



For Lyme Disease Awareness & Action

Lyme Disease Association of Australia

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MEDIA RELEASE

Lyme disease patients appalled by recent claims about Lyme disease testing

“FOR IMMEDIATE RELEASE”

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The Lyme Disease Association of Australia (LDAA) has grave concerns for patients following the release of a statement from the Royal College of Pathologists of Australasia (RCPA) directed at medical practitioners. It states that testing for Lyme disease as inappropriate unless a patient has travelled overseas.

The LDAA sees the latest announcement as a further attack on Lyme disease following on from the RCPA's 'position statement' which was [broadly criticised](#) for lacking scientific basis and contemporary evidence.

The RCPA's position on Lyme disease ignores the evidence of a rapidly increasing number of people who are testing positive to Lyme disease and who have never left the country. There are a growing number of people in Australia affected by what seems to be a Lyme-like illness, mirroring the symptoms and reactions of those with Lyme disease in other parts of the world. Until recently, Australian health officials have persistently denied the existence of Lyme disease and Lyme-like illness, but increasing cohorts of very sick people provide evidence to the contrary.

The RCPA's latest advice to doctors, apparently based on 'current evidence', infers that Lyme disease pathology requests must be growing at a significant rate to have made the top ten list. Yet data to support these claims is not provided, which makes any independent assessment about the scope of the alleged inappropriateness impossible. In requesting pathology tests for Lyme disease, an increasing number of doctors must think it is an appropriate course of inquiry based on the clinical presentations of their patients.



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Increasing pathology requests for Lyme disease are a result of increasing awareness in the community among both doctors and patients. However instead of investigating the increasing demand for testing as a potential indicator of an emerging epidemic, as evidenced in other parts of the world, the RCPA considers the increasing demand for tests as an 'inappropriate practice' on behalf of doctors.

The RCPA advises doctors not to test for Lyme disease in the absence of travel to an area where Lyme disease is endemic, but they fail to acknowledge that many Australians are testing positive to Lyme disease without ever having left the country.

Pathology tests play an important part in helping doctors determine whether *Borrelia*, the organism that causes Lyme disease, is present. To confirm a case of Lyme disease, patients must test positive on two separate pathology tests. The first test must prove positive before a second follow-up test can be requested. In Australia, these tests have proven to be highly unreliable. In a recent [public statement](#), the Department of Health acknowledges that there are "different approaches used by different laboratories in this process which leads to different diagnoses for the same patients". This is an unacceptable issue from the perspective of both doctors and patients.

Doctors must be assured of the clinical utility of the tests they request and patients need to have faith that the tests their doctor relies upon are in fact reliable. The Department of Health claims to be working to see if the different approaches can be harmonised.

In the meantime, patients are forced to send their blood overseas to specialist labs or to private Australian laboratories for expensive, non-subsidised diagnostic tests. Yet the RCPA routinely dismisses results provided by these non-accredited labs as inaccurate because they are not 'validated'. The RCPA does not mention that there is no externally-monitored Quality Assurance Program (QAP) for Lyme disease serology in Australian laboratories - thus no 'validation' in Australia.

Many doctors are able to competently make diagnostic decisions about their Lyme patients but are routinely let down by the inaccuracy and unreliability of most Australian Lyme disease tests. For the patient this means repeated testing or misdiagnosis or no treatment at all until their disease has progressed, sometimes irreversibly.

The NSW Department of Health's [Lyme disease Testing advice for Clinicians](#), advises doctors that a Lyme disease diagnosis must be supported by laboratory testing and that doctors should keep an open mind about locally acquired Lyme disease.

Sharon Whiteman, president of the Lyme Disease Association of Australia believes the RCPA's advice is out of step with contemporary thinking and goes against the recommendations of public health officials.



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“Covering up the inadequacy of the current testing regime by suggesting that the increased demand for testing is inappropriate is highly unethical” she said.

“It is disappointing that the RCPA is unwilling to solve the pathological puzzle of discordant results in testing and they remain unable to develop a reliable and effective diagnostic solution for Australians suffering from Lyme disease or an Australian Lyme-like illness.

“Instead the RCPA puts frontline doctors on notice, making it harder for doctors to do their job and impossible for patients who are becoming increasingly debilitated to receive an accurate diagnosis.”

Ms Whiteman says doctors should continue to use their best clinical judgement and keep an open mind in relation to Lyme disease despite the RCPA’s list.

“Early diagnosis and proper treatment of Lyme disease are important strategies to avoid the costs and complications of late-stage illness”.

“Sadly, many patients are living with the results of the inaccurate and poorly designed laboratory testing processes used in Australia” Ms Whiteman said.

“Australians are getting sick after tick bites. We need to know that the tests we are subjected to are accurate and reliable. Immediate resolution of the issues around the differing results in diagnostic testing is needed if we are to minimise the devastation that undiagnosed and untreated Lyme disease has on Australian patients”.

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