The response to Lyme disease as an emerging threat
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Introduction and background

Lyme disease (Lyme borreliosis) is a zoonotic infection transmitted by the bite of infected ticks. Borrelia, the causative organism, has evolved to survive in the warm-blooded vertebrate host; the main reservoirs in nature being small mammals and ground-feeding birds which are known to carry other emerging tick-borne diseases.

The disease itself affects some animals as well as humans. It has been known in Europe since the end of the nineteenth century and is now the most common vector-borne disease in the northern hemisphere. UK incidence has risen sharply but is acknowledged to be seriously under-reported1 and knowledge about the impact in the UK is still lacking.

The multi-systemic clinical features of disseminated Lyme disease are broad and variable, often presenting a diagnostic challenge. Lyme disease may be associated with a significant burden of healthcare costs and morbidity.2

The UK charity Lyme Disease Action was formed in 2003 in response to the dearth of accurate, evidence-based information about the disease in the UK.

History of disease emergence

Mainland Europe
1883 Skin rashes first described by German physicians
1910 Skin rash Erythema Chronicum Migrans (ECM) linked to tick bite
1940 Bannwarth’s syndrome (meningitis, nerve pain, facial palsy)
1949 Successful antibiotic treatment of ECM rash
1970s Widespread European acceptance of tick bite + rash + neurological symptoms = infection
2000 European diagnostic criteria deviate from USA to allow for reduced antigen expression of European Borrelia genospecies

USA
1975 Cluster of juvenile rheumatoid arthritis in Old Lyme, Connecticut, named Lyme Arthritis
1977 USA Lyme Arthritis recognised as a tick borne disease
1981 Bacterium Borrelia burgorferi discovered in American deer ticks and then Swiss sheep ticks
1994 Dearborn Conference – 2 tier serology diagnostics

First UK case report 1977
UK laboratory confirmed cases only* Nos. clinically diagnosed unknown

* PHE / DEFRA

UK Response

- Media response: Sensational headlines, speculation
- Public response: Concern, frustration, mistrust, activism
- 7 Lack of interest
- Lack of appropriate guidelines
- Lack of effective specialist services
- Lack of knowledge
- Lack of experience

“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”

“He 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.”

References

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Lyme Disease Action
www.LymeDiseaseAction.org.uk
Lyme Disease Action Registered Charity no. 1100448 registered in England & Wales
The Lyme disease James Lind Alliance Priority Setting Partnership

The JLA method is designed to lead to changes in the way research funding is granted, with a view to raising awareness of research questions which are of direct relevance and potential benefit to patients and the clinicians who treat them.

See [http://www.jla.nihr.ac.uk/top-tens/](http://www.jla.nihr.ac.uk/top-tens/) for the top 10 research priorities

**Researchers, please note:**

All of the unanswered questions, regardless of their final position in the list of priorities are publicly available through the UK Database of Uncertainties about the Effects of Treatments (UK DUETs).

[http://www.library.nhs.uk/duets/](http://www.library.nhs.uk/duets/)

**HPRU EZI view of Lyme disease:**

A PHE report notes that there have been 6 cases of hantavirus in the UK between 2012 -2014 and the main risk group appears to be pet fancy rat owners with 32.9% testing positive for hantavirus antibody indicating previous exposure. Occupationally exposed groups had the same level of exposure as the general public and are not thought to be at risk.