

A new year underway

Change on the ground seems almost imperceptible sometimes, however, there has been some encouraging progress just since our last newsletter:

- NICE guidelines underway (see this newsletter).
- More doctors are responding positively to letters from LDA about individual patients and this has resulted in treatment for some sero-negative patients.
- More GPs have completed the RCGP e-learning module; over 1,000 completed it up to December.
- PHE has agreed to run some courses for GPs in the South West of England and to add on a PHE doctors' day to our annual conference which is September 17th 2016.
- The Scottish Lyme Borreliosis testing Laboratory at Raigmore has said it will work with LDA along the lines that we work with the English laboratory.
- We attended [2 conferences](#) in the USA leading to lots of contacts.
- We have established dialogue with
 - the Liverpool Health Protection Research Unit;
 - The Global Lyme Alliance and Lymedisease.org in the USA.
- We produced an article for a [major supplement](#) on Infectious diseases which will be distributed at international conferences as well as doing the rounds in the UK.
- We provided a [briefing for the House of Lords](#) debate which was praised by the Health Minister, Lord Prior.
- We presented a poster at an infectious diseases conference in London - see website news item & the conference poster: [The response to Lyme disease as an emerging threat](#).

Our 5 point Action Plan, fully supported by the speakers at the [House of Lords debate and the Minister](#), is as follows:

1. **Find out how many people in the UK are affected, and by what.** Lyme borreliosis? Other infections? Talking to the National Institute of Health Research, it is clear that they need to know how many people a research programme will benefit before allocating funds. This is why this is our NO. 1.
2. **Acknowledge within the NHS the uncertainties in diagnosis and treatment.** The British Infection Association appears not to have cascaded the James Lind Alliance findings to its members, despite having participate in the project and agreed with its outcome. Needless to say, we are discussing this.
3. **Establish partnership working between LDA and the NHS.** Some ID consultants will not read our letters and tell the patient "They're just trying to make money out of you." A long way to go, but getting there!
4. **Develop some UK guidance for health professionals.** Guidance exists for erythema migrans, but nothing else. NICE now plans guidelines.
5. **Establish regional centres of expertise.** Lyme disease is not common; a GP needs someone to telephone who has clinical experience. Someone who has seen some difficult cases, who has some understanding of the disease.

LDA is working on promoting this action plan with all stakeholders.

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No-one can have missed the publicity over the last few months concerning John Caudwell and his family. Rather than giving an account of this LDA has some comments and observations.



There have been articles about Lyme disease in all the national newspapers and a huge raising of awareness in all sectors of society.

Some lesser recognised facts have emerged in the national press: for example the finding of *Borrelia miyamotoi* in the UK in 2009, for which existing tests may not work well.

Visits to the NHS Choices Lyme disease page saw a 350% increase compared with the previous week, reaching 70,897 in the week of the first publicity. LDA website traffic was up from a norm of 2000 visits a day to 7500 visits a day. From Google Trends - UK searches for Lyme disease were four times normal levels.

Requests to the LDA Help Desk more than doubled; many of them genuine, likely cases of Lyme disease hearing about it for the first time.

A promising case study for a national newspaper pulled out because she didn't want her child ostracised in the playground for having a "contagious disease".

The Department of Health and Public Health England have put some of the Lyme disease work that we have been pressing for on hold, in order to answer an influx of questions and FOI requests.

LDA closed the Help Desk to new enquiries and ceased work on research proposals as we have been overwhelmed by questions from journalists and patient groups.



There is evidence that doctors, reading some of the press reports, have reacted with scepticism. We have reports for example of a GP saying "it's very trendy to think you have Lyme disease at the moment" and refusing to even consider it.

John Caudwell is now in the process of establishing a Lyme disease charity and has appointed trustees and a CEO, Veronica Hughes. We wait with interest to hear the charitable objects and find out what the trustees intend to do.

Examples of press coverage

[Daily Mail](#) reporting 11 members of John Caudwell's family affected and speculating about other modes of disease transmission.

[Daily Mirror](#) about a young woman who has spent her entire savings on treatment in America.

[Sunday Express](#) about someone who contracted LB in the Caribbean and has spent £65,000 on treatment. The article claims that the USA form of Lyme Borreliosis is not tested for in Europe.

[The Times](#) published a letter from a retired microbiologist saying that LB tends to be self-limiting and some UK cases with neurological and psychiatric presentations may be related to the after-effects of TBE, which is not endemic here!

... and in the BMJ

The **BMJ** ran an editorial "Lyme disease: time for a new approach?" by a group of European doctors. This can be read on [page 8 of the section pdf](#). The article pointed out the limited evidence for the reasons for treatment failures and the few resources that family physicians have when this happens. The editorial stated -

Recent evidence shedding light on how spirochaetes of the Borrelia genus evade host immune defences and survive antibiotic challenge threaten current beliefs about the persistence of infection, one of the largest points of contention in the medical community. The possibility of persistent infection has important implications for diagnosis, treatment, and doctor-patient interactions.

The authors included a Tick Box listing items which should be on the research agenda. Except the last two - the role of toxins in symptoms and signs and the contribution of environmental factors - these are all covered in the James Lind Alliance [top 10 uncertainties](#) requiring research and are now logged with the UK's National Institute for Health Research. The 47 detailed treatment uncertainties can be found on [UK DUETs](#).

The editorial called for more national and international debate involving all stakeholders and emphasised the importance of including people with different viewpoints who are prepared to remain open minded.

There followed several [Rapid Responses](#) in the BMJ online including a very good response from a Scottish GP who has been diagnosing and treating Lyme borreliosis in his patients for more than 20 years - "we must be open and listen to patients who think they have been affected by Lyme, even if they are challenging us. I continue after 40 years of medical practice to learn most from my patients." LDA's medical director, Dr Sandra Pearson, also responded.

In the same issue of the [BMJ \(page 4\)](#) was a brief Q&A - **Sixty seconds on Lyme disease**. This is a probable reaction of the medical press to the publicity in the lay press, often covering celebrities, which has focused on speculation about sexual transmission and that Lyme disease may cause Alzheimer's, Parkinson's and other conditions.

SO HOW DID THIS "EPIDEMIC" START?
With celebrities, mostly. Avril Lavigne,
Yolanda Foster, Rebecca Wells, Amy Tan,
Ashley Olsen, Jamie-Lynn Sigler ...

It is undeniable that raising awareness is useful. However, the down-side of focusing on celebrities is the risk that it could reinforce the prejudicial view that Lyme disease may just be a 'fashionable disease'.

It is evident to us that some already sceptical doctors have had their disbelief confirmed and deepened.

A great deal of solid progress has been made in persuading healthcare practitioners to listen and take us seriously. Sensational publicity over the last few months seems to have polarised opinion rather than stimulated dialogue and debate.

NICE at last

In this environment we now have the start of the solid, independent process to draw up NICE guidelines. *Nine years* after MPs called for this in an [early day motion](#) in parliament, something is now happening.

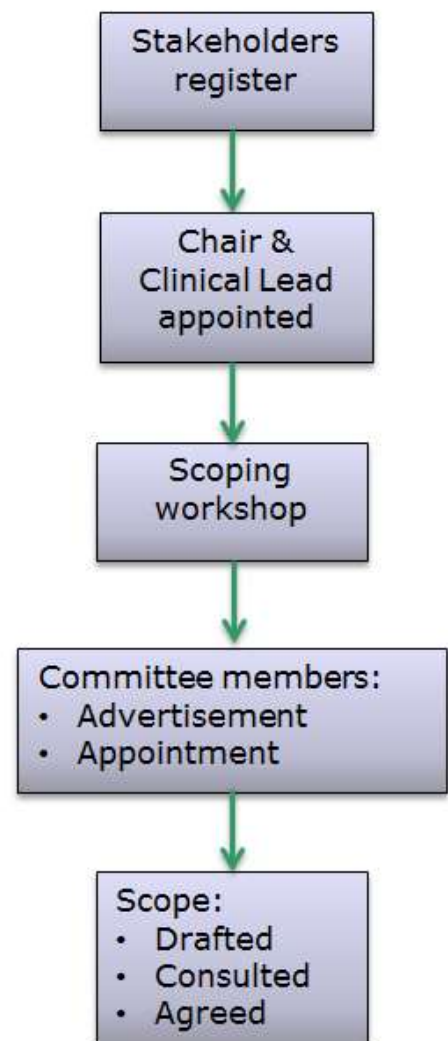
There is a crying need for some guidance to both primary and secondary care on what to do in the cases of relapse and continuation of symptoms. The [BIA position statement](#) on Lyme disease is still being thought of as guidelines, which it is clearly not, and it is time that it was replaced with something that more accurately reflects the evidence for chronic disease.

People involved

Those initially expected to be involved include:

- **Chair** - someone with skill and expertise chairing groups who may not have specialist knowledge of Lyme disease.
- **Clinical lead** - It has been decided not to appoint to this position as clinical input will be gained from those appointed to the committee. The criteria for Clinical lead are: a practicing senior healthcare professional who is in regular clinical practice, undertakes clinical research in Lyme disease and has a credible level of expert committee work.
- **Committee** - Formed from open, competitive recruitment of lay people and health professionals. Consisting of about 12 people, and including at least 2 lay members.
- **Registered stakeholders** - These are organisations who have registered an interest in Lyme disease guidelines. Several patient groups have registered, as have professional, national and public sector organisations and government bodies. All these will have an opportunity to comment on every stage from the draft scope to the draft guideline.
- **Developer team** - This group from the National Clinical Guideline Centre will do all the admin in arranging meetings and consultations as well as draft the scope, support the committee, respond to stakeholder comments and draft the guideline based on the committee decisions.
- **Support team** - a group including project managers and coordinators as well as the information specialists and systematic reviewers who will manage the literature reviews.

Initial stages



NICE continued

Happening next:

- **Announcement of Chair.** The name of the chair will be sent out with papers for the scoping workshop.
- **Scoping workshop is on February 23rd** to decide on the scope of the guideline: the aspects of care where advice is most needed. The composition of the committee will also be decided at this point. The process will be explained in briefing papers and at the meeting. Then a draft scope will be produced for consultation.
- **Recruitment to committee** is via open competitive recruitment following advertisements on the NICE website, at the same time that the scope is being consulted upon.

Unknowns:

- Is there enough evidence on which to base clinical guidelines for anything other than erythema migrans?
- Are there enough willing clinicians with sufficient practical experience in this country?
- Will Scotland decide to participate as a stakeholder in what will be English guidelines, or will they produce their own through [SIGN](#)?

What you can do

LDA has produced a flyer for the RCGP e-learning module. Can you print a copy of this and hand it into your GP Practice reception desk, or take it to a pharmacy, physiotherapist or minor injury unit?

Click on the picture to visit our website for a copy of the flyer. Then email flyers@lymediseaseaction.org.uk with the practice or pharmacy name and postcode. We'll add your effort to the on-line map that will shortly be made public.

Some patients have commented on-line that this course will not help them get treatment and may compromise their situation with their own GP. One person even suggested that "a little knowledge is a dangerous thing".

It is worth stating that the course:

- explains the limitations of the blood tests, giving possible reasons for negative test results in genuine cases of Lyme disease;
- says (as does the PHE referral pathway for GPs) that Lyme disease can relapse;
- does not just concentrate on early disease;
- discusses the uncertain prognosis and the possible need for re-treatment;
- is the only course on Lyme disease freely available to all health professionals;
- is intended for GPs, not consultants who will be dealing with complex cases when other conditions need to be excluded. (Though consultants would also benefit!)

Any information that improves early diagnosis and thus helps prevent the development of chronic disease is worth promoting. You will be helping people who will be contracting Lyme disease through 2016, 2017 and beyond.

