

MyLymeData Researchers Receive National Science Foundation Grant

The National Science Foundation (NSF) has awarded a three-year, \$800,000 grant to researchers to explore the application of predictive analytics, artificial intelligence, and precision medicine to Lyme disease. Mathematicians at the University of California, Los Angeles (UCLA) and Claremont McKenna College will collaborate with LymeDisease.org on the big-data project using information collected by the MyLymeData patient registry.

MyLymeData is a longitudinal study that tracks patients' progress over time. It is an ongoing process where patients contribute their experiences so that trends can be defined.



More than 10,000 patients have enrolled in the project, resulting in more than a million data points related to the nature, duration, and severity of patient symptoms.

“That’s much more information than has ever been collected before about the experiences of Lyme disease patients,” said Lorraine Johnson, CEO of LymeDisease.org and principal

investigator of MyLymeData. “Such a treasure trove of data can greatly improve our understanding of the illness....The more we know about it, the more likely we’ll be able to find a cure.” However, she notes, dealing with such vast amounts of data requires special mathematical techniques to effectively extract and analyze the information.

That’s where researchers Deanna Needel, PhD, of UCLA, and Blake Hunter, PhD, of Claremont McKenna, come in. They bring extensive experience with big-data synthesis, analytics, and the branch of mathematics known as “deep learning.”

“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.”

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According to Johnson, big-data research is essential for advancements in Lyme disease. “The largest government-funded study of chronic Lyme patients enrolled just 129 patients,” she said. “That’s simply too small a sample from which to draw meaningful conclusions.”

Using information from MyLymeData’s 10,000-plus participants will allow researchers to zero in on why some patients recover from treatment and others do not. Furthermore, the precision medicine approach lets researchers develop treatments that target the particular needs of individuals, often based on their specific genetic makeup.

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, the project’s co-principal investigator. “Without advancements in these areas, the research environment in Lyme disease will stagnate.”

MyLymeData is open to people who have been diagnosed with Lyme disease and reside in the United States. Family members of Lyme patients who have died may enter information about their loved ones. [Click here to join.](#)

Shortly after the announcement of the NSF grant, Johnson was interviewed by Robert Herriman, MPH, on “Outbreak News This Week Radio Show.” They discussed chronic Lyme disease, differing medical opinions about Lyme treatment, and how the MyLymeData project will empower patients. Click below to hear the interview.



 **Lorraine Johnson, CEO of LymeDisease.org interviewed on Outbreak News This Week Radio Show**

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Editor’s note: Any medical information included is based on a personal experience. For questions or concerns regarding health, please consult a doctor or medical professional.

