

JOHNS HOPKINS MEDICINE LYME DISEASE RESEARCH CENTER

Impact Report 2020



Transforming Lyme Disease

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.

Patient Care Research Education



JOHNS HOPKINS
M E D I C I N E

www.HopkinsLyme.org

Letter from Director, John Aucott

We are pleased to share with you the 2020 Impact Report of the Johns Hopkins Medicine Lyme Disease Research Center. Despite facing challenges during the COVID-19 pandemic our Center continues to be extremely productive. Our telehealth program, the first telemedicine program approved for use at Johns Hopkins Medicine, gives us the flexibility to triage, diagnose, and treat tick bites and Lyme disease remotely.

Our robust pipeline of publications continues to advance vital knowledge in the pathobiology of Lyme disease. Our numerous multidisciplinary collaborations are driving novel insights and innovations to improve patient care. Our application of artificial intelligence to enhance Lyme disease rash recognition is laying the groundwork to future phone apps capable of diagnosing early Lyme disease more accurately than blood tests.

We thank our supporters and donors for helping make our groundbreaking research possible.

We are fervently working towards more accurate diagnoses and effective treatments to bring better outcomes and renewed hope to Lyme disease patients and their families.

We hope you are staying safe and well.

Warm regards,

John Aucott, MD
Associate Professor of Medicine,
Johns Hopkins University School of Medicine
Director, Lyme Disease Research Center

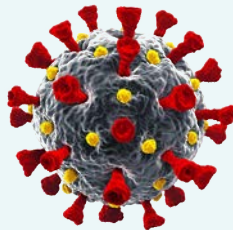
RESEARCH CENTER MILESTONES



We are grateful to all the patients who have participated in our studies. Our dedicated team is urgently working on your behalf towards solutions.

THE IMPACT OF COVID-19

In response to the COVID-19 pandemic, we modified our research operations to COVID-safe protocols for patients, research participants, and staff. In the March-July 2020 period we followed Johns Hopkins guidelines and paused seeing patients in person and pivoted patient care to telehealth services. Despite being offsite during this period our research pipeline stayed productive by prioritizing remote data collection, analysis, and



publication manuscript preparation. We submitted 12 publications to the peer reviewed literature, 7 of which have been published in 2020, and the remaining are currently under review. In late July, Johns Hopkins and IRB protocols enabled us to begin seeing patients in person again and we began carefully resuming on-site research as well. We appreciate the continued flexibility and dedication of our patients, study participants, and research team during these challenging times.

PATIENT CARE IN THE COVID-19 ERA

Telehealth Services

As people are physical distancing to avoid COVID-19 many are spending more time outdoors and encountering ticks. Our telehealth services are growing briskly. During the 2020 pandemic we expanded our telehealth tick bite and Lyme disease rash consultation services beyond Maryland to several other states, including Pennsylvania, Virginia, Delaware, New York, California, and Florida. Prior to a telemedicine appointment, patients are asked to digitally photograph their skin rashes and meet certain state insurance parameters.

Our telehealth digital rash recognition services have been helping diagnose many cases of early Lyme disease that might have otherwise been missed. Early diagnosis and treatment are key to avoiding long term illness. Telehealth will undoubtedly continue to be an important service even after the pandemic wanes.



EDUCATION HIGHLIGHTS

The Center is recognized internationally as a research and thought leader in Lyme disease.

The Center's May Lyme Disease Awareness Campaign conveys important information on Lyme disease, including:

- How to distinguish Lyme disease from COVID-19
- A bulls-eye rash is NOT the most common rash presentation

Our June Continuing Medical Education (CME) course is offered to healthcare practitioners through the Johns Hopkins Medicine Division of Rheumatology.

- In 2020 we shifted to live stream only for the first time
- Attendance increased despite the pandemic and included participants from Canada and Europe

Our website is a valuable resource for information on Lyme disease.

- Website traffic has increased over 50% in 2020 versus 2019



How to distinguish early Lyme disease from COVID-19

Although many of the early “flu-like” symptoms of COVID-19 and Lyme disease are similar, there are important differences that can help distinguish between these infections.

SIMILARITIES

Flu-Like Symptoms:

- Fever
- Chills
- Fatigue
- Body/muscle aches and pains
- Malaise
- Sweats
- Headache



DIFFERENCES

Signs and symptoms present in Lyme Disease but not typical in COVID-19:

- Large expanding red round rash
- Neck and joint pain

Signs and symptoms present in COVID-19 but not typical in Lyme Disease:

- Respiratory issues
- Shortness of breath
- Pain or pressure in the chest
- Loss of taste or smell
- Digestive issues like vomiting or diarrhea
- Diffuse rash or “COVID toes” that look similar to frost bite
- Dry cough
- Trouble breathing
- Nasal congestion
- Bluish lips or face

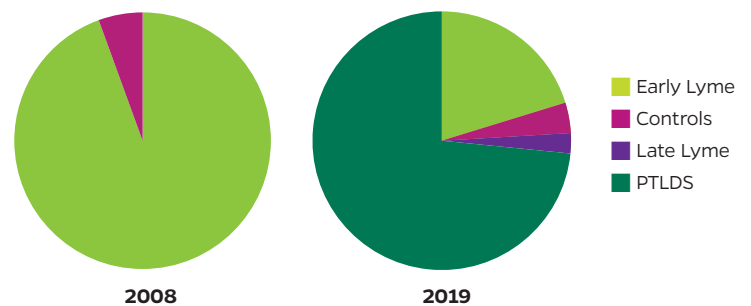
Not everyone with Lyme Disease or COVID-19 will get a rash but when present a rash can be an important distinguishing feature for aiding early diagnosis.

To sign up for our newsletter and awareness campaign please go to www.hopkinslyme.org/subscribe.

Patient-based Research

Our landmark SLICE studies (Studies of Lyme disease Immunology and Clinical Events) enroll patients with all stages of Lyme disease. Our gold-standard biorepository has grown to over 60,000 well-characterized blood and tissue samples. The clinical, biorepository, and epidemiologic data we capture improves the understanding of Lyme disease.

Enrollment of SLICE Studies by Clinical Group



We listen carefully to our patients and meticulously characterize their symptom illness experience.

627 Participants Enrolled in SLICE Studies

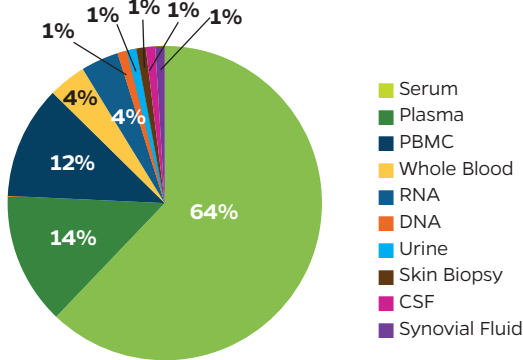
2,006 Participant Visits

85% 1 Year Retention Rate among study participants

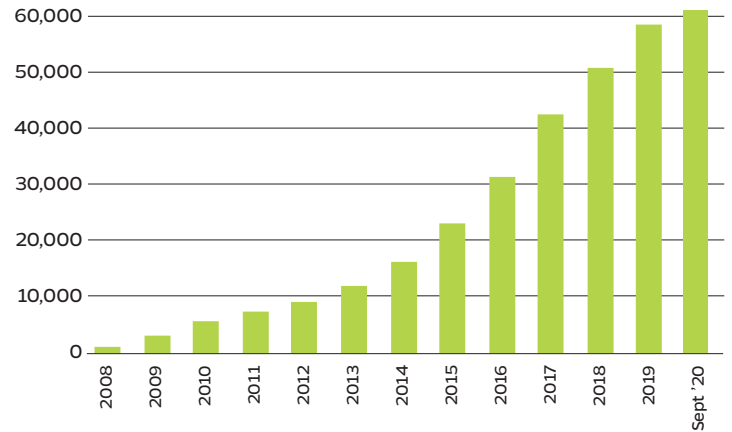
As of August 31, 2020

Biorepository

Sample Types Included in the SLICE Biorepository



Cumulative Numbers of Blood and Tissue Samples Added by Year

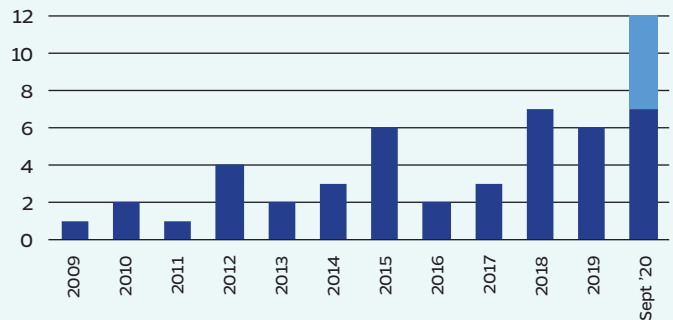


Research Publications

Our 2020 research pipeline continues to be robust even during the pandemic, with 7 studies published through August and an additional 5 under review. Our publications are providing important new insights into disease processes.

■ Under Review ■ Published

Peer-Reviewed Publications by Year



Research Collaboration

Our wheelhouse of collaborations and knowledge generation keeps expanding. Our valuable SLICE Studies samples are vital to improving the understanding of the varied manifestations of Lyme disease and are a cornerstone to our multidisciplinary collaborations with leading worldwide academic, scientific, and medical investigators. Over 7000 samples have been sent to top research collaborators who are employing leading edge technologies to unravel the complex biologic drivers of persistent symptoms in Lyme disease. We strive to discover biomarkers that can improve diagnostics and treatments for Lyme disease patients. Our Center has collaborated with 31 different researchers from 24 different institutions.

RESEARCH NEWS

Unexpected findings warrant further study using objective measures

- **Persistent inflammation found using joint ultrasound in Lyme disease patients**
- **White matter functional and structural abnormalities found in Lyme disease patients' brains using fMRI and DTI**



John Miller, MD

Instructor of Medicine, Division of Rheumatology, Johns Hopkins University School of Medicine

John Miller, MD, joined the Center's clinical research team in February 2020. He brings a deep knowledge of rheumatology, including expertise in infection-triggered inflammatory and autoimmune rheumatic illnesses.

Lyme related joint and musculoskeletal pain can manifest at any stage of Lyme disease and likely has multiple different causes (etiologies): early disseminated infection, late infection with Lyme arthritis, post-infectious Lyme arthritis (PILA), post-treatment Lyme disease (PTLD) and Lyme disease triggered autoimmune arthritis. Diagnostic tools and treatments vary based on etiology. Dr. Miller recognizes that Lyme arthritis has a narrow window of treatment opportunity. If treated early, approximately 90% of patients with disseminated or late Lyme arthritis have complete resolution of symptoms but at least 10% have persistent pain. Treatments for ongoing pain are not one size fits all and can vary from antibiotics to supportive therapies to immune suppressive treatments.

Lyme disease currently lacks objective measures for treatment success or failure. Dr. Miller is enthusiastic about a novel ultrasound study he is conducting that aims to better differentiate, measure, and validate inflamed joints of Lyme disease patients and inform more effective treatment approaches.

Ultrasound can objectively measure synovial fluid, vascularity, and blood flow and thereby characterize the swollen and painful joints with reliable metrics to help track treatment outcomes. Used in conjunction with synovial fluid collection and patient reported outcomes, treatments can then be better refined and adjusted. Ultrasound will also generate an improved understanding of patient heterogeneity and help identify patient subsets, pre-treatment risk factors, and more personalized treatment approaches.

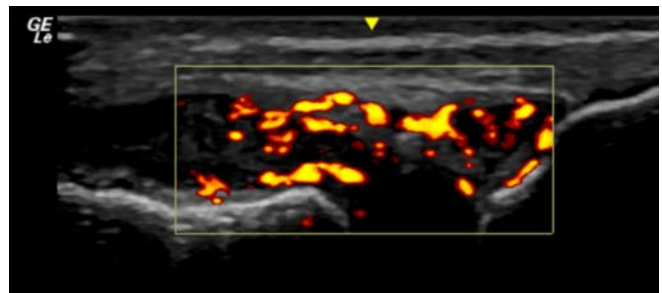
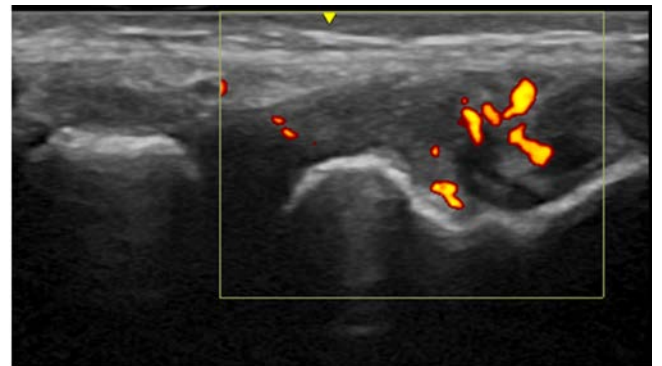


Photo of an actively inflamed joint in a patient with late Lyme arthritis following doxycycline treatment. This degree of inflammation suggests the possibility of treatment failure with antibiotics and may ultimately lead to earlier interventions.



Repeat imaging from the same patient after intravenous ceftriaxone shows decreased but persistent inflammation, now potentially requiring the use of immunosuppressive medications.

Dr. Miller hopes his ground-breaking research will lead to improved patient care for Lyme disease patients.

Center receives DOD funding for novel fMRI research



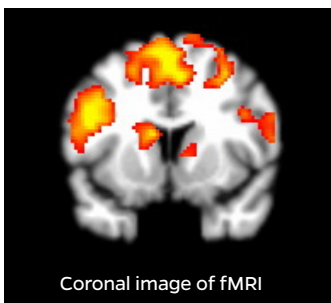
Cherie Marvel, PhD
Associate Professor, Departments of Neurology & Psychiatry, Johns Hopkins University
School of Medicine

In 2020, Cherie Marvel, PhD, received Department of Defense Congressionally Directed Medical Research Program funding to use functional MRI (fMRI) imaging and diffusion tensor imaging (DTI) to study the brains of Lyme disease patients.

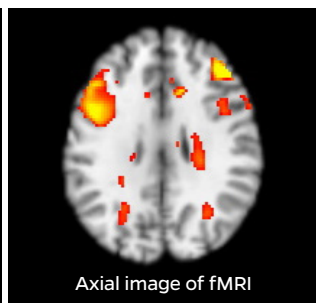
Patients will be recruited and enrolled through our Lyme Disease Research Center. This collaborative 3 year study will build upon Dr. Marvel's prior fMRI work with our Center that suggested the presence of white matter brain abnormalities among Lyme disease patients with persistent symptoms after treatment, compared with controls. This new study will look further into the white matter damage to identify changes in brain activity that may result from infection-triggered inflammation or immune mediated processes.

This DOD grant is breaking new ground in the field of white matter disease and is, to our knowledge, the first fMRI study of white matter in an infectious disease.

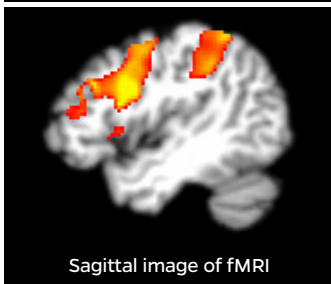
Lyme disease patients with persistent symptoms after treatment often complain of neurocognitive problems (such as memory impairment and slower processing speed) that are frustratingly difficult to capture using traditional cognitive testing.



Coronal image of fMRI

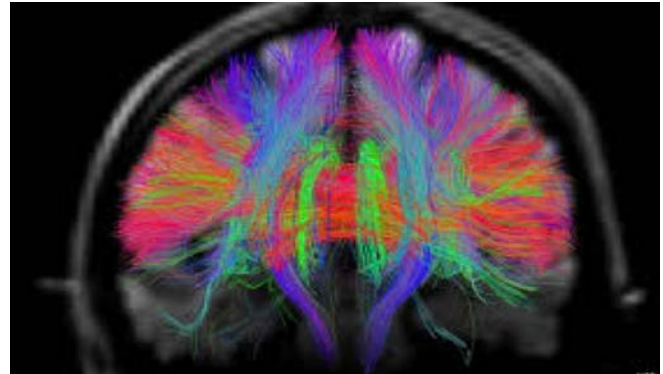


Axial image of fMRI



Sagittal image of fMRI

Visualization of fMRI signals from our healthy control group while performing a short-term memory test. Areas in red/yellow indicate brain activity that increased with task difficulty.



Diffusion Tensor Imaging (DTI) measures the health of white matter tracts in the brain by measuring the consistency with which fibers within a tract travel together or stray from the fiber bundle, indicating "leakiness". In this coronal DTI image, different colors denote directions in which the tracts are traveling.

fMRI is an objective quantitative test that measures brain function during functional tasks. Initial studies indicate that the brains of Lyme disease patients with impaired cognitive functioning are working harder than normal to maintain normal function.

DTI measures structural brain integrity including fiber density, brain connectivity, and white matter integrity.

By using both fMRI and DTI imaging the study will objectively compare functional with structural abnormalities of regions of interest in the brain to understand the basis of patients' cognitive problems. Additionally, clinical testing will include a physical exam, cognitive testing, and blood and cerebrospinal fluid analysis of cytokine and autoantibodies to identify potential immune mediators that may contribute to Lyme disease neurological impairments.

Objectively validating white matter functional and structural abnormalities could have important diagnostic and therapeutic implications for Lyme disease patients.

WHY I GIVE

Tanya Bentley-Young joined the Johns Hopkins Medicine Lyme Disease Research Center's Advisory Board in May 2020 after being a patient of Dr. Aucott's for the past decade. Tanya recounts being terribly sick for five years with intermittent fever, flu-like symptoms, pervasive aches and pains, severe headache, crushing fatigue, and cognitive issues. After multiple doctors' visits and hospitalizations, she was finally diagnosed with Lyme disease by her dermatologist who immediately referred her to colleague and renowned Lyme disease expert, John Aucott, MD, Director of the Johns Hopkins Medicine Lyme Disease Research Center.



Tanya reveals "Dr. Aucott helped turn my life around. For the past decade he has always been a great listener and without his care I wouldn't be back doing what I love." In

“
My most important message to those suffering with Lyme disease is to have hope. The Center provides hope and that's why I give.
”

addition to Dr. Aucott's medical recommendations, Tanya integrates anti-inflammatory nutrition, supplements, a positive attitude, and strong spirit into her healing protocol.

A self-proclaimed "Lyme Warrior", Tanya acknowledges "It is very lonely when you have Lyme disease." She is passionate about helping others as a fitness coach, health advocate, and Advisory Board member and has sent many people to Dr. Aucott for his compassionate care. **"I have supported his clinical research program since inception and am incredibly proud of the extensive progress being made in the Center's numerous leading-edge collaborations."**

Tanya Bentley-Young is a Fitness Lifestyle Coach, NASM-CPT. She has been coaching and advocating healthy lifestyles for over 25 years and has been a Lyme Warrior for 10 years. Tanya lives in Mt. Washington, MD, with her husband, Rob, and they have 3 sons.

RESEARCH CENTER TEAM



CLINICAL RESEARCH TEAM

John Aucott, MD
Associate Professor of Medicine
Director, Lyme Disease Research Center

Alison Rebman, MPH
Senior Research Data Analyst
Co-Director for Clinical and Epidemiological Research

Ting Yang, PhD
Senior Biostatistician

Erica Mihm, 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, BS, MLA
Clinical Research Program Manager

LABORATORY RESEARCH TEAM

Mark Soloski, PhD
Professor of Medicine
Co-Director for Basic Research

Daniella Villegas de Flores, BS
Research Specialist II

Thelio Sewell MS
Research Technologist

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George Roche
Edward St. John
Isaac Yoon, MD
Tanya Bentley Young

EDUCATION AND COMMUNICATIONS LIAISON

Nancy Dougherty
NVantage Consulting, LLC

Philanthropic support makes a difference.

Everyone at Johns Hopkins Medicine is being impacted by the immediate needs arising from COVID-19. We are proud of Johns Hopkins' critical contributions to the local and global response to the pandemic and are equally proud to carry on our important patient care, research, and outreach in Lyme disease.

The work that we are doing today will inform the future of Lyme disease patient care. We remain focused on advancing knowledge and are more grateful than ever for our philanthropic partners who support our work and believe in our mission.

Our Research Center is grateful for the support of:

- Steven & Alexandra Cohen Foundation
- Brennan Family
- Global Lyme Alliance
- Bay Area Lyme Foundation
- Department of Defense
- Individual donors, family foundations and collaborators
- Our Advisory Board

If you would like to contribute to this important work, please contact:

Anne M. Kennan

Johns Hopkins at Keswick
Office of Advancement Services
Attn: RevMgmt—Department of Medicine
3910 Keswick Road, Suite N2100
Baltimore, MD 21211
Email: akennan1@jhmi.edu
Phone: 410-550-9890

You may also make a donation by visiting our website at bit.ly/HopkinsLymeDonate.

Johns Hopkins Medicine Lyme Disease Research Center at Greenspring Station

Joppa Concourse
2360 W. Joppa Road, Suite 320
Lutherville, MD 21093
Provider Office: 410-616-7596
Fax: 410-616-7595

Johns Hopkins Medicine Lyme Disease Research Center at Bayview Medical Center

5501 Hopkins Bayview Circle
JHAAC, Room 1B.7
Baltimore, Maryland 21224

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We appreciate your support which is vital to our program.



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