



For Lyme Disease Awareness & Action

LYME DISEASE  
ASSOCIATION OF AUSTRALIA  
ABN 46 417 706 647

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MEDIA RELEASE

## If I die on your watch, is that doing no harm?

Patients unwell after a tick bite watched SBS Insight this week with hope that the status quo of denying Lyme disease exists in Australia might change. Patients desperately sick with an illness mainstream medicine doesn't understand looked to get some relief from bearing the burden of proof and having to fend for themselves. They hoped the complex medical, scientific, political and power issues that bind this up in a knot might be unravelled a little.

What was unravelled was the justifications used by the medical practitioners who were strident in their denial. Patients have long been made aware that their health needs were coming a far second to the need for doctors to work within a self-regulatory system that insists on evidence before treatment is permitted, even when research hasn't been initiated nor concluded. Patients have been experiencing neglect and discrimination behind the closed doors of medical practices.

Imagine their surprise when Professor Miles Beaman who had earlier stated doctors don't need to think, explained how doctors are constrained by the authorities. That a doctor's license and insurance is at risk if they use treatments successful overseas because Australian mainstream medicine has to use proven therapies. They need scientific evidence that proves treatment works because patients who have been sick for years, who recover after treatment are not considered evidence. Sadly this sort of time consuming, circular approach is costing lives.

The tragic reality is that mainstream medicine some of which is available on the PBS does help patients if treatment starts soon after a tick bite. This preventative strategy has been successfully implemented in many nations overseas. But the denial, lack of funding for research and contentious culture surrounding tick-borne disease in Australia has long been a barrier to effective policy.

Patients don't care what the disease is called. They care about being respected and receiving treatment. Lyme Disease Association of Australia's (LDAA) patient survey early this year found the average time for diagnosis in Australia is over 10 years. By that stage many patients are desperately unwell and fearing for their lives. Patients who are chronically unwell often achieve their health back by seeking global best-practise treatment in countries that are successfully managing this disease.

This was the situation for patient Chanel Moloney who went to Malaysia after seeing 16-19 doctors in Australia and becoming so sick for years her family became concerned about losing her. International tennis champion Sam Stosur said she was glad she was in America to receive treatment as it's much more progressive there.

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The doctors in the audience were quick to avoid the ethical and legal responsibility for treating patients with the treatments that actually work overseas, by claiming that first they must do no harm. Jesse Chadwick a patient whose story was being told challenged this complacency by asking 'if I die on your watch, is that doing no harm?'

Nobody in the audience would answer that question directly other than to say they need funding.

Another hope was dashed when the potential for a unique species of the disease native to Australia, as raised Dr Charlotte Oskam's break through research at Murdoch University, was not explored. Patients are expected to wait years for the research to conclude. New strains of the bacteria that causes Lyme disease have been found around the world with 19 currently known to make people sick. As reported by the Centre for Disease Control (CDC) in February 2016 when the new species *Borrelia mayonii* was announced, 'the patients infected with the new bacteria were treated successfully with the same antibiotics used for those with *Borrelia burgdorferi*'.

The American medical doctors are now indicating that Lyme is actually caused by more than one strain of *Borrelia*. Further the CDC don't expect sick patients to wait years for more research when there is a treatment that actually works! The treatment works for Australian patients as well. The Australian Department of Health has adopted the CDC's approach to determining if the disease is endemic, but not in the management of new strains of the bacteria. If Australian doctors were authorised and trained to treat patients according to world's best practice thousands of lives would be transformed.

In concluding remarks Dr Herzberg suggested the discussion about what bacteria is in Australian ticks be left to the researcher and that the doctors focus on using their skills and experience to help patients get better.

Patients couldn't agree more. Sharon Whiteman President of LDAA said, 'Patients are hanging on to hope that the recommendations from Senate inquiry due 30 November 2016 will be focused on how to immediately help patients who are desperately unwell. Those denying that 'classical Lyme disease' is in Australia, admit that there are many pathogens in our ticks and they are not well understood. Sick Australians should be afforded the human right of world-class medical treatment –while research is urgently prioritised.'

### Senate inquiry public hearing

#### **Growing evidence of an emerging tick-borne disease that causes a Lyme-like illness for many Australian patients**

Date: 2 November 2016  
Time: 8:30am – 4pm  
Place: Room P1  
Portside Centre  
207 Kent St Sydney

#### Agenda:

[http://www.aph.gov.au/Parliamentary\\_Business/Committees/Senate/Community\\_Affairs/Lymelikeillness45/Public\\_Hearings](http://www.aph.gov.au/Parliamentary_Business/Committees/Senate/Community_Affairs/Lymelikeillness45/Public_Hearings)

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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/Lymelikeillness45](http://www.aph.gov.au/Parliamentary_Business/Committees/Senate/Community_Affairs/Lymelikeillness45)

New *Borrelia* discovered in Australia: <https://parasitesandvectors.biomedcentral.com/articles/10.1186/s13071-016-1627-x>

New *Borrelia* species discovered in USA: <http://www.cdc.gov/media/releases/2016/p0208-lyme-disease.html>

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