
A BILL FOR AN ACT

RELATING TO LUPUS.

BE IT ENACTED BY THE LEGISLATURE OF THE STATE OF HAWAII:

- 1 SECTION 1. (a) The legislature finds the following:
- 2 (1) Lupus is an urgent national health issue. Lupus
- 3 results from an immune system that is unbalanced and
- 4 can become destructive to any organ in the body.
- 5 Lupus is unpredictable and potentially fatal, yet no
- 6 satisfactory treatment exists. Its health
- 7 consequences include disfiguring rashes, scarring,
- 8 disabling arthritis, heart attacks, strokes, seizures,
- 9 and organ failure;
- 10 (2) Misdiagnosis of lupus commonly occurs, resulting in
- 11 needless suffering, denial by insurance companies for
- 12 health or life insurance, and higher premiums for
- 13 health insurance;
- 14 (3) National data indicate that more than 1,500,000
- 15 Americans suffer from lupus. According to Lupus
- 16 Hawaii, over ten thousand people in Hawaii are
- 17 affected by lupus;



1 (4) Lupus disproportionately affects Native Hawaiian,
2 Pacific Island, Asian, African American, Hispanic,
3 Latina, and Native American women, a health disparity
4 that remains unexplained. Recent data show that
5 ninety per cent of people with lupus are women, yet
6 eighty per cent of women know little or nothing about
7 the disease lupus;

8 (5) Although recommendations have been made, no new drugs
9 have been approved by the Food and Drug Administration
10 specifically for lupus in fifty years. While current
11 treatments for the disease can be effective, they
12 generate side effects that often prove worse than the
13 disease itself; and

14 (6) Annually, lupus treatment costs the nation in excess
15 of \$31,400,000,000.

16 (b) The purpose of this Act is to create a statewide
17 program to promote public and health professional education and
18 awareness of lupus among public health and human services
19 officials, physicians, nurses, and other health care providers
20 and increase knowledge concerning the causes and consequences of
21 lupus, the importance of early diagnosis and appropriate
22 management, and effective treatment and management strategies.



1 SECTION 2. (a) The director of health shall establish a
2 working group within the department of health to develop a
3 comprehensive plan to improve education and awareness of lupus
4 in the State.

5 (b) The plan shall focus on minority populations and at-
6 risk communities to raise public awareness, educate consumers,
7 and educate and train health professionals, human service
8 providers, and other audiences. The director of health shall
9 consider including the following activities in the plan:

10 (1) Distribution of medically-sound health information
11 produced by national organizations that deal with
12 lupus and government agencies, such as the National
13 Institutes of Health, the Centers for Disease Control
14 and Prevention, the Arthritis Foundation, the American
15 College of Rheumatology, the Lupus Foundation, and the
16 Social Security Administration, through county health
17 departments, physicians and other health
18 professionals, hospitals, health plans and health
19 maintenance organizations, women's health programs,
20 and nonprofit and community-based organizations;



- 1 (2) Development of educational materials for health
2 professionals that identify the latest scientific and
3 medical information and clinical applications;
- 4 (3) Working to increase knowledge among physicians,
5 nurses, and health and human services professionals
6 about the importance of lupus diagnosis, treatment,
7 and rehabilitation;
- 8 (4) Support of continuing medical education programs in
9 the State by provision of up-to-date information;
- 10 (5) Provision of the latest information on clinical
11 advances through statewide workshops and seminars to
12 promote in-depth professional development for health
13 care providers regarding the care and management of
14 patients with lupus; and
- 15 (6) Development, maintenance, and dissemination of a
16 directory of lupus-related services and lupus health
17 care specialist providers who diagnose and treat
18 lupus.
- 19 (c) The working group shall be composed of seven members
20 to be chosen by the director. The members shall have lupus-
21 related experience and shall include representatives from
22 relevant state agencies, scientists with experience in lupus



1 research, health and medical professionals with experience in
 2 lupus, representatives from non-profit women's and health
 3 organizations, and individuals with lupus. The members of the
 4 working group shall designate a chair from among its members and
 5 serve without compensation but shall be reimbursed for travel
 6 expenses necessary to carry out their duties.

7 (d) The director of health shall submit the comprehensive
 8 plan to the legislature no later than twenty days prior to the
 9 convening of the regular session of 2012. The working group
 10 shall terminate on June 30, 2012.

11 SECTION 3. This Act shall take effect upon its approval.

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Report Title:

Lupus; Working Group; Department of Health

Description:

Requires the director of the health to establish a working group to develop a plan to increase education and awareness of lupus.

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