



For Lyme Disease Awareness & Action

LYME DISEASE
ASSOCIATION OF AUSTRALIA
ABN 46 417 706 647

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MEDIA RELEASE

Lyme Disease Association of Australia seeks action from the Senate Inquiry

The Lyme Disease Association of Australia (LDAA) is delighted to have the opportunity to be heard by a Senate Inquiry established to gather evidence of this emerging epidemic. After years of trying to engage with the medical authorities and government so the desperate plight of Lyme-like patients could be alleviated, there is hope that the compelling evidence will be heard and acted upon.

LDAA rejects the narrow definition of Lyme disease that is based on the original bacteria found in the town Lyme in USA and calls for recognition that Lyme-like disease in Australia most often involves multiple pathogens being transmitted by tick bites. It may well be a bacteria unique to Australia that the authorities are not even testing for. Not surprisingly, they are not finding it either.

The Senate Committee is interested to know about the prevalence of the disease; how people are treated by the health system; how to remove the stigma on this disease; issues with diagnosis; signs and symptoms of the disease and current or future research projects. Based on the information provided the committee will present recommendations to the parliament. LDAA hopes they will listen to the heart breaking stories of suffering and neglect and be compelled to act to make the overdue changes that are desperately needed.

Over the years LDAA has collected evidence of prevalence through a web based survey finding over 1500 medically diagnosed cases around the country. International resources and research has been collated to demonstrate how other countries are managing this complex and poorly understood illness. Analysis has been done to try to fathom how such a travesty could be taking place on Australian soil.

LDAA is also helping patients, many of whom struggle with daily life, to share their lived experience of the slow and excruciatingly painful decline in health; the lack of awareness in the medical profession; lack of treatment options in this country; patients bearing the burden of proof that this disease exists; pathology issues that result in negative blood tests, that then lead to a denial of treatment; personal attacks from doctors who deny the disease exists; treating doctor vilified for caring and trying to help; and the crippling expense of trying to regain their wellbeing.

Having worked very closely with Senator Madigan's office, LDAA was delighted that he listened and was willing to take a stand on behalf of Lyme-like patients in Australia. President of the LDAA Sharon Whiteman said, "The LDAA hopes the Senate Inquiry will expose the broad neglect, denial of care and discrimination of Australians with Lyme-like illness."

The Inquiry is a priceless opportunity for patient stories to be heard and for the parliament to act based on the evidence presented by sick Australians whose medical diagnosis is not officially recognised. LDAA is aware of thousands of chronically sick people who need the support of Australia's health system, but are denied it. Being on the outside of the system, through no fault of their own, is mentally, emotionally,

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physically and financially exhausting. Many patients travel overseas at enormous expense to receive help as Australia is falling behind in researching, diagnosing, preventing and treating this debilitating, and if left untreated potentially fatal illness.

President of the LDAA Sharon Whiteman said, "If you're a Lyme disease sufferer, a carer, family or friend of a sufferer or have been impacted in anyway by Lyme-like illness, you can tell your story to the Senate Inquiry and help us take the next step forward in securing recognition."

LDAA with the support of patients around the country, has made enormous progress on the back of a grass roots campaign in securing a Senate Inquiry but the job will not be done until the disease is officially recognised, reliably diagnosed, treated quickly and effectively and ideally prevented by community awareness of the potential danger of tick bites.

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

Senate Inquiry page:

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