



LINDA LINGLE
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STATE OF HAWAII
OFFICE OF THE DIRECTOR
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LAWRENCE M. REIFURTH
DIRECTOR
RONALD BOYER
DEPUTY DIRECTOR

**PRESENTATION OF THE
PROFESSIONAL AND VOCATIONAL LICENSING DIVISION**

TO THE HOUSE COMMITTEE ON FINANCE

TWENTY-FIFTH LEGISLATURE
Regular Session of 2009

Tuesday, March 3, 2009
2:00 p.m.

**TESTIMONY ON HOUSE BILL NO.1362, H.D. 1, RELATING TO GENETIC
COUNSELORS.**

TO THE HONORABLE MARCUS R. OSHIRO, CHAIR,
AND MEMBERS OF THE COMMITTEE:

My name is Noe Noe Tom, Licensing Administrator of the Professional and Vocational Licensing Division ("PVLD"), Department of Commerce and Consumer Affairs ("DCCA"). We thank you for the opportunity to submit testimony in strong opposition to H.B. No. 1362, H.D. 1, Relating to Genetic Counselors.

As DCCA is designated to be the agency to implement this measure, we continue to object to this bill on the following grounds:

- The bill incorrectly represents regulation as "licensure". The proposed regulation is a "certification" regulatory scheme, not a licensing scheme. Certification is when the applicant's competency is demonstrated simply by

submitting a private credential/certification from a certifying body for that profession. That is exactly what H.B. 1362, H.D. 1 proposes. Requirements for "licensure" are much more extensive and are NOT based on private credentialing or certification. The correct classification of the regulation is important for laws under DCCA and we have ensured new licensing programs represent this accurately in the laws which create new regulation. While it may seem such classification is wordsmithing, it is not. Even the Legislative Auditor has recognized the various classifications of regulation and raises similar questions when legislative proposals misclassify a regulatory program. The term "license" is thrown around rather loosely, but in crafting laws accuracy is essential. To fix this bill, all references to "license" or any variation thereof should be replaced with the term "certification" or variations of this term;

- We oppose the inclusion of a grandfathering provision for any new regulatory program and therefore oppose the section in this bill on "Provisional license". This provision would have DCCA issue provisional recognition to a practitioner, giving the person all rights and privileges to practice as a fully state recognized genetic counselor, WITHOUT the person having met the requirements for recognition. It is a grandfathering provision designed to allow current practitioners to obtain state recognition and continue to practice once the law takes effect, but to satisfy requirements for recognition after the fact. For the protection of consumers, once regulation takes effect, only

persons who have met all requirements should receive state recognition. However, to accommodate concerns over a current practitioner's inability to meet requirements with the enactment of regulation, legislative proposals have provided a delayed date (minimally 1 year) for the effective date of the regulation. During the period prior to the effective date, current practitioners obtain what they lack so that at the time the new regulation goes into effect, they have all the credentials required to gain state recognition. DCCA will support such a proposal;

- As a new program, there are costs associated with start up and implementation. Absent receiving general fund monies for these costs, we envision that DCCA's Compliance Resolution Fund ("CRF") will bear the costs for start up. This money would come from the CRF's based reserve of funds collected from other regulated groups. As genetic counselors should be responsible for all costs, including start up, for this new regulatory program, they should reimburse the CRF for all start up costs incurred and paid for by the CRF. As a means for them to reimburse the CRF, an additional fee would be assessed. The authority for the additional assessment should be set forth in this bill and proposed language is provided below. Also, until such time as we are able to determine the exact number of genetic counselors to be impacted by regulation and, hence, our associated costs, we are leaving amounts in the proposal blank. We ask for your consideration to add this provision to the bill.

SECTION . Upon issuance of a new certification and at each renewal period, each genetic counselor shall pay an additional fee of \$____, which shall be deposited into the compliance resolution fund established pursuant to 26-9(o), Hawaii Revised Statutes. Upon the full repayment of \$____, thereafter no surcharge shall be assessed.

- All dates contained in the bill should be blanked out until all concerns with this proposal are resolved; and
- There are substantive changes needed to the bill to conform with other regulatory laws under DCCA but we will bring the requested changes to the attention of the subject matter committees.

Thank you for the opportunity to testify on H.B. No. 1362, H.D. 1 and we request you pass this measure with amendments to address the concerns noted above.



[Make 3 Copies]

Tuesday, March 03, 2009
Conference Room 308
2:00 pm

The House Committee on Finance

To: Representative Marcus Oshiro, Chair
Representative Marilyn Lee – 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 HB 1362 HD1: 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 HB 1362 HD1** 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.

HB 1362 HD1 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 HB 1362 HD1 from this committee. Thank you for the opportunity to testify.

March of Dimes Foundation
Hawaii Chapter
1431 S. King Street, Suite 504
Honolulu, Hawaii 96814
808-973-2155

March 2, 2009

To: Rep. Marcus Oshiro, Chair
Rep. Marilyn Lee, Vice Chair
Committee on Consumer Protection & Commerce

From: Michael Robinson, Chair
Public Affairs Committee
March of Dimes

Re: Support of HB1362

Chair Oshiro, Vice Chair Lee, and members of the committee:

I am writing to express strong support of House Bill 1362, establishing the Genetic Counseling Licensure Program within Department of Commerce and Consumer Affairs and requiring licensure in order to use the title of "licensed genetic counselor".

Rapid changes in scientific knowledge improve the chances for birth of a healthy baby and also create an ongoing need for information about childbearing. Individuals have different risks for having a baby born with an inherited disorder, birth defect, or other abnormal pregnancy outcome. Prospective parents who have unanswered questions about diseases and traits in their families, or about possible environmental or behavioral risk factors, or certain complications of pregnancy, are advised to take advantage of genetic counseling. For example, couples who have recurring miscarriages should be offered genetic testing to learn whether either of them has certain genetic risk factors for miscarriages.

Genetic counselors translate scientific knowledge into practical information that can help families learn about genetic testing and results so that they may make informed decisions. Genetic counseling should take into consideration the family's personal values, and religious and cultural beliefs. Genetic counselors facilitate medical management for genetic conditions, and provide emotional support to the family. Providers of genetic counseling include professional genetic counselors and doctors or nurses with special training in the subject. For physicians, nurses, therapists and other health care providers licensing is necessary to ensure that practitioners can perform at the highest standard. Licensing genetic counselors will ensure they have knowledge and training needed to provide this valuable service to Hawaii's families.

I strongly support SB 1362. Mahalo for allowing me to express that support.

march  of dimes®

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

HB 1362 HD1 RELATING TO GENETIC COUNSELORS

Tuesday, March 3rd, 2009

2:00 pm

State Capitol Building Conference Room 308

To the Honorable Rep. Marcus R. Oshiro, Chair, Marilyn B. Lee, Vice-Chair, and members of the Committee on Finance:

Thank you for the opportunity to provide testimony on HB 1362 HD1. **I strongly support the passage of this bill, 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.

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,

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

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

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Sincerely,

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

State of Hawaii
House of Representatives
Committee on Finance

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Sincerely,

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

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

HB 1362 HD1 RELATING TO GENETIC COUNSELORS

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Sincerely,

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

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

HB 1362 HD1 RELATING TO GENETIC COUNSELORS

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Sincerely,

**Kenneth Ash, M.D.
(808) 983-8670**

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

HB 1362 HD1 RELATING TO GENETIC COUNSELORS

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Sincerely,

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

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

**HB 1362 HD1 RELATING TO GENETIC COUNSELORS
Tuesday, March 3rd, 2009
2:00 pm
State Capitol Building Conference Room 308**

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Sincerely,

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

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

HB 1362 HD1 RELATING TO GENETIC COUNSELORS

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Sincerely,

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

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

HB 1362 HD1 RELATING TO GENETIC COUNSELORS

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Sincerely,

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

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Sincerely,

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

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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,

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

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

HB 1362 HD1 RELATING TO GENETIC COUNSELORS

Tuesday, March 3rd, 2009

2:00 pm

State Capitol Building Conference Room 308

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Sincerely,

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

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

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Sincerely,

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

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

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Sincerely,

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

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

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Sincerely,

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

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

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Sincerely,

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

State of Hawaii
House of Representatives Committee on Finance

HB 1362 HD1 RELATING TO GENETIC COUNSELORS

Tuesday, March 3rd, 2009

2:00 pm

State Capitol Building Conference Room 308

To the Honorable Rep. Marcus R. Oshiro, Chair; Marilyn B. Lee, Vice-Chair; and members of the Committee on Finance:

Thank you for the opportunity to provide testimony on HB1362 HD1, which establishes a licensure program for genetic counselors. I offer my testimony as a physician Medical Geneticist, and I strongly support the passage of HB 1362 HD1.

As a medical geneticist, a physician who works closely with genetic counselors on a daily basis, **I strongly support HB 1362 HD1 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."**

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

RELATING TO GENETIC COUNSELORS

HB 1362 HD1

Page 2

Laurie H. Seaver, MD

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 fees paid by the genetic counselors seeking licensure should cover the cost of such a licensure program for the State of Hawaii. Administration of the licensure program would not be burdensome, since the counselors have met stringent eligibility requirements and there are currently less than 20 genetic counselors in Hawaii that require licensure. For example, the states of Utah and Oklahoma have a similar number of genetic counselors who pay approximately \$150 per year for licensure.**

Thank you for allowing me the opportunity to provide testimony in support of HB 1362 HD1.

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

State of Hawaii
House of Representatives
Committee on Finance

HB 1362 HD1 RELATING TO GENETIC COUNSELORS

Tuesday, March 3rd, 2009

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Sincerely,

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

State of Hawaii
House of Representatives
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HB 1362 HD1 RELATING TO GENETIC COUNSELORS

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Sincerely,

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

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

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Sincerely,

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

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

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Sincerely,

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

State of Hawaii
House of Representatives
Committee on Finance

HB 1362 HD1 RELATING TO GENETIC COUNSELORS

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Sincerely,

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

**State of Hawaii
House of Representatives
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Sincerely,

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

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House of Representatives
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State Capitol Building Conference Room 308

To the Honorable Rep. Marcus R. Oshiro, Chair, Marilyn B. Lee, Vice-Chair, and members of the Committee on Finance:

Thank you for the opportunity to provide testimony on HB 1362 HD1. **I strongly support the passage of this bill, 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.

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,

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

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

HB 1362 HD1 RELATING TO GENETIC COUNSELORS

Tuesday, March 3rd, 2009

2:00 pm

State Capitol Building Conference Room 308

To the Honorable Rep. Marcus R. Oshiro, Chair, Marilyn B. Lee, Vice-Chair, and members of the Committee on Finance:

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Sincerely,

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

State of Hawaii
House of Representatives
Committee on Finance

HB 1362 HD1 RELATING TO GENETIC COUNSELORS

Tuesday, March 3rd, 2009

2:00 pm

State Capitol Building Conference Room 308

To the Honorable Rep. Marcus R. Oshiro, Chair, Marilyn B. Lee, Vice-Chair, and members of the Committee on Finance:

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Sincerely,

Mari Goo, R.N.
(808) 387-2402

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

HB 1362 HD1 RELATING TO GENETIC COUNSELORS

Tuesday, March 3rd, 2009

2:00 pm

State Capitol Building Conference Room 308

To the Honorable Rep. Marcus R. Oshiro, Chair, Marilyn B. Lee, Vice-Chair, and members of the Committee on Finance:

Thank you for the opportunity to provide testimony on HB 1362 HD1. **I strongly support the passage of this bill, which establishes a licensure program for genetic counselors.**

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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,

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

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

HB 1362 HD1 RELATING TO GENETIC COUNSELORS

Tuesday, March 3rd, 2009

2:00 pm

State Capitol Building Conference Room 308

To the Honorable Rep. Marcus R. Oshiro, Chair, Marilyn B. Lee, Vice-Chair, and members of the Committee on Finance:

Thank you for the opportunity to provide testimony on HB 1362 HD1. **I strongly support the passage of this bill, 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.

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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,

Corri-Ann Fujikawa, R.N.
(808) 387-8875

State of Hawaii
House of Representatives Committee on Finance

HB 1362 HD1 RELATING TO GENETIC COUNSELORS
Tuesday, March 3rd, 2009 at 2:00 pm
State Capitol Building Conference Room 308

To the Honorable Rep. Marcus R. Oshiro, Chair; Marilyn B. Lee, Vice-Chair; and members of the Committee on Finance:

Thank you for the opportunity to provide testimony on HB 1362 HD1. **I strongly support the passage of HB1362 HD1, which establishes a licensure program for genetic counselors.**

There has been concern about the operating expenses to implement this program. I want to highlight that the licensee will be charged fees to cover the costs of the license. This has been successful in other states that have a similar number of in-state genetic counselors. For example, Utah has 14 genetic counselors and charges \$150 per year. Oklahoma recently started licensing and charges \$145 per year with 11 in-state genetic counselors. Oklahoma has also reported additional income received from many out-of-state genetic counselors working for national laboratories but provide genetic test result interpretation to health care providers and families in the state. Therefore, additional income to cover the cost of the program will also be provided by out-of-state counselors who will need to obtain licensure if they are providing information to Hawai'i's health care providers and families. This legislation is economically feasible and I hope the committee considers passing this bill.

Every day, more genetic tests are being offered by providers and marketed directly to the consumer (Direct-to-Consumer Testing). The public may 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. Ensuring ethical and competent practice is a safeguard against improper use of genetic information. With no state regulation, incompetent genetic counselors cannot be 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 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
808-927-1139

Committee on Finance
HB 1362, HD1, Relating to Genetic Counselors
Tuesday March 3, 2009
2:00 PM, Conference Room 308

To the Honorable Chair Marcus R. Oshiro and Members of the Committee on Finance:

I strongly support **HB 1362, HD1**, relating to professional licensure of genetic counselors. 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.

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 **HB 1362, HD1**.

NAME (SIGNATURES ON FILE)	TITLE
Acoba, Jared, MD	Physician, Oncology
Aeby, Tod, MD	Physician, Obstetrics/Gynecology
Akaka, Gerard K, MD	Vice President, Medical Affairs Chief Medical Officer
Ayabe, Ronald, MD	Physician, Obstetrics/Gynecology
Bakhshi, Tiki, MD	Physician, Obstetrics/Gynecology

Testimony in support of HB 1362, HD1

For a copy of signatures on file, contact Linda Cheng (doublehelix2000@hotmail.com)

	Tripler Army Medical Center
Bales, Denny, MD	Physician, Cardiology
Behjati, K, MD	Physician, Nuclear Medicine
Berenberg, Jeffrey L, MD	Chief, Hematology/Oncology Services Tripler Army Medical Center
Berlinger, Anne	Diagnostic Medical Sonographer
Boyle, KJ, MD	Physician, Obstetrics/Gynecology Tripler Army Medical Center
Brown, Vincent, MD	Physician, Radiation Oncology
Bryant-Greenwood, Peter, MD	Pathologist, Hawaii Pathologists Laboratory Director, Molecular Diagnostics Vice Chair, Department of Pathology, John A. Burns School of Medicine (JABSOM)
Cadman, Ed, MD	Former Dean, John A. Burns School of Medicine (JABSOM)
Camara Jr., Edward	Patient
Castillo, Marisia	Oncology Data Registry
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
Cho, Jonathan, MD	Physician, Medical Oncology Cancer Research Center of Hawaii
Chong, Clayton, MD	Physician, Medical Oncology
Coel, Marc, MD	Physician, Radiology
Dao, Franklin, MD	Physician, Obstetrics/Gynecology
DeMare, Paul, MD	Physician, Radiation Oncology
Doi, Dearne	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
Grace, Nalani	Medical Student
Halford, Peter, MD	Physician, Surgery
Hemrings, 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)
Humphrey, Terri	Diagnostic Medical Sonographer
Humphreys, Melissa	Diagnostic Medical Sonographer
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
Kelleher, Tim, RN	Registered Nurse
Kelsey, Constance, MA	Contract Coordinator, Revenue Management
Kessel, Bruce, MD	Physician, Gynecology

Kimbell, Jennifer, PhD	Research Development
Scott Kuwada, MD	Professor of Medicine John A. Burns School of Medicine (JABSOM)
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
Ma, Adrienne	Medical Student
Magee, Maggie	Registered Nurse
Masterson, Jan	Diagnostic Medical Sonographer
Matsuo, Alison	Manager, Cancer Center
McClendon, Leslie	Diagnostic Medical Sonographer
Montero, Winston, MD	Resident Physician
Moon, Scott, MD	Physician, Radiation Oncology
Moreland, Mindy	Diagnostic Medical Sonographer
Morita, Shane, MD	Physician, Surgical Oncology
Morris, Paul, MD	Physician, Surgery
Murunaka, Wanda, MD	Registered Nurse
Nakano, Gordon, MD	Physician, Hematology-Oncology

Testimony in support of HB 1362, HD1

For a copy of signatures on file, contact Linda Cheng (doublehelix2000@hotmail.com)

Nakasone, Ken, MD	Physician, Obstetrics/Gynecology
Ng, Karen, RN	Registered Nurse
Nishi, Steven, MD	Physician, Obstetrics/Gynecology
Nishioka, Jocelyn	Oncology Patient Navigator
Ohtani, Robb, MD	Physician, Obstetrics/Gynecology
Onizuka, Lisa	Sonographer
Pang, Laeton, MD	Physician, Radiation Oncology
Pierce, Brian, MD	Physician, Maternal Fetal Medicine
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
Shaeffer, David, MD	Physician, Surgery
Shimizu, David, MD	Physician, Pathology
Silva, Jana, MD	Physician, Maternal Fetal Medicine
Stary, Creed, MD, PhD	Resident Physician
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

Testimony in support of HB 1362, HD1

For a copy of signatures on file, contact Linda Cheng (doublehelix2000@hotmail.com)

Tom, James, MD	Physician, Clinical Research Associate
Tsai, Lynette, MD	Physician, Obstetrics/Gynecology
Tsukenojo, Melissa	Sonographer (Obstetrics and Gynecology)
Varcadipane, Joseph C, MD	Resident Physician
Wakai, Coolidge S, MD	Physician, Cardiovascular Diseases
Warren, Mika, MD	Physician, Pathology
Weaver, A Michelle	Data Oncology Registry
Weinrich, Brooke	Diagnostic Medical Sonographer
Wilburn, Andrea	Oncology Patient Navigator
Wing, Adrienne, MD	Physician, Internal Medicine
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
Zhang, Lei, MD, PhD	Resident Physician

Committee on Finance
HB 1362, HD1, Relating to Genetic Counselors
Tuesday March 3, 2009
2:00 PM, Conference Room 308

To the Honorable Chair Marcus R. Oshiro and Members of the Committee on Finance:

I strongly support **HB 1362 HD1**, 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.

As a prior employee of the Department of Health Genetics Program, I believe that the Department of Health has the expertise and staff to sustain a licensure program for genetic counselors. **I respectfully request that you consider revising the bill to have the Department of Health as the regulatory agency.** Hawai'i is one of the few states that has a Genetics Program with board certified genetic counselors working in the program. No state general fund money is used to fund the program staff. Administration of the licensure would be almost cost neutral since the staff already exists and there are not a large number of genetic counselors in the state. For example, Utah has 14 genetic counselors and Oklahoma has 11 genetic counselors in their states. The license fee charged is approximately \$150 per year which covers all the operating expenses for their programs.

There are over one hundred health providers and health care administrators from the community who have provided their signature in support of Licensure for genetic counselors in Hawaii. This is evidenced by the testimonies submitted for your Committee's hearing. 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 **HB 1362 HD1**.



Linda Cheng, MS, CGC

House Committee on Finance**HB1362, HD1 (HSCR523)
RELATING TO GENETIC COUNSELORS**

Tuesday, March 3, 2009
2:00pm

To the Honorable Chair Marcus R. Oshiro, Vice Chair Marilyn B. Lee, and Members of the House Committee on Finance:

I support HB 1362, HD1 (HSCR523) 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 HB 1362, HD1 (HSCR523).



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