

### News on IDSA Lyme disease review panel

The IDSA Lyme disease Review Panel was due to report by the end of 2009. We were into February before we heard anything and then it was unexpected.

Richard Blumenthal, the Connecticut Attorney General, whose report had triggered the review, sent staff into IDSA to review minutes. They discovered that the panel were not voting according to the two step voting procedure set out in the settlement agreement that IDSA had signed up to. The first vote is supposed to ask whether each of the contested guideline recommendations is "medically/scientifically justified in light of all of the evidence and information provided." This vote requires a supermajority of the panel (6 of 8) in order for a guideline recommendation **to stand**. The second vote determines what level of revisions are required.

The IDSA combined the two voting steps into one. They failed to conduct the vote to determine whether the science was sufficient to support the guideline recommendations and voted on change/no change with a supermajority needed **for any change**.

On the first guideline the Attorney General found that the panel had voted 4-4 on "does this guideline need to change". On the agreed rules this vote would have meant that the guideline would **not** stand (insufficient majority to stand) but on the procedure actually being used the result would be that the guideline **would** stand (insufficient majority for change). The panel did not vote at all on whether the guideline is supported by the medical and scientific evidence.

On February 1 the Attorney General wrote to the IDSA expressing his concern at the "improper voting procedures" used and suggesting that they vote again. This letter was released in response to a Freedom of Information Request and can be read at the link below, on the website of the Californian Lyme Disease Association.

A recent article in the Greenwich Times in the USA contains a response from an IDSA spokesman that the IDSA is "committed to ensuring the review panel conducts its review to the requirements of that action plan." That's all right then. However, the Attorney General has not apparently received a response to his letter yet. The USA and the whole of Europe awaits.

#### More

CALDA and IDSA news: <http://www.lymedisease.org/news/lymepolicywonk/336.html>

### We passed it on

On the assumption that the Department of Health would not wish to be using Lyme disease guidelines drawn up by an organisation that clearly works at times in an unprofessional, not to say unethical, manner, we have written again to the Chief Medical Officer at the Department of Health, and sent him a copy of the letter that the Attorney General sent to IDSA which explains the matter in some detail.

If this matter is not resolved the Department will have to choose between following discredited guidelines or drawing up UK guidelines as LDA has requested.

## Lyme in The Times

The Times in February published an article by a journalist, Alex Wade, on his personal discovery of Lyme disease. A story that many can relate to of a bull's eye rash being ascribed to first a fungal infection then a shaving rash by GP and pharmacist. Unwittingly against HPA advice Alex used Google to match his symptoms and came up with Lyme disease. A positive blood test was followed by antibiotic treatment.

The following week Alex participated in an interview for BBC Radio Cornwall. The link to this is below, the interview with Alex starting at about 34 mins. into the programme. There is a revealing interview with a Cornwall neurologist (at about 36 mins.) discussing the diagnostic difficulties and post infectious disease syndromes. He also says that "until a few years ago we never had a single case we could say was caught in Cornwall" but, "we are now seeing it down here". The neurologist knows of at least 3 cases.

They clearly receive the CMO Update in Cornwall.

### More

Alex Wade's story: [http://www.timesonline.co.uk/tol/life\\_and\\_style/health/article7016850.ece](http://www.timesonline.co.uk/tol/life_and_style/health/article7016850.ece)

BBC Radio Cornwall: [http://www.bbc.co.uk/iplayer/episode/p006bylq/James\\_Churchfield\\_15\\_02\\_2010/](http://www.bbc.co.uk/iplayer/episode/p006bylq/James_Churchfield_15_02_2010/)

## Lloyd's Market Charity Awards 2009

Mark White whose baby son was infected with Lyme disease after receiving a tick bite in the Sevenoaks area, accepted a cheque for £1,000 at the Lloyd's Market Charity Awards 2009 in December on behalf of LDA. Mark and his wife Tarnya nominated LDA, presenting reasons why the charity should benefit from one of these annual awards.

The money will be used by LDA towards the cost of advertisements in medical publications in the Spring to raise awareness amongst doctors. We have to hope that they will find this as interesting as the CMO Update.

LDA relies entirely on donations, and this was a significant contribution to funds.

## Raise awareness in your area?

LDA has a range of leaflets (and cardboard dispensers) for educating the general public and raising awareness. There are also two posters which illustrate the EM rash and list symptoms:

- **What is Lyme Disease?** is suitable for hospitals and GP Practice waiting rooms, pharmacies and libraries;
- **Watch out! Ticks About!** is good in outdoor situations (campsites and parks) and Vet's waiting rooms.

If you feel you could place these when the tick season gets under way, please email us at [Leaflets@LymeDiseaseAction.org.uk](mailto:Leaflets@LymeDiseaseAction.org.uk) and we will send you a small starter pack of leaflets, dispensers and a few posters. There are numerous people who have obtained a diagnosis of Lyme after seeing a picture of "their" rash. You may even prevent a few people from contracting the disease.

Who knows, maybe a doctor will pick up a leaflet from a display. Live in Cornwall, anyone?