

LDA Conference 2016 - Moving forward

The conference is building up well. We expect to be able to launch our new research project and recruit people at the conference, so this should be quite exciting and a good discussion topic; don't miss it!

It might hearten you to know that doctors are being invited to a Public Health England (PHE) conference the day before at the same venue - see page 3 of this newsletter.

It is always good to meet and there will be ample opportunities for networking at the breaks; even more if you stay for Friday or Saturday night.

Venue: Murray Edwards College, University of Cambridge
Friday September 16th: optional meet up and have dinner
Saturday 17th: conference 09.30 -17.30

Saturday evening: we are planning a meal out in Cambridge with the speakers

Dr Sandra Pearson, LDA's medical director will give an account of **PHE's doctors' day** the day before and tell us how it went and what was said.

Conference fee £46
B&B standard £37
B&B en-suite £57
Friday dinner £17

Dr Knut Eirik Eliassen from Norway will describe a project he carried out to obtain a better estimate of the **true incidence of Lyme disease in Norway**. A lesson for the UK?

Dr Gillian Baker will introduce **LDA's research project**. This will be open to everyone to join – past, present and possible future Lyme disease sufferers. Whoever you are, you can contribute and you will get something out of it. We shall discuss what will happen for those taking part and why we are doing this. **During the breaks you will be able to sign up.**

Dr Monica Embers, from the USA will discuss her research on the evidence for **persistence of Borrelia**, and Dr Sandra Pearson will explain the **implication of this research** for humans. It may seem obvious, but just what does it mean for us?

Students and teachers from the Thomas Hardy School, Dorset will explain their project **analysing Dorset ticks for Borrelia**: how they do this and the difficulties they have faced. Anyone from Dorset can take a collecting box back with them to help in this project.

Dr Norma O'Flynn, the National Guideline Centre who will explain how the **NICE process** will work, and what might be expected at the end. This is the time to have your questions answered.

Further details and a link to booking are on the [LDA conference page](#) of the website. Book your place as soon as you know you can come; overnight accommodation is becoming limited, and it is first come, first served, though there are plenty of conference seats left.

NICE - also on the move

This is probably the last time that LDA will be able to comment on the NICE guideline process until the draft guideline is published, when we shall ask for your comments.

The final scope has just been published, together with all the comments submitted by stakeholders. See [our news item](#) on this to see which stakeholder groups commented and for the link to all the comments made and NICE' responses.

The committee has not yet been announced and there has clearly been some difficulty recruiting health professionals as the advert has been placed three times - March, May and July. Selecting members for a committee like this is never easy. They need a range of different stakeholders, but experience shows that guideline groups should avoid those so rooted in their own particular view that they maybe have difficulty looking at things from a different perspective.

What happens now? The technical team will be searching literature for evidence: what has been reported on tests and what is recorded on the effects of treatments.

Once the committee has been announced and has its first meeting (currently scheduled for September 14-15) there will be a close down on news. Published minutes of NICE meetings don't actually say what went on, just the topics discussed. This may seem odd for a supposedly open and transparent process, but consider what this committee has to do.

Everyone reading this newsletter will have been faced with one or more of these questions:

- how do I know I/this person has Lyme disease/still has Lyme disease?
- might treatment help me/this person?
- what treatment will be best for me/this person?

To attempt to answer these, and other, questions, the committee needs access to all potentially relevant knowledge and needs to agree - to negotiate - on what is actually "relevant" knowledge. There will be disagreement, arguments and discussion, and there will be a need to listen and to change minds. This is why a process like this is generally confidential. Studies have shown it is best for there to be a safe space for negotiation where people can speak their minds, and change their minds.

Some might think it possible to develop NICE guidelines from existing American and European guidelines; just altered for the UK perspective. However, one cannot always tell what knowledge was included in those discussions. What did they view as not relevant? What is new? What needs to be looked at afresh? So NICE has to do the job again, from scratch and very thoroughly.

We all know there is a sea of uncertainty, and this committee has to negotiate its own way to some answers. From comments made by the Royal College of General Practitioners:

Overall there seems to be an increasing awareness amongst the population of this condition and yet a great deal of uncertainty amongst non-specialist clinicians as to how to diagnose and treat.

Therefore the RCGP feels that this guideline is much needed.

We doubt that anyone would disagree with that.

PHE doctors' day

This has to rate as Good News! On Friday 16th September, the day before the LDA conference, PHE are holding an open day for health professionals at Cambridge.

An excellent line-up of UK and international speakers:

Knut Eirik Eliassen, Norway Antibiotic Centre for Primary Care, University of Oslo, who is also speaking at the LDA conference

Bart Jan Kullberg Netherlands – The Value of longer term antibiotic treatment for persistent Lyme disease symptoms

For an up-to-date programme and booking form, doctors can contact LymeConference@phe.gov.uk

Mariska Leeflang Netherlands – the diagnostic accuracy of serological tests for Lyme Borreliosis, following the ECDC systematic review (see later article in this newsletter).

Arles Chrdl Czech Republic – Epidemiology of Lyme disease in Eastern Europe

Gareth Tudor-Williams, UK - Managing persistent illness in children in relation to Lyme disease

Steve Green, UK - Managing persistent illness in adults

Brendan Heale, UK - Clinical Perspective of Lyme disease in Wales

The day is free and CPD will be applied for. This is an excellent opportunity for health professionals to listen and discuss their concerns.

UK activity

The Department of Health has announced the commissioning of **3 reviews into Lyme disease** - diagnosis, treatment and transmission. This was following pressure from John Caudwell and will take the form of systematic reviews of the literature. The Minister said in July "*We expect that work to start in the autumn, and the researchers will approach relevant stakeholders.*" This is the sort of work that needs to be done thoroughly and not rushed. How it will interface with the literature reviews NICE are doing we don't yet know.

Ricco Franchi helped us with an article to illustrate Lyme disease [in a Scottish paper](#) two years ago. He has now released a super song [Getting Better](#), available on YouTube.

Woman's Hour included 15 minutes of discussion to raise awareness of Lyme disease on July 12th. This was broadcast to an estimated 1.8 million listeners. [The feature](#) was initiated by Louise Alban whose daughter is affected, and another mother was interviewed.

[The Big Tick Project](#) held a Tick Awareness Key Opinion Leader Meeting in July, bringing together leading figures within the field of ticks and tick borne disease to share information with the veterinary profession. More on this in the next few weeks.

Lyme serology: further insights

How good are the blood tests, and which is best? This is a vital question on which we all need some up to date information.

In April 2016 a report commissioned by the European Centre for Disease Prevention and Control (ECDC) "[A systematic literature review on the diagnostic accuracy of serological tests for Lyme borreliosis](#)" was published. This 95 page report summarises the in-depth review by Leeflang et al in BMC Infectious Diseases. The full paper is open access and involved many European experts.

Mariska Leeflang is a Dutch epidemiologist and is due to present this important piece of work at the Public Health England (PHE) Clinician's Day on September 16th in Cambridge, immediately prior to the LDA conference on the 17th. We hope that any clinician with an interest in testing or diagnosis of Lyme disease in the UK will use this unique opportunity to gain a better understanding of the use and limitations of Lyme serology tests in Europe.

The results confirmed what is already known about sensitivity of Lyme serology tests in erythema migrans giving an average figure of 50%. The results for Lyme neuroborreliosis showed only a 77% sensitivity with quite a broad range of results, which contrasts with the previous (now archived) claims by the Health Protection Agency (HPA) that "*Patients with late-stage LB are very rarely seronegative; there is greater than 99% chance that they will have a positive antibody response.*"

Lyme arthritis showed 96% sensitivity, acrodermatitis chronica atrophicans 97% and "Lyme borreliosis-unspecified" 73%. The estimates for specificity were around 95% when healthy people were used as controls. Specificity was lower when people with other conditions were used as controls - which more realistically reflects the situation in which these tests are used on ill people.

A high degree of variability was found in sensitivity and specificity.

The conclusion suggests that currently available Lyme serology tests in Europe vary widely in terms of diagnostic accuracy and that interpretation should be made carefully in the light of the particular clinical presentation.

The paper states that the currently available published studies are of variable quality and further well-conducted research is needed. It will be interesting to hear this research presented in September.

LDA's medical director, Dr Sandra Pearson will be attending the PHE clinician's conference and will report back about this to the LDA conference on September 17th.

Sensitivity: A test with 73% sensitivity detects 73% of patients with the disease (true positives) but 27% with the disease go undetected (false negatives).

Specificity: A test with 95% specificity correctly reports 95% of patients without the disease as test negative (true negatives) but 5% patients without the disease are incorrectly identified as test positive (false positives).

[See fuller explanation.](#)

ID-Lyme: funding for new test development

In the [July 2015 newsletter](#) we noted several new tests for LB on the (distant) horizon. There is now more news on one of them.

Last year LDA wrote in support of a bid by Netherlands company Innatoss for an EU grant to develop a blood test to reliably detect active disease before antibodies develop. An international consortium, led by Innatoss, has now been awarded €1.9 million for the ID-LYME project by an EU research and innovation programme. Read [the full press release](#) on the Innatoss website; just scroll to the bottom of the screen for the full text in English.

As part of our letter of support for this project we agreed to contribute to the Advisory Board supporting the consortium, and we hope that Brexit will not affect this.

This project hopes to develop a robust test based on the T-cell response. This is a different approach to the ELISAs and immunoblots currently used worldwide which rely on detection of antibodies. We have discussed the limitations of serology before - see January 2015 and May 2015 [newsletters](#).

The T-cell response is an area of much research but no-one has yet produced a test that is reliable enough. Most trial versions produce too many false positives in healthy people, and those suffering from other conditions, to be clinically useful. There is considerable doubt amongst immunologists that the technique will be useful in late or chronic disease. You will notice that the Innatoss press release refers to distinguishing between "latent and chronic infections", and we aim to find out more about this by having further discussions with them. The importance of early detection is twofold -

1. Identify infection early before antibody tests are positive.
2. Distinguish between a new infection and previous exposure. This is important in mainland Europe where a fairly high proportion of people carry antibodies from previous, resolved infection and it is difficult to distinguish these using current tests.

The anticipated release to the market of the finished product is 2019. The test under development by Oxford Immunotec is also a T-cell based test. We wait with some interest to see which comes to market first, but there is still nothing immediately round the corner.

LDA's activity

See our [news items](#), [Twitter](#), [Facebook](#) and [What we are doing](#) on the website.



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