



14th November 2016

Dear All

Following a successful **drop-in meeting for MPs** at Portcullis House in September, a number of MPs showed an interest in finding out more about Lyme disease and the issues faced by UK sufferers. We would like to share the key areas for change that we have identified and to suggest how MPs can help.

We have also included a summary of responses from our members (who now number more than 5200). We feel that it is important for MPs to hear perspectives from a cross section of Lyme disease patients, especially those MPs who have not met patients in their constituencies.

We would be grateful if you would take a few moments to read the information below to ensure that you are fully updated on the latest perspectives from the UK Lyme disease patient community.

Thank you again for your interest in this important issue and we look forward to meeting with you in due course.

Kind regards,

LDUK

Why we need urgent change:

The Government has commissioned three independent reviews (looking into testing, treatment and transmission of Lyme disease in the UK) and initiated the creation of NICE guidelines for the illness. However, these are not due for completion until 2018. In the meantime, the cost to patients' lives and the taxpayer is unacceptable. Public Health England estimates there could be 3,000 new cases of Lyme disease each year whereas the charity Caudwell Lyme Disease estimates that there may be as many as 45,000 new cases per year. Based on a survey of 500 patients, 75% are too unwell to work full time or at all.

Change is desperately needed in the following areas:

- **Awareness** – greater awareness amongst the public and medical staff. This must be in place prior to the start of the main tick season in 2017.
- **Diagnosis** – doctors must be better educated on the subject of Lyme disease and stop relying solely on inaccurate testing until better testing is available in the UK. In the absence of a positive test, a clinical diagnosis must be considered. All patients with chronic conditions should be tested and clinically assessed for Lyme disease and associated pathogens.
- **Treatment** – sufficient antibiotic therapy treatment duration for acute cases needs to be established. In the meantime, patients should be treated in accordance with [ILADS guidelines](#). The NHS needs to recognise cases where early treatment may have been missed/insufficient. Treatment protocols for chronic cases also need to be created.
- **Transmission** – all sufferers should be prevented from donating blood and organs until more research on transmission of Lyme disease is available. Awareness needs to be raised of possible congenital, sexual and other forms of transmission.

How MPs can help:

- Form a Cross Party Collaborative 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. Ensure that warning signs and educational material is placed in GP clinics, parks, 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, other medical professionals and constituents aware that a negative Lyme disease test cannot rule the disease out.

- Encourage GPs and vets in constituencies to attend Lyme disease conferences. Check our ['events'](#) tab on the LDUK website for updates.

Summary of responses from Lyme disease patients when asked what feedback they would like to pass on to MPs:

*"MPs should let their constituents know how **common Lyme disease is and how dangerous.**"*

*"Patients who haven't recovered from a few weeks' of treatment are told by doctors that they have a **post infectious syndrome. This cannot be proven and they could well still have an active infection.** I hope this issue can be resolved with **better testing and treatment.**"*

*"I think there should be some sort of watchdog for doctors/GPs. Many seem to be a law unto themselves. **Doctors seem to dismiss people all the time and say that their symptoms are purely psychological. Doctors should be free to treat their patients as they see fit.**"*

*"**Tick awareness should be part of the school curriculum.**"*

*"In the **absence of accurate testing**, doctors need to be free to make clinical diagnoses of Lyme disease. **There is a lack of competent, fully trained and experienced doctors. We urgently need to explore testing and expertise offered abroad.**"*

*"As well as raising awareness in the general population, it really is time something specific was done to **improve doctors' awareness.** Perhaps the [online e-learning course](#) created by LDA and RCGP should be made a mandatory requirement for doctors. Currently, I understand that only a very low percentage of doctors have accessed this training course - what we have now is not working."*

*"My main problems have stemmed from ignorance of infectious diseases consultants. **Teach infectious diseases consultants that Lyme disease is persistent and can require significantly more than 1 month of antibiotics, that antibiotics are only part of the required treatment, that negative tests should be expected, especially as tests don't cover all strains of Lyme disease. Co-infections should be expected but there are insufficient tests for them too.**"*

*"If infectious diseases consultants can be educated then the knowledge will trickle down. Until this happens, they act as a very significant barrier. To get that to happen, I think the **UK needs a specialist unit** where consultants are specifically looking into Lyme disease persistence and how to treat chronic disease, **including visits to doctors in the USA who treat according to ILADS guidelines and have the necessary expertise.** Then, Infectious Diseases consultants in other parts of the country should be required to go on sabbaticals to learn from them. That way knowledge will eventually spread."*