

553--A

2015-2016 Regular Sessions

I N S E N A T E

(PREFILED)

January 7, 2015

Introduced by Sens. PARKER, AVELLA, SAVINO -- read twice and ordered printed, and when printed to be committed to the Committee on Health -- 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.
- 18 (d) No new drugs have been approved by the U.S. Food and Drug Adminis-
19 tration specifically for lupus in nearly forty years and while current

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

LBD01875-02-6

1 treatments for the disease can be effective, they can lead to damaging
2 side effects.

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

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

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

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

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

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

29 (M) THE DANGERS OF, INCLUDING WAYS TO PREVENT THE INCIDENCE AND SEVER-
30 ITY OF, LUPUS, A DEBILITATING AUTOIMMUNE DISEASE THAT CAN CAUSE INFLAM-
31 MATION AND TISSUE DAMAGE TO VIRTUALLY ANY ORGAN SYSTEM IN THE BODY,
32 INCLUDING THE SKIN, JOINTS, OTHER CONNECTIVE TISSUE, BLOOD AND BLOOD
33 VESSELS, HEART, LUNG, KIDNEY AND BRAIN, AND WHICH AFFECTS WOMEN, PARTIC-
34 ULARLY WOMEN OF COLOR, IN A DISPROPORTIONATE MANNER; PROVIDED THAT THE
35 PROGRAM SHALL INCLUDE AN ADVISORY COUNCIL UNDER THIS SECTION THAT SHALL
36 INCLUDE REPRESENTATIVES OF PEOPLE WITH LUPUS AND THEIR FAMILIES AND
37 HEALTH CARE PROVIDERS WHO SPECIALIZE IN TREATING LUPUS, AMONG OTHERS.

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

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

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

51 S 209-J. GIFT FOR LUPUS EDUCATION AND PREVENTION. A TAXPAYER IN ANY
52 TAXABLE YEAR MAY ELECT TO CONTRIBUTE TO THE SUPPORT OF THE LUPUS EDUCA-
53 TION AND PREVENTION FUND. SUCH CONTRIBUTION SHALL BE IN ANY WHOLE DOLLAR
54 AMOUNT AND SHALL NOT REDUCE THE AMOUNT OF THE STATE TAX OWED BY SUCH
55 TAXPAYER. THE COMMISSIONER SHALL INCLUDE SPACE ON THE CORPORATE INCOME
56 TAX RETURN TO ENABLE A TAXPAYER TO MAKE SUCH CONTRIBUTION. NOTWITH-

1 STANDING ANY OTHER PROVISION OF LAW, ALL REVENUES COLLECTED PURSUANT TO
2 THIS SECTION SHALL BE CREDITED TO THE LUPUS EDUCATION AND PREVENTION
3 FUND AND SHALL BE USED ONLY FOR THOSE PURPOSES ENUMERATED IN SECTION
4 NINETY-SEVEN-PPPP OF THE STATE FINANCE LAW.

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

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

17 S 6. The state finance law is amended by adding a new section 97-pppp
18 to read as follows:

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

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

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

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

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

42 S 7. This act shall take effect immediately.