

Testimony of
Marguerite Lisa Bartholomew, MD
University Women's Health Specialists
John A Burns School of Medicine / University of Hawaii
Assistant Professor, Dept of Ob-Gyn
1319 Punahou Street #540
Honolulu, HI 96826
808-983-6761

Before the House Committee on Health
Honorable Representative Ryan I. Yamane, Chair

Honorable Representative Scott Y. Nishimoto, Vice Chair

Tuesday, February 3rd, 2009, 8:30am

State Capitol, Conference Room 329

Request 9 copies distributed to committee members

RE: STRONG SUPPORT for HB 1362 RELATING TO GENETIC COUNSELORS.
Establishing a licensure program.

Chair Ryan I. Yamane, Vice Chair Scott Y Nishimoto, and committee members, thank you for the opportunity to provide testimony on HB 1362, which establishes a licensure program for genetic counselors. I offer my testimony as a medical professional, citizen and registered Hawaii voter, and I strongly support the passage of HB 1362 for the following reasons:

Genetic counselors provide an invaluable service to patients not only in prenatal diagnosis but in cancer genetics as well. I witness this in my everyday practice. Genetic testing is complicated and confusing for even the most intelligent patients. It can be particularly devastating when the testing is performed on a unborn child. Patients need a professional that can provide accurate and compassionate counseling with continuity. The reality in our medical system is that physicians cannot spend the time necessary to do this job and honestly we aren't trained to do the job of a genetic counselor. Moreover, most physicians (unless they are geneticists) do not understand the complexities of genetic testing, of inheritance, and genetic diseases. Genetic counselors should be licensed and finally recognized for the necessary work they provide in a rapidly advancing medical climate.

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,

Marguerite Lisa Bartholomew, MD
2/1/09

Testimony of
Michele S. Basiliere, MS
Certified Genetic Counselor
Director, Genetic Services
University Women's Health/ University of Hawai'i OB/GYN
1319 Punahou Street, Suite 824
Honolulu, HI 96826
mbasiliere@kapiolani.org
808-282-5633

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Chair Ryan I. Yamane, Vice Chair Scott Y Nishimoto, and committee members, thank you for the opportunity to provide testimony on HB 1362, which establishes a licensure program for genetic counselors. I offer my testimony as a PROFESSIONAL, CITIZEN, and REGISTERED HAWAII VOTER, and I strongly support the passage of HB 1362 for the following reasons:

I have been a practicing genetic counseling in the state of Hawai'i almost 6 years and have been in the field for a total of 14 years. Over these 14 years I have witnessed exponential growth in the availability of genetic testing in this state and across the world. Unfortunately, the knowledge and training of physicians as well as consumers has not matched this growth. At least a couple times a month I meet an oncologist or obstetrician practicing in the state of Hawai'i who has incorrectly referred a patient, or worse yet, has failed to refer a patient altogether. After a small discussion it is apparent that the physician has attempted to provide genetic counseling with the cursory training they received in medical school, sometimes 20-30 years prior, and they are simply unprepared for this level of counseling. Most physicians only take one to two genetics classes in their training, unlike the two years of genetics and psychosocial training a Master's trained genetic counselor obtains.

I believe the cause is a combination of limited medical training and understanding of genetics, limited time available to spend with their patients, lack of realization of

availability of genetic services in the state and a misconception of the genetic counseling process itself. I believe one way to resolve these issues are to support licensure for genetic counselors.

With licensure, the genetic counselors in the state of Hawai'i will be supported in a manner that the physicians will recognize genetic counselors as peers who they will feel they can trust to share in the care of their patients. And, with licensure, the hope is that patients will be covered by their insurer for their time with the genetic counselor and be less concerned with the cost of this valuable service. This is also often stated as a reason why physicians do not refer for genetic counselors, i.e., because they are concerned their patient will be billed for this ancillary service because their insurance may not cover the cost of genetic counseling or risk assessment.

I believe licensure will help provide better guidelines and referral protocols for physicians in the state of Hawai'i, who will use this information to more appropriately refer their patients so that those patients and their families in Hawai'i will gain a more accurate and useful picture of their risks, and the tools available to reduce or eliminate those risks for disease.

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.

**House Committee on Health
HB 1362, Relating to Genetic Counselors**

**Tuesday, February 3, 2009
8:30AM**

To the Honorable Chair Ryan I. Yamane, Vice Chair Scott Y. Nishimoto, and Members of the House Committee on Health:

I strongly support HB 1362, 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 HB 1362.

**Clayton Chong, MD
Physician, Medical Oncology**

nishimoto2-Bryce

From: Elissa Josephsohn [prrrrlisa@gmail.com]
Sent: Monday, February 02, 2009 6:35 AM
To: HLTtestimony
Subject: Subject Heading: "Testimony re: HB1362 for House HLT Hearing on 02/03/09 at 8:30"

elissa josephsohn

public relations/advertising/marketing
3860 sierra drive/honolulu, hawaii 96816
(808) 732-7733/(808) 737-3634 cellular
e-mail prrrrr@hawaii.rr.com

I would strongly urge the Hawaii State Legislature to recognize genetic counselors and the invaluable services they provide to the citizens of our State.

I have been in a war with primary peritoneal cancer for almost two years, and I know the value of genetic counseling. Through it, I learned more about my family (even though my Mother died in 1963) and the hereditary BRCA 1 and 2 mutations that affect Ashekenzi Jews, such as myself, in a significantly larger proportion than the general population. As a result, I can be more vigilant with my health care and am in a clinical trial that will either keep me breast cancer free or detect it so early that the outcome is far different than my Mother's, who died at age 51.

Please expand the services of genetic counselors and license them as the professionals they are.

Respectfully,

Elissa Josephsohn

Testimony of
Arthur K. Yu, MS, CGC – Certified Genetic Counselor

Fetal Diagnostic Center, Kapi'olani Medical Center for Women and Children
1319 Punahou St – Suite 540
Honolulu, HI 96826
(808)983-6769
Arthur.yu@kapiolani.org

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I am currently employed at the Kapi'olani Medical Center as a prenatal genetic counselor. I provide genetic counseling services to help patients assess options regarding pregnancy management and risk assessment. Specialized genetic counselor training enables us to provide a unique clinical service to our patients that many other professions are ill-equipped or ill-trained to provide. Licensure will help to ensure that only the most highly trained and properly educated professionals are given the right to practice in the state of Hawaii. Otherwise, without licensure, we handicap our patients and our healthcare providers from providing the most comprehensive medical care possible.

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.

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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.

House of Representative's Health Committee

H.B. 1362, RELATING TO GENETIC COUNSELORS

Tuesday, February 3, 2009, 8:30am

To the Honorable Ryan Yamane, the Honorable Scott Nishimoto, and Members of the House Health Committee:

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

I **strongly support** H.B. 1362 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. Licensure of genetic counselors would ensure that patients receive optimal services and would protect them from receiving genetic information from providers who lack appropriate knowledge and training. Indeed, communication of genetic information, especially as related to personal or familial risk for disease, can often affect a patient's psychological well-being as well as their decisions regarding medical management, reproductive options, or treatment. In a 2005 study published in the *Archives of Internal Medicine*, Gurmankin and colleagues found that poor risk communication by inadequately trained health care professionals increased patients' perceptions of their risk for breast cancer above their actual risk. Patients' anxiety levels consequently increased which led them to make different, and potentially worse, medical decisions such as prophylactic mastectomies. Licensure would ensure that genetic counselors receive the training necessary to avoid such issues.

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

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

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

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

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.

As a lifelong Mililani resident, I thank you for your time in considering my testimony in support of H.B. 1362.

Lianne Hasegawa, M.S., C.G.C.
Certified Genetic Counselor
94-443 Keaoopua Street, #116
Mililani, HI 96789
808-623-5505

Testimony of
Shera L.C. Sugibayashi, M.D.
1319 Punahou Street, # 824
Honolulu, HI 96826

Before the House Committee on Health
Honorable Representative Ryan I. Yamane, Chair

Honorable Representative Scott Y. Nishimoto, Vice Chair

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RE: STRONG SUPPORT for HB 1362 RELATING TO GENETIC COUNSELORS.
Establishing a licensure program.

Chair Ryan I. Yamane, Vice Chair Scott Y Nishimoto, and committee members, thank you for the opportunity to provide testimony on HB 1362, which establishes a licensure program for genetic counselors. I offer my testimony as a registered voter and a medical professional, and I strongly support the passage of HB 1362 for the following reasons:

Genetic counseling is an important service that is provided to expectant parents. It is essential that parents be provided with accurate information provided by licensed genetic counselors when making decisions regarding their pregnancies and their children's health. It is important that parents receive appropriate counseling when deciding to go forth with genetic testing, as the implications of such knowledge can be dramatic and life changing.

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.

Thank you,

Shera L.C. Sugibayashi, M.D.

Testimony of:

Kirsty McWalter
Genetic Counselor
2006 Saint Louis Drive, Honolulu, HI, 96816
(808)371-1239
Hawaiiirsty2006@hotmail.com

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Honorable Representative Ryan I. Yamane, Chair
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In my experience as a pediatric genetic counselor, it is of the utmost importance that genetic counselors be licensed so that physicians can make referrals to professionals who are trained and qualified in the science of genetic counseling.

Everyday, more genetic tests are being offered by providers and marketed directly to the consumer (Direct-to-Consumer Testing). Primary care providers receive minimal, if any, training in the interpretation of genetic test results. The public, many of whom do not understand the consequences of the testing, will need 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.

Thank you for your time reviewing my testimony.

Sincerely,

Kirsty McWalter

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

**HB 1362
RELATING TO GENETIC COUNSELORS
Tuesday February 3, 2009
08:30 am
State Capitol Building Conference Room 329**

To the Honorable Representative Ryan I. Yamane, Chair and Honorable Representative Scott Y. Nishimoto, Vice Chair, and members of the Committee on Health,

Thank you for the opportunity to provide testimony on HB 1362, 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.

As a medical geneticist, a physician who works closely with genetic counselors on a daily basis, **I strongly support HB 1362 relating to the professional licensure of genetic counselors.** Genetic counselors are a vital part of the healthcare team that provides care to individuals throughout the lifespan. Genetic counselors are frequently the primary providers of genetic information and counseling to pregnant women whose babies are at risk for birth defects and other genetic conditions. They are also the primary provider of genetic risk assessment for men and women with cancer or a significant family history of cancer. Genetic counselors also assist me as I evaluate and manage children and adults with heritable conditions.

Licensure would protect the public by ensuring that genetic counseling is provided only by individuals with the high level of training and certification that genetic counselors possess. A board-eligible or board-certified genetic counselor has a Master's Degree in Genetic Counseling which includes the science of genetics, psychosocial, legal and ethical aspects of genetics, and extensive supervised direct patient contact. They are certified by the American Board of Genetic Counseling or the American Board of Medical Genetics. They are required to maintain their certification and excellence in the rapidly changing field of human genetics by continuing education credits. The 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" 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 HB 1362.

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

Testimony of
Ivica Zalud, MD, PhD, FACOG, FIAUM
Professor and Chief, OB/GYN Imaging Division
MFM Fellowship Program Director
Department of OB/GYN and Women's Health
John A Burns School of Medicine, University of Hawaii
Medical Director, Fetal Diagnostic Center
Kapiolani Medical Center for Women and Children
Honolulu, Hawaii

E-mail: Ivica@hawaii.edu

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House Committee on Health**HB1362
RELATING TO GENETIC COUNSELORS****Tuesday, February 3, 2009
8:30am**

To the Honorable Chair Ryan I. Yamane, Vice Chair Scott Y. Nishimoto, and Members of the House Committee on Health:

I support HB 1362 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.

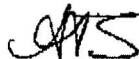
My initial interest in, and attraction to, the field of Genetic Counseling stemmed from what I viewed as an opportunity to work with and serve various individuals who have, or are at risk for, rare conditions that may have a genetic basis. My goal was (and still is) to make a difference in the lives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



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

nishimoto2-Bryce

From: Elaine Marr White [etmarr@gmail.com]
Sent: Saturday, January 31, 2009 8:42 AM
To: HLTtestimony
Subject: Testimony re: HB1362 for House HLT Hearing on 02/03/09 at 8:30am

Testimony of
Elaine White, M.S., C.G.C.
Certified Genetic Counselor with Kapiolani Medical Specialist
1441 Kapiolani Boulevard, Suite 1800
Honolulu, Hawaii 96814

Before the House Committee on Health
Honorable Representative Ryan I. Yamane, Chair
Honorable Representative Scott Y. Nishimoto, Vice Chair

Tuesday, February 3rd, 2009, 8:30am
State Capitol, Conference Room 329
Request 9 copies distributed to committee members

RE: STRONG SUPPORT for HB 1362 RELATING TO GENETIC COUNSELORS. Establishing a licensure program.

Chair Ryan I. Yamane, Vice Chair Scott Y Nishimoto, and committee members, thank you for the opportunity to provide testimony on HB 1362, which establishes a licensure program for genetic counselors. I offer my testimony as a professional, and I strongly support the passage of HB 1362 for the following reasons:

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.

From: Matt White [mfwhite5@gmail.com] on behalf of Matt White [matt@anewway.org]
Sent: Saturday, January 31, 2009 9:02 AM
To: HLTtestimony
Subject: Testimony Regarding HB 1362 For House HLT Hearing on 02/03/09 at 8:30am

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

Before the House Committee on Health

Honorable Representative Ryan I. Yamane, Chair
Honorable Representative Scott Y. Nishimoto, Vice Chair

Tuesday, February 3rd, 2009, 8:30am
State Capitol, Conference Room 329
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RE: STRONG SUPPORT for HB 1362 RELATING TO GENETIC COUNSELORS. Establishing a licensure program.

Chair Ryan I. Yamane, Vice Chair Scott Y Nishimoto, and committee members, thank you for the opportunity to provide testimony on HB 1362, which establishes a licensure program for genetic counselors. I offer my testimony as a registered Hawaii voter, and I strongly support the passage of HB 1362 for the following reasons:

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

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

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

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

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

Sincerely,

Matthew White

**House Committee on Health
HB 1362, Relating to Genetic Counselors**

Tuesday, February 3, 2009, 8:30 am
State Capitol, Conference Room 329

To the Honorable Chair Ryan I. Yamane, Vice Chair Scott Y. Nishimoto, and Members of the House Committee on Health:

I strongly support HB 1362, 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 HB 1362.

**Linda Cheng, MS, CGC
Certified Genetic Counselor
Honolulu, HI**

**House Committee on Health
HB 1362, Relating to Genetic Counselors**

**Tuesday, February 3, 2009
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Thank you for allowing me the opportunity to provide testimony in support of HB 1362.

**David Shimizu, MD
Physician, Pathology**

**House Committee on Health
HB 1362, Relating to Genetic Counselors**

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

**Jana Silva, MD
Physician, Maternal Fetal Medicine**

**House Committee on Health
HB 1362, Relating to Genetic Counselors**

**Tuesday, February 3, 2009
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**Henry Sweeney, MS
Clinical Research**

**House Committee on Health
HB 1362, Relating to Genetic Counselors**

**Tuesday, February 3, 2009
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Thank you for allowing me the opportunity to provide testimony in support of HB 1362.

**Danny Takanishi, MD
Physician, Surgical Oncology**

**House Committee on Health
HB 1362, Relating to Genetic Counselors**

**Tuesday, February 3, 2009
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Thank you for allowing me the opportunity to provide testimony in support of HB 1362.

**Pamela Tauchi-Nishi, MD
Physician, Associate Director of Pathology**

**House Committee on Health
HB 1362, Relating to Genetic Counselors**

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

**Thomas Teruya, MD
Physician, Obstetrics/Gynecology**

**House Committee on Health
HB 1362, Relating to Genetic Counselors**

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**Diane Thompson, MD
Director, The Queen's Medical Center Women's Health Center**

**House Committee on Health
HB 1362, Relating to Genetic Counselors**

**Tuesday, February 3, 2009
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Thank you for allowing me the opportunity to provide testimony in support of HB 1362.

**Donn Tokairin, MD
Physician, Obstetrics/Gynecology**

House Committee on Health
HB 1362, Relating to Genetic Counselors

Tuesday, February 3, 2009

8:30AM

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

James Tom, MD
Physician, Clinical Research Associate

**House Committee on Health
HB 1362, Relating to Genetic Counselors**

**Tuesday, February 3, 2009
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**Lynette Tsai, MD
Physician, Obstetrics/Gynecology**

**House Committee on Health
HB 1362, Relating to Genetic Counselors**

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**Mika Warren, MD
Pathologist**

**House Committee on Health
HB 1362, Relating to Genetic Counselors**

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**Andrea Wilburn
Oncology Patient Navigator**

**House Committee on Health
HB 1362, Relating to Genetic Counselors**

**Tuesday, February 3, 2009
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**Grace Wong, MD
Physician, Obstetrics/Gynecology**

**House Committee on Health
HB 1362, Relating to Genetic Counselors**

**Tuesday, February 3, 2009
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**Charles Yamashiro, MD
Physician, Radiation Oncology**

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**Fredrick Yost, MD
Physician, Surgery**

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**Stacy Yamada
Clinical Dietician**

**House Committee on Health
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**Michelle Kaaihue
Patient Navigator Associate**

**House Committee on Health
HB 1362, Relating to Genetic Counselors**

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**Kaye Kawahara, MD
Physician, Medical Oncology**

**House Committee on Health
HB 1362, Relating to Genetic Counselors**

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**Jennifer Kimbell, PhD
Research Development**

**House Committee on Health
HB 1362, Relating to Genetic Counselors**

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**Sandi Kwee, MD
Medical Staff Physician**

**House Committee on Health
HB 1362, Relating to Genetic Counselors**

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**Lorrin Lau, MD
Physician, Obstetrics/Gynecology**

House Committee on Health
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Melanie Lau, MD
Physician, Gynecology

**House Committee on Health
HB 1362, Relating to Genetic Counselors**

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**John Lederer, MD
Physician, Radiation Oncology**

**House Committee on Health
HB 1362, Relating to Genetic Counselors**

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**William Loui, MD
Physician, Hematology-Oncology**

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**Chris Lum, MD
Physician, Director of Dermatopathology**

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**Maggie Magee
Registered Nurse**

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**Alison Matsuo
Manager, Cancer Center**

**House Committee on Health
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**Shane Morita, MD
Physician, Surgical Oncology**

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Physician, Surgery**

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

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

Wanda Muranaka

**House Committee on Health
HB 1362, Relating to Genetic Counselors**

**Tuesday, February 3, 2009
8:30AM**

To the Honorable Chair Ryan I. Yamane, Vice Chair Scott Y. Nishimoto, and Members of the House Committee on Health:

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

**Ken Nakasone, MD
Physician, Obstetrics/Gynecology**

**House Committee on Health
HB 1362, Relating to Genetic Counselors**

**Tuesday, February 3, 2009
8:30AM**

To the Honorable Chair Ryan I. Yamane, Vice Chair Scott Y. Nishimoto, and Members of the House Committee on Health:

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

**Robb Ohtani, MD
Physician, Obstetrics/Gynecology**

**House Committee on Health
HB 1362, Relating to Genetic Counselors**

**Tuesday, February 3, 2009
8:30AM**

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

**Christine Radcliffe
Registered Nurse**

**House Committee on Health
HB 1362, Relating to Genetic Counselors**

**Tuesday, February 3, 2009
8:30AM**

To the Honorable Chair Ryan I. Yamane, Vice Chair Scott Y. Nishimoto, and Members of the House Committee on Health:

I strongly support HB 1362, 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.

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

**Darlene Sardinha
Administrative Secretary, Cancer Center**

**House Committee on Health
HB 1362, Relating to Genetic Counselors**

**Tuesday, February 3, 2009
8:30AM**

To the Honorable Chair Ryan I. Yamane, Vice Chair Scott Y. Nishimoto, and Members of the House Committee on Health:

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

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

**Renee Sato, MD
Physician, Obstetrics/Gynecology**

**House Committee on Health
HB 1362, Relating to Genetic Counselors**

**Tuesday, February 3, 2009
8:30AM**

To the Honorable Chair Ryan I. Yamane, Vice Chair Scott Y. Nishimoto, and Members of the House Committee on Health:

I strongly support HB 1362, relating to professional licensure of genetic counselors. I am a Medical Oncologist in Honolulu, and a referring clinician to genetic counselors.

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

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

**Jared Acoba, MD
Medical Oncologist**

**House Committee on Health
HB 1362, Relating to Genetic Counselors**

**Tuesday, February 3, 2009
8:30AM**

To the Honorable Chair Ryan I. Yamane, Vice Chair Scott Y. Nishimoto, and Members of the House Committee on Health:

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

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

**Tod Aeby, MD
Physician, Obstetrics/Gynecology**

**House Committee on Health
HB 1362, Relating to Genetic Counselors**

**Tuesday, February 3, 2009
8:30AM**

To the Honorable Chair Ryan I. Yamane, Vice Chair Scott Y. Nishimoto, and Members of the House Committee on Health:

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

**Ronald Ayabe, MD
Physician, Obstetrics/Gynecology**

**House Committee on Health
HB 1362, Relating to Genetic Counselors**

**Tuesday, February 3, 2009
8:30AM**

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**Vincent Brown, MD
Physician, Radiation Oncology**

**House Committee on Health
HB 1362, Relating to Genetic Counselors**

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**Peter Bryant-Greenwood, MD
Pathologist, Hawaii Pathologists Laboratory
Director, Molecular Diagnostics
Vice Chair, Department of Pathology, JABSOM**

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HB 1362, Relating to Genetic Counselors**

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Chao Chen, MD
Physician, Obstetrics/Gynecology