

***Institute of Medicine Lyme Disease Teleconference
Listening session for Georgia, South Carolina, North Carolina
June 2, 2010
12:00 p.m. – 1:30 p.m.***

Speakers (in order):

- 1. Windy Blair, Georgia Lyme Disease Association***
- 2. Jackie Morgan, RN, Georgia Lyme Disease Association***
- 3. XXXXXXXX, Georgia patient***
- 4. XXXXXXXX, Virginia Beach, VA***
- 5. Sara Hesley, Kentucky Lyme Disease Awareness***
- 6. Liz Schmitz, Georgia Lyme Disease Association***
- 7. Angela Allen, South Carolina, Greenville Lyme Advocacy and Support***
- 8. Lisa Higgins, Southeastern Tennessee Lyme Support***
- 9. Dr. Kerry Clark, Associate Professor of Epidemiology and Environmental Health
and Director of the Master of Public Health Program, University of North Florida;
Lyme and Tick-borne Disease Researcher***

Windy Blair, MHE, OT/L, Georgia Lyme Disease Association

Lone Star Ticks and STARI

I'm Windy Blair from Georgia.

Lone stars are very aggressive, and are the most commonly found ticks feeding on humans in the South. People here are bitten by them constantly. We strongly suspect that the Lone star tick is a vector of Lyme disease in humans.

Lyme bacteria have been documented in lone star ticks for years. In some areas of the south, scientists have found BB in 17 to 24% of these ticks. But when public health officials assess risk to humans, they seem to only consider the deer tick.

We hear from far too many patients who develop EM's and symptoms, and test positive for Lyme, following Lone star tick bites. Many of these cases are dismissed as "false positives", but we wonder how a test can be so *good* up north, but so *bad* down south? False positives are actually pretty rare. And "*positive predictive value*" cannot be used to dismiss our positives, when we don't have a sensitive test, and can't determine true prevalence.

Research proved Lone star ticks can't transmit Lyme to some *mice*. However, that doesn't mean they can't transmit to *humans*. Some *lizards* can't be infected, either, but eight lizard species here in the South can actually *harbor* Lyme Borrelia. We can't conclude anything yet.

We've heard that Lone star tick saliva kills Borrelia, if true, why did we waste tax dollars looking for *Borrelia lonestari*? And why have *Borrelia* been seen under the microscope in rashes following lone star tick bites?

Lone star ticks may be transmitting other pathogens, but the hallmark of STARI is that patients *DON'T* test positive for Lyme. We hear from patients who *DO* test positive. A medical College of GA study found that 30% of southern patients with EM's *did* have Lyme.

It's reported that STARI is a mild illness. What we are witnessing in the South, is NOT mild. *Where* are the long term human studies documenting this assumption?

The introduction of STARI seemed to stifle any investigation into human Lyme cases in the South. CDC reporting guidelines were never implemented here, partially due to cases being dismissed as STARI. There is no test for STARI, and not even a known agent. But our Lyme cases are still chalked up to STARI.

Recently some doctors and public health officials stated that "STARI probably doesn't even require treatment". Lyme disease and STARI rashes are indistinguishable. Not treating early can leave hundreds of Lyme patients permanently damaged with ongoing illness. Until we know more, treating EMs is the only responsible thing to advise.

Independent large-scale human studies in the Southeast should be *immediately* funded by the NIH and CDC. And these should be done by *new* scientists – seeing the same researchers appears to be a little biased.

The scientific evidence is still emerging. It's the responsibility of every medical professional and public health official *not* to make assumptions, but to consider *all* the evidence, including that in the South. Our citizens are suffering. We need answers *NOW*. *Thank you*.

Jackie Morgan, RN , Georgia Lyme Disease Association

My name is Jackie Morgan. I'm a registered Nurse and a volunteer for the Georgia Lyme Association.

As a medical professional, I want to address my concerns about how the Lyme controversy appears to be affecting the general perception of us in the medical field.

In the South, Lyme disease doesn't appear to be a differential diagnosis despite the large body of published evidence that should make us look for it in humans. Scientists like Jim Oliver, Lance Durden, Kerry Clark and others have documented the presence of the Lyme bacteria in ticks and nature here for years.

Highly educated, credible people are coming forth with Lyme disease here. These logical people share their disbelief about the denial and lack of response they feel from the medical community. They're often astonished that many clinicians are unaware of the regional scientific evidence. Patients don't understand why their human cases are so quickly dismissed.

Patients report there are many assumptions they hear from health care providers, like, "We don't have the white footed mouse here" –we do, *and* the cotton mouse, which also harbors the bacteria. "We don't have that kind of tick here" - Joe Piesman of the CDC documented the deer tick across the Southeast years ago.

Rashes following tick bites are often misdiagnosed as "Fungus" or "ringworm" and are improperly treated. Patients are sometimes told their positive Lyme tests are false, many with compatible history.

Modern day patients are far more educated due to the accessibility of worldwide, peer-reviewed, published research articles online. At the touch of a button, they can read all of the scientific data.

When patients read the conflicting evidence for themselves, they wonder why *we* aren't familiar with much of it, and why it sometimes directly contradicts what they've been told in the doctor's office. This doesn't help promote an image of knowledgeable and informed professionals.

When very sick patients seek help and are dismissed, scoffed at, or looked at as if they are crazy, it shakes their faith in the medical community at large.

I was recently frustrated reading comments across the internet by Lyme patients, their family members, and friends who feel they've been ignored by the medical community. It's easy to see

that they're very angry. Some even report they feel they've been lied to by the medical community. At the very least, I fear it looks like we're not keeping up with the science.

I worry about the erosion of the doctor-patient relationship and the reputation of the medical community as a whole. I find it so sad to hear Lyme patients say, "whatever you do, don't go to an Infectious Disease doctor."

Citizens are turning to alternative health and away from allopathic medicine in this country. I think we're missing the mark when we don't take these issues seriously, don't acknowledge *all* of the science, and don't open our minds to the possibilities. Lyme is here and we need to study humans in the South.

Lyme disease has been found across the globe and in many cases of chronic illness. Imagine how far medicine might advance, if we allow ourselves to pursue the "*what if's?*"

Thank you.

Sara Hesley, Kentucky Lyme Disease Awareness

The Impact of Flawed Reporting Practices

I'm Sara Hesley, Lyme advocate in Kentucky.

When looking at statistics, it's logical to assume that Lyme disease is not in the SE. We were very confused about the few case numbers reflected in southeastern states. We hear from *so* many patients across the region that *have* contracted Lyme here.

The truth is: we can't compare Lyme case numbers across the country. Cases are not counted and reported using the same methodology. Many states claim they adhere to CDC reporting guidelines, but don't and never have.

Up North, where CDC guidelines are used, *rashes* are counted as cases and have been for years in counties, once they are declared "endemic" by having two or more positive LD cases on

record. Here across the South, we have *never* counted rashes as cases, even in counties where we have clearly documented two cases.

In Georgia, South Carolina, Alabama, Tennessee, and Kentucky, numerous counties have two or more cases on record that meet CDC reporting criteria. Instead of declaring *counties* endemic as they do up north, many declared their entire states “*non endemic*”.

In a single southeastern *neighborhood* alone last spring, there were 9 people with tick bites, rashes, and symptoms in a county that already had two confirmed cases. *Not one* was counted. If we counted rashes, *too*, our numbers would also skyrocket.

Some claim these old cases don't count because they may have been STARI. But the *hallmark* of STARI is that patients *DON'T* test positive for *Lyme*. As of 1994, all these cases on record used the EXACT SAME tests employed to track cases today, both the ELISA and WB. Yet our cases across the south continue to be dismissed as STARI, without any further investigation, even though Bb has clearly been found in nature and the CDC admits there are human cases here.

We can't dismiss cases as STARI, we don't even know what STARI is. We're hearing from patients who *do* test positive for *Lyme disease* after Lone star tick bites. In a medical college of GA study, 30 % of local participants with EMs did, indeed, show evidence of *Borrelia burgdorferi* infection. We need to investigate *each* case and report these.

The flawed statistics further perpetuate the problem, causing doctors to dismiss positive cases as false, so they never report them. Additionally, doctors see the low case numbers, and don't recognize and treat Lyme early, before permanent damage occurs. Many may never be diagnosed and treated.

CDC officials state that only a very small percentage of cases fall outside the Northern United states. But Lyme has been found in humans all over South America. Does it make any sense that Lyme appears in a tiny pocket in the northeastern United States, and then JUMPS across the continent and appears in South America?

PHO need to point out that there is no way to compare statistics from state to state. We can't say Lyme is rare, and we can't determine prevalence until we get a sensitive test.

These flawed statistics cannot be used in positive predictive value formulas, and shouldn't be given to the media, or politicians. Doctors should *never* dismiss Lyme cases based on state statistics. When reporting practices differ so greatly, statistics are meaningless. This is like comparing apples to zebras.

(Sara went on to discuss her case, and how, although she had a classic EM after tick bite, doctors told her she didn't require treatment. She subsequently has chronic symptoms.)

Liz Schmitz, Georgia Lyme Disease Association:

Lyme Disease in Georgia and the Southeast

I'm Liz Schmitz from the Georgia Lyme Disease Association. Thank you for your kind sentiments at the beginning of this call, Dr. King. I absolutely appreciate them and also the opportunity to speak.

In 1989, *Georgia* was 4th highest in the nation in the number of *CDC* reported Lyme cases, with 715 on record. *114 GA counties reported cases*. That year, our legislators funded free blood tests at our health department and found these. The following year, before funding ran out, they documented 161 cases.

Since then, southern scientists have identified *Borrelia burgdorferi* in *thousands* of tick and animal specimens from across our region, including mammals, birds, and wild reptiles. *One* company's lab test confirmed Lyme disease in 600 GA dogs and 600 Florida dogs.

In 1994, Lyme disease made Georgia's *Top 10 Communicable Diseases* list. In 1999, a human study in Georgia found that 30% of EM patients *did* have Lyme disease. Surrounding states have consistently reported cases.

Some now say those 715 Georgia cases were "*False Positives*". But, *where* are the follow up studies to support that assumption?

In 1994, a GA state epidemiologist spoke at our support meeting and was interviewed on TV. He stated -they believed there were *thousands* of Lyme cases being misdiagnosed or undiagnosed across Georgia each year.

We hear from *hundreds* of southeastern patients who have compatible history and positive tests. Many medical professionals don't recognize and treat Lyme disease, and believe it's not here. Positive test results are often not reported. Even public health officials tend to dismiss our positive cases, although Lyme experts have documented that false positives are rare.

At a taped conference in 2007, a CDC official disturbingly advises medical attendees, that if a tick bite patient comes forward in the Southeast, with all symptoms and even positive serology, there's only a 5% probability it's Lyme. He basically tells them to assume these are false positives.

This is troubling from someone who is employed by our government to protect public health. Why wouldn't medical people be encouraged to report these cases and have them investigated?

We must stop reporting that Bb is rare in the SE when independent, large-scale, human studies haven't been done. Flawed reporting practices, insensitive tests that aren't region specific, dismissed cases, and lack of county-by-county tick flagging studies, all combine to prevent us from assessing true prevalence. To assume all these patients only have a "mild" illness called STARI, is *dangerous*.

I reported 75 local cases directly to CDC and GA state officials last year. I was told we don't have funding to study these. *And* I was told, with so few cases on the books, we aren't likely to *get* funding.

So...we have to have *funding* to find *cases*, but we have to have *cases* to get *funding*?

With reasoning so circular, how is an infection ever supposed to emerge?

We need to investigate of the possibility of other tick vectors, Borrelia reservoirs, various hosts and transmission here. Why hasn't this been done by now?

Untreated Lyme is *serious*. Lack of recognition turns a potentially curable illness into one that can cause permanent damage. Public health officials and medical providers have a responsibility to take each report of Lyme disease *seriously* and to investigate these fully.

Thank you.

Angela Allen, South Carolina

Doctors need to be Educated about Basic Lyme facts

My name is Angela Allen and I'm an advocate from South Carolina.

After nearly 30 years of published research, the number of medical providers uneducated about Lyme disease is **alarming**. We frequently hear from Southerners misdiagnosed because many medical professionals do not understand **the most basic Lyme disease facts**. *Everyone* agrees upon the importance of diagnosing and treating this infection **early**, so this should be addressed *immediately*.

Many patients are misdiagnosed at the time they have a rash following a tick bite, because medical providers don't know better than to rely upon negative test results. When the tests come back negative, the doctor declares that they don't have Lyme and send patients away, untreated.

Suffering patients wander from doctor to doctor, while each new medical provider says, "well, you *had* a Lyme test and ruled that out". Patients are often not retested until years later, only to learn that they **do have** Lyme. By this time the infection, that *could* have been effectively treated at the onset, has left permanent damage and ongoing problems. How many people are **never** retested and treated?

The medical literature has long indicated that testing is problematic in the early stages. The majority of patients **will not** test positive for many weeks because antibody levels are not yet high enough. Why do our **doctors not** know this by now?

We even hear from patients who test *fully* "CDC positive", with compatible history, who are being told they cannot possibly have Lyme, and are denied treatment.

We live in a mobile society, people travel and can contract Lyme easily. Even if we only have 25 cases reported in the state this year, a doctor should **never** assume that the patient standing in front of him isn't *the 26th case*.

We hear from an alarming number of citizens who tell us they remove ticks improperly. Doctors should know this **could** play a significant role in transmission, even if the tick hasn't been attached for 24 hours.

Factors that affect test results that many of our doctors don't understand include: use of antibiotics, timing, fluctuating antibodies, and various local Bb strains and species that are not detectible.

Other facts our medical providers need to know include:

- Lyme disease and STARI are indistinguishable at onset so EMs **must** be treated
- Retreatment may be necessary
- In winter months, adult deer ticks do feed on humans in the South.
- Lyme symptoms can appear months to years after a tick bite
- CDC reporting criteria should *not* be used to **diagnose** Lyme
- There is currently **no test** that can rule out Lyme

Most patients will not consult an infectious disease doctor about a tick bite. Therefore, *every single doctor across this country* should know how to recognize, diagnose, and treat Lyme disease EARLY, if we are to protect public health.

Lisa Higgins, Tennessee

Testing needs/CDC's mixed diagnostic message to medical providers

I'm Lisa Higgins, advocate from Tennessee.

We constantly hear from sick people coming forward after tick bites across the South, who test positive for Lyme disease and respond to antibiotic treatment. Some don't have "**CDC reportable**" lab results, but show various bands specific to *Borrelia burgdorferi*, on their Western Blots. Many also have compatible history with tick bites, EMs, and symptoms.

This situation has been ignored for far too long. There is no way to rule out Lyme disease in these patients. They may have traditional Lyme or a strain of *Borrelia burgdorferi* that simply can't be detected with a Western blot that uses a Northern isolate.

Scientists have documented more strains of the Lyme bacteria here in the South, than there are in the North. While some of these strains may not be pathogenic, or could be causing only mild illness, some could be causing symptoms *far* more severe than in cases seen up North. We see patients debilitated by Lyme all the time, yet no independent human studies have been funded here by the CDC or NIH.

A recent Scottish study proved that adding local *Borrelia* strains in a single mixed antigen significantly improved western blot sensitivity. Another study proved in milder climates, there are more diversified strains. We *desperately* need a regional Western Blot using southern strains and species, so that patients won't go untreated.

We're seeing a disturbing problem on lab reports. Despite the warning on the CDC website, *not* to use reporting criteria to diagnose Lyme, written directives now appear on individual patient lab results that are sent *directly to* our doctors, instructing them to adhere to the very strict CDC *surveillance* criteria to diagnose Lyme. The wording of these interpretations actually indicates that all patients must have CDC reportable test results to be diagnosed. This is dangerous and lets thousands of patients fall thru the cracks. Without early treatment, these patients can become disabled and chronically ill, leaving them personally devastated, as well as a costly burden to our nation.

Dr. David Volkman, Lyme researcher and former Senior Investigator at the NIH, recently wrote:

“In order to reliably track the geographically expanding incidence of Lyme disease, the CDC tried to derive a case definition that would include only definitive cases. Dr. Steere and I were members of the “Committee to Develop a Surveillance Case Definition for Lyme disease”. The CDC explicitly cautioned against using this restrictive case definition for clinical diagnosis and reiterated this proscription with every re-issuing of its “Surveillance Definition.” It has been a source of frustration and confusion that some in the medical community wrongly insist that a Lyme patient must satisfy CDC criteria.”

Ticks bites occur daily and year round in the south. We need to study tick vectors, hosts, various strains and species, and *humans*, immediately.

Dr. Kerry Clark, Lyme and Tick-borne Disease Researcher, ***Associate Professor of Epidemiology and Environmental Health and Director of the Master of Public Health Program, University*** of North Florida

Dr. Clark provided comments related to his research findings on Lyme disease in the southern U.S.



Panel members asked questions following many of the commentaries and invited participants to submit their written comments by email.

Even if you did not participate in this teleconference, you may submit your comments. Send them to:

lymedisease@nas.edu

Or

Lyme Disease Comments

Keck Center
500 Fifth St. NW
Washington, DC 20001

For information about this teleconference, visit:

<http://www.iom.edu/Activities/Disease/TickBorne/2010-JUN-02.aspx>