Tick-Borne Infections Council of North Carolina, Inc.

NEWSLETTER 2018, Volume 4

Quote of the season: - "A total of 642,602 cases of 16 diseases caused by bacteria, viruses, or parasites transmitted through the bites of mosquitoes, ticks, or fleas were reported to CDC during 2004–2016. *Indications are that cases were substantially underreported.*" (Ed. italics)

--Trends in Reported Vectorborne Disease Cases — United States and Territories, 2004–2016

Highlights…

- **State tick research and case report numbers**
- **Powassan virus disease in the United States, 2006–2016**
- **CDC report: between 2004-2016 tickborne disease reports have doubled**
- **Citizen-Scientist Study has interesting national findings**
- **Study on profound fatigue**
- **Cats, ticks, and tickborne diseases**
- **Persistent borrelia infection in patients**
- **The *American Veterinarian* prediction about Lyme disease spread**
- **Ant-derived compounds repel lone star ticks**
- **Two public comments recently made to the federal Tickborne Disease Working Group (see end of newsletter)**
    - **Comment 1. Shared Medical Decision Making and the Two Standards of Care in Lyme Disease by Lorraine Johnson, CEO, Lymedisease.org**
    - **Comment 2. A father's story about his young daughter who died from Rocky Mountain spotted fever in spite of prompt and on-going medical care**

Scroll down to see these features and more!

State Vector-Borne Disease Working Group 2018 Meeting Schedule

Tentative 2018 VBWG meeting dates: Nov 9 (in person). Two meetings a year are now held electronically.

(Check with us before going to confirm date as they occasionally change.)

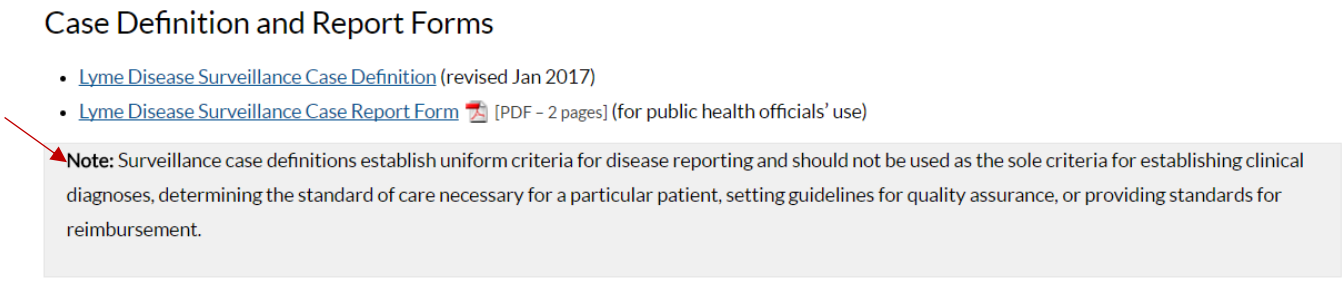
Location:
Office of the Chief Medical Examiner Photo ID required.
4312 District Drive
Raleigh, NC 27607

Links to Letters to Medical Providers from the State Department of Public Health on Lyme Disease and Rickettsial Diseases

These links are to the letters the state Department of Public Health issues every year to medical providers on Lyme disease and the Rickettsial diseases such as RMSF. Please find them on the home page of our website: tic-nc.org.

Where To Find CDC Case Definitions and their Statement that the Surveillance Case Definitions Are "not to be used as the sole criteria for establishing critical diagnosis"

Go to: www.cdc.gov/lyme/healthcare/index.html. (The links below in a clip of the website are not active.) Scroll down and find "Case Definition and Report Forms". See the grey box with "Note" containing the disclaimer.



Case Definition and Report Forms

- Lyme Disease Surveillance Case Definition (revised Jan 2017)
- Lyme Disease Surveillance Case Report Form [PDF – 2 pages] (for public health officials' use)

Note: Surveillance case definitions establish uniform criteria for disease reporting and should not be used as the sole criteria for establishing clinical diagnoses, determining the standard of care necessary for a particular patient, setting guidelines for quality assurance, or providing standards for reimbursement.

Accessed and copied 15 August 2017.

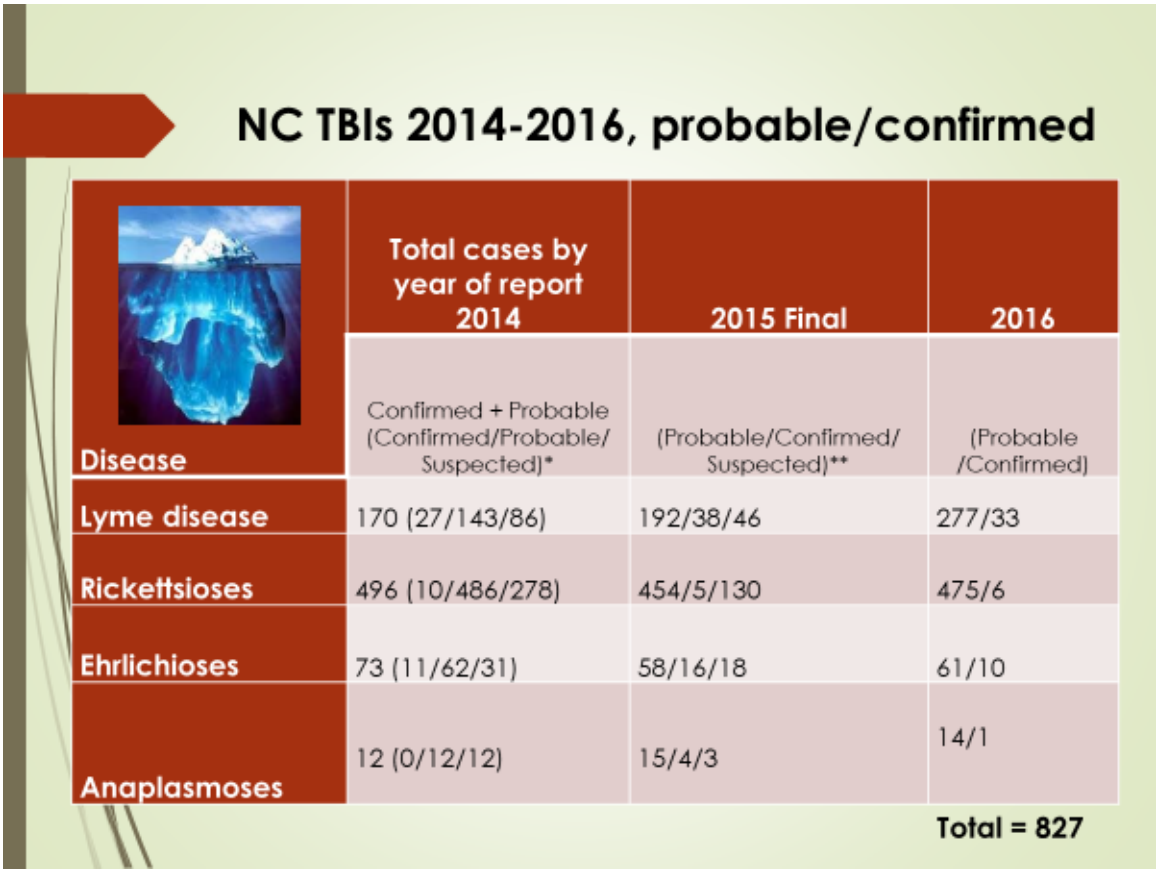
State tick research

Report from state on current tick research, February 2018:

"Currently, the state of North Carolina does not test ticks for Powassan virus (POW) or any other tick-borne illness. We do have contracts with a university partner that collects and identifies ticks in five of the 100 North Carolina counties in order to determine the distribution Ixodes ticks. Those ticks are then sent to partners at CDC, where they test for Borrelia and Rickettsia species. They do not test for POW because the test for POW requires a different panel and a different preservation method.

In early 2017 we partnered with people at the Virginia Department of Public Health to drag and test ticks for POW. Those ticks were also sent to CDC to be tested, and came back negative for POW. We do hope in the future that North Carolina can develop the capacity to test ticks for tick-borne illness at the State Lab of Public Health. So, at the moment, all of our testing, which is limited, is run through CDC."

NC TBIs 2014-2016, probable/confirmed- Final numbers



Disease	Total cases by year of report 2014 Confirmed + Probable (Confirmed/Probable/ Suspected)*	2015 Final (Probable/Confirmed/ Suspected)**	2016 (Probable /Confirmed)
Lyme disease	170 (27/143/86)	192/38/46	277/33
Rickettsioses	496 (10/486/278)	454/5/130	475/6
Ehrlichioses	73 (11/62/31)	58/16/18	61/10
Anaplasmoses	12 (0/12/12)	15/4/3	14/1
			Total = 827

Note: By the *former* CDC definition, six counties had confirmed cases of Lyme disease in two persons who had not traveled out of the county for 30 days after their tick exposure. **Therefore, these counties were endemic for Lyme disease by the former CDC definition: Wake, Guilford, Haywood, Alleghany, Buncombe, and Wilkes.** Counties with one case of locally acquired Lyme disease were: Cleveland (2008), Wilson (2009), Pitt (2009), Carteret (2009), Gates (2011), Perquimans (2011), Rowan (2013), Union (2013), Caldwell (2013), Franklin (2014), Stanley (2014), Duplin 2014.

TIC-NC Talks and Materials Distributed

Brochures/booklets:
- **Umstead State Park**
- **Triangle Land Conservancy**
- **The Nature Conservancy**
- **Grand Trees of Chatham County**
- **NC vet offices**

Booth: UNC Health Expo

Report from the Vector-Borne Disease Work Group meeting

Published in the Spring edition of *The Biting Times* 2018 by the NC Mosquito and Vector Control Association:

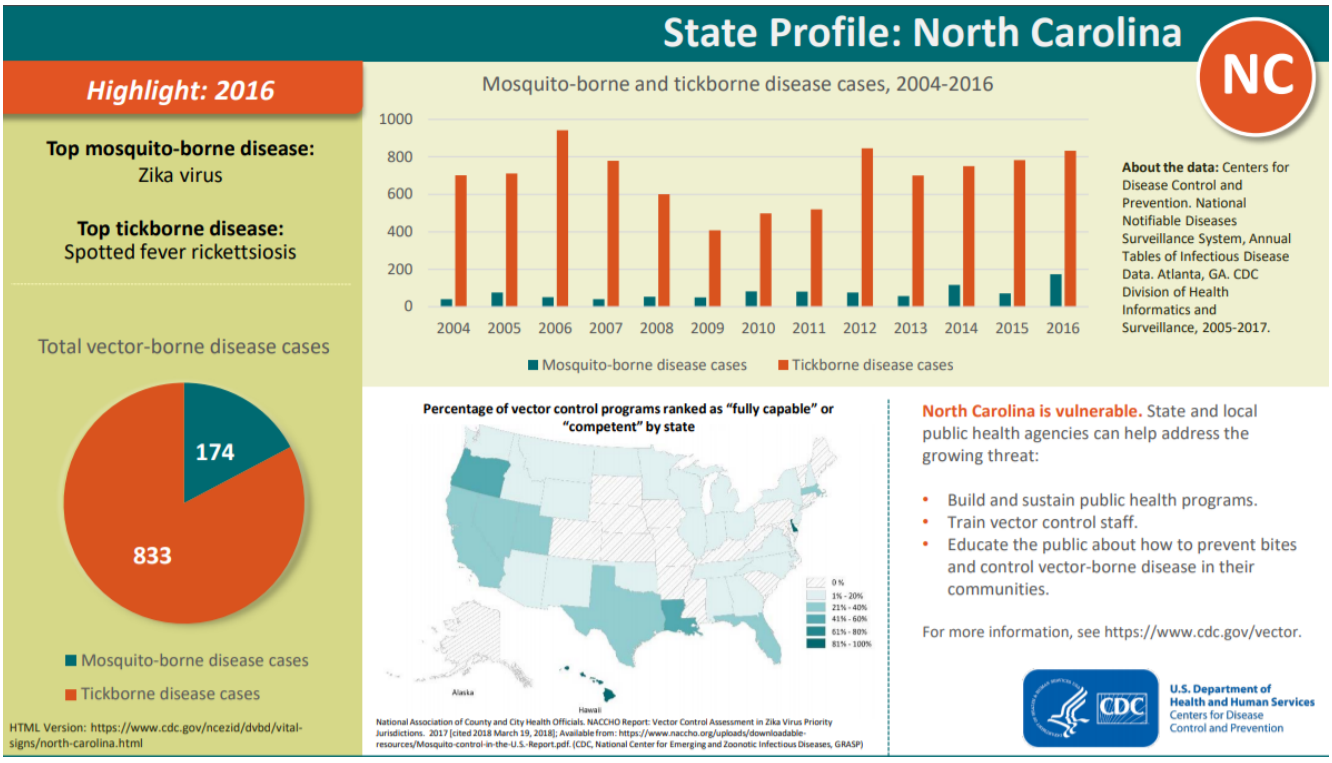
North Carolina Division of Public Health Hopes to Confirm Lyme Expansion into NC
By Dr. Alexis Barbarin, Public Health Entomologist

The North Carolina Division of Public Health Communicable Disease Branch (CDB) has taken the first steps to uncovering the extent of Lyme expansion into North Carolina. Research published by Paul Lantos in 2015 used human disease surveillance data to suggest that Lyme will continue to creep into North Carolina along the southwestern border of Virginia. With the help of CDC Expanding Laboratory Capacity (ELC) funding, the Communicable Disease branch contracted with Dr. Gideon Wasserberg at UNC-G to conduct tick surveillance in five counties in the northwestern part of the state. Those counties include Ashe, Allegheny Surry, Wilkes, and Yadkin. Entomological surveillance in these five counties is ongoing, and ticks collected will be sent to the CDC in Fort Collins for pathogen testing. Preliminary results indicate that *Borrelia burgdorferi* is present in ticks collected via flagging in Stokes and Rockingham Counties, and collected off of deer hosts in Stokes, Rockingham, Yadkin, and Forsyth Counties.

Additionally, the Communicable Disease Branch is also kicking off the North Carolina Tick Identification and Cataloging Program or NC TIC! In an effort to understand the distribution of ticks in North Carolina, state public health entomologists will identify and catalog ticks submitted by veterinarians throughout the state. Data will be coupled with human disease surveillance to identify counties most at risk for high incidence of Rocky Mountain spotted fever, and Lyme disease; data will also be used to determine counties most in need of public education programming for vector borne disease prevention.

Report from the National Center for Emerging and Zoonotic Infectious Diseases (NCEZID)

North Carolina is vulnerable. State and local public health agencies can help address the growing threat.



www.cdc.gov/ncezid/dvbd/vital-signs/pdfs/State-Profile-NC-P.pdf
www.cdc.gov/ncezid/dvbd/vital-signs/north-carolina.html

TIC-NC Activities

Thanks to Dr. Troy Williams at Boehringer-Ingelheim Animal Health for providing support for our booklets and having his reps distribute them to vet offices all over North Carolina. We are hoping he will be able to expand the distribution into Virginia.

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North Carolina and the South

NC study of American dog ticks finds a few carry the RMSF bacteria and many carry related bacteria

Prevalence of *Rickettsia* Species (Rickettsiales: Rickettsiaceae) in *Dermacentor variabilis* Ticks (Acari: Ixodidae) in North Carolina

The American dog tick, *Dermacentor variabilis* (Say), is a vector of spotted fever group (SFG) rickettsiae, including *Rickettsia rickettsii* the causative organism of Rocky Mountain spotted fever (RMSF). In North Carolina, SFG rickettsioses (including RMSF) are a leading cause of tick-borne illness. Knowledge of the infection rate and geographic distribution of *D. variabilis* ticks infected with *Rickettsia* spp. provides information on the spatial distribution of public health risk. Accordingly, we extracted genomic DNA from adult *D. variabilis* collected from field habitats in 32 North Carolina counties from 2009 to 2013. A nested PCR assay of the 23S-5S intergenic spacer (IGS) region of *Rickettsia* coupled with reverse line blot hybridization (RLBH) with species-specific probes was used to detect and identify rickettsiae to species.

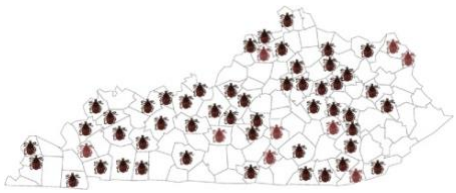
Approximately half of the 532 tick DNA samples exhibited a band of the expected size on agarose gels, indicating infection with *Rickettsia* spp. RLBH analyses showed *R. amblyommatis*(formerly '*Candidatus* R. amblyommii'), *R. parkeri,* and *R. montanensis* were predominant, while other *Rickettsia* species detected included *R. conorii*-like, *R. massiliae*, *R. rhipicephali*, *R. canadensis*, *R. bellii,* and some unknown *Rickettsia* spp. Some ticks were infected with more than one *Rickettsia* species.

Notably, several *Rickettsia*-positive ticks harbored *R. rickettsii*. DNA sequencing was performed on a portion of the 23S-5S IGS amplicons and the results were concordant with RLB assay results. We conclude that *Rickettsia* spp. are common in *D. variabilis* in North Carolina. Geographic patterns in the occurrence of *Rickettsia*-infected *D. variabilis* ticks across the counties sampled are discussed.
Kakumanu et al. *Journal of Medical Entomology*, May 2018. https://doi.org/10.1093/jme/tjy074

Blacklegged and Gulf Coast ticks now found in Kentucky, 11% positive for the Lyme bacteria and 3% for Rickettsia parkeri respectively

Widespread distribution of ticks and selected tick-borne pathogens in Kentucky (USA)

The geographical distribution of *Ixodes scapularis* and *Amblyomma maculatum* ticks is poorly understood in Kentucky. We conducted a convenience survey of wildlife species (white-tailed deer (*Odocoileus virginianus*), elk (*Cervus canadensis*) and black bears (*Ursus americanus*)) for ticks from October 2015 to January 2017. We detected four tick species including *Amblyomma americanum*, *Dermacentor albipictus*, *I. scapularis* and *A. maculatum*. Although the former two tick species were previously known to be widely distributed in Kentucky, we also found that *I. scapularis* and *A. maculatum* were also widespread. Because of the limited data available for pathogens from *I. scapularis* and *A. maculatum*, we tested them for *Borrelia* and *Rickettsia* spp. by polymerase chain reaction assays. Prevalence of *Borrelia burgdorferi* sensu stricto and *Rickettsia parkeri* were 11% and 3%, respectively. These data indicate that public health measures are important to prevent tick-borne diseases in Kentucky. Lockwood et al. Ticks and Tick-borne Mar 2016 Diseases https://doi.org/10.1016/j.ttbdis.2018.02.016



Ozark studies finds lone star ticks more prevalent in valleys and northern slopes

Landscape Physiognomy Influences Abundance of the Lone Star Tick, *Amblyomma americanum*(Ixodida: Ixodidae), in Ozark Forests

The lone star tick, *Amblyomma americanum* Linnaeus (Ixodida: Ixodidae), is emerging as an important human disease vector in the United States… We investigated how habitat features predict host-seeking *A. americanum* adult and nymph abundance within a 12-ha oak-hickory forest plot in the Missouri Ozarks.

We found that both nymphs and adults had greater abundance in valleys as well as on northern-facing aspects. Moreover, nymph abundance was negatively related to temperature variance, while adult abundance had a negative relationship with elevation. These results demonstrate that managers in this region may be able to predict local tick abundance through simple physiognomic factors and use these parameters for targeted management action. Solny et al. *Journal of Medical Entomology*, tjy038, https://doi.org/10.1093/jme/tjy038

First report of Borrelia lonestari in birds

Detection of *Borrelia Burgdorferi* and *Borrelia Lonestari* in Birds in Tennessee

Lyme disease in the United States is caused by the bacterial spirochete *Borrelia burgdorferi* s.s. (Johnson, Schmid, Hyde, Steigerwalt, and Brenner), which is transmitted by tick vectors *Ixodes scapularis* (Say) and *I. pacificus* (Cooley and Kohls). *Borrelia lonestari*, transmitted by the tick *Amblyomma americanum* L., may be associated with a related syndrome, southern tick-associated rash illness (STARI). *Borrelia lonestari* sequences, reported primarily in the southeastern states, have also been detected in ticks in northern states. It has been suggested that migratory birds may have a role in the spread of Lyme disease spirochetes. This study evaluated both migratory waterfowl and

nonmigratory wild turkeys (*Meleagris gallopavo silvestris*, Eastern wild turkey) for *B. burgdorferi* and *B. lonestari* DNA sequences. A total of 389 avian blood samples (163 migratory birds representing six species, 125 wild turkeys harvested in habitats shared with migratory birds, 101 wild turkeys residing more distant from migratory flyways) were extracted, amplified, and probed to determine *Borrelia* presence and species identity. Ninety-one samples were positive for *Borrelia* spp. Among migratory birds and turkeys collected near migration routes, *B. burgdorferi* predominated. Among turkeys residing further away from flyways, detection of *B. lonestari* was more common. All *A. americanum* ticks collected from these areas were negative for *Borrelia* DNA; no *I. scapularis* were found. To our knowledge, this represents the first documentation of *B. lonestari* among any birds. Jordan et al. J Med Entomol 46(1):131-138. 2009 doi.org/10.1603/033.046.0117

For a slide show on Alabama ticks

April 2018 **Ticks** of Alabama, E Merritt - 2018
Ticks of Alabama Created by: Emily Merritt, School of Forestry and Wildlife Sciences, Auburn University
http://aurora.auburn.edu/xmlui/bitstream/handle/11200/49137/Presentation%20for%20Hunter%20Ed.%20Class%207-12-2017.pdf?sequence=1&isAllowed=y

◘◘ National Section ◘◘

Report from the CDC- tickborne disease reports have doubled in past 12 years

Trends in Reported Vectorborne Disease Cases — United States and Territories, 2004–2016.

Vectorborne diseases are major causes of death and illness worldwide. Data reported to the National Notifiable Diseases Surveillance System for 16 notifiable vectorborne diseases during 2004–2016 were analyzed; findings were tabulated by disease, vector type, location, and year.

A total 642,602 cases were reported. The number of annual reports of tickborne bacterial and protozoan diseases *more than doubled* during this period, from >22,000 in 2004 to >48,000 in 2016. Lyme disease accounted for 82% of all tickborne disease reports during 2004–2016. The occurrence of mosquitoborne diseases was marked by virus epidemics.

Vectorborne diseases are a large and growing public health problem in the United States, characterized by geographic specificity and frequent pathogen emergence and introduction. Differences in distribution and transmission dynamics of tickborne and mosquitoborne diseases are often rooted in biologic differences of the vectors. To effectively reduce transmission and respond to outbreaks will require major national improvement of surveillance, diagnostics, reporting, and vector control, as well as new tools, including vaccines. Rosenberg, et al. *Vital Signs*: MMWR Morb Mortal Wkly Rep 2018;67:496–501. DOI: http://dx.doi.org/10.15585/mmwr.mm6717e1. Entire paper is free.

TABLE. Vectorborne disease cases reported to National Notifiable Disease Surveillance System — U.S. states and territories, 2004–2016*

	Year													
Disease	**2004**	**2005**	**2006**	**2007**	**2008**	**2009**	**2010**	**2011**	**2012**	**2013**	**2014**	**2015**	**2016**	**Total**
Tickborne diseases														
Lyme disease†	19,804	23,305	19,931	27,444	35,198	38,468	30,158	33,097	30,831	36,307	33,461	38,069	36,429	**402,502**
Anaplasmosis/Ehrlichiosis§	875	1,404	1,455	1,999	2,107	2,267	2,615	3,586	3,725	4,551	4,488	5,137	5,750	**39,959**
Spotted fever rickettsiosis¶	1,713	1,936	2,288	2,221	2,563	1,815	1,985	2,802	4,470	3,359	3,757	4,198	4,269	**37,376**
Babesiosis**	N	N	N	N	N	N	N	1,128	937	1,796	1,760	2,100	1,910	**9,631**
Tularemia	134	154	95	137	123	93	124	166	149	203	180	314	230	**2,102**
Powassan virus	1	1	1	7	2	6	8	16	7	15	8	7	22	**101**
Subtotal tickborne diseases	**22,527**	**26,800**	**23,770**	**31,808**	**39,993**	**42,649**	**34,890**	**40,795**	**40,119**	**46,231**	**43,654**	**49,825**	**48,610**	**491,671**

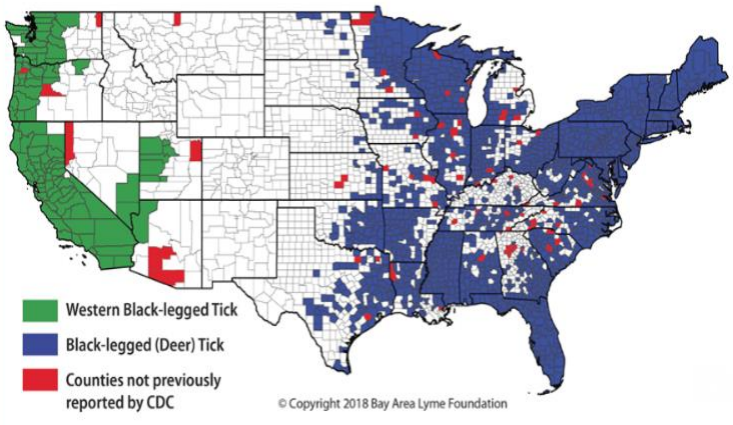
Citizen-Scientist Study is First to Find Ticks Capable of Carrying Lyme Disease in 83 U.S. Counties Where Previously Undetected

Entire paper is free of charge at:
https://journals.plos.org/plosone/article?id=10.1371/journal.pone.0199644

PORTOLA VALLEY, CA, July 12, 2018 — Bay Area Lyme Foundation, a leading nonprofit funder of innovative Lyme disease research in the U.S., today announced the results of the first citizen-scientist study to evaluate the prevalence of disease-carrying ticks throughout the United States. Conducted through a partnership with Northern Arizona University and Colorado State University and published in the peer-review journal PLOS ONE, the study is based on a massive sample of more than 16,000 ticks collected from 49 U.S. states and Puerto Rico. The study found ticks capable of carrying Lyme and other tick-borne diseases in 83 counties (in 24 states) where these ticks had not been previously recorded. The program received a six-fold increase in tick submissions over initial estimates, representing unprecedented national coordination of a 'citizen science' effort and diagnostic investigation.

"Identifying geographic patterns of tick-human contact provides valuable insight that may help public health officials, patients and physicians become more vigilant about Lyme disease, increasing early diagnosis," stated Linda Giampa, executive director at Bay Area Lyme Foundation. "Based on these findings, it is critical that residents throughout the country take precautions and know the symptoms of tick-borne infections, even in areas where ticks have not previously been shown to cause disease."

The 24 states that contain counties with newly documented *Ixodes scapularis* (deer tick) or *Ixodes pacificus* (Western black-legged tick) populations are: Alabama, Arizona, Georgia, Illinois, Indiana, Iowa, Kansas, Kentucky, Louisiana, Michigan, Minnesota, Montana, Missouri, Nevada, North Carolina, Ohio, Oregon, South Carolina, Tennessee, Texas, Utah, Virginia, Washington, and Wisconsin.



"The overwhelming study participation from residents throughout the country and the surprising number of counties impacted demonstrates that great interest and need exist throughout the country for this information," said lead author Nate Nieto, PhD, associate professor in NAU's Department of Biological Sciences. "This study offers a unique and valuable perspective because it looks at risk to humans that goes beyond the physician-reported infection rates and involves ticks that were found on or near people."

Not all public health agencies throughout the United States have tick collection, disease risk assessment systems and/or tick-borne disease reporting requirements. Importantly, this study showed disease-causing pathogens were found in areas that may not have sufficient reporting structures. For example, researchers found ticks carrying *Babesia*, microscopic parasites carried by ticks that cause the disease babesiosis, in 26 counties (across 10 states) in which the public health department does not require physicians to report cases of babesiosis.

Other interesting findings include:

- *Anaplasma, Babesia,* and *Borrelia* pathogens were found in all three of the most commonly encountered ticks collected – *Ixodes, Amblyomma* and *Dermacentor*species
- All life stages of these three tick species, including some larvae, were found to be infected with both *Borrelia burgdorferi* and *Borrelia miyamotoi*
- Several *Amblyomma americanum,* which is commonly known as the Lone Star tick and capable of carrying bacteria that cause disease in humans, were found in Northern California, the first known report of this tick in the state

The study stemmed from the free tick-testing initiative supported by Bay Area Lyme Foundation and conducted by Northern Arizona University. Ticks sent to the initiative from January 2016 through August 2017 were tested free of charge for four of the most common bacterial infections: *Borrelia burgdorferi,* which causes Lyme disease; *Borrelia miyamotoi,* which causes tick-borne relapsing fever; *Anaplasma phagocytophilum,* which causes human granulocytic anaplasmosis, and the protozoan pathogen, *Babesia microti*. These data were categorized, mapped, and recorded, as well as provided to the submitter. Ticks were submitted from every state except Alaska.

Typical tick collection methods involve researchers canvasing various terrain with large sheet-like material, which collects ticks, but does not take into account a tick's natural attraction to mammals. The limitations of citizen studies include uneven awareness of the program across geographic areas, the fact that ticks may remain attached to a person as they travel, and reliance on motivation of people who encounter ticks.

Study from the CDC on permethrin-treated clothing—it works

The study involved three types of ticks that, in the United States, are major carriers of disease — including Lyme disease, Rocky Mountain spotted fever, and what's known as southern tick-associated rash illness, or STARI.

The clothes were pretreated with permethrin, a synthetic form of an insect-thwarting compound from the chrysanthemum flower. It's used in insecticide sprays and shampoos and creams that treat lice and scabies.

Several companies already market permethrin-treated shirts, pants, socks and other clothing, as a way to ward off disease-transmitting pests. The new study adds to evidence that the garments are indeed toxic to ticks, according to senior researcher Lars Eisen, of the U.S. Centers for Disease Control and Prevention.

"All tested tick species and life stages experienced the 'hot-foot' effect after coming into contact with permethrin-treated clothing," Eisen said. This link has good information and videos: https://www.cbsnews.com/news/tick-repellent-permethrin-clothing-really-works-study/

Dog owners: the latest on veterinary data and treatment recommendations for dogs and cats.

American College of Veterinary Internal Medicine (ACVIM) consensus update on Lyme borreliosis in dogs and cats.

An update of the 2006 American College of Veterinary Internal Medicine (ACVIM) Small Animal Consensus Statement on Lyme Disease in Dogs: Diagnosis, Treatment, and Prevention was presented at the 2016 ACVIM Forum in Denver, CO, followed by panel and audience discussion and a drafted consensus statement distributed online to diplomates for comment. The updated consensus statement is presented below. The consensus statement aims to provide guidance on the diagnosis, treatment, and prevention of Lyme borreliosis in dogs and cats. Littman et al. J Vet Intern Med. 2018 Mar 22. https://www.ncbi.nlm.nih.gov/pubmed/29566442
(Eds. Note: this is an open access paper meaning you can get it at no cost. Search the doi #.)

Lone star and dog ticks less sensitive to permethrin-treated clothing, but clothing still reasonably effective

Contact Irritancy and Toxicity of Permethrin-Treated Clothing for *Ixodes scapularis*, *Amblyomma americanum*, and *Dermacentor variabilis* Ticks (Acari: Ixodidae)

Clothing treated with the pyrethroid permethrin is available in the United States as consumer products to prevent tick bites.

A comparison of the impact of a permethrin-treated textile across tick species and life stages revealed the strongest effect on *I. scapularis* nymphs (0% with normal movement 1 h after a 1-min exposure), followed by *A. americanum* nymphs (14.0%), *I. scapularis* females (38.0%), *D. variabilis* females (82.0%), and *A. americanum* females (98.0%).

Loss of normal movement for all ticks 1 h after contact with the permethrin-treated textile required exposures of 1 min for *I. scapularis* nymphs, 2 min for *A. americanum* nymphs, and 5 min for female *I. scapularis*, *D. variabilis*, and *A. americanum* ticks. We conclude that use of permethrin-treated clothing shows promise to prevent bites by medically important ticks. Further research needs are discussed. Robert P et al. *Journal of Medical Entomology*. Entire paper free of charge: https://doi.org/10.1093/jme/tjy062

Knowledge and preventive behaviors towards tick-borne diseases in Delaware

Delaware is among the top 10 states in the United States with the highest incidence for Lyme disease. The Delaware Division of Public Health (DPH) therefore has been working diligently to prevent and control tick-borne diseases through a variety of interventions including awareness campaigns and educational programs. To assess if tick-borne disease related information is reaching Delawareans through these programs, DPH in collaboration with Delaware State University administered an anonymous survey to 1755 participants in all three of Delaware counties during May 2017.

The questionnaire assessed individuals' general knowledge about tick-borne diseases and performance of selected tick-borne disease prevention methods Overall, participants' knowledge of tick-borne diseases was poor; only 38.4% of respondents stated that ticks were problematic in Delaware and only 12.7% of respondents "strongly agreed" that Lyme disease is a problem in Delaware.

A little over half of the respondents (51.6%) indicated having seen advertisements/infomercials/flyers for protection from ticks or the disease agents spread by ticks; the most common places for viewing these advertisements were doctor's offices and through social media. The reported frequency of performing preventive behaviors was variable and disparities were observed by age, race, gender and county of residence. Existing public health communication efforts on tick-borne diseases in Delaware do not appear to be having the desired effect. This study provides important baseline information to rethink communication channels for education and more effectively guide future tick-borne disease awareness campaigns. Gupta et al. Ticks and Tick-borne Diseases, 2018;9:615-622. *doi.org/10.1016/j.ttbdis.2018.01.006.*

Lone star ticks unlikely to transmit Lyme disease

Amblyomma americanum (Acari: Ixodidae) Ticks Are Not Vectors of the Lyme Disease Agent, *Borrelia burgdorferi* (Spirocheatales: Spirochaetaceae): A Review of the Evidence

In the early 1980s, *Ixodes* spp. ticks were implicated as the key North American vectors of *Borrelia burgdorferi* (Johnson, Schmid, Hyde, Steigerwalt and Brenner) (Spirocheatales: Spirochaetaceae), the etiological agent of Lyme disease. Concurrently, other human-biting tick species were investigated as potential *B. burgdorferi* vectors. Rashes thought to be erythema migrans were observed in patients bitten by *Amblyomma americanum* (L.) (Acari: Ixodidae) ticks, and spirochetes were visualized in a small percentage of *A. americanum* using fluorescent antibody staining methods, sparking interest in this species as a candidate vector of *B. burgdorferi*.

Using molecular methods, the spirochetes were subsequently described as *Borrelia lonestari* sp. nov. (Spirocheatales: Spirochaetaceae), a transovarially transmitted relapsing fever *Borrelia* of uncertain clinical significance. In total, 54 surveys from more than 35 research groups, involving more than 52,000 ticks, have revealed a low prevalence of *B. lonestari*, and scarce *B. burgdorferi*, in *A. americanum*.

In Lyme disease-endemic areas, *A. americanum* commonly feeds on *B. burgdorferi*-infected hosts; the extremely low prevalence of *B. burgdorferi* in this tick results from a saliva barrier to acquiring infection from infected hosts. At least nine transmission experiments involving *B. burgdorferi* in *A. americanum* have failed to demonstrate vector competency. Advancements in molecular analysis strongly suggest that initial reports of *B. burgdorferi* in *A. americanum* across many states were misidentified *B.*

lonestari, or DNA contamination, yet the early reports continue to be cited without regard to the later clarifying studies. In this article, the surveillance and vector competency studies of *B. burgdorferi* in *A. americanum* are reviewed, and we conclude that *A. americanum* is not a vector of *B. burgdorferi*. Stromdahl et al. *Journal of Medical Entomology*, XX(X), 2018, 1–14
https://doi.org/10.1093/jme/tjx250

Ticks from cats in the United States: patterns of infestation and infection with pathogens

Tick infestations were documented on 332 cats from 18 states in the United States. Adult and immature stages of *Ixodes*, *Amblyomma*, and *Dermacentor* were recovered.

Molecular assays documented infection with at least one pathogen in 17.1% of ticks. One in 5 cats with ticks spent ≤30% time outdoors; 10 were reportedly indoor only.

Results show cats at risk of tick infestation and exposure to tick-borne pathogens. Little et al. Veterinary Parasitology. http://doi.org/10.1016/j.vetpar.2018.05.002

Ant-derived compounds repel lone star ticks

Repellencies and toxicities of five ant-derived defensive compounds against the lone star tick, *Amblyomma americanum* (Acari: Ixodidae)

The lone star tick, *Amblyomma americanum*, is a vector of several important human and animal diseases. This tick species has rapidly expanded in its geographic distribution, and its aggressive behavior has increased the risk of tick-borne diseases in these new areas. Repellents are recommended by the Centers for Disease Control and Prevention (CDC) for protection against tick bites.

DEET is the most common repellent, but public concerns over its safety have increased the need for alternative safe and efficacious tick repellents. Several naturally derived animal compounds have been tested against other species of ticks or other arthropod pests, but not against *A. americanum*. Based on EC_{50} values obtained using a vertical paper bioassay, decylamine and MT-710 (a 2-tridecanone formulation) were found to be as repellent as DEET. Those two substances along with 2-tridecanone were also found to be as repellent as DEET when their EC_{95} values were compared. Lone star ticks were more susceptible to the toxic effects of DEET in glass vial assays than all of the ant-derived defensive compounds/formulations.

These results suggest that the ant-derived defensive compounds are likely more effective lone star tick repellents than DEET, but they are not as toxic as DEET towards the ticks. The suitability of these compounds for use as personal repellents, as well as at the landscape scale, should be explored. Machtinger, E et al. Appl Entomol Zool (2018). https://doi.org/10.1007/s13355-018-0559-7

Identification of Novel Viruses in *Amblyomma americanum*, *Dermacentor variabilis*, and *Ixodes scapularis* Ticks

Ticks carry a wide range of known human and animal pathogens and are postulated to carry others with the potential to cause disease. Here we report a discovery effort wherein unbiased high-throughput sequencing was used to characterize the virome of 2,021 ticks, including *Ixodes scapularis* (*n* = 1,138), *Amblyomma americanum* (*n* = 720), and *Dermacentor variabilis* (*n* = 163), collected in New York, Connecticut, and Virginia in 2015 and 2016. We identified 33 viruses, including 24 putative novel viral species. The most frequently detected viruses were phylogenetically related to members of the *Bunyaviridae* and *Rhabdoviridae* families, as well as the recently proposed *Chuviridae*. Our work expands our understanding of tick viromes and underscores the high viral diversity that is present in ticks.

IMPORTANCE The incidence of tick-borne disease is increasing, driven by rapid geographical expansion of ticks and the discovery of new tick-associated pathogens. The examination of the tick microbiome is essential in order to understand the relationship between microbes and their tick hosts and to facilitate the identification of new tick-borne pathogens. Genomic analyses using unbiased high-throughput sequencing platforms have proven valuable for investigations of tick bacterial diversity, but the examination of tick viromes has historically not been well explored. By performing a comprehensive virome analysis of the three primary tick species associated with human disease in the United States, we gained substantial insight into tick virome diversity and can begin to assess a potential role of these viruses in the tick life cycle. Tokarz et al. https://msphere.asm.org/content/3/2/e00614-17

Powassan Virus Disease in the United States, 2006–2016

Background: Powassan virus (POWV) is a tick-borne flavivirus that causes rare, but often severe, disease in humans. POWV neuroinvasive disease was added to the U.S. nationally notifiable disease list in 2001 and nonneuroinvasive disease was added in 2004. The only previous review of the epidemiology of POWV disease in the United States based on cases reported to the Centers for Disease Control and Prevention (CDC) covered the period from 1999 through 2005.

Methods: We describe the epidemiology and clinical features of laboratory-confirmed POWV disease cases reported to CDC from 2006 through 2016.

Results: There were 99 cases of POWV disease reported during the 11-year period, including 89 neuroinvasive and 10 nonneuroinvasive disease cases. There was a median of seven cases per year (range: 1–22), with the highest numbers of cases reported in 2011 (*n* = 16), 2013 (*n* = 15), and 2016 (*n* = 22). Cases occurred throughout the year, but peaked in May and June. Cases were reported primarily from northeastern and north-central states. Overall, 72 (73%) cases were in males and the median age was 62 years (range: 3 months–87 years). Of the 11 (11%) cases who died, all were aged >50 years. The average annual incidence of neuroinvasive POWV disease was 0.0025 cases per 100,000 persons.

Conclusions: POWV disease can be a severe disease and has been diagnosed with increased frequency in recent years. However, this might reflect increased disease awareness, improved test availability, and enhanced surveillance efforts. Clinicians should consider POWV disease in patients presenting with acute encephalitis or aseptic meningitis who are resident in, or have traveled to, an appropriate geographic region. Krow-Lucal et al. Vector-Borne and Zoonotic Diseases. doi.org/10.1089/vbz.2017.2239

Paper presents model suggesting reasons for regional differences in Lyme disease risk

The role of Ixodes scapularis, Borrelia burgdorferi and wildlife hosts in Lyme disease prevalence: A quantitative review

Due to the ongoing expansion of Ixodes scapularis (blacklegged tick) throughout the northeastern and midwestern United States, there is need to identify the role wildlife hosts play in the establishment and maintenance of tick populations. To quantify and synthesize the patterns of I. scapularis and Borrelia burgdorferi sensu stricto and sensu lato prevalence relative to wildlife hosts, we reviewed the findings of independent studies conducted throughout the United States…

We found that only 13% of the wildlife mammals sampled comprised species other than Odocoileus virginianus (white-tailed deer) and Peromyscus leucopus (white-footed mouse). To examine whether there were regional differences between the Northeast, Midwest and the Southeast U.S. in I. scapularis infestation rates on wildlife hosts, we used general linear models (glm), with post hoc pairwise comparisons.

In most cases, detection of I. scapularis and B. burgdorferi was significantly higher in the Northeast than the Midwest. Using data on host-specific I. scapularis infestation prevalence, B. burgdorferi prevalence in feeding larvae, and host permissiveness, we developed an epizootiological model to determine the relative contributions of individual hosts to B. burgdorferi-infected nymphs. Our model provides additional evidence that wildlife hosts other than P. leucopus may contribute more to Lyme disease risk than commonly thought. To aid in understanding the ecology of Lyme disease, we propose that additional studies sample non-Peromyscus spp. hosts to obtain more detailed tick and pathogen infestation and infection estimates, respectively, for these less frequently sampled wildlife hosts. Halsey SJ et al. Ticks and Tick-borne Diseases. 2018 Apr 16.

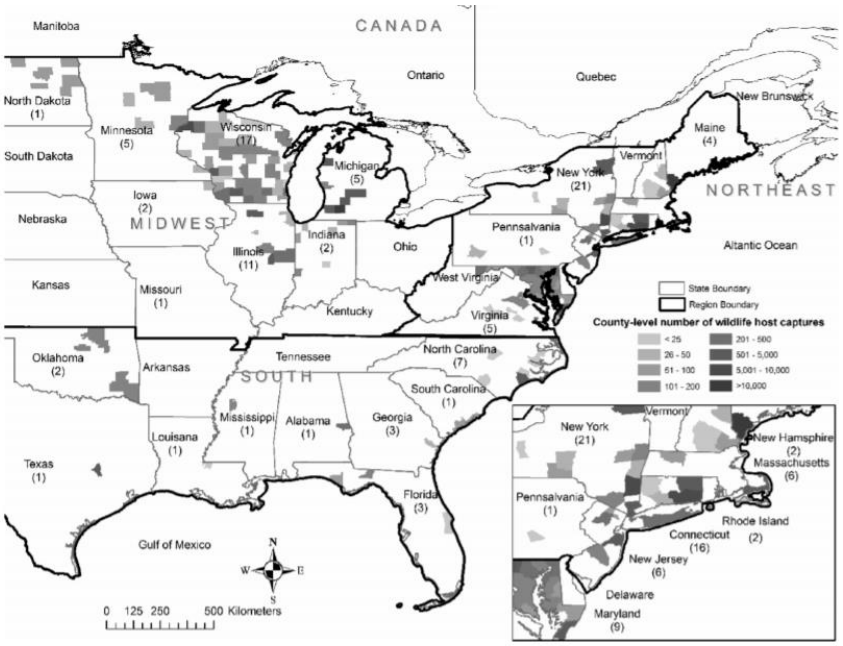


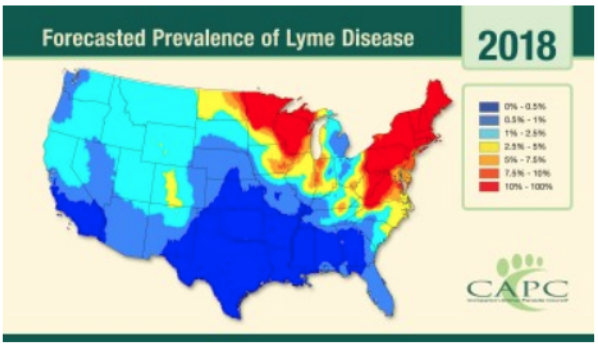
Fig. 2. Map of eastern United States where studies involving animal captures for research on the ecology of Lyme disease took place from 1970 to 2014. The number of studies in each state is indicated in parentheses. Regions according to the US Census Bureau 2010.

What the *American Veterinarian* predicts about the spread of Lyme disease for this year

Each year, the Companion Animal Parasite Council (CAPC) releases an annual parasite forecast for the upcoming year. For 2018, the forecast does not look optimistic.

Lyme Disease

The number of **Lyme disease cases in humans** has tripled over the past 20 years, and the disease continues to rise in prevalence among our furry counterparts. But while infection in dogs occurs more commonly in areas with dense populations of ticks—New England, along the East Coast, and in the upper Midwestern and West Coast states—the CAPC predicts that non-endemic areas will start to see a rise in Lyme disease cases.



As the white-tailed deer population grows across the country and migratory birds carry ticks from endemic to non-endemic areas, pet owners and veterinarians need to be prepared.

The CAPC points out the following about the predicted geographic spread of Lyme disease in 2018:

- Previously non-endemic areas, such as **North Dakota**, **South Dakota**, **Iowa**, **Missouri**, **southern Illinois**, **Ohio**, **Kentucky**, **Tennessee**, and **North Carolina**, need to be aware of the potential spread of Lyme disease.
- **Western Pennsylvania, eastern Ohio**, **West Virginia**, and the **Appalachian region in Virginia** will reportedly have an active year.
- A less active year is being predicted for areas from **Washington, DC** to **Philadelphia, Pennsylvania** and eastward, as well as **the Boston/Cape Cod**, **Massachusetts** region.

http://www.americanveterinarian.com/news/heartworm-lyme-disease-forecast-looks-gloomy

International & General Section

Paper on Intractable Fatigue with Physical and Mental Impairments

The Putative Role of Viruses, Bacteria, and Chronic Fungal Biotoxin Exposure in the Genesis of Intractable Fatigue Accompanied by Cognitive and Physical Disability.

Patients who present with severe intractable apparently idiopathic fatigue accompanied by profound physical and or cognitive disability present a significant therapeutic challenge. The effect of psychological counseling is limited, with significant but very slight improvements in psychometric measures of fatigue and disability but no improvement on scientific measures of physical impairment compared to controls. Similarly, exercise regimes either produce significant, but practically unimportant, benefit or provoke symptom exacerbation. Many such patients are afforded the

exclusionary, non-specific diagnosis of chronic fatigue syndrome if rudimentary testing fails to discover the cause of their symptoms.

More sophisticated investigations often reveal the presence of a range of pathogens capable of establishing life-long infections with sophisticated immune evasion strategies, including Parvoviruses, HHV6, variants of Epstein-Barr, Cytomegalovirus, Mycoplasma, and Borrelia burgdorferi. Other patients have a history of chronic fungal or other biotoxin exposure.

Herein, we explain the epigenetic factors that may render such individuals susceptible to the chronic pathology induced by such agents, how such agents induce pathology, and, indeed, how such pathology can persist and even amplify even when infections have cleared or when biotoxin exposure has ceased. The presence of active, reactivated, or even latent Herpes virus could be a potential source of intractable fatigue accompanied by profound physical and or cognitive disability in some patients, and the same may be true of persistent Parvovirus B12 and mycoplasma infection. A history of chronic mold exposure is a feasible explanation for such symptoms, as is the presence of B. burgdorferi. The complex tropism, life cycles, genetic variability, and low titer of many of these pathogens makes their detection in blood a challenge. Examination of lymphoid tissue or CSF in such circumstances may be warranted. Morris G, et al. Mol Neurobiol.2016 May;53(4):2550-71. https://www.ncbi.nlm.nih.gov/pubmed/26081141.

Persistent Borrelia Infection in Patients with Ongoing Symptoms of Lyme Disease

Introduction: Lyme disease is a tickborne illness that generates controversy among medical providers and researchers. One of the key topics of debate is the existence of persistent infection with the Lyme spirochete, Borrelia burgdorferi, in patients who have been treated with recommended doses of antibiotics yet remain symptomatic. Persistent spirochetal infection despite antibiotic therapy has recently been demonstrated in non-human primates. We present evidence of persistent Borrelia infection despite antibiotic therapy in patients with ongoing Lyme disease symptoms.

Methods: In this pilot study, culture of body fluids and tissues was performed in a randomly selected group of 12 patients with persistent Lyme disease symptoms who had been treated or who were being

treated with antibiotics. Cultures were also performed on a group of ten control subjects without Lyme disease. The cultures were subjected to corroborative microscopic, histopathological and molecular testing for Borrelia organisms in four independent laboratories in a blinded manner. Results: Motile spirochetes identified histopathologically as Borrelia were detected in culture specimens, and these spirochetes were genetically identified as Borrelia burgdorferi by three distinct polymerase chain reaction (PCR)-based approaches. Spirochetes identified as Borrelia burgdorferi were cultured from the blood of seven subjects, from the genital secretions of ten subjects, and from a skin lesion of one subject. Cultures from control subjects without Lyme disease were negative for Borrelia using these methods.

Conclusions: Using multiple corroborative detection methods, we showed that patients with persistent Lyme disease symptoms may have ongoing spirochetal infection despite antibiotic treatment, similar to findings in non-human primates. The optimal treatment for persistent Borrelia infection remains to be determined. Middelveen et al. *Healthcare*. Vol. 6. No. 2. Multidisciplinary Digital Publishing Institute, 2018. https://www.ncbi.nlm.nih.gov/pmc/articles/PMC6023324/

21.6% forest workers in Belgium positive for Lyme disease

Seroprevalence of Borrelia burgdorferi in Belgian forestry workers and associated risk factors
As forest is the preferred environment for ticks, forestry workers are exposed to tick bites and tick-borne diseases. A group of 310 Belgian forest workers was examined to assess the seroprevalence of anti-Borrelia IgG antibodies. Using principal component analysis and binary logistic regression, the joint effects of individual characteristics and environmental characteristics were examined.

Sixty-seven of the 310 workers were seropositive for Lyme disease (LD), leading to a seroprevalence of 21.6%. The seroprevalence was higher among forest workers visiting forests more frequently (P = 0.003) or who reported over 100 tick bites (P-value < 0.001). The intensity of tick bites and the use of protection measures against tick bites have a positive impact on LD seroprevalence while the quantity of shadow from trees at ground level had a negative one. De Keukeleire et al. Parasites & Vectors (2018) 11:277 https://parasitesandvectors.biomedcentral.com/articles/10.1186/s13071-018-2860-2

List of diseases that may involve Lyme disease or manifest as Lyme disease.

https://on-lyme.org/en/solvers/misdiagnoses

The links lead to the relevant PubMed articles that show the connection.

Special section showing two public comments recently made to the federal Tick-Borne Disease Working Group

TBDWG June 21, 2018 - Written Public Comment

All Tick-Borne Disease Working Group (TBDWG) meetings dedicate time for public comment. The TBDWG invited written public comment on issues related to the Working Group's charge. Written comments are submitted via email to the TBDWG mailbox. Below are the written comments submitted, to date, by individuals for the June 2018 meeting. www.hhs.gov/ash/advisory-committees/tickbornedisease/meetings/2018-06-21/written-public-comment/index.html

Ed. note- All the comments are interesting, most valid, some less so. Here are two:

Lorraine Johnson

Shared Medical Decision Making and the Two Standards of Care in Lyme Disease
HHS TBDWG June 18, 2018 comments submitted on behalf of LymeDisease.org by Lorraine Johnson, CEO

There is considerable uncertainty in the diagnosis and treatment of Lyme disease. Most patients know that they should be told the risks and benefits of different diagnostic and treatment approaches of Lyme disease. They also know that they should be told the risks and benefits of different treatment options and be able to make the determination of the best approach in collaboration with their physician. This process is called shared medical decision making and is most often used when science is uncertain, there is no single “best” approach, and trade-offs exist between their benefits and risks and their associated quality of life consequences. Shared decision making is increasingly being promoted by

different government agencies and rigorous evidence assessment protocols. LymeDisease.org believes that the time has come for the government, medical specialty groups, and physicians and to promote shared decision making with Lyme disease patients.

In healthcare, the primary goal is to improve healthcare outcomes that are important to patients. In 2001, the National Academy of Medicine (previously the Institute of Medicine) (NAM) defined patient-centered care as care that is respectful of and responsive to individual patient preferences, needs, and values and that ensures patient values guide all clinical decisions.(1) Patient-centered care focuses on achieving treatment outcomes that patients value, including the restoration of health, prevention of health deterioration and the provision of treatments that have the potential to improve quality of life.(2) To facilitate the development of treatment plans addressing the unique circumstances and values of individual patients, patient-centered care encourages shared medical decision-making.

Shared medical decision-making is an integral part of evidence-based medicine. Evidence-based medicine is the integration of best research evidence with clinical expertise and patient values.(3) Evidence assessment protocols recommended by the NAM, such as Grading of Recommendations Assessment, Development, and Evaluation (GRADE) value the evaluation of outcomes of alternative management strategies and the distribution of values and preferences in patients considering those alternatives as well as shared decision making in encounters between physicians and patients.(4)(5)

The importance of shared medical decision making when different treatment options exist is also being embraced by government agencies. For example, the Patient Centered Outcomes Research Institute,(6) the Food and Drug Administration, (7) the National Quality Forum, and the Agency for Health Research and Quality (8) have each embraced shared-medical decision making as a component of patient centered care. (9) It is also one of the aims of the U.S. Department of Health Services Healthy People 2020 program. (10)

Most recently, the Centers for Medicare and Medicaid Services has begun requiring shared medical decision making for reimbursement of certain procedures. (11) As the CMS explains: "Shared decision making can ensure that treatment decisions, for the many medical conditions that do not have one clearly superior course of treatment, better align with beneficiaries' preferences and values."(12) Under shared decision making, clinicians are viewed as the experts in the evidence and patients are the experts in what matters most to them. (13)

Shared decision making is ideal when there is medical uncertainty and treatment choices involve trade-offs between the risks and benefits of different treatment approaches. For example, breast cancer and prostate cancer patients have tough choices to make. No one knows whether it is better to do watchful waiting, surgery, or hormone therapy for prostate cancer. But we do know that the patient is the one who has to live with the decision and that the medical decision made may significantly affect the course of their life. Often this occurs when there is more than one standard of care for the condition.

Medically recognized standards of care are those accepted by medical experts as appropriate treatments for a disease or condition and commonly used by healthcare professionals. Medical recognition of standards of care is typically represented by publication in a peer-reviewed journal or some form of recognition by a professional medical society. (14) According to the National Guidelines Clearinghouse conflicting guidelines are not uncommon. It has posted conflicting guidelines for over 25 medical conditions and notes that these arise most often when the evidence base for a disease is weak and the guidelines panels hold different values. (15) There have only been only four high level GRADE assessments of the evidence for treating persistent Lyme disease: one by the International Lyme and Associated Diseases Society (ILADS) (16), one by the Hayes and Mead (17) of the Centers

for Disease Control, one by Cochrane (18), and one by England's National Institute for Health and Care Excellence (NICE) (19). All four have acknowledged that the evidence-base for making treatment decisions in Lyme disease is weak.

The National Institute of Health has only funded three small clinical trials for persistent Lyme disease. Sample sizes in these studies were extremely small, ranging from 37 to 129. Nevertheless, two of the three studies demonstrated that retreatment improved some patients' measures, such as fatigue and pain. (20)

In addition, current diagnostic testing for Lyme disease is of poor quality and is unable to detect active infection or cure. Further uncertainty results from the high rate of treatment failure for all stages of Lyme. Some studies of early Lyme disease suggest the treatment failure rate for early Lyme disease may be as high as 36%. (21) In late Lyme disease, treatment failure rates may exceed 50%. (22) Because of the lack of guidance from high quality evidence and the poor quality of diagnostic testing, doctors and patients are uncertain about the best way to diagnose and treat the disease.

This uncertainty is compounded by the fact that persistent Lyme disease can be long lasting and significantly impair patient quality of life. It also may be costly to patients, employers, healthcare systems, and society. In a study of more than 5,000 patients with persistent Lyme disease, half report that they have been ill for more than 10 years. (23) These patients suffer a worse quality of life than those with most other chronic illnesses, including congestive heart failure, diabetes, multiple sclerosis and arthritis. Over 43% report that they had to stop working, and 25% report that they have been on disability at some point in their illness. They are five times more likely to visit healthcare providers and twice as likely to be seen in emergency rooms compared to the general population. The cost of this increased healthcare utilization continues until patients are restored to health.

The diagnostic and treatment uncertainty combined with the significant quality of life impairment suffered by patients who remain ill, has given rise to two medically recognized standards of care that are used by healthcare professionals for diagnosis and treatment. Both standards are reflected in peer-reviewed published guidelines—one by the ILADS (24) and the other by the Infectious Diseases Society of America (IDSA). (25) The ILADS guidelines are more current and adhere to the rigorous GRADE evidence assessment standards recommended by the Institute of Medicine.

The main difference between the IDSA and ILADS guidelines is that in the face of scientific uncertainty, the ILADS guidelines defer to clinical judgment and shared medical decision-making. Those of the IDSA severely restrict the use of clinical judgment and strongly recommend against treatment, regardless of the disease severity, complexity, prior treatment response, or functional impairment of the patient.

The IDSA leaves patients without treatment options when short term therapy fails, as it does in far too many cases. This is why over 95% of patients with persistent Lyme disease are treated by either an ILADS-trained physician, or a family practitioner or internist. (26) Only 3% report being treated by an infectious disease specialist. Similarly, a recent CDC HealthStyles national survey found that only 39% of patients with Lyme disease were treated in accordance with blanket short-term recommendations in the IDSA guidelines. The majority were treated for longer periods. (27)

For diseases that lack the research base essential for evidence-based decisions, shared medical decision making with patients should be encouraged as part of good practice. This involves a discussion between the patient and the physician that presents risks and benefits of alternative treatments in a

balanced manner, identifies the individual patient's preferences and values, and engages patients in decision making among treatment trade-offs.(28) Together, they choose a course of action.

Because two medically recognized standards of care exist for Lyme disease, LymeDisease.org, which represents thousands of patients nationally, believes that:

- Government agencies should provide unbiased public information regarding both standards of care and treatment approaches;

- Physicians should provide information regarding the risks and benefits of all available treatment options and decide with their patients which actions to take; and

- Insurance reimbursement should be available for treatment by either standard of care.

LymeDisease.org has created a shared medical decision-making form that is available for download for physicians and patients to use specifying the different treatment approaches and their associated risks and benefits. (29) This shared decision-making form was also included in the report of the Access to Care subcommittee of the TBDWG.

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Portion of statement from Tony Galbo

Ed. note. This is a tragic story regarding fatal Rocky Mountain spotted fever we have seen played out before whether child or adult. This letter was truncated as it is quite long. The federal TBDWG is not paying sufficient attention to tickborne diseases and conditions other than Lyme disease. It is remarkable that even though a tickborne infection, especially RMSF, may be considered in such a patient, the patient still may not be treated until too late. We have seen a number of cases like this here in North Carolina. Hopefully, this sad letter will get some attention.

My name is Tony Galbo. I want to thank Dr. Allen Richards for asking me to share my Daughter Gabriella Galbo's story and timeline.

Gabriella Giada Galbo was born July 28th, 2006. She was our third and youngest child. Gabby was such a beautiful soul, she knew when to be serious and could make you pop a stitch laughing. She was well beyond her age of five years old. She was the most selfless person I've met. At 3 years old her Uncle had put together a doll house she received on Christmas, after a few minutes of Gabby playing with the dollhouse she stops and goes to tell her Uncle Thanks for putting it together. That's the kind of person our Gabby was. We love and miss her so much.

On Tuesday May 1st, 2012 Gabby woke up with a fever and complaints of her chest hurting. My wife took her to the pediatrician's office. Gabby was tested for strep which was negative, and she was sent home. We controlled her persistent fever with ibuprofen. On Wednesday May 2nd Gabby was feeling

lousy when her fever would spike and playing when it was normal. Later that night at 11:00 p.m. when I got home from work we checked on her, and she was burning up with a fever of 105 and had broken out in a spotted rash all over her body. We took her to our local E.R. The Doctor said she had tonsillitis and gave her 2 shots of Rocephin and we were discharged. My wife called her pediatrician roughly 8 hours later Thursday May 3rd and took Gabby to see her. The pediatrician thought Gabby had atypical coxsackie virus, said her fever would stay high for five days and by Sat/Sun it should subside. We continued to control her fever with ibuprofen. On Saturday May 5th my wife called me at work at 9:00 p.m. and said Gabby's fever spiked to 106.1. We raced her to the E.R. at a level one trauma hospital in Urbana, Illinois where she was seen by the pediatric intensivist. He checked her over and said he could give her I.V. fluids if we wanted. There was no urgency even though she hadn't urinated in 23 hours at this point. We said yes to the I.V. and labs were ordered. At around 3:30 a.m. another E.R. doctor came in and said Gabby could go home. I asked him if her blood work was ok three times, and each time he said that it was fine. My wife and my sister continued to ask the Dr. questions about why her fever would be so high and he stated a fever is the way a body fight an infection. He said, "A fever can run as high 106,107,108 even 110." We didn't buy what he was saying and let that go in one ear and out the other. We were discharged and arrived home, Sunday May 6th at 5:30 a.m. Later that day Gabby's fever was between 99-100, the lowest it had been in six days. We thought that the virus had finally run its course…

Several hospitals later, the child died. The rest of the letter can be read at:
http://www.hhs.gov/ash/advisory-committees/tickbornedisease/meetings/2018-06-21/written-public-comment/index.html

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

Tick-Borne Infections Council of North Carolina is a non-profit 501(c)3 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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