



NYS LUPUS COMMUNITY ADVOCACY VICTORY

Legislation will bring essential lupus education to the public and health professionals

(Albany, NY, November 29, 2016) – The Lupus Agencies of New York State (LANYS) realized a major advocacy victory with the signing into law of S.5216A the Lupus Education and Outreach Bill by Governor Andrew Cuomo. The bill was passed unanimously by both the New York State Senate and Assembly in June. The groups have visited the State Capital each May for the past 8 years to increase public awareness of Lupus and to garner support for education programs and the need for research program support to develop better diagnostic tests and safer, more effective treatments; and ultimately, discover the cure to eradicate this devastating disease.

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 the Governor for signing it into law and applaud Kathleen Arntsen and the many 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."

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 Governor Cuomo for supporting this important legislation and the Senate Sponsor, Senator Diane Savino, and all of the advocates for helping to pass this very necessary law. Though there is much more work to do, this is definitely a step in the right direction."

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. We thank Governor Cuomo for supporting this bill and making it law to improve the health of New Yorkers."

Kathleen A. Arntsen, spokesperson for LANYS stated, "We applaud and thank Governor Cuomo for signing it into law, Senator Diane Savino and Assemblywoman Crystal Peoples-Stokes for sponsoring the Lupus

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NYS LUPUS COMMUNITY ADVOCACY VICTORY (continued)

Education Bill as well as the many legislative champions who helped to get it 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. Kudos to everyone who participated in this effort!”

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 Lupus and Allied Diseases Association, Lupus Alliance of Long Island/Queens, Lupus Alliance of Upstate New York, Lupus Foundation of America, Lupus Research Alliance, and Lupus Friends and Family Foundation. 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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