



STATE OF HAWAII
DEPARTMENT OF HEALTH
P.O. Box 3378
HONOLULU, HAWAII 96801-3378

In reply, please refer to:
File:

SENATE COMMITTEE ON HEALTH

S.B. 224, RELATING TO LUPUS

Testimony of Loretta J. Fuddy, A.C.S.W., M.P.H.
Acting Director of Health

February 16, 2011
2:45 p.m.

1 **Department's Position:** The Department of Health would like to provide comment on S.B. 224,
2 Relating to Lupus.

3 **Fiscal Implications:** No appropriation. The Department would require dedicated staff time and funds
4 to convene a working group and to develop a comprehensive plan to improve education and awareness
5 of lupus in the State.

6 **Purpose and Justification:** Lupus is a chronic, inflammatory, autoimmune disease in which the body's
7 immune system attacks its own health tissues and organs. The disease can damage any part of the body
8 (joints, skin, kidneys, lungs, heart, nervous system, and other organs of the body). Although often
9 difficult to diagnose and there is no known cure, the disease can be, and should be treated by a doctor.
10 The disease predominantly strikes women of color (Asian, African American, Native Hawaiian, Pacific
11 Islander, Native American and Hispanic) between the ages of 15-45.

12 The Department of Health recognizes the need for greater public awareness and education about
13 lupus, the importance of lupus diagnosis and treatment, and community services available to individuals
14 and families affected by lupus.

1 The Department of Health has provided funds to Lupus Hawaii (formerly, Hawaii Lupus
2 Foundation, Inc.) to promote public awareness and education about lupus, provide professional
3 education, and support services for people with lupus, their friends and family since 1997. Funds in the
4 amount of \$25,000 were provided from 1997 to 2009, and reduced to \$10,000 in 2009 due to
5 Department of Health budget reductions.

6 Thank you for the opportunity to provide comment.



HAWAII MEDICAL ASSOCIATION

1360 S. Beretania Street, Suite 200, Honolulu, Hawaii 96814
Phone (808) 536-7702 Fax (808) 528-2376 www.hmaonline.net

Wednesday, February 16, 2011 2:45 p.m. Conference Room 229

To: COMMITTEE ON HEALTH
Senator Josh Green, M.D., Chair
Senator Clarence K. Nishihara, Vice Chair

From: Hawaii Medical Association
Dr. Morris Mitsunaga, MD, President
Linda Rasmussen, MD, Legislative Co-Chair
Dr. Joseph Zobian, MD, Legislative Co-Chair
Dr. Christopher Flanders, DO, Executive Director
Lauren Zirbel, Community and Government Relations

Re: SB 224 Relating to Lupus

In Support

Chairs & Committee Members:

The Hawaii Medical Association strongly supports SB 224 Relating to Lupus.

Lupus is an urgent national health issue. Lupus results from an immune system that is unbalanced and can become destructive to any organ in the body. Lupus is unpredictable and potentially fatal, yet no satisfactory treatment exists.

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

HMA believes it is important to increase knowledge among physicians, nurses, and health and human services professionals about the importance of lupus diagnosis, treatment, and rehabilitation.

Thank you for the opportunity to testify.

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- STEPHEN KEMBLE, MD EXECUTIVE DIRECTOR - CHRISTOPHER FLANDERS, DO

green1 - Karen

224

From: Sharon Au-Curtis [sharonaucurtis@yahoo.com]
Sent: Tuesday, February 15, 2011 2:39 PM
To: HTHTestimony
Subject: Testimony for Measure SB 224

RE: Measure SB 224on February 16, 2011 2:45 p.m.

Dear Sir or Madam:

I wish to stress my support for establishing a working group to raise education and awareness of lupus. I was an active member in a national lupus awareness and fundraising organization (Alliance for Lupus Research or ALR) for the support of ongoing medical research into the causes and a potential cure for this debilitating disease. As a person living with Lupus I spoke at gatherings in support of this organization by relaying to people the devastating effects and consequences of lupus. Many times I was either approached or written to about the impact my talks had on people. It was interesting to note how many times it was not persons WITH the disease who would approach me but rather people who had intimate relationships or friends with lupus that were profoundly moved by what I had to say. They would relate to me how they had no idea what the person they knew dealt with sometimes on a daily basis in order to keep going.

In one particularly moving letter I received a woman related to me that she had sent her friend with lupus a lengthy email I wrote and sent out to all the contacts I had regarding lupus, my daily struggles, advances in research and new medications among other issues pertinent to the disease. This friend broke down in tears realizing she was not alone in her struggles, that someone validated her suffering and that there was hope for the future. Time and again I have found people with lupus living detached from their illness because they simply don't understand it or are afraid to acknowledge the devastation it can invoke. With proper education and resources to seek help these people can attain a renewed lease on life and look forward to the many advances that are continually occurring in this fight.

In 2006 and 2007 as part of the ALR contingent, I traveled to Washington DC to speak on Capitol Hill in support of continued funding for lupus research. As a result of our efforts it was line itemed and eventually \$5,000,000.00 was dedicated to our request.

I urge you to invest in making the population of Hawaii aware of this disease that strikes women of color 90% of the time and generally in their child bearing years. There is a larger population that can be imagined of such women here that must deal with the devastating and sometimes tragic effects of lupus. What is so insidious is that it strikes at the heart of our communities...the young mothers who are nurturing our future.

Please make this a priority.

Thank you for your kind consideration.

Respectfully,

Sharon Au-Curtis

The fish are biting.

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green1 - Karen

From: Sharon Au-Curtis [sharonaucurtis@yahoo.com]
Sent: Tuesday, February 15, 2011 2:36 PM
To: HTHTestimony

Dear Sir or Madam:

I wish to stress my support for establishing a working group to raise education and awareness of lupus. I was an active member in a national lupus awareness and fundraising organization (Alliance for Lupus Research or ALR) for the support of ongoing medical research into the causes and a potential cure for this debilitating disease. As a person living with Lupus I spoke at gatherings in support of this organization by relaying to people the devastating effects and consequences of lupus. Many times I was either approached or written to about the impact my talks had on people. It was interesting to note how many times it was not persons WITH the disease who would approach me but rather people who had intimate relationships or friends with lupus that were profoundly moved by what I had to say. They would relate to me how they had no idea what the person they knew dealt with sometimes on a daily basis in order to keep going.

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Please make this a priority.

Thank you for your kind consideration.

Respectfully,

Sharon Au-Curtis

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