

Dear Lords and MPs,

We write to you as a collective group of Lyme disease organisations that work with one common goal – namely, to provide support to all Lyme disease sufferers, many of whom are in the later and therefore chronic phase of the disease.

We understand that Hugo Swire MP has invited the charity Lyme Disease Action (LDA) to brief Lords and MPs on Lyme disease, and take questions, at a meeting on 16th November 2016. This follows an MP drop-in meeting on 6th September 2016 at Portcullis House, which was organised by a constituent Deb Collins and her MP Teresa Pearce. Lyme Disease UK provided educational materials for this event to highlight various issues faced by sufferers.

We are encouraged to hear of this opportunity for LDA to highlight key issues around Lyme disease. LDA provide excellent information regarding the treatment and prevention of acute Lyme disease, but do not necessarily speak for all patients suffering from chronic Lyme disease and all parties interested in the disease in the UK.

Representatives from the organisations listed below would very much welcome the opportunity to join LDA at this meeting, to share our insights into the issues experienced by sufferers:

- About Time for Lyme (an educational campaign aimed at raising awareness of Lyme disease)
- Caudwell Lyme Disease (a charity focusing on awareness of and research into Lyme disease)
- LymeAid UK (a charity providing private testing grants for people who may have Lyme disease)
- Lyme Disease Northern Ireland (Northern Ireland's patient support group)
- Lyme Disease UK (the UK's largest patient support network with over 5,000 members)
- Lyme Research UK (a research group in the field of tick-borne infections)
- VIRAS (a group of professionally qualified researchers dedicated to expediting progress in the diagnosis and treatment of Lyme disease and associated vector-borne infections).

Given the short notice, members of each group unable to attend request the opportunity to submit any statement or questions they may have.

Yours faithfully,



Lyme Disease North Ireland



lymeresearchuk.org



N.B. Caudwell Lyme Disease, LymeAid UK, Lyme Disease UK, Lyme Research UK and VIRAS are all stakeholders in the current NICE guidelines process.