



# ILADS NEWS

INTERNATIONAL LYME AND ASSOCIATED DISEASES SOCIETY

Volume 7

WINTER 2014

Dear ILADS Member,

Hope that you are all "braving the storm" for what has turned out to be a rough winter across the country. We have seen a nice increase in emails between issues with notifications of the many varied and interesting events and news among our group. Please as always feel free to contact us at any time.

Thank you. Editors: Andrea Gaito, MD, Barbara Buchman, Exec. Director ILADS

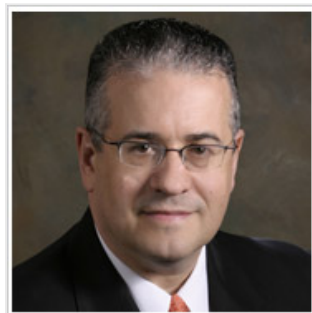
## PRESIDENT'S MESSAGE

### Greetings Colleagues,

I am excited to moderate the upcoming April 12, 2014 ILADS regional conference in Hershey Pennsylvania. We have been working with Julia Wagner and her associates with PA LymeResource

Network to organize our second regional conference for education and networking on tick borne diseases in Hershey. Last year we sold out with more than 150 professionals attending.

This Hershey meeting will include a basic curriculum covered by Drs. Burrascano, Dr. Horowitz and myself, a format that was quite successful in San Diego even for professionals experienced in treating Lyme disease. We have added a roundtable format at lunch to allow attendees to meet network with regional and national leaders. Judy Leventhal will share her work with Encephalopathy in



Children with Tick Borne Diseases and implications for Development and Learning. Stewart J. Greenleaf, PA State Senator will also join us. CME credits are available.

For those coming to the Hershey Workshop early, I will be speaking Friday evening during dinner on evidencebased treatment following Jane Hoffman, PhD presentation on Changing Ecology and Vector Borne Diseases: The Wildlife Perspective.

Also save the dates for the April 25th and 26th Augsburg, Germany conference, October 9, 2014 Overview of Lyme and Tick Borne Diseases, and October 10-12, 2014 Annual Scientific Session in Washington DC. If you would like to present a poster or case study at the annual meeting, contact us. I will be attending both conferences and am looking forward to meeting you.

**Daniel J. Cameron, MD, MPH**  
President, ILADS

## Ridgefield, CT Spring Seminar - *By Sandra Berenbaum, LCSW*

**LYME DISEASE:  
BODY, MIND & SPIRIT**  
Seminar & Health Fair 2014

**SAVE THE DATE**

Tuesday, May 13  
Health Fair: 6 p.m. - 9:30 p.m.  
Speakers: 7 p.m. - 9:30 p.m.

**KEYNOTE SPEAKERS**  
Robert Bransfield, MD  
Steven Phillips, MD  
Sandy Berenbaum, LCSW



Western Connecticut State University  
West Side Campus Student Center 43 Lake Ave. Extension Danbury, CT 06810  
Presented by The Ridgefield Lyme Disease Task Force

As an advisor to the Ridgefield (CT) Lyme Disease Task Force, as well as a member of the Program Committee for the Ridgefield Spring Seminar, I'm pleased to let my fellow ILADS members know about the Seminar we have planned for this year. This Seminar will take place on Tuesday, May 13th, at Western CT State University, Westside Campus, in Danbury, CT. It is free and open to the public.

Now in its eighth year, the Spring Seminar draws a crowd of to 300 and 400 people. While attendance is largely from CT and surrounding states, we have also had attendees come from around the country and Canada.

This year's Seminar is entitled "Lyme Disease: Body, Mind and Spirit". The speakers, all ILADS members, are former ILADS president and leading Lyme disease physician Steven Phillips, MD, former ILADS president and leading Lyme knowledgeable

psychiatrist and psychopharmacologist Robert Bransfield, MD, and Sandy Berenbaum, LCSW, BCD, a leading Lyme-literate mental health practitioner.

The program begins at 6:00pm, with a Health Fair focused on presenting information from laboratories specializing in testing for Lyme and other tick-borne diseases, Naturopathic Physicians and other ancillary professionals, specialists in the field of supplemental treatment as well as tick control products and many other services.

The speakers will start at 7:00pm and run to 9:30pm. In addition to the presentations, we will be honoring Mary Beth Pfeiffer, for her "Courage in Journalism." Ms. Pfeiffer has researched and written a landmark series of articles on tick-borne diseases for the Poughkeepsie (NY) Journal. Her articles are read and appreciated by professionals and patients throughout the country.

This excellent program is sponsored by the Ridgefield Lyme Disease Task Force, an organization founded 11 years ago by Karen Gaudian and Jennifer Reid, together with Ridgefield's First Selectman, Rudy Marconi. Known for their commitment to collaboration within the community, Karen and Jennifer have formed alliances with Town of Ridgefield, Western CT State University, the Ridgefield Visiting Nurse Association, the Leir Foundation, and others, to develop programs that have had an influence far beyond the community in which they are located.

For more information, visit <https://www.facebook.com/RidgefieldLymeResource>

## Ellie Hynote, MD Passes (1957-2013)



Dr. Eleanor Hynote died Dec. 17, 2013, in Napa. She was born in Brookline, Mass., to Francis and Rita Dimento on June 21, 1957.

Hynote graduated from Brookline High School, Vassar College and UC Irvine School of Medicine. She

opened her internal medicine and clinical nutrition practice in Napa in 1989. She enjoyed snow skiing, travel, the beach at Martha's Vineyard and, most of all, her family. She devoted her professional life to the practice of medicine from which she received great gratification.

Hynote is survived by her husband, Robert Hynote of Napa; daughters, Caroline, Julia and Olivia Hynote, all of Napa; parents, Francis and Rita Dimento of Boston; and brothers, James and Francis Dimento, and sister, Melissa Lang, all of Boston.

The family requests that in lieu of flowers, donations be made in Hynote's memory to organizations dedicated to infectious disease research. ILADEF has received several donations in Dr. Hynote's memory.

## Report on Misdiagnosed Patients in Irish News



An Irish Newspaper, The Independent.ie/Irish News had a feature story on Lyme disease November 22, 2013 reporting on a government Lyme hearing.

"There have been 19 cases of Lyme Disease reported to the Health Protection Surveillance Centre of the Health Service Executive (HSE) to date this year, more than double the eight cases reported in 2012.

Yet the actual number is likely to be hundreds, due to the lack of public awareness of the disease as well as among GPs and even consultants, University College Cork Zoology Professor Dr Eoin Healy told the Oireachtas Joint Committee on Health and Children yesterday.

Describing the disease as "endemic" in Ireland, he said the bacterial infection transmitted to humans and animals from the bites of ticks feeding on deer, sheep, cattle and goats, was first identified here in 1982.

It often attacks the nervous system and can result in arthritis, joint and muscle pain as well as cardiac complications, with 40pc of Lyme patients developing long-term health problems..."

ILADS mission is global education about Lyme disease.

## Increased Effort To Combat Lyme Disease in 2014 Omnibus



Washington, D.C. (January 27, 2014) – Efforts to combat Lyme disease get a much-needed boost in the FY 2014 Omnibus spending bill recently signed into law, according to Rep. Frank Wolf, one of the leading champions to find a cure to the debilitating disease.

In addition to providing \$9 million to Centers for Disease Control (CDC) to help to combat Lyme, the bill directs the CDC to develop better diagnostic testing and national surveillance systems. The measure also directs the National Institute of Sciences to continue its efforts to more accurately assess the presence of acute and chronic Lyme disease and encourages the National Science Foundation to continue to support Lyme research efforts.

The four research agencies within the Department of Agriculture are also directed to build on ways to protect humans and livestock from tick-borne illnesses and to consider how such diseases impact the local economy.

The increased effort comes in the wake of recent news reports that suggest Lyme disease affects nearly 300,000 people each year, up to 10 times more than previously thought.

“I know that many are suffering from this devastating disease,” Wolf said. “My approach to Lyme disease always has been two-fold: help those who are sick get the treatment they need; and help prevent healthy people from becoming sick. This Omnibus continues these efforts.”

Wolf has hosted a number of forums in Virginia’s 10th District to help educate residents and medical professionals about the dangers of Lyme. In addition, he is cosponsoring two bills with Rep. Chris Smith (R-NJ) and Rep. Chris Gibson (R-NY) that would change permanent law.

One measure, H.R. 610, would require the secretary of Health and Human Services create a federal Tick-Borne Diseases Advisory Committee charged with coordinating research and advising federal agencies on priorities related to Lyme and other tick-borne diseases, while also recognizing that patients can provide valuable and needed feedback. The other, H.R. 611, builds on H.R. 610 but further increases authorized funding for Lyme disease research.

Lyme is the most prevalent vector-borne disease in the U.S. today. If not diagnosed and treated early, Lyme can lead to disseminated infection and can affect every system in the body, including the central nervous system. Later symptoms of Lyme disease include arthritis of weight-bearing joints; neurological problems such as facial paralysis, encephalopathy, memory problems and weakness of the extremities; and heart symptoms, such as blockages and inflammation.

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## Seeking Lyme Doctor

Ron Gangemi of Lyme Awareness of Cape Cod has purchased a building out of his own funds for the purposes of opening a Lyme Center this Spring.

Walls are coming down and we have an architect drawing up plans and patients lining up but unfortunately we have no LLMD yet to treat them.

If you have any ideas we are most happy to listen. Center will be located in Mashpee Mass just off Route 28 which is a well traveled location.

If interested in working here please contact Lisa Freeman BSN, Nurse advocate and liaison, Lyme Awareness of Cape Cod 508-896-3299 phone and fax

## French Event and Conference on Lyme Disease

The French Lyme Association is organizing 3 independent events to mark World Lyme Day, also known as the World Wide Lyme Disease Project. First, there will be a gathering in the morning at La Place Montparnasse, followed by lunch in a restaurant near the Montparnasse Station. A large conference regarding Lyme disease will be held at Montrouge, featuring specialists on both ticks and Lyme disease. Among the speakers will be Prof. Perrone, Dr. Teulieres, Dr. Bransten, Dr. Boucher and Mme. Vayssier-Taussar. The conference fee for members is 9 euros if purchased before before 3/15/14, and 15 euros for nonmembers.

For more information, visit <http://francelyme.fr/wwlp2014-inscription/> or contact [contact@francelyme.fr](mailto:contact@francelyme.fr).

## ILADS Offers CME Programs This Spring

The conference, geared towards medical professionals, will feature some of the best well known mentors in the Lyme community: Drs. Cameron, Burrascano and Horowitz. The meeting begins with a dinner lecture on Friday night (optional) and then a full day of lectures Saturday. There is a special hotel rate of \$179 per night is good until March 10th. Register now and bring the family to enjoy the lovely Hershey Lodge. To view the full schedule and register go to [http://ilads.org/lyme\\_programs/hershey/ilads\\_hershey.php](http://ilads.org/lyme_programs/hershey/ilads_hershey.php).

ILADS will be returning to Augsburg, Germany April 11-12, 2014 for two days of intensive Lyme training for medical professionals. The first day's course is aimed to teach a Lyme overview of the basics. The second day delves in to more comprehensive subject matter. The European ILADS meetings are smaller than the annual scientific meetings. So, there is ample opportunity to get to know your European peers. All talks will be given in English with simultaneous translation to German. To view the full schedule and register go to [http://ilads.org/lyme\\_programs/augsburg/ilads\\_augsburg.php](http://ilads.org/lyme_programs/augsburg/ilads_augsburg.php).

## ILADS Announces Lyme and Tick Borne Disease Conference in Hershey, PA



### ILADSHERSHEY2014

DIAGNOSIS & TREATMENT OF TICK BORNE DISEASES

#### Objective

To provide physicians and other medical practitioners with insight into recent developments in the understanding of Lyme and other tick-borne diseases, and to provide basic tools and strategies for counseling prevention, and for diagnosing and treating these diseases.

[LEARN MORE ONLINE](#) ▶

**Location:** Hershey, PA; **Date:** April 11-12, 2014

### HIGHLIGHTS OF HERSHEY PROGRAM

7:00pm - Dinner Speaker - April 11, 2014



#### Evidence Based Lyme Treatment

**Daniel J. Cameron**, MD, MPH, ILADS Moderator

8:00-8:45am - April 12, 2014



#### Clinical Presentation of Lyme

**Joseph J. Burrascano, Jr.**, MD

8:45-9:45am - April 12, 2014



## Lyme-MSIDS Part I: Treating the 3 I's: Infection, Inflammation and Immune Dysfunction

**Richard I. Horowitz**, MD

11:45am-12:00pm - April 12, 2014



## Lyme Disease in Pennsylvania

**Stewart J. Greenleaf**, PA State Senator

1:00-2:00pm - April 12, 2014



## Lunch Speaker (Magnolia Room) - Encephalopathy in Children with Tick Borne Diseases: Implications for Development and Learning

**Judith G. Leventhal**, PhD

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# ILADS Announces 2014 Annual European Lyme Disease Conference

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## ILADS AUGSBURG 2014 EUROPEAN LYME DISEASE CONFERENCE

### Objective

The Annual European ILADS Lyme Disease Conference will provide updates in clinical knowledge and treatment techniques for tick-borne diseases with an emphasis on the European experience.

[LEARN MORE ONLINE](#) ▶

**Location:** Augsburg, Germany, **Date:** April 25-26, 2014

## HIGHLIGHTS OF EUROPEAN PROGRAM

8:30am-9:15am - April 25, 2014



## Lyme Disease History and Evolution of Tick Borne Disease

**Raphael Stricker**, MD

10:30am-11:15am - April 25, 2014



## Interpreting and Using Laboratory Tests in Practice

**Armin Schwarzbach**, MD, PhD

1:30pm-2:15pm - April 25, 2014



## Co-infections: Presentation, Diagnosis and Treatment

**Carsten Nicolaus**, MD, PhD

2:15pm-3:00pm - April 25, 2014



## Lyme Disease, Neuropsychological Challenges for Children and Families

**Leo Shea, III**, PhD

9:15am-10:00am - April 26, 2014



## Hyperbaric Oxygen Therapy in the Management of Lyme Disease

**Samuel Shor**, MD, FACP

3:00pm-3:30pm - April 26, 2014



## Lyme Treatment in ALS and MS Patients

**David Martz**, MD

4:00pm-4:30pm - April 26, 2014



## Morgellon's Disease: The Newest Lyme Co-infection?

**Ginger Savely**, DNP, FNP



# Vintage RV Show

Sunday, September 14, 2014  
10:00 – 2:00

To be held at



Vintage & Classic house cars, towable campers, motorhomes, RVs

**DJ - Vendors - People's Choice Awards -  
Concessions by BIGG DAWGGS -  
FUN FOR THE WHOLE FAMILY**

Half of the proceeds will be donated to the  
**International Lyme And Associated Diseases Society  
Education Foundation (ILADS-EF)**

Show vehicle registration is \$10. Registration will be waived for  
show vehicles that book a minimum two-night stay that weekend  
at a reduced single-family daily rate of \$35 (portions of rate  
balances to be donated to ILADS). Remaining proceeds are to  
cover show costs.



DOWNLOAD SHOW VEHICLE AND VENDOR REGISTRATION FORMS AT

[www.countrysidervcamp.com](http://www.countrysidervcamp.com)  
[www.facebook.com/CountrysideRVParkCT](http://www.facebook.com/CountrysideRVParkCT)

Download registration form at:

<https://www.facebook.com/events/517940644944670/>.

## Lyme Disease: Call for a "Manhattan Project" to Combat the Epidemic

Raphael B. Stricker, Lorraine Johnson

*PLoS Pathog 10(1): e1003796. - January 2, 2014 Opinion*

Lyme disease is the most common tick-borne illness in the world today. Until recently, the Centers for Disease Control and Prevention (CDC) reported an average of only 30,000 cases of Lyme disease per year in the United States. Three preliminary CDC studies, however, have indicated that the true incidence of Lyme disease may be greater than 300,000 cases and as high as one million cases per year in the United States. A majority of these cases occur in women and children. Based on this new information, Lyme disease should be recognized as a virulent epidemic that is at least six times more common than HIV/AIDS. In response to these alarming statistics, we review the ongoing problems with diagnosis and treatment of Lyme disease. We propose the need for an HIV/AIDS-style "Manhattan project" to combat this serious epidemic that threatens the physical and mental health of millions of people around the world.

Free, full text: <http://doi.org/10.1371/journal.ppat.1003796>.

## NJ State Dept of Health Issues Warning On Lyme Carditis CARDITIS

The NJ State Department of Health distributed a special report in December to all medical practitioners in the state, warning of 3 cases of fatal Lyme carditis involving patients ages 26-38 years old. In all 3 cases, the diagnosis of Lyme carditis was made by tissue harvesting for organ donation. Donated corneas from two of the patients were transplanted into three recipients before the diagnosis was made. The special bulletin included an alert to monitor all patients with unexplained cardiac symptoms for Lyme disease and encouraged reporting of all cases.



**Congratulations to ILADS Member  
GINGER SAVELY, DNP  
for being awarded the 2014  
AANP State Award for Excellence NP**

## Lyme Disease May Be Sexually Transmitted, Study Suggests.

**CONTACT: Guinnevere Stevens - 415-399-1035**

**FOR RELEASE: January 25, 2014**



**Carmel, CA** - A new study suggests that Lyme disease may be sexually transmitted. The study was presented at

In the study, researchers tested semen samples and vaginal secretions from three groups of patients: control subjects without evidence of Lyme disease, random subjects who tested positive for Lyme disease, and married



the annual Western Regional Meeting of the American Federation for Medical Research, and an abstract of the research was published in the January issue of the Journal of Investigative Medicine.

Lyme disease is a tickborne infection caused by *Borrelia burgdorferi*, a type of corkscrewshaped bacteria known as a spirochete (pronounced spiro'keet). The Lyme spirochete resembles the agent of syphilis, long recognized as the epitome of sexually transmitted diseases. Last summer the Centers for Disease Control and Prevention (CDC) announced that Lyme disease is much more common than previously thought, with over 300,000 new cases diagnosed each year in the United States. That makes Lyme disease almost twice as common as breast cancer and six times more common than HIV/AIDS.

"Our findings will change the way Lyme disease is viewed by doctors and patients," said Marianne Middelveen, lead author of the study presented in Carmel. "It explains why the disease is more common than one would think if only ticks were involved in transmission."

The present study was a collaborative effort by an international team of scientists. In addition to Middelveen, a veterinary microbiologist from Canada, researchers included molecular biologists Jennie Burke, Augustin Franco and Yean Wang and dermatologist Peter Mayne from Australia working with molecular biologists Eva Sapi and Cheryl Bandoski, family practitioner Hilary Schlinger and internist Raphael Stricker from the United States.

heterosexual couples engaging in unprotected sex who tested positive for the disease.

As expected, all of the control subjects tested negative for *Borrelia burgdorferi* in semen samples or vaginal secretions. In contrast, all women with Lyme disease tested positive for *Borrelia burgdorferi* in vaginal secretions, while about half of the men with Lyme disease tested positive for the Lyme spirochete in semen samples. Furthermore, one of the heterosexual couples with Lyme disease showed identical strains of the Lyme spirochete in their genital secretions.

"The presence of the Lyme spirochete in genital secretions and identical strains in married couples strongly suggests that sexual transmission of the disease occurs," said Dr. Mayne.

"We don't yet understand why women with Lyme disease have consistently positive vaginal secretions, whilst semen samples are more variable. Obviously there is more work to be done here."

Dr. Stricker pointed to the unknown risks of contracting Lyme disease raised by the study. "There is always some risk of getting Lyme disease from a tickbite in the woods," he said. "But there may be a bigger risk of getting Lyme disease in the bedroom."

Reference: The Journal of Investigative Medicine 2014;62:280-281. Presented at the Western Regional Meeting of the American Federation for Medical Research, Carmel, CA, January 25, 2014. <http://afmr.org/Western/>. Additional information: [officemanager@usmamed.com](mailto:officemanager@usmamed.com)