Tick-Borne Disease Working Group

Patient Centered Lyme Disease Research & Big Data

lymedisease.org

MyLymeData
A PROJECT OF LYMEDISEASE.ORG

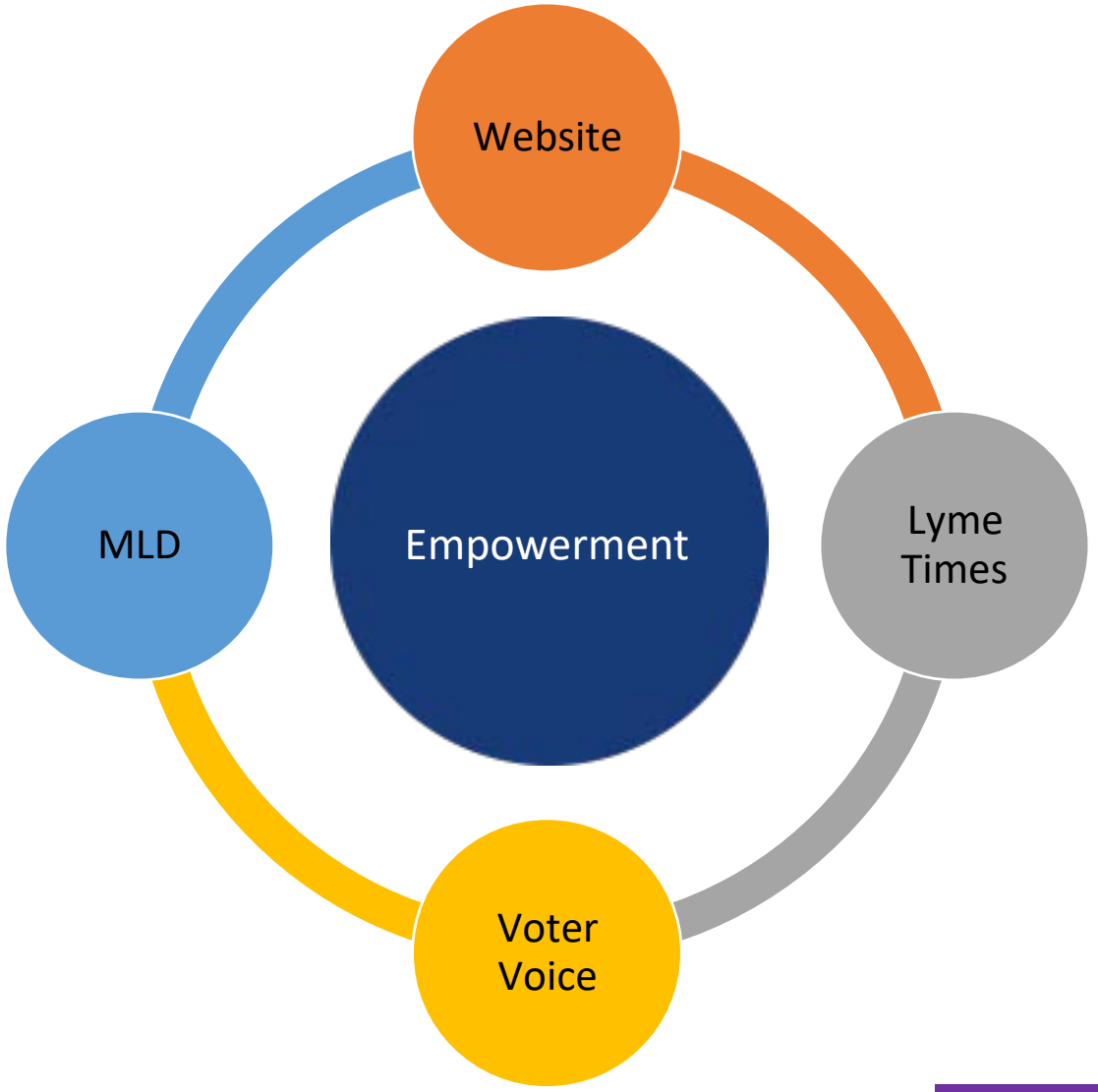
Tick-Borne Disease Working Group (Dec.11th, 2017 Wash. DC)

Lorraine Johnson, JD, MBA CEO LymeDisease.org

Founded in 1989, LDo's focus is on empowering individual patients

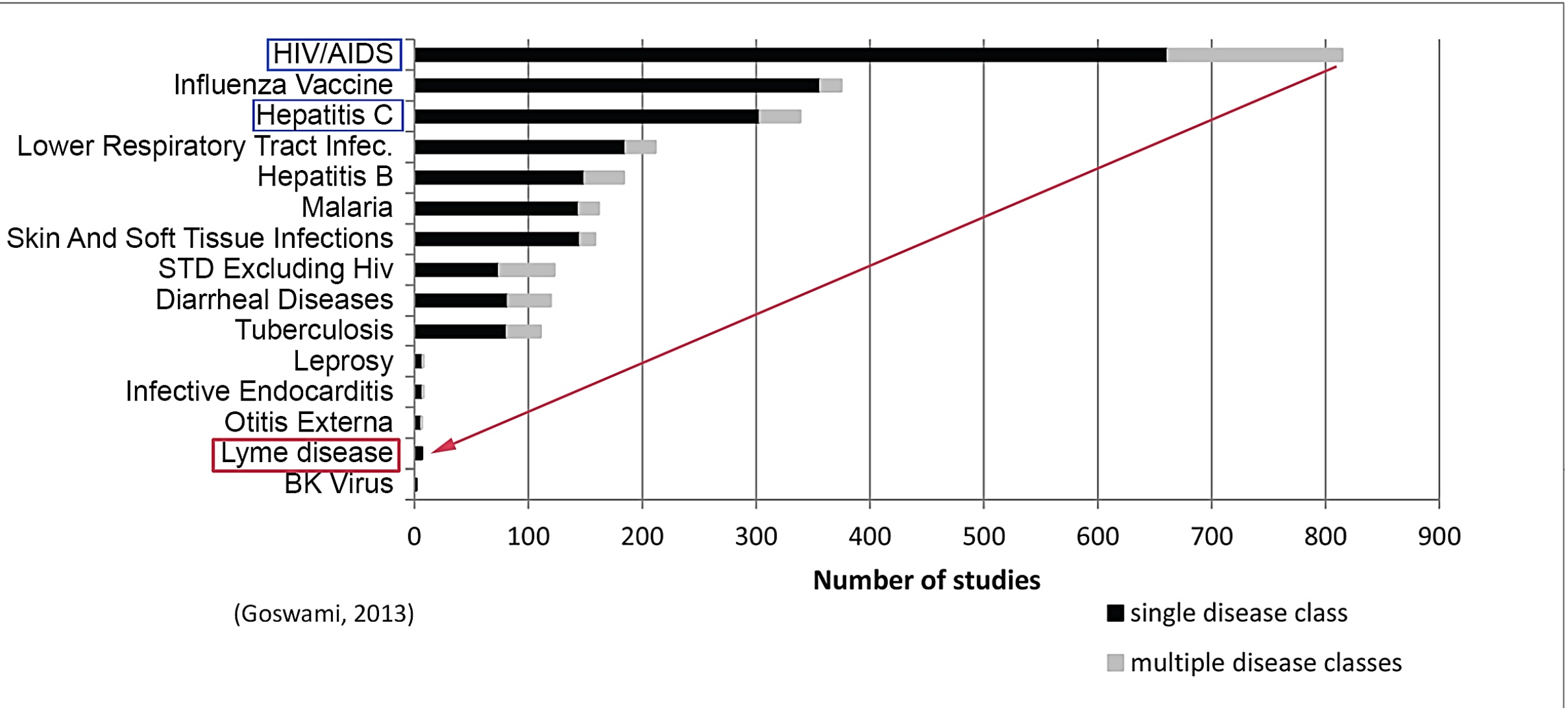
Empowerment is "a **group-based participatory . . . process through which marginalized** or oppressed **individuals . . . gain greater control** over their lives. . ., **acquire valued resources and basic rights**, and achieve important life goals and reduced societal marginalization ".

- **4 million unique visitors to website annually**



Principles of Community Engagement Second Edition

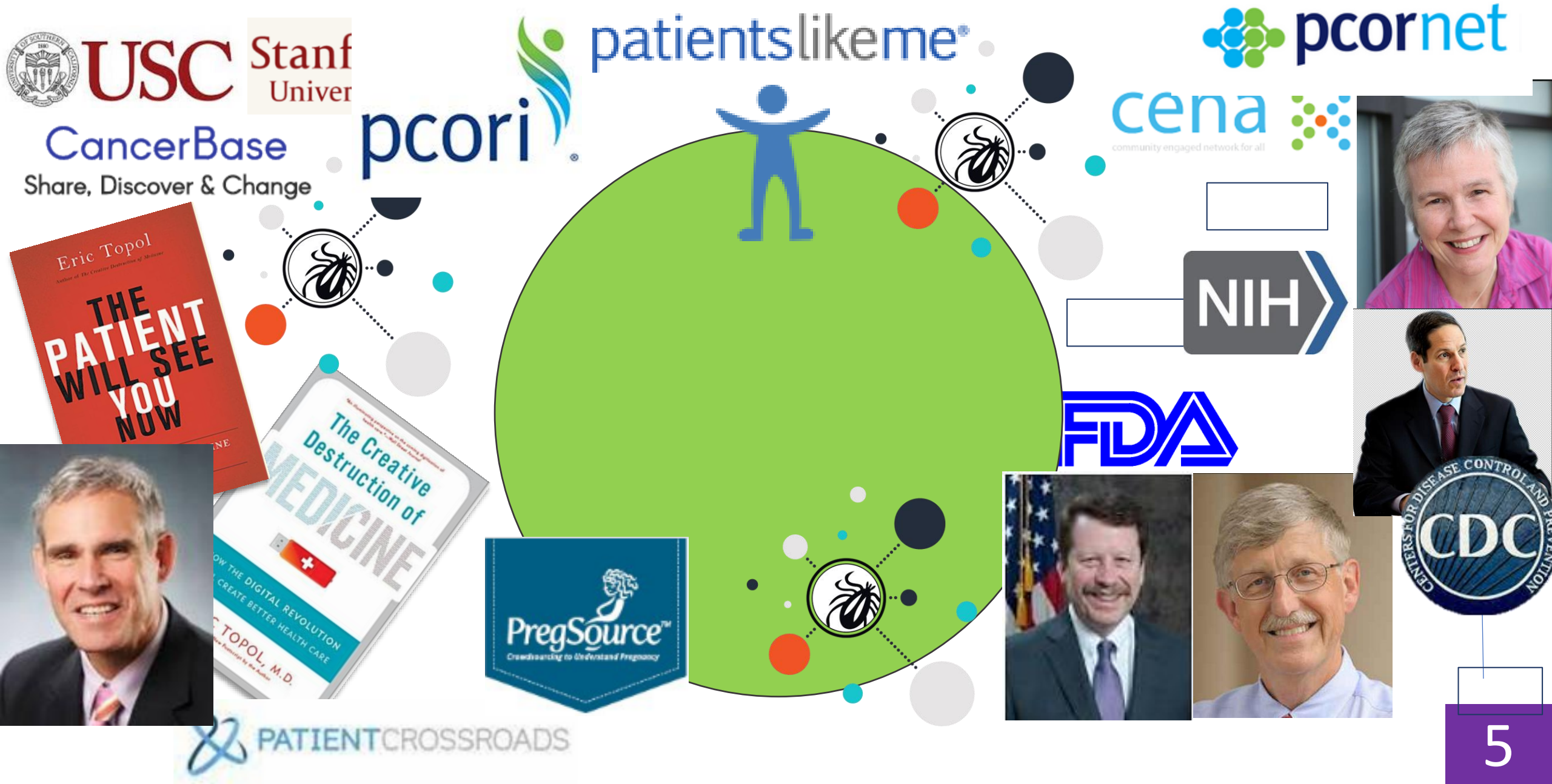
Chronic Lyme disease is a research orphaned disease



(Goswami, 2013)

Goswami, 2013

Patient generated data from e-registries: valued source of data



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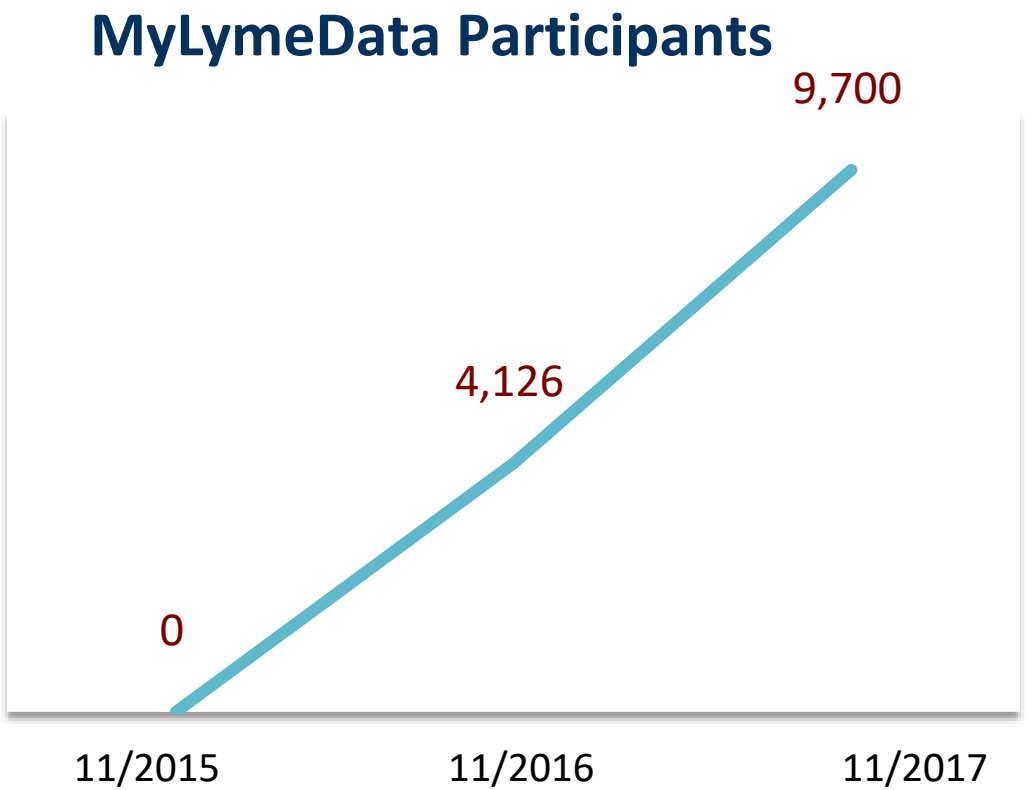
One of the largest and fastest growing patient-led registries in the US

- 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**



FasterCures, 2016

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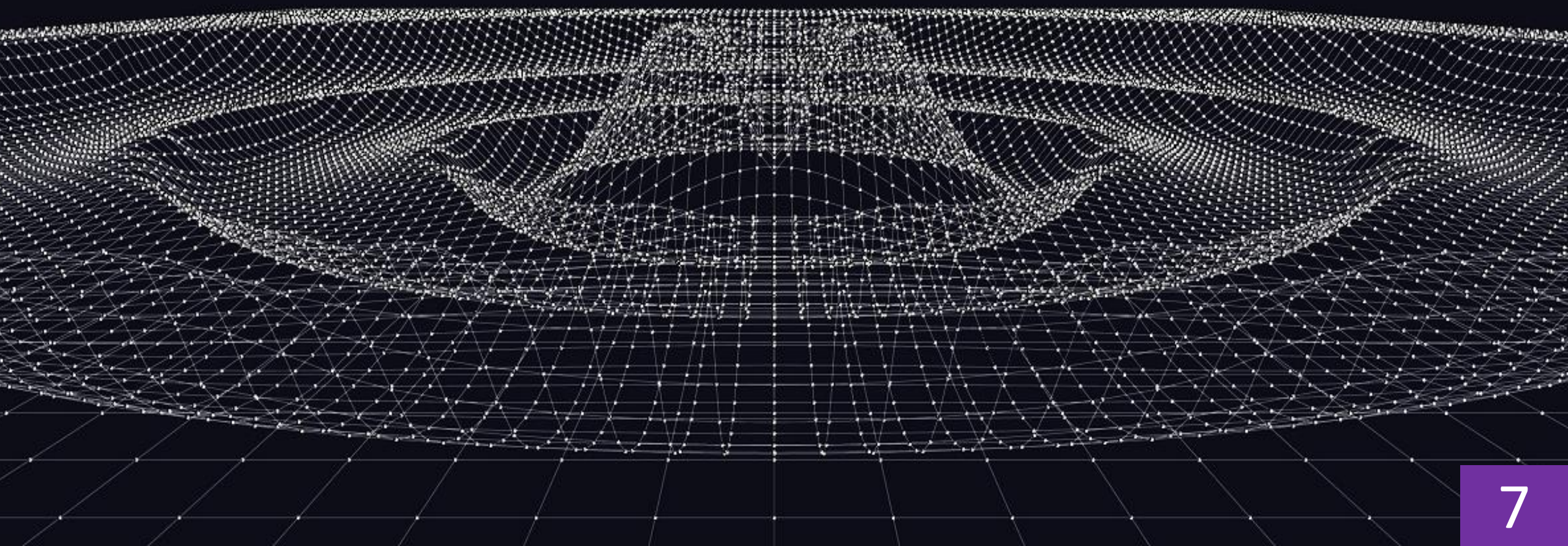
The National Science Foundation (NSF) has granted an $800,000 three-year award supporting research using data collected by MyLymeData registry.



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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[x] Phase I- 3,903 enrolled.
[xx] Sick 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

Top Ten Lyme Disease Research Questions

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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