MS and Lyme disease patients call for more participation in clinical trials

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It is clear that more patients need to be involved in research and clinical trials if we are going to advance our understanding of Lyme disease and improve patient care. Only 4 clinical trials, sponsored by the National Institutes of Health (NIH) have included chronically ill Lyme disease patients. These trials were small and typically included patients 4.7 to 9 years after onset of symptoms and who had already failed initial antibiotic treatment.

Lyme disease patients are not alone. People with multiple sclerosis (PwMS) have called for more involvement in clinical research. And while there has been progress in developing new drugs to treat MS, patients want to be active collaborators, working with researchers to help develop treatments more quickly.

“In the past 23 years, over a dozen disease-modifying treatments have been approved for relapsing remitting multiple sclerosis (RRMS),” writes Smith from KES Business LLC in Lyme, CT. [1] There have been thousands of participants in these multiple sclerosis trials.

“All of these development programs,” says Smith, “required the participation of tens of thousands of people with multiple sclerosis (PwMS) in clinical trials.” But many more will need to be recruited, she adds.

The PwMS community is asking for just that – more involvement.

“The MS community [should] engage patients’ deep insights into the experience of living with MS to identify those measures which most realistically measure the things they care about and which can have potential to provide clinically meaningful information.” [1]

“PwMS can describe the outcomes and functions that are most important to them such as the multifaceted aspects of physical disability, fatigue and cognitive issues, and the need to measure these aspects continuously, rather than as snapshots in time.” [1]

The Lyme disease community echoes the same calls to action and inclusion. LymeDisease.org, a non-profit patient advocacy organization, has developed a tool that allows patients to securely enter their medical data in an effort to accelerate research efforts. MyLymeData, an online registry, has enrolled more than 9,000 patients since its launch in November 2015.

“The project is a true collaboration between researchers and patients — the first of its kind in Lyme disease,” according to Lorraine Johnson, CEO of LymeDisease.org, the non-profit organization that developed the database. [2]

“This allows researchers to examine a vast collection of data and look at how subgroups of patients respond to different treatment approaches,” she says. “It is the first patient-centered research conceived by Lyme disease patients, run by patients and focused on issues that patients care about.”

The National Science Foundation (NSF) recently awarded a three-year, $800,000 grant supporting research that will use data collected by the MyLymeData patient registry.

References:

1. Smith, K., The evolving role of people with MS in clinical research-Some progress but more is needed. Mult Scler, 2017. 23(12): p. 1579-1582.
2. Johnson, L., National Science Foundation awards $800K to researchers using MyLymeData. LymeDisease.org, Sept. 19, 2017. www.lymedisease.org/nsf-mylymedata.

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