

MEDIA RELEASE – FOR IMMEDIATE RELEASE

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Health policy could prove fatal for patients

The Lyme Disease Association of Australia (LDAA) has just released their response to the Department of Health's new Clinical Pathway, a guideline for doctors on diagnosis and treatment of tick-borne illness.

Endorsement of over 60 international Lyme scientists, clinicians and advocates accompanies its statement of deep concern as to how the new guidelines will impact Australian Lyme and other tick-borne illness sufferers. The response will be formally submitted to Minister for Health, Greg Hunt, today.

"The Pathway ignores the World Health Organisation's documentation of the Lyme pathogen in every region of the world and creates unequal and discriminatory access to diagnosis and treatment for all tick-borne disease patients," President of the LDAA, Sharon Whiteman says.

Under the new Clinical Pathway, the diagnosis and treatment of Australian Lyme and associated diseases, labelled Debilitating Symptom Complexes Attributed to Ticks (DSCATT) by the Department of Health, is limited to infectious disease specialists or microbiologists. These practitioners often have waiting periods of several months and their clinics are usually limited to highly populated areas.

According to the WHO and other international guidelines, Lyme disease must be diagnosed and treated early in order to avoid an unnecessarily long and debilitating illness.

"There are many uncertainties with regard to Lyme disease, but a guideline should take a precautionary standpoint and precautionary measures to avoid a lingering and debilitating disease - not disregard these uncertainties," commented Diana Uitdenbogerd-Drenth (PhD), Vice-chair of the Tick-Borne Disease Foundation of Netherlands. "All the uncertainties need much, much more research before a document with so much "certainty" like this can be instituted."

Developing a Clinical Pathway for tick-borne illness was one of twelve recommendations stemming from the 2016 Senate Inquiry into Lyme-like Illness in Australia. "The Australian Lyme community is in a state of shock, fear and disbelief," said Ms Whiteman. "When the Inquiry was announced, we were filled with hope. We certainly could not have predicted that the Pathway would be so detrimental for patients. Our policy-makers need to understand that the world is watching."

In February 2020 the LDAA requested a moratorium on progressing the draft document due to obvious inadequacies, but this was denied by Minister Hunt.



Under the new Clinical Pathway, a Lyme disease diagnosis may only be considered if the patient has travelled overseas, yet thousands of Lyme-positive patients in Australia have not travelled. Many recall exactly where and when they were bitten by a tick/s. And a 2019 <u>study</u> by Dr Jyostna Shah found 36 out of 100 Australian patient samples tested positive for 1 or 2 species of the Lyme bacteria.

Despite the evidence, the Pathway denies Australian-acquired Lyme and associated diseases and leaves patients in a dangerous medical limbo; scared, alone and with no diagnosis for a multitude of symptoms which may become life-threatening.

"This document if instituted, is likely to contribute to ongoing patient suffering and potentially death in Australia," says Dr Richard Horowitz, Eminent Lyme expert, Consultant to the Australian Department of Health and LDAA patron.

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About the Lyme Disease Association of Australia

Lyme Disease Association of Australia is a small yet powerful registered charity and Australia's peak patient body. We are committed to achieving universal recognition and equitable treatment for Australian Lyme and associated disease patients.

Ultimately, we aim to influence the perspective of Australian health authorities to the extent that they commit to urgent and ongoing research into Lyme and other tick-borne diseases. Also, for them to recognise and allow Australian doctors to adopt the International Lyme and Associated Diseases Society (ILADS) treatment protocol.

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