

Tick Borne Disease Educational Symposium



*Tick Wise Education, inc. 501c3
fills the gap between our State Land Management
Authorities and locally run hospitals and health clinics. It
is a program that seeks to improve the health of all New
Yorkers by safeguarding them against tick bites through
education. It does so by arming our most vulnerable
community members with the knowledge and tools
necessary to avoid being bitten by a tick – our children.*

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**Event Committee: April Nill-Boitano, Jane Held,
Jennifer Petrocelli & Lisa-Jae Eggert**

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the First Annual Tick Borne Disease
Educational Symposium**



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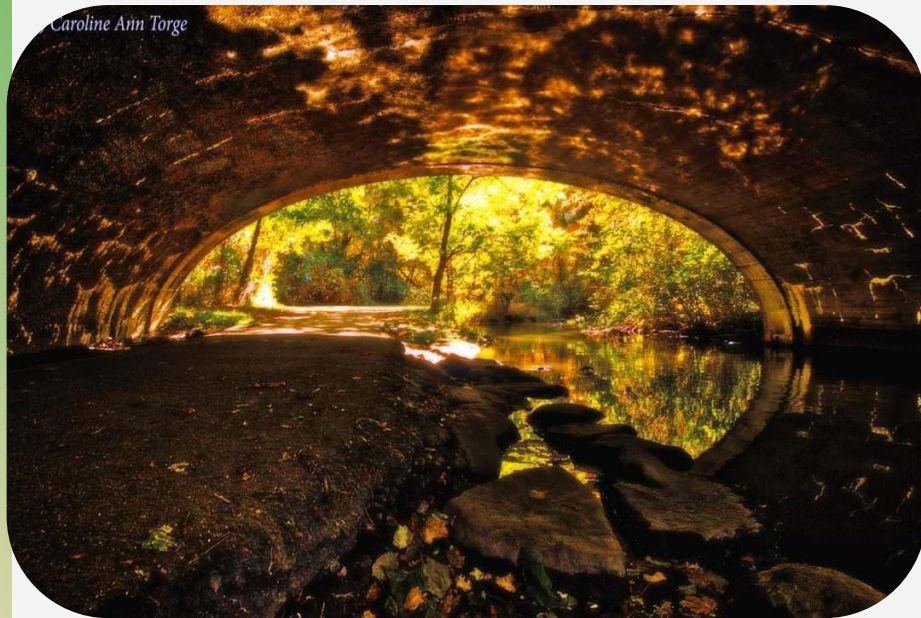
South Fork Natural History Museum (SOFO)

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www.sofo.org (631) 537-9735**

Persistent Lyme Disease...

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You are not crazy, you are not lazy. You are still
sick, and not imagining it. There is help, if you
know where to look. You can feel better even if
there is no cure. We can help you get there -
see that light at the end of the tunnel?



Thank you for joining us!

*With Love, Your friends in the event
committee April, Jane, Jennifer & LJ*



**Art Hike for Tick
Bite Awareness**

AH4TBA

Saturday July 27th, 2019; 10am - 2 pm

South Fork Natural History Museum

Rain or Shine! SOFO 377 Bridgehampton Sag Harbor Tpke, Bridgehampton NY 11932

WWW.TICKWISE.ORG

"Until we have a test for Lyme that is valid, specific and accurate based on sound ethical science we will not know the true breadth and depth of the damage this tick-borne illness is causing to our nation's children & adults." – April Nill-Boitano



Tick Borne Disease Support Group

EMPIRE STATE LYME DISEASE ASSOCIATION

 <p>THE Preston HOUSE & HOTEL 428 E Main St, Riverhead, NY 11901</p> <hr style="border: 2px solid blue;"/> <p>Tick Borne Illness Luncheon Meeting 12:30pm the first Wednesday of every month.</p>	 <p>377 Bridgehampton Sag Harbor Tpke, Bridgehampton, NY 11932</p> <hr style="border: 2px solid red;"/> <p>The 2nd and/or 4th Wednesday of the month @6:30pm Different speakers and projects Topics change weekly.</p>
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Meeting announcements/cancellations on WWW.TICKWISE.ORG

Event Schedule

Morning Session:

1. Registration 9:00am – with Coffee & Tea
2. Hello/Welcome message 9:20am
3. Dr. Bransfield 9:30am - 10:25 am
(one CEU credit available)
4. Dr. Greenberg 10:30am - 11:25 am
(one CEU credit available)
5. Dr. Burrascano 11:30am - 12:25 pm
(one CEU credit available)

LUNCH 12:30-1:00pm, buffet style lunch accommodating all dietary concerns from vegetarian/vegan, to alpha gal allergy, to gluten free, etc. Gourmet wraps, cookies, etc.

Afternoon Session:

1. Dr. Dan Cameron 1:00 pm - 2:00 pm
2. Jenna Luche-Thayer 2:05 pm - 2:45 pm
3. Kris Newby 2:50 pm - 3:30 pm
4. Q&A panel with Dr. Daniel Cameron, Dr. Joe Burrascano, Dr. Suzanne Kirby, Dr. Howard Robbins, Dr. Roxanne Carfora, Dr. Christopher Hussar and Alpha Gal Allergy Patient Advocate Beth Carrison INHC



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Dr. Robert Bransfield

Dr. Robert C. Bransfield, MD, DLFAPA is a graduate of Rutgers College and the George Washington University School of Medicine. He completed his psychiatric residency training at Sheppard and Enoch Pratt Hospital, is board certified by the American Board of Psychiatry and Neurology in Psychiatry and is a Distinguished Life Fellow of the American Psychiatric Association. Dr. Bransfield's primary activity is an office based private practice of psychiatry. In addition, Dr. Bransfield is the Past President of ILADS, the International Lyme and Associated Diseases Educational Foundation and the New Jersey Psychiatric Association. He has held a number of administrative positions with organizations involved with health, mental health and community related activities. He is a Clinical Associate Professor of Psychiatry at Rutgers—Robert Wood Johnson Medical School. Dr. Bransfield has authored and co-authored a number of publications in peer-reviewed literature, other medical publications and books; and has been active in political advocacy on an international, national, state and local level.

PROUD TO SUPPORT TICK WISE EDUCATION

I'm happy to support this year's Tick Borne Disease Educational Symposium and the important efforts of this organization.

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Dr. Rosalie Greenberg

Rosalie Greenberg, MD, FAPA, DFAACAP is a board-certified, child, adolescent and adult psychiatrist in private practice in Summit, New Jersey. Although her practice focuses on children and adolescents with a wide range of psychiatric disorders, she specializes in the psychopharmacology of pediatric mood disorders and neuropsychiatric symptoms secondary to infections, especially tick-borne disorders.

Dr. Greenberg serves as a consultant in psychiatry at Overlook Hospital in Summit, New Jersey. She is a Fellow of the American Psychiatric Association; a Distinguished Fellow of the American Academy of Child and Adolescent Psychiatry and has served on the Executive Board of the New Jersey Council of Child and Adolescent Psychiatry. She has received recognition as a Top Doctor in Child Psychiatry in multiple listings and has received awards in recognition of her patient advocacy. Dr. Greenberg co-authored ***“When Acting Out Isn’t Acting”*** (Bantam Books August 1991), authored ***“Bipolar Kids: Helping Your Child Find Calm in the Mood Storm”*** (DaCapo Press March 2007) co-produced the film ***“Rescuing Childhood – Understanding Bipolar Disorders in Children and Adolescents”*** (2009) and served as creator and host of the multiple Telly Award winning show ***“Kids First with Rosalie Greenberg, MD”***

In recent years, Dr. Greenberg has focused her practice and research on neuropsychiatric manifestations of infectious illnesses: especially tick-borne disorders in youth. An active member of International Lyme and Associated Diseases Society (ILADS), she has presented both nationally and internationally to medical professionals and the public on the potential role of tick-borne disorders and other infections in the development of childhood mental health disorders. She has published critical commentaries on multiple articles in peer reviewed medical journals related to the dissemination of factual information regarding tick-borne infections. Her original articles have addressed multiple areas related to childhood mental illness including among them similarities between Pediatric Autoimmune Neuropsychiatric Disorders Associated with Streptococcal infections (PANDAS) and Pediatric Acute-onset Neuropsychiatric Syndrome (PANS) with pediatric bipolar disorder; the role of tick-borne illness in treatment resistant pediatric mood disorders; and the high frequency of infection in a sample of bipolar youth. Most recently Dr. Greenberg co-authored the paper ***Bartonella henselae Bloodstream Infection in a Boy with Pediatric Acute-Onset Neuropsychiatric Syndrome*** in Journal of Central Nervous System Disease 2019.

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Dr. Joe Burrascano

Dr. Burrascano is a physician who specializes in the diagnosis and treatment of Lyme and associated complex infectious diseases, and the chronic illnesses that accompany them. He is best known for his monographs on diagnostic and treatment guidelines for Lyme and related tick-borne illnesses - a classic series that has been freely circulated around the world beginning in 1989.

With over two decades of experience and research in this field, he has appeared in and on virtually every form of media, has advised the CDC and NIH, testified before the U.S. Senate, an armed services joint subcommittee, and at various governor's councils. A founding Board Member of ILADS, he also served as a Director of the ILADS Educational Foundation.

A graduate of the NYU School of Medicine with a specialty in Internal Medicine, Dr. Burrascano retired from clinical practice in 2006. However, he continues to be active in educating practitioners and the public on issues related to tick-borne diseases.

He currently works full time as an analyst for a private biotech company, helping to bring advanced technologies and treatments out of the lab and into general use. In addition, he is a clinical advisor for a specialty diagnostic lab, and his lifelong interest in nutrition has resulted in his ongoing consultative work with various nutritional supplement suppliers.



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Dr. Daniel Cameron

Dr. Daniel Cameron is a leading Lyme disease expert with 31 years experience. He graduated from the University of Minnesota School of Medicine and their Department of Epidemiology. He completed residencies at both Beth Israel Medical Center and Mt. Sinai in New York City. He is widely recognized as author of the 2004 and 2014 International Lyme and Associated Disease Society (ILADS) practice guidelines, analytic reviews, and his book *Inside Lyme: An expert's guide to the science of Lyme disease*.

Dr. Daniel Cameron has led ILADS twice as their president. He had testified before a number of state legislatures and been interviewed as an expert on the NBC today show, Good Morning America, Fox News, and Sirius radio.

He has posted hundreds of Lyme Disease Science blogs an "in my practice" videos on his website www.DanielCameronMD.com Facebook facebook.com/danielcameronmd/, Instagram instagram.com/drdanielcameron/, and twitter twitter.com/DrDanielCameron.

He continues to see patients in his private practice in Mt. Kisco, New York.



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***Jenna Luché-
Thayer, Author/
Activist***

Jenna Luché-Thayer, MIA, Founder and Director, Ad Hoc Committee for Health Equity in ICD11 Borreliosis Codes. She is a former Senior Advisor to the US Government and the United Nations and is currently assisting institutions and communities to build a humane and rights based patient-centered response to the global borreliosis pandemic.

Luché-Thayer has 33 years of policy and grassroots experience in 42 countries and works across the globe to help Institutions remedy entrenched practices of discrimination that interfere with their higher purpose. Her expertise includes government transparency, accountability, human rights and political representation of marginalized groups.

Luché-Thayer has worked with governments, the United Nations, nonprofits, corporate world and has over 75 publications and her awards include: International Woman's Day Award for Exemplary Dedication and Contributions to Improving the Political and Legal Status of Women (US government), Highest Ranking Technical Area in Accomplishment, Innovation and Comparative Advantage for United Nations Capital Development Fund, the International Lyme and Associated Diseases Society Power of Lyme Award 2018.

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BRIAN KELLY



Brian Kelly is a pioneer. Recognizing the growing epidemic of tick-borne diseases on eastern Long Island, in 1997 he founded East End Tick & Mosquito Control, the very first firm dedicated primarily to combating ticks. But East End Tick is more than a service business, since its inception Kelly has worked hard to educate himself and our community about tick-borne disease prevention. He has partnered with and is a key supporter of *Stony Brook Southampton Hospital's Regional Tick-Borne Disease Resource Center*. Kelly has provided tens of thousands of informational Tick ID cards in both english and spanish to the Tick-Borne Disease Resource Center which distributes them, among other efforts. He is the co-creator and a board member of *Tick Wise*, originators of this symposium. In recognition of his accomplishments and knowledge, the Suffolk County NY Legislature appointed Kelly to their *Tick Control Advisory Committee* which is tasked with devising a countywide tick-borne disease prevention program. Brian Kelly's commitment to public health informs his company's philosophy completely: East End Tick & Mosquito uses the most environmentally-responsible methods available, believing in the fundamental principle that the solution shouldn't be worse than the problem



In Loving Memory of Joseph Nill



Dad had Lyme Disease, and was treated with 3 weeks of antibiotics. *But that didn't fix the problem.*

For 14 years he insisted he still had Lyme, but his 2-tier lab tests for Lyme did not meet CDC criteria for Lyme.

He took medication for his cardiac arrhythmia

-but that didn't fix the problem

He had an ablation for his cardiac arrhythmia

-but that didn't fix the problem

He had open heart surgery, and a pacemaker installed

-but that didn't fix the problem

He finally had a defibrillator installed

-but that didn't fix the problem.

None of these painful and invasive surgeries could do what he really needed done—get rid of the spirochetes in his heart. He died with them still there.



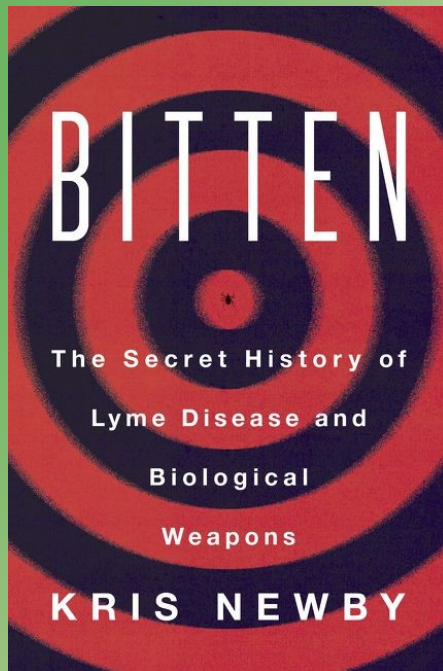
There is no argument that *Borrelia* persist in heart tissue after antibiotic treatment in: monkeys, dogs, guinea pigs, mice and rabbits. If that doesn't prove that they also persist in people—why are we still experimenting on and killing animals for “research studies”?

#borreliapersist



***April Nill-Boitano, MSED + swd
Co-founder and President of
Tick Wise Education***

My journey with Lyme disease likely began in childhood. But the first tick bite I remember clearly was in 1994. I was extremely ill and remember thinking “this is how I die”. Somehow, I survived my “allergic reaction to a spider bite” (I didn’t know what a tick was). After repeated sinus and bronchial infections over the next few months I settled in to a new “normal” aka “I feel bad every day but do my best to ignore it and not complain.” Over the years I underwent many lifestyle changes that either helped or hindered my health; but none were as profound as my first pregnancy. My immune system had found a way to keep the lid on Pandora’s box, but the natural immune suppression that occurs during pregnancy ripped it open. My obstetrician told me “You have sepsis, which is very serious - you could die. You can’t take the medicine you need because it could hurt the baby. You and your husband can make another baby -but we can’t make another you”. I started laughing. I replied “For at least a decade now I have been telling doctors ‘I feel like I’m sick and I’m dying’ and now here you are telling me ‘I’m sick and I’m dying’ and I only feel a little bit sicker than I normally do.” “If I’m going to die, then my baby and I will die together.” I survived two pregnancies with an ongoing persistent borreliosis infection. Both of my children were born with CVID “common variable immunodeficiency” and suffered severe adverse vaccine reactions in toddlerhood. Undiagnosed, undertreated Lyme is an epidemic of behemoth proportions. I truly believe we only see the tip of this dirty iceberg commonly known as “Lyme”; but in reality, many immune dysregulations, autoimmune diseases, learning disabilities, mental illnesses and cancers arise from untreated pathogenic infections. And many can be cured - with the right treatment. Please support my mission to design a study to evaluate the correlation between tick borne illnesses and learning disabilities in the children of Suffolk County. If we can find the cause - then we can find the cure!



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Kris Newby, MSME Author/ Senior Producer

KRIS NEWBY is an award-winning science writer at Stanford University and the senior producer of the Lyme disease documentary *Under Our Skin*, which premiered at the Tribeca Film Festival and was a 2010 Oscar semifinalist. Newby has two degrees in engineering, a bachelor's degree from the University of Utah and a master's degree from Stanford University. Previously, Newby was a technology writer for Apple and other Silicon Valley companies. She lives in Palo Alto.

BITTEN: The Secret History of Lyme Disease and Biological Weapons

While vacationing on Martha's Vineyard, Kris Newby was bitten by an unseen tick. That one bite changed her life forever, pulling her into the abyss of a devastating illness that took ten doctors to diagnose and years to recover from: Newby had joined the ranks of the 400,000 Americans who are afflicted with Lyme disease each year.

As a science writer, she was driven to understand why this disease is so misunderstood and its patients so mistreated. This quest led her to Willy Burgdorfer, the Lyme microbe's discoverer, who revealed that he had developed bug-borne bioweapons during the Cold War and believed that the Lyme epidemic was started by a military experiment gone wrong.

In a superb, meticulous work of narrative journalism, *Bitten* takes readers on a journey to investigate these claims, from tours of biological weapons facilities to interviews with biosecurity experts and microbiologists doing cutting-edge research, all the while uncovering darker truths about Burgdorfer. It also leads her to uncomfortable questions about why Lyme can be so difficult to both diagnose and treat, and why the government is so reluctant to classify chronic Lyme as a disease.

A gripping, infectious page-turner, *Bitten* will shed a terrifying new light on an epidemic that is exacting an incalculable toll on us, upending much of what we believe we know about it.



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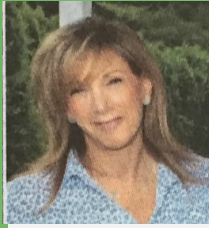
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Jane Held, event committee

When you enter the world of Lyme disease the one striking thing you might notice is that It seems like every Lyme patient has a different story. Tick-borne illnesses often present with a strange variety of symptoms. Often a patient never sees the telltale bulls eye rash. It is no wonder that there is such difficulty in finding proper diagnosis and effective treatment for this illness. And so this is where "my story" begins. For years I felt unexplained dizziness, fatigue, muscle aches and thinking it might be a Lyme infection I was tested annually. My tests always came back negative. Finally in 2012 I was fortunate enough to be treated by my new doctor who was recovering from Lyme. As I sat in his office complaining about my brain fog and fatigue he noticed my face twitching. The doctor looked at me and said that is classic of a Lyme infection. He insisted my blood should be sent to a lab in California known for its accuracy in detecting Lyme. The test results arrived and I was diagnosed with neurologic Lyme. I was treated with seven weeks of IV antibiotics which is considered outside the protocol set forth by the CDC for the treatment of Lyme (and boy if that isn't a whole other story to be told!) For a while post-antibiotic treatment I felt better; but as is typical with chronic Lyme the symptoms would subside only to return and flare again and again over time. Like so many others with a late diagnosis of Lyme, I am considered to be part of the group we now call "chronic Lyme" or "persistent Lyme" patients. I've watched the dialogue change over the last seven years since my initial diagnosis. Doctors finally recognize chronic Lyme as real. The road to progress with this illness is slow, long and winding. Being part of creating this educational symposium is an opportunity to bring those who are suffering with symptoms, the general public and the medical community in to a fresh discussion on newer available treatments and better diagnostic testing. It is essential that we need to keep our minds open in understanding tick-borne illnesses as we are facing a very serious global health epidemic. We hope that members of our community attending the symposium will leave feeling more informed about the need for change in the diagnosis and treatment of tick-borne illnesses. It's been an honor to work with my fellow committee members who are dedicated to creating that change.

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Jennifer Petrocelli, event committee

After countless efforts with a myriad of “specialists,” Jennifer Petrocelli continues to battle chronic Lyme disease and the number of coinfections that come along with it. She was diagnosed with this sometimes debilitating illness by Dr. Daniel Cameron in the summer of 2017 as she was planning the opening of The Preston House & Hotel in downtown Riverhead. Since opening the restaurant and hotel, she has traveled to Arizona and Germany to seek proper treatment to try and conquer this persistent illness. Over the past year and a half, she has made drastic headway by receiving IV treatment, ozone therapy, and multiple supplemental and herbal protocols all for extended periods of time. While many symptoms remain persistent, Jennifer is in a much better place in managing the disease by being in the hands of functional and integrative doctors. “There is so much controversy around this complex disease and countless doctors worldwide that still do not understand it.” Jennifer’s struggle with chronic Lyme disease has taught her things that many mainstream medical doctors do not know. She now uses that knowledge to try to help others understand the extremely frustrating and complex illness. With tick season upon us, it is an opportune time to take a look at this dreaded illness known as Lyme Disease.

Jennifer is dedicated to raising awareness by teaming up with April Nill-Boitano, Jane Held and LJ Eggert who live on the East End of Long Island.



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***Lisa-Jae Eggert, event
committee Founder of 3
Moms Organics***

Lisa-Jae (L-J) Eggert became a tick-borne disease advocate after she and her family were severely affected by neurological Lyme disease. She studied science at Stony Brook and has worked for SoFo and the Bronx Zoo in a multi-year turtle study as well as for the East Hampton Town Natural Resources Department. All this outdoor work exposed her to numerous tick bites. LJ is now devoting her time and talents to helping educate people about tick-borne diseases and how to prevent them. As co-owner of 3 Moms Organics (maker of TickWise, an all-natural DEET-free tick and insect repellent), LJ is now also an active volunteer for the Evelyn Alexander Wildlife Rescue and Rehabilitation Center, she lives in East Hampton with her two teenage children and their two dogs.



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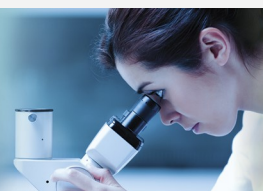
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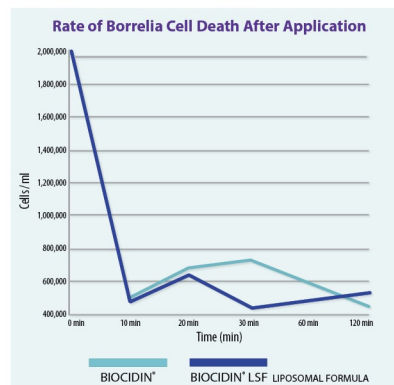
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Gilbert, L. (2016). Preliminary Report on Activity of Biocidin against Borrelia Species (Rep.). University of Jyväskylä, Biological and Environmental Science Dept.

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**Tick Borne Disease Educational Symposium
Saturday, May 18th, 2019, 9:00am-5:00pm
Sea Star Ballroom of the Long Island Aquarium
431 East Main St, Riverhead, NY 11901**



Vendor Appreciation

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Thank You. . .

A huge "Thank You" to Brian Kelly, our Event Naming Sponsor and Tick Wise Education Vice President, for being an all-around exemplary, kind and caring human being. To our Event Committee: Jane Held, Jennifer Petrocelli & LJ Eggert, I am honored to have worked beside such inspiring, intelligent, and compassionate women on this project & in our support groups – we will inspire brains ;) To The Tick Wise Education Board of Directors, Rebecca Levine - CFO, Angela Franciosa, Diane Renna, Frances Nill, & Kimberly Judd-Burns, without all of you and your commitment to this nonprofit, none of this would exist. To our Volunteers: Advocate Linda Osborn, Pamela Mahar, Producer Sean Murphy, Photographer Caroline Ann Torge, Videographers Shala Franciosa & Cal Franciosa, thank you for your gift of time and talent. To our Distinguished speakers: Dr. Robert Bransfield, Dr. Rosalie Greenberg, Dr. Joe Burrascano, Dr. Daniel Cameron, Jenna Luché-Thayer, Kris Newby, Dr. Suzanne Kirby, Dr. Christopher Hussar, Dr. Howard Robbins, Dr. Roxanne Carfora and Beth Carrison, thank you for sharing the gift of your knowledge with all of us. To the local and national businesses that donated items for the event, including The Long Island Aquarium, 3Moms Organics, Author Diane Renna, Bio Botanical Research and Lyme Warrior, thank you for your generosity. Special thanks to all of our supporters, especially to Dr. Jyotsna Shah and IGeneX Laboratories for sponsoring this event program. A huge debt of gratitude goes to Joe P., the Hyatt, the Sea Star Ballroom and the Long Island Aquarium, without whom this day would not have been possible, thank you for having faith that we could pull this off.

A personal note of thanks: To Eva Haughie, President of the Empire State Lyme Disease Association for your wisdom, and to Jennifer Heath, author of *Overcoming Lyme Disease* for coaching me to trust in my abilities and be strong in spite of my sickness. To Dr. Cameron, Dr. Weiss, Dr. Persaud, Dr. Moss, Dr. Hussar, Dr. Wells, STANDwellness and Ampcoil for helping me on my path to overcoming Lyme Disease, to SOFO and the Preston House and Hotel for hosting my support groups. To my husband Tony Boitano for loving me "for richer or poorer, in sickness and in health", to my Mom Fran Nill for always being my editor-in-chief and biggest cheerleader, to my Dad, Joe Nill for inspiring me to have a fierce sense of justice and to "never give up", and my amazing children for giving me a reason to be who I have become. To Andy Abrahams Wilson for the film "Under our Skin" that showed me the truth about Lyme Disease, to Dr. Alan MacDonald who examined my family's blood pro-bono giving us the accurate laboratory answers we desperately sought. And finally to Jenna Luché-Thayer and my global advocacy friends who are fighting beside me to remediate this quagmire called Lyme Disease. Last but not least, thank you God for repeatedly delivering me from death's door, my work here is not yet finished.

With Sincere Gratitude, April Nill-Boitano, MEd + swd
(Emcee/Moderator), President Tick Wise Education

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The effects of a tick-borne illness could be long term and costly. Getting a reliable diagnosis early on is essential!