



HAWAII MEDICAL ASSOCIATION

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Friday, March 11, 2011 3:30 PM 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: SCR 4 DECLARING THE MONTH OF MAY AS LUPUS AWARENESS MONTH
IN HAWAII.

In Support

Chairs & Committee Members:

The Hawaii Medical Association strongly supports SCR 4 DECLARING THE MONTH
OF MAY AS LUPUS AWARENESS MONTH IN HAWAII.

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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Health Committee Hearing
Friday, March 11, 2011
3:30pm
Conference Room 229

Senator Joshua Green, MD, Chair
Senator Michelle Kidani, Vice Chair
And Members of the Health Committee

Testimony in Strong Support of S.C.R. No.4:
Declaring the Month of May as Lupus Awareness Month in Hawaii

As President of Lupus Hawai'i, it would be a great blessing to have May "officially" declared "Lupus Awareness Month" and recognized as such by our state each year. We could work with that to the benefit of bringing to light more awareness within our community and patients. We will utilize this opportunity to develop a PSA dedicated specifically to May being "Lupus Awareness Month" and we will celebrate this in the manner it deserves.

As of today, we hold events in May to celebrate, but having the state recognition would help us tremendously and bring it to another level. We would appreciate having that opportunity come to fruition.

As a lupus patient, with too many challenges to list because of this disease, it would help me see something that I have only seen twice since I have been volunteering and working for lupus awareness. I know it was recognized sporadically before, *but to have a consistent declaration would mean validation that you all can see, hear and acknowledge that lupus is real - it's here affecting our people and it can kill.* For me, this in itself is a victory that I am thankful for and appreciate you all more than I can say.

May I ask that you consider amending the following to S.C.R. No.4 to make it more complete?

1. Paragraph 3: Add (or change to): *"disproportionately affecting women of Native Hawaiian, Pacific Island, Asian, African American, Hispanic, Latina and Native American decent"* instead of "particularly affecting Native Hawaiian women, Pacific Island women, and women of Asian decent;"
2. After Paragraph 4: ADD: *WHEREAS, there is no cure for lupus and although there are drugs that are used to treat lupus, the side effects often prove to be worse than the disease itself; and*
3. Paragraph 8: Add *"rheumatology"* after "scientists in" (I know it says and other fields, but our rheumatologists play a huge role in research and are on the front lines of lupus care, I think it would be fair to include them in the mix)

I apologize asking for changes, and if I am offensive, please forgive me. I am still learning how to navigate my way through this system.

I will be there in person to testify, I can answer any of your questions regarding this disease, Lupus Hawai'i or me personally. But I wanted to submit this early to let you all know that by signing this resolution and hearing it, means a lot to myself, our patients and will definitely benefit our community as it will boost our ability to spread awareness.

Mahalo.

Respectfully Submitted:
Cheryl Ann Jong, President
Lupus Hawai'i



March 8, 2011

Women In Government is pleased to support Representative Barbara Marumoto's and Senator Michelle Kidani's efforts to lead a debate around the topic of lupus education and awareness. This discussion will highlight ways to improve awareness and education about this debilitating autoimmune disease, for both healthcare providers and the public.

Lupus is a serious disease that affects more than 1.5 million Americans, with annual treatment costs exceeding \$31 billion. Studies reveal that women make up over ninety percent of lupus cases, and women among minority populations are disproportionately affected by this condition.

Unfortunately, lupus is a difficult disease to properly diagnose. According to the Lupus Foundation of America, many of lupus's symptoms are similar to those of other diseases, and these symptoms often come, go, and change over time. Even laboratory tests will not always yield a consistent lupus diagnosis. These characteristics have earned lupus the name "the great imitator," and make it an easy disease to misdiagnose.

Due to its many various symptoms and its multi-system nature, treating lupus is often a complex affair. Patients and providers must be informed of exercise requirements, dietary needs, pain management, infection and immunization issues, and managing depression, all of which may prove necessary in the course of lupus treatment.

The importance of educating both the public and healthcare providers about lupus cannot be overstated. Raising awareness of this disease, its symptoms, its complicated diagnosis, and its treatment represents a critical first step in effectively managing its impact upon women and vulnerable populations. Efforts like Representative Marumoto's, Senator Kidani's, and others are important steps toward achieving this goal, and Women In Government supports their efforts to lead this discussion in the legislature.

If Women In Government can provide any assistance as the Committee discusses the issue of lupus awareness, please contact Libby Derting, Director of Policy and Programs, at 202-333-0825 x248 or lderting@womensingovernment.org.

About Women In Government

Women In Government Foundation, Inc. is a national, non-profit, bi-partisan organization of women state legislators providing leadership opportunities, networking, expert forums, and educational resources. Women In Government serves all 1,725 women who serve in state legislatures from across the country.

Friday, March 11, 2011

To: The Honorable Joshua B Green, M.D.
Chair, Senate Committee on Health
and Members of the Senate Committee on Health

From: Tracy H. Okubo

Re: Senate Concurrent Resolution 4-Making the Month of May Lupus Awareness Month

Thank you for this opportunity to testify in strong support for Senate Concurrent Resolution 4-Making the Month of May Lupus Awareness Month. My name is Tracy H. Okubo and I offer this testimony as a private individual and not on behalf of any company or organization that I may be associated with.

Systemic Lupus Erythematosus, often abbreviated to SLE, or Lupus can affect any part of the body a chronic, autoimmune disease that can damage any part of the body (skin, joints, and/or organs inside the body). In Lupus, something goes wrong with your immune system, which is the part of the body that fights off viruses, bacteria, and germs ("foreign invaders," like the flu). Normally our immune system produces proteins called antibodies that protect the body from these invaders. Autoimmune means your immune system cannot tell the difference between these foreign invaders and your body's healthy tissues and creates auto antibodies that attack and destroy healthy tissue. These auto antibodies cause inflammation, pain, and damage in various parts of the body.

Lupus is not contagious, it is not like or related to cancer, and even though Lupus is an autoimmune disease, it is not like or related to HIV (Human Immune Deficiency Virus) or AIDS (Acquired Immune Deficiency Syndrome). In HIV or AIDS the immune system is underactive; in lupus, the immune system is overactive.

It is estimated that at least 1.5 million Americans have Lupus though the actual number may be higher; however, there have been no large-scale studies to show the actual number of people in the U.S. living with Lupus. More than 16,000 new cases of Lupus are reported annually across the country. It is also believed that 5 million people throughout the world have a form of Lupus.

SLE most often harms the heart, joints, skin, lungs, blood vessels, liver, kidneys, and nervous system. The course of the disease is unpredictable, with periods of illness (called flares) alternating with remissions. The disease occurs nine times more often in women than in men, especially in women in child-bearing years ages 15 to 35, and is more common in those also of non-European descent, particularly Asians.

Though SLE is treatable through addressing its symptoms, mainly with cyclophosphamide, corticosteroids and immunosuppressants; there is currently no cure. SLE can be fatal, although with recent medical advances, fatalities are becoming increasingly rare. Survival for people with SLE in the United States, Canada, and Europe

is approximately 95% at five years, 90% at 10 years, and 78% at 20 years. SLE is one of several diseases known as "the great imitators" because it often mimics or is mistaken for other illnesses. SLE is a classical item in differential diagnosis, because SLE symptoms vary widely and come and go unpredictably. Diagnosis can thus be elusive, with some people suffering unexplained symptoms of untreated SLE for years.

Common initial and chronic complaints include fever, malaise, joint pains, myalgias, fatigue, and temporary loss of cognitive abilities. Because they are so often seen with other diseases, these signs and symptoms are not part of the diagnostic criteria for SLE.

There is no cure for Lupus. But thanks to advances in diagnosis and treatment, it is now considered highly treatable. In the 1950s, most people diagnosed with SLE lived fewer than five years, but with the advances in treatment survival is now at the point where over 90% survive for more than ten years, and many can live relatively asymptotically. I am one of the 90%.

When I was 15 years old I began to notice that I had severe joint pains, fatigue and that I was getting sicker much more often and that it took longer to recover. I went to see numerous doctors and endured test after test. I was lucky though, that the lab technician noticed that I had the same symptoms that her sister, who has Lupus and suggested that we ask our doctor to test me for Lupus.

We were lucky that we caught it relatively early and I was able to get the treatment necessary to minimize the long-term damage to my system. Because of that I have been able to live a relatively normal and healthy life, though I am still susceptible to the challenges of living with an auto-immune disease and am subject to certain limitations such as avoiding sunlight for extended periods of time; no small feat when you live in Hawai'i.

I cannot even begin to explain how much heartache my family and I went through when I was first diagnosed. Even though Lupus affects so many people, because it is hard to diagnose and often is coupled with other diagnoses and diseases it get significantly less attention and funding compared to cancer, diabetes, or heart disease. Yet many health problems can be attributed to or associated with Lupus. It was difficult to find any information about this disease or even any support groups.

With the growing number of Lupus patients and this disease's ability to affect every organ, we need to bring more education and awareness on this topic. This concurrent resolution is a step in the right direction. Lupus Hawai'i is a non-profit organization who provides support, resources, education and awareness about this common, but less-known about disease. However, the support from the state, by declaring the month of May as "Lupus Awareness Month", in addition to passage of Senate Bill 224-Relating to Lupus which would establish a working group dedicated to

increasing Lupus education and awareness statewide would greatly boost the value of their mission, and hopefully bring awareness to a new level.

It is my sincerest hope that this increased level of education and awareness will help to spare future Lupus patients and their families the hardship of having to endure years of countless testing before finally reaching a diagnosis, and then having to gather information and support on their own. It is my sincerest hope that this increased level of awareness will help researchers and foundations secure more support, financial and resource-wise, to develop more research on causes, treatment, and hopefully one day a cure. More information on Lupus could potentially help decrease other associated health problems, including kidney disease, eye disease, and heart disease.

More research could also ensure that Lupus patients are not further harmed by the treatment regimens available to them. When I was first diagnosed I was put on prednisone for over a year. Researchers now know that extended use of prednisone (6 months or more) can cause cataracts; something that I learned in my mid-20's when my optometrist discovered that I had cataracts.

Lupus affects every organ. Lupus affects more people than you realize. And Lupus can kill. When I was first diagnosed we were not sure if I would ever even reach 18. This November will make 17 years since I was diagnosed with Lupus. But I am one of the lucky ones who got assistance from someone who knew about Lupus thus helping me to get diagnosed and treated earlier. It does make a difference.

One of the Lupus Foundation of America's slogans is "Someone you know has Lupus." Well, I'm here today to tell you that yes, someone you know does have Lupus and that someone is me. I respectfully request that you pass this concurrent resolution so that we can take that important first step to supporting the efforts of increasing education and awareness of this common but little known about disease. Thank you for this opportunity to testify in strong support for Senate Concurrent Resolution 4-Making the Month of May Lupus Awareness Month.