

# Sen. Schumer Press Conference on TBD \$\$\$; LDA President A Speaker

Podium (L-R) Sen. Charles Schumer – NY, Pat Smith, LDA 

US Senator Chuck Schumer (NY) , Senate Minority Leader, invited LDA President Pat Smith to speak at a press conference he hosted in Woodbury, NY on May 2, 2018. The focus of the conference was to ensure that government monies on Lyme and tick-borne diseases reach those officials at the state and local level who can best ensure the monies are used to help fight tick-borne diseases.

*Remarks by Patricia Smith, President Lyme Disease Association, Inc.*

Trailview State Park, Woodbury, NY May 2, 2018

Before I begin, I need to say that although I am a public member (one of 7) of the 14 member Tick-Borne Disease Working Group under HHS in DC, I am not speaking today on behalf of the Working Group but as President of the national non-profit Lyme Disease Association, Inc.

Lyme, the most prevalent vector-borne disease in the US, is found in over 80 countries worldwide. CDC indicates that only 10% of Lyme cases are reported, thus in 2016 alone, 360,000+ new cases of Lyme disease probably occurred in the US.

Information reported by CDC yesterday indicates over a 13 year period:

- Reported cases of tick-borne diseases (TBD) more than doubled—(2004 to 2016),
- TBD made up 77% of all vector-borne disease reports,

- Lyme disease made up 82% of all TBD case reports,
- NYS is in the top 20% of states in disease cases reported from ticks.

The range of ticks is spreading nationwide, and they now carry a whole host of TBDs which can complicate diagnosis and treatment. Many of us in the Northeast have noted a year round threat as the ticks become active and search for a blood meal when temperatures rise above freezing. Right here on Long Island, 3 main ticks are instrumental in causing diseases in humans, and one tick bite can produce a multitude of diseases.

- Waiting on low lying vegetation for you to brush by, the deer tick may bite and infect you with Lyme, *Borrelia miyamotoi*, babesiosis, anaplasmosis, maybe even Powassan virus, which has no known treatment, a 10% fatality rate, and serious neurologic complications for half its survivors.
- Going after you more aggressively, the lone star tick may bite and infect you with Lyme-like STARI, which has no known cause or available test; or ehrlichiosis, tick paralysis and even alpha gal allergy that causes serious allergic reaction to red meat, which you may then need to remove from your diet.
- Often minimized in tick education, the American dog tick may give you ehrlichiosis, RMSF, tularemia, and perhaps tick paralysis.


The deer tick, which can be as small as a poppyseed, is hard to see and hard to properly remove once it bites you. It has fish hook like barbs and it secretes a cement like substance to glue itself onto you and blood thinners to help it feed, and it can inject all the organisms inside it into you if you squeeze its body while removing it. This tiny tick can transmit a bacterium that wreaks untold havoc: dozens of doctors, years of treatment, lost income, piles of unpaid medical bills, and lost months/years of school time, since our children are at some of the highest risk of getting Lyme

disease. Research studies indicate 15-34% or more of Lyme patients may become chronic.

Lyme is serious. It can enter the central nervous system within hours of a tick bite. It can hide in the skin & joints, evade the immune system, and change into forms not eradicated by conventional antibiotics. It can cross the placenta to the fetus, and it can cause sudden death in patients due to cardiac involvement. Lyme can attack every system in the body and can mimic many other conditions including MS, ALS, Chronic Fatigue, Fibromyalgia, Parkinson's, Alzheimer's, and even an autism-like condition, reversed with treatment.

Research and education against tick-borne diseases require a monetary commitment commensurate with the severity of Lyme and the growing number of TBDs in the US, currently about 20 diseases. The federal government needs to step up to the plate and provide monies for Lyme & tick-borne diseases in congressional appropriations.

Remember, Lyme disease does not discriminate, nor does it confer immunity—another bite, another possible infection. It does not require any risky behavior beyond walking the dog, jogging, playing on the backyard swingset or birdwatching in this beautiful natural environment. The only thing standing between us and Lyme disease is the power of significant new monies to unlock the secrets of these insidious tick-borne diseases and to curb the spread of the ticks now threatening us, our families and our pets. Thank you, Senator Schumer, for continuing to be a leader in Washington in this battle to provide monies and to ensure those monies reach the state and local levels to make families safe here on LI, in NYS, and across the nation from the growing threat of TBDs. After 44 years of Lyme disease we still do not have a gold standard and we don't have a test to check for active infection and this is a disgrace and we all need to work together in order to ensure this money get to the people in the trenches who best know how to use the money.

 Bridget Fleming, Suffolk County Legislator, 2nd District (see tick warning sign)

[Click here for Senator Schumer Press Release](#)

See News Videos Below

<http://abc7ny.com/health/schumer-urges-cdc-to-unlock-funds-for-tick-borne-diseases/3419592/>

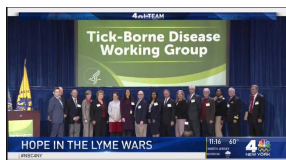
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<http://www.fox5ny.com/news/tick-borne-diseases-funds>

<http://pix11.com/2018/05/02/more-warm-days-bring-greater-risk-of-disease-from-bugs-schumer-calls-for-action/>

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## Federal TBD Working Group Featured on NBC News NY



NBC News 4 New York aired a piece on the federal Tick-Borne Working Group, Tri-State Helps Bring Hope to Lyme Wars Public Health Crisis, on February 21, 2018. The video featured LDA President, Pat Smith; Lyme Society, Inc. President, Bob Sabatino; John Aucott, Co-Chair of the Working Group; as well as a number of patients.

[Click here to watch the NBC clip](#)

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*Health Crisis*, on February 21, 2018. The video featured LDA President, Pat Smith; Lyme Society, Inc. President, Bob Sabatino; John Aucott, Co-Chair of the Working Group; as well as a number of patients.

The Tick-Borne Disease Working Group was established by the 21st Century Cures Act to improve federal coordination of efforts related to tick-borne diseases. Members will review all U.S. Department of Health and Human Services efforts related to tick-borne diseases to provide expertise and help ensure interagency coordination and minimize overlap, examine research priorities and identify unmet needs.

[Click here to watch the NBC clip](#)



### **Tri-State Helps Bring Hope to Lyme Wars Public Health Crisis**

*A major change is happening in the Lyme Wars with top experts taking action with help from people in the tri-state. Natalie Pasquarella reports.*

[Click here](#) for Tick-Borne Disease Working Group News on LDA website

[Click here](#) for Working Group Updates on U.S. Department of Health and Human Services (HHS) website

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# Focus on Lyme Presents Advocacy Award at Scientific Conf.



Focus on Lyme held its 2nd Annual Wave of Change Scientific Conference & Gala on February 23-24, 2017 in Paradise Valley, AZ.

Lyme Disease Association President Pat Smith was honored with the “Excellence in Advocacy” award at the conference for the work done by LDA in regards to legislation, and in particular, Lyme language in the 21st Century Cures Act.



ord, Executive Director, Focus on Lyme; Holly Ahern, MS, MT (ASCP), SUNY Adirondack; Patricia Smith, President, Lyme Disease Association Focus on Lyme held its 2nd Annual Wave of Change Scientific Conference & Gala on February 23-24, 2017 in Paradise Valley, AZ. Lyme Disease Association President Pat Smith was honored with the “Excellence in Advocacy” award at the conference for the work done by LDA in regards to legislation, and in particular, Lyme language in the 21st Century Cures Act.

At the opening of the conference, Tammy Crawford, Executive Director, Focus on Lyme, announced the award presentation, and Holly Ahern, MS, MT (ASCP), State University New York, spoke about the legislative work of Pat Smith, President of the LDA, and a presentation Ms. Smith had made at a Forum sponsored by then Congressman Chris Gibson (NY) several years ago on how to achieve legislation and how that came into play in Pat's subsequent work.

Accepting the award on behalf of patients, Ms. Smith addressed the conference and spoke about her family's experiences with Lyme, Lyme disease symptoms, and the many years of Lyme disease treatment needed to make her family members better. After the event, she commented, "I thank Focus On Lyme for their advocacy award, which I accepted on behalf of patients, treating physicians, and researchers working on persistence, the people who really deserve an award. However, the thrust of the conference was on and should have been on the research we so desperately need to help the hundreds of thousands of those sick with chronic Lyme and other tick-borne diseases, and I especially thank Focus on Lyme for keeping their eye on the prize."

Said Ms. Crawford after the event, "Focus On Lyme was so excited to honor Pat Smith for her life time of advocacy and achievement for those who suffer with Lyme disease. Pat is a true hero to us."

Ms. Ahern's written remarks about Pat Smith "Focus on Lyme – Advocacy in Motion"

In late 2016, the 21st Century Cures Act was passed by Congress and signed into law. The Cures Act includes language that requires the DHHS to convene a new working group on Tick-borne Diseases that will include stakeholders from diverse federal and non-federal scientific and medical backgrounds.

However, if it were not for the leadership and tireless

efforts of Pat Smith, President of the Lyme Disease Association, that achievement would not have been won. Late in the process, the language pertaining to tick-borne disease had been pared down to nothing more than a suggestion that maybe a group should be formed.

Over the long Thanksgiving weekend, Pat and other national leaders conferenced to develop a strategy. It was Pat who pressed the appropriate Congressional offices to restore the original language, while the Lyme community stood poised to demand that it otherwise be removed.

It was only through the leadership and tireless efforts of Pat Smith that we were able to restore the language needed for creation of this federal advisory body to the Cures Act, in the wee hours before final passage of the legislation by Congress.

As a result, for the first time in the 40 year history of Lyme disease in the US, patients and advocates will have a seat at the table and a voice in the national decision-making process with regard to research and public health priorities.

#### About Focus On Lyme

Focus On Lyme was formed in 2015 to discover solutions in diagnostics, prevention, treatment and advocacy for Lyme disease sufferers. The best Lyme diagnostic tools that exist today are only 50 percent accurate and for those that are correctly diagnosed, there is not an accurate tool to evaluate the effectiveness of their treatment. Focus On Lyme is striving to provide immediate diagnosis and treatment to Lyme patients worldwide delivering a higher quality of life and minimal long-term effects. Focus On Lyme is sponsored by Leadership Children's Foundation, a non-profit organization dedicated to helping children by donating money to causes that help preserve childhood and improve the quality of life for young people across the nation. For more information, visit: [www.focusonlyme.org](http://www.focusonlyme.org).



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# Obama Signs 21st Century Cures Bill into Law

December 13, 2016, President Obama signed the 21st Century Cures Act into law. This law has provisions for many diseases, including creating a Working Group for tick-borne diseases. “This is a sweet victory for Lyme patients whose plight has been ignored for decades. They will have an opportunity to sit at the table in Washington, DC, and to provide their input into how significant government research needs to focus on understanding the mechanisms of persistent symptoms, on a test that actually provides accurate information as to whether Lyme is present, and on new treatment modalities. The discussion will take place with advocates, federal members, physicians and researchers also at the table, and will be held in public. Diversity of scientific disciplines and viewpoints are key in this legislation, signed into law as part of 21st Century Cures Act by President Obama,” said Pat Smith, President, Lyme Disease Association.



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## How to Find Lyme Text

The link below goes to the 21st Century Cures Act signed into law in December 2016.

The Section on Tick-Borne Diseases, Section 2062, is on page 47 of the pdf.

If you are in Windows, when you go into the link, hit “control f” to get search box and enter “2062” and hit NEXT two times which brings you to the language on tick-borne diseases.

<https://www.congress.gov/114/bills/hr34/BILLS-114hr34enr.pdf>

[Click here for Congressman Christopher Smith’s Press Release](#)

[Click here for Congressman Christopher Smith's Newsletter](#)

[Click here for Congressman Christopher Smith's video](#)

[Click here for Congressman Chris Gibson's Press Release](#)

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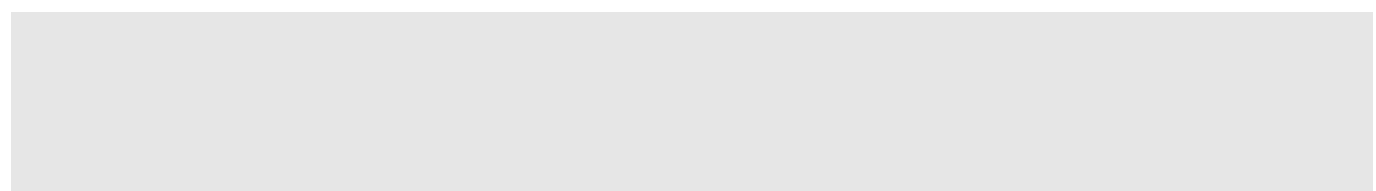
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**Ground Breaking News: Bill  
Language Included to Help  
Lyme Patients!**





Lyme Disease Association, Inc., PO BOX 1438, Jackson, NJ 08527

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# CDC Reduces Numbers Suffering from Chronic Lyme

Investigative journalist Mary Beth Pfeiffer has broken a story in the Huffington Post that has significant impact on patients. For years, the Centers for Disease Control & Prevention (CDC) has been citing 10-20% of patients treated with antibiotics for Lyme will have lingering symptoms. Now, CDC has changed that stat on its website to say a “small percent” will have lingering symptoms that can last for more than 6 months of what is “properly called Post-Treatment Lyme Disease Syndrome,” not “chronic Lyme disease.”

In a website paragraph without even a citation to back it up, the CDC has reverted back to the dangerous dogma which has prevented patients with chronic Lyme from receiving treatment. Ms. Pfeiffer contacted CDC to ask about the change in language and was told it was based on a 2015 study (Weitzner 2015) which indicated a frequency of less than 5% for Post Treatment Lyme Disease Syndrome and on a reevaluation of the Marques study from which the 10-20% estimate was originally derived. [Click here for Huffington Post article](#)

No mention is made by CDC of the many studies which show the figure for chronic Lyme/PTLDS to be much higher, and the Dersch 2015 paper, which is an analysis of dozens of studies showing a resultant 28% with long-term symptoms. No reevaluation information from that Marquez study—a reevaluation they purported to have performed—seems to be provided anywhere, and no peer review on that reevaluation issue appears to have surfaced.

A double standard is in play, as the broad-brushed conclusions on the long-term treatment trials for patients, conclusions supported by both CDC and NIH— long term

treatment provided no benefit to Lyme patients—have been challenged in a number of peer review articles, which refute those broad brushed conclusions; yet to date, neither CDC nor NIH have changed/softened their position on that issue and continue to support that data on websites while ignoring science which refutes those conclusions.

This double standard has enabled the IDSA to continue to select and use the same biased science for the basis of their Lyme treatment guidelines which prevent patients from receiving antibiotic treatment when they remain symptomatic. Many advocates have written to CDC to make it aware of that injustice, but CDC's stance has not shifted (nor has NIH's).

They do NOT want patients to be treated for more than a few weeks for a severely mentally and physically debilitating disease. That has been a fact for most of my 32 years of involvement as an advocate. They never wanted to acknowledge the numbers, or the spread— none in the South and the Midwest they insisted— using selective science to support those stances. Now the increasing Lyme case numbers which CDC has finally had to acknowledge (300,000 cases annually) and the fact that the tick vectors for Lyme now occur in almost 50% of the counties in the US has presented them with a dilemma. More disease in more places means more chronic patients who are seeking treatment.

According to the CDC answer to Ms. Pfeiffer cited in the Post article on the change downward in numbers of PTLDS cases, “this is not a substantive change...The point of the paragraph is simply to make patients aware that PTLDS occurs.” The tens of thousands afflicted with chronic Lyme annually don't need to be told they have a syndrome, nor do they need to be marginalized more than they already have been for decades. They do not need continuing dogma that initiates more studies designed to repeatedly and unsuccessfully camouflage the truth about Lyme and its persistence, “science” that has sucked hundreds of millions of dollars from government coffers—funds that were allocated by our federal representatives to provide real help for sick people not to erase them from the public consciousness.

Patients need and deserve a substantive change, a solution using 21st century science, e.g., persisters, biofilms, other mechanisms the Lyme bacteria use to avoid complete eradication. An agency whose job is to provide disease control and prevention for the American public should be championing that solution rather than standing behind shoddy science destroying individuals and families across this

country and the world. Pat Smith, LDA President