

SB 1208



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

In reply, please refer to:
File:

Senate Committee on Health

S.B. 1208, Relating to Health

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

February 9, 2009, 2:45 p.m.

1 **Department's Position:** The Department of Health (DOH) cannot support this measure. The DOH is
2 not the appropriate agency to license genetic counselors or other healthcare providers, and licensure may
3 be unnecessary since genetic counselors in Hawaii undergo board certification by the American Board
4 of Genetic Counselors (ABGC).

5 **Fiscal Implications:** Costs to the DOH will include staff and operating expenses for a licensing
6 program.

7 **Purpose and Justification:** This measure seeks to establish a genetic counselor licensing program
8 within the Department of Health. A similar bill, S.B. 1085, SD 1, was passed in the 2008 legislative
9 session. The Department did not support the bill, and the Governor vetoed the measure for several
10 reasons: The state auditor conducted a sunrise analysis of a similar bill in 2006, concluding, among
11 other things, that licensing of genetic counselors was not necessary and that such licensing did not meet
12 the criteria for regulation under the Hawaii Regulatory Reform Act.

13 The Department of Health is not the appropriate agency to oversee such a licensing program, and
14 there are no available resources to support such an effort.

15 Thank you for the opportunity to testify on this measure.



Monday, February 9, 2009
Conference Room 016
2:45 pm

The Senate Committee on Health

To: Senator David Y. Ige, - Chair
Senator Josh Green, MD - Vice Chair

From: Venkataraman Balaraman, MD
Kapi'olani Medical Specialists
Professor of Pediatrics/Neonatology Division
UH John A. Burns School of Medicine

RE: Testimony in Strong Support of SB 1208: Relating to Genetic Counselors

My name is Venkataraman Balaraman, MD and I am a Neonatologist at Kapi'olani Medical Specialists and Professor of Pediatrics, Neonatology Division at the University of Hawaii John A. Burns School of Medicine. The Kapi'olani Medical Specialists are an affiliate of Hawaii Pacific Health (HPH), which is the four-hospital system of Kapi'olani Medical Center for Women & Children, Kapi'olani Medical Center at Pali Momi, Straub Clinic & Hospital, and Wilcox Hospital/Kauai Medical Clinic.

I am writing in **strong support of SB 1208** which would establish licensing and regulatory requirements for the practice of genetic counselors. Genetic counselors provide an invaluable service to patients – particularly in prenatal diagnosis. Genetic counselors should be licensed and licensed for the critical work they do. As in many specialized areas of medical practice, licensing is needed to ensure that patient quality is kept at the highest standard. Licensing will also help ensure that genetic counseling services remain economically sustainable by further encouraging third party insurers to provide payment for these services.

I fully support SB 1208. This bill will ensure that genetic counselors practicing in Hawaii will have the training and knowledge to provide the best care to these families particularly when they are confronted with the likelihood of a sick infant and contemplating the impact on future reproductive and health care decisions.

Because of the work that genetic counselors provide and I ask that you pass SB 1208 from this committee. Thank you for the opportunity to testify.

Committee on Health
SB 1208, Relating to Genetic Counselors
Monday February 9, 2009
2:25 PM, Conference Room 016

To the Honorable Chair David Y. Ige and Members of the Committee on Health:

I strongly support SB 1208, 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 1208.

NAME (SIGNATURES ON FILE)	TITLE
Acoba, Jared, MD	Physician, Oncology
Aeby, Tod, MD	Physician, Obstetrics/Gynecology

Ayabe, Ronald, MD	Physician, Obstetrics/Gynecology
Bales, Denny, MD	Physician, Cardiology
Behjati, K., MD	Physician, Nuclear Medicine
Brown, Vincent, MD	Physician, Radiation Oncology
Bryant-Greenwood, Peter, MD	Pathologist, Hawaii Pathologists Laboratory Director, Molecular Diagnostics Vice Chair, Department of Pathology, JABSOM
Cadman, Ed, MD	University of Hawaii Medical School
Camara Jr., Edward	Patient
Chadwick, Darlena, RN, MSN	Vice President, Oncology, Women's Health & Professional Services
Chen, Bruce, MD	Physician, Maternal Fetal Medicine
Chen, Chao, MD	Physician, Obstetrics/Gynecology
Chong, Clayton, MD	Physician, Medical Oncology
Coel, Marc, MD	Physician, Radiology
Dao, Franklin, MD	Physician, Obstetrics/Gynecology
DeMare, Paul, MD	Physician, Radiation Oncology
Doi, Deanne	Oncology Conference Coordinator
Emura, Steven, MD	Assistant Professor, John A. Burns School of Medicine, Department of Obstetrics, Gynecology and Women's Health
Fischberg, Daniel, MD	Physician, Palliative Care
Fujita, Nathan, MD	Physician, Obstetrics/Gynecology
Furuike, Alvin, MD	Physician, Pulmonology

Gloeb, Jay, MD	Physician, Maternal Fetal Medicine
Goldstein, Norman, MD	Physician, Dermatology
Halford, Peter, MD	Physician, Surgery
Hemmings, Daphne, MD	General Surgeon & Assistant Professor Medicine/Surgery
Hew, Denise, MD	Physician, Obstetrics/Gynecology
Higuchi, Carl, MD	Physician, Medical Oncology
Hill, Christina, MD	Physician, Maternal Fetal Medicine
Hirata, Blyth, RN	Registered Nurse
Hirata, Greigh, MD	Physician, Maternal Fetal Medicine
Huddleston, Christine	Sonographer (Obstetrics and Gynecology)
Huynh, Thanh, MD	Physician, Radiation Oncology
Ihara, Karla	Clinical Operations Manager
Ishihara-Wong, Debra	Director, Oncology
Kaaihue, Michelle	Patient Navigator Associate
Kawahara, Kaye, MD	Physician, Medical Oncology
Kelsey, Constance, MA	Contract Coordinator, Revenue Management
Kessel, Bruce, MD	Physician, Gynecology
Kimbell, Jennifer, PhD	Research Development
Kwee, Sandi, MD	Medical Staff Physician
Lakey, Terry	Sonographer (Obstetrics and Gynecology)
Lau, Lorrin, MD	Physician, Obstetrics/Gynecology

Lau, Melanie, MD	Physician, Gynecology
Lederer, John, MD	Physician, Radiation Oncology
Lisehora, George, MD	Physician, Surgery
London, Eris	Nurse Practitioner, Women's Health
Loui, William, MD	Physician, Hematology-Oncology
Lum, Chris, MD	Physician, Director of Dermatopathology
Magee, Maggie	Registered Nurse
Matsuo, Alison	Manager, Cancer Center
Morita, Shane, MD	Physician, Surgical Oncology
Morris, Paul, MD	Physician, Surgery
Murunaka, Wanda, MD	Registered Nurse
Nakano, Gordon, MD	Physician, Hematology-Oncology
Nakasone, Ken, MD	Physician, Obstetrics/Gynecology
Nishi, Steven, MD	Physician, Obstetrics/Gynecology
Nishioka, Jocelyn	Oncology Patient Navigator
Ohtani, Robb, MD	Physician, Obstetrics/Gynecology
Pang, Laeton, MD	Physician, Radiation Oncology
Raddcliffe, Christine	Registered Nurse
Sardinha, Darlene	Administrative Secretary, Cancer Center
Sato, Norman, MD	Physician, Obstetrics/Gynecology
Sato, Renee, MD	Physician, Obstetrics/Gynecology
Seaver, Laurie, MD	Physician, Medical Geneticist

Shimizu, David, MD	Physician, Pathology
Silva, Jana, MD	Physician, Maternal Fetal Medicine
Sweeney, Henry, MS	Clinical Research
Takanishi, Danny, MD	Physician, Surgical Oncology
Tauchi-Nishi, Pamela, MD	Physician, Associate Director of Pathology
Teruya, Thomas, MD	Physician, Obstetrics/Gynecology
Thompson, Diane, MD	Medical Director, The Queen's Medical Center Women's Health Center
Tokairin, Donn, MD	Physician, Obstetrics/Gynecology
Tom, James, MD	Physician, Clinical Research Associate
Tsai, Lynette, MD	Physician, Obstetrics/Gynecology
Tsukerjo, Melissa	Sonographer (Obstetrics and Gynecology)
Warren, Mika, MD	Pathologist
Wilburn, Andrea	Oncology Patient Navigator
Wong, Grace, MD	Physician, Obstetrics/Gynecology
Woodruff, Kelley, MD	Physician, Hematology-Oncology
Yamada, Stacy	Clinical Dietician
Yamashiro, Charles, MD	Physician, Radiation Oncology
Yoshino, Harry, MD	Physician, Obstetrics/Gynecology
Yost, Fredrick, MD	Physician, Surgery

Committee on Health
SB 1208, Relating to Genetic Counselors
Monday February 9, 2009
2:25 PM, Conference Room 016

To the Honorable Chair David Y. Ige and Members of the Committee on Health:

I strongly support SB 1208, relating to professional licensure of genetic counselors. I am a genetic counselor who was been practicing in Hawaii for almost 10 years.

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 1208.



Linda Cheng, MS, CGC



[Make 3 Copies]

Monday, February 9, 2009
Conference Room 016
2:45 pm

The Senate Committee on Health

To: Senator David Y. Ige, - Chair
Senator Josh Green, MD - Vice Chair

From: Ken Nakamura, MD - Chief Medical Officer
Kapi'olani Medical Specialists
Professor of Pediatrics/Neonatology Division
UH John A. Burns School of Medicine

RE: Testimony in Strong Support of SB 1208: Relating to Genetic Counselors

My name is Ken Nakamura, MD and I am the Chief Medical Officer for Kapi'olani Medical Specialists and Professor of Pediatrics, Neonatology Division at the University of Hawaii John A. Burns School of Medicine. The Kapi'olani Medical Specialists are an affiliate of Hawaii Pacific Health (HPH), which is the four-hospital system of Kapi'olani Medical Center for Women & Children, Kapi'olani Medical Center at Pali Momi, Straub Clinic & Hospital, and Wilcox Hospital/Kauai Medical Clinic.

I am writing in **strong support of SB 1208** which would establish licensing and regulatory requirements for the practice of genetic counselors. 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 in the evaluation and management of children and adults with heritable conditions. Medical geneticists and genetic counselors work together much like other physicians work with nurses.

SB 1208 will provide many benefits. First, it will ensure that genetic counselors practicing in Hawaii will have the training and knowledge to provide the best care to these families at a difficult time in their lives – when dealing with a sick infant and contemplating the impact on future reproductive and health care decisions. Second, it would provide the first step towards enabling genetic counselors to bill for their services from third party insurers. Third, licensure will help attract genetic counselors to practice in Hawaii as there are currently not enough trained genetic physicians to provide all genetic services and counseling.

Because of the work that genetic counselors provide and I ask that you pass SB 1208 from this committee. Thank you for the opportunity to testify.

**State of Hawaii
Senate
Committee on Health**

**SB 1208
RELATING TO GENETIC COUNSELORS
Monday February 9, 2009
2:45 pm
State Capitol Building Conference Room 016**

To the Honorable Senators David Y. Ige, Chairman, Josh Green, MD, Vice-Chairman and members of the Committee on Health,

Thank you for the opportunity to provide testimony on SB1208, which establishes a licensure program for genetic counselors. I offer my testimony as a physician Medical Geneticist, and I strongly support the passage of SB 1208.

As a medical geneticist, a physician who works closely with genetic counselors on a daily basis, **I strongly support SB 1208 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. Board-certified genetic counselors have 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 licensure of genetic counselors does not restrict any physician from providing counseling to their patients regarding hereditary diseases or risk factors, but a physician would not categorize himself or herself as a "genetic counselor" or "licensed genetic counselor" but instead as a physician and bill and expect reimbursement, as for any other type of medical office visit or consultation.

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."**

RELATING TO GENETIC COUNSELORS

HB 1362

Page 2

Laurie H. Seaver, MD

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. **Genetic counselors are currently providing vital prenatal and cancer genetic counseling on the neighbor islands**, where there are no other genetic service providers except for my outreach clinics (only one clinic day a month rotating to different islands).

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 and there are currently less than 20 genetic counselors in Hawaii that require licensure.

Thank you for allowing me the opportunity to provide testimony in support of SB1208.

Laurie H. Seaver, MD
19 Ilikupono St.
Kailua, HI 96734
254-1819

Senate Committee on Health
S.B. 1208, RELATING TO GENETIC COUNSELORS
Monday, February 9, 2009, 2:45pm

To the Honorable David Ige, the Honorable Josh Green, and Members of the Senate 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. 1208 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 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.

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. 1208.

Lianne Hasegawa, M.S., C.G.C.
94-443 Keaopua Street, #116
Mililani, HI 96789

Senate Committee on Health**SB1208
RELATING TO GENETIC COUNSELOR LICENSURE**

Monday, February 9, 2009
2:45pm

To the Honorable Chair David Y. Ige, Vice Chair Josh Green, MD, and Members of the Senate Committee on Health:

I support SB1208 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 seven 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.

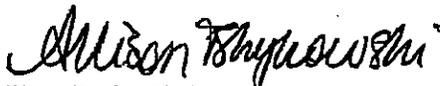
My initial interest in, and attraction to, the field of Genetic Counseling stemmed from what I viewed as an opportunity to work with and serve various individuals who have, or are at risk for, rare conditions that may have a genetic basis. My goal was (and still is) to make a difference in the lives 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 1208.



Allison Taylor Shykowski, MS, CGC
Certified Genetic Counselor
Honolulu, HI

From: Matt White [mfwhite5@gmail.com] on behalf of Matt White [matt@anewway.org]
Sent: Friday, February 06, 2009 6:32 PM
To: HTHTestimony
Subject: Testimony Regarding SB 1208 For Senate HLT Hearing on 02/09/09 at 2:45pm

Categories: Green Category, Blue Category

Testimony of
Matthew White, CTO
Kahala Code Factory
1617 South Beretania St. #1102
Honolulu, HI 96826

State of Hawaii
Senate
Committee on Health

SB 1208
RELATING TO GENETIC COUNSELORS
Monday February 9, 2009
2:45 pm
State Capitol Building Conference Room 016

To the Honorable Senators David Y. Ige, Chairman, Josh Green, MD, Vice-Chairman and members of the Committee on Health,

Thank you for the opportunity to provide testimony on SB 1208, which establishes a licensure program for genetic counselors. I offer my testimony as a registered Hawaii voter, and I strongly support the passage of SB 1208 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 referred 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 to 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

**State of Hawaii
Senate
Committee on Health**

**SB 1208 RELATING TO GENETIC COUNSELORS
Monday February 9, 2009
2:45 pm
State Capitol Building Conference Room 016**

To the Honorable Senators David Y. Ige, Chairman, Josh Green, MD, Vice-Chairman and members of the Committee on Health,

Thank you for the opportunity to provide testimony on SB1208. **I strongly support the passage of SB 1208, which establishes a licensure program for genetic counselors.**

Newborns in the neonatal intensive care unit are diagnosed with genetic conditions on a weekly basis. Genetic counselors are an asset to our families as they often become the primary source of genetic information and counseling after our newborns are discharged from the hospital. They're a vital part to our health care team and we are in full support of their endeavor to establish licensure.

Everyday, more genetic tests are being offered by providers and marketed directly to the consumer (Direct-to-Consumer Testing). Many of these genetic tests and their interpretation are questionable and in some cases, harmful. Recently, well funded companies have begun offering genome wide scans for under \$500. The public does not understand the consequences of the testing and will need to be able to find trained professionals to help them decide what tests may give them useful information and help them understand the test results.

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. With no state regulation, incompetent genetic counselors cannot be punished by the state nor restricted from practicing. This leaves families in Hawai'i vulnerable to physical and psychological harms.

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From the explosion of direct-to-consumer genetic tests to the issues surrounding accessible health care services in Hawai'i, licensure is needed to ensure access to quality specialty genetic counseling services in our state.

Sincerely,

**Daniel T. Murai, MD
(808) 983-8387**

**State of Hawaii
Senate
Committee on Health**

SB 1208 RELATING TO GENETIC COUNSELORS

Monday February 9, 2009

2:45 pm

State Capitol Building Conference Room 016

To the Honorable Senators David Y. Ige, Chairman, Josh Green, MD, Vice-Chairman and members of the Committee on Health,

Thank you for the opportunity to provide testimony on SB1208. **I strongly support the passage of SB 1208, which establishes a licensure program for genetic counselors.**

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Sincerely,

**Lynn M. Iwamoto, M.D.
(808) 983-8670**

**State of Hawaii
Senate
Committee on Health**

**SB 1208 RELATING TO GENETIC COUNSELORS
Monday February 9, 2009
2:45 pm
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Sincerely,

**Sheree Kuo, M.D.
(808) 983-8387**

**State of Hawaii
Senate
Committee on Health**

**SB 1208 RELATING TO GENETIC COUNSELORS
Monday February 9, 2009
2:45 pm
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Sincerely,

**Daniel T. Murai, MD
(808) 983-8387**

**State of Hawaii
Senate Committee on Health**

**SB 1208 RELATING TO GENETIC COUNSELORS
Monday February 9, 2009 at 2:45 pm
State Capitol Building Conference Room 016**

To the Honorable Senators David Y. Ige, Chairman, Josh Green, MD, Vice-Chairman and members of the Committee on Health,

Thank you for the opportunity to provide testimony on SB1208, which establishes a licensure program for genetic counselors. I offer my testimony as a certified genetic counselor, and I strongly support the passage of SB 1208.

I have been practicing as a pediatric genetic counselor for 3.5 years. It is well known that a substantial amount of time is required to see patients for a genetics evaluation and reimbursement for these services does not cover the costs of maintaining such practices [From *Genetics in Medicine* 2002;4(3):142-149]. Currently, most genetic counselors in Hawai'i are not reimbursed for their services. This makes it even more difficult for hospitals and clinics to support these services. Neighbor island families who have the least access to subspecialty health services may receive inaccurate or NO genetic counseling leading to unnecessary genetic tests, or they may not be given access to testing. Licensure is the first step towards genetic counselor reimbursement, making genetic counseling more affordable while ensuring quality health services are accessible to the public.

Licensure also protects the profession itself from any association of malpractice and incompetent care provided by individuals without licensure requirements. Every day, more genetic tests are being offered by providers and marketed directly to the consumer (Direct-to-Consumer Testing). Many of these genetic tests and their interpretations are questionable and in some cases, harmful. Recently, well-funded companies have begun offering genome wide scans for under \$500. The public does not understand the consequences of the testing and will need to be able to find trained professionals to help them decide what tests may give them useful information and help them understand the test results.

Licensure provides the ability to remove a genetic counselor's right to practice if he/she is found to be incompetent. Genetic counselors are involved in ethically charged areas of reproductive and medical decision-making. Ensuring ethical and competent practice is a safeguard against improper use of genetic information. With no state regulation, incompetent genetic counselors cannot be punished by the state nor restricted from practicing. This leaves families in Hawai'i vulnerable to physical and psychological harms.

From the explosion of direct-to-consumer genetic testing to the issues surrounding accessible health care services in Hawai'i, licensure is needed to ensure access to quality specialty genetic counseling services in our state.

Sincerely,

Elaine White, M.S., C.G.C.
1617 South Beretania Street, Apt. #1102
Honolulu, Hawaii 96826

**State of Hawaii
Senate
Committee on Health**

**SB 1208 RELATING TO GENETIC COUNSELORS
Monday February 9, 2009
2:45 pm
State Capitol Building Conference Room 016**

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Sincerely,

**Jerome Lee, M.D.
(808) 983-8387**

**State of Hawaii
Senate
Committee on Health**

SB 1208 RELATING TO GENETIC COUNSELORS

Monday February 9, 2009

2:45 pm

State Capitol Building Conference Room 016

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Sincerely,

**Charles Neal, M.D.
(808) 983-8670**

**State of Hawaii
Senate
Committee on Health**

**SB 1208 RELATING TO GENETIC COUNSELORS
Monday February 9, 2009
2:45 pm
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Sincerely,

**Randy Taniguchi, Kapiolani NICU
(808) 983-8673**

**State of Hawaii
Senate
Committee on Health**

**SB 1208 RELATING TO GENETIC COUNSELORS
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2:45 pm
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Sincerely,

**Jon Izumiasumi, Kapiolani NICU
(808) 983-8629**

**State of Hawaii
Senate
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SB 1208 RELATING TO GENETIC COUNSELORS

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Sincerely,

**Sheree Cambra, R.N.
(808) 554-7372**

**State of Hawaii
Senate
Committee on Health**

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Sincerely,

**Jennifer Ryan, R.N.
(808) 232-1010**

**State of Hawaii
Senate
Committee on Health**

SB 1208 RELATING TO GENETIC COUNSELORS

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Sincerely,

**Kathleen Brown, R.N.
(808) 373-9755**

**State of Hawaii
Senate
Committee on Health**

**SB 1208 RELATING TO GENETIC COUNSELORS
Monday February 9, 2009
2:45 pm
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Sincerely,

**Iyouri Oshiro, R.N.
(808) 221-9003**

**State of Hawaii
Senate
Committee on Health**

**SB 1208 RELATING TO GENETIC COUNSELORS
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Sincerely,

**Kristin Iriguchi, R.N.
(808) 345-2499**

**State of Hawaii
Senate
Committee on Health**

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From the explosion of direct-to-consumer genetic tests to the issues surrounding accessible health care services in Hawai'i, licensure is needed to ensure access to quality specialty genetic counseling services in our state.

Sincerely,

**Susan Kau, Nurse Level V, RNG
(808) 226-1407**

**State of Hawaii
Senate
Committee on Health**

**SB 1208 RELATING TO GENETIC COUNSELORS
Monday February 9, 2009
2:45 pm
State Capitol Building Conference Room 016**

To the Honorable Senators David Y. Ige, Chairman, Josh Green, MD, Vice-Chairman and members of the Committee on Health,

Thank you for the opportunity to provide testimony on SB1208. **I strongly support the passage of SB 1208, which establishes a licensure program for genetic counselors.**

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Sincerely,

**Christina Houson, R.N.
(808) 923-1086**

**State of Hawaii
Senate
Committee on Health**

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Sincerely,

**Jennifer Marsh, R.N.
(808) 330-1494**

**State of Hawaii
Senate
Committee on Health**

**SB 1208 RELATING TO GENETIC COUNSELORS
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Sincerely,

**Laura Fujimoto, R.N.
(808) 983-8673**

**State of Hawaii
Senate
Committee on Health**

**SB 1208 RELATING TO GENETIC COUNSELORS
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Sincerely,

**Cory Clemens, R.N.
(808) 277-2023**

**State of Hawaii
Senate
Committee on Health**

**SB 1208 RELATING TO GENETIC COUNSELORS
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Sincerely,

**Jaime Kobashigawa, R.N.
(808) 387-6906**

**State of Hawaii
Senate
Committee on Health**

**SB 1208 RELATING TO GENETIC COUNSELORS
Monday February 9, 2009
2:45 pm
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Sincerely,

**Kathryn Kirley, R.N.
(808) 271-5754**

**State of Hawaii
Senate
Committee on Health**

**SB 1208 RELATING TO GENETIC COUNSELORS
Monday February 9, 2009
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**Mari Goo, R.N.
(808) 387-2402**

**State of Hawaii
Senate
Committee on Health**

**SB 1208 RELATING TO GENETIC COUNSELORS
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Sincerely,

**Stephanie Hoe, R.N.
(808) 753-5531**

**State of Hawaii
Senate
Committee on Health**

**SB 1208 RELATING TO GENETIC COUNSELORS
Monday February 9, 2009
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**Corri-Ann Fujikawa, R.N.
(808) 387-8875**

**State of Hawaii
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Committee on Health**

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Sincerely,

**Dianalynn Ching, R.N.
(808) 383-3041**

**State of Hawaii
Senate
Committee on Health**

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Sincerely,

**Sherveen Batts, M.D., Neonatal Fellow
(808) 721-4834**

**State of Hawaii
Senate
Committee on Health**

SB 1208 RELATING TO GENETIC COUNSELORS

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Sincerely,

**Derek Ching, M.D.
(808) 733-5111**

**State of Hawaii
Senate
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Sincerely,

**Kathy Parra, R.T.
(808) 230-4090**

**State of Hawaii
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Newborns in the neonatal intensive care unit are diagnosed with genetic conditions on a weekly basis. Genetic counselors are an asset to our families as they often become the primary source of genetic information and counseling after our newborns are discharged from the hospital. They're a vital part to our health care team and we are in full support of their endeavor to establish licensure.

Everyday, more genetic tests are being offered by providers and marketed directly to the consumer (Direct-to-Consumer Testing). Many of these genetic tests and their interpretation are questionable and in some cases, harmful. Recently, well funded companies have begun offering genome wide scans for under \$500. The public does not understand the consequences of the testing and will need to be able to find trained professionals to help them decide what tests may give them useful information and help them understand the test results.

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. With no state regulation, incompetent genetic counselors cannot be punished by the state nor restricted from practicing. This leaves families in Hawai'i vulnerable to physical and psychological harms.

Most genetic counselors in Hawai'i are not reimbursed for their services, making it difficult for hospitals and clinics to support these services. Neighbor island families who have the least access to subspecialty health services may receive inaccurate or NO genetic counseling leading to unnecessary genetic tests, or they may not be given access to testing. Licensure would be the first step towards genetic counselor reimbursement, making genetic counseling more affordable while ensuring quality health services are accessible to the public.

From the explosion of direct-to-consumer genetic tests to the issues surrounding accessible health care services in Hawai'i, licensure is needed to ensure access to quality specialty genetic counseling services in our state.

Sincerely,

**Kenneth Ash, M.D.
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