



For Lyme Disease Awareness & Action

17 September 2015

MEDIA RELEASE

House of Reps Lyme disease roundtable

Lyme Disease Association of Australia (LDAA) welcomes the House of Representative Standing Committee on Health's initiative to hold a public roundtable on Lyme disease. The roundtable is part of the Inquiry into Chronic Disease Prevention and Management in Primary Health Care. This roundtable will bring together patients, advocacy groups, the Department of Health and the medical community. Based on LDAA's previous experience it could highlight the massive discord between the current reality for thousands of people who are sick and the views of the medical establishment.

LDAA will participate representing the 1,494 diagnosed cases and possibly thousands of undiagnosed chronically ill people whose doctors have not been educated to diagnose nor treat the condition. LDAA's recent survey found the average time for diagnosis in Australia is 6.5 years. Tragically, world's best practice in Germany¹ recommends treatment in the first few weeks as that has a 90% chance of success. Australia is well behind world's best practice.

This public forum is an opportunity to share the plight of patients fortunate enough to find a doctor who is aware of Lyme-like disease but who is not trained in effective diagnosis, who will by default refer them to an Australian pathology laboratory. However the Australian Lyme pathology test results have been acknowledged by the Chief Medical Officer as discordant which is why the government has engaged the National Serology Reference Laboratory to undertake further evaluations.

This is a fundamental problem for Lyme-like patients as a positive test from an accredited laboratory is required to receive treatment in Australia. For example, the German vector borne disease laboratory, Infectolab, complies with the same accreditation standard used in Australia but its specialist tests are disregarded by the Australian medical system because it is not accredited by Australia's National Association of Testing Authorities (NATA). However NATA no longer offer international accreditation nor are they members of the International Laboratory Accreditation Cooperation (ILAC) Mutual Recognition Arrangements. Hence there is a gap in the regulation and Australians patients are falling through it.

President of LDAA Sharon Whiteman said, "What purpose does it serve to disregard the effective international tests, other than to deny extremely sick people validation and help? It also forces our precious few Lyme literate doctors to practice outside the system, which exposes their careers and their professional standing to undue judgement."

It should be noted that world's best practise for Lyme disease does not consider a positive blood test to be essential for diagnosis due to the well-recognised challenge of a patient's compromised immune response and the stealth like abilities of the pathogens.

¹ <http://www.borreliose-gesellschaft.de/Texte/guidelines.pdf>

Further, LDAA rejects the narrow definition of Lyme disease and calls for recognition that Lyme-like disease in Australia most often involves multiple pathogens being transmitted by ticks including: bartonella, babesia, rickettsia and candidatus neohrlichia, as well as borrelia. If the Australian health system is to develop an effective policy for this disease, people must be treated for all the pathogens that they have been infected with. An effective emerging disease strategy should have begun years ago. Patients are exhausted from the roadblocks to recovery.

This is a complex and challenging issue that if managed to world's best practice could effectively treat and prevent the personal and public burden of Lyme-like disease. LDAA anticipates more investigation will be required beyond the roundtable to identify all the barriers to the management and prevention of this chronic and debilitating disease.

The roundtable provides an opportunity for those with authority to listen to the desperate plight of Australian Lyme-like patients and act to help patients now. Not just some time in the future when they finally concede enough research has been done. "There is a massive disconnect between the front-line experience of Lyme-like patients and their GPs, the Department of Health and broader medical fraternities" says Ms Whiteman.

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Public Roundtable details: 9:00am – 11:15am
 Friday 18th September 2015
 Macquarie Room, Parliament of NSW, Macquarie St, Sydney

Media contact: media@lymedisease.org.au

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