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LymeDisease.org's Lorraine Johnson tapped to participate in "citizen science" forum at the White House



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LOS ANGELES, Sept. 30, 2015 /PRNewswire-iReach/ -- LymeDisease.org CEO Lorraine Johnson has been selected to participate in a White House forum hosted by the White House Office of Science and Technology Policy and Domestic Policy Council, **"Open Science and Innovation: Of the People, By the People, For the People,"** which will be live-webcast on **Wednesday, September 30th**.

The forum brings together citizen-scientists, researchers, and government to focus on the uses of crowdsourcing and citizen science to promote scientific and societal outcomes. A key goal is to spur bolder citizen-science and crowdsourcing use in challenging scientific areas, including healthcare.

Johnson has served on the Executive and Steering committees of PCORnet, the big data healthcare project of the Patient Centered Outcomes Research Institute (PCORI) and serves on the Patient Engagement Advisory Panel of PCORI as well.

Johnson says the promise of patient-powered research and big data are particularly important for patients with Lyme disease. "This type of research has only recently become possible," she says. "By pooling their healthcare data, patients can help answer such questions as which treatments are most effective and why treatments work for some patients but not others."

LymeDisease.org, a non-profit focusing on research, advocacy and education, has played a leading role in advancing citizen science in Lyme disease. Johnson says the group will launch a

patient-centered big data project soon. "We believe the people who will solve Lyme disease are the patients and see this as the wave of the future."

According to the Centers for Disease Control and Prevention, about 300,000 people contract Lyme disease in the US every year. Some of them are diagnosed and treated promptly, suffering no long-term effects. However, many of them are not. Experts estimate that about a third of Lyme disease patients develop long-term symptoms that may seriously impair their health for years.

The public can follow the forum's livestream at [wh.gov/live](https://www.whitehouse.gov/live) from **8 AM-12 PM EDT on Wednesday, September 30. Comments and questions may be sent to [@WhiteHouseOSTP](https://twitter.com/WhiteHouseOSTP) using the hashtag [#WHCitSci](https://twitter.com/WHCitSci).**

About LymeDisease.org

LymeDisease.org is a leading patient advocacy non-profit working to prevent tick-borne diseases, encourage early diagnosis, and improve the quality of health care provided to people with tick-borne diseases. It conducts and publishes large scale patient surveys on Lyme disease. It publishes a quarterly journal, *The Lyme Times*, runs online support groups across the USA, and provides scholarships to healthcare professionals wishing to learn more about treating Lyme disease and other tick-borne infections. The organization educates the public via its website, www.lymedisease.org, as well as through social media.

About Lorraine Johnson, JD, MBA

Lorraine serves as a patient representative on the Patient Engagement Advisory Panel for the Patient-Centered Outcomes Research Institute (PCORI). For the past 18 months, she has also served on both the Executive and Steering committees of PCORnet, PCORI's national patient-centered big-data project. She co-chairs the steering committee of Consumers United for Evidence-Based Healthcare, a nationwide coalition of consumer groups associated with the international Cochrane Collaboration. Johnson is also a co-author of the guidelines of the International Lyme and Associated Diseases Society. They are the first Lyme treatment guidelines to comply with the Institute of Medicine's new standards for rigorous evidence assessment and patient engagement in the development process. She can be reached at lbjohnson@lymedisease.org or on twitter @Johnson_lbj.

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