

Mid-year Lyme update!



**LYME DISEASE**  
ASSOCIATION OF AUSTRALIA  
For Lyme Disease Awareness & Action

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Dear Lymelighter,



[Thank you!](#)

We here at the LDAA are deeply appreciative of all of our event holders and fundraisers, throughout the month of May, as well as throughout the year. It is often difficult to fundraise, or host an event when ill with Lyme disease, so we highly value the energy and drive you give to LDAA events, and time spent fundraising or awareness raising. We're truly thankful and blessed to have such wonderful support.

Your collective contribution means the LDAA can effectively move forward on initiatives and projects. Thank you for supporting us, and in turn allowing us to support you. We're working towards a better future for Lyme disease sufferers in Australia.



## Positions Open

Join our wonderful volunteer team! LDAA works in a virtual online environment. You must have access to a computer, a stable wifi connection, and have a passion to enact change in your community! LDAA's roles are expanding, often volunteers take on ad-hoc jobs, beyond their initial involvement.

### Our current job positions are:

1. **Marketing/Fundraising** | Need a passionate individual to help Lyme patients, bright/innovative ideas a bonus! Must be able to implement fundraising projects. Twitter expertise a bonus!
2. **IT Web Support** | More details [here](#).
3. **Events Coordinator** | National coordinator of LDAA events, including supervising support groups, policies, maintaining and liaising with event holders, and team work with our fulfilment officer.

Introduce yourself by sending [info@lymedisease.org.au](mailto:info@lymedisease.org.au) an email with the subject header: Volunteer Application! We look forward to speaking with you!



## MP Briefings Update

To date the LDAA has briefed over 40 MPs from many parties, in readiness for parliamentary action. We have around 200 more to brief! But one thing is clear... Australian Lyme patients are being heard! During the 2nd and 3rd weeks of August, Lyme disease was discussed in THREE separate sittings in Parliament.

Federal Labor Member for Canberra, Gai Brodtmann called for more research and

acknowledgement of the LDAA for the support we provide the Lyme community. We're incredibly grateful and blessed to have politicians such as:

Gai Brodtmann and Jill Hall (Federal Labor Member for Shortland) as allies to the community and the LDAA. You can watch Gai Brodtman [here](#), and Jill Hall [here](#). Ken Wyatt (Federal Liberal Member for Hasluck) asked for a 3 minute spot to highlight the plight of Lyme disease patients and read a patient email to parliament.

This is the first step to a long progress (with so much more in development) for recognition. As part of this motion the LDAA will be acknowledged for the May campaign and other work we are doing.

Lobbying is an integral part of advocacy which is why we have really pushed our communication with State and Federal MPs, and response to briefings has been mostly positive. Increased communication has been a direct result of all of our combined efforts with the Postcard Campaign, and its effects are still being felt throughout Parliament, and the LDAA. We hope that this focus brings change for those in the community. Round table discussion will be held on September 18th of this year to further explore the challenges for Lyme patients in Australia. The LDAA will be in attendance. We're excited for the future!



## NATA Testing

We've recently had many people come to us saying they tested negative to Lyme disease (testing from Australian standard Medicare / NATA labs) via neurologists/infectious disease doctors, even though they have since being diagnosed with Lyme. Please be aware that testing NEGATIVE via these labs could still mean you have Lyme disease. Australian testing has been flagged by the Chief Medical Officer of Australia (CMO) as 'inconsistent' or 'discordant'.

If you have a negative test result via these means and you still have no answers for your ill health, and suspect you may have Lyme disease, then you should follow up with a Lyme aware doctor and/or testing ([contact the LDAA for a physician list in your area](#)).

Australian health officials do not recognise Lyme (-like) disease in Australia, which has resulted in inadequate testing options. Australian testing is based on overseas strains of the pathogen(s) that cause Lyme.

While the government is taking steps to correct the discordant NATA testing, in the meantime, the LDAA advises against relying on NATA testing as the final answer for your Lyme disease diagnosis. For conclusive answers you should seek the assistance of a Lyme aware doctor. It is also important to note that 'world's best practise' for Lyme disease diagnosis is a clinical diagnosis by an experienced Lyme-literate doctor. Having a positive blood test is a bonus, but not necessary for diagnosis.



## Lyme in the Media

### 19th August | 2HD Lyme Disease Segment:

On the 19th of August, President Sharon Whiteman talked with 2HD host Brent Bultitude about Lyme disease, the controversy's surrounding it and how many of our doctors are still uninformed about the disease. Sharon would just like to clarify that it is not the government monitoring the doctors, but the Australian Health Practitioner Regulation Agency (AHPRA). Listen to the interview [here](#). If you'd like to thank 2HD for highlighting a Lyme disease story, you can do so here.

### 17th August | Sydney Morning Herald Feature:

Marie Huttley-Jackson, (LDAA volunteer) of Lyons, was present at Parliament House on Monday when Labor MPs spoke to a motion on the need to accept the existence of Lyme disease and about its impact on sufferers. "Lyme-like disease should be recognised as an emerging infectious disease so Australian patients can receive compassionate and effective world's best practice acute and chronic disease support" says Sharon Whiteman, LDAA President. Read [here](#).

### 22nd August | ABC Sunshine Coast Feature:

Tagline: Lyme disease: Federal MP calls for greater recognition of tick-borne illness affecting 'thousands'. Read more [here](#).



## Events Calendar

- **September & October ANPA Webinars | John Coleman, ND:** Lyme Disease: Recognising, diagnosing and treating Borreliosis and co-infections. Webinar 1 takes place Tues 29th Sept, Webinar 2 takes place on Tues 6th October. Read more about these webinars [here](#). Register [here](#).
- **Ticked Off & Travelling:** The Pooley family are travelling around Australia, to raise

awareness and education for Lyme disease, an illness that plagues their entire family. If you want to support their journey/travels, you can connect with the Pooley family via their facebook group [here](#). Or, contact the family [here](#).

*If you'd like your event listed here in the September Events, please email [info@lymedisease.org.au](mailto:info@lymedisease.org.au)*



## From the Committee

The Dept of Health published a brief update on Lyme disease (updated 24th August, 2015) to include and acknowledge the recent Prof. Irwin Murdoch University research:

*"The department welcomes this work and will remain engaged with Prof. Irwin to consider the implications of this research for human health in Australia. The department anticipates research on ticks taken from humans will be published later in 2015."*

So whilst their brief statement/update is nothing major, it is still nice to see their acknowledgement of research. Read the entire update [here](#).

No recent news, just letting us know that their work continues. And as you have read above, we are working very hard on all of your behalf. While we are heartened by the growing political recognition and support for the recognition of Lyme-like illness in Australia, there is still much work to be done. One of the ways you can support us is by volunteering with us, to ensure that our vision of 'dramatic change for Lyme Patients in 2015' is carried over into future years. Our motto has always been steeped in change for the better at LDAA, so join the team to enact change for the community!

Yours in Green,



Sharon Whiteman  
President



**Join our volunteer team!**

**Enquire or Apply**

**Want to include something in our next newsletter? *Let us know at [info@lymedisease.org.au](mailto:info@lymedisease.org.au)***

*Newsletter Editor | Amber Beilharz*

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