

### Hiding behind the panel

On April 23rd, the day after the Infectious Diseases Society of America (IDSA) released the final report of the Lyme disease review panel, LDA was emailed by the Department of Health. The spokesperson attached the full report and said "You will see that the IDSA guidelines were in fact upheld in full as being soundly based in medical and scientific evidence. I trust that reading the full report, rather than having extracts taken out of their proper context, will enable you to better understand the complexities of this topic."

Having by then read the whole report it was somewhat depressing to find that our Department of Health had been unable to understand what the report said; but perhaps they had not actually read it and were just taking extracts out of their proper context.

The Department, and headlines from the US media, are not making clear that there was recorded disagreement amongst the panel in two very significant areas:

- The insistence on a positive test for diagnosis. This was 'felt to be problematic by some members of the panel' - in fact, half of them.
- The insistence that there is no evidence for continuing infection following standard treatment. The panel agreed that the wording needs amending to reflect the reality.

Unfortunately, in both these cases, the panel members have been able to brush aside their misgivings and delay revision of the wording until the guidelines are next due for revision. This report does not reflect well on the honesty and scientific integrity of the IDSA panel, which plainly should not have upheld guidelines that were felt to be problematic.

The blind acceptance of the conclusion of the report, by the Department of Health, is likely to be the cause of significant patient suffering. Across the UK people have been, and are being, denied treatment because they can't remember a rash, they did not notice a tick bite or their symptoms have not been resolved by a short course of antibiotics.

It seems unlikely that the Department will remind front-line clinicians that the panel emphasised that '**Guidelines are not intended to be (and cannot be) rigid dicta, inflexible rules, or requirements of practice**'." And even if they do, what doctor has time to do the necessary reading?

Much of the evidence for continuing infection is from European research. The IDSA panel argues this may not be valid for America because of what the panel describes as 'the well established microbiological and clinical distinctions in Lyme borreliosis on the two continents', but what excuse can the UK Department of Health have for ignoring European science?

What was our response to the Department's email? To suggest that they read the full report, as they clearly had not done so and it should alter their view. Will they read it? If they read it, will they read it critically? If they read it critically, will they choose to do something about it?

#### More

LDA's fuller analysis of the report: [http://www.lymediseaseaction.org.uk/releases/lda\\_40.pdf](http://www.lymediseaseaction.org.uk/releases/lda_40.pdf)

The IDSA report itself: <https://www.idsociety.org/Content.aspx?id=16499>

## Reaching doctors

LDA has, for the first time, placed advertisements in the BMJ. The advert is a quarter page with a colour picture of an erythema migrans rash to grab attention. The text starts with

**“On a patient near you? Maybe not...”**

and then quotes the HPA figures from the 2008 surveillance of those with positive blood tests: only 32% reported a rash and only 40% remembered a tick bite. This is followed by quotes from scientific papers and the test manufacturer showing why reliance should not be placed on the blood test.

This will appear on June 5th in BMJ Clinical Research which is widely read in hospitals (weekly circulation of 72,800 copies) and also the BMJ General Practice which reaches 28,000 GPs within the UK.

The BMJ is delivered on a Friday to the doctor's preferred address which, according to the BMJ sales team, is 90% of the time their home address; giving the doctor an uncluttered and relaxed environment to sit and read the journal. That makes assumptions about doctors' homes, but they're clearly more likely to read it at home than when at work!

## Educating doctors: June 12th in London

The Map of Medicine, an on-line tool provided to the NHS in England and Wales, states that “Lyme disease management remains controversial at present as there are two distinct schools of thought regarding disease epidemiology and treatment duration: the Infectious Diseases Society of America (IDSA) and the International Lyme and Associated Diseases Society (ILADS).”

The Map says that “there is current evidence to support both IDSA and ILADS schools of thought and it may be some time until one set of guidelines becomes generally more accepted than the other.” The Department of Health has not given doctors in the UK much chance to make up their own minds as to the applicability of the ILADS guidelines. They now have the opportunity to hear direct from ILADS.

This ILADS conference is intended for doctors who want to explore the lesser known ILADS approach and should prove thought provoking.

### More

Conference details & booking: [http://www.ilads.org/lyme\\_programs/lyme\\_events.html#page=page-2](http://www.ilads.org/lyme_programs/lyme_events.html#page=page-2)

Map of Medicine: [http://healthguides.mapofmedicine.com/choices/map/lyme\\_disease1.html](http://healthguides.mapofmedicine.com/choices/map/lyme_disease1.html)

## LDA conference in Bristol

Because of the ILADS conference in June we are changing our line up for the LDA conference in September. There is not really room in the year for two conferences on Lyme disease that are geared to doctors and so this year's LDA conference will now focus entirely on patients.

Rather than spending money on bringing international speakers to talk about recent research findings we shall be looking at aspects that patients need to explore to be able to make their way through the maze that represents Lyme disease in the UK. Some of the presentations will certainly be of interest to doctors, but we shall be looking at topics entirely from the patients' viewpoint.

**One day conference, Friday September 3rd, Wills Hall Bristol University**

Details to be announced shortly