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MEDIA RELEASE

Take a bite out of Lyme campaign

The Lyme-like community across Australia is coming together this May to raise awareness and funds to support a poorly understood but very serious health issue in Australia and around the world. May is Lyme Disease awareness month and events will take place across the globe in support of this growing epidemic.

In November 2016 the Senate Inquiry's Final Report into '*Growing evidence of an emerging tick-borne disease that causes a Lyme-like illness for many Australian patients*' stated urgent action should be taken. Five months later the Lyme Disease Association of Australia (LDAA) has not been advised of any progress on the [12 recommendations](#).

The Senate inquiry led to the government and some medical authorities admitting some Australian are sick after a tick bite. This is an improvement on victim blaming and the often repeated diagnosis of a psychological condition that precludes treatment. But there is still no action from the Turnbull government, nor was research funding allocated in the budget in spite of the public statement that Health Minister Greg Hunt has asked the National Health and Medical Research Council 'as a matter of priority' to fast track a targeted call for research into Lyme disease and Lyme-like illnesses in Australia.

The Senate inquiry published overwhelming evidence from the patient community about the neglect, discrimination, denial of treatment, impoverishment and tragically for some the loss of life. Strangely nobody in the self-regulated Australian health system seems to be responsible.

LDAA President Sharon Whiteman said, 'The medical authorities who claim to be the experts are leading the charge to deny Lyme disease is in Australia without offering a solution to those suffering from these complex illnesses. They denigrate the handful of compassionate doctors who are actually saving lives by using world's best practice treatment. We can only wonder why the so called experts, who are responsible for this public health failure are more concerned that they are correct about there being 'no Lyme here', than they are about what is making people sick.'

The designation of the term expert should be reserved for practitioners who have a track record of helping patients recover, not for the 'experts' who have failed to help the sick and dying by myopically focusing on whether the American disease is in Australian ticks. Treating doctors are denigrated by the 'experts' as working outside the guidelines. But there are NO official guidelines for locally acquired Lyme-like illness and there is no official test.

A lack of evidence is used to justify the failure to act. Yet Murdoch University has recently identified 5 novel and possibly uniquely Australian bacteria in Australian ticks. There is more work to do to

provide evidence that this causes disease. The research is underway but more funding is needed. Surely people who deny Lyme disease is in Australia should consider the possibility that there is an Australian Borrelia and associated coinfections and keep an open mind about what treatments helps patient recover.

Patients shouldn't have to wait years for this research to conclude when successful treatment options are understood locally and around the world. These successful treatments should be researched here and available in the public health system! Patients don't care what the diseases are called in Australia, they care about desperately needed treatment. Evidence based medicine is failing Australians in this emerging disease situation. In an emerging disease, when there is no 'evidence', patients are the evidence.

The Lyme Disease Association of Australia (LDAA) has two partners in this campaign including the US based grassroots patient-led initiative #LymeDiseaseChallenge that has expanded too many countries around the world and the Country Women's Association of Australia (CWAA) who are a national partner. CWAA National President Dorothy Coombe said, 'Lyme disease is a real concern to our national membership and our full executive team endorsed the *Bite out of Lyme* campaign for change.'

Ms Whiteman said, 'We are grateful for the support we receive from the people who see through the façade of the Lyme disease deniers. I understand this is a complex and controversial matter and that it is conventional to rely on the expert's opinion. But in this case that is not working, we have deteriorated from an emerging disease situation to a hidden epidemic. Patients are starting to give up hope that there is a solution. Hope is the only thing keeping some of them alive. We need the voice of patients to be heard. Our lived experience can contribute to resolving this **if patients are put first.**'

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Photos of May Lyme Project 'Take a Bite out of Lyme' events can be found on [LDAA's Facebook page](#).

Additional resources for media are available from the Lyme Disease Association of Australia's [website www.lymedisease.org.au/media](http://www.lymedisease.org.au/media)

Senate Inquiry page:

http://www.aph.gov.au/Parliamentary_Business/Committees/Senate/Community_Affairs/LymelikeilIness45

More details about the May Lyme Project 2017 can be found on the LDAA [website](#).



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