

A group of patients sent LDA a series of questions about the new national NHS Lyme disease clinic in Winchester, asking that they be put to Dr Dryden. Following a meeting with Dr Dryden, LDA can provide the following answers. The questions are given below exactly as they were presented to LDA, with answers underneath.

1. If thousands of us are currently experiencing chronic Lyme, how can you possibly still deny it exists?
Nobody denies that symptoms exist; the debate with PHE Porton and Dr Dryden is around what causes the symptoms. See the JLA Uncertainties - is it continuing disease, auto-immune dysfunction, tissue damage or a combination?
2. Can NHS Borrelia ELISA seronegative patients be referred to him but with a medical history suspicious of Lyme disease?
Dr Dryden says "Yes definitely." This will be an important group in whom they need to hunt for unknown strains / pathogens and also monitor the serological response to the main strains of *B. burgdorferi*.
3. If someone fails antibiotic treatment for TB and still has symptoms, why haven't they got post-TB Syndrome?
Dr Dryden responds "Some patients do have post -TB syndromes. The key is to demonstrate no active TB mycobacteria requiring further antibiotic treatment." The challenge with Lyme disease is that Borrelia are difficult to isolate and culture and a practical laboratory test for active disease is not yet available.
4. Will they be prepared to treat people for coinfections if they test positive for them ? (as Porton are going to start testing for them)
Yes, Porton will have the most advanced technology in the world (an Abbott PLEX-ID) for identifying unknown pathogens and the clinic will be using this and treating identified infections.
5. Which co-infections will they be testing for and what strains ?
They will certainly test for Ehrlichia, Babesia, Rickettsia and Bartonella. Within these genera are a lot of genospecies and strains.
6. You deny chronic Lyme exists but base this opinion on those that have been treated Yet still have symptoms. But what do you believe happens if someone is infected with Lyme but is not given any antibiotics for years? Are u suggesting they fight off the infection by themselves? Can u make a clear distinction between chronic Lyme after treatment and late stage Lyme in the absence of any treatment?
Dr Dryden says "I deny nothing. I have an open mind. Lots of people do clear Borrelia with no treatment and no long term effects." Late Lyme disease before treatment is late Lyme disease. There are cases in the medical literature of people benefitting from longer treatment and from repeat treatment. We need to build a case definition of chronic Lyme disease. See also 7 below.
7. Define 'adequate treatment', given that there are studies which show borellia can be cultured from patients who have had the standard 2-3 weeks of doxy. Surely 'adequate' is when they are better?
Dr Dryden's view is that serologically confirmed Lyme responds with 3 weeks oral treatment. He says "Complex seropositive neuroborreliosis responds to a few days IV ceftriaxone with oral treatment for up to 3 months. I have not seen a single failure. We will be keen to hunt for Borrelia and other pathogens in patients with chronic symptoms."

8. Given the recent development of the ALS culture test (which seems to be showing that some chronic lyme patients still have viable, culturable spirochetes) and the embers monkey study, and the JLA/LDA saying that it is unknown whether active infection o...See More [unfortunately the rest of the comment was on Facebook, and unobtainable without a login, which we did not have.]
Everyone is agreed that further investigations are required in patients with continuing symptoms. Dr Dryden is keen that the clinic should see these patients and run samples on the Abbott PLEX-ID at Porton. The monkeys in the Embers study were killed to obtain tissue samples. After early infection there are few Borrelia in blood and the difficulty with people is knowing which accessible tissues to use as samples.
9. What types of coinfections will be tested for and what guidelines will be followed...I.e, will the clinic be free to treat on clinical diagnosis?
See 5) above. Given that the symptoms of Lyme disease overlap with those of so many other diseases and conditions, and that diagnosis is complicated by the possible presence of other tick-borne pathogens, clinical diagnosis is not as straightforward as sometimes thought. There is a plan to develop a diagnostic weighting table to help in clinical diagnosis (see JLA Uncertainties). Dr Dryden says "We need good evidence for infection but I will treat patients who fit our clinical definition."
10. What testing protocols will you be using, given that none of the existing ones in the UK are accurate enough?
It should be remembered that **no** current tests are 100% sensitive: this is not a problem unique to the UK. Immunoblots from different manufacturers vary and may give different results for the same sample. This doesn't mean that one is better: they are just different. Dr Dryden says "testing protocols have not yet been decided, but will include serial immunoblots and search for novel strains/pathogens."
11. What testing do they recommend or will they treat based on clinical diagnosis for patients who have been immunocompromised due to steroid treatment for a misdiagnosis.
See answers above. Abrogation of the immune response by early treatment with antibiotics or steroids is recognised to result in seronegative Lyme disease. An in depth history of the patient is essential to help highlight this possibility.
12. As LDA & James Lind Assoc have identified uncertainties will they be willing to treat empirically to help build a database of what would help patients?
Dr Dryden says "I will be willing to treat patients who fit the case definition". It is hoped that associated with the clinic it will be possible to find funding for careful data collection including detailed testing and long term follow up of patients, with the aim of improving our knowledge of Lyme disease presentation and treatment outcome.
13. Will you be taking into account the fact that some patients do not become ill in the immediate days/weeks following a bite?
"Yes."
14. And that some people are SO ill from the disease that they can't produce any antibodies and therefore won't show up on any test?
The immune response in different circumstances is not fully understood. This is also highlighted in the JLA uncertainties. See answer to 12) above - data collected may help.
15. What are the referral criteria to this Consultant led NHS Lyme clinic ?
GP referral by letter, fax or email. As in any referral letter, or any test request, the quality and relevance of the information provided is key.
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