

LDA Conference

LDA's 2014 conference was held for the second time running at the University of Surrey at Guildford.

We had, as is usual, mostly patients and carers, but also a few health professionals. Introducing the conference Stella Huyshe-Shires, LDA's current chairman, pointed out that we need to pull together to solve the problems that exist. Although we have different aims we do have a shared purpose.

Tim Brooks, Head of the Public Health England's Rare and Imported Pathogens Laboratory (RIPL) made the same point - that to make progress we need to find areas of common ground to work on together and bring mainstream clinicians along. Tim described the current work in Public Health England around Lyme disease and briefly discussed the aim of the future specialised UK clinic.

LDA Lyme Disease Action		Hopes & views	
Our	Shared	Purpose	
Patients Carers Doctors Microbiologists Researchers	experiences knowledge values beliefs	get better improve care advance knowledge get on with the job	

Klaus-Peter Hunfeld from the University of Frankfurt focussed on the utility of different laboratory test systems for the diagnosis of Lyme disease. Problems with test kits arise because of the many European strains of *Borrelia* and lack of standardisation. Two-tier serology testing was discussed including the pros and cons of immunoblotting. Newly developed tests include an ELISA which measures the chemokine CXCL13 in CSF as a marker for early Lyme neuroborreliosis. Tests such as the Lymphocyte Transformation Test (LTT) are non-specific and so not recommended. In conclusion, he said that Lyme diagnostics is not easy but is feasible. Careful interpretation of test results and additional clinical information is usually necessary as there continues to be no marker of disease activity and no test of cure.

Derk-Jan Dijk our local speaker from the University of Surrey discussed circadian rhythms and sleep. He noted that sleep deprivation alters temporal expression of genes involved in immune regulation and this happens after only one week. Sleeping less than 7 hours per night has been found to increase the chances of developing the common cold. Importantly for anyone it has been shown that artificial light in the blue spectrum in the evening delays the rise in melatonin associated with 'opening of sleep gate', and this delays the onset of sleep. Computer screens and televisions all radiate light at this wavelength.

Richard Birtles, from the University of Salford discussed the natural transmission pathways of tick-borne pathogens in the UK. He showed the evidence that UK tick abundance is on the rise and described surveys carried out by his research team, mainly in the NW of England, looking at tick numbers and the prevalence of *B. burgdorferi* in the ticks. Richard also discussed *Anaplasma* and *Babesia*, how these are maintained in their hosts and how they are passed on by different ticks.

*nearly

Martin Andersson from Lund University in Sweden talked about a new pathogen, *Candidatus Neoehrlichia mikurensis*, discovered in ticks across Europe, though not yet in the UK. His research so far has found the bacterium present in 6-7% of *Ixodes ricinus* ticks where it is a co-infection with *Borrelia afzelii*. Of the 11 human cases in Europe over 2011-2013 ten of them were undergoing immunosuppressive treatment, but there is still much to learn about the pathogen and the illness it causes. Seven cases have been recorded in China.



We sent Martin back with over 200 ticks collected from 4 locations in the UK by volunteers in Norfolk, Devon & Bath.

There was some concern that Martin would not get through Heathrow security with the restrictions on the numbers of liquid containers. However, all went smoothly and the ticks are now in Sweden being tested for pathogens. We await the results with interest!

Richard Bingham spoke about the work and progress that he and his team from the University of Huddersfield are making in investigating the outer membrane of *Borrelia*, 'The interface between them and us'. Outer membrane proteins of *Borrelia* bind to the tissues of the extra-cellular matrix which may act as a protective niche in persistent infection. The evidence for *Borrelia* secreting a classic biofilm in order to evade the immune system remains weak, though it is known to form microcolonies and bind to collagen networks.

Richard and his team have now identified four *Borrelia* outer membrane proteins (OMPS) which may bind Factor H and protect against attack by the complement immune response. Further work continues and Richard has agreed to return next year with an update.

Take home messages

- Patients and health professionals need to talk together and work together to make progress (how to persuade some doctors, though!)
- Lyme disease diagnosis is acknowledged, by an experienced mainstream professional, to be "not easy"
- There are UK scientists who know about our ticks and the pathogens they transmit and also some who are beginning to understand something of the complexities of *Borrelia*
- New pathogens are out there and researchers are spotting them
- To improve your chances of sleeping well, expose your eyes to morning light outside and do not look at computer screens late at night. This keeps your internal clock set.

We had a 30 minute panel discussion at the end with questions from delegates, which was a useful additional slot to the conference. PDFs of presentations will be available on the website shortly

Next year? We will have fixed the venue by the time of the next newsletter.

Small pharma

[Oxford Immunotec](#) developed the T-Spot test for TB; it can detect latent and active infection and is now the mainstream test for TB in the NHS. Some time ago it seemed to LDA that this technology might be usefully applied to Lyme disease and in 2008 we contacted the company to make them aware of the borreliosis problem and to see if they had any development plans. Two people from the company attended our conference and then it all went quiet.

In April 2012 we again approached them and were told that they had developed the test for Lyme disease, but were not marketing it because they had no way of validating it. If you cannot prove that a treated person still has infection, you cannot show that your test works! The first test off the production line is bound to have this problem.

Then in February 2013 we contacted them again saying we were talking to Boulder Diagnostics, who had developed the SpiroFind test, using a similar technology, and we wanted to check whether Oxford Immunotec had any similar product in the pipeline as we'd rather deal with someone who has an established relationship with the NHS. They said "Unfortunately our Lyme Disease project is still on hold". So we facilitated a meeting at RIPL with Boulder, to explain the theory behind their SpiroFind test.

One year further forward and [the news breaks](#) that Oxford Immunotec, now a larger company with a USA base as well as a lab in Oxford, has bought Boulder Diagnostics including the rights to SpiroFind.

We have emailed our contacts at both companies to try to find out what impact this may have, if any, on Lyme disease diagnosis, but we have yet to hear back. Will they market SpiroFind? Develop it further? In Oxford, or the USA? Ditch it? We do not know.

We hesitate to watch this space, but glimmers of useful tests from reputable companies are thin on the ground.

Merseyside in October - meet us?

LDA is, for the third year, attending the Royal College of General Practitioners conference and exhibition - this year in Liverpool. The exhibition runs from October 2nd-3rd and we will once again be discussing Lyme disease and its diagnostic and treatment uncertainties with GPs and other healthcare professionals. Can't do this too much! One local volunteer is coming to participate on the stand and we still have room for one more for part of one of the days - [contact us](#) before September 11th if you might be interested and we'll tell you what is involved.

See what we do; help us do it!

After the exhibition we shall be heading east and stopping off at the [Pied Bull Hotel](#), Newton-le-Willows, halfway between Liverpool and Manchester. On **Saturday October 4th** we shall be there from approx. 10.30 am for coffee, through lunchtime, leaving to travel back at about 2.30 pm. If you'd like to meet us and each other, discuss local issues, exchange views etc, then drop in - we'd love to see you. You could pick up posters and leaflets for your local GP surgery, too.

Dorset in October - Café Sci

We are attending Dorchester Café Sci to give a presentation - "Lyme disease - delving into dependent relationships". This is open to everyone and will take place on Wednesday October 22nd 4 - 5.30pm in the [Thomas Hardy School Theatre](#) in Dorchester.

The aim is to raise awareness, not just of ticks and Lyme disease but also the situation we find ourselves in. There are a lot of dependent relationships in this web, and it's not just spirochaetes changing their outer surface proteins to move from tick to mouse and back again!

We are intending to have ticks and microscopes available, so it will be hands on as well. See you there?

L is for Lyme disease

. . . as a nursery book would say. Or is it for Learners? or Left behind? or Lack lustre? All could apply to the new [GOV.UK pages on Lyme disease](#), which really do seem intended for the nursery.

The HPA web pages for Lyme disease have now been migrated to the new Public Health England website under GOV.UK. Well, not so much migrated as cut down, with most useful information removed and a few errors thrown in for good measure. Dumbed down, most definitely.

We have just discussed this with RIPL and it transpires that a great deal of what they wanted in has been left out - including links to NHS Choices and LDA websites. It appears that GOV.UK decreed that information on the website must not have pictures and must not include medical terms. How do you best show what an EM is like? Yes, quite.

This edict has apparently come down from the cabinet office which is clearly determined that everything should be understandable by everyone. While we would applaud having some simple, easy to read, large text suitable for phones and tablets surely it doesn't **all** have to be like that? Could there not be deeper detail behind, or in PDFs? Must everything be dumbed down to the lowest common denominator? Do they think citizens are stupid?

Please don't take it out on RIPL - they are probably more frustrated than we are as this affects their other web pages as well, including those only used by senior doctors, so lack of medical terms is probably a real problem.

At the top of any page there is a blue bar which invites you to say what you think of GOV.UK. We suggest that you tell them. There really is no other reason for anyone to visit those web pages.

We have located the recently produced PHE referral pathway and the PHE leaflets for GPs in the National Archive (!) and amended the links to these from the LDA website, so all is not lost. Let's hope that GOV.UK sees reason.