





# THE YEAR OF THE PATIENT











# WHO WE'RE FIGHTING FOR

MORE THAN 427,000 PEOPLE IN THE UNITED STATES ARE NEWLY DIAGNOSED WITH LYME DISEASE EVERY YEAR.

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

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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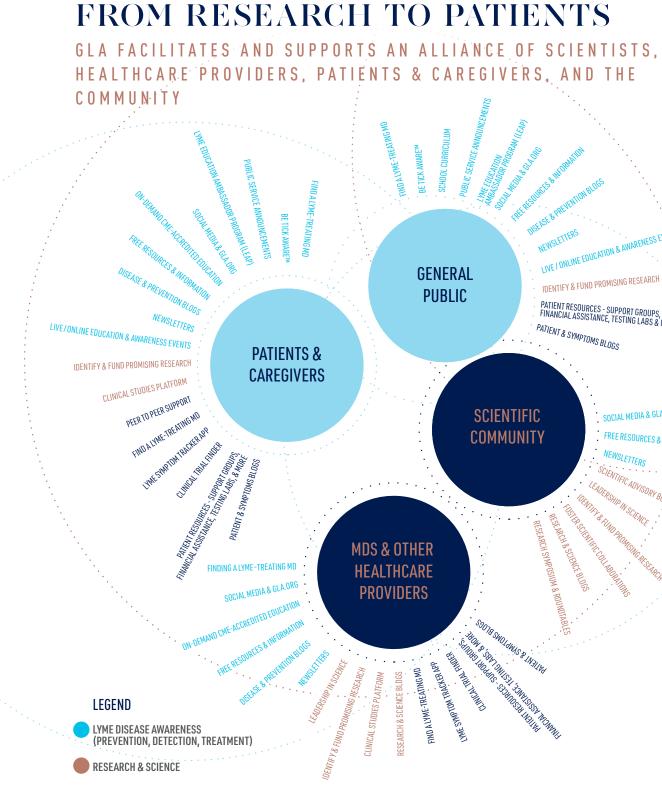


# **PUTTING PATIENTS FIRST** PATIENTS ARE THE CORE OF OUR WORK

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. 



PATIENT SERVICES

THE YEAR OF THE PATIENT

# SUPPORTING OUR ALLIANCE,

IDENTIFY & FUND PROMISING RESEARCH

PATIENT RESOURCES - SUPPORT GROUPS, FINANCIAL ASSISTANCE, TESTING LABS & MORE PATIENT & SYMPTOMS BLOGS

SCIENTIFIC COMMUNITY SOCIAL MEDIA & GLA.ORG

FREE RESOURCES & INF

# A LETTER FROM OUR CEO & CHAIRMAN

# **DEAR FRIENDS:**

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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
P.8 POSSIBLE.
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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 resolute. 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 toptier 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 mentee personally helping a patient with their struggle, we are connecting the world.

We are delighted to share with you some highlights of our work this year. But please note, this is just a glimpse of our progress. To learn more about our future plans turn to the last page of this report, visit GLA.org, sign up for our newsletter and follow us on social media.

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

Sincerely,



Auth falande.

Scott Santarella CEO Global Lyme Alliance

## THE YEAR OF THE PATIENT





Robert Kobre Chairman of the Board Global Lyme Alliance

# **2019: YEAR AT A GLANCE**

Erin Walker, Karma Newberry and Steve Lefkowitz



Burns & Wilcox



Burns & Wilcox partners with PGA Champion Jimmy Walker with its Champions & Charities program, to benefit GLA.

GLA introduces 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.

Announces new online CME-accredited education for physicians and nurses developed in partnership with the state of Delaware's Lyme Disease Education Oversight Board.

GLA-funded 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 Institues of Health Tickborne 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.

Erin and Jimmy Walker host GLA's inaugural event at the Palm Beach International Equestrian Center in Florida.

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 conducts highly successful Lyme Disease Awareness Month campaign, highlighting its Be Tick AWARE™ message, increasing awareness worldwide about the importance of tick bite prevention and the risk of Lyme disease.

Breakfast fundraiser held in Chicago with GLA Board member and equestrian Erin Walker.

2nd Annual Westchester Breakfast and Shop for a Cure event with guest speaker Dr. Daniel Cameron.

Mohawk Valley Community College in partnership with GLA holds educational forum and inaugural 5K walk in Utica, New York.

GLA awards \$2 million in scientific research grants and related projects.

Marisol and Rob Thomas partner with GLA through their Sidewalk Angels Foundation.

GLA launches peer-to-peer mentor support program for patients and caregivers-a first for the Lyme community.

Inaugural Lyme disease awareness event on Nantucket at home of William Bainbridge Steel and Christopher Putnam Drake.



AUb

GLA launches new Kids and Lyme Disease blog series.

Hosts 3rd Annual SubLyme Soiree in Chicago.

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



The New York Times selects and publishes GLA's Letter to the Editor in response to article depicting

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

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

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.

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 is an official Charity Partner of the TCS NYC Marathon for the 2nd year in a row, with five Team GLA runners raising funds and awareness for Lyme.

GLA joins partner The Avril Lavigne Foundation at Reaching the Last Mile Forum in Abu Dhabi to discuss tick-borne diseases and global health.

GLA exceeds its annual fundraising goal of \$5.2 million.



# **RESEARCH ADVANCEMENTS**

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.

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### 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 communitybased, 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.

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.

## 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.



# 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 AL-LIANCE'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.

# PTLD PREVALENCE ESTIMATES FOR 2016 RANGED FROM 69,011 PERSONS TO 1,523,869. PREVALENCE IN 2020 IS PREDICTED TO BE HIGHER THAN 2016, AND MAY BE AS HIGH AS 1,944,189

1,523,869

"This study is extremely relevant in understanding the important public health significance of chronic illness related to Lyme disease," said John Aucott, M.D., Director of the Johns Hopkins Lyme Disease Clinical Research Center. "These numbers are on par with other important public health threats such as HIV. When combined with the recognized severity of PTLD for patients, the impact is even more significant."

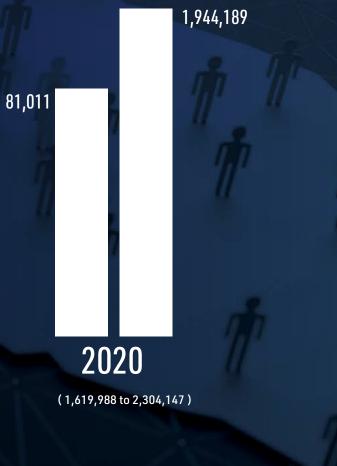
Dr. Hsu, who co-authored the study with Allison DeLong, M.S., a biostatistician at Brown University's Center for Statistical Sciences and a member of GLA's Scientific Advisory Board, identified two goals of the study. The first goal was to develop a rigorous mathematical framework for estimating PTLD 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.

2016

(95% CI 51,796 to 89,312)

69.011

\*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.



# FUNDED RESEARCH

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**

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 noninflammatory arthritis.

STUDY: "Musculoskeletal Ultrasound Evaluation of Tendon Involvement in Lyme Disease"

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"

# 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"

## 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"

### 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"

### 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

# DIAGNOSTICS=**32%**

TREATMENT=**32%** 

BASIC SCIENCE=**36%** 



# 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 GRANTEES, 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.



Dr. John Aucott, Dr. Mayla Hsu,

Dr. Mark Soloski, Dr. Utpal Pal



Dr. Mark Wooten, Dr. Tim Sellati, Dr. John Belisle, Dr. Catherine Brissette



Dr. Tim Sellati, Dr. Ying Zhang, Rob Kobre, Dr. Armin Alaedini

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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.



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."



### RESEARCH AND SCIENCE



Scott Santarella, GLA, Amie Lavigne, The Avril Lavigne Foundation, Dr. Anthony Costello, chair of the Climate Change and Global Health Roundtable

# PUBLISHED RESEARCH

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.

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GLOBAL LYME ALLIANCE'S FUNDING FOR RESEARCH. ADVOCACY AND EDUCATION FOR LYME DISEASE CHANGES THE OUTLOOK FOR PATIENTS. GLOBAL LYME ALLIANCE IS A BEACON OF HOPE FOR THE LYME DISEASE COMMUNITY.

— Samantha H.

### RESEARCH AND SCIENCE

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# **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

P.28 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 staffers. Our ongoing partnership with Ranger Ready Repellents will support future efforts and help with expanding our reach in 2020.



**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."

# WHAT INSPIRES OUR LYME **EDUCATION AMBASSADORS**

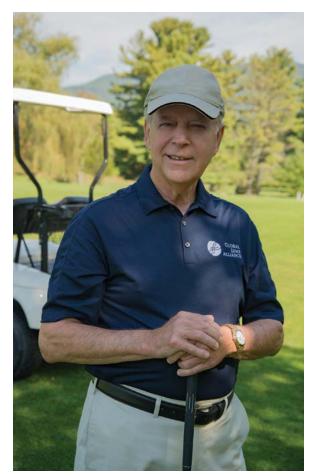


# **CONNECTING WITH THE COMMUNITY**

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.



GLA Ambassadors in Action: Sharon Austin (CO) with GLA's Director of Education and Outreach Sara Tyghter, William Beesmer (NY), and Angela Maniak (ME) (opposite)





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.

### 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

# **EDUCATING HEALTHCARE PROVIDERS**

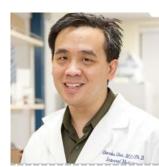
IN 2019 GLA DEVELOPED A NEW CONTINUING MEDICAL EDUCATION (CME) AND CONTINUING EDUCATION (CE)-ACCREDITED LYME DISEASE EDUCATION COURSE, "A CLINICAL GUIDE TO DIAGNOSING AND TREATING LYME DISEASE AND OTHER TICK-BORNE ILLNESSES" IN PARTNERSHIP WITH THE STATE OF DELAWARE'S LYME DISEASE EDUCATION OVERSIGHT BOARD. THE COURSE OFFERS BOTH P.32 PHYSICIAN AND NURSE CREDITS,

AND IS IN FACT MANDATED BY THE STATE OF DELAWARE FOR ALL HEALTHCARE PROFESSIONALS SEEKING LICENSE RENEWAL.

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.

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

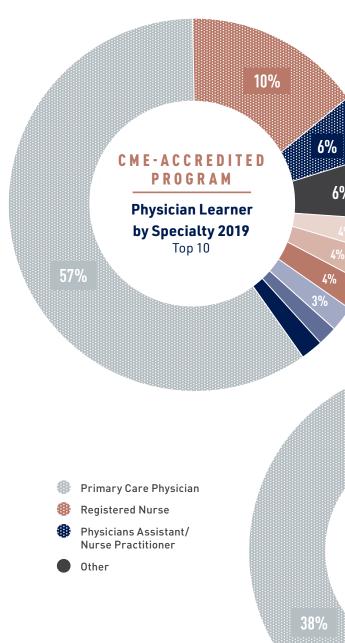
GLA continues to offer its first CME offering, "Pediatric Tick-Borne Disease: Diagnosis and Management", as an on-demand program. More than 10,000 medical professionals have been educated.



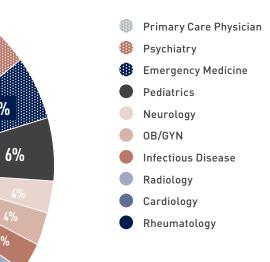
Dr Charles Chiu Professor, Laboratory Medicine and Medicine / Infectious Diseases at University of California, San Francisco

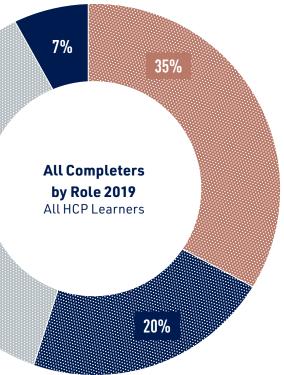


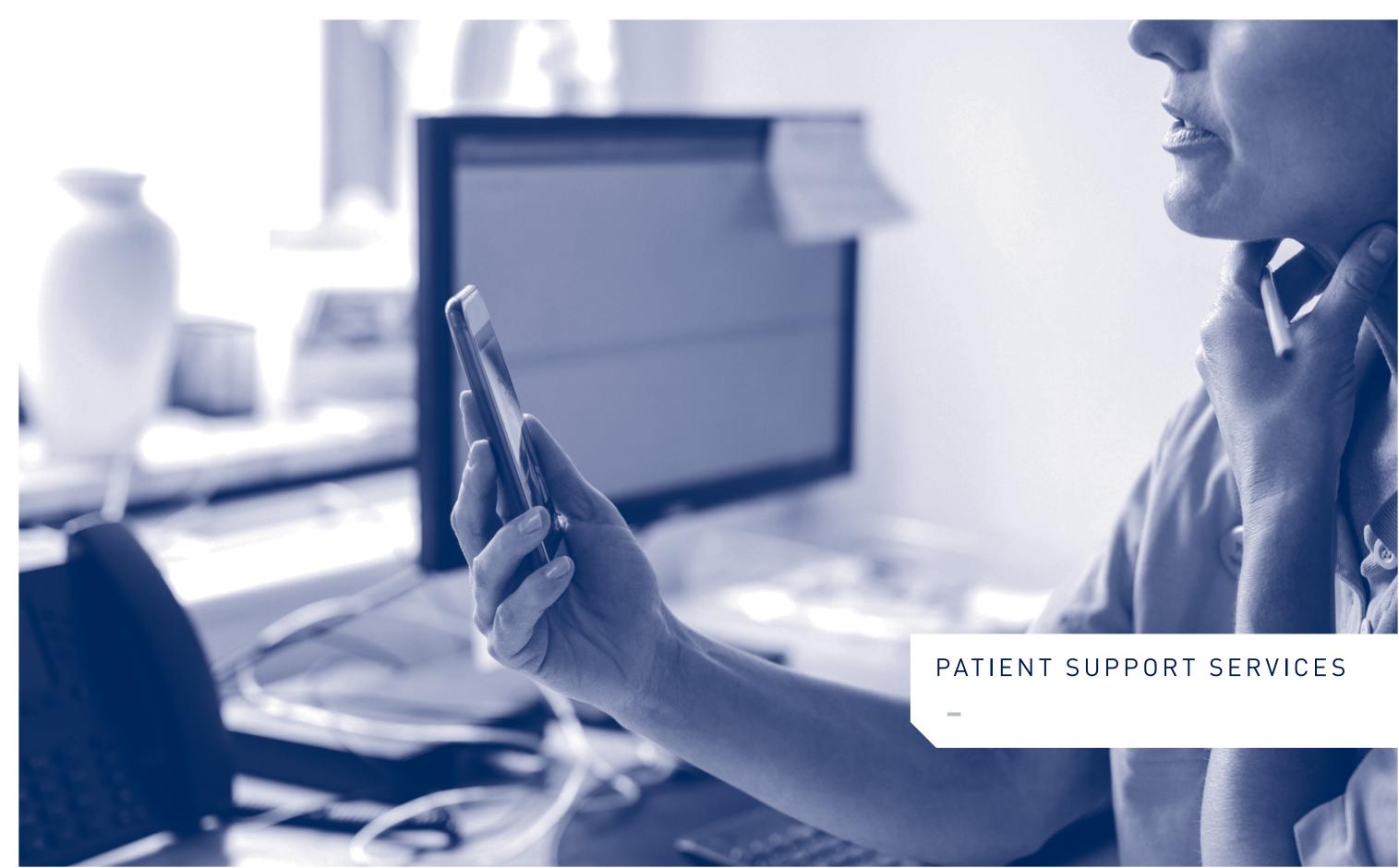
Dr. Elena Frid Neurologist (International Practice). Clinical interests in Autoimmune and Neuro-Lyme disease. Public Speaker, Educator



### EDUCATION AND OUTREACH







# PATIENT SUPPORT SERVICES

GLOBAL LYME ALLIANCE IS UNWAVERING IN ITS COMMITMENT TO HELP IMPROVE THE QUALITY OF LIFE FOR PEOPLE LIVING WITH TICK-BORNE DISEASES AND THEIR FAMILIES. WE ARE THE FIRST LYME DISEASE ORGANIZATION TO OFFER MULTIPLE, FREE PROGRAMS DEDICATED TO HELPING PATIENTS AND CAREGIVERS AT ALL STAGES OF THEIR JOURNEY-FROM DIAGNOSIS AND DETECTION. FINDING A LYME TREATING PHYSICIAN. TREATMENT OPTIONS THAT MANAGE THE DISEASE, TO SUPPORT WHILE LIVING WITH THE DISEASE.

## PEER TO PEER SUPPORT

P.36

GLA launched the first-ever Lyme disease peer-topeer 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.



# PEER PROFILE

## 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. The friend helped further by connecting

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

## PATIENT SUPPORT SERVICES

Samantha with a doctor experienced in treating the tick-borne illness who then guided her through the early days of her treatment.

Samantha more recently used her new-found knowledge to help friends who had gone to a camp in Northern California and afterward became very ill from an unknown cause. 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."

# PATIENT SUPPORT SERVICES cont.

# 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.



P.38

TOP 3 SYMPTOMS OF LYME DISEASE REPORTED BY APP USERS:

Fatigue, tiredness
 Unexplained fevers
 Flu-like symptoms

# TOP 3 SYMPTOMS OF EARLY LYME DISEASE RECORDED BY APP USERS:

1. Neck stiffness

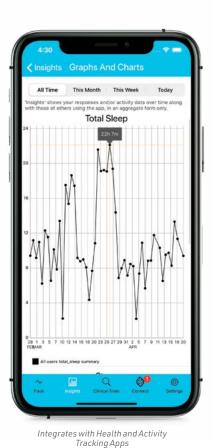
- 2. Flu-like symptoms
- 3. Severe headache







Performance Tracker





# 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.



# 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.

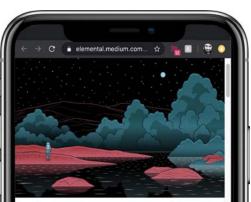


Illustration by Anuj Shrestha

When Lyme Kills The extremely rare complication you should know about





This story is part of <u>"Tickpocalypse,"</u> a multi-part special report.

oseph Elone just felt tired at first, like he wasn't sleeping well. A 17-year-old highschool student from upstate Poughkeepsie, New York, Joseph was a quiet but popular science whiz and electric-guitar lover who had just finished a summer environmental fellowship at Brown University. He'd spent two weeks studying on campus and hiking in the Rhode Island woods and was still riding high from the experience. It was late July, and life had a carefree feeling to it, "He was really happy that he had this 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

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:

The New York Times. People Magazine, Parade.com, Daily Mail, US Weekly, Bustle, CBS New York, NBC New York, American Association for the Advancement of Science, Physician Family, Entertainment Tonight, FOX5, The Atlantic, Good Day New York, Alliance Health Education Initiative, Yahoo!, Nantucket Magazine, N magazine, Nantucket Community Television, New York Post, OK Magazine, US Weekly, Greenwich Time, WGCH, WTNH, Stamford Patch, Connecticut Post, Showbiz 411, Look to the Stars, Westport News, Just Jared Jr. Middletown Transcript, The Jewish Voice, The Buffalo News, Erie News Now, The Evening Leader, Intern Daily, Ridgway Record, Pittsburgh Post-Gazette, Daily Herald, Markets Insider, The Mighty, Cornell Chronicle, The Wheatgrass Warrior.



Talia Jackson and GLA CEO, Scott Santarella on FOX 5.

# **EVENTS WITH IMPACT**

GLOBAL LYME ALLIANCE IS FORTUNATE TO HAVE AN ENTHUSIASTIC COMMUNITY JOIN AND CONTRIBUTE TO A VARIETY OF EVENTS THROUGHOUT THE YEAR FROM OUR ANNUAL NEW YORK GALA TO MORE INTIMATE FUNDRAISERS. THESE EVENTS ARE IMPORTANT TO RAISE BOTH AWARENESS AND FUNDS AS WELL AS TO SUPPORT OUR MISSION.

## NEW YORK GALA. OCTOBER 10, 2019 CIPRIANI 42ND STREET, NEW YORK, NY

P.44 GLA's 5th annual New York City Gala raised over \$2.5 million and was attended by more than 700 quests. 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.









Gala Honorees: David Nolan, Adrienne Nolan-Smith and GLA CEO Scott Santarella



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.

Gala Chef Charlie Palmer

Genevieve Gorder and Crystal Hefner

# EVENTS WITH IMPACT, cont.





SubLyme Soiree: Chairs, Darcy Rogers, Laura Kimmel and Alex Moresco

### SubLyme Soiree: Zach Abraham, Trina Abraham Heffley

### SubLyme Soirée August 22, 2019 P.46

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.

### 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.





### Utica Lyme Walk May 19, 2019

Dozens of walkers participated in this inaugural event organized by the Health Center at Mohawk Valley Community College to raise awareness and funds to conquer Lyme disease.

### GLA on Nantucket: Lyme disease Awareness Event June 28, 2019

GLA's inaugural event on Nantucket was held at the home of Will Steele (GLA Board member Emeritus), and Chris Drake. Guests listened to GLA CEO Scott Santarella talk about Lyme disease and the latest treatment advances and GLA Grantee Lise Nigrovic, M.D., Harvard Medical School and Boston Children's Hospital, who shared details of her groundbreaking pediatric Lyme research.

### Lyme Disease Awareness Golf Tournament August 11, 2019

Brooke Fuchs, a student living with chronic Lyme disease for almost six years, hosted a golf tournament to raise awareness and funds for GLA. The tournament consisted of nine holes of golf at Canyon Springs Golf Course in Twin Falls Idaho, followed by a dinner.

### Christmas Coffee House December 22, 2019

To ring in Christmas week and celebrate the spirit of the season, The OSC Charitable Foundation held its 7th annual Christmas Coffeehouse. Those who attended the Buffalo, New York event enjoyed homemade desserts, coffee and listened to holiday music.

## ENDURANCE EVENTS

For the second year, GLA participated in the TCS New York City Marathon as an official Charity Partner. There were five members of Team GLA including captain Jesse Ruben, Erin Conant, William Egan, Mia Sapienza, and Taryn Tomczyk. All five finished the 26.2 mile course, and raised \$20,000 to help support tick-borne disease research.

In addition to the Marathon, for the first time GLA had a runner in the iconic Berlin marathon, expanding our global endurance impact. We also had participants in events such as Tough Mudder, Rock 'n' Roll Nashville Half Marathon, a fun Rock 'n' Run 5k event in Pawling, New York, and special shout out to Charlotte Dequeker who completed the grueling Orcas Island marathon, with funds going to GLA

ABOVE LEFT : Palm Beach - Jimmy Walker, Erin Walker, Julia Knox-Comeau, Robert Kobre, Diane Blanchard, Scott Santarella

ABOVE RIGHT: Nantucket - Chris Drake, Will Steele, Dr. Lise Nigrovic, Scott Santarella Debbie Siciliano

RIGHT: Marathon Runner - Taryn Tomczyk





# **AN ALLIANCE OF POWERFUL PARTNERS**

# STRONG AND COMMITTED PARTNERS PLAYED AN INTEGRAL ROLE IN HELPING GLA ACHIEVE ITS MISSION. WE COULDN'T DO IT WITHOUT THEM.

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<sup>™</sup> 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<sup>™</sup> 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<sup>™</sup> 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 CLÕZTALK LITTLE BIRDIES HCG HONEY & VINEGAR REGENERON NEWMAN'S OWN WILLIAM PITT | SOTHEBY'S FAE CRATE SPOTFUND DESIGNS THAT DONATE MIXOLOGY



— Rob Thomas, Ever the Same

WE ARE ALL AT RISK OF LYME DISEASE. REGARDLESS OF HOW MANY LEGS OR HOW MUCH FUR WE HAVE. CASES OF LYME CONTINUE TO SKYROCKET-FOR PEOPLE, CASES HAVE DOUBLED OVER THE LAST 10 YEARS; FOR DOGS, IT'S DOUBLED OVER THE LAST FIVE YEARS.

Marisol and Rob Thomas, through their organization Sidewalk Angels Foundation (SWA) and Global Lyme Alliance (GLA) join forces to share the importance of protecting your entire family from Lyme and other tick-borne diseases and bring to light the injustice faced by hundreds of thousands of Lyme patients around the globe. From the President of a foundation and wife of one of the worlds most acclaimed musicians, to a child playing in their backyard, to a beloved pet - we are all at risk of contracting a tick-borne illness.

LEARN HOW TO PROTECT YOURSELE & YOUR PETS FROM LYME DISEASE AT GLA.ORG/SWA



ABOVE Left to Right: Marisol and Rob Thomas with Sidewalk Angels Foundation appear in public service announcement ad. Genevieve Gorder and Terminix ad. Ready Ranger and GLA Ad.

### AWARNESS AND IMPACT







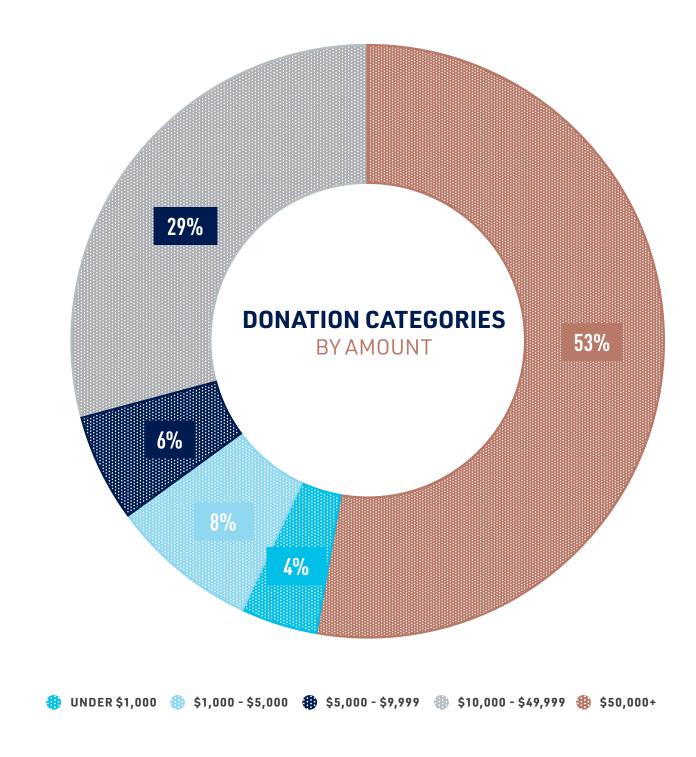
# **EVERY DONATION MATTERS**

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.

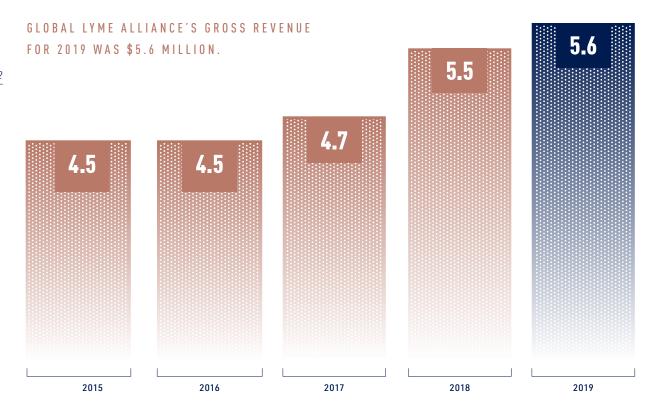


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GLA IS DRIVEN BY DONATIONS FROM THE COMMUNITY, WHETHER IT'S \$50 OR \$5,000, EVERY DOLLAR COUNTS. THE GENEROSITY AND COMMITMENT OF OUR SUPPORTERS PROPELS GLA'S MISSION TO CONQUER LYME DISEASE, AND MOST IMPORTANTLY, HELP PATIENTS.



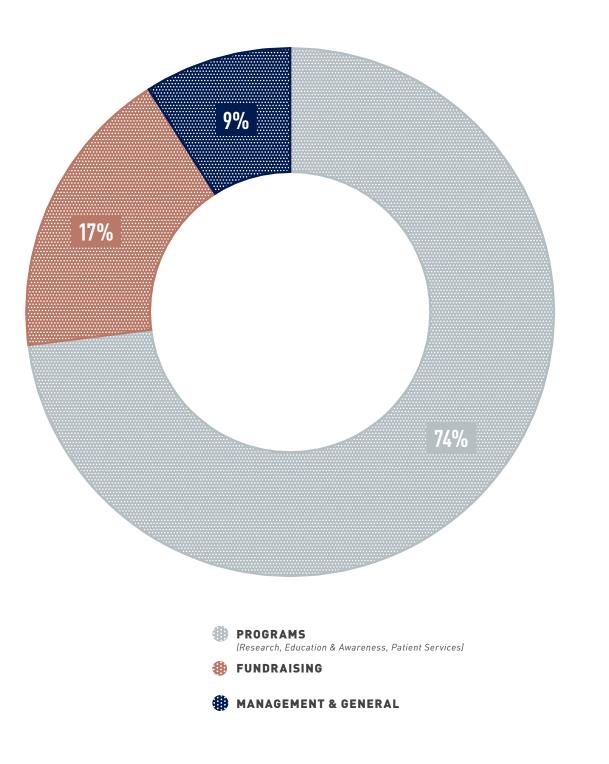
**NOTES:** 2015 and 2016 exclude extraordinary in-kind donations. For complete financial information, including current IRS-990, go to **GLA.org/financials** 

# **GLOBAL LYME ALLIANCE, INC.** STATEMENTS OF ACTIVITIES AND CHANGES YEARS ENDED DECEMBER 31, 2019 & DECEMBER 31, 2018

SUPPORT & REVENUE
Contributions
Special Events Income, Net of \$572,627 and \$651,567 for the ended December 31, 2019 and 2018, respectively, of Direct
In-kind Contributions
Investment Income
TOTAL SUPPORT & REVENUE
EXPENSES
Program
Management & General
Fundraising
TOTAL EXPENSES
CHANGES IN NET ASSETS
NET ASSETS, BEGINNING OF YEAR
NET ASSETS, END OF YEAR

2019	2018
\$2,567,635	\$2,380,147
\$2,392,348	\$2,345,037
\$44,589	\$78,783
\$49,812	\$39,469
\$5,054,384	\$4,843,436
\$3,286,742	\$3,321,391
\$410,740	\$413,887
\$767,825	\$797,488
\$4,465,307	\$4,532,766
\$589,077	\$310,670
\$4,674,219	\$4,363,549
\$5,263,296	\$4,674,219
	\$2,567,635 \$2,392,348 \$44,589 \$49,812 \$5,054,384 \$3,286,742 \$410,740 \$767,825 \$4,465,307 \$589,077 \$589,077

# **2019 BUDGET ALLOCATIONS**



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

## ASSETS

CURRENT ASSETS
Cash & Cash Equivalents
Contributions Receivable, Current
Prepaid Expenses
Loan Receivable
Accrued Interest Receivable
TOTAL CURRENT ASSETS
TOTAL CURRENT ASSETS CONTRIBUTIONS RECEIVABLE, LONG TERM
CONTRIBUTIONS RECEIVABLE, LONG TERM
CONTRIBUTIONS RECEIVABLE, LONG TERM

## LIABILITIES AND NET ASSETS

CURRENT LIABILITIES
Accounts Payable & Accrued Expenses
Grants Payable
Deferred Revenue
Deferred Rent
TOTAL LIABILITIES
NET ASSETS
Without Donor Restrictions
With Donor Restrictions
TOTAL NET ASSETS
TOTAL LIABILITIES AND NET ASSETS

AWARNESS AND IMPACT

2019	2018
\$3,503,307	\$3,444,250
\$1,408,055	\$762,894
\$65,594	\$56,446
\$150,000	\$-
\$3,567	\$-
\$5,130,523	\$4,263,590
\$280,672	\$398,263
\$178,000	\$178,000
\$47,806	\$69,101
\$40,000	\$40.000
\$5,677,001	\$4,948,954

\$255,884	\$191,543
\$123,784	\$-
\$-	\$50,000
\$34,037	\$33,192
\$413,705	\$274,735
\$2,861,054	\$3,129,781
\$2,861,054 \$2,402,242	\$3,129,781 \$1,544,438
\$2,402,242	\$1,544,438



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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.

P.56

Scott Santarella, CEO

Robert Kobre, Chairman of the Board

## BOARD OF DIRECTORS

Charles Balducci, Vice Chair
Diane Blanchard, Vice Chair
Debbie Siciliano, Vice Chair
Henry Dosch, Treasurer
Brett Kristoff
Lorrie Nadel
Ed O'Connell
Karen Peetz
Paul Ross

**Ridgway Barker Chris Corrinet Nancy Del Genio David Gerstner** Staci Grodin Julia Knox-Comeau **Avril Lavigne** Steve Lefkowitz Lew Leone **Steve Martin** 

Dana McAvity Karma Newberry David Nolan Peter Norley Norma Russo **Alexander Tisch** Janet Vaccaro, Secretary 99

## Erin Walker

## SCIENTIFIC ADVISORY BOARD

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Mayla Hsu, Ph.D. Director of Science & Research GLA

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