Dr Richard Schloeffel, OAM

7th February 2025

Committee Secretariat Senate Inquiry
Parliament House Canberra, ACT 2600

Subject: Supplementary Submission to the Senate Inquiry Access to diagnosis and treatment for people in Australia with tick-borne diseases – Dr. Richard Schloeffel OAM

Dear Committee Members,

I am writing to provide this supplementary submission in response to questions on notice from the Hearing for the Senate Inquiry - Access to diagnosis and treatment for people in Australia with tick-borne diseases. As an experienced clinician at the forefront of diagnosing and treating vector-borne diseases (VBD) in Australia, I have treated over 1,200 patients suffering from these debilitating conditions. My work has been dedicated to advancing scientific understanding, clinical care, and education in this critical area of public health.

Over the years, I have witnessed firsthand the urgent need for recognition, research, and appropriate clinical care for VBD patients in Australia. Despite my extensive experience and the compelling number of cases I have managed, efforts to establish a structured approach to treatment have been met with resistance.

In 2018, I presented the Australian Chronic Infectious and Inflammatory Disease Society (ACIIDS) Clinical Pathway to Prof Brendon Murphy and Gary Lum. I made a representation personally in Canberra, but my Guideline was not accepted and no further discussion was undertaken. I was encouraged when Gary Lum suggested a reconsideration of my thoughts and preliminary Guidelines. Is it possible for the committee to more formally encourage this dialogue?

This rejection reflects a broader systemic dismissal of the issue, where I and my colleagues have been encouraged to develop clinical guidelines, collect patient data, and contribute to scientific advancements, only for these efforts to be ignored or rejected by health authorities.

Additionally, there is compelling evidence that Australian doctors diagnosing and treating VBD have been systematically targeted. At least 15 practitioners have been reported to regulatory bodies such as AHPRA and the HCCC, resulting in restrictions on their ability to practice or even deregistration. This environment of professional risk has created a chilling effect, deterring medical professionals from addressing this emerging health crisis, despite the clear need for specialized care.

To move forward, I propose several key actions.

First, integrative doctors, who utilize both conventional and complementary approaches, must be formally recognized, supported, and protected within Australia's healthcare framework, as they are best placed to diagnose and manage these complex, multi-system illnesses. This may require legislation like those outlined by Prof Holly Ahern in New York or with constitutional adjustments as deemed necessary.

Secondly, ACIIDS should be funded by the government to act as the primary educational body for doctors on the diagnosis and treatment of tick-borne diseases. This would ensure that evidence-based, clinically relevant training is made widely available to medical professionals.

Finally, ongoing patient-focussed, scientific research and biomarker development must be prioritized. Current projects underway and requiring further funding support to complete are:

1. The Snow Foundation's study on chronic tick-borne infections is currently underway and will provide a patient treatment pathway supported by longitudinal evidence.

> *"We are thrilled to support the Tick-Borne Disease Research Program, in partnership with the NORTH Foundation. As a family, we have been directly impacted by this disease and this unique study aims to build crucial evidence about how to diagnose and then tailor treatment for those that suffer from chronic tick-borne illnesses. The funding will support a world-renowned multidisciplinary team and back crucial research into better understanding the source of infection, diagnosis and treatment pathways for patients suffering with potential tick-borne diseases. There are limited diagnostic tests available in Australia, which means that potential tick-borne disease is often not recognised or misdiagnosed. The research team will be undertaking a significant and first-of-its-kind clinical research program which places patients at the centre of the study. An additional major legacy from this project will be a bio bank of samples collected that will be made available to other researchers once this research program is complete. In the long term, we hope to change the government's mind to fund patient-related research as a priority. We welcome any others that want to join us in supporting this incredible research project."*

2. Creating a vital biobank that includes disease biomarkers and Government funding and collaboration in this effort would significantly enhance our ability to understand and manage tick-borne diseases in Australia.

> Biomarker and treatment discovery for myalgic encephalomyelitis/chronic fatigue-associated infectious diseases: Understanding the pathological mechanisms and triggers. *(Heng, Benjamin (Primary Chief Investigator); Schloeffel, Richard (Chief Investigator); Macquarie Medical School*.

Please note I have been involved in these research projects since their inception and we are approaching publications this year.

I urge the Senate Committee to consider the evidence presented and take immediate steps to support experienced practitioners and researchers working on behalf of Australians affected by tick-borne diseases. These actions will ensure that patients receive appropriate care, medical professionals can operate without fear of reprisal, and scientific advancements are effectively translated into treatment pathways.

Thank you for your time and consideration.

Sincerely,

Dr Richard Schloeffel OAM