

Lupus Agencies of New York State

MEMORANDUM OF SUPPORT

A02169 (Peoples-Stokes) / S04268 (Savino)

A02788 (Peoples-Stokes) / S05489 (Parker)

S01703 (Parker)

April 25, 2017

The Lupus Agencies of New York State strongly support legislation to amend the public health law, the tax law, state finance law, and vehicle and traffic law, in relation to creating the lupus research enhancement program and fund, providing for taxpayer gifts in order to establish the lupus education and prevention fund, and creating a lupus license plate to increase statewide awareness and educate the public about Systemic Lupus Erythematosus (lupus).

A02169 / S04268 promotes basic and clinical research programs designed to reduce or prevent suffering from Lupus, by providing funding, if available, to state academic medical institutions within the state currently conducting or having an interest in conducting basic and clinical, social, translational, technological, epidemiological, and behavioral research. The Commissioner of Health shall establish a multidisciplinary Lupus research advisory council to monitor progress and make granting recommendations to the department. The council shall be comprised of fifteen (15) members representing a broad range of expertise and experience on Lupus.

A02788 / S05489 establishes the lupus education and prevention fund which will be financed by optional contributions derived from a taxpayer check-off placed on all corporate and personal income tax forms in order to create the lupus health care and wellness education and outreach program within the Department of Health.

S01703 relates to authorizing the creation of a lupus awareness license plate in relation to establishing the lupus research and education fund.

Lupus is a chronic inflammatory autoimmune disease in which a triggering agent causes the immune system to attack the patient's own tissue affecting virtually any organ system of the body; including the skin, joints, kidney, brain, heart, lungs, blood and blood vessels. It is more common than AIDS, sickle-cell anemia, cerebral palsy, multiple sclerosis, and cystic fibrosis 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 unpredictable, highly individualized, debilitating and potentially fatal. 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. According to The Centers for Disease Control and Prevention, there is a 70 percent increase in lupus-related deaths in black women despite the overall decrease in the mortality rates associated with lupus.

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 are 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 awareness of the symptoms and consequences of Lupus. Early diagnosis and treatment are vital components in reducing the physical and economic impact of the disease. Creating a statewide education and outreach program with an emphasis on minority and at-risk populations that increases overall community awareness and focuses attention on lupus will improve public understanding as well as educate and train health care professionals resulting in improved quality of life for those affected.

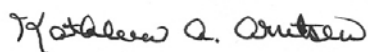
Lupus research is under-funded in comparison with diseases of comparable magnitude and severity. Existing treatments for lupus are not adequate; many are toxic and cause detrimental side effects with long-term use. There are only 4 drugs currently approved for lupus so the majority of treatments are considered off-label and no single test exists to identify lupus, resulting in many patients suffering more serious complications before a diagnosis is reached. Finally, after 56 years of waiting, a drug was specifically developed and approved for treating lupus in 2011.

Lupus is a significant national public health issue that deserves a comprehensive and coordinated response by state and federal governments in collaboration with the health care provider, patient advocacy and public health communities. Establishment of the research advisory council consisting of members of the lupus community most affected by this disease will allow lupus patients, family members and clinicians most familiar with lupus to work with the Department of Health on the statewide program.

We applaud Assemblywoman Peoples-Stokes and Senator Savino and Senator Parker for their efforts to bring much-needed awareness and provide vital statewide education and research enhancement programs with A02169 / S04268, and A02788 / S05489, and S01703.

The proposed legislation would directly address the above issues and positively impact the health and well-being of New Yorkers affected by lupus.

For the above reasons, we the undersigned representatives of the Lupus Agencies of New York State, strongly encourage the passage of this legislation into law and respectfully request your support.




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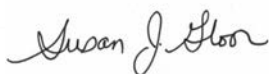
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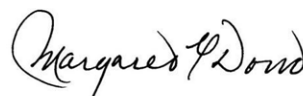
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