



*National Science Foundation Grant Supports MyLymeData Research*

*LymeDisease.org Announces Major Award That Explores Big Data Techniques*

LOS ANGELES, September 18, 2017 /PRNewswire-USNewswire/: The National Science Foundation (NSF) has awarded a three-year, \$800,000 grant to explore predictive analytic techniques using data collected by the MyLymeData patient registry. Researchers at the University of California Los Angeles (UCLA) and Claremont McKenna College will collaborate with LymeDisease.org on the big data project.

Lyme disease, a bacterial infection transmitted by the bite of a tick, can be difficult to diagnose and treat. Many patients diagnosed with Lyme disease remain ill after treatment, while others improve. Precision medicine uses predictive analytic tools and artificial intelligence to identify and target treatment approaches to those patients most likely to respond

LymeDisease.org, a national patient advocacy organization, launched MyLymeData in 2015. **The project has enrolled over 9,000 patients since then, putting it in the top 5% of patient-led registries in the nation.** FasterCures, a non-profit organization that promotes innovation in medical research, recently surveyed patient-led registries. Out of over 110, only two had enlisted more than 10,000 people. MyLymeData is on the brink of 10,000 patients enrolled.

**MyLymeData**  
A PROJECT OF LYMEDISEASE.ORG

**The National Science Foundation (NSF) has granted an \$800,000 three-year award supporting research using data collected by MyLymeData registry.**

More than one million data points have been collected, related to the nature and severity of symptoms, how long it has taken patients to be diagnosed and what treatments have been most effective. According to Lorraine Johnson, CEO of LymeDisease.org and Principal Investigator of MyLymeData, the registry expects to be the largest study of Lyme disease ever conducted.

“Big data research is key to advancements in Lyme disease,” said Johnson. “The largest government-funded study of chronic Lyme patients enrolled just 129 patients. Our goal is not only to gather data to help find a cure, but also to help recruit patients for clinical trials.”

The research effort will be led by Drs. Deanna Needell (Professor of Mathematics at UCLA) and Blake Hunter (Assistant Professor, Claremont McKenna College). The team has extensive experience with big data synthesis, analytics, and deep learning approaches.

“The NSF grant will allow us to develop cutting-edge mathematical tools,” said Dr. Needell. “Validation of these tools requires a large real-world database, and MyLymeData fits the bill perfectly.”

The infographic is divided into three main sections at the top. The left section, titled 'Largest Government Study', features an icon of the US Capitol building and states '129 patients enrolled'. The middle section, titled 'LYME DISEASE RESEARCH', includes the LymeDisease.org logo. The right section, titled 'MyLymeData', features a network diagram with a tick icon and states '> 9,000 patients enrolled'. Below these sections is a central banner with a group of diverse people and the text: 'MyLymeData is the largest study of Lyme disease ever conducted. It has collected over 1 million data points.' Below this banner is a row of icons representing various medical and research concepts: a clipboard, a microscope, a syringe, a flask, a brain, and an eye. To the right of these icons is a green banner that reads: 'Researchers funded by the National Science Foundation are using MyLymeData to see why some patients get well.' At the bottom, there are two orange banners. The left one says: 'It is patient-centered. It was conceived by patients, is run by patients & focuses on issues patients care about.' The right one says: 'Add your Lyme data to MyLymeData today. Visit [www.MyLymeData.org](http://www.MyLymeData.org)' with a laptop icon.

Patient registries play a vital role in the progress of data-driven science. “MyLymeData is part of an essential shift in research recognizing the importance of precision science, precision diagnostics and precision medicine,” said Dr. Raphael Stricker, a San Francisco internist and co-principal investigator on MyLymeData. “Without advancements in these areas, the research environment in Lyme disease will stagnate.”

MyLymeData is open to patients diagnosed with Lyme disease who reside in the United States. Additional information can be found on the LymeDisease.org website. Johnson will present preliminary results from MyLymeData later this week at the annual Columbia University/Lyme Disease Association meeting in Philadelphia.

**About MyLymeData:** MyLymeData is a longitudinal study that tracks patients' progress over time. It is an ongoing process where patients contribute their experiences so that trends are defined. Patients at all stages of the illness, as well as those who have recovered, are encouraged to join. Family members of deceased patients can report information on their loved ones' behalf.

**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 science-based advocacy.

**About the National Science Foundation:** Created by the U.S. Congress in 1950, the NSF promotes the progress of science, advances national health, prosperity, and welfare, and works to secure our national defense.

Media Contact:

Lorraine Johnson

LymeDisease.org, CEO

[lbjohnson@lymedisease.org](mailto:lbjohnson@lymedisease.org)

323-387-3848

Related Links

<http://www.lymedisease.org>