

Senate Approves \$1 Million Investment To Combat Lyme Across New York State



FOR RELEASE: Immediate, Tuesday, June 19, 2018

<http://www.nysenate.gov> SENATE APPROVES \$1 MILLION INVESTMENT TO COMBAT LYME ACROSS NEW YORK STATE

Historic Levels of Funding Build Upon the Senate's Commitment to Increasing Public Awareness, Treatment, and Prevention of Lyme and Other Tick-Borne Illnesses. The New York State Senate today approved a resolution to provide a record \$1 million to help fight the scourge of Lyme and other tick-borne diseases (TBDs) throughout the state.

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The New York State Senate today approved a resolution to provide a record \$1 million to help fight the scourge of Lyme and other tick-borne diseases (TBDs) throughout the state. The new funding will help support a wide variety of local investments identified by the Senate's Task Force on Lyme and Tick-Borne Diseases to increase education, research,

prevention, and treatment options, and combat the [ongoing increase](#) in TBDs throughout New York.

The Senate Majority – and specifically the Task Force – led the charge in securing this historic level of funding in the 2018-19 state budget. Based on the Task Force’s recommendations, the final budget restores \$400,000 in Executive Budget cuts and includes \$600,000 in new funding for a total of \$1 million.

Senator Sue Serino, Chair of the Task Force on Lyme and Tick-Borne Diseases, said, “With the State Senate successfully securing an unprecedented \$1 million in this year’s budget to bolster awareness, prevention and research initiatives, we are sending a strong message to New Yorkers who have spent years grappling with the devastating impacts of Lyme and tick-borne diseases. This critical funding will play a direct role in helping us to combat the spread of Lyme and TBDs in the state, and with the Hudson Valley sitting at the epicenter of this epidemic, I am especially proud to have secured funding that will go directly to our local community. I thank Senator Kemp Hannon, Chair of the Senate’s Health Committee, who has partnered with me to continue building momentum on this important issue. Working together with partners at all levels, we can ensure that New York has an effective statewide action plan in place to empower patients and better protect residents against the scourge of Lyme and TBDs.”

Senator Kenneth P. LaValle (R-C-I, Port Jefferson) said, “I am pleased that the Senate was able to secure \$1 million for Lyme and Tick Borne Disease (TBD) funding. My colleagues and I fought hard to secure this funding, recognizing the importance of fighting the spread of Lyme and TBD’s throughout the state. My district is particularly hard hit, especially on the East End of Long Island. This money will allow for the continuation of the highly successful Tick Borne Disease Center at Southampton Hospital, a four poster program on Shelter Island directly targeting the spread of ticks from the deer

population, and the creation of a new state-of-the-art infectious disease lab at Stony Brook University.”

Senator Betty Little (R-C-I, Queensbury) said, “I represent a beautiful region of New York State and we want people outdoors, enjoying nature. But the fear of contracting Lyme Disease is increasingly a deterrent and that’s a shame. My experience is that the statistics of reported cases fall short of what is actually happening. A mere mention of Lyme disease among a group of people and you immediately hear horror stories of misdiagnosis and costly long-term treatments. The good news is we are making progress and the Senate task force is playing a major role. We’ve secured funding and spearheaded legislation. We have taken our direction from the public we serve, from those leading the effort to improve diagnosis and treatment and from the incredible insight of patients themselves. This additional funding will make an impact in the North Country and I am very grateful to have helped secure it as part of this year’s budget.”

Highlights of the resolution passed today include:

- **Cary Institute of Ecosystem Studies, Inc. – \$192,000 to research community-based prevention methods** by continuing and expanding “The Tick Project,” a five-year research project. The funding will help determine whether neighborhood-based prevention can reduce human cases of Lyme and other TBDs.
- **Stony Brook University – \$175,000 to open a state-of-the art infectious disease laboratory**, which will have an insectary dedicated solely for work on ticks. The laboratory will be open to Stony Brook scientists and others as a regional facility with unique research capabilities. The funds will be used to support activities in the laboratory and new research on TBDs.
- **Cornell University – \$130,000 to study the distribution of ticks and the diseases they carry in various parts of the state** through the Tick Outreach and Surveillance

Project for New York. Run through the New York State Integrated Pest Management (IPM) Program at Cornell University, the research will primarily focus on the spread of ticks by species within certain counties. Other areas of study include ways to reduce human exposure to TBDs, tick management workshops, and best practices in schools, camps, parks, and places where people gather outdoors.

- **New York State Association of County Health Officials (NYSACHO) – \$112,000 to increase public awareness throughout New York** through eight to 10 regional educational lectures. The informational seminars will focus on community awareness, best practices for TBD investigation, tick surveillance, and disease prevention to local parts of the state heavily impacted by the effects of Lyme and TBDs.

- **SUNY Adirondack – \$100,000 for laboratory research on lesser-known TBDs**, including infectious diseases known to be comorbid with Lyme disease, such as Babesia, Bartonella, Ehrlichia, Anaplasma, and Powassan virus. The work would help provide much needed information about the rates of these coinfections in people with Lyme disease in New York.

- **Southampton Hospital – \$75,000 to fund the Tick-Borne Disease Resource Center**, which helps doctors in multiple disciplines collaborate with researchers and community outreach experts to inform and treat individuals from across the region.

- **New York State Department of Health – \$60,000 to increase the number of tick collection sites in New York**, and the number of ticks tested for pathogens statewide. The funding will also be used to hire temporary staff to assist with sampling and testing, as well as targeting of educational messages in a more efficient manner.

- **SUNY College of Environmental Science and Forestry – \$50,000 to monitor seasonal variations of ticks in Western and Central New York** to help provide a better understanding of how disease transmission risks are changing. The study will also provide public information to better explain the risks of tick exposure.

- **Paul Smith's College – \$30,000 to study the emergence of TBDs in the North Country** by continuing and expanding academic studies that monitor ticks and TBDs.

- **Cornell Cooperative Extension – \$26,000 for a series of regional Lyme and TBD forums** to be hosted throughout the state. The forums will help provide the public with information on tick identification, tick bite prevention, Lyme disease and co-infection awareness, impact on pets and livestock, and health resources that are available for individuals who have been bitten by a tick.

- **New York State Department of Health – \$25,000 to continue database mining**, which would include various projects associated with Lyme carditis, as well as deaths associated with Lyme and other TBDs.

- **Town of Shelter Island – \$25,000 to help combat the spread of ticks on Shelter Island**, which is one of the worst hit areas of the public health crisis. The town has developed a four-poster program to stem the spread of ticks associated with the deer population. The town has built and installed four-poster stations, to remove ticks from deer across the Island, and this funding would maintain and expand the efforts of this critical initiative.

In addition to the \$1 million announced today, the Senate was instrumental earlier this year in passing a [package of bills](#) aimed at combating Lyme and TBDs, based on the recommendations of the Senate's Task Force on Lyme and Tick-Borne Diseases.

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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/>

https://www.nbcnewyork.com/on-air/as-seen-on/Urgent-Warning-Ahead-of-Tick-Season_New-York-481547201.html

<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/>

NYS Senator Seward Calls for Study of Link Between Lyme & Mental Health



r
James Seward The following excerpts are from New York State Senator James Seward's Press Release:

ALBANY, 03/29/18 – State Senator James L. Seward (R/C/I/Ref-Oneonta) joined this week with his senate colleagues to call on the state to investigate the impact Lyme and tick-borne diseases (TBD) may have on mental health. The senate unanimously passed legislation (S.7171) co-sponsored by Senator Seward that would require the state to study the link between infectious diseases, blood-borne pathogens and mental

illnesses. The bill is the first step in a process that could lead to a better understanding of the incredible impact these diseases can have on the overall health of New Yorkers.

In August of 2017, Senator Sue Serino, chairman of the Senate's Task Force on Lyme and TBDs (of which Senator Seward is a member) and Senator Kemp Hannon, chairman of the Senate Health Committee, held a comprehensive public hearing to look critically at the state's response to the Lyme and TBD epidemic. It was there that testimony was given by patients, public health experts and mental health professionals that indicated that psychiatric symptoms related to Lyme and TBDs could directly impact quality of life and long-term health of patients if not properly addressed. Patients described battles with mood disorders, anxiety, depression and other mental health related issues. However, witnesses also testified that because health care providers and advocates may not immediately connect mental health issues with the emergence of these diseases, too often these symptoms go unchecked or are ultimately attributed to other causes leading to ineffective treatment and stigmatization.

"The Senate Task Force on Lyme and Tick-Borne Diseases has performed groundbreaking work and helped focus the spotlight on tick-borne illnesses," said Senator Seward. "We know more today than ever before about these debilitating ailments and are making strides in prevention and treatment. Studying Lyme in relation to mental health is a logical step forward that can lead to improved diagnosis and treatment plans that can improve patient outcomes in the short- and long-term."

[Click here for the full press release](#)

[Click here to Download Bill Text and for more info](#)

Lyme Protection Amdt. May Hurt NY Docs

In Dec 2014, Governor Cuomo signed the Lyme disease doctor protection bill into law. When he signed, he indicated he only signed on the condition an amendment would be passed in the New Year (2015), and at that time, the amendment was not made public, but some groups were told it would be just a “technical” amendment. Due to the uncertain nature of that amendment and lack of process transparency, the LDA withheld its judgment on the New York bill with the upcoming amendment and how it might affect New York doctors treating long term. After examining the amendment, now released by NYS and yet to be passed, the LDA does NOT support its adoption.

(UPDATE NOTE: NY Voices of Lyme posted on Feb 11 the following: On February 10th, the chapter amendment to the NYS Doctor Protection/Patient Rights Law was passed in the NYS Assembly Health Committee. The NYS Assembly is on recess until February 25th, so the chapter amendment will not be brought to a floor in the NYS Assembly vote until after that date. On February 9th, the chapter amendment to the NYS Patient Rights/Doctor Protection Law passed on the floor of the NYS Senate.)

On balance, the proposed new language may be more harmful than helpful in protecting licensed health care practitioners from intrusive investigations lacking a meritorious basis and may facilitate rather than discourage investigations (no matter how they are labeled) launched to find something wrong. The question becomes, “Why pass something that, in the best case, would be unlikely to provide any significant benefit or relief, but may likely make things significantly worse?”

(See amendment text here <http://open.nysenate.gov/legislation/bill/S1693-2015>.)

[Click to here for LDA letter to Gov. Cuomo to sign 2014 bill](#)

History: Before the 2014 NYS law passage, the 2005 memo served as a finding that a treatment modality in itself was not misconduct and closed the case without identifying or investigating the licensee. Because one could argue the legal weight of the 2005 memo, some New York legislators, groups and individual residents wanted to codify it, which was done by the 2014 legislation. The 2005 memo provided that, so long as a treatment modality effectively treats human disease, [etc.], it is contrary to the policy and practice of the Office of Professional Medical Conduct

(OPMC) to identify, investigate or charge (emphasis added) a physician, PA, or specialist assistant based solely on that practitioner's recommendation or provision of such a treatment modality.

The bill signed into law in Dec. 2014, modified the language on the memo, but seemed to largely preserve the provisions and the intent of the memo. The language as cited above, "based solely on" and "a treatment modality that effectively treats human disease," provided the board for professional misconduct and the OPMC a great deal of flexibility and latitude to conduct investigations or initiate investigations.

Proposed Amendment: The newest amendment language agreed to by the NY Governor and legislature behind the scenes and now awaiting action, largely guts the 2005 memo and the Dec. 2014 bill signed into law of their practitioner protections. In our opinion, not only does the 2015 proposed amendment not strengthen health care practitioner protections, it makes it easier to go after licensed practitioners – requiring initiation of an investigation no matter the source or the basis of a complaint and mandating that the investigation include a review of clinical practices.

Sec. 230 of the existing Public Health Law (codified) paragraph 10.(a)(i) [\[Scroll to page 6 of Public Health Law here\]](#) says that the board and the OPMC may investigate on its own any suspected professional misconduct, and shall investigate each complaint received regardless of the source. Paragraph 10(a)(i) is being modified by the proposed amendment to add language: "By the conclusion of a preliminary review, including an internal clinical review (emphasis added), the Director shall determine if a report is based solely on the upon the recommendation or provision of a treatment modality by a licensee that is not universally accepted by the medical profession, including but not limited to varying modalities used in the treatment of Lyme disease or other TBD. Upon a determination that a report is based solely upon the provisions of a treatment modality that is not universally accepted, no further review shall be conducted and no charges shall be brought. Nothing in this section shall preclude the Director from making such a determination earlier in, or subsequent to, a preliminary review."

The new amendment provides that only after the conclusion of a "preliminary review, including an internal clinical review" will the Director make a determination on the merits of a complaint/report. Proponents of the new amendment language say that it is only a "preliminary investigation." However, a search for a definition of a

preliminary investigation in NYS law that would cover the Public Health Law has not been unearthed by LDA. The new language says that the preliminary investigation will (NOT MAY) include an “internal clinical review.” Not only will a practitioner be identified and an investigation launched, but every review shall include at least some type of “internal clinical review.” So how “preliminary” is that?

We could not find a definition of “internal clinical review” in Sec. 230 of the Public Health Law,” but paragraph 10.(a)(ii) [\[Scroll to page 7 of Public Health Law here\]](#) does say, “If the investigation of cases referred to an investigation committee involves issues of clinical practice, medical experts shall be consulted.” Since the “preliminary review” is mandated by new language to include issues of clinical practice, it may mean that medical experts are mandated to be brought into the investigation no matter the merits of the complaint/report, i.e., in all cases. LDA does not think that saying “internal” clinical review precludes the use of “medical experts.” In addition, to say that the Director may make a determination “earlier in, or subsequent to, a preliminary review” does not seem to provide meaningful relief, since the phrase “earlier in” has no meaning in that “preliminary review” has no definition or limits and “subsequent to” just means after the review has been conducted.

Other language added by the proposed amendment is problematic. New amendment language also modifies the underlying law by adding the language “for which the licensee is treating a patient” after “recommends or provides a treatment modality that effectively treats human disease, pain, injury, deformity or physical condition.” This opens wide the door to arguing that longer-term antibiotic treatment is not effective in treating Lyme, as opposed to the existing language specifying that the treatment modality (i.e., longer-term use of antibiotics) be effective at treating human disease. Also – in the same sentence, the new language “to a particular patient” is added after “provision of that modality.” Addition of the new language “to a particular patient” facilitates making arguments that a “pattern” of providing a treatment modality to patients is misconduct or possible misconduct requiring further investigation.

One also needs to question whether the signing into law of a bill in Dec. 2014 on the condition of amending it in the New Year was a tactic to generate a sense of complacency in those who wanted real doctor protection. If this language had been offered last year, it likely would have been soundly rejected, but as an agreed upon amendment to an already passed bill, who knows if it can even be stopped.

NY Governor Signs Lyme Bill

Governor Cuomo signed the Lyme doctor protection bill into law in NY. The legislature and Governor have agreed to some kind of amendment, however, and that amendment has not yet been made public. The action on the amendment (Dec 17, 2014: APPROVAL MEMO.27) is noted on the following website where the bill history and text are noted <http://open.nysenate.gov/legislation/bill/S7854-2013>. As soon as LDA knows the content of the memo and its significance, we will post it.



[Click here to read Poughkeepsie Journal Article – Cuomo Signs Bill Safeguarding Lyme Treatments](#)

[Click here to read Assemblymember Didi Barrett's Press Release](#)

[Click here for LDA's letter to Governor Cuomo](#)

Email Gov. Cuomo – Sign the Lyme Bill

The Lyme Disease Association, Inc., LDA, is pleased to announce that New York State [Lyme bill S7854 / A7558b](#) unanimously passed both houses in June and NEEDS Governor Andrew Cuomo's signature to become law.



This bill is crucial to the welfare of ALL Lyme patients, since some of the most well known Lyme literate medical doctors are in NYS. They have been continually under investigation by the state medical disciplinary board which could lead to revocation of their licenses. As you know, there are 2 "standards of care" and multiple published guidelines. This bill protects all NY patients' rights to choose scientifically based, cutting-edge treatments by protecting doctors from unfounded harassment. Bill S7854 "prohibits the investigation of any claim of medical professional misconduct based solely on treatment that is not universally accepted by the medical profession._

NY Voices of Lyme Effort: 10 Days – 10,000 Emails



Governor Cuomo is being lobbied by vested interests pressing him to veto the bill. The Governor has until the end of the year to sign the Lyme Bill. We need to flood his office with emails from his New York constituents demanding a change!

Go to www.Cuomo123.com

Add in Comment Box: Sign Lyme bill with no amendments along with 1 personal comment

([see flyer for suggestions](#))

One email per person / Non NYS Residents please distribute to NY'ers

Helpful Materials:

[Flyer](#)

[Sample email to send to friends & family](#)

[FAQ & Other Campaign Materials](#)

[Follow campaign on Facebook](#)

[Voter Voice email to Gov. Cuomo](#)

Follow Us on [Facebook](#) & [Twitter](#)

LDA Writes to Governor Cuomo

...Doctors' ability to treat should not be subject to the changing political climate which readily allows a policy memo to be followed or not, since policy does not have the full force of law behind it. The time is here to end the uncertainty for doctors and patients. Lyme is not going away. More people now need doctors to diagnose and treat them. Although estimates vary, literature shows 10-20% and more of patients fail an early course of treatment. Yet NYS has again initiated investigations of the group of doctors who treat chronic Lyme disease, leaving thousands of families struggling to get help, many out of work or out of school. Signing this bill will be the first



step to helping patients prevent chronic Lyme and helping those with it to be productive members of society. . .

[Click here for full letter](#)

NYS Legislators Call on Cuomo to Sign Bill

NYS Assemblymember Didi Barrett and US Senator Charles Schumer call on Governor Cuomo to Sign Lyme bill. Barrett's bill garnered unanimous support in both the Assembly and Senate. "The outpouring of support for this bill speaks to the urgency of the situation," stated Didi Barrett. "We are counting on Governor Cuomo to do the right thing and hear the voices of the people."

[Click here for press release](#)

[Click here for YouTube Video](#)

Also of Interest:

2014-06 [Combatting Lyme Disease](#), NYS Senate Press Release

2014-06 [Senate Majority Coalition Task Force On Lyme & Tick-Borne Diseases](#), NYS Senate

Make NYS Bill S07854 / A07558B Law

Thank you for for being a big part of getting the NYS bill passed. Now we urgently need your help one more time!

THIS FINAL PUSH IS NEEDED

MAKE NY STATE BILLS S07854 AND A07558B NYS LAW!

NEW YORK STATE RESIDENTS use the voter voice link below to contact Governor Cuomo to tell him to sign this into law, to ensure lyme disease patient rights to treatment

— NYS Residents use this link —

<https://www.votervoice.net/NYSCOALITION/Campaigns/36501/Respond>

— NON- NYS Residents use link below or call —

ALL INTERESTED READERS SHOULD CALL OR WRITE GOVERNOR CUOMO AND URGE HIM TO SIGN S7854-A7558B.

LDA letter to Governor Cuomo

The Honorable Andrew M. Cuomo

Governor of New York State

NYS State Capitol Building

Albany, NY 12224

(518) 474-8390

<http://www.governor.ny.gov/contact/GovernorContactForm.php>

PLEASE SHARE THIS WITH YOUR FRIENDS AND FAMILY ASKING THEM TO JOIN US

— After doing the above you may wish to read the following—

The Press Release and Report by the NYS Senate State Lyme Disease Task Force is astounding in its breath of important initiatives proposed for combating this scourge, including adopting “a resolution calling on the Centers for Disease Control to reevaluate its guidance on Lyme and other tick-borne diseases and for the National Institutes of Health, the Department of Defense, and other federal agencies to provide more funding for these diseases.”

New Task Force Report & Recommendations to Address Lyme and Tick-Borne Diseases

Posted by Majority Press on Wednesday, June 18th, 2014

<http://www.nysenate.gov/press-release/new-task-force-report-recommendations-address-lyme-and-tick-borne-diseases>

Report from the Senate Majority Coalition Task Force On Lyme and Tick-Borne Diseases

http://www.nysenate.gov/files/pdfs/2014_LYME_task_force_report_0.pdf

#183359285 / gettyimages.com

NY Senate/Assembly Pass Doc Protection

In an end of the session surprise move, the New York Senate passed on June 18 a doctor protection bill, S7854, introduced by Senator Kemp Hannon, a recent supporter of the passage of doctor protection legislation in New York. The Senate version of the bill was not the same as the one which recently passed the Assembly, so the Assembly had to vote on the new Senate version, which it passed on June 19. The NYS Coalition on Lyme and Tick-borne Diseases, a coalition consisting of NYS Lyme groups, is primarily responsible for the current efforts to get doctor protection passed in NYS. The doctor protection bill has been sent to the Governor of New York who will most likely sign it into law.

See link to the bill text and language which memorializes the OPMC memo on

protection which has been in place in NYS.

<http://open.nysenate.gov/legislation/bill/S7854-2013>

The Office of Professional Medical Conduct (OPMC) memo that has been in place since 2005, was put into place after extensive meetings in Albany in an effort led by the LDA, the Hudson Valley LDA, and NY Lyme partnering with then Assemblymen Joel Miller, Adam Bradley and Nettie Meyersohn to obtain doctor protection legislation. At that time, the governor and legislature did not want to pass the protection legislation which we felt was needed, so the compromise was a memo that was sent to the OPMC staff reminding them that there were already principals in place protecting physicians who provide non-conventional treatment and specifically mentioning Lyme disease.

The NY Task Force on Lyme also released its recommendations.

<http://www.nysenate.gov/press-release/new-task-force-report-recommendations-address-lyme-and-tick-borne-diseases>

NYS Assembly Passes Lyme Legislation

Cheers to Assemblymember Didi Barrett, this is fabulous news. It passed in the NYS Assembly 133 to 0 (7 absent)! Next is the Senate, We will need your help with this; TOGETHER WE ARE POWERFUL!

Jill Auerbach

Hudson Valley Lyme Disease Association, Chairperson

New Yorkers, contact your [NYS senator](#) (automatic letter writing campaign coming soon)

Legislation to Improve the Care of Lyme Disease Patients Passes Assembly

May 13, 2014

Assemblymember Didi Barrett (D-Hudson) announced that legislation she authored that authorizes physicians to prescribe long-term antibiotic therapy to a patient with symptoms of chronic Lyme disease has passed the Assembly (A.7558-A). The legislation garnered bipartisan support and unanimously passed the chamber.



“The number of cases of Lyme and other tick borne disease has reached crisis proportions, and yet the treatment remains mired in misconception,” said Assemblymember Barrett. “Patients deserve the best course of care possible, and my bill allows doctors to prescribe vital, long-term antibiotics to their patients if they see fit without any fear of disciplinary action.”

The Hudson Valley has become the epicenter of the Lyme disease epidemic in the Northeastern United States. Patients with Lyme disease should have the same rights as those with other diseases. They must have the right to be seen and treated by the practitioner of their choice, have the right to be informed that there are differing professional judgments about the appropriate care for Lyme disease, and to participate in the choice of treatment as it pertains to their circumstance and preference. The rights of the patient hinge upon the availability of the practitioner to act in the best interest of the patient without fear of reprisal from the professional discipline system when more than one set of guidelines exists.

“Physicians should not face disciplinary actions for treating patients who show symptoms of Lyme disease but test negative,” said Assembly Health Committee Chair Richard N. Gottfried. “Lyme is an extremely complex illness to test for, and symptoms vary among patients. While it is important for

healthcare providers to follow rigorously-developed evidence, it is also important to recognize that innovation and disagreement are essential to the progress of medicine.”

“Serious tick-borne illnesses continue to increase and spread in New York State with no end in sight,” said Jill Auerbach, Chairwoman of the Hudson Valley Lyme Disease Association. “We applaud Assemblywoman Barrett for daring to tackle this serious medical situation for both patient and physician.”

In addition to passing legislation, Assemblymember Barrett recently authored and passed a resolution proclaiming May 2014 as Lyme Disease Awareness Month. Lyme Disease Awareness Month provides an opportunity to focus on these complex illnesses, to provide information on and raise public awareness of its causes, effects, and treatments, and to underscore important education and research efforts surrounding Lyme and tick-borne diseases.

NY Doctor Protection

Memorandum

The following memorandum was issued June 15, 2005 by OPMC Director Dennis Graziano to every staff member of the Office of Professional Medical Conduct (OPMC) and copied to all the members of the Board for Professional Medical Conduct and its chief counsel:

Victory in New York!

Dear Friends,

The following memorandum was issued June 15, 2005 by OPMC Director Dennis Graziano to every staff member of the Office of Professional Medical Conduct (OPMC) and

copied to all the members of the Board for Professional Medical Conduct and its chief counsel:

“Subject: Investigation of Practitioners Utilizing Treatment Modalities That Are Not Universally Accepted by the Medical Profession.

“This memorandum is intended to memorialize and endorse the principles that are currently in place in the Office of Professional Medical Conduct regarding the investigation of physicians, physician assistants and specialist assistants who use treatment modalities that are not universally accepted by the medical profession, such as the varying modalities used in the treatment of Lyme disease and other tick-borne diseases.

“As you know, Article 131 of the Education Law defines the practice of medicine. Paragraph (e) of subdivision four of §6527 of the Education Law provides that Article 131 ‘shall not be construed to affect or prevent...[a] physician’s use of whatever medical care, conventional or non-conventional, which effectively treats human disease, pain, injury, deformity or physical condition.’ Under current law, therefore, it is clear that so long as a treatment modality effectively treats human disease, pain, injury, deformity or physical condition, the recommendation or provision of that modality does not, by itself, constitute professional misconduct. Consequently, it is contrary to the policy and practice of the Office of Professional Medical Conduct to identify, investigate or charge a physician, physician’s assistant or specialist assistant based solely on that practitioner’s recommendation or provision of such treatment modality.

“Please note that this prohibition does not exonerate such practitioners from otherwise applicable professional requirements.”

According to New York doctor Joseph Burrascano, “This memorandum means that the pressure is now off of Lyme-treating physicians in New York, and it is certainly a reward for all the hard work and efforts of the Lyme community.” ([click here for printable pdf of memorandum](#))

The Lyme Disease Association and Voices of Lyme/NY Lyme are pleased to announce that the New York State OPMC has issued this memorandum on investigating doctors who are treating Lyme disease and other tick-borne diseases. The extensive public grass roots work of the Lyme community enabled a number of private meetings to be held in

Albany, culminating with a January 2005 meeting with the Governor's counsel. This meeting set in motion the issuing of the memorandum.

We are grateful to New York Assembly members Adam Bradley, Nettie Mayersohn, and Joel Miller for their constant support of the Lyme community including their initiation of and attendance at this January 2005 meeting with the Governor's office, the Lyme Disease Association and Dr. Brian Fallon, Columbia University College of Physicians & Surgeons.

We thank Governor Pataki who responded to the thousands of communications he received from Lyme patients seeking protection for their medical care. He was instrumental in the work leading to the issuance of this memo.

Most importantly, we thank the Lyme community for its continued dedication to addressing the conditions in NY which had threatened the medical care of Lyme disease patients. Without your continued grass roots efforts over the past four years through phone calls, faxes, emails, letters, and testimonies, this memorandum would not have been issued.

We also thank our physicians who have freely provided their time and expertise in this process, particularly ILADS and Dr. Brian Fallon. Jill Auerbach deserves special recognition for her role in the meeting process.

Thanks to Monica Miller of FAIM, who, working independently, consistently provided invaluable direction to the Lyme disease effort. Also thanks to Richard Gottfried, Chair, Assembly Health Committee, who called the Assembly hearings on Lyme disease and has been fighting very hard along with us for the OPMC reform bill.

YOUR CONTINUED EFFORTS AND SUPPORT CAUSED THIS TO HAPPEN!

THANK YOU ALL!

Pat Smith President

LDA

Ellen Lubarsky Voices of Lyme/NY Lyme