JOHNS HOPKINS MEDICINE

Lyme Disease Research Center And Clinical Care Program
A Multidisciplinary Approach

TRANSFORMING LYME DISEASE

IMPACT REPORT 2024

SLICE STUDIES

www.HopkinsLyme.org

Letter from Director, John Aucott, MD

This year has been an exciting year of progress for our clinical research center. We have significantly enhanced our patient care clinic thanks to the generous support of the Steven & Alexandra Cohen Foundation.

By adding clinicians with special expertise in neuropsychiatry and autonomic dysfunction within our clinic, we are expanding care for our complex chronic Lyme disease patients.

Our augmented patient care model connects directly to our robust multidisciplinary research program. Moreover, our research publications highlight the diversity of research in the Lyme Center. Basic laboratory findings have illuminated aberrant immune responses and autoantibodies in Lyme disease. Clinical research is untangling the impact of dysautonomia and sex- and gender-based differences in Lyme disease. The patient experience is being highlighted by descriptions of the problem of illness invalidation by medical professionals. Geospatial analysis of internet searches have identified a way to detect the leading-edges of Lyme disease's geographic expansion. Many of these research highlights are featured in this report.

Thank you for recognizing the value of our clinical research program and for your unwavering support. We could not achieve this progress without your continued generosity. We are grateful, too, for our patients and research study participants who dedicate time and trust to enable us to advance knowledge to improve patient care.

Be well.
Warm regards,

John Aucott

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

RESEARCH IS KNOWLEDGE

KNOWLEDGE IS HOPE

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

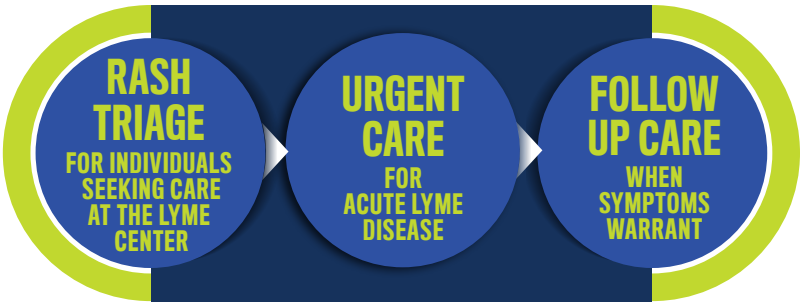
PATIENT CARE
RESEARCH
EDUCATION

PATIENT CARE

Our multidisciplinary clinic offers evaluation and treatment for acute Lyme disease as well as for Lyme infection-associated chronic illness, commonly referred to as chronic Lyme disease.

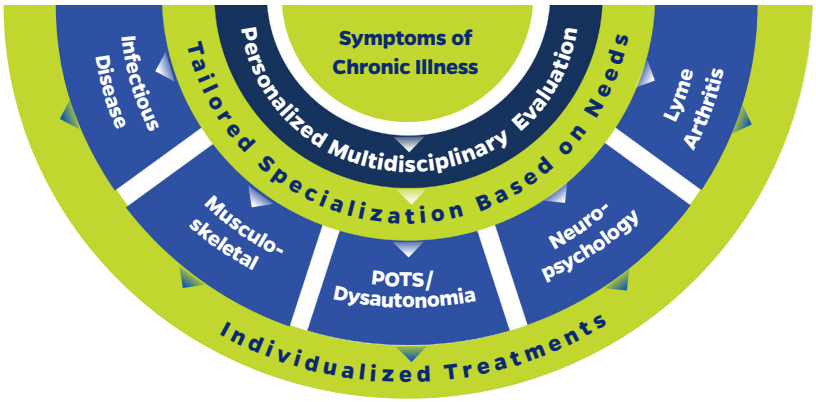
For acute cases, our clinic provides a Lyme disease rash consultation for early triage and urgent clinical care. We also offer follow-up care when symptoms linger.

Rash Triage and Clinical Care for Acute Lyme Disease



Our collaborative and multidisciplinary model of care is broadening to include additional medical specialties.

Multidisciplinary Patient Care for Chronic Lyme Disease



Our Center's team of health practitioners continues to expand, enabling us to provide an enhanced multidisciplinary approach to addressing the complex needs of chronic Lyme patients.

We leverage Johns Hopkins Medicine's cross-functional strength by growing our internal expertise in the clinic to include not only infectious disease, musculoskeletal, and Lyme arthritis practitioners but also neuropsychology specialists and physicians skilled in postural orthostatic tachycardia syndrome (POTS) and dysautonomia (autonomic nervous system dysfunction). Based on rigorous personalized health assessments, we direct care when needed to appropriate medical specialties and work collaboratively across disciplines to customize treatments for our patients.

We listen carefully to our patients to better understand their symptoms, concerns, and priorities.

Our clinical experience informs our research, and our translational research aims to bridge the gaps in patient care through robust scientific discovery.

We strive to provide illness validation, hope, and a path forward to renewed health.

GIVE
STEVEN & ALEXANDRA COHEN FOUNDATION

WE ARE GRATEFUL TO THE STEVEN & ALEXANDRA COHEN FOUNDATION FOR GENEROUSLY SUPPORTING THE EXPANSION OF OUR CLINICAL CARE PROGRAM.

RESEARCH

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

SLICE STUDIES

- **S**tudies of
- **L**yme disease
- **I**mmunology &
- **C**linical
- **E**vents

848	2,641	82%
Participants Enrolled in SLICE Studies	SLICE Studies Research Visits	Retention Among Study Participants
Cumulative	*Cumulative*	*1 Year Rate*

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

Our Center's multidisciplinary studies are producing findings that enhance the understanding of Lyme disease, including Lyme infection-associated immune dysfunction, novel brain changes in structure and function, and previously indiscernible musculoskeletal inflammation, sex- and gender-based differences, and autonomic nervous system dysfunction. Our studies aim to discover unique biomarkers and innovative treatment approaches.

MILESTONES

102,607 SLICE Blood and Tissue Samples Collected

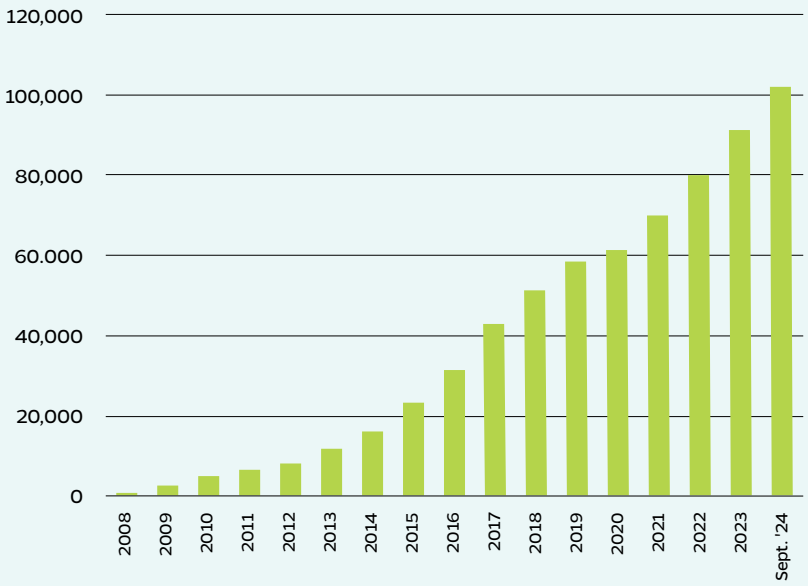
43 External Research Collaborations

76 Peer-reviewed Studies Published

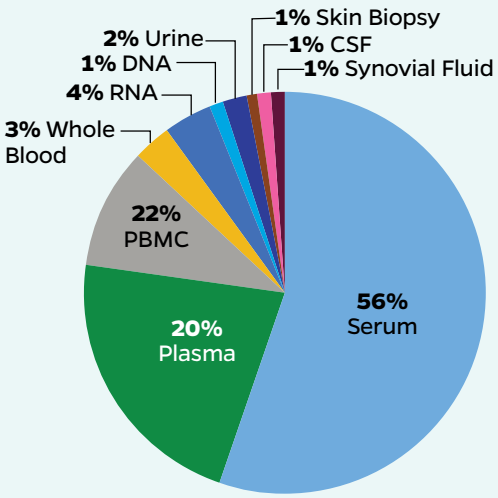
SLICE BIOREPOSITORY

Our robust SLICE biorepository features comprehensive clinical and epidemiologic data along with longitudinally collected blood and tissue samples from individuals with validated acute and chronic Lyme disease. The high-quality SLICE samples are foundational to progressing the scientific understanding of Lyme disease and form the basis for many innovative multidisciplinary collaborations.

Cumulative Number of Blood and Tissue Samples



Sample Types Included in the SLICE Biorepository



RESEARCH COLLABORATIONS

Our rigorously characterized SLICE biorepository is regarded as an invaluable resource for advancing academic, scientific, and medical discoveries.

11,866
blood and tissue samples from our well-characterized biorepository have been utilized by:

43 different academic, scientific, and medical collaborators

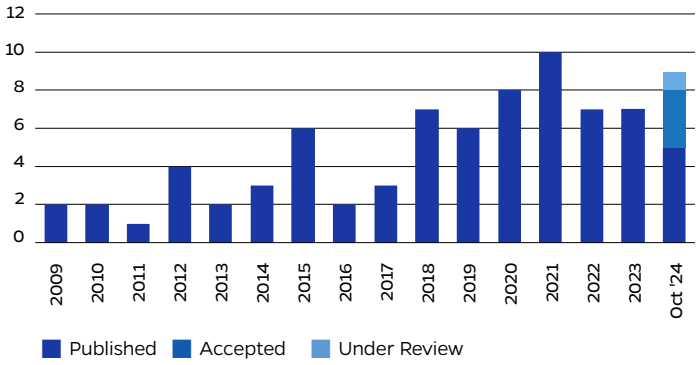
at **29** distinct institutions

Our internal and external research collaborations utilize state-of-the-art multidisciplinary scientific approaches to interrogate our samples and try to unravel the complex biologic mechanisms of Lyme disease, including biomarker identification and diagnostic test validation. Cutting-edge research tools include immune profiling, transcriptomics, proteomics, metabolomics, microbiomics and direct diagnostic pathogen detection methods.

RESEARCH PUBLICATIONS

Our Center has a productive research program, and cumulatively we have published 76 peer-reviewed studies. Our biologic, clinical, and epidemiologic findings are frequently cited by scientists and clinicians to progress knowledge in the field.

Peer-Reviewed Publications by Year



LYME ARTHRITIS PROGRAM

The Lyme Arthritis Program, headed by John Miller, MD, Assistant Professor of Medicine examines the musculoskeletal and autoimmune problems that can occur in Lyme disease.

Cumulative Highlights

147 Study Participants Enrolled

141 Ultrasound Evaluations

292 Blood & Tissue Samples Collected

LYME ARTHRITIS PROGRAM HIGHLIGHTS

Musculoskeletal Ultrasound

The program's major focus is on Lyme arthritis and post-infectious Lyme arthritis (PILA). It has been estimated that 90% of patients with Lyme arthritis return to health after antibiotics and at least 10% of patients have persistent inflammation, termed PILA. Recent research revealed that 10% is likely an underestimate of the burden of persistent inflammation. By using musculoskeletal ultrasound, our research team found subtle inflammation (not discerned on exam) is present in up to 25% of patients with persistent symptoms, and importantly, these patients have symptomatic improvement when treated. The teams' use of musculoskeletal ultrasound, patient-reported outcome measures, and search for biomarkers aims to identify patients at high risk of PILA, and enable earlier, targeted therapies in efforts of preventing PILA.

Biomarker discovery

One potential biomarker is the RA33 antibody, an antibody that has previously been described in autoimmune arthritis, such as rheumatoid arthritis. Researchers at the Johns Hopkins Lyme Disease Research Center recently discovered that 20-25% with Lyme arthritis make these antibodies, too.

The discovery of RA33 antibodies in Lyme arthritis patients is the first time RA33 antibodies have been linked to an infection-associated arthritis.

Other Lyme Arthritis Research

A rare complication of Lyme disease is that a subset of patients can develop autoimmune arthritis (e.g., rheumatoid arthritis, psoriatic arthritis) in the months-to-years after infection. Dr. Miller's team is working to describe this phenomenon clinically and to explore the mechanistic links that drive this autoimmune response. Use of electronic medical records is also allowing his team to better estimate the true incidence of post-Lyme autoimmune arthritis which has historically been underreported.

FEATURED PUBLICATIONS

Illness Invalidation by Medical Professionals

Illness invalidation by health practitioners in Lyme disease is a problem that Alison Rebman, MPH, Assistant Professor in Medicine and Director for Clinical and Epidemiological Research at the Research Center, set out to identify and quantify. In a recently published **peer-reviewed study** in **Scientific Reports**, Alison and her team showed that invalidating encounters with medical professionals are common for post-treatment Lyme disease (PTLD) patients, particularly women and younger patients. Patients who experienced the greatest levels of invalidation were found to have higher symptom severity, inferior quality of life, and lower trust in physicians. Women more often received alternative diagnoses (such as another contested or psychologized illness) which in turn correlated with more discrediting and delays in appropriate treatment. The study points to the need for improved physician education regarding how illness invalidation can impact a patient's healing trajectory.

Identifying the Geographic Leading-Edge of Lyme Disease

Lyme disease cases are expanding geographically in the US and yet are significantly underreported (by a factor of 8-10x) by standard surveillance approaches. More timely and effective methods are needed to better identify Lyme disease geographic risk, including distinguishing underrecognized and emerging regions that form the leading-edge of disease expansion.

Researchers at our Center, in collaboration with Frank C. Curriero, PhD, and Cara Wychgram, MPP, in the Johns Hopkins Bloomberg School of Public Health, utilized Google Health Trends data to analyze internet Lyme disease searches to identify geographic patterns over time. Our **peer-reviewed study**, that was just published in **PLOS ONE**, finds geographic Lyme disease risk, including underreported and leading-edge areas, can be detected in near real time using Google Health Trends data. This novel tool can potentially be used dynamically to complement traditional disease surveillance systems (case reports, lab test results, insurance claims data, electronic health records) to help inform the public and health care providers of high incidence, underreported, and emerging geographic regions of Lyme disease.

EDUCATION

Please sign up for our newsletter to stay abreast of our research news:

- **Educational Videos**
- **Research Updates**
- **Webinar Notifications**
- **Pilot Study Information**
- **May Lyme Disease Awareness Month Education**

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WHY WE GIVE

Lynn and Terral Jordan have been longtime supporters of Dr. John Aucott's Lyme disease research program since its inception in 2008, including Terral serving as a founding Board member of The Lyme Disease Research Foundation of Maryland. Terral played an important strategic role for the Foundation which led to the successful establishment of the Lyme Disease Research Center in the Division of Rheumatology at Johns Hopkins University School of Medicine in 2015.

Both Lynn and Terral have personally navigated challenging Lyme disease journeys, including Terral experiencing a second debilitating case that required prolonged care from his then internist, Dr. Aucott. During his treatment and recovery, Terral became aware of Dr. Aucott's goal to develop a rigorous longitudinal biorepository to identify the biologic mechanisms driving Lyme infection-associated chronic illness. Over the years, Terral and Dr. Aucott developed a close friendship and enjoyed many hikes together in Oregon Ridge Park in Maryland, where conversations ranged from their common love for the outdoors to deep strategy sessions on how to optimally develop the SLICE Studies and expand the Lyme disease research program.

When asked why they give, Lynn, speaking on behalf of Terral who is presently in memory care, said, "We are enthusiastic supporters of the fellowship program and excited about Dr. Aucott's multidisciplinary approach to enhancing patient care."

> **"We are grateful to be involved with such a deeply impactful program. It is meaningful to see the profound impact this groundbreaking research is having on Lyme disease knowledge and education.**
>
> **Through Terral's illness, our family has a unique lens on the complexities of Lyme disease-associated chronic illness. Now another family member, unfortunately, is coping with Long COVID, with many similar symptoms.**
>
> **Remarkably, we hear that Lyme disease research at the Center may help reveal potential shared mechanisms in these infection-associated chronic illnesses, and this has become another reason why we give."**

RESEARCH STUDIES AND PILOT TREATMENT TRIALS

THE SLICE STUDIES

SLICEstudies.org

The SLICE studies are enrolling individuals just diagnosed with the Lyme erythema migrans skin rash or with acute neurologic Lyme disease, such as Bell's palsy or carditis. This case series designed study characterizes those patients with established ongoing post-treatment Lyme disease (PTLD).

TETRACYCLINE PILOT STUDY

SLICEstudies.org/treatment-trial

The tetracycline pilot study is investigating the tolerability of extended tetracycline treatment in people with post-treatment Lyme disease. (This study is sponsored by the Clinical Trials Network for Lyme and Other Tick-borne Diseases, established by the Steven & Alexandra Cohen Foundation.)

PSILOCYBIN PILOT STUDY

HopkinsPsychedelic.org

The psilocybin pilot study is part of a larger Johns Hopkins study funded by the Steven & Alexandra Cohen Foundation to determine if psilocybin is safe and helpful in certain medical conditions, including post-treatment Lyme disease. Enrollment is now complete and findings are expected to be published in 2025.

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
Assistant Professor in Medicine
Director for Clinical and Epidemiological Research

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

Glenn J. Treisman, MD, PhD
Professor of Psychiatry and Behavioral Sciences

Ting Yang, PhD
Senior Biostatistician

Cheryl Novak, MSN, CRNP
Certified Registered Family Nurse Practitioner

Caroline Davis, MS
Physician Assistant-Certified

Susan Joseph, BSN, RN
Senior Research Nurse

Verna Scheeler, BSHA, MA
Clinical Research Program Manager

Erica Kozero, BS, CCRP
Senior Research Program Coordinator

Isabella Brothers, BS
Research Program Coordinator

Leah Young, BS
Research Program Coordinator

Cindi Crews
Senior Medical Office Coordinator

Mylasia Blake
Medical Assistant

LABORATORY RESEARCH TEAM

Mark Soloski, PhD
Professor Emeritus
Senior Advisor

Daniela Villegas de Flores, MEd
Biorepository Manager

Harshini Balaga, MS
Research Specialist

Research Center Team

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EDUCATION AND COMMUNICATIONS LIAISON

Nancy Dougherty
NVantage Consulting, LLC

Philanthropic Support Makes A Difference.

Philanthropy empowers the Johns Hopkins Medicine Lyme Disease Research Center to pursue innovative research, uncover new findings, and deepen our understanding of Lyme disease and tick-borne illness. Your donations drive continued advancements in diagnostics, treatments, and overall health outcomes for our patients. We deeply appreciate our philanthropic partners for their unwavering support and faith in our mission.

Our Research Center is grateful for the support of:

- 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
- 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

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.

Thank you for your unwavering support of our program.

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