



Georgia Lyme Disease Association

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Working to fight Lyme & tick-borne diseases

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Mr. Orlando Montoya
Georgia Public Broadcasting
260 14th Street NW
Atlanta, GA 30318
ask@gpb.org

Dear Mr. Montoya,

Thank you for your August 12th report, ***Ticked Off? Georgians Study Parasite***. Your story about the much-needed tick research in the South raises a number of concerns.

First, ticks should *never* be removed using fingers. Scientists have indicated that ticks should not be handled, to avoid possible infectious secretions. If an attached tick's body is crushed or pressed, it may cause the tick to inject bacteria into the patient, possibly resulting in infection even if the tick was not attached for long.

Secondly, I am concerned by the report's questionable assertion that ticks in our region rarely transmit Lyme disease. The Georgia Division of Public Health's Vector-Borne epidemiologist Laurel Garrison wrote in the February 2009 *Georgia Epidemiology Report*, "**There is a need for surveillance in ticks and wildlife in order to determine risk of human exposure to *B. burgdorferi* throughout the state**" because the threat has never been determined. Since risk to humans has not been assessed, despite the ample evidence gathered over the years documenting *B. burgdorferi* in thousands of tick and animal specimens from across the Southeast, and in countless humans, too, how can anyone logically make a broad statement that Lyme disease in humans is rare? Yet we see this assumption reported all the time, with no questions asked.

Here at the Georgia Lyme Disease Association, we can attest that Lyme disease does not appear to be, by any means, "rare" in Georgia. We talk to hundreds of patients across the Southeast who are suffering from Lyme disease, and the majority of them report that they contracted it in our region. Many report multiple infected family members. I personally know of three patients who have apparently contracted Lyme disease twice, and one who has developed it *three* times, right here in our state.

I was alarmed when I discovered 75 suspected Lyme disease cases within a 25-mile radius of my house a few years ago. I reported these to the Georgia State Division of Public Health, and then later, directly and in person to members of the CDC's Vector-Borne division. Surprisingly, officials did not appear shocked, and my report didn't seem to warrant any action. I was told by

both public health officials that they don't have funding to investigate these human cases. A Georgia State official explained we would not likely receive CDC funding to investigate our cases because we have "so few cases on the books." Curiously, you have to *have* cases to get *funding*, but *funding* to get *cases*. With this circular reasoning, how is a disease ever supposed to emerge?

If statistics are a factor in assuming human infection is rare, it may interest you and Dr. Beati to know that apparently most states across the Southeast haven't counted Lyme disease cases using the CDC's standardized surveillance definition.* In many northeastern states, LD case numbers soared over the years because once a county was deemed endemic by documenting two or more patients with positive tests, subsequent cases of erythema migrans (*rashes*) in those counties then counted as cases. In most southern states, this practice was not implemented. There are states with numerous counties that have two or more documented cases on record, yet subsequent rashes (EMs) in those counties were not counted. Statistics cannot be compared when the same definition for Lyme disease is not employed from one region to the next. Case numbers are inaccurate and invalid.

There are numerous other surveillance problems that significantly contribute to the severe underreporting of southeastern Lyme disease, including the fact that cases are often dismissed as a mild illness of unknown etiology called "STARI", without further investigation. True prevalence of human Lyme disease across the Southeast remains unknown. Surveillance problems should all be exposed and addressed, instead of exploiting flawed statistics as an accurate portrayal of incidence rates in the South.

Why is Lyme disease now considered rare here? The CDC documented native cases of human Lyme disease in 27 counties in Georgia, (and in Florida and Alabama) in the late 1980's (1). When state legislators allocated funding for testing at the Georgia State Health department in 1989, **715** Georgia Lyme disease cases were documented here in a *single year*, making Georgia the 4th highest in CDC-reported incidences (2). You may find the 1993 *Lyme Disease in the Southeast* scientific conference notes interesting (3), as well as our websites' *Lyme in the Southeast* page. How many cases could be identified, and patients helped, if our medical providers were educated about Lyme and were encouraged to investigate the possibility? In speaking with our citizens, it would appear there are *far* more cases than many may imagine.

Citizens complain that doctors tell them Lyme disease is not in the Southeast; some say their medical providers won't even order a test. A number of patients have reported they are denied treatment, even with positive tests (some fully "CDC-reportable" positive) and compatible histories including tick bite, rash, and symptoms. Often patients report they are told their test results are "false positives," although false positives are actually rare. Many describe being misdiagnosed with fibromyalgia, chronic fatigue syndrome, rheumatoid arthritis, STARI, lupus, ALS, multiple sclerosis, or other illnesses.

Timely treatment of Lyme disease is *crucial*. Many patients suffer greatly and some are permanently disabled because the disease was not recognized and treated early, when it could have been more readily cured. We know southeastern patients who have experienced blindness, strokes, seizures, major heart problems, meningitis, severe arthritis, and more, all due to delayed diagnosis and treatment. Some patients cannot walk or drive, many have lost their jobs. Children cannot attend school or play sports. Patients have even lost their homes due to medical bills. To obtain diagnosis and treatment, often our citizens must travel out of state. Can you imagine how hard it is to travel, when some of these patients can hardly even get out of bed?

Research funding is scarce. I am concerned that \$2 million dollars is being used to study a premise that hasn't been well established, i.e., "*Lyme isn't in patients in the South,*" rather than to investigate the southeastern patients who are actually suffering with the disease. It's also already well documented that many lizards can harbor the bacteria. In the lab, Dr. Michael Levin demonstrated some species of lizards' ability to contract and maintain Lyme disease spirochetes. Dr. Kerry Clark found 8 species of lizards in the wild, in the Southeast, harbored *Borrelia burgdorferi*. Dr. Clark's findings in wild lizards have since been duplicated by other scientists in additional studies across the globe.

Reporting that Lyme disease is "rare" is dangerous. In the interest of protecting the health of our citizens, I urge you and Dr. Beati to promptly retract and revise your statements. Lyme disease prevalence in humans across the Southeast is currently unknown, and citizens must never be advised to use their fingers to remove ticks.

Perhaps another, more extensive news story and a different study – not focusing on "*why Lyme isn't here*", but rather, "*why Lyme cases are going unrecognized in the Southeast*" - would help our people immensely.

Sincerely,

Liz Schmitz
Director
Georgia Lyme Disease Association

*With the 2008 change in the case definition, some states have begun using a *modified*, but still not exact, version of the CDC's reporting guidelines.

- (1) <http://www.doacs.state.fl.us/pi/enpp/ento/entcirc/ent326.pdf> (see paragraph 5)
- (2) <http://www.cdc.gov/mmwr/preview/mmwrhtml/00001640.htm>
- (3) <http://www.osti.gov/bridge/purl.cover.jsp?purl=/379002-z9yDKA/webviewable/>