

ME – Joint Health & Human Services Committee

April 16, 2013

The Honorable Senator Cravens and Representative Farnsworth
Joint Health & Human Services Committee
Attn: Anna Broome, committee analyst
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Maine Legislature

Dear Senator Cravens and Representative Farnsworth,

At this time, I know that your committee is considering LD 597, a bill which directs that “The Maine Center for Disease Control and Prevention shall maintain a publicly accessible website to provide public aware-ness and education on Lyme disease and other tick-borne illnesses.” That is certainly a worthy goal to help the public prevent future cases of Lyme and other tick-borne diseases and also to help those already afflicted with the diseases. It also happens to be the mission of the Lyme Disease Association, Inc. (LDA), designated by IRS as a public charity operating under 501(c) (3) non-profit status. (EIN # 22-3123551, Maine Charities License # C03875)

LDA has been in existence since 1992. 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. In 2011, 120 individuals volunteered 20,451 hours to assist with LDA programs. LDA gets approximately 1 million unique viewer page views per year on its website.

The LDA respectfully asks that this committee consider adding

to its resource list the LDA website, www.LymeDiseaseAssociation.org. To that end, I am providing some background on the LDA.

On average, 95% of funds raised by LDA go directly to programs. LDA presents fully accredited CME 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 41 associated organizations nationwide that work together on national issues. LDA has been awarded the Guidestar.org seal for transparency.

For the past 7 years, the LDA has been accepted into the Combined Federal Campaign, CFC, with the LDA designated as a national charity on the CFC's list of government approved charities for federal workplace giving. Additionally, the LDA is a partner in the (EPA) Environmental Protection Agency's PESP program. In that capacity, the LDA helped EPA form a network of government and outside groups including the federal Centers for Disease Control & Prevention (CDC) called the Network to Reduce Lyme Disease in School-Aged Children. LDA and several others from that Network collaborated to author an article which appeared in May 2010 NASN School Nurse, the official publication of the National Association of School Nurses. Additionally, LDA co-chaired a session with the national CDC in the EPA's Lyme Disease Prevention conference in Virginia in 2010. LDA was also invited by EPA in 2013 to present at another conference for educators in which EPA chaired the Lyme section, but due to a blizzard, LDA was unable to attend but did provide a PowerPoint for attendees.

In 2007, the national CDC invited me to meet with them in Ft. Collins, CO, where I spent the day with the Vector-Borne Disease Division which oversees Lyme and tick-borne diseases. I have just been invited back for another visit in June 2013. In 2012, I was invited to testify on the plight of patients

worldwide before the Foreign Affairs Global Health & Human Rights Subcommittee Lyme hearing in 2012 in DC, since Lyme disease is now found in approximately 65 countries.

In its search for prevention and diagnosis of and a cure for Lyme disease, the LDA has funded dozens of research projects coast-to-coast at institutions including Columbia University College of Physicians & Surgeons, NJ Medical School, Fox Chase Cancer Center (PA), University of California, Davis, University of New Haven (CT), and Stony Brook University (NY), NY Medical College, Boston Medical, Rockefeller University, University of North Florida, Shenandoah School of Pharmacy (VA), and University of Rhode Island. The LDA has even provided research grants to the US Department of Agriculture for tick killing nematodes and to a researcher for a combined project under the NIH and NASA looking at lone star ticks.

Much of LDA-funded research has been featured in 29 peer-reviewed journal publications to date, including Journal of the American Medical Association (JAMA), 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, Archives of General Psychiatry, Journal of Medical Entomology, Neurobiology of Disease, PLOS One, Gene, and Genetics.

In 2007, Columbia University in New York opened the Lyme & Tick-Borne Diseases Research Center, the first in the world devoted to the study of chronic Lyme disease. LDA co-funded the Center and has recently given a grant creating a tissue bank there to store samples for Lyme disease research, now ongoing. Genome work initially funded by LDA through University of Medicine & Dentistry 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. 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.

The LDA has presented 13 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. The 14th LDA conference will be held at the University of Minnesota on June 1 & 2, 2013 with a faculty of 17, physicians & researchers, including one from Switzerland. The LDA website contains video clips of various conferences.

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 almost \$250,000 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 designed especially for parents and educators, The ABCs of Lyme Disease.

The LDA's extensive resource list also includes free materials such as 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 through the US and some other countries.

LDA has educated through public, school, corporate and government seminars. It has developed bill-boards including an electronic one on Times Square in 2012 featuring the spread of chronic Lyme worldwide and several in PA and MA. Annually, LDA awards education grants to many other Lyme groups, universities and other organizations to further their mission against tick-borne diseases.

If you require further information from me, do not hesitate to have your offices contact me at President@LymeDiseaseAssociation.org or 888-366-6611.

Sincerely,

Patricia V. Smith
President