



Senate inquiry into the Growing evidence of an emerging tick-borne disease that causes a Lyme like illness for many Australian patients

Lyme disease Association of Australia (LDAA) Questions taken on notice

Perth Public Hearing 14 April 2016

Question: 1

Hansard page reference: 19

Hansard extract:

Senator MADIGAN: In evidence earlier this morning I asked the WA health department about something people have said to me, which is that it can be spread by a blood transfusion, through the womb or through sexual contact. The department said that there was no evidence to suggest that. Can the LDAA point the committee to any papers or evidence that refutes that claim?

LDAA response: LDAA's submission covers these other forms of transmission on pages 81- 82 and includes references to research papers. A number of research papers and alerts have been issued regarding the risk of contracting tick borne diseases via blood transfusion, through the womb or through sexual contact. Further there are numerous case studies presented in the patient submissions.

The alternative forms of transmission are very important considerations in the Australian context. This raises significant questions about the assumption that the causative agent must be found in Australian ticks for the disease to be considered endemic. If people are infected through other pathways without having ever been bitten by a tick, they could have true positive test results without ever having left Australia. The assumption that a *Borrelia burgdorferi* positive test result is a false positive because the bacteria hasn't been isolated from an Australian tick is an error of the most substantial and devastating proportion.

The following papers are detailed for reference:

Blood transfusion

Herwaldt, B.L., Linden, J.V., Bosserman, E., Young, C., Olkowska, D. and Wilson, M., 2011. Transfusion-associated babesiosis in the United States: a description of cases. *Annals of internal medicine*, 155(8), pp.509-519.

The womb

MacDonald, Alan B. "Gestational Lyme borreliosis. Implications for the fetus." *Rheumatic diseases clinics of North America* 15.4 (1989): 657-677.

Sexual contact

Middelveen MJ, Burke J, Sapi E et al. Culture and identification of *Borrelia* spirochetes in human vaginal and seminal secretions [version 3; referees: 1 approved, 2 not approved]. *F1000Research* 2015, 3:309

Raphael B Stricker & Marianne J Middelveen (2015): Sexual transmission of Lyme disease: challenging the tickborne disease paradigm, *Expert review of anti-infective therapy*, 13(11), pp.1303-1306.

Question: 2

Hansard page reference: 19

Hansard extract:

Senator MADIGAN: I have personally heard a lot of cases of people who present at hospitals or to doctors saying that they believe they have Lyme disease or a Lyme-like illness. We are told by departments that patients are supposed to be treated with respect. Is the LDAA able to give the committee—take it on notice if you like—figures of how many of your members have presented at hospitals or GPs and have not actually been treated with respect; they have been told they have a few

kangaroos loose in the top paddock? Of people who I have met, a number of people have had it suggested that they be scheduled. Can the LDAA furnish the committee with some numbers of people, members, who have been subjected to this sort of thing?

LDAA Response: Almost all of the patient submissions have raised concerns about the lack of respect they have been shown by medical professionals. Though not all the submissions are publicly viewable, a fair approximation would be over 800.

The LDAA's submission (page 23) also outlines the number of patients (22% or 191) who have reported they attended a hospital for treatment of their Lyme-like condition. Of those 191 patients, nearly 70% said they encountered difficulty obtaining treatment, some of them on more than one occasion. As a result many patients, usually the most debilitated, deny themselves the serious medical attention they need because of the increasing stigma associated discrimination they have experienced. Patients repeatedly tell us they "avoid hospital like the plague and certainly don't mention the L word".

Question: 3

Hansard page reference: 19

Hansard extract:

Senator MADIGAN: In evidence earlier today, we were trying to thrash out people who have come overseas from Lyme-endemic areas, as identified in the WA health department's submission to us. Has the LDAA got any figures on how many people in Australia currently have got a positive test from overseas—people who have contracted Lyme overseas with a positive result from any of the laboratories?

LDAA Response: The following data is taken from LDAA's report, 'Lyme disease: Australian patient experience in 2012'. This survey represents the first consolidated collection of data from the Australian Lyme disease patient community. Of the survey received there were 224 respondents who reported they reside in Australia and as of July 2012, had been formally diagnosed with Lyme disease. Participants who reported they recall a tick or other bite were asked the geographic location of where they were bitten. 35 respondents (20.8%) reported they were bitten while travelling overseas in the countries indicated in Table 3. So there is indeed a cohort of patients in Australia with 'overseas-acquired' Lyme disease, however these are in the minority (21%) of Australian patients who participated in the survey.

In addition to the detailed patient situation surveys, LDAA makes available a survey that counts people who live in Australia and report they have been diagnosed with a Lyme-like illness by a medical practitioner. We recently called for an update to this map and now plot 2,126 people.

The number of people responding to LDAA’s survey has increased from 224 in 2012 to 2,126 in 2016. The 2016 survey did not ask about overseas acquired Lyme disease. However the significant increase in survey participation is indicative that the numbers from the 2012 survey could be an under-estimation of the actual figures.

TABLE 3: INTERNATIONAL BITE LOCATIONS

Where were you when you were bitten?	
Africa	2
Asia	6
America (North)	11
Europe	14
Oceania	2
Total	35