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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 PROGRAM

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:

3 CHAPTER 87

4 THE RHODE ISLAND LUPUS EDUCATION AND AWARENESS PROGRAM

5 **23-87-1. Short title.** -- This chapter shall be known and maybe cited as the “Rhode
6 Island Lupus Education and Awareness Program 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 four thousand two hundred
14 (4,200) people with lupus in Rhode Island.

15 **23-87-3. Purpose.** -- The purpose of this chapter is to create a multi-pronged, statewide
16 program to educate healthcare professionals and persons affected with lupus about diagnosis,
17 management, and treatment of lupus by taking the following actions:

18 (1) Conducting educational and training programs for health professionals on lupus

1 diagnosis and management.

2 (2) Disseminating medically-sound educational materials and information on lupus to
3 healthcare professionals.

4 (3) Conducting educational forums and workshops on lupus for patients and their
5 families.

6 (4) Organizing statewide lupus awareness activities and programs.

7 **23-87-4. Establishment of the lupus education and awareness program (LEAP). --**

8 (a) There is hereby established within the state of Rhode Island a Lupus Education
9 Awareness Program (LEAP).

10 (b) The Rhode Island department of health shall work with the Lupus Foundation of
11 America, Inc., to implement programs to:

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

18 (2) Develop educational materials for health professionals that identify the latest
19 scientific and medical information and clinical applications.

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

22 (4) Support continuing medical education programs presented by the leading state
23 academic institutions by providing them the most up-to-date information.

24 (5) Provide statewide workshops and seminars for in-depth professional development
25 regarding the care and management of patients with lupus to bring the latest information on
26 clinical advances to care providers.

27 (6) Develop and maintain a directory of lupus-related services and lupus healthcare
28 providers with specialization in services to diagnose and treat lupus. The department shall
29 disseminate this directory to all stakeholders, including, but not limited to, individuals with lupus,
30 families, and representatives from voluntary organizations, healthcare professionals, health plans,
31 and state and local health agencies.

32 **23-87-5. The interagency and partnership advisory panel. --** (a) The director of the
33 department of health shall establish and coordinate an interagency and partnership advisory panel
34 on lupus consisting of six (6) members, all of whom shall be appointed by the director of the

1 department of health. The chairperson of this panel shall be appointed by the director.

2 (b) The panel shall be composed of:

3 (1) At least one individual with lupus;

4 (2) One scientist with experience in lupus and who participates in various fields of
5 scientific endeavor, including, but not limited to, biomedical research, social, translational,
6 behavioral and epidemiological research, and public health;

7 (3) One medical clinician with experience in treating people with lupus; and

8 (4) Two (2) representatives from relevant nonprofit women's and/or health organizations;

9 and

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

11 (c) All members of the panel shall serve terms of two (2) years. A member may be
12 appointed to serve not more than two (2) terms, whether or not consecutive.

13 (d) The panel shall meet at the call of the chair, but not less than once annually.

14 SECTION 2. This act shall take effect upon passage.

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EXPLANATION
BY THE LEGISLATIVE COUNCIL
OF

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RELATING TO HEALTH AND SAFETY - - THE RHODE ISLAND LUPUS EDUCATION
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- 1 This act would establish the “Lupus Education and Awareness Program” and an advisory
- 2 panel to promote this program.
- 3 This act would take effect upon passage.

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