Tick-Borne Disease Working Group
Patient Centered Lyme Disease Research & Big Data

Tick-Borne Disease Working Group  (Dec.11th, 2017 Wash. DC)
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Empowerment is “a **group-based participatory** . . . process through which marginalized or oppressed individuals . . . gain greater control over their lives. . ., **acquire valued resources and basic rights**, and achieve important life goals and reduced societal marginalization”.

- **4 million unique visitors to website annually**
Chronic Lyme disease is a research orphaned disease

(Goswami, 2013)
Patient generated data from e-registries: valued source of data
FasterCures reports that there are over 110 patient foundation-led registries

- 47% had ≤1,000 participants or fewer
- 44% had between 1,000 and 5,000 participants
- Only 2 registries had more than 10,000 participants

One of the largest and fastest growing patient-led registries in the US

MyLymeData Participants

- 0 participants in 11/2015
- 4,126 participants in 11/2016
- 9,700 participants in 11/2017

FasterCures, 2016
The National Science Foundation (NSF) has granted an $800,000 three-year award supporting research using data collected by MyLymeData registry.
MyLymeData patients are diagnosed late and have coinfections

- **70%** not diagnosed until late stage
- **72%** are initially misdiagnosed
- **60%** diagnosed with a co-infection

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*Phase I- 3,903 enrolled.*

*xxSick for six months or longer, Phase I MyLymeData.*

*Images: Freepik from www.flaticon.com*
Top 10 Research Priorities

Over 7,000 responses from:

Patients
Physicians
Researchers
Advocacy groups

HELP
SET THE
LYME
RESEARCH
AGENDA

#Top10LymeResearch
1. What direct diagnostic test would be both highly sensitive and specific for Lyme disease and co-infections?
2. What is the most effective treatment protocol to restore health to patients with Lyme disease?
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. MS, 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 reactive chronic/late stage Lyme disease or co-infections after remission?
9. How do co-infections affect the immune response and course of illness in patients with Lyme disease?
10. Are treatment regimens tailored for specific symptoms more effective? (e.g. neurologic)
IMAGINE A WORLD where people with Lyme disease are diagnosed and treated correctly and go back to living their lives.

YOU CAN BE PART OF MAKING THIS HAPPEN

MyLymeData

To learn more, visit lymedisease.org/mylymedata
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