

Big data and patient-powered research aim to solve complex diseases
Thousands enroll in patient registry to solve Lyme disease

Los Angeles — Over the past forty years, little has been learned about how to prevent, diagnose and effectively treat one of the most complex infectious diseases in the country — chronic Lyme disease. But now, big data tools like patient registries have the potential to change that.

Lorraine Johnson, chief executive officer of LymeDisease.org, will join representatives from the White House Office of Science and Technology and Johns Hopkins Medicine at the annual meeting of the American Association for the Advancement of Science (AAAS) on February 13 in Washington, DC. They will discuss the tremendous promise big data holds for solving complex illnesses like Lyme disease. Johnson's talk, *Big Data and Patient Powered Research*, will explain why patient-centered big data may be a game changer for chronic Lyme disease.

LymeDisease.org recently launched MyLymeData, the first national patient-powered registry to accelerate research for chronic Lyme disease. The registry has received an overwhelming response — enrolling more than 3,000 patients in three months.

Traditional randomized controlled trials can provide important information. However, only three trials in chronic Lyme disease have been funded by the National Institutes of Health (NIH) and they studied too few people (37 to 129) to yield meaningful results. "You need sample sizes in the thousands to perform the subgroup analysis necessary to tell us why some patients respond to treatment, while others don't," says Johnson.

Subgroup analysis can be critical in Lyme disease where treatment response may depend on different factors, such as how early the patient was diagnosed or whether the patient also had been infected with other tick-borne pathogens. Patient-powered research networks like MyLymeData are uniquely suited to study this diverse patient population and evaluate complex treatments that are provided in a real-world practice.

Big data tools allow patients to pool their data so that research can be performed quickly and inexpensively. "The last treatment trials of chronic Lyme disease were funded over 15 years ago. We now have the technology to do this today. Patients no longer need to wait," says Johnson.

The Centers for Disease Control and Prevention (CDC) recently revised its estimate on the number of Lyme disease cases in the U.S. from 30,000 to 300,000 annually. The disease is six times more prevalent than HIV/AIDS and almost twice as common as breast cancer.

Many patients who contract Lyme disease remain seriously ill after treatment. In fact, some studies suggest treatment failure rates may be as high as 35% to 50%. "Nobody knows for sure, but estimates based on treatment failure rates suggest that between 1 and 3 million people may currently be living with Lyme disease — a number that grows larger every year," says Johnson.

The financial costs of failing to address this problem are staggering as well. Research indicates that medical expenditures alone for treating Lyme disease may exceed \$1.3 billion. Other studies suggest the cost to society, in terms of loss of productivity, may be even higher. Forty-three percent of patients report having had to stop work due to the disease, while 24% report that they are receiving disability.

“The only way we are going to increase our understanding of chronic Lyme disease and be able to answer the important questions that directly impact patients’ lives is through big data projects like MyLymeData,” explains Johnson. “It is going to be individual patients coming together and sharing their information that will accelerate research to figure out this disease once and for all.”

About LymeDisease.org

Founded in 1989, LymeDisease.org advocates nationally for high-quality, accessible health care for patients with Lyme and other tick-borne diseases. The organization is committed to shaping health policy through advocacy, legal and ethical analysis, education, physician training, and medical research. LymeDisease.org’s mission is to prevent Lyme disease, prevent early Lyme disease from becoming chronic, and obtain access to care for patients with chronic Lyme disease. More information is available at <https://www.lymedisease.org>.

About MyLymeData

MyLymeData is the first national patient-powered research project for chronic Lyme disease. It was conceived by patients, is run by patients, and addresses the issues that patients care about. Through a secure online portal, patients can share health information and experiences living with the disease that can help drive research to improve their lives. MyLymeData will allow researchers to better understand the progression of the disease, what treatments are most effective and why some people stay sick, while others do not. To enroll or learn more about MyLymeData, visit www.lymedisease.org/mylymedata.

Media Contact:

Dorothy Leland
dleland@lymedisease.org
530-574-8123