

July 1, 2016

Honorable Andrew M. Cuomo
Governor
Executive Chamber
Albany, NY 12224

Dear Governor Cuomo:

On behalf of the Lupus and Allied Diseases Association and the many New Yorkers both directly and indirectly devastated by lupus, including myself, I passionately urge you to please support A.3072-A / S.5216-A the Lupus Education and Outreach Bill by making it law.

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. It 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 both patients and the physicians who treat them.

An estimated 322,000 to 1.5 million Americans suffer from Lupus, women are affected 9 times more often than men, with 80% of new cases developing between the ages of 15 and 44 during the prime of life. Lupus disproportionately affects women of color; it is 2 to 3 times more common among African-Americans, Hispanics, Asians, and Native Americans and minority women tend to develop Lupus at a younger age, experience more serious complications, and have higher mortality rates—up to three times the incidence and mortality of Caucasians.

Lupus suffers from the lack of awareness more than any other major disease. Not only is the public knowledge of Lupus lacking, but many 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. For example, my own diagnosis took over eight frustrating years even though I saw multiple healthcare providers during that time period. By then my disease had progressed to several organs and I was near death when finally diagnosed.

The Lupus Education and Outreach Bill creates a statewide program within the Department of Health in order to promote understanding of the causes and magnitude of Lupus to both the public and healthcare professionals. It provides for an education program with a highlighted focus on minority populations and at risk communities to raise public awareness and educate healthcare professionals, human services providers and other audiences.

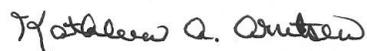
The legislation also provides for the establishment of an advisory council comprised of individuals with Lupus, advocates and healthcare professionals in the appropriate specialties for Lupus to work with the Department of Health on the program. Creating a statewide education and outreach program will increase public understanding of the disease as well as educate and train healthcare professionals, resulting in improved quality of life for those affected.

The Lupus and Allied Diseases Association is a passion-driven, all-volunteer, patient advocacy organization dedicated to improving quality of life for those impacted by Lupus and allied diseases and conditions of unmet need by promoting innovative advocacy, awareness and biomedical research program initiatives. We are committed to fostering collaboration among stakeholders in order to encourage patient-centered care and ensure public policy keeps pace with biomedical research innovation. We are a proud member of the Lupus Agencies of New York State (LANYS).

Having an education program throughout the state that promotes public and healthcare provider awareness will result in earlier diagnosis and treatment which are vital components in diminishing the physical impact of Lupus. We appreciate that the legislature recognized that for complex diseases of unmet need like Lupus, a New York State Education and Outreach Program will result in earlier medical intervention and more positive outcomes for those impacted.

For the above reasons we ask you to please support A.3072-A / S.5216-A by signing it into law and thank you for your ongoing support of initiatives that improve health outcomes for New Yorkers, especially women.

Sincerely-



Kathleen A. Arntsen
President/CEO

Cc: Alphonso David, Counsel
Axel Bernabe, Assistant Counsel