

# About LymeDisease.org



We were founded in 1989 as a small grass-roots organization in Ukiah, California. Today, we are one of the most trusted sources of information by patients – annually reaching over 3.5 million unique visitors on our website.

LymeDisease.org is grounded in the principles of patient empowerment, participation, and self-determination. We fight to make the patient voice stronger to

- support science-based advocacy
- bring about legislative change, and
- create a future where Lyme patients can receive the treatments they need to get well.

LymeDisease.org empowers individual patients by educating them, amplifying their collective voice, and providing research tools like our published big data surveys and the MyLymeData patient registry. We believe that there is strength in numbers.

## **Patient Driven Big Data 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.

### **Empowering Patients:**

One of our key goals is patient involvement at all levels of decision making, from research project selection to guideline development and, ultimately, to individual treatment decisions. Our CEO, Lorraine Johnson, is a co-author on the Lyme disease treatment guidelines of the International Lyme and Associated Diseases Society. When legislation to form the federal Tick-Borne Disease Working Group was being enacted, over 14,000 Lyme patients used our legislative tools to close the vote within a matter of days. We advocate for patient voices to be heard in health policy-making circles and at the physician's office. We encourage all concerned with Lyme disease to become advocates for change—to improve the plight of the Lyme patient by increasing public awareness and pressing for legislative research solutions.

### **We believe:**

- Lyme patients must have access to quality medical care.
- Patients have the right to be shown respect and that those involved in their healthcare should be accountable.
- Patients have the right to make choices about their doctors and their treatment options.
- Patients must be given the information necessary to make informed choices.
- Research that matters to patients must be funded.
- Patients must have a voice whenever policymakers make decisions about Lyme disease.

These issues are urgent. We challenge the status quo and hold public officials accountable as we shine a public spotlight on controversy.