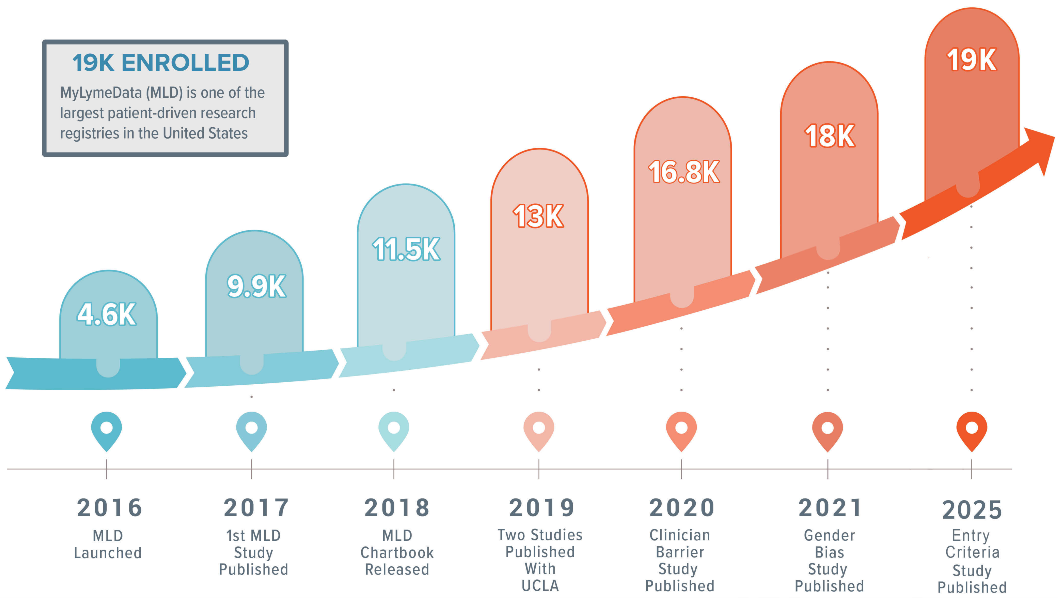
MyLymeData Patient Registry Highlights

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.

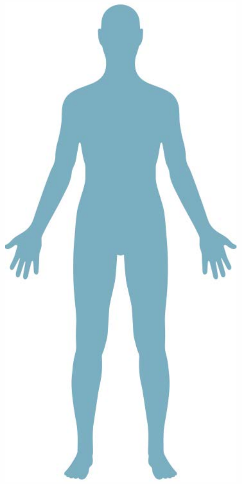
19K ENROLLED
MyLymeData (MLD) is one of the largest patient-driven research registries in the United States



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.

Most severe symptoms of persistent Lyme disease



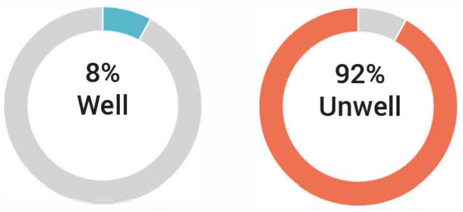
- Fatigue 54%
- Sleep Impairment 38%
- Muscle Aches 38%
- Joint Pain 38%
- Neuropathy 34%
- Cognitive Impairment 28%
- Psychiatric 28%
- Memory Loss 27%
- Gastrointestinal 25%
- Headache 19%
- Twitching 9%
- Heart Related 9%

Common co-infections in persistent Lyme disease

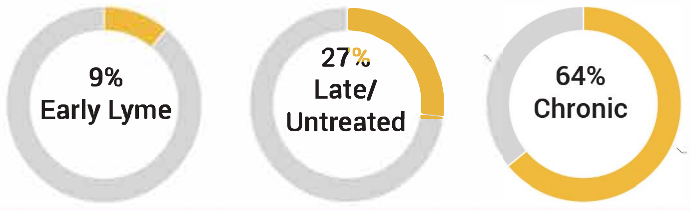
Co-infection	Diagnosis	With labs	Without labs
Diagnosed with Co-infection	75%		
Babesia	73%	64%	36%
Bartonella	70%	63%	37%
Mycoplasma	28%	78%	22%
Ehrlichia/Anaplasma	25%	74%	26%
RMSF	14%	76%	24%

Registry by the numbers

Percentages of Well & Unwell Patients

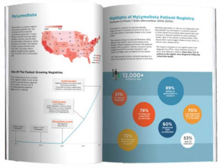


Disease Stage of Well & Unwell Patients



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

Our impact



- 19,000 enrolled
- 10 million data points
- 8 peer reviewed studies
- Over 100 citations in other peer-reviewed publications
- 2 text book highlights
- 4 scientific posters
- 7 white papers
- 40+ conference presentations
- 100 federal report references
- 4 MyLymeData conferences
- 2 clinical trials recruited
- Included in 4 NSF awards
- CDMRP Award Recipient

Publications

Johnson L, Shapiro M, Needell D, Stricker RB. Optimizing Exclusion Criteria for Clinical Trials of Persistent Lyme Disease Using Real-World Data. Healthcare. 2025;13(1):20. https://doi.org/10.3390/healthcare13010020

Johnson L, Shapiro M, *et al*; Does Biological Sex Matter in Lyme Disease? The Need for Sex-Disag-gregated 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/health-care10101882

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

Functional Impairment

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

Demographics

- Sex
- Race
- Education
- State of residence

Treatments

- Antibiotics
- Alternative
- No treatment
- Treatment duration

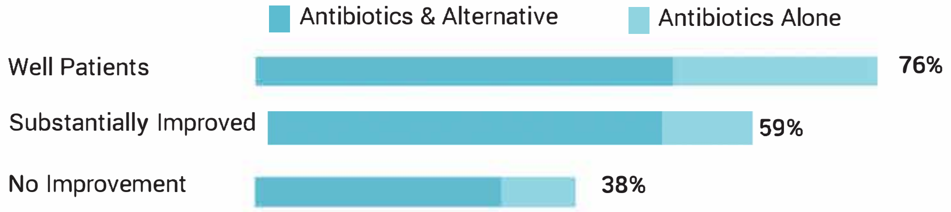
Quality of Life

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

Symptoms

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

More well and substantially improved patients use antibiotics



Persistent Lyme Disease Patients Have A Lot to Teach Us About Lyme Disease

19,000+ enrolled to date

97% willing to participate in research

10% diagnosed within one month

78% of diagnosis supported by serology

77% not diagnosed until late or chronic stage (> 6 months)

75% diagnosed with co-infection

74% misdiagnosed before Lyme diagnosis

41% saw >5 clinicians