

What We Do

Education And Outreach

We educate the community and policy makers through our website and blogs. We also help inform the medical community, researchers, and policymakers through medical journal publication. Our board members have over [40 peer-reviewed publications](#).

The Lyme Times

We inform the community about Lyme disease news, treatment approaches, research and political action through our [quarterly digital journal](#). [Join today](#) to receive The Lyme Times.



Grassroots Advocacy

Solving the critical health problems faced by Lyme patients requires grassroots involvement as well as local and national advocacy. We promote these efforts through our state-based

internet groups that teach patients how to make a difference in the fight for early diagnosis and treatment. We also lead the charge in protests and petitions. Our petition calling for revision of the treatment guidelines of the Infectious Diseases Society which deny care to patients with Lyme disease has drawn over 30,000 signatures.

Research

LDo funds research that matters to patients. Our research committee includes scientists, physicians and patients working together to determine and fund patient centered research. LDo has funded research at Stanford, the University of Connecticut at New Haven, Stony Brook, and Johns Hopkins. We engage patients in crowdfunding campaigns to promote the work of Lyme research. Over 10 years ago, we started collecting and publishing patient data through surveys of thousands of patients. Today, our big data project, MyLymeData, is the largest study of Lyme disease ever conducted—with over 10,000 patients enrolled. The National Science Foundation has granted \$800,000 to academic researchers at UCLA and Claremont McKenna to explore big data techniques using data from the registry.

Healthcare Policy

LDo provides legal, ethical and healthcare policy analysis for the Lyme community. We fight for access to appropriate medical care for Lyme patients and for the rights of their treating physicians. We review state and federal legislation and compile data from our surveys to support policy change. We were a driving force behind the Connecticut Attorney General's civil investigation of the Infectious Diseases Society of America's Lyme guideline development process. We provide a number of [healthcare policy resources](#), as well.

We seek to change public healthcare policy through advocacy and science. For the past 10 years, our executive director has been actively involved in the arena of evidence-based medicine and patient-centered care, both nationally and internationally. Currently, she leads the Patient Council for PCORnet, the research network of a government funding agency called the Patient Centered Outcomes Research Institute. She also is Co-Chair of Consumers United for Evidence-Based Medicine, a coalition of 40 patient organizations, and is a consumer peer reviewer for the Cochrane Colloquium.