Dear ILADS Member,

May is Lyme Disease Awareness month! This issue features the many projects that our members have planned. Please consider making a donation to ILADEF this month to honor the work of all of our members. Your tax deductible contribution will go a long way to promote our mission.

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

PRESIDENT’S MESSAGE

Greetings Colleagues,

ILADS continues to grow as evidenced by our spring conferences in Hershey, Pennsylvania and Augsburg, Germany. I was encouraged by the ever-growing number of professionals that attended these conferences that are new to the field. Their interest in the field was clearly demonstrated by the numbers that applied to be members of ILADS and expressed an interest in ILADS physician training program.

ILADS messaging is coming through loud and clear in the media. Recent coverage in the Wall Street Journal, National Geographic, Prevention Magazine and the Huffington Post continued to encourage the dialogue we need to solve the Lyme disease problem.

The ILADS Board of Directors and staff are eagerly preparing for what should be the best professional conference yet in Washington October 10-12, 2014. The conference will continue its leadership in professional education and training. The basics course that was so well received in San Diego in 2013 will be repeated in Washington, October 9, 2014.

We always like to hear from our stakeholders, you! Please feel free to reach out to us at contact@ilads.org We always appreciate your suggestions as we continue to enhance member benefits.

Daniel J. Cameron, MD, MPH
President, ILADS

Ever Wondered How ILADS Is Governed?

ILADS Board of Directors consists of 10 members who are each responsible for a different aspect of ILADS work. This year, we will be replacing two current Board members whose terms are expiring at the annual meeting.

The Board meets on a monthly basis, currently the second Wednesday of each month via telephone call. In between Board members schedule evening meetings with their committees and respond to e-mails of general interest to the Board. All agree the satisfaction of service is rewarding. Each Board member has a term of three years with the possibility of one renewal. The By Laws states that all Board members need to be voting members of ILADS.

If you are interested in exploring the possibility of serving on the Board of Directors of ILADS, please contact Leo J. Shea, ILADS Elections

ILADS Elections will be held at the annual member meeting in October 2014 in Washington DC. We are seeking individuals who would like to be considered for board positions and help to advance the mission and goals of ILADS.

Board members are expected to participate actively in the ongoing work of the board by:

1. Attending monthly telephonic board meetings of approximately 2 hours in duration,

2. Chairing or participating in specific committees defined to advance the goals of ILADS with a monthly commitment of 5-10 hours of committee time,

3. Attendance at twice-annual offsite organizational meetings of 1 day in duration and
III, PhD, Chairman of Nominating at contact@ilads.org.

4. Willingness to participate in other activities as requested by the National Director.

Candidates should be voting members and have a history of development and management of organizations and have an understanding of financial and fundraising activity. Please submit a statement to contact@ilads.org of no more than 500 words indicating why you wish to be a member of the board of directors and what contributions you would bring to it.

NEW! Member’s Presentations & Papers on ILADS’ Website

Recent Member Postings

**Advances in Pleomorphic Forms of Borrelia**
Leona Gibert’s Presentation on 26 April 2014, ILADS European Conference, Augsburg, Germany.

**The Establishment of a Blacklegged Tick Population by Migratory Songbirds in Ontario, Canada**
John D. Scott, Lyme Disease Association of Ontario

If you are an ILADS member, and you would like to include papers you have written in the new public Members’ Presentations & Papers section on the ILADS website, please send your paper to contact@ilads.org for consideration.

ILADS PRESENTS: Half Day Lyme Fundamentals Course

**ILADS MONMOUTH 2014**

**LYME DISEASE FUNDAMENTALS COURSE**

The Fundamentals of Diagnosis and Treatment of Lyme Disease & Coinfections : Implications for Adult and Pediatric Neuropsychiatric Issues

An Evidenced Based Course for Health Care Professionals. This half day course is designed to teach the practitioner how to recognize signs and symptoms in the differential diagnosis of early and late stage Lyme disease and common co-infections. Various testing techniques and treatment options will be discussed with neuropsychiatric implications for adults as well as children. The course will provide ample opportunity for Q & A and open discussions with nationally known speakers.

Location: Monmouth University, 400 Cedar Avenue, West Long Branch, NJ 07764-1898;
Date: September, 13, 2014

Registration will up shortly. If you would like to stay updated on course information, please fill out our "Stay Updated" form by clicking here

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ILADS COMES TO DC:
2014 ILADS Annual Conference and Fundamentals Course

The 2014 ILADS annual conference will be held at the Grand Hyatt DC Hotel in Washington, D.C. Thursday through Sunday, October 9-12, 2014. ILADS has negotiated a special sleeping rate of $189 per person for registrants good until September 17, 2014. See www.ilads.org for details.

The first day, Thursday October 9, 2014 is a Lyme Fundamentals intensive course for professionals only. The Friday through Sunday noon basic schedule is plenary sessions each morning followed by breakout sessions in the afternoon. Medical professionals are invited to register early. Others will be allowed to register within a month of the meeting, space pending.

The Grand Hyatt is located at 1000 H Street, N.W., Washington, D.C. and is conveniently situated at the Metro Center station of the Washington Metro system. The nearest airport is Ronald Reagan Washington National Airport from which the hotel is accessible by Metro or taxi.

Most of the Washington area’s major attractions may be reached either by walking or a short Metro ride, so a car is not necessary. The Capitol itself is nearby, the closest Metro stops being either Union Station (closer to the Senate Office Buildings) or Capital South (closer to the House of Representative Office Buildings. To arrange tours or the Capitol, please go the the website www.visitthecapital.gov.

Other nearby sites include the Library of Congress, the Smithsonian Museums on the National Mall, The National Archives, the International Spy Museum and the White House. The Washington Monument has also just reopened, following extensive repairs. The neighborhood surrounding the hotel is home to some of the city’s best restaurants and casual eateries as well as many shops. One good source for information regarding the neighborhood is www.dc.about.com.

Charles Ray Jones, MD 2014 Pioneer in Lyme Awardee

This year, Dr. Charles R. Jones, an ILADS training physician and pediatrician will be awarded the second annual PIONEERS IN LYME DISEASE AWARD October 11, 2014 at the Grand Hyatt Hotel in Washington, DC. We will be asking everyone who has been touched by Dr. Jones to participate either by attending or by posting tributes on our web site.

As stated by Gordon Medical, “Even though Dr. Jones is in Connecticut, every child and pregnant mother who has been treated for Lyme disease will have been affected by the work and research of Dr. Jones over his long career, and every doctor who treats children with Lyme will have learned from him.”

Please plan to join us in DC for a special night of celebration Dr. Jones’ legacy.
ILADS Screening of UOS II

On Thursday October 9th ILADS will be screening the sequel to Under Our Skin, the power Lyme film that raised awareness about the plight of chronic Lyme disease patients. Registrants of the ILADS conference, plan to join us the evening of October 9th for a special reception hosted by IGENEX. Andy Wilson, the film’s producer, will be on hand to greet you and answer questions about his journey in making the films. www.underourskin.com/sequel.

John Drulle, MD Memorial Lectureship

Each year one speaker at the annual ILADS conference is chosen to be the grantee of the John Drulle Memorial lectureship. Dr. Drulle was a creative thinker who knew no limits to help his chronic Lyme patients. ILADS is delighted that the 2014 recipient will be announced at the annual meeting and will receive a stipend of $5,000.

Case Discussions At Annual Meeting

Anyone who anticipate attending the fall annual conference in October, please consider a 10-15 minute case presentation. Dr. Sam Shor is accepting requests. Contact him at contact@ilads.org and put in the subject line Case Presentation for Annual Meeting. Include your contact information as well as your case presentation.

New ILADS Research Committee

Armin Schwarzbach, MD, PhD and Leona Gilbert will be heading a new Research Committee for members who are doing research relevant to tick borne diseases. From time to time, one or the other will be updating the membership as to the activities of the working group and asking for input from the ILADS membership.

Prevention Magazine Publishes Article Supporting Lyme Disease

By Katherine Harmon Courage

The Truth About Lyme Disease. Why One Man Volunteered To Have 8 Blood-Sucking Ticks Attached To His Knee. Not concerned about Lyme disease? You might want to rethink that if you ever go outside. Read the article.

The Karl McManus Foundation

We needs funds urgently to set up a Lyme disease research centre at the University of Sydney so that Australians suffering from Lyme disease can get proper diagnosis and treatment. A donation at www.karlmcmanusfoundation.org.au will help us to do this. You can also help us get Lyme disease recognised in Australia if you are inclined to be politically active with your state and/or federal MP. Thank you for your support.

ILADS IN AUGSBURG

Carsten Nicolaus MD, PhD
This year’s European ILADS Conference took place on April 25th and April 26th 2014 in Augsburg (Germany). People from 17 countries took interest in the topic and came to the Bavarian city of the Fuggers, near Munich.

The conference welcomed 115 participants overall and was supported by 11 exhibitors and 13 speakers who exposed current information about the topic. The BCA-clinic in Augsburg organized the ILADS Conference on site. The day before the official inauguration, Dr. Carsten Nicolaus and Dr. Armin Schwarzbach welcomed approximately 30 participants within the premises of the BCA-clinic, where they were able to learn about the possibilities of diagnosis with Infectolab (partner of the BCA-clinic) and therapies in the BCA-clinic.

After the official welcoming speech of the Board and the organizer of the program, Dr. Carsten Nicolaus, ILADEF treasurer, the first day of the conference was inaugurated. Traditionally, the first day is designed for ILADS-therapists as its purpose is to convey standards in diagnostics and therapy for physicians who want to work according to the ILADS guidelines. Every participant receives a certificate which shall represent a standard of quality for therapists. ILADS will only transfer patients to physicians who are in possession of this certificate.

The introductory speech was held by Raphael B. Stricker, MD. He presented in a general overview of tick-borne diseases and exposed the history of the disease, its epidemiology and its pathogens. He emphasized on the different borrelia strains and the clinical dilemma that arises from the diversity of symptoms of chronic Lyme disease, the known co-infections and other additional infections.

Christine Green, MD, discussed the difficulties emerging from the diversity of symptoms in tick-borne diseases, which should be

The second speaker of the day was Samuel M. Shor, MD, FACP. He explained the use of hyperbaric oxygen therapy to treat tick-borne diseases. He describes from his own practice the successful treatment and therapy possibilities of chronic and other diseases such as cystitis or MS.

Mrs. Leona K. Gilbert, PhD gave very important input for therapy by presenting the pleomorphic forms of borrelia that she had studied. She showed that the results of her study did not confirm the existence of “cystic” forms of borrelia. Those forms are not cell wall deficient but have a cell envelope. She calls those forms “round bodies”. They are cable to develop rapidly back into bioactive, mobile forms. These proven pleomorphic forms (round bodies, biofilms and bubbles/loop shaped forms) allow a protection against the immune system and, therefore, lead to a chronic disease. She has proven this in an experiment in the laboratory.

Armin Schwarzbach, MD, PhD explained the limitations of the laboratory diagnostics in Lyme disease. He highlighted the low sensitivity of ELISA and Immunoblot-tests. To compensate this, additional cellular immune system tests should be carried out: LTT-Elispot and CD-57-NK-cells as laboratory cells. In the second part of his presentation, he explained the possibilities to use the laboratory tests for the diagnostics of co-infections and additional infections.

A clear appeal was made by Albin Obitschnig, MD, to perform a direct proof for borrelia in different tissues. First, he explains the issues related to indirect laboratory tests. Then, he offered various methods for direct pathogenic evidence. He presented, for instance, the setting of a culture from a tissue sample (low sensitivity), the histopathological examination and the PCR. Thanks to his hand surgery practice he has been able to examine samples of tissues and, as a consequence of the results, had to question many
registered on standardized questionnaires. She also presented the diverging opinions of the CDC, the IDSA and the ILADS about the subject. She insistently pled that therapists should listen carefully to what the patients have to say.

Armin Schwarzbach MD, PhD, informed about the interpretation and application of laboratory tests when treating tick-borne disease. He highlighted the importance of preanalytics for lab results. He differentiated various tests such as PCR, ELISA and immunoblot, CD-57-NK cells as well as LTT-Elispot in reference to multisystem diseases.

Samuel M. Shor MD, FACP, reported on his personal practice of treating tick-borne diseases. In the first part of his presentation, he showed how to explain the therapy to the patients and what supportive measures have to be taken, i.e. detox, diet, and treatment of the intestine to reduce side effects and improve the sleep. In the second part of his presentation, he explained the different antibiotic therapies he uses, either with synthetic or natural antibiotics (herbs). He commented on the application of i.v. schemes, such as combination therapies and pulsing.

Carsten Nicolaus, MD, PhD, presented a European view of the epidemiology and pathogenesis. The varied co-infections were put in the spotlight. He presented thoroughly the different tick-borne co-infections, but also 5 those transmitted or caught otherwise (additional infections). He exposed the symptoms of those infections and highlighted the difficulty of diagnosis due to the overlapping symptoms. At last, he presented the combination therapy he applies for multiple infections.

Leo J. Shea III, PhD, dedicated his presentation to a special subject: the neuropsychological challenges of Lyme disease for children and families. As a psychiatrist, he conducted a study on 77 children. He described extensively the effect of the disease on the central nervous system and how these psychological symptoms and dysfunctions show in the patient. He explained which neurological and psychiatric surgical operations.

Pol de Saedeleer, RPharm, started the second half of the day thanks to his presentation on adrenal stress. He presented the highly complex processes that lead to adrenal stress. He showed that adrenal stress could trigger disturbances in the immune system, dysfunctions in the intestine, the brain and to the mitochondrial system. Extreme stress and continuous stress also trigger chronic disturbances, and therefore chronic diseases. This way, it also promote chronic infections, as mentioned by the speaker.

Raphael B. Stricker’s, MD, presentation of sexual transmission of borrelia had already been a discussed subject. He presented a collaborated study which isolated and proved the existence if B. burgdorferi in vaginal secretion and sperm. As a consequence of this result, a sexual transmission of borrelia cannot be denied. However, a more amplified study is necessary and it does not prove that every sexual partner is infected.

Christine Green, MD, reports that chlamydia pneumoniae have similar escape mechanisms (similar polymorphism forms). These pathogens are not only transmitted by ticks, but also by other means such as the air. She also presented symptoms, diagnostics and treatment of Chlamydia infections.

The presentation performed by David C. Martz, MD, was extremely impressive. Many years ago, he got ill himself and got a “death sentence” with MND (or ALS). His thesis is that MND could be a special manifestation of an infection with B. burgdorferi. Thus, he presented the history of his disease and the results of his practice. Out of his 900 patients, 120 have had a MND diagnosis. He treats them in his practice with a antibiotic-monotherapy (Cetrifaxon). 28 patients managed to stop the progress of the disease and 14 patients showed improvements. He reached out to many doctors in order to help these condemned patients.

Frau Ginger R. Savely, DNP, reported about morgellons and insisted on her thesis that it is a new co-infection related to Lyme. She is trying to prove that morgellons are a special form of
diagnoses should also be checked on tick-borne diseases. Anxiety Disorder or ADHD, for instance, are examples that were mentioned. In his study, he also effect those symptoms have on the families of the affected children.

Further, Samuel Shor, MD, FACP, pled for a practice based on evidence when it comes to tick-borne diseases. He explained the reasons for opening such a practice from the ILADS’ point of view and showed the different positions of IDSA and ILADS. He, then, mentioned existing literature.

In the evening of the first day, the Mayor of Augsburg had organized a reception in the impressive Golden Hall of the Town Hall of Augsburg. On behalf of the Mayor Dr. Kurt Gribl, Max Weinkamm cordially welcomed the participants of the congress and highlighted that the City of Ausburg is proud to host yet again the International Congress and to be the home for a renowned European Lyme Center. This day ended with a cozy evening and professional conversations in the historical “Ratskeller” of Augsburg.

On the main day of the congress the speakers presented new scientific studies and how their findings affect the examination of Lyme and co-infections.

After the inauguration of the second day, Valerie Obsomer, PhD presented the results of a survey about the spreading of tick-borne diseases that she conducted in Belgium. To begin with she spoke about the results of another study that had been carried out under her supervision. Thus, she could prove the presence of up to 95 different pathogens in ticks. In specific examined regions, there are more than 45% of the ticks infected with borrelia. She also informed the audience that 30% of the ticks spread by birds were infected with up to 6 human pathogenic strains. 41% of the interrogated participants had more than 5 tick bites. The means of transport are extremely diverse but 27% of the participants were bit in their own garden.

To conclude the day, Bernhard Ammann, Dipl.-Ing. (FH) presented “Lymecare”. He demonstrated the difficulties lyme patients have when it comes to control the development of their symptoms. “Lymecare” is an app that the patient uses daily to record his state of health and symptoms on his smartphone or laptop. The results are registered and can be seen on a weekly or monthly basis. This way, both patient and doctor have a daily development without having to meet as often. Moreover, the patient would get the information if intolerance or even a dangerous side effect occurs as a response to the antibiotics. This app could also be useful for other chronic diseases and/or for medical follow-up studies. It should be considered by many universities who conduct a variety of studies.

To close the conference, a yoga workshop was given for which 16 participants were present. The speaker and trainer Mrs. Katherine Kirk first demonstrated the difference between regular yoga and MSIDS-yoga. She reported the benefits of certain yoga exercises for patients affected with multisystem diseases. The presented exercises had been specifically designed for the particular group of patients, according to their needs and abilities.

Photos from the ILADS Augsburg Conference are posted on the website.

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**Position Available**

Busy Naturopathic practice looking for an experienced and integrated Lyme Literate practitioner (ND, DO, MD, NP). We have a 9-month waiting list for new patients. Therapeutics commonly used in our practice are oral and IV antimicrobial therapy, nutrition, botanical

**ILADS Member, Gary Kaplan, DO Has Written a New Book of Interest to the Lyme Community**

In Total Recovery, Dr. Gary Kaplan argues that we’ve been thinking about disease all wrong. Drawing on dramatic patient stories and cutting-edge research, the book
Complex, Late Stage, or Chronic Lyme Disease?

WILTON, CT – Has your life been significantly impacted by Lyme disease?

Steven Phillips, M.D., a Yale trained physician specializing in the diagnosis and treatment of Lyme disease, has re-opened his practice. Dr. Phillips initially began his practice in Ridgefield in 1996, and then about 7 years later moved just over the border to the Georgetown part of Rt. 7 in Wilton, where he practiced until June 2011. At that time, a serious medical condition with his back required that he take a leave of absence. Now that his back is better, he is very much looking forward to offering regular medical care as of 9/1/13.

Lyme disease, as well as other vector-borne pathogens such as Babesia, Ehrlichia, and Bartonella, can seriously disrupt the lives of previously healthy individuals. These infections can be difficult to diagnose and treat if not caught early.

About the practice

We’re located at 944 Danbury Road, Wilton. Just South of Bruce Bennett Nissan. Tel 203-544-0005. If you need an appointment, please leave your contact information to join our waiting list.

About Steven Phillips, MD

Dr. Phillips has been a proponent of treating stubborn cases of Lyme disease with longer, more intensive courses of antibiotics. His long list of accomplishments include:

- Being well published in the medical literature on the topic of Lyme disease;
- Having been asked by the states CT, NY, and RI to give numerous testimonies as a Lyme disease expert at the state level; and
- Being a past president of The International Lyme and Associated Diseases Society (ILADS.org). He has extensive experience not only in the management of Lyme disease, but its other associated vector-borne infections as well. An internationally known physician/researcher, he has treated patients from over 20 countries. Contact: JoAnn Nadeau, Steven Phillips, MD PC 203-544-0005

Dr. Margaret Helene Bayer - July 8, 1931 - May 12, 2014

by Pat Smith

Margret H. Bayer, a researcher whose early work with her husband, Dr. Manfred Bayer, on Lyme disease PCR, is still cited today, died on May 12. The Drs. Bayer received funding from the LDA for their groundbreaking research which resulted in the often cited publication in Infection 24 (1996) (abstract below). Her contribution to Lyme research with that project and others that followed showed her dedication to helping provide Lyme patients with answers as to why they
continue to be sick despite treatment for the disease. It is sad to lose someone with her talent and dedication and we send our condolences to her husband, Dr. Manfred Bayer, and to her entire family for their loss.

Groundbreaking research publication

Infection 1996: Borrelia burgdorferi DNA in the Urine of Treated Patients with Chronic Lyme Disease Symptoms: A PCR Study of 97 Cases, Bayer ME, Zhang L, Bayer MH. Author affiliation Fox Chase Cancer Center, Philadelphia, PA 19111, USA

Stewart Bint Takes Barefoot Walk

UK novelist Stewart Bint is going completely barefoot 24/7 for two months culminating in a 10k barefoot walk to raise awareness of Lyme Disease. Stewart takes up the story: “I discovered that my Twitter and Facebook friend, Cat Kozich, from Tennessee, suffers from Lyme Disease. Although I had heard of it I didn’t actually know anything about it, and was horrified when I found out the effects it has on people if not treated early. And I was equally horrified to learn that some sections of the medical profession don’t recognise it as a disease.

“I wanted to do something to raise awareness, and as I had already signed up to do the organised Amis Sans Shoes 10k barefoot walk in the UK on July 20, I decided to dedicate it to Cat, and use it to bring this dreadful disease into the public eye.

“To increase the opportunity of both gaining media coverage and talking to people, I have decided to do everything barefoot in the two months leading up to the walk. So I will be having bare feet 24/7 from May 20 until the walk. I am confident that many people will stop me in the street to ask why I’m barefoot, and I’ll be able to bring Lyme Disease to their attention.

“As an experiment last week I gave an author talk at a local school, barefoot, and was quizzed by the children about it...in fact they were more interested in that, than they were in my books! So the ball is rolling, and it’s working.”

“Although the purpose is principally to raise awareness, it would also be nice if people could sponsor me. ILADS has set up a campaign and donating page at www.ilads.org/fundraise/campaigns/for-cat-kozich-the-barefoot-lymie/.

If you would like to set up your own Crowdfunding Campaign, click below.

Start Your Own Campaign

LYME COMMUNITY EVENTS

The Mayday Project
Date: May 22 & 23, 2014
Website: www.themaydayproject.org

Ticked Off Art: Understanding Lyme Through Art
Date: May 5 - 29
Opening Reception: May 8, 6:30-8:30pm
Where: Maple Grove Arts Center is located at 7916 Main Street, Maple Grove, MN 55369
State Coordinator: Vicki Koecher & Kara Welch

Dr. Horowitz speaking at Lyme Seminar in Norway
Date: May 26-27, 2014
National Lyme Disease Research Center in the Netherlands

On May 5, 2014 the House of Parliament unanimously supported the proposal of MP Henk van Gerven to establish a national Lyme disease research and treatment center. Van Gerven, “It is a unique event that a citizens initiative has been taken over by the House of parliament. This will hopefully give more insight into the diagnosis of Lyme and tickbite related diseases and offers better chances on the proper treatment of thousands of Lyme disease patients in the Netherlands.”