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# 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 unbalanced immune system and can
- 4 become destructive to any organ in the body. Lupus is
- 5 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 of health or life
- 12 insurance, and higher premiums for health insurance;
- 13 (3) National data indicate that more than 1,500,000
- 14 Americans suffer from lupus. According to Lupus
- 15 Hawaii, over ten thousand people in Hawaii are
- 16 affected by lupus;
- 17 (4) Lupus disproportionately affects Native Hawaiian,
- 18 Pacific Island, Asian, African American, Hispanic,



1 Latina, and Native American women, a health disparity  
2 that remains unexplained. Recent data show that  
3 ninety per cent of people with lupus are women, yet  
4 eighty per cent of women know little or nothing about  
5 lupus;

6 (5) Although recommendations have been made, no new drugs  
7 have been approved by the Food and Drug Administration  
8 in the last fifty years specifically to treat lupus.

9 While current treatments for the disease may be  
10 effective, they have side effects that often prove  
11 worse than the disease itself; and

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

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

21 SECTION 2. (a) The director of health shall establish a  
22 working group within the department of health to develop a



1 comprehensive plan to improve lupus education and awareness in  
2 the State.

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

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

19 (2) Development of educational materials for health  
20 professionals that identify the latest scientific and  
21 medical information and clinical applications;



- 1 (3) Working to increase knowledge among physicians,  
2 nurses, and health and human services professionals  
3 about the importance of lupus diagnosis, treatment,  
4 and rehabilitation;
- 5 (4) Supporting continuing medical education programs in  
6 the State by provision of up-to-date information about  
7 lupus and lupus research;
- 8 (5) Providing the latest information on clinical advances  
9 through statewide workshops and seminars to promote  
10 in-depth professional development among health care  
11 providers regarding the care and management of lupus  
12 patients; and
- 13 (6) Developing, maintaining, and disseminating a directory  
14 of lupus-related services and lupus health care  
15 specialist providers who diagnose and treat lupus.
- 16 (c) The working group shall be composed of seven members  
17 to be chosen by the director of health. The members shall have  
18 lupus-related experience and shall include representatives from  
19 relevant state agencies; scientists with experience in lupus  
20 research; health and medical professionals with experience  
21 treating lupus patients; representatives from non-profit women's  
22 and health organizations, including Lupus Hawaii; and



1 individuals with lupus. The members of the working group shall  
2 designate a chair from among its members and serve without  
3 compensation but shall be reimbursed for travel expenses  
4 necessary to carry out their duties.

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

9 SECTION 3. This Act shall take effect July 1, 2050.



**Report Title:**

Lupus; Working Group; Department of Health

**Description:**

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

Effective 07/01/2050. (SD2)

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