

**TICK-BORNE DISEASE — LYME-LIKE ILLNESS**

*Motion*

**HON ALISON XAMON (North Metropolitan)** [10.34 am] — without notice: I move —

That this house notes the 2016 Senate committee report on the “Growing evidence of an emerging tick-borne disease that causes a Lyme-like illness for many Australian patients” and calls on the government to establish an ongoing mechanism for ensuring that the Western Australian context is represented in the implementation of recommendations made in this report.

I thought I would begin by setting the scene for members on why this issue has arisen. We know that for decades Australians, including a significant number of Western Australians, have been reporting chronic and debilitating symptoms that are quite complex, and they have been attributing these to ticks. We know that the people who are experiencing this illness are caught in a catch 22 because of the complexities surrounding the ability to diagnose, as well as the different approaches that are taken because no data has been collected. Because of the lack of data on the number of people who have been affected, trying to find a solution has been considered to be less urgent. People who are incredibly unwell are being turned away without a proper diagnosis and are being told far too often that simply nothing can be done, and so they cannot get the support that they need.

There are many terrible stories of the suffering that has resulted from this particular syndrome. Sadly, we know that some people who have suffered have subsequently died by suicide because of the crippling effects of their illness and the extent of their sense of hopelessness. I want to quote Bevan Jeffery of Manjimup, who said —

It’s hard not to come to the conclusion that you are screwed once you get this disease.

He also said —

It is a reduced existence ...

I can’t help waiting for medical science to find the underpinnings of this disease so that future suffering may be prevented for many people.

I understand that Mr Jeffery died a couple of years ago and my condolences go to his family.

Further contributing to the distress of people who find themselves with this crippling disease is their interaction with the medical system. There is limited awareness amongst medical practitioners about the nature of this condition, which means that too many patients are not able to readily access the treatments that they need in any sort of timely manner. Unfortunately, people are reporting feeling stigmatised, bullied and harassed by health professionals, who often simply do not believe that such a syndrome exists within Australia.

The establishment of the Senate inquiry was a big step forward towards validating the experiences of thousands of Australians and acknowledging that there are massive gaps in the understanding and the subsequent treatment of these complexes. There is no doubt that we have a vexed conundrum, but it is one that we cannot continue to put into the too-hard basket. Submissions were made by 1 260 people in one form or another to the inquiry. It is clear that too many people are being let down by the health system. The recommendations made by the Senate committee represent a good start and we in Western Australia must ensure that the Western Australian experience is included in the research and that our government is augmenting the work done federally through our state agencies to best support those who are affected.

Such is the complexity of this issue that there is not even a universally agreed case definition of the nature of this chronic condition. However, we do know that the constant reference to Lyme disease has proven to be an unhelpful distraction. The reason for that is that the pathogen that causes Lyme disease in Europe and the United States has not been proven to exist in Australia, which leads many in the medical profession to disregard the presence of all tick-borne illness in Australia, despite evidence to suggest that Australian-specific and, indeed, Western Australian-specific—that is why it is so important that we participate in the national research—organisms are carried by ticks here. One of the recommendations made by the Senate committee was to —

**remove ‘chronic Lyme disease’, ‘Lyme-like illness’ and similar ‘Lyme’ phrases from diagnostic discussions.**

I used the phrase “Lyme-like illness” in this motion because I wanted members to understand what it was I was referring to. I note also that a WA-based group has been set up to provide peer support and advocacy for people who are suffering from the condition, and it has adopted the name “multiple systemic infectious disease syndrome”, or MSIDS, to reflect the multiple infectious causes and multisystemic nature of this condition. For the purposes of this motion and so that members will understand, I will use the term MSIDS from here on.

I turn to the recommendations of the Senate committee report, which look at increasing research into potential pathogens and their prevalence and also, importantly, their geographical distribution, while at the same time developing an evidence-based approach to treating people who have already been affected. We know the federal government has committed \$3 million through a National Health and Medical Research Council targeted call for research, and that is a good start. NHMRC has established a committee of independent scientific experts and consumer representatives to help frame the research question for TCR. However, it is worth noting that there is currently no WA representation on the advisory committee. That is something that I certainly hope can be resolved as we move forward.

Given the potential for multiple-cause agents to be identified with co-occurring infections that might differ across geographic locations, it is going to be vital, as I said before, for WA to be specifically represented in this research. We are quite fortunate in WA because we have considerable expertise in this field already. Professor Peter Irwin and his team work in the waterborne pathogen research group at Murdoch University, and they have already started researching tick-borne viruses. I note that Professor Irwin has observed that the situation in Western Australia is likely to be subtly different from that of the eastern states. For example, paralysis ticks are found over east but not found here, thank goodness. The paralysis tick is part of a family of ticks that are found overseas and are well known to be transmitters of Lyme disease, but we do not know what we are dealing with here in Western Australia.

Although research is clearly important, it is not going to detract from the need to ensure that people who have already contracted MSIDS receive appropriate treatment and access to decent medical care. We also need to ensure the timely implementation of recommendation 9 across Western Australian health services. Recommendation 9 states, in part, the need to —

**consistently adopt a patient-centric approach that focusses on individual patient symptoms, rather than a disease label ...**

Recommendation 6 is also of particular relevance to the states and territories, and calls on the Council of Australian Governments' Health Council to develop a consistent national approach to addressing tick-borne illness. It is imperative that WA comes to the forum with a considered approach on what is needed to best support Western Australians who are suffering from MSIDS.

Undoubtedly, the inquiry findings represent progress; however, the government's response to many of the recommendations demonstrates once again the conundrum that many patients have found themselves lost in—that is, that the government is not going to conduct treatment trials unless a causative agent is found. Likewise, the government argues that it cannot undertake an epidemiological assessment of the prevalence of the condition without the evidence or ability to accurately diagnose uncharacterised tick-borne illness. We can only hope that a significant investment in research will serve to disrupt a vicious cycle.

Prevention also has an important role to play in this space. We know that illnesses acquired through tick bites are ultimately entirely preventable. There is already enough evidence to prompt the government to take a precautionary approach by raising awareness of MSIDS and the best known way to prevent it, even if the exact causative agent has not yet been identified. Professor Irwin said —

“Over the last 30 years recognition of a ‘Lyme-like’ syndrome has emerged, the onset of which has been attributed to people bitten by native Australian ticks,” ... “There have been manifestations of an undiagnosed illness causing significant patient distress, with symptoms presenting in a similar fashion to tick-borne diseases overseas.”

Prevention is recognised as a key strategy in overcoming the burden of this chronic disease. The House of Representatives' Standing Committee on Health's inquiry into chronic disease prevention and management in primary health care has already classified tick-borne and Lyme-like illness as a chronic disease within Australia. But due to the low level of awareness about the potential for illness from a tick bite, no prevention strategies are in place in Western Australia. As I mentioned before, the stigma and controversy around this particular illness presents a barrier to community awareness and the coordinated development of prevention strategies.

I urge the state government to take action now to raise awareness of the potential for illness as a result of tick bites and to start conveying messages about how best to avoid being bitten in the first place. We need to ensure that WA is included in the research and that our interests are properly represented. Unlike the federal Parliament, to date there has been little government or political attention on the issue within Western Australia, despite the fact that we know that many Western Australians are suffering. The state government has a role to play to safeguard the health of our constituents and it also has obligations in respect of emerging diseases. These diseases require targeted and urgent responses. We should all have a right to medical care, irrespective of what caused that illness in the first place. We need to ensure that Western Australians will not be at a disadvantage compared with other Australians through a lack of awareness, participation and research or because of a lack of modes of treatment.

We encourage the WA government to pick up on the important work that has been recommended as a result of the federal committee's report and take a strategic approach to this issue to ensure that some formal mechanisms are in place, accompanied by sufficient resourcing, to ensure that our expertise, our operating environment and our geographical context help inform the implementation of the Senate inquiry recommendations. Having spoken to many people within the community, I am aware that one of the first things people seek is information about what the Department of Health intends to do in order to progress this matter, and specifically the structures being looked at in order to ensure that the health department is receiving appropriate advice and guidance not only from researchers and professionals, but also from those people who are living with this insidious illness. I know that this issue would not necessarily be at the forefront of many people's minds but I am sure that many members here know of people who live with this particularly complex illness and recognise that it is utterly debilitating. It is important that we progress work in this area.

**HON ALANNA CLOHESY (East Metropolitan — Parliamentary Secretary)** [10.48 am]: I thank Hon Alison Xamon for bringing the motion to the house. Both the Minister for Health and the Western Australian Department of Health acknowledge that chronic symptoms of an unknown cause, which is sometimes attributed to Lyme disease or other tick-borne illnesses, have a serious impact on Western Australian residents. Both the minister and I empathise with those Western Australians who have been afflicted with those, as the member rightly pointed out, debilitating symptoms that are similar to and consistent with symptoms experienced by sufferers of what I will call Lyme disease. The member pointed out, in referring to the Senate committee report, the tensions around identifying, naming and labelling that collection of symptoms. I will go into some of that during my contribution on behalf of the government.

We are aware of the ongoing impacts on both health and mental health for people who are experiencing these symptoms and the frustration of not being able to confirm the diagnosis, the source of their affliction or even to establish a clear pathway for treatment and recovery. We understand the impact of these symptoms stretches beyond health and mental health wellbeing and impacts people's ability to study, work and go about their everyday lives. We also understand, as with any major condition, the flow-on impacts on loved ones who care for or rely on those people. We are aware that Australian ticks are important vectors of human disease. For example, we have evidence that they are associated with rickettsial infections, Q fever and the newly described mammalian meat allergy.

As the member pointed out, here in WA we are fortunate to have a world-class research laboratory at Murdoch University that has specialist skills to study tick-related illnesses. Scientists at this laboratory have received government funding to investigate the microorganisms carried by ticks in Australia. After many years of extensive research, neither a causative microorganism nor a vector capable of transmitting classical Lyme disease have been found. Although the formal position of most medical bodies in Australia supports that there is no evidence that classical Lyme disease can be acquired in Australia, I am aware that there are some key reasons that other doctors hold different opinions. Firstly, I am advised, is that the illness is very difficult to diagnose with any certainty from the history and clinical presentation, as these can mimic numerous other conditions. Secondly, there are difficulties in interpreting laboratory tests for Lyme disease. I took the opportunity to read the report, and both of those issues are canvassed at length by the committee. This is why the Department of Health holds the position that laboratory tests should be carried out in an accredited laboratory that uses validated methods. There are many commercial laboratories overseas, and at least one unaccredited laboratory in Australia, that offer Lyme disease tests using assays the accuracy and clinical usefulness of which have not been adequately established. These laboratories are more likely to report Lyme disease tests results that are falsely positive. Upon review and further investigation, these patients are often found to have other conditions. I am informed that some Australian doctors refer samples from their patients for Lyme disease testing to unaccredited overseas laboratories, at great expense to those patients and their families, and promote lengthy treatment courses that are inconsistent with credible scientific evidence. I am advised that although relatively small in number, there is published medical literature showing that treatments that are not evidence-based have contributed to injury and even deaths of patients. Unfortunately, treatment of Lyme disease with therapies that are not evidence-based can be falsely reassuring to patients who believe that they have a debilitating chronic infection and thus do not seek treatment for other conditions.

Testing and treatment for classical Lyme disease is available in WA by consulting with a general practitioner, and if appropriate obtaining a referral to an infectious disease physician or specialist at any public hospital or in private practice. If tests for Lyme disease are required, they can be ordered by a registered medical practitioner and should be conducted at any Australian state public health laboratory. In Western Australia the state public health laboratory is PathWest Laboratory Medicine WA. All positive tests for Lyme disease from an accredited laboratory such as PathWest will be referred to Westmead Hospital's laboratory in Sydney for confirmatory testing. People who are diagnosed with Lyme disease through this process can access appropriate assistance from an infectious disease physician or specialist at any public hospital.

As the member alluded to, in 2016 the Senate Community Affairs References Committee tabled the final report of its inquiry titled "Growing evidence of an emerging tick-borne disease that causes a Lyme-like illness for many

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Australian patients". As a result, in November last year the federal Minister for Health, Hon Greg Hunt, MP, responded to the report and allocated \$3 million towards funding research, as the member pointed out, into debilitating symptom complexes attributed to ticks. The commonwealth government recently announced that pilot clinics for people with Lyme disease and other illnesses attributed to ticks will be established in other parts of Australia. The location of these clinics will be decided at a national level through the Australian Health Protection Principal Committee, a subcommittee of the Australian Health Ministers' Advisory Council. The operation of these clinics will not be without its challenges, in no small part because of the difficulty in distinguishing this group of patients on the basis of clinical features, or laboratory testing from a large number of other patients with medically unexplained symptoms. But WA Health will monitor closely the outcomes of these pilot projects and will consider the lessons learned. The Minister for Health has asked the Department of Health to stand ready to apply any learnings to improve the lives of Western Australians experiencing these or similar conditions.

Given that the recommendations from the inquiry relate to the Parliament of Australia and the federal government, a response from the federal Minister for Health is appropriate. Although there is limited scope for the WA health minister to act directly on the recommendations of the report, Minister Roger Cook has taken note of the findings and recommendations from the inquiry. The WA health minister is encouraging WA Health to actively seek out opportunities to partner with federal and other state counterparts to ensure we have the most up-to-date science on Lyme disease and conditions that carry similar symptoms to Lyme disease that may be locally acquired. WA Health monitors regular updates and revisions from the federal Department of Health to ensure that educational material on tick bite prevention and first aid remain current. WA Health is also vigilant in adhering to the Australian guidelines for the diagnosis of overseas-acquired Lyme disease—borreliosis.

I noticed that the member also said that the National Health and Medical Research Council committee does not currently have a Western Australian representative on it. I undertake to talk to the Minister for Health and look into that matter to see what we can do about it. WA Health also seeks to participate in relevant medical education meetings and conferences to not only provide input from Western Australian experience, but also inform WA stakeholders on progress being made in Australian research. The commonwealth Department of Health will host such a forum in Melbourne on 18 April 2018 to consider the outcomes of the Australian government's response to the Senate committee report. The federal Minister for Health, Hon Greg Hunt, will open the forum, and state and federal government health officials, medical specialists, and community groups will be in attendance. A representative from WA Health will participate in the forum and report to the WA Minister for Health on key findings and outcomes.

Once again, I thank the honourable member for bringing this motion to the house and for raising this issue. I have pointed to some of the current directions that WA Health is taking in both prevention and research, and I have noted the minister's concern and interest in this area.

**HON COLIN HOLT (South West)** [10.59 am]: I thank Hon Alison Xamon for bringing the motion to the house today. First, I congratulate the Lyme Disease Association of Australia, which is full of very passionate members, some of whom reside in Western Australia, which has been fighting for this disease to be recognised for a very, very long time. In fact, the Senate inquiry and report would not exist without its hard work and advocacy in this space, so we must congratulate it on that first and foremost.

I have listened intently to the debate and members talking about Lyme disease, but I want to concentrate on the federal government's response and the second part of the member's motion that refers to ongoing engagement within Western Australia. The mover of the motion can correct me if I am wrong, but I think the Senate handed down its report in November 2016.

Recommendation 5 of that report states —

The committee recommends that the Australian Government Department of Health facilitate, as a matter of urgency, a summit to develop a cooperative framework which can accommodate patient and medical needs with the objective of establishing a multidisciplinary approach to addressing tick-borne illnesses across all jurisdictions.

That was 15 months ago—a matter of urgency! I note that the Minister for Health's representative in this house referred to a forum that will be held on 18 April, but it is not clear to me whether that is being held in response to recommendation 5, which is about the establishment of a framework. The Lyme Disease Association of Australia has been invited to that forum, and I will get back to the timing of that in a minute. However, the heading of the letter of invitation to that forum states —

**Forum to consider the outcomes of the Australian Government's response to the Senate Community Affairs References Committee final report: ...**

We have not even arrived at a point of establishing a framework, but it wants people to get together and talk about the recommendations. That is a good idea and a good first step, but I am not sure whether we have recognised just yet the sense of urgency in recommendation 5. What concerns me the most is that the invitations for this forum to

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be held on 18 April, which will discuss the inquiry's recommendations on such an important issue, went out only on 26 March. Get yourselves organised, people! The association, people with expertise and state government departments have to get themselves organised to go to the next most important step on this journey. I am very pleased to hear the parliamentary secretary suggest that a representative from the Department of Health will be going—good on her! I look forward to seeing the report that comes out of that meeting, and maybe she might like to indulge us and table that so that we can refer to it in the future. But, seriously, I think it is disappointing that people are being given only three weeks to get organised to go to a summit to discuss this very important issue, given that the Senate inquiry happened 15 months ago. I think that is really disappointing.

**Hon Alannah MacTiernan:** Which government is in power over there?

**Hon COLIN HOLT:** The minister knows who it is. She does not need to ask me, unless she has forgotten; I am not sure. I think that is very disappointing.

**Hon Alannah MacTiernan** interjected.

**Hon COLIN HOLT:** I am trying to talk about a serious issue. If the minister wants to raise politics, she can do that in her contribution.

I think that how the Minister for Health and the Chief Medical Officer have approached this issue is disappointing. I know that the Lyme Disease Association of Australia is looking forward to any sort of engagement. I am sure it will attend the forum and represent itself very well. It has also requested that some international expertise be in the room—I am not sure how that can occur within three weeks—and that a better way to approach the matter would be by the use of independent facilitators.

I commend the government for sending a representative from the Department of Health to interact at this level. I agree with Hon Alison Xamon when she says that the membership of the standing committee is not adequate for Western Australia. Certainly, the Lyme Disease Association members who reside in this state would like to see that. If we can push for that at the federal level, we should. I thank the member for raising this very timely matter. Again, we need to set up processes to address a matter of urgency that do not take 15 months. It needs to be discussed so that people suffering from these diseases and the Lyme Disease Association are given further ways and outcomes for defining the disease and recognising treatment. I thank the member for bringing the motion to the house and I thank the parliamentary secretary for her contribution.

**HON Dr STEVE THOMAS (South West)** [11.04 am]: I thank the member for the opportunity to make a few comments on this important issue. I would like to start by making sure that members are aware of the complexity of this disease process, because it is not a simple issue. It has been very easy for people over time to try to make it a very simple issue. Unfortunately, around the world the science and pseudoscience community has made it much more complicated and has probably done us more harm than good. I will read from the introduction to the Australian government's Department of Health fact sheet on Lyme disease. I know that we moved on to a different definition, Hon Alison Xamon, but this helps to describe the complexities of the issue. It reads —

Australians in the affected community and their healthcare providers and supporters believe this illness is chronic Lyme disease or something similar. However, the concept of chronic Lyme disease is disputed and not accepted by most conventional medical practitioners, not only in Australia but around the world. The likelihood that Australia has an indigenous form of classical Lyme disease is questionable given a causative microorganism with a competent vector is yet to be found. Whether a form of tick-borne human borreliosis exists in Australia is yet to be determined.

The government goes on to say that it obviously recognises classical Lyme disease where it has been adequately tested. We know that it exists in Europe and the US. I will quote a bit of research that came out of Canada. Canada is obviously not far from the US, where Lyme disease has been found, tested and recognised as an endemic disease at this point. This is a 2015 scientific paper by Gregson, Evans, Patrick and Bowie entitled "Lyme disease: How reliable are serologic results?" I will not read the whole thing in, but I want to make a couple of observations from this paper. It states —

Patients with chronic subjective symptoms without a diagnosis can be vulnerable and desperate for an answer as to the cause of their illness. Giving them a false diagnosis based on flawed testing is misleading. Inappropriate therapy based on such results leads to economic, psychological and physical adverse outcomes.

Under "Key points" it states —

*Specialty laboratory tests have a high rate of false-positive results owing to their use of non-evidence based interpretation criteria, particularly when results rely solely on Western blot analysis.*

Bear in mind that this research paper is from Canada. It continues —

**Extract from Hansard**

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*Most Canadians who are told that they have Lyme disease based solely on results from specialty laboratory typically have other causes for their symptoms.*

The member was quite sensible in her contribution as she talked about a syndrome that affects a number of people rather than getting bogged down in the debate about Lyme disease and whether it is or is not in Australia. I will try to make sure that members have a realistic view of where this debate is going to go. We are talking about a group of people with an incredibly vague set of symptoms. At this point, medicine is not able to come up with a set diagnosis. What one finds is that someone classically comes along who is very fatigued—that is why chronic fatigue often gets thrown around in the process—has muscle and joint pain generally; and generally feels extremely unwell and lethargic, which often leads on to some mental health issues. Not infrequently it involves headaches and inflammation around the brain stem and the nerves as well, and there are some other bits and pieces. The problem is that there are so many possible causes for that. We may well find when the research is finished in a decade or two, perhaps, that this is a group of people with a whole plethora of causative organisms—some biological, perhaps even some psychological. We may well find at the end of this process that there is not a definitive organism causing a definitive syndrome. What has happened with the Lyme disease component is that there are a lot of people out there who almost certainly do not have Lyme disease but who have a set of symptoms that are similar. Chronic fatigue looks incredibly similar. In many cases, we do not have a definitive cause for chronic fatigue either. What we usually know is that there has been a biological infection of some form. In some cases it may be as simple as the common cold. It gets into a body that is unable to cope with it and the result is that the organism lodges in certain parts of the body. The result of that is these chronic symptoms. In many cases the original organism is never found and there is no chance of doing so because it may be something very common. It may be found that this syndrome of illnesses has so many causes that it will never be diagnosed as a particular syndrome. There may not be a set solution to this. The parliamentary secretary was quite right when she said in her contribution that individual treatments for individual cases are critical to this process. That is absolutely true.

We need to be particularly cautious about that group of people who, in desperation at being desperately unwell for a long period, grab hold of what is effectively a pseudoscience. For close to a decade we have seen a diagnostic process occur in Australia. They go through the classics and look at things that look very similar. Ross River virus and Barmah Forest virus can look very similar. A lot of things look like Lyme disease. They go through a diagnostic process and nothing comes up. Often that is probably because the cause of the virus was a very common one that doctors would not bother testing for. Even if it were tested for now, it might be found that the virus has gone but the symptoms remain because this is a reaction of the immune system to a residual process, which is not uncommon. That is probably why chronic fatigue syndrome is called chronic fatigue syndrome—the causative organism has probably gone many years before, but the body continues to respond as though it were there. Unfortunately, the human body, like a lot of animal bodies, is a pretty imperfect thing. It does not always get it right. If it did, we would not have cancer, diabetes or any of those issues. The problem in this debate is that a group of people desperately grabbed hold of the diagnosis that a very small proportion of the medical profession was prepared to push. They generally did this by using inappropriate laboratories, particularly in the United States, which conducted testing that was not effective, efficient or accurate enough. In many cases, they have been given a diagnosis that is not accurate. That is not to say that work should not be done.

I think that the way Hon Alison Xamon has phrased this motion is particularly good because we are not having a debate about whether Lyme disease is in Australia. I think the member has done a very good job of that. We are having a debate about a group of people with a set of medical symptoms—thousands around Australia who may all have thousands of different causative diseases—and managing that process. I am here today to say that although we accept that these things occur—we could debate for hours on all the causative organisms that might present a chronic fatigue or Lyme disease-type syndrome in a patient because there are a great number of them. The first thing that happens is that everyone says, “They haven’t found anything so nothing is wrong with you.” The critical thing is that we do not say that nothing is wrong. We need to be cautious that at the end of the process, as we should do with chronic fatigue syndrome, we should not be telling those people that nothing is wrong with them. Their bodies have probably reacted abnormally to some sort of infective organism, although it does not have to be an infective organism; toxins can do a similar thing on occasion. Heavy metals can certainly do something quite similar. The build-up and concentration of lead is an example, as people in Esperance found out when birds started dropping out of the sky. Bear in mind, I understand that Russian toxins can do something similar as well. A whole range of things can deliver this set of outcomes, so we need to be particularly cautious that we do not raise expectations that we will find a singular biological cause for a general set of syndromes that may well have thousands of individual causes. It is very difficult for members of Parliament and politicians because everybody comes in wanting an answer. I have met with a number of people who are adamant that they have Lyme disease. I have to sit down and go through the process if they have not had a blood test done in an accredited laboratory. I agree that Australian laboratories and Western Australian laboratories should be the place to go, but there are doctors who are prepared to say, “Don’t listen to Australian laboratories. We’ll find you a lab that’ll give you the

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diagnosis that you want.” This debate particularly falls down when the doctor gives in and says, “We’ll get you the diagnosis you’re after”—enormous damage gets done. I caution that we may never get to a single organism cause. The motion calls on the need for more work, which is great.

**HON COLIN de GRUSSA (Agricultural)** [11.14 am]: I want to thank Hon Alison Xamon for raising this very important issue for debate in the house. It is absolutely vital that we as a state and a nation recognise the illnesses, debilitation and suffering that people go through because of a Lyme-like disease or Lyme disease itself. For me, it is important out of this debate, first and foremost, that there is recognition, as well as research and treatment options available for people. To give a bit of context, I will share a story that was sent to me yesterday from a friend of mine in Esperance. I will share that story about her Lyme journey. It states —

My name is Nathalie ... I am 46 years old and live in the small country town of Esperance. I started having some weird symptoms in February 2016—including fatigue, dizziness and not being able to think straight. These symptoms were so strong and distinct that I knew something was very wrong, as I had always been fit and never having any health issues before.

I went to 3 local Doctors and received 3 different diagnoses:

1. Chronic Fatigue Syndrome
2. Fibromyalgia
3. Depression.

These diagnoses were provided without any further testing, any differential diagnoses, nor were I given any referrals to any specialists and the only treatment options I was given anti-depressants.

These diagnoses didn’t feel right to me, mainly because these diagnoses came from very limited discussion, limited testing and very limited investigation, also it did not match my history—I have never suffered from any mental condition before nor any physical ailment—In fact, I was a triathlete and marathon runner. I felt more like these doctors were only trying to fit me in a box where they could justify not helping me out further because they did not have any idea.

Only by chance, posting on a facebook about my health issues, another user said that my symptoms sounded like they could be ... lyme like she had and I should see a Lyme Literate MD and get tested.

I looked for such a doctor, only to be shocked ... that only one existed in Western Australia—and his patient waiting list was 6 months. Luckily, I got in fairly quickly due to a cancellation.

Finding such a doctor without help would have been virtually impossible and since talking to other Lymies I have found that on average it takes people 9 years to find such a doctor and I know many people that have been sick with Chronic Lyme for over 20 years before they were diagnosed. The thought that this could have been me also horrifies me.

In April, —

In 2016 —

this doctor sent my blood for testing at NATA accredited Australian laboratory (St John of God) and a well-known accredited German laboratory.

My blood came back with a positive ELISA IgM (known to be a very poor test) and a positive Western Blot IgM for borrelia—the Lyme bacteria, from the NATA accredited Australian Laboratory.

Nathalie tested positive to *Borrelia*, which is known as the Lyme bacteria, in an accredited laboratory. Her story continues —

Much debate has been had on where I contracted Lyme, with one possibility being Peru many years ago, triggered by the stress of when I gave birth to my son and over exercising—as there is no consensus on that it can be contracted in Australia. However, I have now meet many people that have not left Australia that have also been diagnosed with Lyme.

However, it does not seem to matter whether I did get bitten overseas or not as when I go to hospital, if I mention that I have Lyme, I am subjected to not being treated properly and getting treated like I have a mental condition—with the doctor using his time to argue the fact of whether Lyme exists rather than to treat me. They never ask where overseas I got bitten—they just argue that I can’t possibly have Lyme because it doesn’t exist in Australia.

My current treatment is long term antibiotics, but I am looking into overseas treatment because I know of people that have recovered by doing Hyperthermia (in Germany), Hyperbaric and Ozone treatment.

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Chronic lyme symptoms are constant they do not “give you a break”—having Chronic Lyme is like having my life stolen away and having to fight to get it back every second of the day and night, while still trying to be a mum to a 4 year old and a wife AND while having to constantly convince people you are really sick.

Since little is known about Chronic Lyme in Australia, I don’t get the understanding and support I need (that other seriously ill people get) to cope and fight this illness.

I know I am not as sick as other Lymies but I am still scared.

I am scared for my future — I don’t know if I will get better, even with access to antibiotics, and I don’t know if my doctor will be targeted ... banned from treating Lyme disease (which happened to a number of other doctors in Perth ...

I am scared that if I need to go to the hospital that I won’t receive proper treatment (I know many Lymies refuse to go to the hospital regardless of how sick they get due to previous bad experiences).

I am scared that I will run out of money treating this disease.

To know so many 1000s of other people are suffering from Chronic Lyme in Australia without basic recognition and support from the Government and health departments is unbelievable and certainly unconscionable.

That is one story. Obviously, there are thousands more. One of the most interesting points that Nathalie made was that she tested positive for the *Borrelia* bacteria through a National Association of Testing Authorities–accredited Australian laboratory but still cannot get treatment.

**Hon Dr Steve Thomas:** You did say that it was a Western blot test though, didn’t you?

**Hon COLIN de GRUSSA:** A Western blot test, yes.

**Hon Dr Steve Thomas:** The scientific papers say they are quite unreliable.

**Hon COLIN de GRUSSA:** According to the research I have looked at, it is recognised as the most reliable test.

She was diagnosed with that bacteria and still cannot get treatment. I listened intently to what the parliamentary secretary said in her contribution about how other tests would be done. There may be a pathway for this person and perhaps we can have a discussion about how she might be able to get some treatment.

I again thank Hon Alison Xamon for raising this very important debate that we need to have. I hope that we can, as a Parliament, encourage this government to take an active role in investigating Lyme disease and Lyme-like illnesses.

**HON ALANNAH MacTIERNAN (North Metropolitan — Minister for Regional Development)** [11.21 am]: I also want to thank Hon Alison Xamon for raising this issue. I think it is interesting that the three members opposite who have risen have all been country members because this condition seems to differentially affect people from regional areas. That tends to lead one to think that it might be something coming from their specific environment that causes the set of very alarming symptoms that so many Western Australians and Australians are experiencing.

I was in federal Parliament when this issue emerged, which led to the referral to the Senate’s Community Affairs References Committee. As Hon Colin Holt said, the work of the Lyme Disease Association of Australia is pretty extraordinary. I have met people from across Australia who are involved in this group and one of the things that absolutely impressed me is that we are talking about highly intelligent people. One of the themes that comes through that really disturbs people who suffer from this condition is an implication that they are somehow troubled individuals who have mental illnesses and who are seeking to look elsewhere for a cause of their emotional and perhaps psychosomatic conditions. In my experience, the group is made up of almost extraordinarily exceptional people. Maybe these are the ones who get involved in the association. A young fellow, the son of a friend of mine—Louis Marchant —

**Hon Alison Xamon** interjected.

**Hon ALANNAH MacTIERNAN:** I think he might have some association with the member’s team, although I do try to get him to move across to the side of rightness!

Louis and his uncle were tarping in Cunderdin, I believe it was. When they came back from the weekend, they thought they had several tick bites. Some weeks after, they both started to develop the classic symptoms that were described by Hon Dr Steve Thomas—lethargy and pain—and the extraordinary thing is that this has endured for years. The story that was set out by Hon Colin de Grussa seems to be the standard experience for people who present to their general practitioners with these sorts of conditions.

**Extract from Hansard**

[COUNCIL — Thursday, 29 March 2018]

p1418b-1426a

Hon Alison Xamon; Hon Alanna Clohesy; Hon Colin Holt; Hon Dr Steve Thomas; Hon Colin De Grussa; Hon Alannah MacTiernan

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While I was in Canberra, I had a policy of employing ex-Western Australians who were at the Australian National University to do part-time work and I employed an incredibly smart young guy, who was an intern. He revealed that he had had Lyme disease following a camping trip when he was 12. He was bedridden for four years. He could not go to school but, obviously as testament to his incredible intellect, when he finally went back to school he managed to do extremely well and excelled in his final year of school and is completing his degree at ANU. These are extraordinary people. They are not people who are looking about for some reason to explain why their life is not going well. I urge us not to trivialise this.

I understand totally that this is a challenging issue in a scientific sense. It has certainly been very, very difficult to find the *Borrelia burgdorferi*, which is associated with European Lyme disease. It is possible that our ticks have an entirely different set of bacterium that is capable of engendering this problem. When I was in the federal Parliament, one of the things that fed into the response from the federal government and that the parliamentary secretary referred to was a team of scientific researchers from Murdoch, Curtin and Sydney Universities, led by Professor Peter Irwin of Murdoch University. They investigated, among other things, whether Australian ticks carried organisms that can trigger Lyme-like diseases. It is quite interesting because they were looking at that particular form of *Borrelia*, which is classically associated with this condition in the northern hemisphere. However, it is important to note now that people are thinking that it is probably not just one particular bacterium but that a cocktail of bacteria is involved, and it has led to this definitional issue.

The research team conducted 196 tests on ticks, mainly from the northern beaches of Sydney. They found no evidence of the *Borrelia* but one tick carried a single isolate of *Borrelia* bacteria, which is linked to relapsing fever. They were not able to give a clear idea of the significance of this, but this isolate of *Borrelia* is linked to “relapsing fever *Borreliae*”, which includes all the symptoms we have spoken of—fever, lethargy, myalgia, photophobia and facial palsy. I guess we are seeing in science much of our Australian biome, which, of course, is an issue in agriculture. How well do we really understand our Western Australian soils; how well do we understand the microbial life here? I see my good friend Hon Jim Chown getting upset because I am saying let us have a look at some of these micro rhyzobius that exist in our soil and see what are the benefits of them to farming. We might not have to pay chemical companies large amounts of money; we might have something already here that we could utilise. It is really very important that we keep our minds open to this. We should certainly not typecast people who genuinely present with these symptoms as suffering from some sort of mental health problem.

I am really pleased that the research is continuing. We certainly do not have the answer. It may well be, as Hon Dr Steve Thomas said, that we might never find the answer, although looking at the huge amount of scientific data and the rate at which analysis is done leads me to some optimism that at some point we will find the Australian cocktail involved.

Motion lapsed, pursuant to standing orders.