



For Lyme Disease Awareness & Action

24th November 2017

LDAA statement to Government response

After almost a year, the Australian Government Department of Health has responded to the Senate Community Affairs References Committee's inquiry into *'The growing evidence of an emerging tick-borne disease that causes a Lyme-like illness for many Australian patients'*.

The time taken to respond ignores committee guidelines, disregards the Committee's call for urgency, and demonstrates the Department's indifference toward the thousands of seriously ill patients who it is obligated to support. The Department's response is grossly inadequate and shamefully dismissive.

Despite reams of information, hundreds of pages of evidentiary data, empirical test results, personal testimonies of both patients and expert opinions from international doctors with considerable experience in treating Lyme-like illness, the Department still claims there is 'insufficient evidence' that the illness is largely tick-borne.

Incomprehensibly, the Department's introduction (largely a copy and paste from an earlier document) returns us to a debate about evidence while they veritably ignore all that has been provided.

A cohort of approximately 1200 patients reported heartbreaking stories of neglect by, and within, the Australian medical system, yet the national organisation responsible for protecting our health remains willfully ignorant of their situation. The tokenistic acknowledgement of concern for the thousands of people who are suffering following a tick bite is disgraceful.

There remains a growing cohort of Australians who are being medically neglected by an Australian health system that can't define or diagnose their illness, ignores the detailed empirical data they hold and leaves them untreated and chronically ill. The Department, through their inability to address this issue with comprehensive national action, are complicit in their neglect and discrimination of these patients.

Of the 12 recommendations proposed by the Committee, the Department deflects seven; those are particularly related to outcomes for patients. For the Department it is all about sequence; the myopic focus on finding a causative agent – now lauded not to be tick related – before diagnostic tests will be addressed, and prior to considering patients, leaves us questioning their competence to address an emerging epidemic of tick-borne illness that they categorically disregard.

The Department appears to have undertaken a complete back-flip on the issue. Their response to the Senate's Interim report was in favour of awareness and prevention information, better guidelines and treatment information - at least for classical Lyme disease. One must seriously ponder what has changed?

Internationally comparable jurisdictions recognise the world-wide increase in tick-borne illness. Many have prioritised funding for tick-borne illness, developed national action plans, embarked on awareness and prevention campaigns, deployed pan-Borrelia diagnostic tests, and are already treating their patients in multidisciplinary clinics. Meanwhile in Australia, our health department deny we have a problem with tick-borne illness, have delayed publication of the results of study into the discordance in Australia's pathology testing, and might have some more 'discussions' about a way they can ethically tell sick patients they have a psychiatric disorder! Only when a non-funded researcher can find the 'causative agent', likely to take years, will they get around to helping patients, but they've deflected all that to the States and Territories.

Physicians, as well as patients, anticipated that the Australian Government would take an innovative and progressive leadership approach to this situation, and they have failed us. Instead we see a national health department who has no focus on health protection and who continues to put the burden of proof onto patients. The patient community has lost confidence in the Government's interest in, and ability to solve, issues of emerging tick-borne disease.

The Department's response is grossly inadequate and completely ignores the responsibility of the Government in its role to protect the health of all Australians. This is a failure of leadership and must be remediated as a matter of urgency.

Contact:

Sharon Whiteman | President
president@lymedisease.org.au