

## **PE1662/BB**

Anonymous submission of 14 February 2020

In support of Petition PE01662 - Improved treatment for patients with Lyme disease and associated tick-borne diseases.

My sister was bitten by a tick in September '18 whilst on holiday in Achmelvich, west coast Scotland. The purpose of this holiday was to aid her recovery from major adrenal surgery, which is doubly cruel.

The tick was attached for 24+hrs and she like many others, developed no EM rash. Still, concerned about her already compromised immune system and having a little knowledge of Lyme she attended her GP who dismissed her and advised there was no reason for concern.

In the following weeks and months my sister developed numerous 'muddled' symptoms – flu like malaise, knee joint pain, headaches, brain fog and latterly extreme nerve pain, altered gait and neurological problems. All recognised as classic Lyme disease symptoms. We requested Lyme tests and treatment from the GP on several occasions. 2 ELISA tests were performed, both negative.

We did our own research and discovered just how flawed the NHS tests are with potentially half of Lyme+ patients receiving false negative results. We educated our GP about this, the NICE guidelines re re-testing should symptoms persist and that the fact that she was on prescription steroids post adrenal surgery at the time of the tick bite meant that she would never likely receive a true Lyme+ test result. We also advised our GP of the Raigmore specialist research and testing facility and requested a further Immunoblot test. 4 or 5 weeks later and we still await those results on a test that should have taken 5-10 days.

Due to my sisters persistent and increasingly worrying neurological symptoms we pressed the GP to follow the NICE guideline and prescribe an initial course of antibiotic medication. She experienced a definite Herxheimer reaction and subsequent improvement but despite this, we were advised that during a telephone conversation between the GP and an Infectious Disease doctor at Aberdeen Royal Infirmary, the ID doctor claimed what my sister was experiencing were not Lyme symptoms. That doctor was wrong. At no point has that doctor met, spoken with or examined my sister. Antibiotic treatment ceased and again she began rapidly declining over the next few weeks.

The GP admitted that his hands were tied. I personally know of 2 other Lyme patients with serious neurological problems who were misdiagnosed and dismissed by Aberdeen Royal Infirmary ID doctors. We have now received a referral to a spinal surgeon to explore her neurological problems. That surgeon has urged us to begin a series of spinal surgeries to alleviate her symptoms. That surgeon flatly denied any possibility of a link between Lyme/Neuroborreliosis and Cervical Myelopathy. That surgeon is also wrong. As my sisters classic Lyme, co-infection and Neuroborreliosis symptoms intensify we become increasingly frightened and frustrated.

We travelled to the United States to consult with a world leading infectious disease and Lyme literate doctor. During a 5-hour consultation, examination, full patient history and discussion we received a clinical diagnosis of Lyme and several other co-infections – all are far more common than understood. It was a gruelling trip which took a massive toll on my sister and the financial burden is one we're not sure how we'll manage. We have had to source all her medications in the U.S and will likely have to return 3/6 monthly for the foreseeable future. An added concern at this most difficult time is how we can ensure a good working relationship between our LLMD (Lyme literate medical doctor) and the NHS, especially problematic when NHS practitioners are not aware or educated in Lyme and I understand do not accept the findings of an overseas specialist. We will require support and medical supervision throughout treatment. Complete and comprehensive medical treatment for Lyme Disease has been likened to the challenges faced by cancer patients undergoing chemotherapy. Lyme patients often endure this alone and often without any positive input from the NHS.

The lack of Lyme awareness, accurate Lyme disease & co-infection testing, communication and whole patient approach is not only unhelpful but is indeed damaging. My sisters' condition need never have declined to where we are now. Precious time wasted.