



**Lyme Disease Action**

[www.LymeDiseaseAction.org.uk](http://www.LymeDiseaseAction.org.uk)

@LymeAction

**Working together ?**

Stella Huyshe-Shires

Who are "we"?

## Them & Us

Doctors

Patients



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Them

**Johnson, Barbara J. (CDC/OID/NCEZID)**

**From:** Susan O'Connell [Susan.O'Connell@suht.swest.nhs  
**Sent:** Tuesday, October 09, 2007 4:05 AM  
**To:** (b)(6); muham  
lzemel@ccmckids.org; Johnson, Barbara J. (CDC/O  
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**Cc:** Paul.Cleary@yale.edu  
**Subject:** Re: Lyme rally in front of the University of CT Health  
**Attachments:** Baum0907.pdf

A friend sent me this attached piece yesterday. FYI.  
Keep the faith!  
Sue

.. established to mount "a socio-political offensive"

Dr Sue O'Connell  
Lyme Borreliosis Unit



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Them

## 2011 The Lancet Infectious Diseases

### Antiscience and ethical concerns associated with advocacy of Lyme disease

*Paul G Auwaerter, Johan S Bakken, Raymond J Dattwyler, J Stephen Dumler, John J Halperin, Edward McSwegan, Robert B Nadelman, Susan O'Connell, Eugene D Shapiro, Sunil K Sood, Allen C Steere, Arthur Weinstein, Gary P Wormser*

Advocacy for Lyme disease has become an increasingly important part of an antiscience movement that denies both the viral cause of AIDS and the benefits of vaccines and that supports unproven (sometimes dangerous) alternative medical treatments. Some activists portray Lyme disease, a geographically limited tick-borne infection, as a disease



## UK Lyme Disease Priority Setting Partnership The Top 10 Research Priorities

The following are the top 10 **verified uncertainties** in the diagnosis and treatment of Lyme disease agreed by clinicians and patients.

- **What is the best treatment** for children and adults presenting with a) early Lyme disease without neurological involvement and not including erythema migrans and b) late Lyme disease. Consideration should include consideration of drug(s), cost, and side effects.

- **What key questions** (clinical and laboratory) would help make a diagnosis of Lyme disease? Would a weighting table be useful?



- **How effective are the current UK tests** in detecting infections due to the genospecies and strains of *B burgdorferi* s.l. in the UK and which single test

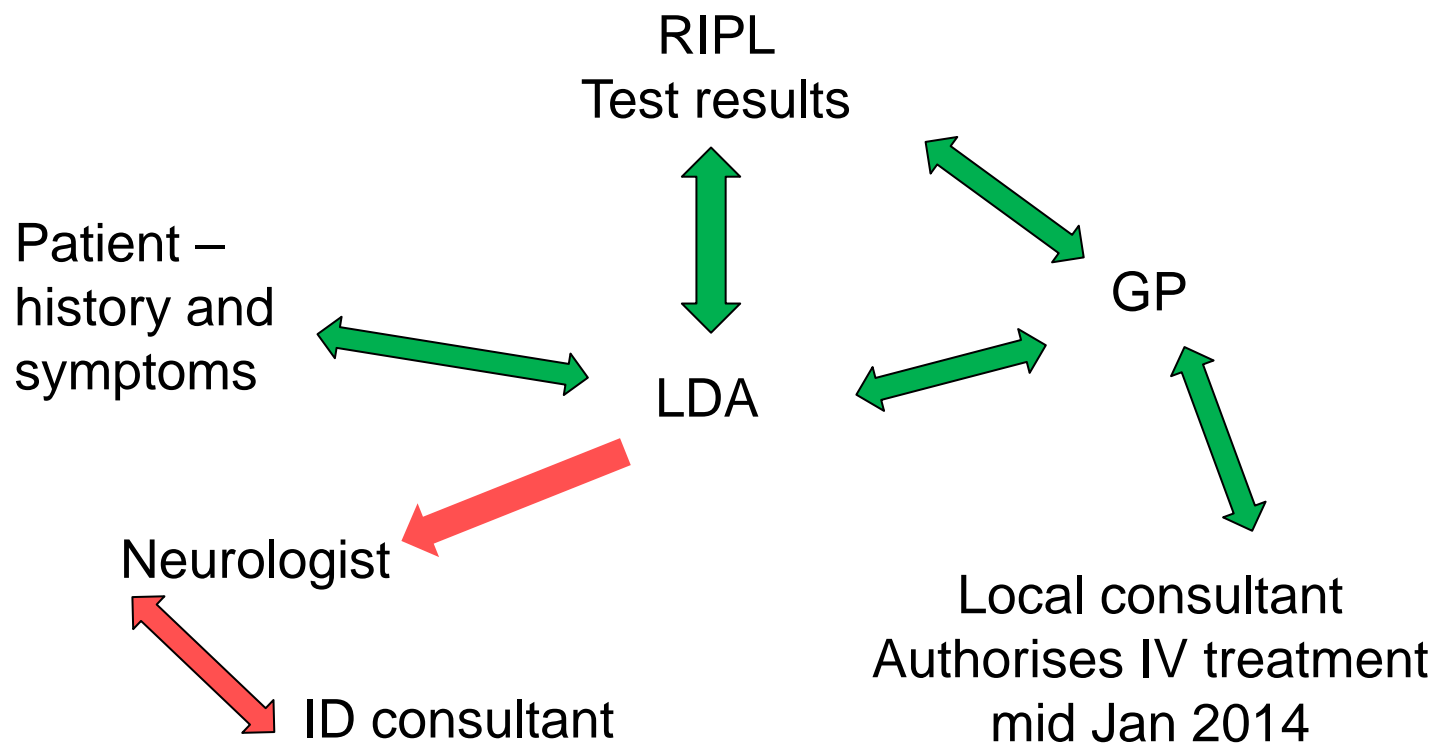
- Hospital admission, bilateral facial palsy, neuropathy hands & feet
- No known bite, no rash
- Positive ELISA, diagnosed LNB, started doxycycline
- Positive C6 EIA, negative immunoblot
- Diagnosed Guillain-Barré; stopped doxycycline
- Deterioration: unable to drive, difficulties walking due to pain and balance. Re-started doxycycline – improvement
- Lumbar puncture : CSF IgM +ve, IgG negative -> not LNB
- Stopped doxycycline – relapsed. Buys a walking stick.

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Patient with objective symptoms admitted June 2013:  
consistent with LNB; not typical Guillain-Barré  
improves with doxycycline, relapses when stops  
C6 positive, **rising**. CSF: IgM positive, IgG **sub threshold band**.





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# Failure to work together

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Patient with unexplained illness starting 2010

2012 positive C6 EIA, negative immunoblot.

2<sup>nd</sup> test C6 EIA risen slightly. Fought for treatment - 3 weeks IV with marked improvement

2014 August symptoms returned

3 x A&E visits through autumn. Neuropathy, facial palsy, limb weakness, lack of coordination. Negative serology sent home.

Frightened patient. Doxycycline 100mg bd 2 weeks from on-line pharmacy

Dec 2014 GP offered 7 days doxycycline. Refused.



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# Failure to work together

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- Jan 2015 Deteriorating. Disorientated, very scared and “I didn’t know where my arms were.” Sound & vision out of sync.
- Feb 2015 GP says he’s been told “not Lyme disease” Patient starts doxycycline from on-line pharmacy. Sister contacts LDA.
- March GP agrees to contact LDA medics support. LDA documents case in letter: rising C6 values. Patient admitted A&E.
- A&E consultant says “you are **not** getting IV”. Refuses to read LDA letter “not taking advice from a private clinic”.
- Neurologist refuses to read LDA letter “.. They make money out of telling people they have Lyme” .
- After consultation hospital finally agree to IV.
- LDA obtains further details of test results: Anaplasma rising titre as well as LB C6 rising values.
- Immunoblots still negative “no serological evidence of Lyme disease”

**Who is in charge of the patient?**

# Where do “we” stand?



**LDA**

**DH**

**PHE**

**Patients**

**GPs**

**Overseas labs**

**Consultants**

**Patients**

**BIA**

# Working together



## How we could....

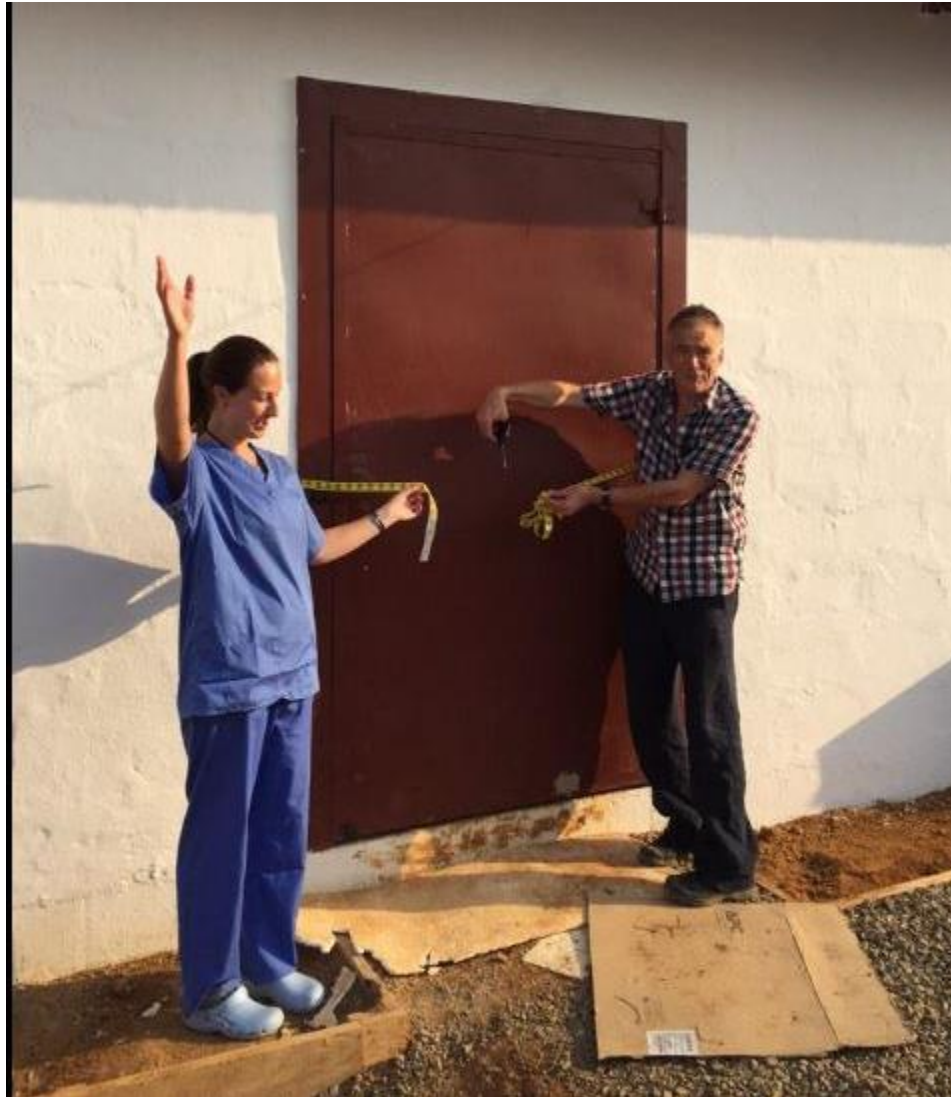
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...immediately agree to work together:

- Scotland – Raigmore communication with LDA
- Test ticks collected by volunteers
- New BIA position: dialogue with LDA
- Improved medical education
- Improved clinical diagnostics
- International collaboration
- Get a handle on incidence, impact & cost
- Designated, progressive, informed, regional service
- Closed groups – become less closed



It can be done!



# Still a way to go







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**Striving for the prevention and treatment of Lyme disease and associated tick-borne diseases**