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LDAA Newsflash

Dear Lymelighter,

The LDAA committee has grown!

It's been some time since we've been in communication with you, but just so you know, we've been busy! We are excited to announce that a new committee quorum has put their hands up to lend their hand to Lyme awareness in Australia. The LDAA has attracted a broad range of individuals who are multi-skilled and passionate to facilitate change in Australia. We are excited to come together to support the mandates of the LDAA.

Firstly, we'd like to ask for a huge round of applause and express a BIG thank you to Nikki Coleman, founding committee member and outgoing President. Nikki has offered an irreplaceable contribution to the Lyme awareness campaign in Australia and I've lost count of the number of people who've told me they 'owe their life to Nikki'. Thank you so much Nikki! We wish Nikki the very best as she prioritises her time to family and PhD pursuits. Very fortunately for the LDAA, Nikki is remaining involved in a consultative capacity - we are very grateful for her knowledge, wisdom and continued contribution.

We'd also like to acknowledge and thank founding committee member, Melitta Marr.

Melitta has stood down as Vice President in order to 'disappear into babyland' with new little gorgeous Flynn. Melitta also remains committed to the aims of the LDAA and will contribute in an ad hoc basis in the future.

Also remaining with the LDAA is Brad Mendieta, assisted by Ross Floate. These two gentlemen have been behind the scenes tirelessly volunteering in assisting the distribution of the Igenex kits to those that order them. This service has eliminated the international shipping challenges and delays that Lyme patients have previously experienced. Thank you to Brad & Ross!

For Lyme Awareness & Action

Founding committee member, Sharon Whiteman, who has been supporting the LDAA behind the scenes as facebook page admin, has been elected as President of the LDAA in 2013. Sharon brings a broad background in nursing, business, leadership, personal development and most critically, is about 75% recovered from advanced disseminated Lyme disease. Stay tuned to our webpage over the coming months as we introduce the whole committee.

Our first priority for new initiatives are to: 1) Support the successful outcomes of the Worldwide Lyme Protest; 2) Update and streamline our branding, website, membership and newflash system; 3) Develop several other creative ideas for projects in the 'incubation' stage, including our new 'Random Acts of Lymeness' community activists program! If you have ideas for important initiatives and/or skills to contribute, please contact the LDAA committee via info@lymedisease.org.au. We continue to partner with you to make the multi-levelled ignorance of Lyme disease in Australia a thing of the past"

Worldwide Lyme Protest Australia - May 10-11, 2013... There's still time to participate!

In February of this year the LDAA committed to being a national sponsor of the Worldwide Lyme Protest #lymeprotest. Lyme activists, Karen Smith & Janice Foster - Australian World Wide Lyme Protest co-ordinators, have done an outstanding job in preparing for the best WWLP on May 10-11 in Australia. There are over 50 events happening in almost 30 countries globally, some of which are protest events and most awareness events. In Australia, we're proud to share that there are 10 events booked across the country and 14 major landmark buildings lighting up green to demonstrate for Lyme Awareness. Special mention and thank you to Zara Ward for establishing a record 8 landmark buildings in SE QLD to #lymelight green on May 10th or 11th. A HUGE congratulations to the grass roots, passionate community. We celebrate you!

Find out how you can help and learn more here:

<http://worldwidelymeprotestaustralia.weebly.com/index.html>

<https://www.facebook.com/WorldwideLymeProtestAustralia>

Lighting Australia Green #lymelight:

<http://worldwidelymeprotestaustralia.weebly.com/australian-landmarks-lighting-up-for->

A Milestone - The First Australian Tick Borne Disease Conference

Nikki Coleman had a front row seat. "It was a VERY productive day, and all the organisers at the Karl McManus Foundation should be incredibly proud of what they have achieved in bringing such great speakers to Australia, and mobilising doctors to learn more about Lyme Disease. I look forward to the next conference & meeting up with other lovely members of the Lyme Disease community.

A real highlight for me was seeing the Chief Medical Officer of Australia at the conference. I assumed that he would turn up at the end and just make some closing remarks, but he was at the conference for every session, taking notes, and asking his staff questions. He made insightful comments at the end, stating that he feels strongly that it is important to keep an open mind about the existence of Borrelia in Australia, and that he will be working on this with a Lyme Disease Advisory committee in the coming months (they met on Tuesday following the conference & I have subsequently been appointed to that committee as a patient representative). He is keen for an Australian test for Lyme Disease to be worked on, as it may be that we have a specific strain of Lyme Disease in Australia (which would make a lot of sense given that there are different strains of Lyme Disease all over the world, but we only test for the US strain here). He was horrified at the discrimination faced by Lyme Disease patients, and was touched by the stories of 190 people that were presented to him in the folder by Jacqui VT. The comment that spoke the most to me about the future for Lyme patients was that he said that it was a "brave thing to say that there is no Lyme Disease in Australia" and this I think signals a turning of the tide against the Russell & Dogget dogma that has been influencing doctors and health departments in Australia for the past 20 years. Professor Baggoley also stated that transparency is important, which gives me great hope that the way Lyme Disease is debated in Australia will change." ~ Rev Nikki Coleman

Please read Nikki's full report here: <http://www.lymedisease.org.au/news/>

The Australian Government is Stepping Up

Clinical Advisory Committee on Lyme Disease (CACLD), chaired by Prof Chris Baggoley, was formed in March of this year. The first meeting was on March 19th and at that time it was agreed that a patient representative from the Lyme Disease Association of Australia (LDAA) be appointed to the CACLD. The LDAA recommended that Rev. Nikki Coleman, consultant to the LDAA currently residing in Canberra be that representative. The Terms of Reference for the CACLD were officially published on April 23rd (<http://www.health.gov.au/internet/main/publishing.nsf/Content/ohp-lyme-disease.htm>).

Thank you to the many people in the Lyme disease community who gave us their feedback on the ToR - we took all of your comments into consideration - if you don't see your feedback listed, it may be because the executive felt that it related more to the content of CACLD discussions, rather than the ToR - but please be assured we are attempting to represent the entire patient community, to make sure your voices are heard. We know how deeply the community has been affected by Lyme disease and how overdue this action is. The LDAA is committed to making this process as transparent as possible. The submission for amendments to the Terms of Reference for the CACLD was sent on April 29th for Prof. Chris Baggoley's consideration. You can read the submission here: (<http://www.lymedisease.org.au/wp-content/uploads/2010/11/20130430LDAACACLDToRSubProfBaggoleyWeb.pdf>).

While there is much work to be done and the process of full recognition of Lyme disease in Australia will be a lengthy one, it's fair to say this is the most significant move forward in behalf of the government to date.

We hope you enjoyed our 'new-style' newsflash. We'll endeavour to connect with you more frequently in 2013 as we go forward in building the #lymelight for Lyme disease in Australia. Make sure you see our new postal address below.

In Health & Lymelight,
Sharon

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Sharon Whiteman  
President (2013)  
Lyme Disease Association of Australia

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Contributing Editors
Rev. Nikki Coleman
Sharon Whiteman

Tweet for Lyme

Join us in tweeting for Lyme Awareness,
follow @lymediseaseaus

Random Acts of Lymeness

Coming soon - Grass Roots community
action list. Watch [this page](#) over the coming
months & there will be something you can
do!

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