

Senate Inquiry into Lyme Disease - Submission

Committee Secretary
Senate Standing Committees on Community Affairs
PO Box 6100
Parliament House
Canberra ACT 2600

28th December 2015

This submission is to highlight the lack of appropriate recognition and medical care available to sufferers of Lyme Disease in Australia using my sister, Amy O'Sullivan's experience as an example. Amy's critical health situation at this time means Amy is unable to write this submission herself. This submission has been written on behalf of Amy, in close consultation with her.

Patient Name: Amy O'Sullivan

Patient Age: 30

[REDACTED]

[REDACTED]

Public: Amy wants her story to be made public

Lyme Illness Acquired at: unknown but assumed in Australia prior to any travel experience

Diagnosis: Amy was acutely sick for 1 year before diagnosis, but has been unwell intermittently for about 10 years

Blood Tests: Positive blood tests from Igenex and Infectolab

Positive Tests for: Serum Relapsing Fever Borrelia, Borrelia miyamotoi, Borrelia burgdorferi

No. of doctors/ practitioners: many (specialists, GPs, neurologists, naturopaths etc.)

Amy has been admitted to hospital twice for her illness: [REDACTED] where she received negligent treatment by medical staff suggesting her illness was solely psychological and insisting that Lyme Disease doesn't exist in Australia. Also, later at the [REDACTED] where she was treated for Relapsing Fever Borreliosis. She has had 4 horrific, negligent ER experiences in the last 18 months – she has been treated like a drug addict, treated like she was faking an illness, told that she was not to waste a hospital bed, discharged without discharge papers and without waiting for a carer before allowing a very sick, incoherent, confused person to leave the hospital.

Amy's Story:

Amy was diagnosed with Chronic Neurological Lyme Disease 14 months ago. A healthy, fit, strong, 30 year old, Amy's health quickly deteriorated. She went from working full time as a personal trainer to now being in a wheelchair and being cared for full time by her parents.

Amy's symptoms resemble a combination of Parkinson's disease, Alzheimer's Disease, MS, Epilepsy and other inflammatory brain diseases and neurological disorders.

Amy struggles to hold a conversation, struggles to walk, is constantly in extreme pain, has daily seizures, paralysis; the list goes on.

Amy attended a Lyme Disease clinic in Germany where she underwent testing and treatment from 17th May – 17th August 2015. Amy and her family made the desperate decision to travel to Germany for medical treatment when we realised the Australian medical system simply could not and would not help her when her life needed saving.

In hindsight, Amy trusted and relied on the Australian medical system for too long & is now left battling a debilitating, chronic neurological illness due to multiple misdiagnoses and inappropriate treatment along the way.

The Australian medical community not only fails to recognise the disease but seem to have a proactive aversion to accepting Lyme Disease as a possible diagnosis. This has left Amy in an unnerving cycle of denied care. If she claimed to have Lyme Disease in GP clinics and Melbourne hospitals (even with positive blood tests), she was deemed "crazy or looking for drugs" and didn't receive care because "Lyme Disease doesn't exist in Australia".

Amy and her parents have been the victims of a countless number of disrespectful medical personnel, who have humiliated, dismissed, ignored, laughed at and bullied them when they have mentioned 'Lyme Disease'. They all suffer from Post Traumatic Stress from many horrific hospital experiences in the last 12 months. As a result, they now refuse in most circumstances to call for an ambulance or go to a hospital – instead they have an ICU type set up in Amy's house so that our family can care for her the best we can, all without any medical training.

It has been incredibly difficult to find a Health Practitioner who entertains the idea of someone having Lyme Disease. Amy has had General Practitioners call her and actually refuse appointments when they become aware that she has Lyme Disease. My parents are also constantly dealing with pharmacists wary of prescribing the medications Amy needs, being treated as if they are criminals looking for drugs, when they are just trying to keep their daughter alive.

Amy is currently treating her infections with Natural Therapies, which may take a long time to have effect, and we do not know what irreversible damage there may be when she does recover. Due to Amy's fragile state from her delayed diagnosis, her body cannot cope with the intensive antibiotics. Amy is often asked why she is seeing a Naturopath or 'quack' to treat such a serious disease – the fact is this is the only choice she has when other medical practitioners refuse to acknowledge, support, or care for her, and as a result she is forced to find help in unexpected places.

It is the duty of our medical community to be educated in this serious disease to be able to consider it as a possible diagnosis where necessary – not to ignore it, or hide it.

The impact the medical community's ignorance is having on Amy and her family is enormous. Financially, Amy has been left with nothing – she cannot work and is now fully dependent on her parents. Due to the amount of care, rehabilitation and medications she requires, her family is trying to share the load of care. Amy has lost all independence.

Amy does not recall a tick bite – it could have been here or overseas – however, this should be irrelevant. She has been infected and she is seriously sick as a result. She should be receiving care, accessible treatment and funding support. Currently she is not.

This unchanging situation where all levels of the health and medical community are uninformed needs to be addressed.

I feel an enormous sadness that the Australian medical community has been ignoring this very serious medical issue and allowing healthy Australians like Amy become so very sick and disabled. It is time for the Australian government to make Lyme Disease an urgent Health priority.

What do sufferers need?

- **GPs who consider Lyme Disease as a possible diagnosis**
- **Public hospitals that are informed, educated and supportive of Lyme Disease sufferers**
- **The ability to be treated appropriately in the Australian medical system, rather than having to travel overseas**
- **Funding support for incredibly expensive treatment**

Yours Sincerely,

Emily O'Sullivan (on behalf of Amy O'Sullivan)
www.tickedoff.net.au