

Hello everyone

If you are like me, you're not well enough to get out much, so it's doubly lovely to see you all today, despite the circumstances.

Tomorrow, many awareness events will be held across the country to raise the profile of Lyme disease. It is hoped that these will lead to greater understanding in the community of our condition, the challenges we face, and how the public can minimise the risk of contracting Lyme themselves.

Our gathering today, however, is not an awareness event – it is a protest. An earnest protest and a heartfelt plea to our first world government, for the first world treatment we have been denied for so long.

As many of you know, Federal Chief Medical Officer Prof Chris Baggoley has recently established a Clinical Advisory Committee for Lyme Disease, that aims to investigate the likelihood of Lyme being locally acquired, and best practices in diagnosis and treatment.

We have found Prof Baggoley to be both responsive and empathetic, and hold high hopes for the outcome of the committee.

That said, we also understand that the committee is unlikely to make any recommendations until the end of this year. And at this stage, we don't know how long it will take for those recommendations to be implemented.

In the mean time, Lyme patients in Australia are facing an unacceptable situation, and we believe it is the responsibility of NSW Health to put some interim measures in place, for the protection of NSW residents, and also to act as an example for the health departments of other Australian states and territories, who frequently reference the NSW Health fact sheets on Lyme disease.

Many of us feel that Dr Jeremy McAnulty, NSW Director of Health Protection, has not demonstrated the level of commitment we expected from him, after Sydney's first Lyme disease protest, in September last year.

Professor Baggoley himself has made it clear that any commitments undertaken by NSW Health in response to our last protest, are "not a matter for the Commonwealth"

So, to Dr McAnulty we say:

- Last September, you acknowledged that "Doctors in NSW should keep an open mind about the possibility that ticks may transmit Lyme disease in NSW " and pledged that "NSW Health will review the current Lyme disease resources available on the NSW Health website to ensure that these do not discourage clinicians from keeping an open mind about the possibility of locally-acquired Lyme disease."

It is not acceptable that your 'Lyme disease' fact sheet STILL encourages bias by stating without qualification: "When tests are done in places where a disease is rare or absent (for example, Lyme disease in Australia), many positive tests will be falsely positive."

It is also unacceptable that your 'Testing advice for NSW clinicians' document has a similar message.

- It is not acceptable that the fact sheet references a single flawed study that found that ticks on the NSW coast don't have the American species of *Borrelia*, ignoring the European species that are more likely, given the heritage of modern Australia, the number of animals we have imported from Europe, and the migration patterns of birds in the Northern Hemisphere.
It is also unacceptable that you don't reference the five credible studies that found evidence of Lyme in Australia, in ticks, native animals and humans. One of these studies actually dates all the way back to 1959.
- It is not acceptable that Lyme patients are presenting to hospitals in states of physical and emotional distress, only to be engaged in political debates, and often, turned away without the care they need.
- It is not acceptable that NSW Health has failed to act on the numerous examples of inappropriate treatment of Lyme patients by medical staff.
- It is not acceptable that there are Lyme patients – including at least one here at this protest – who are denied professional carers and left to seizure alone at home every day, risking further injury or even death.
- It is not acceptable that Lyme patients are under huge financial pressure due to the cost of treatment, including many non-PBS medications.
- It is not acceptable that whilst patients of other serious illnesses are able to successfully apply to access their superannuation to help them afford their treatment, Lyme patients cannot.

The Lyme Disease Association of Australia's 2012 patient survey found that

- Over 80% of respondents sought help from at least 4 doctors prior to diagnosis – this is not acceptable
- 75% reported difficulty in finding a doctor to treat their condition – this is not acceptable
- Patients who have located doctors that will treat them travel an average of 236km for appointments – this is not acceptable
- 46% of patients had to quit their jobs – this is not acceptable.
- 38% of respondents had contemplated suicide – this is not acceptable...but it is understandable.

Former LDAA President Nikki Coleman, has observed "Lyme disease patients are regularly denied treatment by local doctors, specialists, emergency departments and allied health professionals, entirely because they have Lyme disease – this level of discrimination, harassment, and inability to get adequate treatment bares hallmarks of how HIV and AIDS patients were treated by the medical establishment in the 1980s"

It is for these reasons that we are joining 27 other countries worldwide in campaigning for:

- Recognition that Lyme disease and other tick-borne infections are serious, sometimes fatal illnesses
- Awareness of the fact that the transmission of tick-borne pathogens via blood transfusion is of global concern
- Agreement that Lyme disease should be listed as a notifiable infection
- Education of the healthcare sector regarding the accurate diagnosis of Lyme disease, which in some cases may be limited to clinical presentation
- Education of the healthcare section regarding affordable and effective treatment of Lyme disease and other tick-borne infections
- Independent funding for research into transmission, testing and treatment of tick-borne diseases

I thank you all for joining us today in demanding the recognition that we have been lacking for so long. The battle for fair treatment has been a long one, and realistically, it is far from won. But as long as people such as yourselves have the passion to stand up for what is right, I am confident that we will keep moving forward, and one day, the stories that are now so common, will be history.

Thank you, and keep on fighting.