

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



13 Freehold Raceway (NJ)
Lyme Disease Association of Central New Jersey
Lyme Disease Awareness Day



Smith, President, LDA, has introduced Congress
Rep. Robert Andrews (NJ) who co-sponsored with LDA the
Lyme Disease Forum for Federal Officials held in NJ in
1999.



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



Smith, LDA President, Joe Larisa, Chief of Staff to Governor Almond, Lisa Larisa, RI Coalition at the bill signing ceremony in 2002.



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



LDA / Columbia Scientific Conference

About the LDA

The Lyme Disease Association, Inc. (LDA) is designated by the IRS as a 501(c)(3) non-profit, a charity focusing on research, education, prevention and patient support.

History



The Lyme Disease Association began as Lyme Disease Association of Central Jersey in 1991 and then became Lyme Disease Association of New Jersey in 1993. Formed by patients and doctors who saw the need to organize, fund research and educate people, by 1997, it had influence far beyond NJ borders. In 2000, the Board changed the name to Lyme Disease Association, Inc. (LDA) with a broader mission expanding research funding (LDA-funded research has appeared in 53 [scientific journal publications](#) to date) and including expanded patient support ([LA4K](#)). At that time, LDA decided to remain an all volunteer organization without paid employees so that almost all of its incoming revenue would be dedicated to the mission. It remains volunteer-run with some professional consultants who provide specific expertise when needed.

Mission Statement

The Lyme Disease Association, Inc. (LDA) has been granted 501(c)(3) non-profit status by the IRS. Its mission is promoting awareness of and controlling the spread of Lyme and other tick-borne diseases (TBD) and their complications through education and other means; raising and distributing funds for Lyme and tick-borne

diseases (TBD) research, education and other related Lyme and TBD issues; assisting underprivileged patients in connection with Lyme and other TBD.

Accomplishments

On average, 97% of funds raised go directly to programs. LDA presents fully accredited [annual scientific/medical conferences](#), [funds research nationally](#), provides monies for children without insurance coverage for Lyme, [provides free literature](#), has free information line, hosts [free online doctor referral](#) and [heads an umbrella organization, LDAnet](#), of 45 associated organizations nationwide that work together on national issues. The LDA is a GuideStar Exchange Gold participant, signifying GuideStar's highest level of transparency. LDA has also been designated as a federally approved national charity for workplace giving in the Combined Federal Campaign. (CFC) for 14 years. Additionally, LDA is an EPA partner in its PESP program to safely eradicate tick populations and reduce the risk of pesticides and is a part of an integrated pest management tick working group with government and public members. To that end, it helped in the planning of the EPA's prevention conference and spoke at and co-hosted a session of the conference with the Centers for Disease Control (CDC). The LDA President was also a co-author of the article produced from a network developed under EPA, Network to Reduce Lyme Disease in School Aged Children. The article "You Can Make A Difference to A Child by Reducing the Risk of Lyme Disease appeared in the May 2010 journal of the National Association of School Nurses.

In its search for a cure for chronic Lyme disease and for prevention, the LDA has funded dozens of research projects coast-to-coast at institutions including Columbia University College of Physicians & Surgeons (NY), New Jersey Medical School (NJ), University of Washington (WA), Northeast Wildlife DNA Laboratory (PA), University of California, Davis (CA), Georgia Southern University Research & Service Foundation (GA), Johns Hopkins University (MD), Kendall County Health Department (IL), University of New Haven (CT), and Stony Brook University (NY), New York Medical College (NY), Boston Medical (MA), Rockefeller University (NY), University of North Florida (FL), and Shanandoah School of Pharmacy (VA). Much of LDA-funded research has been featured in peer-reviewed journal publications (50 to date), e.g., Journal of the American Medical Association, Proceedings of the National Academy of Science, Emerging Infectious Diseases, Psychiatric Clinics of North America, Infection, Journal of Neuropsychiatry & Clinical Neurosciences, Journal of Clinical Microbiology, Journal of International Neuropsychological Society, Neurology,

Immunology, Open Neurology Journal, PLOS One, & Genetics. 119 research grants have been awarded since LDA's inception.

Genome work initially funded by LDA has shown that different strains of *Borrelia* have the ability to exchange genetic material among themselves, a trait greatly benefiting their survival and probably confounding the body's ability to eradicate the organism. LDA funding of genome mapping has led to 17 strains being mapped.

In 2007, Columbia University announced the opening of the Lyme & Tick-Borne Diseases Research Center in New York, the first in the world devoted to the study of chronic Lyme disease. LDA co-funded the Center. LDA has given a grant to create a tissue bank there to store samples for Lyme disease research, now ongoing. The LDA has funded cutting edge published work with University of New Haven into the presence of *Borrelia burgdorferi* biofilms, which may be one of the survival mechanisms of the Lyme organism even after long-term treatment and loaned the University specialized equipment for its work.

The LDA has presented 20 fully CME accredited (continuing medical education) scientific conferences for researchers, doctors, and health care providers, featuring international speakers on the topic of Lyme and other tick-borne diseases, most jointly sponsored by Columbia University Vagelos College of Physicians and Surgeons. The 14th LDA conference was held in Minnesota in 2013, the first CME conference in the Upper Midwest and the 15th and 16th were held in Providence, RI in 2014 and 2015. The 2016 conference was held in St. Paul, Minnesota, the 2017 conference was held in Philadelphia, Pennsylvania, and the 2018 conference was held in Providence, Rhode Island. The 20th LDA conference was held on Sept 21 & 22, 2019 in Philadelphia, Pennsylvania. The LDA website contains video clips of the various conferences. A few conferences have had certifications for other professionals such as social workers, psychologists, dentists, nurses.

Since children ages 5-14 are at the highest risk of acquiring Lyme disease, the LDA created LymeAid 4 Kids, a fund that helps children without insurance. Initiated in conjunction with internationally acclaimed author Amy Tan, a Lyme victim, the LDA fund has awarded \$383,000 in grants. LDA has compiled a website section, Lyme in the Schools, containing tools which can be accessed for free by schools, parents, and the general public. Resource articles, statistics, and an LDA educational PowerPoint, How A Tick Can Make You Sick, can be run for free in the classroom from the computer as can a prevention video for kids that the UMDNJ created in

partnership with the LDA under an EPA grant. LDA's book for children with chronic Lyme, Lyme Disease Is No Fun, Let's Get Well! can be ordered on the site as can free pamphlet for parents and educators, The ABCs of Lyme Disease.

The LDA's extensive resource list also includes free materials (postage charge as of 2014) such as newly updated LymeR Primer, Tickmark, and Tick Card; National Case Map, Case Number graphs, Personal & Property Prevention Posters, Symptoms Lists and at cost materials including conference DVDs, and books. The site also houses an extensive collection of tick and rash pictures and tick-borne microbes. Finding doctors who are experienced in treating tick-borne diseases is difficult, thus LDA created an automatic doctor referral system to help people nation wide.

LDA has educated through public, school, corporate and government seminars. It has developed billboards including an electronic one on [Times Square](#) in 2012 featuring the spread of chronic Lyme. Annually, LDA awards education grants to many other Lyme groups, universities and other organizations to further their mission against tick-borne diseases. 145 education grants have been awarded to date. 95 educational conference scholarships to the LDA/Columbia continuing medical education conferences were awarded.

LDA reps have been asked to testify in many states, and been invited to be a part of press conferences with congressmen, governors and other officials. LDA had led the charge on the introduction and passage of many pieces legislation at the federal and state levels, including the 2014 Lyme bill that passed the House, and has been successful in meeting with officials at all levels of government. The LDA President [testified](#) before the US House of Representatives Foreign Affairs Global Health & Human Rights Subcommittee Lyme hearing in 2012 and before the US House of Representatives Energy & Commerce Health Subcommittee in 2013. LDA has been twice invited to meet with the Vector-Borne Division of the CDC in Ft. Collins, CO, to discuss the spread of tick-borne diseases and other issues. LDA led the team to negotiate the Lyme language which passed in the the 21st Century Cures Act in 2016 which creates a federal Tick-Borne Diseases Working Group which has a patient voice at the table. The LDA President was appointed a ~3 year term on the Congressionally Directed Medical Research Program panel to oversee disbursements of funds for Lyme disease research. Most recently, the LDA President was appointed as a committee member to the Federal Health and Human Services (HHS) Tick-borne Disease Working Group which presented it's first [report](#) to Congress in November of 2018.

LDA Strategic Goals & Objectives

Enhance the capability and productivity of TBD researchers

- Write for grants and hold fundraisers for Lyme disease research
- Develop a direct mail campaign for Lyme disease research funding
- Solicit Request for Proposals, RFPs, and award grants for Lyme and other tick-borne disease research, especially for chronic Lyme disease research
- Utilize national spokesperson, Oscar-nominated actress Mary McDonnell, in national fundraising campaigns
- Provide input into and promote legislative efforts to fund Lyme disease research

Reduce the spread of Lyme and other tick-borne diseases (TBD) throughout the general population

- Provide public forums to present Lyme disease experts
- Participate in public forums as a speaker
- Participate in health fairs
- Produce educational videos for website
- Update and reprint LymeR Primer pamphlet for free distribution
- Maintain a toll free information line
- Maintain a website and links to other Lyme disease sites
- Help develop and promote legislative efforts to reduce the spread of Lyme, through research and education
- Provide free literature in Spanish, including on the website
- Elicit cooperation with government agencies who share the same goal

Reduce the spread of Lyme and other tick-borne diseases in children

- Participate in school in-services on Lyme disease for educator
- Continue Professional Development provider status for State of New Jersey

for educating teachers on Lyme disease

- Distribute free ABC's of Lyme Disease pamphlet for parents and educators
- Develop, publish, and publicize How A Tick Can Make You Sick Powerpoint module for schools to be used free directly from LDA website (complete)
- Continue to raise/distribute funds for children without insurance through LymeAid 4 Kids
- Speak at conferences on the issues of children with Lyme disease
- Support children's education materials and forums sponsored by others, including monetary support
- Provide input into and promote legislative efforts to reduce the spread of Lyme and TBDs and their complications relating to children

Educate physicians about Lyme and other tick-borne diseases

- Host medical conferences offering Continuing Medical Education (CME) credits for physicians
- Facilitate/encourage grand rounds on tick-borne diseases
- Provide free brochures to physicians for them to distribute
- Facilitate communications among physicians and researchers worldwide by keeping database upgraded, providing networking reception after annual conference, hosting small researcher meetings or "think tanks"
- Work with physician groups who share common interest to stop the spread of tick-borne diseases.
- Create case maps and incidence maps for website publication using CDC numbers for 1990-2007 (complete)

Facilitate Lyme disease patient wellness

- Maintain toll free line for automated Lyme disease information
- Maintain free automated doctor referrals
- Educate patients about dangers of TBDs
- Refer patients to other services related to Lyme disease

Improve cooperation with public officials on tick-borne disease strategies

- Meet with state officials including health commissioners, legislators, others to raise awareness and keep them informed of LDA work on the disease and on patient and doctor concerns
- Invite health officials to LDA medical conferences and public forums

including as speakers

- Speak at health department and other official Lyme disease forums
- Provide doctors as speakers for public official forums
- Maintain a current data base of physician and researcher contact information
- Provide input into and promote legislative efforts to fund TBD research
- Attend or arrange speakers for government conferences on tick-borne diseases.

Integrate other groups into LDA nationwide effort

- Speak at forums sponsored by other groups
- Support other groups' educational activities with materials, publicity, LDA personnel, and monetarily when possible
- Increase nationwide travel for improved relationships
- Add additional affiliates, chapters, supporters when feasible
- Hold annual LDA chapter, affiliate, supporter meeting