Newsletter
No 22 May 2015
www.LymeDiseaseAction.org.uk

Lyme Disease Action

LDA Conference

The theme for the 2015 conference in Cambridge will be the treatment of Lyme disease. We know antibiotics do not always have the desired effect, and we shall explore the reasons for this. We have the following international speakers booked:

N.B.
Accommodation must be booked by June 11th, or it cannot be guaranteed.

The college where we are staying is popular with visitors.

- Dr Brian Fallon, Director of the Lyme and Tick-Borne Diseases Research Centre, Columbia University, USA. He will talk about the evidence for long term consequences of Lyme disease.
- Prof Ying Zhang, John Hopkins University, USA who will explain his work on Borrelia persisters and the possibilities of drugs to target them.
- Dr Hadewyche ter Hofstede, Radboud University Medical Centre, Netherlands who will report on the PLEASE trial assessing treatment of patients with persisting symptoms.
- Marije Oosting, Radboud University Medical Centre, Netherlands who will tell us about her work on the immunology of Lyme disease.

The programme will include a substantial interactive discussion with the panel of speakers and we shall explore where their work leaves us.

Saturday September 12th 2015, Buckingham House, Murray Edwards College, University of Cambridge. B&B accommodation is available for Friday and Saturday nights to enable informal networking. Details of prices, booking instructions etc are on our website.

RCGP e-learning module on Lyme disease

This module went live in September 2014. The 30 mins CPD is freely available to all health professionals. It highlights the epidemiology, aetiology, clinical manifestations at various stages of the condition, investigations and treatment and looks at the role and value of GPs in recognising and treating this disease early.

As at May 2015:
Pre-course assessment average score- 78%
Post-course assessment average score- 95%

There are instructions on tick removal and images of rashes from UK patients. Just over 500 people have so far attempted this course and the assessments pre- and post- course show that it has improved their knowledge.

Please draw this module to the attention of GPs and nurses.

Tick Collection

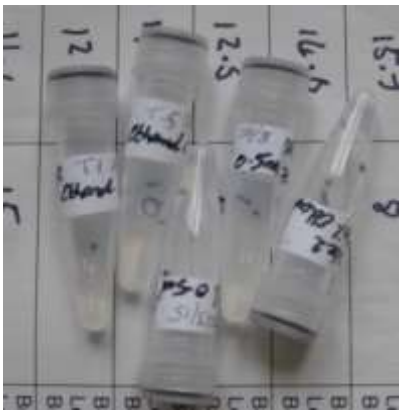
The Tick Activity project highlighted in the January newsletter is now underway. This is being carried out by a PhD student working with Liverpool University and the Medical Entomology & Zoonoses Ecology team at PHE Porton.

From the project website -

The aim of this study is to conduct field surveys throughout England and Wales and in doing so:

- assess the seasonal activity of *Ixodes ricinus* in England and Wales
- identify changes in weather and climate variables that might impact on the tick's lifecycle
- use climate based models to develop forecasting tools to predict Lyme disease risk to the public
- raise public awareness on the risks of tick bites and tick-borne disease, specifically Lyme disease in the UK

Several volunteers took delivery of their tick surveying kit in February and March (including first aid kit and tick removers!) and the surveys are well underway. This involves flagging for ticks by dragging a 1 sq metre white cloth along ten stretches of ground each 10 metres long.



At the end of each 10 m stretch, the flag is then inspected for ticks. Adults and nymphs are picked off and put into labelled tubes of ethanol - a separate tube for each 10 m stretch. Larvae are counted, but not saved. Recently a volunteer counted nearly 50 larvae on just one stretch. They are pretty determined to hang on to the cloth, so have to be picked off with tweezers. Larvae are so small that unless you are blessed with short sight it is very difficult to see their legs without a magnifying glass. Is that a seed, or a tick? Wait for it to walk, which it will!

Larva & nymph - compare with 1 cm.

Finding all these larvae posed the question - to drop them back into the vegetation, or kill them, and if so how? In this particular case, because of the definite possibility of leaving some larvae on the flag, the whole flag was burnt and replaced by another clean one.

PHE are applying for funds to screen all these collected ticks for diseases, and the samples are being stored in suitable conditions to enable this in due course.

Larvae rarely carry *Borrelia burgdorferi* until they feed on an infected animal so they are not high priority for a disease screen - bacteria will accumulate through the nymph and adult stages. Or will they? There is some evidence that different hosts' immune systems affect the different genospecies of *B burgdorferi* in a different way. Birds kill off *B. afzelii*, for example. What about Babesia, which is known to be transmitted transovarially (through egg to larva)? We don't understand the full picture by any means yet.

A better approach to serology

In the January newsletter we covered the limitations of Lyme serology tests and possible reasons for false positive and false negative results. LDA believes that it is in the interests of patient safety that there is awareness of the limitations of serology test kits when interpreting results on an individual basis.

One issue that crops up on a regular basis via the LDA patient helpdesk is the likelihood of a false negative serology result following a short course of early insufficient antibiotics, whether given specifically for Lyme disease or coincidentally for an unrelated infection.

One line of argument which we regularly encounter from UK microbiologists and infectious diseases specialists is that if the Lyme serology test result is negative, this must mean that the pathogen, in this case Borrelia, has been cleared from the body. The assumption here is that any remaining bacteria would definitely provoke a measurable antibody response. We have heard this view expressed, even if the antibiotic in question is a 7 day course of flucloxacillin for which there is no published evidence of efficacy against *Borrelia burgdorferi*.

An alternative argument from evidence-based research is that an early course of sub-curative antibiotics may result in the antibody response falling short of the mark. Immune cells involved in the antibody response (T-Helper cells and B cells) which normally work together to produce antibodies fail to do so when early antibiotics reduce the amount of Borrelia presented to the immune system[1].

This underlines the need for a more informed approach to diagnosis and interpretation of Lyme serology test results, taking into account the full history which may be obtained by carefully engaging with the patient.

GPs are often not aware that Lyme serology is affected in this way and the LDA Help Desk fills the gap by discovering a fuller patient history and joining this to the evidence of the C6 ELISA titre value and any positive and/or sub-threshold bands that might show in the details of the immunoblot. Discussions with RIPL about the test results and then with the GP or the patient have often resulted in successful treatment.

Although PHE have mentioned this abrogated immune response in their Suggested Referral Pathway for GPs, it has yet to reach the wider audience of microbiologists and infectious diseases consultants and it is the latter who are often faced with the difficult cases of clinically suspected Lyme disease associated with negative Lyme serology. An example case study was presented by Dr Pearson, LDA's Medical Director, at the PHE GP Open Day at Porton in May.

It might be useful if doctors would consider suggesting that patients contact the LDA help desk so that we can collect useful information from the patient to help in diagnosis.

1. Dattwyler RJ, Volkman DJ, Luft BJ, Halperin JJ, Thomas J, Golightly MG. Seronegative Lyme disease. Dissociation of specific T- and B-lymphocyte responses to Borrelia burgdorferi. N Engl J Med. 1988 Dec 1;319(22):1441–6. http://www.ncbi.nlm.nih.gov/pubmed/3054554

LDA activity March - May

Talks given

- Cafe Scientifique Exeter - "Lyme disease: who's doing what to whom?"
- For Devon psychiatrists
- PHE Conference, London
- PHE Open day for GPs, Porton

Leaflets & posters provided:

- Wilts & Somerset wildlife trusts
- Hospital & GPs in Dumfries
- Tilhill Forestry Ltd
- Various community pharmacies
- For runners in Twickenham 10K run
- Scotland Countryside Rangers and Community Councils
- English Cadet Forces
- Dartmoor Youth Hostel Association
- West Scotland Scouts' summer camp
- NHS Minor Injuries Units, Outpatients Units and GP Surgeries in England
- NHS Grampian GP Practices and hospitals
- Quantock Hills AONB
- Various schools
- Numerous individuals for local needs

Working with others:

- Reviewed Royal Forestry Society Ticks & Lyme disease leaflet
- Department of Health
- Public Health England
- European and American patient groups

Media requests:

- Photographs ticks & rashes to Trinity Mirror; information for Pharmacy Magazine
- Case study for Wanderlust; interview for student journalist
- BBC local radio: Sheffield & Wales
- BBC: information for "Trust me I'm a doctor"
- Spanish English speaking radio channel interview
- Images to Pet Owners website
- Article for South West Farmers magazine

Exhibitions:

- Primary Care & Public Health conference & exhibition for the 5th year
- Royal Bath & West Show for the first time

Other

- Helping 233 separate individuals via the help desk
- Discussion and awareness raising, House of Lords
- Content provided for NHS England GP Practice Team Bulletin
- Submission to IDSA re planned guidelines review
- Attending Liverpool Neurological Infectious Diseases Course (which, incidentally, didn't mention Lyme disease)

Underpinning all of this, we survived an audit resulting in retention of our Information Standard certification.

Twitter activity in May

Here are some Twitter Analytics for a period in May. This shows how we are able to draw in other organisations like the Clinical Commissioning Groups and Royal Forestry Society.

Impressions: number of times users saw the tweet on Twitter
Engagement: number of times users interacted with the tweet - so clicked a link, re-tweeted or looked at our profile.

	Impressions	Engagements	Engagement Rate
Lyme Disease Action @LymeAction · May 26 Collected ticks in garden for @BathandWest Sorted into tubes in webmaster's kitchen. Unsure what he thought - ticks making bid for freedom! View Tweet details	230	3	1.3%
Lyme Disease Action @LymeAction · May 25 @PearsLDA @CampOther @Lymenews Is flurry of papers because IDSA guidelines up for re-write we wonder? ncbi.nlm.nih.gov/pubmed/?term=L... View Tweet details	80	8	10.0%
Lyme Disease Action @LymeAction · May 24 @SouthnorfolkCCG @DorsetCCG @somersetccg @NEWDevonCCG Ticks, diseases and how to reduce the danger gov.uk/government/new... View Tweet details	458	17	3.7%
Lyme Disease Action @LymeAction · May 24 @royal_forestry @DorsetAONB @Quantockhills @EastDevonAONB Ticks and diseases: the dangers and reducing them gov.uk/government/new... View Tweet details	945	21	2.2%
Lyme Disease Action @LymeAction · May 21 Discussion of #Lyme disease symptoms @PrimaryCare15 stand C64 incl dizziness & parasthesias & photophobia & headache pic.twitter.com/6FtEEdjlvP View Tweet details	685	19	2.8%
Lyme Disease Action @LymeAction · May 20 Showing visitors to standC64 @PrimaryCare15 just how small #ticks can be pic.twitter.com/3hQOVV4AXs View Tweet details	573	22	3.8%
Lyme Disease Action @LymeAction · May 20 How would u recognise Lyme disease? Talk to us stand C64 @PrimaryCare15 View Tweet details	293	1	0.3%
Lyme Disease Action @LymeAction · May 18 Preparing for @PrimaryCare15 on Wed - went to find ticks in garden. Now have 5 tiny larvae, 13 nymphs & 2 adults. Come see them - Stand C64 View Tweet details	546	7	1.3%