

SB2127

Measure Title:

RELATING TO EPILEPSY DISEASE ASSISTANCE.

Report Title:

Epilepsy Disease Assistance; Appropriation (\$)

Description:

Creates epilepsy treatment and education grants-in-aid fund to help epilepsy victims and families. Creates advisory committee to recommend to DOH the creation of treatment and education programs. Exempts fund from transfers for central service expenses and pro rata administrative expenses. Appropriation.

Introducer(s):

CHUN OAKLAND

Current Referral:

HTH, WAM

February 7, 2008

Senator David Ige, Chair
Senator Carol Fukunaga, Vice Chair
Senate Committee on Health

Friday, February 8, 2008 – 1:15 pm
State Capitol, Conference Room 016

RE: SB 2127 – Relating to Epilepsy Disease Assistance

Chair Ige, Vice Chair Fukunaga, 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. SB 2127 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 SB 2127. However, as stated many times within our goal: this is a *community* effort.

SB 2127 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, SB 2127 will aide our educational efforts on all levels, from the layperson to First Responders.

- Committee-We believe a committee as described by SB 2127, 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, SB 2127 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 SB 2127. 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: Senator David Y. Ige, Chair
Senator Carol Fukunaga, Vice Chair

Re: HTH February 8, 2008, 1:15p

SB2127 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.



THE QUEEN'S MEDICAL CENTER

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Senator David Y. Ige, Chair
Senator Carol Fukunaga, Vice Chair
Senate Committee on Health

Friday, February 8, 2008 – 1:15 pm
State Capitol, Conference Room 016

RE: In Support of SB 2127 - Relating to Epilepsy Disease Assistance

Chair Ige, Vice Chair Fukunaga, 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 SB 2127, 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



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

In reply, please refer to:
File:

SENATE COMMITTEE ON HEALTH

SB2127, RELATING TO EPILEPSY DISEASE ASSISTANCE

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

February 8, 2008. 1:15PM

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 SB2127 at this time as it does not have the capacity
5 or resources or authorization to implement all 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:** SB2127 1) establishes a program within the DOH 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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