HB 1362 HD 1

Measure

Title:

RELATING TO GENETIC COUNSELORS.

Report

Title:

Genetic Counselors

Description:

Establishes the Genetic Counseling Licensure Program within Department of Commerce and Consumer Affairs. Requires licensure in order to use the title of "licensed genetic counselor".

requirements. (HB1362 HD1)

Provides exemptions from licensure



LINDA LINGLE GOVERNOR

JAMES R. AIONA, JR.

STATE OF HAWAII OFFICE OF THE DIRECTOR **DEPARTMENT OF COMMERCE AND CONSUMER AFFAIRS**

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LAWRENCE M. REIFURTH DIRECTOR

RONALD BOYER

PRESENTATION OF THE DEPARTMENT OF COMMERCE AND CONSUMER AFFAIRS

TO THE SENATE COMMITTEE ON HEALTH

TWENTY-FIFTH LEGISLATURE **REGULAR SESSION OF 2009**

Friday, March 20, 2009 3:00 p.m.

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

TO THE HONORABLE DAVID Y. IGE, CHAIR, AND MEMBERS OF THE COMMITTEE:

My name is Celia Suzuki, Program Specialist of the Professional and Vocational Licensing Division, Department of Commerce and Consumer Affairs ("DCCA"). The DCCA thanks you for the opportunity to submit testimony in opposition to H.B. No. 1362, H.D. 1.

This bill proposes to establish a genetic counseling licensure program within the DCCA. The DCCA opposes the expansion of its licensing of regulatory programs in the absence of a demonstrated need. Further, the DCCA has numerous concerns with the

bill and will focus on needed substantive amendments, if this bill moves forward and is to be implemented by DCCA.

For this Committee's information, there was an October 2006 sunrise report, wherein the Auditor determined that little evidence of consumer harm existed in Hawaii relating to genetic counselors and that regulation is not warranted nor should legislation be enacted to license genetic counselors. The DCCA respects that finding and thus does not support H.B. No. 1362, H.D. 1 for these reasons.

Should this bill move forward, however, we would like to present substantive concerns we have with this measure. When the Auditor assesses a legislative proposal to newly regulate a profession or vocation, the Auditor reviews the application requirements and determines whether the proposal reflects that of a registration, certification, or licensure scheme. There are distinct differences with the three regulatory schemes and the Auditor cites to these differences when critiquing a bill. In this case, House Bill No. 1362, H.D. 1, although purporting to be a licensure scheme, is reflective of a certification scheme. The DCCA would not support a bill containing a licensing regulatory scheme for genetic counselors when the proposal does not in fact represent that. "Licensing" is defined by the Auditor as the most restrictive form of regulation which protects the title and practice of the profession. House Bill No. 1362, H.D. 1 is not such regulation as it is only a title protection regulation. Also, licensing is dependent on meeting certain qualifications and where these specific qualifications do not include reliance on private certification standards nor is private certification used for licensure. On the other hand, the Auditor defines "certification" as the restriction on the

use of a professional title only for persons who meet certain qualifications, but it does not bar others who practice the same scope as long as they do not use the protected title. Also, state certification normally entails reliance on professional certification or credentialing by private organizations as the qualification for licensure. The Auditor's definition of a "certification" regulatory scheme clearly aligns with what this measure proposes. If a program for genetic counselors is to be implemented by DCCA, we would want the bill amended to replace all references to "licensing" with "certification" to accurately reflect what the regulation truly is.

Another concern we have with this bill is that it includes a grandfathering provision, contained in the "provisional license" section of the bill, that would allow individuals whose competency to practice has <u>not</u> yet been established, to be given a license to fully practice as a genetic counselor. We oppose this as it is not a consumer protection provision. DCCA's position is that for any new regulatory program, all applicants should satisfy all requirements before being allowed to practice, to ensure their competency. However, in order to accommodate a current practitioner's ability to meet the requirements of the enactment of regulation, a delayed implementation date (minimally 1 year) could be provided in the legislative measure. We believe this time frame will allow practitioners to obtain the required credential for state recognition without the need for any grandfathering or provisional license.

Other concerns we have with the bill include the section on endorsement which we feel is unnecessary because the requirement for certification is basic and simple (only a current and unencumbered certification from the American Board of Genetic

Testimony on H.B. No. 1362, H.D. 1 March 20, 2009 Page 4

Counseling is required); the section on renewal requirements which we feel is not comprehensive or complete; and many unnecessary and redundant sections that are already covered, and would be appropriate to this regulatory program, that are in contained in Chapter 436B, our Professional and Vocational Licensing Act.

In closing, to facilitate discussion, the DCCA includes a proposed S.D. 1 that resolves the concerns we note above and presents a regulatory law that is workable for DCCA. Our proposed S.D. 1 reflects a certification regulatory scheme.

Thank you for the opportunity to testify on H.B. No. 1362, H.D. 1 and, while we ask that you hold this bill, if this bill should move forward we ask that it be in the form of our proposed S.D. 1.

STATE OF HAWAII

A BILL FOR AN ACT

RELATING TO GENETIC COUNSELORS.

BE IT ENACTED BY THE LEGISLATURE OF THE STATE OF HAWAII:

1	SECTION 1. The purpose of this Act is to:
2	(1) Safeguard the public health, safety, and welfare;
3	(2) Protect those seeking genetic counseling services from
4	incompetent and unscrupulous persons, and persons
5	unauthorized to perform these services;
6	(3) Assure the highest degree of professional conduct on
7	the part of genetic counselors; and
8	(4) Assure the availability of high quality genetic
9	counseling services,
10	by regulating individuals offering genetic counseling services
11	by certification.
12	SECTION 2. The Hawaii Revised Statutes is amended by
13	adding a new chapter to be appropriately designated and to read
14	as follows:
15	"CHAPTER
16	GENETIC COUNSELORS

- 1 § -1 Definitions. As used in this chapter, unless the
- 2 context requires otherwise:
- 3 "Board certified" means an individual who has passed the
- 4 American Board of Genetic Counseling certification examination
- 5 and remains actively certified by American Board of Genetic
- 6 Counseling.
- 7 "Department" means the department of commerce and consumer
- 8 affairs.
- 9 "Director" means the director of commerce and consumer
- 10 affairs.
- "Genetic counselor" means a person certified under this
- 12 chapter who engages in genetic counseling practice.
- "Genetic counseling practice" means the rendering of
- 14 professional counseling services based on specialized education
- 15 and training to individuals, families, or groups for
- 16 compensation, monetary or otherwise. These counseling services
- 17 include the communication process which deals with the human
- 18 problems associated with the occurrence, or the risk of
- 19 occurrence, of a genetic disorder. "Genetic counseling
- 20 practice" includes:

1	(1)	Obtaining and interpreting individual, family,
2		medical, developmental, and reproductive histories;
3	(2)	Determining the mode of inheritance and risk of
4		transmission of genetic conditions and birth defects;
5	(3)	Discussing the inheritance, features, natural history,
6		means of diagnosis, and management of these
7		conditions;
8	(4)	Identifying, coordinating, interpreting, and
9		explaining genetic laboratory tests and other
10		diagnostic studies;
11	(5)	Assessing psychological factors, and recognizing
12		social, educational, and cultural issues related to
13		having or being at risk for genetic conditions;
14	(6)	Evaluating the client's or family's responses to the
15		genetic condition or risk of having the genetic
16		condition, and providing client-centered counseling
17		and anticipatory guidance;
18	(7)	Communicating information to their clients in an
19		understandable manner;

1	(8)	Facilitating informed decision making about testing,				
2		treatment, and management;				
3	(9)	Identifying and effectively using community resources				
4		that provide medical, educational, financial, and				
5		psychosocial support and advocacy; and				
6	(10)	Providing accurate written documentation of medical,				
7		genetic, and counseling information for families and				
8		health care professionals.				
9	"Cer	tified genetic counselor" means an individual who holds				
10	a certification in good standing to practice genetic counseling					
11	under thi	s chapter.				
12	\$	-2 Genetic counseling certification program. There is				
13	establish	ed a genetic counseling certification program within				
14	the depar	tment to be administered by the director.				
15	\$	-3 Powers and duties of the director. In addition to				
16	any other	powers and duties authorized by law, the director				
17	shall hav	e the powers and duties to:				
18	(1)	Approve the qualifications of all applicants under				
19		this chapter and issue a certification to each				
20		successful applicant granting permission to use the				

1		title of "certified genetic counselor" or "genetic
2		counselor" in this state pursuant to this chapter and
3		the rules adopted pursuant thereto;
4	(2)	Adopt, amend, or repeal rules pursuant to chapter 91
5		as the director finds necessary to carry out this
6		chapter;
7	(3)	Administer, coordinate, and enforce this chapter;
8	(4)	Discipline a certified genetic counselor for any due
9		cause described by this chapter or violation of the
10		rules;
11	(5)	Refuse to certify a person for failure to meet
12		certification requirements or on grounds sufficient to
13		discipline a certified genetic counselor; and
14	(6)	May establish fees for services rendered to carry out
15		the purposes of this chapter.
16	\$	-4 Exemptions. (a) This chapter does not prohibit
17	any perso	ns legally regulated in this state by any other law
18	from enga	ging in the practice for which they are authorized as
19	long as t	hey do not represent themselves by the title of
20	"genetic	counselor" or "certified genetic counselor." This

1	chapter	shall	not	prohibit	the	practice	of	nonregul	ated

- 2 professions whose practitioners are engaged in the delivery of
- 3 human services as long as these practitioners do not represent
- 4 themselves as or use the title of "genetic counselor" or
- 5 "certified genetic counselor."
- 6 (b) Nothing in this chapter shall be construed to limit
- 7 the activities and services of:
- 8 (1) A student, intern, resident, or fellow in genetics or
- 9 genetic counseling seeking to fulfill educational
- 10 requirements to qualify for a license under this
- 11 chapter if those activities and services constitute a
- part of the student's supervised course of study;
- 13 (2) An individual seeking to fulfill the post-degree
- 14 practice requirements to qualify for certification
- under this chapter, as long as the activities and
- services are supervised by a certified genetic
- 17 counselor or physician. A student, intern, resident,
- 18 or fellow shall be designated by the title "intern,"
- "resident," "fellow," or any other designation of
- 20 trainee status; or

1	(3)	An American Board of Genetic Counseling or an American
2		Board of Medical Genetics certified genetic counselor
3		who is brought into the state as a consultant to train
4		health care providers within the state. Nothing
5		contained in this subsection shall be construed to
6		permit students, interns, residents, fellows, or
7		consultants to offer their services as genetic
8		counselors or geneticists to any other person.

- 9 (c) Nothing in this chapter shall be construed to prevent
 10 a physician licensed to practice medicine in this state or
 11 intern, fellow, or resident from performing genetic counseling
 12 within the persons scope of practice the person is not in any
 13 manner held out to the public as a "genetic counselor" or
 14 "certified genetic counselor."
- (d) Nothing in this chapter shall be construed to prevent
 any licensed nurse in this state from performing genetic
 counseling within the nurse's scope of practice the nurse is not
 in any manner held out to the public as a "genetic counselor" or
 "certified genetic counselor".

- 1 (e) Nothing in this chapter shall be construed to prevent
- 2 any licensed social worker, licensed psychologist, or licensed
- 3 marriage and family therapist from practicing professional
- 4 counseling in this state provided that person is not in any
- 5 manner held out to the public as a "genetic counselor" or
- 6 "certified genetic counselor" and does not hold out the person's
- 7 services as being genetic counseling.
- 8 S -5 Certification requirements. (a) Applicants shall
- 9 provide to the department a current and unencumbered
- 10 certification from the American Board of Genetic Counseling;
- 11 with an application form to be furnished by the department.
- 12 (b) Except as otherwise provided in this chapter, no person
- 13 shall:
- 14 (1) Represent one's self as a certified genetic counselor;
- 15 (2) Imply, in any manner, that one's self is a certified
- 16 genetic counselor; or
- 17 (3) Use the abbreviation "C.G.C." or any other words,
- 18 letters, signs, or devices to identify one's self as a certified
- 19 genetic counselor; without having first obtained certification
- 20 as provided in this chapter.

17

Proposed S.D. 1

1	C. Danson I of montification Contifications shall be
1	§ -6 Renewal of certification. Certifications shall be
2	renewed, upon the payment of a renewal fee, triennially not
3	earlier than ninety days before June 30, with the first renewal
4	deadline occurring on Failure to renew a
5	certification shall result in a forfeiture of the certification.
6	Certifications that have been forfeited may be restored within
7	one year of the expiration date upon payment of renewal and
8	restoration fees. Failure to restore a forfeited certification
9	within one year of the date of its expiration shall result in
10	the automatic termination of the certification and the person
11	may be required to reapply for certification as a new applicant.
12	All renewal and restoration fees shall be determined by the
13	director.
14	(b) Proof of maintenance of American Board of Genetic
15	Counseling certification shall be required for certification
16	renewal.

SECTION 3. This Act shall take effect on July 1, 2020.



Friday - March 20, 2009 Conference Room 016 - 3:00 pm

The Senate Committee on Health

To:

Senator David Ige, - Chair

Senator Josh Green, MD - Vice Chair

From: Ken Nakamura, MD - Chief Medical Officer

Kapi'olani Medical Specialists

Professor of Pediatrics/Neonatology Division

UH John A. Burns School of Medicine

RE:

Testimony in Strong Support of 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.

Senate Committee on Health

H.B. 1362, H.D. 1, RELATING TO PROFESSIONAL LICENSURE Friday, March 20, 2009, 3:00pm

To the Honorable David Ige, the Honorable Josh Green, and Members of the Senate Committee on Health:

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, H.D. 1 which establishes guidelines for licensure of genetic counselors to ensure professional and quality services for public safety and welfare. However, I would like to suggest an amendment to make the Department of Health the regulatory body.

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. Most counselors obtain many more than the minimal continuing education in order to keep up-to-date with the changing genetic information. 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 based as compared to obstetricians.

Genetic counselors are important additions to the health care team. Licensing of genetic counselors would ensure that patients receive optimal services and would protect them from receiving genetic

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

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

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

The studies cited above, along with my personal experiences living with a genetic birth defect, are the basis of my dedication to licensure for genetic counselors. Licensure would protect patients and families from harm caused by receiving incorrect information or inappropriate counseling. Licensure would also allow healthcare providers, particularly those with limited genetics knowledge and psychosocial training, to recognize and refer to licensed genetic counselors.

Thank for you for your time in considering my testimony in support of H.B. 1362, H.D. 1.

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

Committee on Health HB 1362 HD1, Relating to Genetic Counselors Friday March 20, 2009 State Capitol Conference Room 016

To the Honotable Chair Ige and Members of the Senate Committee on Health:

I strongly support HB 1362 HD1, 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.

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. 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 heath 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 Genetic Counselor

Committee on Health HB 1362 HD1, Relating to Genetic Counselors Friday March 20, 2009 State Capitol Conference Room 016

QMC GENETICS

To the Honorable Chair Ige and Members of the Senate Committee on Health:

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**.

TITLE
Physician, Oncology
Physician, Obstetrics/Gynecology
Vice President, Medical Affairs Chief Medical Officer
Physician, Obstetrics/Gynecology

Bakhshi, Tiki, MD	Physician, Obstetrics/Gynecology
	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, Deanne	Oncology Conference Coordinator
Emura, Steven, MD	Assistant Professor, John A. Burns School of Medicine, Department of Obstetrics, Gynecology and Women's Health
Fischberg, Daniel, MD	
Tractions & Dattier, MID	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
Hemmings, Daphne, MD	General Surgeon & Assistant Professor Medicine/Surgery
Hew, Denise, MD	Physician, Obstetrics/Gynecology
Higuchi, Carl, MD	Physician, Medical Oncology
Hill, Christina, MD	Physician, Maternal Fetal Medicine
Hirata, Blyth, RN	Registered Nurse
Hirata, Greigh, MD	Physician, Maternal Fetal Medicine
Huddleston, Christine	Sonographer (Obstetrics and Gynecology)
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 Practioner, Women's Health
Loui, William, MD	Physician, Hematology-Oncology
Lum, Chris, MD	Physician, Director of Dermapathology
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, Surgey
Murunaka, Wanda, MD	Registered Nurse
Nakano, Gordon, MD	Physician, Hematology-Oncology

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

Tom, James, MD	Physician, Clinical Research Associate
Tsai, Lynette, MD	Physician, Obstetrics/Gynecology
Tsukenjo, 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

State of Hawaii Senate Committee on Health

HB 1362, HD1 RELATING TO GENETIC COUNSELORS Friday, March 20th, 2009 3:00 pm State Capitol Building Conference Room 016

To the Honorable Senator David Y. Ige, Chair; Josh Green, Vice-Chair; and members of the Committee on Health:

Thank you for the opportunity to provide testimony on HB 1362, HD1. We 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.

Sincerely,

Kapiolani Neonatal Intensive Care Unit Team

(808) 983-8387
(808) 983-8670
(808) 983-8387
(808) 983-8387
(808) 983-8670
(808) 983-8673
(808) 983-8629
(808) 554-7372
(808) 232-1010
(808) 373-9755
(808) 221-9003
(808) 345-2499
(808) 226-1407
(808) 923-1086
(808) 330-1494
(808) 983-8673
(808) 277-2023
(808) 387-6906
(808) 271-5754
(808) 387-2402
(808) 753-5531
(808) 387-8875
(808) 383-3041
(808) 721-4834
(808) 733-5111
(808) 230-4090
(808) 983-8670

Elaine White, MS, CGC Page 1

State of Hawaii Senate Committee on Health

HB 1362, HD1 RELATING TO GENETIC COUNSELORS

Friday, March 20th, 2009 at 3:00 pm State Capitol Building Conference Room 308

To the Honorable Senator David Y. Ige, Chair; Josh Green, Vice-Chair; and members of the Committee on Health:

My name is Elaine White, certified genetic counselor with Kapiolani Medical Specialists, an affiliate program of Hawaii Pacific Health. Thank you for the opportunity to submit testimony in strong support of HB 1362, HD1, which establishes a licensure program for genetic counselors.

I am requesting that the agency to implement this measure be changed to Department of Health (DOH), for the following reasons:

Cost. DOH has had an existing Genetics Program for over fifteen years. The program coordinator is a full time civil service position and there are four full-time genetic counselors on staff. No state general fund money is used to fund the program staff. They are all funded through federal grants. This means the program exists because the genetic counselors write, apply, and successfully win grants to support their own salary. I know this first hand, because I previously worked for the program for 3.5 years. The cost to DOH implementing this measure would therefore not affect state funds. Furthermore, additional operating expenses will be covered by the licensing fees. 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. Oklahoma is the most recent state to begin licensing genetic counselors. They report that many out-of-state genetic counselors are applying for licenses. Some of the counselors work for national laboratories that provide genetic test result interpretation to healthcare providers or families in the state. Hawai'i has more counselors than Oklahoma and it is expected that out-of-state genetic counselors will also obtain licensure especially if they are providing information to Hawai'i health care providers and families.

Elaine White, MS, CGC

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Given the current economic climate, DOH is in the best position to implement this bill. With their highly competent staff and additional operating costs being covered by a modest license fee similar to Utah and Oklahoma, this new regulatory program is feasible and will not incur cost to the state:

- **DOH regulates professionals.** Similar to other health professionals DOH regulates because of its specialized expertise. DOH currently regulates professionals such as:
 - Radiology Technicians
 - Dieticians
 - Clinical Laboratory Directors
 - Medical Technologists
 - Clinical Laboratory Specialists
 - Cytotechnologists
 - Medical Laboratory Technicians

There is no reason genetic counselors should be excluded from this list especially when there is a strong genetics program with the manpower and expertise within the DOH to operate the licensing scheme.

I am also requesting that the enactment date be changed from July 1, 2020 to July 1, 2009.

Thank you for the opportunity to testify on HB 1362, HD1 and I request you pass this measure with the changes noted above.

Sincerely,

Elaine White, M.S., C.G.C. 1617 South Beretania Street, Apt. #1102 Honolulu, Hawaii 96826 808-927-1139

Senate Committee on Health

HB1362, HD1 (HSCR896) RELATING TO GENETIC COUNSELORS

Friday, March 20, 2009 3:00pm

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

I support HB 1362, HD1 (HSCR896) 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 (HSCR896).

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

Matt White [mfwhite5@gmail.com] on behalf of Matt White [matt@anewway.org]

Sent:

Thursday, March 19, 2009 9:30 AM

To:

HTHTestimony

Subject:

Testimony Regarding HB 1362 For Senate HLT Hearing on 03/20/09 at 3:00pm

Categories:

Green Category, Blue Category

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

State of Hawaii Senate Committee on Health

HB 1362
RELATING TO GENETIC COUNSELORS
Friday March 20, 2009
3:00pm
State Capitol Building Conference Room 016

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

Thank you for the opportunity to provide testimony on 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 referred to other instances of harm to the consumer that could be addressed in part by regulating this profession.

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

Presuming consumers are not savvy enough to understand the additional quality control that comes with conferring a state license is to give consumers too little credit.

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

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

Sincerely,

Matthew White

State of Hawaii Senate Committee on Health

HB 1362, HD1 RELATING TO GENETIC COUNSELORS

Friday, March 20th, 2009 at 3:00 pm State Capitol Building Conference Room 016

To the Honorable Senator David Y. Ige, Chair; Josh Green, Vice-Chair; and members of the Committee on Health:

Thank you for the opportunity to provide testimony on HB 1362, 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 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 Hawaii. 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 believe that the responsibility of licensure of genetic counselors should be in the Department of Health Genetics Program where they have the expertise and manpower to oversee the program for the less than 20 genetic counselors in Hawaii. The fees paid by the genetic counselors seeking licensure should cover the cost of such a licensure program for the State of Hawaii. For example, the states of Utah and Oklahoma have a similar number of genetic counselors who pay approximately \$150 per year for licensure. The costs associated with a licensing such a small program through the Department of Commerce and Consumer Affairs would be onerous.

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.

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

Committee on Health

HB 1362, HD1, Relating to Professional Licensure of Genetic Counselors Wednesday, March 20th at 3pm State Capitol Building 016

To the Honorable Senator Ige, the Honorable Senator Josh Green and Members of the Senate Committee on Health

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

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

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

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

I also favor the oversight of genetic counselor licensure to be within the Department of health Genetics Program. The cost associated with placing oversight within the Department of Consumer Protection is prohibitive not only to the individual genetic counselor obtaining licensure, but also for the department itself, who has to staff the oversight. The Department of Health Genetics Program is an established entity with years of experience in clinical genetics service provision, legislation activities, and public health genetics. Given that the number of genetic counselors in the state of Hawai'i is so small (less than 15), the oversight of licensing for these professionals would fit seamlessly into the DOH Genetics Program's current responsibilities.

In Fall 2005, I co-authored a paper published in The Journal of Allied Health (Christianson CA, McWalter KM, Steinberg Warren N. Assessment of Allied Health Graduates'

Preparation to Integrate Genetic Knowledge and Skills Into Clinical Practice. *Journal of Allied Health*. Fall 2005 (34):3; 138-144.). We surveyed recent graduates from allied health programs (audiology, physical therapy, speech-language pathology, nutrition sciences, and medical imaging technology) to determine the amount of genetics education they received during training, the genetics activities they perform in clinic, and their confidence in their ability to perform those genetics activities.

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

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

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

The results of the study cited above, coupled with my personal experiences as a pediatric genetic counselor, underlie my personal commitment to pursuing licensure for genetic counselors in Hawai'i. Patients have the right to be protected from harm potentially caused

HB 1362 Friday March 20th 2009 at 3pm

by incorrect or missing information provided by healthcare practitioners not trained to provide genetic counseling. Furthermore, it would be beneficial for healthcare practitioners to be aware of licensed genetic counselors, who perform the task of genetic counseling exclusively, so as to aid in their referrals of appropriate patients. This would help to ensure that healthcare practitioners, particularly those in allied health fields who have received marginal genetics training, recognize and refer to licensed genetic counselors rather than provide inadequate genetic counseling themselves.

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

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