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STATE OF RHODE ISLAND

IN GENERAL ASSEMBLY

JANUARY SESSION, A.D. 2013

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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, McNamara, Williams, Slater, and Tanzi

Date Introduced: March 27, 2013

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:

3 CHAPTER 88

4 THE RHODE ISLAND LUPUS EDUCATION AND AWARENESS PLAN

5 **23-88-1. Short title.** -- This chapter shall be known and maybe cited as the “Rhode
6 Island Lupus Education and Awareness Plan.”

7 **23-88-2. 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 **23-88-3. 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 **23-88-4. 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 eleven (11) members, all of whom shall be appointed by the director of the department of health.
3 The first chairperson shall be a representative of the Lupus Foundation of New England, Inc. and
4 shall serve for a two (2) year term. Subsequent chairpersons shall be elected by the membership
5 of the study commission from among its members.

6 (b) The commission shall be composed of:

7 (1) Three (3) 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 from the Lupus Foundation of New England, Inc.;

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

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

21 (c) Members of the commission shall serve terms of two (2) years. A member may be
22 appointed to serve not more than two (2) terms, whether or not consecutive.

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

25 (e) Six (6) members of the study commission shall constitute a quorum. A majority vote
26 of a quorum shall be required for any official action of the study commission.

27 **23-88-5. Establishment of the lupus education and awareness plan (LEAP). -- (a)**

28 The study commission established in this chapter shall:

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

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

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

34 (b) Upon completing the needs assessment described in subsection (a), the study

1 commission shall report on the results of its assessment to the department of health and to the
2 general assembly. Utilizing the results of such assessment, and with input from the committees of
3 the general assembly, having cognizance of matters relating to public health and the department of
4 health, the study commission shall develop a comprehensive lupus education and awareness plan.

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

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

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

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

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

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

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

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

33 (d) The study commission shall report its findings and recommendations to the Rhode
34 Island department of health and to both chambers of the general assembly annually on or before

1 [December 1, commencing in 2015. The study commission may make periodic revisions to the](#)
2 [plan that are consistent with the purposes of this section.](#)

3 SECTION 2. 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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