

2009/2010 Lyme Bill FAQ's

If you are confused about the Lyme bill or have any questions please review the LDA's FAQ to help you educate and advocate more efficiently.

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The Bill Basics

1. Where can I find information concerning the federal Lyme disease bill?

You can find information about the federal Lyme disease bill on the Lyme Disease Association's easy-to-navigate website. Click on the link below to find the bill text; changes in the bill wording; press releases; lists of congressional cosponsors that have signed on; action alerts; a list of organizations, businesses and groups supporting the bill; sample blurbs and letters to use when contacting your representatives and more.

To find the new LDA Legislation pages, [CLICK HERE](#) or go to the Lyme Disease Association web site [www.LymeDiseaseAssociation.org] and click on 'Legislation' at the top of the page.

If you would like to learn more about communicating with your representatives, understanding the legislative process, how bills are passed, public disclosures, committees and their reports, congressional records, votes, daily activities, government resources and other bill-related information, please click below link

<http://thomas.loc.gov/>

To see a list of frequently asked questions concerning the legislative process: <http://thomas.loc.gov/help/>

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2. Who is responsible for creating the Lyme and tick-borne diseases legislation?

Since the early 1990s, Pat Smith, President of the Lyme Disease Association, a national non-profit organization which has associated organizations – 36 chapters, affiliates, and supporter in 25 states – with the assistance of numerous Lyme leaders and other volunteers from

across the country, has been educating state and Congressional leaders. In 1996, realizing the growing Lyme disease epidemic was spreading quickly across the country, Congressman Christopher Smith (NJ) and his staff started working on legislation to make changes for the betterment of those affected by Lyme disease.

LDA has been joined by Time For Lyme, its CT affiliate, who has been working in congress, particularly on the Senate side on the legislative issues for the last several years. The California Lyme Disease Association (CALDA), another LDA affiliate, has joined the efforts to help educate officials and the public about the need for the Lyme bill.

Over the 13 years since the introduction of the first federal Lyme bill, increasing numbers of legislators have supported it, from 30 congressional and six senatorial cosponsors in 1998, to 116 House cosponsors and 15 Senators as cosponsors of the Lyme bill in 2008. Individual patients and their families, state and local support groups and health care professionals have also been instrumental in educating legislators concerning the problems we all face with Lyme and tick-borne diseases.

In their effort to design legislation to best suit the needs of the people, legislators considered input from all concerned constituents. The legislation underwent reviews and input in each Congress.

Congressman Christopher Smith introduced the most recent legislation, ***Lyme and Tick-Borne Diseases Prevention, Education and Research Act of 2009***, HR 1179, on February 25, 2009. Senator Chris Dodd introduced Lyme disease legislation last session in the Senate which, like its companion bill in the House, would have significantly strengthened and coordinated efforts to provide prevention, education and research. Senator Dodd is introduced the Senate Lyme June 2009.

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3. What are the key elements of the bill and its goals?

The bill covers a number of key issues affecting Lyme patients and health care professionals, which are briefly described below.

The Establishment of an Advisory Committee

Purpose

- Facilitate communication and coordinate activities between Lyme organizations and government agencies that currently handle Lyme disease policies.
- Regularly advise government agencies on priorities concerning tick-borne diseases.
- Minimize overlap of activities between agencies and close current gaps in the system.
- Ensure a “broad spectrum” of scientific viewpoints is represented in public health policies pertaining to both acute and chronic Lyme and tick borne diseases.
- Advise the Health & Human Services (HHS) agency concerning ongoing activities, progress and goals that need to be accomplished.

Mandatory- Duties/Responsibilities of the Committee

Regular committee meetings will be held and minutes will be recorded.

Public meetings for gathering input from patients, organizations,

government agencies and health care professionals shall be announced in advance and held 2 times per year, or more. Details and reports concerning all activities for public meetings must be recorded and kept on record.

Committee

The Secretary will “assure” that members of the Committee represent a “diversity of scientific perspectives.” Sec. 3 (c)(1)(C) The Committee is required to submit detailed reports to HHS Secretary on a regular basis.

HHS Secretary

The HHS Secretary shall report on meetings to Congress and include information concerning the committee function, members, activities in the recent year, and any issues regarding functioning of the committee.

Members

HHS Secretary must ensure committee diversity & broad viewpoints

The Committee must include “2 health care providers, including at least 1 full-time practicing physician, with relevant experience providing care for individuals with a broad range of acute and chronic tick-borne diseases,” and scientists “representing a broad spectrum of viewpoints.”

The committee must include patients or a person whose family member has been diagnosed with a tick-borne disease and members from volunteer organizations. Those members chosen for the Committee cannot be employed by the government.

Representatives from government agencies currently involved with prevention, education and research, will be included on the Committee as non-voting members.

Bill authorizes appropriations of \$20 million a year for 5 years

The bill allows for \$100 million dollars in additional funding to be used for tick- borne disease prevention, long-term treatment outcome research, improved diagnostic tests, improved reporting and surveillance, and physician and public education.

The monies will be distributed over a 5-year period. This will be additional funding for tick borne disease research and will not affect what is currently budgeted for this purpose.

Tests – research priorities mandated in the bill will include the development of gold standard diagnostic tests.

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4. Who is responsible for deciding the language found in the bill?

Congressional staffers, legislative counsel, cosponsors, the general public, government agencies and others can educate and provide input, but the ultimate responsibility for the language lies with the bill sponsor.

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5. What changes were made to the Lyme disease bill this session?

After considering input from patients, health care professionals and

Congressional leaders, a few minor changes were made by Congressman Smith's office in order to strengthen the bill language. A list of these changes can be found at the following site, along with a bill summary, the bill text and additional information.

http://www.cwork.com/index.php?option=com_content&view=article&id=121&Itemid=109

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6. How do we find out the most up-to-date information about the bill?

To follow the bill's progress you can track it by visiting the following government web site. In the search section, click on "bill number" and type in "HR 1179".

<http://thomas.loc.gov/>

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7. How does the legislative process work in the House and Senate?

If you would like to learn more about: communicating with your representatives, the legislative process, how bills are passed, public disclosures, committees and their reports, congressional records, votes, daily activities, government resources and other bill related information, please click on the links below.

House bills:

http://www.house.gov/house/Tying_it_all.shtml

Senate bills:

http://www.senate.gov/legislative/common/briefing/Senate_legislative_process.htm

Use this link if you would like more information concerning the specific workings of the legislative process:

<http://thomas.loc.gov/help/>

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8. How does Congress enact a law?

There are as many opinions on this subject, as there have been bills. To see the official explanation, please visit this site below.

<http://thomas.loc.gov/home/enactment/enactlawtoc.html>

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Supporting the Bill

9. What can individuals do to help get the bill passed?

The Lyme Disease Association has been working closely with many Congressional staff members over the years in order to assure the best chance of having the Lyme disease bill passed. Your participation in actively supporting the bill is a key element that can help a bill become

law. We encourage you and everyone you know to contact your legislators, tell them your story, and explain why it is important to have them co-sponsor the bill. They need to hear from their constituents.

The LDA publishes **Action Alerts** several times a year for you to read and then forward to everyone you know. They have been keeping people informed about the bills progress and any obstacles or positive encounters along the way. Often the **Action Alerts** will ask you to take a specific action to better ensure the passage of the bill or to address attempts being made to stop its progress.

If you would like to add your name to the list to receive these notices, please click on the link below.

http://www.cwork.com/index.php?option=com_content&view=article&id=111&Itemid=57

To read current **Action Alerts** and review those that have already been issued, please check this site:

http://www.cwork.com/index.php?option=com_content&view=article&id=122&Itemid=108

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10. How can I find out who my legislators are and how to contact them?

The LDA provides names, addresses, fax numbers, phone numbers and an email form link for all members of Congress on its web site.

If you don't know who your legislators are but know your zip code, you can use this site to locate your Congressional legislators:

<http://www.visi.com/juan/congress/>

If you know who represents you in Congress, please click on the LDA website page below. There you can click on the name of your state – on the left side, menu bar – to view your legislators contact information. You can also check to see if your legislator has signed on to the Lyme disease bill as a cosponsor and find other bill related information by going to this link:

http://www.cwork.com/index.php?option=com_content&view=article&id=111&Itemid=57

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11.What shall I say when I call or write to my legislators?

LDA *Action Alerts* (posted on the web site) often include a sample blurb to use when writing or calling your legislators. If you are unsure of what to say on the phone, you may feel more comfortable writing them an email instead. If you have difficulties or are still unable to prepare something to use in your communications, please let us know. Click here to see sample blurbs:
http://www.cwork.com/index.php?option=com_content&view=article&id=48&Itemid=118

Likewise, if you get a response that you would like to share with us, please send it to us, via email. LDA.Lyme@gmail.com

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12.What can organizations and businesses do to support the

bill?

The LDA provides a short form that can be completed by the authorized representative of a group, organization or business. Signing up in support of the bill shows Congressional representatives and the public that you take Lyme and tick-borne diseases seriously and you support the Lyme disease bill.

If you are the representative of a business, organization or group you can complete the sign up form indicating your support by clicking here:

http://www.cwork.com/index.php?option=com_content&view=article&id=117&Itemid=112

To see a list of those who have signed on in support of the bill, please click here:

http://www.cwork.com/index.php?option=com_content&view=article&id=126&Itemid=112

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Having a Voice in the Process

13.How do I share my thoughts about the bill?

To share your thoughts on the Lyme disease bill, contact your representative by clicking the link below:

<http://www.visi.com/juan/congress/>

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14. What is the purpose of a Congressional hearing and do we need one?

A hearing is a formal meeting of a Senate, House, joint, or special committee of Congress. It is usually open to the public and its purpose is to obtain information and opinions on proposed legislation, conduct an investigation into a serious situation, or evaluate the activities of a government department.

Congressional hearings may also be purely exploratory or fact-finding and can be used to hear testimony and collect data about topics of interest. The information at a hearing can take up to two years to be published.

Hearings usually include oral testimony from witnesses, and members of Congress can question them.

Committees hold legislative hearings on measures or policy issues that may become public law. They provide a forum where facts and opinions can be shared by Congressional members and other government officials, special interest groups, scientists, and citizens who may be affected by proposed legislation.

Oversight hearings may be implemented to review a law or particular issue, including the performance government officials and programs. Oversight hearings often seek to improve the effectiveness of government operations. A significant part of a committee's hearings are dedicated to oversight of various agencies.

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15. Have hearings on Lyme disease been requested in DC?

The Lyme Disease Association, with the assistance of patients and support groups around the country have pushed for years for legislative hearings and for bill hearings to bring the facts to light and get them on record. Last year, to the surprise and dismay of the Lyme community and many Congressional members, a hearing that was to be scheduled did not appear on the calendar before the session ended.

With the force of Congressional members and the bill's sponsor and cosponsors behind us, the LDA is continuing to push from several directions, using all available means and options to get a legislative hearing on tick-borne diseases issues scheduled for this session.

To see a clip of Congressman Christopher Smith (NJ) and one of the bill's cosponsors, Congressman Frank Wolf (VA), expressing their support for the bill, the proposed hearings and our situation in general, click the link below:

http://www.lymerights.org/Pallone_v2.wmv

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16. Can the bill still be passed without a hearing?

Yes, it is possible to have a bill pass without having a hearing, however, the LDA has actively been trying to accomplish both goals, for the benefit of our community. A bill hearing would allow testimony on all aspects of Lyme disease.

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17.Can other actions be taken for Lyme disease?

Yes, LDA has been and continues to pursue other actions including inserting language and monies into appropriations bills. Congressman Smith was successful in getting monies into Department of Defense appropriations for Lyme disease in the 1990's.

LDA has also been able to arrange a number of meetings and briefings in DC with the help of Congressman Christopher Smith. LDA briefed CDC and NIH officials as early as 1992, has briefed military officials from all branches of the armed services, Health & Human Services under Secretary Tommy Thompson (CDC and NIH officials were teleconferenced in) the former Director of the CDC Dr. Julie Gerberding and the Science Director of the CDC (LDA was subsequently invited to Ft. Collins CO to present to the Vector-Borne disease Division), the Food and Drug Administration on the vaccine which was subsequently removed from the market, US Army CHPPM where organisms in ticks are being studied, and twice in 2008 with help from the House Lyme Disease Caucus, briefed House staffers. Additionally at the request of Senator Chris Dodd, LDA briefed the HELP (Health Education and Labor) Committee in 2008. The LDA pulled together teams of experts including physicians and researchers for many of these meetings. Other meetings and briefings were held in DC with key staff members over the past 11 years.

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The Advisory Committee

18. Who decides which individuals will be chosen to serve on the Lyme and Tick-Borne Diseases Advisory Committee?

The new Secretary of Health and Human Services (HHS), Kathleen Sebelius, is charged with appointing all of the voting members to the Committee from amongst individuals who are not officers or employees of the federal government. Secretary Sebelius will also select, as non-voting members, representatives overseeing tick-borne disease activities from the following agencies: Centers for Diseases Control and Prevention, National Institutes of Health, Agency for Healthcare Research and Quality, Food and Drug Administration, Office of the Assistant Secretary of Health, and such others as deemed appropriate.

To learn more about Health and Human Services and the role they have in protecting our health: Official site: www.hhs.gov

HHS- What We Do:

<http://www.hhs.gov/about/whatwedo.html/>

To see an example of the important role HHS will have in Lyme and Tick-Borne Disease activities by means of the bill and the kind of reporting and record keeping involved, please see the link below.

HHS- Chronic Fatigue Syndrome Advisory Committee Report 2008:

<http://www.hhs.gov/advcomcfs/meetings/minutes/cfsac20081028min.html>

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19.How many years will the Committee members serve?

The Committee members will each serve a four-year term except for the public co-chairperson, who will serve a two-year term.

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20.Who will be on the Committee?

The bill provides for an Advisory Committee which will, for the first time, include voting members consisting of Lyme patients and/or families of Lyme patients, physicians experienced in treating patients with acute *and* chronic tick-borne diseases, scientists representing a “broad range” of viewpoints, volunteer Lyme organization and representatives of local or state health departments and organizations. The selected members listed above cannot be officers or employees of the federal government.

The bill provides for additional non-voting members, which include representatives currently overseeing tick-borne disease activities from the CDC, NIH, FDA, Agency for Healthcare Research and Quality, Office of the Assistant Secretary for Health, and additional federal agencies, as deemed appropriate.

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21. Will the Advisory Committee hold public meetings?

The bill directs the Committee to hold public meetings, at least twice a year or more often. The Committee is required to announce the schedules for the meetings in advance.

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22. Will patients and health care providers be able to make suggestions and share their ideas with the Advisory Committee?

The general public will be able to make suggestions or share their ideas with representatives of the tick-borne diseases voluntary organizations who are Advisory Committee members.

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23. Will there be Congressional oversight to be sure the various government agencies are following through with the bill's instructions and intent?

There are a number of safeguards to ensure transparency and accountability built into the bill's language.

For example- the bill mandates a regular Committee report, to include specific details, in order to establish a firm foundation and keep track of all records and proceedings in the future.

Additionally, the bill specifically states how the funding will be used, i.e., test development, improved surveillance and reporting, prevention efforts, education of the public and health care workers, clinical research, long term outcomes of the disease and determination of the effectiveness of different treatment modalities by establishing treatment outcome objectives.

The Secretary will be responsible for submitting to congress the report on the activities carried out under this act.

The recommendations included in the Advisory Committee's report will be by the Secretary and the various agencies involved. The Committee has also been instructed to report on the activities and the progress concerning the various agencies, or lack thereof, on a regular basis.

To see an example of the details recorded in reports to the HHS Secretary:

HHS-CFS Advisory Committee Report 2008

<http://www.hhs.gov/advcomcfs/meetings/minutes/cfsac20081028min.html>

To learn more about the Congressional Record:

http://thomas.loc.gov/home/cr_help.htm

To review the concepts behind Congressional oversight:

<http://www.fas.org/sgp/crs/misc/97-936.pdf>

For more details, please see the Congressional oversight manual:
<http://www.fas.org/sgp/crs/misc/RL30240.pdf>

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24.How was the Committee structure determined?

The Committee structure closely follows that of other disease advisory committees already created by Congress.

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Funding for Research, Prevention, Education and More

25.What about the money – who gets it and how will it be used?

The bill allows for \$100 million dollars in new funding which will be distributed over a 5 year period and used to fund projects which consider the broad spectrum of scientific viewpoints.

Activities to be conducted or supported under this bill include tick-borne disease prevention, long-term treatment outcome research, improved diagnostic tests, improved reporting and surveillance, and physician and public education. This will be additional funding for tick borne disease research and will not affect what is currently budgeted for this purpose.

The Advisory Committee, which will for the first time allow patients a voice in the process, is responsible for offering input to advance all

tick-borne disease research, prevention and educational efforts. It has been instructed to focus on specific areas and goals. After suitable plans are drafted by the Committee, the final recommendations will be sent to the various agencies by the Secretary of Human Health. The Secretary, in conjunction with the Committee, shall provide for the “support of the following” activities with specified goals:

A. TESTS – The development of accurate diagnostic tests capable of determining active infection from past infection. Improving the use of current tests to allow for the multiple manifestations attributable to both acute and chronic Lyme and the timely evaluation of any promising new diagnostic methods.

B. REPORTING and SURVEILANCE – Improve methods of determining the number of actual cases of Lyme and tick borne diseases. Evaluating the feasibility of including physician diagnosed cases that don’t meet the current criteria and a national lab reporting system that would make reporting by labs mandatory.

C. PREVENTION – Providing and promoting access to a comprehensive up to date clearing house of peer reviewed literature on Lyme and tick-borne diseases. Increasing public education through expansion of community based programs of the CDC including expanded access to the public. Creating a physician education program that includes the full spectrum of scientific research related to Lyme and other tick-borne diseases. Sponsoring scientific conferences on Lyme and other tick-borne diseases including the full spectrum of clinically based knowledge.

D. CLINICAL OUTCOMES RESEARCH – Establishing research objectives to determine the long-term course of illness for Lyme disease; determining the effectiveness of different treatment modalities by establishing treatment outcome objectives.

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Overcoming Our Obstacles

26. How will this bill protect doctors who are being targeted for treating patients who are chronically ill?

Doctor protection is a state not a federal issue. However, cutting edge research and development of new diagnostic tests would open the doors for improved diagnosis and treatment.

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27. What activities are being done at other government levels to help patients and their doctors?

The Lyme Disease Association continues to explore all avenues that could possibly improve the Lyme disease situation at local, state and national levels, including development and support of state legislation; briefing state, county and local legislators and health department officials.

www.LymeDiseaseAssociation.org

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Staying Informed

28. How can we keep informed about legislation and other efforts being made?

Click here to sign up to receive LDA Action Alerts at http://www.cwork.com/index.php?option=com_content&id=115&catid=34&ionid=5

&Itemid=108

Also, take time to review the new LDA legislative website and take advantage of information provided.

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29. How can we share our own ideas and concerns about legislation and other efforts being made?

You can share your ideas with your legislators by clicking on the word "Legislation" at the top of the main page on the LDA website. There you will find your states Congressional leaders and their contact information.

The LDA works with 31 other associated organizations – chapters, affiliates and supporters representing 19 states across the country. The groups communicate regularly amongst themselves and with other groups and with scores of individuals who are interested in Lyme and tick-borne diseases on a variety of issues that affect the community.

Hundreds of thousands of people have taken the opportunity to use the LDA website to locate valuable information on a variety of issues. Anyone with questions or comments can share their thoughts with LDA by way of website.

30. Please take advantage of one or more free services the LDA offers (links below)

- Mailing Address: Lyme Disease Association, Inc., PO Box 1438, Jackson, NJ 08527
- Toll Free Information Line: 1-888-366-6611
- Lyme Disease Association- Main Website (news, events, Lyme information and more) www.LymeDiseaseAssociation.org

- LDA Legislative website (sign up to receive LDA Action Alerts)
http://www.cwork.com/index.php?option=com_content&id=115&catid=34&ionid=5&Itemid=108
- LDA Chapter, Affiliates and Supporters: <https://lymediseaseassociation.org.previewdns.com/Affiliates.html>
- Lyme Disease Association Contact List Form: <https://lymediseaseassociation.org.previewdns.com/ContactUs.html>
- Lyme Disease Association- Automated Doctor Referral (free): <https://lymediseaseassociation.org.previewdns.com/referral/LogIn.php?setcookie=yes>
- Order free brochures: <https://lymediseaseassociation.org.previewdns.com/Brochures.html>
- Lyme disease case maps <https://lymediseaseassociation.org.previewdns.com/Maps/index.html>
- LDA Introduces the FREE Educational On-Line Module: How A Tick Can Make You Sick (grades 6 through Adult) https://lymediseaseassociation.org.previewdns.com/ledu_home.html

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