

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 56 [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 Platinum

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 15 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 (54 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. 122 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 \$399,400 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. 155 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.