

# Senate Majority Coalition Task Force

On

## Lyme and Tick-Borne Diseases



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# Executive Summary

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The Senate Majority Coalition Task Force on Lyme and Tick-Borne Diseases was convened on October 8, 2013, to address rising concerns in New York State regarding the outbreak and spread of Lyme and Tick-Borne diseases. The Task Force was charged with examining state and federal efforts to combat the continued spread of these diseases and make recommendations for submission to the New York State Department of Health for a State Action Plan to facilitate improved prevention, diagnosis, and treatment protocols in order to better protect New York residents.

While Lyme and Tick-Borne diseases have had a significant history in New York to date, recent events have raised the level of alarm regarding the broader consequences that these diseases may have - in significant contrast to information that was previously reported. According to new analyses of State Health Department records, over the past thirteen years, Lyme disease was listed as the cause of death for nine New Yorkers, outside of New York City. Five of the victims lived in the mid-Hudson Valley. Given the tragic consequences of Lyme and Tick-Borne diseases, the Senator Majority Coalition Task Force recognizes this epidemic as a pressing public health crisis, and has initiated steps to create a comprehensive statewide response.

Lyme disease is a bacterial infection spread through the bite of infected ticks. The blacklegged deer tick (*ixodes scapularis*) is primarily responsible for the spread of the disease in the northeastern, mid-Atlantic, and north-central United States. If left untreated, the disease can cause a number of health problems, including a serious infection that can spread to the joints, heart and nervous system. Treatment efficacy and the likelihood of long-term health effects largely depend on timely diagnosis and treatment plans. According to the Department of Health, since Lyme disease first became reportable in 1986, over 95,000 cases have been confirmed in New York State and the number is still growing.

In fact, as of the week ending June 7, 2014, there have been 462 provisional cases of Lyme disease in New York State for the year 2014. Carriers of the disease can be found in our homes, schools, and workplaces – and even carried by the family pet. Our State parks report high incidences of infected tick populations. For example, 40% of the ticks collected in western New York's Gargoyles Park (Olean, New York) tested positive for Lyme disease in 2013. Additionally, half of all ticks collected in central New York's Newtown Battlefield State Park (Chemung County, New York) tested positive for Lyme disease in 2012. These high percentages evidence the spread of Lyme disease from its initial outbreak location in Long Island the Hudson Valley to all corners of New York State.

The geographic spread of Lyme and Tick-Borne diseases demand a comprehensive response by the State to encourage detection and prevention initiatives, and facilitate diagnostic and treatment advancements. While the impact of Lyme disease is widespread, a large number of the cases remain unreported. This lack of reporting is a cause of concern given that Lyme disease remains the most prevalent Tick-Borne disease in New York State. As such, the Task Force recommendations include various initiatives to help assist the Department of Health increase reporting and data collection in the State.

***One Simple Fact: According to the Centers for Disease Control, as of 2012, there were estimated to be nearly 300,000 new cases of Lyme disease each year, however only 30,000 of these cases were actually reported.***

While Lyme disease remains an area of great concern given the substantial growth in cases, other Tick-Borne diseases continue to emerge and threaten the health and well-being of the public at large. The Department of Health currently investigates several Tick-Borne diseases, including babesiosis, ehrlichiosis (both human granulocytic anaplasmosis and human monocytic ehrlichiosis) and Rocky Mountain spotted fever. Recently, babesiosis and anaplasmosis cases have increased in prevalence. Those infected by babesiosis experience flu-like symptoms, with some individuals reporting serious compromise to vital organs, and even death. Individuals with anaplasmosis have reported severe clinical presentations including difficulty breathing, hemorrhage, and renal failure. Notably, since 2004, fifteen cases of Powassan encephalitis, an arbovirus resulting from tick bites, have been reported. Five of the fifteen cases have proved fatal. Because New York is home to premier research institutions that are primed to help address these rising public health concerns, the Task Force has incorporated opportunities for the Department of Health to research these emerging Tick-Borne diseases at institutions throughout the State.

***One Simple Fact: This is a serious public health issue. Approximately one third of all cases of Powassan encephalitis result in death.***

The Senate Majority Coalition Task Force on Lyme and Tick-Borne Diseases has identified the aforementioned issues as a significant public health concern. Drawing on the immense research and prevention resources that New York State has, the Task Force recommends the following actions to form a Department of Health State Action Plan to reduce the incidence of infections and increase detection, diagnosis and treatment where cases do occur. New York should be a leader at the forefront of controlling and addressing this epidemic.

# Timeline

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Since the Majority Coalition Task Force on Lyme and Tick-Borne Diseases' inception, members have been activity engaged in stakeholder meetings highlighting the pertinent issues that our State is facing with respect to these diseases. These have included conversations and correspondences with researchers, health care professionals, advocates, patients and the general public. To date, the Task Force has accomplished the following:

October 2013: Senate Majority Coalition Task Force on Lyme and Tick-Borne Diseases was created to study and make recommendations for the development of a State Action Plan by the Department of Health to address Lyme disease and Tick-Borne illnesses in New York.

December 2013: Initial meeting of the Task Force members

January 2014: Meeting of the Task Force with scientific experts in the field to discuss the background on Lyme and Tick-Borne diseases and efforts to address the illnesses.

Presenters:

- Timothy Stellati, PhD, a researcher and faculty member of the Trudeau Institute in Saranac Lake;
- Byron Backenson, PhD an epidemiologist and research scientist with the New York State Department of Health.

February 27, 2014: New York State Senate Resolution was adopted declaring May 2014, Lyme Disease Awareness Month.

March 2014: Meeting of Task Force members with advocates for Lyme and Tick-Borne disease sufferers to gain insight into the difficulties Lyme disease patients are facing, and learn what more could be done.

Presenters:

- Holly Ahern, a SUNY Adirondack Associate Professor of Microbiology and co-founder of the Lyme Action Network.
- Jill Auerbach, who is part of various Lyme and Tick-Borne disease related organizations including the Hudson Valley Lyme Disease Association.

April 1, 2014: Senate secures funding in the SFY 2014-15 Executive Budget including:

- **\$500,000** for services and expenses in support of recommendations made by the Senate Majority Coalition Task Force on Lyme and Tick-Borne Diseases.
- **\$100,000** for the 21<sup>st</sup> Century Workgroup for Disease Elimination and Reduction within the Department of Health
  - Enabling language articulated in legislation sponsored by Senator Patty Ritchie (S. 2115 of 2014) which, as of the date of this report, is slated to be sent to the Governor for signature and enactment.

June 11, 2014: Meeting of the Task Force to discuss recommendations to be presented to the Department of Health for incorporation in a State Action Plan on Lyme and Tick-Borne diseases.

June 2014: New York State Senate takes legislative steps to begin addressing the on-going needs of those suffering from Lyme and Tick-Borne diseases.

- New York State Senate resolution was adopted calling on the federal government to address Lyme and Tick-Borne diseases with provisions including: (a) a call on the Centers for Disease Control to reevaluate its guidance on Lyme and other Tick-Borne diseases; and (b) a call on the National Institutes of Health, the Department of Defense, and other federal agencies to provide more funding for these diseases in light of the high number of cases found each year.
- The New York State Senate passed legislation sponsored by Senator Kemp Hannon (S. 7854 of 2014) that would ensure that the New York State Office of Professional Medical Conduct shall not identify, investigate, or charge a practitioner based solely on their recommendation or provision of a treatment modality that is currently not universally accepted by the medical community.

# Preliminary Task Force Actions

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Based on concerns expressed by relevant stakeholder groups and New York residents during discussions with the Senate Majority Coalition Task Force on Lyme and Tick-Borne Diseases, the Task Force has taken initial steps, within its purview, to help foster discussion and improvements in the area of public health related to Lyme and Tick-Borne Diseases.

***New York State Senate Resolution Calling on Federal Action Related to Lyme and Tick-Borne Diseases:*** Because funding and research in this area are largely within the jurisdiction of the federal government, the New York State Senate adopted a resolution calling on the federal government to address Lyme and Tick-Borne diseases with provisions including: (a) a call on the Centers for Disease Control to reevaluate its guidance on Lyme and other Tick-Borne diseases; and (b) a call on the National Institutes of Health, Department of Defense, and other federal agencies to provide more funding for these diseases in light of the high number of cases found each year.

***Public Information Campaign:*** In order to encourage increased public awareness and education, particularly during peak seasons in New York State, the New York State Senate will distribute brochures and wallet cards related to identification tools and resources available to those who suspect they may have been infected with Lyme or Tick-Borne disease.

***Codification of Department of Health Protocols Related to Medical Treatment Modalities, Including those for Lyme and Tick-Borne Diseases:*** The New York State Senate passed legislation sponsored by Senator Kemp Hannon (S. 7854 of 2014) that would ensure that the New York State Office of Professional Medical Conduct shall not identify, investigate, or charge a practitioner based solely on their recommendation or provision of a treatment modality that is currently not universally accepted by the medical community.

# Task Force Recommendations to the Department of Health for a State Action Plan on Lyme and Tick-Borne Diseases

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## RESEARCH

***Statewide Conference with the Lyme Disease Research Community:*** The Senate Majority Coalition Task Force on Lyme and Tick Borne Diseases will host a statewide conference to bring together the numerous universities and institutes across the State working on these issues. The conference will focus on building collaboration between the research community and the New York State Department of Health for the purpose of promoting data sharing and collaboration, and increasing access to federal National Institutes of Health grants.

The conference should include but is not be limited to:

American Museum of Natural History  
Binghamton University  
Cary Institute for Ecosystem Studies  
Colgate University  
Columbia University  
Cornell University, College of Veterinary Medicine  
City University of New York/ Hunter College  
Fordham University  
Jamestown Community College  
New York City Department of Health and Mental Hygiene  
New York Medical College  
New York State Museum  
Paul Smith's College  
Suffolk County Department of Health  
SUNY Adirondack  
SUNY Oswego  
SUNY Plattsburgh  
Trudeau Institute  
Union College  
University at Albany  
University at Stony Brook  
Upstate Medical University

***Data Mining:*** The Department of Health currently has access to electronic records related to Lyme and Tick-Borne diseases dating back to 1994, and paper records back to 1986. This initiative will conduct data mining activities on co-infections, retrospective studies, and health care symptoms including myocarditis. This data mining will assist researchers to better understand the impact Lyme and Tick-Borne diseases have on patients over time.

***Adirondack Medical Center:*** This initiative will form a partnership with the Trudeau Institute, Paul Smith's College and Middlebury College to pursue a joint field initiative in Lyme and Tick-

Borne disease research. The study will have research scientists and students explore host-parasite relations, including the ecology of deer, rodent and tick populations.

***Increasing the Number of Tick Collection Sites:*** Increasing the collection of ticks across the State would assist the Department of Health in formulating a comprehensive evaluation of tick populations and infectivity. This, in turn, would allow them to more appropriately assess at-risk populations, and target educational messaging.

***21st Century Work Group for Disease Elimination and Reduction:*** The Senate and Assembly passed legislation (S. 2115 Ritchie/A. 829 Magnarelli) and allocated \$100,000 for the 21<sup>st</sup> Century Work Group for disease elimination and reduction in the SFY 2014-2015 Executive Budget. This bill specifically requires a study of the severity, frequency of occurrence, likelihood of recurrence, existing animal vaccines and potential human vaccines for various diseases including Lyme disease.

***Perform a Serosurvey for Powassan Encephalitis Infection:*** The Task Force recommends that the Department of Health perform a serosurvey (a test of blood serum to determine susceptibility to a particular disease) of Powassan Encephalitis infections of humans. While there have been few cases, the infectivity rate in ticks, birds and small mammals is high. This information would assist the Department of Health in determining if there are unknown infections and their rate of occurrence.

***Study of Deaths Where Lyme Disease is a Contributing Factor:*** Recent information has emerged from deaths in the Northeast, that while the primary cause of death may not be Lyme or Tick-Borne disease, it has been a significant contributing factor. The Task Force recommends that the Department of Health study deaths, particularly those involving cardiac arrest, where the patient was also infected with Lyme or Tick-Borne disease.

## EDUCATION

***County Learning Collaborative:*** Since Lyme and Tick-Borne diseases were first discovered in New York, they have traditionally been isolated to certain regions of the State. However, over recent years, the number of Lyme and Tick-Borne disease cases has spread north and west. The Task Force recommends this collaborative initiative in order to bring together counties that have been the epicenter of Lyme and Tick-Borne diseases, with those counties experiencing recent outbreaks in order to encourage the sharing of “best practices” for educational programs and models, as well as data collection. The map provided in the appendix of this report shows the frequency of Lyme disease in New York State, which notably includes a 100% or more increase in case frequency in at least fifteen upstate counties.

***State-Wide Educational Campaign:*** A comprehensive Lyme and Tick-Borne disease educational campaign has not occurred since 2005. It is vital that new educational programming is initiated as personal protective measures are vital to controlling the spread of Tick-Borne diseases. As a result, the Task Force recommends a state-wide educational campaign to educate citizens on best practices to avoid tick exposure. New signs have already been created and placed in State Parks this season to provide information to individuals about Tick-Borne illnesses and how they can be prevented. An educational campaign should also specifically target pet

owners regarding the dangers of ticks attaching to pets and the tick-borne illnesses pets can contract.

***Continuing Medical Education:*** There have been new scientific developments regarding Lyme and other Tick-Borne pathogens since these illnesses were first discovered. The Task Force recommends this initiative to provide physicians and other medical professionals with continuing medical education on Lyme disease and other Tick-borne pathogens in order to best serve their patients and community.

***Veterinary Education:*** The Task Force also recommends that curriculum be developed and provided to veterinarians across the State regarding the methods of transport, and impacts of Lyme and Tick-Borne illnesses in pets and animals. This initiative will help provide the public with available resources to not only protect their pets and animals from infection, but to also institute preventative measures to prohibit the carriers.

## PREVENTIVE MEASURES

***“4 Poster” Devices:*** The ‘4 Poster’ device is an innovative measure designed to kill species of ticks that feed on white-tailed deer. Notably, studies of the four-poster system, including one by Cornell University, have shown a remarkable reduction in the tick population. The devices consist of a central bin containing clean kernel corn used as bait and two sets of applicators that transmit permethrin, the tick killing agent, without harm to the deer. The Task Force recommends that these devices be maintained where they are currently used, and that the Department of Health in consultation with the Department of Environmental Conservation look to expand the use of these feeders to other areas of the State.

***Evaluation of control measures:*** Individuals often use pesticides around their homes to prevent ticks. Given that these measures are often not evaluated for effectiveness, and new measures to control tick populations have come to light, including organic fertilizers, evaluations would be a significant asset in determining whether or not pesticides or other substances are effective. This information can help determine which methods are preferable at reducing the number of ticks or the number of tick-borne illnesses cases for New Yorkers’ homes.

***Evaluation of Oral Bait Vaccine:*** Oral Bait Vaccines are used by distributing vaccinated pellets in areas with a high concentration of ticks. Animals, such as mice that are known to host tick-borne diseases, come into contact with the pellets and become vaccinated against certain diseases. Studies suggest that oral vaccines are as effective as injectable vaccines as well. Therefore, the Task Force recommends that this vaccination method be studied by the Department of Health to determine its effectiveness and subsequent use.

## DIAGNOSIS AND TREATMENT

***Creation of a Lyme and Tick-borne Disease Advisory Board:*** The Task Force recommends the creation of an advisory board to capitalize on the knowledge of experts in the field. The Advisory Board should make recommendations regarding issues facing Lyme disease and other

Tick-Borne illnesses, including the development of diagnostic tools, appropriate treatment guidelines including the effects of long term antibiotic treatment, the development of a curriculum for continuing medical education for physicians on diagnosis and treatment, and the development of uniform notices to patients.

***Insurance Coverage:*** The Task Force recommends that the Department of Financial Services, in collaboration with the Department of Health, review insurance coverage of Lyme and Tick-Borne disease treatment in New York, and make recommendations regarding any coverage limitations that may be found.

***Clinical Trials of Treatment Modalities:*** New York State is home to many premier health care and research institutions capable of conducting clinical trials designed to evaluate various treatments for Lyme and Tick-Borne disease that manifests as a chronic illness. The Task Force recommends that the State facilitate clinical trials in order to provide additional evidence-based treatment options.

***Medical Misconduct:*** The Task Force recommends that the Department of Health, through its Office of Professional Medical Conduct, ensure that 2005 guidance issued by the Office is being complied with. The guidance, in pertinent part, states that the Office shall not identify, investigate, or charge a practitioner based solely on their recommendation or provision of a treatment modality that is currently not universally accepted by the medical community. This includes treatment modalities for Lyme and other Tick-Borne diseases.

***Diagnostic Testing:*** The Task Force recommends that the Department of Health re-evaluate the tests and facilities it authorizes for Lyme and other Tick-Borne diseases in order to help facilitate earlier diagnoses, and better outcomes, across the State.

# CONCLUSION

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The Senate Majority Coalition Task Force on Lyme and Tick-Borne Diseases calls upon the Department of Health to issue, and implement, a State Action Plan incorporating the recommendations herein. Upon completion of the State Action Plan, the Task Force requests that the Department of Health share the plan with the members of the Task Force, the Legislature, and the public at large to enable future collaboration, input, review, and discussion.

# APPENDIX

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