

### LDA Conference

There are still some places left for September 12<sup>th</sup> in Cambridge. Accommodation is almost all booked up, but if you haven't booked and would like B&B then email us at [conference@lymediseaseaction.org.uk](mailto:conference@lymediseaseaction.org.uk) and we'll check for you.

We shall be looking at treatment. Antibiotics often work, but sometimes don't - **why not?** Is it the person, the antibiotic or the bacteria? **What other options might there be?**

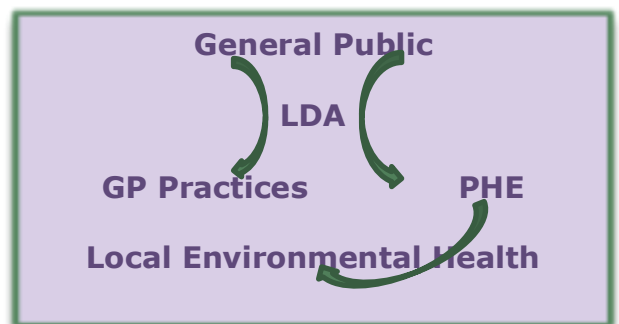
Join us for a briefing and a discussion.

### Working together

During June, a couple of incidents in Nottingham provided an opportunity for a number of groups to coordinate for (eventual) patient and public benefit. A participant on the Facebook discussion forum run by Lyme Disease UK posted about a friend's baby with an apparent erythema migrans rash following a tick bite. On presenting at A&E the mother had been told not only that **ticks don't bite babies under 1 year old** but also that Lyme **"doesn't cause a bullseye rash, it causes a spotty rash on your tummy"**.

Our help desk has a large collection of erroneous comments made by health professionals about Lyme disease, but those were new to us.

The second incident, a day or so later, also raised on the same Facebook forum, was a nice clear erythema migrans which the GP (who had probably never seen one before) thought was a natural reaction to an insect bite. In this case the tick hadn't been noticed - there was just a rash.



For both cases, contributors to the discussion board suggested contacting the LDA Help desk. Once we had first-hand information we were able to help both mothers. We talked to the GP of one who didn't know that **"Lyme disease had reached this far North"**. This is a great advance on the usual "You can't get that in the UK", but does rather hamper a diagnosis. We also discussed with the health visitor of the other mother who was having problems getting a small child to take the medication.

Following these incidents, we notified Public Health England - the medical zoonoses team which deals with ticks - they then contacted the local environmental health officers. We were able to inform this local team where the ticks may have been picked up and the mothers gave their permission to be contacted. Maybe this will lead to increased awareness in the area.

What we do about A&E is another matter and not quite so simple to address.

The [Tick Activity Project](#) is now trying to find a volunteer near Nottingham - any offers?

## New test development

There are several companies working on the development of new tests - which is an acknowledgement that the current ones are not as perfect as some previously thought.

**Innatoss**, Netherlands <http://www.innatoss.com/innatoss/lyme-disease/>

A range of biomarkers has been identified based on a patent licensed from a partner in the US. They expect to utilize a two-step approach: one test immediately post tick bite, one test 4 weeks later. Initially, the immune response shows no activity (a low level of biomarkers) - only "old" infections will show. After 4 weeks, if infection is present, the T-cells will be very active. The company produce a similar test for Q Fever.

**Current status** - Proof of Concept study on biomarkers starting 2015, research trials starting Spring 2016. Expect results of trial 2018.

**Launch**- Expect tests available 2019

This is part of the IXODES project proposal which has been submitted for European funding. A decision on funding is expected shortly.

**Global Lyme Diagnostics**, Founded to bring a particular test to market. "We have identified a set of chimeric proteins that we believe can identify all human and veterinary variants of Lyme disease in the US and Europe. Our research also indicates that we can distinguish between earlier stage of the disease as well as later stage." LDA has put the company in touch with RIPL as a possible source of European samples.

**Current status** - Research

**Launch**- Unknown

**Oxford Immunotec**. The SpiroFind test was brought to trial stage by Boulder Diagnostics (see [LDA newsletter May 2013](#)) and has been bought by Oxford Immunotec ([LDA newsletter August 2014](#)). It assesses the innate immune system responses to specific antigens to detect active Lyme disease. In theory it distinguishes between current infection and past exposure.

**Current status** - Trials currently taking place in the USA and Romania.

**Launch** - No information

**NIHR Health Protection Research Unit in Emerging and Zoonotic Infections**, based within the Institute of Infection and Global Health, Liverpool <http://www.hpruezi.nihr.ac.uk/> We have minimal information on this research but the aim is to identify biomarkers distinguishing Lyme disease from other conditions and diseases.

**Current status** - Research

**Launch** - Unknown; not even a proposed product yet

Despite the Unit's professed [public engagement strategy](#) - "we will engage patients and the public in our research right from the initial concept and design stage" - LDA has not been contacted.

### How to plug the gap?

While we wait for these new tests, doctors rely on the existing ones and some patients go undiagnosed. As well as raising public awareness, we need to -

- educate doctors;
- remove the dependence on current serology tests;
- **establish clinics manned by doctors with knowledge and experience.**

Awareness is rising, at least amongst the public and GPs, but this is causing a bottleneck of informed patients struggling to make themselves heard by consultants. A long way to go yet.

## LDA Activity in June & July

### Talks given

- To Bath & NE Somerset CCG Practice nurses
- Science Café Teignmouth - "Lyme disease: who's doing what to whom?"

### Leaflets & posters provided:

- Bicycle shops & Garden centres
- NHS Minor Injuries Units
- Several outdoor centres
- Several schools
- Numerous individuals for local needs
- Several B&Bs, many in Scotland

### Working with others:

- Department of Health
- Companies researching new tests
- Public Health England

### General public articles:

- Working with journalists from The Times, Independent, Daily Express and Daily Mail
- Podcast on tick removal with [Big man in the woods](#)
- Article for Singletrack magazine
- Articles for Smallholder magazine and SW Farmer
- BBC "Trust me, I'm a Doctor" (see below) and BBC Points West

### Scientific articles published

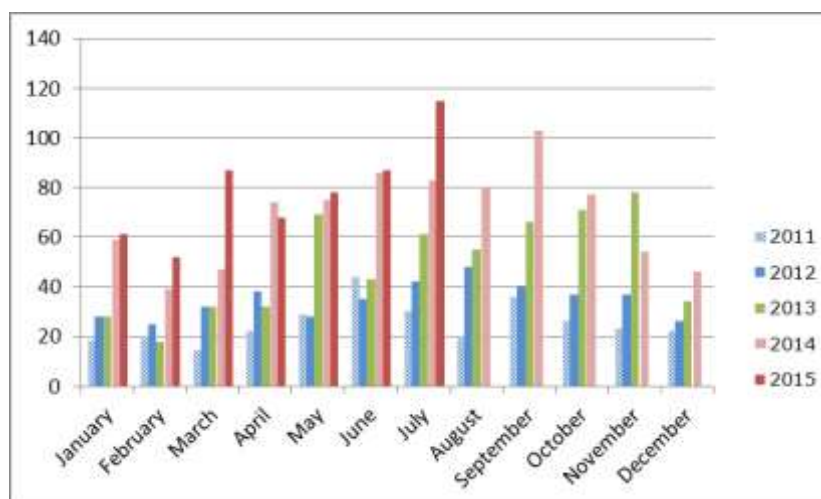
- British Global Travel Health Association
- Quarterly Journal of Forestry

### Other

- Book review of Alan Barbour's "Lyme Disease" for a nursing journal
- Attendance at a Dog Show to raise awareness
- Fundraising & selling tick removers outside a Devon supermarket
- Fine tuning the September conference

### LDA Help Desk

- Helping 202 individuals through the help desk; discussing test results with RIPL, helping GPs, generally linking facts together for GP and patient benefit.



## Clinician education

### GP Practices

Our medical director, Sandra Pearson, has given a number of talks to doctors, including one at a GP Open Day at PHE Porton. In July she presented a seminar for the Practice Nurse Forum of Bath & NE Somerset CCG in July. The nurses will cascade this information to GPs and others in their Practice. Talks such as this cost Sandra quite a lot of travelling time but are very effective in increasing awareness. They also allow us to illustrate the difficulties in diagnosing and treating with case studies from the LDA Help Desk.

Has your GP completed the RCGP elearning course? Take them [this flyer](#). Pharmacists, nurses, physiotherapists too.

### A&E?

We're looking for ways we can improve awareness. We do supply leaflets - refills at their request - to some minor injury units, and maybe we have to try to increase this.

### Infectious Diseases Consultants?

A harder nut to crack, but we have had at least one good contact through the help desk and gradually some are realising that we have a legitimate, scientific view to contribute.

## Trust me, I'm a Doctor!

In March 2015 LDA was approached by a researcher working with the BBC Science department seeking LDA's advice and input for a possible feature on Lyme disease for Series 3 of 'Trust Me I'm A Doctor'. Those of you who have watched the programme will know that it focusses on health rather than medicine and disease.

The aim was to produce a short item that would be of interest and have take-out information and tips for a broad audience. There is a running theme of 'red flags' ie things not to ignore, running through this series. We realised this would be an important opportunity to raise awareness about tick bites and the erythema migrans (EM) rash on a reputable programme airing at peak viewing time.

We had a series of about 30 emails and also phone discussions. The BBC team were very keen to get things right and happy to modify their script as we suggested.

The programme went out on Wednesday 22nd July and probably reached a wide audience, which would have included healthcare professionals as well as the general public. Some doctors in Nottingham may have viewed it with a newly awakened interest!

If you would like to view the clip from Episode 2 of Series 3 visit the BBC iplayer [web-page](#) which covers the programme material and links to the LDA web-site.

## Further reading ....

A fascinating recent paper reporting on the isolation of strains of *Borrelia* from UK ticks: there are differences between these and the strains used in European serology test kits. [Read more.](#)