NEW YORK STATE SENATOR

Fred Akshar

12.10.19 - Senator Fred Akshar and Assemblywoman Donna Lupardo Announce “Demos Ford Act” to Help Families Dealing with Lyme Disease

FRED AKSHAR December 10, 2019

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

(BINGHAMTON, N.Y.) Senator Fred Akshar and Assemblywoman Donna Lupardo announced new bi-partisan legislation to help families dealing with Lyme disease receive more definitive diagnosis from their health care providers.

“The Demos Ford Act,” is named for a 10-year-old community member dealing with long-term Lyme disease who met with Akshar inspired him to introduce the bill and seek Assemblywoman Lupardo as a cosponsor.

Their proposal (S.6657/A.8640) directs the Commissioner of the New York State Department of Health (DOH) to work with health care providers and experts to establish specific protocols to help guide providers in properly diagnosing and treating Lyme and tick-born diseases (TBDs) and require them to provide patients with a notification form to better educate them about their test results.

> *“Lyme disease presents so many obstacles for families on both the physical and personal level, and Demos Ford’s story is a story shared by far too many families across our community, our state and our country,” said Senator Fred Akshar. “There are already bills in the legislature that would mandate insurance coverage for long-term Lyme and other tick-borne illnesses so we approached the problem from another angle. We’re doing what we can to help empower families like Demos’ and help them get the diagnosis and treatment they need in a more streamlined, less confusing process.”*

“Lyme disease has affected more people in New York than almost every other state in the nation and the number of new diagnoses continues to grow,” said Assemblywoman Donna Lupardo. “In order to reverse this trend, it’s important to have a universal approach to educate and guide both providers and patients. This bill will help those suffering with tick-borne illnesses, like Demos Ford, receive accurate diagnoses and get them the proper treatment more quickly.”

“Our family is honored to be included in the development of this important act,” said DLouisa Ford. “Our son Demos has faced so many serious Lyme-related issues that could have been avoided if it were detected earlier. We are thrilled that Senator Akshar and Assemblywoman Lupardo are working together to draw attention to this important issue and help educate doctors and patients on the realities of Lyme.”

Much of the language of the proposal stems from the 2017 report issued by the NYS Senate Task Force on Lyme and Tick Borne Diseases. The Task Force traveled the state conducting hearings to listen to testimony from doctors, health experts, Lyme disease patients and their families on the issue.

It is commonly accepted that Lyme disease can be effectively treated with antibiotics if detected early. However, as was discussed by many of the witnesses at the hearings , 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. The Demos Ford Act would arm patients with the information they need to more effectively advocate for themselves and receive swift, effective treatment.

As part of the protocol outlined in the bill, the commissioner would be required ensure providers distribute a standardized notification form to each person under their care being tested for Lyme disease or other TBDs.

This form would explain, in plain language:

- the symptoms and risk factors for Lyme disease

- the available methods for the detection and diagnosis of Lyme disease, including information on detection and diagnostic techniques and
- the medical protocol as established by the commissioner

The protocol is also required to be updated if there are any advancements in the testing and treatment of Lyme disease.

The Centers for Disease Control and Prevention estimates there are roughly 300,000 people diagnosed with Lyme disease each year in the United States. According the NYS Department of Health, Lyme disease cases in the Southern Tier region rose by 424% between 2012 and 2017.

RELATED LEGISLATION

2019-S6657

- Introduced
-
  - In Committee Assembly
  - In Committee Senate

- - On Floor Calendar Assembly
  - On Floor Calendar Senate
- - Passed Assembly
  - Passed Senate
- Delivered to Governor
- Signed By Governor
-

Directs the commissioner of health to establish protocols for the diagnosis and treatment of Lyme disease and other tick borne diseases

August 19, 2019

In Senate Committee Health

Sponsored by Fred Akshar

Do you support this bill?