

“Lobby For Lyme”

Information Sheet 1



Lobby for Lyme - In Parliament

Julia Goldsworthy MP has introduced an Early Day Motion in the current session of Parliament that urges the Government to make Lyme disease notifiable as a first step to tackling the disease. Lyme Disease Action is wholly supportive of this motion.

Lyme Disease Action is urging everyone affected by Lyme disease and associated tick-borne diseases to lobby their MPs about this serious issue. On Information Sheet two you can find a reminder of ten action points to help you explain to your MP why things are not working well for patients at the moment.

Will you help us make history and start to get the serious issue of Lyme disease thoroughly understood and debated in Parliament? Please ask your MP to sign Early Day Motion (No. 958):

Early Day Motion on Lyme Disease

“That this House acknowledges that Lyme disease, also known as Lyme borreliosis, is a serious and potentially chronic disease which is becoming more widespread across the United Kingdom; notes the growing body of evidence which suggests patients with the disease are frequently subject to misdiagnosis and under-treatment; is concerned that the disease appears to be under-reported and inadequately investigated; and calls upon the Government to put in place a national strategy for reducing the growing toll of ill-health caused by this disease, including the development of clinical guidelines specific to the UK for the use of all medical professionals dealing with patients with this disease.”

To All Lymies - Please Contact Your MP

Please tell us about your letters/visits to your MPs, any press coverage you receive and any other lobbying activities by going to our website and following the 'Please tell us' link, or by writing to our PO Box (see below).
www.lymediseaseaction.org.uk/lobby/

Why Are We Lobbying For Lyme ?

Many of us at LDA are Lyme affected too. We know that too few of us get the prompt diagnosis and treatment that we need and have the right to have. We know that only then can we get on the road to recovery and return to our lives. We know we need full recognition that these tick-borne diseases are here in the UK and that the problem is already large and increasing.

CONTACT US

Information on Lyme disease and on all our activities and how you can help if you are well enough, can be found on our website: <http://www.lymediseaseaction.org.uk> Or you can write to us at Lyme Disease Action, PO Box 235, Penryn, TR10 8WZ, (with an SAE if you want a reply). If you need general help, please follow the 'contact us' menu on the LDA website and click on 'Patient_help'.

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Information Sheet 2



Ten Steps to better control of Lyme disease

Lyme Disease Action is calling upon the Government to take urgent steps to ensure that people who have Lyme disease are recognised and accorded their full human rights:

1. By ensuring that people with Lyme disease receive prompt, adequate and appropriate treatment which, in some cases, may be long-term.
2. By ensuring that more specialist clinicians trained in the clinical diagnosis, treatment and care of Lyme disease patients become available within the National Health Service.
3. By ensuring that clinical guidelines for diagnosis and treatment of patients are developed for all medical staff and ending over-reliance on current laboratory tests in diagnosis.
4. By ensuring that every effort be made to gain a reliable laboratory test or set of tests for Lyme borreliosis (Lyme disease) and closely associated tick-borne diseases.
5. By ending over-reliance upon a tick bite risk assessment in the diagnostic procedures for Lyme disease.

Lyme Disease Action is calling upon the Government to take all possible measures to form an accurate assessment of the scale of the problem and to improve disease prevention measures:

6. By granting notifiable status to Lyme disease throughout the United Kingdom.
 7. By ensuring that every effort be made to gain reliable case numbers of Lyme disease.
 8. By further assessment of tick surveillance procedures and their relationship to case numbers.
 9. By taking the lead in ensuring that full information on Lyme disease and its prevention is widely disseminated to all sectors of society.
 10. By urgently bringing about a programme of research into all aspects of Lyme disease and associated tick-borne diseases.
- Lyme Disease Action is calling upon the government to do everything in its power to prevent people from falling victim to this potentially devastating disease.

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