



NYS LUPUS COMMUNITY ADVOCACY VICTORY

Legislation will bring essential lupus education and access to appropriate treatments

(Albany, NY, June 27, 2016) – The Lupus Agencies of New York State (LANYS) realized dual advocacy victories this legislative session in both the New York State Senate and Assembly with the unanimous passage of S.5216A / A.3072A the Lupus Education and Outreach Bill and S.3419C / A.2834D the legislation to limit Step Therapy protocols. The groups have been coming to the State Capital each May for the past 8 years to increase public awareness of Lupus and to garner support for education programs and critical access to care issues such as step therapy.

The Lupus Bill creates a statewide program within the Department of Health (DOH) to promote understanding of the causes and consequences of Lupus to both the public and health professionals. It provides for an education program with an emphasis on minority populations and at risk communities to raise public awareness and educate healthcare professionals, human services providers and other audiences. It also establishes an advisory council consisting of individuals with Lupus, advocates and clinicians most familiar with the disease to work with the DOH on the program. Creating a statewide education and outreach program will increase public understanding of the disease as well as educate and train healthcare professionals, resulting in improved quality of life for those affected.

"Americans know less about Lupus than almost every other disease," stated Senator Diane Savino. "Not only is there public misconception, but there is no identifiable cause or cure, and it can take years to diagnose. More than 1.5 million Americans suffer from this devastating condition, but the number of total cases may be much higher because symptoms vary, arrive in stages, and mirror other diseases. An Education and Outreach program created by the NYS DOH will help to put Lupus on the radar of patients, family members and healthcare providers, which will ultimately lessen the physical, emotional and economic impact for those affected. I commend Kathleen Arntsen and the other passionate lupus advocates for their tireless efforts in getting this bill passed and thank Assemblywoman Crystal Peoples-Stokes for sponsoring this important legislation with me and look forward to the Governor signing it into law."

Assemblywoman Peoples-Stokes said "Lupus affects more than 1.5 million people in the United States and can occur at any age and impact either sex and is three times more common in black women than in white women. It is also more common in women of Hispanic/Latina, Asian, and American Indian descent. A NYS DOH sponsored education and outreach program will significantly increase awareness about Lupus. I thank the Senate Sponsor, Senator Diane Savino, and all of the advocates, especially Kathleen Arntsen for helping to pass this very necessary legislation. Though there is much more work to do, this is definitely a step in the right direction."

The second bill passed is practical, pro-consumer legislation that includes basic patient protections to improve the safety and efficiency of step therapy protocols instead of prohibiting insurer use of them. It requires that the standards used by an insurer to establish such protocols cannot be driven exclusively by cost and are recognized evidence-based and peer reviewed clinical review criteria that takes into account the needs of atypical patient populations and diagnoses. The bill also requires a clear and expedient process allowing prescribers to request an override of a step therapy protocol. This legislation protects New Yorkers facing a severe or life-threatening illness by ensuring timely access to appropriate medications.

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Senator Catharine Young said, “It is heartbreaking when an individual comes to you and shares the pain they’ve suffered while waiting to get the treatment for a condition like Lupus. Forcing someone to delay receiving a prescribed care until their condition proves to be unresponsive to a lower-cost drug can have serious long-term consequences. It was a true team effort to get this measure passed, and I thank all the advocates for their support. Passing this legislation will make certain that doctors remain in control of their patients’ care and encourage patients to pursue the care prescribed to them.”

“This bill’s passage has been a long time coming. My colleagues in both the Assembly and the Senate clearly understand the importance of getting patients the medications they need – and this bill does just that,” said Assemblyman Matthew Titone. “With Governor Cuomo’s signature, doctors and patients will be assured that the medical needs of all are put ahead of the bottom line of insurance companies. I am incredibly proud to have had the honor of carrying this significant legislation that will positively affect the health of so many people. Thank you to the strong coalition of patients and advocates who over the years have educated all of us on this important issue.”

A step therapy or fail first protocol is used by an insurer to require a patient to try and fail on other, generally less expensive drug options before coverage is granted for the medication prescribed by the patient’s health care provider. Such protocols involve drug sequences determined by the insurer based on cost and expectations about potential treatment responses within a generalized patient population. These protocols are not based on a patient’s specific medical profile or the physician’s assessment of the best treatment option for the patient’s condition. As a result, step therapy protocols can lead to delays in access to medications that offer the greatest potential medical benefit, often leading to disease progression.

Dr. Max Hamburger, President of the New York State Rheumatology Society said, “As a rheumatologist it is difficult to diagnose and frustrating to treat an individual with a heterogeneous and unpredictable disease such as Lupus. Having a statewide education program that promotes public and health provider awareness will result in earlier diagnosis and treatment which are vital components in diminishing the physical impact of Lupus. I am also ecstatic that parameters have been placed on step therapy protocol that will allow me, as a physician who is educated and ethically bound to treat to the uniqueness of a patient, to do just that and prescribe the most appropriate therapies. Our hope is that it will alter the course of the prescribing of treatments for all atypical, complex patients in the state and we urge Governor Cuomo to support these bills and make them law to improve the health of New Yorkers.”

Kathleen A. Arntsen, spokesperson for LANYS stated, “We applaud and thank Senator Diane Savino and Assemblywoman Crystal Peoples-Stokes for sponsoring the Lupus Education Bill and Senator Catharine Young and Assemblyman Matthew Titone for sponsoring the Step Therapy Bill as well as the many legislative champions who helped to get them passed. We are excited that the legislature recognizes that for complex diseases of unmet need like Lupus, education and outreach programs will result in earlier medical intervention and more positive outcomes for those impacted. We are also thrilled that the step therapy bill has finally passed and are honored to have been part of such a wonderful example of advocacy in action through stakeholder collaboration. If this legislation can prevent another person like me from being harmed, then it is a triumph. We certainly hope that Governor Cuomo will sign both of these bills into law. Kudos to everyone who participated in these incredible efforts!”

About Lupus

Lupus is a chronic autoimmune disease that causes inflammation and tissue damage to virtually any organ system in the body and there is no known cause or cure. Lupus is a leading cause of kidney disease, stroke and premature cardiovascular disease in young women and is highly individualized, extremely volatile, debilitating, life-diminishing, and potentially fatal. Lupus is an unpredictable condition in which symptoms come and go (flares) and complications can arise suddenly, frustrating patients and the physicians who treat them. Lupus suffers from the lack of awareness more than any other major disease. Not only is the

public knowledge of lupus lacking, but even health professionals can be unaware of the symptoms and effects of lupus, resulting in delayed diagnosis and proper medical intervention and demonstrating the urgent need for increased public and professional education and access to the right treatments.

About the Lupus Agencies of New York State

The Lupus Agencies of New York State (LANYS) include the Lupus and Allied Diseases Association, Lupus Alliance of Long Island/Queens, Lupus Alliance of Upstate New York, Lupus Friends and Family Foundation, Lupus Foundation of America, S.L.E. Lupus Foundation, Alliance for Lupus Research, and Lupus Research Institute. LANYS is dedicated to improving the quality of life for individuals with lupus and their loved ones by providing education, support and outreach services, and promoting collaborative programs of awareness, advocacy, and research.

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