

Newsletter

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www.LymeDiseaseAction.org.uk



UK Guidelines on the way?

You may be aware that in February 2008 Julia Goldsworthy MP raised an Early Day Motion in Parliament on our behalf calling for a national strategy for Lyme disease including clinical guidelines specific to the UK. The Department of Health, however, has always maintained the excellence and applicability of the guidelines from the Infectious Diseases Society of America.

It was brought to our notice recently that the British Infection Association (BIA) is putting together a society statement on Lyme disease and canvassing its members for views. So LDA's chairman contacted the BIA president and during a very helpful discussion discovered that the society statement is only the first stage – the second stage is preparation of evidence based guidelines for the UK. The president said that the BIA is aware that one cannot extrapolate guidelines across countries because of the different ticks and the different species of Borrelia.

Well, well, well. It is nice that someone has listened to us.

Or have they? Anyone who has listened to what LDA has been saying will know that evidence based guidelines for the UK are not yet possible. Where is the evidence on what treatment works? Early 2010 saw the European Federation of Neurological Societies (EFNS) issue guidelines which state quite clearly that for late Lyme neuroborreliosis in Europe (ie infection of more than 6 months) **"There are no randomized treatment studies [on effective agents]"** and **"There are no comparative controlled studies of treatment length"**.

Because of this lack of evidence, the EFNS issued guidelines based in part on subjective "good practice". Will the BIA simply do likewise? In the UK so far the Clinical Knowledge Summaries (CKS) restrict guidance to early disease, where there is some evidence, and the Map of Medicine refers to both ILADS and IDSA guidelines noting that there is evidence supporting both views. The Department of Health? They say that ILADS is unreliable and IDSA is definitive. What is a clinician to do? Observe the evidence of the presenting patient and use clinical judgement perhaps? They don't seem ready for that yet.

The BIA is a well respected association, has prepared several guidelines and states that they are not intended to override clinicians' judgment. There will be many members who are open minded and who view evidence based medicine as important. They will be aware how many patients do not recover following currently recommended treatment regimens and also aware of typical Lyme disease patients who do not test positive with the current tests and who are therefore denied treatment altogether.

Let us hope that these members speak up.

Meanwhile, we cannot wait for the BIA to discover that evidence is lacking, and we cannot risk the fact that their members might draw up guidelines based on what a few of them might consider, subjectively, under pressure, to be good practice. So we shall proceed to document exactly what is known and what is unknown about Lyme disease.

More

BIA: <http://www.britishinfection.org/drupal/content/bia-newsletter> see July Newsletter

LDA Guidelines page: <http://www.lymediseaseaction.org.uk/articles/articles03.htm>

Uncertainties and priorities

The James Lind Alliance (JLA) is principally funded by the Department of Health and the Medical Research Council and provides an infrastructure for patients and clinicians to work together to identify and confront the uncertainties about the effects of treatments. LDA is now a JLA affiliate and has committed funds to a JLA Priority Setting Partnership (PSP).

How does this work? An independent researcher will conduct an extensive search of the literature, documenting existing evidence. In parallel with this clinicians and patients will discuss and document the uncertainties **in both diagnosis and treatment** that currently exist. Finally the two groups will come together to draw up a set of shared priorities. These documented priorities will then feed into the national research agenda.

We know where to find the patients, but where will we find the clinicians to participate in this partnership? In the current murky waters surrounding the politicisation of Lyme disease, it is difficult to see the clinicians who will be prepared to be involved. There are some organisations which, like LDA, are JLA Affiliates and we hope to interest these but the attitude of the Department of Health has not exactly encouraged clinicians to voice their concerns and uncertainties. Will they come forward?

More

James Lind Alliance: <http://www.lindalliance.org/>

Meeting with the Minister

In October we met with Anne Milton, Parliamentary Under Secretary of State for Public Health. At this meeting she, and the Departmental officials present, said they saw no reason why the Department could not support the JLA PSP and encourage clinicians to participate.

This looks like progress.

The clinician participants in the JLA will discuss diagnosis and treatment uncertainties and canvas their colleagues across the NHS. LDA will do the same with patients and carers. Out of this will come a set of joint priorities.

Then at last we can move forward to finding some solutions.

Conference 2010

The LDA Conference this year took a different form from usual and, between some interesting presentations, focused on workshops for patients and carers.

Out of these came, from both carers and patients, the strong view that increasing awareness within the medical profession must be a high priority. It is hoped that engaging clinicians in the JLA PSP will facilitate this. What comes from within the profession will inevitably be accepted more readily.

More

Conference presentations: <http://www.lymediseaseaction.org.uk/conf2010/index.htm>