
THE GENERAL ASSEMBLY OF PENNSYLVANIA

SENATE BILL

No. 398 Session of
2013

INTRODUCED BY SOLOBAY, STACK, GREENLEAF, ALLOWAY, RAFFERTY,
VULAKOVICH, BROWNE, FONTANA, FERLO, BREWSTER, WASHINGTON,
TARTAGLIONE, COSTA AND FARNESE, FEBRUARY 4, 2013

REFERRED TO PUBLIC HEALTH AND WELFARE, FEBRUARY 4, 2013

AN ACT

1 Establishing the Lupus Education and Awareness Program and the
2 Interagency and Partnership Advisory Panel on Lupus; and
3 providing for powers and duties of the Department of Health.

4 The General Assembly of the Commonwealth of Pennsylvania
5 hereby enacts as follows:

6 Section 1. Short title.

7 This act shall be known and may be cited as the Lupus
8 Education and Awareness Act.

9 Section 2. Legislative findings and purpose.

10 (a) Findings.--The General Assembly finds and declares as
11 follows:

12 (1) Lupus is an urgent national health issue. Lupus is
13 the result of an immune system that is unbalanced and can
14 become destructive to any organ or tissue in the body. Lupus
15 is unpredictable and potentially fatal, yet no satisfactory
16 treatment exists. Its health consequences include heart
17 attacks, strokes, seizures and organ failure.

18 (2) National data indicates that more than 1.5 million

1 Americans live with some form of lupus. Lupus affects women
2 nine times more often than men, and 80% of newly diagnosed
3 cases of lupus develop among women of childbearing age. An
4 estimated 65,000 people with lupus reside in this
5 Commonwealth.

6 (3) Lupus disproportionately affects women of color. It
7 is two to three times more common among African Americans,
8 Hispanics and Latinos, Asians and Native Americans and is
9 generally more prevalent in minority populations, a health
10 disparity that remains unexplained.

11 (4) No new drugs have been approved by the Food and Drug
12 Administration specifically for lupus in 50 years and, while
13 current treatments for the disease can be effective, they can
14 lead to damaging side effects.

15 (5) The pain and fatigue associated with lupus can
16 threaten one's ability to live independently, make it
17 difficult to maintain employment and lead a normal life. One
18 in five people with lupus is disabled by the disease and
19 consequently receives support from government programs,
20 including Medicare, Medicaid Social Security disability and
21 Social Security Supplemental Security Income.

22 (6) The estimated average annual total of direct and
23 indirect costs for an individual with lupus is \$21,000. For
24 people who have the most serious form of lupus, medical costs
25 can greatly exceed this amount, causing a significant
26 economic, emotional and social burden to the entire family
27 and society.

28 (b) Purpose.--The purpose of this act is to create a
29 multipronged, Statewide program to promote public and health
30 professional awareness among State and local health and human

1 services officials, physicians, nurses and other health care
2 providers and increase knowledge concerning the causes and
3 consequences of lupus, the importance of early diagnosis and
4 appropriate management and effective treatment and management
5 strategies by taking the following actions:

6 (1) Conducting educational and training programs for
7 health professionals on lupus diagnosis and management.

8 (2) Disseminating medically sound educational materials
9 and information on lupus research findings to patients and
10 health care professionals.

11 (3) Fostering greater public understanding and awareness
12 of lupus Statewide.

13 Section 3. Definitions.

14 The following words and phrases when used in this act shall
15 have the meanings given to them in this section unless the
16 context clearly indicates otherwise:

17 "Department." The Department of Health of the Commonwealth.

18 "Panel." The Interagency and Partnership Advisory Panel on
19 Lupus established under section 5(a).

20 "Program." The Lupus Education and Awareness Program
21 established under section 4(a).

22 "Secretary." The Secretary of Health of the Commonwealth.

23 Section 4. Program.

24 (a) Program established.--Subject to appropriation, there is
25 established within the department the Lupus Education and
26 Awareness Program. The program shall be composed of various
27 components, including, but not limited to, public awareness
28 activities and professional education programs.

29 (b) Department duties.--The department shall promote and
30 maintain the program with an emphasis on minority populations

1 and at-risk communities in order to raise public awareness,
2 educate consumers and educate and train health professionals,
3 human service providers and other audiences.

4 (c) National lupus organization.--The department shall work
5 with a national organization that deals with lupus to implement
6 programs to raise public awareness about the symptoms and nature
7 of lupus, personal risk factors and options for diagnosing and
8 treating the disease, with a particular focus on populations at
9 elevated risk for lupus, including women and communities of
10 color.

11 (d) Program initiatives.--The program shall include
12 initiatives to educate and train physicians, health care
13 professionals and other service providers on the most up-to-date
14 and accurate scientific and medical information regarding lupus
15 diagnosis, treatment, risks and benefits of medications,
16 research advances and therapeutic decision making, including
17 medical best practices for detecting and treating the disease in
18 special populations. These activities shall include, but not be
19 limited to, all of the following:

20 (1) Distribution of medically sound health information
21 produced by a national organization that deals with lupus and
22 government agencies, including, but not limited to, the
23 National Institutes of Health, the Centers for Disease
24 Control and Prevention and the Social Security
25 Administration, through the following:

- 26 (i) Local health departments.
- 27 (ii) Schools.
- 28 (iii) Agencies on aging.
- 29 (iv) Employer wellness programs.
- 30 (v) Physicians and other health professionals.

- 1 (vi) Hospitals.
- 2 (vii) Health plans and health maintenance
3 organizations.
- 4 (viii) Women's health programs.
- 5 (ix) Nonprofit and community-based organizations.
- 6 (2) Development of educational materials for health
7 professionals that identify the latest scientific and medical
8 information and clinical applications.
- 9 (3) Working to increase knowledge among physicians,
10 nurses and health and human services professionals about the
11 importance of lupus diagnosis, treatment and rehabilitation.
- 12 (4) Support of continuing medical education programs
13 presented by leading State academic institutions by providing
14 them with the most up-to-date information.
- 15 (5) Providing Statewide workshops and seminars for in-
16 depth professional development regarding the care and
17 management of patients with lupus in order to bring the
18 latest information on clinical advances to care providers.
- 19 (6) Development and maintenance of a directory of lupus-
20 related services and lupus health care providers with
21 specialization in services to diagnose and treat lupus. The
22 department shall disseminate this directory to all
23 stakeholders, including, but not limited to, individuals with
24 lupus, families and representatives from voluntary
25 organizations, health care professionals, health plans and
26 State and local health agencies.
- 27 (e) Duties of secretary.--The secretary shall do all of the
28 following:
- 29 (1) Designate a person in the department to oversee the
30 program.

1 (2) Identify the appropriate entities to carry out the
2 program, including, but not limited to, the following:

3 (i) Local health departments.

4 (ii) Schools.

5 (iii) Agencies on aging.

6 (iv) Employer wellness programs.

7 (v) Physicians and other health professionals.

8 (vi) Hospitals.

9 (vii) Health plans and health maintenance
10 organizations.

11 (viii) Women's health organizations.

12 (ix) Nonprofit and community-based organizations.

13 (3) Base the program on the most current scientific
14 information and findings.

15 (4) Work with governmental entities, community and
16 business leaders, community organizations, health care and
17 human service providers and national, State and local
18 organizations to coordinate efforts to maximize State
19 resources in the areas of lupus education and awareness.

20 (5) Use public health institutions for dissemination of
21 medically sound health materials.

22 Section 5. Panel.

23 (a) Panel established.--Subject to appropriation, the
24 Interagency and Partnership Advisory Panel on Lupus is
25 established to oversee the program and advise the department in
26 implementing the program. The panel shall consist of the
27 following members, one of whom shall be appointed by the
28 secretary as chair:

29 (1) At least three individuals with lupus.

30 (2) Three representatives from relevant State agencies,

1 including the department.

2 (3) Three scientists with experience in lupus who
3 participate in various fields of scientific endeavor,
4 including, but not limited to, biomedical research, social,
5 translational, behavioral and epidemiological research and
6 public health.

7 (4) Two medical clinicians with experience in treating
8 people with lupus.

9 (5) Four representatives from relevant nonprofit women's
10 and health organizations, including one representative from a
11 national organization that deals with the treatment of lupus.

12 (b) Nominations.--Individuals and organizations may submit
13 nominations to the secretary to be named to the panel.

14 Nominations may include the following:

15 (1) Representatives from appropriate State departments
16 and agencies, such as entities with responsibility for health
17 disparities, public health programs, education, public
18 welfare and women's health programs.

19 (2) Health and medical professionals with expertise in
20 lupus.

21 (3) Individuals with lupus and recognized experts in the
22 provision of health services to women, lupus research or
23 health disparities.

24 (c) Terms.--All members of the panel shall serve terms of
25 two years. A member may be appointed to serve not more than two
26 terms, whether or not consecutive.

27 (d) Quorum.--A majority of the members of the panel shall
28 constitute a quorum. A majority vote of a quorum shall be
29 required for any official action of the panel.

30 (e) Meetings.--The panel shall meet at the call of the

1 chair, but not less than two times per year.

2 (f) Compensation.--All members shall serve without
3 compensation, but shall be entitled to actual, necessary
4 expenses incurred in the performance of their duties as members
5 of the panel in accordance with the reimbursement policies for
6 the State.

7 Section 7. Funding.

8 (a) Expenditures.--Subject to the availability of funds, the
9 department may make expenditures of up to \$2,500 for fiscal year
10 2013-2014 for use toward providing educational materials to
11 clinics serving a high percentage of minorities in this
12 Commonwealth.

13 (b) Additional funding sources.--The secretary may accept
14 grants, services and property from the Federal Government,
15 foundations, organizations, medical schools and other entities
16 as may be available for the purposes of fulfilling the
17 obligations of the program. Any such funds shall only supplement
18 any appropriations made for the implementation of this act.

19 (c) Federal waiver.--The secretary shall seek any Federal
20 waiver that may be necessary to maximize funds from the Federal
21 Government to implement the program.

22 Section 8. Staffing.

23 The department shall provide staffing and administrative
24 support for the implementation of this act.

25 Section 9. Effective date.

26 This act shall take effect in 60 days.