

Federal Bill HR 4701, July 23rd Version

The Lyme Disease Association (LDA) is supporting HR 4701, July 23 version, **no amendments**, which will see committee action Tuesday 29 & Wednesday 30. The bill sets up a working group with patients and physicians at the table and contains language requiring the Secretary of HHS to submit a strategic plan to Congress including “a plan for improving outcomes of Lyme disease and other tick-borne diseases, including progress related to chronic or persistent symptoms and chronic or persistent infection and co-infections.... ”

Click link below for supported version

<http://docs.house.gov/meetings/IF/IF00/20140729/102597/BILLS-113-HR4701-P000373-Amdt-3.pdf>

ACTION FOR YOU TO TAKE IMMEDIATELY: Lyme leaders, patients, & general public: The LDA is seeking immediate action. Please contact the Democratic members of the Energy & Commerce Committee. Tell them to support HR 4701, July 23 version, with NO amendments. There is a short window of time (July 28-July 30) to influence the passage out of the Energy & Commerce Committee of this important bill.



PLEASE DO THE FOLLOWING:

- [Click on this link.](#) Pick out the democratic members (D) and call or fax them.
- Tell Democratic Committee Members the following:

Pass HR 4701, July 23 version, with NO amendments *

****(Please use exact underlined words when referring to bill.)***

This bill allows Lyme patients, Lyme non profits, and physicians treating Lyme & tick-borne diseases to sit at the table of the working group. The Strategic Plan for Lyme & tick-borne diseases research calls for a plan for improving outcomes of Lyme and other tick-borne diseases. Thank you.

HISTORY of LYME BILLS: For decades, Lyme disease patients, advocates, treating physicians, and many researchers have pushed for federal legislation that would unshackle Lyme disease from entrenched biases that have been holding back progress on the science of Lyme. Patient-supported Lyme legislation was again introduced early this Congress in both the House and Senate, legislation designed to provide broader input to federal research agendas and to help move the science forward. The Lyme community was then chagrined to learn that a vector-borne diseases (VBD) bill was going to be introduced and passed through the House instead of the other pieces of patient-vetted legislation. The community's fear was that the language of the VBD was too diluted and would be harmful to Lyme disease patients. In a sincere effort to cooperate with House and Committee leadership, members of the Lyme community worked tirelessly to improve the language of the VBD bill to ensure that it would be helpful to Lyme stakeholders. The resulting bill – HR 4701 – while not ideal, was strengthened to ensure it would provide meaningful benefit to Lyme and other TBD stakeholders.

WHAT WE WANTED: The original HR 4701 (below), as introduced, created an advisory committee that would operate under the decades old Federal Advisory Committee Act (FACA), which stresses transparency and accountability. Congress passed FACA, because many believed that too much of the government functioned behind closed doors and did not sufficiently represent the public interest. FACA requires committee

membership “to be fairly balanced in terms of the points of view represented and the functions to be performed.” Under this original HR 4701, working groups/advisory committees would provide a seat at the table for experienced physicians, non-federal scientists, and patients and family members, and advocates. Any existing VBD working groups also would be required to operate under FACA.

Bill Favorable to Lyme patients

The original bill introduced May 24th in the US House “HR 4701” (Gibson) provides:

Patients with a seat at the table
Transparency in government (Covered under FACA)
Open meetings
Balanced representation

WHAT CONGRESS SUBSTITUTED: The “Amendment in the nature of a substitute to HR 4701,” which was passed June 19, 2014 by the Health subcommittee, simply institutionalizes the existing HHS internal Lyme disease and other TBD working group. The only members of the working group are HHS employees, no patients, advocates, private physicians or non-federal researchers will be working group members, although it directs the committee to “consult with” outside parties. The HHS working group also is not under FACA— its meetings, papers, records, minutes, etc. may be kept under wraps. A single public meeting before the issuance of a report every five years does not provide a reasonable level of public input and transparency and likely occurs after the committee deliberative work is done. It is disgraceful that the substitute bill retains the words “Accountability and Transparency” in the title because the bill makes great efforts to purge itself of those attributes.

Unfavorable to Lyme patients

The revised June 19 bill “Amendment in the nature of a substitute to HR 4701”(Gibson, Pitts) provides:

No patient seat at the table

Permits secret meetings (Not covered under FACA)

Provides no balanced representation on the working group

Permits the old boys network to operate without oversight

THANKS TO LYME GROUPS: The LDA requested Lyme leaders to sign on to a letter against the Amendment in the Nature of a Substitute to HR 4701. Letter with signups was sent 7/7/14 to Energy & Commerce with this note: “Attached please find a letter stating the position of 154 groups from over 35 states across the US opposing the Lyme disease legislation, ‘Amendment in the Nature of a Substitute to HR 4701’ that was passed through the Energy & Commerce Health Subcommittee on June 19, 2014. This information was collected over an approximate three-day period over the July 4 holiday weekend. We look forward to your response. Thank you.”

As a result of the letter, the bill sponsor, working with LDA and others, was successful in obtaining language that accomplished the goals of having patients at the table with a working group that operates in a transparent fashion. It also includes “chronic or persistent infection and co-infections” language. (Go to top of page to see new version.)

[Click here for LDA letter to Energy & Commerce](#)

[House E & C Committee Passes Lyme Bill , HR 4701, July 23, 2014 version](#)

[Victory in the US House of Representatives:](#) Lyme bill, HR 4701 – “Vector-Borne Disease Research Accountability and Transparency Act of 2014”

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, & Obey

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.

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, & Obey

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. LDA 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.

2015 Combined Federal Campaign

Federal Employees: LDA CFC Eligible GOOD NEWS for Lyme disease!

The LDA has been found eligible for inclusion on the National Part of the 2015 Combined Federal Campaign (CFC) Charity list. Each year, federal employees can contribute to charities that meet the requirements of the CFC. The LDA must demonstrate it provides services in 15 states to be part of this program and is the only Lyme charity that has been selected for inclusion.

The LDA's CFC 2015 identification for donors is #11424 and Lyme Disease Association, Inc. will appear in the listing of National/International Independent Organizations which is published in each local campaign charity list. See your federal employer for details.

Check the CFC website at: <http://www.opm.gov/cfc/>.

LDA also has made the 2006 – 2015 CFC campaigns and thanks to all those who have been contributing.

Lyme Disease Forum for Congressmen, Senators and Federal Officials, c.1998.

Lyme Disease Forum for Congressmen, Senators and Federal Officials, c.1998.

Lyme Disease Forum for Congressmen, Senators and Federal Officials, c.1998, 2 hours (1 tape), \$5.00. Speakers include Brian Fallon, MD; Nick Harris, PhD; Ken Liegner, MD; Anthony Lionetti, MD; Dorothy Pietrucha, MD; Steven Schutzer, MD; and Pat Smith, President, LDANJ.

{j2store}9|cart{/j2store}