

Newsletter

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www.LymeDiseaseAction.org.uk



Progress!

Over the last year there have been significant changes which we hope will gradually start to benefit patients.

At the end of March 2012

Southampton was still the main testing laboratory for Lyme disease in England & Wales.

The Southampton laboratory staff were not engaging in discussions with LDA.

The blood tests for Lyme disease were said by Southampton to have a >99% chance of identifying late disease.

The Southampton lab refused to participate in the James Lind Alliance (JLA) project documenting uncertainties in diagnosis and treatment.

The Department of Health refused to meet LDA.

The Department of Health was steadfast in a belief that LD does not persist following "adequate" treatment and that "anyone believing they have chronic Lyme can be definitively diagnosed by NHS tests."

Now - April 2013

The Lyme Borreliosis Unit is now established at HPA Porton within the Rare and Imported Pathogens Laboratory (RIPL). This may seem like a small change, but it brought with it a change of personnel and outlook.

LDA now has regular meetings at RIPL with the staff responsible for the Lyme disease testing.

There is recognition that the current tests are not as "definitive" as previously claimed and RIPL are investigating alternative ELISAs.

The move to RIPL was in time for RIPL staff to attend the final JLA workshop prioritising the uncertainties, as observers.

The Department of Health also attended the JLA workshop and we now exchange emails and phone calls.

The Department has clearly recognised the validity of the JLA process and the sound intentions of LDA, and is engaged with LDA and with RIPL in compiling improved information.

There is still a long way to go, but at least we are now moving ahead - LDA, RIPL and the DH together. The major work now is to cascade this new openness down to doctors who are responsible for diagnosis and treatment.

We have a new "Lyme Neuroborreliosis" leaflet (booklet, actually) in print which is much more detailed than our previous leaflets and an excellent briefing for doctors. Watch out.

Worldwide Lyme protest - UK

If all of this on the previous page has been achieved, why protest? The organisers of the UK event state their aim to "*Increase the awareness of the dire situation with Lyme disease and related tick-borne diseases in the UK.*" The situation may be improving, but patients are still faced with GPs and hospital specialists who inflexibly believe in serology test results and one course of antibiotics eradicating Lyme disease in all patients.

It will take time for the new approach of the HPA and the Department of Health to filter down to doctors. However, with spring, and the tick season, well and truly under way it is vital that awareness and knowledge amongst doctors is increased. No-one, least of all anyone concerned about the overburdened NHS, wants to add more ill patients to those already requiring multiple GP visits and referrals. It has taken us years of lobbying to get this far, and we do need to ensure that the voices of patients are heard and listened to.

[The UK protest](#) will be held on Friday 10th May between 12.00 and 16.00 outside the Department of Health in London.

Where now with the uncertainties?

The top 10 uncertainties have been picked up for investigation by the [National Institute for Health Research](#). After preliminary consideration, they have now asked for information on the background of what they term "the two overarching uncertainties":

What is the best treatment for children and adults presenting with a) early Lyme disease without neurological involvement and not including erythema migrans and b) late Lyme disease of any manifestation? To include consideration of drug(s), dose, duration.

How effective are the current UK tests in detecting infections due to the genospecies and strains of *B burgdorferi* s.l in the UK and **which single test and what combination of tests performs best** in diagnosing or ruling out active Lyme disease. Should stage of the disease and patient age be taken into account when interpreting these tests?

It does not take much thought to realise that neither of these are absolutely simple questions. For example, hidden in the question on tests is the implied question "*What genospecies and strains are present in the UK?*"

An element of the briefing to NIHR is explaining another underlying question of "What is Lyme disease?" Where do the other borrelioses fit in? What about *B miyamotoi*? See our news article [Borreliosis: not just Lyme](#). This has always been one of our core concerns.

Research takes time, so answers are not just round the corner, however now there is recognition of the uncertainties in the diagnosis and treatment of Lyme disease. In 2007 the DH informed us much was already known and that research was not a priority. We have moved forward.

Keep up to date

Want to know what's going on? Then visit our website and click on the Facebook or Twitter link on the left.



Twitter: you can just look, though if you want to follow us, see who we are following, or who follows us, then you need to have your own account. You don't have to tweet; you can just register. Alternatively simply watch the bottom of our website and you will see the 3 most recent LDA Tweets.



Facebook: you can also just look to see our posts and other people's comments. If you want to leave a comment yourself, then you have to log in.

We use both of these as a quick way to provide links to interesting articles and to notify when we have added or changed something on the website. Click on the icons above and have a look.

We use Twitter more to communicate with professionals, and Facebook more to communicate with the public. You can view any of these conversations, though.

And for light relief there's our ["Ticking away"](#) blog.

A new test

Boulder Diagnostics are now marketing a new test for Lyme disease - the SpiroFind. This is based on research at Radboud University, Nijmegen in the Netherlands and aims to detect an active infection, whether early or late and whether before or after treatment. Monocytes, a type of white blood cell, are separated out from a patient's blood sample and incubated for 24 hours with a mixture of antigens from the 3 main genospecies of *Borrelia* causing Lyme disease. The cytokine IL1 β is produced and measured: this immune response is elevated when an active *Borrelia* infection is present.

In February we arranged for Boulder Diagnostics, and the principal researcher from Radboud University, Dr Leo Joosten, to visit HPA Porton and explain the principles of this new test to us and to an HPA immunologist and Dr Tim Brooks, head of the Lyme Borreliosis reference laboratory. We can no longer say the HPA are failing to listen to us!

The test seems potentially useful though we have to emphasise that, like serology, it is an indirect test and does not detect the actual presence of *Borrelia*. It depends on the trained response of the monocytes as part of the innate immune system. We don't yet know how useful it will be in late disease as the immune response in Lyme disease is not yet fully understood. More information is available on the [Boulder Diagnostics website](#).

HPA Porton are now proposing to investigate this test. One of the difficulties any new test faces is the difficulty of validation: how do you select a group of patients with active Lyme disease if you have no means of ascertaining whether their symptoms are due to active disease? Back to the [uncertainties](#)!

Public Health England and website changes

The Health Protection Agency, together with several other agencies and departments, moved on April 1st to [Public Health England](#) (PHE). The HPA website pages will shortly be transferred and at that point the pages on Lyme disease will be updated with new and improved information.

We shall keep our eyes on it, but have been assured that the changes we asked for will be made.

The Department of Health, as a ministerial department, has moved to [.gov.uk](#) where you will find a [useful interactive diagram](#) of the Department and the other health and care organisations. Old website addresses will continue to work for a while.

Conference 2013

Booking is open [on the website](#). Overnight accommodation for Friday or Saturday nights must be booked ASAP or the University cannot guarantee to hold rooms.

Saturday July 13th 2013 University of Surrey, Guildford, UK

Friday 12th July 2013

- 5.30 pm Residential registration opens
- 7.00 pm Conference dinner

Saturday 13th July 2013

- 8.30 am Day delegate registration opens
- 9.30 am Welcome and Conference start
- 5.30 pm Conference closes

Conference fee £38 including lunch, and refreshments
Accommodation is available on site at £32 en-suite B&B

We are delighted to confirm that **Dr Richard Bingham** will be providing an update on his team's research into Borrelia outer surface proteins; it might sound rather technical, but it was the highlight of last year's conference in Carlisle.

Another confirmed speaker is **Dr Leo Joosten** from Radboud University who will explain the SpiroFind test. By then we may have some idea of whether this is a possible test for use in the UK.

LDA's medical director **Dr Sandra Pearson** will be speaking on Lyme neuroborreliosis following publication of our new leaflet. Further speakers will be announced as the programme is confirmed, and we look forward to seeing as many of you as can make it in July.