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My 29 year old sister Beki's life has been turned upside down and bought to a standstill due to suffering from chronic neurological Lyme disease that was diagnosed in November 2014. As a result of Beki's illness our entire family has also been impacted by watching Beki suffer and struggle on a daily basis and it is simply heartbreaking. We are also supporting Beki financially and also on many other levels to assist her with accessing medical treatment and making general decisions about her personal affairs when she is too unwell.

As a result of Lyme disease not being recognised in Australia we commenced a fundraising and awareness campaign in May 2015. We have raised almost $50,000.00 through fundraising to partially fund Beki's medical treatment however Beki's treatment in Australia so far (and all associated expenses including travel to consult doctors up to 1000 kilometres away and interstate) and a recent trip to the United States has exceeded $50,000.00 to date. Beki has been unable to utilise her private health insurance as Lyme disease is not recognised and also cannot obtain a Centrelink disability pension.

Beki's medical treatment in Australia has been difficult and lengthy and Beki was reviewed by over 10 medical practitioners and private specialists before obtaining a diagnosis. Beki is now under the care of her third Lyme literate doctor due to treatment restrictions and guidelines in Australia causing treatment problems for the first two Lyme literate doctors. On 29 January 2016 Beki's current doctor appeared to also be facing some potential threats from his clinic and the practitioner moved to a new clinic as a sole practitioner. Beki had to arrange back-up medical assistance interstate in Sydney from April 2016 (first available appointment) in the event that her current doctor faces further treatment difficulties.

On 20 February 2016 Beki travelled to the United States to meet with a world leading Lyme specialist given that such expertise and assistance is not available in Australia. Air fares with Beki's full time carer cost in excess of $4,000.00 and the medical appointment cost $2,100.00 with medication, supplements and blood testing costing an extra $2,000.00. The entire trip cost in excess of $10,000.00 including accommodation, train fares, living away from home expenses including meals and treatment/testing required to be performed in the United States.

Another fight that Beki is battling is gaining access to her superannuation Total & Permanent Disablement insurance benefits. Beki was working full time for the same employer for many years prior to becoming unwell and has significant superannuation insurance benefits however Beki has now been examined by a number of doctor for the insurer who agree that she is too unwell to work however they have taken the position that Lyme disease does not exist and if the real cause of Beki's symptoms could be found, and a diagnosis made, then she could receive appropriate treatment, recover and possibly return to work. Therefore the non-recognition of Lyme disease in Australia is causing doctors to argue that despite Beki having now seen more than specialists and undergoing every single blood test, scan and investigation possible she must suffer from another condition aside from Lyme disease or one that has not yet been discovered (even though she has a positive blood test from a laboratory in Germany and from a laboratory in the United States for *Borellia burgorferi*) and therefore there may be some treatment available. This is an entitlement that Beki should easily receive if Lyme disease was recognised as a disease in Australia.

If Lyme disease was recognised in Australia Beki could readily access medical treatment that is presently only available overseas, freely consult with medical practitioners in relation to treatment, utilise her private health care cover, access a Centrelink disability pension and access her superannuation insurance entitlements.

I have addressed each of the Senate Inquiry Terms of Reference below:

(a) the prevalence and geographic distribution of Lyme-like illness in Australia

The Centre for Disease Control (CDC) in the US has recently conceded that Lyme disease is under-reported and that there are 300,000 to 500,000 new cases every year. This make the disease twice as common as breast cancer and six times more common than HIV/AIDS in the US. Figures in Australia are not precisely known and it appears misdiagnosis particularly based on Australia's inadequate testing could reveal that the number of patients suffering is significant.

In Australia the Lyme Disease Association of Australia (LDAA) has almost 1,500 registered cases of Lyme disease however it is estimated that currently in Australia more than 15,000 people suffer from Lyme-like disease and conservative estimates suggest another 200,000 undiagnosed people. A large problem with not knowing the exact numbers is that Lyme-like disease mimics many other diseases and patients are misdiagnosed with other conditions before discovering they in fact suffer from Lyme-like disease many years later.

It appears there are geographical hot spots in Australia including the central coast of New South Wales and the Whitsundays/Rockhampton area given large numbers of patients in these areas have been diagnosed however it appears it is not just prevalent in coastal tick species as persons even in rural and regional Australia have contracted the disease.

This therefore reiterates that thorough testing of ticks in Australia from a variety of geographical locations and from all tick species (Australia currently has about 75 species) needs to be performed urgently.

(b) methods to reduce the stigma associated with Lyme-like illness for patients, doctors and researchers;

The stigma surrounding Lyme disease is not the type of stigma that is related to mental health issues for instance. The issue with Lyme disease is that it is not recognised in Australia and the Australian guidelines for the diagnosis and treatment of Lyme disease do not allow for adequate investigation, diagnosis or treatment which results in patients feeling unsupported and their legitimacy questioned, doctors feeling cautious and concerned and also fearful of judgment from other medical practitioners and other areas of medical practice and overall fearful of retribution.

In relation to researchers there appears to be two types of research going on – one to prove Lyme disease does not exist (and arguably incorrect testing methods are being used) and thorough and ground breaking research at the Murdoch University to test an extremely large sample of ticks collected and provided from all around Australia.

Initially the Australian Government needs to allow medical practitioners to investigate, diagnose and treat the illness that Australian people are developing following being bitten by infected ticks regardless of what the illness is. Medical practitioners needs to be educated about the occurrence of this illness to slow the rapidly growing epidemic. By taking these steps medical practitioners can diagnose and treat Lyme disease in the way they treat any other disease and issues of stigma associated with the illness will be instantly resolved.

Also the Australian Government needs to instigate, support and fund testing of Australian ticks so resolve conflicting research agendas and eliminate stigma of the type of research being performed.

The failure to recognise Lyme disease in Australia is what is causing the stigma and some simple steps as set out above can resolve this.

(c) the process for diagnosis of patients with a Lyme-like illness, with a specific focus on the laboratory testing procedures and associated quality assurance processes, including recognition of accredited international laboratory testing;

The process of obtaining a diagnosis with Lyme disease in Australia is tumultuous and almost impossible. Doctors in Australia are not educated about Lyme disease and some do not even know what it is or that it exists. If a doctor is aware of Lyme disease and willing to investigate/make a diagnosis they face repercussions for treating outside the Australian guidelines for the treatment of Lyme disease and understandably may be reluctant to do this.

Testing in Australia is not available to conclusively determine if a person suffers from Lyme disease. Accurate blood testing can only occur in Germany or the United States at a cost of at least several hundred dollars to the patient. I personally know of many persons who are not even able to access the overseas treatment as their medical practitioner in Australia will not sign the paperwork required to send a blood sample overseas and be associated with the testing. Patients however require access to the overseas testing as Australia testing only tests for a few strains of *Borrelia* whereas overseas testing tests for multiple strains of *Borrelia*.

In Australia a diagnosis is only accepted if it is obtained from a laboratory with NATA accreditation however NATA accreditation is based on CDC criteria and as set out below the CDC in the United States is infiltrated with corruption and personal financial motifs.

To date seven medical practitioners in Australia have faced disciplinary action for treating patients for Lyme disease and have had to cease patient treatment. This highlights not only the difficult process for obtaining a diagnosis but also the difficulty in obtaining and maintaining treatment from a Lyme-literate medical practitioner.

In 2013 Dr Andrews Ladhams in Queensland faced disciplinary action and the below is taken from the Australian Health Practitioner Regulation Agency:

- On 20 December 2013, the Medical Board of Australia (the Board) imposed the following conditions on the registration of Dr Andrew Ladhams (the practitioner)):

  1. For the purposes of these conditions, Lyme Disease includes any illness caused by an organism known as Borrelia burgdorferi (including any strains of that organism, namely Borellia garinii, Borrelia afzelii and Borrelia Burgdorferi (stricto senso)).

  2. The practitioner must not diagnose and/or treat Lyme disease without his having obtained a positive diagnosis of Lyme Disease from a laboratory accredited by the National Association of Testing Authorities (NATA) using Centres for Disease Control (CDC) criteria.

  3. The practitioner must not treat any patient for Lyme disease with intravenous antibiotics without having referred the patient to an Infectious Diseases Specialist for the development of a written Medical Treatment Plan. Before referring any patient to an Infectious Diseases Specialist, the practitioner must first obtain the approval of the Medical Board of Australia to refer patients to that specialist for that purpose.

  4. The practitioner must only treat any patient referred to an Infectious Diseases Specialist pursuant to condition 3 in accordance with the written Medical Treatment Plan developed by the Specialist.

  5. An AHPRA representative for the Board will contact and exchange information with the practitioner’s employer/ partners/colleagues in his practice and every person who is, or may be, responsible for booking consultations with the practitioner, at such time or times as the Board or its representative shall determine for the purpose of monitoring the practitioner’s compliance with these conditions.

  6. The Medicare Program, Department of Human Services, Australia and Private Health Insurance Funds are required to provide information to the Board or its representatives about the practitioner’s practice of his profession.

  7. The practitioner must allow an AHPRA representative for the Board to access, and prescribing records at his practice locations for the purpose of monitoring his compliance with the conditions.

As per condition 2 Dr Ladhams was restricted to only diagnosing and treating a patient with Lyme disease if they obtain a positive diagnosis from a laboratory accredited by NATA using CDC criteria. And secondly Dr Ladhams cannot treat a patient with intravenous antibiotics without having referred the patient to an Infectious Disease Specialist and even must obtain approval from the Medical Board of Australia before making a referral! The restrictions placed on this doctor for simply referring a patient to an infectious disease specialist or treating with IV antibiotics (a recognised treatment for Lyme disease) are onerous and restrictive.

The second issue with doctors facing possible conditions such as these being placed on them in that they can only make a diagnosis or treat a patient if a patient has a positive result from a NATA accredited lab is that NATA labs follow CDC criteria. The issue is that the CDC and IDSA in the US have both been fettered with corruption involving personal financial gain and Australia is mandating that doctors only treat persons diagnosed from a lab that follows guidelines set amidst corruption.

The Infectious Disease Society of America (IDSA) in the United States set the guidelines in relation to treatment of disease and Australia follows these guidelines. The IDSA recognises Lyme disease can develop following a tick bite but it only accepts that a few weeks antibiotic treatment is adequate and the guidelines stipulate that <u>chronic</u> Lyme disease does not exist. Connecticut Attorney General Richard Blumenthal investigated the IDSA panel members (who set the guidelines in relation to treatment of Lyme disease - and Australia follows these guidelines) for possible violation of antitrust laws and conflicts of interest. Of the 14 panel authors of the first edition guidelines: 6 of them or their universities held patents on Lyme or its co-infections, 4 received funding from Lyme or co-infection test kit manufacturers, 4 were paid by insurance companies to write Lyme policy guidelines or consult in Lyme legal cases, and 9 received money from Lyme disease vaccine manufacturers. Some of the authors were involved in more than one conflict of interest. (Source: ‘Under Our Skin‘ [2008])

(d) evidence of investments in contemporary research into Australian pathogens specifically acquired through the bite of a tick and including other potential vectors;

Research in Australia into ticks in Australia is outdated and limited. A very limited research study of ticks was performed in 1994 with a small sample of ticks collected from only the central New South Wales coast. This research is now 22 years old and apparently was arguably in any event was performed incorrectly.

In 2015 two studies testing 656 Australian ticks found Australian ticks contained at least 8 different bacteria, including 5 [novel] new species that have not been discovered elsewhere. In 2015 Professor Irwin’s research at the Murdoch University in Western Australia undertook initial research on a small sample of ticks from a very large sample awaiting testing and discovered a new strain of relapsing fever that has not previously been discovered along with other bacteria in a tick collected from an echidna. At that time almost only 200 ticks had been tested out of 20,000 ticks and Professor Irwin developed a new testing technique that resulted in identifying a relapsing fever strain that may be responsible for the Australia strain of Lyme-like disease. The same tick also harboured *Bartonella, Rickettsia* and *Leptospira*. Despite these findings the medical guidelines in Australia have remained unchanged and it has been suggested that this will not be accepted as a bacteria that is possible to pass to humans until it is identified in a human.

Urgent research in Australia into pathogens acquired through the bite of a tick and other potential vectors is needed to identify previously undiscovered pathogens and pathogens known to cause illness in animals and/or humans.

Australia’s Chief Medical Officer Dr Baggley published a report in 2015 stating, “The conclusive finding of a bacterium that could cause Lyme disease like syndrome in

Australia has yet to be made". It is not accepted that ticks in Australia carry the bacteria *borrelia* – although many people bitten who have developed Lyme disease have never left Australia. Borrelia bacteria were first identified in 1959 in Australia by the CSIRO, and there have been other positive reports since that time. The Queensland Health Department recognized Lyme disease in Australia until the early 1990s. Then mysteriously their policy was revised. Around this time the NSW Health Department provided advice that Lyme disease could not be detected in Australian ticks. Studies have proven persistent infection after antibiotic treatment for mice, dogs, ponies, monkeys, cows, iris biopsy and ligamentous tissue – yet late stage/chronic Lyme is still denied. Also following autopsies in Australia at least two reported cases of human *borrelia and babesia* have been documented.

(e) potential investment into research to discover unique local causative agents causing a growing number of Australians debilitating illness;

The Australian Government needs to acknowledge and assist with funding the work of Profession Irwin at the Murdoch University in Western Australia or invest in other research to discover *Borrelia* or other local causative agents causing debilitating illness in Australia.

(f) the signs and symptoms Australians with Lyme-like illness are enduring, and the treatment they receive from medical professionals; and

In 2010 Beki suffered a bulls-eye rash on her right ankle after several tick bites and presented at her local hospital for a diagnosis and treatment as she also had enlarged lymph nodes on the right side of her body and a general feeling of malaise. The rash was misdiagnosed as a spider bite and was marked with pen to determine if it was spreading. The rash continued to spread outside of the pen outline for over two weeks. During the two weeks Beki also consulted a GP as she continued to suffer pain down her right side and all lymph nodes on that side of her body were swollen. The rash was again misdiagnosed as a spider bite. Had the rash been properly diagnosed as a bulls-eye rash (the bacteria *Borrelia* is the only known pathogen to cause this type of rash) – Beki could have taken oral antibiotics for a few weeks and avoided becoming devastatingly ill and having her life threatened by Lyme-like disease.

Between 2010 and 2013 Beki developed various symptoms however once investigated they were blamed on various causes. For instance Beki was vomiting several times every day (up to 7 times) and experiencing excruciating stomach pain for 10 months and it was blamed on lactose intolerance. At the time the diagnosis for these symptoms (without any knowledge of Lyme disease) seemed possible but not a complete answer or entirely accurate. During the 2010 to 2013 period Beki also became unwell easily and suffered numerous colds and flus.

In mid 2013 Beki developed bruises all over her body (without being injured) and several different skin rashes. Lymph nodes in Beki's neck and arm pits also swelled to over two centimetres and she also had several large lymph nodes swollen at the base of her tongue making it difficult to swallow. Beki suffered from headaches, fatigue, ear aches, burning sensations, skin crawling and itching sensations, numbness, night sweats, unexplained weight loss and a cough. Beki's right hand also started to noticeably tremor and there was a noticeable right sided difference in Beki's symptoms which was the side originally affected by the ankle tick bite and bulls-eye rash in 2010.

By August 2013 Beki had to cease her job as a tour guide on a tourist boat in the Whitsundays that she loved and travel to Brisbane for intensive medical investigation over several months whilst living with our mother. Over several months in late 2013 Beki was reviewed by several specialists in an attempt to determine the cause of her symptoms and to obtain a diagnosis with the view to undergoing treatment to return to work and a healthy life.

Beki was initially reviewed by an infectious disease specialist at a private hospital who clinically diagnosed Beki with Hodgkin's Lymphoma and as a result Beki underwent a Gallium radium scan. This was clear however the infectious disease specialist continued testing for Hodgkin's Lymphoma. Beki then underwent a bone marrow biopsy and also a fine needle aspiration of a lymph node in her neck however these were again negative. As a result of the fine needle aspiration the Lymph node haemorrhaged and Beki developed a large haematoma in her neck. Beki was then told lymph nodes in her neck would need to be removed to confirm that she definitely did not suffer from Hodgkin's Lymphoma. Beki then had surgery to have lymph nodes removed for biopsy investigation and this returned a result of reactive follicular hyperplasia. Following this surgery Beki developed a second haematoma which then became infected and led to Beki being hospitalised with her neck re-opened and left open for four weeks and aggressive antibiotic treatment administered to overcome these complications. Beki is left with large scars on her neck from these procedures. The infectious disease specialist referred Beki on to an immunologist however the immunologist felt it was an infectious disease causing Beki's symptoms as nothing could be identified on Beki's blood tests or from any other investigations in regard to immunology. After undergoing a barrage of investigations, procedures and blood tests for every type of rare disease given her workplace exposure to overseas tourists Beki was informed that she suffered from a disease that had not yet been discovered and was told to return home and simply rest. Doctors commented they had never before seen so many large lymph nodes swollen at the base of a patient's tongue like Beki's.

In early and mid 2014 Beki's symptoms continued however Beki struggled slowly to return to work and built up from working initially one day a week to four days a week again. This took extreme determination but Beki loved her work and wanted her old life back. Returning to work however caused Beki's symptoms to flare and new symptoms to develop. Beki was on the verge of fainting up to five times a day whilst working at sea on her work tourist boat, she was taking multiple pain killers for severe pain and was developing large black bruises all over her legs. Beki's ill health became too risky to continue working.

After ceasing work in early 2014 Beki was then referred to two different ear, nose and throat specialists and a gastroenterologist as Beki's voice became hoarse and she had a large amount of lymph nodes swollen on the base of her tongue making it difficult to swallow. Beki was also suffering from a cough. A gastroenterologist investigated Beki's excruciating stomach pain that left her lying on the floor in agony for hours on end.

In late 2014 a family member informed Beki of a television segment on a patient with Lyme disease in Australia – Beki had come across this disease in 2013 when researching her symptoms however she was told by her GP and other doctors that it did not exist in Australia and there was no point in testing for it.

Beki then started to attempt to arrange blood tests to be sent overseas to Germany to accurately test for Lyme disease and another GP refused to sign Beki's pathology paperwork to allow the blood tests to occur stating that Lyme disease did not exist in Australia and even said that if Beki did have it there was no cure and therefore no point doing any testing. The GP then proceeded to tell Beki she had not been tested for the rare condition of Hepatitis E and arranged testing for that instead.

Between 2010 and 2014 not one single doctor willingly suggested Lyme disease or referred Beki's blood samples for testing allowing the disease to establish itself in her body and become a chronic infection.

Finally in late 2014 Beki found a GP willing to perform an Australian Elisa test for Lyme disease which returned negative as it is an inaccurate test that only uses one primer.

Beki came under the care of a Lyme-literate doctor in late 2014 who arranged for blood samples to be sent to Germany at a cost of $900.00AUD. Beki received a positive diagnosis for Borrelia burgdorferi.

In early 2015 Beki developed intermittent Bell's Palsy with the right side of her face drooping periodically. Beki could also no longer raise her right eyebrow with facial expressions.

In early 2015 Beki also sought a diagnosis for her hand tremor and for her hypokinetic tongue/tongue fasciculations and an explanation for hypo-profusion of both the frontal and left temporal lobes of her brain that was revealed on an SPECT scan of her brain from a neurologist in Townsville. The neurologist was arrogant, rude and dismissive and despite Beki failing some physical tests he ordered her to perform he declared she must have deep down buried anxiety that she was unaware of and it had manifested into neurological symptoms. He further explained that Beki had too many neurological symptoms to fit into any neurological diseases he knew of so therefore because he did not know of a disease with that many symptoms it had to be all self-manifested. He also went on to say that 'he is no expert on Lyme disease' but then gave Beki a lengthy lecture of the 'non-existence of Lyme disease or Lyme-like disease in Australia'. He also stated that even though Beki has travelled to America there is no way she could have contracted Lyme disease on this trip as people who contact it in America are diagnosed straight away. Beki asked why her tongue would be erratically moving in her mouth without intent and he said not to be concerned about it. Beki also asked why she has hypo-profusion in parts of her brain and he also said to forget about that test – even though it was a SPECT brain scan. The report that the neurologist sent to Beki's GP allegedly outlined the appointment but included false statements including a statement that he had looked at Beki's tongue and it was fine and that Beki had then bought up her concerns about her tongue and when he re-checked it the tongue was hypokinetic. However he had only checked Beki's tongue once the one time she questioned the symptoms involving her tongue and when she asked him to check it as he had not previously checked it. He also stated Beki passed a physical walk test however when Beki performed this test she was barely able to stand up and really struggled with the test.

In early 2015 Beki presented at her local hospital Emergency department suffering from extreme excruciating stomach pain that was no longer physically tolerable. Beki informed medical staff of her diagnosis with Lyme disease and she was ridiculed by staff. Beki overheard a head nursing staff member mocking her outside the treatment room and telling another staff member that 'she thinks she has Lyme disease' followed by laughing. This particular head nurse was so rude and rough with Beki's physical examination and pushed on Beki's stomach with extreme force unnecessarily resulting in extreme pain that caused Beki to scream out in pain. This treatment and behaviour was reported and dealt with by the head of the hospital.

In 2015 Beki was reviewed by a second infectious disease specialist at a public hospital in Brisbane and he believed Beki has developed chronic fatigue syndrome after infection with a bacteria or virus. Then in August 2015 Beki was hospitalised by a private respiratory specialist at a private hospital in Brisbane for worsening symptoms including breathing difficulties and Beki was reviewed by a third infectious disease specialist, a rheumatologist and a pain specialist whilst hospitalised. During this hospitalisation Beki was diagnosed with chronic asthma, eosinophilic oesophagitis, fibromyalgia, costochondritis, reflux and the third infectious disease specialist diagnosed Beki with non-specific connective tissue disorder/disease and stated Beki did not suffer from chronic fatigue syndrome as it is not a proper diagnosis and Beki is suffering from some form of illness. Beki mentioned her positive blood test result for Borrelia burgdorferi to the infectious disease specialist and he said it was a false positive, that her bulls-eye rash had been a neurotoxin from the tick (even though the rash remained and spread for almost three weeks) and lastly said as Beki had never developed a swollen knee or ankle (despite suffering pain in these joints) she could not possibly suffer from Lyme disease. Beki then asked his opinion on recent research results including a Borrelia strain of bacteria having been discovered in Australia and the specialist stated he was aware of the research and that the Borrelia bacteria found was from a tick on an echidna – he then mockingly asked Beki whether she had been cuddling echidnas.

Beki has been reviewed by more than 13 specialists (including three infectious disease specialists, an immunologist, a neurologist, a rheumatologist and others) since mid 2013 at significant financial expense and not once was Lyme disease raised or tested for until late 2014 due to Beki's persistent requests. This allowed the Borrelia bacteria in Beki's body to establish and affect many different parts of her body including her brain and as a result is making treatment of Beki's condition very difficult.

The Diagnosis

In September 2014 Beki received a positive diagnosis for Borrelia borgdorferi after sending blood samples to Infecto Lab in Germany for testing. Beki was also clinically diagnosed with the co-infections Bartonella and Babesia.

The Treatment

Between November 2014 and February 2015 Beki underwent five months of oral antibiotic treatment. This treatment made Beki incredibly ill and she suffered from vomiting and diarrhoea on a daily basis along with continued symptoms of tremors in both hands, brain fog, extreme head pressure, sound sensitivity, sporadic loss of words and thoughts in conversation, night sweats, chronic joint and muscle pain, severe tiredness and fatigue, skin itchiness, nerve vibration, numbness, pins and needles, nausea, skin rashes, constant headaches and migraines, loss of balance, limited mobility, nausea and nerve pain. The antibiotic treatment did however slow the fast progression and deterioration of Beki's symptoms. BL's treatment had to be stopped because her stomach was unable to handle the treatment and within a few weeks of stopping antibiotic BL's symptoms started progressing and deteriorating again.

Beki also had to commence a strict diet eliminating all dairy, sugar, carbohydrates and gluten resulting in increased meal preparation requirements.

In late 2015 my sister had to find new medical practitioners and along with her long term partner relocated from Airlie Beach to the [redacted] in September 2015 to enable Beki to access life-saving treatment. This meant Beki's partner being forced to leave a job he loved (with the same employer my sister also had to leave due to ill-health) and the financial security of an income to support Beki.

After moving Beki commenced IV antibiotic treatment and IV vitamin and mineral treatment along with hyperthermia treatment in an attempt to treat her condition in late 2015. As Beki's condition has reached chronic stages, and many different body systems are involved and is causing neurological symptoms, Beki was told that her treatment would be difficult and may not be successful. This treatment was not successful despite being horrendously physically gruelling on Beki's body and a large financial cost.

As a result of exhausting all options in Australia Beki travelled to the United States in February 2016 and has come under the care of one of the world leading Lyme disease practitioners. The practitioner was instantly able to point out why the treatment Beki had undergone in Australia had not worked as it was not correct and not thorough enough. The practitioner has devised a 12 month treatment plan for Beki that is intensive and multi-faceted and told Beki to expect improvement within just 7 days. After two weeks Beki has already noticed a reduction in her joint pain which has been beyond unbearable for almost two years and has even made her question wanting to live.

Beki's private health insurance has not been available to cover the costs associated with diagnosis and treatment of chronic Lyme disease due to the guidelines stating that Lyme disease does not exist in Australia. Beki's partner has also not been able to obtain assistance as a carer given Lyme disease is not recognised.

(g) any other related matters.

Australian practitioners are not allowed to treat chronic Lyme disease regardless of whether a person is bitten by a tick in Australia or overseas. It is not treated like other conditions such as malaria that is treated medically no matter the origin of where the disease was contracted. Medication that is subsidised for malaria is not subsidised for someone suffering from Lyme disease.

We regularly vaccinate our cattle against tick borne illness (including tick fever) and also treat our working dogs for ticks however tick borne disease occurring in people is not acknowledged or recognised. Cattle suffering from tick borne disease can be treated by antibiotics. And dogs. And other pets and animals. But not my sister or anyone else suffering terribly in Australia.

I have witnessed by sister suffer medically and watched the medical profession refuse to diagnose/treat or assist my sister with antibiotics (the only simple treatment available) as in Australia it is an act of malpractice to treat Lyme disease with antibiotics and of course understandably medical professionals do not want to lose their ability to practice and their hands are tied by medical guidelines.

I am desperate to initiate changes that would allow persons suffering and debilitated from Lyme disease to be diagnosed and treated in Australia and to raise awareness that infected ticks (also known as 'hot ticks' in the cattle industry) are passing diseases on to people following a tick bite.

My knowledge of Lyme disease has left me speechless, flabbergasted and downright disgusted that humans in Australia in this era could be treated in this way. It is unfathomable that a disease that is proven through positive serology on a blood test, and not a disease that could be a figment of the imagination, is simply deemed 'non-existent in Australia' and 'impossible to become chronic' – yet thousands of people have positive blood tests and are suffering terribly symptomatically with typical symptoms of the disease. Also we treat animals in Australia for these very conditions – but not humans.

Australia needs the following:-

(a) Recognition of Lyme-like disease in Australia (regardless of whether bitten in Australia or overseas).

(b) Adequate testing to enable patients suffering to be tested without necessitating blood tests to be sent overseas at significant personal expense.

(c) Education of the medical profession to enable doctors to be aware of symptoms, refer patients for accurate testing and make a clinical diagnosis especially given time is of the essence with immediate antibiotic treatment following a tick bite.

(d) Treatment for Lyme-like disease that is available overseas (Australia has hyperthermia used for cancer treatment however patients are unable to be heated to the correct temperate as this requires anaesthesia and this is not allowed in Australia for Lyme disease) and PBS subsidised medication for antibiotics used for the treatment of Lyme disease.

(e) Urgent research into ticks in Australia to determine the types of bacteria in existence.

I am very concerned about anyone working with livestock particularly cattle and horses (including myself) and people living and working on properties in rural areas who are sometimes exposed to ticks on a daily basis. People in urban areas are also exposed to ticks however from pets and animals and hobbies such as gardening and bushwalking.

Thank you for consideration of my submission.

Yours faithfully

Elisha Parker