

# LDo Launches MyLymeData

## Add your Lyme data to MyLymeData to make Big Data work for all patients

By Lorraine Johnson, JD, MBA

Over 300,000 people contract Lyme disease in the United States each year. It's six times more prevalent than HIV/AIDS and almost twice as common as breast cancer. Many people with Lyme stay sick for years. Yet there has been little research on how to help people recover from the illness.

*LymeDisease.org* has launched MyLymeData to help change that. Over the last decade, LDo has launched the largest patient surveys on Lyme disease in the U.S. Our surveys have reached thousands living with Lyme disease — as many as 9,000 individuals took part in a single survey. Data generated by our surveys has been published in major medical and scientific journals, helping to inform treating doctors as well as to influence policy makers.

Now MyLymeData raises the concept of patient surveys to a higher level. It's a way for thousands of Lyme patients to contribute specific information about their Lyme disease experience over time. What symptoms? What treatments? What results?

### A new approach

The term "Big Data" is being used more and more in healthcare these days. When massive amounts of information from thousands of patients with the same disease are gathered and analyzed using computer technology, researchers begin to see patterns that help find solutions. With enough data over time, we can find answers to questions like, "What treatments work best?" and "Why do some patients get better and others don't?"

NIH-funded research has not improved patient outcomes. Forty years after the discovery of Lyme disease, we still do not know the best ways to treat it. Traditional research is expert-centered, driven by the questions and curiosities of individual researchers



themselves. These questions may have little relevance to patients.

Traditional treatment trials for Lyme disease have failed to improve patient care for a number of reasons. Their sample sizes are too small to provide meaningful results. Only 55 patients completed the treatment arm of the Klempner treatment trial — the largest **one** for chronic Lyme disease (CLD). Selection criteria have excluded typical patients from participating.



One NIH researcher screened over 3,368 patients to enroll just 23 in his treatment trial — that's less than 1% of those who applied. None of the NIH trials included patients with co-infections, yet our surveys have found that the majority of patients with chronic Lyme also have co-infections. Most patients do not consider 90 days of treatment to be long-term treatment, but the NIH has never conducted longer treatment trials.

The last NIH-funded treatment trials for chronic Lyme disease closed recruitment over 10 years ago. Because of technological advances in data analysis, patients no longer need to wait for research that may never come. The time has come for patients to press research forward using their own data.

### Patient-centered research


Patient-powered research like MyLymeData puts patients at the center. The LDo project was conceived by patients, is run by patients, and will address issues patients care about. People suffering from Lyme disease want to get well — period. They want researchers to find new and better treatments so they can get their lives back. Research using MyLymeData must address questions important to patients and further their interest in improving quality of life.

Large amounts of patient data will allow researchers to determine the natural progression of the disease, how co-infections affect the course of the illness, and whether Lyme is transmitted sexually or from mother to child. It will also provide information essential to shaping healthcare policy, such as the severity of the disease, the financial toll on families, and its cost to society.

MyLymeData will allow researchers to track patient treatment for years, looking at outcomes that are important to patients. A recent study estimated the cost of CLD based on the assumption that those with the chronic form of the disease are only ill for 4.6 years. Why? Because no one has studied the duration of CLD. We can change that.

Patient-powered research looks at treatment results from real patients. How do co-infections impact patients and their ability

# MyLymeData – PATIENT-DRIVEN RESEARCH



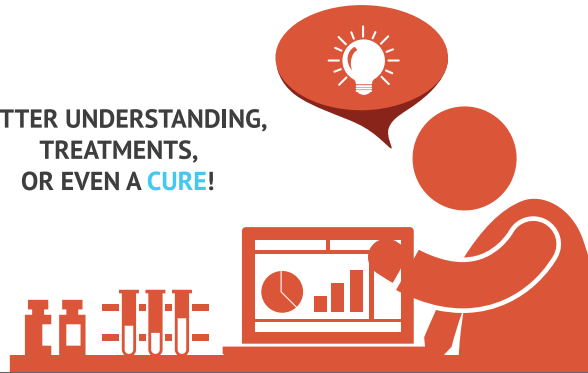
**300,000 PEOPLE  
A YEAR**

If you have Lyme disease, you're not alone. More than 300,000 people in the United States develop this tick-borne disease every year. Yet not much is known about Lyme.



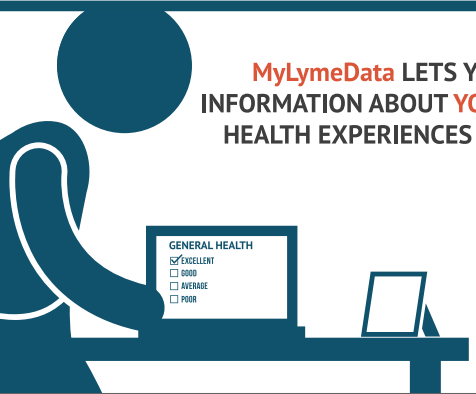
Such as how it progresses. Or the best way to diagnose it. Or why some people get better with treatment and others do not.

## *Add your Lyme data to MyLymeData*



BETTER UNDERSTANDING,  
TREATMENTS,  
OR EVEN A CURE!

... and those patterns could lead to better understanding, treatments, or even a cure for Lyme disease.



**MyLymeData** LETS YOU ENTER  
INFORMATION ABOUT **YOUR** PERSONAL  
HEALTH EXPERIENCES AND **IDEAS...**

MyLymeData allows everyone with Lyme disease to confidentially contribute their personal health experiences and ideas.

MyLymeData is a project of [lymedisease.org](http://lymedisease.org)

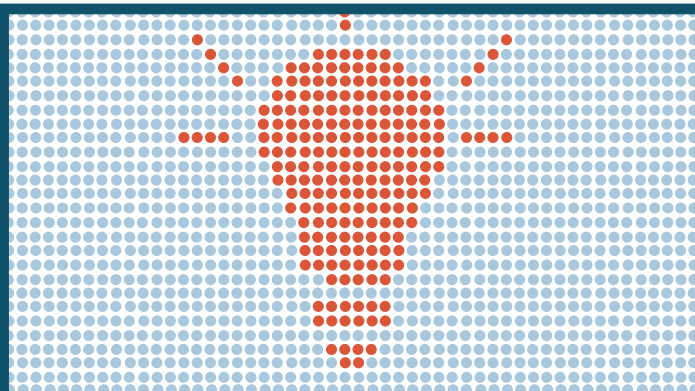
# THAT USES BIG DATA TO SOLVE BIG PROBLEMS

BIG DATA IS A BIG DEAL!

## MyLymeData



Today, there is a new kind of research that allows you to fight Lyme disease with your own health information. It's called Big Data—and Big Data research is a big deal.



When researchers look at your Lyme data and the data of thousands of others living with Lyme disease, they can see patterns.

*and help find a cure for Lyme disease.*

...AND IT'S QUICK, SIMPLE, AND ENSURES YOUR PRIVACY



It's quick, simple, and ensures your privacy. It's also patient-powered, making sure the voices of those living with Lyme disease are heard—loud and clear.

## HELP FIND A CURE!



Today, with the help of big data, it's within your power to add your voice to the voice of thousands of others. Add your Lyme data to MyLymeData—and help find a cure for Lyme disease.

Watch the video at [lymedisease.org](http://lymedisease.org)

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to get well? How do patients respond to treatment that's longer than three months? This project offers a way to answer those questions. MyLymeData will provide information on treatments people are actually using, whether prescribed by their physician or independently chosen by the individual. Did the patient use IV rocephin? If so, for how long and with what result? What about far-infrared saunas or other alternative treatment approaches?

### How MLD works

Participating Lyme patients share their personal experiences via a secure website designed to protect their privacy. Once an individual is registered with MyLymeData, the person will come back periodically to update his or her progress. What treatments have been tried? Did they help? Have any symptoms cleared up? Have new ones developed? Patients can also see how they compare generally with other patients in the project. For example, a patient who had an EM rash can see how many other patients in MyLymeData had such a rash. Patients with Lyme disease are justifiably concerned about

privacy. Participating patients control who has access to their data and the purpose it may be used for. Researchers using this information must demonstrate to LDo that it is being used for projects that will benefit patients. MyLymeData puts privacy in the hands of patients where it belongs.

Many patients want to help advance the Lyme disease cause, but are too sick to take on any extra task. Some patients barely make it through the day. But MyLymeData is quick and easy to use. Silver Feldman, who was diagnosed with Lyme at age 13, describes it this way: "People are still suffering unnecessarily given the tools and research possible today. When I was at my sickest I couldn't do much to help, but I could have done this."

To get started, simply visit [LymeDisease.org](http://LymeDisease.org) and click the *MyLymeData* button. We hope you will add your Lyme data to MyLymeData to help find a cure for Lyme and other tick-borne diseases. And why not go one step further? Invite other Lyme patients you know to participate as well. The more people who take part, the more powerful the database will be.

## Why I will join MyLymeData ... and you should, too!



My name is Jo Anne and I've been involved with LDo for over eight years. I'm usually happy to contribute in the background, and you might never know I'm here doing administrative work that helps LDo help Lyme patients everywhere.

But right now, LDo is launching its patient registry — MyLymeData — and I can't sit back and hope that you take the time to join the registry. I have to jump up (figuratively) and ask you to participate.

You see, in my family it is my mother who has Lyme. She contracted it in her 70's and has suffered a great deal. We caught it early and treated her right away, yet she continues the battle. My mom is in her 80's now, and sadly not much is known about Lyme in geriatric patients — no studies, no research, no experts. Zero. Zip.

On day one, I will be standing in line (with my mom by my side) to enter her history of diagnosis, treatment and ongoing symptoms into MyLymeData. I want her experience to count for something. I want LymeDisease.org and approved researchers to gather information on all of the "over-80's" dealing with Lyme, so that someday soon someone else's little mother will have a better outcome.

Join me. It's safe and secure — we greatly value your privacy. Let's build the body of data that researchers and doctors need to unlock the key to effective testing and treatment. Let's share our health information, so we'll be able to say that, although our families suffered, we did what we could to lead researchers to a cure.

Email me at [jvidal@lymedisease.org](mailto:jvidal@lymedisease.org) if you have questions about the registry.