

Basic facts on Lyme disease.

- Lyme disease or Lyme Borreliosis (LB) is an infectious disease transmitted to humans by the bite of an infected tick.
- Animal studies have failed to demonstrate transmission by anything other than ticks. Although placental transmission has been reported in autopsies of stillborn children, congenital transmission to a surviving child is unproved.
- Ticks are small blood sucking arthropods related to spiders and feed on a variety of hosts: mice, birds, small mammals and larger mammals such as badgers and deer.
- Ticks carrying LB occur throughout the UK, including in town parks.
- Ticks can be very tiny - the stage that most often transmits LB is the size of a poppy seed, though it grows larger as it becomes engorged with blood.
- UK studies report about 1 in 3 people with Lyme disease did not see a tick.
- Initial symptoms appear on average 14 days after the tick bite and may include a characteristic spreading, non-itchy rash and 'flu like symptoms.
- Disseminated disease can affect almost any part of the body, though individual presentations vary.

What has made LB contentious?

- If a tick bite is not seen and the typical rash not noticed a patient presents with non specific symptoms of unknown origin.
- The first report of Lyme disease in the UK was 1977 and many doctors have never seen a case. Experience of typical cases is therefore limited.
- Because of the lack of UK expertise, reliance has been almost exclusively on the blood test which detects antibodies to the disease. The specific antibodies tested for do not always develop in some people for a range of reasons, so negative test results in cases of LB can occur. (1)
- Antibodies (and therefore positive test results) can persist for months, sometimes years, in cured people and there is no test of either cure or persisting disease.
- A previous head of the Health protection Agency (HPA) Lyme disease reference laboratory (retired 2012) promulgated a very certain view to colleagues, officials and the general public via the HPA website and other communications maintaining
 - LB blood tests had a >99% chance of being positive in LB of more than 6 weeks duration;
 - standard antibiotic treatment was usually successful and that remaining symptoms were likely to be from another cause;
 - patients were "anti-science"

This created an unproductive culture amongst UK health professionals. (2)

- Although early treatment is almost always successful, the best treatment in late-diagnosed cases is unknown and some people do fail to recover completely following the recommended course of antibiotics.
- It has been proved that the bacteria can survive recommended courses of antibiotics and persisting symptoms could in any one case be due to persisting

disease, and auto immune reaction of tissue damage. There is currently no test to confirm this. Repeat courses of antibiotics have been used successfully in the UK.

- Because many UK doctors (perhaps most) have absolute belief in blood tests and a belief that standard course of antibiotics eradicate the disease, patients are often driven abroad in search of tests which will demonstrate Lyme disease and in search of long term antibiotic treatment. There are private overseas laboratories which will give an apparent diagnosis on the basis of tests which are not specific for Lyme disease and not licensed for diagnostic use.
- Patients know that there are uncertainties in diagnosis and treatment but doctors on the whole do not. This creates inevitable tensions; as witness the current national publicity and patient response to the press articles concerning John Caudwell.

What has been achieved in the last 2 years?

- An improved dialogue with the Department of Health which now communicates with LDA and has a better understanding of the problems.
- Dialogue and shared working with some staff at the Public Health England (PHE) Lyme disease reference laboratory with whom LDA are able to discuss difficult cases and shed light on negative and equivocal test results.
- An on-line training course for GPs created in a partnership between the Royal College of General Practitioners and LDA, and funded by LDA.
- An understanding with the Department of Health and PHE that national guidance is needed and a national clinic is desirable. There is no firm agreement, though, on how to achieve this.
- Increased research into UK ticks and the diseases they carry. There are current projects at, for example, the Universities of Salford, Bath and Bristol; by the PHE medical zoonoses team and in Scotland at the James Hutton Institute. There is research on *Borrelia* continuing at Huddersfield University.

What needs to be done?

1. Find out how many people in the UK are affected, and by what.

- a. Only positive test results for LB are reported: approximately 1200 cases p.a.
- b. Any person diagnosed clinically (often from the characteristic rash) is not counted.
- c. There is no follow up: we have no figures on the percentage of people who do not recover from the standard treatment.

It is acknowledged that reported cases may be the tip of an iceberg, but **we do not know the true scale of the problem** so there are no facts to justify allocating resources. Other tick-borne infections are known to complicate the picture, but the prevalence of these is unknown and they are rarely tested for.

It would be possible to mount a national or regional research project to address this but it requires funding and support from within the NHS community. Notifiable status is being discussed & PHE needs funding to screen tick collections for diseases.

2. Acknowledge within the NHS the uncertainties in diagnosis and treatment.

We need to persuade doctors' professional bodies, in particular the British Infection Association which represents infectious diseases consultants and

microbiologists, to acknowledge the uncertainties. Whilst ever consultants maintain that blood tests are perfect and treatment successful, the cost to the NHS will continue to rise and the public controversy will continue to grow.

3. Establish partnership working between LDA and the NHS.

LDA runs an email help desk for patients, and also for medics. Patients email a query (eg "My doctor says my test is negative, what can I do?"). LDA gathers information and history from the patient and discusses details of tests with the laboratory. LDA then provides the patient with information for the doctor, which perhaps includes a re-interpretation of the case. Doctors are sent a letter documenting the case and offered a conversation with LDA's medical director to discuss issues and concerns in general.

This partnership between patient, LDA, laboratory and GP works. It has resulted in successful treatment of patients. It saves the GP time and uses the expertise and knowledge which LDA has built up over many years.

This could be built on.

4. Develop some UK guidance for health professionals

The only guidance is via NICE Clinical Knowledge Summaries, which is for primary care. There is no guidance for secondary care where it is badly needed.

PHE has recognised that guidance is urgently needed and had intended to convene a committee for this purpose, including patient participation. This looks likely to be delegated to NICE for comprehensive guidelines with inevitable delays. Interim guidance could be produced much more quickly if the will was there.

5. Establish regional centres of expertise.

Because of the lack of experience amongst doctors the only source of expertise on Lyme disease available to a doctor is LDA, and most will not avail themselves of the proffered help.

The UK needs either or both

- regional GPs with a specialist interest who can develop expertise and offer information and advice to colleagues.
- regional clinics with specialist nurses and infectious diseases consultants who can call on specialist neurology, rheumatology and cardiology services as required.

The current level of knowledge in the NHS is appalling. Doctors do not understand the tests, the epidemiology or the disease itself. Consultants refuse (with a few exceptions) to accept proffered assistance from LDA.

Quotes related by patients to the LDA help desk include:

- "his initial response was that it was very unlikely that I was suffering from Lyme disease as my walking is restricted to the south and west of Wales"
- "asked her next door neighbour who is a duty Dr at Heathrow Airport what he could tell her about Lyme- he replied- we don't get that in this country"

- “my doctor says he has spoken to a professional at the lab where the blood test was done and has been assured that as long as it is not within two weeks of being bitten then I can’t have Lyme Disease.”
- “On the basis of me having not seen any deer in the area where we were riding, not having seen a tick or a rash, she did not think it was Lyme disease.”
- “he has completely dismissed the possibility [my child] has lyme disease, because he has heard back from someone high up in Infectious Diseases Department at the John Radcliff that this is highly unlikely with a negative antibody test (even though he has had a tick bite, an erythema migrans, and now exhibits a lot of the late stage symptoms!)”
- “He also said that they (JR) had said that if it was Lyme, it would do more harm than good to treat at this late stage.”
- “I’m in London. That was another reason they said the test wouldn’t be conducted. I was asked if my cat had been out of London, which he hasn’t.”
- “In answer to your question as to why my son’s doctor will not undertake the test on the NHS is because he said it is all in his head”

There is no doubt that public safety is at risk from the current state of medical knowledge and there are ways to address this if the collective will can be found. Considerable advances can be made without even incurring costs.

Further reading:

- 1) An explanation of negative Lyme disease tests. LDA Newsletter January 2015 see page 3. <http://www.lymediseaseaction.org.uk/wp-content/uploads/2015/01/LDA-Newsletter-Jan-2015.pdf>
- 2) A video (17m 30 s) giving a historical perspective. From LDA’s 2013 conference <https://www.youtube.com/watch?v=uXyHYQVoa84&feature=youtu.be>
- 3) An extremely good comment on the recent press reports from Dr Richard Bingham, a researcher at the university of Huddersfield https://www.facebook.com/richard.bingham.961/posts/10153640960274407?hc_location=ufi

For any specific queries, printed copies of leaflets or for a telephone conversation with either Stella Huyshe-Shires (chairman) or Dr Sandra Pearson (Medical Director), please email lobby@lymediseaseaction.org.uk.

Lyme Disease Action

Lyme Disease Action (LDA) is a [UK registered charity](#) formed in 2003. Accredited to NHS England’s Information Standard, the charity’s main activities are

- producing quality leaflets on ticks and Lyme disease
- running a help desk for patients and medics
- attending medical conferences and exhibitions to increase knowledge amongst health professionals
- running an annual conference
- responding to national and international requests for information on Lyme disease
- developing working relationships wherever possible with the Department of Health, Public Health England, research institutes and universities.

Income is entirely from donations and LDA has no paid employees.