

2777--B

2013-2014 Regular Sessions

I N S E N A T E

January 23, 2013

Introduced by Sens. PARKER, AVELLA, DILAN, SAMPSON, SAVINO -- read twice and ordered printed, and when printed to be committed to the Committee on Health -- committee discharged, bill amended, ordered reprinted as amended and recommitted to said committee -- recommitted to the Committee on Health 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 public health law, 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.

S 2. Subdivision 1 of section 207 of the public health law is amended by adding a new paragraph (j) to read as follows:

(J) THE DANGERS OF, INCLUDING WAYS TO PREVENT THE INCIDENCE AND SEVERITY OF, LUPUS, A DEBILITATING AUTOIMMUNE DISEASE THAT CAN CAUSE INFLAMMATION AND TISSUE DAMAGE TO VIRTUALLY ANY ORGAN SYSTEM IN THE BODY, INCLUDING THE SKIN, JOINTS, OTHER CONNECTIVE TISSUE, BLOOD AND BLOOD VESSELS, HEART, LUNG, KIDNEY AND BRAIN, AND WHICH AFFECTS WOMEN, PARTICULARLY WOMEN OF COLOR, IN A DISPROPORTIONATE MANNER; PROVIDED THAT THE PROGRAM SHALL INCLUDE AN ADVISORY COUNCIL UNDER THIS SECTION THAT SHALL INCLUDE REPRESENTATIVES OF PEOPLE WITH LUPUS AND THEIR FAMILIES AND HEALTH CARE PROVIDERS WHO SPECIALIZE IN TREATING LUPUS, AMONG OTHERS.

S 3. Subdivision 7 of section 207 of the public health law, as amended by section 16 of part A of chapter 109 of the laws of 2010, is amended to read as follows:

7. In addition to state funds appropriated for programs under this section, the commissioner may accept grants from public or private sources for these programs. The commissioner, in administering this section, shall seek to coordinate the department's programs with other public and private programs, and may undertake joint or cooperative programs with other public or private entities, INCLUDING MAKING GRANTS (WITHIN AMOUNTS APPROPRIATED THEREFOR AND CONSISTENT WITH APPLICABLE LAW) TO PUBLIC OR NOT-FOR-PROFIT ENTITIES.

S 4. The tax law is amended by adding a new section 209-I to read as follows:

S 209-I. 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

1 TAXPAYER. THE COMMISSIONER SHALL INCLUDE SPACE ON THE CORPORATE INCOME
2 TAX RETURN TO ENABLE A TAXPAYER TO MAKE SUCH CONTRIBUTION. NOTWITH-
3 STANDING ANY OTHER PROVISION OF LAW, ALL REVENUES COLLECTED PURSUANT TO
4 THIS SECTION SHALL BE CREDITED TO THE LUPUS EDUCATION AND PREVENTION
5 FUND AND SHALL BE USED ONLY FOR THOSE PURPOSES ENUMERATED IN SECTION
6 NINETY-SEVEN-LLLL OF THE STATE FINANCE LAW.

7 S 5. The tax law is amended by adding a new section 630-d to read as
8 follows:

9 S 630-D. GIFT FOR LUPUS EDUCATION AND PREVENTION. AN INDIVIDUAL IN ANY
10 TAXABLE YEAR MAY ELECT TO CONTRIBUTE TO THE LUPUS EDUCATION AND
11 PREVENTION FUND. SUCH CONTRIBUTION SHALL BE IN ANY WHOLE DOLLAR AMOUNT
12 AND SHALL NOT REDUCE THE AMOUNT OF STATE TAX OWED BY SUCH INDIVIDUAL.
13 THE COMMISSIONER SHALL INCLUDE SPACE ON THE PERSONAL INCOME TAX RETURN
14 TO ENABLE A TAXPAYER TO MAKE SUCH CONTRIBUTION. NOTWITHSTANDING ANY
15 OTHER PROVISION OF LAW ALL REVENUES COLLECTED PURSUANT TO THIS SECTION
16 SHALL BE CREDITED TO THE LUPUS EDUCATION AND PREVENTION FUND AND USED
17 ONLY FOR THOSE PURPOSES ENUMERATED IN SECTION NINETY-SEVEN-LLLL OF THE
18 STATE FINANCE LAW.

19 S 6. The state finance law is amended by adding a new section 97-llll
20 to read as follows:

21 S 97-LLLL. LUPUS EDUCATION AND PREVENTION FUND. 1. THERE IS HEREBY
22 ESTABLISHED IN THE JOINT CUSTODY OF THE COMMISSIONER OF TAXATION AND
23 FINANCE AND THE COMPTROLLER, A SPECIAL FUND TO BE KNOWN AS THE "LUPUS
24 EDUCATION AND PREVENTION FUND".

25 2. SUCH FUND SHALL CONSIST OF ALL REVENUES RECEIVED BY THE DEPARTMENT
26 OF TAXATION AND FINANCE, PURSUANT TO THE PROVISIONS OF SECTION TWO
27 HUNDRED NINE-I AND SECTION SIX HUNDRED THIRTY-D OF THE TAX LAW, AND ALL
28 OTHER MONEYS APPROPRIATED, CREDITED OR TRANSFERRED THERETO FROM ANY
29 OTHER FUND OR SOURCE PURSUANT TO LAW. NOTHING CONTAINED IN THIS SECTION
30 SHALL PREVENT THE STATE FROM RECEIVING GRANTS, GIFTS OR BEQUESTS FOR THE
31 PURPOSES OF THE FUND AS DEFINED IN THIS SECTION AND DEPOSITING THEM INTO
32 THE FUND ACCORDING TO LAW.

33 3. MONIES OF THE FUND SHALL BE EXPENDED ONLY FOR LUPUS EDUCATION AND
34 PREVENTION PROJECTS. AS USED IN THIS SECTION, "LUPUS EDUCATION AND
35 PREVENTION PROJECTS" MEANS EDUCATIONAL PROJECTS, INCLUDING GRANTS FOR
36 LUPUS EDUCATION AND PREVENTION PROGRAMS, WHICH ARE APPROVED BY THE
37 DEPARTMENT OF HEALTH.

38 4. MONIES SHALL BE PAYABLE FROM THE FUND ON THE AUDIT AND WARRANT OF
39 THE COMPTROLLER ON VOUCHERS APPROVED AND CERTIFIED BY THE COMMISSIONER
40 OF HEALTH.

41 5. TO THE EXTENT PRACTICABLE, THE COMMISSIONER OF HEALTH SHALL ENSURE
42 THAT ALL MONIES RECEIVED DURING A FISCAL YEAR ARE EXPENDED PRIOR TO THE
43 END OF THAT FISCAL YEAR.

44 S 7. This act shall take effect immediately.