

Smith, Patricia V.

Patricia V. Smith, BA

President, Lyme Disease Association, Inc.

Advisory Board Member, Columbia University Lyme & Tick-Borne Diseases Research Center

Programmatic Panel Member, TBD Research Program,
DoD Congressionally Directed Medical Research
Program

Conference Organizer/Program Committee, Jackson, NJ



Welcome/Overview of Lyme/Introductions

Patricia V. Smith, a Monmouth University graduate, is in her 20th year as President of the all-volunteer run national non-profit Lyme Disease Association, LDA and is a member of Columbia University's Lyme & Tick-Borne Diseases Research Center Advisory Committee, member of the Food & Drug Administration's (FDA) PESP Partnership to promote avoidance of tick exposure, and member of the Tick IPM Working Group with federal and non federal members, from the IPM Institute of North America, to eradicate tick-borne diseases. She was appointed in 2016 as a member of the US Army Medical Research and Materiel Command (USAMRMC) Tick-Borne Disease Research Program (TBDRP) as a member of the Congressionally Directed Medical Research Program Programmatic Panel.

Ms. Smith is also former Chair, (NJ) Governor's Lyme Disease Advisory Council. She was EPA's PESP 2011 Lyme prevention conference session co-chair with CDC. In 2011 she presented a Lyme session to the New Jersey Education Association's Annual Meeting. She is a member & former officer of ILADS, International Lyme & Associated Diseases Society, a professional medical and research organization.

Ms. Smith is former President/12-year member of the Wall NJ Board of Education where she earned state board member-

certified status. She is a former officer of Monmouth County School Boards Assn. and was a member of the Federal Relations Network for New Jersey School Boards Association/National School Boards Assn.

During her LDA presidency, Ms. Smith has led the effort to raise funds for researchers nationally, with more than 106 research grants awarded – research acknowledged in 42 scientific journals. She has organized 18 continuing medical education (CME) accredited Lyme scientific conferences for doctors and researchers with international faculty, held in different areas of the US, most jointly sponsored by Columbia University. She has spoken at many conferences on Lyme including those presented by the University of New Haven (CT) and the California Lyme Disease Association (now LymeDisease.org), Midcoast Maine Lyme Education and Support, Colorado Tick-Borne Awareness Association, and ILADS. She has been a speaker at hundreds of public, school, business, & government events.

She led the LDA in its effort with a partner organization, to endow the Columbia Lyme & Tick-Borne Diseases Research Center in New York, which opened in 2007. She developed the ABCs of Lyme Disease pamphlet for parents and educators and also the LymeR Primer brochure now featuring 20 tick-borne diseases, the Tick Mark bookmark, and helped design Tick Awareness cards. More than 2.5 million education items have been distributed.

Ms. Smith has testified for and secured passage of state and federal bills for Lyme research and physician's right to treat. She has been invited to state capitals in CT, MA, MD, MN, NH, NJ, NY, PA, RI, to present oral testimony and education on Lyme and has provided written testimony in many others. Based on her written testimony, LDA was recently included in ground breaking Maine legislation as a website resource on Lyme disease on Maine's DPH website. She was invited to testify on two occasions before the NY Assembly

Health Care Committee and also before the Rhode Island (Governor's) Lyme Disease Advisory Commission and has spoken before the California Lyme Disease Advisory Council. Over time, she has personally met with many State Health Commissioners and with Governors in NH, RI CT on Lyme issues and with then Governor Pataki's office on many occasions along with several NY state legislators. She has also presented before the Pennsylvania House of Representatives Majority Policy Committee and was an invited speaker for Lyme forums hosted by a member of the Massachusetts House of Representatives and the Majority Caucus Administrator for the Pennsylvania House of Representatives and the Minnesota State Senate Health Committee.

She has twice been invited to present to CDC Vector-Borne Diseases Division, Ft. Collins (2007, 2013); met with then CDC Director Dr. Julie Gerberding/5 Congressmen in DC; organized & led a team that met with HHS Asst. Sec. of Health with CDC/NIH officials teleconferenced in; met with military leaders in DC; and briefed the Senate HELP Committee Members and House Subcommittee on Health. She met several times with US Army CHPPM/Public Health Command at Aberdeen Proving Grounds. She met in DC with the NIH Program Director and research coordinator and presented educational PowerPoints on Lyme to employees at the Environmental Protection Agency (2008, 2014), to the Dept. of Energy, and to Homeland Security in 2014. In 2014, she helped develop language for a federal bill on Lyme and led the nationwide effort which successfully passed the bill through the House. Ms. Smith spoke at a 2014 press conference with Senator Charles Schumer (NY) on the doxycycline shortage for Lyme patients. In 2012, she testified before the House Foreign Affairs Committee, Africa, Global Health & Human Rights Subcommittee on issues affecting Lyme patients. In 2013, she testified before the House Energy & Commerce Health Subcommittee on HR 610 to establish a federal Lyme & Tick-Borne Diseases Advisory Committee. She co-authored an article which was read into the Congressional Record on

Lyme disease research priorities from the patient perspective. In 2015, she spoke at the American Association for the Advancement of Science in DC on patient research priorities. In 2016, she spoke before the Women in Government's annual conference. In 2016, she led the negotiations with House leadership for the Lyme language subsequently passed in the 21st Century Cures Act which creates a federal working group on tick-borne diseases with patient and advocates reps.

Chosen Jackson NJ's Chamber of Commerce 2008 Woman of the Year, she has also received commendation from the NJ legislature, a Special Congressional Recognition certificate from RI Cong. Langevin, and had a flag flown over the US Capitol by request of NJ Cong. Chris Smith in honor of her Lyme work. Ms. Smith helped to organize and presented at educational forums held by 3 congressmen (Langevin, Pitts, C. Smith). She has received awards from Dr. Brian Fallon, Columbia, from various Lyme groups, and was given the Courage in Advocacy Award in 2015 from Connecticut based Lyme Connection and Focus on Lyme Excellence in Advocacy (AZ) award in 2017.

Other activities include providing input into a NJ law requiring teacher education for staff who teach students with Lyme disease, performing school in-services for educators on Lyme disease, and working with parents of students who are classified due to Lyme disease. Working with author Amy Tan, she created LDA's LymeAid 4 Kids, a fund for children with no health coverage for Lyme, a fund that has awarded \$338,400 for uninsured children to date.