



## **APPG Meeting Handout**

23rd January 2018

### **About LDUK**

Non profit organisation run entirely by volunteers, campaigning for better awareness, education, diagnosis and treatment of Lyme disease. We have a website, a large social media presence, an email support service and an Online Community on Facebook.

Seeks to bring knowledge from around the world to our membership by interviewing international Lyme treating practitioners who dedicate their time to answering our members' questions

### **About our Online Community**

Facebook group with over 8000 members, the majority residing in the UK. Approximately 200 new members join per month, with higher numbers during the warmer months.

### **Why do people join?**

- Concerns about a recent bite or rash
- Frustration when NHS GPs/Consultants have ruled out possibility of Lyme in numerous situations including a known tick bite, EM rash (current or previous), exposure risk and Lyme disease symptoms
- Frustration when no other explanation or effective treatment offered for multi-systemic symptoms indicative of Lyme disease
- Concerns regarding relapse following a short course of antibiotics on the NHS and ongoing symptoms then being attributed to something else
- Uncertainty about reliability of test results (both NHS testing and foreign testing)
- Not knowing where to turn for treatment when the NHS draws a blank
- Needing to share fears, frustrations and experiences of medical ignorance/negligence (e.g. EM rashes being ignored, being told that Lyme disease does not exist in the UK, being told that illness is all in their head or that they have been spending too much time on Google)
- General friendship, emotional support and understanding from other patients

### **What do patients want?**

- Accurate and timely diagnosis
- Better tests and for doctors to have the education and freedom to be able to make clinical diagnoses
- Effective treatment on the NHS, leading to symptom resolution
- For NHS doctors to be aware of Lyme disease co-infections
- Action now. It is understood that some changes will take time, however the number of newly infected cases must be reduced through increased awareness particularly before the end of the winter months when people start going outside more
- To be treated with respect when discussing the possibility of Lyme disease instead of being dismissed by doctors

### **How are acute and long term cases being failed?**

- Misdiagnosis and missed diagnosis in early cases - doctors often attributing symptoms to ringworm, 'summer flu', CFS, fibromyalgia or psychosomatic disorders
- Ignorance and lack of knowledge from medical staff - e.g. EM rashes going untreated, ticks being removed incorrectly, testing being done too early, over-reliance on flawed testing
- Lack of treatment options (people being told that one course of antibiotics will cure Lyme disease, relapses after initial course of antibiotics despite improvement, people exploring private treatment options which are often overseas, self-treating or left to deteriorate - many people are housebound and/or disabled)
- Patients feeling stigmatised and constantly needing to challenge the misconception that it is 'all in their head'
- Doctors are afraid to admit that they don't know enough about Lyme disease when patients' would prefer honesty. Instead, patients are being told that they most definitely do not have Lyme disease by doctors who, in some cases, do not believe it is possible to catch in the UK

### **Why does it matter?**

- Desperate human suffering, ruining lives
- Negative impact on society and economy
- Growing problem - number of cases rising dramatically
- Some medical professionals who have worked in both fields state that Lyme disease is on a par with AIDS
- Everyone is at risk - Lyme disease can even be caught in people's back gardens
- Patient groups around the world are currently lobbying their Governments to act on exactly these issues e.g. US TickBD Working Group, France, Australia and closer to home, in the Scottish Parliament
- Medical professionals who deny the existence of persistent Lyme disease change their minds as soon as they experience Lyme in their family, opting for long term, private treatment
- The independent government reports show that the research evidence came almost completely from abroad, because no studies have been done in the UK. However, it is clear that patient organisations are facing the same challenges in the US, UK and Europe