Impact Report 2018-2023

PROJECT

lyme

SR

"It's heartwarming to see all the support Project Lyme has been given. We remain dedicated to our mission, and to building a team that will take us forward, pursuing solutions to this most complicated and devasting problem." Jennifer Weis and Nan Kurzman, Board Chairs

MISSION

Our mission is to eradicate the epidemic of tick-borne diseases through awareness and education, support of cutting-edge science, and advocacy for solutions to end the suffering.

IMPACT

We strive to end the epidemic of tick-borne diseases. We work tenaciously

- Educating the public in innovative ways.
- Funding research in diagnostics and therapeutics.
- Advocating for meaningful solutions.
- Supporting patients through their Lyme Journey.





Financial Summary

Revenue

We have raised over \$5 million to combat the effects of tickborne diseases.



Expenses

Project Lyme's Board of Directors covers all of our operational expenses, meaning 100% of donor contributions directly fund our programs. Here is a look at how funds are distributed.





We offer extensive programming to educate patients, doctors, and the public about tick-borne diseases. These programs include -

• National Public Service Announcements: Our Lyme is a Thief PSA series aired a total of 19,365 times on 64 different TV stations in 30 states across the country including ABC, CBS, NBC, FOX, PBS, and more!



Featured patient advocate Ashley Trent

- **Information Driven Webinars:** Since December 2020 we have hosted <u>20+ webinars</u> attended by thousands of doctors, patients, and their family members.
- **Cutting-Edge Website:** In March 2021, we launched a brand new <u>projectlyme.org</u>, which incorporates "Your Lyme Journey" as a tool for to easily access targeted information on tick-borne diseases.
- **Multi-Channel Communications:** We share relevant information daily on social media and weekly via the <u>LymeNotes newsletter</u>, providing updates on research, patient resources, and support opportunities in the world of tick-borne diseases.

45,000+

5,000+

SOCIAL MEDIA FOLLOWERS

NEWSLETTER SUBSRIBERS



Education

• Engaging In-Person Events: In an increasingly virtual world, getting people together in person has gotten significantly harder. However, it does not make it any less important. Since 2018 we have hosted many events aimed at educating attendees and raising funds, including 4 galas in New York City and 2 gatherings in Chicago. Featuring celebrities and well-known scientific experts, we have had thousands of people in attendance.







Keynote speaker Dr. John Aucott

• **Building Lightings:** Since 2021, Project Lyme has partnered with mutiple buildings and national landmarks to educate about tick-borne disease. Partners include The Helsmley Building in NYC, Willis and Hancock Towers in Chicago, as well as Niagara Falls Park Service. They all have lit green to raise awareness and honor patients.





The Helmsley Building in NYC, May 2021

Hancock Tower in Chicago, May 2023



Education

• **Sponsor Powerful Films:** Cinema can change the hearts and minds of the masses. That is why Project Lyme decided to support The Quiet Epidemic. It has since been featured in mutiple film festivals and debuted at #1 on the Itunes Documentary section. Project Lyme is proud have funded a portion of the films distribution and marketing costs, as well as sponsor 3 screenings across the country, in New York City, Jacksonville, Florida, and Hagerstown, Maryland.



Dr. Kerry Clark speaking to a crowd of 200+ at the screening in Jacksonville

A clip from The Quiet Epidemic

Jr. Board Member Ashley Baker speaking at the screening in Maryland

• **Support Scientific Conferences:** Educating doctors is one of the best things we can do to directly improve patient care. Since 2022, Project Lyme has sponsored several conferences aimed at educating doctors. Our partnership with the International Lyme and Associated Diseases Society (ILADS) has funded 10 doctors attendance at their annual scientific conference. We were also a sponsoring member of the 2023 Tick Academy conference, offered by the Integrated Pest Management Institute.



Project Lyme's table at the 2023 ILADS conference in Boston, Massachusets



Doctors observing a presentation at the 2022 ILADS conference in Orlando, Florida



Education

• **Media Engagement:** Members of Project Lyme have been featured in numerous publications over the years including the <u>New York Times</u>, <u>NBC</u>, <u>USA Today</u>, and more!

What It's Like to Live With a Tick-Borne Disease

Chronic pain, fatigue, rashes: As tick territories are expanding, so too are the number of illnesses they cause.



Jacksonville Lyme disease patients say they had to ask a dozen times for a test

Researchers at the University of North Florida say official Lyme disease statistics underestimate the number of people with Lyme disease.



What happens when coronavirus and Lyme disease intersect? It's a scary time for patients

With overlapping symptoms and a ferocious tick season already upon us, we're in for a confusing - and dangerous - summer.

Isabel Rose and Dana Parish Opinion contributors Published 6:00 a.m. ET June 22, 2020 | Updated 2:28 p.m. ET June 22, 2020







Research

Our Partnership

Project Lyme is proud of our partnership with the Bay Area Lyme Foundation (BAL). Since joining forces in 2018, we have granted over \$1,700,000 to BAL managed research projects. We continue raising funds to put towards impactful projects focused on developing better diagnostic methods and more effective therapeutics.



Our Research

We have supported 17 projects with 15 different researchers. The following information describes multi-year projects. It is important to note that many of the projects are still in progress and Project Lyme may have only contributed a % of total funds.



Projects Summary

2018

- Brian R. Crane, PhD, Cornell University is identifying antimicrobial treatment for Lyme.
- Yuko Nakajima, PhD, Brandeis University is blocking immune evasion by Borrelia burgdorferi and other pathogens.
- Geetha Parthasarathy, PhD, Tulane University is developing novel therapeutics for Lyme neuroborreliosis
- **Michal Caspi Tal, PhD, Stanford University** is determining if a protein marker prevents the immune system from killing Borrelia burgdorferi and screen compounds that may be able to block this interaction.
- Yong Zhou, PhD, Institute for Systems Biology is exploring the host response during acute and prolonged exposure to Borrelia burgdoferi.

2020

- Artem Rogovskyy, DVM, PhD, DACVM, Texas A&M University is working to develop a better diagnostic for Lyme disease by exploring the Raman spectroscopy-based approach for the diagnosis of Lyme disease.
- Janakiram Seshu, PhD, University of Texas at San Antonio is limiting or eliminating the survival and transmission of Lyme disease pathogen between ticks and reservoir hosts
- Flightpath Biosciences, Inc. is studying clinical biomarkers for Persistent Lyme Disease.
- William Robinson, MD, PhD, Stanford University is studying the molecular mechanisms of autoimmune diseases and developing therapeutics.

Research Highlight

 By evaluating human blood samples, the research team at Texas A&M University was able to identify Borrelia infection with 88% accuracy, 85% sensitivity, and 90% specificity using Raman spectroscopy. This light-based test is commonly used in chemistry labs to evaluate human blood samples and may serve to address the immediate need for more sensitive diagnostics in Lyme disease This <u>research was published</u> October 26, 2022, in the peer-reviewed journal Frontiers in Cellular and Infection Microbiology.



Artem Rogovskyy, DVM, Ph.D. Texas A&M University



Projects Summary

2022

- **Sapient** is working to develop a chronic Lyme disease molecule marker.
- Emir Hodzic, PhD, UC Davis & Duke University is evaluating the efficacy of tethered inhibitors of HtpG for eliminating Borrelia burgdorferi infection in a mouse model.
- Artem Rogovskyy, DVM, Ph.D., and Dzmitry Kurouski, DVM, Ph.D., Texas A&M University are validating the Raman spectroscopy-based approach for the diagnosis of Lyme disease. This is our second time providing funds to this project.
- Monica Embers, Ph.D, Tulane University is analyzing human tissue specimens for Borrelia burgdorferi.
- Geetha Parthasarathy, Ph.D., Tulane University is assessing the fibroblast growth factor system in human biological fluids as novel biomarkers of Lyme disease.
- Kerry Clark, PhD, University of North Florida searching for tick-borne pathogens in Rocky Mountain Wood ticks in the Bitterroot Mountains of Western Montana.

2023

- **Tim Haystead, Ph.D., Duke University**, is working to develop novel small molecule inhibitors that target the Borrelia burgdorferi's proteins and eliminate the bacteria. By attaching fluorescent chemical compounds called fluorophores to the inhibitor, scientists can also use them as a diagnostic.
- **Geetha Parthasarathy, Ph.D., Tulane University**, is furthering her 2022 research evaluating fibroblast growth factor receptor (FGFR) inhibitors as a therapeutic. This is our second time providing funds for this project.

Research Highlight

 By applying a molecular targeting strategy to Borrelia burgdorferi, the research team at Duke University has developed a novel drug candidate. Building on the foundational research of the late Dr. Neil Spector, an extremely promising drug HS-291was created. In lab studies, this compound can irreversibly damage Borrelia burgdorferi in vitro. This <u>research was</u> <u>published</u> November 1, 2023, in the peer-reviewed journal Cell Chemical Biology.



Tim Haystead, Ph.D., Duke University





Our Work

Lyme disease is historically underfunded compared to other infectious diseases. To combat this disparity Project Lyme became a founding member of the Center for Lyme Action, a bipartisan 501 c4 non-profit organization dedicated to growing federal funding

for Lyme disease in an effort to find a cure.

\$282M

ADDITIONAL FUNDING FOR TICK-BORNE DISEASE SINCE 2019



Project Lyme annually support this initiative with:

- **Funding:** We have granted a total of \$225,000 since 2019, including the initial seed funding needed to establish the 501c4.
- **Representation:** We represent 25% of Center for Lyme Action's board leadership.
- **Volunteers:** Our community is vast and dedicated to the cause. During legislative events, we help organize patient representatives to speak directly with legislators.

Project Lyme stands at the forefront of advocacy, championing the cause for patients by offering essential resources and actively collaborating with organizations like the Center for Lyme Action. Together, we advocate for crucial policy reforms at the federal level, striving to ensure that patients can access required care.

Alexandra Moresco, Project Lyme Board Member



Support

Meet-ups are an invaluable resource providing connection, support, inspiration, hope, and guidance to mothers caring for children with Lyme Disease."

Anne Marie-Moneta, Mothers Aginst Lyme member

Our Groups

Project Lyme serves as an incubator for patient support groups. Our first support initiative, Generation Lyme, was founded in 2019 to create a community for young people facing Lyme disease. They quickly grew and became their own 501c3 in 2022. The Mothers Against Lyme program took their place as Project Lyme's support prgram, hosting meet-ups for mothers who are sick or have sick children.





Our Methods

- **Meet-Ups:** One of the best avenues of support for Lyme patients is to connect personally with other patients. Mothers Against Lyme <u>hosts Meet-Ups</u> twice a month.
- **Stories:** Lyme disease impacts people of all ages, genders, and backgrounds. Through our unique, intimate, and informative social media campaigns, we aim to share the full range of ways in which Lyme disease impacts lives.

Our Results

100+

1000+

MEET-UPS

ATTENDEES



YME

EDUCATION | ADVOCACY | RESEARCH | SUPPORT

Thanks For Your Support

From everyone on the Project Lyme team

Staff

Director- Noah Johnston Marketing Manager- Davia Sills

Executive Committee

Melissa Bell Kim Dickstein Susan Goldenberg Nan Kurzman Nina Levene Ali Moresco Scott Moresco Isabel Rose David Roth Mark Weber Jennifer Weis

Board At-Large and Advisory Members

Steve Abrams Phyllis Bedford Scott Bedford Dr. Robert Bransfield Bob Forster Dr. Jane Marke Dr. Richard Horowitz

DONATE

Junior Board

Olivia Abrams Ashley Baker Ryan Bell Grace Burns Kim Katz Annabel Monsky Reema Shah Rohan Shah

