



Public Health
England

Lyme disease conference

Short and long term wins in Lyme disease

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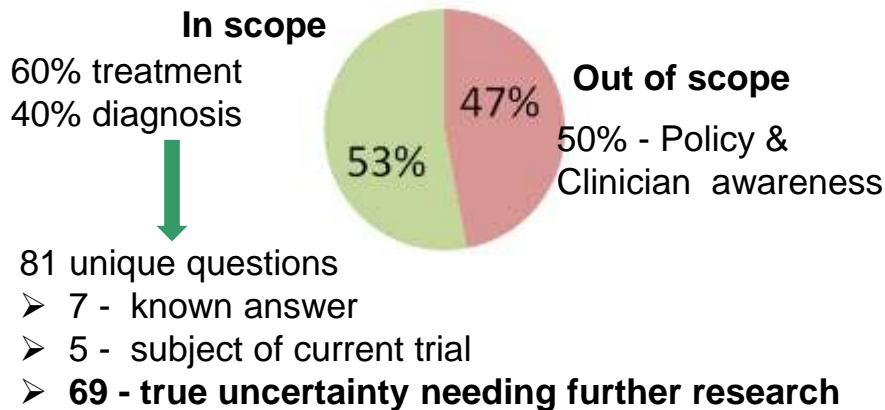
I was given this title and asked to go through what can we achieve quickly, and what will take a long time.

I don't intend to just present LDA's Wish List as there isn't time. To just say "research into continuing symptoms / better tests / effective treatment" is just repeating what this charity has been saying for 10 years. This conference is about participation and I want to prompt your thoughts.

One of the major wins is under our belt. To have a joint conference like this would have been out of the question until April 2012, so there is no denying this country has moved forward.

However, there is still a long way to go.

Lyme Disease Priority Sharing Partnership
957 questions submitted by clinicians & patients



Over the last 2 years LDA funded a project to document the uncertainties in Diagnosis & treatment of Lyme disease and to agree with clinicians the top 10 priorities for research. This project concluded in January of this year. It involved surveying clinicians & patients on the uncertainties they had found.

957 separate questions were submitted.

It is a reflection of the subject matter that 47% of the questions submitted were out of scope - and half of these were concerning clinician awareness of the disease and policy for diagnosis and treatment. It is these questions that we are probably dealing with this afternoon.

The In Scope questions, following merging of duplicates, resolved into 81 unique questions. A review of the reliable medical literature found only 7 of these had a known answer: the others were true uncertainties.

We published these uncertainties; what we thought was a big step forward - met with very little interest. I'm not even convinced that all clinicians who participated on the steering group circulated these uncertainties within their professional organisations. Many patients were also not particularly interested and didn't see the point.

Clinicians

Patients



We have a bit of a gulf.

Clinicians mainly consultants over on one side - know 21 days treatment is enough and tell their colleagues this: not interested in uncertainties.

Patients on the other side - some know always need months of treatment with high doses, that NHS tests are unreliable, but private foreign ones are better. They tell their friends this. They also have few uncertainties.

This has led to distrust and a gulf. LDA is trying to straddle the gap.

Acknowledge uncertainties	short
Close the gap between Them & Us	long

My first win, is for everyone to acknowledge what we have proved - there are uncertainties.

Can we just try to remove the Them and Us, and gain some common ground - close the gap a bit perhaps? Stop viewing the other side with suspicion?

RIPL & LDA are working together - here on the same platform, and we have regular meetings. Could everyone else do that too? remove the walls; change the culture; don't assume that ALL patients are mis-informed or that ALL doctors are blinkered.

Top 10 research priorities

- What is the best treatment ?
- How effective are the current UK tests ?
- What causes continuing symptoms ?
- Transmission by other means ?
- etc.

The JLA process resulted in a top 10 - voted by clinicians and patients - these are now with NIHR and all the Treatment uncertainties - 80 odd, are with UK DUETS, the Database of Uncertainties in the Effects of Treatments.

Acknowledge uncertainties	short
Close the gap between Them & Us	long
Research into treatment & diagnosis	long

We are hoping research will flow from here on these topics. This is a long win!

We struggled to get clinicians involved in this process of prioritising the uncertainties.

One anonymous ID consultant submitted a question:

I have always been able to easily find evidence-based guidelines on how to manage all aspects of Lyme Disease, and am not left with uncertainties about how to prevent, diagnose or manage Lyme Disease.

EFNS guidelines on the diagnosis and management of European Lyme neuroborreliosis

Å. Mygland^{a,b,c}, U. Ljøstad^a, V. Fingerle^d, T. Rupprecht^e, E. Schmutzhard^f and I. Steiner^g

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Germany

Recommendations

1. Adult patients with definite or possible late LNB with peripheral neuropathy and ACA should be treated with oral doxycycline (200 mg daily) or IV ceftriaxone (2 g daily) for 3 weeks. **(not enough evidence: GPP).**
2. Adult patients with definite or possible late LNB with CNS manifestations (myelitis, encephalitis, vasculitis) should be treated with IV ceftriaxone (2 g daily) for 3 weeks. **(not enough evidence: GPP).**

So - just out of interest, let's have a look at the evidence based guidelines - let's have a look at these guidelines.

The European Federation of Neurological Societies - EFNS Guidelines of 2010

Recommendations are given in the abstract - straightforward treatment recommendations for early and late LNB.

But if you actually read the text, you find the small print - **Not enough evidence**

So there are guidelines, but they are not based on evidence because the evidence doesn't exist. There are uncertainties - we don't know how best to treat except in very early disease.

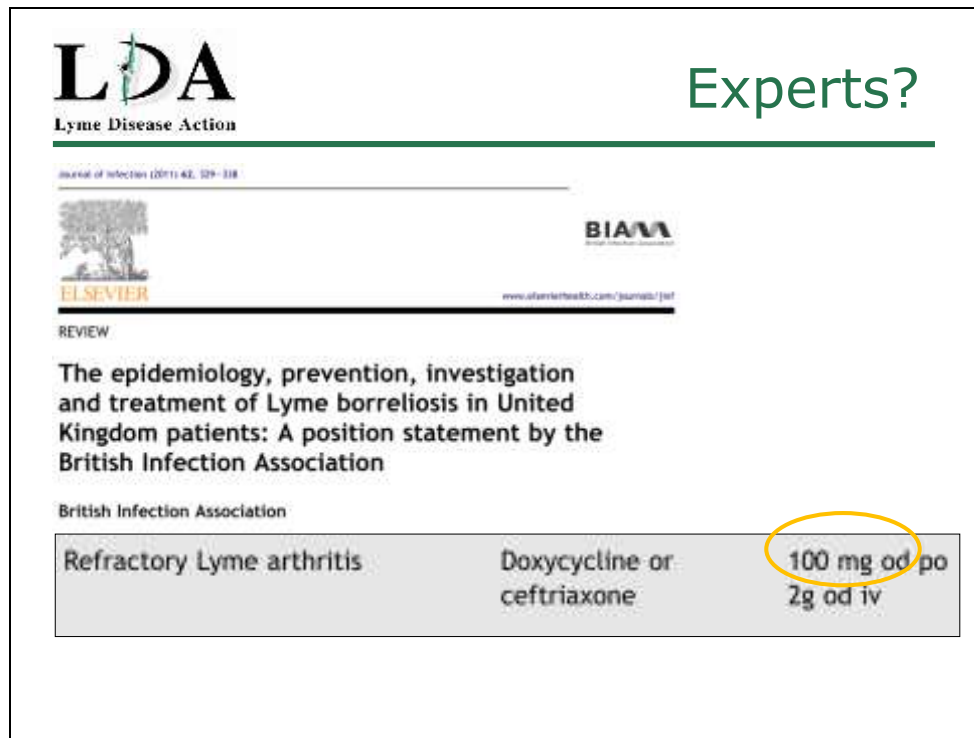
GPP = Good Practice Points ie what the experts say.

For anything other than erythema migrans -
“ Refer to a specialist”

Looking at UK guidance - CKS “refer to a specialist”

So all these guidelines are based on what the experts say -

Who are these experts?



Well, in the UK, they are generally neurologists, microbiologists and ID consultants who each probably see between 1 and 5 people with Lyme disease a year.

The British Infection Association represents ID consultants & microbiologists and has produced this paper to reassure its members.

From the table of treatment recommendations for different presentations - that for Lyme arthritis suggests treatment with doxycycline 100mg once a day. This dosing regimen is not just at variance with the evidence that they cite. This would not reach MIC in tissues. **It is an inadequate dose.**

Is anyone tweeting? "BIA position statement is a risk to patient safety. DOES contain nuts. No safety warning!"

We have pointed this out to the BIA, together with several other errors and misleading statements in this document, but they either don't believe us, or they feel the risk to patient safety is negligible. They assure us that this document went through consultation and peer review. Peer review by the people who provide treatment advice to GPs.

The only conclusion can be that either it did NOT go through peer review or those who reviewed it did not know that this was an ineffective dose for Lyme disease.

We do, however.

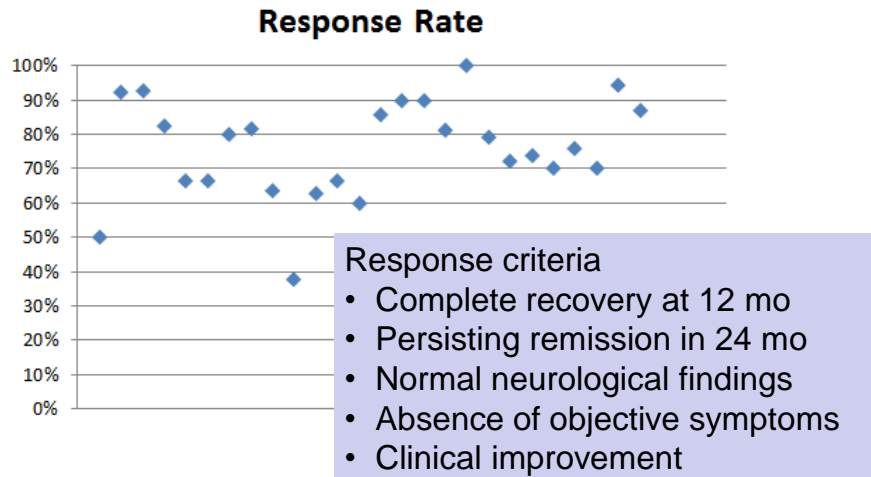
Acknowledge uncertainties	short
Close the gap between Them & Us	long
Research into treatment & diagnosis	long
Engage the expert patients	short
Remove BIA position statement	short

This leads me to two further wins:

1. Develop and engage the expert patients. We have knowledge - harness it and use it.
2. A very quick win - remove the BIA position statement from the RIPL webpage where it sits at the top of the Guidelines for Health Professionals page. I know a re-write of the website is planned, but this is just reinforcing patient distrust. Such an easy thing to do. QUICK WIN!

If LDA was to maintain a document on its website that had not been considered carefully - we would lose our Information Standard accreditation.

Response to treatment



If I can go back to the EFNS guidelines and look at the trials that were reviewed to draw up the guidelines. If you plot response rate, this is what you find.

Doxycycline & ceftriaxone for 14-28 days is said to give an excellent response. 75% means a quarter don't recover - not really excellent from the patient's point of view!

Who is it who doesn't recover; what are risk factors? RESEARCH again - a long win

Before we leave this, can we look at how **Response** was defined in these trials?

Some of them used complete recovery at 12 months.

ONE used persisting remission at 24 months - interesting distinction - someone thinks it relapses! LONG TERM FOLLOW UP is needed.

Other trials however, used - absence of objective symptoms, normal neurological findings. But - the patient may still have headaches, episodes of dizziness, parasthesias: not a very good response to treatment!

Acknowledge uncertainties	short
Close the gap between Them & Us	long
Research into treatment & diagnosis	long
Develop / engage expert patients	short
Remove BIA position statement	short
Patient based outcomes / PROMs	long

So the next win - a Long win - in studies, trials, assessments of treatments - we need long term follow up with patient based outcomes, patient reported outcomes

Improving patient outcomes is why we are here. Improve outcomes and you reduce NHS costs. But we need to record the right sort of outcome.

“We must put citizen and patient voice absolutely at the heart of every decision we take in purchasing, commissioning and providing services.”

Tim Kelsey
National Director of Patients and Information
NHS England

This is a statement from NHS England

“We must put citizen and patient voice absolutely at the heart of every decision we take in purchasing, commissioning and providing services.”

Tim Kelsey, National Director of Patients and Information, NHS England

OK, so could I ask the policy makers amongst you to do just that?

A national referral clinic has been announced. Who has defined and planned this clinic?

LDA knows more about Lyme disease than most other ID consultants. We can help. Use us. We have run a support email line for patients for years. Last week at the RCGP conference we launched medics@lymediseaseaction.org.uk - so we now provide the same service for clinicians.

Just read that again - **patient voice at the heart of every decision.**

Healthcare is not done TO us, it is done WITH us.

Acknowledge uncertainties	short
Close the gap between Them & Us	long
Research into treatment & diagnosis	long
Develop / engage expert patients	short
Remove BIA position statement	short
Patient based outcomes / PROMs	long
Promote LDA support services	short
Regional centres of expertise	long

So 2 more wins

1. Link to LDA support services from the RIPL web pages. There is a link to the Ramblers Association - why not LDA?
2. Everyone knows we need regional centres of expertise - can we have some GPs with a specialist interest, linked to secondary care support services? Let a few centres develop expertise and involve LDA in training & supporting them.



In fact involve LDA in designing, specifying and delivering these services

All this is possible. There are mechanisms. People have thought through this process already. We can make it happen.

Patient voice at the heart of every decision?

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Close the gap between Them & Us	long
Research into treatment & diagnosis	long
Develop / engage expert patients	short
Remove BIA position statement	short
Patient based outcomes / PROMs	long
Promote LDA support services	short
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So these are LDA's wins - there are others of course, but my slide is too small and my time is too short.



Ad hoc International Lyme Group

“This battle cannot be won on a scientific front; we need to mount a socio-political offensive.”

A lot has been achieved in the last 12 months, and this conference is evidence of that.

There is however, an elephant in the room, and it would be good to acknowledge it and deal with it. We will all get on much better.

This Ad Hoc International Lyme Group was established with the express purpose of denigrating patients and denying the existence of chronic infection. They said they wouldn't win using science and so they mounted an offensive by publishing papers promoting their views.

This is why it has taken us 10 years to get to this point?

This has not just been an academic journey; for patients it is personal. A lot of troubled water has passed under the bridge and it has taken patients' lives with it. I don't just mean quality of life, pain and financial hardship. I mean the death of at least one patient - as a direct consequence of the attitude of the medical profession - fostered by this group.

Troubled waters take time to disperse but can be helped by calming measures. Today I hope is a start.

My Final quick win would be to ask, not for someone to say **sorry**, because the individuals most responsible in this country have gone, but to ask if it is possible for someone to just acknowledge that the authorities - those leading clinicians and professional bodies, those heads of agencies and committees - could have done better and acted sooner.

However, this is a difficult thing for government agencies to do and I think we accept that this conference today is in itself an acknowledgement and a turning point.



I'll leave you with the troubled waters, because although today is a good start, and is perhaps the acknowledgement that we need, it is not all over yet.

We all have to work together to keep the boat afloat.