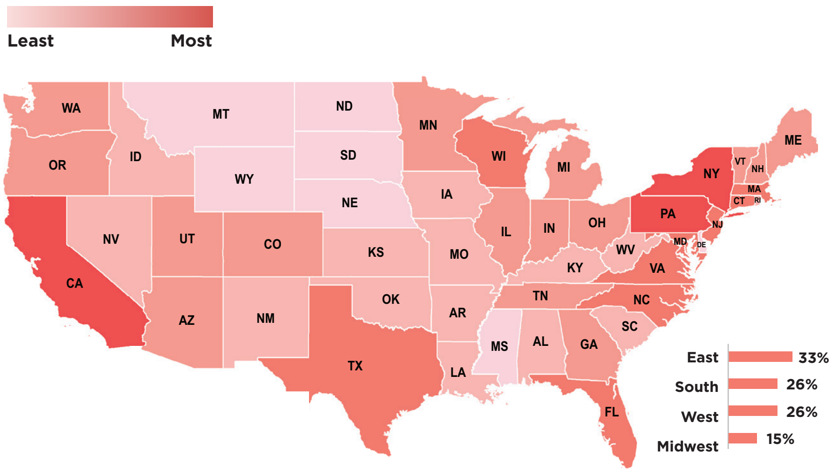
MyLymeData Patient Registry Highlights

MyLymeData
A PROJECT OF LYMEDISEASE.ORG

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.

18,000 patients enrolled

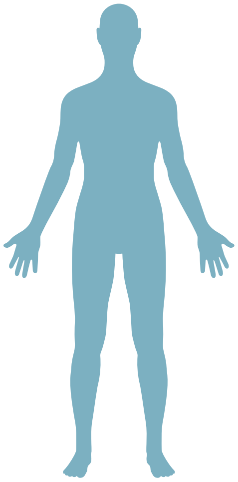


Research projects & collaborations

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. MyLymeData has been included in two National Science Foundation awards.

NSF
LYME DISEASE BIOBANK
A BAY AREA LYME FOUNDATION PROGRAM

Most severe symptoms of persistent Lyme disease



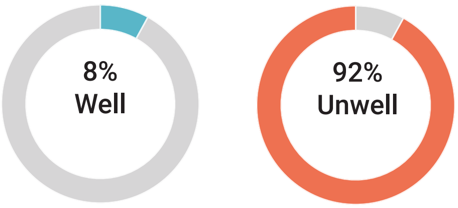
- Fatigue 54%
- Sleep Impairment 38%
- Muscle Aches 38%
- Joint Pain 38%
- Neuropathy 34%
- Cognitive Impairment 28%
- Psychiatric 28%
- Memory Loss 27%
- Gastrointestinal 25%
- Headache 19%
- Twitching 9%
- Heart Related 9%

Co-infections are common in persistent Lyme disease

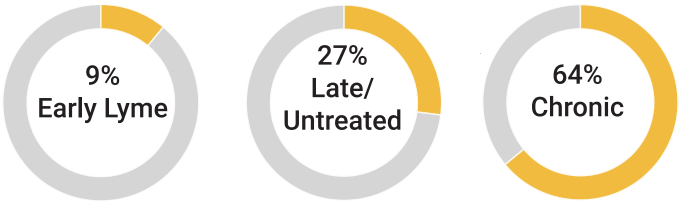
Co-infection	Diagnosis	With labs	Without labs
Babesia	44%	52%	48%
Bartonella	42%	45%	55%
Mycoplasma	19%	79%	21%
Ehrlichia/ Anaplasma	16%	69%	31%
RMSF	7%	71%	29%

Registry by the numbers

Percentages of Well & Unwell Patients

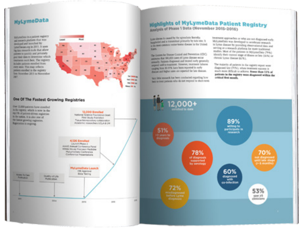


Disease Stage of Well & Unwell Patients



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

Our impact



- 18,000 enrolled
- 5 million data points
- 7 peer reviewed studies
- Over 100 citations in ot peer-reviewed publications
- 2 text book highlights
- 4 scientific posters
- 7 white papers
- 40+ conference presentations
- 90 federal report references
- 4 MyLymeData conferences
- 2 clinical trials recruited
- Included in 2 NSF awards

Publications

Johnson L, Shapiro M, *et al*; Does Biological Sex Matter in Lyme Disease? The Need for Sex-Disaggregated Data in Persistent Illness. Int J Gen Med. 2023; https://doi.org/10.2147/IJGM.S406466

Johnson, L.B.; Maloney, E.L.; Access to Care in Lyme Disease: Clinician Barriers to Providing Care: Healthcare 2022; https://doi.org/10.3390/healthcare10101882

Johnson L, Shapiro M, *et al*; Antibiotic Treatment Response in Chronic Lyme Disease: Why Do Some Patients Improve While Others Do Not? Healthcare. 2020; https://doi.org/10.3390/healthcare8040383

Vendrow J, Haddock J, *et al*; Feature Selection from Lyme Disease Patient Survey Using Machine Learning. Algorithms. 2020; https://doi.org/10.3390/a13120334

Johnson L, Shapiro M, *et al*; Removing the Mask of Average Treatment Effects in Chronic Lyme Disease Research Using Big Data and Subgroup Analysis. Healthcare. 2018; https://doi.org/10.3390/healthcare6040124

Johnson L, Wilcox S, *et al*; Severity of chronic Lyme disease compared to other chronic conditions: a quality of life survey. PeerJ. 2014; Published 2014 Mar 27. doi:10.7717/peerj.322

Johnson L, Aylward A, *et al*; Healthcare Access and Burden of Care for Patients with Lyme Disease: A Large United States Survey. Health Policy. 2011; https://doi.org/10.1016/j.healthpol.2011.05.007

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

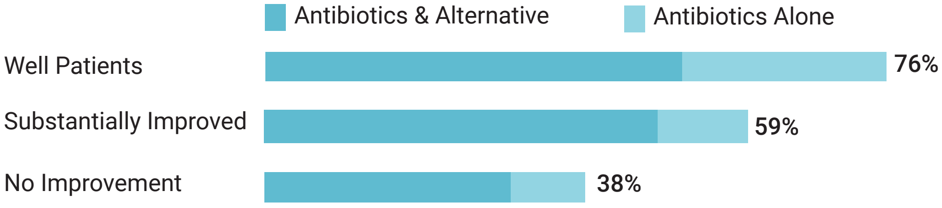
Treatments

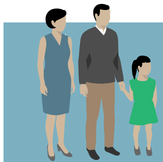
- Antibiotics
- Alternative
- No treatment
- Treatment duration

Symptoms

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

More well and substantially improved patients use antibiotics





Patients have a lot to teach us about Lyme disease

51% >3 years to diagnosis

78% of diagnosis supported by serology

89% willing to participate in research

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

72% misdiagnosed before Lyme diagnosis

60% diagnosed with co-infection

53% saw >5 clinicians

Download a copy of the Chartbook. Visit https://www.lymedisease.org/assets/chartbook-physicians-access-to-care.pdf