

# 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.

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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



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



Pat Smith, President, LDANJ, has introduced Congressman Robert Andrews (NJ) who co-sponsored with LDANJ the Lyme Disease Forum for Federal Officials held in NJ in 2009.



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

