# Federal Legislative/Policy Accomplishments

The LDA has an 18 year history of achievements in the area of legislation, and policy achievements. Below are some of the most significant ones where LDA played a lead role in passage/adoption of laws/policies which help Lyme patients or preventing passage of those items which could have hurt Lyme patients/physicians or LDA played a lead role in educating.

#### 2015 New Monies for Lyme Research Under Defense Health Program

Congressman Chris Smith (NJ-4) announced today that Congressionally Directed Medical Research Program (CDMRP) funds for Lyme disease have been included in the Department of Defense Appropriations bill which passed the Defense Subcommittee last week, and the bill passed the full Appropriations Committee today. It will now move to the floor of the House. Click here for full article

### 2015 Unanimous: US House E & C Com. Passes Lyme Bill in 21st Century Cures

The Energy & Commerce Committee (E&C) passed *The 21st Century Cures Act*, HR 6, by a vote of 51-0, today, May 21, 2015. Chairman Fred Upton (MI) included in an expected amendment to the sweeping public health legislation, the exact language from the *Tick-Borne Disease Research Accountability and Transparency Act of 2014* (C. Gibson-NY), into which LDA and the Lyme community provided input and secured full House passage last Congress. Click here for full article

#### 2015 LDA Provides Input Into US House 21st Century Cures Initiative

The Lyme Disease Association, Inc. (LDA) submitted input into the US House of Representatives Energy & Commerce 21st Century Cures Initiative which will reform a number of areas in healthcare. E & C sought public input during their development process. Click Here for LDA Letter to Energy & Commerce Committee

#### 2014 Lyme Victory in the US House of Representatives

The Lyme Disease Association, Inc., LDA, is pleased to announce that the Lyme bill, HR 4701 — "Vector-Borne Disease Research Accountability and Transparency Act of 2014" as amended, was discussed on the floor of the U.S. House of Representatives today, September 9, and passed the House by voice vote. Click here for full article

#### 2014 House E & C Committee Passes Lyme Bill

The LDA is pleased to announce that the Lyme bill, HR 4701, July 23, 2014 version, passed with voice vote out of the Energy & Commerce Committee, today, July 30. Click here for full article

#### 2013 Lyme Bill Was Heard in DC: LDA Testifies

The Lyme Disease Association, Inc. (LDA) announced that the House Committee on Energy and Commerce, Subcommittee on Health held a hearing to include tick-borne

diseases legislation (HR 610) at 2 PM, Wednesday, November 20, 2013 in 2123 Rayburn House Office Building, Washington, DC. Congressman Joseph Pitts (PA) chaired the hearing.

LDA President Pat Smith testified on HR 610, discussing the serious and growing threat of Lyme and other tick-borne diseases (TBD), the dire effects on patients, many of whom are children, and the economic impacts and the need for a patient voice in the process. (written testimony / oral testimony) Click here to read full article

#### 2013 Lyme Press Conference - Public Invited

To raise awareness about Lyme & other tick-borne diseases in New Jersey, the NJ based national non-profit Lyme Disease Association, Inc. (LDA), in cooperation with Congressman Christopher H. Smith (NJ-4), is hosting a press conference on Tuesday, April 30 @ 1 pm — Public Invited. Click here to read full press release

#### 2012 Senate Hearing on Lyme Disease

US Senator Richard Blumenthal (CT) held a 2 hour offsite HELP (Health, Education, Labor, & Pensions Committee) full committee field hearing — Lyme Disease: A Comprehensive Approach to an Evolving Threat — in Stamford, Connecticut, on August 30, 2012 . Several panels of individuals testified and everyone attending the hearing in the audience was invited to submit testimony, which then became part of the hearing record.

Click here for Senator Blumenthal's website — view hearing video, transcript and witness testimonies

Click here for Pat Smith submitted written testimony

Click here for media report in StamfordAdvocate.com

Click here for photo

#### 2012 DC Lyme Hearing: View & Take Action

The 2 hour July 17, 2012 Congressional hearing, Global Challenges in Diagnosing and Managing Lyme Disease — Closing Knowledge Gaps, was held by the Africa, Global Health and Human Rights Subcommittee on July 17, 2012 in Washington, DC. Click here for full article

## 2009 HR 3293 / S1352 "Fiscal Year 2010 Labor, Health & Human Services, Education Appropriations bill" Efforts by Congressman Smith, Wolf, & Obev

Omnibus bill including the above signed into law by President Obama on 12-16-09. Includes report language with "chronic Lyme disease" and "persistence" and monies for CDC to investigate new tests. LAD led this campaign for patients.

#### 2002 Congressional Lyme Disease Forum

Representatives James Langevin (RI) and Rob Simmons (CT) co-hosted an educational forum in Westerly, RI, in 2002. Lyme clinicians, public health officials, and Lyme advocates from several states discussed diagnosis and treatment. LDA was invited speaker.

#### 2002 Private Meeting with FDA on Vaccine

A public hearing in 1998 ended with the FDA committee narrowly approving marketing of LYMErix, but expressing numerous concerns about safety. Adverse effects during marketing caused the FDA to hold an advisory committee hearing in 2002. Testimony by

people claiming injury from the vaccine obliged the FDA to request the manufacturer to complete follow-up studies on safety ASAP. The LDA testified at this hearing. The LDA asked for a private meeting with the FDA on continued distribution of the vaccine in early 2002. The LDA brought a physician and a consultant familiar with the vaccine to the meeting. Prior to the meeting, the LDA had submitted a list of questions for the FDA to answer at the meeting. Instead, one month after the meeting, the FDA faxed its answers to LDA—three days before the manufacturer withdrew the vaccine from the market.

#### 2001 GAO (Government Accounting Office) Investigation

Senators Christopher Dodd (CT), Rick Santorum (PA) and Congressmen Virgil Goode, Jr. (MD), Joseph Pitts (PA), and Christopher Smith (NJ) requested the GAO investigation.

Lyme activists including LDA initiated through congressmen, a General Accounting Office (GAO) report, GAO-01-787R, to Congress on federal funding for Lyme research and on Lyme disease activities. The GAO "found that CDC, NIH, and FDA have generally met the requirements for disclosure and review of financial interests related to Lyme disease." The GAO did note, however, that CDC was not able to provide them with some of the forms they expected to receive, and some they did receive, contained irregularities.

#### 1999 The Department of Defense Appropriations Act 1999

Provided \$3 million for research and surveillance activities related to Lyme and other tick-borne diseases. Senator Christopher Dodd (D-CT) and Representative Christopher Smith spurred the provision for Lyme. LDA pushed for this funding.

#### 1999 Congressional Lyme Disease Forum

Representative Joseph Pitts (PA) presided over a noteworthy conference on Lyme and other tick-borne diseases in Chester County, PA, in 1999. LDA was invited speaker.

#### 1994 The Department of Defense Appropriations Act 1994

Authorized \$1 million for a Lyme research program to be utilized by the Army Representative Christopher Smith (R-NJ) initiated the authorization. LDA(NJ) pushed for this funding.