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Consumer Protection  
Committee  
Rm:325  
Monday  
3/24/08

March 24, 2008

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To: Rep. Robert N. Herkes Chair  
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From: Cynthia J. Goto, M.D., President  
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Philip Hellreich, M.D., Legislative Co-Chair  
Paula Arcena, Executive Director  
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Re: SB 1805 SD1 Relating to Genetic Counseling

The Hawaii Medical Association supports SB 1805 SD1, in its current form.

A previous committee amended the bill at our request and we would appreciate retention of the revisions. The amendment read as follows:

*(c) Nothing in this chapter shall be construed to prevent a physician licensed to practice medicine in this State or intern, fellow, or resident from performing genetic counseling within the person's scope of practice as long as the person is not in any manner held out to the public as a "genetic counselor" or "licensed genetic counselors"*

HMA's concern was that previous versions of the bill would not allow physicians to provide genetic counseling to patients. The above amendment addresses this concern.

Thank you for the opportunity to testify on this matter.

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## House of Representative's Committee on Health

### S.B. 1805, S.D. 1, RELATING TO GENETIC COUNSELORS

Monday, March 24, 2008, 2:00pm

To the Honorable Robert Herkes, the Honorable Angus McKelvey, and Members of the House Committee on Consumer Protection and Commerce:

My name is Lianne Hasegawa, and I am a board-certified pediatric genetic counselor with the Hawai'i Department of Health Genetics Program. However, I am not testifying in my official capacity and am instead providing testimony as a private citizen.

I **strongly support** S.B. 1805, S.D.1 which establishes guidelines for licensure of genetic counselors to ensure professional and quality services for public safety and welfare, and I ask that it be passed unamended.

With the completion of the Human Genome Project in 2003, genetics has fast become an important part of the health care field. Our knowledge about genetics and its application to the medical community is also rapidly increasing. Disease-causing genetic mutations are constantly being classified, and improvements in biomedical techniques result in the rising number of genetic tests available to patients and their families. However, these rapid advances often present a challenge to practicing healthcare providers who must keep up with the array of topics related to medical genetics.

The difficulty of maintaining up-to-date knowledge about genetics is aptly shown in a 2000 needs assessment conducted by the Department of Health Genetics Program. The assessment found that approximately 30% of surveyed Hawai'i physicians had not received any continuing education about genetics within the past year. In addition, family practitioners and internists, who were least likely to have attended a continuing education event on genetics, were self-described as being unlikely to incorporate genetics into their practices.

In contrast, genetic counselors certified by the American Board of Genetic Counselors (ABGC) are required to obtain at least 250 hours of continuing education in the field of genetics within 10 years of receiving their certification. As a result, genetic counselors are often more knowledgeable than primary care physicians regarding genetic risks for disease and current genetic testing techniques. This is shown in two separate, but related studies comparing the genetic risk assessment of obstetricians and genetic counselors:

- Cohn and colleagues (1996) found that, when compared to obstetricians, genetic counselors discovered an additional 35.6% of patients at risk for significant genetic disease based on family history.
- Similar results were obtained by Kosciwa and colleagues (2001) who showed that, through family history alone, genetic counselors found an additional 38.0% of patients at risk for significant genetic conditions as compared to obstetricians.

Genetic counselors are important additions to the health care team. Licensing of genetic counselors would ensure that patients receive optimal services and would protect them from receiving genetic information from providers who lack appropriate knowledge and training. Indeed, communication of



genetic information, especially as related to personal or familial risk for disease, can often affect a patient's psychological well-being as well as their decisions regarding medical management, reproductive options, or treatment. In a 2005 study published in the *Archives of Internal Medicine*, Gurmankin and colleagues found that poor risk communication by inadequately trained health care professionals increased patients' perceptions of their risk for breast cancer above their actual risk. Patients' anxiety levels consequently increased which led them to make different, and potentially worse, medical decisions such as prophylactic mastectomies. Licensure would ensure that genetic counselors receive the training necessary to avoid such issues.

On a personal note, I was born with a genetic birth defect called a cleft lip and palate. Although my lip and palate were surgically repaired before my second birthday, I was left with a noticeable scar on my upper lip that left me open to questions from curious friends, teasing from thoughtless children, and doubts about my appearance and self-worth. I used to view my birth defect as a curse inflicted on me by God or Fate, and I constantly wondered why this had happened to me. Despite the fact that I saw many healthcare providers including plastic surgeons, speech pathologists, and otolaryngologists, none of them could offer me an answer to my question. Far from helping me increase my self confidence, one physician actually suggested that I not have children when I grew up to avoid the "hassle" of caring for a child who might be born with the same birth defect that I had. His offhand remark retains the same sting that it did twenty years ago. It was only after I entered a master's program to become a genetic counselor at the age of 23 that I finally came to terms with my feelings, forgave the physician, and began to accept myself.

I know from firsthand experience that learning of and living with a genetic condition is an emotionally trying time most for families. I also know that interacting with healthcare professionals who lack the skills necessary to provide support during this important period can have long-lasting emotional effects. Genetic counselors are uniquely trained to provide psychosocial support to families as they come to terms with their diagnosis while having the medical knowledge necessary to accurately answer any questions. Licensure would ensure a family's ability to identify genetic counselors who are appropriately trained, and avoid the emotional distress caused by providers who lack the skills to support and inform.

I realize that the recent auditor's report did not recommend licensure for genetic counselors. While it is true that the American Board of Genetic Counselors (ABGC) certifies genetic counselors, it only assures that there is a minimum standard of knowledge that genetic counselors must maintain to pass their certification exam and obtain continuing education. The ABGC does not regulate the profession, and it is only through state licensure that this will occur. Without state licensure:

- There is no body that can impose sanctions on someone providing unethical or unqualified genetic counseling services; and
- There is no body to which the public may report when harmful or damaging genetic counseling services are received.

In addition, I believe that PhD geneticists should be removed from S.B. 1805. It would be too difficult to regulate two distinct professions with different scopes of services and which are accredited by different organizations.

The studies cited above, along with my personal experiences living with a genetic birth defect, are the basis of my dedication to licensure for genetic counselors. Licensure would protect patients and families from harm caused by receiving incorrect information or inappropriate counseling. Licensure

would also allow healthcare providers, particularly those with limited genetics knowledge and psychosocial training, to recognize and refer to licensed genetic counselors.

Thank for you for your time in considering my testimony in support of S.B. 1805, S.D.1.

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From: Linda Elento  
Representative of the Hawaii Down Syndrome Congress

To: COMMITTEE ON CONSUMER PROTECTION & COMMERCE  
Rep. Robert N. Herkes, Chair, Chair  
Rep. Angus L.K. McKelvey, Vice Chair

Re: CPC Monday, March 24, 2008 2:00 pm  
**SB1805, SD1, In Support**  
**Genetic Counselors: Licensure**

In Hawaii, approximately 22 individuals annually are born with Trisomy 21, aka Down syndrome, a genetic difference that can be confirmed shortly after birth.

The news can be devastating and very misunderstood, but it doesn't have to stay that way.

Qualified genetic counselors have served our families in Hawaii, including mine. The information is also critical to our **health and educational programs funded by state funds.**

In particular, the State's lead agencies implementing the federal *Individuals with Disabilities Education Improvement Act of 2004* must understand the developmental and educational implications of our individuals with Down syndrome, and those individuals with other chromosomal disorders.

The Department of Health's Early Intervention Program and the Department of Education's Special Education Program do not fully understand how valuable the research and information that the field of Genetics offers (in Hawaii, we are fortunate to have Dr. Laurie Seaver, M.D., Genetics); however, the qualifications recognized only through licensure of Genetic Counselors, will further benefit our State's efforts to aid these individuals and their families.

Thank you for the opportunity to present testimony in strong support of **SB1805, SD1.**



Testimony Of  
Jennifer Bojanowski, MS, CGC  
Certified Genetic Counselor

Before the House Committee on Consumer Protection & Commerce  
Honorable Representative Robert Herkes, Chair  
Honorable Representative Angus McKelvey, Vice Chair

Wednesday, March 24, 2008, 2:00 pm  
State Capitol, Conference Room 325  
Request 15 copies distributed to committee members

**Re: STRONG SUPPORT for SB 1805, SD 1(SSCR855) RELATING TO GENETIC COUNSELORS.  
Establishing a licensure program.**

Chair Robert Herkes, Vice Chair Angus McKelvey, and committee members, thank you for the opportunity to provide testimony on SB 1805, SD 1, which establishes a licensure program for genetic counselors. I offer my testimony as a Board Certified Genetic Counselor. As a professional, citizen, and registered voter, **I strongly support SB 1805, SD 1.**

Genetic counseling is the communication process which deals with the human problems associated with the risk or occurrence of a genetic disorder in a family. One of the basic tenets and perhaps the most defining feature of genetic counseling is adherence to a non-directive, non-prescriptive, approach. The genetic counselor's role is to make complex medical genetic information accessible and meaningful to individuals, so that they may use that information to make medical and other decisions that are aligned with their own belief and value system.

At no time has such a service been more important. Not only are there more than 9,000 single gene disorders currently described, but the vast majority of common diseases – cancer, diabetes, heart disease – are multifactorial, known to be due in part to genetic risk factors. Most cases of congenital malformation, mental retardation, autism, developmental delay, depression, schizophrenia, bipolar disorder, and other related conditions are due at least in part to genetic predisposition. As a whole, such multifactorial conditions affect more than half the population. Even susceptibility and severity of infectious diseases like HIV/AIDS are influenced by genetic factors. Genetic variation is the human condition and impacts every one of us directly or indirectly at some point in our lifetime.

Every day, additional causative and predisposing genes are described and new genetic tests made available, including the recent rash of direct-to-consumer (DTC) genetic tests. DTC gene tests can be purchased through the internet or even in grocery stores and multiple medical professionals and public health officials have issued cautions about the interpretations of such tests. Without receiving appropriate pre- and post-test counseling, there are serious concerns that individuals may be inappropriately panicked or reassured about their health risks. Misinterpretations of such tests could lead to distressing psychological responses and/or unfortunate laxity in following public health-based recommendations for screening, risk reduction, and prevention of various illnesses.

Many non-genetics providers lack adequate and current specialized training in medical genetics. Even physicians may have had little more than a module or single course in genetics in their training, and without a special interest in the topic, it is difficult keep abreast of current knowledge and trends in genetics, which change on a daily basis. The fact that few primary care providers feel knowledgeable about genetics has been repeatedly documented (Pichert et al, 2003; Kussman, 2004).

While not unique to genetic counseling, non-directiveness is a focus of the field that is somewhat outside the traditional, prescriptive medical model. The importance of non-directiveness in relation to genetics is important for many reasons, not the least of which being vigilance to avoid repeating the exploitation and discrimination characteristic of historical eugenic movements. Without giving attention to the 'art' of genetic counseling, many patients will have a difficult time comprehending the 'science.' Without a clear understanding of testing and reproductive options and support around related psychosocial challenges, making free and informed decisions

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becomes difficult. Indeed, there is evidence to suggest that parental coping with pediatric genetic diagnoses is highly dependent on the ability of health care providers to share accurate and sensitive information (Starke et al, 2002). Other data suggests that pregnant patients faced with a diagnosis of a fetal sex chromosome anomaly make different decisions about keeping or ending a pregnancy based on the type of provider counseling them. While sex chromosome conditions are highly variable and many types are relatively mild, women are more likely to undergo abortion if they receive counseling from a non-genetics provider, as opposed those receiving information from a genetic counselor (Abramsky, et al, 2001; Hall et al, 2003). Even when non-genetic providers have appropriate training and experience with psychosocial counseling and a non-directive approach, it is quite difficult to find time in a busy medical practice to give adequate attention to these psychosocial dimensions.

Licensure for genetic counselors in the state of Hawaii would help protect the public from receiving substandard support and information when coping with a genetic risk or diagnosis. A multitude of case examples illustrate the harm that can be caused by the provision of “genetic counseling” by unlicensed professionals, well-meaning but inadequately informed licensed healthcare providers, as well as currently practicing genetic counselors who are not meeting minimal standards of competency.

**The following cases illustrate harm caused by unlicensed professionals.**

**Case 1.** A marriage counselor called a genetic counselor about a client for whom she was providing pre-marital counseling. Her client had been diagnosed with *Opitz syndrome* as a child but never been told of her diagnosis. This marriage counselor believed that this syndrome caused her client to have emotional outbursts and other behaviors that would make her an unfit mother, so had decided to put her client on birth control. She called the genetic counselor hoping that she would tell her that her client’s syndrome would be passed on to her children, further justifying her insistence that her client not have children. The genetic counselor explained that there are many different syndromes with the name “Opitz” in them and that they are inherited through families in different ways. Without knowing which syndrome this young woman had, there was no way to know what if any risk there was that this woman would pass the condition to her children. A great disservice was done to this family because of the assumptions made by an authority figure lacking the knowledge and training needed to provide accurate genetic information in an appropriate manner. This marriage counselor inappropriately influenced this newly married couple’s decisions about starting a family of their own. This case underlines the importance of allowing patients and other medical providers to identify a group of professionals who have the training and experience to provide genetic information in a manner that respects the rights of patients to make their own informed reproductive decisions. (Laurel Berkheim, MS, of Utah)

**Case 2.** Huntington disease is an inherited, progressive, and fatal disorder that begins in adulthood, usually in the 30’s - 40’s, leading to uncontrolled body movements, dementia, and mental health problems including a high risk of suicide. A genetic test is available for relatives of affected individuals to learn if they will develop the condition before symptoms appear. Because of the life-altering implications of this test, a comprehensive protocol including a neurological evaluation, a psychiatric evaluation, and genetic counseling was developed for genetic testing of asymptomatic individuals. This enables individuals to carefully consider whether or not having this information is in their best interests, and if they do decide to have the testing, that they are psychologically prepared for the results. In this case, a man from a rural area called the genetic counselor in a panic. His symptom-free wife had Huntington disease genetic testing performed by a physician’s assistant without counseling and had received a positive result over the telephone. This man and his wife didn’t know what to do and were beside themselves with fear. Following emergency appointments with the whole Huntington team (genetic counselor, neurologist, psychologist) the couple was able to cope much better with the wife’s. This couple was psychologically harmed by not receiving adequate genetic counseling, the outcome of which could have been much more devastating. A licensed genetic counselor would have known about the increased risk of suicide and the importance of following a standard-of-care predisposition testing protocol. (Bonny Baty, MS, CGC, of Utah)

Licensure would prevent unlicensed providers from acting as “genetic counselors” without appropriate training and information, a situation that could lead to loss of freedom of reproductive choice, untoward psychological consequences, and other negative outcomes.

With increased public awareness of training and competency requirements that comes with licensure of genetic counselors, it is likely that the public will be more discriminating in their choice of who provides genetic services, even when choosing exempted licensed non-genetic counseling providers. For example, many physicians, nurses, and other licensed providers exempted by this licensure bill may not have the background knowledge, psychosocial

intervention skills, and/or time to stay abreast of the explosion of knowledge in the field of genetics. Even those with appropriate training and knowledge are unlikely to have the time available to provide thorough and appropriate genetic counseling services in their busy practices. As a consequence, physicians may be more likely to refer patients to a genetic counselor who could spend the additional time and offer the blend of up-to-date genetics expertise and psychosocial intervention skills their patients deserve. **Below are case examples of harm done by well-meaning but inadequately prepared licensed providers.**

**Case 3.** Mutations in the BRCA 1 and BRCA2 genes are known to give individuals up to an 85% chance of developing breast cancer in their lifetime. A patient was told by her physician that she had tested “negative for BRCA1/2 mutations”. After developing breast cancer within 2 years, the patient went to a genetic counselor. When the genetic counselor tracked down the patient’s records, it was discovered that she had not undergone BRCA1/2 gene testing. Instead, she had normal CA 27-29 testing, a test used to determine whether a person diagnosed with cancer has had progression of the metastatic disease. The test result was of course normal, because it was done two years before she developed breast cancer. The genetic counselor also reviewed the “results letter” the physician wrote to the patient, which stated, “Your breast cancer marker test came back totally normal at 6, so this is very reassuring news in terms of your breast cancer risk.” The physician proceeded to keep the patient on hormone replacement therapy, resulting in increasing her risk to develop breast cancer. (genetic counselor in Wisconsin)

**Case 4.** A patient whose mother had breast cancer diagnosed post-menopause was referred for genetic counseling. The patient stated she had been tested at her doctor’s office for BRCA1/2 mutations and was told the test results were negative. The genetic counselor requested copies of testing and discovered that the patient had actually been tested for two tumor markers associated with breast cancer and that she did not have elevated levels of these markers. She had not in fact been tested for BRCA1/2 mutations. The doctor’s nurse, who had ordered the testing, had read the results (which were in mg/ml) as negative and put a note in the patient’s chart that she was negative for BRCA1/2. When the nurse was contacted by the genetic counselor to clarify the testing ordered, the nurse insisted that these were “breast cancer markers” hence “genetic” testing and that the patient had the correct testing was done. In this case, the primary care providers ordered inappropriate testing increasing the cost of health care for the patient and insurance provider as well as giving the patient false reassurance about her cancer risks. (genetic counselor in Ohio)

In my own practice, I have seen cases where individuals have experienced psychological distress from inaccurate information or education about medical genetic issues. Others have experienced directive or judgmental counseling by well-meaning providers. I have seen the parent-child bond and other family relationships negatively impacted by stigmatizing comments and actions of providers caring for patients with genetic disabilities. I have counseled parents of children with sickle cell disease who had previously decided never to have additional children, assuming all future children would have the disease. Without formal genetic counseling, they had not understood that they only had a 25% chance for recurrence and that there were options for testing in future pregnancies. One parent burst into tears of relief upon learning the genetic basis of her child’s thalassemia, a form of inherited anemia. In the 11 years of her child’s life she had blamed herself for her son’s disease, thinking she had done something to cause it during her pregnancy. Her child’s physical needs had been tended to in weekly medical visits, but no provider had ever taken the time to address the family’s emotional and educational needs. I have counseled women with a strong family history of breast cancer who had previously received little more than informed consent for hereditary breast cancer gene testing from well-meaning physicians. It was not until receiving formal genetic counseling that they could explore their grief over losing a mother or sisters to breast cancer, as well as fear and lack of understanding about their actual individual risk for breast cancer. Truly informed decisions for predisposition testing such as this also require an understanding of the true meaning of a negative, positive, or uncertain gene test result. Understanding cancer risk reduction and screening options, the impact of gene testing on familial relationships, and the extent of protection available against possible employment or insurance discrimination are also critical.

Equally important, genetic counselors themselves must be accountable to enforceable regulations and standards of competency to protect the public from harm. **The following case illustrates the importance of regulating the genetic counselors themselves.**

**Case 5.** A genetic counselor in a prenatal genetics clinic saw a pregnant woman with a prior 1-year-old child with three café au lait (light brown) spots on the skin and an otherwise negative medical and family history. Suspecting possible Neurofibromatosis type I (NF-1), a genetic condition that causes multiple neurofibromas (tumors) and skin changes including café au lait spots, the genetic counselor ordered a \$2000 genetic test for NF-1 on the child. However, this test could only find the responsible mutation in about half of older individuals with a clinical diagnosis of NF-1.



After three weeks of waiting, results came back negative, neither confirming nor ruling out an NF-1 diagnosis in the child. The mother, was very anxious and spoke to her pediatrician, who referred her 1 year-old to an M.D. clinical geneticist. No additional signs of NF-1 were found, and they were told that small numbers of café au lait spots are fairly common in this child's ethnic group and often are a harmless finding, unrelated to NF-1. The parents were both examined; and no signs of NF-1 were found. Appropriately, the child was put on a protocol to monitor for future signs of NF-1, but based on the genetics evaluation, the chance for NF-1 in future children (even if their 1 year-old was found to be affected in the future) was reduced to almost zero. Had the prenatal genetic counselor initiated the referral to pediatric genetics rather than attempting diagnostic testing of the child herself, the parents would have received reassurance about low risks to the current pregnancy a month sooner and the cost of the protein truncation testing would have been saved.

Each day, knowledge gained from the Human Genome project makes its way into mainstream medical practice in the form of screening and diagnostic tests that can identify predispositions, risk factors, disease, and disorders. The application of this technology often proceeds without careful consideration of its far-reaching implications. As our knowledge outpaces our ability to thoughtfully and responsibly apply it, there is a great need for the guidance of specialists. The field of genetic counseling has done much to avoid a return to society's eugenic past, when social ills were blamed on "hereditary degeneracy", states passed laws to forcibly sterilize individuals with genetic disabilities, and exploitation was rampant in the research and treatment of individuals with genetic conditions. However, social stigmatization and discrimination in insurance and employment are of real concern for individuals with genetic differences. Genetic counselors play an important role informing patients and society about these and other implications of genetic testing and diagnoses. By providing informed and supportive counseling services, genetic counselors can help prevent unnecessary psychological distress, avoid inappropriate testing and other medical costs, and protect patients' rights to free and informed medical and reproductive decision-making.

This responsibility is significant, as is the need for creating clear training, continuing education, certification, and clinical competency standards for all practicing genetic counselors. Designating the State to oversee compliance with these standards would further allow employers, physicians, and the public to identify adequately trained genetic counselors and hold them accountable. The cost of administering a licensure program would be minimal given the availability of the already existing national certification standards of the American College of Medical Genetics.

Given all this, I am baffled that genetic counseling is one of the very few allied health professions that is unlicensed in Hawaii. It is a reality that defies common sense in a state with a population over 1 million and typically only about a dozen certified genetic counselors. We have a gap in a service that is needed at an exploding rate. While not a popular justification for licensure, the reality is that third party reimbursement for medical services is rare in the absence of licensure. Without reimbursement for services, sustaining positions is exceedingly difficult in today's healthcare climate. We have already seen the loss of the only genetic counseling position in the entire Kaiser Permanente Hawaii system due to fiscal issues. Other states such as Utah have seen an increase in funding for positions following licensure and third party reimbursement, sustaining the availability of the service for the state's populace. The benefits of licensure would be as multifaceted as the field of genetic counseling itself, improving sustainability and access for a needed service, while ensuring the quality and integrity of that service to protect the public.

The important and growing need is there, but adequate and quality services won't be for Hawaii's citizens without taking this critical first step of licensure for genetic counselors. **I strongly support SB 1805, SD1 and thank you for your consideration of this matter.**

#### References:

- Abramsky L, et al. What parents are told after prenatal diagnosis of a sex chromosome abnormality: interview and questionnaire study. *BMJ*. 2001 Feb 24; 322(7284):463-466.
- Hall S, et al. Health professionals' reports of information given to parents following the prenatal diagnosis of sex chromosome anomalies and outcomes of pregnancies: a pilot study. *Prenatal Diagnosis*. 2003 Jul; 23(7):535-538.
- Kussman, et al. Current and desired roles in the provision of genetic services among family physicians in the United States. *J Genetic Counseling*. 2004; 13(6):543-544.
- Pichert G, et al. Swiss primary care physicians' knowledge, attitudes and perception toward genetic testing for hereditary breast cancer. *Fam Cancer*. 2003; 2(3-4):153-158.
- Licensure for Genetic Counselors in the Commonwealth of Massachusetts: Cases of Harm. A compilation of case presentations from across the country. (document can be forwarded on request)

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**From:** Susan Donlon [sdonlon@hawaii.rr.com]  
**Sent:** Friday, March 21, 2008 11:39 AM  
**To:** CPCtestimony  
**Subject:** SB1805

Testimony of  
 Susan Donlon  
 President, Ohana Genetics Inc.  
 Honolulu, HI

Before the House Committee on Consumer Protection & Commerce  
 Honorable Representative Robert N. Herkes, Chair  
 Honorable Representative Angus L.K McKelvey, Vice Chair

Monday, March 24, 2008, 2:00 pm  
 State Capitol, Conference Room 325  
 Request 15 copies distributed to committee members

**STRONG SUPPORT for SB 1805, SD 1 (SSCR855) RELATING TO GENETIC COUNSELORS.** Establishing a licensure program.

Chair Robert Herkes, Vice Chair Angus McKelvey, and committee members, thank you for the opportunity to provide testimony on SB 1805, SD 1 which establishes a licensure program for genetic counselors. I offer my testimony as a PROFESSIONAL, CITIZEN, and REGISTERED HAWAII VOTER, and **I strongly support the unamended passage of SB 1805, SD 1** for the following reasons:

- Genetic counseling is an established profession (25 years).
- Genetic counselors are certified under the American Board of Medical Genetics or American Board of Genetic Counseling
- The scope and applications of genetic counseling are growing and will soon have the potential to benefit our entire population.
- Certified Genetic Counselors (CGC) provide a service (genetic risk assessment) that has the potential to optimize health care for the individual and their family.
- Due to the complexity of a genetic risk assessment, those who are not CGC's can provide information which may be detrimental to the health of the individual and their family.
- CGC's are trained to handle the psychosocial, legal and ethical implications of genetic information and uphold the highest standard of patient confidentiality.
- The CGC is a recognized member of interdisciplinary team management for prenatal, pediatric and adult care. Many organizations including The American Society of OB/GYN, American Society of Clinical Oncologists, American Academy of Pediatrics, and the American College of Medical Genetics have established position statements outlining the necessity for genetic counseling.
- Well known public health advisory entities such as the US Preventive Services Task Force (USPSTF) address the need for genetic counseling.

The explosion of Direct-to-Consumer (DTC) genetic tests since the State Auditor's Sunrise Report presents a major risk for harm to the public if misinterpreted or used inappropriately. Contrary to the report's conclusion, the emergence of DTC genetic tests makes identification of and access to quality-assured genetic counseling services absolutely critical. In addition, prior testimony has referring to other instances of harm to the consumer that could be addressed in part by regulating this profession.

A mechanism must be established to remove a genetic counselor's right to practice if he/she is found to be incompetent or unscrupulous. Genetic counselors are involved in ethically charged areas of reproductive and medical decision-making. Ensuring ethical and competent practice is a safeguard against discriminatory or otherwise improper and damaging use of genetic information. State regulation of genetic counseling specialists should not be the only approach to protecting consumers from, but it should certainly be one prong of consumer protection. Presuming consumers are not savvy enough to understand the additional quality control that comes with conferring a

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te license is to give consumers too little credit.

There is no sustainable insurance reimbursement for genetic counseling services in Hawaii, despite multiple efforts by the genetics community to collaborate with government and third party insurers. There is a new billing code that could be used to obtain fair reimbursement for genetic counseling services from insurers, but only if the profession becomes licensed. Hawaii is facing the loss of healthcare providers and specialists at an alarming rate. We do not want to lose access to this specialty service when we should be seeing increased access for outer islands and other underserved populations.

From the explosion of direct-to-consumer genetic tests and the exodus of healthcare specialty providers from Hawaii, we need to take multiple approaches to consumer protection. Licensure is one needed approach to ensure access to quality specialty genetic counseling services in our state.

I regret that I will not be able to testify in person. Please accept this letter as my sincere testimony in support of this bill.

00150

3/24/2008

**House Committee on Consumer Protection and Commerce  
SB 1805, SD 1, Relating to Genetic Counselors**

Monday, March 24, 2008 at 2:00 PM  
Hawai'i State Capitol

**Please make 5 copies of this testimony**

To the Honorable Chair Robert Herkes, Vice Chair Angus McKelvey and Members of the House Committee on Consumer Protection and Commerce:

My name is Edward Camara and I am in support of SB 1805 SD1. In late 1993 and early 1994, I gained over 50 lbs., I had high blood pressure, and bad acne.

My doctor diagnosed me with Cushing Syndrome which over produces a hormone called ACTH from the adrenal glands. My doctor had me take a chest x-ray. The x-ray showed baby tumors in my lungs which was the reason for the over producing of the adrenal glands. The doctors could not find the primary tumor. I had a lung biopsy in '94 and the result was an unknown type of carcinoma. My doctors did not know how to treat the tumors, so they decided to take my adrenal glands out in '96.

In '98, I had a foot of my colon taken out due to diverticulitis. I began losing weight slowly because of chronic diaherra. In 2003, I had a Transient Ischemic Attack (TIA) which is a minor stroke. My doctors did not know why I was having these medical problems at a young age.

In 2005, my wife was three months pregnant and visited her OB doctor. The OB doctor suggested that my wife and I should see a genetic counselor since I was born with clubfoot. We decided to go genetic counseling and I told my story of my medical problems.

When I came back the following week, I was told that I had a disease called Multiple Endocrine Neoplasia Type 2B (MEN2B). Genetics made the diagnoses based on my club feet, puffy lips, the bone structure of my arms, the inside of my mouth, my adrenal glands, the diaherra, and my tumors. But I needed to take a DNA test to confirm that I have the disease. A little over a month later, the DNA confirmed that I had MEN Type 2B. Majority of my medical problems was symptoms of MEN. MEN type 2B causes Meduallary Thyroid Cancer (MTC). So, I had a biopsy of my thyroid and it showed that I have Meduallary Thyroid Carcinoma Cancer.

MEN Type 2B is heredity, so there was a 50/50 chance that my daughter might have the disease. After she was born, we had a DNA test done and it was confirmed that she has the same disease. We were told that she needed surgery to take her thyroid out before the age of 1 year. A few months later

she had her thyroid taken out. My daughter (Estelle) will have to be monitored for the rest of her life to check for signs of the MTC and to take at least one adrenal gland out before the age of 10yrs. old. One of the symptoms of MEN 2B is adrenal gland cancer.

I finally know what is causing my medical problems because of the work of genetic counselors. Genetics helped my daughter by preventing a incurable cancer and helped me by diagnosing me with MEN. Now my doctors know what to look for and how to treat my existing problems. Although, Genetics is new in the medical field, they can help many people with medical problems and save lives.

Thank you for your time.  
Edward Camara Jr.

**State of Hawaii**  
**House of Representatives**  
**Committee on Consumer Protection and Commerce**

**SB 1805 (SD1)**  
**RELATING TO GENETIC COUNSELORS**

Monday, March 24, 2008

2:00 pm

Conference Room 325

To the Honorable Rep. Robert N. Herkes and Rep. Angus L.K. McKelvey and members of the Committee on Consumer Protection and Commerce,

As a medical geneticist, a physician who works closely with genetic counselors on a daily basis, **I strongly support SB 1805 (SD1) relating to the professional licensure of genetic counselors.** Genetic counselors are a vital part of the healthcare team that provides care to individuals throughout the lifespan. Genetic counselors are frequently the primary providers of genetic information and counseling to pregnant women whose babies are at risk for birth defects and other genetic conditions. They are also the primary provider of genetic risk assessment for men and women with cancer or a significant family history of cancer. Genetic counselors also assist me as I evaluate and manage children and adults with heritable conditions.

Licensure would protect the public by ensuring that genetic counseling is provided only by individuals with the high level of training and certification that genetic counselors possess. A board-eligible or board-certified genetic counselor has a Master's Degree in Genetic Counseling which includes the science of genetics, psychosocial, legal and ethical aspects of genetics, and extensive supervised direct patient contact. They are certified by the American Board of Genetic Counseling or the American Board of Medical Genetics. They are required to maintain their certification and excellence in the rapidly changing field of human genetics by continuing education credits.

The ability for the public to identify an appropriately trained genetic counselor is increasingly important because of the explosion of direct-to-consumer (DTC) marketing of genetic testing. During the time that licensure of genetic counselors in Hawaii has been studied, a special report was commissioned by the U.S. Senate Special Committee on Aging regarding DTC marketing of genetic testing. Sen. Gordon Smith from Oregon noted during this hearing, **"I am deeply disturbed by the GAO's finding that consumers are being misled and exploited."**

Licensed genetic counselors are crucial as the primary source to assist patients and their physicians who have questions about indications for genetic testing, validity of testing, reliability of laboratories providing genetic testing, and interpretation of genetic test results. Even when genetic tests are medically indicated, there is abundant documentation of the lack of genetic knowledge in non-genetics health care providers at all levels who

RELATING TO GENETIC COUNSELORS

SB 1805 (SD1)

Page 2

Laurie H. Seaver, MD

often do not understand the indications, benefits, limits and risks of genetic testing, nor do they know how to interpret the results. Genetic counselors are crucial members of our health care team to assist physicians and patients with information and counseling before and after genetic testing.

**In recognition of the value of genetic counseling in the practice of medicine, the AMA has recently approved a CPT® (Current Procedural Terminology) code for Genetic Counseling. These codes can only be used by licensed health professionals.**

Licensure of genetic counselors is necessary in order for genetic counselors to bill for their services. Currently, hospitals or clinics have to subsidize this cost, which places these positions at risk with every budget cycle. We are all aware of the health care crisis in Hawaii, and that hospitals are increasingly abandoning such “non-billable”, but yet vital, health care services. Licensure ensures the sustainability of genetic counselors in our hospitals; with licensure, Hawaii will likely lose genetic counselors to states that have licensure and where their services can thus be recognized and sustained within the healthcare setting.

Licensure of genetic counselors has the potential to reduce healthcare costs since genetic counselors are reimbursed at a lower rate than physicians. Further, there are not enough trained genetic physicians to provide all genetic services and counseling necessary in most communities. This is especially true in Hawaii, where, for several years there was no physician medical geneticist to care for children and non-pregnant adults. During this time, the genetic counselors provided vital communication and consistency to patients who were being seen by mainland physicians.

I hope that the State of Hawaii joins several other states that have passed Genetic Counselor Licensing bills, and several other states that are currently poised to pass similar legislation. These states are leaders in recognizing the importance and complexity of the genetic contribution to health and human disease and the need for highly qualified health care providers. The cost of such a licensure program for the State of Hawaii should be low, since the eligible genetic counselors are already passed national certification after stringent eligibility requirements.

Thank you for allowing me the opportunity to provide testimony in support of SB 1805 (SD1).

Laurie H. Seaver, MD

19 Ilikupono St.

Kailua, HI 96734

254-1819

00154

mckelvey3

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**From:** Ann [earlesan@hawaiiantel.net]  
**Sent:** Thursday, March 20, 2008 10:00 PM  
**To:** CPCtestimony  
**Subject:** SB 1805, SD 1

To Whom it May Concern;

As a voting Hawaii constituent, I **STRONGLY URGE THE COMMITTEE TO PASS SB1805 , SD 1 REGARDING GENETIC COUNSELORS WITH NO AMENDMENT AT THE HEARING ON MARCH 24.**

Since the State Auditor's Sunrise Report was released, many developments have increased the need for state regulation of the genetic counseling profession. From the explosion of direct-to-consumer genetic tests and the exodus of healthcare specialty providers from Hawaii, we need to take multiple approaches to consumer protection. **Licensure is one needed approach to ensure access to quality specialty genetic counseling services in our state.**

The Sunrise Report concludes that licensure "would not protect the public from incompetent, unscrupulous, and unauthorized persons" in part because the bill "has no bearing on direct, commercial marketing of DNA testing and counseling." I disagree. The Federal Trade Commission (FTC) has published a consumer alert regarding "at-home" genetic tests. The FTC cites the FDA and CDC's recommendation that results of such tests should be "interpreted by a doctor or trained counselor who understands the value of genetic testing for a particular condition....Most companies that sell at-home genetic tests do not interpret the results." The agencies further caution that "some of these tests lack scientific validity, and others provide medical results that are meaningful only in the context of a full medical evaluation." Receiving misinterpreted or misinformed results from an unqualified or unscrupulous provider could lead to consequences that impact reproductive and medical decision-making. State regulation of genetic counseling specialist should not be the only approach to protecting consumers from slippery-slope and ethically-questionable use of genetic tests, but it should certainly be one prong of consumer protection. Presuming consumers are not savvy enough to understand the additional quality control that comes with conferring with a state licensed is to give consumers too little credit.

As a worker in minority health for over 20 years I am all too familiar with the consequences of genetic misinformation and bias. I urge your to do your part to prohibit some of the mistakes made with other ethnic minorities from happening here in our ethnically diverse state.

Again, I respectfully URGE that SB 1805, SD 1 to be PASSED WITHOUT AMENDMENT.

Respectfully,  
Ann Earles, RN/PNP  
68-1979 Lina Poepoe St.  
Waikoloa, HI 96738  
808-883-3919

00155

3/24/2008



Testimony of  
Jeremy Michelson, P.E.  
828 Fort Street Mall, Suite 600  
Honolulu, HI 96813

Before the House Committee on Consumer Protection & Commerce  
Honorable Representative Robert N. Herkes, Chair  
Honorable Representative Angus L.K McKelvey, Vice Chair

Monday, March 24, 2008, 2:00 pm  
State Capitol, Conference Room 325  
Request 15 copies distributed to committee members

Re: STRONG SUPPORT for SB 1805, SD 1 (SSCR855) RELATING TO GENETIC COUNSELORS.  
Establishing a licensure program.

Chair Robert Herkes, Vice Chair Angus McKelvey, and committee members, thank you for the opportunity to provide testimony on SB 1805, SD 1 which establishes a licensure program for genetic counselors. I offer my testimony as a registered Hawaii voter, and **I strongly support the unamended passage of SB 1805, SD 1** for the following reasons:

- The explosion of Direct-to-Consumer (DTC) genetic tests since the State Auditor's Sunrise Report presents a major risk for harm to the public if misinterpreted or used inappropriately. Contrary to the report's conclusion, the emergence of DTC genetic tests makes identification of and access to quality-assured genetic counseling services absolutely critical. In addition, prior testimony has referring to other instances of harm to the consumer that could be addressed in part by regulating this profession.
- A mechanism must be established to remove a genetic counselor's right to practice if he/she is found to be incompetent or unscrupulous. Genetic counselors are involved in ethically charged areas of reproductive and medical decision-making. Ensuring ethical and competent practice is a safeguard against discriminatory or otherwise improper and damaging use of genetic information. State regulation of genetic counseling specialists should not be the only approach to protecting consumers from, but it should certainly be one prong of consumer protection. Presuming consumers are not savvy enough to understand the additional quality control that comes with conferring a state license is to give consumers too little credit.
- There is no sustainable insurance reimbursement for genetic counseling services in Hawaii, despite multiple efforts by the genetics community to collaborate with government and third party insurers. There is a new billing code that could be used to obtain fair reimbursement for genetic counseling services from insurers, but only if the profession becomes licensed. Hawaii is facing the loss of healthcare providers and specialists at an alarming rate. We do not want to lose access to this specialty service when we should be seeing increased access for outer islands and other underserved populations.

From the explosion of direct-to-consumer genetic tests and the exodus of healthcare specialty providers from Hawaii, we need to take multiple approaches to consumer protection. Licensure is one needed approach to ensure access to quality specialty genetic counseling services in our state.

**mckelvey3**

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**From:** Matt White [mfwhite5@gmail.com]  
**Sent:** Sunday, March 23, 2008 12:05 PM  
**To:** CPCtestimony  
**Subject:** March 24 House CPC Hearing at 2pm re: SB1805 SD1 SSCR855

Testimony of  
Matthew White, CTO  
Kahala Code Factory  
1649 Mahina Ave.  
Honolulu, HI 96816

Before the House Committee on Consumer Protection & Commerce  
Honorable Representative Robert N. Herkes, Chair  
Honorable Representative Angus L.K McKelvey, Vice Chair

Monday, March 24, 2008, 2:00 pm  
State Capitol, Conference Room 325  
Request 15 copies distributed to committee members

**Re: STRONG SUPPORT for SB 1805, SD 1 (SSCR855) RELATING TO GENETIC COUNSELORS.  
Establishing a licensure program.**

Chair Robert Herkes, Vice Chair Angus McKelvey, and committee members, thank you for the opportunity to provide testimony on SB 1805, SD 1 which establishes a licensure program for genetic counselors. I offer my testimony as a registered Hawaii voter, and I strongly support the unamended passage of SB 1805, SD 1 for the following reasons:

I am a potential consumer of genetic testing. I have a family history of Huntington's Disease with a high risk of inheriting this condition. It is an adult onset degenerative genetic condition leading to uncontrolled movements, loss of intellectual faculties, and emotional disturbance. With the current pace of genetic discovery and technology, I want to have confidence in the services regarding my potential disorder. Licensure for genetic counselors will enable me to easily recognize qualified genetics professionals who provide these services.

The explosion of Direct-to-Consumer (DTC) genetic tests since the State Auditor's Sunrise Report presents a major risk for harm to the public if misinterpreted or used inappropriately. Contrary to the report's conclusion, the emergence of DTC genetic tests makes identification of and access to quality-assured genetic counseling services absolutely critical. In addition, prior testimony has referring to other instances of harm to the consumer that could be addressed in part by regulating this profession.

A mechanism must be established to remove a genetic counselor's right to practice if he/she is found to be incompetent or unscrupulous. Genetic counselors are involved in ethically charged areas of reproductive and medical decision-making. Ensuring ethical and competent practice is a safeguard against discriminatory or otherwise improper and damaging use of genetic information. State regulation of genetic counseling specialists should not be the only approach to protecting consumers from, but it should certainly be one prong of consumer protection. Presuming consumers are not savvy enough to understand the additional quality control that comes with conferring a state license is to give consumers

00157

too little credit.

There is no sustainable insurance reimbursement for genetic counseling services in Hawaii, despite multiple efforts by the genetics community to collaborate with government and third party insurers. There is a new billing code that could be used to obtain fair reimbursement for genetic counseling services from insurers, but only if the profession becomes licensed. Hawaii is facing the loss of healthcare providers and specialists at an alarming rate. We do not want to lose access to this specialty service when we should be seeing increased access for outer islands and other underserved populations.

From the explosion of direct-to-consumer genetic tests and the exodus of healthcare specialty providers from Hawaii, we need to take multiple approaches to consumer protection. Licensure is one needed approach to ensure access to quality specialty genetic counseling services in our state.

Sincerely,

Matthew White

00158

3/24/2008

**House Committee on Consumer Protection and Commerce  
SB 1805, SD 1, Relating to Genetic Counselors**

Monday, March 24, 2008, 2:00 PM  
Hawai'i State Capitol Room #325

**Please make 5 copies of this testimony**

To the Honorable Chair Robert Herkes, Vice Chair Angus McKelvey and Members of the House Committee on Consumer Protection and Commerce:

I strongly support SB 1805, SD 1, relating to professional licensure of genetic counselors. Upon completion of my clinical and academic training, I have been a practicing genetic counselor in Hawaii for the past seven years.

Genetic counselors are health professionals with specialized graduate degrees and experience in the areas of medical genetics and counseling. We are board certified by the National Board of Genetic Counseling. The responsibilities of a genetic counselor are threefold: (i) to provide expertise in clinical genetics; (ii) to counsel and communicate with patients on matters of clinical genetics; and (iii) to provide genetic counseling services in accordance with professional ethics and values.

The National Society of Genetic Counselors (NSGC) Code of Ethics is based upon the relationships genetic counselors have with themselves, their clients, their colleagues, and society. These values are drawn from the ethical principles of autonomy, beneficence, nonmaleficence, and justice. The primary concern of genetic counselors is the interests of their clients. We strive to maintain information received from clients as confidential, unless released by the client or disclosure is required by law.

Heightened public awareness, coupled with scientific advances in adult disorders and reproductive technologies, have increased the demand for genetic counselors. Genetic counselors are the primary source in Hawai'i to assist patients and their physicians who have questions about indications for genetic testing, validity of testing, reliability of laboratories providing genetic testing, and interpretation of genetic test results. The recent explosion of direct to consumer genetic testing truly underscores the need for the public to be able to recognize who is qualified to provide genetic counseling services and to interpret genetic test results. Licensure will ensure the responsible practice of genetic counselors in Hawaii, protecting the consumer from harm and providing a mechanism for recourse when consumers are harmed.

I respectfully urge you to pass SB1805, SD1 unamended. Thank you for allowing me the opportunity to provide testimony in support of SB 1805, SD 1. Please contact me if you have questions.

Linda Cheng, M.S., C.G.C.  
Certified Genetic Counselor  
The Queen's Comprehensive Genetics Center  
1329 Lusitana Street, Suite B-8  
Honolulu, HI 96813  
Phone: (808) 537-7633

00159

**House Committee on Consumer Protection and Commerce**  
**SB 1805, SD 1, Relating to Professional Licensure**  
Monday, March 24, 2008 at 2 PM  
**Hawaii State Capitol**  
**Please make 20 copies of this testimony**

To the Honorable Chair Robert Herkes, Vice Chair Angus McKelvey, and Members of the House Committee on Consumer Protection and Commerce:

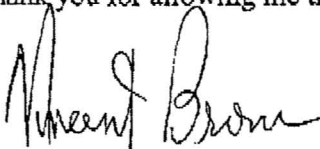
I strongly support **SB1805 SD1**, relating to professional licensure of genetic counselors. I am a physician in Hawaii who works with genetic counselors regarding patients of a variety of indications.

Genetic counselors are health professionals with specialized graduate degrees and experience in the areas of medical genetics and counseling. They are board certified by the National Board of Genetic Counseling. Genetic counselors work as members of a health care team, providing information and support to families who have members with birth defects or genetic disorders and to families who may be at risk for a variety of inherited conditions. They serve as patient advocates and educators for other health care professionals and for the general public.

The American Medical Association (AMA) has recently approved a CPT® (Current Procedural Terminology) code for Genetic Counseling in recognition of the value of genetic counseling in the practice of medicine. These codes can only be used by licensed health professionals. Licensure is the first necessary step toward establishing genetic counselors as allied health professionals that may someday receive reimbursement from third party payors for the services they provide to patients. At this time, most genetic counselors in Hawai'i are not reimbursed for their services, making it difficult for hospitals and clinics to support these services. Just as physicians and nurses have both board certification and state licensure, so should genetic counselors.

Heightened public awareness, coupled with scientific advances in adult disorders and reproductive technologies, have increased the demand for genetic counselors. Genetic counselors are the primary source in Hawai'i to assist patients and their physicians who have questions about indications for genetic testing, validity of testing, reliability of laboratories providing genetic testing, and interpretation of genetic test results. The recent explosion of direct to consumer genetic testing truly underscores the need for the public to be able to recognize who is qualified to provide genetic counseling services and to interpret genetic test results.

Thank you for allowing me the opportunity to provide testimony in support of **SB1805 SD1**.



Vincent Brown, MD  
Radiation Oncologist

00160

**House Committee on Consumer Protection and Commerce  
SB 1805, SD 1, Relating to Professional Licensure**

Monday, March 24, 2008 at 2 PM

**Hawaii State Capitol**

**Please make 20 copies of this testimony**

To the Honorable Chair Robert Herkes, Vice Chair Angus McKelvey, and Members of the House Committee on Consumer Protection and Commerce:

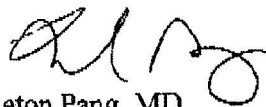
I strongly support **SB1805 SD1**, relating to professional licensure of genetic counselors. I am a physician in Hawaii who works with genetic counselors regarding patients of a variety of indications.

Genetic counselors are health professionals with specialized graduate degrees and experience in the areas of medical genetics and counseling. They are board certified by the National Board of Genetic Counseling. Genetic counselors work as members of a health care team, providing information and support to families who have members with birth defects or genetic disorders and to families who may be at risk for a variety of inherited conditions. They serve as patient advocates and educators for other health care professionals and for the general public.

The American Medical Association (AMA) has recently approved a CPT® (Current Procedural Terminology) code for Genetic Counseling in recognition of the value of genetic counseling in the practice of medicine. These codes can only be used by licensed health professionals. Licensure is the first necessary step toward establishing genetic counselors as allied health professionals that may someday receive reimbursement from third party payors for the services they provide to patients. At this time, most genetic counselors in Hawai'i are not reimbursed for their services, making it difficult for hospitals and clinics to support these services. Just as physicians and nurses have both board certification and state licensure, so should genetic counselors.

Heightened public awareness, coupled with scientific advances in adult disorders and reproductive technologies, have increased the demand for genetic counselors. Genetic counselors are the primary source in Hawai'i to assist patients and their physicians who have questions about indications for genetic testing, validity of testing, reliability of laboratories providing genetic testing, and interpretation of genetic test results. The recent explosion of direct to consumer genetic testing truly underscores the need for the public to be able to recognize who is qualified to provide genetic counseling services and to interpret genetic test results.

Thank you for allowing me the opportunity to provide testimony in support of **SB1805 SD1**.



Laeton Pang, MD  
Radiation Oncologist

00161

**House Committee on Consumer Protection and Commerce  
SB 1805, SD 1, Relating to Genetic Counselors**

Monday, March 24, 2008 at 2 PM

Hawai'i State Capitol

**Please make 20 copies of this testimony**

To the Honorable Chair Robert Herkes, Vice Chair Angus McKelvey and Members of the House Committee on Consumer Protection and Commerce:

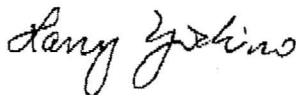
I strongly support SB 1805, SD 1, relating to professional licensure of genetic counselors. As a practicing physician specializing in obstetrics and gynecology, I work directly with genetic counselors in my practice.

Prenatal Genetic counselors are medical professionals with specialized training in genetics and genetic disease. Genetic counseling is provided by Board Certified genetic counselors for prenatal diagnosis, family planning, interpretation of test results, and other supportive services. Genetic counseling helps alleviate the anxiety which patients may feel, by providing accurate information regarding their genetic concerns and offering them support and guidance in a non-directive manner.

In a genetic counseling session, the potential need for carrier testing and the risks and benefits of amniocentesis and relevant genetic tests are discussed. Interpretation of test results and accuracy are addressed and the patient's genetic family history and individual concerns are examined. If the result of prenatal testing is abnormal, a meeting with a genetic counselor can offer the patient professional guidance and support during a difficult time. The counselors' genetic expertise enables them to make proper referrals, arrange appropriate testing, and offer a wide variety of resources to their patients.

Licensure will create clear educational, certification, and continuing education standards for all genetic counselors in the state. Licensure will ensure greater patient access to competent genetic counselors. The goal is for patients to make more informed decisions about their genetic health care enabling them to seek methods to prevent disease and stay healthy.

Thank you for allowing me the opportunity to provide testimony in support of SCR 31.



Harry Yoshino, M.D  
Obstetrician/Gynecologist  
(808) 599-4200

00162



**House Committee on Consumer Protection and Commerce  
SB 1805, SD 1, Relating to Genetic Counselors**

**Monday, March 24, 2008 at 2 PM**

Hawai'i State Capitol

**Please make 20 copies of this testimony**

To the Honorable Chair Robert Herkes, Vice Chair Angus McKelvey and Members of the House Committee on Consumer Protection and Commerce:

I strongly support **SB1805 SD1**, relating to professional licensure of genetic counselors. I am a practicing physician in Hawaii who refers patients to genetic counselors for a variety of indications.

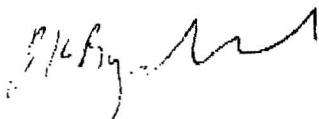
Genetic counselors are health professionals with specialized graduate degrees and experience in the areas of medical genetics and counseling. They are board certified by the National Board of Genetic Counseling. Genetic counselors work as members of a health care team, providing information and support to families who have members with birth defects or genetic disorders and to families who may be at risk for a variety of inherited conditions. They serve as patient advocates and educators for other health care professionals and for the general public.

The American Medical Association (AMA) has recently approved a CPT® (Current Procedural Terminology) code for Genetic Counseling in recognition of the value of genetic counseling in the practice of medicine. These codes can only be used by licensed health professionals. Licensure is the first necessary step toward establishing genetic counselors as allied health professionals that may someday receive reimbursement from third party payors for the services they provide to patients. At this time, most genetic counselors in Hawai'i are not reimbursed for their services, making it difficult for hospitals and clinics to support these services. Just as physicians and nurses have both board certification and state licensure, so should genetic counselors.

Heightened public awareness, coupled with scientific advances in adult disorders and reproductive technologies, have increased the demand for genetic counselors. Genetic counselors are the primary source in Hawai'i to assist patients and their physicians who have questions about indications for genetic testing, validity of testing, reliability of laboratories providing genetic testing, and interpretation of genetic test results. The recent explosion of direct to consumer genetic testing truly underscores the need for the public to be able to recognize who is qualified to provide genetic counseling services and to interpret genetic test results.

Thank you for allowing me the opportunity to provide testimony in support of **SB1805 SD1**.

Peter Bryant-Greenwood, MD  
Pathologist, Hawaii Pathologists Laboratory  
Director, Molecular Diagnostics  
Vice Chair, Department of Pathology, JABSOM  
(808) 547-4271



**00163**

**House Committee on Consumer Protection and Commerce**  
**SB 1805, SD 1, Relating to Professional Licensure**  
Monday, March 24, 2008 at 2 PM

**Hawaii State Capitol**  
**Please make 20 copies of this testimony**

To the Honorable Chair Robert Herkes, Vice Chair Angus McKelvey, and Members of the House Committee on Consumer Protection and Commerce:

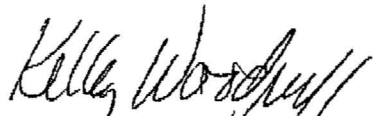
I strongly support **SB1805 SD1**, relating to professional licensure of genetic counselors. I am a physician in Hawaii who works with genetic counselors regarding patients of a variety of indications.

Genetic counselors are health professionals with specialized graduate degrees and experience in the areas of medical genetics and counseling. They are board certified by the National Board of Genetic Counseling. Genetic counselors work as members of a health care team, providing information and support to families who have members with birth defects or genetic disorders and to families who may be at risk for a variety of inherited conditions. They serve as patient advocates and educators for other health care professionals and for the general public.

The American Medical Association (AMA) has recently approved a CPT® (Current Procedural Terminology) code for Genetic Counseling in recognition of the value of genetic counseling in the practice of medicine. These codes can only be used by licensed health professionals. Licensure is the first necessary step toward establishing genetic counselors as allied health professionals that may someday receive reimbursement from third party payors for the services they provide to patients. At this time, most genetic counselors in Hawai'i are not reimbursed for their services, making it difficult for hospitals and clinics to support these services. Just as physicians and nurses have both board certification and state licensure, so should genetic counselors.

Heightened public awareness, coupled with scientific advances in adult disorders and reproductive technologies, have increased the demand for genetic counselors. Genetic counselors are the primary source in Hawai'i to assist patients and their physicians who have questions about indications for genetic testing, validity of testing, reliability of laboratories providing genetic testing, and interpretation of genetic test results. The recent explosion of direct to consumer genetic testing truly underscores the need for the public to be able to recognize who is qualified to provide genetic counseling services and to interpret genetic test results.

Thank you for allowing me the opportunity to provide testimony in support of **SB1805 SD1**.



Kelley Woodruff, MD  
Hematologist-Oncologist

00164

**House Committee on Consumer Protection and Commerce  
SB 1805, SD 1, Relating to Genetic Counselors**

**Monday, March 24, 2008 at 2 PM**

**Hawai'i State Capitol**

**Please make 20 copies of this testimony**

To the Honorable Chair Robert Herkes, Vice Chair Angus McKelvey and Members of the House Committee on Consumer Protection and Commerce:

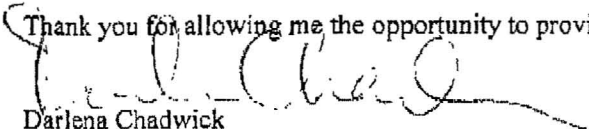
I strongly support SB 1805, SD 1, relating to professional licensure of genetic counselors. As Director at The Queen's Medical Center, I oversee the genetic counselors at our facility.

Genetic counselors are health professionals with specialized graduate degrees and experience in the areas of medical genetics and counseling. They are board certified by the National Board of Genetic Counseling. Genetic counselors work as members of a health care team, providing information and support to families who have members with birth defects or genetic disorders and to families who may be at risk for a variety of inherited conditions. They serve as patient advocates and educators for other health care professionals and, for the general public.

The American Medical Association (AMA) has recently approved a CPT® (Current Procedural Terminology) code for Genetic Counseling in recognition of the value of genetic counseling in the practice of medicine. These codes can only be used by licensed health professionals. Licensure is the first necessary step toward establishing genetic counselors as allied health professionals that may someday receive reimbursement from third party payors for the services they provide to patients. At this time, most genetic counselors in Hawai'i are not reimbursed for their services, making it difficult for hospitals and clinics to support these services. Just as physicians and nurses have both board certification and state licensure, so should genetic counselors.

Heightened public awareness, coupled with scientific advances in adult disorders and reproductive technologies, have increased the demand for genetic counselors. Genetic counselors are the primary source in Hawai'i to assist patients and their physicians who have questions about indications for genetic testing, validity of testing, reliability of laboratories providing genetic testing, and interpretation of genetic test results. The recent explosion of direct to consumer genetic testing truly underscores the need for the public to be able to recognize who is qualified to provide genetic counseling services and to interpret genetic test results.

Thank you for allowing me the opportunity to provide testimony in support of SB 1805, SD 1.



Darlena Chadwick

Vice President, Oncology, Women's Health & Professional Services

00165

**House Committee on Consumer Protection and Commerce  
SB 1805, SD 1, Relating to Genetic Counselors**

Monday, March 24, 2008 at 2 PM

Hawai'i State Capitol

**Please make 20 copies of this testimony**

To the Honorable Chair Robert Herkes, Vice Chair Angus McKelvey and Members of the House Committee on Consumer Protection and Commerce:

I strongly support SB 1805, SD 1, relating to professional licensure of genetic counselors. As a practicing physician specializing in obstetrics and gynecology, I work directly with genetic counselors in my practice.

Prenatal Genetic counselors are medical professionals with specialized training in genetics and genetic disease. Genetic counseling is provided by Board Certified genetic counselors for prenatal diagnosis, family planning, interpretation of test results, and other supportive services. Genetic counseling helps alleviate the anxiety which patients may feel, by providing accurate information regarding their genetic concerns and offering them support and guidance in a non-directive manner.

In a genetic counseling session, the potential need for carrier testing and the risks and benefits of amniocentesis and relevant genetic tests are discussed. Interpretation of test results and accuracy are addressed and the patient's genetic family history and individual concerns are examined. If the result of prenatal testing is abnormal, a meeting with a genetic counselor can offer the patient professional guidance and support during a difficult time. The counselors' genetic expertise enables them to make proper referrals, arrange appropriate testing, and offer a wide variety of resources to their patients. Licensure will create clear educational, certification, and continuing education standards for all genetic counselors in the state. Licensure will ensure greater patient access to competent genetic counselors. The goal is for patients to make more informed decisions about their genetic health care enabling them to seek methods to prevent disease and stay healthy.

Thank you for allowing me the opportunity to provide testimony in support of SCR 31.

*Robb Ohtani*

Robb Ohtani, M.D.  
Queen's Physicians Office Building II  
1329 Lusitana Street, Suite 402  
Honolulu, HI 96813

00166

**House Committee on Consumer Protection and Commerce  
SB 1805, SD 1, Relating to Genetic Counselors**

Monday, March 24, 2008 at 2 PM

Hawai'i State Capitol

**Please make 20 copies of this testimony**

To the Honorable Chair Robert Herkes, Vice Chair Angus McKelvey and Members of the House Committee on Consumer Protection and Commerce:

I strongly support SB 1805, SD 1, relating to professional licensure of genetic counselors. As a practicing surgeon in Hawaii, I refer patients to genetic counselors who have a personal and/or family history of cancer.

Prenatal Genetic counselors are medical professionals with specialized training in genetics and genetic disease. Genetic counseling is provided by Board Certified genetic counselors for prenatal diagnosis, family planning, interpretation of test results, and other supportive services. Genetic counseling helps alleviate the anxiety which patients may feel, by providing accurate information regarding their genetic concerns and offering them support and guidance in a non-directive manner.

In a genetic counseling session, the potential need for carrier testing and the risks and benefits of amniocentesis and relevant genetic tests are discussed. Interpretation of test results and accuracy are addressed and the patient's genetic family history and individual concerns are examined. If the result of prenatal testing is abnormal, a meeting with a genetic counselor can offer the patient professional guidance and support during a difficult time. The counselors' genetic expertise enables them to make proper referrals, arrange appropriate testing, and offer a wide variety of resources to their patients.

Licensure will create clear educational, certification, and continuing education standards for all genetic counselors in the state. Licensure will ensure greater patient access to competent genetic counselors. The goal is for patients to make more informed decisions about their genetic health care enabling them to seek methods to prevent disease and stay healthy.

Thank you for allowing me the opportunity to provide testimony in support of SCR 31.



Paul Morris, M.D.  
Thoracic and Cardiovascular Surgeon  
(808) 521-4664

00167

**House Committee on Consumer Protection and Commerce  
SB 1805, SD 1, Relating to Genetic Counselors**

Monday, March 24, 2008 at 2 PM

Hawai'i State Capitol

**Please make 20 copies of this testimony**

To the Honorable Chair Robert Herkes, Vice Chair Angus McKelvey and Members of the House Committee on Consumer Protection and Commerce:

I strongly support **SB1805 SD1**, relating to professional licensure of genetic counselors. I am a practicing physician in Hawaii who refers patients to genetic counselors for a variety of indications.

Genetic counselors are health professionals with specialized graduate degrees and experience in the areas of medical genetics and counseling. They are board certified by the National Board of Genetic Counseling. Genetic counselors work as members of a health care team, providing information and support to families who have members with birth defects or genetic disorders and to families who may be at risk for a variety of inherited conditions. They serve as patient advocates and educators for other health care professionals and for the general public.

The American Medical Association (AMA) has recently approved a CPT® (Current Procedural Terminology) code for Genetic Counseling in recognition of the value of genetic counseling in the practice of medicine. These codes can only be used by licensed health professionals. Licensure is the first necessary step toward establishing genetic counselors as allied health professionals that may someday receive reimbursement from third party payors for the services they provide to patients. At this time, most genetic counselors in Hawai'i are not reimbursed for their services, making it difficult for hospitals and clinics to support these services. Just as physicians and nurses have both board certification and state licensure, so should genetic counselors.

Heightened public awareness, coupled with scientific advances in adult disorders and reproductive technologies, have increased the demand for genetic counselors. Genetic counselors are the primary source in Hawai'i to assist patients and their physicians who have questions about indications for genetic testing, validity of testing, reliability of laboratories providing genetic testing, and interpretation of genetic test results. The recent explosion of direct to consumer genetic testing truly underscores the need for the public to be able to recognize who is qualified to provide genetic counseling services and to interpret genetic test results.

Thank you for allowing me the opportunity to provide testimony in support of **SB1805 SD1**.



George Lisehora, MD

Surgeon

(808) 524-1856

00168



**House Committee on Consumer Protection and Commerce**  
**SB 1805, SD 1, Relating to Professional Licensure**  
Monday, March 24, 2008 at 2 PM  
Hawaii State Capitol  
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Thank you for allowing me the opportunity to provide testimony in support of **SB1805 SD1**.



William Loui, MD  
Hematologist-Oncologist

00169



**House Committee on Consumer Protection and Commerce**  
**SB 1805, SD 1, Relating to Professional Licensure**  
 Monday, March 24, 2008 at 2 PM  
**Hawaii State Capitol**  
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Thank you for allowing me the opportunity to provide testimony in support of **SB1805 SD1**.



Sandi Kwee, MD  
 Medical Staff Physician

00170

**House Committee on Consumer Protection and Commerce**  
**SB 1805, SD 1, Relating to Professional Licensure**  
Monday, March 24, 2008 at 2 PM  
**Hawaii State Capitol**  
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Thank you for allowing me the opportunity to provide testimony in support of **SB1805 SD1**.



Daniel Fischberg, MD  
Physician, Palliative Care

00171

**House Committee on Consumer Protection and Commerce**  
**SB 1805, SD 1, Relating to Professional Licensure**  
Monday, March 24, 2008 at 2 PM  
**Hawaii State Capitol**  
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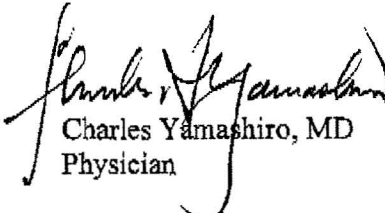
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Thank you for allowing me the opportunity to provide testimony in support of **SB1805 SD1**.

  
Charles Yamashiro, MD  
Physician

00172

**House Committee on Consumer Protection and Commerce  
SB 1805, SD 1, Relating to Professional Licensure**

Monday, March 24, 2008 at 2 PM

**Hawaii State Capitol**

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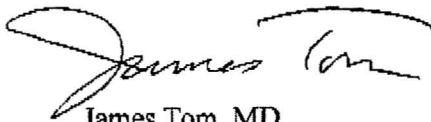
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Thank you for allowing me the opportunity to provide testimony in support of **SB1805 SD1**.



James Tom, MD  
Clinical Research Associate

00173

**House Committee on Consumer Protection and Commerce**  
**SB 1805, SD 1, Relating to Professional Licensure**  
Monday, March 24, 2008 at 2 PM  
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Thank you for allowing me the opportunity to provide testimony in support of **SB1805 SD1**.

Paul DeMare, MD  
Radiation Oncologist

00174

**House Committee on Consumer Protection and Commerce  
SB 1805, SD 1, Relating to Genetic Counselors**

Monday, March 24, 2008 at 2 PM

Hawai'i State Capitol

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Thank you for allowing me the opportunity to provide testimony in support of **SB1805 SD1**.



Peter Halford, MD

Surgeon

(808) 536-1107

00175



**House Committee on Consumer Protection and Commerce  
SB 1805, SD 1, Relating to Genetic Counselors**

Monday, March 24, 2008 at 2 PM

Hawai'i State Capitol

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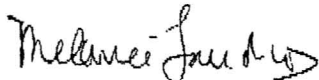
I strongly support SB 1805, SD 1, relating to professional licensure of genetic counselors. As a practicing physician specializing in obstetrics and gynecology, I work directly with genetic counselors in my practice.

Prenatal Genetic counselors are medical professionals with specialized training in genetics and genetic disease. Genetic counseling is provided by Board Certified genetic counselors for prenatal diagnosis, family planning, interpretation of test results, and other supportive services. Genetic counseling helps alleviate the anxiety which patients may feel, by providing accurate information regarding their genetic concerns and offering them support and guidance in a non-directive manner.

In a genetic counseling session, the potential need for carrier testing and the risks and benefits of amniocentesis and relevant genetic tests are discussed. Interpretation of test results and accuracy are addressed and the patient's genetic family history and individual concerns are examined. If the result of prenatal testing is abnormal, a meeting with a genetic counselor can offer the patient professional guidance and support during a difficult time. The counselors' genetic expertise enables them to make proper referrals, arrange appropriate testing, and offer a wide variety of resources to their patients.

Licensure will create clear educational, certification, and continuing education standards for all genetic counselors in the state. Licensure will ensure greater patient access to competent genetic counselors. The goal is for patients to make more informed decisions about their genetic health care enabling them to seek methods to prevent disease and stay healthy.

Thank you for allowing me the opportunity to provide testimony in support of SCR 31.



Melanie Lau, M.D.  
Queen's Physicians Office Building II  
1329 Lusitana Street, Suite 406  
Honolulu, HI 96813

00176

**House Committee on Consumer Protection and Commerce  
SB 1805, SD 1, Relating to Genetic Counselors**

Monday, March 24, 2008 at 2 PM

Hawai'i State Capitol

**Please make 20 copies of this testimony**

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I strongly support SB 1805, SD 1, relating to professional licensure of genetic counselors. As a practicing physician specializing in obstetrics, gynecology, and prenatal diagnosis, I work directly with genetic counselors in my practice.

Prenatal Genetic counselors are medical professionals with specialized training in genetics and genetic disease. Genetic counseling is provided by Board Certified genetic counselors for prenatal diagnosis, family planning, interpretation of test results, and other supportive services. Genetic counseling helps alleviate the anxiety which patients may feel, by providing accurate information regarding their genetic concerns and offering them support and guidance in a non-directive manner.

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Thank you for allowing me the opportunity to provide testimony in support of SCR 31.



Norman Sato, M.D.  
Queen's Physicians Office Building II  
1329 Lusitana Street, Suite 402  
Honolulu, HI 96813

00177

**House Committee on Consumer Protection and Commerce  
SB 1805, SD 1, Relating to Genetic Counselors**

**Monday, March 24, 2008 at 2 PM**

**Hawai'i State Capitol**

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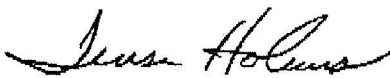
I strongly support SB 1805, SD 1, relating to professional licensure of genetic counselors. As Director of Clinical Laboratories, Genetics and Pathology Services at The Queen's Medical Center, I oversee the genetic counselors at our facility.

Genetic counselors are health professionals with specialized graduate degrees and experience in the areas of medical genetics and counseling. They are board certified by the National Board of Genetic Counseling. Genetic counselors work as members of a health care team, providing information and support to families who have members with birth defects or genetic disorders and to families who may be at risk for a variety of inherited conditions. They serve as patient advocates and educators for other health care professionals and, for the general public.

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Thank you for allowing me the opportunity to provide testimony in support of SB 1805, SD 1.



Teresa Holmes

Director, Clinical Laboratories, Genetics and Pathology Services at The Queen's Medical Center

00178

**House Committee on Consumer Protection and Commerce  
SB 1805, SD 1, Relating to Genetic Counselors**

**Monday, March 24, 2008 at 2 PM**

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Thank you for allowing me the opportunity to provide testimony in support of **SB1805 SD1**.



Chris Lum, MD  
Director of Dermatopathology  
(808) 547-4271

00179

**House Committee on Consumer Protection and Commerce  
SB 1805, SD 1, Relating to Genetic Counselors**

**Monday, March 24, 2008 at 2 PM**

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Thank you for allowing me the opportunity to provide testimony in support of **SB1805 SD1**.

*Pamela Tauchi-Nishi*

Pamela Tauchi-Nishi, MD  
Associate Director of Pathology  
(808) 547-4271

00180

**House Committee on Consumer Protection and Commerce  
SB 1805, SD 1, Relating to Genetic Counselors**

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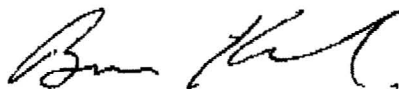
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Bruce Kessel, MD  
Obstetrician/Gynecologist  
(808) 585-5494

**00181**



**House Committee on Consumer Protection and Commerce  
SB 1805, SD 1, Relating to Genetic Counselors**

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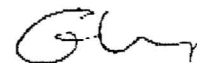
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The American Medical Association (AMA) has recently approved a CPT® (Current Procedural Terminology) code for Genetic Counseling in recognition of the value of genetic counseling in the practice of medicine. These codes can only be used by licensed health professionals. Licensure is the first necessary step toward establishing genetic counselors as allied health professionals that may someday receive reimbursement from third party payors for the services they provide to patients. At this time, most genetic counselors in Hawai'i are not reimbursed for their services, making it difficult for hospitals and clinics to support these services. Just as physicians and nurses have both board certification and state licensure, so should genetic counselors.

Heightened public awareness, coupled with scientific advances in adult disorders and reproductive technologies, have increased the demand for genetic counselors. Genetic counselors are the primary source in Hawai'i to assist patients and their physicians who have questions about indications for genetic testing, validity of testing, reliability of laboratories providing genetic testing, and interpretation of genetic test results. The recent explosion of direct to consumer genetic testing truly underscores the need for the public to be able to recognize who is qualified to provide genetic counseling services and to interpret genetic test results.

Thank you for allowing me the opportunity to provide testimony in support of **SB1805 SD1**.

Grace Wong, MD  
Obstetrician/Gynecologist  
(808) 596-0091



**00182**

House Committee on Consumer Protection and Commerce  
SB 1805, SD 1, Relating to Genetic Counselors

Monday, March 24, 2008 at 2 PM

Hawai'i State Capitol

Please make 20 copies of this testimony

To the Honorable Chair Robert Herkes, Vice Chair Angus McKelvey and Members of the House Committee on Consumer Protection and Commerce:

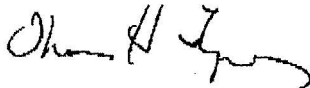
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Thank you for allowing me the opportunity to provide testimony in support of **SB1805 SD1**.



Thomas Teruya, M.D.  
Obstetrician/Gynecologist  
(808) 599-4200

00183

**House Committee on Consumer Protection and Commerce  
SB 1805, SD 1, Relating to Genetic Counselors**

Monday, March 24, 2008 at 2 PM

Hawai'i State Capitol

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Thank you for allowing me the opportunity to provide testimony in support of **SB1805 SD1**.

*Steven Emura MD*

Steven Emura, M.D.  
Obstetrician/Gynecologist  
(808) 218-7900

**00184**

**House Committee on Consumer Protection and Commerce  
SB 1805, SD 1, Relating to Genetic Counselors**

Monday, March 24, 2008 at 2 PM

Hawai'i State Capitol

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Thank you for allowing me the opportunity to provide testimony in support of **SB1805 SD1**.

Ken Nakasone, M.D.  
Obstetrician/Gynecologist  
(808) 599-4200

*Ken Nakasone M.D.*

**00185**

**House Committee on Consumer Protection and Commerce  
SB 1805, SD 1, Relating to Genetic Counselors**

**Monday, March 24, 2008 at 2 PM  
Hawai'i State Capitol**

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Thank you for allowing me the opportunity to provide testimony in support of **SB1805 SD1**.

Franklin Dao, M.D.  
Obstetrician/Gynecologist  
(808) 537-2211

**00186**

**House Committee on Consumer Protection and Commerce  
SB 1805, SD 1, Relating to Genetic Counselors**

Monday, March 24, 2008 at 2 PM

Hawai'i State Capitol

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To the Honorable Chair Robert Herkes, Vice Chair Angus McKelvey and Members of the House Committee on Consumer Protection and Commerce:

I strongly support SB 1805, SD 1, relating to professional licensure of genetic counselors. As a practicing physician specializing in obstetrics and gynecology, I work directly with genetic counselors in my practice.

Prenatal Genetic counselors are medical professionals with specialized training in genetics and genetic disease. Genetic counseling is provided by Board Certified genetic counselors for prenatal diagnosis, family planning, interpretation of test results, and other supportive services. Genetic counseling helps alleviate the anxiety which patients may feel, by providing accurate information regarding their genetic concerns and offering them support and guidance in a non-directive manner.

In a genetic counseling session, the potential need for carrier testing and the risks and benefits of amniocentesis and relevant genetic tests are discussed. Interpretation of test results and accuracy are addressed and the patient's genetic family history and individual concerns are examined. If the result of prenatal testing is abnormal, a meeting with a genetic counselor can offer the patient professional guidance and support during a difficult time. The counselors' genetic expertise enables them to make proper referrals, arrange appropriate testing, and offer a wide variety of resources to their patients.

Licensure will create clear educational, certification, and continuing education standards for all genetic counselors in the state. Licensure will ensure greater patient access to competent genetic counselors. The goal is for patients to make more informed decisions about their genetic health care enabling them to seek methods to prevent disease and stay healthy.

Thank you for allowing me the opportunity to provide testimony in support of SCR 31.



Nathan Fujita, M.D.  
Queen's Physicians Office Building II  
1329 Lusitana Street, Suite 402  
Honolulu, HI 96813



**House Committee on Consumer Protection and Commerce**  
**SB 1805, SD 1, Relating to Professional Licensure**  
 Monday, March 24, 2008 at 2 PM  
 Hawaii State Capitol  
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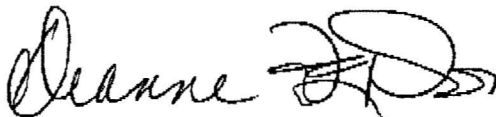
I strongly support **SB1805 SD1**, relating to professional licensure of genetic counselors. I work with genetic counselors within a large medical facility in Honolulu.

Genetic counselors are health professionals with specialized graduate degrees and experience in the areas of medical genetics and counseling. They are board certified by the National Board of Genetic Counseling. Genetic counselors work as members of a health care team, providing information and support to families who have members with birth defects or genetic disorders and to families who may be at risk for a variety of inherited conditions. They serve as patient advocates and educators for other health care professionals and for the general public.

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Thank you for allowing me the opportunity to provide testimony in support of **SB1805 SD1**.



Deanne F. Doi  
 Tumor Conference Coordinator  
 Secretary, Oncology Data Registry

0018188

**House Committee on Consumer Protection and Commerce  
SB 1805, SD 1, Relating to Genetic Counselors**

Monday, March 24, 2008 at 2 PM

Hawai'i State Capitol

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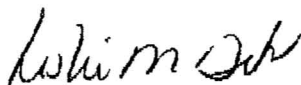
I strongly support **SB1805 SD1**, relating to professional licensure of genetic counselors. As an Advance Practice Registered Nurse, I work with genetic counselors within a large medical facility in Hawaii.

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Leslie Detor, APRN

00189

**House Committee on Consumer Protection and Commerce**  
**SB 1805, SD 1, Relating to Professional Licensure**  
 Monday, March 24, 2008 at 2 PM  
 Hawaii State Capitol  
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Jocelyn Nishioka  
 Oncology Patient Navigator

00190



**House Committee on Consumer Protection and Commerce**  
**SB 1805, SD 1, Relating to Professional Licensure**  
Monday, March 24, 2008 at 2 PM  
Hawaii State Capitol  
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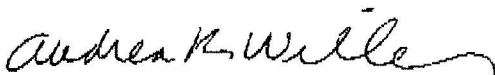
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Andrea Wilburn  
Oncology Patient Navigator

00192

**House Committee on Consumer Protection and Commerce  
SB 1805, SD 1, Relating to Genetic Counselors**

**Monday, March 24, 2008 at 2 PM**

**Hawai'i State Capitol**

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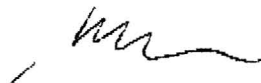
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Thank you for allowing me the opportunity to provide testimony in support of **SB1805 SD1**.

Steven Nishi, MD  
Obstetrician/Gynecologist  
(808) 290-3198



**00193**



**House Committee on Consumer Protection and Commerce  
SB 1805, SD 1, Relating to Professional Licensure**

Monday, March 24, 2008 at 2 PM  
Hawaii State Capitol

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Diane A. Faran, MD  
Physician

00194

House Committee on Consumer Protection and Commerce  
SB 1805, SD 1, Relating to Professional Licensure

Monday, March 24, 2008 at 2 PM  
Hawaii State Capitol

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Adam Bracha, MD  
Resident Physician

**House Committee on Consumer Protection and Commerce  
SB 1805, SD 1, Relating to Professional Licensure**

Monday, March 24, 2008 at 2 PM

**Hawaii State Capitol**

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Thank you for allowing me the opportunity to provide testimony in support of **SB1805 SD1**.

C.S. Wakai, MD  
Physician

00196

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Genetic counselors are health professionals with specialized graduate degrees and experience in the areas of medical genetics and counseling. They are board certified by the National Board of Genetic Counseling. Genetic counselors work as members of a health care team, providing information and support to families who have members with birth defects or genetic disorders and to families who may be at risk for a variety of inherited conditions. They serve as patient advocates and educators for other health care professionals and for the general public.

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Heightened public awareness, coupled with scientific advances in adult disorders and reproductive technologies, have increased the demand for genetic counselors. Genetic counselors are the primary source in Hawai'i to assist patients and their physicians who have questions about indications for genetic testing, validity of testing, reliability of laboratories providing genetic testing, and interpretation of genetic test results. The recent explosion of direct to consumer genetic testing truly underscores the need for the public to be able to recognize who is qualified to provide genetic counseling services and to interpret genetic test results.

Thank you for allowing me the opportunity to provide testimony in support of **SB1805 SD1**.

K. Behjati MD  
Physician, Nuclear Medicine

00197

**House Committee on Consumer Protection and Commerce  
SB 1805, SD 1, Relating to Genetic Counselors**

Monday, March 24, 2008 at 2 PM

Hawai'i State Capitol

**Please make 20 copies of this testimony**

To the Honorable Chair Robert Herkes, Vice Chair Angus McKelvey and Members of the House Committee on Consumer Protection and Commerce:

I strongly support SB 1805, SD 1, relating to professional licensure of genetic counselors. As a practicing physician in Hawaii, I refer patients to see genetic counselors for a variety of indications.

Prenatal Genetic counselors are medical professionals with specialized training in genetics and genetic disease. Genetic counseling is provided by Board Certified genetic counselors for prenatal diagnosis, family planning, interpretation of test results, and other supportive services. Genetic counseling helps alleviate the anxiety which patients may feel, by providing accurate information regarding their genetic concerns and offering them support and guidance in a non-directive manner.

In a genetic counseling session, the potential need for carrier testing and the risks and benefits of amniocentesis and relevant genetic tests are discussed. Interpretation of test results and accuracy are addressed and the patient's genetic family history and individual concerns are examined. If the result of prenatal testing is abnormal, a meeting with a genetic counselor can offer the patient professional guidance and support during a difficult time. The counselors' genetic expertise enables them to make proper referrals, arrange appropriate testing, and offer a wide variety of resources to their patients.

Licensure will create clear educational, certification, and continuing education standards for all genetic counselors in the state. Licensure will ensure greater patient access to competent genetic counselors. The goal is for patients to make more informed decisions about their genetic health care enabling them to seek methods to prevent disease and stay healthy.

Thank you for allowing me the opportunity to provide testimony in support of SCR 31.

Denny L.Bales, M.D.  
Cardiologist  
(808) 521-7402

00198

**House Committee on Consumer Protection and Commerce  
SB 1805, SD 1, Relating to Professional Licensure**

**Monday, March 24, 2008 at 2 PM  
Hawaii State Capitol**

**Please make 20 copies of this testimony**

To the Honorable Chair Robert Herkes, Vice Chair Angus McKelvey, and Members of the House Committee on Consumer Protection and Commerce:

I strongly support **SB1805 SD1**, relating to professional licensure of genetic counselors. I am a physician in Hawaii who works with genetic counselors regarding patients of a variety of indications.

Genetic counselors are health professionals with specialized graduate degrees and experience in the areas of medical genetics and counseling. They are board certified by the National Board of Genetic Counseling. Genetic counselors work as members of a health care team, providing information and support to families who have members with birth defects or genetic disorders and to families who may be at risk for a variety of inherited conditions. They serve as patient advocates and educators for other health care professionals and for the general public.

The American Medical Association (AMA) has recently approved a CPT® (Current Procedural Terminology) code for Genetic Counseling in recognition of the value of genetic counseling in the practice of medicine. These codes can only be used by licensed health professionals. Licensure is the first necessary step toward establishing genetic counselors as allied health professionals that may someday receive reimbursement from third party payors for the services they provide to patients. At this time, most genetic counselors in Hawai'i are not reimbursed for their services, making it difficult for hospitals and clinics to support these services. Just as physicians and nurses have both board certification and state licensure, so should genetic counselors.

Heightened public awareness, coupled with scientific advances in adult disorders and reproductive technologies, have increased the demand for genetic counselors. Genetic counselors are the primary source in Hawai'i to assist patients and their physicians who have questions about indications for genetic testing, validity of testing, reliability of laboratories providing genetic testing, and interpretation of genetic test results. The recent explosion of direct to consumer genetic testing truly underscores the need for the public to be able to recognize who is qualified to provide genetic counseling services and to interpret genetic test results.

Thank you for allowing me the opportunity to provide testimony in support of **SB1805 SD1**.

Daphne Hemmings, MD  
General Surgeon & Assistant Professor Medicine/Surgery

00199



**House Committee on Consumer Protection and Commerce  
Relating to Genetic Counselors**

**Monday March 24, 2008**

**2:00pm**

**Please make 5 copies of this testimony**

To the Honorable Robert Herkes, Honorable Angus McKelvey, and Members of the House Committee on Consumer Protection and Commerce:

I strongly support SB 1805 SD1 relating to professional licensure of genetic counselors.

Genetic counselors are health professionals with specialized graduate degrees and experience in the areas of medical genetics and counseling. They are board certified by the National Board of Genetic Counseling. Genetic counselors work as members of a health care team, providing information and support to families who have members with birth defects or genetic disorders and to families who may be at risk for a variety of inherited conditions. They serve as patient advocates and educators for other health care professionals and for the general public.

The American Medical Association (AMA) has recently approved a CPT® (Current Procedural Terminology) code for Genetic Counseling in recognition of the value of genetic counseling in the practice of medicine. These codes can only be used by licensed health professionals. Licensure is the first necessary step toward establishing genetic counselors as allied health professionals that may someday receive reimbursement from third party payors for the services they provide to patients. At this time, most genetic counselors in Hawai'i are not reimbursed for their services, making it difficult for hospitals and clinics to support these services. Just as physicians and nurses have both board certification and state licensure, so should genetic counselors.

Heightened public awareness, coupled with scientific advances in adult disorders and reproductive technologies, have increased the demand for genetic counselors. Genetic counselors are the primary source in Hawai'i to assist patients and their physicians who have questions about indications for genetic testing, validity of testing, reliability of laboratories providing genetic testing, and interpretation of genetic test results. The recent explosion of direct to consumer genetic testing truly underscores the need for the public to be able to recognize who is qualified to provide genetic counseling services and to interpret genetic test results.

Thank you for allowing me the opportunity to provide testimony in support of SB 1805 SD1.

Constance Kelsey, MA  
Contract Coordinator, Revenue Management

00200

**House Committee on Consumer Protection and Commerce****SB 1805 SD1  
RELATING TO GENETIC COUNSELORS**

Monday March 24, 2008  
2:00 pm

To the Honorable Chair Robert Herkes, Vice Chair Angus McKelvey, and Members of the House Committee on Consumer Protection and Commerce:

I support SB 1805 SD1 relating to the professional licensure of Genetic Counselors in the State of Hawaii.

I am a Genetic Counselor who has been working in the State of Hawaii for nearly six years. I am in strong support of Genetic Counselor licensure. I believe that licensure will not only assist in recognition and reimbursement of our profession, but also ensure high level quality services to the people of Hawaii, and efficient use of health care dollars.

My initial interest in, and attraction to, the field of Genetic Counseling stemmed from what I viewed as an opportunity to work with and serve various individuals who have, or are at risk for, rare conditions that may have a genetic basis. My goal was (and still is) to make a difference in the lives of these individuals and families - by educating them, helping them with difficult decisions, and providing them with emotional support.

Through my time to date as a Genetic Counselor, I have learned that the field of Genetic Counseling is far broader than I had first envisioned. Conditions with a genetic component, I have learned, are far from rare. In fact, many common conditions, including cancer, heart disease and diabetes, have genetic components. What this means is that many individuals and families benefit from consultation with a Genetic Counselor - not just the rare few as I had first thought.

Medicine is a booming field: developments and new discoveries are coming out at faster and faster rates. And certainly, within the field of medicine, genetics is one of the most rapidly growing areas. As a result, more and more people will be impacted by genetics. Unfortunately, what also comes with exciting developments is the potential for misuse or misinterpretation of genetic information. Thus, it is crucial that a standard be set so that the people of Hawaii will be ensured accurate information from the highly trained and motivated professionals that Genetic Counselors are. In addition, licensure will help to ensure the security of this profession, and move away from its vulnerability due current lack of billing for our services. It is vital that Genetic Counselors be available to serve the current and upcoming needs of our population.

Genetic Counselor licensure will support the high quality and qualifications of Genetic Counselors, and will ensure high level quality services to our population, and efficient use of health care dollars.

Thank you for the opportunity to provide testimony in support of SB 1805 SD1.



Allison Taylor Shykowski, MS, CGC  
Certified Genetic Counselor  
Honolulu, HI  
(808) 375-0224

00201

**mckelvey3**

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**From:** Tammy Lynn Stumbaugh [tammys@hawaiiintel.net]  
**Sent:** Sunday, March 23, 2008 7:09 PM  
**To:** CPCtestimony  
**Cc:** jenboj@hotmail.com  
**Subject:** support passage of SB1805, SD 1

Testimony of  
Tammy Stumbaugh, M.S.,C.G.C,  
The Fetal Diagnostic Institute of the Pacific

Before the House Committee on Consumer Protection & Commerce  
Honorable Representative Robert N. Herkes, Chair  
Honorable Representative Angus L.K McKelvey, Vice Chair

Monday, March 24, 2008, 2:00 pm  
State Capitol, Conference Room 325  
Request 15 copies distributed to committee members

**STRONG SUPPORT for SB 1805, SD 1 (SSCR855) RELATING TO GENETIC COUNSELORS.** Establishing a licensure program.

Chair Robert Herkes, Vice Chair Angus McKelvey, and committee members, thank you for the opportunity to provide testimony on SB 1805, SD 1 which establishes a licensure program for genetic counselors. I offer my testimony as a genetic profession and REGISTERED HAWAII VOTER] and **I strongly support the unamended passage of SB 1805, SD 1** for the following reasons:

I have been practicing prenatal genetic counseling in the state of Hawaii for over 10 years now. I have personally helped thousands of patients through very emotional times during pregnancy. All of my patients receive complicated medical information at their level of understanding and in a non-directional manner. There is a vast amount of information regarding genetics and it can be very confusing for both a patient and their physician especially if the doctor is not trained in genetics.

The explosion of Direct-to-Consumer (DTC) genetic tests since the State Auditor's Sunrise Report presents a major risk for harm to the public if misinterpreted or used inappropriately. Contrary to the report's conclusion, the emergence of DTC genetic tests makes identification of and access to quality-assured genetic counseling services absolutely critical. In addition, prior testimony has referring to other instances of harm to the consumer that could be addressed in part by regulating this profession.

A mechanism must be established to remove a genetic counselor's right to practice if he/she is found to be incompetent or unscrupulous. Genetic counselors are involved in ethically charged areas of reproductive and medical decision-making. Ensuring ethical and competent practice is a safeguard against discriminatory or otherwise improper and damaging use of genetic information. State regulation of genetic counseling specialists should not be the only approach to protecting consumers from, but it should certainly be one prong of consumer protection. Presuming consumers are not savvy enough to understand the additional quality control that comes with conferring a state license is to give consumers too little credit.

There is no sustainable insurance reimbursement for genetic counseling services in Hawaii, despite multiple efforts by the genetics community to collaborate with government and third party insurers. There is a new billing code that could be used to obtain fair reimbursement for genetic counseling services from insurers, but only if the profession becomes licensed. Hawaii is facing the loss of healthcare providers and specialists at an alarming rate.

00202

do not want to lose access to this specialty service when we should be seeing increased access for outer islands and other underserved populations.

From the explosion of direct-to-consumer genetic tests and the exodus of healthcare specialty providers from Hawaii, we need to take multiple approaches to consumer protection. Licensure is one needed approach to ensure access to quality specialty genetic counseling services in our state.

Tammy Stumbaugh, MS, CGC  
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1600 Kapiolani Blvd, #1025  
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808-945-2230 (fax)

House Committee on Consumer Protection and Commerce

SB1805 SD1, (HSCR1096-08) Relating to Genetic Counselors

Monday, March 24th at 2:00 p.m.

To the Honorable Rep. Robert Herkes, Honorable Rep. Angus McKelvey, and Members of the House Committee on Consumer Protection and Commerce.

My name is Kirsty McWalter and I am a board-certified pediatric genetic counselor who works for the Hawai`i Department of Health Genetics Program. My testimony does not represent the view of the Department of Health as I am not providing testimony in an official capacity.

I strongly support the House bill relating to professional licensure for genetic counselors (SB 1805 SD1, HSCR1096-08). I ask that it be passed, unamended.

I believe that it is important for genetic counselors who meet the training and certification standards set forth by our professional organization (the American Board of Genetic Counseling) to be recognized as licensed genetic counselors because:

- (1) this will protect the public from harm potentially caused by inadequately trained practitioners;
- (2) this will allow adequately trained genetic counselors to be readily identified by the public and by other healthcare professionals;
- (3) an increased awareness of genetic counselors as licensed practitioners will lead to an increase in referrals to licensed genetic counselors and, thus, an increase in the number of families who have access to genetic counseling.

Licensure is an important step towards allowing the public to determine who can give them accurate information about their genetic risks and testing and making sure genetic counselors can move towards being reimbursed for the important services they provide.

In Fall 2005, I co-authored a paper published in *The Journal of Allied Health* (Christianson CA, McWalter KM, Steinberg Warren N. Assessment of Allied Health Graduates' Preparation to Integrate Genetic Knowledge and Skills Into Clinical Practice. *Journal of Allied Health*. Fall 2005 (34):3; 138-144.). We surveyed recent graduates from allied health programs (audiology, physical therapy, speech-language pathology, nutrition sciences, and medical imaging technology) to determine the amount of genetics education received during training, the genetics activities performed in clinic, and confidence in their ability to perform those genetics activities.

Overall, 78% of respondents rated the amount of genetic knowledge or skills they received during their training program as marginal or none. Keeping this statistic in mind, it is interesting to note that 61.2% of respondents reported that they elicit genetic family histories from their patients. Furthermore, of this group, only 51% reported that they had a high confidence in their ability to perform this task. These numbers are concerning, particularly if patients believe that they are receiving genetic counseling from someone with genetics knowledge and skills training.

SB 1805 SD1, HSCR1096-08  
Monday, March 24th, 2008 at 2:00 p.m.

Eliciting a patient's family history is an essential and unique component of genetic counseling; it allows the healthcare professional to identify the presence of heritable conditions within a family, provide recurrence risk figures, explain appropriate inheritance patterns, and discuss available genetic tests or screening recommendations. In an ideal world, I believe that the family history would be elicited by a licensed genetic counselor, physician, or genetics nurse specialist. However, there is a shortage of genetics professionals nationwide, particularly given the increasing numbers of genetics tests and amounts of genetics information available to consumers. If and when allied health professionals elicit family history information, I believe that it is important for those practitioners to recognize that there are licensed genetic counselors available for referrals in cases when a genetic condition is identified or when the healthcare practitioner does not have adequate training to interpret the family history.

As a pediatric genetic counselor, I work with children and their families affected by or at risk for genetic conditions. On numerous occasions, patients have thanked me for the time I have spent counseling them as to the implications of their family history and the options available to them. Most significantly, a number of patients and their families have expressed their satisfaction with the comprehensive genetic counseling they received from a genetic counselor, as opposed to the limited time that they were able to spend with another healthcare provider. Genetic counselors are not physicians and do not have the oppressive time demands that physicians have. I am able to spend more time with families and ensure that their questions and concerns have been addressed to their satisfaction. Many times, once a physician has left the room, the patient has asked follow-up questions or expressed concerns that may not have been voiced within the time constraints of a physician's visit. Genetic counselors provide a valuable service and are trained exclusively to provide genetic counseling; based on personal feedback from families and patients, I believe that genetic counselors should be licensed.

The results of the study cited above, coupled with my personal experiences as a pediatric genetic counselor, underlie my personal commitment to pursuing licensure for genetic counselors in Hawai'i. Patients have the right to be protected from harm potentially caused by incorrect or missing information provided by healthcare practitioners not trained to provide genetic counseling. Furthermore, it would be beneficial for healthcare practitioners to be aware of licensed genetic counselors, who perform the task of genetic counseling exclusively, so as to aid in their referrals of appropriate patients. This would help to ensure that healthcare practitioners, particularly those in allied health fields with marginal genetics training, recognize and refer to licensed genetic counselors rather than provide inadequate genetic counseling themselves.

I urge the Committee to pass this bill. Thank you for the opportunity to testify.

Kirsty McWalter. M.S., C.G.C.  
2006 Saint Louis Drive  
Honolulu, HI 96816  
(808) 371-1239

00205