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**Subject: TESTIMONY IN STRONG SUPPORT OF HR  
68, Proposed HD1**

Wednesday, April 02, 2014, 9:00 a.m.  
Hawai'i State Legislature Room 329

To: **The House of Representatives Committee on  
Health**

Rep. Della Au Belatti, *Chair*  
Rep. Dee Morikawa, *Vice Chair*  
Rep. Mele Carroll  
Rep. Richard Creagan  
Rep. Mark J. Hashem  
Rep. Jo Jordan  
Rep. Bertrand Kobayashi  
Rep. Marcus R. Oshiro  
Rep. Justin Woodson  
Rep. Lauren Kealohilani Matsumoto

From: **Divina Telan Robillard, Fulltime Caregiver to  
Husband with ALS; also Volunteer BOD  
member/President**, ALS Ohana of Hawaii, 244  
Akiohala St., Kailua, HI; [debsoxo@gmail.com](mailto:debsoxo@gmail.com);  
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Measure Title: HR 68, Proposed HD1: Requesting the Auditor to assess the social and financial effects of requiring health insurers to provide coverage for brain injury.

Proposed HD1: Urging community awareness of Amyotrophic Lateral Sclerosis, also known as ALS or Lou Gehrig's Disease, and community support for finding a cure for ALS and the provision of assistance to ALS patients.

My name is Divina Telan Robillard. I am the fulltime primary caregiver of my husband of 31 years, retired UH Prof. Britt Robillard who has had ALS for 29 years. Almost two decades ago, I co-established the ALS Support Group which received support from the Muscular Dystrophy Association. This support group was finally incorporated last year as the ALS Ohana of Hawaii. We are presently awaiting IRS approval of our application for tax-exempt status as a non-profit organization. AALSOhana As the only local ALS organization in Hawaii, ALSOhana is community-based and volunteer-led. We strive to work with all agencies – private and public, local and national - in order to fulfill our mission of helping ALS families in Hawaii enhance their quality of life through efforts that are practical and compassionate. These efforts are directed primarily to the support and enhancement of family strengths.

I am submitting testimony in vigorous support of HR 68, Proposed HD1, with the following revisions as published in

[http://www.capitol.hawaii.gov/session2014/bills/HR68\\_HD1\\_PROPOSED\\_.HTM](http://www.capitol.hawaii.gov/session2014/bills/HR68_HD1_PROPOSED_.HTM): ...the measure requires two technical changes. In the 2<sup>nd</sup> BE IT FURTHER RESOLVED, the words “ALS support group” should read “ALSOhana”. Delete the words “support group”. In the 3<sup>rd</sup> or final BE IT FURTHER RESOLVED, the words “and ALSOhana” should appear as recipients of a certified copy of the resolution....(retrieved 4:21 p.m. March 31, 2014).

My support of this measure is based on what I perceive as an extensive impact of the illness on families and the community on various levels:

1. Economic. Depending on which population data used, there appear to be 70-100 persons with ALS (pALS) in the State, with 10-20 new cases added every year. ALS is one of the rare diseases (a total of less than 200,000 in the nation) and thus, reporting is not mandatory. Despite its relatively low prevalence, its impact on family members and friends of the afflicted - their finances, resources, employment – tend to increase exponentially. With the high cost of living in Hawaii, it is generally known that families depend on two incomes to live decently. ALS forces many ALS families to survive on less. I speak from experience: I resigned as a Nurse Instructor from Kapiolani CC in order to care



for my husband fulltime, because the cost of his care at home, even for the eight hours a day I would be at work, is many times more than I could earn. After work, I would still have to provide the care he needed the rest of the 24 hours. Thus, one career was sacrificed to support the other. Multiply this experience among families in our ALS community. Home care is only one of the many types of extraordinary expenses – and sacrifices - incurred by families;

2. Caregiver Health. One of the most researched social and health subjects is caregiver stress. As ALS tends to strike at midlife into late adulthood, the pALS may experience other concurrent health concerns such as diabetes and hypertension. The plurality of conditions that plague the pALS significantly drains the physical and emotional resources of family caregivers. It explains increases in employee absenteeism, chronic stress-related conditions such as carpal tunnel syndrome, sciatica, and depression; and
3. Emotional and Relationship Costs. Any kind of disability requiring the amount of care ALS imposes on families, eventually takes its toll on relationships within, especially between spouses. As roles shift, expand and/or get redistributed within families, relationships are disrupted and require constant monitoring and renegotiating. When relationships are unable to withstand the stresses, family disruptions occur, undermining the very basic fabric of social and community life.



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In my almost 30 years as a spouse caregiver and 20 years as a volunteer in ALS-related efforts, I have not ceased to be amazed at how resilient families are despite limited help from health insurance, insignificant level of community awareness (including within the medical profession and caregiving institutions) about ALS and its sequelae; bureaucratic delays in the delivery of medically necessary equipment at home and a home care industry that struggles to fulfill and understand respite needs of families living with ALS.

*Mahalo nui loa* for the opportunity to express my strong support of this measure. Our families deserve the help the resolution proposes; it is a good start.

Sincerely,

Divina Telan Robillard  
Volunteer BOD Member/President  
ALS Ohana of Hawaii

Wednesday, April 2, 2014

Honorable Della Au Belati,  
Chairwoman, and Members  
House Committee on Health  
Hawaii State Legislature

Re: H.R. No. 68, HD1 Urging Community Awareness of ALS or Lou Gehrig's Disease, and  
Community Support for Finding A Cure for ALS and the Provision of Assistance to ALS Patients

Chairwoman Au Belati and Committee Members:

My name is Fred Fisher, and I am the President and CEO of The ALS Association Golden West Chapter. I am pleased to submit this testimony in support of H.R. 68, HD1. The ALS Association Golden West Chapter is pleased to support this resolution because it sends a strong message of support to the ALS community of Hawaii.

ALS, more commonly known as "Lou Gehrig's disease" is among a spectrum of neurodegenerative brain disorders that affect thousands of people. The top five neurodegenerative brain disorders (ALS, Alzheimer's, Parkinson's, Huntington's and Frontal-temporal dementia) are the 5<sup>th</sup> leading cause of death in the country. It is estimated that by 2040, they will have grown to be the 2<sup>nd</sup> leading cause of death in the U.S. None of them currently has an effective treatment or cure.

While some forms of ALS are hereditary, passing from one generation to the next, 90% of ALS is sporadic – people get it without warning and there is no way to predict or prevent its onset.

There are two risk factors, other than genetic; aging is the biggest risk factor. The only other risk factor that we know of is military service. Research has proven that veterans, regardless of their branch of service, regardless of where they served, regardless of whether they served at home or overseas, regardless of when they served – veterans get ALS twice as often as the general population.

More than half of Hawaii's population is over 40. The risk of being diagnosed with ALS for men over 40 is 1:800, for women it is 1:1,000. This, combined with the number of veterans living in Hawaii, means that ALS is an appropriate health concern for this committee, and for the Hawaii legislature.

The first question that is often asked is "why do our veterans get ALS twice as often as everyone else?" The simple answer is, "we don't know." But there is a way to find out the answer to this and other important questions about why people get ALS. The ALS Registry, created by the Federal Centers for Disease Control, is designed to collect data from every living person with



ALS. In the same way that epidemiologist had access to data that enabled them to connect military service to ALS. We want to give epidemiologists and other scientists access to data about the ALS population. This data may help them to discover common factors in people who have ALS, and give them clues about how to treat it.

Currently, Hawaii is among the states that are under-represented in the ALS Registry. Awareness is the first step. We need every person with ALS in Hawaii to know about the registry, and participate in the extensive data collection surveys. Doing so will provide valuable data to scientists. The registry also provides every person with ALS the opportunity to participate in research for a cause and a cure for ALS.

To fully understand the issues here, it is first important to know that ALS is a disease of the brain. Motor neurons, which the brain uses to communicate with our muscles, slowly die. Eventually, ALS affects nearly every muscle in the body, the heart being among the most notable exceptions. The typical course of ALS is 2-5 years. Some progress quicker, some progress at a much slower pace. Whether quick or slow, over time, ALS takes away a person's ability to move, to speak, to swallow, and eventually, to breathe. For most, they are fully aware of this debilitating progression. For about 30% of those with ALS, cognitive impairment is also a feature of the diseases progression.

There is no cure for ALS, and there is only one drug approved by the FDA to slow its progression. This drug, Riluzole, slows the progression of ALS by about 2-4 months. Not much impact. But research has shown that by providing robust multi-disciplinary community and clinic based care, we can extend an ALS patient's life by 10 months, nearly three times as long as the only FDA approved drug. Providing programs and services that help people live longer and better is the number one service priority of The ALS Association Golden West Chapter.

Given the nature of the progression of ALS, it takes nine different medical experts to address the symptom expression. None of us has the ability to see nine different doctors. Our "Standard of Care" – the model that has proven to extend the quality and length of an ALS patient's life, the model that is reflected in the American Association of Neurology practice parameter for the treatment of ALS – calls for these medical experts to meet in a "one-stop-shop" setting, where the patients and their family sit in an exam room at a clinic, and all nine disciplines, (Neurologist, Gastroenterologist, Nutritionist, Speech therapist, Occupational Therapist, Physical Therapist, Respiratory Therapist, Pulmonologist, and a Social Worker) each meets with the patient and family. Over the course of 3-4 hours, every patient is seen by every medical discipline and a comprehensive treatment plan is established and executed by the Golden West Chapter Community Care Manager.

This level of care is not yet available in Hawaii. For those who can afford it, they come to one of our 13 multidisciplinary ALS specialty clinics in CA. But the Golden West Chapter had a challenging time helping them access the service and support they need to continue living in their homes. That's why, at the request of these families, the Golden West Chapter expanded to service the Hawaiian ALS community, in Hawaii. We want to build a robust care program to address the needs of Hawaii's ALS community.

For too long, those with ALS in Hawaii have had to endure the devastating effects of this disease with few resources to address their diverse set of needs. The community needed help, and the Walk to Defeat ALS became the tool that the Hawaiian ALS community used way to raise awareness of ALS, and raise the money that could be used to establish a full program of support for these families.

The ALS Association Golden West Chapter is reinvesting the money raised to establish our model of care here in Hawaii, not just here on Oahu, but on the neighbor islands as well.

Our work would not be possible without the generous commitment of time and money by the Hawaiian ALS community. It is they who make our work possible; those here at this meeting today and those in their homes. No longer is this just Lou Gehrig's Disease. It is their disease, it is our disease, it is the community's disease, and we must do all we can to irradiate it.

I would like to propose the follow amendments to the resolution:

The following paragraph be deleted:

~~WHEREAS, ALS does not affect a patient's mental capacity, and thus, the patient remains alert and aware of the loss of motor functions and the inevitable outcome of deterioration and death; and~~

And replace it with:

WHEREAS, ALS does not typically affect a patient's mental capacity, and thus, the patient usually remains alert and aware of the loss of motor functions and the inevitable outcome of deterioration and death; and

The following paragraph be deleted:

~~BE IT FURTHER RESOLVED that the ALS support group and the ALS Association Golden West Chapter in Agoura Hills, California, be recognized for their joint efforts to achieve the goal of a Hawaii ALS Registry; and~~



and replace it with this paragraph:

BE IT FURTHER RESOLVED that The ALS Association Golden West Chapter, and ALS Ohana of Hawaii, be recognized for their joint efforts to serve and support the Hawaii ALS community and their efforts to achieve the goals of the National ALS Patient Registry; and

The following paragraph be deleted:

~~BE IT FURTHER RESOLVED that certified copies of this Resolution be transmitted to the ALS Association Golden West Chapter and the ALS Association.~~

And replace it with this paragraph:

BE IT FURTHER RESOLVED that certified copies of this Resolution be transmitted to the ALS Association Golden West Chapter and ALS Ohana of Hawaii.

On behalf of the ALS community we serve, thank you for your consideration of this resolution, and the amendments herein.

Mahalo,

Fred Fisher  
President and CEO  
The ALS Association Golden West Chapter  
P.O. Box 11284  
Honolulu, HI 96828



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### TESTIMONY IN STRONG SUPPORT OF HR68 HD1

Measure Title: Urging Community Awareness of Amyotrophic Lateral Sclerosis. Also known as Lou Gehrig's Disease, and community support for finding a cure for ALS and the provision of assistance to ALS patients.

Committee of Health

Wednesday, April 2, 2014, 8:30AM, House of Representatives, The Twenty-Seventh Legislative, Conference Room 329, State Capitol, 415 South Beretania Street

TO: Rep. Della Au Belatti, Chair, Rep. Dee Morikawa, Vice Chair, Rep. Mele Carroll, Rep. Bertrand Kobayashi, Rep. Richard Creagan, Rep. Marcus R. Oshiro, Rep. Mark J. Hashem, Rep. Justin H. Woodson, Rep. Jo Jordan, Rep. Lauren Kealohilani Matsumoto

FROM: Natalie Jones, Treasurer, ALS Ohana of Hawaii

My name is Natalie Jones. My mother-in-law, Violet Jones-Medusky was diagnosed with ALS in 2004. I was 18 at the time and dating her son, Daniel. I became one of her primary caregivers. Vi was an avid surfer and tri-athlete and an amazing woman. She embodied the Aloha spirit. I watched my mother-in-law slowly lose mobility and eventually was completely bed ridden, relying on a ventilator to breathe for her, not being able to move but feeling everything. She lived with ALS for 7 years and passed away on March 29, 2011. We were blessed that she outlived the 2-5 year time frame given to her by doctors, but devastated by this unexplainable, unimaginable disease.

Vi was a strong advocate for spreading awareness about ALS and raising funds to help find a cure. After she passed, she left money to start an organization, which we now call ALS Ohana of Hawaii. Our mission is to provide practical and compassionate support for those families affected by ALS in Hawaii.

ALS Ohana of Hawaii and myself are strong supporters of this bill. In the State of Hawaii there are about 70 people with ALS at any one time. We need to spread awareness about this terrible disease. No one should have to face it alone.

Thank you for taking the time to hear this proposed bill, and for your consideration to support its passing.

TESTIMONY in SUPPORT of HR68 HD1 relating to ALS in Hawaii  
Wednesday, April 2, 2014, 8:30 a.m. Conference Room 329

TO: COMMITTEE ON HEALTH

Rep. Della Au Belatti, Chair  
Rep. Dee Morikawa, Vice Chair  
Rep. Mele Carroll      Rep. Bertrand Kobayashi  
Rep. Richard Creagan      Rep. Marcus R. Oshiro  
Rep. Mark J. Hashem      Rep. Justin H. Woodson  
Rep. Jo Jordan      Rep. Lauren Kealohilani Matsumoto

FROM: Ronaele Whittington, parent of adult child diagnosed with ALS; secretary of Board of Directors of ALSOhana of Hawaii. [RonaeleW@aol.com](mailto:RonaeleW@aol.com) tel 808 261 8400  
810A N. Kalaheo Ave. Kailua, HI 96734

HR 68

REQUESTING THE AUDITOR TO ASSESS THE SOCIAL AND FINANCIAL EFFECTS OF REQUIRING HEALTH INSURERS TO PROVIDE COVERAGE FOR BRAIN INJURY.

Proposed HD1

Status

Proposed HD1: URGING COMMUNITY AWARENESS OF AMYOTROPHIC LATERAL SCLEROSIS, ALSO KNOWN AS ALS OR LOU GEHRIG'S DISEASE, AND COMMUNITY SUPPORT FOR FINDING A CURE FOR ALS AND THE PROVISION OF ASSISTANCE TO ALS PATIENTS.

I strongly support this measure to recognize ALS, to create community awareness, and to provide assistance for ALS patients while continuing to search for a cure.

As published, [http://www.capitol.hawaii.gov/session2014/bills/HR68\\_HD1\\_PROPOSED\\_.HTM](http://www.capitol.hawaii.gov/session2014/bills/HR68_HD1_PROPOSED_.HTM), HD 1 (retrieved 4:21 p.m. March 31, 2014) the measure requires two technical changes. In the 2<sup>nd</sup> BE IT FURTHER RESOLVED, the words "ALS support group" should read "ALSOhana". Delete the words "support group". In the 3<sup>rd</sup> or final BE IT FURTHER RESOLVED, the words "and ALSOhana" should appear as recipients of a certified copy of the resolution.

Until 2010, ALS was a dreaded disease other people dealt with. When our daughter received the ALS diagnosis, my husband and I felt blindsided, devastated, and numb. Our daughter is alive and trying to beat the gruesome odds for survival. Her husband and two grown daughters serve as primary caregivers. In the meantime, my husband and I have taken the challenge to learn as much as we can and do as much as we can with other families to meet this disease head on. We are grateful to the families who have battled ALS and created pathways of coping for newcomers. One such pathway represents the wishes of ALS families, resulting in the incorporation of ALSOhana. I am privileged to serve as secretary of ALSOhana. I have learned that family life and quality of relationships can grow and deepen, regardless of the nasty disease. We want to do more for Hawaii in the years ahead.

House Health Committee members – Thank you very much for supporting this measure. Thank you for collaborating with the various groups of our community who urge recognition of ALS.

Respectfully submitted,  
Ronaele Whittington



Wednesday, April 2, 2014

Honorable Della Au Belati,  
Chairwoman, and Members  
House Committee on Health  
Hawaii State Legislature

Re: H.R. No. 68, HD1 Urging Community Awareness of ALS or Lou Gehrig's Disease, and  
Community Support for Finding A Cure for ALS and the Provision of Assistance to ALS Patients

Chairwoman Au Belati and Committee Members:

I am Elroy Chun, who continues to serve as voluntary Hawaii spokesman in behalf of Hawaii's ALS community and their families at the Congressional level. It is a privilege and, of course, a responsibility undertaking such a role. Fortunately, for the past nine years, our island Congressional delegation has continued to be overwhelmingly responsive to our plea for support of budgetary requests for medical research to find a cure for the devastating Lou Gehrig disease.

Like many other islanders who have lost loved ones to the disease, I too have experienced the trauma of learning that some families who have one so afflicted prefer to remain anonymous and die without many of their friends aware of the cause of their passing. In 2008 Congress passed the National ALS Registry Act, administered by the Centers for Disease Control and Prevention (CDC) as a way for the 50 states to establish a registry. That meant involving all parties who would have knowledge and access to those who have been diagnosed for ALS.

This resolution has a two-part objective: first, to promote community-wide awareness there is support available and that not only the civilian population subject to the disease but that military veterans are also likely to develop the disease while in service; and second, to marshal together as a cohesive, cooperative group the organizations and professionals most likely to be the initial contacts for those afflicted, and through collaborative efforts effect improvements in the servicing of each known victim.

Your support of the Resolution will help bring needed public awareness as support groups prepare for Hawaii's second "Walk to Defeat ALS" on September 6 at Kapiolani Park, Waikiki. Thank you for your kindness and interest to join us in the fight to find a cure.

Aloha,



Elroy Chun

P.O. Box 17659

Honolulu, HI 96817

echun@hilocal675.com

April 1, 2014

Aloha Hawaii House of Representatives, Committee on Health,

Did you know that every 90 minutes someone is diagnosed with ALS, and every 90 minutes someone loses their battle to this fatal disease?

- The average life span after diagnosis is 2-5 years
- Military veterans are twice as likely as the general population to die from ALS
- Living with ALS can cost more than \$200,000 per year

We know these facts because my husband at the age of 65, Gary "Black" Miyashiro, was diagnosed in October 2012 with progressive bulbar palsy, a form of this deadly disease. ALS is such an urgent & devastating disease and many neighbor islanders like us who live on Kauai are not able to get access to support services needed. It took many months simply getting appointments with doctors. We went from doctor to doctor on Kauai and Oahu, however, Gary was unable to get a diagnosis. Time is not a luxury any ALS patient has. It took more than a year since Gary's first symptoms appeared, to finally receive a diagnosis at the University of California, San Francisco ALS Multidisciplinary Center. We were fortunate that Gary was able to travel. Many neighbor island patients are not able to make it to Honolulu.

A diagnosis of ALS presents a tremendous financial burden on a family. In addition to watching their loved ones deteriorate from this deadly disease, ALS families are in constant worry about how they will pay their mounting doctor bills, costs for medical equipment, redesigning their homes for greater access, and in many cases 24/7 care. For neighbor island patients, travel off-island only amplifies this financial burden. Navigating through the healthcare insurance system is confusing, time consuming, and frustrating and add unneeded stress to families already struggling with ALS.

On September 21, 2013, the Golden West Chapter (California) of the ALS Organization helped to sponsor Hawaii's first Walk to Defeat ALS. This walk became a reality for Walk Chairman Nohea Naka'ahiki and her children Max and Mahea, who lost their husband and father, Clarence "Bully" Naka'ahiki, another Kauai native to ALS. Nohea believed that no family in Hawaii should suffer like they did battling this fatal disease. Unfortunately a few months ago, Nohea relocated to San Jose to take a job that would help their family get back on their feet. Nearly four years after Bully's passing, the Naka'ahikis are still struggling to overcome the enormous financial burdens placed upon them from this disease.

I stand in support of H.R. 68 requesting the auditor to assess the social and financial effects of requiring health insurers to provide coverage for brain injury; for my dear friend Nohea, and all families struggling with the devastating effects of ALS.

With fondest aloha,

Joanne Fujio  
321 Kalili Place

Kapaa, HI 96746  
808-651-6385



Subject: TESTIMONY IN STRONG SUPPORT OF HR 68, HD1 Proposed.

Date: Wednesday, April 02, 2014, 9:00a.m.

Room: Hawai'i State Legislature Conference Room 329

To: The House of Representatives Committee on Health

Rep. Della Au Belatti, Chair

Rep. Dee Morikawa, Vice Chair

Rep. Mele Carroll

Rep. Richard Creagan

Rep. Mark J. Hashem

Rep. Jo Jordan

Rep. Bertrand Kobayashi

Rep. Marcus R. Oshiro

Rep. Justin Woodson

Rep. Lauren Kealohilani Matsumoto

From: Richard K Raker

55 S. Judd St., Apt. 1710

Honolulu, HI 96817

rraker@hawaii.rr.com

Measure Title: HR 68, Proposed HD1: Requesting the Auditor to assess the social and financial effects of requiring health insurers to provide coverage for brain injury.

Proposed HD1: Urging community awareness of Amyotrophic Lateral Sclerosis, also known as ALS or Lou Gehrig's Disease, and community support for finding a cure for ALS and the provision of assistance to ALS patients.

My name is Richard K Raker. I am a longtime resident of Honolulu, Hawaii. I have been living with ALS for the last eight years. I am submitting testimony in strong support of HR 68, Proposed HD1 because I understand firsthand how difficult it is for the patient, the family and the caregivers, to cope with the daily struggles of this disease.

Imagine being frozen in your body, unable to move anything but your eyes. You cannot speak, you cannot eat, you get nutrition through a tube in your stomach, you need a ventilator to breathe, and you spend most of your hours/days in a hospital bed. You are completely dependent on others. You rely on your caregivers and family to do everything for you.

But, let me start at the beginning. You felt sick, lethargic and weak for almost 6 months before you were finally admitted into the hospital. Your primary care physician had no idea what was wrong. It took 10 days of testing by specialists to determine the diagnosis. When you first heard the words "ALS – Lou Gehrig's disease," you knew nothing about it, except that it was named after a famous baseball player. When the neurologists gave you the news, and handed you a printed page from a website, that you had a terminal illness and that statistically you only had 3 to 5 years to live, you reacted with disbelief, prayer and courage. "I feel okay, I can beat this."

Within a year, all of your motor neurons had started to shut down. Your muscles began to atrophy. You fell down the stairs several times. You couldn't lift yourself off the toilet. You couldn't drive anymore. You had to stop working. Your children could not rely on you to take them to school or soccer practice. Your wife continued to work, as well as care for you, but your physical condition had worsened to the point that you could no longer be left alone. Expensive paid caregivers, not covered by medical insurance, were needed. The medical bills started to grow. Equipment needed to be purchased, or rented. Insurance only covers so much... Durable Medical Equipment is expensive. With one income, you could not make your mortgage payments and keep up with the medical bills. You started to tap into your 401(k) plan and retirement savings. You had to sell your house and move into an apartment. Then, sadly, you couldn't breathe on your own. And so the disease progresses...

The above paragraph does not match my particular progression/situation exactly, though most of it is true. I've been lucky. I can still speak. I use speech recognition software to control my computer and send this testimony to you. I have Long Term Disability and Social Security income, decent medical insurance along with Medicare. I have a wonderful family, competent caregivers, good friends, and the support of the MDA, and the local Hawaii ALS Support Group. I'm grateful. I'm surviving – eight years now. I try to remain positive, still, the difficulties remain. I worry about the future, when my LTD and medical insurance expire. I wonder how long I can continue to be a financial and emotional burden on my family.

ALS is a relatively rare disease that most people have never heard of. Even my doctors, who are extremely compassionate and competent, had had little experience with the disease. Increasing public and private awareness of the disease can help organizations like the MDA, and local and national ALS organizations, raise funds for research, treatment, and direct support to patients and their families. There are so many competing diseases out there – cancer, Alzheimer's, diabetes, etc. – ALS, because it occurs relatively infrequently in the overall population of Americans, is often overlooked. Please help by declaring that the Hawaii State Legislature is in favor of promoting awareness of the disease, and that you support research funding to find a cure and treatment.

But, I challenge you to do more. Are there other creative things that you can do to help support ALS patients and their families?

Thank you for hearing this measure and for the opportunity to express my strong support of HR 68, HD1 Proposed.

Sincerely,  
Richard K Raker

Personal Testimony by Jim Shon

RE HR 68 HD1 URGING COMMUNITY AWARENESS OF AMYOTROPHIC LATERAL SCLEROSIS, ALSO KNOWN AS ALS OR LOU GEHRIG'S DISEASE, AND COMMUNITY SUPPORT FOR FINDING A CURE FOR ALS AND THE PROVISION OF ASSISTANCE TO ALS PATIENTS.

I support this Resolution, as well as aspects of the original language relating to brain injury. ALS raises several important issues and challenges for our health care system. These include:

- The need for a more fully-developed long-term, chronic care delivery system;
- The importance of aging-in-place social services not only for the aged, but also for any that might have a chronic debilitating condition, such as ALS;
- The difficulty in “fitting” certain conditions within the conventional frameworks of either injury or disease when it applies to the brain;
- The relationship of genetic vs. environmental causes (if indeed veterans are more likely to suffer from ALS);
- The additional financial burdens of any health condition that may require intense and repeated treatments or doctor visits (such as a 20% co-payment).

Jim Shon



Subject: TESTIMONY IN STRONG OPPOSITION OF HR 68, HD 1 Proposed.

Date: Wednesday, April 02, 2014 9:00 a.m.

Room: Hawai'i State Legislature Conference Room 329

To: The House of Representatives Committee on Health

Rep. Della Au Bellatti, Chair  
Rep. Dee Morikawa, Vice Chair  
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Rep. Mark J. Hashem  
Rep. Jo Jordan  
Rep. Bertrand Kobayashi  
Rep. Marcus R. Oshiro  
Rep. Justin Woodson  
Rep. Lauren Kealohilani Matsumoto

From: Robert Lundy, Person with ALS  
75-6161 Haku Mele Pl  
Kailua Kona, HI 96740  
[Rlundy2@charter.net](mailto:Rlundy2@charter.net), phone 760-715-0962

Measure Title: HR 68. Proposed HD 1:

HD1: *Urging community awareness of Amyotrophic Lateral Sclerosis, also known as ALS or Lou Gehrig's disease, and community support for finding a cure for ALS and the provision of assistance to ALS patients.*

My name is Robert Lundy from the Big Island and I have ALS.

I am submitting testimony in strong OPPOSITION of HR 68, Proposed HD 1 because it contains many errors and omissions. For example on page 2 starting on line one. The information is incorrect, what is correct The US Congress passed S. 1382 a National ALS Registry. It is actually administered by the Agency for Toxic Substances and Disease Registry (ATSDR) not the CDC as was originally planned for in the Bill. Lines 1 & 2 are incorrect. This Resolution is very concentrically centered around Oahu and completely ignores/forgets the horrific effects of Lou Gehrig's disease on Persons residing on the neighbor islands.

Page 2 lines 29 – 38 We already have laws in place requiring broadcasters, both TV and Radio to provide ample opportunity for public awareness, it is not a good thing for the legislature to mandate or legislate the community to support a large corporation from California as this Resolution is doing. I'm on the committee for the ALS Association promoted "Walk to Defeat ALS" and as committee members we need to do the leg work, not let a California large corporation bypass the ALS community here in Hawaii and go to the legislature. Do they really know better than we do in this State as they are saying!

Page 2 lines 40 – 43. We see that Agoura Hills, California is the perpetrator and quietly tried to attach a new goal and attach to HR 68 a “Hawaii ALS Registry” and they want the State of Hawaii send them Certified copies of the Resolution they are pushing, as far as I’m concerned they can get their copies off of the web site the same as the rest of us! Back in 2008 the People with ALS (PALS) community nationwide was very excited to push for legislation for a National ALS Registry. We made a lot of mistakes in that bill that I would hate to see Hawaii make. Unfortunately there was no language for transparency, it is a money pit with 40 million spent so far and I just got off the phone with the ATSDR and they hope to put out the first report hopeful the end of May 2014. By not being specific scope creep, excessive costs have plagued that attempt to identify the epidemiology of ALS, and hopefully six years later PALS may see some data from this “Registry”

Thank you for the opportunity to express my strong OPPOSITION for this proposed HD1

Sincerely,

Robert Lundy

ALS sufferer

**LATE**

I am submitting written testimony in support of HR68HD1. ALS is a debilitating disease that prevents signals from the brain to reach nerve endings that trigger muscle movement. A person with ALS loses the ability to control the muscles that tell us to raise an arm, walk, hold a cup, or swallow food. Eventually a person with ALS is unable to breathe. Those with the disease must cope with the progressive loss and degeneration of quality of life. I know of this firsthand because my husband has ALS. I urge the House to pass HR68 and to recognize the Walk to Defeat ALS on September 6. In doing so, we can raise awareness and community support for finding a cure.

Roberta Murray

**LATE**

April 2, 2014

Re: Proposed bill HR 68 HD1

Good morning, my name is Karen Fujii and I am here to Support proposed bill HR 68 HD1.

Today, April 2nd, 2014 is my husband's birthday, Rowland Fujii would have been 68. He passed away last Sunday from complications of ALS.

A little over a year ago, my husband Rowland was diagnosed with ALS in February of 2013.

His symptoms began with weakness in his hands and arms. He stopped driving in June, four months later.

With the help of good friends, we closed his Koa woodworking business on January 11 of this year because he could no longer use his hands. The strength in his legs, chest and abdomen were continuing to show signs of decline.

I know from our experience how frustrating it was to see that Doctors have very little or no real experience with ALS patients.

We had no clue on what to expect from the progression of the disease, and it was very disappointing to see that the doctors also lacked information or experience on how to treat someone with ALS.

They were not able to offer any information unless we asked the question first.

Unfortunately, we were like the general public, we knew nothing of the disease. We had no clue of what questions to ask. All we knew from the doctor was that there was no cure, so you would probably end up in a wheelchair and die between 3 to 5 years after being diagnosed, a few were lucky to have more years.

There was no ALS Clinic in Hawaii, so I asked to be sent to one of the ALS clinics in the mainland. Of course, our insurance would not approve any part of the trips cost or services at this ALS Clinic in San Francisco.

With the help of the ALS Association Golden West Chapter and the Muscular Dystrophy Association, we were guided to an ALS clinic in San Francisco November of last Year.



The staff was very thorough, kind and knowledgeable offering handouts and suggestions specific to our needs. They even loaned us a BiPAP Breathing machine on that visit, something we were trying to get from our doctor since July.

At our visit, we were lead to an examining room. One by one the different doctors/specialists met with us in that same room.

A change from our experience in Hawaii, going to our different appointments on different days. It was difficult because I took off from work every time he had an appointment.

Last week, when my husband was in ICU, I was comforted by our ALS caseworker and the ALS Ohana Support group. They provided guidance to the hospital staff to ensure my husband was given the best treatment for an ALS patient. Which made me feel confident that Rowland was not suffering.

Lastly, I want to say we need help in Hawaii to bring Awareness to the community and to enlighten doctors/Nurses/Staff on ALS treatment and ultimately to provide a clinic for the ALS patients to give them hope, that we are on our way to finding a cure one day soon and that they are not alone in this fight. There is support out there for them.

Rowland lost his battle with ALS this past Sunday March 30, please make Hawaii a better place and approve this proposal.

Thank you for your kind attention.