

12/12/2015

Committee Secretary  
Senate Community Affairs Reference Committee  
PO Box 6100  
Parliament House  
Canberra ACT 2600

Dear Sir/Madam

**Re: New enquiry - Growing evidence of an emerging tick-borne disease that causes a Lyme like illness for many Australian patients**

Summary of submission:

- **You can't diagnose what you don't think about:** This is about training Australian doctors to 'see' insect borne infections, to understand the considerable complexities of the illnesses that they cause, and the tenacity and compassionate understanding that will be required of them to treat them effectively.
- **You can't diagnose what you cannot confirm:** This is about training Australian doctors to know when pathology testing is not required to treat an insect borne infection, training them what to ask for when ordering pathology tests (so they can be confident that they are covering all the bases), and training Australian Pathology labs how to use the best possible tests, and how to provide better information to doctors and patients on their pathology reports.
- **You can't treat chronic illness with 10-minute, dispensary medicine:** This is about helping Australian doctors to appreciate that tick-borne infections cause a COMPLEX of symptoms and illnesses, and that treatment may be very long term and will involve multiple therapies. Those who are obliged to practice ten-minute, industrial medicine will have to be able to refer their patients to someone who has the time to build a relationship with the person, provide continuity of care, and who can spend the time necessary to understand, support and treat the multiple difficulties their patients will be experiencing.  
It is about an understanding that a little bit more money has to be invested as early as possible, into diagnosis and treatment to prevent a catastrophic cascade of dependency that imposes entirely avoidable costs on the state at a later date.

**In my submission, the words 'Lyme Disease' are used for classic Lyme Disease and its co-infections, one or more of its co-infections only, as well as any as - yet undiscovered Australian tick-borne infection that causes chronically fatiguing and/or neurological/neuropsychiatric illness.**

## **Background:**

In 2007 during a period of intense stress, I experienced a physical neurological symptom (left foot drop), but severe fatigue and other vague symptoms had preceded the foot drop for many years. For nearly two years, I remained in diagnostic limbo land. During this time, my research indicated that the symptoms I was experiencing were most closely aligned to what is known as Lyme Disease. My history of tick bites and other insect bites both in Australia and overseas, indicated that it was entirely feasible that I had a chronically fatiguing neurological illness caused by one or more tick (or insect) borne infections.

I asked for a 'Lyme' test, was given the ELISA test, and was told it was negative. As far as orthodox Australian medicine was concerned, that was the end of the road for an investigation of tick-borne infection. I had hit the infamous Australian diagnostic dead end.

By early 2009, I was suffering considerable disability without any lesions yet visible on MRI. I was referred to specialist neurologists in Sydney, and it was felt that there was evidence of 'subtle changes on MRI'.

The diagnostic protocol for MS (possibly uniquely) insists on disease activity becoming entrenched before a diagnosis is confirmed. In April 2009 I was given a diagnosis of MS, and because of my age and gender was told it was likely to be progressive MS, that there were no approved treatments, and that I was likely to get progressively worse, as the name implied.

A little over a year later I did get dramatically worse, but after asking for a course of oral steroids and recovering a lot of function, I was told that this was demonstrating a distinct attack followed by remission which indicated a probable relapsing remitting course, and I was given access to an injectable disease modifying drug that is approved for this type of MS. By this point I had waited a little over three years, whilst whatever was provoking my symptoms was having a field day in my body.

MS drugs are not curative, do not prevent progression and nor do they necessarily treat symptoms. In fact, many of them come with a range of side effects which add an extra layer of miserable drug induced symptoms to whatever MS symptoms are already plaguing you. Some of the side effects are quite serious (like death for example).

MS drugs seem largely based on the unproven 'autoimmune' theory of MS, and so either seek to suppress or 'modulate' the immune system. The word 'modulate' is used, because for at least one of the drugs used for MS, the literature admits that it is not known how it 'works'. Of course, if neurological symptoms are being caused by a chronic infection, suppressing the immune system is probably the worst thing you can do.

I got considerably worse on the injectable MS drug, so a new oral drug was tried. I still got worse, so a second new oral drug was tried, and when I continued to get worse, I was told I was experiencing a progressive course after all, and I had reached the end of the line for treatment.

After three years on disease modifying drugs I experienced a rapid decline. In short order, I lost my job, my driver's licence, and my capacity to walk. I was 'living' in a miasma of pain and fatigue. I could understand the straightforward paralysis that is expected of MS, but I didn't understand why I felt so SICK all the time. It was like having a constant case of the flu.

Left to my own devices, my research again kept bringing me back to Lyme disease. Lyme is called 'the great imitator' and I had all of the Lyme Disease symptoms that overlap with MS, but

significantly, I also had Lyme Disease symptoms that did not overlap with MS symptoms. Fortunately, I found a Lyme Literate Medical Doctor (LLMD) and although it was difficult for me to travel, I travelled many hours there and back to see him. In order to be properly tested for Lyme and co-infections, blood had to be sent at huge personal expense to an overseas lab. It came back positive for Borrelia species, and I have also tested positive for three co-infections.

It was clear that I had been carrying the infections from well before my MS diagnosis, and it had gone untreated for six years after the MS diagnosis, so what we were looking at was LATE STAGE LYME DISEASE (COMPLEX). That is, chronic intracellular infections that have gone untreated for years or decades and which were now deeply entrenched and causing all sorts of havoc both physically and neurologically in multiple body systems.

Coincidentally, my GP had referred me to a new neurologist. He had worked overseas and was allegedly interested in an infectious cause for MS. Greatly hopeful, I showed him my positive tick-borne infection results.

I asked him if I had walked into his rooms 8 years ago when I had my first symptom, if he would have considered Lyme Disease as a differential diagnosis. He said no, never considered it, never crossed his mind.

Holding my positive serology in his hands, he told me that he doubted it was in Australia. I believed I had contracted a tick-borne infection in Australia, but I had also travelled overseas, and he hadn't asked about overseas travel, so I asked him whether, despite his scepticism that it was in Australia, what he thought about it being in my body?

Still holding my positive serology in his hands, he told me that he had never seen a Lyme Disease patient in his offices, but if he did, a short course of antibiotics should clear it up.

**This is what we are facing in Australia. If even a specialist neurologist with experience in countries where Lyme is common, and who is interested in an infectious cause for MS is so dismissive of Lyme or Lyme-like illness, and doesn't even consider it as a differential diagnosis for MS, even though Australians love to travel, then what chance do patients with a Lyme-like complex of illnesses have in this country? I would suggest that currently, if it was not for a handful of LLMD's it would be Buckley's or none.**

I left the neurologist's office with a confirmed diagnosis of progressive Multiple Sclerosis. I accept I have a diagnosis of MS. I also accept I have a diagnosis of chronic intracellular infections which can mimic all of the symptoms of MS, and although I have obviously had them undiagnosed for many, many years, they are still treatable. I often wonder how different things might have been if I had been given a comprehensive investigation for chronic infections early on in those first two years while I was still waiting for a diagnosis, and had received treatment, support and physical rehabilitation.

**Chronically fatiguing and neurological/neuropsychiatric tick-borne infections need to be a standard part of the diagnostic process of elimination (differential diagnosis) for suspected MS as they are in other parts of the world.**

### **YOU CAN'T DIAGNOSE WHAT YOU DON'T THINK ABOUT:**

In order for an Australian Doctor to diagnose Lyme Disease, it has to be something that crosses their mind. Lyme disease was not even recognized in America until 1975 and the Lyme Spirochete was not isolated until seven years later in 1982. My family doctor advised me that he did not study Lyme Disease at medical school. But in my view his job was to send me to a neurological specialist, not necessarily to diagnose me beforehand. It was more the job of a neurologist to look at any and all chronic infections that might be causing my symptoms, or at least refer me to someone who could. But as we have seen, even a neurologist may not consider Lyme Disease as a possible cause of chronically fatiguing or neurological/neuropsychiatric illness in Australia.

**The first hurdle is the name itself.** Australian Doctors have been told that Lyme Disease does not exist in Australia, so why would they even look for it? And even though Australians travel a lot, an Australian doctor would have to be extraordinarily aware in order to diagnose this illness, which will present so differently depending on how long a person is infected, and their individual immune response.

From a patient's perspective they don't care what the disease is called. If a person has all the symptoms of Lyme Disease, but the doctor cannot diagnose that disease because it doesn't exist here, then they will go home with their unbearable pain, tremors, seizures, sensory sensitivities, weakness, paralysis, exercise intolerance, headaches, flu-like symptoms, crushing fatigue, anxiety, depression (and on, and on) and may simply be left to rot away until they die.

Let's not get hung up on the name. Let's get hung up on supporting and treating these patients while we find out what is causing their symptoms.

MS has no known cause or cure, but that didn't stop people naming it. It has been nearly 150 years since it was named, but the lack of a causal agent has not stopped patients being offered help. It is a real disease, there is understanding for those who suffer from it, and support and treatment is offered.

So let's find a name for the mysterious Australian tick-borne infection that causes chronically fatiguing and neurological/ neuropsychiatric illness in this country. Then, whilst medical science is looking for the cause, lets offer understanding, support and treatment for it.

**Note: It needs to be understood that this illness may be caused as much by the patient's own immune response to the causative agent, as by the causative agent itself. We may not be looking for just one infection. Many different infections may provoke the same response.**

**The second hurdle is alerting Australian doctors as to what to look for.**

Firstly, Australian doctors need to be looking for classic Lyme Disease that was acquired overseas. The presentation may be different depending on whether it was acquired in America, Europe, or Asia. Secondly, Australian doctors need to be looking for "the mysterious Australian tick-borne infection that causes chronically fatiguing and neurological/ neuropsychiatric illness" in this country. A regular GP would have to devote an impossible amount of time to thoroughly understand the implications of this illness once it becomes chronic. Instead, they need to be able to spot it as a potential diagnosis, and send the person to the most appropriate specialist. If it is a recent infection, they need to be confident enough to treat it quickly, if a referral will take too long.

Anecdotally, neurologists and infectious disease specialists may not be the best people to send them to at this point. A LLMD is likely to be the only professional with sufficient expertise to diagnose and treat this complex properly, unless we start training neurologists and infectious disease specialists in a very special way.

Neurologists and infectious disease specialists deal with the whole gamut of neurological and infectious illness. Lyme complex is a specialty in itself. LLMD's often devote themselves almost exclusively to one disease complex, so they can actually know the disease inside and out, backwards and forward.

**The third hurdle is the reliability of tests...**

**YOU CAN'T DIAGNOSE WHAT YOU CAN'T CONFIRM:**

Suspecting an illness exists because of a medical history and clinical presentation is one thing, but where a pathology test exists, a positive test is usually required to make a confident diagnosis. As currently dictated (and I use that word advisedly) Lyme testing in this country seems to stand in the way of diagnosis.

In endemic areas, a tick bite followed by a bullseye rash with symptoms is sufficient to make a diagnosis of Lyme Disease, but not in Australia, because (remember) Lyme Disease doesn't exist here. In Australia, tick bite followed by a bullseye rash, or any other kind of rash means nothing, even if followed by the horrifyingly disabling symptoms of classic Lyme Disease. You may slowly waste away and die, but the tick bite and rash are not linked to the symptoms in this country.

However, until this changes, Australian doctors have to be made aware that tick bite followed by a bullseye rash in patients who have travelled to Lyme endemic areas, is definitive for Lyme.

It also appears that it may not even be possible to be diagnosed by an Australian Pathology lab in Australia if you have not been overseas, because (remember) Lyme disease does not exist here.

Australian Government guidelines on overseas acquired Lyme Disease were published in late 2015.

[http://www.health.gov.au/internet/main/publishing.nsf/Content/ohp-lyme-disease.htm/\\$File/Aust-guideline-diagnosis-overseas-acquired-Lyme-disease.pdf](http://www.health.gov.au/internet/main/publishing.nsf/Content/ohp-lyme-disease.htm/$File/Aust-guideline-diagnosis-overseas-acquired-Lyme-disease.pdf)

The document frankly states: "classical Lyme disease cannot be acquired in Australia".

This means that if you have not left the country and are bitten by Australian ticks and get sick with Lyme symptoms, it is not possible to be diagnosed with Lyme Disease in Australia (by Australian Government dictate), even if you do have Lyme Disease. Surely this is not scientific?

If blood from sick Australians is sent to an Australian lab (where the government has declared it does not exist), and to a highly respected, highly certified lab in America and/or Europe (where Lyme is accepted to be endemic), and the Australian test comes back negative for Lyme, but the overseas test(s) come back positive for Lyme, what are we to think?

How are people in America and Europe diagnosed using these labs, if the Australian medical industry regards their testing regime as inferior, or otherwise suspect?

If the person has never left Australia and their test comes back positive, is that necessarily a false positive? If the person has never left the country, will they be denied a Lyme test in the first place, because the government says it doesn't exist here?

The anecdote on this website outlines this phenomenon:

[http://blogs.abc.net.au/nt/2014/03/thousands-of-australians-have-lyme-disease-and-dont-know-it.html?program=darwin\\_afternoons](http://blogs.abc.net.au/nt/2014/03/thousands-of-australians-have-lyme-disease-and-dont-know-it.html?program=darwin_afternoons)

The anecdote tells us of the person who was tested for Lyme in Australia, then told that the positive serology must have been a false positive, because Lyme does not exist here. If that is the attitude, why test at all? This attitude means that in Australia you essentially can't test positive for Lyme Disease, even if you have got Lyme Disease.

In this case, Lyme will never be found to be endemic to Australia by pathology testing, because you cannot find what does not exist.

Lyme Disease is emerging in many countries now, where it was not known to be present previously. Why not Australia?

This paper discusses a mysterious species of spirochete found recently in Brazil, but it is so hard to isolate and test for, that it still remains mysterious. Nevertheless, it exists, and is making people very sick with classic Lyme-like symptoms [http://www.scielo.br/pdf/ramb/v56n3/en\\_v56n3a25.pdf](http://www.scielo.br/pdf/ramb/v56n3/en_v56n3a25.pdf)

This paper in the Lancet discusses the multiplicity of emerging tick-borne infections in China:

[http://www.thelancet.com/journals/laninf/article/PIIS1473-3099\(15\)00177-2/abstract](http://www.thelancet.com/journals/laninf/article/PIIS1473-3099(15)00177-2/abstract)

It states: "The non-specific clinical manifestations caused by tick-borne pathogens present a major diagnostic challenge and most physicians are unfamiliar with the many tick-borne diseases that present with non-specific symptoms in the early stages of the illness. Advances in and application of modern molecular techniques should help with identification of emerging tick-borne pathogens and improve laboratory diagnosis of human infections. We expect that more novel tick-borne infections in ticks and animals will be identified and additional emerging tick-borne diseases in human beings will be discovered." How is it that the Chinese are enthusiastically looking to further their knowledge of tick-borne infections, but Australian patients are having to fight every inch of the way to get the Australian Government to look into this?

Since the 1980's in China, 33 emerging tick-borne infections have been found, 15 of which cause human illness. The technology which allows scientists to detect these infectious agents is improving.

If these infections are 'emerging' overseas, what makes us think Australia is immune? Animals have been brought here from overseas since European arrival, and migratory seabirds visit. Some animals are probably imported illegally, and others escape from ships and in cargo. Apart from infectious agents that are brought here, we may well have several of our own indigenous infectious agents in our ticks that remain to be discovered.

The infectious agent may not necessarily be in ticks alone, but may well be in some other vector.

But there have been several scientific enquiries already which have found Borrelia species in Australian ticks, (including an indigenous species (*Borrelia queenslandica*) and the tests that have been held up to deny that Borrelia is found here, have been criticised for not testing for all of the relevant species. One study apparently found spirochetes, but these were eventually dismissed as 'artefacts'. If the testing process could be confused by 'artefacts' how reliable was the testing?

Dr Peter Mayne published a paper where he documented the discovery of *Borrelia burgdorferi* species isolated from erythema migrans rashes on Australian patients bitten by Australian ticks  
<http://www.ncbi.nlm.nih.gov/pmc/articles/PMC3426269/>

Recent testing of Australian ticks by Peter Irwin using advanced methodology detected an unknown *Borrelia* species, probably from the relapsing fever group. This website notes that late stage (untreated) relapsing fever caused by *Borrelia* species can cause meningitis, cranial-nerve palsies, encephalitis, hemiplegia, seizures, coma, paresthesias, radiculopathy, insomnia, hypersomnia, narcolepsy, catalepsy, cognitive deficits such as impaired memory and impaired concentration, dizziness, polyneuropathy, extra pyramidal symptoms, tingling, Bell's palsy, dysarthria and dysphagia, gait disturbance, flaccid paralysis, depression, paranoia, anxiety, panic attacks, hallucinations and photophobia: <http://www.karlmcmannusfoundation.org.au/lyme-disease-borreliosis-relapsing-fever>

Dr Irwin has been quoted as saying that the testing protocols are inadequate: "Dr Irwin said a lack of diagnostic services for Lyme in Australia meant the disease was nearly impossible to detect accurately. "It's difficult to diagnose Lyme because there's no single definitive blood test you can do," he said. "There are loads of tests which give bits of an answer but nothing conclusive."

In that case, surely it would be wise to take a precautionary and supportive approach to patients who present with a medical history and clinical picture indicative of Lyme (particularly with any supportive serology), whilst working on a better testing regime?

How can the government say that classic Lyme cannot be acquired here? Classic Lyme is essentially about classic symptoms, and Australian tick bite sufferers certainly have classic symptoms, not to mention serology. What evidence will the government accept as proof positive that the Lyme spirochetes are in our ticks, if even positive biopsies of tick bite rashes is not acceptable?

Even if a doctor was to accept a positive Lyme test from an Australian tick bite, the difficulties of even getting a positive test in this country in the first place are multifaceted.

**Firstly**, it appears Australia follows CDC guidelines for diagnosis. CDC guidelines make it seemingly impossible to achieve a positive diagnosis for Lyme. You have to achieve a positive ELISA to be tested by Western blot, and you have to achieve a positive ELISA, and both positive IgM and IgG Western Blot serology by CDC standards to be considered positive for Lyme. If infection is suspected to be long term you must have an IgG response, and the guidelines instruct not to even test for IgM responses in that case. These guidelines assume that all testing labs are equally as thorough, that their tests are sensitive enough to detect all species of *Borrelia*, that their tests are standardised and comparative to other labs, that everyone will react in the same way to the infection, that there is no aberrant individual immune response, that Lyme does not modulate the immune system in ways that produce different test results in different people, and that the body's response to testing does not vary over time. The medical literature tells us that this is not the case.

So, irrespective of your clinical picture, medical history, or actual disease status, you may be denied treatment if the strict CDC criteria is not met.

However, the scientific literature is full of criticisms of the CDC testing regime, and full of explanations of situations where confirmed cases of Lyme Disease do not test positive under these criteria, and where the immune response changes over time. These documents are easily located by anyone who wishes to investigate this issue.

**Secondly**, the testing methods themselves have been criticised. The ELISA test is regarded as inadequate by LLMD's and not worth performing. Even people from Lyme endemic areas who have bullseye rashes that initially go unnoticed can fail the ELISA, and that means they reach a diagnostic dead end, and will be left to their fate as the disease destroys their mind and body. This short video (with sub-titles) from a French news service very neatly encapsulates the problems caused by this two tier testing regime.

<https://www.youtube.com/watch?v=ABji9ebeKf0&feature=youtu.be>

Not all species of *Borrelia* are tested for, and even in Lyme endemic areas, not every person who has the disease will show up as positive. When talking about 'Lyme' it has to be kept constantly in mind that we are not only looking for *Borrelia* species, but the many co-infections. When testing for 'Lyme' we need a 'Lyme panel' that tests comprehensively for *Borrelia* AND all of its co-infections.

When testing for *Borrelia*, my understanding is that Lyme-specific bands which only code for a part of the Lyme spirochete, can't be anything else. Given the horrific symptoms of late stage Lyme, even one positive Lyme-specific band should ring alarm bells and at least warrant further investigation.

This website outlines the problems with Australian testing protocols

<http://www.karlmcmannusfoundation.org.au/mkf-reply-to-r CPA>

**We need world's best practice Lyme and co-infections testing protocols, and we need to develop country-specific testing regimes, not slavishly follow anyone else.**

**Thirdly**, doctors who have studied the disease in depth, report that Lyme will modulate the immune system to suit itself, and some people have immune systems that do not respond as expected – those with primary or secondary immune deficiencies for example. This means that even people with confirmed Lyme infection may be seronegative when tested. Sometimes the immune system can only produce an IgM response, even years after infection, and this phenomenon seems to be closely associated with chronic or late stage Lyme. Some people will not seroconvert or test positive for Lyme DNA until they have been challenged by a course of antibiotics.

**We need to search diligently for the Lyme bacteria, using a multiplicity of tests if necessary, and we need to acknowledge that given the potentially catastrophic outcomes of missing a diagnosis, even one Lyme specific band should be enough to keep searching, until such time as we have access to tests that are totally reliable.**

Norwegian scientists have found a new method of microscopy to visualise *Borrelia* spirochetes. People who have tested negative using European pathology tests are being found to indeed be infected with *Borrelia* spirochetes, which can now be directly visualised.

[http://www.apollon.uio.no/english/articles/2013/2\\_borrelia.html](http://www.apollon.uio.no/english/articles/2013/2_borrelia.html)

**We need to add specialised microscopy techniques to our battery of tests to help detect the causative agent of Australian Lyme and Lyme-like illness. We need tests that are 100% accurate, not 75%, 50% or 25% accurate.**

**Finally**, when someone is tested for Lyme, there is no point just testing for *Borrelia*. All of the co-infections need to be tested for at the same time. Common co-infections include Babesia, Bartonella, Ehrlichia, Anaplasma, Rickettsia, Mycoplasma and Chlamydia pneumoniae.

**Pathology labs need to test using a 'panel' that includes all of the *Borrelia* species for which Australian patients are testing positive for at overseas labs, all of the co-infections, and to provide**



**good quality information with their results, and to suggest other tests that may be indicated by the pathology and symptomology, to make it as easy as possible for doctors to help their patients.**

**YOU CAN'T TREAT CHRONIC ILLNESS WITH 10 – MINUTE, DISPENSARY MEDICINE:**

The controversy over long term treatment of chronic Lyme Disease, late stage Lyme Disease, or post treatment Lyme Disease in America seems to be about insurance costs, where the natural desire of insurance companies is to capitalise profits and socialise costs. Many American states have had to pass legislation to protect doctors who treat this chronic disease long term.

In Australia, we also have a bizarre split private/personal system where profits are capitalised and costs are socialised, but not to the same extent. There is no need for us to embroil ourselves in the political difficulties of the American healthcare sector. In a country where healthcare and social welfare are essentially guaranteed by the government, it doesn't make any sense to fail to invest in a little bit of education, first class, totally comprehensive testing regimes, and effective early treatment protocols, to avoid the staggeringly high costs (not to mention personal misery) that the disability accompanying Lyme Disease inevitably brings.

The tick-borne infections that seem likely to produce Lyme Disease symptoms in Australian patients cause a COMPLEX of symptoms and illnesses. Treatment may be very long term and will involve multiple investigations and therapies.

We wouldn't expect tuberculosis or entrenched Q fever to be cured in a few days, so why would we expect Lyme Disease to be cured so easily, especially when it may have gone undiagnosed for years or decades?

Dr Richard Horowitz (USA) has had more than 27 years' experience with more than 12,000 Lyme Disease patients. He uses the MSIDS (Multiple Systemic Infectious Disease Syndrome) model to treat his patients. It has 16 points of investigation, of which treating infections is only the first. He notes that not everyone will have all of the sixteen points, but they all need to be ruled out, and where they are present, unless they are treated, the person won't get better. Dr Horowitz travels internationally, training both doctors and government officials in his treatment methodology. Perhaps he could be invited to Australia to advise the government on how best to help these patients, and to help save a fortune on disability support and lost productivity?

**Conclusions:**

Sometimes science in Australia and around the world seems to be about protecting a position, or protecting a belief system, rather than being open minded and expanding our knowledge. The men who discovered that stomach ulcers were caused by a bacterium, also discovered this anti-scientific side to 'science'. They were ridiculed.

Primarily, Lyme was not discovered because of scientists. It was discovered because of one strong woman who stuck to her guns and kept telling the health authorities that the symptoms that she, her family and her community were experiencing, must have a common cause. Even though she was ridiculed and sent for psychiatric assessment, she kept going. Why did she have to face such antagonism from a 'caring profession'? Why are doctors who try to help people with these long term chronic infections also treated aggressively and made to feel that they are on the fringes of their profession?

Chronic or late stage Lyme only needs intensive support because the patient has been misdiagnosed or neglected. If properly diagnosed and treated, we should only see chronic Lyme in those few patients for whom the infection persists for as-yet unknown reasons, and instead of ignoring those patients, we should be compassionately trying to find out why they react to the infection in the way that they do, and helping them through it.

In conclusion, I would like to summarise what I think are the key points to make things better for Australian patients with Lyme Disease.

- Education and training for Australian doctors so that they will have Lyme at the forefront of their minds, and be able to spot the possibility of this infection and refer patients on.
- Education and training for Australian specialists so that they will be able to treat and support people with the many manifestations of Lyme.
- The adoption of a chronic disease model for the treatment of Lyme and other chronic diseases. Richard Horowitz' 16 point MSIDS map may be a good starting point, but moving people to a chronic disease Medicare plan that allows them more time with their physicians would help too. The model should provide persistent, observational, investigational, integrated, holistic health care.
- Improve our testing regimes using best practice from around the world. We need to stop insisting that Australian labs know best, and have the best of the best from America, Europe and Asia come here, and train our pathologists in what to look for and how to do it, then keep communicating and innovating.
- Ensure that if a person is tested for Lyme they are automatically tested for a panel of the best Lyme tests as well as all of the other co-infections.
- Provide for the latest microscopy techniques to visualise the spirochetes and other infective agents.
- Ensure that patients who have a medical history and clinical presentation suggestive of Lyme, but a negative Lyme test and negative test for co-infections will be given further intensive investigation and medical support, not abandoned to their fate. This may include an antibiotic challenge and re-testing.
- Understand that the disease process may be as much about the patient's own immune response as it is about the direct effects of the infection, and provide immune support, rehabilitation and other supports to help the patient overcome it.

In the meantime, I would like to make the following suggestions:

- Please inform the public about the possibility of Lyme Disease symptoms following tick bites and the suspicion that there is a unique causative agent, or an as-yet undiscovered *Borrelia* species in Australia. Please give them somewhere to go for help. Please encourage them to ask for a comprehensive Lyme panel of tests, and if they do not test positive for Lyme and co-infections, to be referred to an infectious diseases specialist for intensive investigation and support.
- Please set up an ongoing study to encourage anyone with a recent tick bite that is followed by a rash to have the rash biopsied and tested for infectious agents. If the tick is still attached, please have that examined too.

- Please set up an ongoing study for people in Australia who have already been diagnosed with Lyme to be thoroughly examined and investigated (if they will participate) to further our understanding of the complexities of the illness, and how to treat it on all levels.
- Please consider that Lyme in Australia may include something subtler than direct infection, maybe something more akin to an auto-allergic reaction – something perhaps related to the recently discovered mammalian meat allergy that is caused by a protein secreted by our ticks.
- Many people with Lyme and other chronic illnesses are immobilised, and have difficulty attending appointments. Now that we are in the 21<sup>st</sup> Century and are supposed to be innovating, could we please embrace telemedicine, and at the very least, make Skype appointments Medicare rebatable?
- Please ensure that a Lyme Panel (Lyme and co-infections) plus other Australian infections that can cause chronically fatiguing and neurological/neuropsychiatric disorders becomes part of a standard differential diagnosis protocol for suspected multiple sclerosis.
- Please make proper testing panels and medical support for Lyme-like illness available on Medicare.
- Please consider supporting the creation of a medical facility for treating infection using heat treatment which has been pioneered in Germany. It replicates fever conditions, and raises body temperature above the limit that the infectious agents can survive. If we can replicate the treatment here, it will create a new Australian medical facility and save Australians the huge cost of travelling overseas for treatment.

Thank you for the opportunity to make this submission.