



For Lyme Disease Awareness & Action

LYME DISEASE
ASSOCIATION OF AUSTRALIA
ABN 46 417 706 647

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MEDIA RELEASE

Australian Lyme-like patients' face a David and Goliath battle

Australian Lyme-like patients are facing a David and Goliath battle to make the case to the Senate inquiry on Lyme-like disease, that the people who are ill from this poorly understood disease should be helped as a matter of urgency, not in a few years' time once research has been concluded.

LDAA fully supports the ubiquitous calls for more research that can be found in the submissions to the inquiry. But not at the expense of patients who need help now, nor without the commensurate funding and necessary prioritisation. Identifying a need for research is not sufficient in this highly competitive, contested medical research space. Further, the stigma must be addressed as it is a barrier to engaging researchers who do not want to limit their careers by getting involved in a controversy.

Lack of investment over the last 25 years into tick borne diseases research has left Australia way behind other first world countries. As a consequence the Australian health system is unable to reliably test and diagnose the disease. This has led to a denial of treatment and compassionate care for patients who are suffering from a disease that is outside the evidence based system. Not because evidence is absent, but because no official research has been done that identifies the bacteria.

As submissions to the inquiry have shown, many of Australia's medical authorities are myopically focused on classic, single pathogen Lyme disease and use that definition to justify denying this disease is in Australia, even though that is outside the Terms of Reference of the inquiry. Prof Irwin of Murdoch University identified what might prove to be an indigenous species of the bacteria *Borrelia* that causes Lyme disease in research published in 2015. But says it will take years of research before the scientific process is concluded.

LDAA President Sharon Whiteman says, "It is unconscionable for the government to make patients wait any longer before they are treated based on effective Borreliosis guidelines. Sadly thousands of Lyme-like patients have lost their quality of life, their livelihoods, their homes and some have tragically died. Others have taken their own lives because they lost all trust in the medical system that was supposed to support them; their hopes and dreams shattered by the hopelessness of their situation."

Though it is too late to help the departed, LDAA will not rest until patients are cared for according to world's best practice. Multiple species of *Borrelia* have been identified around the world as causing disease and the disease is recognised to have reached epidemic proportions in many countries such as USA and Germany. International research, pathology laboratories, treatment regimens and diagnostic guidelines are available. Ms Whiteman says, "Denying this disease exists in Australia is a knee jerk, dogmatic policy failure. LDAA asks that the absence of evidence be understood to be the result of an absence of investment in conclusive official research, not an absence of a problem that needs an immediate effective policy response."

The narrow definition does nothing to help the Australian government, patients and the community understand this complex disease. The Lyme Disease Association of Australia (LDAA) asserts a broader

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umbrella term is required to encapsulate the multiple pathogens that are making people sick. While the denial of Lyme disease in Australia continues, the term Lyme-like is often used to try to shift the attention from this one strain of the one bacteria. As that excludes consideration of other pathogens that could be making people sick.

This is a socially, politically, medically and scientifically complex issue. LDAA calls on the Australian government to show leadership on Lyme-like illness and address this public health crisis. A crisis clearly demonstrated by the hundreds of submissions from people suffering from the disease. LDAA's submission to the Senate inquiry¹ is publically available and is an excellent source of information to understand this hidden health crisis. It provides very good insight into the conundrum faced. It also refers to numerous international research papers to support the case that there is sufficient evidence to justify helping patients within the Australian health system.

"The microscopic strain of the bacteria that causes this illness may eventually be found to be different from classic Lyme disease and be uniquely Australian. Causing a disease that conventional medicine in Australia has been unable to name, diagnose, treat or explain. However, the symptoms and effective treatment are well matched. Surely that is what good health policy should focus on. I call on the Senate Committee to make recommendation that focus on helping patients as a matter of urgency." says Ms Whiteman.

Senate Inquiry into Growing evidence of an emerging tick-borne disease that causes a Lyme like illness for many Australian patients

Perth Public Hearing

Date: 14 April 2016
Time: 8am (tbc)
Place: International on the Water Hotel
1 Epsom Ave, Ascot WA 6104
Phone: (08) 9429 8088

Brisbane Public Hearing

Date: 15 April 2016
Time: 8am (tbc)
Place: Royal on the Park
152 Alice St, Brisbane QLD 4001
Phone: (07) 3221 3411

Canberra Public Hearing

Date: 20 April 2016
Time: tbc
Place: tbc

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Media contact: media@lymedisease.org.au 0406 378 792

Additional resources for media are available from the Lyme Disease Association of Australia's [website](http://www.lymedisease.org.au/media)

Senate Inquiry page:

http://www.aph.gov.au/Parliamentary_Business/Committees/Senate/Community_Affairs/Lyme-like_Illness

¹ http://www.aph.gov.au/Parliamentary_Business/Committees/Senate/Community_Affairs/Lyme-like_Illness
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