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MyLymeData: The Value of Using Big Data and Subgroup Analysis in Lyme Disease

Lorraine Johnson, JD, MBA, is the Chief Executive Officer of LymeDisease.org, which launched the first national Lyme disease patient driven registry and research platform, MyLymeData in 2015. The registry has enrolled over 8,000 patients and is in the top 10% of patient registries in the nation.

She has published over 40 peer-reviewed articles on issues related to Lyme disease, including two large scale patient surveys and two commentaries on big data and patient-powered research networks. ([Johnson, et al. 2011](#); [Johnson, et al. 2014](#) ; [Stricker and Johnson 2016](#); [Fleurence RL, Beal AC, Sheridan SE, Johnson LB, Selby JV](#)) She co-authored the treatment guidelines of the International Lyme and Associated Diseases Society.

She currently serves on the Open Science Expert Panel of the Patient Centered Outcomes Research Institute (PCORI). She has also served as a patient representative of the Patient Engagement Advisory Panel for PCORI, sat on the Executive and Steering committees of PCORI's patient-centered big-data project, PCORnet, and chaired its Patient Council. She participated in the White House Citizen Science convening on precision medicine. She serves on the steering committee of

Consumers United for Evidence-Based Healthcare, a nationwide coalition of consumer groups associated with the international Cochrane Collaboration.

She has spoken before government and scientific conferences nationally and internationally including as a plenary speaker at the Cochrane Colloquium, at the Stanford MedX conference, and at the National Institute of Health Collaboratory. She presented at the American Association for the Advancement of Science annual meeting on the topic of Big Data and Patient Powered Research.

Conference Lecture Summary

In 2015, LymeDisease.org launched the first national Lyme disease patient centered registry and research platform, MyLymeData. The registry has enrolled over 8,000 patients and is in the top 10% of patient registries in the nation. The registry will be used to answer questions that are important to patients and to track real world treatment effectiveness and quality of care improvement. It will also be used as a framework for clinical trials. This presentation will focus on patient-generated data from Phase 1 of MyLymeData and the value of subgroup analysis using big data. This will be illustrated with examples drawing on chronic Lyme disease case definitions, average treatment effect verses subgroup analysis of treatment effect, and the use, effectiveness, and side effects associated with different alternative therapies.