# LymeDisease.org launches MyLymeData – the first patient-powered research project aimed at improving care for Lyme disease patients

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LOS ANGELES, Nov. 12, 2015 /PRNewswire-USNewswire/ -- LymeDisease.org, one of the largest non-profit Lyme disease patient advocacy organizations in the world, today announced the launch of MyLymeData, the first-of-its-kind national patient-powered research project aimed at improving the quality of care for Lyme disease patients.

The MyLymeData registry allows patients to pool their health information through a secure website. "Big data" projects use advanced technology to gather and analyze huge amounts of patient data, which can assist researchers in studying disease patterns and answering important questions such as *Why do some people recover from Lyme disease, while others remain ill?*
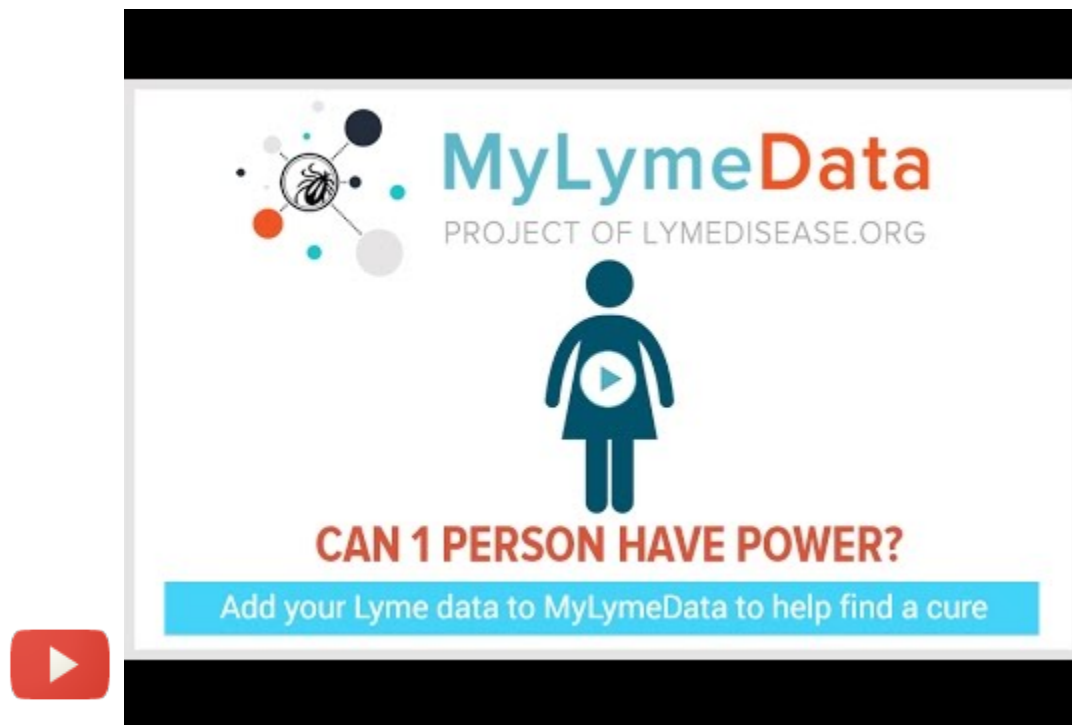
MyLymeData is a patient-powered research project. It was conceived by patients, is run by patients, and addresses the issues that patients care...

"Patients have more at stake in the diagnosis and treatment of Lyme disease than anyone else involved in their healthcare," says Lorraine Johnson, JD, MBA, Chief Executive Officer of LymeDisease.org. "Analyzing large amounts of data can provide insight into how the disease progresses and how effective certain treatments are."

MyLymeData comes at a time when concern over the tick-borne disease is grabbing national headlines. The number of reported cases has exploded in recent years. At least 300,000 people in the U.S. are diagnosed with Lyme disease annually according to the Centers for Disease Control and Prevention (CDC). The tick-borne disease is twice as common as breast cancer and six times more prevalent than HIV/AIDS.

Yet there has never been a large-scale study of chronic Lyme disease. Only 55 patients completed treatment in the largest trial conducted by the National Institutes of Health (NIH), and it's been more than 15 years since the NIH has funded a treatment trial for chronic Lyme disease.

Big data projects look at the actual care ordinary patients are prescribed by their treating doctors. "This is real-world research. We need to find out what treatments are the most effective in actual clinical practice and what factors affect treatment response," says Dr.Raphael Stricker, a Lyme disease specialist in San Francisco.

LymeDisease.org developed MyLymeData in response to an outcry from patients over ineffective treatments. "The time has come for patients to push research forward using their own data. MyLymeData will accelerate research that is essential for finding answers that patients need," says Johnson.

In addition to analyzing disease patterns, MyLymeData hopes to attract researchers interested in launching clinical trials. Patient privacy is critical. To ensure data is protected and secure, LymeDisease.org has partnered with PatientCrossroads, the leading provider of patient registries for the National Institutes of Health.

For more information or to enroll in MyLymeData, visit LymeDisease.org.

About LymeDisease.org
Since 1989, LymeDisease.org has advocated nationally for quality accessible healthcare for patients with Lyme and other tick-borne diseases. We are committed to shaping healthcare policy through advocacy, legal and ethical analysis, education, physician training, and medical research. Our mission is to prevent Lyme disease, prevent early Lyme disease from becoming chronic, and to obtain access to care for patients with chronic Lyme disease.

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