

5178

2013-2014 Regular Sessions

I N S E N A T E

May 14, 2013

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

AN ACT to amend the public health law, in relation to the lupus education 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-American
17 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 (i) to read as follows:

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

31 S 3. Subdivision 7 of section 207 of the public health law, as amended
32 by section 16 of part A of chapter 109 of the laws of 2010, is amended
33 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. This act shall take effect immediately.