To whom it may concern,

Re: Senate inquiry into the growing evidence of an emerging tick-borne disease that causes a Lyme‑like illness for many Australian patients

I am a practising infectious diseases specialist in a major urban teaching hospital as well as in private practice. Over the recent years, I have been referred many patients who have either been given the diagnosis of Lyme disease or whose doctors have raised the possibility of it.

A minority of such patients referred to me have been those who have travelled to areas known to be endemic for Lyme disease, such as the north-eastern part of the USA and parts of continental Europe. Such patients have all been positive on standard testing of serum using ELISA followed by Western Blot analysis. Treatment with oral doxycycline for two weeks has led to excellent outcomes.

The much larger group of patients are those who have not travelled to known Lyme-endemic areas and have what has previously been coined in the literature as “chronic fatigue syndrome”, “mixed unexplained symptoms” or “myalgic encephalopathy”. Very few have actually witnessed a tick bite, but rather recall being in an area where there may have been ticks or having had a non-specific red spot. Clearly these patients are unwell and are very troubled by their illness, and take up many hours of clinic time exploring their symptoms and testing for various possible diagnoses. However, all of these patients have been negative for Lyme disease when their blood tests are performed at NATA-accredited laboratories using ELISA and Western Blot analyses.

Some of these patients have been given the diagnosis of Lyme disease based on tests that are performed at non-NATA accredited laboratories at very high cost to the patient. Examples of these include Infectolab, Igenex and Australian Biologics. I contacted the staff at Australian Biologics to ascertain how accurate their testing was. They sent me data to say that testing on random samples of blood from patients presenting to a Rheumatology Clinic and also random blood samples from well Australians showed positive results in approximately 70% and 35%, respectively. Thus the false positive rate appears to be extremely high with such interferon gamma release assays. PCR testing by some of these groups uses short primers and a very high number of cycles, both of which are known to be sources of false positives in all PCR tests.

Patients having these tests have often had a wide variety of investigations for their illness and are understandably frustrated that their doctors cannot make a diagnosis easily. However, I am certainly suspicious when they are charged over $1000 for a test with a very high false positive rate and are then obliged to sign up for long-term treatment plans that cost patients in excess of $500 per week in many cases. Some of these patients have ended up at my hospital when they have run out of money and are hoping that we can continue to pay for their treatment for them. This is despite most of them stating that they are not in any way convinced that the treatment is helping.

Extensive work up of such patients has led to other diagnoses being made in most patients. Examples include disseminated malignancy, motor neurone disease, Parkinson’s disease, depression, repeated physical abuse by an alcoholic partner and autoimmune conditions like lupus or polymyositis. Some of these patients had appropriate treatment delayed because of the focus on misdiagnosed Lyme disease and the patient with malignancy died as their cancer was diagnosed too late for treatment. In addition, I have seen patients who have had major complications of the treatment being prescribed for their Lyme disease, examples being line-related bloodstream infections and *Clostridium difficile*-associated disease.

There is no doubting that these patients are unwell and I, like my colleagues, are very keen to try to help the patients referred to us. If there were any solid evidence that their illness is due to a tick-borne infection or that their illness was antibiotic-responsive, we would happily treat them as such and at far less cost to the patient than what they are being charged by the so called “Lyme-literate doctors”.

This is a very emotive area and these people suffering from this type of illness are understandably frustrated that treating physicians like me often find it hard to make a definitive diagnosis. Clearly they are desperate for answers. However, telling such a person a dogmatic statement that they absolutely have Lyme disease, based on a very expensive test that is almost always positive, and then committing the person to years of very expensive and unproven therapy certainly raises a lot of suspicion about the motives of the people promoting the belief that this is caused by Lyme.

I am old enough to recall phases when this same condition was always put down to Epstein-Barr Virus or Human Herpes Virus 6, based on difficult to interpret serological results before the era of PCR testing. More recently, there was a group promoting the belief that this condition was caused by Xenotropic Murine Leukaemia Virus (XMRV). When other more reputable laboratories started testing for this and were not finding it in anyone, the workers in those latter laboratories received death threats. Other research groups who have undertaken research into such patients and have published work stating that they have not been able to identify a biological cause have also received death threats from people who didn’t want to see the message spread that there is no known cause so it must be “all in their head”. Unfortunately for the patients, this has led to many research groups abandoning work in this area.

In areas of the world with known Lyme disease, cases of chronic symptoms post Lyme disease are in the range of 1 in every hundred to 1 in every thousand acute Lyme disease cases. Thus, if Australia has these thousands of patients with chronic Lyme symptoms, we should have hundreds of thousands or even millions of cases of acute Lyme disease. As we do not, this makes it extremely unlikely that we have all these chronic Lyme cases.