



lymedisease.org

POWERED BY PATIENTS

Founded 1989

LymeDisease.org is one of the oldest and most trusted Lyme disease advocacy organizations in the country. Tens of thousands of patients help us improve patient care, advance Lyme disease research, and impact healthcare policy. We do this by giving patients the information they need to get well and engaging in science-based advocacy through the MyLymeData patient-led research project, which pools patient data to accelerate research using real-world evidence.

We Empower Patients through Education and Research

LymeDisease.org is fueled by patients. We believe there is strength in numbers. Informed patients who participate in their own treatment, advocacy, and research are powerful.

We aggregate patient data about their healthcare journey in the MyLymeData patient registry to increase our scientific understanding of chronic Lyme disease at a time when the federal government has halted all therapeutic trials for chronic Lyme disease. The registry's data is published in peer-reviewed papers and used to improve state and federal health care policy. To help develop better diagnostic testing, MyLymeData has also helped researchers recruit for two diagnostic studies.

We Believe:

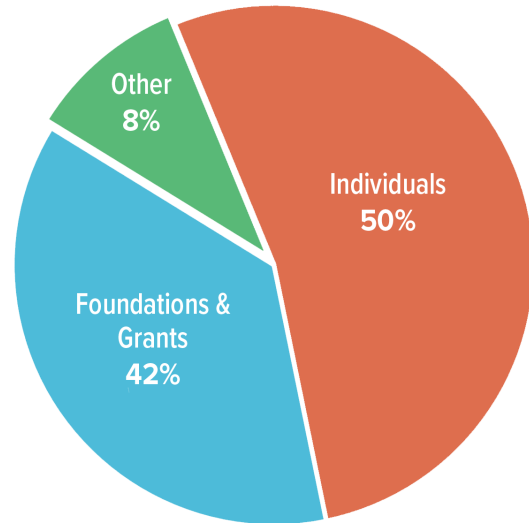
- Lyme patients must have access to quality medical care.
- Medical care should address the needs of patients.
- Patients are entitled to make choices about their treatment options.
- Patients must be given the information necessary to make informed choices.
- Research that matters to patients must be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

Your donations support our efforts on behalf of Lyme patients throughout the nation.

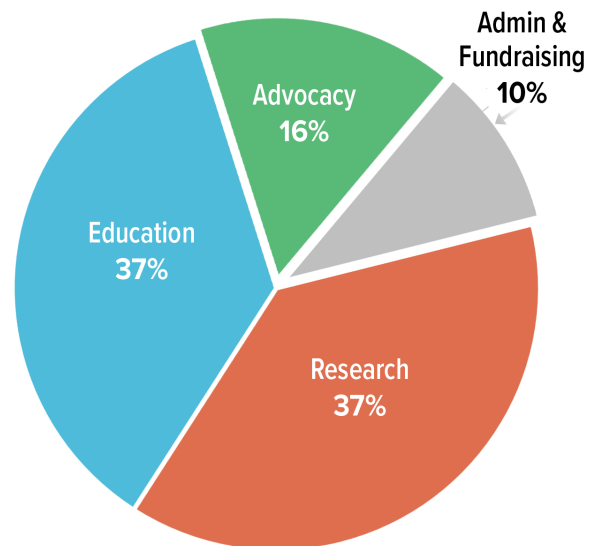
Grassroots donations are a major source. We keep administrative costs to 10%.

Where our money goes:

2022 Sources of Funds



2022 Uses of Funds



In 2021, LymeDisease.org surveyed 155 US clinicians from 30 states to better understand the challenges that clinicians face when treating patients with persistent or chronic Lyme disease.

The results highlighted the extensive experience of clinicians who treat persistent Lyme disease, as well as the stigma and legal challenges they face. It also addresses the complexity and time intensity of the care provided and the fact that the traditional insurance-based health-care model does not work in chronic Lyme disease.

“ 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

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 18,000 participants, collected over 5 million data points, published seven 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 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

We amplify the patient voice, create the tools necessary to drive healthcare policy change, and represent the patient community. Public policy reform cannot happen without healthcare data supporting the need for change. We generate patient and physician data through surveys and the MyLymeData registry. Patients use this data and the peer-reviewed studies we publish to promote Lyme-related legislation in their states and in the federal arena.

We also gather patients together for focused action. For example, we marshaled the Lyme community to contact Congress urging passage of the 21st Century Cures Act of 2016, which formed the Tick-Borne Disease Working Group. For the first time, Lyme patients were included in a federal advisory committee--and discussions that would have occurred behind closed doors were now required to be public. Representatives from our organization served on TBDWG subcommittees, gave public testimony, and drafted key portions of the reports to Congress. Along the way, we made sure Lyme patients were informed about the Working Group. Without our news coverage, Lyme patients would have had no easy way to stay abreast of developments that could profoundly affect their future.

Symptom Checklist and Physician Directory

LymeDisease.org provides patients with tools to get promptly diagnosed and treated. Our Symptom Checklist is designed to educate both patients and physicians. After completing the checklist, patients can take a printout of their results to their physicians to assist in diagnosis.

We also connect patients with Lyme-literate doctors via our Physician Directory.