# 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 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

Least   Most

| Region	%
East	33%
South	26%
West	26%
Midwest	15%
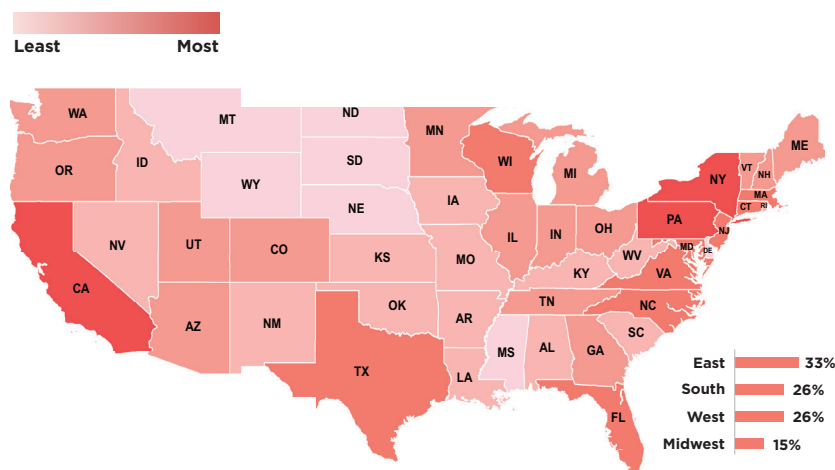
Research projects & collaborations

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
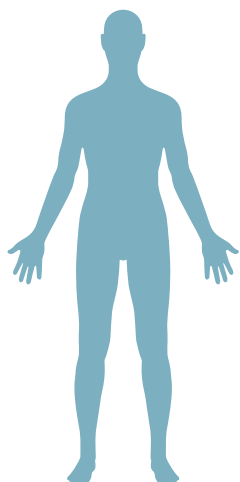
- Fatigue 54%
- Sleep impairment 38%
- Muscle aches 38%
- Joint pain 38%
- Neuropathy 34%
- Cognitive impairment 28%
- Psychiatric 28%
- Memory loss 27%
- Gastrointestinal 25%
- Headache 19%
- Twitching 9%
- Heart related 9%

Co-infections are common in persistent Lyme disease

Co-infection	Diagnosis	With labs	Without labs
Babesia	44%	52%	48%
Bartonella	42%	45%	55%
Mycoplasma	19%	79%	21%
Ehrlichia/ Anaplasma	16%	69%	31%
RMSF	7%	71%	29%

Registry by the numbers

- 7% Well
- 9% Early Lyme
- 27% Late/ Untreated Lyme
- 64% Chronic Lyme
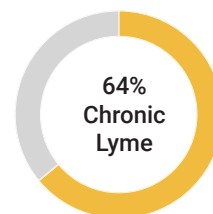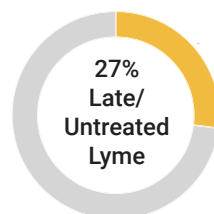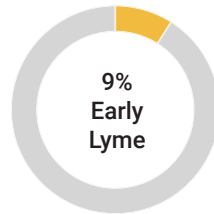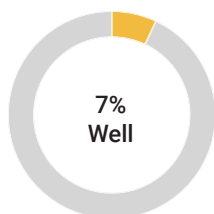
Our impact
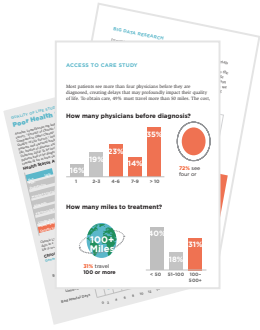
- 14,000 enrolled
- 5 million data points
- 4 peer-reviewed studies
- 2 text book highlights
- 4 scientific posters
- 7 white papers
- 40 presentations
- 60 federal report references
- 4 conferences convened
- 1st clinical trial recruited

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

Legend: ■ Antibiotics & Alternative ■ Antibiotics Alone

Well Patients	76%
Substantially Improved	59%
No Improvement	38%
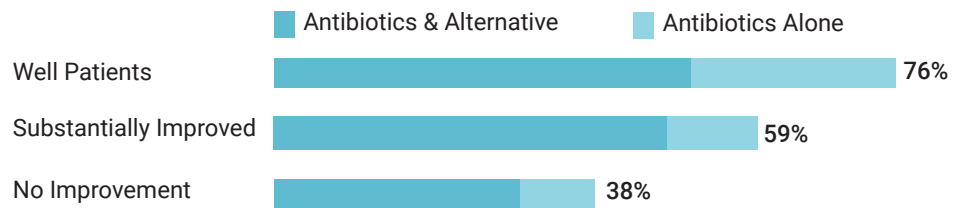
Patients have a lot to teach us about Lyme disease

51% >3 years to diagnosis

89% willing to participate in research

70% not diagnosed until late stage (> 6 months)

78% of diagnosis supported by serology

72% misdiagnosed before Lyme diagnosis

60% diagnosed with co-infection

53% saw >5 clinicians

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