

LDA Conference 2013

LDA's 2013 conference was held in Guildford in July. Presentations are available on the LDA website. The last part of the afternoon was given over to workshops.

The clinicians workshop concluded that what GPs need is quick and easy information - a definitive test and straightforward treatment recommendations. Unfortunately, as shown by the JLA uncertainties, none of this exists.

The local initiatives workshop discussed ways of raising local awareness and also ways of providing information to local GP Practices. It was suggested that the LDA Patient Support email service could be used to request sound information to present to GPs.

Next LDA Conference

5th July 2014,
University of Surrey
Guildford

The third workshop offered an opportunity to discuss almost every concern from diagnosis through treatment to politics. Unsurprisingly, it only came to an end when the conference had to conclude.

A summary of the feedback is available on the [website conference page](#) and the detailed feedback provided will contribute to the planning of next year's conference.

Anyone who has further ideas on topics or speakers is welcome to send suggestions by email to [the LDA conference team](#)

Public Health England - open event on Lyme disease

As announced at the LDA conference in July, Public Health England has planned an open seminar on Lyme disease. This will take place in early October at a venue in central London and is aimed at both doctors and patients - it is hoped to have an equal number of both - and to have representation from England, Wales and Scotland.

Planned presentations include:

- what is being done now in terms of tests
- the aims of the new clinic
- current issues and deficiencies from the patients' point of view

There will be an open question and answer session to enable everyone to ask questions about testing, diagnosis, treatment and policy. The aim is to provide an opportunity for us all to get together and discuss ways to improve the overall service.

There will be a booking system which will operate on a first come, first served basis. PHE and LDA will advertise this as soon as the date and venue have been finalised.

We all need to ensure this opportunity is productive and not a "one-off, tick the box" consultation.

National Lyme disease referral clinic

As announced in a local Hampshire newspaper and [reported on the LDA website](#), a new NHS Lyme disease clinic in Winchester has been agreed and it will start taking patients from across the country in November. Straightforward early cases with an erythema migrans and/or a positive blood test can of course be treated by GPs, although it is obvious from queries to LDA's patient support line that many doctors need help in this. [PHE have published a leaflet](#) which goes some way to fulfilling that need, at least for GPs; where consultants are going to obtain good quality information still needs clarification.

There is however a range of cases which are less straightforward - negative serology, delayed diagnosis, relapses, continuing symptoms, coinfections etc. - and this has to be the rationale for setting up a national referral clinic where expertise can be developed and applied.

PHE Leaflet for GPs states

- not everyone recalls a tick
- transmission can be within a day
- LB occurs across the country
- the rash may be absent
- the rash should be treated
- early tests may be negative

The new Lyme clinic will be able to arrange skin biopsies of erythema migrans and other Lyme-related rashes. The results will be used to identify the species of *Borrelia* present in samples from across the UK.

Generally speaking, infectious disease consultants have probably seen a very tiny proportion of the UK Lyme disease cases - see our discussion of a 2012 paper "[Lyme Disease in A British Referral Clinic](#)". However, there is more experience in Hampshire, where some of the first cases in the UK were reported and this is where Dr Matthew Dryden has seen 500+ patients over the past 20 years and where he will be holding the new referral clinic.

LDA met Dr Dryden at PHE Porton at the end of July and put to him some questions which had been submitted to us by patients. These [questions and answers](#) are now on the LDA website and there will be an opportunity at the PHE open event in October for doctors and patients to find out just how the clinic may work in practice.

The concern of the clinic may well be that it could be overwhelmed with every case of "medically unexplained symptoms" that could possibly be due to Lyme disease, so there will have to be some referral criteria for concentrating on those who might need treatment for Lyme disease and related tick borne infections rather than those who probably do not. Given the nature of the "New Great Imitator" and the lack of a definitive test this is not going to be easy.

The concern of LDA is that one clinic, with one consultant seeing patients 2 days a week, is insufficient for the national need.

However, something is better than nothing and there are clear benefits: some patients will now get the serious consideration that they have been denied, and data on UK presentations, detailed test results, co-infection statistics and long term outcomes can at last be collected prospectively rather than as an afterthought.

At LDA's recent meeting with staff at PHE Porton and with Dr Dryden, it was clear that a) Dr Dryden believes he has cured all his 500 patients with "up to 3 months antibiotics" and b) PHE Porton will not recommend more than 1 month's antibiotics because they currently don't believe that *Borrelia* survive it. As a team, they have some differences and this highlights the uncertainties documented in the JLA project.

As an important component of this team, LDA will bring evidence to bear on these discussions and patients, real patients, will help to provide that evidence.

The Berwick Report

[The Berwick report on NHS patient safety](#) has been published and with it 3 letters: to government officials, to clinicians & managers and to the people of England.

One of four guiding principles recommended is **“Engage, empower, and hear patients and carers throughout the entire system, and at all times.”** The advisory group is urging the entire NHS to do this. There are several summaries of actions - that for patients and carers is below -

Box 2: Actions for Patients and Carers

We seek to engage everyone in improving safety, as far as they can and wish to be involved. This includes patients and carers. Below are our suggested actions for them:

- Patients and carers should seek to establish relationships with healthcare staff and know their names. Patients and carers should seek to build constructive relationships with their caregivers and develop mutual respect, honesty and trust.
- Patients and carers should try to share their histories, family situations, needs and hopes to help staff build true and effective partnerships during their care. They should aim as far as possible, to become co-producers of their care.
- Patients should share their goals, participate in creating plans for their care, engage their families and bring carers or relatives to visit, particularly during ward rounds and other clinical meetings.
- Patients and their carers should alert those working in healthcare when care is not meeting their needs or when they see a practice that they feel is not safe.
- Patients should, when they wish, advise leaders and managers by offering their expert advice on how things are going, on ways to improve, and on how systems work best to meet the needs of patients. This may mean giving time to attend meetings, participating in sessions to learn how the health care system works, learning the “inside” language that they will encounter, and learning to speak effectively to “authority”.

This review was instigated following the Francis Report following the breakdown of care at Mid Staffordshire Hospitals, but it is worth remembering that patient safety applies across the whole of healthcare. When applied to Lyme disease “Safety” may have different meanings to different people -

Patient’s view

Safety

Access to experienced NHS doctors

Danger

Doctors who will not heed evidence

Doctor’s view

Safety

Adhering to established guidance

Danger

Prolonged antibiotic treatment

In actual fact, no-one would argue with the patients’ view, so we all have to work on providing good quality evidence to support evidence based guidance, encouraging doctors to listen and increasing NHS experience. That way doctors’ views are accommodated too.

The crest of the wave

Reading these pages it is obvious that there are a number of initiatives which can provide a huge impetus to the improvement of diagnosis and treatment of Lyme disease in the UK: PHE listening to patients, a new Lyme disease clinic and calls to empower patients.

It seems to LDA that we are all poised on the crest of a wave which will either drag us under or propel us forward and that we need to work together to take advantage of this momentum. Patients need to try to understand the difficulties and concerns that doctors face and doctors need to give more weight to what patients are saying.

A few evidence based facts to get us going:

Lyme disease is a multi-system disease that has a wide range of presentations.

Not everyone with muscle pain, fatigue, headache, sound sensitivity, arthritis and sleep disturbance suffers from Lyme disease.

Lyme disease is not always cured by 28 days of antibiotics.

Many people are completely cured of Lyme disease by 14 days of antibiotics.

Lyme disease is Lyme borreliosis and there are an increasing number of Borrelia genospecies known to cause disease.

We do not know which Borrelia genospecies are present in the UK, but many residents acquire infection abroad.

Blood tests are not 100% sensitive.

Blood tests detect many cases but because there is no way of identifying all cases, true sensitivity cannot be determined.

Most NHS doctors have limited experience of Lyme disease and rely heavily on serology test results for diagnosis.

Some NHS doctors have treated sero-negative patients with good results.

Some NHS doctors tell patients with continuing symptoms following treatment of Lyme disease that "it is all in your head".

Some NHS doctors treat continuing symptoms and relapses of Lyme disease successfully with further courses of antibiotics.

Scientists have discovered that the bacteria that cause Lyme disease can spread and persist by evading the immune system.

There are many conditions and diseases for which there are no definitive tests and uncertainty regarding treatment.

There are uncertainties in the diagnosis and treatment of Lyme disease.

We are where we are because of the overall complexity of this disease and the recent history, in the UK and beyond, as explained in this video of Stella's presentation at the LDA conference - [Illuminating history](#). Given the combined will of doctors and patients, let us hope we can move forward to everyone's benefit.