

Nikki's notes (for the public) regarding the Clinical Advisory Committee on Lyme Disease meeting, 28 May 2013

The first half of the meeting the committee discussed each of the recommended changes to the Terms of Reference proposed by the Lyme Disease Association of Australia

- Recommendation 1 – Evidence of Borrelia in Australia - **The LD community request that the wording proposed on Recommendation 1 be amended from “*whether there is evidence of Borrelia spp causing illness in humans in Australia*” to read “*the extent to which there is evidence of Borrelia spp causing illness in humans in Australia;*”** after discussion the committee accepted this change
- Recommendation 2 – Lyme Disease vs Borreliosis - **The LD community request that the wording of the current fourth ToR be amended to read *the most appropriate ways to disseminate information to health professionals and the general public on borreliosis/Lyme disease.* ;”** after discussion the committee accepted this change
- Recommendation 3 – Co-infections - **The LD community recommends an addition to the ToR that common co-infections associated with borreliosis also be addressed in the work of the committee. Recommended wording is ‘*the prevalence of co-infections with borreliosis/Lyme disease be examined, in regard to diagnosis and treatment*’.** After discussion the committee came to the consensus (after being advised of the CMO's position), that currently co-infections can not be addressed by this committee (there is a concern that this may distract the committee from finding the causative agent of Lyme disease in Australia), but that the committee is keen to make sure that these are addressed in the education of the medical and wider community and that the health department make this clear in the creation of diagnosis and treatment protocols and guidelines.
- Recommendation 4 – Discrimination -**The LD community recommends another addition to the ToR that may provide an interim position and address the discrimination faced by Lyme patients in Australia. Wording for consideration “*to develop and disseminate policy recommendations to government and non-government agencies dealing with potentially Lyme-infected patients.*”** The committee was advised by the chair that the suffering (both from Lyme disease itself and as a result of discrimination) was what prompted the CMO to set up this committee. Unfortunately it is not the role of this committee to create or dissemination policy recommendations regarding Lyme disease, but the CMO plans to do this, once the causative agent of Lyme disease is identified in Australia.
- Recommendation 5 – members of the committee declared their conflict of interest to the committee at the beginning of the meeting, also the LDAA received feedback from the CMO prior to the meeting regarding the terms

of reference for the committee & were advised that as an advisory committee we will be giving him advice regarding the committee, but that ultimately decisions will be made by him – we have found him to be very open to informed discussion and he seems to have a genuine concern for Lyme sufferers in Australia.

- Recommendation 6 – Monitoring of Lyme disease - **the LD community request the committee immediately propose alternative methods of collecting statistics on ‘Lyme like’ illness in Australia by accessing information:**
  - a) **from the medical community, based on case records of Doctors clinical observations;**
  - b) **by contacting overseas reference Labs running tests on Australians (IGeneX, InfectoLab);**
  - c) **working with the Lyme disease patient community to collate existing laboratory test results for patients already diagnosed.**

**Instead of relying on the current statement ‘*The Australian Government is monitoring Lyme disease, in consultation with the states and territories, through the Communicable Diseases Network Australia*’.** The committee was advised by the chair that the monitoring of Lyme disease in Australia is the responsibility of the Communicable Diseases Network of Australia and as this committee is not responsible for this Network, we can not directly influence their work through our terms of reference. However, individuals and organisations are able to contact the CDNA to request a change to how they are monitoring Lyme disease (and to provide them with information).

- Recommendation 7 – Blood Supply & Organ Donation - **The LD community suggest that the government immediately implement a blood donor deferral policy, and an organ donation permanent deferral policy, as a prudent precautionary measure until the findings of the committee are known.** The committee was advised by the chair that is a great concern to the CMO and the Federal Health department, and that they are advising departments within health & the Red Cross/Blood Bank regarding this (note from Nikki – the Karl McManus Foundation has already been working with the Red Cross in regards to this, quite successfully). The chair advised that the current policy of the Federal Health Department is that anyone who is a regular or potential blood donor who mentions that they have Lyme disease will not be able to donate blood. Policies regarding organ donation are being examined. The committee decided that the dissemination of this information needed to be wider, and needs to be addressed in Terms of Reference 4.
- Recommendation 8 – Communicable Disease Network of Australia – **The LD community recommends that the committee be expanded to include an expert on the zoonotic aspects of borrelia – particularly a researcher currently working in this field.** The Chair advised that two members of the committee were veterinarians, and also that the CMO may appoint a current researcher who works in zoonotic diseases later in the process of the CACLD.

The Chair summarised his work in consulting with each committee member regarding Lyme disease in Australia. The three main areas that he looked at were

- 1) The perspective of each member of the committee on the existence of Lyme disease in Australia
- 2) Current diagnostic pathways for Lyme disease in Australia
- 3) Current treatment options for Lyme disease in Australia

The chair advised that there are a variety of views on the existence of Lyme disease in Australia, with the potential for an indigenous strain of Lyme disease caused by a unique form of borrelia. The chair also advised although he is acutely aware that current diagnostic and treatment protocols need to be clarified, it was the view of the chair and the CMO that these can't be considered until the causative agent of Lyme disease in Australia is identified, but that after it has been identified, the diagnostic and treatment protocols will be an urgent priority (along with educating the medical and wider community regarding Lyme disease).

Finally, it was decided that the most important aspect of the CACLD's work is to find the causative agent for Lyme Disease in Australia. With this in mind, a scoping study will be done to

- work out the best way to find the causative agent for Lyme disease/Borreliosis in Australia (ie by looking at skin biopsies and blood from lyme disease patients; by looking at ticks as a possible vector for Lyme disease etc)
- work out the cost of this next study (and how it will be funded)
- work out who the best people to do the study may be (and look into the potential for a multi-discipline, multi-organisation team approach)
- to look at the specific geographic regions of the study
- to consult with each member of the CACLD in the design of the study to find the causative agent for Lyme disease in Australia

The chair advised that the person being considered to conduct the scoping study is a very well respected researcher, who has not published research in Lyme disease previously (note from Nikki – which means they are more likely to be unbiased in their approach to designing the study to isolate and classify the causative agent for Lyme disease in Australia).

The scoping study will be reported back to the CACLD, and the next step for the CMO & the CACLD after this will be the actual research to find the organism that is causing Lyme disease in Australia, so that a definitive statement can be made by the CMO regarding Lyme – from this will flow diagnostic testing, treatment guidelines and education of medical professionals and the wider community regarding Lyme disease.

This process is slower than we like (the committee and the CMO are very aware of the current suffering of Lyme patients in Australia), but it is important to get this right, given that previous attempts around Lyme disease in the 1990's have been so disastrous for Lyme patients since that time.

Summary of the Clinical Advisory Committee on Lyme disease meeting 28 May, 2013  
– terms of reference 1 & 4 will be changed (as requested by the LDAA) to read  
1 - “whether there is evidence of *Borrelia* spp causing illness in humans in Australia “  
to read “the extent to which there is evidence of *Borrelia* spp causing illness in  
humans in Australia;” - previously it read “whether there is evidence of *Borrelia* spp  
causing illness in humans in Australia” – this is much more respectful for the tens of  
thousands of Lyme sufferers around Australia).

4 - the most appropriate ways to disseminate information to health professionals  
and the general public on borreliosis/Lyme disease (previously it read only  
borreliosis)

Finding the organism that causes Lyme disease in Australia is the top priority  
for the CMO & the CACLD. With this in mind, a scoping study will be done to  
work out the best way to find the organism, and how to fund this research. The  
next step (after the scoping study) will be the actual research to find the  
causative agent that is causing Lyme disease in Australia.

This process is slower than we like (the committee and the CMO are very aware of the  
current suffering of Lyme patients in Australia), but it is important to get this right,  
given that previous attempts around Lyme disease in the 1990’s have been so  
disasterous for Lyme patients since that time.