

Johns Hopkins Medicine Lyme Disease Research Center

March 2022 Newsletter

RESEARCH UPDATE

LONG HAUL LYME DISEASE RISK FOUND, EVEN IN EARLY TREATED PATIENTS

Researchers at our Center found a high risk for long haul Lyme disease in early diagnosed and promptly treated acute Lyme disease patients. Study results were published in the *International Journal of Infectious Diseases* in January 2021.



Lyme Disease Research Center, explains Hopkins Medicine Lyme Disease Research Center, explains key findings and emphasizes that the study shows "persistent symptoms are significant, real, and not in patients' heads". If you are experiencing persistent symptoms and/or are encountering skepticism that Lyme disease can trigger persistent illness, please watch this VIDEO.

This prospective controlled peer-reviewed <u>study</u> found that despite early treatment with standard of care antibiotics, 14% of the Lyme disease patients suffered functionally impairing persistent symptoms when examined 6 to 12 months after treatment compared to 4% in the control population without Lyme disease.

Infection-associated illnesses such as Lyme disease, long haul COVID, and myalgic encephalomyelitis/chronic fatigue syndrome (ME/CFS) share similar symptoms like fatigue, pain, and cognitive dysfunction, and our research could help determine if these conditions have some common biologic mechanisms.

This study contributes to the scientific evidence that infections can trigger persistent illness.



Our annual <u>IMPACT REPORT</u> highlights the tremendous progress our Research Center is making to transform Lyme disease research.

The report shows important insights that our multidisciplinary studies are revealing about the symptoms and biology of acute Lyme disease and persistent symptoms after treatment.

FELLOWSHIP PROGRAM

New Johns Hopkins Medicine Fellowship Program Training the Next Generation of Lyme & Tickborne Disease Doctors

Our Center is launching the first Lyme Disease and Tick Borne Disease <u>Fellowship Program</u> in Internal Medicine in the world. This advanced physician education and training program at Johns Hopkins University Department of Medicine addresses the unique care needs of Lyme disease patients by synergizing the practice of evidence-based, compassionate patient care with leading-edge scientific training and research. The second year of our fellowship includes a capstone research project and fully paid Master's Degree from the Johns Hopkins Bloomberg School of Public Health. We have completed the initial recruitment process and are excited to be welcoming our first fellow on July 1, 2022.

Our mission is to understand and urgently address the varied manifestations of Lyme disease and translate our pioneering multidisciplinary research into improved patient care, education, and health outcomes



HOPE AND RESILIENCE

Ben Goldweber's recovery story offers hope to many patients who are suffering from long haul Lyme disease.

Ben's illness started in 2011 after a camping trip. He returned with a tell-tale Lyme disease bull's eye rash and was treated promptly with three weeks of doxycycline, the standard of care. However, a month later he started suffering from severe headaches, and in the years ahead numerous other symptoms such as heart palpitations, panic-like attacks, joint pain, skin rashes, fatigue, and cognitive problems that were not diagnosed as related to Lyme disease. A splitting headache years later precipitated an emergency room visit that spiraled into



Ben Goldweber kayaking down Great Falls on the Potomac River in Maryland Photograph by Caroline Steel 2021

partial paralysis, along with depression, suicidal ideation and myriad other symptoms. He was seen at the Johns Hopkins Lyme Center for consultation for neuropsychiatric Lyme disease.

Ben, now 26 years old, 11 years after initial infection and six years post IV ceftriaxone, is working full time and enjoying the activities he loves. During the pandemic, Ben rediscovered his passion for white water kayaking and has been embracing life fully again with the thrill, fun, and community he's found on the river. He traverses the twists and turns of the choppy rapids with the same gritty persistence and determination he used to navigate his illness, and he is extremely grateful for his renewed health and spirit.

Ben hopes his story provides others with hope that healing from Lyme disease is possible.

RESEARCH IS KNOWLEDGE • KNOWLEDGE IS HOPE

Recovering from Lyme Disease can be immensely challenging. If you are depressed or have suicidal tendencies:

- Call 911
- Go to the nearest emergency room
- Call the National Suicide Prevention Lifeline number. 1-800-273-8255. Available 24 hours/day
- Text HELP to Crisis Text Line at 741-741. Available 24 hours/day

988 is the new 3-digit dialing code that will route callers to the National Suicide Prevention Lifeline. While some areas can currently connect to 988, this dialing code will be available to everyone in the US starting on July 16, 2022.

SAVE THE DATE: MAY 4, 2022, 7-9 PM:

Center Director, John Aucott, MD, will be speaking about RECENT ADVANCES IN LYME DISEASE in a <u>LIVESTREAM WEBINAR</u> sponsored by the Lyme Care Resource Center.

SUPPORT THE CENTER

Thank you for your continued interest and support. Together we are bringing hope to the Lyme disease community.

HOW TO GIVE



Clinical Research Team

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