

## 18 April 2018

## MEDIA RELEASE

## International biomedical experts take on vector-borne illness in Australia: thousands of Australians infected, and numbers are growing

- More than 4,000 Australians, diagnosed in the Australian healthcare system, with serious Lyme-like illness most having waited for an average of 10 years before receiving an accurate diagnosis are struggling to obtain adequate healthcare due to a lack of health policy around vector-borne disease
- The number of Australians who've contracted the illness but remain undiagnosed could be around 10,000 each year, based upon statistics modelling in the USA
- Local and international biomedical and clinical medicine experts have formed an advisory committee, in conjunction with the Lyme Disease Association of Australia, to inform the Australian government, healthcare sector and insurers of the need for accurate diagnosis, proper treatment and compassion for Australian patients caught up in policy delays that restrict their treatment options
- Sydney (particularly the Northern Beaches), Melbourne, Perth and Brisbane along with the southeast coast are among the regions with the highest recorded rates of locally-acquired Lyme-like illness
- Children, outdoor workers, day trippers and people with an outdoor lifestyle are among those at highest risk

International biomedical science and clinical medicine experts have joined local experts to form a Scientific Advisory Committee (SAC), in conjunction with the Lyme Disease Association of Australia (LDAA).

The Advisory Committee's aim is to address the lack of world-class treatments available to Australians who suffer with this condition and combat the spread of Lyme-like illness. Ignoring the debate about nomenclature - vector-borne disease, tick-borne disease, Debilitating Symptom Complexes Attributed to Ticks (DSCATT) or multi systemic infectious disease syndrome – the SAC sees thousands of patients left stranded, undiagnosed and untreated in the Australian health system.

"The reality is we are seeing an increased number of cases of vector borne illnesses in Australia every year. In fact, a senate inquiry revealed that there significant numbers of people awaiting treatment – one clinic reports 800 people on their waiting-list," commented Professor Gilles Guillemin, neuroscientist at Macquarie University and Chair of the Committee.

Healthcare policies, the experts say, need to reflect the situation as it stands and prioritise diagnosis and treatment of this emerging illness. Research also needs to be done to understand why increasing numbers of Australians are becoming ill after tick bites. Children, outdoor workers, day trippers and people with an outdoor lifestyle are at higher risk of contracting the disease.

"The Scientific Advisory Committee will add significant expertise to the debate and prioritise research that puts patients first and contributes to a national policy framework for vector-borne

disease. We need to make sure that the world's best practice healthcare is available to patients, particularly those in <u>identified endemic areas in Australia</u> – the major cities of Sydney (with the Northern Beaches having particularly high incidence with *hundreds* of identified victims), Melbourne, Perth and Brisbane as well as the south-east coastal region," said LDAA CEO Ms Sharon Whiteman.

The lack of accurate diagnosis and treatment for those who have Lyme-like illness in Australia is due to a legacy issue where healthcare policy makers refuse to recognise the disease. Patients wait an average of 10 years before receiving an accurate diagnosis which leaves them with chronic disease. This often results in permanent disability accompanied by an unacceptable financial burden.

"Tick and vector-borne diseases are on the radar for many scientists, given the systemic role they play in infection of tissue, blood and organs, and their potential impact in neurodegenerative diseases. Our priority on the Committee is to build multidisciplinary teams for research and treatment and establish world class, innovative treatment centres for patients with Lyme-like illness in Australia. Making tick-borne diseases notifiable will help to build the risk profile of tick bites and allow the impact of such diseases to be better understood," Professor Guillemin commented.

Australia is not alone in its fight against Lyme-like illness. With increasing evidence indicating that multiple alternative strains of bacteria worldwide, in addition to the well-characterised *Borrelia burgdorferi* that causes Lyme disease in the USA, could be causing Lyme-like illness.

"This is a world-wide epidemic. We need to take this very seriously because it can be passed from mother to child and now tick-borne infections are in the blood supply. This is causing major disability for millions of people and future generations will also be affected,' concluded Dr Richard Horowitz, member of the US Congress-established Health and Human Services Tick-Borne Disease Working Group and Patron of the LDAA.

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Additional resources for media are available from the Lyme Disease Association of Australia's website here.

The Lyme Disease Association of Australia (LDAA) commenced operations in r 2009. Since that time, we have evolved into a powerful organisation with the assistance of many volunteers who are passionate about awareness and education, and ultimately eradication of the illness, which can be debilitating, life changing, and in some cases deadly. To learn more about symptoms, please visit this page, and if you are concerned about your health and would like support please contact us.