



NEW YORK STATE SENATOR

Kathleen A. Marchione

## A Special Message from Senator Kathy Marchione: Important News in the Fight Against Lyme and Tick-Borne Diseases

KATHLEEN A. MARCHIONE November 3, 2017

| ISSUE: **LYME AND TICK-BORNE DISEASES, LYME DISEASE, LYME DISEASE TASK FORCE**



Our Senate Task Force on Lyme and Tick-Borne Diseases, which I serve on, has released a comprehensive report aimed at combatting the spread of Tick-Borne Diseases (TBDs) in the state. Based on the findings presented at a public hearing convened by our Task Force, the report highlights the immediate need for a statewide action plan, as well as a legislative commitment to empowering patients and funding critically necessary research to reduce the tick population.

The August public hearing convened experts in the field, medical professionals, insurance industry representatives, patients, and advocates to develop effective solutions to empower patients and prevent New Yorkers from contracting the diseases. As tick-borne disease rates increase across the state, it is clear that New York is facing a direct threat that requires a significant investment to improve identification techniques, reporting and treatment options.

Testimony provided by patients at the hearing painted a grave picture of life with a tick-borne illness. Patients described agonizing pain, dangerous loss of memory and motor skills, financial ruin as a result of a severe lack of effective treatment options, and more. A common theme that ran throughout patient testimony was the rampant inaccuracies plaguing the test currently used to detect TBDs, with some suffering with symptoms for years before an accurate diagnosis and treatment.

It is commonly accepted that Lyme disease can be effectively treated with antibiotics if detected early. However, as was discussed by many hearing witnesses, the test used to detect Lyme disease is simply not reliable. Too often patients are led to believe that they are in the clear after receiving a 'negative' serology test for Lyme disease, which ultimately delays critical treatment resulting in worsening—sometimes irreversible—symptoms.

New legislation, Senate Bill S.6926, which I co-sponsor, would arm patients with the information they need to more effectively advocate for themselves and receive swift, effective treatment. Additionally, our Senate Task Force recommends the following action steps:

- Creation of a Statewide Action Plan and Dedication of Significant Funding in preparation for the 2019 Executive Budget Cycle;
- Reinstating the NYS Health Care Quality Cost Containment Commission to accurately assess the cost of insurance and consider coverage for long-term treatment of symptoms;
- Promote testing in children who present with TBD related symptoms to ensure swift treatment and avoid the long-term consequences of misdiagnosis;
- More effectively utilize proven information systems, information technology and social media to increase awareness about the dangers of Lyme and TBDs; and
- Actively pursue outside funding to invigorate critical research.

Our report is posted here so you can see the recommendations, as well as read and download the comprehensive report in full. Thank you.

Kathy Marchione

State Senator, 43rd District