



For Lyme Disease Awareness & Action

29 January 2014

Attention: Dr Gary Lum

Professor Chris Baggoley
Chief Medical Officer of Australia
Department of Health
Canberra

Dear Professor Baggoley,

Re: Public Response to Scoping Study to Develop and Research Project(s) to Investigate the Presence or Absence of Lyme Disease in Australia

Thank you for providing an opportunity for members of the Lyme community to submit comments on the Scoping Study which forms part of the Chief Medical Officer's review into Lyme disease in Australia.

In developing a response to the Study, the LDAA engaged in extensive community consultation and welcomed collaboration with members of the Australian Lyme patient community. Invitations to participate in the consultation process were delivered nationally to ten Lyme community groups, the LDAA mailing list and to various Facebook support groups. This represents a potential reach of between two and five thousand Lyme patients, their carers and families.

In addition, a private online focus group was created to receive input from interested persons. In this group, comprising a total of 125 individuals, some were only well enough to indicate with a tick beside which comments or issues were important to them, while those with higher cognitive functioning actively engaged in discussions. Lyme community members with diverse professional backgrounds and relevant skills conducted further research into the issues raised during the month-long consultation process and then assisted with drafting the final submission.

The high levels of cooperation and teamwork demonstrated in this collaboration between strangers was cemented by a single common denominator. Each of the contributors has had their lives deeply impacted by Lyme disease, either as a direct sufferer of Lyme-like illness or via a friend, a family member or loved one. There's nothing like having your life as

you know it taken away from you or watching this happen to someone you love to motivate people into rising up, taking action and working toward effecting changes that will make a positive difference for those afflicted by this disease.

The LDAA owes an immense debt of gratitude to all who contributed to this process, no matter how great or small; each gave to the full extent of their capability and many extended themselves even beyond this, sacrificing their time at the expense of their health and family time. They have done this because many realise that this review process is the best chance to have the urgent plight of Lyme sufferers considered at the highest levels of decision-making in our country.

It is worth noting that this community does not actually need further research to convince them of the presence or absence of Lyme-like illness in Australia; they are living it as a reality each and every day. It will be evident in reading the LDAA's response to the Study, for the Lyme community, it is not so much a question of establishing whether or not Lyme disease is here in Australia, but *how can we get rid of it*, or at least alleviate some of the suffering and discrimination surrounding it?

As you will find in the attached Scoping Study response submission, we support a multi-pronged, simultaneous approach as the way forward to support the Lyme disease situation in Australia. Australia urgently needs research dedication, effective patient testing and an immediate directive to support treatment of sick patients now.

Our submission provides a response to the research projects proposed in the Study, as well as recommending the inclusion of two more areas of study oriented toward a more patient-focused research agenda. We also provide an extensive commentary addressing the Study's contents arising from our critical examination of the material presented. On the basis of this analysis, we offer a number of general recommendations and a prioritisation of the research agenda.

Throughout the commentary, we note the Study's omission of consideration for the needs of key stakeholders, namely the existing sufferers of Lyme-like illness, as well as members of the Australian public who remain at risk of infection in the absence of measures to protect them from exposure. To fill this shortfall in the Study we include, as an Appendix, a strategic action plan which approaches the Lyme problem from a patient focus. This document could potentially serve as a blueprint for the Chief Medical Officer to initiate responses that would have significant immediate and far-reaching impacts in the lives of these stakeholders.

We understand the CACLD has a clinical role and research interests but we urge you, not just as Australia's Chief Medical Officer but as a parent, grandparent and fellow Australian, to carefully consider our submission and the priorities we have raised and then invite you to join with us in doing everything humanly possible to address the suffering that results from this illness.

The situation for sufferers of Lyme disease and Lyme-like illness in this country is dire and urgent. Not one more day should go by without us being able to turn the tide of ignorance and neglect that recently has resulted in a small child being referred to a psychologist following a recent overseas tick bite instead of receiving urgently required medical treatment, due to Australian doctors' unpreparedness to treat this disease.

Thank you for the opportunity to provide input to this review process and we look forward to our continued successful collaboration into the future.

Yours sincerely

A handwritten signature in black ink, appearing to read 'Sharon Whiteman', written in a cursive style.

Sharon Whiteman
President.