

Bill as
Introduced

SB 240-FN – AS INTRODUCED

2012 SESSION

12-2898

10/01

SENATE BILL **240-FN**

AN ACT relative to the regulation of the practice of genetic counseling.

SPONSORS: Sen. Carson, Dist 14; Sen. Odell, Dist 8; Rep. Harding, Graf 11; Rep. Gile,
Merr 10; Rep. Griffin, Rock 4

COMMITTEE: Executive Departments and Administration

ANALYSIS

This bill establishes the genetic counselors governing board in the office of licensed allied health professionals for the regulation of the practice of genetic counseling in this state.

Explanation: Matter added to current law appears in ***bold italics***.
Matter removed from current law appears [~~in brackets and struck through~~].
Matter which is either (a) all new or (b) repealed and reenacted appears in regular type.

STATE OF NEW HAMPSHIRE

In the Year of Our Lord Two Thousand Twelve

AN ACT relative to the regulation of the practice of genetic counseling.

Be it Enacted by the Senate and House of Representatives in General Court convened:

1 1 New Chapter; Genetic Counselors. Amend RSA by inserting after chapter 326-J the following
2 new chapter:

3 CHAPTER 326-K

4 GENETIC COUNSELORS

5 326-K:1 Definitions. In this chapter and RSA 328-F:

6 I. "ABGC" means the American Board of Genetic Counseling, its equivalent, or successor.

7 II. "ABMG" means the American Board of Medical Genetics, its equivalent, or successor.

8 III. "Board" means the genetic counselors governing board established in RSA 328-F.

9 IV. "Genetic counselor" means an individual, who is licensed by the board under this
10 chapter, to engage in the competent practice of genetic counseling.

11 V. "NSGC" means the National Society of Genetic Counselors, its equivalent, or successor.

12 VI. "Practice of genetic counseling" means, but shall not be limited to:

13 (a) Obtaining and evaluating individual, family, and medical histories to determine
14 genetic risk for genetic or medical conditions and diseases in a patient, his or her offspring, and other
15 family members;

16 (b) Discussing the features, natural history, means of diagnosis, genetic and
17 environmental factors, and management of risk for genetic or medical conditions and diseases;

18 (c) Identifying and coordinating genetic laboratory tests and other diagnostic studies as
19 appropriate for the genetic assessment;

20 (d) Integrating genetic laboratory test results and other diagnostic studies with personal
21 and family medical history to assess and communicate risk factors for genetic or medical conditions
22 and diseases;

23 (e) Explaining the clinical implications of genetic laboratory tests and other diagnostic
24 studies and their results;

25 (f) Evaluating the client's or family's responses to the condition or risk of recurrence and
26 provide client-centered counseling and anticipatory guidance;

27 (g) Identifying and utilizing community resources that provide medical, educational,
28 financial, and psychosocial support and advocacy; and

29 (h) Providing written documentation of medical, genetic, and counseling information for
30 families and health care professionals.

1 326-K:2 Exemptions from Licensure. The requirements for licensure under this chapter shall
2 not apply to:

3 I. Any person licensed by the state to practice in a profession other than that of genetic
4 counseling when acting within the scope of the person's profession and doing work of a nature
5 consistent with the person's training. Such person shall not hold himself or herself out to the public
6 as a genetic counselor.

7 II. Any person employed as a genetic counselor by the federal government or an agency
8 thereof if such person provides genetic counseling services solely under the direction and control of
9 the organization by which he or she is employed.

10 III. A student, if the following conditions apply:

11 (a) The student is enrolled in an ABGC accredited genetic counseling educational program;

12 (b) The genetic counseling services performed by the student are an integral part of the
13 student's course of study;

14 (c) The genetic counseling services are performed under the direct supervision of a
15 licensed genetic counselor; and

16 (d) The student is designated by the title, "genetic counseling intern."

17 IV. A genetic counselor working for an out-of-state employer or organization providing occasional
18 genetic counseling services in this state who is not licensed in the state of New Hampshire, and:

19 (a) Is licensed as a genetic counselor in the state where he or she is employed; or

20 (b) If licensure is not available in the genetic counselor's state of employment, the genetic
21 counselor shall be certified or have active candidate status conferred by the ABGC or the ABMG.

22 326-K:3 Eligibility for Initial Licensure. In addition to requirements under RSA 328-F, the
23 board shall require the following as a minimum to qualify for licensure. Each applicant shall:

24 I. Comply with the NSGC Code of Ethics.

25 II. Provide satisfactory evidence of having fulfilled the following criteria:

26 (a) Genetic counselor certified by ABGC or ABMG; or

27 (b) Medical geneticist certified by ABMG; or

28 (c) An individual who has worked as a genetic counselor for a minimum of 10 years
29 preceding the effective date of this chapter and who provides the following documentation:

30 (1) A master's or higher degree in genetics or related field of study; and

31 (2) Proof of having never failed the ABMG/ABGC certification examination; and

32 (3) Three letters of recommendation from at least one genetic counselor who qualifies
33 for licensure under this chapter, and either a clinical geneticist certified by ABMG or medical
34 geneticist certified by ABMG. The board shall consider a letter from a supervising physician if
35 clinical or medical geneticist is not available. All individuals submitting letters of recommendation
36 shall have worked with the applicant in an employment setting during the last 10 years and can
37 attest to the applicant's competency in providing genetic counseling services; and

1 (4) Proof of attending ABGC approved continuing education programs within the
2 last 5 years.

3 III. An individual who submits the documentation required in subparagraph II(c) not later
4 than 180 days after licensure under this chapter is first available or no later than 180 days after
5 accepting a position in New Hampshire may apply to the board for licensure without meeting the
6 certification requirement.

7 326-K:4 Provisional License.

8 I. A provisional license may be issued by the board to an applicant who meets all of the
9 requirements for licensure except for the certification component and has been granted active
10 candidate status by ABGC.

11 II. A provisional license shall be valid for the ABGC examination cycle for which active
12 candidate status by the ABGC has been granted. Such provisional license shall expire automatically
13 upon the earliest of the following:

- 14 (a) Issuance of a full license;
15 (b) Thirty days after the applicant fails to pass the certification examination; or
16 (c) The date printed on the provisional license.

17 III. A provisional licensed genetic counselor shall work under the general supervision of a
18 licensed genetic counselor or a licensed physician at all times during which the provisional licensed
19 genetic counselor performs genetic counseling. An application for extension of the provisional license
20 shall be signed by a supervisor.

21 326-K:5 Prohibition on Unlicensed Practice; Professional Identification.

22 I. No person shall practice or represent himself or herself as a genetic counselor in this state
23 without first applying for and receiving a license or provisional license from the board to practice as
24 a licensed genetic counselor.

25 II. A genetic counselor whose license is suspended or revoked or whose surrender of license
26 with or without prejudice has been accepted by the board, shall promptly deliver the original license
27 to the board.

28 III. Individuals holding currently valid licenses issued under this chapter may use the title
29 "genetic counselor" and write the designation "licensed genetic counselor" following his or her
30 written name.

31 IV. No person shall represent himself or herself or the services offered by using the term
32 genetic counselor unless he or she is licensed in accordance with this chapter. No person, who is not
33 so licensed may use in connection with his or her name or place of business, the title "genetic
34 counselor," "licensed genetic counselor," "gene counselor," "genetic consultant," "genetic associate," or
35 any words, letters, abbreviations or insignia indicating or implying a person holds a genetic
36 counseling license, or any similar words if the intent of such use is to imply that the person is
37 licensed, unless licensed under this chapter.

1 V. Any person who states or implies by word or act that he or she is currently licensed to
2 practice genetic counseling at a time when he or she does not hold a currently valid license shall be
3 guilty of a misdemeanor.

4 326-K:6 Reciprocity. An applicant who satisfies the board that he or she is licensed under the
5 laws of another state, territory, or jurisdiction of the United States, which in the opinion of the board
6 imposes substantially the same licensing requirements as required by RSA 328-F, RSA 326-K:3, and
7 the rules of the board, may be granted a license pursuant to this chapter.

8 2 Allied Health Professionals; Definition; Governing Board. Amend RSA 328-F:2, II to read as
9 follows:

10 II. "Governing boards" means individual licensing boards of athletic trainers, occupational
11 therapy assistants, occupational therapists, recreational therapists, physical therapists, physical
12 therapist assistants, respiratory care practitioners, [~~and~~] speech-language pathologists, **and genetic**
13 **counselors**.

14 3 New Paragraph; Allied Health Professionals; Genetic Counseling. Amend RSA 328-F:2 by
15 inserting after paragraph IX the following new paragraph:

16 X. "Genetic counseling" means genetic counseling as defined in RSA 326-K:2.

17 4 Governing Board; Establishment. Amend RSA 328-F:3, I to read as follows:

18 I. There shall be established governing boards of athletic trainers, occupational therapists,
19 recreational therapists, respiratory care practitioners, physical therapists, [~~and~~] speech-language
20 pathologists, **and genetic counselors**.

21 5 New Paragraph; Genetic Counselors; Governing Board; Appointment. Amend RSA 328-F:4 by
22 inserting after paragraph IX the following new paragraph:

23 X. The genetic counselors governing board shall consist of 4 licensed genetic counselors, who
24 have actively engaged in the practice of genetic counseling in this state for at least 2 years, and one
25 public member. Initial appointment of professional members by the governor and council shall be
26 qualified persons practicing genetic counseling in this state. All subsequent appointments or
27 reappointments shall require licensure.

28 6 Renewals; Dental Hygienists Added. Amend RSA 328-F:19, I to read as follows:

29 I. Initial licenses and renewals shall be valid for 2 years, except that timely and complete
30 application for license renewal by eligible applicants shall continue the validity of the licenses being
31 renewed until the governing board has acted on the renewal application. Licenses issued pursuant
32 to RSA 328-A, RSA 326-G, and RSA 326-J shall expire in even-numbered years and licenses issued
33 pursuant to RSA 326-C, RSA 326-E, [~~and~~] RSA 326-F, **and RSA 326-K** shall expire in odd-numbered
34 years.

35 7 Effective Date. This act shall take effect July 1, 2012.

LBAO
12-2898
12/05/11

SB 240-FN - FISCAL NOTE

AN ACT relative to the regulation of the practice of genetic counseling.

FISCAL IMPACT:

The Legislative Budget Assistant has determined that this legislation has a total fiscal impact of less than \$10,000 in each of the fiscal years 2012 through 2016.

Committee Minutes

**SENATE CALENDAR NOTICE
EXECUTIVE DEPARTMENTS AND ADMINISTRATION**

- ✓ Senator Sharon Carson Chairman
- ✓ Senator Fenton Groen V Chairman
- ✓ Senator Sylvia Larsen
- ✓ Senator Jim Luther
- ✓ Senator Raymond White

*9:45 AM
close 10:10*

For Use by Senate Clerk's Office ONLY	
<input type="checkbox"/>	Bill Status
<input type="checkbox"/>	Docket
<input type="checkbox"/>	Calendar
Proof: <input type="checkbox"/>	Calendar <input type="checkbox"/> Bill Status

Date: January 5, 2012

HEARINGS

Thursday

1/19/2012

EXECUTIVE DEPARTMENTS AND ADMINISTRATION

SH 100

9:00 AM

(Name of Committee)

(Place)

(Time)

EXECUTIVE SESSION MAY FOLLOW

9:00 AM	SB213-FN	relative to the authority of state agencies to assess fines and penalties.
9:30 AM	SB240-FN	relative to the regulation of the practice of genetic counseling.
9:45 AM	SB249-FN	requiring a request for proposals for the administration and management of the New Hampshire retirement system.
10:05 AM	SB365-FN	authorizing state residents to join the state health care program.
10:25 AM	SB331	clarifying the definition of surviving spouse for eligibility for line-of-duty death benefits for police officers or firefighters killed in the line of duty.
10:45 AM	SB370-FN	relative to the breeding of dogs for sale or transfer.

Sponsors:

SB213-FN

Sen. Tom De Blois
Sen. Jeanie Forrester
Sen. Gary Lambert
Rep. John Reagan

Sen. John Barnes, Jr.
Sen. James Forsythe
Sen. Andy Sanborn

Sen. David Boutin
Sen. John Gallus
Rep. Mark Warden

Sen. Sharon Carson
Sen. Fenton Groen
Rep. Andrew Manuse

SB240-FN

Sen. Sharon Carson
Rep. Mary Griffin

Sen. Bob Odell

Rep. Laurie Harding

Rep. Mary Gile

SB249-FN

Sen. John Gallus

Sen. Raymond White

Rep. Neal Kurk

SB365-FN

Sen. John Gallus

Rep. Edmond Gionet

Rep. Robert Theberge

SB331

Sen. Jim Rausch
Rep. Sherman Packard

Sen. David Boutin
Rep. John Cloutier

Rep. John Graham

Rep. Kenneth Hawkins

SB370-FN

Sen. Bob Odell
Rep. Mary Gile

Sen. Sharon Carson

Rep. David Bettencourt

Rep. Mary Cooney

Executive Dept. and Administration Committee

Hearing Report

TO: Members of the Senate

FROM: Deb Chroniak, Legislative Aide

RE: Hearing report on SB 240-FN – relative to the regulation of the practice of genetic counseling.

HEARING DATE: January 19, 2012

MEMBERS OF THE COMMITTEE PRESENT: Senator Carson, Senator Groen, Senator Luther, Senator Larsen, Senator White

MEMBERS OF THE COMMITTEE ABSENT: No one

Sponsor(s): Sen. Carson, Dist 14; Sen. Odell, Dist 8; Rep. Harding, Graf 11; Rep. Gile, Merr 10; Rep. Griffin, Rock 4

What the bill does: This bill establishes the genetic counselors governing board in the office of licensed allied health professionals for the regulation of the practice of genetic counseling in this state.

Who supports the bill: Rep. Laurie Harding, Rep. Mary Stuart Gile, Lisa Demers, MS, CGC, Bradley Arrick, Medical Oncologist, Chief of Hematology/Oncology, Dartmouth-Hitchcock Medical Center, Eleanor Riggs, MS, CGC, Jeff and Jennifer Swenson, Jen Tansey, MS, CGC, Sheila Upton, MS, CGC, Kasia Bloch, MS, CGC, Joseph Lascurain, Valerie LaCroix, MS, CGC, Derin Applebee, MS, CGC, Kathryn Bomba, MS, CGC, Rebecca Kerr, MS, CGC, Gary Kaufman, MD, Janet Monahan, NH Medical Society, Tom Prasol, NH Genetic Counselors, Erica Stelmach, MS, CGC

Who opposes the bill: No one.

Summary of testimony received:

The Vice Chair, Fenton Groen, opened the hearing at 9:47 a.m.

Senator Sharon Carson spoke to the bill saying that SB 240-FN was relative to the regulation of the practice of genetic counseling and that the bill seeks to establish the genetic counselors governing board in the office of licensed

allied health professionals for the regulation of the practice of genetic counseling in this state. The background surrounding this bill, she was approached approximately two years ago to bring this bill forward for consideration. The genetic counselors want to come and have a discussion about this particular practice, how it is a new field, and that they want to be a licensed profession.

- **Lisa Demers, MS, CGC, (in support) (testimony provided)** noted that she is a Certified Genetic Counselor in the Dartmouth-Hitchcock system in Nashua, NH, as well as co-chair of the NH Genetic Counseling Licensure Committee. She went to state the genetic counselors are a critical part of a health care team, providing support and information to individuals and families who are concerned with genetic disorders. The counselors training and expertise is obtained through a two year Masters level program. Their role in clinical care can be thought of as analogous to that of a nurse practitioner, physician assistant, etc.

- There are approximately 20 genetic counselors in New Hampshire.

- Licensing is necessary to help protect the public from potential harms that may result from this field being unregulated, and would ensure minimum standards for individuals in terms of academic achievement, clinical experience, and counseling skills.

- Approximately 72% of non-genetic physicians rate themselves as having fair to poor knowledge of genetics; approximately 30% of non-genetic health care providers misinterpret the results of genetic testing.

- **Eleanor Riggs, MS, CGC, (in support) (testimony provided)** noted that she is a Certified Genetic Counselor at Dartmouth-Hitchcock Medical Center, Lebanon, NH, as well as co-chair of the NH Genetic Counseling Licensure Committee.

- Noted that the services genetic counselors provide not only increase the quality of health-care, but also cost-effectiveness.

- Assure genetic tests are utilized appropriately.

- Notes that non-genetics health care professionals have demonstrated to underestimate patients' genetic risks because of ineffective family history evaluation.

- Presently, there is no mechanism in the State of New Hampshire that assures New Hampshire citizens that the individual who is providing information is qualified to do so.

- Licensure is the gold standard for identifying competent health care professionals.

- **Senator Luther** asked, who typically orders genetic testing and does the general practitioner also interpret these tests? **Ms. Riggs** stated that there are a lot of people who order genetic tests, obviously genetic counselors do sub-specialty physicians that they work with, such as medical oncologists, maternal field medicine specialists, medical geneticists, but any physician is allowed to order a genetic test. The problem is the interpretation; if they are not current in genetics it is difficult, with large room for error because most results are not clear cut without the proper training.

- **Bradley Arrick, (in support) (testimony provided)** Medical Oncologist, Dartmouth-Hitchcock Medical Center stating that approximately fifteen years ago, as genes which underlie heritable predisposition to cancer were identified, he was part of a group of physicians and genetic counselors that developed a program to help individuals and families in which such genetic syndromes were suspected.

- Trained genetic counselors have the knowledge and skills needed for the provision of vital clinical services, and are better trained than board-certified primary care physicians in advising patients on the use and interpretation of genetic tests. Their expertise will become more important in the years ahead. **Senator Larsen** stated that given this is a growing field, and seeing that ten years ago this information was not as available, is there a push in the medical field to train physicians so that they are not getting inaccurate information from those whom you see first? **Mr. Arrick** stated that frequently there are medical education events on genetic advances and testing, but frankly, the pace of which things are changing, and the knowledge base is growing, outstrips the ability to stay up-to-date unless it is a primary focus. **Senator Larsen** next asked if it was his feeling that having licensed specialists is more effective than having the broad range of the medical profession being brought up-to-date. **Mr. Arrick** stated that he did not believe that the latter was achievable and that ideally it is a joint effort.

- **Jeffrey and Jennifer Swenson, (in support) (testimony provided)**, stating that their genetic counselor, Eleanor Riggs had asked them to come and speak because they had dealt with her a few years ago after some issues with an ultrasound. They met with Eleanor who was very knowledgeable. It was a very difficult situation for both himself and his wife due to not understanding what was happening with some medical tests. It became clear immediately, that without the knowledge and ability to communicate with them, the situation would have been worse. They felt very comfortable and informed to make the right decision. **Senator Luther** then asked how they were referred to the genetic counselor. **Mr. Swenson** stated it was through their OBGYN at a different hospital, who stated to them that they needed to go to Dartmouth.

- **Jodi Grimbilas** who represents the NH Dental Society stated that she had just turned to page 4 of the bill, section 6, Renewals; Dental Hygienists Added. She would ask that there be a review of that section.

- **Hearing closed at 10:10 a.m.**

Funding: The Legislative Budget Assistant has determined that his legislation has a total fiscal impact of less than \$10,000 in each of the fiscal years 2012 through 2016.

Future Action: The committee took the bill under advisement.

DAC

[file: SB0240-FN report]

Date: January 20, 2012

Speakers

SENATE EXECUTIVE DEPARTMENTS AND ADMINISTRATION COMMITTEE

Date: January 19, 2012 Time: 9:30 a.m. Public Hearing on SB 240-FN

SB 240-FN - relative to the regulation of the practice of genetic counseling.

Please check box(es) that apply:

Please check if

SPEAKING FAVOR OPPOSED

NAME (Please print)

REPRESENTING

<input type="checkbox"/>	<input type="checkbox"/>	NAME (Please print)	REPRESENTING
<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	SENATOR SHARON CARSON	SD # 14
<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	Lisa Demers, MS, CGC	
<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	Eleanor Riggs, MS, CGC	
<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	Bradley Amick, MD, PhD	
<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	Jeff + Jennifer Swenson	
<input type="checkbox"/>	<input checked="" type="checkbox"/>	Jen Tansley, MS, CGC	
<input type="checkbox"/>	<input checked="" type="checkbox"/>	Sheila Upton, MS, CGC	
<input type="checkbox"/>	<input checked="" type="checkbox"/>	Kasia Bloch, MS, CGC	
<input type="checkbox"/>	<input checked="" type="checkbox"/>	Joseph Lascurain	
<input type="checkbox"/>	<input checked="" type="checkbox"/>	Valerie LaCroix, MS, CGC	
<input type="checkbox"/>	<input checked="" type="checkbox"/>	Devin Applebee MS, CGC	
<input type="checkbox"/>	<input checked="" type="checkbox"/>	Kathryn Bomba, MS, CGC	
<input type="checkbox"/>	<input checked="" type="checkbox"/>	Rebecca Kerr, MS, CGC	
<input type="checkbox"/>	<input checked="" type="checkbox"/>	Gary Kaufman, MD	
<input type="checkbox"/>	<input checked="" type="checkbox"/>	Janet Monahan NH Medical Society	
<input type="checkbox"/>	<input checked="" type="checkbox"/>	Rep. LAWRENCE HARDING	
<input type="checkbox"/>	<input checked="" type="checkbox"/>	Rep. Mary Stuart Gale	
<input type="checkbox"/>	<input checked="" type="checkbox"/>	TOM PRASOL	NH GENETIC COUNSELORS

Testimony

TESTIMONY OF LISA D'AMBRUOSO DEMERS, MS, CGC
before the
STATE OF NEW HAMPSHIRE
STATE ED&A COMMITTEE
January 19, 2012

Thank you Chairwoman Carson and distinguished members of the Senate ED&A committee, for allowing us to speak to you about the need for genetic counseling licensure in the State of New Hampshire. I am Lisa Demers and I am a certified genetic counselor as well as the co-chair of the New Hampshire Genetic Counseling Licensure Committee.

Before you can truly see the need for licensure for our group, you must first understand our background and our mission. Genetic counselors are healthcare providers with significant training and expertise in genetics and psychosocial counseling obtained through a two year Masters level program.

Genetic counselors are a critical part of a health care team providing information and support to individuals and families concerned with genetic disorders. Genetic counselors collect and interpret family and medical histories, identify individuals and families at risk, explain inheritance and natural history, quantify chance for occurrence and recurrence, review available testing options, and discuss management, prevention, and research opportunities. We also serve as patient advocates and refer individuals and families to community or state support services as appropriate. Genetic counselors are employed in a wide range of clinical care, academic, laboratory, research and biotechnology settings. Though our occupation is unique, our role in clinical care can be thought of as analogous to that of a nurse practitioner, social worker, or physician assistant.

There are currently 31 genetic counseling programs in the United States and over 2,500 certified genetic counselors. Membership to our national organization has increased by 50% over the last 6 years. Needless to say, the field is growing and anyone who hasn't heard of genetic counseling will likely do so in the near future.

Currently there are 18 genetic counselors in the state of New Hampshire, most of them working within the state and in direct patient care. In 2011, our genetic counselors helped a minimum of 4,000 New Hampshire residents. As the quest for genetic knowledge continues to explode, these numbers are certain to follow suit. The information itself will be more complex in nature. SB 240 will help protect the public from potential harms that may result from this field being unregulated. Harm caused by untrained individuals attempting to provide genetic counseling includes misinformation regarding genetic risk or lack of risk, as well as misunderstanding of the implications of genetic information. Either could lead to unnecessary costs, as will be discussed by my co-chair Eleanor, and significant emotional turmoil. It has been reported that 72% of non-genetics physicians rate themselves as having fair to poor knowledge of genetics. This translates to the quality of care, as approximately 30% of non-genetics health care providers misinterpreted the results of genetic tests that they ordered for their patients.

Our mission as genetic counselors is to decode the complexities of genetics and translate, if you will, genetic information as it pertains to our patients. Our expertise in the science, the medical significance, and personal reactions make us ideal to be on the front line of this genetics revolution. We urge you to enact this legislation as it would ensure minimum standards for individuals in terms of academic

achievement, clinical experience, and counseling skills. Additionally, licensure will assure employers that they are hiring skilled individuals. This can allow for the expansion of services within the state. We are seeing that genetic counselors are viewing licensing as desirable when seeking employment. Most states with licensure have seen an increase in qualified genetic counselors since regulation has been enacted. This is partly due to an increased need, but also due to counselors having licensure across states. New Hampshire will most certainly be providing licenses to genetic counselors NOT living within the state.

The quality of services provided within the state will be increased, with regulation in place. The cases of harm submitted for your review are examples of poor genetic counseling. Most often the error is made by the primary physician. SB240, when enacted, will not hinder the abilities of trained clinicians, but rather it will highlight our scope of practice and our unique abilities. Some of the reported cases of harm are unfortunately caused by genetic counselors themselves. An inadequacy of continuing education and failure to remain current with technology increases liability. This is one career where longevity does not necessarily equal aptitude. Licensure will require a high level of competency within this rapidly changing field.

Thank you for allowing us to prove the need for licensure in our state.

#2

TESTIMONY OF ELEANOR R. RIGGS, MS, CGC
before the
STATE OF NEW HAMPSHIRE
STATE SENATE
EXECUTIVE DEPARTMENT AND ADMINISTRATION COMMITTEE

January 19, 2012

Chairwoman Carson and distinguished Members; my name is Eleanor Riggs, and I am a Certified Genetic Counselor, working at Dartmouth-Hitchcock Medical Center in Lebanon. I am also one of the co-chairs of the NH Genetic Counselor Licensure Task Force. On behalf of the NH Genetic Counselors, we would like to thank Senator Carson for introducing SB 240. I appreciate the opportunity to testify in support of this important legislation that would provide licensure for certified genetic counselors in New Hampshire.

I wanted to speak to how the services genetic counselors provide not only increase the quality of health-care but also the cost-effectiveness. In a time when the cost of health-care is a major concern for both the general public and legislators alike, genetic counselors have the unique ability to save health care dollars by preventing misguided testing.

Genetic counselors assure genetic tests are utilized appropriately. Many non-genetic health care providers often order unnecessary or even incorrect genetic tests, thus increasing overall health care costs. A classic example is ordering full gene sequencing when testing for a single familial mutation (known as targeted mutation analysis) would be appropriate. If you think of a gene as a book, full sequencing would be like doing a "spell-check" of the entire book, whereas targeted mutation analysis allows us to go to the specific page and line where a mutation has been previously identified. The difference in cost of these two tests is substantial – full gene sequencing costs around \$1500, whereas targeted mutation analysis costs around \$300. That is a savings of at least \$1200.

One well-known lab that performs many genetic tests, ARUP Laboratories in Utah, uses genetic counselors to review all the genetic tests ordered, as they have found that mistakes in genetic tests ordering occur approximately 30% of the time. They reported that in an eleven-month period, the genetic counselors found 1,182 mis-ordered tests, which translated into \$402,357 in health care dollars saved. And this is just one lab's data!

Non-genetics health care professionals have also been demonstrated to underestimate patients' genetic risks because of ineffective family history evaluation. Furthermore, fewer than half of them have taken continuing education courses in genetics. For many genetic conditions, 50% of first degree relatives (siblings, parents, children) of a person with a genetic mutation will also carry a mutation and are at risk to manifest symptoms of the disease or transmit the mutation. Identifying those who carry a mutation offers the opportunity for preventive screening and treatment, thus lowering the chance of disease manifestations. The cost of screening often pales in comparison to the cost of treating a specific disease. Moreover, identifying those family members who do *not* carry a mutation eliminates the need for expensive clinical follow-up.

In a personal experience, I have seen evidence of these issues with patients of mine. For example, last year I saw a patient because of her personal history of breast cancer and colon polyps. She had been diagnosed with breast cancer at age 47, but also had a history of colon polyps that began developing in her mid-20's. At age 28, she had a colectomy (removal of colon). She had been evaluated by a non-genetics health care provider who ordered genetic testing for the 2 genes associated with an increased risk for breast and ovarian cancer, although the patient did not have a strong family history of breast or ovarian cancer, and was actually at a pretty low risk to be a carrier of either of those genes. That health care provider did not mention anything about her colon polyps or the potential for a hereditary predisposition to colon cancer. This was a major oversight. The patient sought out a second opinion after she began developing more colon polyps in the remaining part of her rectum. When I saw her, I had a high suspicion for a genetic syndrome that predisposes a person to colon polyps and colon cancer. We did the genetic testing for that condition (known as FAP) and she came back a carrier. In addition, she also came back positive for a second, different genetic condition related to colon polyps and colon cancer (known as MYH). Both of these conditions significantly increase a person's risk for colon cancer. Determining that she had both conditions had significant impact on her surgical decision-making, as she was contemplating having the remaining part of her rectum removed, as well as her future colon screening. Additionally, her children were now at risk for 2 different genetic conditions and needed to be counseled about the appropriate follow-up. In summary, this patient's non-genetic health care provider not only erroneously ordered a genetic test (and in doing so wasted \$3500), but she completely missed testing for the conditions that were much more likely given the patient's history! This had immediate consequences for the patient and downstream consequences for family members.

Finally, the field of genetics is changing rapidly and genetic counselors are key players in appropriately and effectively integrating genetic and genomic applications into health care. (Please refer to attached chart). Clinicians and patients need to know that the genetic counselors they work with are adequately trained and up-to-date on genetic information. We urge you to enact this legislation as it would establish requirements for the licensure of genetic counselors ensuring minimum standards for individuals in terms of academic achievement, clinical experience, and skills necessary to deliver high quality genetic counseling services. Currently in New Hampshire there is no legal standard for who can represent themselves as genetic counselors. As the field of medical genetics grows, there is and will continue to be a need to provide the citizens of New Hampshire with accurate information regarding their genetic risks and results of genetic tests. At present, there is no mechanism that assures citizens that the individual who is providing this information is qualified to do so. Licensure is the gold standard for identifying competent health care professionals. In a climate where genetic testing is becoming more commonplace, direct-to-consumer genetic testing via internet companies is widely available, and where the complexity of genomic tests are increasing, the citizens of New Hampshire need to have access to professionals who have been deemed qualified by the state to help them understand their potential genetic risks.

Thank you for your time and attention.

Testimony of Brad Arrick
Medical Oncologist
Chief of Hematology/Oncology
Dartmouth Hitchcock Medical Center

Good morning.

My name is Bradley Arrick. I am a medical oncologist and Chief of Hematology/Oncology at Dartmouth-Hitchcock Medical Center. Approximately 15 years ago, as some of the genes which underlie heritable predisposition to cancer were identified, I was part of a group of physicians and genetic counselors that developed a program to help individuals and families in which such genetic syndromes were suspected. Over the years, as our understanding of the human genome has grown, the complexity of this field and its potential to have a positive impact on people's lives has also increased. It is already quite clear that proper interpretation of genetic information in a setting that facilitates a person's ability to understand its consequences for themselves and their family is essential. In my experience, trained genetic counselors have the knowledge and skills needed for the provision of this vital clinical service. Indeed, in this rapidly changing field, genetic counselors are better trained than board-certified primary care physicians to advise patients on the use and interpretation of genetic tests. Having seen numerous examples of the inappropriate use of genetic tests by physicians without up-to-date genetic training, I was part of a group that promulgated a policy at Dartmouth-Hitchcock mandating the provision of genetic counseling by properly trained individuals, before such genetic tests could be obtained.

In recent years, the cost of DNA sequencing has been dropping rapidly. Soon, it will cost no more to decode an individual's entire DNA than it does to sequence one gene today. With this tremendous technological advancement will come great potential

to inform people and their doctors of an individual's risk of various ailments, the best way to screen and prevent those diseases, and the best medications to use.... Personalized Medicine at its best. However, the potential for real harm to patients by the misguided interpretation of genetic test information will also increase. Thus, in my view, the role of genetic counselors will become even more important in the years ahead. It is critical that health care providers in the community have access this resource, and can trust that a person offering genetic counseling services is indeed qualified to do so. Licensure at the state level is the appropriate mechanism to achieve this. The administrative burden involved in state licensure is well worth the benefits to our population. I therefore urge you all to support SB 240.

#4

State Licensure Testimony- 1/19/2012

In the spring of 2009 my wife and I were excited to find out the sex of our first child. We headed to Brattleboro Hospital for our 1st ultrasound. We were having a girl. The next day we received a call saying we needed to schedule an emergency ultrasound at Dartmouth Hitchcock Hospital in Hanover. This was scary for us. We were so nervous and unclear as to why this was happening. We arrived at Dartmouth and were greeted by a caring, knowledgeable and compassionate person, our genetics counselor, Eleanor. We were sat down and explained all the reasons we were there and what to expect with our visit. She took the time to clearly communicate the causes, the outcomes and suggestions on how to handle the situation we were about to be approached with. The professionalism and integrity of this position became clear from the start. This person, Eleanor was here to educate us, make us comfortable and make us as informed as possible about what to anticipate and what avenues could be taken.

From that point on, Eleanor was with us 100% of the way. It's very clear to us that had we been met with an inexperienced, unprofessional and less than compassionate person, our painful experience would not have felt so comfortable and manageable. Now I know that not all people are the same, but I am confident that with proper training, mentoring, growth and experience, that we would not have felt the same way.

We were so lucky to have had the opportunity to be educated and cared for by such a professional. Eleanor went out of her way to make a painful situation as comfortable and educational as possible. The entire department went out of their way to be supportive.

We hope you consider the importance of strict regulations of someone's competence and understand how detrimental the effects of poor education and training could negatively impact people's ability to make the right decisions in their situation. Having all the knowledge and feeling informed and cared for could never be highlighted enough. To be redundant, it's no ones job to tell you what to do in these difficult situations, but to educate, inform and gain as much knowledge into your situation to make the best possible informed decision

We often look back and reflect on how grateful we were to receive the care and professionalism we did in a less than ideal situation. Please help ensure that all individuals are able to receive the same quality care in which we did.

Sincerely Jeffrey and Jennifer Swenson

The Demers Group

5 Carriage Lane
Hanover, NH 03755

Date: January 11, 2012

To Whom It May Concern:

I am writing in support of genetic counselor licensure in the State of New Hampshire. I write from personal experience as a recent patient and as a physician often considering how genetic testing may influence decisions made by my patients.

About 2.5 years ago my wife and I sought out the advice of a genetic counselor to assist in decision making for testing when we learned that my wife was pregnant. As we were nearing 40 years of age, and of Jewish heritage, we wanted information to guide us in deciding what testing (if any) was necessary since we felt that we were at higher than average risk. We had an extremely helpful visit on a number of fronts. First, we were confident that the information we were receiving was accurate and up to date. Second, it was communicated in a clear, confident and comforting way. And third, we were not pressured into any decisions, but given fair choices that we were able to make on our own. As I knew many of the staff at Dartmouth-Hitchcock, I was specifically referred to a particular genetic counselor and immediately respected their opinion. Because of the institution and the provider recommendation that we received, I did not question their credentials, however, had it been another scenario, I would have wanted to know their training, background and licensure to confirm the validity of the information I had received.

As a gastroenterologist, I have opportunity to consider genetic based disease related to both cancer and inflammatory bowel diseases. I believe that once our patients speak with a genetic counselor, their guidance becomes gospel and patients base incredibly important decisions (e.g., treatment, surgery, pregnancy) on the data provided. I would hate to think that someone less qualified has the ability to represent themselves as a genetic counselor if they did not have the proper training. Truly, life and death (or life altering) decisions are made based on advice given, and there is little room for error.

Finally, my research is focused on exploring optimal ways to communicate complicated data to patients. I was very impressed with the communication skills and tools presented to us by our provider, and the quality of the data is only as useful at the clarity of its presentation. Clearly, even good data in the wrong hands can be misrepresented and misinterpreted, and any regulation around who is communicating information would be helpful.

I have had great experiences with genetic counselors as a patient and a provider, and I support the plan for licensure so that any patient or provider can easily determine if an individual is qualified to provide genetic counseling services.

Sincerely,

A handwritten signature in black ink, appearing to read 'Corey Siegel', with a stylized flourish at the end.

Corey Siegel, MD, MS

January 14, 2012

We are writing in support of the bill to establish state licensure requirements for Genetic Counselors practicing in New Hampshire. Through our experiences over the past four years with genetic counseling, we truly cannot overstate the importance of ensuring that patients have access to qualified and competent professionals in the field of genetic counseling.

During the pregnancy with our first daughter in 2008, we received unsettling news at our first ultrasound. The presence of "choroid plexus cysts" in our daughter's brain was a marker for possible medical complications. We were referred for genetic counseling where we were provided with a very thorough explanation of our risks and our options for further tests and treatments. The genetic counselor was knowledgeable about current medical practices and was able to answer our many questions with sensitivity and in language we could understand. We appreciated that she was nonbiased in presenting information about our options. As a result, we were able to confidently make a decision which was best for us and our daughter, who was ultimately born without medical complications or conditions.

Two years later, we again met with a genetic counselor during the pregnancy with our second daughter, who appeared to have significant cardiac and other physical abnormalities on an ultrasound. We were again able to make a decision we felt comfortable with because of a genetic counselor who was skilled in working with patients in need of current and comprehensive information at such a vulnerable time.

When we learned that our second daughter did not have cardiac abnormalities but did have Down syndrome, a genetic counselor provided us with extensive resources regarding her condition and skillfully addressed our numerous questions with compassion. She gave us an overview of the health concerns we needed to be aware of as parents of a child with Down syndrome, and again empowered us to be informed, confident decision makers in our daughter's medical care.

During these critical times when we were feeling both fearful and vulnerable, professionals in the field of genetic counseling guided us to where we could confidently make the right decisions for our family. They determined our risks and the up-to-date treatment options for us, but more importantly they knew how to communicate the appropriate information we needed without putting pressure on us.

Patients should have access to Genetic Counselors who are knowledgeable, professional, and skilled, like those who worked with us. Patients need accurate and current information which is relevant to their specific situation and is presented in a way that they understand. Requiring professionals to meet the qualifications of state licensure will better protect patients from potential harm that receiving inaccurate, biased or outdated information may lead to. Please consider this important legislation for the protection of patients in New Hampshire.

Respectfully submitted by:
Bart and Erin Pospychala
94 Jewell Road
Wilmot, NH 03287

1/15/2012

To Whom it May Concern,

In December of 2010, we learned through a routine ultrasound at our community hospital that our son had acquired multiple birth defects while developing in the womb, including a missing leg and hip. A more detailed follow-up ultrasound was ordered at Dartmouth Hitchcock Medical Center, where we were also to see a genetic counselor immediately before the ultrasound.

In the two days between hearing the results of our first ultrasound and our follow-up appointment at DHMC, we were emotionally overwhelmed, suffered from lack of sleep, and felt very vulnerable. As a result, we were nervous and hesitant about the genetic counseling appointment and the ultrasound to follow.

It is at times such as these, when your life changes forever in a very sudden, unexpected fashion, that parents can feel weak and helpless, and it was certainly no different for us. That's why it was so important that the care we received by the genetic counseling staff (and other staff as well) at DHMC was compassionate, authentic, experienced, and well-informed. Fortunately, this was indeed the case for us. Our son is now a thriving nine month old, and we can look back on his life and feel satisfied that our family received great care from the very beginning.

The very nature of a genetic counselor's job requires them to work with clients and patients who are likely to be quite vulnerable, be it emotionally (as we were), medically, financially, etc. Because of this, it important that the care given by genetic counselors is consistently of high quality and that the positive experience we had is routine.

If the regulation of genetic counseling through licensure will achieve this goal, then we offer our support of this bill.

Thank you,

Jacob & Leigh Vincent
9 Day St.
Windsor, VT 05089



NHGCLTF

New Hampshire Genetic Counselor Licensure Task Force

Compiled List of Support for SB 240

Sat Dev Batish, PhD, FACMG
Athena Diagnostics

Leslie DeMars, MD
DHMC

Patricia M. Martin, CNM, MPH
Dover Women's Health

Elizabeth E. Schwartz, CNM, MSN
Dover Women's Health

Charles M. Blitzer, M.D.
Seacoast Orthopedics & Sports Medicine

Fred H. Brennan, Jr., D.O.
Seacoast Orthopedics & Sports Medicine

Peter D. Buckley, M.D.
Seacoast Orthopedics & Sports Medicine

Peter J. Dirksmeier, M.D.
Seacoast Orthopedics & Sports Medicine

Mark J. Geppert, M.D.
Seacoast Orthopedics & Sports Medicine

Robert H. Harrington, M.D.
Seacoast Orthopedics & Sports Medicine

Moby Parsons, M.D.
Seacoast Orthopedics & Sports Medicine

David C. Thut, M.D.
Seacoast Orthopedics & Sports Medicine

Gavin R. Webb, M.D.
Seacoast Orthopedics & Sports Medicine

Paul M. Ernsting, D.O.
Dover Family Practice

Judy E. Garber, M.D., MPH
Dana Farber

Jon L. Hart
Genzyme Genetics

Joyce Wilcox Graff, Executive Director
VHL Family Alliance

Gregory J. Tsongalis, Ph.D., HCLD, FACB
DHMC

Mary Beth Dinulos, MD
DHMC

MaryAnn Whalen Compton, MS, CGC
Boston University

Judith E. Tsipis, PhD
Brandeis University

James Filiano, MD
DHMC

Jeffrey R. Johnson, M.D.
DHMC Manchester

Gary E. Kaufman, M.D.
DHMC Nashua

Teresa Ponn MD, FACS
Elliot Breast Health Center

Mark A. Israel, M.D.
DHMC

Cecilia Stupois, M.D.
DHMC

Williams Edwards, MD
DHMC

John F. Modlin, M.D.
DHMC

Tina Foster MD, MPH, MS
DHMC

John B. Moeschler, M.D., M.S.
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Steven A. Paris, M.D.
DHMC Manchester

Brad A. Arrick, M.D., PhD
DHMC

Burton L. Eisenberg, M.D.
DHMC

Kari Rosenkranz, MD
DHMC

Richard H. Reindollar, MD
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Emily R. baker, M.D.
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Julie A. Bleyenbergh, D.O.
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Molly M. Steele, CNM
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Great Bay Family Practice

Margret Garcia, M.D.
Lee Family Practice

Peter Degnan, M.D.
Seacoast Integrative Medicine

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Matthew Goldberg, D.O.
Lee Family Practice

Anna Pilzer, APRN
Hilltop Family Practice

Maria Lourdes F. Rodriguez, M.D.
Lee Family Practice

Jennifer Thomas, APRN
Barrington Health Center

Nancy Stoll, M.D.
Adult and Children's Medicine of Dover

Girish C. Joshi, M.D.
Adult and Children's Medicine of Dover

Finola Cox, PA-C
Adult and Children's Medicine of Dover

Committee Report

STATE OF NEW HAMPSHIRE
SENATE
REPORT OF THE COMMITTEE
FOR THE CONSENT CALENDAR

Date: February 9, 2012

THE COMMITTEE ON Executive Departments and Administration
to which was referred Senate Bill 240-FN

AN ACT relative to the regulation of the practice of genetic
counseling.

Having considered the same, the committee recommends that the Bill:

BE REFERRED TO INTERIM STUDY

BY A VOTE OF: 5-0

CONSENT CALENDAR VOTE: 5-0

Senator Sharon M. Carson for the Committee

SB 240-FN was at the request of the Genetic Counselors to seek to establish a governing board in the office of licensed allied health professionals for the regulation of the practice of genetic counseling in this state. It was decided that this bill be placed into Interim Study for further review.

Deb Chroniak 271-1403

New Hampshire General Court - Bill Status System

Docket of SB240

Docket Abbreviations

Bill Title: relative to the regulation of the practice of genetic counseling.*Official Docket of SB240:*

Date	Body	Description
1/1/2012	S	Introduced 1/4/2012 and Referred to Executive Departments and Administration; SJ 1 , Pg.5
1/5/2012	S	Hearing: 1/19/12, Room 100, SH, 9:30 a.m; SC2
2/9/2012	S	Committee Report: Referred to Interim Study, 2/15/12; Vote 5-0; CC; SC7
2/15/2012	S	Refer to Interim Study, MA, VV; SJ 5 , Pg.124

NH House

NH Senate

Other Referrals

COMMITTEE REPORT FILE INVENTORY

SB 240-FN ORIGINAL REFERRAL _____ RE-REFERRAL

1. THIS INVENTORY IS TO BE SIGNED AND DATED BY THE COMMITTEE AIDE AND PLACED INSIDE THE FOLDER AS THE FIRST ITEM IN THE COMMITTEE FILE.
2. PLACE ALL DOCUMENTS IN THE FOLDER FOLLOWING THE INVENTORY IN THE ORDER LISTED.
3. THE DOCUMENTS WHICH HAVE AN "X" BESIDE THEM ARE CONFIRMED AS BEING IN THE FOLDER.
4. THE COMPLETED FILE IS THEN DELIVERED TO THE CALENDAR CLERK.

- DOCKET (Submit only the latest docket found in Bill Status)
- COMMITTEE REPORT
- CALENDAR NOTICE
- HEARING REPORT
- HANDOUTS FROM THE PUBLIC HEARING
- PREPARED TESTIMONY AND OTHER SUBMISSIONS
- SIGN-UP SHEET(S)

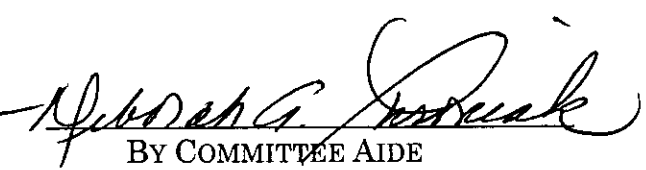
ALL AMENDMENTS (passed or not) CONSIDERED BY COMMITTEE:

____ - AMENDMENT # ____ ____ - AMENDMENT # ____
____ - AMENDMENT # ____ ____ - AMENDMENT # ____

ALL AVAILABLE VERSIONS OF THE BILL:

AS INTRODUCED ____ AS AMENDED BY THE HOUSE
____ FINAL VERSION ____ AS AMENDED BY THE SENATE

____ OTHER (Anything else deemed important but not listed above, such as amended fiscal notes): _____

DATE DELIVERED TO SENATE CLERK 6-26-12 
BY COMMITTEE AIDE