

Lyme Disease Association of Australia – input to April Ministerial Forum on Lyme- like illness

Ms Whiteman, CEO of the Lyme Disease Association of Australia was invited by Minister Hunt to speak on behalf of all Lyme patients at the April Ministerial Forum.

Ms Whiteman told forum attendees the LDAA received more than 100 requests per month for patients seeking doctors who might have knowledge of Lyme like illness; many of those patients are in dire needs of support due to their significantly failing health. She reported the LDAA are in a difficult position in having to advise patients to seek treatments overseas since there are no Australian doctors who are willing or open to treating them because our government maintains there is no Lyme disease in Australia.

Ms Whiteman also reported an increase in the number of patients who are in contact with the LDAA who have been bitten by ticks overseas in recognised endemic areas, and even they cannot get treatment here despite the Australian Governments published *guidelines on the diagnosis of overseas acquired Lyme Disease/Borreliosis*". Many of these patients are being misdiagnosed with other neurodegenerative diseases.

Ms Whiteman suggested there is a serious emerging disease here in Australia that is on the rise because we have not prioritised research that looks for it. We are not looking for it. She suggested that in an emerging disease situation, patients are the evidence and directed attendees to the patient empathy wall that the LDAA had installed.

Minister Hunt acknowledged this installation and asked forum participation to recognise that these people have enormously debilitating conditions they haven't been able to resolve".

Ms Whiteman summarised that there is a huge global challenge, especially with diagnosis and testing and reminds participants that global best practice diagnostics for Lyme disease remains clinical diagnosis, but our doctors are undereducated on that issue. The best experts in this illness are those who are at the coal face.

In addressing the outcomes for patients, Ms Whiteman urged participants to acknowledge there is something making Australians sick, and questioned why we have reverted to questioning the role of ticks in this illness. Ms Whiteman suggested that patients need a personalised medicine approach to this illness. She called upon the group to prioritise awareness and education to prevent more people entering the funnel of illness and make actions to support the prompt treatment of any patient with a rash following tick bite.

Patient wall images:

