

LDA Conference 2010

The venue and date of next year's conference are now fixed and we are devising a programme with international speakers, taking into account the increasing interest of the medical profession.

Venue: Wills Hall, University of Bristol
Date: Thursday 2nd September - pre-conference dinner
Friday 3rd September 2010 - 1 day conference

Within easy reach of the M5, Wills Hall is on the outskirts of Bristol at Stoke Bishop with plenty of parking and with a variety of accommodation on site.

We have had an offer of sponsorship from Sunvil, a specialist holiday company run by Noel Josephides, whose wife has Lyme disease. This has enabled us to book a larger venue than Leicester University and will provide the opportunity of splitting some sessions into two to accommodate separate discussions for doctors and patients.

More

Wills Hall: <http://www.bris.ac.uk/Depts/Wills/conference/index.htm>

Sunvil: <http://www.sunvil.co.uk/>

Patient Help

Since October 2007 Lyme Disease Action has received just over two thousand enquiries through our <patients_help@lymediseaseaction.org.uk> email address. We endeavour to answer these as soon and as best as we can.

The overwhelming majority of these are from people who suspect they may have Lyme disease. This could be because of a tick bite, a rash, or other symptoms typical of Lyme borreliosis. Some have already seen numerous NHS consultants only to be misdiagnosed or told there is "nothing wrong" with them and to "get on with their lives".

The apparent ignorance about tick-borne diseases amongst the UK's mainstream medical profession is extremely worrying. Patients are sometimes refused the basic blood tests because "Lyme doesn't exist in the UK", or because "the patient hasn't recently visited the New Forest". Frequently patients are told "Your blood test is negative so you don't have Lyme." On one occasion a GP, on being presented with a textbook bull's eye rash, in utter disbelief licked his finger and tried to rub the colourful mark off the patient's limb!

Sadly, by the time some patients find us, they have spent thousands of pounds seeing 'alternative practitioners' and tried any number of 'alternative therapies' – most of which haven't done them an iota of good. Others – fortunate enough to have a positive blood test or a clinical diagnosis for Lyme – find that after the basic NHS treatment of a couple of weeks low dose antibiotic, many of their original symptoms return.

We at Lyme Disease Action are left to help – and, unless we can convince the medical profession to change, this is likely to continue. On which note you should perhaps not turn the page!

The Chief Medical Officer speaks out

The recent CMO Update has caught the eye of doctors who would normally glance at it and pass it by, so it may have had a major and unfortunate influence. LDA wrote to Justin McCracken, CE of the HPA, pointing out that this is yet more evidence of the bias of the Lyme Reference Unit (LRU): I think everyone will agree that this was a very pointed article. The letter was copied to the CMO and somewhat to our surprise we received a response not only from Justin McCracken, but also from the CMO himself.

Justin McCracken (having answered some of our questions) says he will now not correspond with us any further, except on new issues, because the staff who provide the response (presumably at the LRU) have a very heavy workload.

Sir Liam Donaldson finds our concerns "extremely unfair". He is "made aware all too often of patients who have received a false diagnosis of Lyme borreliosis or a diagnosis of 'Chronic Lyme'.." He discusses the official tests, how the antibody response develops and says that the chance of a positive antibody test increases to about 80% by six weeks and there is a greater than 99% chance that patients with late stage Lyme Borreliosis will have a positive antibody response.

The 20% failure rate of the test at 6 weeks will be news to many doctors, as the greater than 99% success rate in late Lyme is news to us.

However, we now have the Chief Medical Officer engaged in the discussion, even if he stays but briefly.

More

CMO Update see p 14: http://www.dh.gov.uk/en/Publicationsandstatistics/Lettersandcirculars/CMOupdate/DH_106527

LDA response: <http://www.lymediseaseaction.org.uk/releases/cmoupdate.pdf>

LDA 2009 conference

This year's conference raised some very interesting discussions. A summary is being prepared and should shortly appear on the LDA website. Apart from difficulty understanding one of the speakers from Europe and the poor ventilation of the conference room, feedback was complimentary and everyone learnt a great deal; patients, carers and doctors alike.

How many people knew that in the 18th century it took the earliest clinical trial to show that both authorities were wrong in their views on what it took to prevent and cure scurvy? The Royal College of Physicians favoured sulphuric acid and the Admiralty favoured vinegar. We were shown by Mark Fenton the route towards clinical trials for Lyme disease treatment.

There was enough meat in the presentations to challenge everyone. Although non-biologists struggled with the depth of Judith Miklossy's neuroscience, no-one failed to understand her comparison of chronic Lyme disease with chronic syphilis - the similarity in both the history of understanding and misunderstanding of the diseases and their pathophysiology.

Notable headlines from the day could have included:

- Do some Alzheimer's patients have undiagnosed Lyme disease?
- French hospital reports on the effectiveness of long term treatment for Lyme disease
- Cardiff study shows tests failed to identify more than 40% of clinically diagnosed patients

Next year's conference should be just as thought provoking. Watch this space.