

Newsletter no. 27

February 2020

www.LymeDiseaseAction.org.uk



Why no newsletters since August 2016?

Partly because we have tended to issue more news via Twitter and Facebook, but mainly because we have just been too busy. We had to remove our patient support email address following the major 2015 publicity but that didn't stop people writing to our other email addresses, and emails requesting information cannot go unanswered.

Since the last newsletter we have gained two new trustees and lost one. Gail Lowe, whom many of you will know, has decided to retire to spend more time with her family. As the longest standing LDA trustee her well-earned rest was much overdue and we owe her a huge debt of gratitude for staying so long and doing so much.

We have been joined by Andrew Gold and Rachael Pope. [Read more](#)

What have we been doing?

Trying to Keep Calm and Carry On, but mainly reviewing our priorities and strategy!

The landscape has changed over the years. We have moved from being one of two UK charities working in the area of tick-borne disease, then when BADA-UK closed being the only one, and now we are one of 5, each with a slightly different focus. The other 4 are:

Caudwell LymeCo

LDUK

Lyme Resource Centre

Vis-a-Vis Symposiums

There are also a number of patient groups which work, or have worked, in this area: About Time for Lyme, EuroLyme, Fight Lyme Now, Lyme Research UK, Lyme Support UK, Lyme Voices UK, LymeAid UK, VIRAS. There are also several local, individually run, support groups. The multiplicity of charities and groups reflects the size and scope of the problem.

We also now have the NICE Guideline. This was published in early 2018 and met with a mixed reception.

- European clinicians didn't altogether like it - treatment too long, lumbar puncture not routinely recommended for LNB;
- Some UK patient groups weren't that keen either, mainly because there was no explicit recognition of chronic Lyme disease.

We could see some drawbacks but broadly welcomed the Guideline, not least for confirming uncertainties by issuing Research Recommendations. [Read our reaction](#)

So now that there is a NICE Guideline and there are many other groups working to raise awareness, our highest priority is working towards a specialist clinic for Lyme disease.

Specialist Clinic Development.

We planned the first [clinic specification workshop](#) for November and held a Skype conference and phone calls with all the UK charities in the lead up to the workshop to keep them informed.



We invited key health professionals as well as patients and had a successful day. We are now set to move forward in developing this further.

The clinic specification needs to define everything from referral by GPs through to follow up of patients. It will involve the views of GPs, researchers, patients, commissioners, consultants, and laboratories.

We shall consult widely as we get down to detail.

The Explore Project

We continue maintaining our library of papers to support the information we provide, but we wanted to explore serology tests further to assess our views.

With the help of several patients we sent blood samples to [Innatoss Laboratories](#) in the Netherlands for a series of different serology tests. We [described the project](#) at our 2018 conference and included an abstract in our submission to the 2019 HPRU EZI research workshop - see later in this newsletter.

What has happened in the UK recently?

New insights into UK incidence of Lyme disease

One of the stumbling blocks to stimulating significant research funding is that the National Institute of Health Research (NIHR) wants to know how many people in the UK will be helped by research - how many people are affected by Lyme disease each year? No-one can answer this question!

Only positive blood tests are reported and although these are rising, 2019 saw only about 2,000 new positive tests in the UK. Some studies have now looked at GP records and hospital records to get a better handle on a real diagnosis figure. Those of you who came to our 2018 conference will remember John Tulloch and his difficulties in getting information out of GP databases.

Several interesting papers were published in 2019 which may help move things forward and another is in the press. All these are open access - just click on the images to read.



RCGP Spotlight project



The Royal College of General Practitioners (RCGP) selected Lyme disease for one of its Spotlight projects. LDA provided £29,000 to support this. 4 workshops for GPs were held and there is a lasting legacy of an [on-line Toolkit](#) on the RCGP website, available to all health professionals.

HPRU EZI Research Workshop

Back in 2017 the Health Protection Research Unit for Emerging and Zoonotic Infections at Liverpool (HPRU EZI) held a national workshop "Lyme & other tick-borne diseases: Present & future research in the UK". No patients were invited to this, although the results were presented at the [LDA 2017 conference](#).

The 2019 follow up workshop "Lyme and tick-borne disease research in the UK: addressing the scientific uncertainties" *did* include patient groups. Held in November, this two-day workshop was not actually *addressing* the uncertainties, it was rather *discussing* them and trying to reach a consensus on the priorities for research.

Patient groups were invited to the second day only of this workshop in what felt a little like a tick-box exercise. Will the patient views be taken into account? Will anyone invite patient representation to design the badly needed key studies which were discussed?

The research bodies do not have a good record so far of inviting patient input, so we hope that, now the researchers have seen that patient groups are not intimidating, we may all take a step forward. [Read more about the workshop](#).

Following this workshop Kate Bloor of Lyme Research UK, organised a conference call for all the patient group participants to share feedback.

What has happened elsewhere?

NorthTick project

In October 2018 LDA was approached by a Norwegian consultant asking us to become partners in a new project being initiated by researchers and clinicians from Denmark, Sweden and Norway within the [North Sea Region](#). We discussed with the Norwegian patient group, NLBF, and agreed to be involved. However, over the following year as the project developed, LDA slipped from a possible "partner" to a patient group supporter. This is probably understandable, as not all European researchers agree with LDA's approach and the partners are receiving funding for specific projects.

The project published its [first newsletter for supporters](#) in January 2019, and this explains what has happened in the project so far. Scotland is receiving €570,000 for various projects, including local awareness, details of which we shall cascade outwards as we hear more.

Clinical Trials across the World

There are a lot of clinical trials in progress, assessing different treatments, a vaccine and diagnostic tests: 16 trials were registered with the World Health Organisation in 2019. Read [more](#).

Our next newsletter will bring you up to date on treatment advances.

Diagnostic tests

Serology, the detection of antibodies to *Borrelia*, continues to be the mainstay of diagnosis. A team in the USA are developing the TBD serochip to identify antibody responses to 8 different tick-borne diseases. But this is still at the research stage so currently not available as a commercial test; it is also for USA infections, not those in Europe.

In Europe a Finnish group has produced TickPlex: a test that claims to identify polymicrobial infections by detecting various antibodies. From publications, and from discussions with the researchers, this does not look to be helpful and includes tests for some childhood infections that many healthy people will have antibodies to, such as Epstein Barr Virus.

Some private laboratories in Europe offer T cell tests, but research is increasingly showing that these are not useful, although it is possible they will be further developed in the future.

All the above use immune system reactions or antibody testing with its inherent limitations - although most patients develop the "right" antibodies, some will not. The next advances are to find other biomarkers in patients which can be reliably linked to a tick-borne disease. The difficulty comes when validating any new test - it is easy to check it against those with positive serology, but how do you prove any "other" patients actually have Lyme disease? That's when direct detection of the pathogen itself - *Borrelia* or something else - comes into its own.

More on this in the next newsletter, and the research taking place in the UK.

What next for LDA?

We maintain a [diary of events](#) on the website, so you can see what we have done and what we have planned. We continue to print and send out our awareness leaflets and to give presentations to diverse groups, and we are continuing our discussions with researchers.

Having had a gap last year, we are now planning another conference - possibly November this year; we'll let you know. Suggestions for topics are welcome!

Access the past newsletters



You will find them in the ["What we are doing"](#) section, you can see all past newsletters, with an index of what's where. They tend to contain longer articles.

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Lyme Disease Action
Striving for the prevention and treatment
of Lyme disease and associated tick-borne diseases

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