

Submission to the Senate Inquiry into Access to Diagnosis and Treatment for People with Tick-Borne Diseases in Australia

I am writing to bring to the Senate's attention the urgent need for reform in the diagnosis and treatment of tick-borne diseases in Australia, with a focus on the devastating experience of my friend's 11-year-old child (at the time of being bitten by a tick) who, for years, suffered without proper care and treatment.

For five long years I have witnessed the experienced physical and emotional symptoms that were dismissed as psychosomatic by Australian medical professionals. Despite the family's repeated pleas for testing, the head of Infectious Diseases at a prominent hospital in Australia told the family and the child that the condition was "functional," attributing his pain, fatigue, neurological issues, and cognitive decline to being psychological rather than a physical disease. No tests were conducted for tick-borne illnesses, and they were left to watch their once healthy child deteriorate with no answers.

This rejection of testing and treatment, based on outdated and inaccurate assumptions about tick-borne diseases, had profound consequences. The toll the child and the family was unbearable— including accessing testing from overseas at a huge financial cost . As friends, we felt utterly powerless as we watched this family's world unravel in front of us, while medical professionals insisted it was "all in his head" and the family were left without care.

Finally, after finding a doctor who was prepared to send bloods overseas and provide professional treatment for the presenting symptoms the family started to get answers and the child had a pathway to some form of care and treatment. Blood tests confirmed the presence of multiple bacteria commonly associated with tick bites. With this diagnosis, they pursued an intensive treatment plan and after extensive care over many years the child is now living an almost normal life. However, the damage caused by the delay in diagnosis and treatment is still felt. This family has faced immense emotional distress, financial hardship, and the ongoing physical repercussions of a delay in diagnosis.

The most frustrating part of this experience is that the doctor who saved their child's life has now been restricted in their ability to practice due to current medical regulations.

The laws around Lyme disease in Australia are severely limiting, forcing doctors to choose between treating their patients appropriately or facing professional repercussions. This is an unacceptable situation that must change.

Australia's approach to tick-borne diseases is not only outdated, but it is causing unnecessary harm to countless families. The failure to recognize, test for, and treat these diseases has left many suffering in silence for years. It is time for a complete overhaul of the medical framework surrounding tick-borne illnesses in Australia, including better education for healthcare professionals, access to accurate testing, and a shift in policy to allow for proper treatment options. The health and wellbeing of our children—and the financial and emotional stability of their families—depend on it.

I urge the Senate to take immediate action to ensure that no more Australian families are subjected to the pain and suffering that our friends endured. Lives are being lost to neglect, and the medical system must be held accountable for its failure to act.