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I N   S E N A T E

March 19, 2010

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Introduced by Sen. PARKER -- read twice and ordered printed, and when printed to be committed to the Committee on Health

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  
20 treatments for the disease can be effective, they can lead to damaging  
21 side effects.
- 22     (e) The pain and fatigue associated with lupus can threaten people's  
23 ability to live independently, make it difficult to maintain employment  
24 and lead normal lives, and one in five people with lupus is disabled by  
25 the disease, and consequently receives support from government programs,

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

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1 including Medicare, Medicaid, social security disability, and social  
2 security supplemental income.

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

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

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

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

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

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

32 S 3. Subdivision 7 of section 207 of the public health law, as added  
33 by chapter 414 of the laws of 2005, is amended to read as follows:

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

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

44 S 209-H. GIFT FOR LUPUS EDUCATION AND PREVENTION. A TAXPAYER IN ANY  
45 TAXABLE YEAR MAY ELECT TO CONTRIBUTE TO THE SUPPORT OF THE LUPUS EDUCA-  
46 TION AND PREVENTION FUND. SUCH CONTRIBUTION SHALL BE IN ANY WHOLE DOLLAR  
47 AMOUNT AND SHALL NOT REDUCE THE AMOUNT OF THE STATE TAX OWED BY SUCH  
48 TAXPAYER. THE COMMISSIONER SHALL INCLUDE SPACE ON THE CORPORATE INCOME  
49 TAX RETURN TO ENABLE A TAXPAYER TO MAKE SUCH CONTRIBUTION. NOTWITH-  
50 STANDING ANY OTHER PROVISION OF LAW, ALL REVENUES COLLECTED PURSUANT TO  
51 THIS SECTION SHALL BE CREDITED TO THE LUPUS EDUCATION AND PREVENTION  
52 FUND AND SHALL BE USED ONLY FOR THOSE PURPOSES ENUMERATED IN SECTION  
53 NINETY-SEVEN-JJJJ OF THE STATE FINANCE LAW.

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

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

11 S 6. The state finance law is amended by adding a new section 97-jjjj  
12 to read as follows:

13 S 97-JJJJ. LUPUS EDUCATION AND PREVENTION FUND. 1. THERE IS HEREBY  
14 ESTABLISHED IN THE JOINT CUSTODY OF THE COMMISSIONER OF TAXATION AND  
15 FINANCE AND THE COMPTROLLER, A SPECIAL FUND TO BE KNOWN AS THE "LUPUS  
16 EDUCATION AND PREVENTION FUND".

17 2. SUCH FUND SHALL CONSIST OF ALL REVENUES RECEIVED BY THE DEPARTMENT  
18 OF TAXATION AND FINANCE, PURSUANT TO THE PROVISIONS OF SECTION TWO  
19 HUNDRED NINE-H AND SECTION SIX HUNDRED THIRTY-C OF THE TAX LAW, AND ALL  
20 OTHER MONEYS APPROPRIATED, CREDITED OR TRANSFERRED THERETO FROM ANY  
21 OTHER FUND OR SOURCE PURSUANT TO LAW. NOTHING CONTAINED IN THIS SECTION  
22 SHALL PREVENT THE STATE FROM RECEIVING GRANTS, GIFTS OR BEQUESTS FOR THE  
23 PURPOSES OF THE FUND AS DEFINED IN THIS SECTION AND DEPOSITING THEM INTO  
24 THE FUND ACCORDING TO LAW.

25 3. MONIES OF THE FUND SHALL BE EXPENDED ONLY FOR LUPUS EDUCATION AND  
26 PREVENTION PROJECTS. AS USED IN THIS SECTION, "LUPUS EDUCATION AND  
27 PREVENTION PROJECTS" MEANS EDUCATIONAL PROJECTS, INCLUDING GRANTS FOR  
28 LUPUS EDUCATION AND PREVENTION PROGRAMS, WHICH ARE APPROVED BY THE  
29 DEPARTMENT OF HEALTH.

30 4. MONIES SHALL BE PAYABLE FROM THE FUND ON THE AUDIT AND WARRANT OF  
31 THE COMPTROLLER ON VOUCHERS APPROVED AND CERTIFIED BY THE COMMISSIONER  
32 OF HEALTH.

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

36 S 7. This act shall take effect immediately.