



May 2015

MEDIA RELEASE

## Exposing Australian Hidden Epidemic

Lyme disease has reached epidemic proportions in parts of Europe and USA, outstripping the incidence of both Breast Cancer and HIV/AIDS in the USA. Australia is far behind in the contemporary recognition that Lyme disease is a rapidly emerging epidemic with devastating impacts upon those who acquire it; even worse is the fact that it is entirely preventable.

The national May Lyme Project is the Lyme Disease Association of Australia's (LDAA) annual campaign with local patient groups staging over 23 events across Australia to help raise awareness of Lyme disease.

In May, Australian Lyme patients are uniting to raise public awareness and will be campaigning for:

- Recognition of tick-borne diseases and Lyme-like illness
- Professional support for GPs and health professionals treating patients for Lyme-like illness
- The accurate diagnosis and effective treatment of Lyme and other tick-borne diseases
- Epidemiological study and coordinated surveillance of Lyme-like illness
- Funding for research into transmission, testing and treatment of tick-borne diseases

### **Lyme disease and co-infections in Australia**

Lyme disease is a complex and poorly understood infectious disease caused by a bite from a tick carrying the bacteria called *Borrelia*. Ticks also carry myriad other infectious diseases equally as debilitating or deadly as Lyme disease. In people whose predominant infection is *Borrelia* (Lyme disease) these accompanying infections are referred to as co infections.

Australians who are sick with Lyme disease face enormous difficulties getting access to reliable pathology tests, an accurate diagnosis, knowledgeable doctors and effective treatment.

Sharon Whiteman, the LDAA's President, said "People are becoming seriously ill while being denied proper medical treatment because a cause for our Lyme-like illness has not yet been 'officially' discovered in Australia."

"If treated early the chances of full recovery are good, but left untreated Lyme disease becomes a chronic infection and can totally destroy lives. The tragedy of our situation is that Lyme disease is preventable and with early intervention, treatable."

The LDAA was formed in response to the challenges presented by the growing prevalence of Lyme disease in Australia. It's a grass roots volunteer organisation that, despite enormous obstacles, has built a committed and passionate community of members. The LDAA focuses on providing information, support, education and awareness about Lyme disease.

The current level of corporate, government and community awareness about Lyme disease and the reality of the patient situation in Australia is low. This has vast implications for the patients and doctors who try to support them. Many patients are left with no option but to send their blood overseas for testing, or to go overseas for treatment at considerable personal cost with varying levels of success.

Australians attending overseas clinics are left without the safeguards of medical regulation that exist in Australia. There are, however, many patients who cannot afford any treatment at all. This is especially true for those who have been chronically unwell for years and have already suffered financial devastation as a result of their illness.

Lyme disease and the common co-infections are very complex and the lack of contemporary research impedes a full and accurate assessment of the problem here in Australia.

### **Government action is needed**

The National Health and Medical Research Council funded a report, written in 1994 by Russell and Doggett (Russell RC, 1994) that was broadly criticised for its narrow focus and its incomplete scientific inquiry. It has resulted in misconceptions and led to erroneous policy. This report, now more than 20 years old, is often cited as the scientific justification denying the existence of Lyme disease in Australia. This report remains a barrier to an effective contemporary policy on an emerging epidemic and contributes to the lack of support from the medical profession.

While the debate about Lyme disease in Australia continues, the term Lyme-like is often used to try to avoid the controversial issues that surround pathology testing, diagnosis and bacterial strains, rather than addressing the more substantive issues that affect patients.

In the last year progress has been made by the Chief Medical Officer (CMO) of Australia. He established the Clinical Advisory Committee on Lyme Disease (CACLD) and initiated a scoping study to inform a program of research in Australia. The LDAA played an important role in representing the patient voice in that process and presented the government with a Strategic Action Plan, setting out the activities required to address the epidemic from a patient perspective, hopeful that support would be imminent.

That was over 15 months ago and nothing has been done to address the issues raised. The federal government acknowledges Australians are getting sick after tick bites and there is a Lyme-like illness here affecting Australians, however coordinated action is required by all health ministries. Media exposure and public accountability is needed to spur the government into action to invest in research and develop the policy required to address this growing health crisis.

To date, funding for the CMO's research has not been prioritised. Patients' sick with Lyme-like disease cannot wait years for research outcomes before they are helped. Currently, the average time for a diagnosis of Lyme disease in Australia is 6.5 years (LDAA, 2012 p. 7). This results in most Australian Lyme disease patients progressing to a chronic long term illness which is much harder and significantly more costly to treat.

LDAA welcomes the ACT Health Minister Simon Corbell's recent statement in relation to Lyme disease that doctor's must use their best clinical judgement as to the cause of any illness and act accordingly.

### **Lyme disease epidemic**

It is very difficult to accurately estimate the number of Australian's living with Lyme disease due to a broad lack of awareness. Despite the recommendation of the World Health Organisation that surveillance of vector-borne disease should form part of any national health information system, Lyme disease is not on the notifiable disease list, so there is no surveillance and therefore no official statistics on its prevalence. The LDAA keeps the only statistics available. In the past 2 years more than 1000 people report a positively diagnosed case of Lyme disease. Sadly, our ongoing data collection illustrates that Lyme disease occurs everywhere and to anybody.

In many areas of the world Lyme disease has reached epidemic proportions. In 2013 the Centers for Disease Control and Prevention (CDC) revised its annual estimate of Lyme disease cases in the United States from



**Someone You Know Has Lyme Disease**

Lyme Disease Association of Australia | [www.lymedisease.org.au](http://www.lymedisease.org.au)  
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30,000 to 300,000<sup>1</sup>. A sobering 10 fold increase. Shockingly, cases of Lyme disease in the United States now outstrip cases of HIV/AIDS and Breast Cancer<sup>2</sup>. We anticipate that the numbers in Australia would be statistically similar if Australians had access to reliable diagnostic tests and educated doctors. It's crucial that the Australia government address this emerging epidemic without delay.

As an example of world's best practice, German doctors are educated to treat flu like symptoms that occur as the result of the tick bite with a 2-3 week course of antibiotics. Early intervention has great success in stopping the disease from progressing to a debilitating and potentially fatal illness. Australian doctors have not been educated to consider this course of action.

Perhaps more distressing is the fact that with a concerted effort directed toward awareness, prevention and behaviour change campaigns, we could avoid Lyme disease altogether and avert much suffering. Simple, cost-effective interventions like using insecticidal sprays, wearing protective clothing and managing our home environments would prevent the disease.

It will take funds and political commitment to address the Lyme epidemic - education and awareness, epidemiological studies, surveillance, diagnostic support and medicines – and to conduct urgently needed research.

It is unthinkable to many Australians that sick people could be left untreated and dying of preventable infectious diseases right under roof of public hospitals. This is an extreme situation for the patients. Many Lyme patients suffer from a sense of alienation, depression and hopelessness and many more Australians could be on their way to a similar fate.

“Patients who have been lucky enough to find a doctor to diagnose and treat Lyme disease are already getting better and some have been able to resume normal lives and contribute to society again. This disease is not just costing individuals, it's also taxing the Australian economy if people remain sick when they could be well with proper treatment,” Ms Whiteman said.

It is time to recognise Lyme in Australia.

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The May Lyme Project event locations can be found via [www.lymedisease.org.au/events](http://www.lymedisease.org.au/events) while a full media kit can be obtained from the Lyme Disease Association of Australia's website [www.lymedisease.org.au/media](http://www.lymedisease.org.au/media).

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<sup>1</sup> <http://www.cdc.gov/hiv/statistics/basics/>

<sup>2</sup> <http://www.cancer.org/cancer/breastcancer/detailedguide/breast-cancer-key-statistics>



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