LYME DISEASE
ASSOCIATION OF AUSTRALIA
For Lyme Disease Awareness & Action

A patient perspective

Submission to the Western Australian Sustainable Health Review on the Growing Evidence of an emerging tick-borne disease that causes a Lyme-like illness for many Australian patients, including those residing in Western Australia

Lyme Disease Association of Australia
OCTOBER, 2016

> *"In the fullness of time, the mainstream handling of chronic Lyme disease will be viewed as one of the most shameful episodes in the history of medicine because elements of academic medicine, elements of government and virtually the entire insurance industry have colluded to deny a disease. This has resulted in needless suffering of many individuals who deteriorate and sometimes die for lack of timely application of treatment or denial of treatment beyond some arbitrary duration".*
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> *Dr Kenneth B. Leigner*

S Whiteman

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Sustainable Health Review Secretariat
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EAST PERTH WA 6004

Via email SHR@Health.wa.gov.au

Dear Panel

Sustainable Health Review

Thank you for the opportunity to make a submission to the Sustainable Health Review and to the Panel for their time and efforts in this endeavour.

Please note, it has come to our attention that this review has not been advertised widely and we are aware that many medical practitioners and individuals would have liked to have had the opportunity to submit their response to the Panel. I note that in the ToR you state, "The Panel will invite submissions from the wider community through a public advertisement". Would you please advise the timeline of this advertisement and a closing date for further submissions? The LDAA would be happy to furnish the Panel with more information, and indeed any updated information, at that time.

Lyme Disease Association of Australia (LDAA)

The Lyme Disease Association of Australia is a small yet powerful registered charity and Australia's peak patient body for sufferers of Lyme (or Lyme-like illness) in Australia.

Mission

We are committed to achieving multi-sector recognition and world's best practice diagnosis and treatment for Australian Lyme and associated disease patients in Australia. The Association undertakes activities in six key areas: information, support, advocacy, education, awareness and research.

Aims

The aim of the LDAA is to:

Advocate for individuals and families living with Australian Lyme and associated diseases with governments, doctors and local communities;

Facilitate world's best practise patient care and support;

Represent the perspective, lived experience and interests of the Australian patient community;

Act as a conduit between international developments, research, treatments and other Lyme communities;

Fundraise to facilitate improvements for people living with Australian Lyme and associated diseases by supporting the education of doctors and other health professionals;

Fundraise to support research and innovation in epidemiology, diagnosis and treatment of Australian Lyme and associated diseases; and

Educate the public and medical sector about the risks of Lyme disease and the need for early diagnosis and treatment (early detection makes this an easily treatable disease).

What is Lyme disease?

Lyme disease is an infection caused by a bacteria known as Borrelia. The bacteria, a spirochete, is transmitted when an individual is bitten by a vector e.g. tick. Lyme disease can impact many bodily systems and organs and can, in some cases, mimic other illnesses e.g. Lupus. As well as giving people Lyme Disease, the ticks often also transmit other diseases (co-infections).

What are the symptoms of Lyme disease?

Lyme Disease is generally categorized into acute and chronic stages of disease, each with varying symptoms.

Acute Lyme disease

Flu like symptoms such as headache, fever, muscle soreness and unexplained fatigue.

Fewer than 50% of people with Lyme Disease develop the “bulls-eye” (or Erythema Migrans) rash a few days or even a few weeks after their tick bite (if they remember the bite).

Chronic Lyme disease

The following symptoms can be attributed to Lyme Disease when it has reached the Chronic stage of disease.

Unexplained hair loss
Headache, mild or severe, Seizures
Pressure in head, white matter lesions in brain (MRI)
Facial paralysis (Bell’s Palsy, Homer’s syndrome)
Tingling of nose, (tip of) tongue, cheek or facial flushing
Stiff or painful neck
Twitching of facial or other muscles
Jaw pain or stiffness
Dental problems (unexplained)
Sore throat, clearing throat a lot, phlegm, hoarseness, runny nose.

Background to our statistics

The exact number of people with Lyme disease in Australia is not known because our public health officials do not collect statistics about it. To change this situation, the Lyme Disease Association of Australia (LDAA) started to collect bi-annual statistics about the number of Australians with Lyme disease and their experiences in 2011. Full statistics are included in our patient survey reports. The reality of the Australian situation is plotted in our mapping available at http://www.lymedisease.org.au/stats/.

Patient surveys and statistical collection

As Lyme Disease in Australia is not currently notifiable so it is important the LDAA collects and collates necessary data to inform on-going strategy and development of necessary submissions and counter-arguments.

There is a lack of coordinated action to address the health issue affecting thousands of Australians when they are sick and have a tick bite history. For many patients, the situation is dire and requires urgent attention. Governments empty platitudes of compassion and inaction are offensive and do more harm than good, patients don't need words, they need action and the time is now.

Submission to the Australian Government

The LDAA has made submissions to the Australian Government's Senate Inquiry into Lyme-like illness in Australia and all submissions are freely available on our website at http://www.lymedisease.org.au/.

Under the Terms of Reference (ToR), we submit the following:

Summary of statistical information and recommendations:

1. Improve patient centred service delivery, pathways and transition

Clinicians discount the possibility of Lyme disease in their diagnoses because of an entrenched scientific position. This position is based on a single study of indigenous ticks and excludes other studies with positive evidence of Lyme pathogens. They have perpetuated the stance that Lyme disease cannot exist in Australia, regardless of travel history and symptom presentation in their patients despite there being no contemporary research for the past 20 years. They are also reluctant to consider diagnosing Lyme disease because of the controversy surrounding the disease. Patients suffer escalated discrimination and flat refusal by some doctors to even consider Lyme disease or testing for it. The LDAA recommends:

Implementation and early intervention strategy where infection is suspected. Administer early antibiotic treatment for a total of six weeks minimum;

The Western Australian Health Minister request the Australian Government's inclusion of pharmaceuticals regularly used in Lyme treatment protocols on the Pharmaceutical Benefits Scheme (PBS);

Implementation of a Western Australian strategy to reduce controversy and stigma associated with Lyme-like illness along with a strategy to train clinicians; and

Monitor the incidence of Lyme disease in the Australian population with the initiation of a State based surveillance program, in conjunction with an Australia wide program.

2. Maximise health outcomes and value to the public

Develop educational guidelines to the public for preventative measures, which will in turn lessen the burden on the health system.

3. Encourage and drive digital innovation

There are many physicians, both here and overseas, that are world leaders in the diagnosis and treatment of Lyme-like illness and partnerships with these people would circumvent the insular medical opinions keeping Australians sick and suffering and drive innovation in this regard. Skype, face time, the internet and a myriad of other technological advances remove any barriers to contacting physicians world-wide who are Lyme literate.

The International Lyme and Associated Disease Society (ILADS) offers physician training and research papers. ILADS promotes understanding of Lyme and its associated diseases and strongly supports physicians and other health care professionals dedicated to advancing the standard of care for Lyme and its associated diseases.

Partnering with these such organisations to drive innovation would be beneficial and costs minimised to the taxpaying public.

4. Partnership opportunities (duplication across government agencies)

Murdoch University is currently undertaking a pilot study of vector and waterborne pathogens using cutting edge, advanced DNA technology.

The LDAA would also be happy to be involved in any partnership opportunity in some form should it arise.

5. Improvements in safety and quality for patients

United Nation Human Rights

It is no longer appropriate for Australians to be denied medical diagnosis and treatment, and the stalling by health departments of denying that Lyme disease does not exist in Australia is no longer acceptable. The LDAA does not wish to enter into the politics of whether "Lyme" is the correct terminology for the illness we simply want action for sufferers.

> *The United Nations Human Rights Council Special Rapporteur outlined how his mandate could address these violations. The human rights violations include the obstruction to treatment options that meet international standards for clinical guidelines and the denial of benefits for many serious complications and disability caused by Lyme borreliosis.*
>
> *"In the context of scientific debate about the biological origins of chronic Lyme, policy makers have a duty to proactively protect the right to health." Ethically speaking, it is not possible to justify the risk involved in continuing to obstruct access to medical care for chronic Lyme patients, stated O'Leary. The WHO has described this in their AAAQ framework: the 'Availability, Accessibility, Acceptability & Quality of Care'.*

Currently the quality and safety for patients suffering Lyme disease in Australia is extremely limited to physicians who are prepared to risk their licence. Diagnoses and treatment is a basic human right.

6. New efficiencies and change

Research

Put simply, the research in relation to Lyme or Lyme-like illness in Australia is scant and it appears many authorities are not yet convinced of its existence. In the meantime, patients (from young babies to older Australians) are suffering needlessly. Some patients find that suicide is their only option in eradicating the illness. The LDAA is aware of seven patients who have suicided due to this illness.

In short research is being undertaken on the pathogens, now research must be undertaken on its treatment, prevention, and ultimately eradication.

Lyme disease in Australia

The misconception that Lyme disease does not exist in Australia is based on a study in 1994 by Russell and Doggett. There were numerous problems with this study and its methodology, which are the focus of an upcoming article in the Medical Journal of Australia. By contrast Willis was able to identify the bacteria that causes Lyme Disease in Australian ticks in 1995. In addition to this Carly and Pope found an Australian strain of Borrelia, Borrelia Queenslandica in 1962. A 1959 study by Mackerras isolated Borrelia on Australian fauna – kangaroos, wallabies, and bandicoots, this was also omitted. Adding to this is the fact that a large number of diagnosed Lyme Disease patients in Australia have never travelled outside of Australia. More study is desperately needed on Lyme Disease in Australia.

Lyme Disease diagnosis is not common, but Lyme disease itself appears to be grossly under diagnosed in Australia. The Lyme Disease Association of Australia estimates, based on United States of America figures, that an Australian extrapolation means approximately 18,000 new cases per year. Since the publishing of Russell and Doggett's 1994 study there are potentially 378,000 patients in Australia who have gone undiagnosed or misdiagnosed.

There are 14 genospecies of Borrelia Burgdorferi senso lato (the bacteria that causes Lyme disease) - which includes BB senso stricto. This diversity is thought to contribute to the antigenic variability of the spirochete and its ability to evade the immune system and antibiotic therapy, leading to chronic infection.

Only 35% of people with Lyme Disease get the classic bulls-eye rash. Only 30% of people who are diagnosed with Lyme Disease remember a tick bite. The tick injects local anaesthetic into your skin before it bites, so that it may stay attached longer. This means that most people don't remember the tick bite at all.

At any time during the tick being attached it can regurgitate the infectious disease containing contents of its stomach into your blood stream. This is why removing the tick carefully is so important, as squeezing the tick has the same effect.

Western Australia's South Western region a known "hot spot" for the Lyme Disease

This is an excerpt of an email from a Lyme literate GP in Western Australia:

> *"In Saturday morning surgeries where I saw patients who were wanting to see "any generic GP" in 2013/2014 I found 3 certain, and 6 more probable symptomatic patients with Lyme Disease. This was from a total of 103. Only 3 had proper testing and were positive. 3 more had highly suggestive tests but were unwilling to spend more on definitive tests, and 3 had symptoms and signs I normally get positive tests from. I would conservatively estimate 5-6% of all general practice presentations.*
>
> *So every GP in Australia on average would be seeing 5-10 patients a week with symptomatic Lyme Disease. A large proportion are to some extent disabled. Some are on pensions. Most of my patients reduce their disability over a period of 2 years treatment from disabled to part or full time working. I have had a few come off disabled pensions.*
>
> *5 of my patients have suicided, and 2 have died of conditions associated with Lyme Disease. Both were over 65. It is likely 3 or 4 of my current patients will die.*
>
> *4 or more states in the USA have passed legislation protecting doctors treating Lyme Disease from prosecution by state medical boards (usually motivated by US Health Insurance companies).*
>
> *This is a major public health and disability problem. Almost entirely yet to be recognised."*

Proof of Lyme disease and Borrelia in Australia

There are a number of journal articles proving the existence of Lyme disease in Australia, some of which are difficult to locate however they have been sourced via Australia's National Library below:

1982 – Lyme Disease in the Hunter Valley; - Medical Journal of Australia 1982;

1986 – Lyme Disease on the South Coast of NSW; McCrossin - Medical Journal of Australia;

1991 – Detecting the Cause of Lyme Disease in Australia; Med Journal of Australia;

1998 – Lyme Disease in Australia; Australia/New Zealand Journal of Public Health;

1998 – Culture Positive Lyme Borreliosis; Hudson Medical Journal of Australia;

2005 - Audit of the laboratory diagnosis of Lyme disease in Scotland; Journal of Medical Microbiology;

There are also a number of other journal articles identifying the existence of Borrelia in Australia which can be made available.

Lyme disease testing

The following is an excerpt from the 2015 Australian Productivity Commission report (page 116):

> *"In Australia, the National Health and Medical Research Council plays a gatekeeper role for clinical guidelines. This includes guideline development (often in partnership with health organisations, such as professional colleges) and approving guidelines produced by other organisations. It has estimated that there are over 1000 guidelines in circulation in Australia, produced by more than 130 developers (NHMRC 2014). However, despite their potential value, clinical guidelines have been the subject of much criticism (box 2.6), and Australia does not appear to be getting as much value from these guidelines as it could.*
>
> *One problem is the content and quality of the guidelines, including the ways in which they are developed, prioritised and maintained.* ***The vast majority of published guidelines are not supported by documented evidence, are out of date or do not mention conflicts of interest*** *(NHMRC 2014). An earlier study found that most general practitioners felt that guidelines lacked credibility and user friendliness due to having been prepared by non-clinicians (Gupta, Ward and Hayward 1997)."*
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> Efficiency in Health: Commission Research Paper, (2015), Productivity Commission Australian Commonwealth. (emphasis added)
> https://www.pc.gov.au/…/efficiency-he…/efficiency-health.pdf

Testing for Lyme Disease is not currently reliable, and so the diagnosis of Lyme disease is a clinical diagnosis based on medical history and clinical symptoms. The testing is unreliable for two reasons – firstly the bacteria that causes Lyme Disease often does not reside in the blood but in tissues, heart, nervous system, in collagen and in joints, which makes it very difficult to isolate during a blood test. Secondly, testing for an immune response to the Lyme Disease bacteria is hampered by the fact that the Lyme Disease bacteria directly supresses the immune system and the production of antibodies against the bacteria. This means that there is a high level of false negative blood test results for Lyme Disease. The consequences of this fact are that a negative result for a blood test for Lyme Disease is not proof that a patient does not have Lyme Disease, rather that their immune system has not been able to mount an adequate defence against the infection. Anecdotally it has been found that the sicker a patient is with Lyme Disease, the higher the chance they will receive a negative blood test – sometimes after successful treatment of the Lyme Disease and resolution of symptoms, the blood test will come back positive, when it was previously negative. Adding to this is the fact that the testing for Lyme Disease in Australia is very unreliable – most Lyme Disease patients send their blood to the USA or Germany for testing, which is an extremely expensive exercise.

In July 2014 Prof Chris Baggoley, then Chief Medical Officer (CMO), published words confirming that Australian testing for Lyme disease was discordant and he committed to fixing that issue. However, It is now 2017 and testing is still being carried out, negative results still offer a denial of diagnosis, and a positive result offers a 'false positive', leaving Australians sick and unsupported.

During the Senate Inquiry's public hearings, we heard from Ms Sue Best of the National Serology Reference Laboratory. Her organisation had been contracted by the Government, as a result of deliberations of the then Clinical Advisory Committee on Lyme Disease, established by the former CMO, to conduct a study on the pathology tests for Lyme like illness. Ms Best told the committee her study was almost complete and would be reported on in early 2017; indeed the contracted time has elapsed and nine months later the government has not reported those results. Once again, the stalling, inaction, and outright negativity is not helping the sick and dying.

Lyme disease transmittal

Lyme disease has been found in stillborn babies whose mother was infected with Lyme disease. There are a growing number of children in Australia diagnosed with Lyme disease who have never travelled out of Australia and whose mother *has* diagnosed Lyme disease. Syphilis and Lyme disease have similar etiologic (but not the same), clinical, and epidemiologic characteristics (and both are caused by spirochete bacteria). Because Syphilis can be transmitted sexually, there is research substantiating that Lyme disease can also be transmitted sexually (backed up by the fact that the bacteria that causes Lyme disease has been found in semen and vaginal secretions). Lyme disease can affect every system in the body. Because it is a slow replicating bacteria it is also very difficult to kill. The bacteria that cause Lyme disease can penetrate into the brain, they can cause numerous neurological and psychiatric symptoms in some patients.

More study needs to be done on the sexual transmission of Lyme disease, which is currently a controversial diagnosis.

Blood transfusions are also being carried out also potentially transmitting the illness.

Children have also been told that they have psychological issues. In the meantime, treatment has been denied. Lyme Disease (particularly neurological Lyme disease) can be fatal.

Productivity

Under the current model, productivity is severely compromised whether it is the health system, school system, welfare system, the Australian taxpayers or the individual, and the inequity is diverse. For instance, patients are being refused treatment when revealing a

Lyme diagnosis in their medical history. Patients have been denied welfare income payments and children are denied disability support because their illness is not currently listed for consideration on Centrelink paperwork. These same children are unable to perform to their potential and are frequently unable to attend school. Adults cannot contribute meaningfully to the workforce and are debilitated (some partially, some totally). Many are forced to mortgage/sell homes and travel overseas for treatment.

The burden on the health system could be minimised by the potential of private clinics in Western Australia, rather than patients having to travel overseas for treatment (where they can afford to do so). Many, who cannot afford to do so, will remain sick; potentially for years. Whilst private clinics are a solution, patients who cannot afford treatment at these clinics should not be penalised under the public health system.

Lost productivity as far as doctor/hospital visits, wrongful testing, diagnoses and/or treatment, potential over-prescription of medication, and the like must all be an added productivity and cost burden.

Teaching and training

Australian laboratory tests appear biased towards a high false negative rate (when compared to same-sample overseas testing). Positive test results are often dismissed as being erroneous. The LDAA believes that a thorough review of current Australian testing procedures should be undertaken by studying laboratory practices in all countries testing for Lyme-like illness to ascertain ‘world’s best practice’.

Uncertainty about the causative factors for Lyme-like illness in Australia has meant most clinicians rule out Lyme disease as a differential diagnosis. The LDAA believes that retrospective, clinical, and epidemiological research based on current patients with Lyme-like illness should be undertaken.

Research into Lyme disease appears to falter once simplistic causative factors have been identified, leaving many questions unanswered as to alternate potential causes of Lyme-like illness, and patients can be excluded when their presentations of the condition fall outside narrow definitions endorsed for diagnosis and treatment. A study of the unique presentations of Lyme-like illness in Australia are necessary before conducting research based on assumptions from other locations where Lyme disease and Lyme-like illness occurs.

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There is an acute shortage of Lyme-aware doctors available to treat patients with Lyme-like illness in Australia. This may be due to the very real threat of doctors being struck off, however there are many doctors and teaching facilities both here and around the world who share their knowledge, and we have no doubt are willing to share their knowledge with our health authorities.

Diet has now become a cutting-edge issue, along with the gut and bacterial issues. Diet is not taught comprehensively in medical schools, however it forms a huge part of Lyme sufferers (but not just limited to) wellness or lack thereof. Naturopathic and holistic medicine is very much aware of the Hippocrates quote “let food be thy medicine and medicine be thy food”.

Culture

Inappropriate treatment

Patients attending GPs and specialists are prescribed inappropriate treatments, particularly antidepressants and steroids, and patients attending public hospitals (particularly emergency departments) have been refused treatment when revealing a Lyme diagnosis in their medical history. Patients presenting with a recent tick bite have been refused early intervention treatment with antibiotics (adding to the burden) or incorrect antibiotics and Lyme disease sufferers bear unsustainable expenses because many of the prescribed medicines they require are not covered under the PBS.

This culture is defined extremely eloquently by Dr Kenneth Liegner, Physician since 1988

> *“In the fullness of time the mainstream handling of chronic Lyme disease will be viewed as one of the most shameful episodes in the history of medicine because elements of academic medicine, elements of government, and virtually the entire insurance industry have colluded to deny a disease. This has resulted in needless suffering of many individuals who deteriorate and sometimes die for lack of timely application of treatment or denial of treatment beyond some arbitrary duration”.*

Patients attending GPs, specialists and public hospitals (particularly emergency departments) have been subjected to humiliation along with refusal of treatment when revealing a Lyme diagnosis in their medical history. Parents have been threatened with losing custody of their children due to school non-attendance and/or told their children’s obvious symptoms are psychosomatic when revealing they are suffering from Lyme-like illness, or are accused of Munchausen’s syndrome by proxy. Every parent knows their children’s capability and is acutely aware when they are unwell or are displaying uncharacteristic illnesses, and such behaviour and arrogance from the medical profession is simply appalling and unacceptable. The LDAA has reports of multiple patients being scheduled under the Mental Health Act because their presenting symptomatology does not fit into the fixed diagnostic criteria current in Australia.

Leadership development

The LDAA suggests the development of educational guidelines and training programs for clinicians in diagnosis of Lyme-like illness focussing on the patient’s individual needs.

Australian laboratory tests appear biased towards a high false negative rate (when compared to same-sample overseas testing). Positive test results are often dismissed as being erroneous despite patients still reporting many of the symptoms which Lyme-like illness can display. We believe that a thorough review of current Australian testing procedures and a study of laboratory practices in all countries testing for Lyme-like illness to ascertain ‘world’s best practice’ is required.

Uncertainty about the causative factors for Lyme-like illness in Australia has meant most clinicians rule out Lyme disease as a differential diagnosis. A thorough epidemiological research based on current patients with Lyme-like illness, together with retrospective research and clinical research is required.

Research into Lyme disease appears to falter once simplistic causative factors have been identified, leaving many questions unanswered as to alternate potential causes of Lyme-like illness, and patients can be excluded when their presentations of the condition fall outside narrow definitions endorsed for diagnosis and treatment. A study of the unique presentations of Lyme-like illness in Australia should be undertaken before conducting research based on assumptions from other locations where Lyme disease and Lyme-like illness occurs.

Procurement

We have no comment.

Improved performance monitoring

We have no comment.

7. Implementation of Government-endorsed recommendations

The LDAA recommends the immediate treatment by doctors of Lyme disease or patients with Lyme-like illness, irrespective of where they are diagnosed, and without repercussions. Further that formal authorisation of doctors treating Lyme disease or patients suspected of being bitten be enacted forthwith. In emerging disease situations, patients are the evidence and they deserve world's best practise standard and compassionate care.

We are not aware of the Service Priority Review and Commission of Inquiry into Government Programs and Projects, therefore we are unable to respond.

8. Scope and sequencing of Implementation

The LDAA has a great deal of research and data on the scope of Lyme-like illness and would be happy to discuss issues of implementation. Of utmost importance is the acceptance and implementation of the illness and the treatment therein.

We are not aware of the new 10-year State Health Plan, therefore we are unable to respond.

9. Any further opportunities

Australians are generally unaware of the potential sources of, and risks associated with, transmission of Lyme-like illness and tick bites. Education in the prevention of Lyme disease is a must, however until acceptance of the illness is a given, people will remain uneducated as to the dangers.

The LDAA recommends development and dissemination of a public awareness campaign together with the erection of warning signage in areas of potential high-risk exposure.

There is a risk of transmission through blood banks and organ donation, as opting out is voluntary and only an option for those who have been correctly diagnosed.

We recommend that GPs are aware of the risks and are ready to administer appropriate treatment for early intervention.

Mothers may transmit pathogens to babies during pregnancy and breast-feeding.

The LDAA recommends issuing public health warnings to prospective parents and treatment of expectant mothers to minimise transmission risk.

In closing the LDAA believes early intervention at the time of the rash, other symptoms following a bite or history of high risk activity, rather than ignorance leading to chronic illness simply makes sense. Lyme Sufferers willingly want to contribute to society in a meaningful way and not be a burden on the welfare system, yet chronic, undiagnosed Lyme disease is exponentially on the rise and we urge the Western Australian Government to be proactive – not reactive – in its acceptance of the disease.

Once again, thank you for the opportunity to make this submission.