Senate Community Affairs References Committee

ANSWERS TO QUESTIONS ON NOTICE

HEALTH PORTFOLIO

Inquiry into growing evidence of an emerging tick-borne disease that causes a Lyme like illness for many Australian patients

2 November 2016

Question no: 1

Topic: Causes of symptoms of Lyme-like illness

Type of Question: Written

Senator: Rachel Seiwert

Question:

Dr Richard Horowitz, Medical Director, Hudson Valley Healing Arts Centre, (sub 936) has suggested that the symptoms of Lyme-like illness may be caused by multiple underlying etiologies, and that we may be underestimating the prevalence of Lyme disease worldwide due to the non-specific nature of symptoms, and lack of gold standard for diagnosis. What is your view on this?

Answer:

The department's opening statement at the hearing on 2 November 2016 recognises that many pathological processes may be involved and not limited to microbial ætiologies.

"Many people use "Lyme disease" as a collective term for not only so-called chronic Lyme disease but also coinfections, as well as the inclusion of multiple vectors including arthropods[1] *and leeches plus disease acquisition through sexual contact and during child birth. It may be, there are multiple groups within a broad "neuropathic fatigue" syndrome. What hasn't been fully explored or confirmed is the presence of single microorganism disease, multiple microorganism*[2] *disease*[3] *or environmental intoxication or other medical conditions.*

Arguably, a term is needed to describe a chronic (possibly arthropod-borne) neuropathic syndrome, which can collectively describe what are probable multiple pathological problems."

Dr Horowitz's testimony describes how a single diagnostic approach is not available and so a gold standard for diagnosis is elusive. His testimony alludes to a multiple pathology syndrome for which a neat diagnostic pathway is unlikely.

In the absence of an agreed case definition including a name for the syndrome, an accurate prevalence is not available. The nonspecific nature of the symptoms which can have manifold causes makes case ascertainment difficult.

1 Segmented animal with an exoskeleton but no backbone.
2 Polymicrobial
3 Not limited to bacteria but combinations of bacteria, viruses, and parasites.

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2 November 2016

Question no: 2

Topic: Lyme-Multiple Systemic Infectious Disease Syndrome

Type of Question: Written

Senator: Rachel Seiwert

Question:

Are you familiar with the submission made by Dr Richard Horowitz, one of the founding members of the International Lyme and Associated Diseases Society (ILADS)? Could you please, on notice, respond to what Dr Horowitz writes concerning "Lyme-MSIDS", or Lyme-Multiple Systemic Infectious Disease Syndrome?

Answer:

The department is familiar with Dr Horowitz and the International Lyme and Associated Diseases Society. The concept of multiple systemic infectious diseases syndrome (MSIDS) is confined to the advocates of chronic Lyme disease and associated coinfections. Dr Horowitz's testimony however, goes beyond infectious ætiologies and captures more his hypothesis of a chronic inflammatory basis for the symptom complex which can be associated with multiple pathological processes and not limited to infection.

The integrative medicine approach Dr Horowitz takes also encompasses practices that are currently outside the scope of evidence-based medicine.

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2 November 2016

Question no: 3

Topic: False seronegativity

Type of Question: Written

Senator: Rachel Seiwert

Question:

Some submitters *[e.g. Horowitz, 936, p. 7]* have said that false seronegativity has been extensively reported in peer reviewed medical literature. Can you respond to this, and tell the committee what, if any, bearing this has on Australia's established diagnosis protocols?

Answer:

In classical Lyme disease, the period to seropositivity can be longer than with other bacterial infections because the appearance of immunoglobulin classes M and G (IgM and IgG) can be delayed. For example, at the time of rash <50% of patients will have reactive serology. IgM can take between 1 and 2 weeks to appear while IgG can take between 2 and 6 weeks to appear. Both immunoglobulins usually remain elevated even after successful treatment in persons who have been infected with a bacterium from the *Borrelia burgdorferi* sensu lato genospecies complex.

In patients without classical Lyme disease, who present with nonspecific symptoms and who come from an area of low prevalence, the usual reason for seronegativity is because the patient has not been exposed to any bacteria in the *Borrelia burgdorferi* sensu lato genospecies complex.

The reporting of nonreactive results from specific Lyme disease testing of patients presenting with multiple nonspecific debilitating symptoms, continues to support the absence of Lyme disease in Australia.

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2 November 2016

Question no: 4

Topic: Helping sufferers of Lyme-like illness

Type of Question: Written

Senator: Rachel Seiwert

Question:

Lyme disease and Lyme-like illness divides opinion in Australia, but there appears to be agreement that something unidentified in Australian ticks is making some people very sick. The pathogen will likely be discovered with enough research, but this may take some time—how do we help people who are sick now?

Answer:

The department's opening statement and the answers provided by Dr Lum emphasise the importance of a multidisciplinary approach to patient care and management.

The concept involves having multidisciplinary care centres in areas where most of the patients reside with the possibility of telemedicine access for patients in regional areas.

It is evident there are no simple answers and a thorough patient examination including a comprehensive medical and family history is important. Coupled with diagnostic testing and input from generalists and specialists, each patient needs evaluation for a customised treatment plan.

"Professor Lindsay Grayson from the Austin Hospital in Melbourne, recently managed the referral of a large number of patients who were sent to see him with the chronic debilitating symptoms being discussed as part of this inquiry. Prof. Grayson who wrote about his experience in a submission (820) to the senate inquiry prior to the election, rapidly developed a multidisciplinary team approach to care and management of these patients. This involved staff specialists and consultants in microbiology, infectious diseases, rheumatology, oncology, neurology and psychiatry. All the patients were referred for a large number of pathology tests and were seen by a team of doctors. This case investigation is illuminating and instructional.

The department believes there is merit in engaging with states and territories to develop a multidisciplinary clinical approach to patient management and care. Such an approach also needs to focus on general practice, with strong linkages to hospital based services."

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Question no: 5

Topic: Consulting medical specialists

Type of Question: Written

Senator: Rachel Seiwert

Question:

If this Lyme-like illness is an emerging disease which we know very little about in terms of transmission, manifestation or treatment, then do you see a benefit in consulting the medical specialists who believe they have expertise in treating people?

Answer:

The department has met with medical practitioners who are treating patients. This has included meetings with members of the Australian Chronic Infectious and Inflammatory Diseases Society, separate meetings with Dr Richard Schloeffel and a treatment roundtable which brought together nine treating general practitioners along with other specialist medical practitioners to consider treatment options. Dr Lum has also attended a two-day meeting of the International Lyme and Associated Diseases Society.

The former Chief Medical Officer's Clinical Advisory Committee on Lyme disease also had treating medical practitioners in its membership, including an international medical practitioner from Germany.

The department will continue to engage with registered medical practitioners who are treating patients. This will include people like Professor Lindsay Grayson who has developed a multidisciplinary patient treatment and management model, as well as other experts in emerging diseases.

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2 November 2016

Question no: 6

Topic: Treatment outcomes

Type of Question: Written

Senator: Rachel Seiwert

Question:

Has the department looked at or compared treatment outcomes between patients who travel to specialists overseas, such as for example Dr Horowitz in the US, and those who receive treatment in Australia?

Answer:

No. The department does not have information on patients who are seeking treatment overseas or within Australia. This information is not publicly available.

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2 November 2016

Question no: 7

Topic: Consultation of doctors

Type of Question: Written

Senator: Rachel Seiwert

Question:

Evidence before the committee suggests that we are at an impasse in terms of both diagnosis and treatment, with some very different views expressed by people with considerable expertise. Has any work been done by the authorities to consult doctors who say they are successfully treating these patients, to perhaps examine their methods and see if anything can be learned?

Answer:

Please see the answer to question 5.