



APPG MEETING
23rd January 2018
Presentation

Thank you for the opportunity to attend and speak at this meeting today. We are spokespeople for LDUK and also Lyme patients ourselves.

Lyme Disease UK is a non-profit organisation with an Online Community of over 8000 members, the majority being from the UK. As well as supporting our members, Lyme Disease UK campaigns for **better awareness, diagnosis and treatment of Lyme disease.**

The situation in the UK is dire. We see continual examples of mistakes in diagnosis, testing and treatment. We see patients being dismissed if they have negative UK tests, people becoming housebound, disabled and even suicidal. We also see patients driven to self-treating or paying for expensive private treatment abroad. This represents an unacceptably high cost for individuals, society and the economy.

We are grateful to all of you for showing an interest and the determination to improve the situation. We believe that the APPG should push for change in the following areas: **public awareness, education of medical staff, and research** so that better testing and treatment protocols are made available.

The recognition of Lyme disease as a serious illness, which can be caught in British back gardens, with effects on a par with AIDS and cancer, is essential to give impetus to the drive for change.

Public awareness of the risk of Lyme needs to be addressed, immediately, by government-sponsored media campaigns and obligatory information notices in relevant locations accessible to the public.

Change is needed in the medical system to ensure that front-line staff, including pharmacists, practice nurses and A&E staff, are able and equipped to remove ticks safely, and can recognise an EM rash and other early symptoms.

Doctors need to be aware of, and compliant with, current guidance and best practice and especially need to be made aware of testing limitations. The information received by them from the RIPL lab should be explicit on this point. Until we have a better test, it is not possible for a diagnosis of Lyme disease to be made on blood tests alone. Change is needed in the medical system to give greater emphasis to clinical diagnosis, only supported, not limited, by testing. Establishing better tests is of paramount importance.

There should be a precautionary **halt on blood and organ donation** by Lyme sufferers until safety is established.

Concerning treatment of patients, the draft NICE guideline made it abundantly clear that there is an alarming dearth of good quality evidence for effective treatment protocols at all stages of disease. Until there is better primary evidence, we would like to see clinicians encouraged to exercise professional judgement in diagnosis and treatment decisions.

We would recommend that UK doctors are encouraged to visit, observe and learn from established **ILADS American and European Lyme specialists**. LDUK would be pleased to use its contacts to facilitate such opportunities. It is critical to explore innovative ways to improve care for current Lyme disease patients as soon as possible.

Co-infections have been found in the UK and yet the ignorance surrounding the possibility of these other tick-borne infections is even worse than that of Lyme disease. More attention and publicity needs to be given to these infections so that they can be treated as well.

A research budget needs to be established urgently to fund the NICE research recommendations and other gaps identified. Improvements in research, treatment, education and awareness must be mutually supportive and mutually dependent, each increasing the effectiveness of the other. There is otherwise a danger that they are addressed in an ad-hoc fashion with no cross-fertilisation or resource-sharing.

Centres of excellence of some kind should be considered as engines of this integration of different strands. More patients seen in a virtual or real-world centre would allow for longitudinal research studies, concentrated doctor experience, faster accumulation of expertise and treatment trials.

We need the APPG to push for progress in all of these areas. However, we believe **immediate focus should be on preparing for the next tick season, improving treatment for existing patients and pressing for a generous research budget.**

Individual APPG members can learn more about the Department of Health Reviews on Lyme Disease as well as the draft NICE guideline, and see comments from stakeholders, on all our various websites. Reaching out to sufferers in your own constituencies and helping them negotiate current provision would also inform you on the effects of the disease.

The UK has, for a long time, been behind other countries in tackling Lyme disease. We now have an opportunity to take the lead and coordinate a world-leading approach to the care of Lyme disease patients, which will both reduce the cost to individuals' lives and the taxpayer.

We would be happy to respond to any queries you might have, either now in person or via contact through our website. We leave with you a short handout detailing the suggestions that we have outlined. Thank you for your attention and interest.