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STATE OF RHODE ISLAND

IN GENERAL ASSEMBLY

JANUARY SESSION, A.D. 2012

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A N A C T

RELATING TO HEALTH AND SAFETY - - THE RHODE ISLAND LUPUS EDUCATION
AND AWARENESS PLAN

Introduced By: Representatives Diaz, Naughton, Ferri, Tanzi, and Slater

Date Introduced: February 28, 2012

Referred To: House Health, Education & Welfare

It is enacted by the General Assembly as follows:

1 SECTION 1. Title 23 of the General Laws entitled "HEALTH AND SAFETY" is hereby
2 amended by adding thereto the following chapter:

CHAPTER 87

THE RHODE ISLAND LUPUS EDUCATION AND AWARENESS PLAN

5 **23-87-1. Short title.** -- This chapter shall be known and maybe cited as the “Rhode
6 Island Lupus Education and Awareness Plan Act of 2012.”

7 **23-87-2. Legislative findings.** -- It is hereby found and declared as follows:

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

12 (2) The Lupus Foundation of America, Inc. estimates that more than 1.5 million
13 Americans live with some form of lupus, including an estimated five thousand two hundred
14 (5,200) people with lupus in Rhode Island.

15 **23-87-3. Purpose.** -- The purpose of this chapter is to create a study commission which
16 will develop a multi-pronged, statewide plan to educate healthcare professionals and persons
17 affected with lupus about the diagnosis, management, and treatment of lupus.

18 **23-87-4. Establishment of the lupus study commission.** -- (a) The director of the

1 department of health shall establish and coordinate a study commission on lupus consisting of
2 nine (9) members, all of whom shall be appointed by the director of the department of health. The
3 first chairperson shall be a representative of the Lupus Foundation of America, Inc. and shall
4 serve for a two (2) year term. Subsequent chairpersons shall be elected by the membership of the
5 study commission from among its members.

6 (b) The commission shall be composed of:

7 (1) Two (2) individuals with lupus;

8 (2) One scientist with experience in lupus and who participates in various fields of
9 scientific endeavor, including, but not limited to, biomedical research, social, translational,
10 behavioral or epidemiological research recommended by the medical and scientific council of the
11 Lupus Foundation of America, Inc;

12 (3) Two (2) physicians with experience in treating people with lupus and recommended
13 by the Rhode Island medical society;

14 (4) One nurse practitioner with experience in treating people with lupus and
15 recommended by the Rhode Island nurse practitioners' council;

16 (5) One local representative from the Lupus Foundation of America, Inc.;

17 (6) One representative recommended by the department of health's minority health
18 advisory committee; and

19 (7) One representative recommended by the women's health council of Rhode Island.

20 (c) All appointments to the study commission shall be made not later than sixty (60) days
21 after the effective date of this chapter. Members of the commission shall serve terms of two (2)
22 years. A member may be appointed to serve not more than two (2) terms, whether or not
23 consecutive.

24 (d) The commission shall meet at the call of the chair and no less than on a quarterly
25 basis each year.

26 (e) Five (5) members of the study commission shall constitute a quorum. A majority vote
27 of a quorum shall be required for any official action of the study commission.

28 **23-87-5. Establishment of the lupus education and awareness plan (LEAP).** -- (a)
29 The study commission established in this chapter shall:

30 (1) Analyze the current state of education on lupus in the state;

31 (2) Evaluate materials and resources currently available from government agencies,
32 hospitals, lupus advocacy organizations; and

33 (3) Identify gaps in the current lupus education modalities in the state through a needs
34 assessment or similar mechanism.

1 (b) Upon completing the needs assessment described in subsection (a), the study
2 commission shall report on the results of its assessment to the department of health and to the
3 general assembly. Utilizing the results of such assessment, and with input from the committees of
4 the general assembly, having cognizance of matters relating to public health and the department of
5 health, the study commission shall develop and implement a comprehensive lupus education and
6 awareness plan.

7 (c) The study commission shall develop and implement a comprehensive plan to improve
8 education and awareness surrounding lupus for healthcare practitioners, public health personnel,
9 patients, and persons who may have lupus. The plan shall include the recommendations on how
10 to best:

11 (1) Distribute medically-sound health information produced by the Lupus Foundation of
12 America, Inc., the Lupus Foundation of New England and/or government agencies, including, but
13 not limited to, the National Institutes of Health, the Centers for Disease Control and Prevention,
14 and the Social Security Administration, through local health departments, schools, agencies on
15 aging, employer wellness programs, physicians and other health professionals, hospitals, health
16 plans and health maintenance organizations, women's health, and nonprofit and community-
17 based organizations;

18 (2) Utilize volunteers in the community to distribute brochures and other materials that
19 promote lupus education and awareness;

20 (3) Develop educational materials for health professionals that identify the most recent
21 scientific and medical information and clinical applications regarding the treatment of lupus;

22 (4) Work to increase knowledge among physicians, nurses, and health and human
23 services professionals about the importance of lupus diagnosis, treatment, and rehabilitation;

24 (5) Support continuing medical education plans in the state's leading academic
25 institutions by providing them the most recent scientific and medical information and clinical
26 applications regarding the treatment of lupus;

27 (6) Conduct statewide workshops and seminars for extensive professional development
28 regarding the care and management of patients with lupus in an effort to bring the latest
29 information on clinical advances to care providers; and

30 (7) Develop and maintain a directory of lupus-related healthcare services, that includes a
31 listing of healthcare providers with specialization in services to diagnose and treat lupus and that
32 can be disseminated, within available appropriations, by the department of health to individuals
33 with lupus, family members of those with lupus, representatives from voluntary organizations,
34 healthcare professionals, health plans, local health agencies and authorities and to other agencies

1 of the state.

2 (d) The study commission shall report its findings and recommendations to the Rhode
3 Island department of health and to both chambers of the general assembly annually on or before
4 December 1, commencing in 2014. The study commission may make periodic revisions to the
5 plan that are consistent with the purposes of this section.

6 SECTION 2. The state department of health may, within available appropriations,
7 provide assistance to the lupus study commission established pursuant to section 1 of this act, in
8 carrying out its functions. Such assistance may include, but shall not be limited to, the
9 dissemination of educational materials to state healthcare providers serving minority populations.
10 The director of health may accept funds from any source to implement the provisions of this act.
11 The director shall take such actions as the director deems necessary to maximize federal funding
12 to implement the provisions of this act.

13 SECTION 3. This act shall take effect upon passage.

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EXPLANATION
BY THE LEGISLATIVE COUNCIL
OF

A N A C T

RELATING TO HEALTH AND SAFETY - - THE RHODE ISLAND LUPUS EDUCATION
AND AWARENESS PLAN

1 This act would establish the “Rhode Island Lupus Education and Awareness Plan” and a
2 lupus study commission to develop a statewide plan that would educate healthcare professionals
3 and persons affected with lupus. The commission would report its findings and recommendations
4 to the department of health and to the general assembly on an annual basis.

5 This act would take effect upon passage.

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