



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

In reply, please refer to:  
File:

**HOUSE COMMITTEE ON HEALTH**

**HB2286, RELATING TO EPILEPSY DISEASE ASSISTANCE**

**Testimony of Chiyome Leinaala Fukino, M.D.  
Director of Health**

**February 8, 2008. 8:00AM**

1 **Department's Position:** The Department of Health appreciates the challenges and struggles faced by  
2 individuals with epilepsy. It also recognizes the value of education, awareness and treatment of this  
3 condition and acknowledges the role and efforts of the Epilepsy Foundation of Hawaii and its partners.  
4 However, the Department of Health cannot support HB2286 at this time as it does not have the  
5 resources or authorization to implement the requirements of this measure.

6 **Fiscal Implications:** Appropriations out of general funds for deposit into the epilepsy treatment and  
7 education grants-in-aid fund. No funds are allocated for staffing or program costs to carry out the duties  
8 of the Department. This measure exempts the special fund from transfers for central service expenses  
9 and pro rata administrative expenses.

10 **Purpose and Justification:** HB2286 1) establishes a program within the DOH to provide education,  
11 awareness, and treatment initiatives designed to address gaps in service and treatment needs of people  
12 impacted by epilepsy; 2) establishes an epilepsy advisory committee to advise the DOH on their duties  
13 and submit recommendations to establish a regional treatment and education program; and 3) provides  
14 grants-in-aid to fund educational activities and to develop and maintain services for persons with  
15 epilepsy and their families, as managed through an epilepsy program.

1 The DOH does not have the capacity or resources to carry out this measure and there is no mechanism to  
2 provide grants to unspecified recipients.

3 Thank you for the opportunity to testify.

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February 7, 2008

Representative Josh Green, Chair  
Representative John Mizuno, Vice Chair  
House Committee on Health

Friday, February 8, 2008 – 8:00 am  
State Capitol, Conference Room 329

**RE: HB 2286 – Relating to Epilepsy Disease Assistance**

Chair Green, Vice Chair Mizuno, and Members of the Committee:

My name is Corrynne Lopez, and I'm the Executive Director for the Epilepsy Foundation of Hawaii (Epilepsy Foundation of Hawaii). The Epilepsy Foundation of Hawaii is a private, nonprofit organization; who's mission is to increase public awareness of epilepsy and to build a sense of community, enabling persons with epilepsy to participate fully in the community at large. HB 2286 is a more direct way for us to fulfill that mission. We cannot accomplish our goals of educating the public and assisting persons with epilepsy, without such a collaborative effort, as presented in HB 2286. However, as stated many times within our goal: this is a *community* effort.

HB 2286 represents the acknowledgement of a gap in services to our diverse Hawaii community as a whole, particularly our Neighbor Islands and rural Oahu. This break in services increases alienation, stigma, social bias and solidifies feelings of isolation by people with epilepsy, their families and caregivers. By partnering with Department of Health, Epilepsy Foundation of Hawaii would be able to bridge this gap.

- Funding-Epilepsy Foundation of Hawaii currently relies on the Aloha United Way for funding. With the change in AUW's funding policy, our application is still pending, which can result in a loss of more than 30% of the current costs to provide services.
- Programs-we currently offer a support group on Oahu, legal assistance, travel assistance, and community referrals. Programs that we've had to put on hold as a direct result of funding are-social work services, Keiki & Young Adult Support networks, day-camp for children with epilepsy, and our First Responders training. We have not prioritized these programs by importance, but by what our current funding will allow.
- Materials/Services-Epilepsy Foundation of Hawaii is a wealth of up-to-date information on epilepsy, treatment options, medications, etc. Unfortunately, we do not have the staff, volunteer or otherwise, to get this out to the community with the increased demand for education. Current staff is limited to ONE part-time employee and 2 office volunteers. We also cannot afford to continually supply the schools with materials, which has put efforts by the Public Health Nurses to continue epilepsy education of school personnel at a standstill. Partnering with DOH will ensure that all of our schools receive necessary materials. Aside from the school personnel, HB 2286 will aide our educational efforts on all levels, from the layperson to First Responders.

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- Committee-We believe a committee as described by HB 2286, can fully address most of the needs of people with epilepsy, as well as the concerns of the State and DOH. The Committee would ensure that results are measurable, help create attainable and ongoing goals, working with Epilepsy Foundation of Hawaii's mission, as well as the needs of the community.

Most importantly, HB 2286 expresses a need to improve quality of life for all of Hawaii residents through education. On behalf of Epilepsy Foundation of Hawaii, I strongly request your support of HB 2286. I thank you greatly for the opportunity to testify today.

Sincerely,

Mrs. Corrynne E. Lopez  
Executive Director  
Epilepsy Foundation of Hawaii

From: Linda Elento, Member of The Hawaii Down Syndrome Congress

To: COMMITTEE ON HEALTH  
Rep. Josh Green, M.D., Chair  
Rep. John Mizuno, Vice Chair

COMMITTEE ON HUMAN SERVICES & HOUSING  
Rep. Maile S. L. Shimabukuro  
Chair Rep. Karl Rhoads, Vice Chair

Re: HLT/HSB February 8, 2008, 8:00a

**HB2286** In Support  
Relating to Epilepsy Disease Assistance.

Thank you for the opportunity to present testimony in support of HB2286. If the needs addressed in the bill were already being met with existing resources and state agencies, then this bill would not have been introduced in the first place. Please also support the Epilepsy Foundation of Hawaii as they support our keiki, families, co-workers and those we love.

People who will develop, have, or once had epilepsy, a.k.a. seizure disorder, come in all sizes and ages. In my family that would include me and my son Jason who was born with Down syndrome (Trisomy 21) seven years ago. Causes for mine were inconclusive despite being tested and treated for over twenty years. Causes for my son's are most likely due to his Trisomy 21.

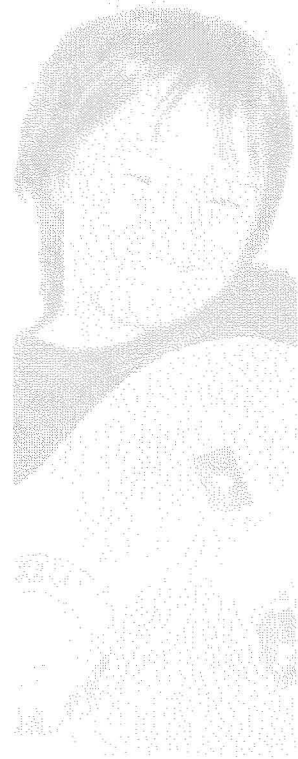
There are over thirty types of seizures with different causes, if the causes are even known. Some can be diagnosed with an EEG. Many cannot. Some people are not diagnosed for many years, missing out on effective treatments. Others are mis-diagnosed with other disorders such as schizophrenia or severe depression. Or, a person with severe depression may also have epilepsy.

A complex partial seizure and generalized seizures are two very different seizures, with different causes and different effects, and can happen to one person, daily or once a year. A complex partial seizure for one person causes different effects than in another person.

A Congressman who experienced seizures initiated measures that turned into the Americans with Disabilities Act. Individuals now find it difficult to meet the eligibility for protection from their disability of seizures because medicine may control the seizures, or seizures "come and go." No doubt this "coming and going" affects every day of my life, more so on some days than others.

Over the years I've only been aware of one organization that performed puppet shows to teach students at schools about epilepsy, dependent on grants and volunteers. Not only did the show catch the children's interest, the show also taught them something they didn't know, but will help them understand how seizures can affect individuals they many come to meet the rest of their lives.

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# THE QUEEN'S MEDICAL CENTER

1301 Punchbowl Street • Honolulu, Hawaii 96813 • Phone (808) 538-9011 • FAX: (808) 547-4646 • www.queens.org

Representative Josh Green, Chair  
Representative John Mizuno, Vice Chair  
House Committee on Health

Friday, February 8, 2008 – 8:00 am  
State Capitol, Conference Room 329

## **RE: In Support of HB 2286 - Relating to Epilepsy Disease Assistance**

Chair Green, Vice Chair Mizuno, and Members of the Committee:

My name is Dr. Alan Stein, epileptologist (epilepsy specialist) and the Medical Director of The Queen's Medical Center Epilepsy Center, the only comprehensive epilepsy center in the State of Hawaii. We support HB 2286, which seeks to expand treatment and education programs to epilepsy patients and their families. We look forward to working with the Department of Health and epilepsy advisory committee to address the service gaps and treatment needs of people impacted by epilepsy.

Epilepsy is a disease of the brain that results in unprovoked seizure episodes. Control of seizure episodes is imperative to preserve brain function. The State of Hawaii has an estimated 15,000 individuals with active epilepsy. Approximately 70% of these will be adequately controlled with medications. Conservative estimates are that 2,000-2,500 of the remaining 30% with intractable (hard to cure or treat) epilepsy will benefit from specialty care including electroencephalographic (EEG) monitoring and further evaluation for state-of-the-art treatment for epilepsy, which Queen's can provide.

Currently, there are numerous barriers to these patients finding access to appropriate care. These barriers include are but are not limited to...

- 1) Adequate numbers of medical specialists
  - a. Neighbor islands are very limited in the number of neurologists
  - b. Most neurologists in the State of Hawaii do not accept Medicaid/Quest
    - i. Many patients with epilepsy cannot hold normal jobs and therefore tend to be covered by medical assistance programs
  - c. There is only a single epilepsy center in the state of Hawaii, and this is staffed by a single neurologist with subspecialty training in epilepsy.
- 2) Transportation to services
  - a. Most epilepsy patients are not allowed to drive
  - b. Most commercial insurance will not pay for inter-island travel even if no qualified specialist is available on their home island
- 3) Lack of knowledge that alternatives and resources exist
- 4) Limitations in treatments available due to insurance limitations

In addition to these barriers to treatment, other issues related to epilepsy permeate the life of those affected individuals. Examples of these issues include:

- 1) Difficulties with employment
  - a. Patients not allowed to work certain jobs
  - b. Difficulties in transportation to/from work
  - c. Employer's fears about epilepsy
- 2) Difficulties with housing or affordable housing
- 3) Family and relationship issues due to misconceptions about epilepsy
- 4) Educational limitations
  - a. Due to mental/physical difficulties as a consequence of seizures
  - b. Due to misconceptions about epilepsy (i.e. send a child home after every seizure rather than simply let them recover for an hour in a health room).

In short, we hope that this bill will provide additional resources for epilepsy patients who routinely experience financial, psychosocial, and physical hardships.

Thank you for this opportunity to testify.

Alan G. Stein, MD  
Medical Director, Epilepsy Center  
The Queen's Medical Center

**FROM: KEONI "JOHN" DEVEREAUX, JR., MS, PHD (Neuroscience)**

FORMERLY: Executive Director, Epilepsy Foundation of Hawaii

PRESENTLY: Project Director/Executive Director, Psychosocial Research Center of the Pacific

President, Hawaii Caregivers Institute for Social Responsibility

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**TESTIMONY FOR: H.B. NO. 2286 (Relating to Epilepsy Disease Assistance)**

**Aloha Kakou!**

Epilepsy as an issue for the public health community has a relatively short history in the United States. Not since the 1970s, when Congress established the Commission for the Control of Epilepsy and Its Consequences and the publication of its formal report, "Plan for Nationwide Action on Epilepsy," has significant attention been paid to the public health implications of epilepsy. In fact, until the U.S. Congress established a small epilepsy program at the Center for Disease Control and Prevention 13 years ago, the condition was practically invisible at all levels of organized public health much more so in the school/education area.

The public is not aware of the spectrum of the severity of Epilepsy. The spectrum it creates is broad, ranging from a very limited effect on the individual to a devastating impact on all aspects of life. Children whose seizures are not well controlled often experience social, emotional, and academic problem and compromise various stages of development. I know, I was a child with epilepsy. These problems commonly extend to adult life, where the issues becoming chronic barriers to employment and independence.

Today, especially in the state of Hawaii, although there had been efforts to increase public information about epilepsy and increase support for those affected and their family specifically provided by the Epilepsy Foundation of Hawaii, there are massive gaps of services all over the state. Significant geographic and cultural barriers to care and information exist in Hawaii, resulting in poor health for many especially in numerous underserved populations and communities. This finding also applies to those who have Epilepsy and other related disorders including their families/caregivers. Factors that contribute to disparities in Hawaii, especially in rural areas, are many and include a lack of health care providers (HCPs) with a specialty in neurology area, lack of trust in Western medicine, lack of knowledge on how to access support/help to providers, and general lack of knowledge of epilepsy and other related disorders and personal health. Factors which contribute to the shortage of health care providers in rural areas include geographic isolation, sparse populations, lack of interaction with the medical community, and lack of access to current medical information and technology.

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Furthermore, cultural needs, understanding, and expectations are also barriers to acceptance of Western medical knowledge. In Hawaii, there is wealth of Pacific cultures with distinct expectations and ideas about medicine in many areas such as neurology, psychiatry, geriatrics, and so on. Furthermore, they may have difficulty understanding current medical practices of the language of healthcare providers.

For more than 31 years, the Epilepsy Foundation of Hawaii, a not-for-profit organization has provided *reliable* information, created supportive programs and services for families, increased resources for epilepsy and research, and influenced changes in public policy. The Epilepsy Foundation of Hawaii is the only organization dedicated exclusively to and serves as the premier source of information and support for the approximately 15,000 people or more in Hawaii with Epilepsy (since it's not a reportable health condition) and, approximately 55,000 family caregivers and 115,000 people who care about them (friends, neighbors, co-workers, church members, etc. The mission of the Epilepsy Foundation of Hawaii is to increase public awareness of epilepsy, build a sense of community, and enable persons with epilepsy to participate fully in the community at large. The goals are to improve quality of life for individuals affected by epilepsy, their families and caregivers; to increase community awareness and compassion towards families impacted by epilepsy; and to reduce the caregiver stress.

The foundation relies it's funding from Aloha United Way, and may soon be affected negatively when Aloha United Way will implement their new policies in allocating and providing financial support to non-profit organizations that meets AUW guidelines. Epilepsy Foundation of Hawaii will likely not able to match AUWs criteria for continued funding. In addition, although an affiliate of Epilepsy Foundation of America, the Epilepsy Foundation of Hawaii also gets it's funding from small, short-term grants and limited public donations.

## **SUPPORTING H.B. NO. 2286**

- I. The Bill, if approved, will provide stability in providing services and support to those affected by epilepsy, their families, and caregivers because it's going to be state funded and managed by state agency such as the Department of Health (DOH)
- II. The Bill, if approved, will be able to reach (MUA) medically underserved areas and (MUP) medically underserved population due to the state larger and stronger infrastructure.
- III. In most situations, the public seemed to have favorable attitude and positive response to government managed programs and versus to non-profit agency for various reasons.
- IV. A government agency managing Epilepsy services will have naturally larger network with various types of organizations (public and private) for partnerships and collaborations necessary and critical in delivering services to those affected by Epilepsy and their families.
- V. The Bill, if approved, the managing state agency such as DOH will be able to provide various support to the Epilepsy Foundation of Hawaii and vice-versa, a symbiotic relation will be developed with positive outcomes for those affected and their families.

The long and winding road. Believe me, it's been like that for me. Aloha! My name is Victoria Kahapea, I am a volunteer worker at the Epilepsy Foundation of Hawaii. I'm also a part-time student attending University of Hawaii, West Oahu. I'm currently taking a psychology course. I find it very interesting, realistic, and it has helped me to realize for certain that my goal is to work with and help people with epilepsy, especially the younger kids, and their parents. I'm saying this from the heart, because I myself have epilepsy.

I know how it feels and what my parents go through. I understand the sacrifices they made, the dreams they gave up and the financial setbacks they put themselves into, so that I can experience my life.

It's been over 20 years since I've been diagnosed with epilepsy, and 10 of those with both grand mal and petit mal seizures. Unfortunately, I can't say that treatment has been always helpful. I've had to constantly change medications, and try new things, just to get my seizures under control. Yes, I do have many hurdles everyday and every night-but how I learned to control my anger and better myself is through my daily prayers, and working with others like me at the Epilepsy Foundation of Hawaii. People who have been a big inspiration for me have been Keoni Devereaux and Corrynne Lopez. The reason: Although they both have the same disability that I have, they don't let it keep them down. We may have gone through some mutual experiences in life, especially with people's ignorance. But it doesn't stop them from living their life. I see them as a positive role model for me.

Having an Epilepsy Disease Assistance Program will be a plus, because there's too many people here in Hawaii that just don't know what epilepsy is all about. Or, if they see someone having a seizure, the general reaction is to "freeze up." This program can change that.

Thank you for letting me testify today.

Ms. Victoria Kahapea  
Volunteer  
Epilepsy Foundation of Hawaii

Shanelle Lum  
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Waipahu, HI 96797  
808-386-2600

February 6, 2008

Representative Josh Green, M.D.  
Chair, House Committee on Health  
Hawaii State Capitol, Room 327  
415 South Beretania Street  
Honolulu, Hawaii 96813

Representative John Mizuno  
Vice-Chair, House Committee on Health  
Hawaii State Capitol, Room 436  
415 South Beretania Street  
Honolulu, Hawaii 96813

Re: In strong support of Epilepsy Disease Assistance HB2286, Relating to Epilepsy Treatment and Education fund to help Epilepsy patients and families. House Committee on Health, February 8, 2008, 8 a.m., Room 329

Dear Chair Green, Vice-Chair Mizuno, and members of the House Health Committee:

I am writing to express my strong support of House Bill 2286, otherwise known as the Epilepsy Bill. This bill mandates funding for Epilepsy treatment and education that would benefit Epilepsy patients and their families.

My son has been affected by Epilepsy since he was exactly 11 months old and he is now 10 years old. Epilepsy has become the most prevalent diagnosis that my son has; he was also diagnosed with Autism in 2001 at 3 years of age. However, the Epilepsy is a condition that requires him to have access to immediate medical assistance as well as adequate medical coverage. I work a full time and part time job to ensure that we have dual medical coverage because without it, his hospital bills would be mounting. My husband and I are lucky because we have family who help watch our son so that we can take time for ourselves. We have been unable to take any 'family' vacations due to his Epilepsy. We are unsure if at any moment that he will have a seizure, and if we're flying on an airplane-well, we don't want to take that chance. The ambulance service knows our son well and our neighbors are also aware of his condition, so that they won't be shocked every time an ambulance is called to our residence.

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It's been a struggle to have to take off of work to rush to the emergency room every time our son has a seizure. He is in a fully contained special education classroom at his public elementary school. His age appropriate level is that of a 2-3 year old and he just turned 10 years old. More needs to be done to ensure that children like my son get adequate care and related services to help ease his diagnosis. I would also like more education to raise awareness about Epilepsy and seizures. People ALWAYS stare while my son is having a seizure and that's part of the reason we don't go to shopping malls/public places as much. I've blogged with other parents who feel as though they have to become 'hermits' because their child's seizures are not controlled and they hate the attention that they get because of it. It's not that their embarrassed about their child, it's that this is a serious medical condition that hasn't received much attention at all and people take it as something completely different. The Epilepsy Foundation has such a limited funding ability that they are unable to support the local parents. Some of us blog on-line and that way we can find comfort in the littlest achievements that our children make. I hate hearing stories about child abuse, neglect, etc... because I always think to myself, those people should be happy because their child was not born with a particular medical or social challenge like how my son is.

I know that my son is happy because he is unaware of the stigma that surrounds him, but I am. As a parent, I feel I owe it to my child to try and make this community a better, more tolerant and accepting place for him. If we can successfully educate people about Epilepsy and seizures as well as provide adequate services and supports for people living with Epilepsy and alleviate some of the financial burdens of those family members who are trying to hold it all together, I think we can accomplish great things for Epilepsy patients.

I urge you to pass House Bill 2286 and make life a little brighter for those who are affected by Epilepsy. We live in such a beautiful place and I feel as though my son and those who share his diagnosis should be allowed to live their lives to the best of their ability.

Thank you for your consideration.

Sincerely,  
  
Shanelle Lum

Mother of Jaren Lum, 10 years old, diagnosed with Epilepsy & Autism