

Two Important Projects: Scoping study submissions and Lyme Patient Consultative Group nominations.



LYME DISEASE
ASSOCIATION OF AUSTRALIA
For Lyme Disease Awareness & Action

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LDAA Newsflash

Dear Lymelighter,

Lyme Patient Consultative Group 2014 - REMINDER Closure Date Jan 7th

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1. Lyme Patient Consultative Group - 2014 (deadline Jan 7th)
2. CACLD Scoping Study Submissions (deadline Jan 31st)

REMINDER: Nominations for Lyme Patient Consultative Group - closure date Jan 7th, 2014

An Invitation to Lyme Patient Consultative Group

This group is intended to not only give the wider Lyme community a voice and more formalised mechanism of inclusion but also to draw out the best minds, inspiration and highest outcomes for all. It will also serve as a community communication/collaboration pathway into the future. Our best outcomes for a better Australia for Lyme patients will

come from an aligned and cohesive community voice.

We would love a representative from each regional and/or support group. Please nominate a representative for your group by emailing info@lymedisease.org.au by January 7th, 2014. Please provide the following information:

1. Name of nominated patient representative
2. Group being represented
3. Email and phone contact
4. Agenda item(s) submission

If you are not a part of any group and would like to have a voice, simply email info@lymedisease.org.au letting us know and we've assigned an LDAA executive member to represent you.

Read the full letter here: <http://www.lymedisease.org.au/wp-content/uploads/2013/12/20131213LPCGInviteLtrFinal.pdf>

REMINDER: The CACLD's last meeting of the year is complete, there's an invitation to submit to the scoping study

The Chief Medical Officer (CMO) of Australia, Professor Chris Baggoley stressed that there are a large number of people in Australia who's lives are miserable because of the Lyme disease or Lyme-like illness that they suffer. For some it has completely altered their lives; impacting on their family, work, social lives and finances. These people are the focus and inspiration for the CMO to keep working on this problem and reinforces the need to honour the experience of Lyme patients around Australia.

The CACLD was set up as a time limited committee to finish at the end of 2013, however, the work will not be finished this year and will now continue into 2014.

The CACLD received the report of the scoping study by Professor John Mackenzie. This report will be uploaded to the CMO's webpage in the next few days and the CMO invites people to respond to this report. It will also be sent to all the Chief Health Officers of each state and territory around Australia to comment on. The CACLD discussed their views on the report and some factual errors and concerns were highlighted by some members. The CACLD gave the CMO feedback on which of the 5 recommendations are most important – so that if funding is limited, the most important research can be done first.

The CMO noted that this research will be vital in helping those who are not yet convinced that Lyme is in Australia, to come to a new understanding. It will also be vital for lobbying government departments such as the Pharmaceutical Benefits Scheme to cover medications for Lyme disease patients in Australia.

The CMO is inviting people to provide him with feedback about the Scoping Study,

particularly in relation to the 5 recommendations. Details on how to do this is on the Department of Health and Aging (DOHA) website here. [Scoping Study - Word 207 KB](#)

Patient feedback is welcomed - the deadline for submissions in January 31st, 2014.

Anyone - individual or group can put in a response. The more the merrier. Some will write detailed responses, and others short, it doesn't matter - the CMO is wanting to hear from as wide a range of people as possible. If you'd prefer to collaborate on a group response, there is a Facebook group set up for this

purpose: <https://www.facebook.com/groups/597370956982867/> If you're not on Facebook, but would like to comment, feel free to send your input here and we'll forward onto the team collaborating a group response.

Thank you and we look forward to a great collaboration as we move forward to a better Australia for Lyme patients!!

Warm Regards,

Sharon

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Sharon Whiteman - President 2013  
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### **Random Acts of Lymeness**

Grass Roots community action list. Check out [this page](#) and let us know if we can help!

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