May 5, 2011
Georgia Governor
Nathan Deal
Issues Statewide Proclamation
Declaring May
“Lyme & Tick-borne Disease Awareness Month”

Above right: State Senator Ronnie Chance presented the Proclamation to Georgia Lyme Disease President Liz Schmitz during the Lyme Disease Awareness Program at the Georgia State Capitol in Atlanta, Thursday, May 5, 2011. Below: GALDA volunteers, patients & guest speaker Dr. Kerry Clark pose with the Governor’s proclamation in the Capitol’s North Wing.
Georgia Senator Ronnie Chance welcomed attendees to the Georgia State Capitol and the 2011 Lyme and Tick-Borne Disease Awareness Month Program. He spoke about the seriousness of Lyme disease and shared a story about a friend who suffered with the illness. He stressed the importance of our mission: to create awareness about these diseases and to educate Georgians about them.

Senator Chance read and presented the 2011 Georgia State Proclamation signed by Governor Nathan Deal which designated the month of May, “Lyme and Tick-Borne Disease Awareness Month” across the state of Georgia. We are grateful to Governor Deal and Representative Ramsey, and to Senator Chance for stepping in for Representative Ramsey (who was unable to attend due to a family emergency).
Georgia Lyme Disease Association (GALDA) President Liz Schmitz: *What happens when there’s a missing link between science and medicine?*

Liz described contracting Lyme disease in Georgia twenty years ago. She was misdiagnosed with “probable Multiple Sclerosis”. “It’s understandable that Lyme disease wasn’t recognized here back then,” she said. It’s inexcusable that it isn’t now. She acknowledged the hundreds of suffering Georgians who report to GALDA that they have chronic Lyme disease symptoms and/or permanent damage and disabilities all because Lyme disease often *still* goes unrecognized, misdiagnosed and untreated in patients during the early stages, when treatment is far more successful.

Although there are over a dozen diseases ticks may carry in the Southeast, Liz said that many patients can’t find area medical providers knowledgeable about them. Many very ill Lyme patients report they are dismissed, refused tests, or told their test results are “false positives”, even though false positives are rare. (Anecdotal tales and positive tests should never be simply dismissed in a region where Lyme bacteria have been so abundantly documented in nature.) Sometimes, patients are even denied treatment for these serious infections. Additionally, some doctors don’t understand the tests, relying upon them in early stages before detectible antibodies form. Others are unaware of the conflicting medical/scientific evidence and the two very different guidelines available for treating Lyme disease (IDSA and ILADS).

Liz said there’s obviously a missing link between science and medicine in the South and encouraged public health officials to help bridge this gap. Why are medical providers unaware of the twenty years of published research documenting the presence of *Borrelia burgdorferi* in thousands of ticks and animals from across the Southeast? In 1989, Georgia was 4*th* highest in the nation with 715 CDC-reported human cases & 161 cases were reported in 1990. The CDC identified 27 Georgia counties with native LD cases. Yet twenty years later, Georgia patients still report that many medical providers do not recognize Lyme disease, or think it’s rare. Citing different reporting practices used by most southeastern states, Liz pointed to the misleading national Lyme statistics as one reason people claim the disease is rare here. When cases are counted differently and tests don’t detect all regional strains/species, true LD prevalence remains unknown. Public health officials must constantly alert medical providers to watch for Lyme borreliosis and other tick-borne infections in humans.

More strains of Lyme bacteria have been identified in the South than the North and two new species have been found here. Researchers at Medical College of Georgia expressed the need for region-specific tests *over a decade ago*; Liz wondered why we’re *still* waiting for these. Suffering patients may be denied treatment because the old tests still used today are based upon a New York Bb strain and may not detect all southern cases. Immediate funding of research to develop new region-specific tests should be top priority.

This issue should no longer be placed on the back burner. Twenty years is too long to wait; too many people are suffering. Bridging the gap *right now* is critical. Even if we don’t yet know everything about these pathogens, actively educating citizens and healthcare providers to become aware of Lyme and tick-borne diseases in the South may prevent immeasurable human suffering.
Special guest speaker

Dr. Kerry Clark,

Lyme and Tick-borne Disease researcher and Associate Professor of Epidemiology and Environmental Health at the University of North Florida. Dr. Clark presented:

*Lyme Disease in the South: What We Know and What We Need to Know.*
Dr. Kerry Clark, a.k.a. “The Tick Doctor”, traveled to Atlanta to share some of his research findings at GALDA’s Lyme Disease Awareness program. By examining some of the myths about Lyme disease in the South, Dr. Clark discussed much of the evidence documenting the presence of *Borrelia burgdorferi* here for many years. Dr. Clark, who has presented at both the International Lyme and Associated Diseases Society (ILADS) and the Columbia University/Lyme Disease Association conferences, reported from a unique perspective - he became ill himself following a tick bite he got last year in Georgia during a tick-collecting expedition. (Ironically, our presenter last year also contracted Lyme disease in Georgia, not once, but twice!) We’re grateful for Dr. Clark’s ongoing research and his commitment to protecting public health.
A Brother and Sister Contract Lyme in Georgia

Courageous Georgia Lyme volunteer Chelsea Ashworth shared her family’s horrible ordeal when both she and her brother, at ages 8 and 10, were infected in their back yard north of Atlanta with unrecognized, misdiagnosed Lyme disease. Both may have been treated effectively if the disease was detected and treated early.

Her brother has suffered with seizures, and Chelsea developed Gastro paresis (paralyzed stomach). She had to receive nourishment through a feeding tube. Neither child could attend school or participate in recreational activities. The family was financially devastated - with very sick children, they had to travel far north to seek help, because Lyme disease is not recognized and/or is so poorly understood by many medical providers in the Southeast.

Positive, bright and hopeful, Chelsea now works to bring change and help to others.
We Don’t Treat That Here

Natalie Craig, who grew up in Georgia, has had many tick bites. She described her painful bout with Lyme disease and recalled the day the doctor told her she tested positive. With his back turned toward her, she wondered what was wrong when he remarkably told her, “We don’t treat that here.” She was promptly referred to a rheumatologist, not even an infectious disease specialist.

After initial treatment, Natalie still suffered with extreme fatigue, twitches, swollen joints, and cognitive issues. She couldn’t use her hands, could hardly walk and had trouble completing thoughts and sentences.

Natalie didn’t understand why many medical providers turned away instead of helping her. She had to travel 675 miles one-way to find the treatment that helped her function again.

Now that Natalie is feeling better, she admirably devotes much of her time educating others about Lyme disease and other tick-borne illnesses.
A New Georgia Patient

Last year, when West Cobb County realtor Terri Schrews described her symptoms, she was asked by a medical provider if she had been bitten by a tick. Not being an outdoorsy person, she remembers laughing about this with her husband. But her test results proved positive.

When Terri continued to suffer following a two week course of antibiotics, she was advised to make an appointment with an infectious disease specialist. By phone, without even examining her, someone at that practice unbelievably told her there is no cure for Lyme disease; they’d never seen a true case, and Terri’s test results were probably a “false positive.” (Editor’s note: This, despite the fact that false positive Lyme tests are very rare and the presence of Lyme bacteria has been documented in Georgia for over 20 years. Could it be that they never see true Lyme cases here because they dismiss patients by phone?)

Hardly able to make it out of bed for months, Terri had to walk away from her business and couldn’t care for her four children. Thinking of her multiple trips to the ER and appointments with a cardiologist, a neurologist, a rheumatologist, and an infectious disease specialist, she wonders why medical practitioners told her not to worry. They assured her, Lyme disease is “no big deal” and said it’s no worse than the common cold.

Terri, too, had to leave Georgia to find effective therapy. She refused to accept that nothing could be done and feels much better now after longer antibiotic treatment. She can’t understand why healthcare professionals aren’t being educated about tick-borne diseases, leaving people to suffer. She kindly agreed to share her story to help others and raise awareness.
The Impact on Families

Jackie Morgan of Powder Springs described the tremendous concerns families and caregivers face when a loved one suffers with ongoing Lyme disease and/or co-infections. She discussed the astounding costs to families and to society, and the emotional, physical and even psychological burdens placed upon family members of tick-borne disease patients.

Although Lyme disease may be curable if treated adequately in early stages, often times, because the disease isn’t recognized and is severely underreported, it isn’t diagnosed and treated in time. This can leave patients chronically ill and even disabled.

Previously a healthy husband & father, Jackie’s husband Norman was a tennis player, camper, and hiker. He can no longer work and now spends much of his time confined to a wheelchair. His illness has severely altered and impacted the entire family.

Jackie and Norman appeared on the Walter Reeves radio show and have distributed educational brochures at various events. Last year, they donated Tick-borne disease preventative/educational packets and tick removal kits to all the young campers at Mr. Steve Scruggs “Let’s Get Wild” camp. The Morgans and their daughters admirably continue to work educating others.
There was hardly a dry eye in the audience as Katherine described her family’s heart-wrenching ordeal. Determined to discover what was wrong with her children, Mr. and Mrs. Leslie left no stone unturned. When their daughter was finally diagnosed with PANDAS by a leading expert, Katherine learned that many children with this disorder also have Lyme disease. A specialist suspected, and tests confirmed, that the children were indeed infected with Lyme and other tick-borne pathogens.

After some treatment, we’re happy to report that, already, Isabella is beginning to do things she hasn’t been able to do for over a year. The family knows it may be a long road, but they’re thankful they finally have a diagnosis.

We appreciate Katherine Leslie and her family for speaking out. Their story will soon be featured on the Children’s Lyme Network. They don’t want this to happen to anyone else.
When former school teacher Laurie Rader and her family moved from Florida to a wooded lot in Fayette County, Georgia a few years ago, they weren’t aware of the number of citizens who report contracting Lyme disease in our state. Soon Laurie began suffering with mysterious symptoms and was diagnosed with the illness. She recalled a public health official’s ignorant comment at the time, “If she has Lyme disease, she’s the first case ever in Georgia.” (Editor’s note: In 1989, 715 CDC-reported LD cases were documented in GA. The CDC identified 27 Georgia counties with native cases.)

When Laurie discovered that her young son was also infected, suddenly the months of his unusual cognitive issues at school and home began to make sense. Her son could no longer attend regular school or do many things most kids his age enjoy. Laurie knows that kids with Lyme feel isolated, misunderstood, and sad – they just want to be like all of their friends. It’s hard, too, when school officials don’t understand how tick-borne diseases can affect children. The fatigue and cognitive problems can make it nearly impossible for these children to keep up with regular studies.

Months after she and her son were diagnosed, her husband was diagnosed with heart block. It was discovered, he was also infected with Lyme disease bacteria. And, incredibly, Laurie learned that two of the former occupants of her home also had to be treated for tick-borne illnesses.

Laurie and her family travel outside of Georgia for treatment. She described calling several medical offices before she finally gave up and decided to go North.

Laurie is interested in starting a support group for kids infected with Lyme disease and their families. She continues to try to create awareness about this life-altering illness.
Multiple Family Members with Lyme Disease

In 1999, Jennifer Toombs had never been to so-called “Lyme endemic states.” She and her family visited a wooded lot in Conyers, Georgia as they looked for a house. Little did she realize, this would result in five out of six of her family members contracting Lyme disease.

Over the years, Jennifer’s family has spent over a quarter of a million dollars and has made over 40 trips to the North to find medical providers knowledgeable about tick-borne infections. Responsible, hardworking people, she described the heartache and embarrassment she felt when, due to their medical expenses, her family had to declare bankruptcy.

Jennifer explained that she became so ill; her young son - her hero - took care of her and her young daughter, something a child should never be called upon to do. She spoke of how the disease robbed the family of so many things over the years.

When she contacted federal public health officials to share her family’s story, Jennifer couldn’t believe their response: You live in the South, you DON’T have Lyme disease. With her family’s many positive tests and their years of emotional, physical and financial suffering, it was impossible to understand why their cases weren’t investigated instead of dismissed.

Jennifer surmised that although it was a horrible experience, fighting Lyme disease made them stronger as a family. Their love and support for one another is tremendous. They want to stop this from happening to other families. They want Lyme and tick borne diseases recognized in the South.
GALDA volunteer Lyndsay Sweeney contracted Lyme disease during high school. Her infection was not recognized early when treatment would have been more effective. Despite symptoms, her positive tests were dismissed as “false positives”. She and her family had to seek costly treatment outside our state.

Lyndsay spoke during GALDA’s Awareness Program last year. She and her family members constantly educate others about Lyme disease. Lyndsay prepared a Georgia Faces of Lyme slide presentation which debuted at the Georgia Capitol this May. She was instrumental in publicizing this year’s Lyme Disease Awareness Program. Thanks, Lyndsay and Sweeney family!
Right: During the program, Georgia Lyme Disease Association presented an Honorary Award of Appreciation to Dr. Kerry Clark for his research of tick-borne pathogens in the southeastern United States and for his dedication to protecting public health.

Jackie Morgan surprised Georgia Lyme’s Liz Schmitz and presented her with a Certificate of Appreciation.

Georgians from all walks of life are affected by Lyme disease. They realize cases here are not recognized, counted, and reflected in statistics - almost everybody knows somebody else with Lyme disease. Many in the audience traveled from locations across the state to attend the program. Patients are concerned because they cannot find medical providers who are familiar with all of the conflicting scientific & medical literature. They need help now.
Following the program, Georgia Lyme and tick-borne disease patients mingled with political representatives and other families afflicted by these devastating conditions.

GALDA introduced our new Lyme Disease brochure.
We are Georgia citizens – volunteers - working to create awareness about the dangers of Lyme disease and other tick-borne illnesses in the South.
Lyndsay Sweeney, Natalie Craig, Elizabeth Williams & Marilyn Sherlock

More photos from the 2011 Lyme and Tick-Borne Disease Awareness Program
Thank you!

Georgia Lyme Disease Association sincerely thanks Governor Nathan Deal for acknowledging the serious need to raise awareness about tick-borne diseases in our state. We appreciate our Governor proclaiming May 2011, LYME & TICK-BORNE DISEASE AWARENESS MONTH to help protect the health of our citizens.

We’re grateful to all of our volunteers, speakers and to all who came out to show their support.

Special thanks to Representative Matt Ramsey and his staff, Senator Ronnie Chance and his staff, Senator Johnny Isakson, Congressman Paul Broun, Congressman Tom Price, Jordan Dawson, David LeBlang, Jordan Chinouth, Lucia Hames, Nancy Negris, and Rita Smith.

We also thank our GALDA volunteers who helped make the event at the Georgia Capitol possible: the Sweeney Family, the Morgan Family, the Ashworth Family, the Toombs family, the Hansford Family, the Leslie Family, the Schrews Family, the Rader Family, the Williams family, Marilyn Sherlock, Kris Schmitz (official photographer), Jill Daniel, Beth Stormont, Natalie Craig, Valli Caldwell, Rhonda and Jerry Stapleton, Wanda Cooley, Kathryn and Paul Harmsen and all of our terrific advisors including Dr. Kerry Clark, Dr. Marcia Herman-Giddens, Dr. David Volkman, Dr. Elizabeth Maloney, Phyllis Mervine, Lorraine Johnson, The Lyme Disease Association, California Lyme Disease Association, and to scientists and medical professionals everywhere who continue to seek the truth on behalf of sick Lyme and TBD patients.

A special thank you goes to volunteer Lyndsay Sweeney for her extraordinary efforts. Lyndsay not only spent days contacting the media and our political representatives about this event, she created the wonderful Georgia Faces of Lyme Disease slide presentation shown at the end of our program. We also thank her terrific, supportive parents, Gary and Lorena Sweeney, for their audio/video expertise and to Lyndsay’s entire family for their help in set up and tear down at the Capitol.

We appreciate the constant love and support of our friends and family members.

P.S. Dear Windy: We miss you and love you! Get well soon.
Lyme Disease:

Lack of recognition may turn a potentially curable illness into a chronic one.

Early diagnosis and treatment are the key.