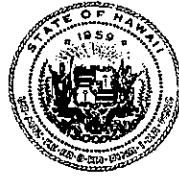


# LATE TESTIMONY

NEIL ABERCROMBIE  
GOVERNOR OF HAWAII



LORETTA J. FUDDY, A.C.S.W., M.P.H.  
ACTING DIRECTOR OF HEALTH

STATE OF HAWAII  
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In reply, please refer to:  
File:

## HOUSE COMMITTEE ON HEALTH

### HCR 194/HR 168, REQUESTING THE CREATION OF THE LUPUS AWARENESS TASK FORCE

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

March 29, 2011  
9:00 a.m.

1 **Department's Position:** The Department of Health would like to provide comment on HCR 194/HR  
2 168, Requesting the Creation of the Lupus Awareness Task Force.

3 **Fiscal Implications:** No appropriation. The Department would require dedicated staff time and funds  
4 to convene a task force and to develop a comprehensive plan to improve education and awareness of  
5 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.

7

Representative Ryan Yamane, Chair  
Representative Dee Morikawa, Vice Chair  
And Members of the Health Committee

Comments on HCR 194 & HR 168:

Requesting the Creation of a Lupus Awareness Task Force

**HCR 194 & HR 168: Thank you for your consideration**

On behalf of Lupus Hawai'i, we'd like to thank you all for your consideration in recognizing lupus as the chronic and debilitating disease it is. Just saying that it is complex and sometimes fatal is not enough, it is recognizing that Hawai'i has a population base of patients who are either not identified yet but falls into the "risk" category of people who are disproportionately affected by lupus. People of color, Native Hawaiians, Pacific Islanders, Asians, Hispanics, Latinos, African Americans, Native Americans and others are affected more than not, although the cause is not yet known. Just knowing this, you can imagine the impact lupus must have on our state, as per capita, we must rank pretty high in the actual number of patients. At this time, though, we just don't know. We don't have an epidemiology study to help us just yet, and it is our hope that one day soon we will be able to have one created and begin the demographic and ethnic study of lupus so we can have current numbers. It will help us direct our focus, education and all-around awareness more appropriately.

In addition to this, you have now given lupus a face. It has been many years that we have tried to bring lupus to the forefront, and you have done so with the previous bills and now with these resolutions. We thank you for that.

For those of you who don't know me, I am also a patient. Although I was initially diagnosed at 16 (which was the year I had my first mini-stroke) it wasn't until I was 42 that I was diagnosed with the correct type of lupus. My lupus affects my central nervous system – because of this, every muscle, nerve and organ that they touch in my body are affected. It is the most rare and most fatal type of lupus but I'm still hanging around. I have no intention of going anywhere I have too many things to do and not enough time to do it.

But it's important to share with you my history because just 2 years ago, I couldn't lift my head, my inspiratory and expiratory rate was at 10% & 20% respectively. And yet, I couldn't get diagnosed correctly, thereby I wasn't able to have insurance pay for my appropriate equipment (like a bi-pap machine) that I needed to survive. I literally had to leave the state. This is what it is like to live as a lupus patient. Unfortunately, not everyone is able or willing to fight.

Even through all my journeys and challenges, I am still being treated with chemotherapy that is NOT covered by insurance and drugs that have side-effects that are worse than the disease. But, the promise of a glimmer of hope that if I stick it out and give them a few weeks or months to work, after the side-effects subside (if they do), maybe some of the symptoms will as well. My theory is, everything is a learning experience. You won't know if you don't try.

Just like this process, we wouldn't have known if we didn't try. I appreciate the process, opportunity and look forward to our future with all of you.

Respectively Submitted,  
Cheryl Ann Jong  
President, Lupus Hawai'i

**From:** Tobacco2 [tobacco2@doh.hawaii.gov]  
**Sent:** Monday, March 28, 2011 5:41 PM  
**To:** HLTtestimony  
**Subject:** HCR194/HR168 Requesting the Creation of the Lupus Awareness Task Force

HCR194/HR168 Requesting the Creation of the Lupus Awareness Task Force

3/29/11

9:00am

Rm. 329

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