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Big Data and Precision Medicine are Helping Identify Patients who Improve with Lyme Disease Treatment

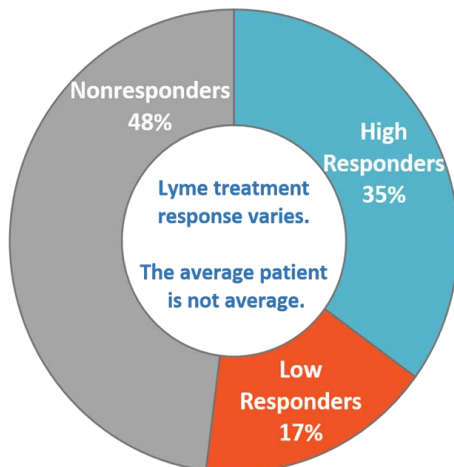
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35% of MyLymeData patients report moderate to high improvement following treatment

LOS ANGELES, June 8, 2017 /PRNewswire-USNewswire/ -- A new study suggests that developing effective treatments for Lyme disease may depend on understanding which patients respond to different treatments. Data collected from over 3,400 patients through LymeDisease.org's MyLymeData online patient registry suggest that big data analysis techniques can identify subgroups of patients that respond well to treatment. Some chronic Lyme disease treatment studies done in the past have failed to identify treatment successes, but relied on samples of patients too small (37-129 patients) for subgroup analysis.

Finding effective treatments is critical. Over a third of those diagnosed and treated for Lyme disease develop persisting debilitating symptoms following short-term antibiotic therapy. According to the CDC, at least 380,000 people are diagnosed with Lyme disease in the U.S. every year.



At PharmaSUG's recent Baltimore conference, biostatistician Mira Shapiro presented a paper examining how much patients' condition changed following antibiotic treatment. When treatment response was averaged over all patients in the sample, treatment effects were small. However, when patients were broken into three subgroups, it was clear that some patients reported a large treatment effect while others reported minimal or no treatment effect.

The survey used a global rate of change scale, typical of those used by clinicians in practice. Patients reported whether their condition was improved, unchanged, or worse on a 15 point Likert Scale, used in studies of other diseases. Response choices ranged from "a very great deal worse" to "a



very great deal better," with a midpoint of "unchanged" or "almost the same."

Responses were grouped into 3 categories: High Responders ("moderately better" to "a very great deal better"), Low Responders ("hardly better at all" to "somewhat better") and Nonresponders ("no change" to "a very great deal worse").

Forty-eight percent of the patients in the study were characterized as Nonresponders. They reported that their condition had either gotten worse or had not changed following treatment. More than 50% of patients surveyed reported some degree of improvement. Thirty-five percent were High Responders, while Low Responders accounted for 17%.

Subgroup analyses involves splitting participant data into subgroups to permit comparison between the groups. Shapiro says that, big data allows us to identify important subgroups that respond to treatment. "Patients with chronic Lyme disease vary in their response to treatment," she explains. "Averaging results across patients can mask important differences in treatment response."

According to Lorraine Johnson, JD, MBA, Chief Executive Officer of LymeDisease.org and coauthor of the study, this type of analysis is the key to improving the lives of Lyme disease patients. "Other diseases like tuberculosis categorize patients into groups based on how they respond to treatment. It's time for Lyme disease research to enter the 21 Century," she says.

Since its launch in November 2015, MyLymeData has enrolled over 8,000 patients in its registry. This study included registry data compiled from 3,400 patients who self-identified as "unwell" during Phase 1 of the project, which was completed in November 2016. Patients in this preliminary study reported living in the United States, being diagnosed with Lyme disease by a healthcare practitioner and receiving antibiotic treatment.

The newest phase of MyLymeData is open to both current and new enrollees who may register at LymeDisease.org. Patients currently participating in MyLymeData simply log into their accounts to complete the new survey sections.

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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