

# Success in 2020: Help LDA Work for You in the New Year!

This year has been a challenge for all of us, and in particular, for those with chronic conditions such as Lyme disease, which is still unrecognized by the federal government. The Lyme Disease Association, Inc. (LDA) has been

working for Lyme and tick-borne diseases (TBD) for 30 years, with individuals who are patients and family members of patients driving the programs. We care about you, your family, your friends, your pets, who have or might acquire Lyme disease and other TBD. That is why ~97% of our funds generally go directly to programs. We continue to have no employees to keep administrative costs down and we utilize consultants to provide expertise as needed. Guidestar.org has designated LDA as a charity at its highest level committed to transparency, Platinum. LDA's financial reports are on Guidestar. For 15 years, LDA has been designated as a national charity included in the Combined Federal Campaign (CFC) lists. Annually, federal employees are provided with approved charity lists for their workplace giving through CFC. Please help us continue our programs to help Lyme patients. **DONATE TODAY**

**RESEARCH GRANTS:** Over time, LDA has awarded 121 research grants resulting in 54 peer-reviewed journal articles— one published in 2020 by Columbia University's Brian Fallon, MD. The LDA partnered to help to establish the endowed Columbia University Lyme & Tick-Borne Diseases Research Center 13 years ago. The *Brain, Behavior & Immunity* article conclusion states: "The finding of elevated anti-neuronal autoantibodies in our small sample of those with a prior history of Lyme disease but



not in those without prior Lyme disease, if replicated in a larger sample, suggests an immune priming effect of repeated infection." Published research moves the scientific field forward & brings us closer to a cure.

A 2020 published report resulting from a 2018 LDA grant awarded to Pennsylvania researchers to study infection rates of ticks (PA ranks #1 in Lyme cases in the US) indicates that in Pike County, PA, *Borrelia burgdorferi* prevalence in *I. scapularis* ticks overall was 39%, *Bartonella* next with 18.5%. Further publications are expected in peer review soon. The 4 researchers awarded grants in 2019 by LDA have been granted a time extension for completion due to the pandemic. Research grants for 2020 will be awarded by LDA by year's end.

**MEDICAL SUPPORT GRANTS:** To date, LDA's LymeAid 4 Kids program has awarded \$400,400 in grants (\$17,000 in 2020) to families across the US who have financial difficulty, to help with their children's medical expenses.

**EDUCATION:** The LDA has awarded 154 education grants over time (2020 grants to be awarded by year's end), to other Lyme organizations/institutions who are providing programs materials, and help to patients. We have partnered with Columbia University annually to provide 20 Continuing Medical Education Conference designed for doctors, researchers, and the public. Unfortunately, due to the pandemic, we made the decision to cancel our conference plans for 2020. LDA has distributed millions of pieces of literature on Lyme & TBD and in 2020, we had our *LymeR Primer* brochure translated into Spanish and published online. LDA brochures can be downloaded for free from the website and ordered for shipping costs. LDA provides a free online nationwide doctor referral system -(a state-of-the-art searchable system to be available in 2021). LDA created a webpage in 2020, *COVID-19 & Lyme*, to provide information for patients who have Lyme/TBD and then became infected with COVID-19. It includes protocols for COVID-19 as well as information for patients with both TBD & COVID-19.

We participated in educational radio and print media interviews and Zoom meetings throughout the year including LDA President Pat Smith speaking along with Robert Bransfield, MD, LDA Professional & Scientific Advisory Board Member, on the webinar hosted by Project Lyme on December 17. The webinar discussed newly released IDSA Lyme guidelines and their impact on patients and physicians.

**PUBLIC OFFICIAL EDUCATION:** We continue to educate public officials. In 2020, we provided language included in the Congressional Lyme Caucus letter to the *Subcommittee on Labor HHS, Education & Related Agencies House Committee on Appropriations*. The language was for specific area increases for the agencies for Lyme/TBD. Increases for Lyme/TBD have just been passed by Congress and LDA will provide updated information soon. Additionally, we provided input into language the Caucus sent to *Subcommittee on Defense House Appropriations* for funding for the Congressionally Directed Medical Research Program (CDMRP), awarding research grants for Lyme/TBD, and language to ensure the burden of disease falls on Lyme disease. Past work by LDA through Congress led to the original inclusion of Lyme/TBD into the Department of Defense (DoD) CDMRP program and also led to an increase in funding in 2019. Additionally, working with Congressman Chris Smith, LDA helped to achieve in 2020 the passage by the House amendment #587 to the National Defense Authorization Act, which "Requires the GAO [Government Accountability Office] to conduct a study of possible experimentation of ticks, insects, or vector-borne agents by the DOD between 1950 and 1977 for use as a bioweapon."

**FEDERAL GOVERNMENT:** In addition to my LDA work, I have just completed two terms over four years, as a public member of the HHS Working Group (TBDWG), helping to drive recommendations to Congress on Lyme & TBD. The 2020 report that was produced by the TBDWG contained recommendations that often dovetail with LDA efforts. I was Co-Chair of the Physician Education &

Access to Care Subcommittee Chapter on which the patient section of the 2020 report to Congress is based. The 2020 report is now on the HHS Secretary's desk for review and submission to Congress.

This year, a contentious situation developed pitting me in my TBDWG role as advocate/family member of patient against those members who are continuing to suppress anything supporting chronic/persistent Lyme disease. Despite intense efforts to remove/water down all patient information, I was able to keep much of the material in the patient chapter of the report included in 2020, but it was an epic battle. You can read some of the comments I made to win the battle in an 8-6 vote and other battles in the LDA TBDWG Section.

I also served on the DoD's CDMRP Programmatic panel from its inception through early 2020 (4 years). I helped to make decisions for grant monies awarded by the DoD on Lyme and TBD. My grant work on LDA provides me with a better understanding of the entire research process necessary for this panel.

Please donate today. Help us provide a healthier New Year for people everywhere. Donations are tax-deductible to the fullest extent allowed by law.

Thank you & Happy, Healthy 2021.

Pat Smith  
President  
Lyme Disease Association, Inc.