

Newsletter

No 8 February 2012

www.LymeDiseaseAction.org.uk



The Quality of our Information

If you have visited our website, or looked at our Facebook page, you will know that at the end of last year LDA was certified as a provider of high quality health information by The Information Standard scheme. This scheme was developed by the Department of Health to help the public identify trustworthy health and social care information easily.

This is not just a rubber stamp. LDA has processes in place for writing and reviewing information and what we produce has been shown to be, and will continue to be, impartial as well as accurate, balanced as well as evidence-based.

Where there is controversy or uncertainty, we will tell you. If you want to know which references back up our information, whether you are a doctor or a patient, [just ask us](#).

Relevant pages on our website have this logo and it will appear on new versions of our leaflets.



You will see Lyme Disease Action appearing on other official websites, such as NHS Choices. You, your doctors, your colleagues can all look to us for quality information on Lyme disease.

LDA on Facebook and the LDA website



You can dip into Facebook without signing up to it, so use the link from our website and have a look at our page. If you want to look more often, then simply save the link in your web browser favourites list.

We are using our Facebook page to give notice of news items added to the LDA website and we post something roughly every week, and sometimes more frequently.

If you would rather just watch the website, then use that. On the right is a current snapshot from the Latest News list on the Home Page of the website. All those items have a link to a longer article.

If you haven't looked, why not go and have a read

<http://www.lymediseaseaction.org.uk/>

Latest News

Immune response develops in waves

Trust in Healthcare

Guidelines matter

Where your dog goes, so do you!

Neurological care criticised by National Audit Office

2012 - We can hope

JLA Survey Report

Through the last half of 2011 LDA held a survey to collect from clinicians and patients their uncertainties about the diagnosis and treatment of Lyme disease. The survey closed in November and the survey report is now available on our website.

The majority of submissions were from patients and carers but over a fifth were from clinicians in primary care. It is good to know that GPs recognise that there are uncertainties. There was only a few responses from secondary care clinicians but we hope to get a better response from that group when it comes to voting on which uncertainties are the most important.

Some people included more than one question in a sentence, so these have been broken down into separate questions. As a result the totals are -

253 respondents
submitted
810 raw uncertainties
which have resolved into
975 separate questions

The questions revealed the high levels of frustration in both patients and clinicians. Understandably, there were many responses from patients along the lines of

"Why do medical professionals rely solely on tests / not acknowledge chronic Lyme / know so little about the UK's fastest growing infectious disease.. etc etc"

Perhaps less understandable was a clinician's submission of

"I have no uncertainties and can easily find evidence based guidelines..."

That person has clearly never read the EFNS (European Federation of Neurological Societies) guidelines which state very clearly which of the recommendations (several) are based on opinion (and are uncertain) because the evidence does not exist. If you are a doctor reading this, check the [Guidelines page](#) on our website, where you will find links to, and comments on, all English language guidelines.

Where now? We are sorting the 975 separate questions into:

- Out of scope (not about diagnosis or treatment of Lyme disease)
- Not uncertainties (the answer is known)
- ✓ True uncertainties

Watch this space!

Starter for 10 - blood test results

It is generally thought that in early infection the immune system mounts first an IgM response which gradually increases, then an IgG response which also grows smoothly giving a strong reaction on the immunoblot that is used to confirm Lyme disease.

Not so certain, apparently.

Two German researchers have published the results of a study that show an undulating immune reaction in early disease (the first 10 weeks). It looks as if a person in early infection can test positive one week, negative later and then back to positive again. Early diagnosis might hinge on this snapshot of a test.

You can see this undulating response in the graph below taken from the paper Elisabeth Aberer and Gerold Schwantzer, "Course of Antibody Response in Lyme Borreliosis Patients before and after Therapy," *ISRN Immunology*, vol. 2012, Article ID 719821, 4 pages, 2012. doi:10.5402/2012/719821

You can read a summary of this paper on our website - [see latest news](#).

It is also available on-line if you want to read the full text.

The study was in early disease, and we do not know what happens in later disease - does the immune reaction carry on undulating?

Could this be one of the reasons why people test negative with one test and positive with another?

Is there, by any chance, an uncertainty here?

As is recommended throughout Europe, a 2 tier system of testing was used for these patients - an ELISA first, as it is thought to be more sensitive, followed by an immunoblot. The authors of the paper state that

"In our study, IB was found to be more sensitive than ELISA; therefore only IB results were analysed...."

Another uncertainty?

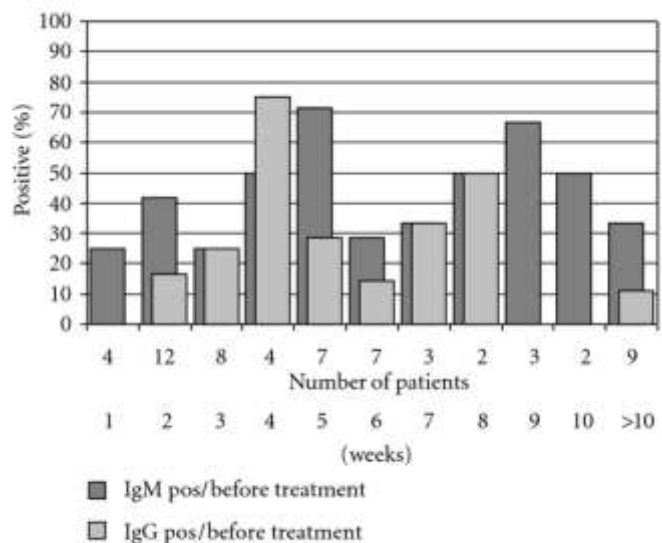


Figure 1: Development of immune response from tick bite (weeks).

LDA Conference 2012

The LDA conference has been moving South over the last few years, but after 2 years at Bristol we are now heading North to Cumbria. We already have some interesting speakers booked, and will give you full details when the programme is complete.

Date: Saturday July 21st

Venue: University of Cumbria at Carlisle

Carlisle has a purpose built conference lecture theatre and accommodation will be on campus as in previous years for those who want to stay the night before and/or the night after.

Just off the M6, Carlisle has a good main line train station with frequent trains from Glasgow, Edinburgh, Newcastle, Liverpool and many more centres.

Ticks? They have those too in the area, so we expect interest from local GPs across Cumbria, Northumberland and Scotland. In a couple of months we shall open booking and provide flyers for doctors and patients.

From Conference 2011 - an update

At the LDA 2011 conference Faith Smith told us about her research project at Bristol University surveying pet dogs to estimate the prevalence of Lyme disease infected ticks. Her paper has just been published.

Smith FD, Ballantyne R, Morgan ER, Wall R. Prevalence, distribution and risk associated with tick infestation of dogs in Great Britain. Medical and veterinary entomology 2011 Mar
Available from: <http://www.ncbi.nlm.nih.gov/pubmed/21418263>

The random samples of ticks were from dogs inspected at veterinary surgeries across the UK. Samples positive for *Borrelia burgdorferi*, the bacteria that cause Lyme disease, were found in ticks from Scotland to the Southwest of England and other places in between.

The paper concluded

"The data suggest that the prevalence of *Borrelia* in the UK tick population is considerably higher than most recent estimates indicate."

More detail, as usual, [on our website](#)