

PHE Lyme disease open day - held March 25th

The initial date in April had been changed because PHE, as a government organisation is not allowed to hold public events within 6 weeks of a general election. Although it could have been put back, this would have placed it well into the main tick and Lyme disease season, so the decision was taken to move it forward. This also avoided the uncertainty of the future availability of key PHE staff who are spending a lot of time in Sierra Leone working on the Ebola crisis.

In the event many clinicians were able to come and attendance was almost half and half patients and clinicians, with a slightly greater number of patients. This was a useful day and it was good to hear of progress and have the opportunity to ask questions.

PHE had managed to field national and international speakers:

- **Dr Brian Fallon**, Director of the Lyme and Tick-Borne Diseases Research Centre at Columbia University, USA gave a balanced, well referenced talk on continuing symptoms following treatment for Lyme disease.
- **Dr Randi Eikeland**, Head of the new National Advisory Unit for Tick-borne Diseases in Norway, went through the challenges and experiences of Norway. They no longer refer to "stages" of Lyme disease, preferring to use acute/disseminated although IV treatment is generally given to those whose infection is of longer duration.
- **Dr Sue Best**, Director of the National Serology Reference Laboratory in Australia. She described how and why NSRL has been asked to perform a review of diagnostic tests for Lyme disease from across the world. They are not yet certain whether they have Lyme Borreliosis in Australia, and they want to be ready.
- **Dr Roger Evans** from Raigmore Hospital Inverness explained how recorded incidence of laboratory confirmed cases in Scotland was falling because of early diagnosis of the rash, without the need for a test. His presentation described progress, concerns and aims of future work.









In addition, there were presentations by PHE staff from the Medical Entomology & Zoonoses Ecology team. As a tick specialist, Dr Jolyon Medlock highlighted the conflict between reducing city heat by increasing green spaces, and providing a habitat and corridor for wildlife with ticks. The hedgehog tick, *Ixodes hexagonus*, is increasingly being found on cats and some humans.

[PDFs of the presentations](#)
are on the LDA website

LDA's chairman, Stella Huyshe-Shires described 2 case studies from the LDA help desk - one showing how GP, RIPL and consultant can all work together with LDA for the benefit of the patient and one illustrating how it can all fall apart so easily. She said that although the Department and RIPL, together with some GPs, have started to work with LDA, many consultants and in particular the British Infection Association are refusing to engage. A group of patients who have become impatient with the apparent lack of change in key areas has also formed a closed group and in doing so disengaged with LDA, particularly on issues such as the scientific basis of live blood microscopy and the use of overseas labs.

Have we progressed?

At the October 2013 PHE Open Day, Stella was asked to talk about "Short and long term wins in Lyme disease". So where do we stand now - have any of these been achieved?

Acknowledge uncertainties	short	 partly
Close the gap between Them & Us	long	 partly
Develop / engage expert patients	short	
Research into treatment & diagnosis	long	
Remove BIA position statement	short	
Patient based outcomes / PROMs	long	
Promote LDA support services	short	
Regional centres of expertise	long	

Three out of eight; this would have been better had not the Ebola crisis arisen.

At the recent PHE Open Day, the following were the areas where Stella suggested that we (patients, LDA, Department of Health, PHE, GPs, Consultants, British Infection Association, Overseas labs) could immediately agree to work together-

- Scotland – Raigmore communication with LDA (as RIPL does already)
- Test ticks collected by volunteers for pathogens
- New BIA position: dialogue with LDA (unachieved short win from 2013)
- Improved medical education
- Improved clinical diagnostics
- International collaboration
- Get a handle on incidence, impact & cost of Lyme disease in the UK
- Designated, progressive, informed, regional service for Lyme disease
- Closed groups – become less closed (patients' groups as well as doctors' groups)

The first was agreed at the meeting last week and now just has to be formalised.

For the rest? Well, it is up to all of us. We'll look back at these aims in subsequent newsletters to see how we progress during the next 12 months.

Meanwhile, how about telling local GPs about the medics support line and the RCGP e-learning module - details of both in [one handy flyer](#).

LDA's February in numbers

February is normally not particularly busy, but 2015 this February has seen 30% more new cases to the help desk than in February last year so maybe it's going to be a busy year.



827 Emails sent on LDA business



52 New cases opened on the Help Desk
6 cases discussed with RIPL
2 GPs helped via the medics help desk



31 Tweets and Facebook posts



28 Full text papers added to our reference library bringing the total to 1077



11 Shop orders fulfilled



6 Press enquires dealt with



4 Requests for leaflets including 1200 to Somerset Wildlife Trust



3 Fundraisers helped with their events

Other work during February included

- Two publications: a [review of Lyme disease in Nurse Prescribing](#) and a response to a letter in the [Quarterly Journal of Medicine](#), a high impact journal for doctors;
- Work on a Lyme disease awareness video;
- Providing assistance to a PhD student starting the [Tick Activity Project](#);
- Meeting at Porton with RIPL staff and having discussions with the Department of Health;
- Identifying resources for a Scottish H&S training centre;
- Organising speakers for the LDA September Conference;
- Preparing for the Bath & West Show and Primary Care exhibition, both in May;
- Discussions with Netherlands & Norwegian patient groups;
- Completing our Information Standard annual assessment to maintain valuable accreditation status.

Since then, March has been so busy that this "March" Newsletter is probably only just going to make it within March!

Treatment of Lyme disease

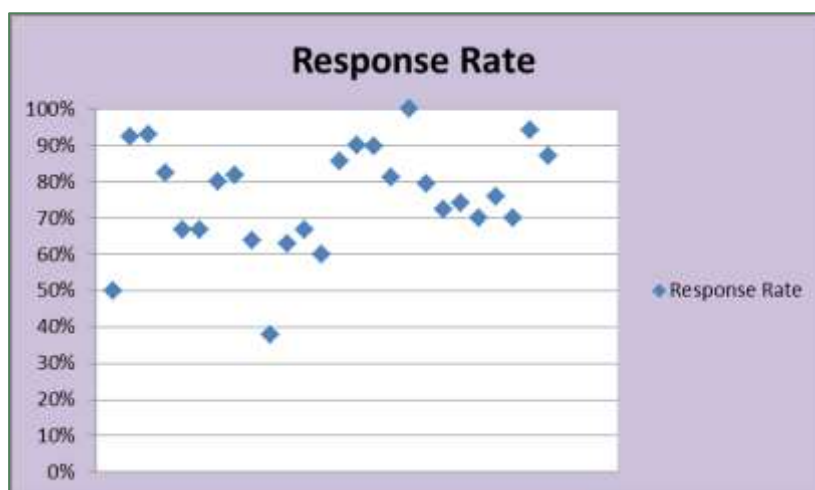
What is there, other than doxycycline (or amoxicillin) and IV ceftriaxone?

The [guidelines for Lyme Neuroborreliosis](#) (LNB) from the European Federation of Neurological Societies state that

- "there are no class I comparisons of different treatment durations."
- "there are no randomised treatment studies of European late LNB".

We don't know the best antibiotic, dose or duration of treatment and for 3 of the 5 recommendations the guidelines state "not enough evidence: GPP." GPP=Good Practice Points - ie what doctors do in the absence of backup from good quality European trials.

If you plot the "response" from the trials that these guidelines examined, you get the following-



Some of the patients had previously received oral antibiotics, so this was a second course of treatment. In each trial the Response Rate is defined differently and it ranges from "absence of objective findings" to "complete recovery at 12 months".

You can see why we need better studies into more effective treatment.

LDA Conference, September - a look at treatment

The 2015 conference is concentrating on treatment. We are going to explore what might be making treatment difficult and what possibilities there are to overcome this. International speakers confirmed so far include

- Dr Hadewych ter Hofstede from Radboud University Medical Centre in the Netherlands to discuss the [PLEASE trial](#) for those with persisting symptoms after antibiotics;
- Professor Ying Zhang from Johns Hopkins University in the USA to explain persister cells - see our [discussion of his latest paper](#) in which we explain what these cells are, why they may be a problem and also the research into a possible solution.

We have limited accommodation places and they must be booked and paid for by 11th June, so if you know you would like to attend, [book ASAP!](#)