

2012-2013 WINTER NEWSLETTER

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Quote of the month... "In questions of science, the authority of a thousand is not worth the humble reasoning of a single individual." --Galileo Galilei

Save your ticks! Researchers at the University of North Florida want ticks for testing. See our website, <u>TIC-NC.org</u>, for their submission forms.

State Vector-Borne Disease Working Group Meeting Schedule

- April 12, 2013
- August 16, 2013
- November 8, 2013

All meetings are from 10 a.m. to 12 p.m. and are open to the public. Cardinal Conference Room, Building 1, 5505 Six Forks Road, Raleigh, NC.

North Carolina Now Has Three Counties Endemic for Lyme Disease

	Total cases by year of report 2010 FINAL	Total cases by year of report 2011 Preliminary	Cases between 1/1/12 and 12/31/12
Disease	(Confirmed/Probable/Suspected)	(Confirmed/Probable/Suspected)	(Probable + Confirmed)
Lyme disease	82 (21/61/400)	88 (18/70/135)	127 (33 confirmed)
Rickettsioses*	286 (15/271/296)	327 (16/311/281)	598 (14 confirmed)
Ehrlichia	99 (19/80/77)	83 (27/56/102)	112 (19 confirmed)
Anaplasma	28 (0/2/178)	21 (1/20/19)	21 (all probable)

^{*}RMSF now subsumed under Rickettsioses

Note: Haywood County now has a second confirmed case of Lyme disease in a person who had not traveled out of the county for 30 days after their tick exposure. Therefore, Haywood County is now considered endemic for Lyme disease bringing the total of endemic counties in NC to 3. (Wake, Guilford, and Haywood)

Beat The Bite Donation to TIC-NC

December 4, 2012

Beat the Bite (BTB) is a non-profit organization whose mission is to educate the general public about Lyme disease, prevent the spread of the disease by raising awareness, and raise money for research to find solutions for the growing epidemic.

BTB was founded by Kristen Bailey and Anna Edney in April 2012 - a year and a half after a loved one was



(Kristen Bailey, Susan Walser, Anna Edney)

diagnosed with Lyme. After seeing first-hand the effects of Lyme on an individual, and subsequently their family members and friends, the two were inspired to take action. Both passionate about fitness and health, Kristin and Anna's idea of organizing a race as a platform for raising awareness about Lyme (as a part of all-around health) made perfect sense. http://www.beatthebite.com

The sisters attended our board meeting on December 4 to give a final report on the Beat the Bite 5K & 1 Mile Fun Run/Walk and present TIC-NC with a check from the proceeds made in the race. The amount was an amazing \$2,500!! Thank you so much Kristen and Anna.

The October event had 204 participants with 78 of these competing in the 5K race. The 1 mile event had 100 participants. More events will be coming from Beat the Bite.

TIC-NC Now Has a Facebook Page

Please visit our new Facebook page and join us! http://www.facebook.com/TICNC

Watch for updates on our activities, interesting articles, events, and newsletter postings.

TIC-NC Has a New Logo

Did you notice our new logo at the top of the newsletter? We're excited to roll out the new logo, thanks to volunteer and board member Sandy DeMaioNewton, a Graphic Designer with SHE Design: http://www.she-design.com/

Local Support Groups

Triangle Lyme Disease Support Group (Apex, NC)

This support group meeting schedule fluctuates depending on room availability at the library: Eva Perry Library, 2100 Shepherd's Vineyard Dr., Apex, NC 27502. The group meets on Sundays, generally the second or third one of the month, usually from 3:00pm to 4:30pm.

Contact: Peter Smith, pssmith2@gmail.com, 919-412-7933

NC Lyme Disease Foundation (Raleigh, NC) sponsors a monthly support group meeting usually on the first Sunday of every month from 2pm to 4 pm at the Starbucks Coffee at 3800 Lake Boone Trail, Raleigh. However meetings may be rescheduled. Announcements for the meeting are made through the Foundation's website at www.nclyme.net. Interested individuals may contact the Foundation to be added to their email list and get notification of meetings.

Contact: John Dorney, swampjrd@earthlink.net

National Capital Lyme and Tick-Borne Disease Association Starts a North Carolina Chapter (Charlotte, NC)

The National Capital Lyme Disease Association is an all volunteer not-for-profit organization that is committed to helping patients diagnosed with tick-borne illnesses. It was founded in 2001 and is headquartered in McLean, VA. www.natcaplyme.org

Answering the growing needs for support and awareness, they are pleased to announce the opening of The Central North Carolina Chapter of the National Capital Lyme and Tick-Borne Disease Association. It is devoted to support, education and awareness, and educational outreach. Informal monthly meetings are held the 2nd Saturday of each month from 1pm to 4pm. The location is: Queens Grant High School, 10323 Idlewild Road, Matthews, NC 28105. This location is easily accessed from I-485. Anyone who has been touched by Lyme disease or just wants to learn more is welcome to attend.

John Lee McLean and his wife Barbara lead the group. John Lee had been misdiagnosed with early-onset Alzheimer's disease, when in fact it was eventually found that he had been suffering for 9 years with Lyme disease. The McLean family vowed to raise awareness in their state if John Lee ever returned to a place of sufficiency, which he did following treatment for Lyme disease. Mr. McLean can be reached at charlottelyme@yahoo.com

<u>Lyme Disease Test Bill Passes Virginia House--Awaiting Governor's Signature</u> February 20, 2013

Update as we go to press (from NatCapLyme): Today the State of Virginia passed groundbreaking Lyme legislation, once again proving that Virginians are pioneers in the battle against Lyme and tick-borne diseases. Governor Bob McDonnell signed into law House Bill 1933 known as the Lyme Disease Testing Information Disclosure Act.

A huge thank you to all who were instrumental in making this happen. This was truly a successful grass roots effort, proving that people working together can bring about real change to benefit victims of Lyme disease.

Congratulations, Virginia.

Virginia House Bill 1933 requires doctors to inform patients of the limitations of tests for the tick-borne disease. Under the proposed law, a doctor who orders a laboratory test for Lyme disease must provide the patient with a written notice that says, in part: "Current laboratory testing for Lyme disease can be problematic and standard laboratory tests often result in false negative and false positive results."

House Bill 1933 now goes to Gov. Bob McDonnell, who appointed a task force in 2010 to explore prevention and treatment of Lyme, the sixth-fastest growing disease in the United States. The panel later called for better public education and outreach about Lyme and a more open-minded approach by the medical community to diagnosing and treating the tick-borne illness. As of late February, 2013, the bill is awaiting the governor's signature.

Advocates for Lyme patients said the bill passed Tuesday is a landmark measure that will educate Virginia patients about the limitations of serologic tests that are used to detect Lyme. If McDonnell signs the measure, the bill could become a model that other states replicate, said Monte Skall, the executive director of the National Capital Lyme Association.

The notice further states that a negative test result "does not necessarily mean you do not have Lyme disease" and advises the patient to contact his or her doctor if symptoms continue. The bill also gives physicians immunity from civil liability for providing the written information.

The Medical Society of Virginia opposed the version that was passed, arguing that it would codify a standard of care and interfere with the doctor-patient relationship. The Medical Society supported the version to require the health department to post information on its website.

Full story: http://ww2.roanoke.com/politics/wb/320597/

Wording of the bill:

- ${\bf 1} \ A. \ Every \ licensee \ or \ his \ in-office \ designee \ who \ orders \ a \ laboratory \ test \ for \ the \ presence \ of \ Lyme$
- **12** *disease shall provide to the patient or his legal representative the following written information:*
- 13 "ACCORDING TO THE CENTERS FOR DISEASE CONTROL AND PREVENTION, AS OF 2011
- **14** LYME DISEASE IS THE SIXTH FASTEST GROWING DISEASE IN THE UNITED STATES.
- **15** YOUR HEALTH CARE PROVIDER HAS ORDERED A LABORATORY TEST FOR THE PRESENCE
- **16** OF LYME DISEASE FOR YOU. CURRENT LABORATORY TESTING FOR LYME DISEASE CAN BE

- 17 PROBLEMATIC AND STANDARD LABORATORY TESTS OFTEN RESULT IN FALSE NEGATIVE AND
- **18** FALSE POSITIVE RESULTS, AND IF DONE TOO EARLY, YOU MAY NOT HAVE PRODUCED **19** ENOUGH ANTIBODIES TO BE CONSIDERED POSITIVE BECAUSE YOUR IMMUNE RESPONSE
- **20** REQUIRES TIME TO DEVELOP ANTIBODIES. IF YOU ARE TESTED FOR LYME DISEASE, AND
- **21** THE RESULTS ARE NEGATIVE, THIS DOES NOT NECESSARILY MEAN YOU DO NOT HAVE LYME
- **22** DISEASE. IF YOU CONTINUE TO EXPERIENCE SYMPTOMS, YOU SHOULD CONTACT YOUR
- **23** HEALTH CARE PROVIDER AND INQUIRE ABOUT THE APPROPRIATENESS OF RETESTING OR
- **24** ADDITIONAL TREATMENT."
- **25** B. Licensees shall be immune from civil liability for the provision of the written information required
- **26** by this section absent gross negligence or willful misconduct.

This link is to the Virginia House of Delegate's debate prior to voting on the bill. http://www.youtube.com/watch?v=fng4PwOYA6I

\$1,000 Donation Given to Honor TIC-NC's Scientific Advisor

TIC-NC was pleased to recently receive a generous donation from a Raleigh family affected by Lyme disease, in honor of Marcia Herman-Giddens. Dr. Herman-Giddens is a founding member of TIC-NC, a current board member, Scientific Advisor, and its president emeritus. Dr. Herman-Giddens provides support to our members, the public, and the organization with her tireless research on all issues related to ticks and tick-borne illnesses. We are very grateful for this contribution.

2012 State Letters on Lyme Disease and Rickettsial Diseases (such as RMSF) for Health Departments and Medical Providers

These links are to the letters the North Carolina Department of Public Health issues every year to medical providers on Lyme disease (LD) and the Rickettsial diseases such as Rocky Mountain Spotted Fever (RMSF):

http://epi.publichealth.nc.gov/cd/ticks/TBRD_memo_2012.pdf http://epi.publichealth.nc.gov/cd/ticks/Lyme_memo_2012.pdf

The letters are emailed to each local health department so they can distribute them to providers in their communities. They have also been posted on the state public health website:

http://epi.publichealth.nc.gov/cd/ticks/providers.html and they have been posted on the website of the NC Medical Society: http://www.ncmedsoc.org/blog/index.php/archives/12749.

New Tick-Borne Pathogen Found in U.S.-- Borrelia miyamotoi

A report in a January 2013 issue of the New England Journal of Medicine describes progressive mental deterioration in an older, immunocompromised patient, presumably due to *B. miyamotoi* infection as it was directly detected in her cerebrospinal fluid. A letter in the same issue on 18 patients with evidence of antibodies to *B. miyamotoi*, and three with symptoms whose titers were sufficiently high to suggest recent infection.

Borrelia miyamotoi was first identified in 1995 in Japan, and is now found worldwide. It is carried by the same ticks as *B. burgdorferi*, but with a much lower prevalence. A series of almost 50 cases was reported from Russia in 2011, with clinical manifestations of the relapsing fever form of illness. Borrelia miyamotoi is related to the spirochete that causes Lyme disease, and it may be an underappreciated cause of disease in locations where Lyme disease is endemic as well as areas that have not been studied for this organism such as the south.

Gugliotta J, et al "Meningoencephalitis from *Borrelia miyamotoi* in an immunocompromised patient" *N Engl J Med* 2013; 368: 240-245 and Krause P, et al "Human *Borrelia miyamotoi* infection in the United States" *N Engl J Med* 2013; 368: 291-293.

Doctors in Pittsburgh Treating Possible Lyme Disease Immediately

PITTSBURGH (TV Station KDKA – CBS Local Affiliate) — Doctors are saying don't wait – treat – because sometimes it can take a while to get diagnosed with Lyme disease. "So, we do see a number of cases that are delayed in diagnosis because the initial rash is missed or the symptoms are misinterpreted," says Dr. Andrew Nowalk, an infectious diseases specialist at Children's Hospital of Pittsburgh. "By the time they get to me, I can see them a month after they've had their first symptoms or a year and a half after they've had their first symptoms."

 $\underline{http://pittsburgh.cbslocal.com/2012/09/25/doctors-change-treatment-recommendations-for-lyme-\underline{disease/}}$

Science Blog That Sometimes Covers Tick Issues

This blog post includes information on a recent NC study.

This science blog is by Maryn McKenna, a journalist for national magazines and the author of *Superbug* and *Beating Back the Devil*. She finds emerging diseases strangely exciting.

She has been keeping track of new news regarding other diseases transmitted by insects and arthropods. Here's an end-of-year round-up. It's not cheery (she says, "Are my posts *ever* cheery?"), but maybe it will prompt some New Year's resolutions to wear repellents and long pants outdoors. Her post includes the NC study on treated clothes. It found almost one-quarter of the NC workers showed serologic evidence that they had already been



infected with at least one of several tick-transmitted organisms. (The organisms were *Rickettsia parkeri*, *Rickettsia rickettsii* and *Rickettsia amblyommii*.) These diseases are no fun. http://www.wired.com/wiredscience/2012/12/ticks-new-meat/

The North Carolina Study:

Meagan F. Vaughn and Steven R. Meshnick

Exposure of Outdoor Workers in NC to Tick Species and Tick-Borne Infections

Forestry, parks, and wildlife workers have prolonged outdoor exposure, increasing their risk of being bitten by ticks and infection by tick-borne microbes. In 2011, we initiated a two-year investigation of the protection from tick bites provided by permethrin-impregnated clothing. Outdoor workers enrolled in our cohort study self-reported ticks bites and collected attached ticks. The ticks were identified to species and tested for common bacterial pathogens. The lone star tick (*Amblyommma americanum*), was the predominant species collected, accounting for 95% of the 429 ticks submitted. Other species collected included the Gulf Coast (*Amblyomma maculatum*), American dog (*Dermacentor variablis*) and black-legged ticks (*Ixodes scapularis*). Rickettsial organisms detected in ticks will be presented. Serologic tests of blood samples obtained at enrollment (n=127) revealed that many participants had pre-existing titers against spotted fever group rickettsiae. A minimum endpoint IFA titer of 1:128 was observed in 19% of participants against *Rickettsia rickettsii*, 23% against *R. parkeri*, and 11% against *R. amblyommii*. Fewer subjects had baseline titers against *E. chaffeensis* (4%). Comparison of titers from pre and post-season serum samples indicated that several participants seroconverted to spotted fever group rickettsiae and *Ehrlichia chaffeensis* during the course of the first year of follow-up.

¹University of North Carolina, Chapel Hill, NC, United States, ²Centers for Disease Control and Prevention, Atlanta, GA, United States, ³North Carolina State University, Raleigh, NC, United States, ⁴Centers for Disease Control and Prevention, Chapel Hill, NC, United States, ⁵N.C. State University, Raleigh, NC, United States

<u>Dog Dies After Contracting Ehrlichiosis During Walks on Forest Road at the Edge of The Croatan National Forest in NC</u>

January 1, 2013

Joe Sosik holds a picture of his dog Troy, who was put down after he said the dog contracted a tick borne disease. He said he wants residents to be aware of the dangers ticks can have on dogs. http://www.havenews.com/news/local-news/after-dog-dies-havelock-pet-owner-warns-of-tick-diseases-1.72428

NC Department of Public Health (DPH) 2012 Tick and Mosquito Data

Marcee Toliver, DPH entomologist, has put together a very informative presentation with maps and disease numbers. http://www.ncmvca.org/sitebuildercontent/sitebuilderfiles/12toliversummary.pdf

North Carolina Deer Crash Data 2009-2011

Department of Transportation data 2009 - 2011: 61,046 crashes, 17 fatalities Most dangerous season: October through December Use caution driving, especially at dawn and dusk.

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TIC-NC is grateful for the financial contributions of Insect-Shield, LLC.

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.

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Any contact information is provided for you to learn about tick borne illnesses and related issues. Our organization is not responsible for the content of other material or for actions as a result of opinions or information expressed which may appear from time to time.

It is the responsibility of you as an individual to evaluate the usefulness, completeness or accuracy of any information you read and to seek the services of a competent medical professional of your choosing if you need medical care.

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