

Wednesday, February 16, 2011

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

**LATE  
TESTIMONY**

From: Tracy H. Okubo

Re: Senate Bill 224-Relating to Lupus

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Thank you for this opportunity to testify in strong support for Senate Bill 224-Relating to Lupus. 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.

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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 bill 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, even in the form of a working group 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 bill 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 Bill 224-Relating to Lupus.