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 facilitate research by generating research hypotheses and recruiting patients for trials. Enroll in MyLymeData today to become a part of the solution. Visit www.mylymedata.org.

14,000 patients enrolled

Research projects & collaborations

MyLymeData is a research engine that seeks to work with researchers, biorepositories, and clinicians to accelerate the pace of research. We collaborate with researchers at 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</th>
<th>With labs</th>
<th>Without labs</th>
</tr>
</thead>
<tbody>
<tr>
<td>Babesia</td>
<td>44%</td>
<td>52%</td>
<td>48%</td>
</tr>
<tr>
<td>Bartonella</td>
<td>42%</td>
<td>45%</td>
<td>55%</td>
</tr>
<tr>
<td>Mycoplasma</td>
<td>19%</td>
<td>79%</td>
<td>21%</td>
</tr>
<tr>
<td>Ehrlichia/Anaplasma</td>
<td>16%</td>
<td>69%</td>
<td>31%</td>
</tr>
<tr>
<td>RMSF</td>
<td>7%</td>
<td>71%</td>
<td>29%</td>
</tr>
</tbody>
</table>

Registry by the numbers

- 7% Well
- 9% Early Lyme
- 27% Late/Untreated Lyme
- 64% Chronic Lyme
Our impact

- 14,000 enrolled
- 5 million data points
- 4 peer-reviewed studies
- 2 text book highlights
- 4 scientific posters
- 7 white papers
- 40 presentations
- 60 federal report references
- 4 conferences convened
- 1st clinical trial recruited

What types of information can you find in the MyLymeData patient registry?

**Diagnosis**
- 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>38%</td>
<td>76%</td>
</tr>
<tr>
<td>Substantially Improved</td>
<td>59%</td>
<td>38%</td>
</tr>
<tr>
<td>No Improvement</td>
<td>38%</td>
<td>59%</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
- 60% diagnosed with co-infection
- 89% willing to participate in research
- 70% not diagnosed until late stage (> 6 months)
- 53% saw >5 clinicians

Enroll today to add your Lyme disease data to MyLymeData! Visit www.MyLymeData.org