Transforming Lyme Disease Research





Lyme Disease Research Center

IMPACT REPORT 2023

www.HopkinsLyme.org

Letter from Director, John Aucott, MD

This year, in an exciting development the NIH issued a request for proposals to study Lyme disease associated chronic illness. The NIH recently awarded seven prestigious RO1 grants to study post-treatment Lyme disease, and I am excited to announce that our Center is among the recipients. Members of our team are the principal investigators for two of the seven RO1s and co-investigator on a 3rd.

Our clinical research program is helping elucidate the biology of Lyme disease from inflammatory mechanisms to changes on brain imaging.

I am grateful for your support that has enabled us to generate the initial studies that led to these NIH grants and for your ongoing philanthropy that sustains and expands our program. We are also so grateful to our patients and study participants for whom we are urgently working towards solutions.

Be well.

Warm regards,

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John Aucott, MD The Barbara Townsend Cromwell Professor in Lyme Disease and Tick-Borne Illness Associate Professor of Medicine, Johns Hopkins University School of Medicine Director, Lyme Disease Research Center Receiving NIH RO1 funding is a major milestone for our Center and validates the rigor and value of our program.

Patient Care · Research · Education



NIH RO1 FUNDING

ENDOWED PROFESSORSHIP



HIGHLIGHTS



RESEARCH CENTER MILESTONES

NIH RO1 FUNDING

The National Institute of Health (NIH) RO1 research grant is the oldest and most prestigious grant awarded to independent biomedical researchers. In the fall of 2022, the NIH for the first time put out a request for applications to research the underlying causes of signs and symptoms of post-treatment Lyme disease (PTLD). Following a highly competitive process, the NIH awarded seven RO1 grants in 2023 to study PTLD, three of which the Lyme Disease Research Center is expressly involved in.

Receiving this initial NIH funding is strong validation of the Center's leadership role in studying the multifactorial causes of persistent symptoms of Lyme disease.

Center Director, John Aucott, MD, is the Principal Investigator (PI) of the RO1 grant to investigate the determinants of clinical subgroups in post-treatment Lyme disease. Neurologic, musculoskeletal, and other symptom constellations will be evaluated. The major goals of this project are to 1) identify clinical risk factors for post-treatment Lyme disease (PTLD), 2) define and validate novel autoantibodies, and 3) identify the early immunometabolomic effects of infection. This work holds promise in improving the understanding of Lyme disease, predicting who is at risk for PTLD, and helping inform the development of novel targeted therapeutics. Another R01 was awarded to our research collaborator, Cherie Marvel, PhD, Associate Professor of Neurology and Psychiatry and Behavioral Sciences, Johns Hopkins University School of Medicine, to study neuroimaging and blood markers in post-treatment Lyme disease patients with persistent neurologic symptoms. Dr. Marvel is the PI and Dr. Aucott the co-investigator (Co-I) on this R01 grant. The major goals of this project are to use advanced analytics and imaging modalities, including fMRI, DTI, and others, to: 1) characterize brain changes in Lyme disease during the first year following infection, 2) investigate the underlying basis of brain changes, especially in white matter, and 3) correlate brain changes with blood markers.

This RO1 involves five different departments at Johns Hopkins Medicine: Neurology, Psychiatry, Rheumatology, Physical Medicine and Rehabilitation, and Radiology which underscores the value of our multidisciplinary approach to Lyme disease.

Dr. Aucott is also a co-investigator (Co-I) on a RO1 with Arizona State University on the discovery of early immunologic biomarkers for risk of PTLD through machine learning-assisted broad temporal profiling of humoral immune response.

National Institutes of Health More than a decade of impactful philanthropy has enabled us to reach a major goal of NIH RO1 funding for post-treatment Lyme disease, which helps us continue our vital work towards a cure.



ENDOWED PROFESSORSHIP IN LYME DISEASE AND TICK-BORNE ILLNESS

In September 2023, The Barbara Townsend Cromwell Professorship in Lyme Disease and Tick-Borne Illness was established, the first such Professorship in a Department of Medicine in the United States. Recognized for his leadership in the field, John N. Aucott, M.D. was installed as the inaugural recipient of this groundbreaking endowed chair. Individuals supported by endowed professorships conduct some of Johns Hopkins most significant research, and this is recognized as the highest honor Johns Hopkins Medicine can bestow upon a member of the faculty.

> John N. Aucott, M.D. being awarded the Professorship Medallion by Theodore L. DeWeese, M.D., Interim Dean of the Medical Faculty CEO, Johns Hopkins Medicine



A key attribute of this endowed chair is that it can attract bright and dedicated clinical researchers in perpetuity.

During the dedication ceremony, Dr. Aucott was acknowledged by the Johns Hopkins University School of Medicine and Division of Rheumatology for his thought leadership, rigorous research protocols and impactful world-renowned biorepository and SLICE studies that are transforming disease understanding and biomarker discovery. The Center's rigorous translational clinical investigations have made advances, including identifying key causes, novel prognostic factors, biomarkers, sexbased differences, effects on the African American community, public health impacts & outcomes for Lyme disease patients. Dr. Aucott's team has also revealed the utility of AI for rash recognition, and of PET imaging and fMRI for understanding the neurologic impacts of the disease. There are now young faculty at Johns Hopkins studying Lyme disease associated autonomic dysfunction, neurological impacts, and post infectious arthritis.

The Center's multi-disciplinary longitudinal studies have shown that a Lyme disease triggered chronic illness is real, and is biologically driven.

Findings in Lyme disease will also likely help provide insights into other infection-associated chronic illnesses, such as long COVID, ME/CFS, and others.



Barbara Townsend Cromwell receiving her Medallion from John N. Aucott, M.D., inaugural Professorship recipient



An endowed chair at Johns Hopkins Medicine in Lyme Disease and Tick-Borne Illness is a landmark achievement that will help support continued work towards translating research into improved education and patient care.

PATIENT CARE

OUR CENTER HAS OVER 1300 CLINICAL AND RESEARCH APPOINTMENTS PER YEAR. We strive to provide illness validation, hope, and a path forward to renewed health.

WE LISTEN CAREFULLY TO OUR PATIENTS to better understand their symptoms, concerns, and priorities.

OUR CLINICAL EXPERIENCE INFORMS OUR RESEARCH PROGRAM. Our rigorous translational research program aims to bridge the gaps in patient care through robust scientific research and discovery.

RESEARCH

Clinical Characterization • Biorepository • Collaborations • Epidemiology • Immune Response Early Diagnosis Biomarkers • AI Rash Recognition • Neurologic & Joint Imaging • Dysautonomia



Data • Analysis • Insights • Research Publications • Citations • Education • Patient Care

SLICE BIOREPOSITORY

Our SLICE biorepository is comprised of extensive clinical and epidemiologic data along with longitudinally collected blood and tissue samples from individuals with validated acute and chronic Lyme disease. These rigorously characterized samples are foundational to advancing the scientific understanding of Lyme disease and have been the basis for numerous innovative research projects and collaborations.

100,000 90.000 80,000 70,000 60,000 50,000 40,000 30,000 20,000 10.000 0 2012 2010 2013 2015 2016 2018 2019 123 2009 2011 2014 2017 2020 2021 2022 , env

Cumulative Number of Blood and Tissue Samples

Sample Types Included in the Slice Biorepository



RESEARCH COLLABORATIONS

Our robust SLICE biorepository is sought after by leading-edge investigators. Over 9,768 samples from our biorepository have been utilized by 39 different academic, scientific, and medical collaborators at 27 different institutions. Our collaborative research program employs sophisticated multidisciplinary scientific approaches to generate novel insights into the complex biologic drivers and mechanisms of Lyme disease, including biomarker discovery. Advanced research tools include immune profiling, transcriptomics, proteomics, metabolomics, microbiomics, and direct diagnostic pathogen detection methods.

Our interdepartmental collaborations within Johns Hopkins University (JHU) are growing, too. In addition to our many internal interdisciplinary SLICE projects, we have other projects including a program to pursue the use of artificial intelligence for Lyme disease rash recognition.



RESEARCH PUBLICATIONS

The productivity of our Center's research pipeline continues to be strong, with 67 peer-reviewed studies published, including 6-10 publications each year for the past 5 years. Our growing body of peer-reviewed publications are increasingly cited and helping to expand the knowledge base in the field.

📕 Published 📕 Under Review

Peer-Reviewed Publications by Year





John Miller, MD, Assistant Professor of Medicine, runs the Lyme Arthritis Program. Dr. Miller investigates the musculoskeletal and autoimmune complications that can develop in Lyme disease patients. He is building a well-characterized biorepository of blood and tissue samples from Lyme disease associated arthritis patients, and his assessments include advanced ultrasound for the detection of subtle inflammatory changes.

DYSAUTONOMIA RESEARCH LAUNCHING DYSAUTONOMIA AND POTS PROGRAM

The Research Center has a new program focused on dysautonomia in Lyme disease. Brit Adler, MD, Assistant Professor of Medicine in the Division of Rheumatology, is spearheading this program in collaboration with Dr. Aucott's clinical team. Dr. Adler is a translational physician-scientist with an interest in postural orthostatic tachycardia syndrome (POTS) and dysautonomia (autonomic nervous system dysregulation), conditions that occur in Lyme disease patients. She evaluates patients with Lyme disease, and other illnesses such as Long COVID, in the Johns Hopkins Autonomic Testing Lab, performing the tilt table test and other autonomic assessments.

Through our Center's clinical evaluations, we recognize that Lyme disease can trigger dysautonomia, and in particular, a syndrome called Postural Orthostatic

Tachycardia Syndrome (POTS). POTS results when the body is unable to adjust blood flow when changing positions. This leads to venous pooling and reduced blood flow when patients are standing in an upright position, which then leads to a fast heart rate to compensate. POTS symptoms include brain fog, severe fatigue, dizziness and weakness with prolonged standing, racing heart, exertional intolerance, and muscle aches.



280+

Annual

Patient

Visits

BRAIN

Study

Participants

Enrolled

- Brain fog
 Migraine
- Severe fatique
 Reduced concentration

91

Ultrasound

Evaluations

MUSCLE

Profound weakness with prolonged standing

191

Blood & Tissue

Samples

Collected

- Blood pooling
- Muscle aches after exercise
- Post-exercise malaise (PEM)

HEMODYNAMIC

- Racing heart
- Exertional intolerance
- Orthostatic intolerance
- Impaired heart rate & blood pressure regulation

Objective measures of autonomic dysfunction in Lyme disease are lacking, and it is unclear how much dysautonomia contributes to symptoms in post-treatment Lyme disease (PTLD).

If POTS and dysautonomia are common in PTLD, it will open the door to new treatments that may help manage symptoms. Dr. Adler is about to start a study using

transcranial doppler ultrasound to measure blood flow to the brain during changes in tilt in patients with PTLD.

LEARN MORE ABOUT POTS IN LYME DISEASE HopkinsLyme.org/Lyme-education/what-is-dysautonomia/

ONGOING STUDIES AND PILOT TREATMENT TRIALS

THE SLICE STUDIES

The SLICE Studies include longitudinal studies of early Lyme disease. SLICE studies are currently enrolling for individuals just diagnosed with the skin lesion erythema migrans, or for those with acute neurologic Lyme disease, such as Bell's palsy, or carditis.

LEARN MORE ABOUT CURRENT OPPORTUNITIES TO PARTICIPATE IN OUR SLICE RESEARCH STUDIES SLICEstudies.org

CLINICAL TRIALS NETWORK FOR LYME AND OTHER TICK-BORNE DISEASES

The Steven & Alexandra Cohen Foundation established the first National Clinical Trials Network (CTN) for Lyme and Other Tick-borne Diseases in 2022 to study more effective treatments for patients with chronic manifestations of Lyme and tick-borne diseases.

Columbia University Irving Medical Center in NYC serves as the Clinical Trials Network coordinating center. The Johns Hopkins Lyme Disease Research Center is a CTN investigation center along with Children's National Hospital in Washington, DC, and SUNY Upstate Medical University, and other CTN investigation nodes are pending.

THE STEVEN & ALEXANDRA COHEN FOUNDATION

has been a significant supporter of our research program and provided instrumental funding to support our SLICE biorepository and numerous innovative collaborative research investigations. Our Center is grateful for the Steven & Alexandra Cohen Foundation's major pioneering support and new commitment to develop an expanded clinical program at our Center for the diagnosis and treatment of Lyme disease associated chronic illnesses.



TETRACYCLINE PILOT STUDY

In 2022, our Center began a CTN-sponsored pilot tetracycline study to investigate tetracycline treatment tolerability in people with post-treatment Lyme disease.

Results of CTN pilot studies will determine the feasibility of conducting larger controlled treatment trials and hopefully potential new treatment options for those suffering from tick-borne illness.

LEARN MORE ABOUT THE TETRACYCLINE STUDY SLICEstudies.org/treatment-trial

PSLILOCYBIN PILOT STUDY

The Steven & Alexandra Cohen Foundation is also funding research at Johns Hopkins Medicine to study psilocybin, to see whether this psychoactive substance found in certain kinds of mushrooms is safe and helpful in certain medical conditions, including post-treatment Lyme disease. Our Center is collaborating with Principal Investigator, Albert Garcia-Romeu, PhD, on this pilot psilocybin study in Lyme disease patients.

LEARN MORE ABOUT THE PSILOCYBIN STUDY HopkinsPsychedelic.org/Lyme

WHY I GIVE



Barbara Townsend Cromwell is a teacher and philanthropist who has championed many causes and charitable institutions, particularly those focused on education, medicine, and history. Ms. Cromwell was raised in Pocomoke City, Maryland, attended Washington College, and pursued a career in teaching elementary school. Her love of education led her to many philanthropic pursuits, including her lifelong support of Washington College where she served on the Board of Visitors and Governors and established the Barbara and George Cromwell Hall, home to the Barbara and George Cromwell

Center for Teaching and Learning. She also funded the Barbara and George '49 Cromwell Centennial rotunda at Severn School, her late husband's alma mater.

Ms. Cromwell has been a generous supporter of research at the Johns Hopkins University School of Medicine, including gifts to neonatal care, cardiology, and the Lyme Disease Research Center in the Division of Rheumatology. She supported Lyme disease research at a critical time in the Center's early development. Her remarkable patronage continues with the endowment of the Barbara Townsend Cromwell Professorship in Lyme Disease and Tick-Borne Illness. This momentous endowed chair establishes a perpetual translational research position to advance the understanding of tick-borne conditions and improve patient care.

Asked why she gives, Ms. Cromwell responds, **"I want my philanthropy to have a meaningful impact, one** that is visible and changes things for the better in my lifetime. I believe Dr. Aucott's Lyme disease team has been essential for improving education and patient care as well as research. I see the progress this research is achieving and believe my endowed support for a Professorship at Johns Hopkins Medicine will make a lasting difference."

RESEARCH CENTER TEAM



CLINICAL RESEARCH TEAM

John Aucott, MD

The Barbara Townsend Cromwell Professor in Lyme Disease and Tick-Borne Illness

Associate Professor of Medicine Director, Lyme Disease Research Center

Alison Rebman, MPH Instructor in Medicine, Director for Clinical and Epidemiological Research, Lyme Disease Research Center

John Miller, MD Assistant Professor of Medicine Lyme Arthritis Program

Brit Adler, MD Assistant Professor of Medicine Lyme Disease Dysautonomia Program

Pegah Touradji, PhD Assistant Professor of Physical Medicine & Rehabilitation, Lyme Disease Rehabilitation Neuropsychology Program Jonathan Zenilman, MD Professor of Medicine, Infectious Diseases Ting Yang, PhD

Senior Biostatistician Erica Kozero, BS, CCRP

Senior Research Program Coordinator

Cheryl Novak, MSN, CRNP Certified Registered Family, Nurse Practitioner

Susan Joseph, BSN, RN Senior Research Nurse

Cindi Crews Senior Medical Office Coordinator

Verna Scheeler, BSHA, MA Clinical Research Program Manager

Isabella Brothers, BS Research Program Coordinator

Abigail Mathews, BS Research Program Coordinator

LABORATORY RESEARCH TEAM

Mark Soloski, PhD Professor Emeritus Senior Advisor

Daniela Villegas de Flores, MEd Biorepository Manager

Won Seok Song, BS Research Specialist

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EDUCATION AND COMMUNICATIONS LIAISON

Nancy Dougherty NVantage Consulting, LLC

To stay abreast of our pilot studies and other research news, please sign up for our newsletter. HopkinsLyme.org/Subscribe

Philanthropic Support Makes A Difference.

Philanthropy enables the Johns Hopkins Medicine Lyme Disease Research Center to pursue groundbreaking research that is critical to improving diagnostics, treatments, and health outcomes for Lyme disease patients. By bridging the gaps in Lyme disease knowledge, we strive to improve education and patient care. We are grateful for our philanthropic partners who continue to support and believe in our mission.

Our Research Center is grateful for the support of:

- Steven & Alexandra Cohen Foundation
- Barbara Townsend Cromwell
- Brennan Family
- Ashraf Habibi, Afsaneh & Michael Beschloss
- Global Lyme Alliance
- Bay Area Lyme Foundation
- The Lyme Care Resource Center
- Our Advisory Board
- Individual donors, family foundations and collaborators

SUPPORT OUR RESEARCH

YOUR GIFT ADVANCES KNOWLEDGE TOWARDS A CURE

You may make a donation by phone, email, or by mail at:

Department of Medicine Development Office Phone: 410-550-3417 Email: DOMDevelopment@jh.edu

If making a gift by check, please make payable to: Johns Hopkins University, with "The Lyme Disease Research Center" noted.

Mailing address:

Johns Hopkins University and Medicine Attn: Department of Medicine/Lyme Disease Research Center PO Box 49143 Baltimore, MD 21297-9143

We appreciate your support which is vital to our program.

YOU MAY ALSO MAKE A DONATION ONLINE AT HopkinsLyme.org/Donate

To learn more about funding opportunities, make a gift of stock, and/or include the Lyme Disease Research Center in your will or estate plans, please contact:

Molly C. Dolan

Senior Associate Director of Development Johns Hopkins Department of Medicine Phone: 630-309-0692 Email: mdolan6@jh.edu

If you prefer not to receive fundraising communications from Johns Hopkins Medicine, please contact us at 1-877-600-7783 or FJHMOptOut@jhmi.edu. Please include your name and address so that we may honor and acknowledge your request.



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