



lymedisease.org

POWERED BY PATIENTS

Founded 1989

LymeDisease.org is one of the oldest Lyme disease 501(c)(3) nonprofit organizations in the nation. We work to make the patient voice stronger, to support patient-centered research, to create legislative change, and to bring about a future where Lyme patients can receive the treatments they need to get well. We do this through patient empowerment and science-based advocacy—a dynamic combination.

We Empower Patients through Education and Research

LymeDisease.org is powered by patients. We believe there is strength in numbers. We represent hundreds of thousands of patients and provide them with the tools essential to empowerment. Educated and informed patients are the key to improving health care outcomes. We provide patients with information and tools to pursue the care they need.

True power comes from having informed patients involved in all levels of decision making—from education, to legislation, and even science. Together we amplify the patient voice to drive health care policy change. Through the MyLymeData patient registry, we develop the data necessary to better characterize chronic Lyme disease.

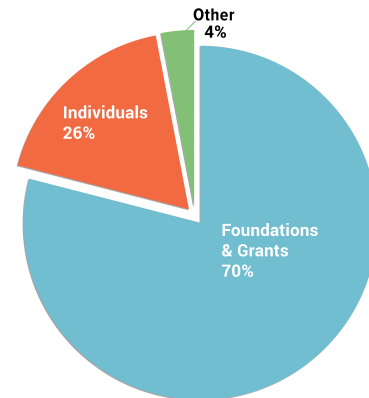
We Believe:

- Lyme patients must have access to quality medical care.
- Medical care should address the needs of patients.
- Patients are entitled to make choices about their treatment options.
- Patients must be given the information necessary to make informed choices.
- Research that matters to patients must be funded.
- Patient-driven research that is clinically relevant is necessary for progress.

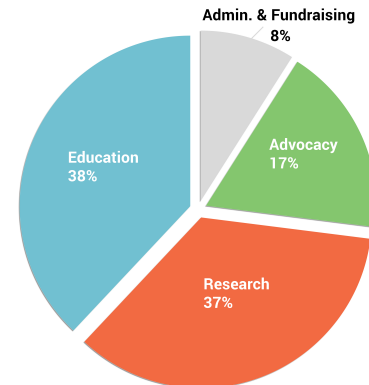
By donating, you support our efforts to continue to conduct patient-centered research, educate the public, and engage in science-based advocacy supporting Lyme patients throughout the nation.

Grassroots donations are a major funding source. We keep administrative cost as low as possible.

2020 SOURCES OF FUNDS



2020 USES OF FUNDS



2021 was a watershed year for LymeDisease.org in terms of national press coverage. LymeDisease.org has been quoted in U.S. News and World Reports, Business Insider, The New York Times, The Wall Street Journal and The New Yorker magazine regarding access to care and other pertinent Lyme patient issues.

Accurate testing continues to be a hurdle for practitioners and patients alike. During the past year, LymeDisease.org has helped recruit participants for two separate clinical trials. Our trusted social media and communications network allows us to quickly message our followers to recruit participants for the studies.

“ I am convinced that being able to find all this information quickly from LymeDisease.org website, set out in concise ways, played a big part in my recovery last year. The clear information about chronic Lyme disease is also vital, as are the details about possible recurrence. — Christopher-UK

One of the trials reached its participant goal within 12 hours of the launch!

Communications

LymeDisease.org is the largest and most trusted Lyme disease patient communication network in the nation. Our patient reach is unparalleled, with widely distributed website content, blogs, social and print media, including our digital publication, The Lyme Times.

New patients rely on us to provide information to get promptly diagnosed, tested, and treated. Patients with chronic Lyme disease rely on us for timely, accurate news and commentary through our website, blogs, and newsletters. Patients can join our online support and discussion forum: U.S. National Lyme Group.

MyLymeData and Big Data Surveys

Patients are the most underutilized resource in medical research. MyLymeData is a patient-led research registry that uses innovative technology that bypasses traditional research bottlenecks. It allows patients to pool their data to accelerate research using real-world evidence. The registry uses one of the highest quality and most secure registry platforms – the same one that serves National Institutes of Health patient registries.

MyLymeData seeks to:

- Generate actionable data and a knowledge base to improve care and promote policy reform.
- Build the Lyme community research capacity.
- Foster research partnerships and collaborations with researchers, clinicians, and blood/tissue biobanks.
- Identify treatment response subgroups and determine the factors that make patients well.
- Facilitate traditional research by helping researchers develop hypotheses, determine outcomes that matter to patients, and recruit patients for clinical trials.

We have enrolled over 15,000 participants, collected over 5 million data points, published five peer-reviewed studies, and seven white papers and scientific posters. MyLymeData has been highlighted in two chapters in college textbooks and three government white papers on patient registries. We collaborate with academic researchers at UCLA and the University of Washington as well as the Lyme Disease Biobank, a project of the Bay Area Lyme Foundation.

We recently published our fifth big data study with UCLA researchers who received a National Science Foundation grant to explore artificial intelligence techniques using data from the registry.

Patient Advocacy

Our advocacy efforts benefit from the thousands of patients who lend their voices to promote change. Over 14,000 patients answered our call to contact legislators to pass the 21st Century Cures Act that created the Tick-Borne Disease Working Group, where patients for the first time have a seat at the table and discussions that would have occurred behind closed doors are now public. Representatives from LymeDisease.org have served on Working Group subcommittees since its inception, drafting portions of the report that goes to Congress and testifying at their hearings.

Symptom Checklist and Physician Directory

LymeDisease.org provides patients with the tools to get promptly diagnosed and treated. Our Symptom Checklist helps patients determine whether they have been exposed to Lyme disease and assess whether they should see a healthcare practitioner. The checklist is designed to educate both patients and physicians. After completing the checklist, patients can take a print out of their results to their physicians to assist in diagnosis. Millions of people have used the symptom checklist to help obtain an earlier diagnosis.

We also connect patients with Lyme-literate doctors who specialize in caring for patients with Lyme disease. Tens of thousands of patients have used our directory to locate physicians to diagnose and treat their Lyme disease.