

Lobby news

A small group of LDA trustees had an interesting meeting in June with Oliver Letwin, MP for W Dorset. Oliver has come to realise "that all our efforts to pursue this debate with calm, rational persuasion are naïve." The view now is that we need some sort of test case to force the Department of Health to take our concerns seriously and this is a potentially very expensive exercise. However, it seems likely that the Department is doing this for us: the GMC investigation, however inappropriately raised, will have to examine the issues of UK diagnosis and treatment. An initial report is expected shortly.

We have recently written to Justin McCracken, CE of the HPA, expressing concern at the HPA's attitude to patients as displayed on the Lyme disease pages of their website and in their responses to us as a patient charity. He is looking into what we have raised and will "send us a substantive reply shortly."

More

Oliver Letwin's article: http://www.dorsetecho.co.uk/news/4419055.MP_Oliver_Letwin_backs_Lyme_disease_charity/

Press & PR

We are very grateful to Sue Ockwell for taking on the Press Officer role which has been vacant for some time. Because of her extensive PR experience she will advise on all press and PR matters and her input has been felt immediately in the issuing of press releases and very fast responses to media requests.

The HPA's press release in May to raise public awareness of ticks and Lyme disease generated a lot of media requests for human stories. We are building a portfolio of case studies so that we can be more prepared to respond. Know anyone who might make a good study?

We have been able to contribute to a number of media articles on radio, television, newspapers and magazines. Most recently Sue herself was interviewed live on BBC radio Solent. Her expert handling of the interview is an example to us all. We are putting together some briefing notes (helpful hints and salient sentences) and anyone asked to speak to the media should contact us at press@LymeDiseaseAction.org.uk.

More

HPA press release: <http://tinyurl.com/mbfrpp>

LDA press stories: www.LymeDiseaseAction.org.uk

Leaflets and Shop

Leaflets have been flying out of the boxes. In June and July over 4,000 went to destinations all over England and Scotland. Significant quantities have been distributed by volunteers in both Kent and Surrey and the NHS has taken delivery of batches in Cirencester, Southampton and Swanage.

Sales of tick lifters are now diminishing but 380 were sent out over June and July. These not only generate a small profit but also bring donations with them - in some cases very generous ones. So for June and July profits of around £750 and donations of £120.

IDSA: hope for the future

The IDSA Lyme disease review panel hearing will probably be the highlight of 2009 though it is possible that it may be eclipsed by the panel's conclusions. Patients have been heartened to witness the public airing of the issues.

The panel will now be reviewing the evidence presented, literature and the 150 submissions by organisations (including LDA) and individuals. It is expected to reach a conclusion by the end of the year.

The presentations and the webcast of the hearing are available on line. Steven Philips' presentation is highly recommended if you want to point anyone in the direction of a clear exposition of why the IDSA guidelines need re-writing, but they are all, on both sides, interesting in their ways.

More

IDA Webcast: <http://idsociety.org/Content.aspx?id=15026>

LDA submission to IDSA hearing: http://www.lymediseaseaction.org.uk/releases/lda_37.htm

LDA 2009 conference

Planning for the conference in September is now complete. We are focusing this year on the problems faced by GPs when confronted with an ill patient on the one side and the HPA on the other inflexibly using IDSA guidelines. The conference will include significant slots for discussion to which we hope both patients and doctors will contribute.

There are a lot of uncertainties in the diagnosis and treatment of Lyme and initiation of a review of UK practice depends on the Department acknowledging these uncertainties. Whilst ever the HPA view of "there is nothing new" prevails, there will be no progress. Concerted attempts to obtain a speaker on Antimicrobial resistance from the HPA, by the way, failed completely, despite their avowed interest in this topic.

The conference will conclude with Mark Fenton from the James Lind Initiative discussing "What you can do when you don't know". Anyone attending the conference might like to prepare some questions in advance as there are going to be doctors present to listen to this debate.

More

LDA conference: <http://www.lymediseaseaction.org.uk/conference.htm>

Database of Uncertainties about the effects of treatments: <http://www.library.nhs.uk/DUETS/>

News from other charities

Of interest to many will be the Arthritis Research Council's publication *Complementary and alternative medicines for the treatment of rheumatoid arthritis, osteoarthritis and fibromyalgia*. Free hard copies of the report can be obtained on 01904 696994 or by sending your name and address to arc@bradshaw.sdirect.co.uk or you can view it on their website. Evidence from randomised controlled trials was reviewed and 40 medicines rated for effectiveness and safety.

The British Lung Foundation funded research into the effects of long term macrolide antibiotic therapy in patients with COPD (Chronic Obstructive Pulmonary Disease). This was found to be effective, and **not** associated with adverse events.

More:

ARC report on complementary medicines: <http://www.arc.org.uk/arhinfo/documents/6300.pdf>