



The Royal Australasian
College of Physicians

RACP Submission
Senate Inquiry into the “*growing evidence of an emerging tick-borne disease that causes a Lyme-like illness for many Australian patients*”

Introduction

Thank you for the opportunity for The Royal Australasian College of Physicians (the College) to provide a written submission to this Senate Inquiry into the *“Growing evidence of an emerging tick-borne disease that causes a Lyme-like illness for many Australian patients”*.

This issue is of great relevance to a wide range of College Fellows (including infectious disease physicians, neurologists, and public health physicians). It is a contentious issue in Australia where, to date, no reliable scientific evidence/research has demonstrated that Lyme disease or ‘Lyme-like illness’ can be acquired locally. It is also a contentious issue in areas where Lyme Disease is endemic such as the United States, where ‘Chronic Lyme Disease is the latest in a series of syndromes that have been postulated in an attempt to attribute medically unexplained symptoms to particular infections’.¹

‘Lyme-like’ illness is a term that has been used in the Australian context; however, the particular range of clinical manifestations it is being used to describe is unclear. Thus, it is not possible to provide reliable information on its occurrence and location.

The College is aware that a number of infectious disease physicians have reported seeing patients with typical signs and symptoms of Lyme Disease confirmed by reliable, locally-available testing as outlined in the Royal College of Pathologists of Australia’s (RCPA)² evidence-based *Position Statement: Diagnostic Laboratory Testing for Borreliosis (‘Lyme Disease ‘ or similar syndromes) in Australia and New Zealand*. To date, all of these patients had a history of travel to Lyme Disease endemic areas.

The College fully supports the RCPA’s view that ‘only a genuine case in a non-travelling Australian patient would confirm the disease as being present in Australia’³. As such, we support further scientifically rigorous research into this issue. Any research in this area would need to be competitively funded by reputable funding organisations such as the National Health and Medical Research Council (NHMRC) and the Australian Research Council.

The College is aware of anecdotal testimonials from Australian patients believing or having been advised by clinicians that they have acquired Lyme Disease or ‘Lyme-like illness’ in Australia. A number of organisations and clinicians lobbying for the recognition of locally-acquired Lyme Disease or ‘Lyme-like illness’ in Australia are generating and perpetuating unverified claims to the detriment of patients. We empathise with those patients whose suffering is real but for which the causes have not been clinically identified. We understand that, in some cases, they feel their concerns have not been appropriately acknowledged and listened to by the medical profession. Emotional testimonials are often presented in the mainstream media with little understanding of the scientific evidence in this area; this contributes to creating a great deal of confusion amongst the general public. As with all conditions, the priority for clinicians is to provide a clinically-sound diagnosis based on the best scientific evidence available at the time and to offer evidence-based therapies and treatments where the benefits to the patient outweigh the risks.

Some patients who have been advised they have Lyme Disease or ‘Lyme-like disease’ argue that they have tested positive to the disease. The College is concerned that these patients are receiving dubious positive diagnostic tests from unaccredited laboratories both in Australia and overseas. In some instances, these laboratories may perform unvalidated tests that are not accredited, or perform validated tests with the use of criteria that are not evidence-based.⁴ As a result, many of these patients are being misdiagnosed and receiving inappropriate treatments with significant risks of harm and adverse effects. These harms and adverse effects include line infections from parenteral therapies, potential toxins from unregulated medications and known antibiotic side effects. In some cases, patients are being prescribed antibiotic therapies over periods of times that far exceed the length of time recommended in guidelines for the treatment of Lyme Disease which has been confirmed by validated tests and accredited laboratories. Restrictions on the use of

unproven long term antibiotic therapies should be imposed so as to curb potential harm to both individual patients and communities, as this does not only put patients at unnecessary risk but the long term use of antibiotics further exacerbates the emergence of antibiotic resistant organisms in Australia.

In some instances, patients who are misdiagnosed as having Lyme Disease or 'Lyme-like illness' may suffer from potentially treatable conditions including fibromyalgia, complex neurodegenerative disorders, chronic fatigue syndrome or psychiatric illness such as major depression with somatisation.⁵ In other instances, patients may have received a diagnosis that they are reluctant to accept and have sought an alternative diagnosis of Lyme Disease or 'Lyme-like illness'.⁶

As with all conditions, it is essential for clinicians to correctly diagnose symptoms and offer evidence-based therapies and treatments where the benefits to the patient outweigh the risks of adverse effects. Australian clinicians have access to the previously mentioned Royal College of Pathologists of Australia's (RCPA)⁷ evidence-based *Position Statement: Diagnostic Laboratory Testing for Borreliosis ('Lyme Disease' or similar syndromes) in Australia and New Zealand*. This document includes testing guidelines for both patients who have never left Australia and those who have travelled to areas where Lyme Disease is endemic.

In the best interest of patients, we urge the Senate Inquiry to carefully consider and appraise the evidence it receives and to uphold the importance of the scientific process in looking at this important issue.

¹ Feder et Al (2007), *Review Article, Current Concepts, A Critical Appraisal of 'Chronic Lyme Disease'*, The New England Journal of Medicine

² These are publicly available from the RCPA website: <https://www.rcpa.edu.au/Library/College-Policies/Position-Statements/Diagnostic-Laboratory-testing-for-Borreliosis-Lyme> [last accessed 23/02/16]

³ The Royal College of Pathologists of Australia (RCPA) (2014) *Position Statement: Diagnostic Laboratory Testing for Borreliosis ('Lyme Disease' or similar syndromes) in Australia and New Zealand*. Available online: <https://www.rcpa.edu.au/Library/College-Policies/Position-Statements/Diagnostic-Laboratory-testing-for-Borreliosis-Lyme> [last accessed 23/02/16]

⁴ Feder et Al (2007), *Review Article, Current Concepts, A Critical Appraisal of 'Chronic Lyme Disease'*, The New England Journal of Medicine

⁵ The Royal College of Pathologists of Australia (RCPA) (2014) *Position Statement: Diagnostic Laboratory Testing for Borreliosis ('Lyme Disease' or similar syndromes) in Australia and New Zealand*. Available online: <https://www.rcpa.edu.au/Library/College-Policies/Position-Statements/Diagnostic-Laboratory-testing-for-Borreliosis-Lyme> [last accessed 23/02/16]

⁶ Feder et Al (2007), *Review Article, Current Concepts, A Critical Appraisal of 'Chronic Lyme Disease'*, The New England Journal of Medicine

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