2019 ANNUAL REPORT

THE YEAR OF THE PATIENT
WHO WE’RE FIGHTING FOR

IT’S ESTIMATED THAT TWO MILLION INDIVIDUALS COULD SUFFER FROM POST-TREATMENT LYME DISEASE BY THE END OF 2020.

More than 427,000 people in the United States are newly diagnosed with Lyme disease every year.

Here are a few of the millions of faces of those who have been affected by Lyme—our community of patients, caregivers, researchers and supporters. They are the ones GLA is fighting for. Who we are all fighting for.

Our mission is not only an investment in research, education and awareness programs; it’s an investment in people.
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PUTTING PATIENTS FIRST

Patients are the core of our work

GLA is dedicated to ending the collective suffering of those with Lyme disease, and preventing future generations from contracting a tick-borne illness. Our mission and work impacts everyone in the community, from those seeking prevention guidance, to patients needing support, from spearheading the most impactful research, to overseeing valid and impactful clinical studies.

"When Lyme patients talk about what makes Global Lyme Alliance different, we want them to say it’s because of our continuing investment in innovative ideas and results driven research for the benefit of Lyme disease patients and their families."

— Scott Santarella, CEO, GLA
DEAR FRIENDS:

2019 was a year of truly astonishing progress which created momentum in nearly every aspect of Global Lyme Alliance’s (GLA) work. We are so grateful for your support in helping to make these achievements possible.

Our mission to conquer Lyme and other tick-borne diseases through research, education, awareness, and patient services has never been more focused and resolved. It assumes greater importance, too, in light of the continued, rapid rise in tick-borne illnesses around the globe.

Research continues to be the key driver of GLA’s mission, as finding the answers to improved diagnostics and sound treatment options will have the greatest impact on patients. Today, tick-borne disease research has reached a tipping point. Advancements we could not have dreamed of a few years ago are now clearly within our sights. At the direction of GLA’s scientific leadership team and our Scientific Advisory Board, we are working tirelessly to make that vision a reality.

Due to our ongoing success in supporting top-tier researchers and deepening the scientific understanding of the Lyme bacteria, in 2019 our research team strategically undertook more projects that will have a direct impact on patients. We will continue to add the “patient’s voice” to our methodologies, thus focusing on research investments that will end so much suffering. Our ultimate goal is to shift the paradigm of treating Lyme disease from uncertainty, misunderstanding, and helplessness, to one of clarity.

As part of our achievements, our connection to the general public as well as Lyme patients and caregivers was optimized this year. Our educational, awareness, and patient programs had unprecedented reach. Whether it was a GLA ambassador speaking to a classroom of students, our board member Avril Lavigne sharing our Lyme awareness message with her followers, or a peer mentor personally helping a patient with their struggle, we are connecting the world.

On behalf of all of us at GLA, we thank you again for your support.

Sincerely,

Scott Santarella
CEO
Global Lyme Alliance
The New York Times selects and publishes GLA's Letter to the Editor in response to an article depicting Lyme as “easy to treat.”

GLA opens competition for research grants by asking applicants to submit Letter of Intent (LOI).

GLA sends a letter to the Assistant Secretary of Health and Human Services regarding changes to the Tick-borne Disease Working Group.

Holds 5th Annual NYC Gala with Bob and Karen Kelly, Adrienne Nolan-Smith and David Nolan serving as honorees, raising $2.5 million.

GLA SAB member Dr. Utpal Pal announces he is serving as one of three collaborators on a Department of Defense grant to study tick-borne infection using 3D models of human blood vessels.

GLA announces first observational study on Lyme disease treatment protocol.

GLA launches a new Kids and Lyme Disease blog series.

GLA launches new Lyme Disease Symptom Tracker mobile app at The White House as part of the U.S. Department of Health & Human Services Tech Health Sprint.

GLA announces new online CHEM–accredited education for physicians and nurses developed in partnership with the state of Delaware's Lyme Disease Education Oversight Board.

GLA-fund researcher Monica E. Embers, Ph.D., of Tulane University publishes findings on Borrelia persistence in the presence of Doxycycline.

GLA publishes response to changes put forth by the National Institutes of Health Tick-borne Diseases Strategic Plan.

GLA partners with Mighty Well, a company offering accessories and apparel designed specifically for patients.

GLA hosts 9th Annual Lyme Disease Research Symposium for its Scientific Advisory Board (SAB), funded grantees and fellows.

GLA issues release highlighting several drugs and drug combinations that show success in treating Lyme disease, including the combination of Daptomycin + Cefuroxime + Doxycycline, Vancomycin, and Disulfiram.

GLA partners with Ranger Ready Repellents, Terminix, and Genevieve Gorder to raise awareness about tick-bite prevention and risk of Lyme disease.

New study co-authored by Mayla Hsu, Ph.D., GLA's Director of Research and Science estimates that two million people in the U.S. could suffer from post-treatment Lyme disease by 2020.

GLA's Chief Scientific Officer responds publicly to IDSA proposed guidelines.

GLA announces its first observational study on Lyme disease treatment protocol.

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GLA exceeds its annual fundraising goal of $5.2 million.

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GLA’s Chief Scientific Officer responds publicly to IDSA proposed guidelines.

GLA launches new Kids and Lyme Disease blog series.

GLA hosts 3rd Annual SubLyme Soiree in Chicago.

GLA’s Chief Scientific Officer responds publicly to IDSA proposed guidelines.

Progress announced in the development of GLA-funded Ionica Sciences diagnostic test.

Team GLA has a runner in the iconic Berlin Marathon for the first time, expanding its global endurance impact.

GLA expands educational initiatives, adding videos and content to its programming.

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GLA CONTINUED TO ADVANCE RESEARCH, WITH AN INCREASED FOCUS ON BRIDGING THE GAP BETWEEN THE LABORATORY AND PATIENTS. GLA’S RESEARCH TEAM IDENTIFIED SIX KEY RESEARCH ADVANCES IN 2019 THAT HAVE THE POTENTIAL TO TRANSFORM PATIENTS’ LIVES. HERE’S HOW GLA WAS INVOLVED.

ADVANCEMENTS IN NOVEL TREATMENT THERAPIES, INCLUDING DISULFIRAM

An FDA-approved drug used to treat alcoholism is showing promise in the treatment of Lyme. Studies from Stanford University, and Ken Liegner, M.D., have shown in early testing that Disulfiram was successful in attacking the Lyme bacteria. GLA is now taking these findings a step further. GLA-funded researcher Brian Fallon, M.D., Director of Columbia University’s Lyme and Tick-Borne Diseases Research Center, is now conducting a first of its kind clinical study to determine the therapeutic efficacy of Disulfiram.

A FASTER, MORE RELIABLE DIAGNOSTIC TEST

GLA has funded multiple diagnostic studies which have shown progress. Significant headway has been made in the development of a highly sensitive Lyme disease detection test through GLA’s partnership with Ionica Sciences. Initial results of the test demonstrate 100% accuracy in identifying samples from patients with active Lyme infections and 96% accuracy in identifying samples from patients without active Lyme infections. GLA and Ionica are collaborating with GLA-funded investigator Lise Nigrovic, M.D., M.P.H., of Boston Children’s Hospital and Harvard Medical School, to demonstrate the efficacy of the assay using the full set of hundreds of pediatric bio-banked samples available through Dr. Nigrovic’s network of emergency departments known as Pedi Lyme Net.

GLA LAUNCHES FIRST IN A SERIES OF CLINICAL STUDIES

While current standard of care antibiotics are effective at successfully treating many Lyme disease patients, when diagnosed and treated early, up to 20% continue to experience symptoms of the disease. GLA is taking the bold step of validating community-based, physician-developed, Lyme disease treatment regimens by way of a rigorous evidence-based clinical research process. The first study will focus on the treatment regimen developed by Joseph Jemsek, M.D. of Washington, D.C. We hope that this study will identify biological indicators of treatment success that can be broadly used in evaluating other treatment options being pursued by patients suffering from persistent Lyme symptoms.

IMPROVING CARE FOR CHILDREN WITH LYME DISEASE

Children are especially vulnerable to tick-borne diseases as they are closer to the ground and typically play in woodlands, grasses, leaves and have physical contact with tick habitats. To gain a greater understanding of how Lyme disease impacts children, the GLA-funded Pedi Lyme Net expanded into new regions across the U.S., including Children’s Minnesota, a large academic pediatric hospital system in a hyper-endemic Lyme disease area. Lise Nigrovic, M.D., M.P.H., oversees the program from Boston Children’s Hospital. The samples collected from children will be used to better assess the extent of Lyme disease and tick-borne co-infections in this most vulnerable segment of the Lyme patient population. The network will continue to expand in 2020.

CONNECTION BETWEEN LYME PERSISTERS AND DOXYCYCLINE

Continuing to drive advances in the understanding of Borrelia burgdorferi persistence, GLA funded a study by Monica E. Embers, Ph.D., of Tulane University and her colleagues to better identify why B. burgdorferi can form antibiotic-tolerant persisters in the presence of drugs such as Doxycycline. Dr. Embers found that exposure to Doxycycline altered the expression of certain specific genes which regulate bacterial growth versus dormancy. The study has helped researchers attain a better understanding of antibiotic-tolerant persisters and may identify novel targets for treatment.

NATIONWIDE STUDY OF LYME DISEASE AND MENTAL ILLNESS

It has been reported in the medical literature that infection with Borrelia burgdorferi may lead to psychiatric disorders and suicidal behaviors. In the first nationwide epidemiologic investigation of the possible link between psychiatric disorders and B. burgdorferi, GLA has funded a two-year study in Denmark, a country that tracks all of its residents from birth in its demographic and health databases. The study is a collaboration between Brian Fallon, M.D., of Columbia University, and Michael Benros, M.D. of the Mental Health Center in Copenhagen, Denmark. It will include the entire Danish population born after 1977, about 2.4 million people.

THANK YOU FOR ALL YOU DO BUT ESPECIALLY FOR BEING A POWERHOUSE OF CONTINUED SUPPORT AND MOTIVATION FOR ANYONE AFFLICTED WITH LYME DISEASE AND TICK-BORNE ILLNESS. YOUR CONTINUED RESEARCH AND AWARENESS EFFORTS DO NOT GO UNNOTICED.

— Kelly T.
LYME AND TICK-BORNE DISEASES ARE A PUBLIC HEALTH CRISIS

2 MILLION BY 2020

According to a groundbreaking study published this year, co-authored by Mayla Hsu, Ph.D., Global Lyme Alliance’s Director of Research & Science, it is estimated that two million people in the United States could have post-treatment Lyme disease (PTLD) by 2020.* The study, published by the Journal BMC Public Health, is a vital first step toward understanding the large number of people suffering from Lyme disease and public health impact of tick-borne disease.

“Dr. Hsu, who co-authored the study with Allison DeLong, M.S., a biostatistician at Brown University’s Center for Statistical Sciences and a member of GLA’s Scientific Advisory Board, identified two goals of the study. The first goal was to develop a rigorous mathematical framework for estimating PTLD prevalence; the second was to actually calculate it, using different epidemic growth scenarios. The scientists used advanced mathematical modeling to calculate the total number of patients with PTLD.”

*Estimate of cumulative number of post-treatment Lyme disease cases in the US, 2016 and 2020. BMC Pub Health vol 19:352. Delong et al. April 2019. Post-treatment Lyme disease specifically refers to the 10 to 20% of patients who were diagnosed and treated early yet continue to experience symptoms of the disease.
Infectious diseases may be a trigger for Alzheimer’s disease and other dementias. This study will analyze RNA libraries from a large collection of brain tissues and compare samples from dementia and non-dementia patients to determine whether Borrelia bacterial genes are associated with neurodegenerative illness.

**STUDY:** “An Interesting Necroptosis Angle: Tick-borne Disease and Alzheimer’s Disease”

With the growing recognition that multiple tick-borne illnesses, including Lyme, can come from a single tick bite, there is a need for diagnostic tests that can accurately identify multiple pathogens from the same blood sample. Dr. Tokarz will further develop his TBD-Serochip to optimize its ability to detect more than eight tick-borne infections simultaneously.

**STUDY:** “Development and Validation of a Multiplex Serologic Assay for Tick-borne Diseases”

Plant-derived essential oils such as oregano and cinnamon bark have been shown to be active against persistent *Borrelia burgdorferi* in test tube cultures. Dr. Zhang will identify what combinations of essential oils are most potent and will further test these combinations in vivo using the mouse model of Lyme disease.

**STUDY:** “High Activity of Selective Essential Oils Against Borrelia Persisters”

**POSTDOCTORAL BLACKMAN FELLOWS**

- George Aranjuez, Ph.D., University of Central Florida
- Ashley Groshong, Ph.D., University of Connecticut
- Chrysoula Kitsou, Ph.D., University of Maryland
- Matthew Muramatsu, Ph.D., University of Texas-Southwestern
- Bijaya Sharma, Ph.D., Tufts University

**OUR TEAM IS ENCOURAGED BY BOTH THE DEPTH AND DIVERSITY OF RESEARCH GRANT FUNDING REQUESTS IT SEES. IN 2019 GLA AWARDED $2 MILLION FOR NEW RESEARCH GRANTS AND RELATED PROJECTS, BRINGING OUR INVESTMENT IN URGENTLY NEEDED TICK-BORNE DISEASE RESEARCH TO NEARLY $12 MILLION. THE MOST RECENT GRANTS WERE AWARDED TO SIX TOP SCIENTISTS AT LEADING INSTITUTIONS IN THE UNITED STATES AND ABROAD. GLA ALSO LAUNCHED ITS FIRST OBSERVATIONAL STUDY FOR LYME DISEASE TREATMENT AND MADE AN UNPRECEDENTED COMMITMENT TO INVEST IN CLINICAL TRIAL PROJECTS.**

**GRANTEES & PROJECTS**

1. **SHEILA ARVIKAR, M.D.**
   Harvard Medical School
   Arthritis is a common symptom of post-treatment Lyme disease, and may occur in patients even after antibiotic treatment. Ultrasound detection of calcification in the knee hamstring tendons may be a rapid non-invasive way to assess and diagnose Lyme arthritis and to guide treatment decisions. This study examines a potential relationship between ultrasound findings and clinical outcomes in Lyme patients and will include a control group of patients with non-inflammatory arthritis.

   **STUDY:** “Musculoskeletal Ultrasound Evaluation of Tendon Involvement in Lyme Disease”

2. **MICHAEL ERIKSEN BENROS, M.D., PH.D.**
   Mental Health Center, Copenhagen University Hospital
   This study is a large-scale epidemiological analysis of the psychiatric effects of Lyme disease, examining the medical records of the entire population of Denmark. The risk of mental disorders in general, with particular focus on depression and suicidality will be investigated to determine a possible relationship with a history of Lyme disease.

   **STUDY:** “Nationwide Cohort Studies Examining Psychiatric Disorders and Suicidal Behavior after Lyme Disease”

3. **BENJAMIN READHEAD, PH.D.**
   Arizona State University
   Infectious diseases may be a trigger for Alzheimer’s disease and other dementias. This study will analyze RNA libraries from a large collection of brain tissues and compare samples from dementia and non-dementia patients to determine whether Borrelia bacterial genes are associated with neurodegenerative illness.

   **STUDY:** “An Interesting Necroptosis Angle: Tick-borne Disease and Alzheimer’s Disease”

4. **RAFAL TOKARZ, PH.D.**
   Columbia University
   With the growing recognition that multiple tick-borne illnesses, including Lyme, can come from a single tick bite, there is a need for diagnostic tests that can accurately identify multiple pathogens from the same blood sample. Dr. Tokarz will further develop his TBD-Serochip to optimize its ability to detect more than eight tick-borne infections simultaneously.

   **STUDY:** “Development and Validation of a Multiplex Serologic Assay for Tick-borne Diseases”

5. **YING ZHANG, M.D., PH.D.**
   Johns Hopkins Bloomberg School of Public Health
   Plant-derived essential oils such as oregano and cinnamon bark have been shown to be active against persistent *Borrelia burgdorferi* in test tube cultures. Dr. Zhang will identify what combinations of essential oils are most potent and will further test these combinations in vivo using the mouse model of Lyme disease.

   **STUDY:** “High Activity of Selective Essential Oils Against Borrelia Persisters”

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**FUNDING COMMITMENT BY TYPE**

- **DIAGNOSTICS: 32%**
- **TREATMENT: 32%**
- **BASIC SCIENCE: 36%**
IT WAS THROUGH GLA THAT I FOUND THE PRACTITIONER WHO TESTED ME FOR CO-INFECTIONS AND SUCCESSFULLY TREATED ME FOR LYME AND BABESIA. I’D STILL BE SICK WITHOUT A PROPER DIAGNOSIS AND TREATMENT.

— JILL K.

ADVANCING PROGRESS THROUGH COLLABORATION

GLA HELD ITS 9TH ANNUAL LYME DISEASE RESEARCH SYMPOSIUM IN MARCH. THE THREE-DAY SYMPOSIUM BROUGHT TOGETHER RENOWNED LYME AND TICK-BORNE DISEASE SCIENTISTS, INCLUDING GLA SCIENTIFIC ADVISORY BOARD MEMBERS, CURRENT RESEARCH GRANTEES, PAST GRANTEEES, AND OTHER TOP SCIENTISTS. THESE RESEARCHERS CAME FROM AROUND THE U.S. AND Sought TO CONTRIBUTE SCIENTIFIC GUIDANCE AND PERSPECTIVE IN IDENTIFYING AREAS OF FUTURE RESEARCH OPPORTUNITIES.

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— JILL K.

Throughout 2019, GLA’s on-staff Ph.D’s visited research labs around the country and Canada, and also participated in important conferences such as the “Chronic Lyme Clinical Studies Roundtable“ at Brigham & Women’s Hospital, Boston, Massachusetts; “Emerging Research, Diagnosis and Treatment of Lyme Disease and Tick-Borne Illness Conference“ at Stanford University, Palo Alto, California; the “2nd International Babesiosis Meeting“ at Yale University, New Haven, Connecticut; “Central Mass Lyme Foundation’s Lyme Disease and Wellness Conference“ in Sturbridge, Massachusetts; the “Reaching the Last Mile Forum“ in Abu Dhabi, United Arab Emirates, and the “4th Annual Lyme Disease In the Era of Precision Medicine Conference“ in New York, where GLA’s Chief Scientific Officer moderated an international panel: “Lyme Disease Impacts on Global Health.”
In 2019, Global Lyme Alliance-affiliated scientists continued to make strides in the fight against tick-borne diseases. Their published studies confirmed that GLA’s rigorous submission and peer-review process continues to fund a broad spectrum of projects by innovative researchers, each of whom are doing their part in the fight against Lyme and other tick-borne diseases.
EDUCATION AND OUTREACH

EDUCATING THE WORLD

LEARNING ABOUT LYME DISEASE AND PREVENTING TICK-BORNE ILLNESSES MUST BE AN INTEGRAL PART OF HEALTH EDUCATION TODAY, GIVEN THE INCREASED RISK OF TICK-BORNE DISEASES (TBDS). GLA PROVIDES FREE, COMPREHENSIVE, MULTI-PLATFORM EDUCATIONAL TOOLS AND RESOURCES FOR SCHOOLS, SUMMER CAMPS, HEALTHCARE PROFESSIONALS, AND THE GENERAL COMMUNITY, INCLUDING:

EDUCATING THE PUBLIC: LYME EDUCATION AMBASSADOR PROGRAM

GLA's Lyme Education Ambassador Program (LEAP) educates the public about Lyme and TBD prevention, symptoms, and the importance of early detection. GLA's growing team of volunteer Ambassadors are formally trained to educate schools, local government, corporations, high-risk groups, and others, about how to recognize the signs and symptoms of Lyme disease. To date, more than 65 dedicated Ambassadors are educating their communities worldwide. Our footprint has expanded to three cities in Canada and one in the Netherlands. We are pleased to see the continued growth of this educational initiative and plan to double our reach in 2020.

EDUCATING SCHOOLS & STUDENTS: CURRICULUM

Children are at the highest risk for Lyme and other tick-borne illnesses. To educate students in grades K-12 about staying tick-safe, thousands of educators throughout the United States have accessed GLA's interactive online curriculum: "It's Time to Be Lyme Alert" in 2019. The curriculum, which features lessons in a fun, interactive comic format, teaches students and educators to identify ticks, learn about tick habitats and tick prevention. It also covers the importance of showing empathy to fellow classmates who may be dealing with a chronic illness.

EDUCATING CHILDREN & SUMMER CAMPS: BE TICK AWARE™

GLA expanded its successful and popular Be Tick AWARE tick bite prevention program in 2019, adding videos and an enhanced prevention kit. Moreover, GLA continued its partnership with Ivy Oaks Analytics to educate summer camp directors, staff, and campers themselves about tick bite prevention. Through the program, GLA has protected more than 250,000 children, families and camp staffs. Our ongoing partnership with Ranger Ready Repellents will support future efforts and help with expanding our reach in 2020.

WHAT INSPIRES OUR LYME EDUCATION AMBASSADORS

DOMINIC D. SMITH, a native of The Netherlands, has suffered from Lyme and co-infections for nearly two decades. Only recently diagnosed, he knew he wanted to share the risks and symptoms of Lyme disease with others in his community.

Part of what drives Dominic is the dismissal he received from the doctor who said he had nothing to worry about, despite proof of being bitten by three ticks, simply because he did not present with the bulls-eye rash. It wasn’t until he started to experience severe neurological symptoms and having epileptic seizures, did he get tested for Lyme; the test was positive. Following years of treatment, Dominic is feeling better.

Today Dominic describes himself as a person who enjoys life and gaining new knowledge and sharing it with others. “I want to use my work experience as well as my professional knowledge in landscape architecture, spatial planning and forestry management,” Smith says, “for GLA and those who suffer from tick-borne diseases. By sharing my personal experiences, I hope to inspire others to create greater public awareness.”

KONYE GUTHRIE’S daughter, Whitney, died a week after finishing first grade. She was seven. She had every symptom of Rocky Mountain spotted fever, but she died without ever being tested for the tick-borne disease.

Despite having a high fever, a rash, and severe pain, one doctor said that Whitney had strep throat, without even taking a throat culture. As Whitney quickly grew worse, with a 104 fever, another doctor gave her a shot of penicillin. “She’ll be fine,” he said. She was just spoiled. Just days later Whitney was dead.

Being aware of tick dangers might have saved Whitney’s life. We’ll never know absolutely. But for Konye, who lives in Texas, her mission is clear, “I do not want this to ever happen to another child. I’ll continue to raise awareness until everyone knows how dangerous just one tick bite can be.” She has been advocating at the Texas State government level for changes in its health curriculum, which she credits “for acknowledging the need for teaching tick-borne illness in the public schools.”
Currently there are GLA ambassadors in the U.S., Canada, and Europe. In the U.S., more than half of the states are covered by GLA ambassadors, from Boston, Massachusetts - Coral Springs, Florida - Decatur, Texas - Vancouver, Washington.

**GLA's Network of Trained Lyme Education Ambassadors Provide Key Prevention and Awareness Education Worldwide. They Have a Broad Reach and Are Educating Various Members of Their Communities Ranging from Local School Systems to Government Agencies in an Effort to Affect Change in Policy.**

**Canada**
- Abbotsford, British Columbia, Canada
- Halifax, Nova Scotia, Canada
- Surrey, British Columbia, Canada

**Europe**
- Groningen, Netherlands

**United States**
- Boston, Massachusetts
- Butler, Pennsylvania (2)
- Byron Center, Michigan
- Canton, Connecticut
- Champaign, Illinois
- Chicago, Illinois (2)
- Clifton Park, New York
- Columbia, Maryland
- Columbus, Ohio
- Cooperstown, New York
- Coral Springs, Florida
- Crown Point, Indiana
- Decatur, Texas
- Dickinson, Texas
- Duncan, Oklahoma
- Eagleville, Pennsylvania
- East Greenbush, New York
- Essex Junction, Vermont
- Farmington, Minnesota
- Fayetteville, North Carolina (2)
- Follansbee, West Virginia
- Fort Benning, Georgia
- Fort Collins, Colorado
- Houston, Texas (2)
- Huntsville, Missouri (2)
- Knoxville, Tennessee
- Louisville, Kentucky
- Middlebrook, Virginia
- Midlothian, Virginia
- Monument, Colorado
- New Market, Maryland
- New York, New York
- Norwell, Massachusetts
- Northport, Maine
- Oldsmar, Florida
- Rancho Santa Fe, California
- Rostraver Township, Pennsylvania
- Saint Augustine, Florida
- Saint Cloud, Florida
- Saint Louis, Missouri
- San Diego, California
- Sands Point, New York
- Scarsdale, New York
- Somerset, New Jersey
- University Park, Texas (2)
- Uxbridge, Massachusetts
- Vancouver, Washington (2)
- Verona, Pennsylvania
- Virginia Beach, Virginia
- West Harrison, New York
- West Hurley, New York
- Walnut, Illinois
- Woodbridge, Virginia
In 2019, GLA developed a new Continuing Medical Education (CME) and Continuing Education (CE)-accredited Lyme disease education course, “A Clinical Guide to Diagnosing and Treating Lyme Disease and Other Tick-Borne Illnesses” in partnership with the State of Delaware’s Lyme Disease Education Oversight Board. The course offers both physician and nurse credits, and is in fact mandated by the State of Delaware for all healthcare professionals seeking license renewal.

By the end of the year, nearly 8,000 healthcare professionals accessed this educational activity.

GLA continues to offer its first CME offering, “Pediatric Tick-Borne Disease: Diagnosis and Management”, as an on-demand program. More than 10,000 medical professionals have been educated.

Serving as faculty for the course are GLA Scientific Advisory Board member Charles Chiu, M.D., Ph.D., Professor of Laboratory Medicine and Medicine, Division of Infectious Diseases, University of California, San Francisco, and Elena Frid, M.D., a board-certified neurologist and clinical neurophysiologist in private practice in New York.
THE POWER OF PEER SUPPORT...

Samantha H. learned first-hand of the importance of peer support for Lyme disease sufferers.

She was afflicted with a severe digestive disorder that required her to receive TPN, via a PICC line, a long-term IV that goes straight to the circulatory system to provide nutrition. She contracted sepsis twice, was put on IV antibiotics and both times her symptoms improved. Her father was convinced that a bacterial infection was causing her symptoms, but for some reason no doctor would give the idea a second thought.

After Samantha posted her story on Facebook, a friend reached out and told her family about Lyme disease. She then pursued testing and was diagnosed with Lyme disease. She told them about Lyme, they were tested and positively diagnosed for the illness.

Today, as a GLA Peer Mentor, Samantha says she’s excited to help others. “There is power in peer support,” she enthuses. “Together we are stronger and will win the battle against Lyme disease.”

PEER TO PEER SUPPORT

GLA launched the first-ever Lyme disease peer-to-peer support program. The program provides personal 1 to 1 support for those affected by Lyme and other TBDs. Lyme patients, caregivers, and family members connect with trained volunteers (mentors) who have faced similar journeys for emotional support, guidance, and hope. By the end of the year, there were 50 certified peer mentors and over 170 peer mentees seeking support.

“Connecting patients and caregivers to others who understand, first-hand the emotional and physical impact of living with Lyme disease is an invaluable source for support, insight, hope, and a path forward.” - Sara V. Tyghter, GLA’s Director of Education and Outreach

FIND A LYME-TREATING PHYSICIAN

GLA connects patients and caregivers with Lyme-treating physicians around the globe. Given the discrepancies in tick-borne disease diagnostics among the medical community, it’s imperative for patients to find a healthcare provider who understands the nuances of diagnosing and treating Lyme and other TBDs.

RESOURCES

GLA is the leading source to access resources for patients, caregivers, and the community, including an interactive map to find local support groups, financial support, diagnostic and tick-testing labs, recommended reading materials and more.

BLOGS

GLA blogs are a go-to resource for thousands of patients, with topics ranging from symptoms, living with the disease, how to communicate with your doctor, communicating with family, and Lyme Q&As.

“CONNECTING PATIENTS AND CAREGIVERS TO OTHERS WHO UNDERSTAND, FIRST-HAND THE EMOTIONAL AND PHYSICAL IMPACT OF LIVING WITH LYME DISEASE IS AN INVALUABLE SOURCE FOR SUPPORT, INSIGHT, HOPE, AND A PATH FORWARD.”

— Sara V. Tyghter, GLA’s Director of Education and Outreach
LYME SYMPTOM TRACKER MOBILE APP

THOUSANDS OF USERS FROM AROUND THE WORLD DOWNLOADED THE APP IN 2019!

The complexities and day-to-day struggle of living with Lyme disease can make keeping track of one’s symptoms difficult. To help patients, GLA launched its Lyme Symptom Tracker app, in partnership with TrialX. The app was officially introduced at The White House as part of its health and technology initiative. The app makes it easy for patients to track their symptoms daily, monitor cognition, and activities using wearable devices (Fitbit) and mobile sensors to download and share with their healthcare practitioner. This free app is available at the iOS App Store and the Android Play Store.

TOP 3 SYMPTOMS OF LYME DISEASE REPORTED BY APP USERS:
1. Fatigue, tiredness
2. Unexplained fevers
3. Flu-like symptoms

TOP 3 SYMPTOMS OF EARLY LYME DISEASE RECORDED BY APP USERS:
1. Neck stiffness
2. Flu-like symptoms
3. Severe headache

CLINICAL TRIALS

Clinical trials are research studies which assess new ways to diagnose, treat, and prevent Lyme and other tick-borne diseases. Through participation in a trial, patients have an opportunity to access the most innovative treatment options which may not be otherwise available outside of the clinical trial setting. For those who are hesitant about clinical trials, GLA provides important facts about the studies, and also helps patients find and link to trials around the world.

OUR ULTIMATE GOAL IS TO SHIFT THE PARADIGM OF TREATING LYME DISEASE FROM UNCERTAINTY, MISUNDERSTANDING, AND HELPLESSNESS, TO ONE OF CLARITY. OUR LYME COMMUNITY HAS EXPRESSED FRUSTRATION WITH THE SLOW PROGRESS IN LYME RESEARCH, LACK OF TREATMENT OPTIONS AND SPECIFICALLY, THE LACK OF SCIENTIFIC BUY-IN ON COMMUNITY-BASED TREATMENT REGIMENS. WE LISTENED TO THEIR CONCERNS AND ARE COMMITTED TO SUPPORTING RESEARCH THAT IMPACTS THE LYME COMMUNITY TODAY.

— Scott Santarella, CEO, GLA
GLOBAL DISEASE DEMANDS GLOBAL IMPACT

IN 2019, AS MORE PEOPLE AROUND THE GLOBE WERE EXPOSED TO TICKS AND TICK-BORNE ILLNESS, GLA EXPANDED ITS REACH AND SUPPORT TO THOSE WHO ARE IMPACTED.

200+ COUNTRIES HELPED PATIENTS & CAREGIVERS

10 MILLION+ PEOPLE AWARENESS PROGRAMS REACHED

622,344 USERS WELCOMED TO GLA.ORG

HELPED MORE THAN 250,000 CHILDREN, FAMILIES & CAMP STAFFERS STAY TICK-SAFE THROUGH OUR IVY OAKS ANALYTICS PARTNERSHIP

388 FACEBOOK FUNDRAISERS BENEFITED GLA

birthday parties, breakfasts, shopping events and more!

65 EDUCATION AMBASSADORS NAMED

In communities worldwide educating the public about Lyme disease.

200+ MEDIA OUTLETS
GLA WORKED YEAR-ROUND TO KEEP THE LYME DISEASE CONVERSATION GOING IN NATIONAL, INTERNATIONAL AND REGIONAL MARKETS INCLUDING:


IN 2019, AS MORE PEOPLE AROUND THE GLOBE WERE EXPOSED TO TICKS AND Tick-BORNE ILLNESS, GLA EXPANDED ITS REACH AND SUPPORT TO THOSE WHO ARE IMPACTED.
GLA's 5th annual New York City Gala raised over $2.5 million and was attended by more than 700 guests. The gala honored Bob and Karen Kelly, entrepreneurs, philanthropists, Lyme patients, and staunch advocates; Adrienne Nolan-Smith, wellness and patient advocate, founder of WellBe, a media company and lifestyle brand, and David Nolan, father of three Lyme survivors and former vice chairman of Millennium Partners. Rosanna Scotto, co-host of FOX 5’s “Good Day New York” hosted the event.

The ceremony was followed by a performance by Tony Award winner Santino Fontana.

OTHER HIGHLIGHTS INCLUDED: Co-chairs for the Gala were: Amy Marissa Balducci, executive, Sotheby’s International Realty; Charles Balducci, co-founder, Snyder/Balducci Group, Merrill Lynch; Genevieve Gorder, television host and producer, home product designer, and author; Yolanda Hadid, actress, television star and passionate Lyme advocate; Robert Kobre, vice chairman, Credit Suisse; Avril Lavigne, internationally acclaimed singer/songwriter; Lorrie Nadel, GLA board member; Jarrod Nadel, chief product development officer, Tailored Brands, Inc.; Karma Newberry, owner/president, Discovery Hydrovac; Peter Norley, COO, Credit Suisse Securities; Charlie Palmer, celebrated restaurateur and author; Larry Scott, owner, Lawrence Scott Events; Marisol Thomas, philanthropist and animal rights activist; Rob Thomas, Grammy-Award winning singer/songwriter, producer; Erin Walker, GLA board member; and Jimmy Walker, six-time PGA tour winner and 2016 PGA Champion.
SubLyme Soirée August 22, 2019
The 3rd Annual SubLyme Soirée, led by Alex Moresco, Darcy Rogers and Laura Kimmel, raised $112,000. The Chicago foodie fundraiser brought together Lyme disease patients, advocates, researchers and the community to enjoy healthy and delicious food provided by Chicago’s top chefs. The event paid special tribute to Kasey Passen who lost her battle with Lyme disease in 2018.

2019 NJ Wine Event: Taste for a Cure June 1, 2019
Hosted by Rose and James Anastasio, this educational and entertaining event was held in Colts Neck, N.J. Some 58 guests enjoyed a wine tasting conducted by Will Di Nunzio, president of Italian Wine Merchants, followed by a wine-paired dinner. Guests also enjoyed a special performance by singer/songwriter Jesse Ruben. The event raised $50,000.

Breakfast, Lyme Panel and Shopping Event May 1, 2019
More than 150 guests attended this fun and informative breakfast event in Purchase, NY and enjoyed a panel discussion emceed by Tania Tyles Dempsey, M.D. and featuring Dr. Daniel Cameron, M.D., M.P.H, Marian Rissenberg, Ph.D., patients suffering from Lyme disease, and loads of shopping. Hosted by Robin Jacobs and Alyssa Sokoloff, the event raised almost $40,000.

GLA Equestrian Night March 2, 2019
Equestrian and GLA Board member Erin Walker and her husband, PGA Championship winner Jimmy Walker, hosted our inaugural Florida event at the Palm Beach International Equestrian Center. Special thanks to Jen Berkowitz and her husband Brad, as well as Susan Hayes, and Jonathan Sherry for introducing GLA to the team at the Equestrian Center and International Polo Club Palm Beach.

GLA Equestrian Night March 2, 2019
Equestrian and GLA Board member Erin Walker and her husband, PGA Championship winner Jimmy Walker, hosted our inaugural Florida event at the Palm Beach International Equestrian Center. Special thanks to Jen Berkowitz and her husband Brad, as well as Susan Hayes, and Jonathan Sherry for introducing GLA to the team at the Equestrian Center and International Polo Club Palm Beach.

Breakfast & Conversation with Erin Walker April 26, 2019
Guests who attended this Chicago event enjoyed a brunch with a curated main course by Chef Doug Wrobel, followed by a conversation with Lyme warrior and GLA Board member Erin Walker, Gwyn Prentice and Juliana Zobrist.

SubLyme Soirée: Chairs, Darcy Rogers, Laura Kimmel and Alex Moresco
SubLyme Soirée: Zach Abraham, Trina Abraham Heffley

ABOVE LEFT: Palm Beach - Jimmy Walker, Erin Walker, Julie Kracor Connors, Robert Rubin, Diane Blanchard, Scott Santarella
ABOVE RIGHT: Nantucket - Chris Drake, Will Steele, Dr. Lise Nigrovic, Scott Santarella, Debbie Siciliano
RIGHT: Marathon Runner - Taryn Tomczyk
We thank GLA Board member Avril Lavigne and her team at The Avril Lavigne Foundation for the awareness work they did with GLA in 2019. We continue to work together with some exciting initiatives to be announced in 2020.

Through its signature Champions & Charities philanthropic initiative, Burns & Wilcox partnered with GLA on behalf of Lyme patient PGA Championship winner Jimmy Walker and his wife, GLA Board member Erin Walker.

This joint education partnership with Ivy Oaks Analytics enables GLA to help educate more than 250,000 children, families, and camp staff at 250 summer camps across the country with our Be Tick AWARE™ tick bite prevention message and materials.

Ranger Ready Repellents, EPA-registered brand of body-worn repellents, is a key partner with GLA. Together promoting the Be Tick AWARE™ tick bite prevention program and building awareness on the risks of tick-borne illness.

Marisol and Rob Thomas, through their Sidewalk Angels Foundation, joined forces with GLA to share the importance of protecting pets and people from ticks. The joint campaign included public service announcement ads that appeared in selected Condé Nast publications, online and social media.

Terminix launched its Tick Defend System™ in partnership with television host and interior designer Genevieve Gorder in May to coincide with Lyme Awareness month, culminating in a donation of a percentage of its proceeds to GLA.

Additional thanks to:
- SEEK NORTH KOMBUCHA
- MIGHTY WELL
- GIANT MICROBES
- CLÔZTALK
- LITTLE BIRDIES HCG
- HONEY & VINEGAR
- REGENERON
- NEWMAN'S OWN
- WILLIAM PITT | SOTHEBY'S
- FAE CRATE
- SPOTFUND
- DESIGNS THAT DONATE
- MIXOLOGY

Strong and committed partners played an integral role in helping GLA achieve its mission. We couldn’t do it without them.

Marisol and Rob Thomas, through their organization Sidewalk Angels Foundation (SAF) and Sidewalk Angels Library (SAL) promote the importance of protecting your family and pets from Lyme and other tick-borne diseases and bring to light the invisible burden shouldered by thousands of tick-borne disease patients around the globe.

Marisol is the President of a foundation and wife of one of the world’s most acclaimed musicians, to a child playing in their backyard, to a families— we are all at risk of contracting a tick-borne illness.
EVERY DONATION MATTERS

EVERY DONATION HELPS US TO ACCELERATE OUR IMPACT, MOVE CLOSER TO FINDING THE ANSWERS AND EXPAND THE PROGRAMS THAT WILL DIRECTLY HELP PATIENTS. EVERY DONATION MATTERS.

Here is a snapshot of how our donors contributed to GLA in 2019. More than half of GLA’s full year revenue was due to donations valued at $50,000 or more. Less than 20% of donations were valued at less than $10,000.

I AM A PHYSICIAN WHO HAS WITNESSED THE SUFFERING AND DISCRIMINATION OF LYME AND OTHER TBD (TICK-BORNE DISEASES) INDIVIDUALS FOR OVER 20 YEARS. IT IS FANTASTIC THAT ORGANIZATIONS LIKE GLA EXIST TO FURTHER THE KNOWLEDGE AND AWARENESS OF THESE DISEASES. WE ARE ALL WAITING FOR NEW DISCOVERIES, TREATMENTS AND DIAGNOSTICS AS A RESULT OF THE ORGANIZATION’S DEVOTION TO THE CAUSE.

— Max D.
GLA is driven by donations from the community. Whether it’s $50 or $5,000, every dollar counts. The generosity and commitment of our supporters propels GLA’s mission to conquer Lyme disease, and most importantly, help patients.

**Financials**

Global Lyme Alliance’s gross revenue for 2019 was $5.6 million.

**Global Lyme Alliance, Inc.**

**Statements of Activities and Changes**

**Years Ended December 31, 2019 & December 31, 2018**

<table>
<thead>
<tr>
<th></th>
<th>2019</th>
<th>2018</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Support &amp; Revenue</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Contributions</td>
<td>$2,567,635</td>
<td>$2,380,147</td>
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<tr>
<td>Special Events Income, Net of $572,627 and $651,567 for the years ended December 31, 2019 and 2018, respectively, of Direct Expenses</td>
<td>$2,392,348</td>
<td>$2,345,037</td>
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<tr>
<td>In-kind Contributions</td>
<td>$44,589</td>
<td>$78,783</td>
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<tr>
<td>Investment Income</td>
<td>$49,812</td>
<td>$39,469</td>
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<tr>
<td><strong>Total Support &amp; Revenue</strong></td>
<td>$5,054,384</td>
<td>$4,843,436</td>
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<tr>
<td><strong>Expenses</strong></td>
<td></td>
<td></td>
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<tr>
<td>Program</td>
<td>$3,286,742</td>
<td>$3,321,391</td>
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<tr>
<td>Management &amp; General</td>
<td>$410,740</td>
<td>$413,887</td>
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<tr>
<td>Fundraising</td>
<td>$767,825</td>
<td>$797,488</td>
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<tr>
<td><strong>Total Expenses</strong></td>
<td>$4,465,307</td>
<td>$4,532,766</td>
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<tr>
<td><strong>Changes in Net Assets</strong></td>
<td>$589,077</td>
<td>$310,670</td>
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<tr>
<td><strong>Net Assets, Beginning of Year</strong></td>
<td>$4,674,219</td>
<td>$4,363,549</td>
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<tr>
<td><strong>Net Assets, End of Year</strong></td>
<td>$5,263,296</td>
<td>$4,674,219</td>
</tr>
</tbody>
</table>

**Notes:** 2015 and 2016 exclude extraordinary in-kind donations. For complete financial information, including current IRS-990, go to GLA.org/financials.
2019 BUDGET ALLOCATIONS

74% MANAGEMENT & GENERAL
17% PROGRAMS (Research, Education & Awareness, Patient Services)
9% FUNDRAISING

GLOBAL LYME ALLIANCE, INC.
STATEMENTS OF FINANCIAL POSITION
DECEMBER 31, 2019 & DECEMBER 31, 2018

ASSETS

<table>
<thead>
<tr>
<th>2019</th>
<th>2018</th>
</tr>
</thead>
<tbody>
<tr>
<td>CURRENT ASSETS</td>
<td></td>
</tr>
<tr>
<td>Cash &amp; Cash Equivalents                  $3,503,307</td>
<td>$3,444,250</td>
</tr>
<tr>
<td>Contributions Receivable, Current        $1,408,055</td>
<td>$762,894</td>
</tr>
<tr>
<td>Prepaid Expenses                         $65,594</td>
<td>$56,446</td>
</tr>
<tr>
<td>Loan Receivable                          $150,000</td>
<td>$-</td>
</tr>
<tr>
<td>Accrued Interest Receivable              $3,567</td>
<td>$-</td>
</tr>
<tr>
<td>TOTAL CURRENT ASSETS                     $5,130,523</td>
<td>$4,263,590</td>
</tr>
<tr>
<td>CONTRIBUTIONS RECEIVABLE, LONG TERM      $280,672</td>
<td>$398,263</td>
</tr>
<tr>
<td>INVESTMENT IN THIRD PARTY                $178,000</td>
<td>$178,000</td>
</tr>
<tr>
<td>FIXED ASSETS, NET                       $47,806</td>
<td>$49,101</td>
</tr>
<tr>
<td>OTHER ASSETS                            $40,000</td>
<td>$40,000</td>
</tr>
<tr>
<td>TOTAL ASSETS                            $5,677,001</td>
<td>$4,948,954</td>
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</tbody>
</table>

LIABILITIES AND NET ASSETS

<table>
<thead>
<tr>
<th>2019</th>
<th>2018</th>
</tr>
</thead>
<tbody>
<tr>
<td>CURRENT LIABILITIES</td>
<td></td>
</tr>
<tr>
<td>Accounts Payable &amp; Accrued Expenses   $255,884</td>
<td>$191,543</td>
</tr>
<tr>
<td>Grants Payable                        $123,784</td>
<td>$-</td>
</tr>
<tr>
<td>Deferred Revenue                      $-</td>
<td>$50,000</td>
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<tr>
<td>Deferred Rent                         $34,037</td>
<td>$33,192</td>
</tr>
<tr>
<td>TOTAL LIABILITIES                      $413,705</td>
<td>$274,735</td>
</tr>
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</table>

NET ASSETS

<table>
<thead>
<tr>
<th>2019</th>
<th>2018</th>
</tr>
</thead>
<tbody>
<tr>
<td>Without Donor Restrictions             $2,861,054</td>
<td>$3,129,781</td>
</tr>
<tr>
<td>With Donor Restrictions                 $2,402,242</td>
<td>$1,544,438</td>
</tr>
<tr>
<td>TOTAL NET ASSETS                        $5,263,296</td>
<td>$4,674,219</td>
</tr>
<tr>
<td>TOTAL LIABILITIES AND NET ASSETS        $5,677,001</td>
<td>$4,948,954</td>
</tr>
</tbody>
</table>
LEADERSHIP

IN HONOR OF MY SON WHO HAS BECOME A BRAVE LYME WARRIOR, AND ALL THOSE FIGHTING TO REGAIN THEIR HEALTH FROM LYME AND OTHER TICK-BORNE ILLNESSES, THANK YOU TO GLA FOR OFFERING HOPE TO ALL OF US AFFECTED BY LYME.”

— Christine B.

SCIENTIFIC ADVISORY BOARD

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GLA

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Director of Science & Research
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University of Maryland

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Professor of Medicine, Pathology, Molecular Biology & Genetics and Molecular Microbiology and Immunology
Johns Hopkins University School of Medicine

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— Christine B.
WE’RE IN THIS FIGHT TOGETHER.

While we are inspired by the research progress our scientists are making every day, the team at GLA is moved most by the impact the community has on us. Every day we are inspired by members of our ‘Alliance’ that are motivated to give back, to both GLA and to help their communities.

WHAT INSPIRES YOU?

THANK YOU FOR YOUR ONGOING SUPPORT. TO MAKE A DONATION, VISIT GLA.ORG/DONATE OR CALL 203 969 1333