



## SPRING NEWSLETTER 2007

Tick-borne Infections Council of North Carolina, Inc

### Highlights...

- **Vector-borne diseases conference in Durham in May! Register now.**
- **Chatham County will have its very own TBI presentation on April 19. Please come!**

**Scroll down to see these features and more!**

### Poem of the month...

#### PUBMED

i love you!  
because you are so haphazardous

because you make such supreme human sense  
because I can type in tick and get 16668 documents  
and type TICKS and get 12009 citations  
because if I mis-spell Borrelia on purpose  
I know it will disclose new documents  
entered in error  
long ago

the romance of you, pubmed  
is mystery

the mystery of why abstracts with borrelia burgdorferi  
in the title  
can be under Lyme or borrelia or borreliosis  
but never all three  
and it is random or whimsy  
unknown

there is no conspiracy here  
there is translation and transcription  
and such lovely, lovely  
human error  
Aptos, CA

sarah e olson, LLP & Feral Cat Rescuer,

*w*

### **VECTOR-BORNE DISEASES OF THE SOUTHEASTERN UNITED STATES CONFERENCE, DURHAM, NC, MAY 8-9, 2007**

This conference provides a unique opportunity to learn about mosquito and tick-borne problems in our area. Registration for the May 8-9, 2007 "Vectorborne Diseases of the Southeastern United States" conference is now open! There are local and national speakers. Please visit the following page to access the online registration form. An agenda is available as well. Registration is free to anyone who's affiliated with a SECEBT institution.

There is no charge for the conference. Registration is very easy at [http://www.secebt.org/conferences/detail.cfm?conference\\_id=12](http://www.secebt.org/conferences/detail.cfm?conference_id=12).

## **CHATHAM COUNTY PROGRAM ON TICKS AND TICK-BORNE DISEASES APRIL 19.**

Chatham County Center of the North Carolina Cooperative Extension Service will sponsor a program on "Ticks and Tick-borne Diseases" at the Agriculture Building in Pittsboro on Thursday April 19. The program will begin with a catered barbeque dinner at 6:00 p.m. A \$5.00 charge will cover part of the cost of the meal and materials. Pre-registration is required. Those interested in attending should call 919.542.8202 to reserve a seat. The program will cover aspects of tick biology, tick control, tick-borne illnesses in North Carolina, and disease prevention. Lead speaker on the program will be Dr. Charles Apperson, William Neal Reynolds Professor of Agriculture and a member of the Department of Entomology at NC State University.

## **RALLY PROTESTING THE IDSA GUIDELINES**

### **Hundreds rally to protest new Lyme disease treatment guidelines.**

By LIZ ANDERSON THE JOURNAL NEWS

Original publication: December 1, 2006)

**VALHALLA -** Hundreds of people rallied yesterday outside Westchester Medical Center to decry new treatment guidelines for Lyme disease that discourage the use of long-term antibiotics to treat lingering symptoms.

The voluntary guidelines were issued last month by the Infectious Diseases Society of America; the lead author was Dr. Gary Wormser, chief of the division of infectious diseases at the hospital.

Protesters from as far away as California and Texas waved a sea of neon-green signs at passing cars at the intersection of Woods and Grasslands roads, some of which personally mocked the doctor with messages like, "Wormser lies ... Patients Die" and "Dr. Wormser - You Make Me Sick!" Others read, "Gross Medical Neglect," and "Stop the Ignorance." Lyme disease, caused by the bite of a deer tick, can lead to an initial infection including a rash and muscle and joint pain; later it can result in arthritis and neurological symptoms. The new guidelines call for a bite to be treated with a single dose of preventative antibiotics, but say prolonged antibiotic treatment "has not proven to be useful." They also seek to differentiate between patients with "post-Lyme syndrome" and those with just the "aches and pains of daily living."

Patients and advocates yesterday said the study did not take their illnesses, or their efforts to find successful treatment, seriously enough.

"We are here today to fight back," declared Karen Gaudian of Ridgefield, Conn., who decried the new regulations as the result of organizations "corrupted by the quest for financial gain."

Pat Smith, president of the Lyme Disease Association, brought a clock that runs backward to illustrate a study she said was "taking us back in time."

"We cannot and will not allow the IDSA and their followers to take our disease away," she declared.

Protesters cheered Dr. Joseph Burrascano, vice president of the International Lyme and Associated Diseases Society, which supports the use of long-term antibiotics in some cases and has called on the IDSA to retract the recommendations.

"If they weren't so seriously flawed, I would say it was a joke," he said of the guidelines. He urged those at the rally to fight back "by uncovering the truth."

Doug Maass, 62, of Sleepy Hollow said he came to the rally because he was concerned he and thousands of other patients would lose insurance coverage or be cut off from treatment for chronic Lyme disease. He believes that he has had the disease since 1988, and that it is the cause of symptoms like his recurring left-side headaches and swollen glands; his wife, who is also ill, has symptoms that are even worse, he said.

"I've been on nine different antibiotics over six years," he said. "When I'm on antibiotics I feel pretty good. I go off for six or seven months, and the symptoms come back."

An attempt to reach Wormser for a response through a Westchester Medical Center spokeswoman was unsuccessful.

Reach Liz Anderson at [ecanders@lohud.com](mailto:ecanders@lohud.com) or 914-696-8538.

<http://www.newstimeslive.com/news/story.php?id=1029701>

Jan 28 2007

## **State lawmakers propose Lyme disease task force**

By Robert Miller, THE NEWS-TIMES (partial story below)

In 2002, the state of Connecticut recorded more than 4,631 cases of Lyme disease. In 2003, that number dropped to 1,403. By 2005, it was up to 1,810 -- still less than half the 2002 levels.

The lower numbers don't mean black-footed ticks in the state are fewer or less prone to spread Lyme disease.

They mean the state decided to stop counting cases of Lyme disease reported through laboratory tests -- about half the Lyme reports it received. Instead, it only counted cases confirmed in doctors' offices.

"We were No. 1 in Lyme disease in the United States in 2002," said state Rep. Jason Bartlett, D-Bethel. "Now we're No. 5."

On Monday at 11:30 a.m., Bartlett and state Rep. William Tong, D-Stamford, will hold a meeting at the State Legislative Office Building in Hartford to announce two new bills on Lyme disease.

The first will require the state to again add laboratory test results to its Lyme disease tally. The second will create a permanent state Lyme Disease Task Force.

For Maggie Shaw, a member of the Newtown Lyme Disease Task Force, both acts are long overdue. She said when Dr. J. Robert Galvin, the state Commissioner of Public Health, held a conference on Lyme disease in 2004, he promised more state involvement in treating the disease.

"Since then, we can't get even get through to the commissioner's office," Shaw said Wednesday.

Bartlett, a freshman state representative, said he learned about the problems of Lyme disease from his mother, Pat, who leads the Bethel Lyme Disease Task Force.

He's also met with Shaw and others to hear their concerns. Those discussions led to the bills he and Tong are introducing Monday.

"I think we really need to get a handle on the number of cases we have in the state," he said. "I don't believe they're declining. I think we have a Lyme disease epidemic in Fairfield County and the rest of the state."

Lyme disease advocates said inaccurate counts mean the state will be eligible for less federal money to treat the disease. More importantly, they said, it may convince people Lyme disease isn't that large a problem in the state.

State Attorney General Richard Blumenthal has also been pushing this issue. In a series of letters to Galvin dating back to July 2006, Blumenthal has insisted that it's the Department of Public Health's responsibility to get the fullest, most accurate count of Lyme disease cases in the state.

"The under-reporting of this disease is particularly harmful for the public health," Blumenthal said in one letter. "If the public is wrongly led to believe that the incidence of the disease is declining, they will be less diligent in their preventive efforts."

"When we tell people, they're shocked that nothing is being done in the state," said Jennifer Reid, a member of the Ridgefield Lyme Disease Task Force.

Dr. Matthew Cartter, an epidemiologist with the state Public Health Department, said the state only counted lab results for a few years, as part of a special program funded by the federal Centers for Disease Control and Prevention, to study the effect of the Lyme disease vaccine.

When the vaccine was pulled off the market, Cartter said, that funding was shifted to other programs and the state stopped the laboratory counting.

But Cartter said the health department has never downplayed Lyme disease. "We've always said we have one of the highest rates of Lyme disease in the world," he said.

Cartter also said the public health department is now implementing an electronic reporting system from laboratories, and that Lyme disease has been added to the list of reportable diseases for that system. But the system will only begin collecting data by mid-summer. It won't be until 2009 that all state laboratories hook up to the system, he said. "We're not talking about hundreds or even thousands of reports here," he said. "It's a huge number."

#### **INTERESTING NEWS ON TICK REPELLANT RESEARCH**

PA Farm News, Quarryville PA, January 26, 2007

#### **Old-Time Mosquito Remedy May Work Against Ticks, Too**

By Luis Pons, ARS Public Affairs Specialist

BELTSVILLE, MD -- A granddad's wisdom, already helpful in the fight against mosquitoes, may also prove useful in battling disease-spreading ticks. Last year, Agricultural Research Service (ARS) scientists in Oxford, Miss., isolated compounds from a plant called American beautyberry that enable its crushed leaves to repel mosquitoes.

This work, led by chemist Charles Cantrell at the ARS Natural Products Utilization Research Unit in Oxford, was inspired by a tip another ARS scientist—botanist Charles Bryson in Stoneville, Miss.—got long ago from his grandfather: that beautyberry (like the one shown at left) was used in northeastern Mississippi to protect people and farm-work animals from biting bugs. Now ARS scientists in Beltsville, Md., have shown that two beautyberry compounds—callicarpenal and intermedeol—may effectively repel blacklegged ticks as well.

Blacklegged ticks are the principal carrier of bacteria that in humans cause Lyme disease, an affliction known for its fevers, headaches and bull's-eye rash. Left untreated, this disease can cause severe and chronic illness.

ARS entomologists John Carroll, in the Animal Parasitic Diseases Laboratory, Beltsville, and Jerome Klun, in the Chemicals Affecting Insect Behavior Laboratory, also in Beltsville, tested the compounds by administering them to cloth strips wrapped around a person's finger in dosages at which the commercial repellent DEET repels ticks. The treated strips repelled more than 95 percent of blacklegged tick nymphs.

Callicarpenal did especially well in a separate duration test, repelling all the blacklegged ticks tested for three hours after application, and 53 percent after four hours. The researchers also tested the natural compounds against nymphs of lone star ticks, which transmit potentially serious human diseases known as ehrlichioses.

The two compounds, as well as DEET, were considerably more potent against blacklegged ticks than against lone star ticks. An experimental repellent developed by ARS and known as SS220 was most effective against the lone star variety. While the

findings are preliminary, the beautyberry compounds' usage history leads Carroll to believe that callicarpenal and intermedeol have potential for human use. ARS is the U.S. Department of Agriculture's chief scientific research agency.

### **STUDY ON DNA SHEDDING OF THE LYME DISEASE BACTERIA IN URINE**

This lab test is controversial in the United States. This study supports appears to support its validity. (*Ed note*)

#### ***Course of Borrelia burgdorferi DNA Shedding in Urine after Treatment.***

*Aberer E, Bergmann AR, Derler AM, Schmidt B. Department of Dermatology, Medical University of Graz, Auenbruggerplatz 8.*

Diagnosis of Lyme borreliosis by urine polymerase chain reaction (PCR) has been recognized as having better diagnostic sensitivity in patients with erythema migrans than serological methods. We made serial tests with 192 urine specimens from 70 patients with erythema migrans and 60 urine specimens from 21 patients with acrodermatitis chronica atrophicans to evaluate the course of positive urine PCR after antibiotic treatment. Before treatment, urine samples from patients with erythema migrans showed a positive PCR in 27/34 samples (79%), and those from patients with acrodermatitis chronica atrophicans in 7/11 (63%). The specificity of bands was proven by hybridization with GEN-ETI-KTM-DEIA kit in 40/41 samples. Borrelia DNA in urine decreased gradually within the observation period of one year in both patients with erythema migrans and acrodermatitis chronica atrophicans, and persisted without clinical symptoms in 4/45 patients with erythema migrans (8%) after 12 months. Urine PCR can serve as a diagnostic method in early Lyme borreliosis and also in seropositive patients with unclear clinical symptoms.

### **CDC FUNDING FOR LYME DISEASE RESEARCH, OCTOBER 2006**

The Centers for Disease Control and Prevention (CDC) awards more than \$3.5 million per year to 10 institutions for new research on Lyme disease. The studies are designed to improve understanding of the disease and to examine new methods for testing, prevention, and control.

Lyme disease is a bacterial infection spread through the bite of an infected tick. It is the most prevalent vector-borne infectious disease in the United States, with more than 23,000 cases reported in 2002.

"We know that early diagnosis is crucial to enable prompt treatment to prevent long-term complications from Lyme disease," said Dr. James M. Hughes, Director of CDC's National Center for Infectious Diseases. "These awards will lead to improvements in surveillance, clinical testing, tick control and community-based prevention programs."

Brief descriptions of the studies along with the names of the principal investigators and institutions are included below:

## Diagnosis, Immunology, and Pathogenesis Research

- *Diagnosis and Pathogenesis of Early Lyme Disease*, Allen C. Steere, M.D., Massachusetts General Hospital, Boston, Massachusetts. The goals of this project are to improve the accuracy of serodiagnostic testing for Lyme disease, and to identify bacterial and host factors that lead to more severe disease. Laboratory markers for patients who would benefit from more intensive treatment may be developed.
- *Pathogenesis of Lyme Borreliosis in the Rhesus Monkey*, Mario T. Philipp, Ph.D., Tulane University Health Sciences Center, New Orleans, Louisiana. This proposal will advance understanding of the effects of Lyme disease on the central nervous systems. Mechanisms of neural injury will be determined using primate cells in culture.
- *Analysis of pgf 54 Members in Lyme Disease Serodiagnosis*, James A. Carroll, Ph.D., University of Pittsburgh, Pittsburgh, Pennsylvania. This study will identify and evaluate proteins that vary as Lyme disease bacteria cycle between ticks and mammals. These variably expressed proteins will be evaluated in diagnostic tests and as vaccine candidates.
- *Innate Immunity in Vector-Borne Lyme Borreliosis*, Linda Bockenstedt, M.D., Yale University, New Haven, Connecticut. This study will explore factors that contribute to susceptibility to infection. It also will examine the characteristics of Lyme disease bacteria that are "crippled" by antibiotic treatment.
- *Lyme Disease Diagnosis with Host Gene Expression Arrays*, Ira Schwartz, Ph.D., New York Medical College, Valhalla, New York. This investigation will examine how cells from mice and humans respond to infection by Lyme disease bacteria. Gene expression that changes with infection will be monitored using a technique called microarray analysis. New diagnostic tests for active infection may be developed based on these changes.

## Tick-Control Research

- *Spatial Risk Model for Ixodes scapularis-borne Borrelia*, Durland Fish, Ph.D., Yale University, New Haven, Connecticut. This project will lead to the development of a GIS-based surface map of the population density of nymphal ticks and prevalence of Lyme disease spirochete infection to estimate human infection risk in the eastern United States.
- *Assessing Community-based Tick Control for Lyme Disease Mitigation*, Thomas N. Mather, Ph.D., University of Rhode Island, Kingston, Rhode Island. This proposal will assess and evaluate tick control attitudes and practices before and after implementing an aggressive community outreach program for tick control in Rhode Island. A comprehensive training manual for implementing community-wide tick control programs throughout the Northeast also will be developed.
- *Control of Ixodes scapularis*, Eddy A. Bresnitz, M.D., New Jersey Department of Health and Senior Services, Trenton, New Jersey. This investigation will test integrated pest management strategies, assess effectiveness of a

sustained deer reduction program, and evaluate effectiveness of broad-scale, seasonal acaricide (pesticide against ticks) applications to reduce tick populations and Lyme disease incidence in New Jersey. In addition, educational materials on tick management to improve tick control practices in New Jersey will be developed.

### Community-based Prevention Programs

- *A School-Based Intervention to Reduce Lyme Disease*, Nancy Shadick, M.D., M.P.H., Brigham and Women's Hospital, Boston, Massachusetts. This project will evaluate the effectiveness of an efficient, cost effective, school-based intervention program in reducing the incidence of Lyme disease in endemic areas.
- *Prevention of Lyme Disease in Connecticut*, Matthew Cartter, M.D., M.P.H., Connecticut Department of Public Health, Hartford, Connecticut. This study will evaluate the effectiveness of integrated prevention measures to reduce the risk of Lyme disease in the United States, and will evaluate the costs of these interventions in relation to the number of cases prevented.

# # #

*CDC protects people's health and safety by preventing and controlling diseases and injuries; enhances health decisions by providing credible information on critical health issues; and promotes healthy living through strong partnerships with local, national, and international organizations.*

## Lyme disease debate provokes treatment divide, legal action

**In what may be a first, the government has taken steps to investigate the drafting of medical guidelines.**

By [Susan J. Landers](#), *AMNews staff*. Dec. 25, 2006.

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**Washington --** Dueling guidelines developed by two medical organizations for treating patients with Lyme disease have sparked such an uproar that Connecticut's attorney general has stepped in to see if one side ran afoul of antitrust statutes.

The Infectious Diseases Society of America and the International Lyme and Associated Diseases Society each assembled expert panels that sat down separately and examined the evidence on the nature of and best treatment for this tick-borne illness. But they arrived at different conclusions.

IDSA, a scientific organization of physicians, scientists and other health care professionals who specialize in infectious diseases, characterizes Lyme disease as primarily acute and treated successfully in the vast majority of cases with, at most, a few weeks of antibiotics. ILADS, which is a multidisciplinary medical society focused on the diagnosis and treatment of Lyme disease, holds out the possibility that the disease is chronic and may need months of antibiotics.

The differing conclusions call into question how best to treat the more than 20,000 people who contract the infection each year. Although Lyme disease has been reported in nearly all states, most cases are found in the Northeast, mid-Atlantic and North Central regions of the nation. Left untreated, the infection can spread to joints, the heart and the nervous system, according to the Centers for Disease Control and Prevention.

It is not unusual for different medical and scientific groups to take varying clinical positions on specific conditions. But this particular situation quickly has become far from typical.

The battle over how to treat the infection grew so heated that, in Connecticut, the state in which the disease was first recognized and named, Attorney General Richard Blumenthal began an investigation in mid-November. "We issued a subpoena to the IDSA because its guidelines may severely constrict choices and legitimate diagnosis and treatment options for patients," he said.

Advocacy groups in the state and elsewhere had expressed outrage over the IDSA guidelines and applauded Blumenthal's action. "Clinical guidelines now drive the standard of care, and these IDSA guidelines have already been published on the CDC Web site," said Pat Smith, president of the Lyme Disease Assn. The advocacy community contends that the guidelines deny the existence of chronic Lyme disease and could lead to limits on physicians' treatment options.

IDSA, which notes that it is responding fully to the subpoena, believes its guidelines are based on the best that science currently has to offer. It was the association's development and Nov. 1 publication in *Clinical Infectious Diseases* of an updated version of its guidelines that resulted in the current furor.

For its part, ILADS finds the rival guidelines to be very restrictive to the point of limiting treatment options and even excluding certain treatments that have been used by physicians for years, said the group's president, Raphael Stricker, MD.

What's more, insurance companies may deny coverage of treatments not supported by the infectious diseases society guidelines, said Daniel Cameron, MD, MPH, who led the panel that developed ILADS' guidelines.

These perspectives have contributed to the guidelines' scrutiny.

"At this stage, to debate the guidelines is a bit like debating religion or science," said Paul Auwaerter, MD, clinical director of Baltimore's Johns Hopkins School of Medicine's Division of Infectious Diseases and a fan of the IDSA guidelines.

"I don't think there is anyone in the middle," he noted. "I'm sure both of us are right in some regards and wrong in other regards. But that's always the case with medicine."

Gary Wormser, MD, who led the IDSA team in the development of its guidelines, pointed out that they are, after all, recommendations and, according to a statement included on the document's first page, are not intended to replace physician judgment.

"We don't dispute that there are patients who had Lyme disease and who continue to have symptoms, whatever the reason," he said. "We think this illness is a real problem and definitely needs more research and attention. But I think where we differ is the idea of treating these individuals indefinitely with antibiotics."

Antibiotic overuse has been seen as a major contributor to the rising number of infections that are resistant to these once-powerful weapons, and the IDSA has been among those campaigning for their judicious use.

ILADS supporters point out that diseases such as tuberculosis are treated with long-term antibiotic use and no one questions that treatment's validity and effectiveness.

Although a spectrum of opinions is not unusual in medicine, the issuing of a subpoena is rare when it comes to guidelines. "We have done other investigations of the health care industry, but none, as far as I can recall, having to do with guidelines," Blumenthal said. His inquiry triggered a variety of responses from those closely involved.

"While I don't support in principle the government interfering with medical affairs, I think in this situation, IDSA has so overstepped its bounds and abused its power in promulgating these guidelines that I think there is no other option," said ILADS' Dr. Stricker.

The response from Dr. Auwaerter, an IDSA guideline proponent: "My sense is that [Blumenthal] won't find anything improper."

Dr. Cameron's: "The attorney general's response is in reaction to the frustrations patients are having with getting more attention to the problems of chronic Lyme disease." Dr. Cameron, who was the ILADS panel leader, and lives in Westchester County, N.Y., coincidentally just a few miles from Dr. Wormser, pointed to one study showing that significant numbers of Lyme patients in his area had persistent symptoms.

In general, guidelines continue to have a key place in physicians' toolkits -- a likely reason why this debate has been so intense.

"There is so much data out there that we rely on expert panels to review available evidence and come up with recommendations," said Dr. Auwaerter.

More than 1,800 guidelines are posted under the "disease/condition" heading on the federal National Guideline Clearinghouse Web site. Both IDSA and ILADS guidelines are there. The site gets more than 100,000 visits each month, said Jean Slutsky, MSPH, director of outcomes and evidence at the Agency for Healthcare Research and Quality, the overseeing agency.

Feb 26, 2007

### **Wilton-based group raises \$1 million for Lyme disease research**

The National Research Fund for Tick-borne Diseases, Inc. (NRFTD), the nation's only non-profit organization dedicated exclusively to funding scientific research in the rapidly expanding field of tick-borne diseases, has announced that its funding campaign has now surpassed the \$1 million mark.

NRFTD National Chairman Dr. Leo J. Shea III said, "This is a milestone for the NRFTD, and a wonderful vote of confidence in our mission. We believe that our primary focus on funding research will advance the cause of scientific understanding of Lyme disease and other tick-borne diseases. Our plan is to raise funds aggressively across the country to insure that this needed research continues. It will result in scientific evidence that will clarify the pathogenesis of tick-borne diseases and thus, enhance their diagnosis and treatment. We hope to rapidly increase our donor base and seek to raise several million dollars to support the needs of researchers worldwide."

Most recently, the NRFTD announced the awarding of four research grants totaling \$240,000 under its 2006 Pilot Project Grant Program. The grant winners included Dr. Wayne Hynes of Old Dominion University, Dr. Brian Stevenson of the University of Kentucky College Of Medicine, Dr. Jason Carlyon, also of the University of Kentucky and Dr. Patricia Holman from Texas A&M University's College of Veterinary Medicine and Biomedical Sciences.

### **LYME DISEASE SURVEY AND BOOK FOR CHILDREN**

Dr. Diane M. Wilcox is doing of the impact of chronic Lyme Disease on workplace performance. She has started a Blog entitled Chronic Lyme and the Workplace and have posted a survey there for chronic Lyme patients to take - <http://www.lyme-and-work.blogspot.com/> . It has already been make available to support groups in Virginia. Sixty-five patients from Virginia and California have already filled it out.

This is unfunded research. Dr. Wilcox plans to write some articles for health psychology and business journals so employers begin to understand exactly how the disease impacts ability to think and work. She is hoping that if she gets enough good data, it can be used to justify workplace accommodations for Lyme patients.

Also, she recently self published a children's book entitled "We Don't Sit in the Grass Anymore." To see it at <http://www.lulu.com/content/666131> . Dr. Wilcox may be reached at:

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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.*

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