

JOHNS HOPKINS LYME DISEASE RESEARCH CENTER

Impact Report 2019



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

Letter from Director, John Aucott

We are pleased to share with you the 2019 Impact Report of the Johns Hopkins Lyme Disease Research Center. Our patient-based research program is continuing to advance the understanding of the complex pathogenic processes of Lyme disease. Insights from our studies are improving Lyme disease education and helping drive innovations that will benefit patient care.

Our groundbreaking program 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 will bring better outcomes and new hope to Lyme disease patients and their families.

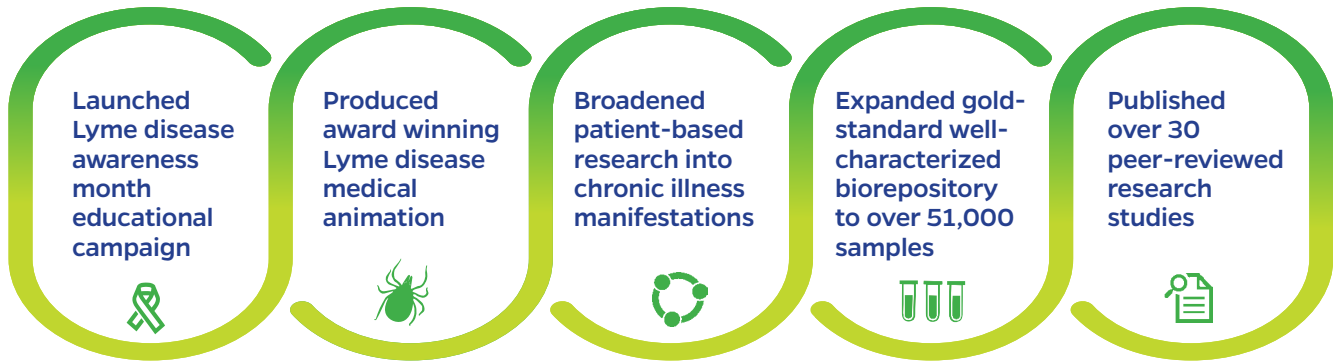
Warm regards,

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



JOHNS HOPKINS
MEDICINE

MILESTONES



PATIENT CARE

Our Center has an experienced clinical research team that includes a physician-scientist, nurse, nurse practitioner, data analyst, biostatistician, and research coordinator. We also provide selective e-consultations and offer specialty clinics for rash consultation, neuro Lyme evaluation, and

joint aspiration. Urgent appointments can be made for a rash consultation by calling our Center. Patients with late or chronic manifestations of Lyme disease, including neuro Lyme and Lyme arthritis, are seen on a consultative basis by referral from a primary care physician.



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 NEED FOR RESEARCH AND IMPROVED CARE

Lyme disease is a multi-system bacterial infection caused by the spirochete, *Borrelia burgdorferi*, which is transmitted to humans through the bite of an infected deer tick. Lyme disease is endemic across large regions of the northern hemisphere, with over 300,000 new cases per year in the US. The geographic range continues to expand as infected ticks spread into new regions.

Early Lyme disease symptoms are often mistaken for a summer flu-like illness. Diagnostic tests can be falsely negative, particularly in the earliest stage of disease when making the diagnosis is crucial. The characteristic rash of Lyme disease is not always present or easily recognizable. Misdiagnosis and delayed diagnosis are significant problems that can lead to delayed treatment and prolonged illness. Even following antibiotic treatment, some patients experience symptoms that are severe, may persist for years, and can profoundly affect their well-being and ability to function. Previously healthy and productive individuals can become chronically ill with symptoms that include severe fatigue, insomnia,

musculoskeletal pain, and neurologic symptoms such as trouble focusing and concentrating.

Deer ticks can also transmit other pathogens either alone or in conjunction with each other and/or with *Borrelia burgdorferi*, the agent of Lyme disease. These include Anaplasma, Babesia, *Borrelia mayonii*, and a relapsing fever like organism, *Borrelia miyamotoi*. Some tick-borne conditions can be life-threatening and may warrant immediate medical attention including Lyme carditis, Powassan virus, Rocky Mountain spotted fever, Ehrlichiosis, and alpha-gal allergy.

Physicians urgently need enhanced education and clinical tools to improve Lyme disease diagnostics, treatments, and health outcomes. To learn more about Lyme disease, please visit our website at www.HopkinsLyme.org.



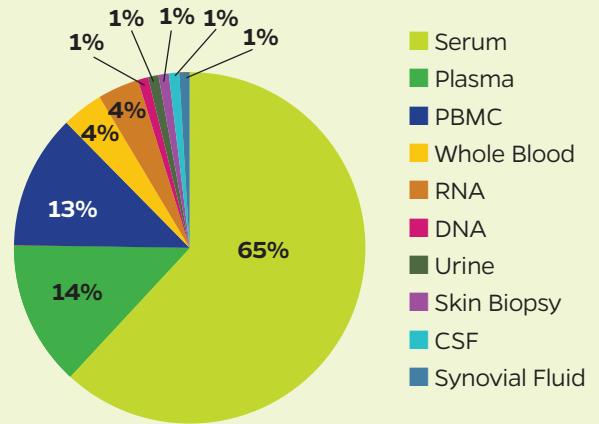
RESEARCH

Our clinical research team works closely with our research lab which includes an immunologist, research fellow, research specialists and lab technologists. Our landmark SLICE studies (Studies of Lyme disease Immunology and Clinical Events) have established a robust biorepository of over 51,000 well-characterized blood and skin tissue samples from patients with all stages of Lyme disease. These valuable samples are critical to improving the understanding of Lyme disease and its varied manifestations and are the cornerstone to innovative multidisciplinary research collaborations with leading worldwide academic, scientific, and medical investigators. Our SLICE studies are providing important insights into disease processes and enabling novel avenues for diagnostic and treatment innovation.

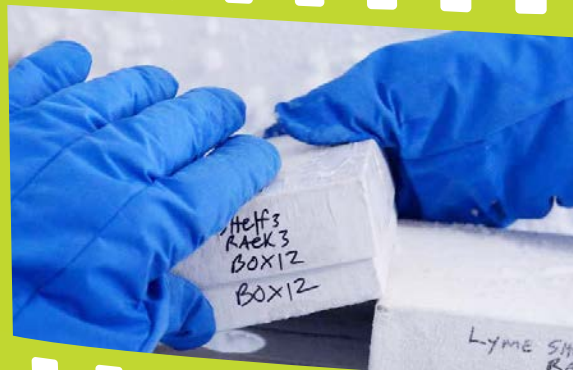
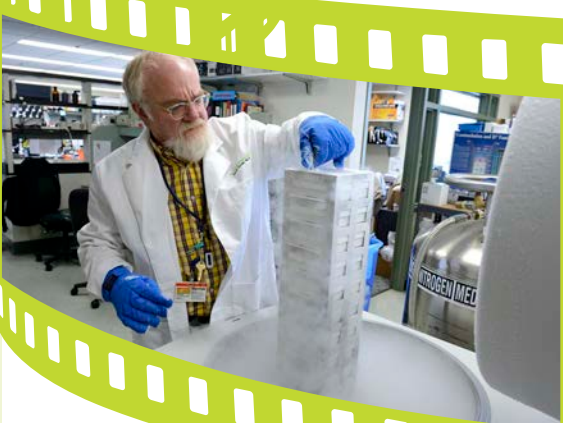
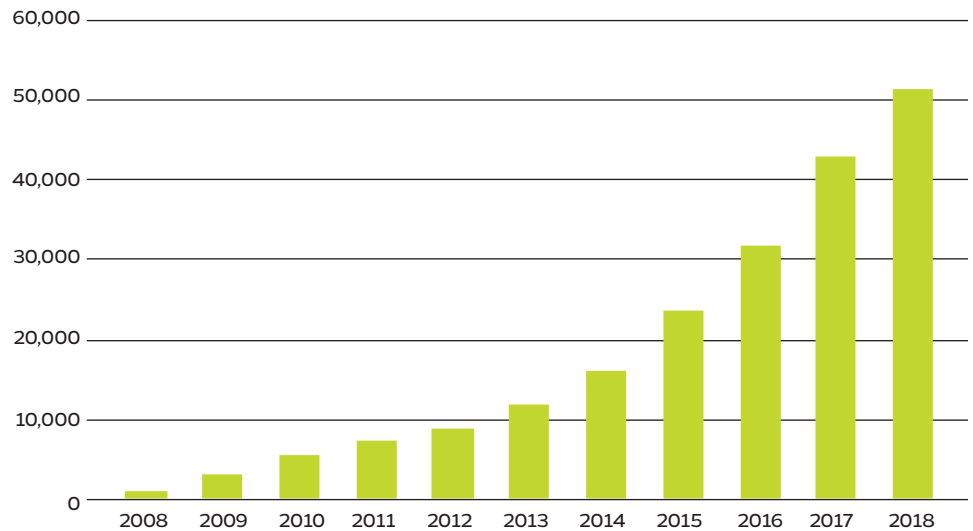


Biorepository

Sample Types Included in the SLICE Biorepository



Cumulative Number of SLICE Studies Samples



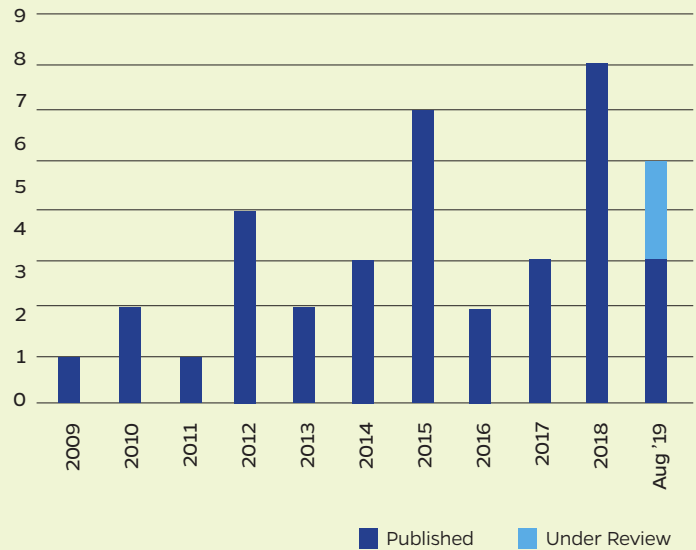
Research Publications

Our Center publishes studies in peer-reviewed journals across a range of disciplines, including infectious disease, rheumatology, dermatology, immunology, neuroinflammation, neuropsychology, sex and gender-based medicine, quality of life, and public health.

Our goal is to advance understanding of the complex pathophysiology of Lyme disease and translate research findings into improved patient healthcare.

Our SLICE studies are helping unravel the potential roles of immune dysfunction, autoimmunity, inflammation, persistent bacterial infection, neural network alteration, and other biologic processes involved in driving ongoing Lyme disease illness.

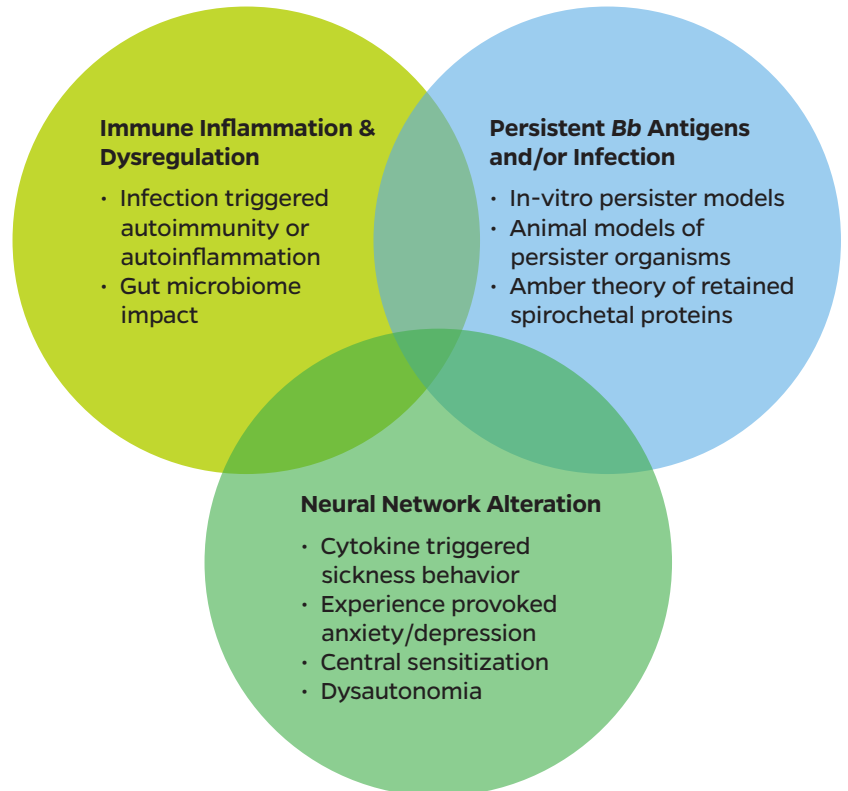
Publications by Year



Value of Research Subsets

Lyme disease encompasses a range of biologic processes and disease manifestations. Our research establishes well-defined subgroups as an essential foundation for improving the understanding of this complex heterogeneous illness. Post Treatment Lyme Disease (PTLD) is one such subset of patients who have been diagnosed and treated for early Lyme disease with standard of care antibiotics but have ongoing symptoms 6 months or more following treatment. Our research is improving the understanding of the biology of the infection and the human immune response in PTLT to enable the development of more accurate diagnostics, more effective treatments, and tests that can monitor treatment success or failure.

Hypotheses Regarding Potential Mechanisms of Persistent Symptoms of Lyme Disease, including PTLT



Patient-Based Research

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

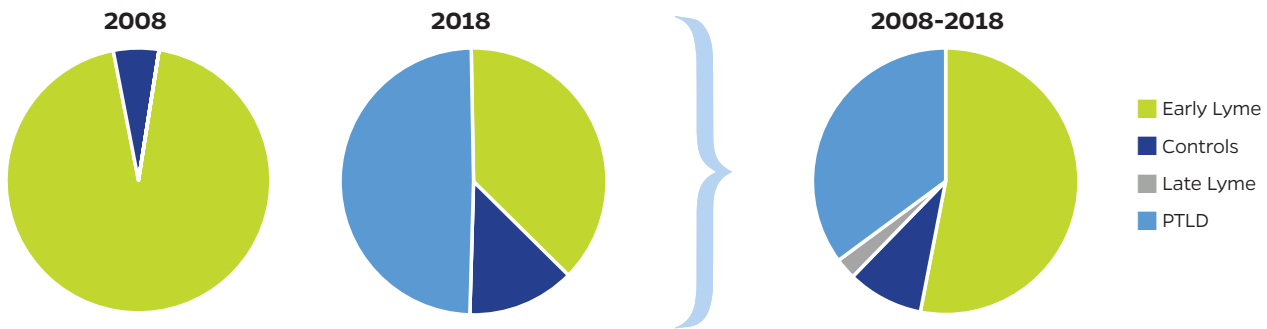
592 Participants Enrolled in SLICE Studies

1,924 Participant Visits

85% 1 Year Retention Rate in Early Lyme Longitudinal Studies

As of August 31, 2019

Enrollment by Clinical Group: 2008-2018



Our SLICE studies have expanded beyond focusing solely on early Lyme disease to also studying persistent manifestations of Lyme disease, including the subset, Post Treatment Lyme Disease. In 2018, the enrollment distribution of SLICE studies participants was **38% Early Lyme, 49% PTLD, and 13% Controls.**

Our clinical, biorepository, and epidemiologic data is invaluable for discovering and testing biomarkers that can better inform and improve the clinical understanding of Lyme disease.

Collaboration

Lyme disease is a complex illness requiring a dynamic, collaborative, and innovative approach to research. Open-minded, interdisciplinary expertise enables us to expand knowledge, and collaboration is at the heart of our research program. Since the beginning of the SLICE studies, we have collaborated with **over 30 different researchers from over 20 different scientific affiliations.**



HIGHLIGHTS

From Our Recent Studies

Early Rash Detection

Automated Detection of Erythema Migrans Rash in Early Lyme disease via Deep Learning can Improve Early Diagnosis <https://doi.org/10.1016/j.compbimed.2018.12.007>, February 2019

This research study shows that deep machine learning can be utilized to more accurately identify erythema migrans (EM) rashes in early Lyme disease.

Lyme disease can be difficult to diagnose because early symptoms of fever, severe fatigue, and achiness are also common in many other illnesses. In addition, many cases are initially misdiagnosed because diagnostic blood tests are not always dependable, and the EM rash is not always present or recognizable in early Lyme disease.


Recognition of the varied presentations of the EM rash is crucial to early diagnosis and treatment. Delayed diagnosis and treatment can lead to serious ongoing illness including neurological, cardiac and rheumatologic complications. Accurate recognition of the early presenting EM rash by both patients and clinicians is key to facilitating early diagnosis and prompt initiation of appropriate treatment.

Despite common belief, the stereotypical ring within a ring bullseye rash is only present in a minority of Lyme disease patients. Instead, the majority of Lyme disease rashes are uniformly red or blue-red and do not have a central clearing or bullseye. The rash is almost always round or oval and expands over days to a diameter greater than 2". The Lyme rash is often confused with a spider bite, despite spider bites not expanding in this way.



Computer-based deep learning is likely a more sensitive prescreen tool than patient self-assessment and has the potential to be more accurate than diagnosis by a general non-specialist physician, who would ordinarily serve as the screening gatekeeper for acute onset EM rashes. Improved rash recognition using deep learning methodology to prescreen patient rash photos may promote earlier diagnosis and treatment and help prevent later serious manifestations of Lyme disease.

This study was published in conjunction with the Johns Hopkins Applied Physics Laboratory and Malone Center for Engineering in Healthcare. This work was supported by JHU APL internal research and philanthropic support from generous friends of the Center.



1ST LIVE LYME DISEASE EDUCATIONAL WEBINAR WITH CENTER DIRECTORS JOHN AUCOTT, MD, MARK SOLOSKI, PhD
View content at <https://www.hopkinslyme.org/news-impact/events/>

EDUCATION Highlight Reel

LYME DISEASE AWARENESS MONTH (MAY) CAMPAIGN



Weekly content sent in May from Center through JHU Division of Rheumatology to over 6,200 subscribers

Neuroinflammation

Imaging Glial Activation in Patients with Post-treatment Lyme Disease Symptoms: a pilot study using [¹¹C]DPA-713 PET <https://jneuroinflammation.biomedcentral.com/articles/10.1186/s12974-018-1381-4>, December 2018

This research study uses a neuroimaging radiotracer with positron emission tomography (PET) to quantify cerebral glial activation in brains of patients with post-treatment Lyme disease (PTLD). Results show elevated central nervous system immune activation in patients with PTLD as compared to controls.

The pathophysiology of PTLD may be linked to overactive immunity including aberrant activity of microglia, the brain's resident immune cells. These findings could indicate a potential biological link to patients' cognitive symptoms. More research is needed to determine

if an aberrant microglia neuroimmune response could be linked to the neuropsychiatric symptoms of post-treatment Lyme disease and whether immune-modulating therapeutic strategies, such as those used in other central nervous system conditions, could benefit these patients.

This study was published in conjunction with the Department of Psychiatry and Behavioral Sciences and Russell H. Morgan Department of Radiology and Radiological Science, Johns Hopkins University School of Medicine. This work was supported by a Johns Hopkins Discovery Award, the Alexander Wilson Schweizer Fellowship, a Johns Hopkins Doris Duke Foundation Early Clinician Investigator Award, the National Institutes of Health, and the Steven & Alexandra Cohen Foundation.

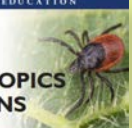
3rd ANNUAL LYME DISEASE TOPICS AT JOHNS HOPKINS

CME-accredited course for health practitioners

CONTINUING MEDICAL EDUCATION

Save the Date
Third Annual
LYME DISEASE TOPICS
at **JOHNS HOPKINS**

Friday, June 14, 2019 • 1:00 – 5:30 pm




BIANNUAL NEWSLETTER


Sign up on
HopkinsLyme.org

NATIONAL AND INTERNATIONAL PRESENTATIONS AT SCIENTIFIC CONFERENCES AND PATIENT SYMPOSIUMS

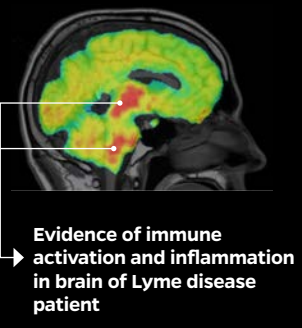
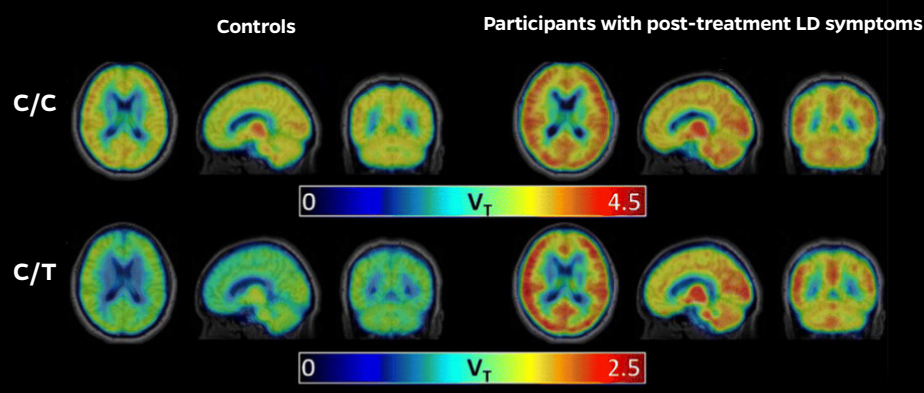
Canadian Lyme Disease Research Network Advisors



LYME DISEASE MEDICAL ANIMATION

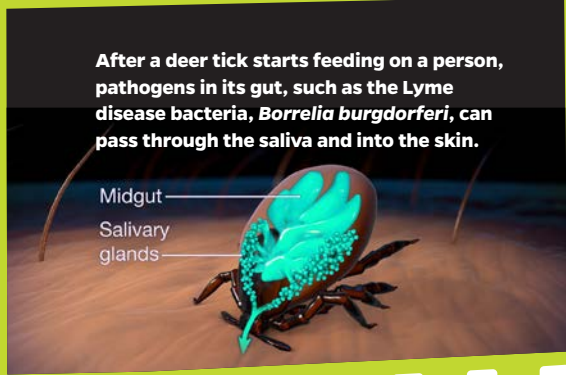


Pilot PET Imaging Study of Patients with Post Treatment Lyme Disease Shows Brain Inflammation



EDUCATION

Award Winning Lyme Disease Animation



In 2019 the Center released a first of its kind medical animation to help explain the complex disease processes of human Lyme disease. The animation has received a prestigious Award of Excellence from the Association of Medical Illustrators. The 7-minute video depicts the initial Lyme disease infection, the mechanisms of immune system evasion, and the dissemination and progression of disease.

The Lyme disease animation was created over the course of a year by medical animator, Lydia J Gregg, MA, CMI, Associate Professor, Director of Operations in the Department of Art as Applied to Medicine and Director of the Visualization Core Lab in the Division of Interventional Neuroradiology, Department of Radiology, Johns Hopkins University School of Medicine. Funding was provided by Carol Brown Goldberg and Henry H. Goldberg. Script authors included Center Co-Directors, John Aucott, MD, and Mark Soloski, PhD, and Mary Blue, PhD, Associate Professor, Department of Neurology and Neuroscience at Johns Hopkins University School of Medicine. The team spent the year planning the animation content with meticulous detail and many rounds of review.

The animation shows the biological processes involved in a Lyme disease infection starting with how a tick transmits Lyme disease bacteria, *Borrelia burgdorferi* (*Bb*), to

humans and how the *Bb* bacteria evade the immune system, create a strong inflammatory response, and infect numerous systems of the body. The animation also depicts the clinical progression of Lyme Disease from the appearance of the rash to migration of the bacteria into capillaries as well as the clinical progression of symptoms. With a passion for accuracy, the team ensured that all aspects of the animation were presented at relative scale and based on measurements and molecular data from the primary literature.

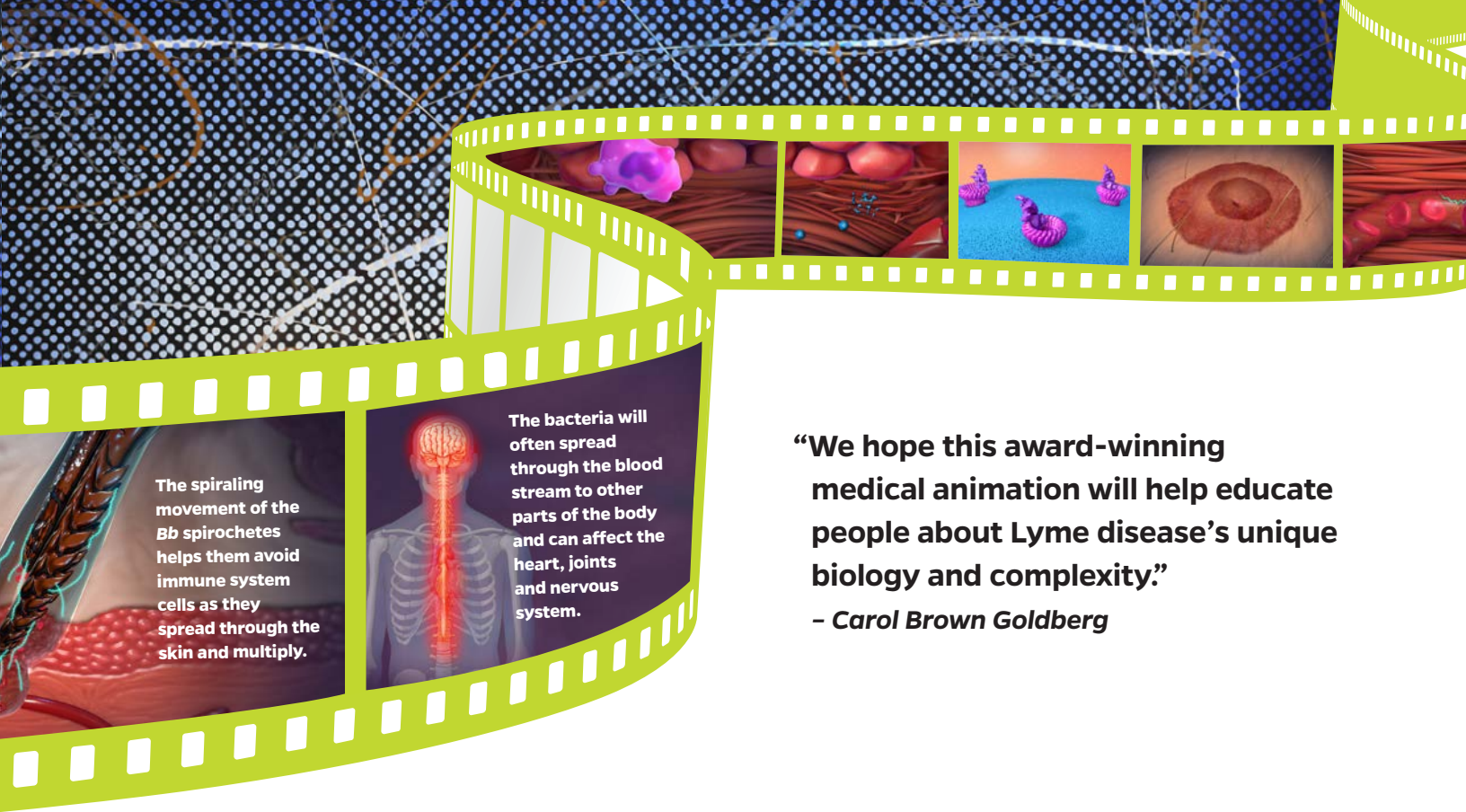
Animation Project Team



John Aucott, MD, Carol Brown Goldberg, Mark Soloski, PhD, Mary Blue, PhD



The video, animated by Lydia Gregg, MA, CMI, can be viewed at www.HopkinsLyme.org/lyme-education.



The spiraling movement of the *Bb* spirochetes helps them avoid immune system cells as they spread through the skin and multiply.



The bacteria will often spread through the blood stream to other parts of the body and can affect the heart, joints and nervous system.

“We hope this award-winning medical animation will help educate people about Lyme disease’s unique biology and complexity.”

- Carol Brown Goldberg

WHY WE GIVE: Carol Brown Goldberg and Henry H. Goldberg

Carol Brown Goldberg is an accomplished artist who while painting in her studio frequently takes inspiration from the scientific world, especially the shapes, movements, and behavior of the microscopic world. Many of her distinguished works are vibrant visualizations inspired by the microbiologic world. Several of Carol’s colorful paintings grace the walls of the Center.



Through her keen interest in art and biology, Carol discovered an animated film series that explains basic biologic processes visually. In sharing these videos with her grandchildren, she noticed how captivated they became and how easily they absorbed the material. Recognizing the power of film as a teaching tool for

biology she then envisioned the idea of creating a Lyme disease educational animation. Carol, who serves as an Advisory Board member of the Center, pitched the concept to Center Director, John Aucott, MD, who loved the idea, especially since a medical animation had not previously been done for Lyme disease. With generous funding from Carol and her husband, Hank Goldberg, the innovative project proceeded, and after a year of development was released in the spring of 2019.

The Goldbergs have been generous annual supporters of the Center. Asked why they give, Carol replies **“Lyme disease has significantly impacted our family. Dr. Aucott’s compassionate care has been important to us, and his groundbreaking research program at the Center is helping to unravel the mysteries of this complex disease.**

We recognize the need for vastly improved education and patient care for this debilitating illness and know our support will help provide the answers patients desperately need.”

SOME KEY TAKEAWAYS FROM OUR EDUCATION PROGRAM



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

Leonardo Diaz, BS, CCRP
Clinical Research Program Manager

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



Laboratory Research Team

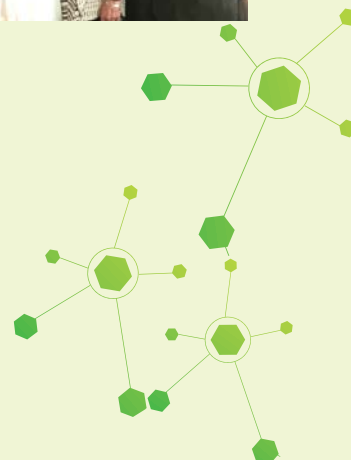
Mark Soloski, PhD
Professor of Medicine
Co-Director for Basic Research

Maria Gutierrez-Hoffmann, PhD
Post-Doctoral Research Fellow

Daniella Villegas de Flores, BS
Research Specialist II

Thelio Sewell, MS
Research Technologist

Jinshui Fan, PhD
Research Associate



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 is President of the Edward St. John Foundation and Executive Director of Special Projects for St. John Properties. She has served with the organizations 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. Her work is included in many museums and private collections. She has taught at American University and University of Maryland and was Artist in Residence at Chautauqua Institute. Carol is the recipient of numerous awards, including the Maryland State Arts Award. She serves on several Boards including Defiant Requiem and The Phillips Collection in Washington, DC.

Marianne Schmitt Hellauer is a partner with DLA Piper, concentrating her practice primarily in the areas of estate and tax planning, business entity planning, and charitable giving. She has been repeatedly named a Maryland Super Lawyer and recognized in *Best Lawyers in America* for Trusts and Estates Law. Marianne is a Fellow of the American College of Trust and Estate Counsel and past Chair, Estates and Trusts Section Council, Maryland State Bar Association, and past Chair, Investment Committee for Horizon Foundation where she continues as ex-officio member. 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 graduated from Bucknell University with a BS in Business Management. She was in retail store development at Under Armour for over 10 years, most recently leading brand strategy and customer experience for new concepts. Nora is a Director at the Kenney Family Foundation, with a focus on disease research, holistic wellness, and community restoration.

Lawrence M. Macks is Co-Chairman and CEO of Chesapeake Realty Partners and 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 serves as Senior Advisor to New York Private Finance. Previously, Alex served as President and Chief Operating Officer of CIT Group, Vice Chairman & Chief Operating Officer and Director of Mercantile Bankshares, and was head of global corporate finance practices for Deutsche Bank AG and for Bankers Trust. A graduate of Princeton University, Alex currently chairs the Investment Committee and serves on the Board of Mercy Medical Center in Baltimore. Alex also chairs the Advisory Boards of the Lyme Disease Research Foundation and the Lyme Disease Research Center at Johns Hopkins.

Dale Mathias has had a career in finance and private investments for over 25 years. 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 USAID (Chair of The Partners Forum Advisory Board); 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. She is a graduate of Mary Washington University.

Jeffrey D. Mills is Chief Investment Officer at Bryn Mawr Trust Wealth Management. He is responsible for investment strategy across BMT's Wealth Management platform, including the development of alternative capabilities to attract high net-worth clients, as well as institutions, endowments, and foundations. Jeff previously served as Managing Director and Co-Chief Investment

Strategist for PNC Financial Services Group. Prior to this position, he was Chief Investment Strategist for PNC's Hawthorn Group. Jeff earned a BA in international relations from the University of Pennsylvania, MBA from the University of Oxford, and Master of Science focused in investment management from MIT.

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, McCormick & Co., Inc., and Enoch Pratt Library. 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 contributed, pledged, and gifted through donations by the Foundation, St. John Properties, and Edward St. John to a variety of educational and nonprofit organizations.

Isaac Yoon, MD, is Medical Director of Patient First family medicine centers in Lutherville, Columbia, and Sicklelerville Maryland. He is certified by the American Board of Physician Specialties and has been practicing primary and urgent care for over 25 years. Dr. Yoon is an undergraduate of Johns Hopkins University, a graduate of Tulane University School of Medicine and completed a residency in internal medicine at the Mayo Clinic in Rochester, Minnesota.

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
- Brennan Family
- Global Lyme Alliance
- 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

Department of Medicine Development Office
Fund for Johns Hopkins Medicine
5200 Eastern Avenue
MFL Center Tower, Suite 355
Baltimore, MD 21224-2735
Phone: 410-550-9890
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akennan1@jhmi.edu

You may also make a donation by visiting our website at www.HopkinsLyme.org

Johns Hopkins Lyme Disease Research Center at Greenspring Station

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

Johns Hopkins 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.



JOHNS HOPKINS
M E D I C I N E