

# Newsletter

## No 17 May 2014

www.LymeDiseaseAction.org.uk



### LDA Conference

**Venue:** University of Surrey, Stag Hill Campus at Guildford

#### Friday 4<sup>th</sup> July 2014

5.30 pm Residential registration opens  
7.00 pm Conference dinner

#### Saturday 5<sup>th</sup> July 2014

8.30 am Day delegate registration opens  
9.30 am Welcome and Conference start  
5.30 pm Conference close  
7.00 pm Post-conference dinner

Conference fee £38  
*(refundable to doctors in training grades)*  
B&B £34  
Dinner £18

[On-line booking](#) open

#### Speakers

Martin Andersson Lund University, Sweden	A new tick-borne pathogen in Sweden; implications for the UK?
Richard Bingham, University of Huddersfield	The outer membrane of Borrelia; the interface between them and us
Richard Birtles, University of Salford	Unravelling the natural transmission pathways of tick-borne pathogens in the UK
Tim Brooks, Public Health England	Current work in PHE around Lyme Disease
Derk-Jan Dijk, University of Surrey	Circadian rhythms and sleep; implications for health and disease
Klaus-Peter Hunfeld, University of Frankfurt	Laboratory Diagnostics; The Pros and Cons of Different Test Systems

You will note that we are not addressing treatment of Lyme disease this year. This is primarily because at the moment there is nothing new to say. ILADS say one thing and we all know what that is, and however satisfying it may be for patients to hear it, it doesn't move us forward. IDSA say something else, and we know what that is too.

The James Lind Alliance project confirmed what European organisations and researchers have been saying for some time - we don't know the best antibiotic, dose or duration of treatment. We need to build on that. This conference will include an interactive session with the panel of speakers so that we can discuss some of the known uncertainties which may be affecting diagnosis - based on the presentations of the day - and decide what we can do to resolve them.

To provide more opportunity for networking we are adding a post-conference dinner and also offering B&B for the Saturday night after the conference.

Next year we shall focus on treatment and we already have speakers lined up for this.

## UK summer initiatives

There are many groups and many individuals working to bring about change in the UK and this summer quite a lot is in the diary. This is a reflection of a widespread need for improved awareness, diagnosis and treatment. Many doctors believe that "the problem" lies with patients reading mis-information on the internet, but the real problem lies in the lack of knowledge in secondary care and the apparent unwillingness to read and consider anything other than what they have been told in the past.

**Worldwide Lyme disease protest.** Last year this was held in London and this year the main event was in Manchester on Friday May 16<sup>th</sup> with a secondary event in London on the Saturday. There is quite a lot to protest about - our summary of how things stood at the turn of the year is unchanged.

**The London Tick-Borne Disease Symposium**, for interested doctors, veterinarians, and researchers, organised and funded by a patient for the beginning of June.

**The Spirochaetal Alzheimer's Association** was established to promote awareness of, and more research into, the discoveries made by Dr. Alan B. Macdonald and Dr. Judith Miklossy, who found *Borrelia* and *Treponema spirochaetes* in autopsied Alzheimer brain tissue. They are holding a launch event in London on June 4<sup>th</sup> - see their website for details.

**Lyme Disease UK** provides mutual support via a Facebook discussion group and has conducted some interesting surveys. A link to the discussion group can be found on their website.

**Local support groups** run by various people meet face to face in several locations, mainly in the SE of England. Details of these can be found on the Lyme Disease UK website above.

**EuroLyme discussion group** is a long-standing discussion group providing mutual support, information and exchange of ideas for patients, doctors and researchers across Europe.

**Lyme Research UK** are a group of researchers whose main aim is to explore and engage with research that is related to policy and practice in tick-borne infections in the UK and Ireland.

## Scandinavia

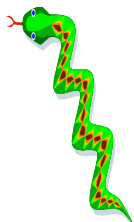
The UK has much in common with Scandinavian countries: similar problems and outlook both amongst public and doctors. **ScandTick** have a public seminar in September.

Following on the professionals' **NorTick conference** in Norway is a patient organised conference **NorVect** May 26-27<sup>th</sup>. We hope some doctors are attending.

In the Netherlands the Dutch civilians' initiative with the 71,500 signatures was discussed on 15<sup>th</sup> May in their Second Chamber (House of Commons) with the Minister of Health.

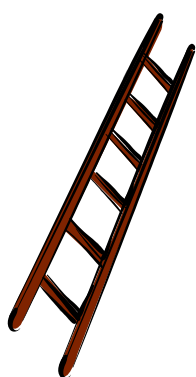
## UK progress

Not a lot so far this year; some ladders, mostly snakes, though.



- The national Lyme disease clinic in Winchester closed
- We have regular calls to our help desk with abundant evidence that neither GPs nor consultants are aware of the reasons for negative serology in Lyme disease.
- The old HPA website with its outdated and biased information remains stubbornly unchanged and possibly influencing a new generation of doctors.

There are a few upward moves:



- The Department of Health and Public Health England are officially referring the public to our website.  
<https://www.gov.uk/government/news/lyme-disease-clinic-update>
- LDA is being consulted over official awareness information for both health professionals and the public, though some of these have not yet materialised.
- South Norfolk CCG is to send out an awareness notice to GP Practices, citing LDA as a resource for both Primary Care and the Public.
- We are continuing discussions with RIPL over difficult cases and test interpretation.
- We are collaborating with the Royal College of General Practitioners to produce an on-line training resource on Lyme disease for GPs.

## Twitter

Twitter has enabled conversations in ways not possible before: between LDA and the public and between LDA and microbiologists, CCGs, health professionals and others.

Sandra Pearson, as LDA's medical director, attended ECCMID this month - European Congress of Clinical Microbiology and Infectious Diseases. She tweeted direct from presentations with findings and papers and she tweeted details of posters. Back in the UK we were able to answer, add points to the conversation, draw in others and post links to the posters and talks themselves.

Anyone "listening in" could follow some proceedings - you just need to search for the relevant hashtag on Twitter - in this case #ECCMID2014.

If you want to follow NorVect, search for #NorVect on Twitter and you will see what delegates are tweeting.

We have a hashtag for the LDA conference - #LDA2014 - and will bring that into use as we move towards the conference.

## Primary Care 2014

For the third year we attended the Primary Care conference and exhibition at the NEC. Delegates included nurses, GPs, commissioners, podiatrists, physiotherapists, practice managers and any healthcare professionals associated with Primary Care.

We were able to

- discuss uncertainties in diagnosis and treatment with GPs;
- suggest to nurses what helpful notes to add to request slips for blood tests, to provide laboratories with better information;
- provide awareness leaflets and posters for waiting rooms;
- inform delegates about the [background to the controversy](#);
- demonstrate that erythema migrans is not always a neat bull's eye;
- discuss individual cases;
- demonstrate proper tick removal.



In addition we were approached by four publishers asking for articles on Lyme disease for their journals:

- Nurse Prescribing
- Journal of Community Nursing
- Family Health
- British Global & Travel Health Association

We also had a presentation accepted for the Public Health stream: read Sandra's presentation - ["Lyme disease; now you see it, now you don't"](#).

Awareness raising, literature distribution, networking, information gathering and myth busting - we'll have a bigger stand in 2015 to facilitate easier in-depth conversations.