

Smith, Patricia

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, Inc., LDA, and is a member of Columbia University’s Lyme & Tick-Borne Diseases Research Center Advisory Committee and has been appointed to the Fiscal Year 2016 (FY16) Programmatic Panel for the Tick-Borne Disease Research Program (TBDRP), a new program in the Department of Defense’s (DoD) Office of Congressionally Directed Medical Research Programs (CDMRP)—a typical 3-year term-of-service. She is a 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.

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 100 research grants awarded – research acknowledged in 39 scientific journals. She has organized 17 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), the American Association for the Advancement of Science (AAAS), and the California Lyme Disease Association (now LymeDisease.org), and the International Lyme & Associated Diseases Society. 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 15 tick-borne diseases, the Tick Mark bookmark, and helped design Tick Awareness cards. More than 2.5 million of these 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.

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.

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 \$1/4 M for uninsured children to date. [Click for Publications](#)

Asbury Park Press: Rep. Chris

Smith on Lyme 'Culture of Denial'

Asbury Park Press recently featured an article by Jerry Carino: *Rep. Chris Smith on Lyme disease 'culture of denial,'* a Q&A with the congressman, who has crusaded for Lyme disease research and formal recognition of chronic Lyme. The article highlights the congressman's U.S. Representative Chris Smith (NJ-4) Lyme legislation victories and new



Smith is encouraged by "the beginning of a sea change in the attitudes of the federal officials who are responsible for coordinating the Lyme disease initiative," he speaks about "the culture of denial that exists surrounding the prevalence and toxicity of Lyme – exacerbated by the fact that the Infectious Disease Society of America (IDSA) definition precludes chronic Lyme, contrary to significant evidence, patient experience, and clinician testimonials."

Congressman Smith began his crusade for Lyme disease when he met Pat Smith (Lyme Disease Association President) in 1992, and she asked him to get involved. Congressman Smith shares the feedback he has received by his constituents and the Lyme community over the years, including patients' misdiagnoses and lack of treatment creating more serious symptoms, the continued suffering of Lyme patients after their initial round of antibiotics, and the fact that they are told chronic Lyme doesn't exist. The results are demoralizing, and patients in addition can face financial ruin due to medical costs that are not covered by insurance companies influenced by the outdated IDSA guidelines.

[Click here to read the full article](#)

[Click here to read Pat Smith's Letter to the Editor – "True threat of Lyme disease finally emerging"](#)

Watch Dr. Horowitz & Pat Smith Videos

During the 9th Annual Lyme Connection Patient Seminar & Health Fair, 5-12-15, Western CT State University, with hundreds in attendance, LDA President, Pat Smith was presented with the first Courage in Advocacy Award, which she dedicated to chronic Lyme patient/advocates. ([Click here to watch video](#)).

Lyme-treating physician & Times bestselling author, Dr. Richard Horowitz gave a talk on Lyme disease ([Click here to watch video](#)).

Pat Smith presented a national overview of Lyme & tick-borne diseases ([Click here to watch video](#)).

[Click here for full article about the event](#)

Rep. Chris Smith (NJ) Plans Lyme Hearing

Congressman Christopher H. Smith (NJ-4), Chair of the Africa, Global Health, and Human Rights Subcommittee in the US House of Representatives, announced his plans for a Lyme disease hearing in his March Newsletter to his constituents.

In an article titled, *The Fight on Behalf of Lyme Disease Patients Continues, Smith Legislation Aims to Broaden Scientific Community Base Represented in Public Health Policy*, Congressman Smith states "As chairman of a House subcommittee which includes global health and global human rights within its jurisdiction, I plan to convene a hearing within the next couple of months on the global health problem of Lyme and other tick-borne diseases and their impact especially and including right here in N.J. It is anticipated the hearing will examine the scope of the worldwide problem of tick-borne diseases, current and emerging science and technologies, and impacts on patients."

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Congressman Christopher Smith (NJ)

September 27, 2008 US House Floor in Washington, DC

Click picture for video links to floor debate

(Video shows Congressmen Christopher Smith (NJ) and Frank Wolf (VA) appearing on the US House floor in 2008 asking then Chair of the Energy & Commerce Health Subcommittee Congressman Pallone (NJ) to have a hearing on the Lyme disease bill. Mr. Pallone agreed to a 2009 session hearing but that was never held.)

The LDA has worked with Congressman Smith's office for more than 20 years

and has been instrumental in highlighting issues affecting Lyme patients to his Office as well as to other Members of Congress in Washington. Congressman Smith, along with his colleagues, has written official letters to agencies who deal with the disease such as the CDC and the NIH, including concerns on inadequate surveillance, lack of research, treatment guidelines and even on the Institute of Medicine (IOM) hearing.

In 2009, LDA met in the office of Congressman Smith with NIH Lyme Program officials, discussing lack of chronic Lyme disease research. [Click here for more details](#)

According to Lyme Disease Association (LDA) President, Pat Smith, "Congressman Christopher Smith has been a staunch advocate for Lyme issues since the early 90s, hosting the first off site Lyme hearing in the country in 1992 in NJ. He has gotten monies appropriated for Lyme and other tick-borne diseases through measures he initiated in DC. He also introduced the first bill devoted fully to Lyme disease in 1998 and also subsequent iterations of that bill." [Click here for details of these actions](#). Because of his dedication to Lyme disease, in 2009, the LDA gave Congressman Smith an [award](#) at its 10th annual Lyme and Other Tick-Borne Diseases Scientific Conference at National Harbor, MD.

Congressman Smith developed language for 2010 HHS Appropriations which was passed. It included language on **chronic Lyme** and also included research monies toward development of new Lyme disease tests. Congressman Frank Wolf worked to help secure passage in the House. [Click here for more information](#).

Congressman Smith HR 2557 in 2011 "To Provide For the Establishment of the Tick-Borne Diseases Advisory Committee." [Click here for text of bill](#).

Contact your congressman/woman today and urge him/her to co-sponsor HR 2557. [Click here for phone blurb & sample email](#).

Ms. Smith added, "Congressman Smith has been the US House of Representatives' Lyme Caucus Co-Chair for a number of years now, and has facilitated many meetings with Lyme advocates and governmental officials and the military in DC to educate them to the plight of Lyme patients. Now, he is planning a hearing to examine the global scope of the problem and to determine

the path that leads to preventing Lyme disease and finding its cure. Since Lyme cases continue to rise, we are fortunate to have him as an ally and support the need for this long overdue hearing.” [Click here for pdf of newsletter announcement.](#)

Rep. Chris Smith (NJ) Introduces Lyme Bill

July 17, 2011. The all volunteer national Lyme Disease Association (LDA) is pleased to announce the introduction of a bill and proposed legislative actions that focus attention on the growing concerns surrounding Lyme and tick borne diseases.

Congressman Christopher Smith (R-NJ) introduced [HR-2557](#), the Lyme and Tick-Borne Disease Prevention, Education, and Research Act of 2011, on Friday, July 15, 2011, along with cosponsors Frank Wolf (VA), Tim Holden (PA), and Chris Gibson (NY).

Congressman Smith’s bill, HR-2557, requires the Secretary of Health and Human Services to establish a Tick-Borne Diseases Advisory Committee to address a variety of important issues. The Committee will be charged with advising Federal agencies on priorities related to Lyme and tick-borne disease issues and will be composed of scientists, representatives from government agencies, health care providers and patient representatives. The Committee is charged with ensuring that a broad spectrum of scientific and stake-holder viewpoints are represented in public health policy decisions and that information disseminated to the public and physicians is balanced.

Congressman Smith, Chairman of the Congressional Lyme Disease Caucus for

the past seven years, has worked diligently to foster greater knowledge about tick-borne diseases over the years. Amongst his many Lyme-related endeavors, he hosted a Lyme and Tick-Borne Diseases Forum last summer in Wall Township, NJ, for health officials, medical professionals and the public, with over 300 people in attendance. Pat Smith of the LDA was one of the guest speakers.

Senator Richard Blumenthal (D-CT) has plans to highlight legislation to combat the spread of Lyme disease. He will meet with volunteer patient advocates from the Connecticut based Lyme disease group, Time for Lyme (TFL), an affiliate of the Lyme Disease Association, at the Connecticut Agricultural Experiment Station in New Haven on Monday, July 18, 2011.

Senator Blumenthal, who served an unprecedented five terms as Attorney General in Connecticut, is known for his efforts to make real and lasting difference in the lives of the people. He has been a long-time public defender of Lyme disease patients rights.

The Lyme Disease Association (LDA), an organization that seeks to eliminate tick-borne diseases by funding research, educating the public, and providing scientific conferences for doctors, is grateful to Congressman Smith, Senator Blumenthal, the bill cosponsors and staff for their enduring commitment to improve the health of countless patients suffering from Lyme and tick-borne diseases.

For more information please visit the LDA website www.LymeDiseaseAssociation.org

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[BILL TEXT](#)

[Congressman Christopher Smith Press Release](#) / [Senator Richard Blumenthal Press Release](#)



LDA president Pat Smith with Congressman Chris Smith in his office after a meeting about Lyme disease issues including HR 1179, Lyme & Tick-Borne Diseases Prevention, Research, & Education Act 2009, a bill which will provide monies for better tests and education on Lyme disease.



Senator Blumenthal

Smith Unveils Lyme Disease

Bill

WASHINGTON, D.C. – Congressmen Chris Smith (R-NJ) today announced the introduction of a bill he wrote to combat Lyme disease, and thanked original co-sponsors Bart Stupak (D-MI) Frank Wolf (R-VA) and Tim Holden, (D-PA).

FOR IMMEDIATE RELEASE: Contact: Jeff Sagnip (609) 585-7878

Feb. 27, 2009

<http://chris-smith.house.gov>

CDC Data: Cases on the rise, highest among kids ages 5-14

WASHINGTON, D.C. – Congressmen Chris Smith (R-NJ) today announced the introduction of a bill he wrote to combat Lyme disease, and thanked original co-sponsors Bart Stupak (D-MI) Frank Wolf (R-VA) and Tim Holden, (D-PA).

Smith is the sponsor of the “Lyme and Tick-Borne Disease Prevention, Education, and Research Act of 2009.” The measure, H.R. 1179, would expand federal efforts concerning the prevention, education, treatment, and research activities related to Lyme and other tick-borne diseases, including the establishment of a Tick-Borne Diseases Advisory Committee. Smith, Stupak, Wolf and Holden are co-chairs of the House Lyme Disease Caucus.

H.R. 1179 authorizes a much needed increase in total research and education of \$100 million over five years. The bill also contains measures to ensure that resources are expended effectively to provide the most benefit to people with Lyme and other tick-borne diseases. It also seeks improved surveillance and prevention and clinical outcomes research to determine the long-term course of the illness and effectiveness of

different treatments. The Tick-Borne Diseases Advisory Committee would ensure coordination and communication among many federal agencies, a broad range of medical professionals, and patients.

“Lyme is one of the most prevalent diseases in the U.S. today,” said Smith. “About 220,000 Americans develop Lyme disease each year, and we suspect that number is a conservative estimate. This bill provides a comprehensive national effort to step up the fight against this ever-growing threat. My state of New Jersey is particularly hard hit.”

While Lyme accounts for 90 percent of tick-borne diseases in the U.S., the same tick species spreads other diseases, such as anaplasmosis and babesiosis. Other tick species spread diseases, such as Rocky Mountain spotted fever and southern tick-associated illness. More than 30 affiliate organizations of the Lyme Disease Association Inc., headquartered in Jackson, N.J. in Smith’s district, support the measure.

“I am pleased to join my colleagues on the Lyme Disease Caucus in introducing this legislation to help prevent, accurately diagnose and effectively treat Lyme disease and other tick-borne illnesses that impact more than 200,000 Americans every year,” Stupak said. “Although Lyme disease receives little attention, cases remain on the rise in the United States and in 63 countries around the world. Devoting modest resources to education and prevention will save us millions that would otherwise be spent on treatment down the road.”

“Federal efforts to address Lyme Disease should be a priority,” said Congressman Wolf. “This legislation, which will create a Lyme and Tick-Borne Disease Advisory Committee at the Department of Health and Human Services and authorize funding for the development of a more sensitive and more accurate test to diagnose this dreaded disease, is critical. Not only is this legislation aimed at treatment and research to assist those suffering from Lyme, it would also heighten education and awareness

efforts to ensure those at risk of being infected know how to protect themselves and their families.”

“This legislation represents years of work with the Lyme advocacy community to reach consensus on how to best move forward,” said Rep. Holden. “It aims to deliver on promises made to Lyme patients and their families to better focus the federal government’s efforts on detection and research for more effective treatments.”

The Centers for Disease Control & Prevention (CDC) estimates that only 10 percent of Lyme cases meeting this criteria may be reported. Lyme disease can lead to chronic illness and can affect every system in the body, including the central nervous system. Advanced symptoms include arthritis of weight-bearing joints, neurological and cardiac problems, encephalopathy and memory problems. The CDC has determined that from 1992 to 2006, the incidence of Lyme disease was highest among children aged 5 to 14 years of age.

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