MyLymeData Patient Registry Highlights

MyLymeData is a patient-driven registry and research platform that permits patients to quickly and privately pool their data. Enrolling thousands of patients permits researchers to evaluate care as it is provided in real world practice. It can also generate research hypotheses and help recruit patients for trials. Enroll in MyLymeData today to become a part of the solution. Visit www.mylymedata.org.

15,000 patients enrolled

Research projects & collaborations

MyLymeData seeks to work with scientists, biorepositories and clinicians to accelerate the pace of research. We have collaborations with the University of Washington and the University of California at Los Angeles as well as the Lyme Disease Biobank, a project of the Bay Area Lyme Foundation. UCLA’s efforts are supported in part by a National Science Foundation grant.

Most severe symptoms of persistent Lyme disease

- Fatigue 54%
- Sleep Impairment 38%
- Muscle Aches 38%
- Joint Pain 38%
- Neuropathy 34%
- Cognitive Impairment 28%
- Psychiatric 28%
- Memory Loss 27%
- Gastrointestinal 25%
- Headache 19%
- Twitching 9%
- Heart Related 9%

Co-infections are common in persistent Lyme disease

<table>
<thead>
<tr>
<th>Co-infection</th>
<th>Diagnosis With labs</th>
<th>Without labs</th>
</tr>
</thead>
<tbody>
<tr>
<td>Babesia</td>
<td>44%</td>
<td>52%</td>
</tr>
<tr>
<td>Bartonella</td>
<td>42%</td>
<td>45%</td>
</tr>
<tr>
<td>Mycoplasma</td>
<td>19%</td>
<td>79%</td>
</tr>
<tr>
<td>Ehrlichia/Anaplasma</td>
<td>16%</td>
<td>69%</td>
</tr>
<tr>
<td>RMSF</td>
<td>7%</td>
<td>71%</td>
</tr>
</tbody>
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Registry by the numbers

Percentages of Well & Unwell Patients

- 8% Well
- 92% Unwell

Disease Stage of Well & Unwell Patients

- 9% Early Lyme
- 27% Late/Untreated
- 64% Chronic

Enroll today to add your Lyme data to MyLymeData! Visit www.MyLymeData.org
What types of information can you find in the MyLymeData patient registry?

- 15,000 enrolled
- 5 million data points
- 5 peer reviewed studies
- 75 citations in other peer-reviewed publications
- 2 text book highlights
- 4 scientific posters
- 7 white papers
- 40+ conference presentations
- 60 federal report references
- 30 congressional report references
- 4 MyLymeData conferences convened
- 2 clinical trials recruited

Our impact

- Recollection of tick bite
- Diagnosis by clinician
- Supporting lab tests
- Stage of illness at diagnosis

Demographics

- Sex
- Race
- Education
- State of residence

Quality of Life

- Health status
- Bad physical days
- Bad mental days
- Bed days

Functional Impairment

- Ability to work
- Ability to go to school
- Impact on social activities
- Disability

Treatments

- Antibiotics
- Alternative
- No treatment
- Treatment duration

Symptoms

- Severity
- Present at diagnosis
- Most Common
- Percent of Improvement

More well and substantially improved patients use antibiotics

<table>
<thead>
<tr>
<th></th>
<th>Antibiotics &amp; Alternative</th>
<th>Antibiotics Alone</th>
</tr>
</thead>
<tbody>
<tr>
<td>Well Patients</td>
<td></td>
<td>76%</td>
</tr>
<tr>
<td>Substantially Improved</td>
<td></td>
<td>59%</td>
</tr>
<tr>
<td>No Improvement</td>
<td></td>
<td>38%</td>
</tr>
</tbody>
</table>

Patients have a lot to teach us about Lyme disease

- 51% >3 years to diagnosis
- 78% of diagnosis supported by serology
- 72% misdiagnosed before Lyme diagnosis
- 89% willing to participate in research
- 70% not diagnosed until late stage (> 6 months)
- 60% diagnosed with co-infection
- 53% saw >5 clinicians

Publications


