



Lyme Disease Action  
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# July Webinar Current Research Update

- 11.00 LDA introduction
- 11.10 Dr Nicola Harman, Developing a Core Outcome Set for Lyme Disease
- 11.50 Rosie Milsom, An update from Caudwell LymeCo
- 12.00 10 minute break
- 12.10 Dr Tim Brooks, An update from RIPL
- 12.20 Lucy Delaney, UK Lyme disease cohort project
- 12.50 Discussion of LDA future events and general questions
- 13.00 Formal webinar ends

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## LDA Introduction, Stella Huyshe-Shires, LDA Chairman



What can we do?

Hope



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Having had experience of Lyme disease ourselves, and having worked with both doctors and the public for many years, we know what your priorities are. We realise that what many of you listening want to hear about is progress on solving some of the problems of continuing symptoms following treatment.

In November 2019 we held a workshop to start drawing up a specification for a specialist clinic for Lyme disease. We included consultants, GPs, patients and researchers. There was general agreement both on the overall need and the careful steps necessary in setting up a pilot. We continued discussions into January 2020, but then Covid-19 struck.

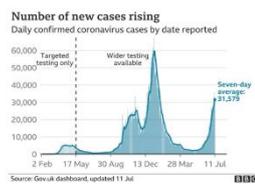


What can we do?

Hope

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Reality



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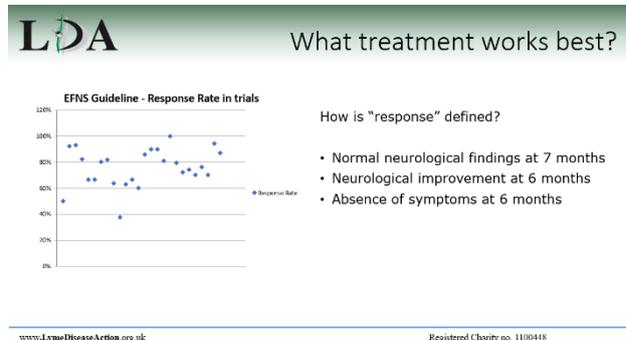
At this point there was no way we could engage with anyone in the NHS as they were completely tied up with Covid work, Even those working on ticks had been drawn into work helping the pandemic.

See the reality even now, we are not out of the Covid wood yet.

However, we needed to move something forward.

The European guideline for Lyme neuroborreliosis was produced some years ago. The committee examined all the papers published at the time and came to conclusions on what treatment should be used.

Some clinical trials reported a 100% response rate and some less than 50%. So one might assume that the treatment in the 100% success trial was better.



But if you look at all those papers (actually read them) you find a confusing picture.

How did each study define what a "response" to treatment is?

They varied:

- Normal neurological findings - couldn't see anything wrong with the patient, facial palsy, reflexes normal, that sort of thing.
- Just an improvement at 6 months after treatment.
- Absence of symptoms – what symptoms? Did subjective pain or fatigue that can't be measured, count? What did they ask the patients?

This is exactly the problem that NICE had. The NICE guideline reported that the evidence for the best treatment is very poor – you cannot compare the different studies because they record different things – different outcomes following treatment.

We decided that during lockdowns and while the NHS was so busy with Covid that we couldn't progress the specialist clinic, what we could do is ask patients what they think is "Recovery" – what outcomes should be recorded by every study.

It sounds easy. The trouble is that we can survey you all, and publish some results, but would anyone believe us? Would anyone running a clinical trial in Europe pay attention and use our definitions? From a patient charity?

To get round this problem, we decided to spend some of our money – which patients (including many of you) over the years have provided in donations - in engaging some specialists, with an international reputation, to do this job. Because then the results will be believed and used.

I'd like to introduce Dr Nicola Harman to explain this project.