



Lyme Disease

Patient Support

MP Drop-In Meeting, 6th September 2016

Who We Are and What We Do

Lyme Disease UK (LDUK) is a volunteer-run patient support network which was established in 2013. We are not an official charity and therefore, we are unfunded. Our team members are all Lyme disease sufferers and we are **not** medical professionals. LDUK offers an online support group on Facebook as well as a website, a public Facebook page and a Twitter account. We also send out a free monthly email newsletter. Our support group is currently made up of over 4500 members, many of whom have been left without any care from the NHS. The LDUK team attends public events, meetings and conferences. We also liaise with international Lyme disease organisations and campaign for an increase in knowledge and advancements in patient care. We are stakeholders in the NICE Lyme disease guideline writing process.

“The stories of personal sacrifice soon started to emerge in our group. We learnt about people re-mortgaging their houses and selling everything in order to pay for private treatment. We learnt about whole families being infected and about people having to fund-raise in order to even get a private test as they were being denied NHS testing by their GPs. We learnt about people being belittled and laughed at by doctors. Lyme disease is more than just an epidemic...it is a humanitarian crisis.” – Natasha Metcalf (Co-founder, LDUK)

The Issues

- Lyme disease is a crippling tick-borne infection which can become a chronic, debilitating and disabling condition if not treated adequately in the first few weeks.
- In 1993, Lyme disease was described by Oxford scientists as a danger to the public.
- A leading specialist described Lyme disease as 'the AIDS of our time'.
- Known to be endemic in areas of Britain since 1989. Tick population is continually growing in the UK with ticks no longer confined to rural 'hotspots' but also found in urban areas as well.
- Data gathered by the World Health Organisation has identified that the number of Lyme disease cases throughout Europe has increased, on average, by 65% every year for the last 20 years.

- The Big Tick Project 2016 found that one third of dogs checked in their study had ticks attached. Pet owners are at risk as ticks can drop off in the home or transfer.
- As Lyme disease is not a notifiable disease in this country, the true number of new cases per year is unknown. PHE estimates that there are 3000 new cases of Lyme disease in the UK every year (1,000 of whom will be children). However, Caudwell Lyme Disease charity estimates that numbers could be as high as 45,000 new cases per year.
- Not everyone experiences the characteristic bull's-eye rash following a tick bite, so many cases go undetected and many bull's-eye rashes are dismissed by GPs, leaving patients without treatment.
- Current GP awareness is poor. GPs are not properly trained to diagnose and treat Lyme disease and only 2% of doctors have voluntarily taken the RCGP physicians' online awareness module for Lyme disease.
- We hear countless stories of people being told by GPs that there is 'no Lyme disease in the UK', that the disease will 'go away without treatment', that the characteristic bull's-eye rash is merely an 'allergy' which requires an antihistamine or a plaster. We also hear of incorrect tick removal techniques being used by medical professionals.
- Lyme disease tests currently used in the UK are unreliable, particularly if the patient is tested too early, after antibiotics or a long time after the bite, meaning that a significant number of cases are being missed. GPs are placing too much reliance on unreliable test results when Lyme disease should be a clinical diagnosis based on symptoms, signs and history of tick exposure.
- Public Health England advocates shorter courses of antibiotics whereas some Lyme disease experts insist that longer courses are necessary to treat both newly infected patients and chronic cases. There is also scientific evidence showing that Lyme disease can persist beyond a short course of treatment but this is largely ignored by the mainstream medical profession. This disagreement needs to be resolved and better treatment protocols need to be researched and developed to reduce the chance of ongoing health problems and relapse.
- Caudwell Lyme Disease charity's survey of 500 Lyme disease sufferers found that 75% are too unwell to work at all. The cost to both the individual and the state is unacceptable. 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 DWP far outweighs the cost of treating Lyme disease appropriately in the early stages.
- Lyme disease is known as the 'Great Imitator' as symptoms are nonspecific and can mimic so many other conditions. Many of our group members have been misdiagnosed with conditions like ME/CFS, fibromyalgia, anxiety and depression. Connections between Lyme disease and Alzheimer's, Parkinson's and ALS have also been made by some scientists and practitioners.
- Ticks often carry more than one infection and so patients are usually dealing with a mixture of diseases. Different infections may require different treatment, making the

recovery process very complicated.

- There is widespread denial of the existence of chronic Lyme disease and so many patients are being left without NHS care and with no choice but to seek out private treatment, often abroad. There are of course those who cannot afford private treatment and who are left disabled and debilitated, without help.
- There is a possibility that the infection can be spread by other biting insects, sexually, congenitally, via the blood supply and organ donation. More research is desperately required in these areas to establish the facts but in the meantime, all sufferers should be prevented from donating blood and organs. Blood reserves should be routinely screened and awareness of potential congenital transmission should be increased amongst maternity care professionals and the general public.

Whilst the government has commissioned three independent reviews (into testing, treatment and transmission) and NICE guidelines are being created, these are not due to be completed until 2018. In this time, many more people will become infected. We have a small window of opportunity to act before the peak tick season begins again next spring.

CHANGE IS NEEDED, FAST

How MPs Can Help

- Form a cross-party group to help us push for change in the way Lyme disease is handled in this country (lobbying for better testing, diagnosis and treatment).
- Raise awareness in constituencies and CCGs - push for warning signs and educational material to be placed in GP clinics, parks and recreational areas, community groups, schools etc.
- Write to Public Health England relaying patient concerns about the government petition response. A full breakdown of the inadequacy of the response can be found [here](#).
- Help to make GPs and other medical professionals aware that a negative Lyme disease test cannot rule the disease out.
- Encourage GPs and vets in your constituencies to attend Lyme disease conferences - check our 'events' tab on our website.

For more information, please see:

Lyme Disease UK
www.lymediseaseuk.com

Caudwell Lyme Disease
www.caudwell-lyme.net

Vis a Vis Symposiums
www.visavissymposiums.org

Thank you for anything you can do to help us and those who will become infected in the future.