S T A T E O F N E W Y O R K

544

2013-2014 Regular Sessions

I N A S S E M B L Y

(PREFILED)

January 9, 2013

Introduced by M. of A. GIBSON, JAFFEE, CRESPO, SCHIMEL -- Multi-Sponsored by -- M. of A. BRENNAN, HOOPER, MARKEY, MAYER, MILLMAN, PEOPLES-STOKES, PERRY, SCARBOROUGH, THIELE -- read once and referred 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:

Section 1. Legislative intent. The legislature hereby finds the following:

(a) Lupus is a serious, complex, 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, lungs, kidney, and brain.

(b) Lupus research estimates that approximately one and a half to two million Americans live with some form of lupus; lupus affects women nine times more often than men and eighty percent of newly diagnosed cases of lupus develop among women of childbearing age.

(c) Lupus disproportionately affects women of color -- it is two to three times more common among African-Americans, Hispanics, Asians and Native Americans and is generally more prevalent in minority populations -- a health disparity that remains unexplained. According to the Centers for Disease Control and Prevention the rate of lupus mortality has increased since the late 1970s and is higher among older African-American women.

(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.

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

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(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 (i) to read as follows:

(I) 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. This act shall take effect immediately.