Lyme disease conference

A Lyme clinic in Winchester

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Hampshire Hospitals Foundation Trust
+ RIPL, PHE, Porton

LYME CLINIC
Lyme clinic in Winchester

- Part of a network of ID services around the country
- Close link with RIPL Porton
- Local hotspot for Lyme
- Local expertise
- Set up in Hampshire Hospitals Foundation Trust as a pilot, pending clear service level agreement
Lyme Borreliosis rate in Winchester – total 508
Lyme Borreliosis rate in Winchester
National rate: 1.7
http://www.hpa.org.uk/Topics/InfectiousDiseases/InfectionsAZ/LymeDisease/ last accessed June 2013
Rates in Europe

- Rates of Lyme disease in some European countries are much higher.
- With an estimated
- 206 per 100,000 population in Slovenia (based on laboratory reports)
- 135 per 100,000 population in Austria (based on physician surveys).

Tick bite

508 patients - Hampshire

- Negative: 33%
- Definite: 38%
- Possible: 29%
- 5% acquired abroad
Presenting symptoms 508 patients

- Rash: 70%
- Neurological: 16%
- Arthralgia: 8%
- Cardiac: 1%
- Pyrexia: 5%
Neurological presentation

- Radiculopathy: 24%
- CN VII: 63%
- CN multiple: 10%
- Meningoencephalitis: 2%
- Myelitis: 1%
Lyme myelitis
Clinic and screen + Lyme

- Encourage urgent referral
- Monitor evolution of serology
- Biopsy lesions
  - Culture
  - PCR
- Monitor clinical progress on treatment
- Collate data on Lyme – acute and chronic
‘Chronic Lyme’ What is it?

- Post infectious pathology
- Immune system activation
- Persisting Borrelia burgdorferi infection
- Co existing infection
  - Babesia,
  - Anaplasma /Ehrlichia
- Another infection
  - Other strains of Borrelia spp.
  - Rickettsia spp.
  - Other chronic infection
- Non-organic component
**Proposed case definitions for Lyme Disease and Chronic Arthropod-borne Neuropathy (CAN)**

<table>
<thead>
<tr>
<th>History of tick or insect bite initiating illness</th>
<th>Lyme Disease</th>
<th>CAN</th>
</tr>
</thead>
<tbody>
<tr>
<td>History of tick or insect bite initiating illness</td>
<td>Ususally</td>
<td>Usually</td>
</tr>
<tr>
<td>B. burgdorferi serology by ELISA and immunoblot</td>
<td>Positive</td>
<td>Negative</td>
</tr>
<tr>
<td>Routine haematology and biochemistry investigations</td>
<td>Normal</td>
<td>Normal</td>
</tr>
<tr>
<td>Inflammatory markers</td>
<td>Rarely raised</td>
<td>Normal</td>
</tr>
<tr>
<td>Early presentation &lt;1month after bite</td>
<td>Rash + occasional non-specific symptoms</td>
<td>Does not usually present early</td>
</tr>
<tr>
<td>Later presentation</td>
<td>Specific neurology +/- constitutional symptoms</td>
<td>Non-specific symptoms, Fatigue, myalgia, cognitive impairment, arthralgia, general paraesthesiae, neurology not specific</td>
</tr>
<tr>
<td>Clinical examination</td>
<td>Rash or specific neurological deficit: CN palsy, radiculopathy, peripheral neuropathy, meningo-encephalitis, myelitis; (arthritis in N.America)</td>
<td>Normal</td>
</tr>
<tr>
<td>Complete response to defined short antibiotic course</td>
<td>Yes. Recurrence or relapse extremely unusual</td>
<td>No. Recurrence or relapse common.</td>
</tr>
</tbody>
</table>
What Lyme Looks Like: Photos Of Some Of My 2 Years Of Lyme Treatment
This is what 2 years of Lyme treatment looks like for most with chronic lyme disease. This photo is only some of my meds, injections and a small portion of IV stuff.
Other Chronic/Persisting Infections

BUT, they all leave a pathological signal...
## Infection clinic in September 2013

<table>
<thead>
<tr>
<th>Clinical Diagnosis</th>
<th>Number</th>
</tr>
</thead>
<tbody>
<tr>
<td>Lyme</td>
<td>11</td>
</tr>
<tr>
<td>CAN</td>
<td>12</td>
</tr>
<tr>
<td>Pyoderma</td>
<td>2</td>
</tr>
<tr>
<td>Dermatophyte infection</td>
<td>1</td>
</tr>
<tr>
<td>Typhoid</td>
<td>1</td>
</tr>
<tr>
<td>Tick typhus</td>
<td>1</td>
</tr>
<tr>
<td>Q fever - Coxiella</td>
<td>1</td>
</tr>
<tr>
<td>Sarcocystis</td>
<td>1</td>
</tr>
<tr>
<td>Cutaneous larva migrans</td>
<td>1</td>
</tr>
<tr>
<td><strong>TOTAL</strong></td>
<td><strong>32</strong></td>
</tr>
</tbody>
</table>
Two patients’ stories - CAN

- 42 yr old woman
  - ?bitten by tick 2008
  - Travel Cyprus
  - Unwell since 2010
  - Fatigue
  - Lack of concentration
  - Myalgia
  - Post exertional fatigue
  - Shooting limb pains
  - Borrelia tests negative
  - Convinced of Lyme diagnosis
  - Positive IgG serology for West Nile Virus

- 15 yr old boy
  - Febrile illness with LN in 2011
  - Complete energy loss, lack of concentration, unable to return to school
  - No specific neurology
  - Diagnosed as Lyme at private clinic based on non-validated blood test
  - Extensive antibiotics and alternative treatments and nutritional supplements
  - Positive persistant OpsC IgM band on Borrelia blot
  - EBV PCR + in 2013
Infection panel for Lyme-like disease

- Borrelia burgdorferi
- Bartonella spp.
- Coxiella spp.
- Brucella sp.
- Babesia spp.
- Anaplasma / Ehrlichia spp.
- Rickettsia
- TBE/WNV
- EBV / CMV PCR
Diagnosis. The clinic offers the latest validated diagnostic technology for *Borrelia burgdorferi* infection – ELISA, immunoblot and polymerase chain reaction techniques.

Clinical assessment. Consultation and investigations for general health including laboratory tests for generalised inflammation, autoimmune disease, other infections.

Research diagnostics. Partnership with the Rare & Imported Pathogens Department, PHE Porton and Southampton University School of Medicine. Investigate novel pathogens and unusual strains of known pathogens, follow the immunological response to *Borrelia burgdorferi*, and the immunological changes in chronic disease, collate clinical data.

Treatment and management. Appropriate treatment and management consistent with clinical presentation and investigations.

LDA. Patient support and advocacy with Lyme Disease Action to promote the understanding, diagnosis and management of tick-borne infection. http://www.lymediseaseaction.org.uk/
BUT...

- The clinic needs to be funded or the pilot can not continue
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