

Newsletter

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www.LymeDiseaseAction.org.uk



The ball is rolling

The James Lind Alliance Lyme Disease Priority Setting Partnership (PSP) is now underway.

Invitations are currently being sent out to clinicians asking them to come to an awareness day on May 18th at the Academy of Medical Sciences in London. At this session the James Lind Alliance will introduce clinicians to the concept and explain why we need to know the uncertainties in diagnosis and treatment of Lyme disease. It's free, it's a short day (11.30 to 3 pm) to allow for travel, lunch is included and they just have to turn up and listen: no commitment to anything is required and they don't have to worry about taking sides.

The Department of Health has been invited, as observers, because this whole process will be open, independent and transparent. As such, the end result of the PSP **will carry weight**.

So if you have a doctor who has treated you for Lyme disease, and who you think may be aware that all is not straightforward, then please send contact details (including email address if you can) to conferenceteam@LymeDiseaseAction.org.uk. The conference team will then send them an invitation.

Send us some names to invite. Doctors are often booked up ahead, so the sooner they receive their invitations, the more likely they are to attend. So think of anyone who has treated you or your family:

◇ Neurologists	Send the clinician's
◇ Rheumatologists	
◇ Paediatricians	name
◇ Obstetricians	address
◇ Infectious Diseases Consultants	e-mail address
◇ GPs	
◇ Physiotherapists	to
◇ Gynaecologists	
◇ Dermatologists	ConferenceTeam@LymeDiseaseAction.org.uk
◇ Psychiatrists	
◇ Immunologists	
◇ Any other?	

This is an awareness meeting to introduce clinicians to the process. After this, we shall be sending out survey forms for completion by clinicians and patients to find out what the uncertainties really are. Then we all get down to voting on the priorities.

More

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

London Lyme Disease

An interesting paper published in December 2010 analyses the features of the patients diagnosed with Lyme disease at a London teaching hospital between 2002 and 2007 and reveals some very interesting points:

- ◇ Of the 77 patients 15.6% had neither an erythema migrans (EM) nor positive serology. **But none the less, they were diagnosed with Lyme disease.** These patients were excluded, very properly, from the detailed analysis so their outcome and the features they exhibited, are not given in the paper.
- ◇ 3 patients (out of the 64 included in the detailed analysis) did not improve and were given a repeat course of treatment. Two still did not improve and were given 21 days IV: so **3 courses of treatment** altogether. Which does seem to indicate that perhaps Lyme disease can survive the recommended courses of antibiotics.
- ◇ 11 patients with negative screening ELISAs had symptoms that convinced their clinicians they did have Lyme and so their blood was sent for immunoblots: **6 had positive results.** Is the ELISA really sensitive enough to use as a screening test?
- ◇ The abstract says "No cases had residual features compatible with the disputed entity described as chronic Lyme disease". One is left wondering what diagnosis would have been given to the 3 patients above if they had not been given repeat courses.

Although immunoblots were negative in 31% of patients, these were said to be "principally" those with early disease. However, length of infection is not given, so the results are impossible to interpret. Had the 3 who were given repeated courses had Lyme for longer?

More

Lyme disease in the UK: clinical and laboratory features and response to treatment

Richard Dillon, Susan O'Connell and Stephen Wright Clinical Medicine 2010, Vol 10, No 5: 454-7

Watch out! Ticks about!

Posters for the community notice board in the village? Leaflets to the vet?

We have a range of printed leaflets (and cardboard dispensers to hold them) as well as posters, so if you feel you can place some, email leaflets@LymeDiseaseAction.org.uk and ask for a starter pack.

Help prevent someone else getting Lyme Disease!

LDA Conference 2011

Date: Saturday September 17th

Venue: Wills Hall, University of Bristol

Further details will be announced in due course.