

House Floor Debate On Lyme bill – 2008

Lyme Disease Controversy made it to the house floor for a heated debate between Congressman Smith (NJ), Congressman Wolf (VA) and Congressman Pallone (NJ).

House Floor Debate on Lyme Bill in 2008 Congress

September 27, 2008 On US House Floor in Washington, DC

Congressmen Frank Wolf (VA) and Christopher Smith (NJ) interact on the House floor with Congressman Pallone (NJ), Chair of the Energy & Commerce Health Subcommittee. Questions arose about why Mr. Pallone boxed the Lyme bill up in his Committee and prevented a hearing on the bill. Mr. Pallone agreed that he would have a hearing in the upcoming 2009 session.

Congressman Christopher Smith (NJ), Bill Sponsor

This video clip addresses the controversy surrounding Lyme and tick-borne diseases. Provides details covering the recent IDSA guidelines and the CT Attorney General's findings of major conflicts of interest and bias towards chronic Lyme. Points out, the bill is not about treatment but about allowing all points of views to be considered and all science included within the Lyme Advisory Committee that is created in the Lyme bill. Congressman Smith states that he believes there is a coverup surrounding Lyme disease.

[Click Here](#) To view 7 min. video clip from C-Span

[Click Here](#) To view 5 min. video clip from C-Span

[Click Here](#) To view below the written excerpts of Congressman Smith's Debate

*when you get get to C-Span it might take a short period of time for the video to appear.

Congressman Frank Wolf (VA), Bill Co-Sponsor

This video clip addresses the Lyme disease epidemic and he adamantly demands why

Congressman Pallone is holding the Lyme bill from going forward in his health subcommittee. He discusses the suffering of patients in his State of VA and along the East Coast and asks why nothing is being done to help reduce this epidemic. He demands a hearing early next year and Pallone agrees the topic is controversial and says he will hold a hearing next year.

[Click Here](#) To view 7 min. video clip from C-Span

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Excerpts from Smith Statements on Lyme Disease Bill

Washington, Sep 27, 2008 —

Mr. SMITH of New Jersey.

Let me just say, to clarify the record, this legislation, which would seek to lay bare the science about Lyme disease, the fact that I believe we do have an epidemic, the fact that Lyme often go misdiagnosed, underdiagnosed. It is called “the great pretender” because so many people have it and don’t know it. It often masquerades as other kinds of anomalies manifesting in a person’s body. And it is not until it gets to a chronic state—very often causing severe disability, including neurological damage—that people finally realize that they have Lyme disease.

There has been, unfortunately, a significant, I believe, cover up of the fact that chronic Lyme exists. The gentleman knows, we have asked him repeatedly, the gentleman from New Jersey, my good friend, Mr. PALLONE, this legislation has been pending

in his subcommittee. He told Pat Smith—no relation to me—who runs a Lyme disease association, that this would get a hearing and would be marked up. It has not been marked up. And meanwhile, this epidemic is growing—it is exploding.

Now, let me just say for the enlightenment of my colleagues; the Infectious

Disease Society of America, which creates—and often does a very laudable job—the definitions, the parameters of what constitutes a certain disease, has looked at Lyme and said that chronic Lyme does not exist. Many of us have raised serious concerns about that because of what we believe to be conflicts of interest on the part of the panel members that made up the Lyme panel.

I would note parenthetically that CHRIS DODD is the prime sponsor of the comparison legislation that I've introduced on the House side. We have worked cooperatively on the legislation, so we have a companion bill on the Senate side. The legislation has over 110—I think it's 112—cosponsors, totally bipartisan, Democrats and Republicans alike rallying around this legislation.

The problem with the Infectious Disease Society of America is that these conflicts of interest, we believe, resulted in the conclusion that chronic Lyme doesn't exist. We don't know absolutely if that's the truth, but Attorney General Richard Blumenthal from Connecticut finally took a look at this and came back with a scathing insightful report that there were conflicts of interest. The red flag should go up everywhere.

What does my legislation do? As Mr. PALLONE knows, the legislation does not prescribe a protocol, as he has suggested. It simply calls for an advisory committee that would take a good, long look at Lyme disease and determine what is fact and fiction, and finally, for the sake of all of those who are suffering immensely from this disease and their families, say what we need to be doing to mitigate and

hopefully stop the spread of Lyme, whether it be long-term and very heavy antibiotic treatment—which I believe probably is the case based on clinical practitioners who have suggested that to be the case—but we want an honest look.

As Mr. PALLONE knows, we did not get an honest look from the Infectious Disease Society of America. And I find that appalling. Conflict of interest with insurance companies has no place in modern medicine. And regrettably, and it has been—again, the full weight of the Attorney General’s report clearly suggests, Richard Blumenthal of Connecticut, that there were significant conflicts of interest on the part of the panel members.

Our legislation says let’s go where the science takes us. If the science says chronic Lyme exists, then all those patients and the insurance companies which need to be providing the coverage, to get the medicines and the like, like antibiotics—because what has happened, as my friend knows, because of this exclusion of chronic Lyme due to a problem in definition, the insurance companies say we don’t have to pay. So when a patient presents with a bill of \$100,000 or some excessive amount of money, the insurance companies say, not us, tough luck, we’re not going to pay for it. And they go right back to what I believe to be a false definition that precludes chronic Lyme as a condition.

Now, you might think that chronic Lyme doesn’t exist, I say to my friend, the chairman, but let’s go where the science takes us. We need this advisory committee and we need it now. All points of view, as our legislation clearly suggests, has to be a part of this group. We want a robust debate, not something that is engineered by insurance companies.

Finally, the legislation would authorize \$100 million over 5 years, \$20 million each year. Frankly, if that drops off due to opposition to new authorization, and is only an authorization, I would like to see it go forward nevertheless,

know this however, we're not spending enough on Lyme.

And Lyme is, as Mr. WOLF said so aptly, growing exponentially. CDC admits we are missing most of the cases. As many as 90 percent of the cases go unreported. Our state, Mr. PALLONE, as you know, is number three in prevalence according to CDC numbers, and even that is probably very much understated in terms of the actual prevalence of Lyme disease.

So I would make the appeal again, as I have made to my friend from New Jersey, as I have made to Mr. DINGELL, as I have made to Mr. BARTON and everyone else, this legislation ought to be on this floor and it ought to be on the floor today. It is truly bipartisan. There ought to be a consensus to go where the science takes us. And again, an advisory committee, a Blue Ribbon panel that would be configured under this legislation would finally end, hopefully, this contentious debate and tell us what it is and what it is not.

I have known dozens of people who have had chronic Lyme. Now, you might say it doesn't exist, the Infectious Disease Society says it doesn't exist. These victims suffer from the spirochete, and have suffered neurological damage, severe joint damage, and many, many other problems.

There is a new book called "Cure Unknown" that I would recommend to the House. I read it in one sitting because it is so incisive in finally breaking through the fog on this disease. People are walking around with Lyme and they don't even know it.

We need to bring the forces to bear of the U.S. Government that an advisory committee of this kind would do a Blue Ribbon panel, a 9/11-type panel of scientists, of the best people we can put together to say, put aside the egregiously flawed Infectious Diseases Society of America's finding, which Blumenthal said was riddled with conflict of interest—and I urge Members to read Blumenthal's opinion, I will put it in

the RECORD so Members can read it—his findings were, ‘‘atrocious, conflict of interest everywhere.’’

This legislation ought to be on the floor and it ought to be on the floor today.

Mr. Speaker, again, I didn't get a chance when Mr. PALLONE was here to correct the Record. I—we—did contact Congressman FRANK PALLONE and NATHAN DEAL by way of letter on May 18, 2007, and wrote at the time as co-chairs of the Congressional Lyme and Disease Caucus, ‘‘we are writing to respectfully request that you mark up and report H.R. 741.

‘‘H.R. 741, the ‘Lyme and Tick-borne Disease Prevention, Education and Research Act of 2007’ would work toward goals for the prevention, accurate diagnosis, and effective treatment of Lyme disease.’’

Then we went on to explain the bill. We pointed out that at the time we had 77 cosponsors. That is now 112 and it is totally bipartisan and includes majority leader STENY HOYER. We also pointed out that Lyme is the most prevalent vector-borne disease in the United States today. More than 220,000 Americans develop Lyme each year. According to the CDC, only 10 percent of the cases that meet its surveillance criteria are reported. Cases that fall outside of the surveillance criteria are not even considered anywhere statistically.

If not diagnosed and treated early, Lyme disease can lead to chronic illness and can affect every system in the body, including the central nervous system and cardiac system. Later symptoms of Lyme disease include arthritis, neurological problems such as facial paralysis, memory problems, extreme weaknesses of the extremities, seizures, heart block and inflammation and even blindness.

So we sent that back in May 18, 2007. And I say that with respect to my colleague.

Let me also point out, and I just will read a very small portion of the statement of Attorney General Richard Blumenthal, the attorney general of Connecticut. And this is his statement.

‘‘Attorney General Richard Blumenthal today announced,’’ and this is May 1, 2008, ‘‘that his antitrust investigation has uncovered serious flaws in the Infectious Disease Society of America's process for writing its 2006 Lyme disease guidelines and the IDSA has agreed to reassess them with the assistance of an outside arbiter.’’

‘‘The IDSA guidelines have sweeping,’’ this is Blumenthal speaking, ‘‘have sweeping and significant impacts on Lyme disease medical care. They are commonly applied by insurance companies in restricting coverage for long-term antibiotic treatment or other medical care and also strongly influence treatment decisions by physicians.

‘‘Insurance companies have denied coverage for long-term antibiotic treatment, relying on those guidelines as justification. The guidelines are also widely cited for conclusions that chronic Lyme disease is nonexistent.’’

Blumenthal goes on to say: ‘‘This agreement vindicates my investigation finding undisclosed financial interests and forcing a reassessment of IDSA's guidelines.’’

Blumenthal said: "My office uncovered undisclosed financial interests held by several," several, "of the most powerful IDSA panelists. The IDSA's guideline panel improperly ignored or minimized consideration of alternative medical opinion and evidence regarding chronic Lyme disease, potentially raising serious questions about whether the recommendations reflected all relevant science. The IDSA's Lyme disease guideline process lacked important procedural safeguards requiring complete reevaluation of its 06 Lyme disease guideline, in effect a comprehensive reassessment through a new panel."

Blumenthal, and I will put this in the RECORD, talks about the conflicts of interest with the insurance companies. Again, I would think this Congress would want to get to the science, find out does chronic Lyme exists, and whether or not this is indeed a coverup.

Organizations/Businesses in Support of Lyme Bill – 2009/2010 Lyme Bill

The Lyme and Tick-Borne Diseases Prevention, Education and Research Act of 2009”
Bill Supporters from Across the Nation, Lyme Groups & Non-profit LDA Friends, Others

“The Lyme and Tick-Borne Diseases Prevention, Education and Research Act of 2009” Bill Supporters from Across the Nation
LDA, LDA Chapters, Affiliates, Supporters:
Lyme Disease Association, Inc. (NJ – National)
Military Lyme Support (NJ – National)
Alaska Lyme Support (AK)
California Lyme Disease Association (CA)
Eastern CT Chapter LDA (CT)

Newtown Lyme Disease Task Force (CT)
Ridgefield Lyme Disease Task Force (CT)
Time For Lyme, Inc. (CT)
Florida Lyme Advocacy (FL)
Southeastern Florida Chapter LDA (FL)
Georgia Lyme Disease Association (GA)
Lyme Association of Greater Kansas City, Inc. (KS)
Cape Cod Chapter LDA (MA)
Harford County Lyme Disease Support Group, Inc. (MD)
Mid-Shore Lyme Disease Association, Inc. (MD)
Minnesota Lyme Action Support Group (MN)
Mid-Missouri Tick Illness Coalition (MO)
Montana Lyme Support (MT)
Wolfeboro Lyme Disease Network (NH)
LymeQuest (NJ)
Corning/Finger Lakes Area Chapter LDA (NY)
Hudson Valley Lyme Disease Association (NY)
New York City Lyme Disease Support Group (NY)
Stop Ticks On People (NY)
Pennsylvania Chapter LDA (PA)
Southeastern Pennsylvania LDA, Inc. (PA)
Rhode Island Chapter LDA (RI)
Greenville Lyme Advocacy and Support Group (SC)
Stand Up For Lyme (TX)
Texas Lyme Disease Association (TX)
Lyme Disease Support Group of SW Vermont (VT)
Lyme Groups & Non-profit LDA Friends:
ILADS – International Lyme and Associated Diseases Society (MD – National)
Lyme Disease Education and Support Groups of America (MD – National)
Lyme Rights (NY – National)
American Hiking Society (National)
East Bay L.E.A.P.S. (CA)
Humboldt Lyme Awareness Group (CA)
Joseph Barsuglia Online Support Group (CA)
Lyme Support Sacramento (CA)
South Francisco SEAL (Support, Education & Advocacy for Lyme) (CA)

Southern California Lyme Support (CA)
National Lyme Disease Memorial Park Project (CA)
Mid-Peninsula Lyme Disease Support Group (CA)
Lyme Awareness (CO)
Lyme My Space (CO)
Lyme Friends (CT)
Lyme Information Network (CT)
National Association for the Education of Young Children (CT)
Wolcott Lyme Disease Network (CT)
Fairfield Lyme Resource (CT)
Deleware Lyme Support (DE)
Southern Deleware Lyme Support Group (DE)
S.L.A.M. (Sturbridge Lyme Awareness of Massachusetts (MA)
Lyme Disease Education and Support Groups of Maryland (MD)
Jersey Shore Lyme Support Group (NJ)
Lawrence Brook Watershed Partnership (NJ)
Morris Lyme Support Group N.J. (NJ)
Sussex County Lyme Support Group (NJ)
Lyme Support for Taos (NM)
New Mexico Lyme Disease Support Network (NM)
Dutchess County Legislative Tick Task Force (NY)
Northern Dutchess Lyme Disease Support Group (NY)
Central PA LYme Disease Support Group (PA)
T.O.F.U., Inc. (PA)
San Antonio Lyme Support Group (TX)
The Greater Austin Lyme Council (TX)
Texas Families Against Lyme Disease (TX)
The New Morgellons Order (TX)
Ladysmith Lyme Support Group (WI)
Lyme Disease Awareness Network (WI)
WI Lyme Yahoo Group (WI)
Others:
IGeneX, Inc. (CA)
University of San Francisco (CA)
Housatonic Valley Council of Elected Officials (CT)

Intellisponse (CT)
Supernets (FL)
Eye On Lyme Network (FL,GA)
Jadoh & Associates (FL)
Illinois Birddog Rescue, Inc. (IL)
Bella Pearls (LA)
Mainely Ticks (ME)
Southern Maine Renewable Fuels (ME)
The Maine Branch (ME)
Independent Consultant for The Pampered Chef (ME)
Breakthrough Consulting (NM)
Balloon-A-Tic (NY)
Lynn McCabe Photography (NY)
A.B.B. Towing(PA)
Tiffany Griffiths, Psy.D. and Associates (PA)
Type 3 Media (RI)
Ava Gardener Landscape Architecture Studio (WA)
If your group is not listed please click here to sign your organization up.

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.

Frequently Asked Questions

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Funding for Research, Prevention, Education and More

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Overcoming Our Obstacles

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

Staying Informed

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

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

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

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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2010 HHS Appropriations Bill Language

Both Houses of Congress use “chronic Lyme disease” and “persistent infection” language to direct federal agencies in their respective roles on Lyme disease. Read both the Senate and House language below.

Senate Appropriations Language

Lyme Disease – The Committee encourages the CDC to expand its activities related to developing sensitive and more accurate diagnostic tools and test for Lyme disease including the timely evaluation of emerging diagnostic methods and improving utilization of diagnostic testing to account for the multiple clinical manifestations of acute and chronic Lyme disease; to expand its epidemiological research activities on tick-borne diseases (TBDs) to include an objective to determine the long-term course of illness for Lyme disease; to improve surveillance and reporting of Lyme and other TBDs in order to produce more accurate data on the prevalence of Lyme and other TBDs; to evaluate the feasibility of developing a national reporting system on Lyme including laboratory reporting; and to expand prevention of Lyme and TBDs through increased community-based public education and creating a physician education program that includes the full spectrum of scientific research on the diseases.

Lyme Disease – The Committee encourages the NIAID to sponsor a scientific conference on Lyme and other tick-borne diseases that would represent the broad spectrum of scientific views on Lyme disease and include input from individuals with Lyme disease. The Committee also encourages NIH to intensify research that will increase understanding of the full range of Lyme disease processes and the physiology of *Borrelia burgdorferi*, including the mechanisms of persistent infection, and research that may lead to the development of

more sensitive and accurate diagnostic tests for Lyme disease capable of distinguishing between active and past infections.

Lyme Disease – The Committee encourages AHRQ to create a comprehensive clearinghouse of peer-reviewed tick-borne diseases literature that will include literature on persistent infection, appropriately organized for use by the scientific community, treating physicians, and the public.

Lyme Disease – The Committee urges the Secretary to improve interagency coordination and communication and minimize overlap regarding efforts to address tick-borne diseases. The Secretary is encouraged to advise relevant Federal agencies on priorities related to Lyme and tick-borne diseases, identify future research needs, and involve CDC, NIH, FDA, and other agencies in the development of a more accurate system of diagnosing and reporting of Lyme disease.

House Appropriations Language

Tick-borne Diseases. – The Committee directs the Secretary to review the coordination of efforts across HHS operating divisions with respect to tick-borne diseases to ensure that: a broad spectrum of scientific viewpoints is represented in public health policy decisions, accurate information is disseminated to the public and physicians, and actions are taken by the Department that will foster significant progress in the development and adoption of improved diagnostics for Lyme disease. The Department shall submit a report to the Committees on Appropriations of the House of Representatives and Senate with the findings from this review not later than September 30, 2010.

Lyme Disease. – The Committee encourages CDC to expand its activities related to developing sensitive and more accurate diagnostic tools and tests for Lyme disease, including the evaluation of emerging diagnostic methods and improving utilization of diagnostic testing to account for the multiple clinical manifestations of acute and chronic Lyme disease; to expand its epidemiological research activities on tick-borne

diseases to include an objective to determine the long-term course of illness for Lyme disease; to improve surveillance and reporting of Lyme and other tick-borne diseases in order to produce more accurate data on their prevalence; to evaluate the feasibility of developing a national reporting system on Lyme disease, including laboratory reporting; and to expand prevention of Lyme and tick-borne diseases through increased community-based public education and creating a physician education program that includes the full spectrum of scientific research on the diseases. □□

The National Center for Zoonotic, Vector-Borne, and Enteric Diseases provides national and international scientific and programmatic leadership addressing zoonotic, vector-borne, foodborne, waterborne, mycotic, and related infections to identify, investigate, diagnose, treat, and prevent these diseases. The programs focus on the continuing challenge of emerging and re-emerging zoonoses and the ecologies from which these diseases have emerged, while recognizing the importance of working collaboratively, not just across CDC and the traditional public health community, but also, with agricultural, wildlife, companion animal, and environmental agencies□and organizations. Within the total for Zoonotic, Vector-Borne, and Enteric Diseases, the Committee includes the following amounts:

Budget Activity	FY 2010 Committee	<u>FY 2010 Committee compared to –</u>	
		FY 2009	FY 2010 Budget Request
Vector-borne Diseases, including West Nile Virus	\$26,717,000	+\$418,000	\$0

Lyme Disease	8,938,000	+3,668,000	+3,668,000
Food Safety	26,942,000	+4,422,000	0
Prion Disease	5,474,000	+86,000	0
Chronic Fatigue Syndrome	4,825,000	+75,000	0

Lyme Diseases.- The Committee encourages NIH to intensify research on tick-borne diseases including research that will increase understanding of the full range of Lyme disease processes and the physiology of *Borrelia burgdorferi*, including the mechanisms of persistent infection. Recognizing NIH's collaborative role with CDC and other agencies in the development of diagnostics, the Committee encourages NIH to support research that may lead to the development of more sensitive and accurate diagnostic tests for Lyme disease capable of distinguishing between active and past infections. The Committee encourages the Director, in collaboration with the Director of NIAD, to sponsor a scientific conference on Lyme and other tick-borne diseases. The Committee believes that the conference should represent the broad spectrum of scientific views on Lyme disease and should provide a forum for public participation and input from individuals with Lyme disease."□□

2009/2010 Lyme Bill Text Changes

Many reps that were co-sponsors of the last Lyme bill are NOT co-sponsoring the current bill. This could be in part due to some Insignificant changes in the current bill language and they don't have time to review the changes. Contact your reps today, explain the changes, or send them this list and urge them to be a co-sponsor today!

Lyme and Tick-Borne Diseases

Prevention, Education, and Research Act 2009

HR-1179 / S-1352

Changes and Updates in Bill Text

After carefully considering input from patients, organizations and others, the following changes were made to the bill by the sponsor.

Section 1. Title- changed from 2007 to 2009, "s" added to

"disease".

Section 2. (2). Better defined *Borrelia burgdorferi*, spirochete and species of tick.

Section 2 (5). Added anaplasmosis to deer tick-borne diseases. Expanded/reworded line concerning bartonella and tularemia. Added "other species of *Borrelia*". Added STARI was carried by the lone star tick, as is Rocky Mountain Spotted Fever and ehrlichiosis. Changed to "multiple diseases" in one patient, vs. "more than one disease".

Section 2. (6, 7) Separated original paragraph content to form an additional line, making it lines # 6-8, rather than # 6-7.

Section 3 (c) 1 b. i- v. Defined the minimum number of people from various backgrounds and specialties that will be included as voting members on the Advisory Committee.

Section 3. (e) Added provisions for an annual report to be generated by the Advisory Committee, defined when and where it will be sent and its minimum contents.

Section 4. (4) C. Divided one line into 2 concerning the "conduct or support of activities".

Section 4. (c) Specifically designated a certain portion of total research funding to be the minimum for the CDC and updated the years to be funded, to reflect the new session.

Section 5. b. (5) Added final comment to expand what is included in the report to Congress.

(5) a copy of the most recent annual report issued by the by the Tick-Borne Diseases Advisory Committee established in Section 3 and an assessment of progress in achieving recommendations of that Committee.

(e) Report- A report shall be prepared not later than one year after enactment of this act and annually thereafter for submission through the Directors of CDC and NIH to the Secretary, which shall contain at a minimum the Advisory Committee's functions, a list of its members and their affiliations, a summary of the Committee's activities and recommendations during the previous year, including any significant issues regarding the functioning of the Committee.