Newsletter
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www.LymeDiseaseAction.org.uk

Lyme Disease Action

Conference 2012 booking open

Date: Saturday 21st July
Venue: University of Cumbria at Carlisle

Conference fee: £38
(refundable to doctors in training grades)

Confirmed speakers

Richard Bingham BSc PhD University of Huddersfield	**Research into new treatment**
Gordon Dimmock MRSC EuroImmun UK	**The laboratory diagnosis of Lyme disease**
Robin Harbour BSc Healthcare Improvement Scotland	**Scottish guidelines development**
Sandra Pearson MBChB MRCPsych LDA Medical Director	**Neuropsychiatry of Lyme disease**
Becky Simm DClinPsy, C.Psychol Southport and Ormskirk NHS Trust	**Practical help in chronic disease**
Edward Wilson BMedSci University of Sheffield	**Understanding & managing the infection risk**

The conference will be held in a purpose built conference lecture theatre at the Fusehill Street campus in Carlisle. Accommodation is available on campus as in previous years.

Booking is now open via our online system at www.LymeDiseaseAction.org.uk where you can also download full details of prices, directions, booking instructions and accommodation.

New Lyme disease reference unit

The functions of the Health Protection Agency (HPA) Lyme Borreliosis Unit are being transferred from Southampton to the Rare & Imported Pathogens Laboratory (RIPL) at HPA Porton which already has considerable experience in testing for other tick borne pathogens, in particular Rickettsia and Coxiella (Q fever). The other two UK reference laboratories in Carlisle and Inverness are continuing as before.

On May 1st two of LDA's trustees spent a very productive day at HPA Porton discussing the move with Dr Tim Brooks, Consultant Medical Microbiologist and his staff.

The RIPL is intending to improve the information on the Lyme Borreliosis web pages and Dr Brooks has asked for input from LDA to help in compiling a set of frequently asked questions and answers. The team has also agreed to participate in LDA's James Lind Alliance PSP documenting the uncertainties in Lyme disease diagnosis and treatment and to involve LDA in research that it is hoped will be undertaken in due course.

A fuller report of this meeting, including details of the serology tests that Porton have decided to use, can be read on the LDA website. Another meeting will take place in 6 months' time.

LDA out and about

LDA took an exhibition stand to **ECCMID 2012 - the European Congress of Clinical Microbiology and Infectious Diseases**. Amongst all the large multi-national companies marketing molecular diagnostic kits, there was a little 3m x 2m stand with LDA discussing evidence based information on Lyme disease with clinicians from across the world.

Setting up the stand:
a new purchase with the help of Ascot Underwriting

Discussions on the Lyme disease issues appeared to follow a North Europe / East Europe divide, with N Europe just beginning to realise that there are problems and E Europe, with a much higher incidence, acknowledging the depth of the problems.

Australia was divided and a doctor from Texas admitted they had to do a U turn when the lone star tick was in the picture.

We explained how the LDA James Lind Alliance project is documenting the uncertainties in diagnosis and treatment and said that we hope:

- patients will believe the outcomes, because they will trust us as a patient organisation
- doctors and the Department of Health will believe the outcomes because the JLA is funded by the National Institute for Health Research and the project is using a validated process.

Many doctors congratulated us on the JLA project as a good way forward and wished us luck.

Sweden, Denmark, Norway:
"It is a problem to us when patients have a negative test and then get a private CD57 test from Germany - they believe this means they have Lyme disease."

Eastern Europe:
"Lyme is a big problem - we need better tests and we don't know how long to treat!"

Australia:
Doctor A *"We don't have Lyme in Australia"*
Doctor B *"We do have it but don't know how it gets here - maybe migrating birds."*

ECCMID - the conference

As well as talking to visitors to the exhibition we attended some conference sessions and talked to other exhibitors.

Lyme disease testing
Boulder Diagnostics came to talk to us about a new test, developed from research at Radboud University in the Netherlands. Because the patent has not yet been granted, they would give us no details except to say that the test is not based on detection of antibodies. They have been running trials in the Netherlands and hope to start testing from a new lab in Frankfurt in "late summer". We are told that the CDC (Centers for Disease Control and prevention) is very interested in this new test, so it clearly holds out considerable promise.

There were many companies marketing serology tests for Lyme disease: ELISAs and immunoblots. The variation in immunoblots is interesting as there is clearly no agreement on an absolute set of specific antigens although many companies view recombinant VlsE as so specific as to be diagnostic. So, in many tests kits, if a test shows that single band to be reactive, it is viewed as a positive test result.

Quorum sensing - bacterial cell to cell communication
Paul Williams, University of Nottingham gave a Keynote lecture explaining that bacteria are not simple organisms, but show community and social behaviour. The bacterial cell to cell communication is via small chemical signalling molecules. Responses to these signals include modifications to population density, changes in virulence, biofilm formation, and effects on motility, plasma transfer and metabolism. See the University's Quorum Sensing site.

Bacteria use various chemically diverse molecules for quorum sensing and as well as having an effect on the colony, other bacteria may be affected, as may the host resulting in immune modulation. Most studies focus on bacteria that are easy to culture, and the Nottingham team have been working with *Pseudomonas aeruginosa*, but quorum sensing has been found in spirochaetes.

Quorum sensing inhibitors
If you can stop bacteria communicating, would it make a difference to disease treatment? Niels Hoiby, University of Copenhagen, presented a session describing a number of compounds that seem to be quorum sensing inhibitors (QSIs). Their mode of action is unknown but they are known to disrupt biofilm. This is potentially useful as biofilms are tolerant to antibiotics and the immune system, so the addition of a quorum sensing inhibitor could enhance antimicrobial treatment. The University offers a Biofilm course for scientists.

QSIs may be natural compounds or synthetic. A number of naturally occurring QSIs have been found including compounds in marine algae, garlic, cauliflower and horseradish. The dosage of natural products is difficult to determine. Quorum sensing inhibiting antibiotics are: Azithromycin, Ciprofloxacin and Ceftazidime. Tetracyclines have no QSI activity.

There is only one trial of this type of treatment in children with cystic fibrosis which was only a small study and under-powered, with some evidence of response.

There is much still to be discovered about bacteria, infection and antibiotics.

LDA in the press

Over last year there was a flurry of personal views on Lyme disease in the medical press to which LDA responded. Two of our letters have recently been published; one more to come.

The Netherlands Journal of Medicine

A balanced editorial in March 2011 "The challenge of Lyme disease: tired of the Lyme Wars" responded to a review of Lyme disease in the same journal by pointing out the limitations of serology tests. The editorial also raised issues with the Klempner paper (which said that 90 days treatment "did not improve symptoms more than placebo") and the use of the phrase "adequate treatment":

> *"Indeed, if 'adequate' signifies that the microorganism has been eradicated and the immune system has come to rest, the problem has been solved, but the issue rather is whether treatment has been 'adequate' or not in patients who continue to feel ill."*

This editorial was very balanced and positive, but the January 2012 edition saw a group of authors continuing the war with Lyme disease: the challenge of accuracy and defending the Klempner trials saying that they :

> *"did not find any evidence, based on over 700 samples from 129 patients that were examined by culture and polymerase chain reaction (PCR) assays, for persistent B. burgdorferi sensu stricto infection in patients with persistent symptoms after treatment for Lyme borreliosis."*

This was too much for LDA because the Klempner trials had specifically excluded any PCR positive cases, so however many samples they took from people included in the trials, they weren't going to find *B burgdorferi*. Our response Lyme disease - the challenge for patients was published in the April edition.

The Lancet Infectious Diseases

In September 2011 this journal published a Personal View "Antiscience and ethical concerns associated with advocacy of Lyme disease" which stated (amongst other rather inflammatory and incorrect statements)

> *"Similar to other antiscience groups, these advocates have created a pseudoscientific and alternative selection of practitioners, research, and publications* .."

Because of the inclusion of a single UK author the implication was that patient charities in the UK are "antiscience" which is very far from the truth. We are not qualified to comment in detail on the situation in the USA, but we are more qualified than those authors to state the position in the UK. So we did, and our response was published, together with some other correspondence on the topic, in the May edition of the Lancet Infectious Diseases.

You will note how the authors' reply completely misses the point by referring to a paper (Cottle et al Lyme disease in a British referral clinic. QJM Feb 2012) which relates to misdiagnosis by doctors in the UK; not patients. Indeed Lyme disease is not alone in posing diagnostic difficulties: a review by the Newcastle CFS service found that 40% of referrals did not have CFS and of these, 47% were diagnosed with fatigue associated with a chronic disease.