



Johns Hopkins Medicine Lyme Disease Research Center

Patient-based Epidemiologic and Clinical Translational Research



Winter 2024 Newsletter

RESEARCH UPDATE

Dysfunction of the Autonomic Nervous System in Lyme Disease

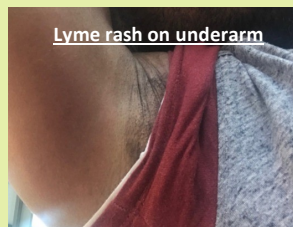


A multidisciplinary team at Johns Hopkins University School of Medicine, led by researchers from our Center, have published a [research review](#) in *Frontiers in Neurology* that implicates dysautonomia (dysregulation of the autonomic nervous system) in post-treatment/persistent Lyme disease. Postural Orthostatic Tachycardia Syndrome (POTS) is the most common manifestation of dysautonomia and is recognized by some clinicians as a contributor to persistent Lyme disease symptoms. Lyme-disease-associated POTS can be debilitating but has not yet been studied in depth. A research study of Lyme disease and POTS has recently been launched at the Johns Hopkins Postural Orthostatic Tachycardia Syndrome Program which also researches ME/CFS and Long COVID. This is the first research program focusing on POTS/dysautonomia in Lyme disease and aims to identify biomarkers to improve diagnostics and treatments.

Please [VISIT HERE](#) for more background information on POTS and Lyme disease, including symptoms, diagnostic tests and treatments.

Racial Inequities in Lyme Disease

[Research](#) led by [Alison Rebman, MPH](#), and published in *JAMA Network Open* revealed that Black patients with Lyme disease are more likely to be diagnosed later than White patients and to have [more advanced stages of disease](#) at the time of diagnosis. Delays in antibiotic treatments increase the risk of the infection progressing to more severe symptoms including cognitive, neurologic, heart problems, arthritis and severe fatigue. Education is lacking in the identification of the EM rash of early Lyme disease among patients with darker skin tones.



More physician education and community awareness are needed to address the racial disparities in Lyme disease diagnosis and treatment.

2023 IMPACT REPORT

Transforming Lyme Disease Research



IMPACT REPORT 2023



www.HopkinsLyme.org

Our Research Center's multidisciplinary research program is advancing Lyme disease knowledge to improve diagnostics, therapies, and patient care. Our [2023 IMPACT REPORT](#) reviews important progress we are making on multiple fronts, including our Center's first major NIH funding.

2023 Highlights

- Awarded NIH R01 Funding
- Established Endowed Professorship in Lyme Disease and Tickborne Illness
- Expanded Lyme Arthritis and Biomarker Discovery Program
- Launched Dysautonomia and POTS Program
- Piloted Treatment Trials
- Broadened SLICE Studies

CURRENT STUDIES

SLICE Studies Have you been recently diagnosed with Lyme disease? Do you have a rash that you think may be Lyme disease? Or, are you interested in participating as a healthy control? [LEARN MORE](#) to see if you may be eligible for our SLICE studies.

Pilot Treatment Study Our Center is conducting a pilot treatment trial as part of the Clinical Trials Network for Lyme and Other Tick-Borne Diseases, established with a grant from the Steven & Alexandra Cohen Foundation. This pilot trial is investigating tetracycline treatment tolerability in people with post treatment Lyme disease. [LEARN MORE](#)

Patient Care ● Research ● Education

OUR MISSION is to bridge the gaps in Lyme disease knowledge and translate our research findings into improved patient care.



NATIONAL NEWS

NASEM Workshop Highlights

NATIONAL ACADEMIES Sciences
Engineering
Medicine

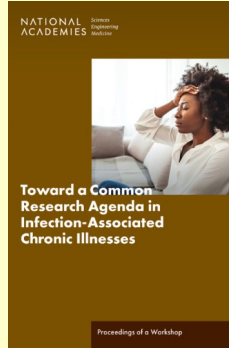
The National Academies of Sciences, Engineering and Medicine held a [June 2023 Workshop](#) to explore opportunities to advance interdisciplinary research, diagnostics, and treatments of infection-associated chronic illnesses.

[Workshop Highlights](#) were published in February 2023 and include acknowledgement of shared symptoms and common potential biologic mechanisms in infection-associated chronic illnesses, including Long COVID, post treatment/persistent Lyme disease, myalgic encephalomyelitis/chronic fatigue syndrome (ME/CFS), multiple sclerosis, and others.

Before the COVID pandemic these infection-associated chronic conditions were largely “under-researched, underfunded and met with skepticism.”

Long COVID has put a spotlight on the seriousness of infection-triggered complex multisystem chronic illness. Researchers, clinicians and patients expressed the need for a personalized medicine approach to address the multifactorial mechanisms, the importance of listening to and engaging patients, the potential for biomarkers in diagnostics and therapeutics, and the urgent need for collaborative research and multidisciplinary patient care when addressing infection-associated chronic illnesses.

John Aucott, MD, presented as a Lyme disease subject matter expert in the NASEM June 2023 Workshop.



LymeX Announces Phase 2 Winners

LYME DIAGNOSTICS PRIZE

The U.S. Department of Health and Human Services (HHS) and the Steven & Alexandra Cohen Foundation announced five [Phase 2 winners](#) in the [LymeX Diagnostics Prize](#) competition. LymeX is a \$25 million public-private innovation competition aimed at accelerating the development of improved Lyme disease diagnostics. The goal is to advance innovative diagnostics toward Food and Drug Administration review, particularly those capable of detecting active Lyme disease infections.

John Aucott, MD, and Center Senior Advisor, Mark Soloski, PhD, serve as scientific advisors to the LymeX program.

[Mark Soloski LymeX Interview](#)

SAVE THE DATE: WEDNESDAY, MAY 22, 2024, 7-9 PM

ADVANCES IN LYME DISEASE AND TICKBORNE DISEASE RESEARCH

Update on diagnostics, biomarker discovery, dysautonomia, advanced neuroimaging, and future treatments

LIVESTREAM WEBINAR by John Aucott, MD

Barbara Townsend Cromwell Professor in Lyme Disease and Tickborne Illness; Director, Lyme Disease Research Center; Associate Professor of Medicine, Division of Rheumatology, Johns Hopkins University School of Medicine

Sponsored by the Lyme Care Resource Center

REGISTER NOW

SIGN UP TODAY for our newsletter

May is Lyme Disease Awareness Month

Subscribe at HopkinsLyme.org/subscribe to stay abreast of the latest in Lyme Disease Research

Please share the link with your family, friends, and health practitioners

Recovering from Lyme Disease can be immensely challenging. If you are in distress or have suicidal thoughts:

- Call 988, the Suicide & Crisis Lifeline. Available 24 hours/day
- Text HELP to Crisis Text Line at 741-741. Available 24 hours/day
- Visit 988lifeline.org for more resources

SUPPORT THE CENTER

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

[HOW TO GIVE](#)

The Center is grateful for the support of the Steven & Alexandra Cohen Foundation, Barbara Townsend Cromwell, the Brennan Family, Ashraf Habibi, Afsaneh & Michael Beschloss, Global Lyme Alliance, Bay Area Lyme Foundation, The Lyme Care Resource Center, NIH, Department of Defense, Individual donors, family foundations, and collaborators. This newsletter is made possible thanks to the support of the Lyme disease education and outreach provided by the Kenney Family Foundation.

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