

### Conference 2012

Held in Carlisle on July 21<sup>st</sup>, this conference witnessed diverse and fascinating presentations and was enhanced by the well-known Cumbrian hospitality provided by the University of Carlisle.

The most popular talk was by Dr Sandra Pearson, LDA's Medical Director - "Neuropsychiatry of Lyme Disease". Rated by delegates equal second were two contrasting talks: one high level dealing with woodland ecology and risk and the other deep down at the molecular level amongst the outer surface proteins of *Borrelia burgdorferi*.

Ted Wilson's very balanced talk explained the risks inherent in woodlands and showed how they could be managed and mitigated. He also pointed out the considerable benefits to be gained from woodlands.

The very last talk had been thought by us to be possibly over-technical for many delegates but proved to be the icing on the cake: "The discovery of a family of transmembrane proteins with Factor-H binding activity in *Borrelia*". Dr Richard Bingham, from Huddersfield University, had us glued to our seats as he took us on a journey through the *Borrelial* outer membrane and explained the implications of the research team's findings.

Definitely a conference to remember.

All presentations are available to download from the LDA website.

### LDA speaks to US Congress

In mid July LDA received an unexpected email requesting participation in a congressional hearing on Lyme disease: "Global Challenges in Diagnosing and Managing Lyme Disease – Closing Knowledge Gaps". This was a hearing before the Foreign Affairs Committee - hence the "global" in the title - and a week before the hearing it was realised that all witnesses to be called were from the USA.

The Deputy Chief of Staff cast his eyes around the web looking for someone to give a balanced view of the challenges and the LDA website came into focus. A long telephone conversation later Stella Huyshe-Shires agreed to provide a witness statement by telephone. After conferring with fellow LDA trustees the written statement was condensed down to the allowed 5 minutes oral summary; well, slightly longer to be honest but we hoped they wouldn't cut us off, and they didn't.

[Links to the hearing](#) are on LDA's website as is our full written testament. If ever you need to explain to anybody how Lyme disease has become the challenge it has, then try referring them to this statement.

## LDA in the press (yet again)

One of the summer issues of the British Medical Journal (BMJ) had a large tick on the front of the cover - an excellent advert for an article inside in the "10 minute consultation" slot. This was entitled "Tick bite and early Lyme borreliosis" and gave some sound advice on what a doctor might think about and say when consulted by a patient with a rash following a tick bite.

Unfortunately the main reference given for further information was the British Infection Association's Position Statement on Lyme Disease. It is not the fault of the authors that their otherwise excellent and timely article was marred by quoting from the BIA statement. How could they know that this association had got it so wrong?

Many will know that LDA has some serious issues with the BIA statement and will have read the [comments we provided](#) to the BIA. To inform BMJ readers, we submitted a Rapid Response to the article: this is the BMJ's vehicle for letter submission. We wished to make the point that LDA is accredited to the Department of Health's Information Standard and therefore has procedures in place to ensure that information is accurate, balanced and evidence based. If the BIA had applied for, and achieved, NICE accreditation then it also would have procedures in place to ensure that guidance was un-biased. However, the BIA has not yet taken that route.

The BMJ decided to publish our letter so we whittled it down to the requisite 300 words for inclusion in the printed edition. This in turn drew a Rapid Response from the BIA to which LDA has replied.

Medical professional societies are not necessarily better at providing unbiased information than charities and LDA works constantly to ensure that both doctors and patients have up to date un-biased information.

We should all be careful what we read; on the web and elsewhere. NICE and the Department of Health have put in place accreditation systems for those providing health information precisely so that readers (both doctors and patients) know which organisations they can trust.

Links to the [BMJ correspondence](#) are on the LDA website.

At the time of writing the last BIA response has appeared in the print edition with the title "BIA position paper on Lyme borreliosis is evidence based" which is most unfortunate as readers scanning this letter may think "That's all right then"; and of course, it isn't.

LDA is in discussion with the BIA about this statement, so we are still talking.

***A collective noun  
for Spirochaetes?***



an infiltration  
a slithering  
a devastation

## Lyme disease in the Liverpool ID clinic

A paper published earlier this year has already become widely quoted and so it is worth a brief comment to put this in perspective.

### [Lyme disease in a British referral clinic](#)

Cottle, Mekonnen, Beadsworth, Miller & Beeching.

QJM : Monthly Journal of the Association of Physicians June 2012

The paper describes the patterns of referral, investigation, diagnosis and treatment of patients who had been referred to the infectious disease unit in Liverpool with suspected Lyme disease over the 5 years 2006-2010.

The findings were that of the 115 patients referred for suspected Lyme disease:

- 27 (23%) were diagnosed with Lyme disease
- 38 (33%) were diagnosed with chronic fatigue syndrome (CFS)
- 3 (11%) were diagnosed with other medical conditions
- 38 (33%) were given no diagnosis at all.

Among the 38 patients the clinic diagnosed with CFS instead, 17 (45%) had been misdiagnosed as having LD by non-NHS practitioners.

The authors' conclusion was

*A minority of referred patients had LD, while a third had CFS. LD is over-diagnosed by non-specialists, reflecting the complexities of clinical and/or laboratory diagnosis. Patients with CFS were susceptible to misdiagnosis in non-NHS settings, reinforcing concerns about missed opportunities for appropriate treatment for this group and about the use of inappropriate diagnostic modalities and anti-microbials in non-NHS settings.*

What immediately struck LDA was the small number of patients that this clinic sees. The 5 years 2006-2010 saw about 4,150 laboratory confirmed Lyme disease cases in England and Wales; the Liverpool clinic saw **16 of these** plus a further 11 who had negative serology but an erythema migrans. So this major infectious diseases clinic in the NW of England saw less than half a percent of the Lyme disease cases that occurred in the UK in that period.

It is clear that the expertise in diagnosing Lyme disease does not lie with infectious diseases consultants, and it also seems that they rely heavily on serology. Unfortunately, the remaining 4,130 Lyme disease patients in those years would have been spread very thinly over the country's GPs, so they are not going to build up much experience either.

Everyone acknowledges that Lyme disease is difficult to diagnose when serology is negative but it is worth pointing out that Lyme disease is not the only disease without a definitive test and subject to misdiagnosis.

Two recent papers have assessed the accuracy of CFS diagnosis made by referrers to specialist CFS clinics. At [St Bartholomew's Hospital London](#) researchers found that half the patients had been misdiagnosed. The [Newcastle specialist clinic](#) found 40% had been misdiagnosed, and of these 47% had fatigue associated with a chronic disease.

We expect 21<sup>st</sup> century diagnostics to come up with answers, but we are not there yet.