**Introduction and background**

1977

1st reported case in the UK

UK laboratory confirmed cases only
Numbers clinically diagnosed are unknown

An emerging zoonotic disease in the UK

Limited public awareness
Lack of knowledgeable specialists
Little research on tick co-infections
Reliance on serology

Many documented diagnostic & treatment uncertainties

Unnecessary diagnostic & treatment failures
Increasing healthcare costs

Public concern & frustration
Use of overseas private labs & clinics

Intense media coverage

**Method**

Lyme Disease Action (LDA) is a not-for-profit patient organisation founded in response to the lack of quality information in the UK on tick-borne diseases.

To assist both patients and doctors, LDA established a formal email help line to enable patients and doctors to request case specific information.

- Confidential email ticket system via secure server
- Operates 365 days/year including evenings
- Wide range of questions and queries
- 2 volunteers: establishing facts, giving information, refining questions
- Input from Medical Director
- On-line reference library > 1300 papers
- > 1,000 callers/year and rising
- 10 to 20 open tickets daily
- Medics helpdesk responds to clinicians’ queries

LDA has developed a working relationship with the Lyme Borreliosis reference laboratory run by Public Health England. This includes an arrangement to enable access to detailed test results and case based discussions.

The aim is to combine relevant clinical history with detailed test results and with knowledge from research papers. This enables a more informed approach to an individual’s diagnosis and treatment.

**A collaborative approach**

Lyme Disease Action

Takes the time to ask relevant questions

E&W Reference Laboratory

Provides detailed test results

**Historic diagnostic pathway in the UK**

**Patient**

Could Lyme disease be the cause of my symptoms?

“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.”

“The hospital said that if it was Lyme, it would do more harm than good to treat at this late stage.”

Lyme disease is only in places like swamps.

“Babies under 1 year do not get bitten.”

**Doctor**

I see few cases; It can’t be Lyme disease.

“How do I get the German test?”

**England & Wales Reference Laboratory**

<50% samples have clinical details

2-tier serology C6 EIA + blot

Automated Viramed line blot - no B garinii antigens

Negative serology – “No evidence of active B burgdorferi infection”

Repeat positive – “Compatible with Lyme disease at some time”

**Conclusion**

The working relationship between patient, GP and laboratory, with LDA as the central hub, enables a more detailed analysis of a complex, poorly understood disease history. LDA has the knowledge and time to ask the necessary questions and formulate a comprehensive case for clinical discussion and consideration.

This integrative approach openly acknowledges the strengths and weaknesses of serology testing in Lyme borreliosis diagnostics and supports a pragmatic approach to medical treatment. It has resulted in a number of patients obtaining a diagnosis and treatment with a successful outcome. Additional benefits include the fostering in doctors of an increased understanding of tick-borne disease and a reduction in patients’ alienation and frustration.