

February 5, 2008

~~Sen. David Ige, Chair~~
~~Representative Josh Green, Chair~~

~~Representative John Mizuno, Vice Chair~~

~~House Committee on Health~~

Senate

Sen. Carol Fukunaga, Vice Chair

Friday, February 8, 2008 – ~~8:00 am~~ 1:15pm
State Capitol, Conference Room ~~329~~ 016

SB2127

RE: ~~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~~ as long as the Department of Health works collaboratively with Queen's and the ^{SB 2127} Epilepsy Foundation of Hawaii, which is a local non-profit that already provides epilepsy education and awareness.

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