

Dear MP,

I am writing to you as one of your constituents and a sufferer of the tick-borne disease, Lyme borreliosis. May I ask you to act on my behalf and for the sake of other Lyme disease patients? Would you be willing to meet or communicate with a growing number of MPs who are concerned about the situation and to form an all-party group to look at the problems surrounding available care for Lyme disease patients?

Neil Coyle MP began to co-ordinate action by hosting a survey on his website which has now been moved to the website of Robert Buckland MP. The survey has nearly reached its target of 1000 participants and the data gathered will hopefully encourage a cross-party effort to expedite some action in terms of notifying the public, schools and doctors in the hope that increased awareness ensures immediate recognition of the illness in new cases. Those who are already infected and who are chronically ill desperately need support.

On 24th May 2016, a protest was held in Parliament Square which was attended by Lyme patients, Lady Mar, several MPs and journalists. A petition with over 10,000 signatures was also submitted and the government has now issued a largely unsatisfactory response. The issues and questions raised by the Lyme disease community are outlined in a table. (<http://lymediseaseuk.com/wp-content/uploads/2016/07/PetitionResponse1.pdf>) Would you be prepared to write to the Department of Health to seek further clarification following the government response to the petition?

Lyme borreliosis is a crippling infection which leaves many people unable to work or lead anything resembling a normal life. It is a persistent infection, if not caught in the first few weeks. Each year, it is estimated by PHE that another 3,000 UK citizens (about 1,000 of whom will be children ) are likely to become infected with Lyme borreliosis. Since this is not a notifiable disease, the official figures are understated but several documented sources estimate that there are between 15,000 and 45,000 new cases each year. It has been known to be endemic in areas of Britain since 1989, and in 1993 it was described by Oxford scientists as a danger to the public. It was also known by scientists and doctors at that time to be an infection that is hard to cure and could lead to recurring episodes of illness. There have even been fatalities - the infection has been known to cause stroke, heart block, and conditions similar to Motor neuron disease and Multiple sclerosis. Unfortunately the Lyme disease tests currently used in the UK are inaccurate and unreliable and are missing a significant number of patients. GPs are not properly trained to diagnose and treat the disease and this is reflected in the fact that only about 2% of doctors have voluntarily taken the RCGP physicians' online awareness module for Lyme disease. It appears that there hasn't been any pressure on doctors from the Department of Health to complete this brief course. Many Lyme disease patients are misdiagnosed with ME/CFS, fibromyalgia and depression and many are denied treatment on the NHS, leaving them with little choice but to seek expensive private care, often overseas.

Lack of diagnosis and treatment costs both the individual and the state a great deal. By missing the opportunity to treat people early, healthcare and benefit costs are spiralling. The burden of chronically ill people on the NHS and the Department for Work and Pensions far outweighs the cost of treating Lyme disease appropriately in the early stages of disease. A leading specialist has described Lyme disease as 'the AIDS of our time'.

There is a possibility that the infection could be spread sexually, congenitally, via the blood supply and organ donation. More research is desperately required in these areas to establish the truth. Additionally, ticks can often carry more than one infection so often patients are dealing with a mixture of diseases which puts great strain on their immune systems.

I do hope that there will be a way forward to lobby the health ministers to be more proactive in tackling Lyme borreliosis and all tick-borne diseases.

As your constituent, I implore you to take action to help me and the thousands of Lyme disease victims like me who need better care and a chance to improve our lives.

Yours sincerely,