# 2012 -- H 7834 SUBSTITUTE A AS AMENDED

LC01668/SUB A

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# STATE OF RHODE ISLAND

#### IN GENERAL ASSEMBLY

### JANUARY SESSION, A.D. 2012

### AN ACT

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

<u>Introduced By:</u> Representatives Diaz, Naughton, Ferri, Tanzi, and Slater

<u>Date Introduced:</u> 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 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 heath and the department of
5	health, the study commission shall develop a comprehensive lupus education and awareness plan.
6	(c) The study commission shall develop a comprehensive plan to improve education and
7	awareness surrounding lupus for healthcare practitioners, public health personnel, patients, and
8	persons who may have lupus. The plan shall include the recommendations on how to best:
9	(1) Distribute medically-sound health information produced by the Lupus Foundation of
10	America, Inc., the Lupus Foundation of New England and/or government agencies, including, but
11	not limited to, the National Institutes of Health, the Centers for Disease Control and Prevention,
12	and the Social Security Administration, through local health departments, schools, agencies on
13	aging, employer wellness programs, physicians and other health professionals, hospitals, health
14	plans and health maintenance organizations, women's health, and nonprofit and community-
15	based organizations;
16	(2) Utilize volunteers in the community to distribute brochures and other materials that
17	promote lupus education and awareness;
18	(3) Develop educational materials for health professionals that identify the most recent
19	scientific and medical information and clinical applications regarding the treatment of lupus;
20	(4) Work to increase knowledge among physicians, nurses, and health and human
21	services professionals about the importance of lupus diagnosis, treatment, and rehabilitation;
22	(5) Support continuing medical education plans in the state's leading academic
23	institutions by providing them the most recent scientific and medical information and clinical
24	applications regarding the treatment of lupus;
25	(6) Conduct statewide workshops and seminars for extensive professional development
26	regarding the care and management of patients with lupus in an effort to bring the latest
27	information on clinical advances to care providers; and
28	(7) Develop and maintain a directory of lupus-related healthcare services, that includes a
29	listing of healthcare providers with specialization in services to diagnose and treat lupus and that
30	can be disseminated, within available appropriations, by the department of health to individuals
31	with lupus, family members of those with lupus, representatives from voluntary organizations,
32	healthcare professionals, health plans, local health agencies and authorities and to other agencies
33	of the state.
34	(d) The study commission shall report its findings and recommendations to the Rhode

- 1 <u>Island department of health and to both chambers of the general assembly annually on or before</u>
- 2 December 1, commencing in 2014. The study commission may make periodic revisions to the
- 3 plan that are consistent with the purposes of this section.
- 4 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 AND AWARENESS PLAN

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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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