

On December 11, 2017 I had the privilege of addressing the inaugural meeting of the federal Tick-Borne Diseases Working Group. The first meeting was open to the public and invited patients, family members, and patient advocates to discuss a wide variety of topics related to tick-borne illness.

As the CEO of LymeDisease.org, the largest communications network for individuals with Lyme disease, I was in a unique position to share not only my perspective as a former Lyme patient, but also as the principal investigator for MyLymeData, a research project with more than 11,000 participants.

The meeting was held in Washington, D.C., and I delivered my presentation remotely. You can watch it here; the video begins at 15:49:



I concluded my presentation with the following list of the top ten research priorities for Lyme disease, which was derived from our survey of more 7,000 patients, researchers, physicians, and advocacy groups weighing in.

Top Ten Research Priorities for Lyme Disease

1. What direct diagnostic test would be both highly sensitive and specific for Lyme



disease and coinfections?

- 2. What is the most effective treatment protocol to restore health to patients with Lyme and other tick-borne diseases?
- 3. What is the impact of delayed diagnosis on the course of Lyme disease?
- 4. What natural therapies and protocols are most effective?
- 5. What other diseases (e.g., M.S., Parkinson's) may be caused by Lyme disease?
- 6. What are the most effective methods for rehabilitating the brain in neurologic Lyme disease?
- 7. Why do some people develop chronic Lyme disease after antibiotic treatment?
- 8. What triggers reactivate chronic/late stage Lyme disease and coinfections after remission?
- 9. How do coinfections affect the immune response and course of illness in patients with Lyme disease?
- 10. Are treatment regimens tailored for specific symptoms (e.g., neurologic) more effective?

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.