LDA Celebrates 30 Years of Service!

Lyme Disease Association, Inc., LDA, is proud to celebrate 30 years of advocacy and volunteerism to improve research, education, and patient support surrounding Lyme and tick-borne disease.

Dr. Nick Harris (2nd from L) and Dr. Terry MacKnight are flanked by LDANJ Officers Pat Smith and Corey Lakin at a Congressional Forum in Pennsylvania where they were about to speak in 1999. Dr. Harris & MacKnight went on to found ILADS, International Lyme & Associated Diseases Society

Early Years
By 1990, the total US reported Lyme disease case numbers were 7,943 cases – NJ was second in the nation for the highest number at 1,074 cases – and New York was first. (1990 LDA MAP) At that time, two groups of patients and doctors, in Northern and Central NJ, were already loosely organized and advocating
for Lyme patients – the latter group formed the basis for what is now LDA and was formally incorporated as Lyme Disease Association of Central Jersey Inc. As cases grew, the organization became the Lyme Disease Association of New Jersey Inc. and funded some of the first publicly funded Lyme research in the country on Lyme PCR published in peer review, and some of the first Lyme laws in the country were developed here and passed in NJ (View article on NJ Legislation Affecting Lyme in Schools).

In 1997, Pat Smith, founder & Chair of a NJ grassroots lobbying group and 12-year departing president of her town’s Board of Education, was elected President of LDANJ. In 2000, when US reported cases reached 17,730, she led the Board to a broader focus, with a new name, Lyme Disease Association, Inc. (LDA) – registered in states throughout the US – and focused on a national mission.

**Programs**

Since its inception, LDA has presented 20 fully accredited CME scientific conferences for researchers and health care providers. It continues to fund tick-borne disease research nationally, provide monies for children without insurance coverage for Lyme treatment, provide on-line brochure ordering for postage-only, host a free online doctor referral system and head the umbrella organization, LDAnet – a group of 40+ associated organizations nationwide that work together on national issues regarding Lyme and other tick-borne diseases.

**Research Grants**

In its search for a cure for chronic Lyme disease and other tick-borne diseases, the LDA celebrates funding 119 research projects coast-to-coast at various institutions (GRANTS AWARDED), and in 2007, LDA partnered with then Time for Lyme to open the first endowed research center for Lyme disease and tick-borne diseases in the US. To date, LDA-funded research has appeared in 53 peer-reviewed journal publications, (PUBLICATIONS FROM LDA RESEARCH) helping to move the field
forward.

**Education Grants**
The LDA also aides other organizations and institutions in their missions to educate about Lyme and other tick-borne diseases and has awarded 145 education grants for publications, conferences, billboards, and other activities. LDA has also provided 95 conference scholarships to health care providers, medical students, public health officials, and advocates. (EDUCATIONAL GRANTS)

**Shaping Public Policy**
LDA President, Pat Smith, is a second-term member of the Health and Human Services (HHS) Tick-Borne Disease Working Group (TBDWG) established by Congress in 2016. (LDA’S TBDWG PAGE) She was instrumental in the creation of the original Lyme legislation and its passage through the US House of Representatives and then its revision as it was placed into the 21st Century Cures Act. LDA led an advocacy effort to get the legislation passed in that Act which created the existent Working Group. She has also testified before 2 of the US House of Representatives Subcommittees on Lyme disease and effects on patients. She has also helped to write and has testified before many state legislatures on Lyme disease legislation. (TESTIMONY)

**Fiscal Responsibility**
The LDA has always consisted of patients and families of patients, volunteers who run the organization. It has never had employees but has consultants who provide expertise in necessary areas. The LDA averages 97% of its funds going to its programs. As LDA celebrates 30 years, we look for help from across the US to help unlock the secrets of Lyme and other tick-borne diseases.
30 Years of Service in Photos

Lyme Awareness Press Conference; Pat Smith, LDA, at Podium

Congressman Chris Smith (NJ); Pat Smith (LDA), Brian Dashore & Mother

LDA Celebrates 20 Years of Scientific Conferences
Pat Smith, LDA, and Brian Fallon, MD, MPH, Columbia University

LDA Partner Organizations Throughout the US

Congressman Chris Smith (R, NJ); Pat & Rich Smith, LDA

LDA / Columbia Scientific Conference
Combined Federal Campaign (CFC) Donors Keep Pledging! Feb. 22 Deadline

The deadline for the 2018 Combined Federal Campaign has been extended to February 22, 2019, providing donors with a few more weeks to complete a pledge online or submit a paper pledge form to a Keyworker or Campaign Manager. Make a pledge to Lyme Disease Association, Inc. CFC#11424

Donors can make a pledge by logging on to opm.gov/ShowSomeLoveCFC to complete a pledge online or submitting a paper pledge form no later than February 8th. Donors should mail paper pledge form to: CFC Processing Center, P.O. Box 7820, Madison, WI 53707-7820

Link to federal employee pledge form
Link to retiree pledge form
Congressman Smith Introduces: National Lyme & Tick-Borne Diseases Control & Accountability Act of 2018
2018–The Lyme Disease Association, Inc. announces the introduction of HR 5900,* "National Lyme and Tick-Borne
Diseases Control and Accountability Act of 2018’’ into the US House of Representatives by Congressman Christopher H. Smith (NJ-4). The Act will establish the Office of Oversight and Coordination for Tick-Borne Diseases in the Office of the Secretary of Health & Human Services (HHS) to be headed by a director appointed by the Secretary. Representatives Peterson (D-MN7), Faso (R-NY19), Comstock (R-VA10) and Posey (R-FL8) have joined Mr. Smith in co-sponsoring the bill.

Its purposes are to oversee the creation and establishment of an integrated national strategy to overcome Lyme disease and other tick-borne diseases (TBD) and to oversee and coordinate Lyme and TBD programs and activities across agencies and offices of HHS.

Reps. Chris Smith (R-NJ) and Collin Peterson (D-MN), the co-chairs of the Congressional Lyme Disease Caucus, and the other co-sponsors are pushing the bipartisan legislation to create a new national strategy for Lyme disease and strengthen treatment and prevention of Lyme and other tick-borne diseases.

According to LDA President Pat Smith, “There is an urgent need for the House to pass this bill so that Lyme and other tick-borne diseases (TBD) are addressed in a coordinated fashion. The US needs to play a leadership role in this effort, since Lyme is spreading around the globe as are many other TBD, ~20 in the US alone. The public is at risk, as are our children, since tick-borne disease cases have doubled over the past 13 years. I applaud Congressman Smith’s continued focus on the impact upon individuals and families who have TBD and upon the public at large who may contract these diseases from ever increasing existing tick populations, and perhaps in the future, from a new tick such as the invasive longicornis tick now found in NJ—the impact of which tick is yet little understood.”

Objectives of Office of Oversight and Coordination for Tick-
Borne Diseases include expansion and enhancement of epidemiological research & basic translational, clinical and biomedical research; expansion and improvement of surveillance and reporting of Lyme and TBD including coinfections; development of effective diagnostic tests to accurately and timely diagnose Lyme & TBD, including direct detection tests; development of treatments to cure or improve the lives of those affected with Lyme & TBD or who suffer from tick-induced disorder; design and conduct clinical trials of sufficient size and duration to support clinical recommendations; development of patient registries; documentation of experiences of health care professionals in diagnosing TBD; inclusion individuals with chronic Lyme disease in clinical, research, and service efforts; and coordination with international bodies to integrate and inform the fight against Lyme and TBD globally.

The Lyme Disease Association provided input into the development of the bill with the Office of Congressman Christopher Smith.

*LDA Note: HR 5900 introduced on 5/21 is the same as HR 5878 introduced on 5/18 – due to a technical glitch

Click here for full bill text HR 5878 (the same as HR 5900)

Click here for Congressman Smith’s press release

Click here for LDA’s Newsletter on Lyme bill
Important Directives Targeting Lyme & Tick-Borne Diseases

The Consolidated Appropriations Act, 2018, signed into law on March 23, 2018 (Public Law 115-141), funds the Federal government through Sept. 30, 2018. It includes increased funding of $12.2 million for CDC’s vector-borne diseases activities and an increase of $353.6 million for the National Institutes of Allergy & Infectious Diseases, NIAID, which is the NIH Institute that funds Lyme disease research, influenza, and other infectious diseases.
the Federal government through Sept. 30, 2018. It includes increased funding of $12.2 million for CDC’s vector-borne diseases activities and an increase of $353.6 million for the National Institutes of Allergy & Infectious Diseases, NIAID, which is the NIH Institute that funds Lyme disease research, influenza, and other infectious diseases. Vector-borne diseases funding cannot be found in the actual language of the consolidated bill, but can be found in the joint explanatory statement for the Consolidated Appropriations Act, in Book III of the Congressional Record for March 22, 2018. Similarly, 2017 Vector-borne Diseases funding can be found in the May 3, 2017 Congressional Record. In addition, each individual appropriations bill that passed either the House or Senate Appropriations Committee has a committee report that provides explanations of Congressional intent and directions to agencies in expending appropriated funds, such as referenced below.

The Lyme Disease Association, Inc., LDA, worked with the office of Congressman Chris Smith (NJ) in developing several provisions that were included in the appropriate committee report, i.e., H. Report 115-244. Those provisions included: ensuring transparency, input from treating physicians and representation of the broad spectrum of scientific viewpoints in CDC’s physician education program for Lyme disease; a written rationale for treatment guidelines included on CDC’s website; research that will increase understanding of full range of Lyme disease processes and physiology of Borrelia burgdorferi and B. mayonii, including mechanisms of persistence; development of more sensitive and accurate diagnostics for Lyme and other TBD, including next generation PCR and new methodologies, such as omics; a bibliography of peer-reviewed TBD literature to include literature on possible mechanisms of persistent Borrelia infection. Other stakeholder and patient advocacy organizations developed report language submitted through members of Congress, including major improvements in surveillance and prevention, expanded research
NJ Legislature Observes May Lyme Awareness & Salutes LDA

Almost 400,000 cases of Lyme disease occur in the US annually, something recognized by Assemblymen David Rible and Sean Kean (R-30) who on May 19 presented the Lyme Disease Association, Inc. (LDA) President, Pat Smith, Wall Township, with a Joint Legislative Resolution joining one the LDA received from NJ Gov. Chris Christie proclaiming May 2017 Lyme Disease Awareness Month, and one passed by the Legislature in 2008 recognizing each May as such. (L to R) Assemblyman Sean Kean, LDA Pres. Pat Smith, Assemblyman Dave Rible.
Resolution from the NJ Senate and General Assembly introduced by them and Senator Robert Singer (R-30). In part, it states: “...Be It Resolved by the Senate and General Assembly of the State of New Jersey: That this Legislature hereby joins in the observance of Lyme Disease Awareness month during May 2017, salutes the Lyme Disease Association Inc. for its outstanding dedication and commitment, and urges all New Jerseyans to learn the prevention methods and techniques utilized in the removal of ticks;...”

According to LDA President Pat Smith: “It is important that through the efforts of Assemblymen Rible and Kean, and Senator Singer, the State Legislature of NJ recognizes the significance of Lyme disease— a State which ranks 2nd nationwide with 48,000 cases in 2015 alone, and Monmouth and Ocean Counties which rank 2nd and 5th in the State in case numbers, respectively. Despite the numbers, the public, and even some physicians, are not only unaware of the risks, especially to children ages 5-14, who are at the highest risk of acquiring Lyme, but also of the importance of proper, timely tick removal.”

Ticks should be removed immediately, as tick-borne diseases, including Lyme, can be transmitted in hours and sometimes, as with Powassan virus, in minutes. Proper removal means grasping with pointed tweezers as close to the head end of the tick as possible and pulling the tick straight out. Do not twist the tick, do not squeeze the body of the tick, do not put any substance onto the tick. Doing any of those things can cause the tick to regurgitate whatever organisms it has inside into you, greatly increasing the risk of infection. Put antiseptic on the bite site, wash your hands, and do not touch the tick. For tick disposal, wrap the tick in tape. To save the tick for testing, put it into a sealable plastic bag. Call your physician.
The LDA has worked with Congressman Chris Smith (NJ-04) for 25 years, raising awareness, passing legislation, securing funds to help stop the spread of Lyme and other tick-borne diseases (TBD). Mr. Smith Co-Chairs the US House Lyme Disease Caucus in Washington, DC. His comments on the Resolution follow.

“I commend Assemblymen Dave Rible and Sean Kean for their leadership on this much needed legislation—which empowers people to mitigate their risk and get a quick and accurate diagnosis if infected. Lyme disease can no longer be ignored—the time to act is now,” said Rep. Chris Smith (NJ-04). “We are all grateful to Lyme Disease Association President Pat Smith for her tireless efforts to ensure that local and federal officials—as well as the medical community—more effectively combat Lyme disease.”

The public also needs to recognize that one tick bite from the
blacklegged/deer tick (Ixodes scapularis) can cause more than one disease, including anaplasmosis, babesiosis, ehrlichiosis, bartonellosis, tick paralysis, and Powassan virus. Powassan does not occur frequently, but case numbers are on the rise. It is dangerous, since there is no treatment except palliative care, it has a 10-15% fatality rate, and 50% of those who recover are left with neurologic damage.

It is also very important to note that other ticks in NJ, particularly the lone star tick (Amblyomma americanum) and the American dog tick (Dermacentor variabilis), transmit a number of diseases. The lone star transmits diseases including STARI, a Lyme like illness; ehrlichiosis; and tick paralysis, a paralysis that begins at the feet and moves upward and can only be stopped by removal of the attached tick. The lone star tick bite can cause a dangerous allergy to red meat, which can cause anaphylactic shock, and some physicians may not be aware of a tick bite as the cause. The American dog tick transmits diseases including Rocky Mountain spotted fever and also tick paralysis. Any tick bite needs to be taken seriously.

The LDA’s website, www.LymeDiseaseAssociation.org, has more information on tick removal, symptoms of tick-borne diseases, and a free downloadable .pdf of its LymeR Primer and Tick Identification Card and on ordering of LDA brochures in quantity for cost of postage, and much more information on Lyme disease and other TBD.

LDA President Appointed to DoD Lyme Research Program
Wall NJ–Lyme Disease Association, Inc. (LDA) President Pat Smith has been appointed to the Fiscal Year 2016 (FY16) Programmatic Panel for the Tick-Borne Disease Research Program (TBDRP), a new program in the Department of Defense’s (DoD) Office of Congressionally Directed Medical Research Programs (CDMRP)—a typical 3-year term-of-service.

“I am pleased to be appointed to the TBD Programmatic Panel to aid in the determination of grant awards for Lyme disease research. With 300,000 individuals acquiring Lyme disease in the US annually, with more than 15 other TBD found in the US, and with a scarcity of research funding, it’s imperative that available monies are used judiciously to address priorities such as a definitive diagnostic test and chronic disease. All programs managed by the CDMRP ‘share the common goal of advancing paradigm shifting research,’ a much welcomed goal for Lyme disease research, which has suffered from enforcement of a rigid paradigm,” said LDA President and Wall, Pat Smith.

Each year, DoD’s CDMRP assesses scientific opportunities to advance research in designated areas. The TBDRP was established as one of the programs following Congressional action to include $5 million for tick-borne disease research in FY16 DoD funding bill. CDMRP strives to achieve breakthroughs in healthcare for Service
Members and the American public through innovative, impactful research, targeting research gaps other agencies may not fund. Two process hallmarks of CDMRP are reviewing applications using two-tier formal review recommended by the National Academy of Science’s Institute of Medicine, with no standing peer review panels, and involving consumer advocates throughout the program cycle.

The two-tier review model goals include scientific excellence and programmatic relevance. In the first tier, peer review, applications are evaluated, based on announced criteria, on scientific and technical merits. The second tier, programmatic review, high scientific and technical merit applications are compared, using criteria including peer review panel evaluations, programmatic relevance and innovation/impact. All review panels are composed of scientists, clinicians, military members as applicable, and consumers from advocacy communities. Consumers are full voting members and play a major role in maintaining a research focus that is relevant and has the potential to make a significant impact on the affected community. Panel members cannot apply for funding.

The Programmatic Panel also participates in a stakeholders meeting, develops a vision for the annual program cycle, and advises CDMRP staff and program support contractors at critical decision points.

The LDA has been pushing Congress to place Lyme/TBD into the CDMRP for many years and has worked with Congressman Smith who has led the Congressional effort, to make that happen. The Consolidated Appropriations Act, 2016, which funded federal agencies, including the new TBDRP, passed both houses & was signed into law December 2015. The LDA thanks House Lyme Caucus Co-Chairs Congressmen Chris Smith (NJ-4), Collin Peterson (MN-7), Caucus Members, and Congressman Rodney Frelinghuysen, DoD Subcommittee Chair (NJ-11), for their efforts to get Lyme/TBD included in the CDMRP.

Click here to read: Lyme Monies in Defense Health Program
LDA Offers Lyme Conference Scholarships for Medical Students – Apply by Oct 15

NO MORE SCHOLARSHIPS AVAILABLE

New Jersey September 2015 – The Lyme Disease Association, Inc. (LDA) announces availability of scholarships for its annual conference, Lyme & Other Tick-Borne Diseases: Science Bridging the Gap, Warwick, Rhode Island, November 14-15. Jointly provided by Columbia University, it is designed for doctors and researchers who can receive CMEs for attendance. Registration is also open to the public.

The LDA is offering a limited number of conference scholarships to eligible medical students, residents, post-doctoral candidates, fellows, veterinarians with equivalent status to the above, and nurse practitioner candidates enrolled in a doctoral program. Applications must be received by October 5, 2015 for consideration. Several more medical student scholarships are available, so the date to apply has been extended until October 15. NO MORE SCHOLARSHIPS AVAILABLE

Said LDA President Pat Smith, “It’s important that those studying to become physicians/researchers gain an understanding of the current science and how that can influence clinical practice, especially with so many newly emerging tick-borne diseases– more than 16 now found in the US. They can build on this knowledge and help educate their peers to the severity of Lyme, which now boasts 300,000 new cases each year according to the CDC.”

The LDA thanks the Steven & Alexandra Cohen Foundation for their generosity in funding these scholarships. Click here for Conference details

About the LDA: Lyme Disease Association, a national non-profit which funds research, education and patient support has awarded 100 grants to researchers across the US, and its supported research has been acknowledged in 36 peer-reviewed scientific journals. LDA has provided 102 educational grants, and the upcoming conference is the 16th continuing medical education Lyme conference presented by the LDA. LDA’s LymeAid 4 Kids fund, initiated in conjunction with internationally acclaimed author Amy Tan, has provided over $250,000 to aid children in getting a diagnosis and
treatment, as children are at the highest risk of acquiring the disease.

**About the Steven & Alexandra Cohen Foundation:** The Steven & Alexandra Cohen Foundation is committed to inspiring philanthropy and community service – with special interest in children’s health, education, veterans, and the arts – by creating awareness, offering guidance, and leading by example to show the world what giving can do. The Cohen Foundation’s Lyme Initiative is investing to cure Lyme, which infects over 300,000 Americans each year and leaves 10-20% with persistent, life-altering symptoms. Through funding leading researchers and innovators, the Foundation will improve our ability to prevent, diagnose, and treat all stages of Lyme disease.


Conference details
Lyme Comm. Unites: Protect Patient Rights

UPDATE 5-6-15: Click here for LDA/LDo Press release on IDSA guidelines process

In a move designed to spotlight concerns about the Infectious Diseases Society of America (IDSA) guidelines’ development process, groups in the Lyme community nationwide have come together to make their voices heard. The effort to date
consists of three different letters which were signed on by multiple groups representing dozens of states across the U.S. and were then sent to the US House of Representatives Lyme Disease Caucus, the US House of Representatives Energy & Commerce Committee, and the IDSA itself, which requested input into its newly structured guidelines development process.

Citing concerns about the lack of patient representation— a concept the Institute of Medicine (IOM) has endorsed for guidelines' development in general— and also the lack of clinicians in the trenches who are treating not only Lyme but the often concurrent tick-borne diseases seen in many patients, the groups have requested specific actions to be taken by each letter recipient.

Further actions may be forthcoming by the Lyme Community. As other actions occur, we will post them.

NOTE: The IDSA has just extended its Lyme Guidelines Process Comments until April 24th. Anyone who has not replied to the IDSA directly can go to their website and register their comments. Click here for IDSA website.

 VIEW LETTERS RESULTING FROM LYME GROUP LETTERS

Click here for Letter from US House of Representatives Lyme Disease Caucus to the IDSA

 VIEW LETTERS FROM THE LYME GROUPS

Click here for Letter to US House of Representatives Lyme Disease Caucus on the proposed new IDSA Guidelines process from 57 Groups

Click here for Letter to US House of Representatives Energy & Commerce Committee
asking for a hearing on issues surrounding the IDSA Guidelines process from 57 Groups

Click here for LymeDisease.org and Lyme Disease Association Letter of Comments to IDSA Guidelines process from 67 Groups

Click here for LymeQuest Submission on behalf of 22 groups & 67 groups *

*NOTE: IDSA extended its filing time but would not permit LDA/LDo to submit additional comments with additional groups signed on. So LymeQuest submitted the additional comments to IDSA on behalf of all the groups, total of 89 (22 + 67).

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VIEW LDo’s PATIENT SURVEY RESULTS

Click here for LymeDisease.org’s IDSA Guidelines Patient Survey Results

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VIEW LETTERS’ FROM LDA/LDo TO IDSA PARTNER ORGANIZATIONS INVOLVED IN GUIDELINES’ DEVELOPMENT PROCESS

Click here for AAFP President
Click here for AAN President
Click here for AAP President
Click here for ACR President
Click here for AMMI-CA President
Click here for CNS President
Click here for ESA President
Click here for ESCMID President
Click here for PIDS President
Click here for ACP President
Click here for IDSA President

*NOTE: Each mailing contained the cover letters shown above and copy of the two group submissions to IDSA.
VIEW LETTERS FROM OTHER COUNTRIES

Click here for comment letter to IDSA from the UK

Click here for comment letter to IDSA from Deutsche Borreliose Gesellschaft e.V. (German Society of Lyme Borreliosis)

VIEW HISTORY OF LYME GROUP ACTIONS AND IDSA PROJECT PLAN

Click here for history of Lyme Group actions

Click here for IDSA Project Plan: Guidelines for the Prevention, Diagnosis, and Treatment of Lyme Disease by the Infectious Diseases Society of America, the American Academy of Neurology, and the American College of Rheumatology (Note: By clicking this link, you will leave the LDA website and be on the IDSA website)

*The groups represented in photo above may or may not be signed on to one or more of the letters

Lyme Press Conference –
Public Invited

April 29, 2013

FOR IMMEDIATE RELEASE

Press Conf. Set for Tuesday, April 30 @ 1 pm – Public Invited

Lyme Disease Awareness Month Kick Off

New Jersey-3rd in nation in Lyme case numbers, children at highest risk

To raise awareness about Lyme & other tick-borne diseases in New Jersey, the NJ based national non-profit Lyme Disease Association, Inc.(LDA), in cooperation with Congressman Christopher H. Smith (NJ-4), is hosting a press conference on Tuesday, April 30 @ 1 pm – Public Invited.

The event will take place at the Wall Township N.J. Municipal Building, on Tuesday, April 30, 2013, at 1:00PM . Address is 2700 Allaire Rd, Wall, NJ 07719 (behind the Wall police station and Wall library). Click here for directions. The following individuals will be present to speak and answer questions:

Congressman Christopher H. Smith, co-founder and co-chair of the Congressional Lyme Disease Caucus, will discuss federal legislation on Lyme and tick-borne diseases and the work he has been doing in Washington to prevent the spread of Lyme disease, which the CDC says is on the rise and is still underreported. CDC ranks NJ as 3rd in Lyme case numbers.

James Occi, MA, MS is a Research Teaching Specialist at the University of Medicine and Dentistry of New Jersey whose expertise in microbiology and medical entomology has spanned 20 years. His expertise in tick-borne diseases began as a MS thesis collecting and identifying ticks and analyzing them for infectious agents by PCR and fluorescent antibody. As an
offshoot of this work, he developed a seminar for the lay public as well as health-care professionals and lectured extensively throughout the state for years. Jim is on LDA’s professional and scientific advisory board. He will discuss ticks and prevention

**Patricia V. Smith** has been president of the Lyme Disease Association, Inc. (LDA) for 16 years. She is former chair of the NJ Governor’s Lyme Disease Advisory Council, and testified last year in DC at the Lyme hearing in the US House of Representatives Foreign Relations Global Health Subcommittee chaired by Congressman Smith. Children are at the highest risk for acquiring the disease and she has been an advocate for children with Lyme, utilizing her experience as former president of the Wall Board of Education. She will discuss the spread, research, and impact upon patients. www.LymeDiseaseAssociation.org

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**Spring Ahead: Prevent Lyme Disease**

Spring officially began today, bringing positive thoughts of increasing daylight and warmer temperatures. As we look forward to shedding winter wear and spending more time outdoors, the national Lyme Disease Association (LDA) reminds everyone that ticks, which transmit Lyme disease, become more active when
temperatures are above 35°.

Lyme is found in ~65 countries worldwide and is endemic in many areas. In 2011, the US Centers for Disease Control and Prevention reported 33,097 Lyme disease cases. With only 10% of cases actually reported, numbers may exceed 300,000 annually. The top 10 states were PA, NY, NJ, WI, CT, MA, MN, MD, NH, and VA.

If not diagnosed and treated early, Lyme can lead to disseminated infection, affecting every system in the body, including cardiac and central nervous systems. Mental confusion, memory problems, weakness, arthritis, and gastrointestinal problems may occur.

Blacklegged (deer) ticks, feed once per stage – larva, nymph, adult– and can pick up Lyme and pass it on at each feeding. They can also transmit Babesia, bartonella, anaplasma, tularemia, and Powassan virus. The poppy seed-sized nymph probably causes more disease. Other types of ticks can transmit different diseases.

Effective tools to manage Lyme are lacking. Diagnostic tests have significant limitations causing treatment regimens to be problematic and controversial. To that end, LDA is sponsoring its 14th annual Lyme & Tick-Borne Diseases CME Conference June 1-2 in Minnesota. While hosting scientific conferences and funding research on Lyme—$250,000 awarded in 2012 grants alone— the LDA emphasizes the importance of prevention, such as wearing protective clothing and immediate tick checks after being in tick infested areas, especially on the edges of woods and paths. See more prevention tips on LDA’s website.

While LDA and other groups are advocating for better patient care, federal legislators have joined the fight to improve Lyme research and education. Congressman Christopher Smith (NJ-4) joined last month by Congressmen Wolf (VA), Gibson (NY), and Peterson (MN), introduced HR 611, a bill that
expands federal efforts in Lyme and other tick-borne diseases’ prevention, treatment, education, and research activities. It also establishes a Tick-Borne Diseases Advisory Committee to improve communication among federal agencies, medical professionals, patients and advocates to ensure that the best science is represented in public health policy decisions.

Legislators in nineteen states have introduced bills in recent years to address Lyme. Virginia Governor McDonnell signed a law earlier in March requiring doctor disclosure of limitations of Lyme diagnostic tests. See LDA’s website for a state-by-state Lyme legislation table. Fighting for patients for 21 years, LDA is gratified that so many others have joined in to develop tools to prevent, treat, and cure tick-borne diseases.

ABOUT LDA: A national nonprofit dedicated to Lyme disease education, prevention, research, and patient support, LDA’s been accepted into Combined Federal Campaign 2012, an approved charity for federal workplace giving. It’s also a Guidestar.org exchange member, recognized for transparency. LDA’s an Environmental Protection Agency PESP Partner and offers LymeAid 4 Kids program for children without insurance.