

PE1662/Y

Sarah Cameron petition of 14 February 2020

My Experience of Lyme Disease

In October 2017 a family member fell ill. They were twelve years old at the time, just six weeks into high school. For several months, they suffered from intermittent fevers, whooping-cough like throat and cough, aching limbs, anxiety and an inability to concentrate. The GP treated them for tonsillitis, gave two weeks of Doxycycline. It had no effect. They had numerous blood tests, all of which were inconclusive.

Six months on, she was still unwell. The most pervasive symptoms were fatigue, stiff legs, brain “fog” and a very painful sore throat. We were given a diagnosis of CFS/ME and encouraged to keep taking them into school on a part-time basis. It made them worse. They were given a course of counselling from CAMHS which eased some anxiety but made other symptoms worse. They attended a few sessions of Graded Exercise Therapy which also increased their physical exhaustion. Beyond that, the advice was to “keep it until it gets better”.

It didn't get better. In the course of the next year, they became increasingly bedbound, struggling to attend school for even a couple of hours each week. Even minimum activity left them needing several days to recover. They could no longer read and retain information. They became intolerant of light and noise and spent most of their time in a darkened room.

Around Easter 2019, we took them out of school altogether, and sought private medical advice. A doctor specialising in fatigue advised changes of diet and supplements including magnesium, iodine and Vitamin D, which increased their energy levels to the extent that, by summer 2019, they were able to be out of bed one or two days a week.

In August 2019, they developed new symptoms, severe involuntary muscle twitches and spasms in legs, arms and head which had us at Forth Valley Hospital on two separate occasions, once by blue light ambulance. We were dismissed. One senior paediatrician, with total lack of curiosity or compassion, told us “people get tics”.

By that stage, my family member could no longer walk unaided. They needed a wheelchair to get about the house. Their body was in constant spasm. In September 2019, MRI scans of head and spine showed nothing untoward.

NHS blood tests were negative for Lyme disease, although persistent abnormalities pointed to some sort of parasitic or bacterial infection. However, test results from Arminlabs in Germany, a specialist in tick-borne disease, indicated current cellular activity against *Borrelia burgdoferi*, and suppression of the immune system consistent with *Borrelia* and other bacteria. NHS specialists in infectious diseases were not interested.

We sought help elsewhere and were able to find a medical herbalist specialising in Lyme disease. On the basis of the Arminlab tests and the symptoms she has

diagnosed plant-based medication that is having a strong positive effect. After six weeks of treatment, my family member's health has improved to the point that they are able to be out of bed and active five days a week and we are considering a return to their education.

We have no recollection of an individual tick bite, and there was no diagnostic bullseye rash, but we live in a rural area and they were frequently outside in long grass. Wild deer are numerous in the fields and woods around our house and I have, on occasion, been bitten by ticks while gardening.

You cannot know the pain of being turned away again and again by NHS medical staff, of being told that the roots of illness are anxiety not bacteria, that "people get tics", to "keep it until it gets better", of having positive test results from elsewhere dismissed, even ridiculed. I have been treated as neurotic and hysterical for trying to get adequate treatment for my child. My family member has lost two and half years of their schooling and has now to recover from the emotional impact of lack of treatment as well as physical recovery from a long-term illness.

There is inadequate public awareness of the disease and our actions would have been different had been better informed. We would have pushed for better testing and let our family member rest when they were most unwell. GPs and consultants, working within their own specialities, receive inadequate training in recognising Lyme. We received a wrong diagnosis of CFS/ME and then damaging treatment through inappropriate NICE guidelines. The Lyme testing offered by the NHS looks for only one strain of infection, when multiple infections are common and relies on antibodies which, due to suppression of the immune system, are not always present.

We urge the NHS to widen the scope of its enquiry into this complex and devastating illness, to consider more up to date testing and cooperation with international experts in the field, including investigation of the immense potential of plant-based medication. Doctors need the confidence to offer diagnosis based on symptoms as much as blood tests. Too many people are suffering. It is time for change.