

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 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 [Island department of health and to both chambers of the general assembly annually on or before](#)
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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LC01668/SUB A
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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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