Transforming LYME DISEASE | Impact Report 2018

Johns Hopkins Lyme Disease Research Center

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.

JOHNS HOPKINS MEDICINE

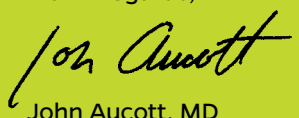
Letter from Director John Aucott

We are pleased to share with you the inaugural impact report of the Johns Hopkins Lyme Disease Research Center.

Established in the spring of 2015, the Johns Hopkins Lyme Disease Research Center is the first research center in a major department of medicine in the United States focused on patient-based research in all aspects of Lyme disease. The Center is impacting research and education in the field by improving the understanding of the complex pathogenic processes of Lyme disease. Our translational research program bridges basic science investigative findings to advances in clinical care.

Our ground-breaking research would not be possible without the support of grants, collaborations, and donors. Thank you all for making this possible. We strive for a future where more accurate diagnoses and effective treatments bring new hope to Lyme disease patients and their families.

Warm regards,



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

Lyme Disease Research Center Milestones

Established gold-standard well-characterized biorepository

Advanced multidisciplinary SLICE studies collaborations

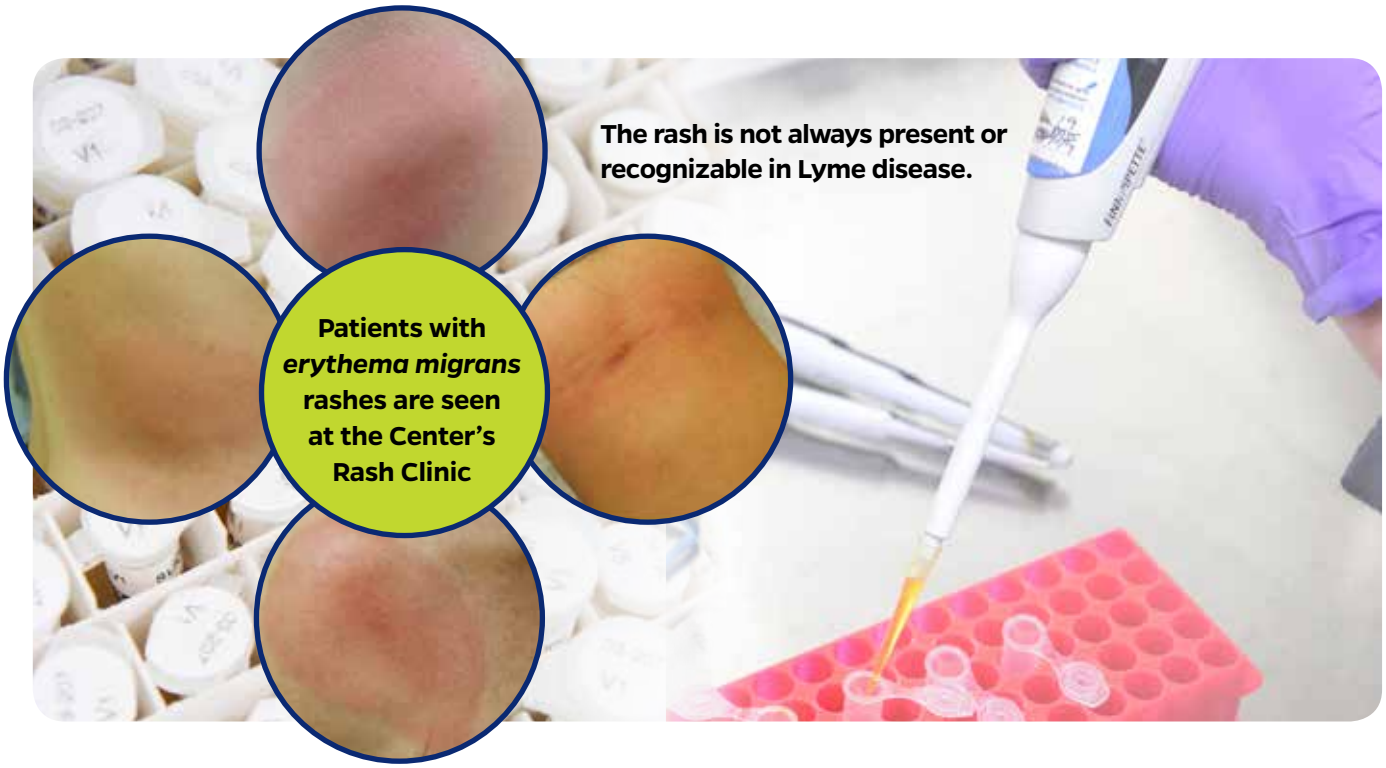
Widened network of SLICE studies participant recruitment

Expanded clinical and research staff

Published over 28 peer-reviewed research studies

PATIENT CARE

By expanding our experienced clinical research staff we have been able to increase the range of patients seen at the Center. Our dedicated team now includes a MD/scientist, nurse, nurse practitioner, data analyst, biostatistician, and research program coordinators. We have expanded our programs to offer specialty clinics that include a new Rash Clinic, Neuro Lyme Clinic, Joint Aspiration Clinic, as well as some E-consultations.



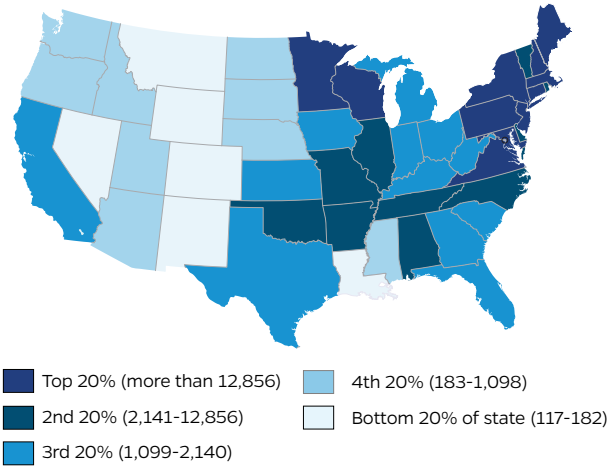
RESEARCH

The Need for Research

Lyme disease (*Borrelia burgdorferi* infection) is a significant worldwide illness. There are over 300,000 new cases annually in the United States, and Lyme disease has been diagnosed in all 50 states. The geographic range of the tick-borne epidemic is expanding as infected ticks spread into new regions, and many previously healthy and productive individuals are becoming chronically ill. Misdiagnosis and delayed diagnosis are significant problems that can lead to serious and prolonged illness. Diagnostic tests can be falsely negative, particularly in the earliest stage of disease when making the diagnosis is crucial, and the characteristic rash of Lyme disease is not always present or easily recognizable. Even following antibiotic treatment, some patients experience symptoms that are severe, persist for years, and profoundly affect their well-being and ability to function. Pervasive symptoms include fatigue, insomnia, musculoskeletal pain, and trouble focusing and concentrating. Some tick-borne conditions can be life-threatening and warrant immediate medical attention such as Lyme carditis, Lyme meningitis, Lyme encephalitis, Powassan virus, Rocky Mountain spotted fever and alpha-gal allergy. Physicians urgently need enhanced education and clinical tools to improve patient care and health outcomes.

Lyme Disease and Tick-Borne Illnesses are Growing Rapidly and Expanding Geographically

Disease Cases from Ticks (2004-2016 Reported)
Maps show case counts, not disease risk.



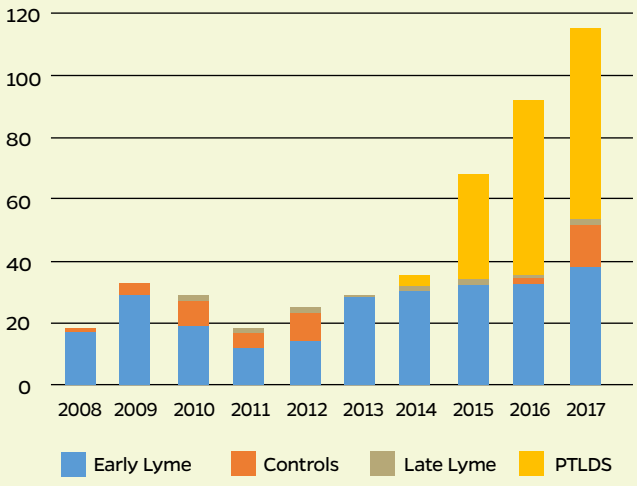
Source: Rosenberg R.,et al. Trends in Reported Vector-Borne Disease Cases—United States and U.S. Territories, 2004-2016. MMWR Morb Mortal Wkly Rep. Vol 67, 2018.

SLICE Studies

Findings generated by the SLICE studies are providing important insights into disease processes which can better inform diagnostics and treatments.

Our clinical research program has produced the largest biorepository of well-characterized blood and skin tissue samples from patients with all stages of Lyme disease. These valuable samples are the cornerstone to research collaborations aimed at improving the understanding of Lyme disease and its varied manifestations. Our landmark SLICE Studies (Studies of Lyme disease Immunology and Clinical Events) are enabling multidiscliplinary research including integrative big data scientific analyses.

Enrollment by Clinical Group: 2008-2017



512 Participants Enrolled in SLICE Studies

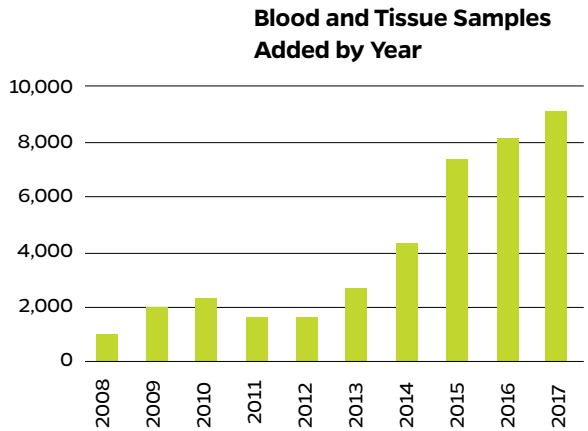
1,731 Participant Visits

87% 1 Year Retention Rate in Early Lyme Longitudinal Studies

SLICE Studies Participant Recruitment Network

SLICE Studies Biorepository

Over 45,000 individual samples of patient blood and skin tissues have been collected in our biorepository



SLICE Studies Collaborations

Clinical research is conducted at the Center by our experienced Johns Hopkins Division of Rheumatology research team and through our collaborative investigations with other Johns Hopkins School of Medicine departments, including joint projects with Neurology, Physical Medicine and Rehabilitation, and Radiology, as well as the Departments of Molecular Microbiology and Immunology, and Environmental Health and Engineering within the Johns Hopkins Bloomberg School of Public Health. In addition, the Center has formed innovative multidisciplinary collaborations with other leading academic, scientific, and medical institutions.

Our pioneering partnerships leverage sophisticated analytic technologies across a breadth of disciplines to identify the complex biologic mechanisms involved in driving ongoing illness. This research involves immune and antibody profiling, *Borrelia* pathogen detection, genetics, genomics, proteomics, metabolomics, microbiomics, and clinical/behavioral/neurological data analyses.

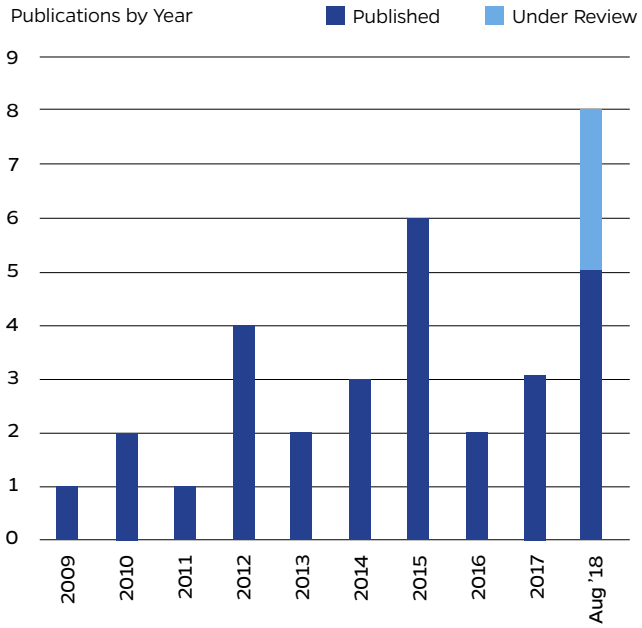
Other Center Collaborations:

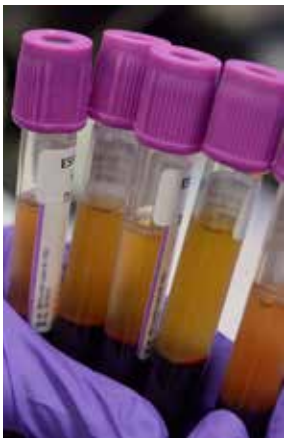
- In conjunction with Johns Hopkins Applied Physics Laboratory we are developing an automated artificial intelligence prescreening rash identification tool to improve early Lyme disease diagnosis.

- Our tick surveillance collaboration with Stevenson University and Mount Sinai School of Medicine is identifying the pathogens found inside ticks across different regions of Maryland.

Insights from our research program are aimed at helping improve diagnostics, treatments, patient care, and health outcomes for those suffering from Lyme disease.

Research Publications



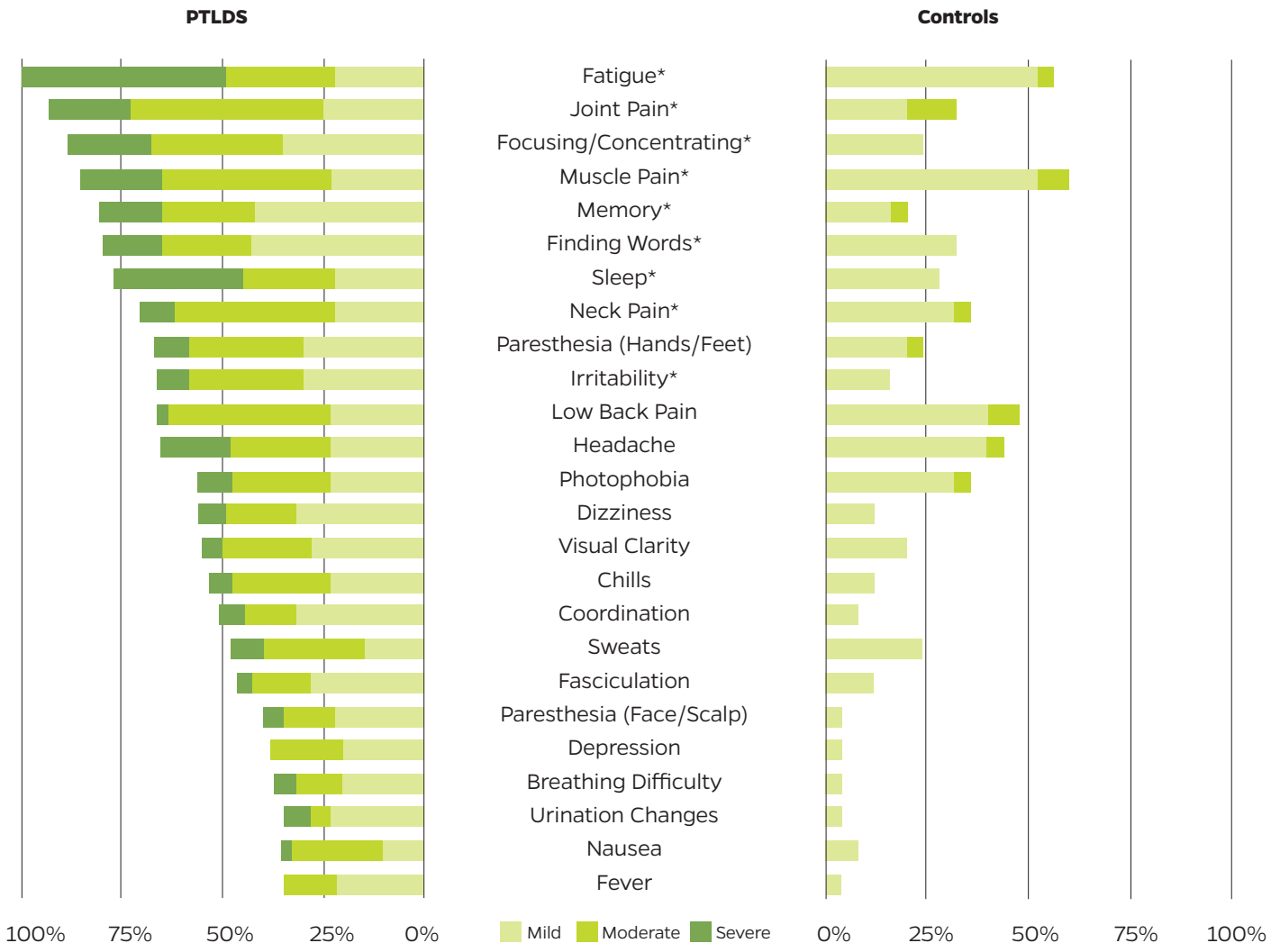


Highlights from our recent studies

Johns Hopkins Lyme Disease Research Center Study Shows that Patients with Post-Treatment Lyme Disease Syndrome are Highly and Clinically Significantly Symptomatic Compared to Controls. December 13, 2017. **Read entire article.**

Research at the Center is focused on identifying biologic causes and disease processes that are driving ongoing Lyme disease illness. Without reliable diagnostic biomarkers it has been difficult to diagnose chronic Lyme disease. Post-Treatment Lyme Disease Syndrome (PTLDS) is a research subset of chronic Lyme disease patients who suffer from ongoing symptoms following standard of care antibiotic therapy. Our study, "The Clinical, Symptom, and Quality-of-Life Characterization of a Well-Defined Group of Patients with Post-Treatment Lyme Disease Syndrome", published in *Frontiers of Medicine* in December 2017, demonstrates PTLDS patients are highly symptomatic, with statistically and clinically significant quality of life impairment.

The graph on the next page illustrates the range and the severity of PTLDS patients' symptoms and can be used to help educate health care practitioners that patients with PTLDS suffer significant symptom impacts on their quality of life.

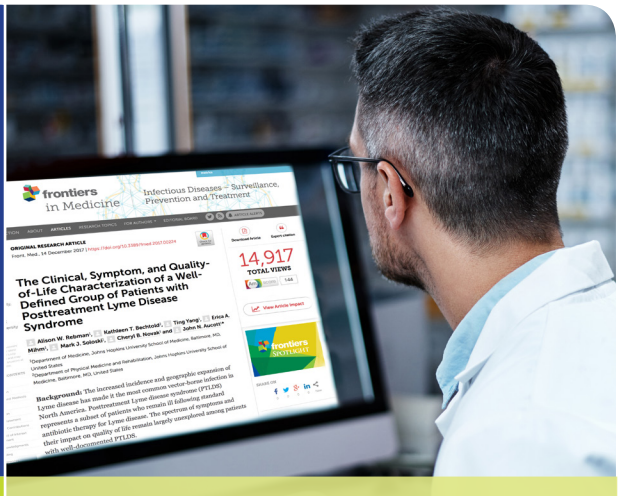


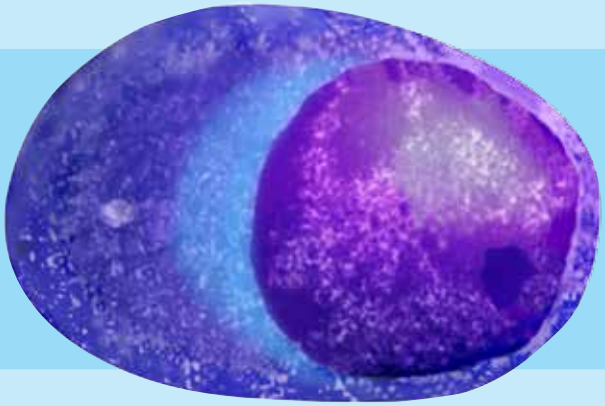
Participants with Post Treatment Lyme Disease Syndrome (PTLDS) and controls were asked about presence and severity of 36 signs/symptoms over the past 2 weeks. Displayed are the 25 signs/symptoms with a statistically significant difference in severity by group ($p < 0.05$) ordered by frequency within the PTLDS group. The nine signs/symptoms with a statistically significant difference at the $p < 0.001$ level are indicated with an asterisk.

What is the impact of this research?

Health practitioners and patients are interested in learning how to better recognize and validate Lyme disease and this study provides important insights and validation. Frontiers of Medicine 97% Views Rank Metrics indicate the research has been generating significant interest.

*This work was supported by the Global Lyme Alliance and the Steven and Alexandra Cohen Foundation.





B CELL PLASMABLAST

This is an image of the cell that can produce large quantities of antibodies that help neutralize and clear *Borrelia burgdorferi* from blood and tissues.

A Recent Collaborative Publication with Stanford University School of Medicine, Tulane University, and Johns Hopkins Researchers Finds Robust B Cell Responses Predict Rapid Resolution of Lyme Disease July 17, 2018.
Read entire article.

This study provides insight into an important immune mechanism of *Borrelia burgdorferi (Bb)* clearance and identifies a potential biomarker associated with return to health following treatment for Lyme disease *Bb* infection. The study shows that in patients who lack a strong B cell response, antibiotic treatment with doxycycline alone does not ensure full resolution of symptoms. However, robust B cell plasmablast responses that encode *Borrelia burgdorferi*-inhibiting antibodies are shown to be associated with more rapid resolution of Lyme disease.

What is the impact of this research? Presently, immune mechanisms for human Lyme disease recovery are not well understood and biomarkers to measure treatment success are lacking in patient care. B cell plasmablast responses that encode *Borrelia burgdorferi*-inhibiting antibodies could provide the basis for next-generation diagnostics and therapeutics for Lyme disease.

Two months post-publication this research already is having an impact with an 85% Views Rank.

*Funding was provided by the Bay Area Lyme Foundation

LISTENING TO PATIENT NARRATIVES HELPS IMPROVE DISEASE UNDERSTANDING AND INFORM OUR RESEARCH

"Lyme disease turned out to be a lot more severe, serious and complex than I had imagined."

—Chris Harris, Lyme disease patient

"In the hospital the tests came out negative so no one ever suspected Lyme."

—Anne King, Lyme disease patient

"You just feel like you've been running on batteries your whole life and you had six batteries in you and somebody came along and took five out. Now you've got to do the same things but on only one battery."

—Anne King, Lyme disease patient

In many cases a first test will come back negative. Anne's follow up test was positive.

EDUCATION

Our Center is having an important impact in Lyme disease education. Our published peer-reviewed research has provided crucial disease insights to scientists, health practitioners and patients and generated hundreds of scientific citations. Our website is among the top resources in Lyme disease Google searches and offers education in prevention, diagnosis, signs and symptoms, and treatment. We host a health practitioner CME-accredited course annually, publish a biannual newsletter, have produced numerous educational videos, and inform audiences through informational TV, print, presentations, and podcasts.

Educational Website:
www.HopkinsLyme.org

Top educational videos viewed:

- Transforming Lyme Disease Research at Johns Hopkins Lyme Disease Research Center
- Preventing Lyme Disease
- Signs & Symptoms of Lyme Disease

Biannual newsletter:
Our newsletter provides updates on the latest information on Lyme disease including the Center's most recent research publications and educational programs. Sign up is available on our website.

WHY WE GIVE: The Kenney Family

The Kenney family is committed to making a difference in Lyme disease research and education. In spring of 2008, Phil Kenney, founder and recently retired CEO and President of Hopkins Medical Products, developed a serious and life-altering case of neurologic Lyme disease. When recounting his health challenges, Phil describes "a burning inflammation" throughout his body, which periodically claims his vibrant and active life by "zapping his energy, causing intense pain, and testing his spirit". He declares, "Lyme disease has devastated my life". After making progress under the care of John Aucott, MD, however, Phil came to recognize Dr. Aucott's clinical research program as "an important driving force to improving the understanding of this illness". As a self-described "guy of action" and determined to be a "victor, not victim", Phil, with the support of his daughter, Nora, and son, Drew, hosted 3 successful fundraisers in 2010-2012 to promote awareness and raise funds for Dr. Aucott's groundbreaking research program. For the past decade, the Kenney Family Foundation has directed generous annual contributions to the program.

Nora Kenney joined the Lyme Disease Research Center's Advisory Board shortly after Dr. Aucott's research program was established as a Center at Johns Hopkins Rheumatology in spring 2015. When asked why she serves, Nora explains "Lyme disease is not as sexy, trendy, or as well understood as other illnesses. We need to advance research and education so practitioners can better recognize and treat the illness." Phil agrees and adds, "Many doctors have no idea how complex Lyme disease is, and we need to help them connect the dots for all manifestations of the illness."

Choosing to live with a positive mantra of "coping with hope", Phil is also actively involved with the patient community and runs the Lyme Care Resource Center group he cofounded in 2016 with Shireen Rusby. The support group meets monthly and hosts speakers on a variety of Lyme disease topics including prevention, diagnosis, signs and symptoms, holistic treatment approaches, and advances in research. Speakers have included Dr. John Aucott, Dr. Mark Soloski, and Alison Rebman from the Center.

Thanks to the ongoing support of the Kenney Family Foundation, an accredited Continuing Medical Education (CME) course on Lyme Disease was initiated and is now offered annually by the Center. Over 150 health practitioners participated in its first two years. The Kenney family hopes the information learned in the CME course about Lyme disease diagnosis, treatment, and prevention will help improve patient care and health outcomes. Phil believes that "through continued research and education there will be a resolution to this illness someday."

"That is why we give."

"Many doctors have no idea how complex Lyme disease is, and we need to help them connect the dots for all manifestations of the illness."

—Phil Kenney

< Phil Kenney, with daughter, Nora, and son, Drew, are committed to making a difference in Lyme disease research and education

RESEARCH CENTER TEAM

Clinical Providers, Research Leadership, and Staff

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

Leonardo Diaz, BS, CCRP
Clinical Research Program Manager

Erica Mihm, BS
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

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

Maria Gutierrez, PhD
Post-Doctoral Research Fellow

Daniella Villegas de Flores, BS
Research Specialist II

Thelio Sewell, MS
Research Technologist

Rafaello Cimbro, MS
Flow Cytometry Lab Manager

ADVISORY BOARD

Peter Agre graduated from Johns Hopkins School of Medicine in 1974, and following clinical training joined the Johns Hopkins faculty in 1981. Agre shared the 2003 Nobel Prize in Chemistry for discovery of the aquaporin water channel proteins. Refocused on malaria, Agre has served as Director of the Johns Hopkins Malaria Research Institute since 2008.

Sharon L. Akers has served as Executive Director of the Edward St. John Foundation and Vice President of Corporate Relations for St. John Properties since 2007. She works to promote and strategically position St. John Properties, a privately held commercial real estate company in Baltimore, Maryland. She is responsible for providing oversight and facilitating the philanthropic support of the Foundation, Company, and Edward St. John.

Carol Brown Goldberg is a Washington, DC painter and sculptor, with over 100 solo and group exhibitions in the United States and abroad. She has created two award-winning films and several outdoor sculpture installations, including a 2016 installation at the Wilmer Eye Institute at Johns Hopkins. She has taught at American University and University of Maryland, was Artist in Residence at Chautauqua Institute, is a recipient of the Maryland State Arts Award, serves on the board of The Phillips Collection in Washington, DC, on the Collector's Committee of the Reading Public Museum, and on the Contemporary Art Accessions Committee of the Baltimore Museum of Art.

Marianne Schmitt Hellauer is a partner with DLA Piper, concentrating her practice in the areas of estate and tax planning, business entity planning, and charitable giving. Repeatedly named a Maryland Super Lawyer and recognized in *Best Lawyers in America*, Marianne is also a Fellow of the American College of Trust & Estate Counsel and a Past Chair, Estates & Trusts Section, Maryland State Bar Association. She currently serves on the Boards of the University of Baltimore Foundation, Trustees of Catholic Charities of Baltimore, and the Lyme Disease Research Foundation. She is a graduate of University of Maryland and University of Baltimore School of Law.

Nora Kenney is Director of Store Development for Under Armour and has been growing their retail global footprint for over 10 years. She studied Business Management at Bucknell University and is passionate about Lyme Disease research and raising awareness.

Lawrence M. Macks is Co-Chairman and CEO of Chesapeake Realty Partners and is responsible for all facets of residential and commercial development. Larry is the former President of The Associated Jewish Charities of Baltimore, has served on several governmental advisory boards, and currently serves on the Boards of Roti Mediterranean Grill (Roti.com), and the Lyme Disease Research Foundation. He is a graduate of Washington University and the University of Maryland School of Law.

Alex Mason is currently a consultant to financial services firms in Baltimore and New York. Previously, Alex served as President of CIT Group, Vice Chairman and Director of Mercantile Bankshares, and was head of global corporate finance practices for Deutsche Bank AG and for Bankers Trust. Alex chairs the Advisory Board of the Lyme Disease Clinical Research Center at Johns Hopkins. He also serves as the President of the Lyme Disease Research Foundation and serves on the Board of Mercy Medical Center in Baltimore. He is a graduate of Princeton University.

Dale Mathias has had a 25 year career in finance and private investments. She invests in early stage technology companies in both the U.S. and sub-Saharan Africa. Previous positions include Vice President of Lazard Freres and Associate Dean at Columbia Business School. Dale has served on several Boards and currently holds Board positions at Tate Modern, Africa Acquisitions Committee; The Metropolitan Museum of Art's International Council; and Marine Biological Laboratories, University of Chicago. Dale is a graduate of Harvard College and a Life Member of the Council for Foreign Relations.

Beth McCrickard was formerly involved in research at Bowman Gray, Dartmouth Medical School, the University of Virginia, and the Brady Institute at Johns Hopkins. Her community involvement includes The Walters Museum of Art, Bridges Program at St. Paul's School and St. Ignatius Loyola Academy.

Jeffrey Mills is Managing Director and Co-Chief Investment Strategist for the PNC Financial Services Group. In this role, Jeff oversees all investment strategy-related activities for the Wealth Management, Hawthorn (ultra-high-net worth), and Institutional Asset Management businesses. Jeff is also the co-founder of an early stage venture capital fund at the University of Oxford that seeds young companies run by Oxford alumni. Jeff earned a BA in international relations from the University of Pennsylvania, MBA focused in finance from the University of Oxford, and a post-MBA Master of Science focused in investment management from the Massachusetts Institute of Technology.

Robert Mills previously served as a Partner at KPMG, CFO for UBS for the Americas, and Chief Operating Officer For Assured Guaranty Ltd. Bob currently serves as a Director of Williams Industrial Services Group Inc. and Syncora Holdings Ltd.

Ryan Perdue is spokesperson and VP of Pet Products at Perdue Farms where he founded the Full Moon and Spot Farms brands. Ryan is a graduate of Dartmouth College and served on the Lyme Disease Research Foundation Board before the research program was established as a Center at Johns Hopkins.

George Roche retired as Chairman and President of T. Rowe Price Group, Inc. in December of 2006 after nearly 39 years with the firm. Mr. Roche was an analyst and portfolio manager of the New Era Fund from 1979 to 1997. He was also the Chief Financial Officer of T. Rowe Price Associates from 1984 to 1997 and was Chairman and President of T. Rowe Price Group, Inc. from 1997 to 2006. He has served on the boards of the Greater Baltimore Committee, Downtown Partnership, The Walters Art Gallery, and McCormick & Co., Inc. He earned a B.A. from Georgetown University and an MBA from Harvard Business School.

Edward St. John is Founder and Chairman of St. John Properties, a privately held commercial real estate company he started in 1971 in Baltimore, Maryland. In 1998, he established the Edward St. John Foundation, a separate 501(c)3, focused on educational enrichment for children and other worthwhile causes. More than $60 million has been gifted by the Edward St. John Foundation to educational and nonprofit organizations.

Isaac Yoon, MD, is Chief Medical Director for Patient First. He is board certified in Family Practice and has been practicing primary and urgent care for over 30 years. Dr. Yoon is an undergraduate of Johns Hopkins University, a graduate of Tulane University School of Medicine and did his residency at the Mayo Clinic in Rochester, Minnesota. Prior to Patient First, he was an emergency medicine physician in Rochester, Minnesota and is a member of the American College of Emergency Physicians.

Philanthropic support makes a difference.

Private support is instrumental to advancing the Johns Hopkins Lyme Disease Research Center's pioneering research program. Philanthropy provides the Research Center with the ability to pursue groundbreaking research that is critical to improving diagnostics, treatments, education, and health outcomes for Lyme disease patients.

Our Research Center is grateful for the support of:

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

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

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Baltimore, MD 21224-2735
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You may also make an online donation:
DONATE NOW

Johns Hopkins 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 Lyme Disease Research Center at Bayview Medical Center
Division of Rheumatology
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Center Tower, Suite 4100
5200 Eastern Avenue
Baltimore, MD 21224

We appreciate your support which is vital to our program.

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