May 2, 2012: Georgia State Capitol

Governor Nathan Deal

Issues a Statewide Proclamation Declaring May

*Lyme & Tick-Borne Disease Awareness Month*

*Top left:* Speakers for GALDA’s 2012 Lyme & Tick-Borne Disease Awareness Month Program

*Top Right:* Director Of Constituent Services Mr. Dan Regenstein presented the proclamation on behalf of Governor Deal

*Middle:* GALDA President Liz Schmitz is presented the proclamation which deemed May, Lyme & Tick-Borne Disease Awareness Month
During GALDA’s 2012 Lyme & Tick-Borne Disease Program, The Tick Doctor Kerry Clark, MPH, Ph.D. presented an overview of what is known about Lyme borrelia in the Southeast. He shared some of his remarkable research findings. Although current dogma suggests only one species of Lyme borrelia causes Lyme disease in the United States (and tests are only geared to detect this one species), Dr. Clark has discovered evidence of other Lyme borrelia species infecting humans here and in other regions of the country.

Dr. Clark contracted Lyme disease in Georgia while on a tick collection field study a few years ago, despite claims that the disease doesn’t exist in our state. For the past three years, Dr. Clark has graciously worked with Georgia Lyme Disease Association in an ongoing investigation to collect and study ticks from several Georgia neighborhoods where citizens report they’ve become ill following tick bites.

Dr. Clark is a tick-borne disease scientist and Associate Professor at the University of North Florida where he teaches courses in epidemiology and environmental health. He holds a Masters in Public Health Epidemiology and a Ph.D. in Environmental Health Sciences with an emphasis on arthropod vectors and vector-borne disease ecology. Dr. Clark’s investigations include Lyme borrelia and other tick-borne pathogens and their hosts and vectors with an emphasis on the Southeastern United States.
Dr. Kerry Clark speaks to the audience about Lyme disease in the South.
GALDA President Liz Schmitz welcomed the audience and thanked Governor Deal for proclaiming it “Lyme & Tick-Borne Disease Awareness Month.”

Liz said the Georgia Lyme Disease Association website opened 3 years ago and, in that time, hundreds of Georgians have reported that they have contracted Lyme disease (LD) in our state. Several have caught LD more than once over the years and many citizens report multiple infected family members. This doesn’t happen if a disease is “rare” in a region. For decades, Lyme disease in humans has been dismissed and ignored in the Southeast.

It’s critical to treat Lyme disease patients in early stage disease, Liz explained. Lack of recognition turns a treatable infection into a chronic disease - one that often results in permanent damage before true diagnosis is made (if it’s ever made). Medical providers may assume that Lyme disease is rare here partially because cases aren’t reflected in statistics. What they may not understand is that different reporting practices prevent most cases from being counted: what qualifies as a reportable case in the Northeastern United States is routinely dismissed in the South. True prevalence in our region remains unknown. Assuming the disease is rare puts patients in danger.

Scientists show that the Southeastern U.S. has more Lyme borrelia species (7) and strains (hundreds) than any other region of the nation. Yet many medical providers tell patients “Lyme disease is not in Georgia” and refuse to consider it. Some patients are denied even a test, while others with tick bites, rashes, symptoms and positive tests are told their results are “false”. Unbelievably, patients often report they are denied treatment.

Liz concluded that because ticks in the Southeastern USA can carry one or more of over a dozen disease-causing organisms, we urge medical providers and citizens to become better educated. Any illness following a tick bite should be taken very seriously. Southerners are so frequently bitten by ticks; all patients with unexplained chronic illness should be evaluated for tick-borne infections.
For four years, Karen Huppertz’s daughter Rachel suffered with odd, unexplainable symptoms including vertigo, headaches, nausea, swollen knees and right upper quadrant abdominal pain. Fifteen different medical specialists tried to help. They ran multiple tests, MRIs, lumbar punctures, etc. Nobody ever mentioned the possibility of Lyme disease.

The pain and symptoms intensified over the years and Karen’s daughter developed numbness in her hands and feet. When she could no longer walk to classes, Karen’s daughter had to leave college.

Doctors suspected the beginnings of multiple sclerosis but test results were negative. As Karen read about MS, she learned that Lyme disease often mimics the disorder. A neurologist ran a Lyme disease test which indicated Karen’s daughter had been exposed to Lyme borrelia. Unable to locate tick-borne disease knowledgeable medical providers in Georgia, the family travels to a specialist in the Northeastern United States to seek treatment for Rachel.

Karen was baffled. She said medical specialists had genuinely tried to help her daughter but they had prescribed 35 medications, some very strong, for her daughter to “try”. She couldn’t understand why nobody tried antibiotic treatment or tested for tick-borne illnesses. Her daughter faces a long road to recovery due to lack of recognition of tick-borne diseases in the South. Karen is now determined to raise awareness about Lyme disease.
Atlanta businessman G.E. had logical reason to suspect that his sudden, summertime flu-like symptoms might be due to Lyme disease. He lives by a wooded, natural area filled with deer where he frequently walks his dogs.

G.E. was treated with a minimal dose of antibiotics but became very ill again as soon as the prescription ran out. He visited an urgent care center and was told, “You’re fine.” The problem was...he wasn’t fine. His symptoms were all compatible with Lyme disease.

He tried visiting other doctors but no one would prescribe treatment. He couldn’t understand why doctors wouldn’t allow him to try Doxycycline - an antibiotic so safe, it’s often used long term to treat teenagers with acne.

G.E. became increasingly ill with fatigue, joint pain, tremors and cognitive issues. As a business owner, he was used to public speaking. He now experienced such brain fog; he struggled to find the right words. He was so debilitated, he had difficulty even making it out of bed some days. He began to wonder if he might have to sell his company.

When an open-minded physician finally agreed to test him, a western blot indicated G.E. had Lyme disease. He was properly treated at last and today is doing quite well. He is very appreciative that his new doctor listened. We appreciate G.E. sharing his story, especially the happy ending.
In 2009, Holly Bryman began experiencing pain, swelling and joint stiffness in her hands and feet. She was diagnosed with the beginnings of rheumatoid arthritis. She questioned this diagnosis because it didn’t fit her family history. She inquired about gout or Lyme disease but said that no doctor was willing to even discuss Lyme borreliosis as a possibility. By 2010, every joint felt under attack and Holly could not walk or sit or lie down without a great deal of pain. Holly contacted Georgia Lyme Disease Association and then decided to travel north to seek a knowledgeable physician. She started treatment that helped her begin to feel better and function normally again. We’re grateful to Holly for initiating a fundraiser for GALDA this year. Her company also designed GALDA’s new logo, pro bono, and Holly and her family made a donation of GALDA Lyme Disease brochures. Holly feels it’s very important to educate others.
Gary Sweeney’s daughter Lyndsay was diagnosed with Lyme disease over 4 years ago and still battles symptoms. When they first searched for the cause of their daughter’s illness, they went from doctor to doctor. Medical providers couldn’t pinpoint the problem through numerous expensive tests, so the family was told, “It’s all in her head.” Counseling was suggested.

Despite positive Lyme disease tests, Lyndsay’s symptoms were dismissed. She wasn’t diagnosed or treated until the family sought help outside of Georgia. Because Lyndsay lived in the South and had no travel history, the myth that Lyme disease is rare here had a devastating effect on her health and the Sweeney family.

In addition to the physical and emotional stresses, Gary described the huge financial burden placed on victims and their families. He explained that Lyme patients spend $16,199 annually on average. In just four years, the Sweeney family paid $60,000 in out-of-pocket medical costs, depleting their savings. Although they did not file bankruptcy, Gary described how medical costs are a major factor in a huge number of bankruptcy cases in this country. (See box on right.)

Gary urged families and friends to be supportive of Lyme patients and to be careful not to neglect their emotional needs because patients already feel isolated by the questions of validity surrounding their illness. He credited his courageous wife, Lorena, for being the biggest cheerleader for their daughter, helping to pull her and their family through the difficult days.

Thank you, Gary, for your presentation and your determination to bring attention to the troubling issues faced by Lyme patients and their families.
Medical providers couldn’t explain Sommer Robich’s mysterious symptoms which included brain fog with word-finding difficulties, severe fatigue, and more. As the young mother searched for a diagnosis, doctors told her she was “fine”. Routine tests revealed little. She described feeling bullied into taking antidepressants. Because of her neurological symptoms, a doctor mentioned the possibility of “pre-Multiple Sclerosis” and was ready to prescribe expensive drugs for M.S.

Sommer said that despite her having 90% of Lyme disease symptoms and her begging them for a test, medical providers kept telling her, “There is no Lyme disease in Georgia.” In September 2011, the West Georgia mom awoke to find she’d lost partial vision in one eye. At last, a doctor agreed to test her for Lyme disease. The results were specific enough to suggest that Sommer had been exposed to Lyme disease bacteria, *Borrelia burgdorferi*. (Editor’s note: With over 7 Lyme species and hundreds of strains in the Southeast, the western blot criteria, which are geared to detect one species, need to be adjusted to detect regional Borrelia strains. Studies in other countries show this makes the tests far more sensitive.)

Sommer has just begun treatment and still suffers with constant vision problems. Like so many others, she sought help out of state. Thank you Sommer for helping to create awareness about tick-borne diseases and their prevention in our state!
Lyndsay Sweeney called for news media and political representatives to acknowledge and address the problems Lyme and tick-borne disease patients face. Due to lack of recognition of the disease in our region, diagnosis is often delayed, resulting in permanent damage and chronic Lyme. Patients have difficulty finding medical care in our state and pay high costs for both treatment and travel. Many can no longer work and file disability – another cost to society.

For the 2nd year, Lyndsay produced a *Georgia Faces of Lyme Disease* slide show and presented it at the conclusion of our program. Lyme patients from across Georgia sent in their photographs, the location in GA where they were infected and how long they have had the disease (many have had it for years). Many patients who were unable to attend showed their support by adding their pictures to the slide show – it’s testimony proving that medical providers and citizens need to be vigilant about Lyme disease and other tick-borne illnesses across our state.

Lyndsay Sweeney was recognized with GALDA’s *Outstanding Volunteer Award*. Lyndsay has assisted Georgia Lyme Disease Association for 3 1/2 years, even while battling her own health issues. Thank you, Lyndsay, for your hard work and dedication to helping others!
Top: Georgia Lyme Disease Association’s 2012 Honorary Award of Appreciation went to Dr. Nataliia Rudenko in recognition of her many outstanding scientific contributions in the study of tick-borne disease pathogens (especially in the Southeastern United States). Dr. Clark, the recipient of our 2011 award, accepted the 2012 award on behalf of Dr. Rudenko who was unable to attend.

Support Lyme

Disease Research

Below: Georgia Lyme Disease Association again recognized Dr. Kerry Clark with an award to support and thank him for his important research investigations.
There are over a dozen disease-causing agents ticks in the Southeastern United States can carry including Borrelia burgdorferi (Lyme disease); Borrelia miyamotoi and Borrelia turicatae (Relapsing fever); Rickettsia rickettsii (Rocky Mountain Spotted fever); Rickettsia parkeri; Rickettsia amblyommii; Ehrlichia chaffeensis, Ehrlichia ewingii; Bartonella (several species); Babesia microti; Babesia duncanii, Anaplasma phagocytophilum; Coxiella burnetii (Q fever); and Francisella tularensis (Tularemia or "Rabbit Fever"). Many are newly identified and researchers expect to discover more.
2012 Lyme & Tick-borne Disease Awareness Month Program

Our sincere thanks go to Governor Nathan Deal, Mr. Dan Regenstein, Mr. Ben Smith, Governor Deal’s staff, Representative Matt Ramsey, Ms. Lucia Hames, Ms. Nancy Negris, the Georgia Building Authority, Dr. Kerry Clark, Gary & Lorena Sweeney, Holly Bryman, Karen & Rachel Huppertz, G.E., Sommer Robich, Lyndsay Sweeney, Marilyn Sherlock, Natalie Craig, Ashley Ivester, the Jahn Family, Leanne Carter, Chris & Jessica Mills, Elizabeth Williams & family, Jackie & Norman Morgan, Wanda Cooley, April Dyer, Kris Schmitz, ImageFlow Services, LymeDisease.org, Dr. Jim Oliver, Dr. Natasha Rudenko, Dr. Marcia Herman-Giddens, Dr. Robert Carter, Dr. David Volkman, and Phyllis Mervine. We thank our generous donors for their contributions: Sarah & Mike Etheridge, Ashley Ivester, Julie Holsenbeck, Orlow & Knoxie Walstad, James & Beth Stormont, Patricia Groves, David & Mary Jo Lumsden, Mr. & Mrs. Ronald Seay, Nancy Jacobsen, Deanna Jones, Holly Bryman, Imageflow Services, Valli Caldwell, Critter Control of Atlanta, James Ruwoldt, Eric Jennings, Bikram Yoga Decatur, and all of our I-Give supporters who help us daily through online shopping. Our special thanks go to our families and friends for their support and to those special medical providers who read all the published Lyme disease science and do the right thing in trying to help suffering Lyme borreliosis patients everywhere.

Help stop the spread of Lyme disease. Find a cure for chronic infection.

Above: The skylights in the Georgia Capitol made us really look like we were standing in the Lyme light. We all volunteer because it’s a place where nobody should have to be.

Awareness  Prevention  Education  Research