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PATIENT ADVOCATES AUSTRALIA

Thursday, 16 January 2025

Senate inquiry.

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

In 2020 I was approached by Sharon Whiteman from the Lyme Disease Association of Australia to provide healthcare advocacy for about 6 of her clients who had Lyme-like illnesses. Each had illnesses confirmed by mainstream clinicians (clinical history, symptoms and pathological tests), usually immunologists or neurologists, and were always being co-managed by a general practitioner. I collaborated with these doctors during my client's appointments. Most clients were very ill and several were hospitalised multiple times.

These people believed their illness was related to a tick bite and many had had pathology results performed in Australia that were consistent with Lyme disease or had pathology results confirming Lyme disease that had been performed outside Australia.

- Not one of these clients had an acknowledged diagnosis of Lyme-like or tick-borne illness with appropriate treatment.
- Every one of these clients suffered the psychological trauma of being shunned and disbelieved by their doctors despite evidence supporting such an illness.
- Every one of these patients was chronically ill and was a major consumer of (inappropriate) healthcare
- Several of those doctors told me they feared investigating or treating these clients in a way they believed they should (or had previously successfully been treated with antibiotics) because they feared their medical registrations would be at risk.
- Every one of my "Lyme" clients received inferior management, treatment and care to what is the accepted standard of care with the healthcare industry.

I have been a private patient advocate for over 10 years and a registered nurse for 50 years. In my advocacy role, I have seen this kind of medical bias in a few other groups of patients: those with endometriosis, those with chronic pain and those with severe mental health disorders. Similar practitioner behaviour was evident with the management of those patients: disbelief, frustration, victim blaming and fear by the practitioners of professional repercussions.

I make no claims to medical expertise but I know a sick person when I see the evidence and I know bad healthcare when I see it.

From my extensive experience as a private patient advocate, I submit that people with tick-borne disease should have their condition investigated and treated within mainstream medicine as a priority.

I will happily provide further information or answer questions in support of this submission.

Yours sincerely,

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