

Specific demands of the petition:

- 1: That Lyme borreliosis be made a notifiable disease, so that the true incidence becomes apparent.**
- 2: That better methods are actively explored, to test for and diagnose both acute and chronic infections.**
- 3: That doctors are trained in the treatment of borreliosis and other tick-borne infections. Given the number of patients who may now be infected, we ask that special clinics are established where the diverse range of the effects of the disease can be acknowledged and treated.**
- 4: That treatment is extended for as long as necessary, and to include the use of high dose, combination or long-term antibiotics, especially in those patients who have been ill for a long time. Even in those patients who appear to have recovered, a 5-year follow-up would be advisable to monitor the condition.**
- 5: That medical schools and practising physicians are made aware of the research and latest knowledge in diagnosis and treatment of Lyme disease, as well as the other emerging infectious diseases carried by arthropods which may cause co-infections in patients with borreliosis.**
- 6. That all government agencies for the Environment, Health, Sport and Tourism use their resources to make the general public in the UK aware of the potential risks from tick bites and the best ways of avoiding them.**

Background

The first outbreak of modern-day borreliosis disease occurred in the small town of Old Lyme, Connecticut in the mid 1970s. Since then, in the US and Canada, it has become the fastest growing infectious disease, with more cases than AIDS. In Europe, countries such as Germany, Norway and the Netherlands have reported that cases have been doubling every few years. This year, 65,000 Dutch people have signed a petition to their government; they estimate that up to half a million are suffering from chronic Lyme in their country, and they know that tens of thousands are newly-infected each year.

The numbers are likely to be as bad as this in Britain, but because surveillance, diagnosis and blood tests are all proving inadequate, many Lyme patients end up being told they have Fibromyalgia, Chronic Fatigue Syndrome or Myalgic Encephalomyelitis and may suffer from a host of other chronic symptoms which can manifest as arthritis, bipolar disorder, palpitations and other heart arrhythmias, sudden onset schizophrenia, polymyalgia rheumatica, sudden weakness or even paralysis, heart failure, stroke, back pain, skin lesions etc. Lyme has been shown to pass from a mother to the unborn child and has caused stillbirths and birth defects.

When diagnosed early, antibiotic treatment stops the disease, but if treatment is inadequate, the bacteria may lie dormant, as in TB and syphilis, only to reoccur months or years later. Initial infections are missed because tick bites are painless, and the characteristic bull's eye rash, called Erythema Migrans or EM rash, only occurs in 50% of patients and may be atypical and hidden from view or even misdiagnosed as ringworm or eczema. Other initial symptoms, such as chills, 'flu-like fevers and joint aches and muscle pains, may be dismissed by patients and doctors.

While the disease is deemed to be rare, many cases go undiagnosed, and this will perpetuate the myth that Lyme is rare. Many patients will visit several specialists before Lyme is suspected, and this late diagnosis reduces the success with short antibiotic treatment and increases the chances of chronic, difficult to treat symptoms. When patients are undiagnosed, and untreated, the official surveillance statistics are not giving a true picture of how many people have been infected, which makes a strong case for making Lyme a notifiable disease, even though it is not as highly contagious as are other notifiable diseases.

Diagnosis is difficult. It is normally done by testing for the presence of antibodies for the Borrelia bacteria in the blood. Across Europe there is no real standardisation of tests and most of them are based on looking for 1 species, whereas there are many different species of Borrelia causing Lyme disease. Borrelia bacteria can avoid and suppress the immune system, so that patients, some of them the most severely ill, are not making antibodies. Also, there are many documented cases of other bacteria and viruses being passed on in tick bites, and this complicates the clinical picture and the treatment. Some other diseases, e.g. TB, are difficult to diagnose, and scientists sometimes take many weeks culturing the TB bacteria in the laboratory. Given the serious and long-term effects of Lyme, culture and other methods should be considered, even though they are at first sight costly and time-consuming.

Treatment of Lyme and the possible co infections carried by ticks is known to be far from straightforward. Scientific research showed as long ago as 1988 that the bacteria could survive antibiotic treatment so that the patient might relapse afterwards. There are problems in that some people bitten by ticks carry the infection without showing symptoms, so that the diagnosis and decision to treat has to be based on clinical expertise. As in TB, extended treatment with combined or pulsed antibiotics has been shown to be successful, but there is controversy over use of prolonged antibiotic therapy in borreliosis, stemming perhaps from the cost of the medicine and the cost of care during treatment, and from not knowing the end-point of treatment. The ramifications of not solving this problem, and leaving people to suffer, are far-reaching, with serious implications for the public's confidence in medicine and the health services, as well as the cost to society of the increasing numbers of people disabled by Lyme disease.

Please send the signatures supporting this petition to:

UK Lyme Petition
C/o 27 Morven Court,
Aberdeen
AB11 8TW

Many thanks to all those who have signed up.

<http://www.ipetitions.com/petition/uklymepetition/>