Access to diagnosis and treatment for people in Australia with tick-borne diseases Submission 16

Date: 14 December 2024

Committee Secretary
Senate Standing Committees on Community Affairs
PO Box 6100
Parliament House
Canberra ACT 2600

Subject: Submission to the Senate Inquiry into Access to Diagnosis and Treatment for Tick-Borne Diseases

Dear Committee Members,

I am writing to provide my submission to the Senate Inquiry into the access to diagnosis and treatment for people in Australia with tick-borne diseases. I appreciate the opportunity to share my experiences and concerns regarding this important public health issue.

I was diagnosed with overseas acquired chronic neurological Lyme disease in 2014 at 21 years of age and was in my final year of my psychology degree.

Before beginning long-term antibiotic treatment, I was physically incapacitated, with neurological symptoms being my most prominent issue, I experienced daily seizures and tremors and the inability to walk which left me wheelchair bound for a significant period. These symptoms were accompanied by fevers, dizziness, low blood pressure, cardiac and respiratory issues, pain and debilitating fatigue which left me confined to my family home, unable to work or study.

I underwent long-term antibiotic treatment from two Lyme-literate doctors to whom I attribute my health improvement. Both doctors have since been sanctioned by the Australian Health Practitioner Regulation Agency (AHPRA), one no longer able to practice and the other prevented from treating patients, like me with chronic bacterial infections. I attempted to seek assistance from infectious diseases specialists, on multiple occasions, however, each time they breached in their duty of care to treat me, despite having positive serological tests from both Australian and overseas laboratories and my diagnosis verified by a well renowned US Neurologist who specialises in infection induced autoimmune encephalitis.

My improvements can be illustrated through my academic completion of a bachelor's degree in psychology, Juris Doctorate and Graduate Diploma in Legal Practice. The latter two, earned me the title of a lawyer. I am now 32 years of age and have the capacity to work full-time at

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40+ hours per week and often work overtime on the weekends. I also have both the physical and mental capacity to tutor law students, volunteer for the Lyme Disease Association of Australia (LDAA), study French and overall engage in society.

All of the above, is a testament to the treatment I received from my Lyme-aware doctors. All of which was based on scientific evidence and standards of world's best practice. Whilst the disease itself, coupled with the struggle to access treatment, resulted in both economic and non-economic loss, I am profoundly grateful for this second chance at life – a chance that, tragically many others suffering from chronic tick-borne diseases may never experience, unless the Government takes decisive and legislative action which enables Lyme-aware practitioners to provide treatment to patients. This approach has successfully been implemented in overseas comparative jurisdictions.

Thank you for taking the time to review my submission. I sincerely appreciate your attention to this vital issue. I am hopeful that proactive steps will be taken to pursue justice. I look forward to the meaningful actions that will be implemented to combat chronic tick-borne diseases in Australia, ultimately ensuring a fair and just resolution for those affected by this debilitating illness.

Yours sincerely,