

# STATE OF NEW YORK

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5489--B

2017-2018 Regular Sessions

## IN SENATE

March 31, 2017

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Introduced by Sens. PARKER, HOYLMAN -- read twice and ordered printed, and when printed to be committed to the Committee on Investigations and Government Operations -- committee discharged, bill amended, ordered reprinted as amended and recommitted to said committee -- recommitted to the Committee on Investigations and Government Operations in accordance with Senate Rule 6, sec. 8 -- committee discharged, bill amended, ordered reprinted as amended and recommitted to said committee

AN ACT to amend the tax law and the state finance law, in relation to providing for taxpayer gifts for lupus education and prevention, and establishing the lupus education and prevention fund and outreach program

The People of the State of New York, represented in Senate and Assembly, do enact as follows:

- 1 Section 1. Legislative intent. The legislature hereby finds the  
2 following:
- 3 (a) Lupus is a serious, complex, debilitating autoimmune disease that  
4 can cause inflammation and tissue damage to virtually any organ system  
5 in the body, including the skin, joints, other connective tissue, blood  
6 and blood vessels, heart, lungs, kidney, and brain.
- 7 (b) Lupus research estimates that approximately one and a half to two  
8 million Americans live with some form of lupus; lupus affects women nine  
9 times more often than men and eighty percent of newly diagnosed cases of  
10 lupus develop among women of childbearing age.
- 11 (c) Lupus disproportionately affects women of color -- it is two to  
12 three times more common among African-Americans, Hispanics, Asians and  
13 Native Americans and is generally more prevalent in minority populations  
14 -- a health disparity that remains unexplained. According to the Centers  
15 for Disease Control and Prevention the rate of lupus mortality has  
16 increased since the late 1970s and is higher among older African-Ameri-  
17 can women.

EXPLANATION--Matter in italics (underscored) is new; matter in brackets [-] is old law to be omitted.

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(d) No new drugs have been approved by the U.S. Food and Drug Administration specifically for lupus in nearly forty years and while current treatments for the disease can be effective, they can lead to damaging side effects.

(e) The pain and fatigue associated with lupus can threaten people's ability to live independently, make it difficult to maintain employment and lead normal lives, and one in five people with lupus is disabled by the disease, and consequently receives support from government programs, including Medicare, Medicaid, social security disability, and social security supplemental income.

(f) The estimated average annual cost of medical treatment for an individual with lupus can range between ten thousand dollars and thirty thousand dollars; for people who have the most serious form of lupus, medical costs can greatly exceed this amount, causing a significant economic, emotional and social burden to the entire family and society.

(g) More than half of the people with lupus suffer four or more years and visit three or more physicians before obtaining a diagnosis of lupus; early diagnosis of and commencement of treatment for lupus can prevent or reduce serious organ damage, disability, and death.

(h) Despite the magnitude of lupus and its impact on individuals and families, health professional and public understanding of lupus remains low; only one of five Americans can provide even basic information about lupus, and awareness of lupus is lowest among adults ages eighteen to thirty-four -- the age group most likely to develop symptoms of lupus.

(i) Lupus is a significant national health issue that deserves a comprehensive and coordinated response by state and federal governments with involvement of the health care provider, patient, and public health communities.

§ 2. The tax law is amended by adding a new section 209-L to read as follows:

§ 209-L. Gift for lupus education and prevention. A taxpayer in any taxable year may elect to contribute to the support of the lupus education and prevention fund. Such contribution shall be in any whole dollar amount and shall not reduce the amount of the state tax owed by such taxpayer. The commissioner shall include space on the corporate income tax return to enable a taxpayer to make such contribution. Notwithstanding any other provision of law, all revenues collected pursuant to this section shall be credited to the lupus education and prevention fund and shall be used only for those purposes enumerated in section ninety-seven-rrrr of the state finance law.

§ 3. The tax law is amended by adding a new section 630-f to read as follows:

§ 630-f. Gift for lupus education and prevention. An individual in any taxable year may elect to contribute to the lupus education and prevention fund. Such contribution shall be in any whole dollar amount and shall not reduce the amount of state tax owed by such individual. The commissioner shall include space on the personal income tax return to enable a taxpayer to make such contribution. Notwithstanding any other provision of law all revenues collected pursuant to this section shall be credited to the lupus education and prevention fund and used only for those purposes enumerated in section ninety-seven-rrrr of the state finance law.

§ 4. The state finance law is amended by adding a new section 97-rrrr to read as follows:

§ 97-rrrr. Lupus education and prevention fund. 1. There is hereby established in the joint custody of the commissioner of taxation and

1 finance and the comptroller, a special fund to be known as the "lupus  
2 education and prevention fund".

3 2. Such fund shall consist of all revenues received by the department  
4 of taxation and finance, pursuant to the provisions of section two  
5 hundred nine-L and section six hundred thirty-f of the tax law, and all  
6 other moneys appropriated, credited or transferred thereto from any  
7 other fund or source pursuant to law. Nothing contained in this section  
8 shall prevent the state from receiving grants, gifts or bequests for the  
9 purposes of the fund as defined in this section and depositing them into  
10 the fund according to law.

11 3. Monies of the fund shall be expended only for lupus education and  
12 prevention projects. As used in this section, "lupus education and  
13 prevention projects" means educational projects, including grants for  
14 lupus education and prevention programs, which are approved by the  
15 department of health.

16 4. Monies shall be payable from the fund on the audit and warrant of  
17 the comptroller on vouchers approved and certified by the commissioner  
18 of health.

19 5. To the extent practicable, the commissioner of health shall ensure  
20 that all monies received during a fiscal year are expended prior to the  
21 end of that fiscal year.

22 6. On or before the first day of February each year, the commissioner  
23 of health shall provide a written report to the temporary president of  
24 the senate, speaker of the assembly, chair of the senate finance commit-  
25 tee, chair of the assembly ways and means committee, chair of the senate  
26 committee on health, chair of the assembly health committee, the state  
27 comptroller and the public. Such report shall include how the monies of  
28 the fund were utilized during the preceding calendar year, and shall  
29 include:

30 (a) the amount of money disbursed from the fund and the award process  
31 used for such disbursements;

32 (b) recipients of awards from the fund;

33 (c) the amount awarded to each;

34 (d) the purposes for which such awards were granted; and

35 (e) a summary financial plan for such monies which shall include esti-  
36 mates of all receipts and all disbursements for the current and succeed-  
37 ing fiscal years, along with the actual results from the prior fiscal  
38 year.

39 § 5. This act shall take effect immediately.