19/12/24

Committee Secretary
Senate Standing Committee 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 Access to Diagnosis and Treatment for Tick-Borne Diseases. I appreciate the opportunity to share my experiences and concerns regarding this critical public health issue.

Personal Experience

My journey with Lyme disease (or Debilitating Symptom Complexes Attributed to Ticks, DSCAT) began after a tick bite on my right calf during a visit to the Gold Coast in 2018. Following this, I experienced an array of debilitating symptoms, including:

- Severe fatigue
- Tingling in my extremities
- Night sweats
- Nausea
- Joint pain
- Cognitive dysfunction (often referred to as "brain fog")
- Headaches
- Muscle weakness
- Sensitivity to light and sound
- Difficulty concentrating
- Memory loss
- Persistent tinnitus
- Severe nausea impacting my ability to eat and function daily
- Chronic pain in joints and muscles
- Episodes of vertigo and imbalance
- Insomnia and disrupted sleep patterns
- Immense fatigue preventing basic daily functioning

- Heart issues, pericarditis and tachycardia
- Reflux and digestive issues
- Diarrhea and gut issues
- Bell's palsy, facial deformity, and weakness

Over the years, my health deteriorated significantly, and I was forced to relocate from Victoria back to Western Australia to be closer to my family for support.

Despite numerous consultations with infectious disease physicians, general practitioners, neurologists and naturopaths, obtaining a diagnosis proved to be an uphill battle. Many dismissed my symptoms or attributed them to psychological causes. It wasn’t until five years later that I finally received a confirmed diagnosis of Lyme disease and several co-infections, including:

- **Borrelia burgdorferi**
- **Epstein-Barr Virus (EBV)**
- **Coxsackie Virus**
- **Spotted Fever Group Rickettsia (Queensland tick typhus, Flinders Island spotted fever)**
- **Bartonella henselae** and **Bartonella quintana**
- **Pneumonia A**

The inadequacy of diagnostic methods in Australia led me to seek testing through Armin Labs in Germany at a cost of $3,000, which confirmed these infections. Since then, I have been undergoing treatment with antibiotics and antiparasitics under the care of a Lyme-literate doctor. While I have seen some improvements, the journey has been fraught with challenges.

Impact on Quality of Life

The lack of early diagnosis and treatment has resulted in late-stage Lyme disease, accompanied by severe complications:

- **Pericarditis and Lyme carditis**, causing an elevated resting heart rate and inflammation of the pericardium.
- Multiple hospital admissions and an ambulance trip in 2023 due to **tachycardia**.
- **Chronic pain** in joints and muscles.
- **Persistent tinnitus**.
- **Severe nausea** impacting daily life.
- **Seizures**.
- Issues with **brain function**, including memory and cognition.
- Episodes of **vertigo and imbalance**.
- Insomnia and disrupted sleep patterns.
- Frequent and significant bruising.
- Immense fatigue preventing basic daily functioning.
- Reflux and digestive issues.
- Diarrhea and other gut issues.

- Bell's palsy, facial deformity, and weakness.

To date, I have undergone hundreds of blood tests, MRI scans, Holter monitors, brain scans, cardiac stress tests, and ECGs, seeking answers and appropriate treatment. These investigations, while thorough, often resulted in limited insights and further frustration.

These symptoms have profoundly affected my quality of life, limiting my ability to engage with my family, pursue my career, and participate in everyday activities. Financially, I have spent tens of thousands of dollars on consultations, tests, and treatments, with little support from public health systems. The significant physical and emotional toll has been compounded by frequent experiences of medical gaslighting and dismissal by healthcare providers, which delayed critical care.

Barriers to Diagnosis and Treatment

Since the 2016 DSCATT report, awareness and resources for tick-borne diseases in Australia remain grossly inadequate. Healthcare professionals are often underinformed, and diagnostic methods lack accuracy and accessibility. General practitioners and specialists frequently dismiss or downplay the severity of symptoms, perpetuating cycles of medical gaslighting.

For example, during a 2023 hospital admission, my symptoms of **tachycardia** and **severe bruising** were attributed to anxiety, delaying necessary treatment. Such experiences are not uncommon among Lyme patients in Australia.

Inadequacy of the Clinical Pathway

The Debilitating Symptom Complexes Attributed to Ticks (DSCATT) clinical pathway does not meet patient needs. Navigation is cumbersome, and the lack of recognition for chronic Lyme disease leaves many without appropriate care. Improvements must include:

- Broader education for healthcare professionals about tick-borne diseases.
- Integration of international diagnostic and treatment standards.
- Greater funding for research and patient support services.
- Ability for Doctors to provide immediate treatment with antibiotics for a minimum of 6 weeks after a tick bite. To think if my doctor had have done this immediately when I went to see him post the tick bite I would not have lost six years of my life to this illness.

Research and Policy Recommendations

Australian research efforts in this field are insufficient. Key areas requiring attention include:

- Development of reliable diagnostic tests that are subsidised by the government.
- Studies on long-term treatment outcomes for chronic Lyme disease.
- Epidemiological research to understand the prevalence of tick-borne diseases in Australia.

Policy reforms should prioritise:

- Funding for accessible testing and treatment options.
- Establishing a coordinated national response to tick-borne diseases.
- Addressing the stigma surrounding Lyme disease to ensure patients receive compassionate and competent care.

Conclusion

I implore the committee to consider the devastating impact of Lyme disease and related co-infections on Australians. My story reflects the systemic failures in diagnosis and treatment, which have left many like me to navigate this journey alone. By implementing the recommendations outlined, we can pave the way for improved outcomes and quality of life for future patients.

My life, my health, my career and my mental health, my financial security have been completely decimated by this disease and to think, six weeks of antibiotics would have completely changed my life and that of my family.

Thank you for considering my submission. I am available to provide further information or participate in initiatives aimed at addressing this critical public health issue.

Yours sincerely,