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March 12, 2008

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Re: SB 1805 SD1 Relating to Genetic Counseling

The Hawaii Medical Association supports the intent of SB 1805 SD1.

However, we are strongly concerned that as written the bill would disallow physicians, MDs and DOs as defined by the Hawaii Revised Statues, from providing genetic counseling and advertising that they offer genetic counseling. Currently, physicians at Kapiolani Medical Center for Women and Children provide genetic counseling and advertise their services.

To address this concern, we request the following amendment to Section 5c:

- (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 counselor".~~]

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House of Representative's Committee on Health

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

Wednesday, March 12, 2008, 8:00am

To the Honorable Josh Green, the Honorable John Mizuno, and Members of the House Health Committee:

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.

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 Koscica 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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House of Representatives Committee on Health

SB 1805, SD1 RELATING TO REQUIRING PROFESSIONAL LICENSURE OF GENETIC COUNSELORS

To the Honorable Josh Green, M.D., and Members of the House of Representatives Committee on Health:

My name is Elaine Marr, 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 hope the committee considers my testimony regarding SB 1805 relating to professional licensure of genetic counselors to ensure professional and quality services for public safety and welfare.

Genetic counselors work at the crossroads of medicine, technology, and bioethics. It would be suboptimal care for families to place anyone without ABGC credentials and licensure to perform such duties.

The sunrise study reports that the regulation of genetic counselors is not necessary because there is no evidence of harm to consumers that would warrant licensing. This is not entirely true because licensure will distinguish those who are qualified by formal training and credentials from those who are not. Licensing allows the public to be able to more readily identify qualified genetic counseling services and thus protect themselves from substandard services. Since the auditor's report, direct to consumer (DTC) genetic testing has burgeoned. The auditor's report stated that licensure has no bearing on at-home genetic self testing. It does. More harm is present now than ever because the public can order genetic tests that may not have sound clinical validity. The consumer are also not guaranteed interpretation of these results but may potentially make life changing decisions because of them. Genetic test results may also lead one to be susceptible to genetic information discrimination. Furthermore, the Secretary's Advisory Committee Report on Oversight to Genetic Testing due to come out this month states the importance of having trained genetics providers give pre- and post-test information to patients and families. Numerous illustrations are included in this report detailing how the lack of genetics knowledge in non-genetics health care providers can cause harm to patients and families. Licensure of genetic counselors therefore will enable consumers to recognize their choices of optimal versus substandard genetic services that are available to them. Consumers will more readily be able to recognize genetic testing offered by a non-licensed individual and so protect themselves from potential harm in utilizing these unregulated services.

Licensure of genetic counselors will also promote high quality genetic counseling services and thus protect the profession itself from any association of malpractice and incompetent care provided by individuals without licensure requirements. This distinction is extremely important considering genetic counseling often entails helping families face legal, social, ethical issues and malpractice may ensue when these dilemmas are not dealt with by qualified professionals.

Lastly, licensure is a mechanism for genetic counselor billing practices. Health insurers will be able to identify who is qualified to provide genetic counseling services and determine reimbursement models with the new genetic counseling CPT codes. Institutions will then be able to demonstrate that genetic counselors can generate adequate revenue to justify increasing the work force and so attract more genetic counselors to Hawaii. In turn, patients can also expect to have greater access to competent genetic counselors. Currently, pediatric genetic counselors in the State are federally funded or grant funded. These genetic counselors have been awarded grants that allow them to travel to the neighbor islands (Big Island, Kauai, Molokai, Maui, Guam) to provide genetic services to medically fragile children. Hawaii is unique geographically and these services are essential to reduce health disparities in our state. If these grants are withdrawn, genetic services to these children will also disappear. The genetic counselors holding these jobs may also have to leave the state to find employment elsewhere. Therefore licensure establishes a mechanism for patients to have adequate care and genetic services state-wide.

Thank you for this opportunity to testify in writing.

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Testimony Of
Jennifer Bojanowski, MS, CGC
Certified Genetic Counselor

Before the House Committee on Health
Honorable Representative Josh Green, MD, Chair
Honorable Representative John Mizuno, Vice Chair

Wednesday, March 12, 2007, 8:00 am
State Capitol, Conference Room 329

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

Chair Josh Green, M.D., Vice Chair John Mizuno, 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 though 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 becomes difficult. Indeed, there is evidence to suggest that parental coping with pediatric genetic diagnoses is highly

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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

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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.**

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- 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: Basiliere, Michele [MBasiliere@kapiolani.org]
Sent: Monday, March 10, 2008 5:07 PM
To: HLTtestimony
Subject: House Health Testimony SB1805 SD1

S.B. 1805, S.D. 1 Relating to Genetic Counselors

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March 10, 2008

Michele Basiliere

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Dear Michele:

My belated thanks to you for being such an amazing genetics counselor. I was so frightened after my diagnosis and surgery for primary peritoneal cancer, especially since I lost my mother in 1963 to breast cancer, and I worried that I would have cancer as well. Not only did I have it, but as you know, I was treated and have the BRCA1 mutation.

Having you to talk with has been a real blessing. I now know the value of a licensed genetics counselor and the wonderful work you do, not only in evaluating family history but also in helping an individual such as myself plan for vigilant treatment and awareness. I have recommended to many family member that they consider counseling in their respective cities so that they can evaluate their medical futures intelligently and aggressively. I feel that you have had a major part in my being able to do that, and I am most appreciative.

I have a campaign to help educate women with regard to gynecological cancers, as you know, and I feel part of that will come more readily with the licensing of genetics counselors here in Hawaii. Please let me know if I can attest to your value any further since I know the important role you

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have played in my managing my cancer treatment.

Aloha,

Elissa Josephsohn

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House Committee on Health

S.B. 1805, S.D. 1 Relating to Genetic Counselors
Wednesday, March 12, 2008 at 8:00 a.m.
Conference Room 329

To the Honorable Josh Green, John Mizuno and Members of the House Committee on Health:

My name is Sylvia Au and I strongly support S.B. 1805 S.D. 1.

As a disclaimer, I currently am the head of the Hawai'i Department of Health Genetics Program, but am submitting testimony as a private citizen today.

Twenty years ago, I started working in Hawai'i as the one and only formally trained genetic counselor. As the science of genetics has developed, the need for genetic counseling has increased. I've watched the number of genetic counselors grow to the current 12 genetic counselors working in Hawai'i which is not sufficient to meet the demands for our population.

When I worked as a clinical genetic counselor, **I had many families come to me after being told inaccurate or no information about their risk or presence of genetic disease. Many were dismayed at how long it took for them to find a qualified individual to see.** They were so grateful to find me and that I was able to take time to give them accurate information and support. I can only imagine what happened to the families who did not find their way to seeing a genetic counselor.

I urge the committee to make the forfeiture and amount of time allowed for the renewal of an expired license both be either six months or one year (page 10, lines 8-18). Choosing one time period instead of the two different timeframes makes more sense.

In the spirit of keeping my testimony brief, here are some answers to frequently asked questions about genetic counselor licensure:

DON'T GENETIC COUNSELORS ALREADY HAVE CERTIFICATION?

Genetic counselors may take the national board examination and receive certification from the American Board of Genetic Counseling. Eligibility to take the board examination requires appropriate education and training, but is voluntary and, therefore, is not a legally enforceable standard. Licensure will ensure the responsible practice of genetic counselors in Hawai'i, protecting the consumer from harm and providing a mechanism for recourse when consumers are harmed. Just as physicians and nurses have both board certification and state licensure, so should genetic counselors.

DO OTHER STATES HAVE LICENSURE FOR GENETIC COUNSELORS?

Currently seven states have legislation for genetic counselor licensure: California, Illinois, New Mexico, Massachusetts, Oklahoma, Tennessee, and Utah. Licensure bills have been introduced in eight additional states: Florida, New Jersey, Texas, Washington, Missouri, New York, Washington and Hawai'i. Licensure is actively being pursued in at least 12 other states.

WILL LICENSURE FOR GENETIC COUNSELORS AFFECT THE PRACTICE OF NURSES, PHYSICIANS AND THERAPISTS?

The licensure of genetic counselors in Hawai'i and other states will not prevent licensed health care providers from providing patient services within their scope of practice. Physicians, nurses and other health care professionals providing genetic services or counseling under their respective scopes of practice can continue doing so. **Physicians who provide genetic evaluation and genetic counseling are called geneticists and not genetic counselors.**

HOW MANY GENETIC COUNSELORS ARE THERE IN HAWAII WHO WILL BE AFFECTED BY LICENSURE?

There are currently 14 genetic counselors practicing in Hawai'i. This number has doubled in the last ten years and will only continue to grow as the need for genetic specialists increase. Hawai'i genetic counselors work with families throughout their lifespan. We can be found in a variety of settings, including major medical centers, clinical and research laboratories, public health, and academics.

WOULD LICENSURE BE EXPENSIVE?

Utah was the first state to implement licensure for genetic counselors in 2002 for about 14 genetic counselors which is the same number as in Hawai'i. The first time cost for licensure is \$150 and then \$135 annually for renewal. The minimal cost is accomplished by having a small licensure board while other states have decided to forego having a licensure board and giving the regulatory authority to the head of the regulating executive agency.

WHAT ABOUT THE AUDITOR'S REPORT?

Much has happened since the auditor's report in 2006. The number of direct to consumer genetic testing has greatly increased over the internet and through non-genetics professionals. You can now get testing to determine your diet, your skincare regimen and even who you should date. **More troubling are the well funded companies are offering genome wide scans for under \$1000 to families which include testing of minors.** The companies claim that they are not providing health-related testing, but give consumers links to scientific articles that the consumer must decipher or direct them to their ill equipped primary health care providers for interpretation of the results. It is more important than ever that the public be able to find trained professionals to give them accurate information about the pros and cons of having a genetic test and help them interpret the results of any testing that is done.

It is not surprising that the 2006 state auditor's report did not recommend licensure for genetic counselors. It is difficult to find published documented harm since most families wouldn't even realize they had been harmed. **Results of misinformation may not appear until decades later.** For example, a person who is not told that they are at increased risk of colon cancer may not develop colon cancer for years. Of course had they known their increased risk, they could have taken preventive measures. Without regulation, there are no minimal standards and no recourse when a genetic counselor provides incompetent services.

House Committee on Health Page 3
S.B. 1805, S.D. 1 Relating to Genetic Counselors
Wednesday, March 12, 2008 at 8:00 am

The Secretary's Advisory Committee on Genetics, Health and Society will be releasing its report on the Oversight of Genetic Testing later this month. **The report has over two hundred scientific references documenting the harm that families face during pre and post genetic testing when professionals with no training in genetics order and/or interpret genetic tests.**

I urge the House Committee on Health to pass this bill and get the Committee Report out quickly.

Thank you for the opportunity to testify. Please contact me if you have questions.

Thank you.

Sylvia M. Au, M.S., C.G.C.
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000267

**State of Hawaii
House of Representatives
Committee on Health**

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

Wednesday March 12, 2008
8:00 am

To the Honorable Rep. Josh Green, Rep. John Mizuno and members of the Committee on Health,

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 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

mizuno1-Edgar

From: LINDA CHENG [lcheng@queens.org]
Sent: Tuesday, March 11, 2008 8:08 AM
To: HLTtestimony
Subject: House Committee on Health> SB 1805, SD 1> Wednesday, March 12, 2008, 8:00 am

House Committee on Health
SB 1805, SD 1, Relating to Genetic Counselors

Wednesday, March 12, 2008, 8:00 am
State Capitol, Conference Room 329
Please make 20 copies of this testimony

To the Honorable Chair Josh Green, M.D., Vice Chair John Mizuno and Members of the House Committee on Health:

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. We 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. We serve as patient advocates and educators for other health care professionals and, for the general public.

The genetic counseling profession is rapidly expanding and diversifying. Heightened public awareness, coupled with scientific advances in adult disorders and reproductive technologies, have increased the demand for genetic counselors. The explosion of direct to consumer testing and leisure genetic testing recently truly underscores the need for the public to be able to recognize who is qualified to provide genetic counseling services. 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. Just as physicians and nurses have both board certification and state licensure, so should genetic counselors.

Thank you for allowing me the opportunity to provide testimony in support of SB 1805, SD 1. Please contact me if you have questions.

Thank you.

Linda Cheng, M.S., C.G.C.
Certified Genetic Counselor
The Queen's Comprehensive Genetics Center Physicians' Office Building II
1329 Lusitana Street, Suite B-8
Honolulu, HI 96813
Phone: (808) 537-7633
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000270¹

House Committee on Health**SB 1805 SD1 (SSCR 855)
RELATING TO GENETIC COUNSELORS****Wednesday March 12, 2008
8:00 am**

To the Honorable Chair Josh Green, Vice Chair John Mizuno, and Members of the House Committee on Health:

I strongly support SB 1805 SD1 (SSCR 855) 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.

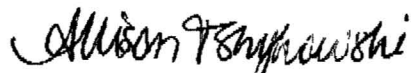
My initial interest in, and attraction to, the field of Genetic Counseling stemmed from what I viewed as an opportunity to work with and serve various individuals who have, or are at risk for, rare conditions that may have a genetic basis. My goal was (and still is) to make a difference in the lives 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 (SSCR 855).



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

000271

Gerald J. McKenna, MD
4374 Kukui Grove St, Ste. 104
Lihue, Hi 96766
246-0663

Date: 03/11/08

To: Rep. Josh Green, M.D., Chair
Rep. John Mizuno, Vice Chair
House Health Committee
Hearing, Wednesday March 12, room 329


Re: Senate bill 2160, SD 2, HD 1, Relating to Medical Liability

I strongly supports SP 2160 SD 2, HD 1 for the following reasons:

1. Tort reform is long overdue in Hawaii. Medical liability reform, based on the successful Texas model, needs to be passed during this session to help stop the steady exodus of physicians from Hawaii.
2. There is a serious shortage of physicians in Hawaii, particularly in critical specialties that are plagued by inordinately high costs for malpractice liability coverage. Not only are physicians in critical specialties leaving the islands, it is almost impossible to attract physicians to practice in Hawaii, given the high cost of living, high threat of malpractice suit, high cost of malpractice liability coverage and low reimbursements for services rendered.
3. With its new medical school and research facilities, Hawaii is positioned to become the medical center of the pacific, but only if we are able to attract the outstanding physicians who would love to come here to practice medicine if the conditions were different. The tort reform measures will be a big step in this direction.
4. The American Medical Association and the Hawaii Insurance Commissioner have both confirmed that medical liability reform will reduce malpractice premiums and improve the practice landscape for all of our physicians, those practicing in the urban centers of Oahu as well as those, like myself, practicing in the rural setting of the neighbor islands.

Thank you for the opportunity to provide this testimony.

Sincerely,



Gerald J. McKenna, M.D.
Psychiatry and Addiction Medicine

000272



THE QUEEN'S MEDICAL CENTER

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

House Committee on Health SB 1805, SD 1, Relating to Genetic Counselors

Wednesday, March 12, 2008, 8:00 am
State Capitol, Conference Room 329
Please make 20 copies of this testimony

To the Honorable Chair Josh Green, M.D., Vice Chair John Mizuno and Members of the House Committee on Health:

I strongly support SB 1805, SD 1, relating to professional licensure of genetic counselors. As Vice President of Oncology, Women's Health & Professional 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.

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

Founded in 1859 by Queen Emma and King Kamehameha IV

House Committee on Health
SB 1805 SD1 (SSCR 855), Relating to Genetic Counselors Professional Licensure

Wednesday March 12, 2008

8:00AM

Please make 5 copies of this testimony

To the Honorable Josh Green, John Mizumo, and Members of the House Committee on Health:

I strongly support SB 1805 SD1 (SSCR 855), relating to professional licensure of genetic counselors. I am the Director of Oncology at the Queen's Medical Center.

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 (SSCR 855).

Debra Ishihara-Wong
Director, Oncology
The Queen's Medical Center

000274

House Committee on Health
SB 1805 SD1 (SSCR 855), Relating to Genetic Counselors Professional Licensure

Wednesday March 12, 2008

8:00AM

Please make 5 copies of this testimony

To the Honorable Josh Green, John Mizumo, and Members of the House Committee on Health:

I strongly support SB 1805 SD1 (SSCR 855), relating to professional licensure of genetic counselors. I am a Hematologist-Oncologist in Honolulu, and a referring clinician to 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.

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Thank you for allowing me the opportunity to provide testimony in support of SB 1805 SD1 (SSCR 855).

Gordon M. Nakano, MD
Hematologist-Oncologist

000275

House Committee on Health
SB 1805 SD1 (SSCR 855), Relating to Genetic Counselors Professional Licensure

Wednesday March 12, 2008

8:00AM

Please make 5 copies of this testimony

To the Honorable Josh Green, John Mizumo, and Members of the House Committee on Health:

I strongly support SB 1805 SD1 (SSCR 855), relating to professional licensure of genetic counselors. I am a physician (Medical Oncologist) in Honolulu, and a referring clinician to 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.

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Thank you for allowing me the opportunity to provide testimony in support of SB 1805 SD1 (SSCR 855).

Kaye Kawahara, MD
Medical Oncologist

000276

House Committee on Health
SB 1805 SD1 (SSCR 855), Relating to Genetic Counselors Professional Licensure

Wednesday March 12, 2008

8:00AM

Please make 5 copies of this testimony

To the Honorable Josh Green, John Mizumo, and Members of the House Committee on Health:

I strongly support SB 1805 SD1 (SSCR 855), relating to professional licensure of genetic counselors. I am a physician in Honolulu, and a referring clinician to 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.

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Thank you for allowing me the opportunity to provide testimony in support of SB 1805 SD1 (SSCR 855).

Paul Morris, MD

000277

House Committee on Health
SB 1805 SD1 (SSCR 855), Relating to Genetic Counselors Professional Licensure

Wednesday March 12, 2008

8:00AM

Please make 5 copies of this testimony

To the Honorable Josh Green, John Mizumo, and Members of the House Committee on Health:

I strongly support SB 1805 SD1 (SSCR 855), relating to professional licensure of genetic counselors. I am a Medical Oncologist in Honolulu, and a referring clinician to 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.

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Thank you for allowing me the opportunity to provide testimony in support of SB 1805 SD1 (SSCR 855).

Carl Higuchi, MD
Medical Oncologist

000278

House Committee on Health
SB 1805 SD1 (SSCR 855), Relating to Genetic Counselors Professional Licensure

Wednesday March 12, 2008

8:00AM

Please make 5 copies of this testimony

To the Honorable Josh Green, John Mizumo, and Members of the House Committee on Health:

I strongly support SB 1805 SD1 (SSCR 855), relating to professional licensure of genetic counselors. I am a Medical Oncologist in Honolulu, and a referring clinician to 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.

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Thank you for allowing me the opportunity to provide testimony in support of SB 1805 SD1 (SSCR 855).

Jared Acoba, MD
Medical Oncologist

000279

House Committee on Health
SB 1805 SD1 (SSCR 855), Relating to Genetic Counselors Professional Licensure

Wednesday March 12, 2008
8:00AM

Please make 5 copies of this testimony

To the Honorable Josh Green, John Mizuno, and Members of the House Committee on Health:

I strongly support SB 1805 SD1 (SSCR 855), relating to professional licensure of genetic counselors. I am the Manager of the Queen's Cancer Center at the Queen's Medical Center, and I work closely with 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 (SSCR 855).

Alison Matsuo, RN
Manager, Queen's Cancer Center

000280

**House Committee on Health
SB 1805, SD 1, Relating to Genetic Counselors**

Wednesday, March 12, 2008, 8:00 am
State Capitol, Conference Room 329
Please make 20 copies of this testimony

To the Honorable Chair Josh Green, M.D., Vice Chair John Mizuno and Members of the House Committee on Health:

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.



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House Committee on Health
SB 1805, SD 1, Relating to Genetic Counselors

Wednesday, March 12, 2008, 8:00 am
State Capitol, Conference Room 329

Please make 20 copies of this testimony

To the Honorable Chair Josh Green, M.D., Vice Chair John Mizuno and Members of the House Committee on Health:

I strongly support SB 1805, SD 1, relating to professional licensure of genetic counselors.

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.

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House Committee on Health
SB 1805 SD1 (SSCR 855), Relating to Genetic Counselors Professional Licensure

Wednesday March 12, 2008
8:00AM

Please make 5 copies of this testimony

To the Honorable Josh Green, John Mizumo, and Members of the House Committee on Health:

I strongly support SB 1805 SD1 (SSCR 855), relating to professional licensure of genetic counselors. I am a Professor at the University of Hawaii Medical School.

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 (SSCR 855).

Ed Cadman
Professor, University of Hawaii Medical School

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