SUMMER - FALL NEWSLETTER 2008

Tick-borne Infections Council of North Carolina, Inc

TIC NC

Sorry this newsletter is so late getting out. Best wishes for a happy holiday to all of you and your families.

Highlights…

Scroll down to see these features and more!

- A summary of TIC-NC activities since Spring of 2008
- Lyme disease tick found biting two people in Chatham County
- "Under Our Skin" showing in Raleigh in September
- Tick repellent advice from a county agent
- Article on the Lyme disease controversy
- Article on persisting forms of *B burgdorferi*

Quote of the season…

Six word biography:
"Another sorry lone star STARI story." Doug G. Berg, 2008

TIC-NC SUMMER AND FALL 2008 ACTIVITES

- TIC-NC was featured in an article in the Chapel Hill Magazine
- We had input in the CDC's efforts to research STARI in NC
- We attended the state Vector-borne Disease Task Force meetings. These quarterly meetings are open to the public. Contact us if you are interested in attending.
- We communicated with vector researchers at the CDC in Fort Collins about tick issues in NC. This included a meeting with Dr. Ben Beard, CDC, Fort Collins, on September 8. The agenda for the meeting is available on request.
- Funds awarded to the state Department of Health and Human Services by the legislature continue to get our monitoring and support.
- TIC-NC was featured in 3 May newspaper stories.
    - Tick-ing time bomb: Beware of 8-legged menace
      Greensboro News Record - Greensboro,NC,USA "Only the tip of the iceberg of cases get

reported," said **Marcia Herman-Giddens**, a professor at UNC-Chapel Hill and one of the founders of TIC-NC. ...

  - Ah, a summer walk in the woods ... oh ick, a tick!
    News & Observer - Raleigh,NC,USA
  - Wilmington Star-News Online, Wilmington, North Carolina
    http://www.starnewsonline.com/article/20080531/ARTICLE/805310326/1005/NEWS/N_C__tick_treatment_divides_professionals#comments

- Documentation of the Lyme-disease vector tick biting persons in Chatham County.
- We have distributed about 1,000 educational brochures so far this year.
- TIC-NC had a booth at the Raleigh showing of "Under Our Skin."
- We have had several letters to the editor published in area newspapers, especially around the aftermath of the "Under Our Skin" showing.
- Advice on tick repellants with links from the Chatham County Agricultural Agent.
- Attended a meeting of UNC researchers interested in tick issues.
- Other activities too numerous to mention!

THE LYME DISEASE VECTOR TICK, *IXODES SCAPULARIS,* COLLECTED ON TWO PEOPLE IN CHATHAM COUNTY

The *I. scapularis* tick, also called the black-legged tick, is well-established in Chatham County and many other parts of the state. (This tick is also sometimes called a 'deer' tick; however, this is confusing since lone star ticks are also often call deer ticks.) It is thought that the black-legged tick rarely bites humans in the south. One person saved two adult black-legged ticks from last winter that had been biting him. (Adults are active in the winter.) Another person was bitten by two nymphal black-legged ticks on two different occasions in the spring. It is not known what proportion of these ticks in Chatham County may carry the Lyme disease bacteria but it is probably fairly low. About a dozen black-legged ticks were recently collected from Chatham County and tested for the Lyme disease bacteria. All were negative. It may be, however, that the currents tests are not picking up our Southern variants. These ticks may also carry other human pathogens. This is another reason to keep all ticks you find on your person! See our website for details. www.tic-nc.org

UNDER OUR SKIN, AWARD-WINNING DOCUMENTARY ON LYME DISEASE

The NC Lyme Disease Foundation sponsored a public showing in Raleigh on September 28. The affair, attended by hundreds of people, was sold out. After the showing there was a story in the News and Observer, a flurry of letters to the newspaper, and a clip on television. Another showing will possibly occur in Charlotte next year.

- http://raleigh.mync.com/site/raleigh/news%7CSports%7CLifestyles/story/9933/r

Raleigh-showing-of-lyme-disease-movie-sparks-questions-- this clip features Gretchen Witzgall at the showing of UOS, Sept 28

- The letter from Dr. Engel, state epidemiologist, clarifying his statement about there being no evidence of LD acquired in NC: http://www.newsobserver.com/opinion/letters/story/1241322.html
- Letter about there being a long history of Lyme disease in NC in the Oct 5 N&O in response to Dr Engel's letter: http://www.newsobserver.com/opinion/letters/story/1242452.html

Body of letter:"Lyme disease is here"

In a People's Forum letter Oct. 3, Dr. Jeffrey Engel, the state epidemiologist, clarified an earlier news report and acknowledged that some reported cases of Lyme disease under investigation in North Carolina might have been acquired here.

In fact, there is a long history of Lyme disease acquisition in this state. In 1990 the Department of Defense declared the risk for Lyme disease at Fort Bragg as "some," and increased it to "moderate" in 1992. A military study found Lyme disease at Camp Lejeune in 2003. A 2000 study found the Lyme disease bacteria are present and naturally transmitted in large regions of North Carolina. Surely an infected tick transmitted the disease to at least one person over these years. Three Virginia border counties are endemic for Lyme. Might infected ticks cross the state line?

I know of patients with symptoms of Lyme disease whose doctors told them "there is no Lyme disease here," and no tests were done. In others, tests came back positive but were declared "false positives." These have been effective ways to keep Lyme disease off our books. This will now change given the growing evidence of Lyme acquisition in our state.

Our citizens deserve the stepped-up efforts Engel described -- improved surveillance and education to the public and medical providers. Citizens need to hold the state accountable and support these efforts.

Marcia E. Herman-Giddens
Pittsboro (The writer is an adjunct professor in the School of Public Health at UNC-Chapel Hill and president of the Tick-borne Infections Council of N.C.)

TICK ADVICE FROM THE CHATHAM COUNTY AG AGENT

"I'm pleased to see that someone (namely Ted Bonus) realizes we are not going to eradicate ticks and suggesting ways to protect ourselves. While the permethrin products mentioned are effective when used as directed, since people use other products, I'm going to point out a website with some general directions and precautions, http://www.ces.ncsu.edu/depts/ent/notes/Urban/repellents.htm

Each product has various advantages and disadvantages, and how you use it on children will vary according to the product. I find it interesting that the oil of lemon eucalyptus products should not be used on children under 3.

I was also interested in the clever use of words on the flier Ted Bonus sited (and we won't blame him for what appear to me contradictory statements). On the one hand, it's "man-made;" on the other hand, it's "originally derived from the chrysanthemum daisy." Not that whether it's man-made or chrysanthemum made makes much difference in efficacy or hazard.

However, I do think it's a good idea to consider protecting ourselves because biting insects are among the 1,000s of creatures with whom we share our world. We're not going to eradicate them. Also note that ticks must remain attached for several hours in order to transmit disease. After visiting likely tick habitat, get in the shower and have a good look at yourself. Use tweezers to remove any undesirable passengers. More about ticks and tick-borne disease at http://www.ces.ncsu.edu/depts/ent/notes/Urban/ticks.htm ."

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INTERESTING ARTICLE ON THE LYME CONTROVERSY

The Lyme Wars: Debate Rages About Treatment

Ann M. Hoppel, Managing Editor, Health Jobs Nationwide.
http://www.healthjobsnationwide.com/news.php?articleID=19

Who knew a little tick could cause so much trouble? When Lyme disease was first described in 1977, did anyone suspect that three decades later, a battle would be raging between two professional organizations about how to treat it? Today, the "war" between the Infectious Diseases Society of America (IDSA) and the International Lyme and Associated Diseases Society (ILADS) leaves clinicians wondering whose guidelines they should follow.

Is it a case of David versus Goliath--the "upstart" ILADS challenging the established IDSA--or evidence-based medicine versus questionable practice? The more you listen to the parties involved, the more difficult it can be to determine the answer.

Chronic Problem

The crux of the Lyme disease treatment debate is whether the condition exists in a chronic form. ILADS practitioners insist that it does; how else to explain the lingering symptoms many patients experience, which they say resolve only with long-term, high-dose antibiotic therapy? IDSA, however, takes the viewpoint that these patients--whose symptoms of fatigue, cognitive dysfunction, and musculoskeletal pain are subjective and vague (belonging on the symptom list for chronic fatigue syndrome and fibromyalgia as well)--never had Lyme disease in the first place, and this is why standard therapy for the condition appears not to work for them.

"It's true that those kinds of symptoms can occur in Lyme disease," says Gary P. Wormser, MD, Chief of the Division of Infectious Diseases at New York Medical College in Valhalla, and lead author of IDSA's guidelines. "But where the disconnect occurs is when people want to ascribe everybody with those symptoms as having Lyme disease, when they have no bona fide evidence [ie, validated laboratory results] of the disease."

ILADS clinicians counter that the IDSA underestimates *Borrelia burgdorferi* (*Bb*), the spirochete that causes Lyme disease. "What we're dealing with is way more sophisticated bacteria than any other bacteria we know," says Ginger R. Savely, RN, FNP-C, a Lyme disease specialist at Union Square Medical Associates in San Francisco. "The more you really study the bacteria and how it works, the more you become incredibly impressed by how many mechanisms this bacteria has for survival and how difficult it is to get rid of it."

Furthermore, Lyme disease specialists contend that the currently available diagnostic tools, the ELISA and the Western blot test, do not have sufficient sensitivity to reliably detect the presence of *Bb* (see Savely GR. Update on Lyme disease. *Clinician Reviews*. 2006;16[4]:44-51). This, they say, is why it can be difficult to validate the diagnosis.

Bottom line: If you can't agree on *what* you're treating, you certainly won't agree on *how* to treat it.

Prolonged Antibiotic Therapy

IDSA's guidelines on the treatment of Lyme disease recommend, in general, 14-day courses of oral antibiotics, with the option of a longer course (28 days) or retreatment where deemed appropriate. "We don't treat bacterial infections with prolonged antibiotics," Wormser points out, citing as examples cystitis, strep throat, and sinusitis. "So when you see 14 days recommended, that's a long course relative to many bacterial infections."

At issue in the Lyme "war" is the fact that ILADS, in the words of President Daniel Cameron, MD, MPH, "likes to offer options to patients who find themselves still sick after 30 days of treatment"--specifically, long-term (sometimes indefinite) high-dose antibiotic therapy.

Wormser is quick to point out that "our guidelines don't really discuss how any individual patient is to be treated. They just tell you a general approach that we think is scientifically based and makes sense, based on all other infectious diseases." In the IDSA's estimation, the research does not support the efficacy of long-term antibiotic therapy for Lyme disease--and in the absence of that support, the risks involved are just too great.

Those risks include the growing problem of antibiotic-resistant bacteria, the possibility of coinfection with an organism such as *Clostridium difficile*, and the potential for sepsis and other complications associated with prolonged IV therapy. "Would you really dialyze somebody who didn't need dialysis?" Wormser asks. "That's an extreme example. But we say to ourselves every time we use them, ‘Do we really need antibiotics here, and what's the *shortest* period of time we can give them, not the longest?'"

"The IDSA loves to say that what we're doing is harmful or dangerous," says Savely, who has treated more than 1,000 patients according to the ILADS recommendations. "The data have not shown that to be true. We have not had problems or complications--certainly not mortality--from the kind of treatment that we do."

Furthermore, ILADS clinicians say they restore hope to patients whom "mainstream" medicine has failed. "People were coming to me with just terrible, terrible conditions, where they had been to so many specialists and every one had told them, ‘There's no hope. We can't do anything for you,'" Savely says. "And then I'd start treating them with high-dose long-term antibiotics, and they would get their lives back."

Wormser understands that many patients feel let down by practitioners who can't provide definitive answers about their condition. "And I know people will turn to whoever says they think they can help--I can't blame them for that," he says. Nonetheless, "it is remarkable the difference that patients with real

Lyme have, in terms of their experience with antibiotics, compared to people who probably don't have Lyme but feel they do."

Risky Business?

So, how should clinicians handle patient inquiries about Lyme disease treatment? ILADS President Cameron believes that all options should be presented. "The patient should be involved in the decision, rather than just offered only one answer," he says, although he respects every clinician's right to say, "There are other options, but I choose this one."

Clinician Reviews Editorial Board member Julia Pallentino, MSN, JD, ARNP, sees patients in her gastroenterology practice in Tallahassee, Florida, who are being treated by other clinicians with long-term antibiotic therapy for Lyme disease. "I respect their right to seek care from where they wish to seek it, and if they feel it has been helpful, I support that," she says. Even so, if she were the one treating them for Lyme disease, "I certainly would not take on a different way of treatment because they want it. I would say, ‘I understand that you think this will help you, and I certainly respect your opinion. However, that's not the method I use. If you want to use a different method, then I would recommend you find a practitioner who does that.'"

Of course, in this day and age, the specter of malpractice hangs over everyone. "As an attorney, I can tell you I'd much rather my client had been using IDSA guidelines than ILADS," Pallentino says. "If you treat a patient according to CDC guidelines [which are the IDSA guidelines, in this case], then it would be very difficult to say that you weren't doing what was accepted, appropriate treatment."

Savely understands all too well how risky treating Lyme disease can be. In 2004, she was voted Texas NP of the Year. Two years later, she says, her supervising physician was more or less intimidated by the medical board into terminating their collaborative agreement. Finding another supervising physician proved so difficult that she accepted an offer from an ILADS doctor to work with him, requiring her to relocate her practice to San Francisco. The changes impacted every area of her life--and yet, she persists in caring for Lyme disease patients according to the ILADS guidelines.

Why? "Somebody's got to take care of these people," she says. "Every time I have a patient saying ‘I cannot even tell you how grateful I am to you for listening to me when no one else would, and for treating me when nobody else would, and for letting me live again,' I just go, ‘Gosh, I *have* to do this. I have to.'"

Whether other clinicians will feel they have to treat Lyme disease using one of the competing regimens is for them alone to decide.

ARTICLE ON PERSISTING FORMS OF BORRELIA BUGDORFERI

Persisting atypical and cystic forms of *Borrelia burgdorferi* and local inflammation in Lyme neuroborreliosis

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Background
The long latent stage seen in syphilis, followed by chronic central nervous system infection and inflammation, can be explained by the persistence of atypical cystic and granular forms of *Treponema pallidum*. We investigated whether a similar situation may occur in Lyme neuroborreliosis.

Conclusion
The results indicate that atypical extra- and intracellular pleomorphic and cystic forms of *Borrelia burgdorferi* and local neuroinflammation occur in the brain in chronic Lyme neuroborreliosis. The persistence of these more resistant spirochete forms, and their intracellular location in neurons and glial cells, may explain the long latent stage and persistence of Borrelia infection. The results also suggest that *Borrelia burgdorferi* may induce cellular dysfunction and apoptosis. The detection and recognition of atypical, cystic and granular forms in infected tissues is essential for the diagnosis and the treatment as they can occur in the absence of the typical spiral Borrelia form.

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Tick-Borne Infections Council of North Carolina is a non-profit organization formed to improve the recognition, treatment, control, and understanding of tick-borne diseases in North Carolina. We are all-volunteer and appreciate donations.

You have received this newsletter because you are on our membership list. If you want to be taken off at any time, just reply with 'unsubscribe' in the subject box.

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TIC NC

Tick-borne Infections Council of North Carolina, Inc

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