of other labs around the world trying to set up PCR. Bernie Hudson and I have been looking at trying to do this. I sent him lots of samples, and he did find some PCR on skin biopsies we took from the rash from around ticks back in the 2000s. There is research going on, but these are minute organisms that are not very easy to find or detect by immune testing. The tests are wrong in relation to the degree of illness.

Dr McManus: I would like to say that the testing in Australia is inadequate in the sense that we apply the CDC criteria to our western blots in NATA accredited labs. CDC criteria is specific for Lyme disease but, from looking at the western blot, it would not be able say if a patient has less than five bands, they would be classified as not having Lyme disease. There should be a different criteria around the world, because the genetic make-up of *Borrelia* changes significantly. For example, in Scotland, they have developed their own unique way of defining what is positive on a western blot. Instead of using five bands, they use two bands. They have specified this, because they have done a screening of *Borrelia* in their area and they defined their positive differently from CDC criteria.

We are about to publish a study, which we did with the tick-borne disease unit, showing that with CDC criteria you do detect no patients having what we call borreliosis. If you apply the Mavin criteria—that is one of the publishers from Scotland—then you get a 70 per cent increase in the patients that are getting positive results.

This criteria on the western blot is very relative and it needs to be adjusted according to the region where you are testing the patients. I think that is one of the biggest blocks, because usually, if patients in Australia get positive ELISA, then the next thing that they do is a western blot, but then hardly anyone in Australia gets five

bands from a western blot. That needs to be redressed by the NATA accredited labs that we are not just focusing on Lyme disease; we are looking at *Borrelia* and they could be relapsing from *Borrelia* because, 10 to one, they are going to get cross-reactive bands coming from the western blot.

CHAIR: When is your publication due?

Dr McManus: Probably by the end of the year.

CHAIR: If we could get a copy, that would be great.

Ms HALL: I am reluctant to ask a question, because I arrived late. Is there any research that has been specifically done looking at the Australian ticks, the strains of ticks here and whether or not there is any particular *Borrelia* virus relating to Australian ticks? Have we actually been homing in on Australian ticks?

Dr Lum: It is clear that Australian ticks have lots of different bacteria inside them. There is no doubt about that at all. To date we have only evaluated a relatively small number and we have not found any of the *Borrelia* of the Lyme disease causing group. But there are other bacteria in these ticks. As other speakers have said, I think it is a bit of a mistake to focus too much on *Borrelia*. If people are getting sick from tick bites, it is quite possible, or at least plausible, that they are being infected by other bacteria, viruses or even protozoa. These ticks are full of micro-organisms. The focus on *Borrelia* I do not think is helpful in this discussion—or at least it is limiting. Certainly, in some of the work we have just recently done, we found that a lot of the paralysis ticks, which are perhaps the most common biters of people here in the eastern states, are full of a bacterium called *Neoehrlichia*, and it is closely related to a known pathogen overseas, so that might be a candidate pathogen here.

Ms HALL: So, rather than there being a campaign saying that there is no Lyme disease in Australia, wouldn't it be better to target research to find out why so many people are getting sick following a tick bite?

Prof. Irwin: I think a metagenomic approach—being able to analyse and search for a large number of different bacteria at the same time using a molecular technique—closing the circle between work that we do in the ticks and the diagnostic work done in people, is perhaps the way to go, but others may want to speak to that.

Ms HALL: Could I just—

CHAIR: I think we have another contribution on that particular question.

Prof. Gilbert: Yes, I just want to add to that. I think that the claim that NATA-accredited laboratories in Australia do not make the right diagnosis is a bit unfair. What laboratories in Australia do is adhere to established, evidence based criteria for diagnosis. Given that we have not proven that *Borrelia burgdorferi* occurs in Australia, the tests that we do, the only tests that are available, are for established pathogens, *Borrelia burgdorferi* and the other related species that occur in Europe and Asia. In the absence of an alternative cause of this syndrome, Lyme disease, it would be negligent for us to change the diagnostic criteria, because we know that, if we accept fewer bands or lower cut-offs in ELISA tests, we will get false positives and very poor predictive value in circumstances where we know that the prevalence of this disease is very low. As far as we can prove, it is limited to people who have acquired it overseas. So it would be negligent of laboratories to arbitrarily change the diagnostic criteria in the absence of proven alternative pathogens causing this syndrome, and I think that is why this research is so important. If we had other criteria, we could develop diagnostic tests specific for those other pathogens, if we could prove that other pathogens were causing this syndrome. I think that is why it is so important for this research to continue, but certainly it would be inappropriate for laboratories to change the criteria for diagnosis, which are based on wide experience of these diseases in high-prevalence countries.

Dr Graves: I would just like to add to this. It is a very interesting discussion, and I think people are right that we are probably just concentrating on *Borrelia* when there is clearly something else involved. The Australian ticks do carry other pathogens, and I suspect many of the patients are not being tested for them.

Dr Schloeffel: Or every patient.

Dr Graves: For example: *Babesia*, *Bartonella*, *Ehrlichia*, *Anaplasma*, *Neoehrlichia*, *Rickettsia*. Now, we detect *Rickettsia* in a lot of patients, and they have symptoms very similar to the Lyme-like illness. And then of course there is that very ubiquitous Q fever. It is not the first time we have had a patient with Lyme disease who has come up positive for Q fever, having caught it from a tick. So there are a whole range of pathogens that we do know are here. Why are we concentrating on this one thing that does not appear to be here, although we know it is overseas? Why don't we put more effort into looking at things that we do know are in Australia?

Dr Schloeffel: Can I—

Dr Graves: Please let me finish, sir. The problem with the diagnostic laboratories is that we can only test what we are asked to test. If we do more than that it is called overservicing, and you get slapped on the back of the wrist. You cannot do it. You can only test what is asked for. So, if the referring doctor, such as Dr Schloeffel, asks

for *Babesia* and *Bartonella*, I cannot test for *Escherichia* and Q fever as the director of the laboratory. That is actually not proper.

Dr Schloeffel: Can I say something there. Every patient I see gets tested for *Borrelia*, *Bartonella*, *Babesia*, Q fever, *Rickettsia*, *Mycoplasma* and *Chlamydia pneumoniae*—standard tests, first off.

Dr Graves: You should really get them done—

Dr Schloeffel: Well, they go to Douglass Hanly Moir. I ask for many of them to be sent to your lab, absolutely, because I think you are doing good work, particularly with *Rickettsia*, and then I get them retested in America or Germany.

My view is: if we are going to do pathology testing, why are they getting tests that are suggestive of all these illnesses? Often I get a patient's tests back from some of these labs and they have four or five of these organisms positive on their tests, and these are Western bloc primarily. I am not doing PCR overseas to any great extent. I think Jennie is doing good work with *Borrelia*, but we are dealing with complex infections. I totally agree: a lot of these patients do not have *Borrelia*. The most common causes of chronic fatigue syndrome are *Mycoplasma*, *Chlamydia pneumoniae* and *Rickettsia*—far more common in my cohort of patients than *Borrelia*. *Borrelia* is only 20 per cent of my practice. I have 3½ thousand people with chronic fatigue syndrome that I have treated, most of whom have had an underlying infection. Most of them have now fully recovered or partially recovered to a level where they have a normal life, and I had to treat them for these infections. That is not the only cause of these conditions.

And I do test for these—every patient—because you are right; we are not dealing with just *Borrelia*. The Borrelias that we see in Australian patients—I think the problem with the Australian testing is that I cannot remember when I got a positive *Bartonella*. I do three other labs around the world and the patients come back with a positive *Bartonella* test. What am I supposed to do? I have a really sick patient with severe neurological symptoms, the potential of death. That is how sick these people are: they are going to die. I have three or four die every year, and some of these people are 20. I am dealing with serious illness here. I am not playing around with some difficult illness. They are terrified to go to hospital to be told they do not have anything wrong with them. They have seizures; they have terrible pain; they are really sick. And then I slowly get them better. I send pathology overseas—to Galaxy lab; particularly IGeneX and Infectolab; and ArminLabs—and they will come back and say they have got *Bartonella* or *Babesia*. *Borrelia* they may not have, so I agree with you.

But with the Australian testing, when I ask for a *Bartonella*, I had one patient who had a positive *Bartonella* test, and these are chronically ill patients. So either the sensitivity is wrong or we are looking for the wrong species of the *Bartonella*. There must be lots of Bartonellas, Babesias and Borrelias. There are so many of these. If you are only looking for a specific organism—and remember that this cohort of patients is not just Australians who have contracted this here; they go on holidays. We are the most travelled people on the planet. They go to Bali. They go to America. They go to Europe. They get a bite, and it is not just tick bites; it is lice bites and bedbugs in Bali. I have had at least a dozen patients say, 'Look, I got bedbugs in Bali and I'm sick.' Then I set about testing them, and they often have *Borrelia garinii*, but they also have Rickettsias. They have a type of *Rickettsia*. Or they will have *Ehrlichia*.

CHAIR: I am sorry; we are just about out of time, and Mr Wyatt has a question.

Dr Schloeffel: Yes, I know; sorry. What I am saying is that we are doing those tests. I agree with you, Stephen, that there is a multitude of infections.

Mr WYATT: I want you to cast your minds back to when we had HIV-AIDS. That was known for some time, but we did not test for it until it became an epidemic in the sense of the way Australia had to react to it. Our laboratories were not ready at the time, and the policy thinkers within health jurisdictions, including the Commonwealth department of health, had not turned their minds to much more investigative work until the information was provided from a number of sources. Then we went into a strong overdrive in treating people with HIV-AIDS, and we looked for cures.

Barry Marshall, with ulcers, had a theory that he put forward and was, in a sense, howled down by colleagues in his profession. He went on to become a Nobel prize winner for the work that he did.

I just find it negligent—extremely negligent—that we have so many Australians suffering from what appears to be either Lyme or some form of Lyme disease, and yet we are having debates around who is right and who is wrong and whether the testing is right or wrong. Why aren't we being proactive? I am going to ask the Department of Health. What is your role and objective in the management of the health of Australians, Dr Lum? I am going to come to some other points in respect of what you said.

Dr Lum: Specifically for these particular patients, Mr Wyatt, or overall?

Mr WYATT: Just overall to start with, because I want to come to the particular elements.

Dr Lum: The mission of the Australian government Department of Health is the welfare of Australians in general, acknowledging that under the Constitution of Australia our responsibility is fairly limited. States and territories have responsibilities for service delivery for most of health care.

From a departmental perspective, there are national programs that the department is able to fund and to manage in cooperation with the states and territories in terms of the delivery of that health care. In the areas of emergency management and national security, the Australian government has a role, and the particular division that I work in, the Office of Health Protection, has a role in protecting the health of Australians when it comes to natural disasters, whether they be communicable diseases or a pandemic of that nature or earthquakes, floods or anything of that nature.

Mr WYATT: Earlier you said that you have multiple projects that are looking at the issue of Lyme disease or, as you said, people who present who associate their illness with a tick bite. What are those projects?

Dr Lum: The main project that we have contracted out was the one that I described to Dr Southcott, working with the National Serology Reference Laboratory, looking particularly at these diagnostic assays that have been in use. It is a well-known problem not just in Australia but also in endemic areas like the United States and Europe, where there is a difference of opinion. This debate that we are having at the moment is not solely related to Australia. There is controversy around the world about this diagnostic entity known as chronic Lyme disease. It can be called many other things, but the difference of opinion relates to whether the chronic symptoms are due to active persistent infection or they are postinfectious sequelae or postinfectious problems. That is the nut of it. When there have been analyses of—

Mr WYATT: I accept that. I accept the work that you are doing, but I am interested in the other projects as well.

Dr Lum: Basically, we provided the scoping study with respect to those research priorities. We have undertaken a number of roundtable discussions with specialists. But, in terms of ongoing research, the department is not doing active research itself. It is a department of state, a policy department. So we are not in a position where we have people who can undertake that research, and that is why we have contracted, particularly for the diagnostic side of things, this work with the National Serology Reference Laboratory.

Mr WYATT: If the outcomes of that work in looking at serology and other elements come forward, and even the Murdoch work, how do you then ascertain what work has to be done in terms of analysis using laboratories, given that we have heard evidence that we are finding the *Borrelia* spirochete in patients in Australia and given the number of Australians who are now suffering?

Dr Lum: Should the analysis of those assays demonstrate results that we can work on to analyse, and should the results suggest that there are *Borrelia* that are causing disease, causing these chronic debilitating illnesses, then that analysis has to be done. It will not necessarily be the Department of Health that does it. Our experience with working with other communicable diseases is that we would work with states and territories, their public health units and their public health experts, as well as universities, in terms of working with experts in the academic field looking at particular diseases and contracting that work so that we can have a better understanding. Without wanting to pre-empt any of the results, because we just do not know what the results are going to be, if the results suggest that there are problems more with interpretation of the tests then we will have to analyse that and see what the ramifications are for Australians.

Mr WYATT: The only other question I have at the moment, before I give it back to a colleague, is: are you working with people who live with what appears to be Lyme disease, or are they excluded from all your processes?

Dr Lum: For the work that is being done with the National Serology Reference Laboratory, those patient samples are coming from Australian patients who have had their specimens submitted either to Australian laboratories, whether they be Australian Biologics or medical-testing-accredited laboratories, or for some of the laboratories overseas that Dr Schloeffel has mentioned—for example, IGeneX, ArminLabs and Infectolab, as well as the Rare and Imported Pathogens Laboratory in the United Kingdom.

Mr STEPHEN JONES: Why was the clinical advisory committee closed down?

Dr Lum: The clinical advisory committee was set up by the Chief Medical Officer as a short-term advisory committee. It was maintained from the outset that it would be a short-term advisory committee. Its terms of reference were to look at incidence, diagnosis and treatment, as well as research.

A decision was made shortly before the last meeting that that would be the last meeting, mainly because there was active research going on with Professor Irwin. We had put out the research priorities, hoping that the Australian medical research community would take those on. When we said that we would have the last meeting, what we did not say was that that was the end of our activity or the end of our interest in this particular problem. We made it clear that we would continue to communicate with former members of the Clinical Advisory Committee on Lyme Disease and that should there be any new advances we would communicate.

For example, when Professor Irwin recently published his work, we held a teleconference of former members of the Clinical Advisory Committee on Lyme Disease. We invited Professor Irwin to speak to his research and we had a general discussion. The Chief Medical Officer of Australia has issued a progress report on our interest in these patients over the last three years. That report has been sent to former members of the Clinical Advisory Committee on Lyme Disease as well as to the presidents of relevant medical colleges, the AMA and state and territory chief health officers.

Mr STEPHEN JONES: My last question goes to testing: given that this is primary care—the first line of presentation is going to be primary care in the GP setting—what guidance is given to GPs regarding testing or other predictive measures in relation to tick bites?

Dr Lum: I should have mentioned one of the other projects—and I suppose that the word 'project' is a little ambitious. The department has been doing a few things—for example, recently we published and provided to medical practitioners an Australian guideline on the diagnosis of overseas-acquired Lyme disease. We recognise, and we have been told—

Mr STEPHEN JONES: Does that mean that if that person did not go overseas they would not go down—

Dr Lum: Those guidelines are not relevant for people who have not travelled overseas to an endemic area—correct.

Ms HALL: What if the person had not left Australia? They would not be tested?

Dr Lum: No. At the moment there are no diagnostic guidelines. I should mention though—and I will ask Dr Graves to comment—the Royal College of Pathologists of Australasia has certainly put out a position statement on diagnostics for classical Lyme disease.

Dr Graves: Just over a year ago the Australian college of pathologists did put out a flow diagram—and I have some copies here—of what to do. The first division is whether your patient has left Australia or has never left Australia and you think they have Lyme disease, and the protocol that we recommend.

CHAIR: Who did you put that out to?

Mr STEPHEN JONES: How does that encompass the comments that you made earlier, when you said that in a sense the focus on Lyme disease is problematic because there is a whole other group of pathogens which provide Lyme-like symptoms? If we are telling our GPs to ignore that unless they have been out of the country, aren't we asking people to turn a blind eye to things?

Dr Graves: No—this is only to be used when the request slip says, 'Please analyse for Lyme disease.' The laboratories are in a bit of a cleft stick because we only do what we are asked to do. We are not research laboratories, so—

Mr STEPHEN JONES: Yes, I understand, but my question went to what—

Dr Graves: If the referring doctor says, 'Look for Lyme disease,' this is what we recommend that the laboratory does. If, however, they say there is a bite in there or a bee sting then that is a different kettle of fish. This is limited to patients where the referring doctor, the GP, has asked the doctor in the laboratory, 'Please look for Lyme disease.' That is the protocol that the college of pathologists is recommending. It is designed to try to find the putative Australian Lyme mite's—

Mr STEPHEN JONES: My apologies: maybe I was not clear enough. My question went to what guidance is given to general practitioners as to what tests they should be conducting when somebody presents with a tick bite or, even further than that, with Lyme-like symptoms.

Dr Schloeffel: Can I answer that? I get at least five GPs a week ringing me and asking for advice. I am a GP, a fellow of the college and also a lecturer. I lecture to GP locals and I lecture to patient groups and interested doctors. I also lecture around the world on chronic fatigue syndrome.

I am always asked this question: how do you diagnose a new patient who has walked in the door and says, 'I've got a tick bite,' or, 'I've got a rash,' or, 'My child's sick,' or, 'I'm sick'? Generally I say: 'Well, you can do a blood count and a Lyme serology ELISA test. It'll be negative; there is a 100 per cent change it'll be negative, no matter what. It's always negative. Just treat the patient, and hopefully they'll get better.' That is for acute.

If it is a chronic patient who has been sick with chronic fatigue syndrome and they have a tick-borne illness, I will ask them to do an Australian test—ELISA and immunoblot—and advise them, if the patient is willing, to have a blood test done with Jennie Burke at Australian Biologics and, if they are well off enough, to pay for an overseas lab to do that as well, so they get three categories of testing. This is before these patients come to me, and this is not just GPs; it is also other doctors and specialists in other fields who have sick people they believe could have a Lyme-like illness. I always request them to do *Bartonella*, *Babesia*, *Rickettsia* and Q fever in all those patients, because we do have enclaves of patients with those. That is my advice, and it is just verbal, over the phone. I do not have a handout that I give to doctors, but I do have a handout I give to patients when they come to see me.

CHAIR: Dr Schloeffel, thanks for that. We have to wrap this session up now, but what is the approximate cost of the overseas testing?

Dr Schloeffel: Ridiculous.

CHAIR: Just quickly—a rough figure.

Dr Schloeffel: Between $1,000 and $2,000. It is prohibitive for people who are very sick. If it is the breadwinner who is sick, how do you afford that? So people have fundraisers and whatnot.

CHAIR: We just wanted to get on the *Hansard* record what the cost was.

Dr Schloeffel: Yes. It is ridiculous, and I personally think those tests should be brought here and done here. We should be doing it here. What the bloody hell are we sending blood overseas for?

CHAIR: We have to wrap this session up. Thank you for your contributions. I admire the passion and the information that we are getting. Thank you.

Proceedings suspended from 10:11 to 10:30

CHAIR: The committee will now commence the second session on the treatment of Lyme disease in Australia. We will invite each organisation to again make a very brief statement. I must insist that it be brief, because we have to allow time for questions. We are going to try to extract as much information as possible from you, and we need to give members of the committee time to ask questions. You do not have to make a statement but, if you can make a brief on the treatment of Lyme disease in Australia, that would be appreciated. We will start with Ms Kiefer.

Ms Kiefer: I cannot make a statement on treatment but I would like to say that I am very concerned, and I know my association will be too, about the affordability of the treatment. It seems to be way beyond the normal person's reach, and I am concerned about that.

Ms Burke: I am pathology; I do not talk about treatment. I am happy to listen but it is not my go.

Dr Schloeffel: Can I have our time? I treat these disorders, and patients assent to me with an expectation of treatment. I acknowledge there is enormous cost in the investigation. One patient told me the other day that he had spent a million dollars trying to work out how to get himself well. So we are talking significant dollars. They spend a huge amount of money seeing naturopaths, seeing other doctors, having lots of tests and doing all sorts of things and then they come to me. I am regarded as probably the doctor of last resort if you have a chronic fatiguing illness. It costs a little bit to see me, but fortunately there is a thing called the Medicare safety net. Most of the time, by the time I have seen the patients they have already reached that because they have seen 20 or 30 other specialists or doctors before they get to me. So I become neutral in the process.

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

The first principle in medicine is do no harm and the second principle is do not lie. So you have to be very careful not to over treat people too often, because they get this so-called Herxheimer response, which is where they get an exacerbation of all their symptoms from the minutest amount of antibiotic. I observe this all the time. There may be some conflict about that, but, when you are watching someone have a seizure and they have taken an antibiotic half an hour before, you realise that you are heading into difficult territory. So I treat them with

antibiotics. Often I will slowly introduce over weeks—sometimes months—very low-dose antibiotics, always covered with an antifungal called nystatin—so they do not get overgrowth of candida in the gut—and a good probiotic. That process will go on for weeks or months, depending on the duration of time these people have been sick.

When you are treating these illnesses, you have to realise that they may well have multiple organisms and multiple symptoms, and none of it makes sense, so apart from antibiotic therapy you also have to manage their seizures. They often have an extreme case of what is called neuropathic pain—that is pain everywhere, with extreme headaches. They will have cognitive dysfunction. They will have twitches—fasciculations, which are big twitches in the body. They often do not sleep properly. They are totally dysfunctional and require full-time carers, so you basically institute a process of medication and manipulation to control the symptoms, plus carers and various people to support them. Then that process goes on for a period of time, and you try to work out exactly what illness they have. Often you will treat one component of the illness and they will get another component.

I do not know whether this is the time to talk about all the treatments, but there are many treatments out there—I will stop in a minute—and the most important part of treatment in these patients is follow-up—having a psychologist and other people working with their psychology. I also use exercise physiology, and I have hospital access to hydrotherapy for rehabilitation. This is over two to five years, so we are talking long-term treatment of these patients. We are not talking a few weeks or a few months; we are talking two to five years for the extremely ill patients, and probably nine to 15 months for a less ill patient.

Dr McManus: In terms of treatment, if we are looking at *Borrelia*, *Borrelia* replicates really slowly. If an average bacterium divides every half an hour, *Borrelia* will divide in 12 to 24 hours. Because antibiotic treatment needs to catch the bacteria dividing, a short-term treatment will not be adequate to actually decrease the bacterial load so that the immune system can take over defeating the infection.

In the USA there are two schools of thought. One school of thought treats for four to six weeks, and if you still have symptoms after that you have post-Lyme syndrome. Another school of thought treats for as long as it takes a patient to get better. Both of them have their pros and cons. One of them is that, with post-Lyme syndrome, the patient then never gets any other treatment. On the other side, the patient has prolonged antibiotic treatment and they can end up with adverse effects from the antibiotics. But the most important thing is that, because the patient has multiple infections, there is an immune dysregulation happening, and there is no monitoring of the immune system of the patient in a really detailed manner to see, at the beginning, what is wrong with the immune system if the patient has been chronically ill. You know that, when the patient's immune system recovers, the patient's symptoms go away, and that is when you stop the treatment. That aspect has not been introduced in the USA.

Also, in the USA, when they do test for Lyme disease, they only test for *Borrelia burgdorferi sensu stricto*. If the patient is negative for *Borrelia burgdorferi*, they do not ask if they could have relapsing fever. There is no routine test for it, because they are two different diseases seen as distinctively different, despite the fact that they are actually caused by the same genus and the symptoms are very similar. I have a handout. You can easily mistake relapsing fever for Lyme disease and Lyme disease for relapsing fever.

We need to be aware of all these things so that, when we are treating patients, we look at and individually address all those issues. As Richard talked about, Herxheimer's is really significant, because you cannot go and give a patient high doses of antibiotics, or even low doses, because the Herxheimer's can cause tissue damage and the patient can end up with massive disabilities. We do not want that. There is also the fact that, with a deficient immune system, you need to support the immune system and provide the complementary medication that the patient needs, because they will be deficient in some sort of mineral line—manganese or magnesium, for example. They will have cramps and things like that. So this is part of the treatment that needs to be addressed. So, in terms of looking at the Pharmaceutical Benefits Scheme supporting these patients, look at the whole aspect—not just supporting the antibiotics but also basically funding the complementary treatments so the immune system is supported and they can get better faster.

CHAIR: Thank you.

Ms Whiteman: I would like to say I agree with my colleagues to the left and will not repeat that. As a general rule, I am representing patients who are not getting treatment. The lucky patients are the ones that see doctors like Dr Schloeffel. Right now we have a shrinking number of doctors willing to receive referrals from us, and we have an increasing number of patients asking us for help to find a doctor to be diagnosed and be supported with treatment.

Right now in Australia we have patients at home. We have a family in this room who are offering ICU treatment to their daughter in their home because they are neglected and rejected in Australian hospitals. I did not

get treatment. I still do not have treatment. When I did finally figure out what was going on by a chance meeting with a US doctor, it took me three years to recover. Our survey shows that on average it takes 6½ years to diagnose this in Australia, and that is only on 386 people from our first survey. By that time you have entrenched disease and it is a very complex approach to treating, because by then the infections or the pathogens are everywhere in the body. I would say treatment is almost not available to patients relative to the numbers who are sick.

Dr Lum: In an effort to prevent tick bites and raise awareness about tick bite first aid, the department has been working with the National Arbovirus and Malaria Advisory Committee as well as states and territories on a tick bite prevention document for public distribution. It is hoped that this year's document will be out shortly. It is also hoped that in the future we will be able to incorporate emerging research into tick bite associated mammalian meat allergy and newer techniques for tick removal. The department acknowledges that care and treatment for patients is usually provided by general practitioners who are drawn to helping patients with chronic and complicated illnesses. The department has met with some of these practitioners at a separately conducted roundtable discussion with general practitioners and medical experts in microbiology, infectious diseases, neurology and psychiatry.

Long-term treatment with multiple antimicrobial agents is favoured by some practitioners and argued against by others, and it is difficult to draw conclusions on treatment while controversy remains around causation and a correct diagnosis. The department remains interested in ongoing discussion in this area given the department's active interest and role in antimicrobial stewardship and antimicrobial resistance and the problems that has for our society.

CHAIR: Thank you.

Prof. Irwin: As a veterinarian, I'd better not comment on the treatment of humans!

CHAIR: You can have a crack!

Dr Graves: Humans are just one type of animal!

The Royal College of Pathologists of Australasia deals with the diagnosis of infectious and other diseases in the laboratory, so we do not have a position on the treatment of Lyme disease.

Prof. Gilbert: It looks like it's up to me to talk about it! I think there are two different situations. One is the situation that everyone agrees on from endemic areas in North America, Europe and Central Asia: Lyme disease confirmed by the laboratory testing we have been talking about before has well-established treatment guidelines—which are disputed by some people, but nevertheless most of the professional bodies in those highly endemic areas have established treatment guidelines which involve short-term antibiotic therapy usually for two weeks initially for acute Lyme disease and in which the vast majority of patients diagnosed with Lyme disease will get better. A very small proportion go on to chronic symptoms, and sometimes that is actual neuroborreliosis, which can be diagnosed by examination of the cerebrospinal fluid. It is a rare but very well recognised complication. There is a recent case report in *The Medical Journal of Australia* in which a case was recognised and treated in Australia that had been acquired in Europe.

I think that is relatively uncontroversial. The major controversy is in the management of patients with chronic symptoms who have a wide variety of different symptoms. I am sure they are a very heterogeneous group, some of whom have completely different chronic neurological diseases and some of whom have what is well recognised as a chronic, symptomatic disease following infection which does not necessarily involve ongoing infectious disease but an ongoing immunological response to an acute infection. This has been recognised for many years as chronic fatigue syndrome, and I think there is little doubt that a significant proportion of patients who have serological evidence in some laboratories of some of these tick-borne diseases have a syndrome of this sort.

Ms HALL: Could I ask you to clarify that? You are saying a syndrome of chronic disease and not Lyme—not associated with ticks?

Prof. Gilbert: Some of them may be associated with tick-borne infections. As we have said, the diagnosis of Lyme disease specifically in patients who have not left Australia is highly controversial and difficult, but we are talking about various sorts of infections like viral infections. I first came across this 30 years ago in abattoir workers who had brucellosis and post-infectious syndromes after they had acquired brucellosis from cattle. So it is a very well recognised syndrome. My response to what Dr Schloeffel was talking about in terms of treatment is that the sort of supportive therapy that he is offering to his patients is extremely beneficial. There is no doubt that many of these patients have suffered for years from chronic symptoms, and often they are quite right in saying they have been rejected and largely dismissed by medical practitioners. The sort of caring attention and concern

that is provided by some doctors who care for patients like this is extremely beneficial. In the absence of some sort of randomised controlled trial, it is very difficult to be sure that antibiotic treatment has any significant additional benefit to all the other supportive therapy.

I think that is where the concern of infectious diseases physicians comes in. There is really little evidence that long-term antibiotic therapy has additional benefit in excess of the other supportive therapy that is being given. There have been some randomised controlled trials in the United States where patients with chronic symptoms or chronic Lyme disease show that long-term antibiotics are not beneficial. We probably need that sort of study to be done in Australia. The real problem is to have a consistent, clinical case definition that will allow us to have consistent criteria for admission to such a study so that we can really assess whether long-term antibiotic therapy has benefit. There is no doubt that long-term antibiotic therapy can have significant harm as well.

CHAIR: Thank you. Professor Stocks, do you have anything to add?

Prof. Stocks: Yes. I want to make a brief statement. There are approximately 30,000 GPs in Australia, many of whom, because of their geographical location or type of practice, will have limited or no experience of Lyme disease. However, most would have a range and a spectrum of patients with chronic fatigue syndrome, postviral illness or similar illnesses. Although there is evidence based antibiotic treatment for acute Lyme disease, there are currently no profession-wide accepted guidelines for the treatment of Lyme-like illness. The RACGP advocates for evidence based practice and, whatever success individual doctors have with their patients, we cannot support many of the treatments currently being used or advocated for those patients with chronic Lyme-like illness. For instance, we have to be concerned about antimicrobial resistance, as already mentioned, in conditions which may be related to the overuse of antibiotics. Although people are seemingly getting some benefit from this anecdotally, we also have to be aware that some patients will be having adverse effects because of long-term antibiotic use, as one example. It is a very difficult area. I think it can only be solved by some further research, as outlined by some of the people already.

CHAIR: Thank you. Ms Whiteman, because I am not going to be here for the third session, about Australians living with Lyme disease, I will just ask you. You have had Lyme disease and have had it treated?

Ms Whiteman: I had various doctors attempt to treat. My current doctor is sympathetic but feels undersupported and underskilled to treat. I have recovered, mostly using my own natural ways, to about 60 to 70 per cent of who I used to be. I cannot walk long. I have a document here, and you will see I cannot proofread or visually scan at all. One of my doctors told me that my brain scan was not the worst he had ever seen but it was right up there, and it was only my sheer intelligence that was keeping me going. But he still did not treat me. That is common. It is unfair for me to be representing my story when we have got thousands of people in that same situation.

I think the most impactful thing I have heard this year in this role is a quote from Dr Schloeffel with regard to emerging diseases. I spoke to Dr Daniel Cameron of the International Lyme and Associated Diseases Society in the US. He is one of the Lyme specialists treating, and they have just published treatment guidelines. He said that, in an emerging disease situation—this might sound harsh, but it is a bit shameful that in Australia it is an emerging disease, because it and different tick-borne pathogens have been identified since the fifties. Fast forward 65 years, and we are in an urgent situation. He says with regard to research progressing that you need to treat a patient with the best medical care of the day while aggressively progressing research. Evidence based is really important, but, in emerging disease, to mitigate public health liability, there needs to be some flexibility. I think that is the biggest message with regard to treatment.

Patient need treatment. Doctors need support. Because doctors treating Lyme patients are spiking outside of the stats about average treating GPs, they are getting identified. We are losing GPs, and patients are frightened. There is nothing worse than being able to offer supportive treatment and having somebody getting—I had a gentleman call me last night. He says he has never left the country. He has a cluster in his area in Victoria and said, 'My doctor now had just had limitations put on him to treat me.' He said: 'I'm going to fight for my life. I thought I was dead before I met him.' Unfortunately, that is not rare, and it is a tragedy.

CHAIR: Dr Schloeffel, how do your treatment times compare to overseas? Have you looked? Also, what about the treatment with an early diagnosis compared to a later diagnosis?

Dr Schloeffel: There are three levels of borreliosis and co-infection. If you get an acute tick bite and some sort of tick-borne illness—and often we do not know what it is—three weeks of doxycycline for an adult and amoxicillin for a child are normally what I do if you are sick after a tick bite. Remember: you do not have to get sick after a tick bite and a lot of people do not know they have had a tick bite, because the nature of a tick is it falls off and breeds. It does not want to get caught in your body. So not everyone knows they have had a bite.

That is fairly straightforward, but the people I see often have been on rotational antibiotics for 18 months or two years by the time they have got to me. They have come from other GPs or have had various doctors treating them on and off for a while. I definitely have been looking at a lot of the American work and I liaise with a fellow called Dr Richard Horowitz and also Dr Steven Harris. They are doctors in the field like I am. They are general physicians working with chronic Lyme patients or borreliosis patients—in America it is Lyme patients—and treating them, as I am, for periods of time. Sometimes it is three to six to nine months.

We are not necessarily talking about massive doses of extremely high antibiotics as some of these doctors do in America. I am horrified sometimes when I see the complexity and level of antibiotic treatment that I see in America. I use very simple triple therapies: doxycycline or another type of tetracycline. I use cephalosporins and I will use tinidazole or Flagyl/Facigyn-type antibiotics. They are my basic treatment if you have just got borreliosis. Then there are a whole lot of other things I will add in, but I will not have patients on all these things at once, and they are often only taken once or twice a week. It is not as if you are bombarding with a massive amount of antibiotics, because you will just make the patient worse.

But there are patients I have treated. The patient I treated longest—and this was back 15 years ago in combination with Bernie Hudson—was on something like 15 months of intravenous antibiotics. She was a young woman of 20 who picked up her Lyme disease in Central Park in New York. She was bedridden and seizuring, and now she is married, two children, never had a symptom once we finished her treatment. But we kept testing her at that stage, sending blood over to the states, and we kept finding the *Borrelia* on PCR months and months after she had been on long-term antibiotics. We kept rotating the antibiotics, and she got better.

The trouble is that no two patients with chronic Lyme disease, borreliosis or co-infection are the same. They are all different. They may not have *Borrelia*. They may have *Rickettsia* or one of these others. I think *Rickettsia* is very common in Australia as a cause of chronic fatigue and illness—much more common in my past life. It is just that I see a lot of *Borrelia* now because they are all referred to me. What I am saying is the treatment varies from patient to patient but is usually prolonged. Three to six months is common. Three years is uncommon, but I have seen patients who have treated that long and have fully recovered.

The other work I am doing is with a group in Germany doing hyperthermia treatment.

Hyperthermia is controversial. This is where you heat the body for nine hours to 41.7 degrees in an intensive care unit run by professors of oncology, and they noted—this is a group of doctors in Germany called Bad Aibling St Georg Klinik—they give high-dose antibiotics while someone is under an extreme hyperthermia intensive care situation, and in that case that treatment seems to be very effective against *Borrelia*. Some people have two weeks treatment of this; they have a couple of sessions in two weeks. They come back from Germany. Over 1,000 Australians have travelled to Germany to this clinic, so this is not something that is a nonsense. Patients are going there every week from Australia. We are the biggest supplier of Lyme borreliosis patients going to Germany to have these treatments—and now Malaysia. So it is not as if this is not happening, and those patients, if they only have *Borrelia* and they are not that sick, I believe have been cured by that treatment, and they come back and come off all their other antibiotics. They have supplements. I do the rehab stuff that I normally do, and those patients seem to be recovering. If they just have *Borrelia*, the Australian patients will take the long-term antibiotics. All I am saying is that there are other novel treatments we need to look at, but we have not even got to the diagnostic stage, let alone the treatment phase. I did write the protocol for the Germans whilst I was there to look at trying to treat co-infections at the same time, but I do not know whether that is going to work. Okay?

CHAIR: Okay. It sounds like a *60 Minutes* show.

Dr Schloeffel: Yes, it does.

Ms HALL: There was some mention of the cost of treatment. I would like to draw that out a little bit more. Also, linking to the cost of treatment, there was a comment about limitations placed on doctors and the cost relating to Medicare and what you can claim.

Dr Schloeffel: Are you happy if I talk about this, because I get this all the time? The doctors ring me. I am in a group called ACIDS, Australian chronic infectious diseases doctors. We specialise, and this was set up because we have this evolving illness. There are three costs the patients incur. The first is obvious: they lose their employment; they cannot work; they are sick. That is one cost, but the other cost is the medical expenses. They often see multiple specialists and have multiple tests. Fortunately, some of those will be covered on the Medicare,, and, because there is a safety net, generally, eventually those tests are covered. But once they get to someone like me, where they need to have overseas testing, you are talking $1,200 to $2,000 to do an IGeneX

blood test. That is just absurd, but that is what it costs. These people are desperate to have some diagnostic criteria to tell them what is wrong with them.

Then, if they are diagnosed, they have got antibiotics. If they are on long-term antibiotics or a lot of these medications, they are off-label. Therefore they have to pay for them. They are not covered. As a doctor, you cannot write a script and put it under health cover, because they are not designated illnesses, so a lot of those patients will be paying that.

Ms HALL: Can I just interrupt there. What would be the average weekly cost or monthly cost of a person who is receiving the—

Dr Schloeffel: Each patient is having supplements as well. Maybe—I do not know—$600 a month for a minor treatment, and some patients spend a lot more than that—probably $2,000 or $3,000 a month.

Unidentified speaker: A lot more—$40,000 to $60,000 a year.

Dr Schloeffel: It is $40,000 to $60,000 a year. That is $5,000 a month. I do not know much about the costs in respect of what the patient pays outside of my clinic, but if they are buying lots of supplements, they are having intravenous therapy treatments and they are paying for nurses at home—a lot of these patients are treated not by me at the coalface but by nurses at home, by other GPs and other nurses, and this is happening. I have at least 100 patients I do not see. Their GPs ring me. They are managed in GP practices and they are managed by nurses if they are too sick at home. Some of them have central lines, and they are being managed by their local doctors. This is a hidden thing, and if we do not get it out here—I had a patient who had a PICC line or central line put in the other day, and it was $2,000. That is just to put the central line in because she does not have any more veins. That is an enormous cost to people. This is a mother and daughter, desperate to get the daughter better. She has been sick since she was nine and they are on pensions. As I said, one patient came in and told me they had spent a million dollars so far before they had seen me on diagnosis and treatment.

Ms HALL: I just wanted to get an idea of the average monthly costs.

Dr Schloeffel: Probably between $20,000 and $50,000 a year per patient.

Ms HALL: The other question is based on the limitations placed on treating GPs. That was stated by somebody a moment ago.

Dr Schloeffel: This is a moral decision. Most GPs are constantly fearful that someone is going to dob them in when they are treating someone. The patient and the doctor have a therapeutic relationship, the patient is getting better, but then someone comes along and dobs them in for whatever reason and then that GP gets fearful. They do not necessarily get deregistered; they get restrictions put on them.

Ms HALL: Overservicing—that is what you are talking about?

Dr Schloeffel: No, not necessarily overservicing but using off-label treatments. If there is any risk of that, I do pro bono; I do not charge the patient at all. I will do it for free to save any hassle. This is never about the money; it is about treating people who are chronically ill and, if you do not treat them adequately, some will be disabled for their whole life at enormous cost to the community and some will die. Some of these people are kids. We have 1,000 children in my practice with autism spectrum disorder. I am doing tests with my colleague who is a paediatrician and some of the research coming out of the states shows that 40 per cent of children with autism have borreliosis or co-infections. That may be the case if translated here. Autism used to be an uncommon disease; now it is one in 100 in Australia. In America it is one in 50; it used to be three in 1,000. So, what is happening to our children? I asked the paediatrician to do IGeneX tests and, low and behold, what did we find? These kids come up positive for *Borrelia*. We treat them, and I guide him in treating under five-year-olds and they get better and they stop being autistic. I have not even started on all the complexity, but the work is already being done. We are already doing it; we are just doing it quietly. I am just making a noise here.

Ms HALL: Thanks.

Dr Graves: From the laboratory perspective, there is a financial consideration and that is that most of the Australian laboratories that are accredited are able to benefit from the Medicare Benefits Schedule, so they bulk-bill. For 99 per cent of the samples that come to my laboratory—the Australian Rickettsial Reference Laboratory—we bulk-bill.

Dr Schloeffel: I bulk-bill my pathology—always.

Dr Graves: That limits the amount left over because, as you probably know, sometimes it does not even cover the cost of doing the test. It does not give you the ability to do extra tests, because that is not permitted. Let's say Dr X sends me a sample to test for Lyme disease. I would like to test for the other transmittable pathogens, but I cannot do that because, firstly, it is not permitted, because he has not requested it, and, secondly, it would cost a

lot of money to do all of those additional tests and there would be no reimbursement for them. That is the other aspect. We could get a lot more data from the diagnostic laboratories in Australia if there were some mechanism by which they could access a fund for research into transmitted diseases, or something like that.

Dr Schloeffel: A tick-borne panel.

Dr Graves: Tick-borne panel like the ones I mentioned before, like for *Babesia*, *Bartonella* and things like that. But this will blow out the costs of the laboratory testing and I would imagine that the health department and the health minister would not like that.

Ms HALL: Maybe you could cut costs in other areas.

Ms Whiteman: We recognise the cost to the government of potentially increasing costs. Having said that, the burden of disease on Australia is significant. Almost 50 per cent of patients in our first very tiny survey—we need more help—had to leave their jobs. I have spent my whole superannuation. We are self-funded. We would have been set. Lyme disease devastates families on every level. GPs need to be educated about inquiring and they need to be trained in how to feel safe and comfortable with treating. It is an urgent situation.

Ms HALL: You are making a good point. It is not only the initial health costs or the costs associated with providing the medication or the costs associated with the tests; it is all the other flow-on costs that have an impact on the bottom line of the budget.

Ms Whiteman: Absolutely, and the bigger point is that no matter what we call this, whatever they are infected with, with proper treatment they return to their lives. That is the most important thing. A large percentage of people that get treatment can return back to their livelihood. I started volunteering three years ago, because I decided there was no point in looking at what I had lost, I could do what I could with what I had regained. So many people get back into the community with some level of treatment.

Ms Kiefer: I wanted to ask a very naive question. Why are we calling it Lyme disease, which is the American thing? Why are we not just calling it a tick-borne virus or illness in Australia?

Dr Schloeffel: It should never be called Lyme disease. It is borreliosis and co-infections, always. Tick-borne diseases; it is not Lyme disease unless you get it in America.

Ms HALL: I have a question for Dr Lum. Is there any reason that the Department of Health has not looked at considering tick-borne disease as an emerging disease, which could have flow-on effects for where we go with this particular disease?

Dr Lum: Thanks for that question. The Department of Health—particularly through the division known as the Office of Health Protection—looks at emerging infectious diseases and other emerging communicable diseases, should they be a major problem for the Australia people. For tick-borne infections—and it is not just limited to ticks but other arthropod-borne infections—we have a subcommittee under the Communicable Diseases Network Australia, known as the National Arbovirus and Malaria Advisory Committee. While that name tends to focus on malaria, which is a mosquito-borne infection, there are a number of entomologists on that committee who are looking at ticks and other potential vectors and looking at infections that are relevant to Australia.

In terms of Lyme disease itself, the New South Wales Chief Health Officer, in 2013, requested that the Communicable Diseases Network Australia look at Lyme disease as being potentially added to the list of nationally notifiable diseases. An assessment was undertaken, and it was not successful in terms of being listed. The main reasons are that getting a good case definition for the symptoms that were being described was not possible, there was no consensus or agreement; and that, certainly, without evidence of a causative organism or a vector in Australia for Lyme disease—that is, classical Lyme disease—it was not possible. What, probably, needs to happen is for somebody to consider a case definition for these chronic debilitating symptoms, to put that together and look at surveillance for that. That assessment committee did suggest that it would be possible for states and territories, through their public health units and their public health laboratories, to do some case analysis. But, again, for something to be added to the national notifiable diseases list, there needs to be state and territory agreement on it, and then it gets added by the Minister for Health.

Ms HALL: That goes back to Mr Jones's point earlier about the committee that was looking at this being dissolved?

Dr Lum: No. That committee did not have anything to do with it.

Mr STEPHEN JONES: Dr Schloeffel, what proportion of the healthcare costs that you estimated—I think you were talking about acute—in the range of $20,000 to $50,000—

Dr Schloeffel: I am talking about chronic; these are chronically ill patients.

Mr STEPHEN JONES: What proportion of those costs are borne by the health system as opposed to the individual?

Dr Schloeffel: I think very little. I think it is borne by the patient. You have to be very careful. If someone comes in for a medical consultation with me, that is probably the least costly thing. That is covered under Medicare, to a certain extent. Some patients are bulk-billed and some patients are charged, and it is relative to their capacity to pay. I can tell you that, if you have a lot of pensioners, there is not a great deal of capacity to pay. So I prefer to go to the treatment. But, when you get to treatment options, the treatment options become very limited if you do not have any income, wealth or support. Some of the patients I am treating are in nursing homes and they are in their 30s. I go to their nursing homes and I have the nurses in the nursing homes treating them with intravenous antibiotics because they cannot swallow anymore. These people are really sick, and they often have families and whatever. They just live off a pension.

I have a number of patients who do fundraising. They give me a certain amount of money which goes into a fund and I use that fund to treat the pro bono patients. That is the bottom end of the food chain. It is donations from carers, families and fundraisers who raise money for the patients who cannot afford it. For the ones who can afford it, it is an enormous impost, if they have the full treatment and do everything. Often that includes overseas treatment. If you go to Germany you are talking about $30,000 to $50,000 for two weeks of treatment for two people, because they will always treat the partner as well as the patient—or if they go to America. It is an open-ended question, because there is an open-ended amount of money that needs to be spent.

Mr STEPHEN JONES: I understand. You answered the question at the outset. My second question is: what legal obstacles exist to the adoption or the use of the type of treatment regime you believe to be best practice?

Dr Schloeffel: I am part of the tick-borne diseases unit at Sydney uni as well, so I also have a research hat. One of the things I would really like to see is a PhD researcher in my unit looking at what we are doing, having fresh eyes, because it is very hard when you are at the coalface doing this work, watching people, monitoring them and getting them better. I was talking to Lyn earlier about how important it is to get evidence-based science into this realm. I think I am getting the patients better.

Mr STEPHEN JONES: So, your capacity to utilise the treatment regimens that you are utilising is because at the time you are doing that you are putting your research hat on?

Dr Schloeffel: No, I am not putting my research hat on at all; I am treating these people. But I think it needs to be researched. I am actually putting in my skill from 20 years of treating this, and some of the protocols coming from other doctors all around the world, which is not best practice in Australia—because there is not a best practice. There is not even the diagnosis here in Australia. How can you have a best practice when you do not have a diagnosis? I have the diagnosis, and my colleagues do. I will go to meetings and there will be 50 doctors there, and they are all GPs—maybe one infectious diseases specialist—and we talk the same language; we have specialists from overseas who talk the same language. But the 30,000 other GPs out there are not aware of this. I do teach at Medicare Locals, and I give lectures to groups in which there are often many doctors, and many doctors follow my advice and they are assisting in treating patients. But as to developing the treatment, no, I make the decisions, because most doctors do not have that skill to know what is safe to do and what is legal to do. There is a legality in this. You have to be—

Mr STEPHEN JONES: To be very, very blunt: I am interested in whether there is a risk of or whether people are using off-label treatments in the treatment regimen.

Dr Schloeffel: I will correct that—

Mr STEPHEN JONES: Do you believe that is occurring?

Dr Schloeffel: No. There is not a paradigm that is saying, 'That is labelled.' I say off-label, but I will not prescribe an antibiotic to someone such that you have to get an authority or an SP that is for something else and you give it for this. You cannot do that. When I say off-label I do not mean that the treatment is off-label, but the medication is prescribed for that illness, and if they do not have that illness then you do not write a script and put the number on it and falsely say that that person has that illness so that the patient gets the medication cheaper. That is what I am talking about. The treatments I use are used around the world by lots of Lyme disease doctors. So, if I go to a conference on chronic fatigue and borreliosis where there are 500 doctors, we all sit there for three days and talk the same language. We are all talking. And there will be speaker after speaker after speaker, all physicians and professors of medicine in other countries, doing what I am doing. It is just that I and a few others are the only people here in Australia doing that, because we have not recognised this emerging illness. We have not even got to first base of getting a pathology consensus, let alone making a diagnostic consensus.

Mr STEPHEN JONES: I understand that, and that in part probably answers the question I had as a follow-up from Professor Gilbert, which is: what steps would need to be put in place to get the sorts of clinical trials around treatment regimens to get a greater consensus on what needs to be put into place for people at the chronic phase?

Dr Schloeffel: I think we need to get the pathology clear first. If the pathology is clear then the treatment may become clearer. But then you have to monitor and follow the patients, and it is difficult.

Mr STEPHEN JONES: I understand. It is a chicken-and-egg thing.

Dr Graves: Perhaps I could add a comment to that. It is very likely that the patients we are talking about are a very heterogeneous group, and they may have different aetiologies. That in itself is going to make it very difficult to do a study of a treatment. What are you going to use as your control group to see whether it is working? And then the other big elephant in the room that no-one has mentioned but that is very, very important in medicine is the placebo effect. If your patients think you are giving them something that is going to help them, 20 to 30 per cent of them will get better anyway. That is why you need proper trials in which people who are the research arm or the experimental arm, as opposed to the control arm, do not know what they are getting.

Mr STEPHEN JONES: I understand that, but surely these are the issues that would have been dealt with in the clinical trials in the US that Professor Gilbert alluded to?

Dr Graves: Absolutely.

Mr STEPHEN JONES: I am sure they are not inventing their own methodologies. They would have all been dealt with in another jurisdiction.

Dr Graves: But that has not been done here.

Mr STEPHEN JONES: And that goes to my question: what are the obstacles to our doing those sorts of trials here around treatment regimens?

Prof. Gilbert: I think the obstacles are first of all a case definition, which probably includes laboratory testing and some sort of criteria but at least, even in the absence of positive laboratory testing or a variety of different things, some sort of clinical case definition. If you are going to do a randomised, controlled trial then you have a control group that gets placebo, not nothing. You have some sort of tablet that looks exactly the same as the antibiotics, as well as all the supportive care that Dr Schloeffel has described. With antibiotics and supplements and the things that are costing money we really do not have proof of exactly the contribution they make to the patient's recovery or, for that matter, how many of the patients who do not recover are suffering from the effects of antibiotics.

Mr STEPHEN JONES: Who is the authoritative body for providing or producing a case definition? Is that one jurisdiction? Does it have to be all jurisdictions? Is it a professional body? Who is the authoritative body that says, 'This is the case definition'?

Prof. Gilbert: I do not think there is an authoritative body for this, because it is such a heterogeneous group of patients, and this is the problem. There is disagreement between the doctors who treat these patients and others who see them as very heterogeneous, and I think that is a real problem. But Richard may have a comment on that.

Dr Schloeffel: I do. If you get someone presenting with a chronically fatiguing, possibly chronic infection disorder, you have to sort them out, because they have multiple causes and multiple symptoms. I am now working on genetic risk. I am looking at why families are full of these illnesses. I am also looking at some of the treatable things that are not due to infections. A majority of my patients would not end up on antibiotics as a first-line treatment. That is never what I do. It is about treating the symptoms and then trying to understand the cause and then treating the cause. And you have to do no harm. You have to keep that in your head all the time when you are treating these patients, because they are already damaged. So I think in trying to get a case definition we need to look at this as a multisystem, multicause disorder where some have infection and some may have borreliosis or other tick-borne illnesses. That is the definition of what we are dealing with here.

Mr STEPHEN JONES: Why are they able to come up with a case definition in the United States or in Europe and we are not able to do it here?

Dr Schloeffel: There are two camps in America. In America 30,000 people a month are diagnosed with borreliosis and co-infections, according to the CDC.

Mr STEPHEN JONES: I do not think that our problems are novel here.

Dr Schloeffel: No, but the illness that we have here—

Mr STEPHEN JONES: They might be different, but I do not think they are novel.

Dr Schloeffel: But we have two groups of patients. We have one group who have stepped off at the airport in Sydney. They were overseas and got a tick bite in Yellowstone National Park and are sick—

Mr STEPHEN JONES: Presumably we have an agreed case definition for that group.

Dr Schloeffel: We do—

Mr STEPHEN JONES: Put them aside.

Dr Schloeffel: But then we get to the patients who have never left Australia. I have plenty of patients who have full diagnostic criteria with Australian labs and overseas labs and never, ever left Australia and have a recognised tick bite and they became ill on that day and they have remained ill and I have treated them and they got better. They are the patients I would use as a representative group of what the case definition is. But the problem is that you are dealing with—you are right—a heterogeneous group of patients. They are all lumped in together as chronic fatigue syndrome or chronic seronegative arthritis or chronic neurological, atypical MS or atypical motor neuron disease, and they all have the same disease. It is just that, wherever the organism is, it causes the damage in that area. These patients all overlap with every specialty. There is no clear way of putting them into one group and saying: 'Let's treat these patients all the same. Don't treat those ones, and compare them.'

The way I would do this is I would go backwards; I would do retrospective studies. One of the things I do when I am treating people is take a questionnaire—150 questions—and then I analyse those questions and come up with a diagnostic thought process and do appropriate tests and treatments to treat the symptoms, to treat the cause. Then I watch their symptoms reduce. That process is what is called being a good physician or a good clinician, and we need to bring those skills back into the treatment of this disorder. We need to give those guidelines, not necessarily exact guidelines of, 'You do this, this and this, and that leads to that outcome,' because it is not going to work for this illness. This is the most complex, difficult illness that I have ever dealt with, in 40 years of practice.

Ms HALL: Can I just add to what Mr Jones was saying. We cannot do the proper tests, because they are not listed to be done—

Prof. Gilbert: No, it is not because they are not listed.

Ms HALL: You are only allowed to do approved tests; that is what Dr Graves said.

Dr Schloeffel: They will often be negative anyway, because the immune response is not there.

Ms HALL: Dr Graves said that they can only test for approved tests.

Dr Graves: No, I said we can only test for what is asked for by the referring doctor.

Ms HALL: You said if you could do more tests, then—

Dr Graves: Yes, that is right.

Prof. Gilbert: But we do not know that there would be more positive diagnoses.

Ms HALL: Can I just finish asking the question.

Dr Schloeffel: I think we are doing the wrong tests in Australia, to be honest. Even when you order everything, *Rickettsia* comes back all the time—thank you, Stephen; you do pick up *Rickettsia.* In all the patients I think have *Rickettsia*, your lab has picked them up on most occasions, and I agree with you. I do not see that for *Bartonella* or *Babesia*, but I will get three labs overseas picking it up. So what is going on with our labs here, compared to overseas? The labs in America and Germany are DAkkS and American Pathologists approved—they are the same as NATA; they have got full approval. They are not money-making labs; they are labs trying to get a diagnostic criteria to diagnose these people. Why do they get positive results and we do not? I think we should be bringing those labs or their skills here, under Australian pathologists.

Dr Graves: This study that the Department of Health is initiating, and the comparison, will, hopefully, help there.

Dr Schloeffel: I am really hoping Gary can—

Dr Graves: You are working on the assumption that they are right and the Australian labs are wrong.

Dr Schloeffel: I am definitely not working on that assumption either.

Dr Graves: It could be the other way around!

Dr Schloeffel: The trouble is that their lab results correlate with what I see. That guides me in the treatment process, and the treatment process leads to the patient getting better. Ultimately, this is about recovery of patients.

Mr WYATT: Dr Lum, you gave an answer to Ms Hall in which you said that case analysis needs to be done. You indicated that public health resides within the different jurisdictions. Both you and I know the Australian

Health Ministers' Advisory Council processes and the Australian Health Ministers' Conference processes. Nothing ever gets up to those for national approaches on issues unless a jurisdiction or the Commonwealth leads the work in regard to that. Why hasn't the Commonwealth done that, given that you have had probably three pieces of work done? In the comment of the spokesperson from the department, there are six dot points. Why hasn't the Commonwealth taken the lead role in having this looked at on a case analysis basis?

Dr Lum: I think the department has taken a lead on—

Mr WYATT: If you have taken that lead, have you taken it to either AHMAC or AHMC?

Dr Lum: Not yet. The discussion so far has only reached the level of a principal committee. So it has gone to discussion at the Australian Health Protection Principal Committee. But any discussion around Lyme disease, Lyme-disease-like syndrome and chronic debilitating symptoms has not gone past the Australian Health Protection Principal Committee.

Mr WYATT: Both you and I know that if you take them to the subcommittees of AHMAC or AHMC they can sit there for 12 months plus or they can be set aside for further work to be done. In the meantime, we have Australians suffering from something that is impacting adversely on their health. Why aren't we expediting this?

Dr Lum: The department is working with states and territories on this.

Mr WYATT: I am sorry, but that is a standard public service response. Why aren't we doing something for Australians suffering these symptoms?

Dr Lum: We are. We have undertaken a contract with the National Serology Reference Laboratory to look at the diagnostics. In terms of treatment, as I said, it is very controversial and we cannot do it alone as government. This is something that needs the efforts and work of various professional bodies. We have heard from Dr Schloeffel about how his group, the Australian Chronic Infectious Disease Society, is looking at this. We also note that the Australasian Society for Infectious Diseases looks at these things in conjunction with the Communicable Diseases Network Australia. These efforts continue, but, in terms of how quickly they continue, it is taken into consideration in terms of other health priorities.

Mr WYATT: Let me go back to the HIV example. When it was decided that was a major issue, the Commonwealth Department of Health expedited, at a very rapid rate, work on this and, in conjunction with states and territories, escalated the actions in terms of treating people. Why aren't we doing that with this one?

Prof. Gilbert: I do not want to interrupt, Gary, but this is—

Dr Lum: This is not the same thing.

Prof. Gilbert: It is a very different circumstance.

Mr WYATT: I know it is not the same thing. I am talking about the process and the principle, because I have constituents who I have seen become so ill that they do not get out of their beds. They have been vibrant young people and yet their GPs are being ostracised for diagnosing Lyme disease. We have a system in this country that is supposed to be focused on the health and wellbeing of Australians. Why are we putting in place roadblocks that are prolonging the period in which they cannot access treatments?

Prof. Gilbert: Can I just answer your point about HIV. HIV infection—

Mr WYATT: No, I am not worried about HIV infection; I am talking about a process associated with it. I worked in health at the time when that all occurred and I worked with the relevant committees. I know how we expedited it. I do not want to go back to that; I used that as an example of the systemic response that included the total health profession in dealing with an issue. Why can't we do the same here?

Prof. Gilbert: Because it is not a single issue. HIV was a single issue, which was well recognised and easy to diagnose. Australia was amongst the leading countries in the world—

Mr WYATT: With all due respect, I accept what you are going to say in terms of HIV-AIDS—

Prof. Gilbert: But that is not the case with this syndrome that we are talking about.

Mr WYATT: No, why aren't we doing work around the diagnosis of the pathogens or the issues that result in what is deemed Lyme disease?

Dr Lum: We are doing that, but it does take time and there is still controversy over the aetiological agents.

Prof. Gilbert: Exactly.

Dr Lum: There is no defined cause for the chronic debilitating symptoms that are affecting these Australians. Not only does the research need to span looking for causative organisms in potential vectors; it also needs to be done in these patients. That is why the department continues to encourage general practitioners who are working

with these patients to work with GPs in medical schools so that that research can be done. That research is not something that the Department of Health or other departments of health from states and territories can actually undertake. It is a coalface issue with these patients.

Mr WYATT: I accept that. You did talk about case analysis needing to be done. Somebody has to lead that. Why isn't the Commonwealth Department of Health leading it in a way that is going to get us the results?

Dr Lum: The information about those patients, as Dr Schloeffel has mentioned, is extraordinarily complex. The department is not a department that will examine patient records and look at patients, and so we need to—

Mr WYATT: Sorry, I have alluded to the fact that you and I have both worked in systems where we know the processes. The Commonwealth agency is not a front-line service.

Dr Lum: Correct.

Mr WYATT: But it is a driver, through both its resources and its national role, in guiding efforts to deal with an issue, and I think that is important.

Dr Lum: I believe that, on taking this on in 2013, the Chief Medical Officer of Australia did take a lead when states and territories were asking him to undertake national coordination, and that is what we have been doing.

Mr WYATT: I shall look forward to the results.

Dr Lum: Can I just say before you go—

Ms HALL: He will read the *Hansard*.

Mr WYATT: I will read the *Hansard*; do not worry.

ACTING CHAIR (Mr Watts): I understand that we have strong feelings, but Ms Kiefer has been trying to get the call for some time.

Ms Kiefer: Another naive question: how many committees does this have to go to before a decision is made? I just feel we have too many committees to—I know we need research but how many—

Dr Schloeffel: Can I make one statement to solve this problem straightaway, please?

ACTING CHAIR: Yes.

Dr Schloeffel: Two sentences—the first thing: every patient who has this condition is notified immediately. So if the call went out to GPs to notify somebody—it does not have to be a notifiable illness but, if you have got a complex patient with a chronic fatigue-like illness, why haven't we got a register of those? Then we would get an idea of numbers and have a cohort of patients with totally different sorts of symptoms and diseases. The Department of Health and our esteemed pathologists can look at those patients maybe in a pattern, so we would have a patient group that we can study. We might find we have got 10,000 patients but, according to my colleague Andrew Lloyd, he says there are 180,000 people in Australia at least with chronic fatigue syndrome. But we do not know that because it is notifiable—just make it notifiable and suddenly you would know what you are dealing with?

Ms HALL: Is that a recommendation to the committee?

Dr Schloeffel: That is what I am recommending to the committee; I think I have recommended it many times.

ACTING CHAIR: We are going to finish this session at 11.30 so, before we finish up, I might give Dr Lum a chance to respond to Dr Schloeffel and Ms Kiefer.

Dr Lum: In terms of the proposal?

ACTING CHAIR: Yes.

Mr STEPHEN JONES: It might also help if you could explain why there are layers of considerations of these things.

Dr Lum: Firstly the question from Ms Kiefer about numbers of committees: it is not so much a matter of committees. We really do need to have a definition of what we are talking about. I think we have spent many hours this morning discussing a group of chronic debilitating symptoms that patients in Australia are experiencing. There is no clear-cut etiology: it could be one pathogen; it might be multiple pathogens—we have not even considered environmental toxins at this stage. Without a consideration of defined etiology so that a case definition can accurately be developed, it is very difficult. It will not require committees to agree in terms of that; it requires that grassroots research to be done and for that work to be put together so that that can be considered.

In terms of whether general practitioners can notify themselves onto a range of registers, that is generally not something that I can specifically answer. I can take a question on notice and get back to the committee and try to source an area within the department that can provide a response to that.

ACTING CHAIR: We are running substantially behind time, so we might finish this session before we move to session 3, Australians living with Lyme disease I thank you all for coming today to assist the committee. If you have been asked to provide additional information or if you have offered to provide additional information, could you please forward it to the secretariat by 5 October. If the committee has any further questions, they will send you these in writing through the secretariat. Thank you all for coming this morning.

KELLY, Ms Elaine, Private capacity

PATSAN, Ms Alex, Private capacity

REES, Ms Lynn, Private capacity

STEVENS, Ms Gabrielle, Private capacity

WALKER, Mr Christopher, Private capacity

WHEELER, Ms Michelle, Private capacity

[11:36]

ACTING CHAIR: Thank you for taking the time to appear before the committee today to give evidence. I will just ask you collectively: do you, as witnesses appearing before the committee, have any objection to being recorded by the media during participation in this hearing? No? Okay. Let's start with a two-minute explanation of your story and why you are here and then we will come back to some of the general themes in a broad Q&A.

Mrs Wheeler: I have a chronic illness. My chronic illness is *Borrelia* or Lyme disease. I also have multiple coinfections. I am a wife and a mother of four children. Because of my illness I can no longer work or help run our family business. I can no longer drive. I do not have the ability to function and care for my family as a mother and wife. I am housebound, and most days I am bedridden or lounge ridden. I cannot walk without aid, and any outings require my wheelchair. My family are now my carers. Chronic illness has stripped my family and me of everything we once knew as normal. I now have no life; I just exist.

Today I would like to take this opportunity to tell you how it has impacted on my family. My two school-age children—Max, 11, and Ruby, 14—share the carer's role with their father. A typical day for them starts with helping to get me out of bed, assisting me to walk, helping me to get dressed, getting my breakfast, making sure I have my medications and then trying to get themselves ready for school. Their afternoons are consumed with the same: helping to care for me and doing household chores that normally would be done for pocket money. But for my children it is a necessity to help in order to keep our household functioning. They then have to fit in their homework, sports training and other commitments.

My children are not the children they once were. The effect of having a mother so ill, who is in pain each day, and having to care for her has created constant worry and stress. It upsets them deeply. They feel guilty when they leave for school or go out for the day, knowing that I am at home alone. It is a torment of emotions for my children. My adult children have made sacrifices to help with the care and also the care of their siblings. They have now become their siblings' substitute parents—taking them to and from school, helping me out with looking after them, taking them to appointments and so on.

On many occasions my adult children have had to take time off work, swap RDOs, or take annual leave to help get me to appointments. They have also rearranged their rosters to help get their siblings to and from school. My main carer is my husband. He is the rock for my family and me. Without him I cannot even imagine where I would be. The demands on him as a husband, father, carer and breadwinner, along with running our small business are overwhelming to say the least. A typical day for him starts at 5 am. He prepares my daily meds. I am currently on 40 tablets over the course of the day. He then—sorry—has the chores of packing lunches, doing the laundry and so on. His work day is not only based on the job that day—sorry, I am getting all emotional—but also the job of making or confirming appointments for me. His carer role does not stay at home when he leaves for work. After a hard day labouring, his carer duties take over with preparing IVs, doing dressings, getting prescriptions, organising medical supplies that we need—then helping the kids with their homework.

Adding to all this is the huge financial burden that my chronic illness has placed on our family. On average it costs around $5,000 a month. There is no help until you reach the PBS and Medicare threshold, and, once this is reached, it helps, but not a lot. There are the extra costs of a hire driver to take me to treatment twice a week, a cleaner to help out with the house, and other costs such as scans, X-rays and blood tests that are not covered by Medicare. There are some medications that are not on the PBS list.

My chronic illness has eaten away our life savings and we are now having to sell our assets to help pay for the ongoing medical expenses. There is no help or assistance for an illness that does not exist. It is a hard, tough role—a coaster ride of stress, anger, sadness and guilt, and sometimes depression for my family who have to deal with my chronic illness. These emotional elements could be partially eliminated if we had access to proper medical care, and some respite and financial assistance. It is my hope that one day, regardless of my diagnosis, the government and the Australian medical profession will indiscriminately provide support and treatment for all Australians suffering from any illness—recognised or not. Thank you.

ACTING CHAIR: I am really loathe to cut people off when they are telling their personal stories, but I think we will have to issue the two-minute guideline. Ms Rees.

Ms Rees: I timed my speech at 6½ minutes and I have tried to cut it down. I am a New South Wales public servant; employed as a ranger with the National Parks and Wildlife Service. I am here in a personal capacity and do not represent my employer. Over my 21-year career in national parks, I have received in excess of 500 tick bites; sometimes 30 to 50 at a time. In 2007, I suddenly became ill and over the next four years received numerous diagnoses for my deteriorating state of health. These diagnoses included, but were not limited to, chronic fatigue, systemic lupus erythematosus, post-traumatic stress disorder, anxiety, depression and perimenopause. I also had frequent bouts of pneumonia, bronchitis, severe asthma and increasing tremors and cognitive impairment. My health continued to deteriorate with strange and bizarre symptoms. I felt that I was slowly dying, so I tried in earnest to fulfil some of the things on my long bucket list with my family before I became to disabled to do them.

My GP at the time advised me to double my happy pills; however, I had stopped taking them as they were not helping. I realised at this point that I had been labelled with a psychosomatic disorder, so I stopped telling my doctor of my increasing symptoms and berated myself for being a neurotic hypochondriac and to get on with life; though, I still continued to deteriorate. Unfortunately, for many Lyme disease sufferers in Australia this is a common theme when doctors cannot find a suitable diagnosis—we are written off as nutters and our complaints are dismissed.

In late 2011 I was discussing my deteriorating health with another National Parks employee, Natalie Young, who had contracted Lyme disease in 2002 but was not diagnosed until 2009. She said that it sounded like I had Lyme disease. At her urging, I visited a Lyme-literate GP with copies of blood tests and medical history over the past four years, together with a high degree of denial and cynicism. After a three-hour consultation I was given a clinical diagnosis of Lyme disease and other tick-borne related diseases. This was the start of a whole new nightmare, as I knew Lyme disease was not recognised in Australia. My blood was then sent to both Australian and USA laboratories for testing. As predicted, my Australian tests came back negative. However, Brucellosis or Brucella was detected.

When my results came back from the USA, it was a shock to be told I had tested positive to *Borrelia*, *Babesia* and two types of *Rickettsia*. That makes five tick-borne infections, most of which are known as common co-infections with Lyme *Borreliosis*. Just one of these diseases, if left untreated or misdiagnosed, can severely disable or kill.

In National Parks there are six staff covered by workers compensation for Lyme *Borreliosis* and associated tick borne diseases, Natalie Young being the first National Parks staff to be diagnosed as positive to *Borrelia* in Australia, Germany and the USA. She travelled to the USA in 2009 to get appropriate treatment, though by this time she was so debilitated by her disease complex that she was told she was unlikely to ever recover fully. She is in fact so ill that she was medically retired from National Parks in 2014. Natalie was only 38. Natalie had to fight hard to be covered by workers compensation and recently won her appeal in the New South Wales Workers Compensation Commission. This long fight for justice came close to destroying her life completely. Natalie's fight with the system paved the way for those of us who followed.

I am one of the few lucky ones with Lyme *Borreliosis* as my treatment costs are covered by workers compensation. That means I can get the Rolls Royce treatment, unlike a lot of people, simply because of the cost. My costs, after nearly four years, are nearing $80,000. The majority of Australians with a Lyme *Borreliosis* diagnosis continue to face discrimination, ridicule and denial. They lose not only their health; they have crippling medical bills and often cannot work or have reduced capacity to work, and families are torn apart.

Last week I was advised by my work health and safety manager that the six cases of Lyme disease in my organisation have so far cost us $1.3 million, and it is rising as we are all chronically ill. This is a staggering amount of money. The cost of six to eight weeks of antibiotics for this disease is approximately $200. If treated early, people recover quickly and fully. My employer not only accepts our diagnoses; it has taken a proactive role in supporting staff to avoid tick bites and equipping them with the tools and information they need to work safely in the bush. In my organisation, I am respected, supported and validated for my diagnosis of Lyme *Borreliosis*. This position is at odds with state and federal advice regarding the presence of Lyme disease in Australia.

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

and denial. Surely with at least 12 published papers dating back to 1956, all isolating *Borrelia*, together with thousands of Australians testing positive from accredited laboratories overseas, that this disease continues to be denied in Australia in 2015 is a miscarriage of justice.

I implore you to end this shameful act of denial of this debilitating disease, which is backed up by science, and make Lyme *Borreliosis* an accepted disease, just like any other disease in Australia today. I implore you as a matter of urgency to undertake the recommendations for research, testing and treatment of Lyme *Borreliosis*, as recommended by both the Lyme Disease Association of Australia and the Carl McManus Foundation, because if it were not for their advocacy and support many of us would not be here today. Thank you.

CHAIR: Thank you, Ms Rees.

Mr Walker: I am a company director. In August 2012 I received a clinical diagnosis of borreliosis. I believe the symptoms first appeared in February 2001 when I was diagnosed with meningitis. At my bedside, four infectious diseases experts convened and advised me that they considered my case of meningitis was most unusual in that they could not identify whether I had viral or bacterial meningitis. Also, I did not have the typical rash that accompanied meningitis. They said that meningitis was typically a teenager's complaint and I was well past my teens. In hindsight, had just one of those four infectious diseases experts taken the time to think why my case was so unusual and look beyond it, it would have saved me the next 15 years of declining health.

During the next decade, I was diagnosed with a raft of ailments: chronic fatigue, Graves' disease, tremors, memory issues, haemochromatosis, peripheral neuropathy, heavy metal toxicity, and the like. I have consulted numerous doctors, including two neurologists and two endocrinologists, all of whom had the opportunity of looking beyond their finite, limited scope to query other symptoms or do clinical diagnosis on my case, which they all failed to achieve. During that time I also had three blood tests: one from Australian laboratories which showed a negative result to Lyme disease; an American blood test which indicated activity, but it only achieved two out of the five bands, so it did not achieve their CDC definition for Lyme disease; and a German laboratory result which indicated an absolute positive for borreliosis. I spent probably $3,000 to $5,000 on those blood tests alone from the overseas laboratories.

I concur with the others: I would spend approximately $5,000 a month on treatment at the present time. The first doctor who diagnosed my borreliosis treated me for about 10 months with what I understand is a typical style of treatment for Lyme disease. After 10 months she said there was nothing more she could do from me and recommended I consider going to Germany for the thermal treatment. I booked to go to Germany and, before I could go to Germany, I needed to have some pre-treatment using IVs. I tracked down a doctor who could help me with those and that doctor did some more tests and said that I was too sick to travel and definitely too sick to do the German treatment. When we sent them the more recent tests, the Germans agreed that I was too sick to do the German treatment, so I have been under the second doctor's treatment for borreliosis. Twelve months ago I would not have been able to attend this meeting and today I am, so that is evidence that the treatment I am receiving is working, regardless of where I contracted the borreliosis, the use of long-term antibiotics, and the like.

One thing that does concern me, though, is that there were 12 years between the first indication that I had borreliosis and actual diagnosis. During that time I was an active blood donor. I do not know how many blood donations I have given. There is a bit of a discussion as to whether it is or is not contagious. I suspect that there are people in Australia who may well be infected with borreliosis who have never left Australia and have never been bitten by a tick, but they have got it courtesy of my blood donations.

It does occur to me that there are some problems in the medical profession. I am not a doctor, but I have met more doctors than I can remember who deny the possibility of anyone in Australia having Lyme disease, which is a little bit confusing because we have such a major population that travels overseas, so we do have a population that is exposed to the diseases. Whether it is contracted here or overseas is irrelevant as to whether the individual is deserving and entitled to being properly treated. Rather than taking up more of your time, that is probably the best contribution I could give.

ACTING CHAIR: Thank you, Mr Walker. Ms Kelly.

Ms Kelly: I have been sick for about 15 years—since 2000. Following on from what Chris just said, I started to get sick just months after coming back from an overseas trip. I went to the UK, the United States and Thailand, but I have not faired any better than anyone that has not left the country. I am not going to talk so much about me; I am just going to talk about general stuff.

The necessity of research and evidence based decisions is understood. The lack of government prioritisation of that research and lack of funding for research has left patients in a dire and miserable situation. I understand that

the professional people are talking about what they have to talk about but, for patients, nothing has happened since the CACLD was formed. If anything, we are in a worse position.

There are few doctors with the knowledge and willingness to treat patients with vector-borne disease, and the surveillance these doctors feel they are under is further endangering us, because the doctors are now pulling back from treatments, requesting less pathology and being very careful in their ordering of scripts according to rigid PBS guidelines. It is unethical to place our treating doctors under intense scrutiny, when mainstream specialists refuse to see or treat patients, send them away, refer them elsewhere and miss or ignore other more general test results. That falls somewhere between sloppy medical practice and negligence, and it is also a waste of Medicare and patient funds. Our treating GPs have no peer support and no back-up medical support services. Their options are to leave patients with no care at all or to do their best to fill in the gaps created by the absence of specialists. Those are not really great options.

There is literally no where for patients to go to receive adequate treatment. For chronic patients, many of whom develop complex immune complications affecting various body systems, there is no adequate specialist care. Patients need to try several of each specialist in the private system, which is not affordable for most, and still cannot get the care and treatment required. Emergency departments send us away. Hospital specialist clinics have lengthy waitlists and are useless in providing any care. Not only do we need doctors to care for us; at this stage we need Medicare to cover all the costs: GP and specialist, and private and public. There is no other way for us to get better now.

Because the debate and research remains on the presence or absence of the disease, no protocol has been put into place relating to complications of the disease, such as hypercalcemia, non-thyroidal illness and such, which means patients cannot access adequate pathology and imaging tests or treatments for the complicating factors. Again, we have no managing specialist. If we were to have cancer, or other recognised diseases, that would not be a problem. We could have the imaging and we could have the tests, but not for us.

Patients should not have to wait for research. We have repeatedly asked interim policies to be put in place. Such interim policies need to include means for doctors to order tests according to individual patient need, not according to existing regulations, which do not cater for our medical situations and have already failed patients. We need a system where doctors can access pathology and imaging for us through a special request system. Mainstream medicine has had years to help patients like me; it has failed. Mainstream doctors have failed, and the system has failed both doctors and patients.

The current review of Medicare, which I believe is ongoing, needs to look at reforming the entire medical system from university curriculum to service delivery. Our doctors do not have enough general knowledge and get paid, even when they have not provided a service and the patient needs to try again elsewhere. There have been occasions where I have walked out of one doctor's surgery straight into another to get some help that I know that I needed. And I have been proved right because, when I eventually got the test I needed, what I thought I had, I did have.

This is an emergency situation. People are sick and suffering. Some will have become infected here; some will have contracted infection overseas. Our system has pushed patients into lives of pain and poverty, and seems happy to keep them in that state. Every day our country remains in limbo on this risks another Australian becoming ill and others moving from acute to chronic illness. Acute means a good chance of regaining wellness for treatment; 10 or 20 years of chronic means lives destroyed. For patients, the current situation is nothing more than government sanctioned torture.

ACTING CHAIR: Thank you, Ms Kelly. Ms Patson.

Ms Patson: I have come down from Newcastle. I certainly would not have done this last year, the year before or the year before that. Prior to being bitten, in Newcastle, I was high-achieving, working in corporate finance. I was fit and I was exercising five days a week—married with two healthy children. I thought I was doing the right thing and took my children bushwalking. We were bitten by a tick in a park in Newcastle. I have a picture of the tick. We kept the tick because my daughter, who was three years old at the time, had a perfect bullseye rash. I have that here.

She and my son and I went on to have a vastly strange array of symptoms from word-block, neurological issues and Parkinson's shakes. My joints came up, I got arthritic and I could not walk or talk properly. I did all the things we are meant to do. I started off with my GP, who I have been with for most of my life, so she knew that there was something going on, but she could not put it together. It was one thing followed by another thing and then I would say I have this stabbing in my muscles, then burning muscle pain, then bone pain, then I would feel like I had meningitis, and then I would have a stiff neck. She was looking at me and my children and doing all the tests

she could, but every test was coming up negative. In fact, one test showed some information in my blood and she knew there was something going wrong. She could see my children were struggling.

I was referred on to a rheumatoid diseases specialist. He ran all the tests he could think of, ruling out ankylosing spondylitis. He could see how sick I was. I was losing the use of one arm. I could not lift a cup to my mouth. I could not brush my teeth or my hair. He said, 'I don't know what it is. You've definitely got something. It is outside of the box. It may be a post-viral event.' And I left him. I have gone back home and I have continued to get worse—I cannot walk, I cannot talk and my husband is helping me get changed. This is all now stemming from a very clear memory of a tick bite. I also remember the paralysis feeling in my neck and telling the doctor that I felt like I had a paralysis. I also had dislike of bright lights. Everything was very strange.

As I have continued to deteriorate I am now getting very concerned for my health, because I have done the GPs and the specialists and it is now time to go into the hospital. So I have gone into John Hunter. They have run numerous tests again and then rang my doctor and said, 'We are not denying that you have something. We do not know what it is. You are not going to die tonight. Go home.' So I went home, where I continued to get sicker. Meanwhile these bacteria or parasites, or whatever I have going on in me, are continuing to proliferate. I am getting sicker and sicker, to the point now where I have lost my vision a bit and I have gone colour blind. So I have gone back into John Hunter, and they do not patch it all together: 'Sorry, most of the tests seem okay. Go down to the Save Sight Institute. They actually said that it is not their area to diagnose tick-borne, but they said, 'Gee, this sounds a lot like a tick-borne disease.' This is where I was going now—from one specialist to another.

The saddest thing is my children. My children are now spending time off school. They are crying out in arthritic pain. They have the bullseye rash and the streaky lines of bartonella. I kept the tick. They are going cross-eyed. It all points to some terrible neurological infection from the bites we got. Fortunately, after all of this—I thought, 'This is it. We have no help because the normal system is failing us'—I managed to find a Lyme literate doctor, or a doctor who understood that there are infections in Australian ticks that are making us sick. He started us on antibiotics and I am very happy to say that after a couple of years now my son won a scholarship and my daughter came first in a cross-country race. That would not have been the case if we were not given antibiotic. If we were given maybe supportive remedies, such as steroids for the joint pains, I guarantee you they would be in wheelchairs. But, with doctors who know how to diagnose and treat, they have returned back into life, back into the system. I am still a bit further behind them, but with the longer term antibiotics I am here today to tell my story.

The other thing I would like to say is that I think we need to lose the Lyme name. The Lyme name comes from a strain that is an American one and causes all of this debate. It is time that we had an Australian name for this cohort of symptoms we have and moved forward with a plan to tackle it.

Ms Stevens: I am married and have four children. Two of my daughters have lung disease and *Borrelia* infections and co-infections. Tara is 20 and Shannon is 15. They have been sick for nine years. I only have a few minutes to share our pain and struggle with you and I am very grateful for the opportunity. We lived in Europe for over a year. We returned to Australia in May this year. My husband is a senior lawyer and he obtained a job in the Hague that enabled our daughters to receive treatment in Europe. Both of our daughters were tested multiple times and have had positive results for borreliosis and other chronic infections. The tests were done by a fully accredited laboratory in Germany. The lab meets the required international standard—and, of course, that means the Australian standard.

My daughters received treatment in the Netherlands and at the borreliosis clinics in Germany and in the Czech Republic. Each time they received treatment in Europe their doctors shook their heads and asked: 'Why is your country so backward? Why can't you get treatment for your disease there? Is there a political problem?' The doctors would say: 'All of the medicine we have here, you have in Australia. Why can they not give you the medicine and treat you properly?' A very experienced paediatrician asked how the Australian doctors could let my little Shannon get so sick: 'Why did they not take responsibility?' I could not answer. I was hurt for my daughter's suffering and I was ashamed of my country.

Shannon is 15 now. When she was six she suddenly came down with a heart condition. I still recall that day vividly. Shannon kept saying, 'Mummy, I have a bad headache in my heart' and she held her chest. I was not a helicopter parent; with four children I had lots to do. I kissed her and said you'll be right, go to school. At school pick-up the teacher said she was worried about how she looked. She said: 'Shannon doesn't look right.' Her face was grey and her lips were blue. She was teary and holding her chest saying, 'It still hurts, Mummy.' I rushed to the medical centre. They did an ECG and called an ambulance. How scared I was. If I only knew that this was just the start of everything—her heartbeat would get to 200 beats per minute. If only Westmead Children's Hospital

had available proper testing for *Borrelia* and co-infections. If only she had been diagnosed at six—we would not have had the nightmare of the last nine years and there would not still be such an unknown future for her.

In Europe they would have tested for *Borrelia*, among many other tests, and my beautiful little six-year-old would have had a chance at a normal childhood. Instead, she went on to have many surgeries, other organs became affected and her neurological symptoms commenced. This reached the stage where she had a dozen daily seizures, difficulty in breathing, dizziness, an inability to think clearly, dementia-like behaviour, paralysis of the limbs and vocal cords, noise sensitivity, chronic fatigue and even more. She last went to school in 2012. Now, Shannon wakes up every morning with a grand mal seizure and often her legs are paralysed for days. Lately, her vocal cords are also paralysed. We keep a tank of oxygen at home because she regularly stops breathing during her seizures. She is on 12 different medications daily and takes 27 pills a day. Her life is not much fun for a 15-year-old. We all work hard caring for her 24 hours a day. But it is not easy. We take it in turns. All she wants to do is attend a normal school and make friends. None of this had to happen. It is terribly sad and it breaks our hearts daily.

Tara is 20. At the age of 12 she demonstrated wide, baffling symptoms. Until then, she had never been sick. Out of nowhere she had respiratory problems and oesophagitis, which crippled her. She was in so much pain she screamed in agony. We had to keep taking her to the hospital. She had trouble breathing, she had joint pain and she developed anaphylaxis. This was distressing and life threatening. She spent days, weeks or months at a time in hospital while doctors were trying to work out what was wrong with her. She then had to attend monthly clinics at the Sydney Children's Hospital, Randwick. She attended the chronic pain clinic, the rheumatoid clinic, the asthma clinic, the immunology clinic and other specialists for many, many years before we got to the problem.

Tara grew worse. She developed neurological symptoms. She had Bell's palsy, and she eventually started to have 30 seizures a day. We feared for her safety and her life. We lost hope with the hospital system. We decided to stop attending. We found a really good doctor who helped and cared for us, and we started treatment. Tara has since also tested positive in Germany. There can be no dispute about her illness. Now Tara is on the road to recovery. She is here in the audience. There is hope. She is not in remission, according to the German doctors, but she is relatively symptom free. Tara missed most of her school years. She is now enrolled in a foundation enabling program at university, which also brings us much joy. She hopes to be studying nursing next year. She wants to help others. Tara would tell you that she is surprised, after nine years of suffering so badly, that she is still alive. She is amazed that she is alive and functioning despite this disease. Tara believes that she will be dealing with the trauma of being doubted by the doctors and dismissed by specialists for a very long time.

The impact on the family obviously is huge. This disease has put a massive strain on the whole family. You could compare us to other families with children suffering from painful and life-threatening conditions, but there is a huge emotional impact. It drains and exhausts us. We often are afraid. We hate to see the children suffer. With many other diseases, at least there is support, recognition and treatment.

We packed our house and family and moved to the other side of the world to get proper treatment. In Australia we are faced with ignorance and even hostility and ridicule at times from doctors. The medicines are here. The hospitals are here. The community nurses, the intravenous lines, the complementary medicines and everything else are here, but Lyme patients cannot get access to them. We need proper treatment here. By that I mean experience, care and knowledge. We need the Australian doctors to learn from the experience of their overseas colleagues. The ILADS-trained doctors overseas know best. Their treatment works. They are astounded by the ignorance and the unwillingness to change of the profession here. The profession needs to change. It will not do so unless pushed. Politicians are elected to lead, and they need to lead in this matter. If politicians do not lead, they will be responsible for some of the continuing suffering and maybe even more deaths of Australians like my beautiful girls. Thank you.

ACTING CHAIR: Thank you, Ms Stevens. Before I pass to my colleagues for questions, I think it is important that we just say on behalf of the committee that we hear and recognise the pain and suffering in the stories that you have told us today. The stories give a very powerful human face to the issues that we were discussing earlier this morning.

Ms HALL: I really do not have any questions to ask. You have told me how it has affected your lives. You have described very visibly and visually what it has done and the struggle that you have had with the diagnosis, the treatment and the costs. I do not think I could ask anything of you other than what you have given so far, so I would just like to thank you. Thank you very, very much.

Ms Patson: Thank you, Jill. I live in Jill's electorate, and I have mentioned to her that in Newcastle, where I am, there are about 60 or so people that have come down with this tick-borne illness. We can all get together and we all recognise each other's symptoms and we all recognise we are getting better on long-term antibiotics. Of

those 60, there are a dozen that got their tick bites in Glenrock park, a park opposite my house. What urgency can I call upon for someone to go and test those ticks?

In fact, I did pass that information on to Professor Irwin. But there is something in our ticks in that area that is making us sick, and very sick—neurologically sick: cannot-walk-or-talk sick, and with pain that would bring a grown man to his feet. It is terrible.

There are hot-spots around the country as well. In fact, I think it is really everywhere—it is all around Australia. We just need to figure it out, give it a new name and stop debating this. Hasn't this been debated for over 20 years? At what point do we give this traction now, give it a name and start doing something about it? There are children going through that park every day, and no doubt someone is going to get bitten by a tick there this week.

Ms HALL: Michelle comes from Lake Macquarie, too.

Mrs Wheeler: There are so many people who are being diagnosed all the time within that area of Newcastle and Lake Macquarie. It is sad, because most of the GPs in Lake Macquarie and on the Central Coast do not believe in Lyme disease, so you are not getting treated urgently. It goes on and on and on. I have been like this for four years. I should not be like this. It should not be like this for anybody.

Ms Patson: In fact, no-one I ever saw—be it my doctors, my specialist, the John Hunter Hospital—ever said to me: 'Do you recall a bite?' I think that is something that should be brought in—that they should start thinking about it now, and ask: 'Have you had a bite?' Of all the infections I had, I also had *Rickettsia*. *Rickettsia* is well-known in Australia, but no-one out of the GPs, specialists or even the hospital tested me for *Rickettsia*. So I was living with that alone for almost a year, on top of *Borrelia*, *Babesia*, *Mycoplasma* and whatever else there is in our ticks.

Ms HALL: How is your GP now?

Ms Patson: My long-serving GP—she had delivered my children—felt uncomfortable continuing to see me, actually. I had seen a doctor who was further out of Newcastle and he had said, 'You'll probably need to have some Bicillin injections.' I was not going to do a four-hour trip to Sydney every so often to do these Bicillin injections, so I went back to my GP, and she said, 'I've got no guidelines; I'm not comfortable with doing this; I'm not going to do it.' So you get left out in the cold again because they feel that they do not have a framework or guidelines. So I lost my family doctor because it was all alien to her.

Ms Rees: My 15-year-old daughter administers my Bicillin injections.

Ms Stevens: We had to administer IV for 14 months. But we were very fortunate, compared to most people. The community nurses supported us and came to our house. But we know of many Lyme patients who cannot get the community nurses to come. They ended up having to train us because it was pulling too much on their resources. So my husband and I had to learn how to do it to my daughter, and I found that very traumatic.

Ms HALL: You are from North Coast New South Wales, aren't you, Lynn?

Ms Rees: Yes.

Mr STEPHEN JONES: Like Ms Hall, I do not come armed with a bunch of questions to ask people who have obviously gone through a lot of suffering, particularly when you have been so generous in sharing your own stories—and generous in actually getting here, in view of all the things that you are dealing with. We were keen to have this inquiry to bring together disparate voices from within the professions to focus on some of the things that we knew were in conjecture, but we also did not want to leave the people who were living with this disease out of that conversation. So your additions to the evidence that we have heard today, from my point of view, have been most important. As to even the concrete suggestion that you have made, Alex, about the word and describing it or wrapping it all up in the name 'Lyme disease', I never heard any conjecture earlier today that there are tick-borne diseases that are impacting on people and creating a whole heap of indications—

Ms Patson: If we can lose that 'Lyme' stigma and the debate about it and move forward with this new name for this Australian illness, I think then we can get some traction.

Mr STEPHEN JONES: The deputy chair will probably make some comments about where we go to from here, but the purpose, when we discussed it, of getting people together was to inform ourselves, as a committee, of whether there was more to look at here. From my point of view, I think there is more to look at here.

Mr Walker: May I make an observation here? About four decades ago the aviation industry suffered some major catastrophic crashes which were tracked back to the industry mentality that the captain was God and whatever he said goes. As result of that, NASA did a big research program and they developed a thing called cockpit resource management whereby, yes, the captain was in charge, but, if any of the other people around him

observed significant matters, they would bring it to his attention. They were obliged to bring it to his attention and increase the level of urgency if the captain did not understand what they were talking about. It seems to me that that style of protocol and technology could probably aid the medical industry at large. Just off the cuff I give an example. Dr Graves was talking about when someone requests that he does a test for Lyme disease and he sits there saying, 'That's negative, but they could have one of these other tick-borne diseases.' There should be some sort of feedback mechanism, or there could be some sort of feedback mechanism, where he can recommend to the medical practitioner, 'Have you considered these other tests that are available?' That could assist.

I concur completely with the terminology. I have met far too many doctors who want to hang their hat on the semantics of Lyme disease relating to a bacterial outbreak in a geographical region in the United States of America. Let them have their semantics. The reality is that people here are sick with tick-borne infections. I for one—and I suspect everyone at this table—has been infected with not just *Borrelia* but with several others: *Rickettsia*, *Babesia*, *Bartonella*—it goes on and on and on. It is like a lucky dip. We do not know how many diseases we are going to get, so why restrict it to one and leave it open to the semantics of the pedantic professionals who are almost negligent in their approach to the diagnosis?

ACTING CHAIR: In the 10 minutes remaining to us, would you like to make any reflections on the evidence you heard this morning? Is there anything particular that you would like to take up from the evidence that was given this morning?

Ms Kelly: I would like to make a comment. There was all the talk about the accuracy of NATA accredited labs. I have had a very long history of very odd pathology. A lot of my pathology would be more normally associated with sarcoidosis. No-one has ever proven me to have sarcoidosis. I decided that the easiest way to get a sarcoidosis diagnosis is to try to prove that you have borreliosis and then they will slap the label on you really quickly. In the context of that, I have always had very elevated calcitriol, which is D 125 dihydroxy, and elevated ACE. There is a chain lab that many New South Wales GPs like to use and then there is a hospital lab that is, I think, considered to be the gold-star lab in this particular test. The results, done in the same week, came back looking like they were from two completely different people. This is a consistent pattern that has happened over a number of years. I know which lab I think is correct because the associated results, like parathyroid hormone, calcium and various other results depict a particular pattern. They came back matching one of the labs. I take great offence when these professionals say how wonderful NATA accredited laboratories are when I have results that tell me one of them is wrong, and that is just an Immuno SA that they are running here. How can that be? Where is the quality control on such tests? No-one has ever been able to give me an answer. I have written that in several letters to various government people associated with this debate. I have never received a reply.

Ms Patson: I would like to reflect on Dr Schloeffel mentioning to Stephen Graves, 'Why not get these American and German experts who are finding different strains of *Bartonella* that we do not find in Australia and bring those guys to Australia so we can update our pathology?' Currently, we have a gap and, if these specialists are finding it overseas and they are all CDC approved—they are top labs—bring some specialists here and let's change our pathology, and we might get a lot more positives and will be able see a true indication of the suffering that is going on out there.

Ms Stevens: Then we might be able to have a clinic where people can go and not feel ridiculed. I am fortunate, even though my daughter is so sick. I was fortunate to sit in a clinic in the Czech Republic last November for a whole month while she was getting treated and I thought, 'Gosh, if only Australia could have a place where they could go and all the patients I know could be accepted.' Obviously, it would be better to go to a hospital ward and be accepted, but I think it will still take a while for acceptance to come through.

Ms Rees: I came in late in proceedings. I picked up on concern about long-term antibiotics. I have had nearly four years of antibiotic treatment. I go off them occasionally just to give my body a rest and see if my disease is coming under control. I have never been symptom-free, but the longest I have gone with symptoms that I can manage is four weeks. As soon as I am put back on antibodies, a lot of the neurological stuff—the pain, the dementia—starts to diminish. I live in fear that I will end up either suiciding or in a nursing home because, if my treatment is withdrawn, I know what my future will be and it is not very bright. If it were not for my kids and Dr McManus and Sharon Whiteman, who have picked me up when I have been pretty close to thinking I cannot cope any longer. The long-term antibiotics really help deal with a lot of the ongoing symptoms and put them back in control. My GP has said he has never seen anyone become resistant to any of the antibiotics. Our bloods are tested every month to make sure that our kidneys and our liver are functioning properly. If we are feeling a bit sick, we go off them and have a break. But the symptoms just keep coming back, though I am recovering slowly.

Mr Walker: I would like to make an observation on an aspect of antibiotics. If it is such a danger that we are using antibiotics, before considering restricting access to antibiotics for people suffering from borreliosis and

similar diseases, the government should turn their attention to the agricultural industry where antibiotics are freely used, particularly in the poultry industry. They are not used for health reasons; they used were fattening reasons. They have the side-effect of fattening the chooks to the extent that they cannot even stand on their own two feet. I believe that is permeating through to the human chain and, if there is going to be an issue about antibiotic resistance, it has great potential to come through that food chain rather than from people like us who need them.

Ms Rees: There are misconceptions. If you withdraw our medication or if our doctors are not allowed to treat us, you will have a health crisis in suicides and in debilitating chronic diseases, and in hospital beds, emergency beds and nursing homes being taken over by us.

Ms Patson: Absolutely.

Ms Rees: That to me is a far greater cost than a $200 treatment of first-line doxycycline.

ACTING CHAIR: Thank you all for coming today and sharing your stories with us. As Mr Jones said, the purpose of this roundtable is to inform the committee about potential subsequent action the committee could take. That is something that we will need to discuss with the other committee members in light of today's roundtable. I will not go out on a ledge and speculate on behalf of Mr Wyatt, Mr Southcott and Mr Irons, but I express my very genuine appreciation and thanks for you adding your stories to the evidence that we heard earlier. It is easy to forget, but I very much view politics as a storytelling profession, and you drive action in our political system. Your presence today has been very important., so thank you for coming.

Ms Rees: Thank you for the respect that you have given to us. It is very much appreciated.

Resolved that these proceedings be published.

CHAIR: I thank my colleagues in all the witnesses for their time today.

Committee adjourned at 12:29