# REPORT OF RECOMMENDATIONS AND FINDINGS

By the Genetic Counselors'
Technical Review Committee

To the Nebraska State Board of Health, the
Director of the Division of Public Health, Department of Health and Human
Services, and the Members of the Health and Human
Services Committee of the Legislature

December 1, 2010

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# INTRODUCTION

The Credentialing Review Program is a review process advisory to the Legislature which is designed to assess the need for state regulation of health professionals. The credentialing review statute requires that review bodies assess the need for credentialing proposals by examining whether such proposals are in the public interest.

The law directs those health occupations and professions seeking credentialing or a change in scope of practice to submit an application for review to the Department of Health and Human Services, Division of Public Health. The Director of this Division will then appoint an appropriate technical review committee to review the application and make recommendations regarding whether or not the application in question should be approved. These recommendations are made in accordance with four statutory criteria contained in Section 71-6221 of the Nebraska Revised Statutes. These criteria focus the attention of committee members on the public health, safety, and welfare.

The recommendations of technical review committees take the form of written reports that are submitted to the State Board of Health and the Director of the Division along with any other materials requested by these review bodies. These two review bodies formulate their own independent reports on credentialing proposals. All reports that are generated by the program are submitted to the Legislature to assist state senators in their review of proposed legislation pertinent to the credentialing of health care professions.

## MEMBERS OF THE GENETIC COUNSELORS' TECHNICAL REVIEW COMMITTEE

**John Tennity, D.P.M. (Chairperson)** **(Lincoln)**
**Representing the State Board of Health**
Podiatrist

**Linda Douglas, Ed.D.** **(Lincoln)**
Retired Director of Special Education, Lincoln Public Schools
Lecturer, UNL-Lincoln
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Social Service Planner, United Way of the Midlands

**Jackie Liess, R.N., A.P.R.N.** **(Omaha)**
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**Representing the Applicant Group**
Genetic Counselor, Southeast Nebraska Cancer Center

**Michael Schmidt, M.D., Ph.D.** **(Lincoln)**
**Representing the Nebraska Medical Association**
Pediatrician and Medical Geneticist

**Jeanne H. Stec, L.M.H.P.** **(Crete)**
**Representing the Nebraska Counseling Association**
High School Counselor, Crete Public Schools

# EXECUTIVE SUMMARY OF THE PROPOSAL AND RECOMMENDATIONS

## Summary of the Applicants' Proposal

The applicant group seeks to license genetic counselors in Nebraska.

The standard for licensure would be completion of a Master's degree and passage of the American Board of Genetic Counseling (ABGC) examination.

The scope of practice sought by the applicant group for Licensed Genetic Counselors would be as follows:

1. Collect and evaluate detailed medical and family histories, asking about diagnostic signs and symptoms that could otherwise go unnoticed.
2. Provide and interpret information about disorders, explain recurrence risks, review available options with both health care providers and families, and provide case management and psychological support systems.
3. Provide "nondirective counseling" concerning genetic risks.
4. Make appropriate referrals to other competent professionals.
5. Provide psychological and practical support to families and their children by linking them with support groups that can address psychological problems stemming from genetic counseling issues.
6. Provide genetic services ethically and respect the beliefs, cultural traditions, inclinations, circumstances and feelings of their clients.
7. Enable their clients to make informed, independent decisions, free of coercion.
8. Conduct educational programs regarding the availability and values of genetic counseling.

- The educational and training programs include didactic, laboratory, and clinical preparation in both inpatient and outpatient settings under the supervision of board certified practitioners. Masters degree programs are typically two years in duration.

- Fifty (50) hours of continuing education (CE) would be required for each two-year licensure renewal period.

- The public would have direct access to independently licensed practitioners.

- The proposal calls for the creation of an auxiliary committee under the Nebraska Board of Medicine and Surgery to regulate the profession.

- There would not be a grandfather clause.

- The proposal would exempt any health professionals licensed in Nebraska who are appropriately credentialed within their respective professions, and whose scope of practice clearly includes genetic counseling. However, the applicant group desires that the term "Genetic Counselor" be a protected title exclusive to the members of their own profession.

## Summary of Committee Recommendations

The committee members voted to recommend approval of the applicants' proposal. The proposal was approved on all four of the statutory criteria. The committee members also made one ancillary recommendation.

### Ancillary Recommendation

Entry-level requirements for licensure should include a Master's degree in an appropriate field as specified in the application and passage of the ABGC examination at the cut-score adopted by the State Board of Medicine and Surgery, upon the recommendation of the Genetic Counselor's Committee.

## ISSUES DISCUSSED BY THE COMMITTEE

1. **Is there harm to the public from the current unregulated practice situation of genetic counseling?**

   The applicants stated that that they are aware of examples of unqualified practice in the provision of genetic counseling services in Nebraska. They added that they are aware of one nurse in the Omaha area who has been providing these services without the necessary education and training, although the person has not been using the title, "genetic counselor," per se. The applicants noted that some non-specialist physicians have provided genetic counseling services to their patients, resulting in errors. [1]

   A physician committee member stated that too many women in Nebraska undergo bilateral prophylactic mastectomies unnecessarily because their physicians rely on the patient's family history instead of obtaining genetic evidence of risk by performing appropriate tests. The applicants added that some physicians realize that there might be a genetic risk after reviewing the patient's family history, but are unsure what tests to order. In some of these situations, patients may incur the costs associated with multiple tests, inappropriate tests, and needless surgeries. [2]

   Concern was expressed by some committee members that the proposal does not contain information that clearly shows that the public needs this proposal for protection from harm. They observed that the information provided in the proposal is anecdotal in nature, and stressed the need for the applicant group to provide data regarding harm and the extent of harm in order to document their case for licensure. They also noted that the proposal does not detail any information or data pertinent to harm to the public in Nebraska. [3]

2. **Would the proposal create significant new harm to the public?**

   The applicants were asked to provide information regarding other health professions that provide genetic counseling services. They responded that physicians and some nurses, including advanced practice nurses, provide these services. Committee members noted that many mental health professionals also provide genetic counseling services through individual and family therapy. [4]

   Committee members stated that the list of exempted professionals is too narrowly defined and that mental health professionals, podiatrists and advanced practice nurses are examples of health professions that should be included on any list of exempted professions. The applicants responded that the application does not seek to be restrictive, and that any licensed practitioner whose scope of practice includes genetic counseling would be allowed to continue to provide these services as long as they do not specifically refer to themselves as "genetic counselors". Only those practitioners who lack the education, training and appropriate credentialing would be excluded. A committee member asked whether there

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[1] Minutes of the Orientation Meeting of the Committee, May 19, 2010
[2] Minutes of the Third Meeting of the Committee, July 14, 2010
[3] Minutes of the Second Meeting of the Committee, June 9, 2010
[4] Minutes of the Second Meeting of the Committee, June 9, 2010

might be nurses who might be excluded. The applicants responded that some nurses would be excluded because not all nurses possess the appropriate training in genetic counseling. [5]

The proposal cannot restrict the scope of practice of physicians because they have an unlimited scope of practice. [6]

An interested party stated that nurses do and should continue to play a role in the provision of genetic counseling services. This person expressed the concern that the proposal might have a negative impact on the ability of nurses to perform this role in the future. [7]

Concern was expressed by some committee members that the proposal might create new restrictions on access to care if qualified members of other health professions are not exempted from the terms of the proposal. [8]

**3. How would the proposal benefit the public?**

The applicants argued that the proposal would help greatly to eliminate unqualified people from providing these services because under the current situation, anyone can set up practice as a genetic counselor. [9]

The applicants stated that there would be an immediate economic benefit from the proposal because it costs about a third less to see a genetic counselor than it does to see a physician. They added that about 90% of their patients self-pay because insurance companies will not pay for their services under the current practice situation. A physician committee member added that the payment for services by a genetic counselor does not include the costs of any tests performed, which are significant. [10]

The applicants explained that genetic counseling is not currently a billable item. The charges for the services of genetic counselors are passed through a physician or hospital for billing. The applicants argued that achieving third-party reimbursement would greatly assist in improving access to care, although there is no guarantee that this would actually occur if the proposal passes. A physician committee member stated that a billing code for genetic counseling services was not implemented by third-party payers until 2007. Prior to that time, patients often declined genetic counseling because of the out-of-pocket expenses. [11]

**4. Would the proposal be the most cost-effective means of addressing the concerns identified?**

Committee members expressed concern that the applicants cite harm by non-licensed practitioners, but have been unable to clearly identify those practitioners. Without specific information, licensure for genetic counselors would not enable regulators to locate and discipline these persons and the harm would continue. Additionally, although a nurse working in an oncologist's office might be ordering the wrong genetic tests, licensing genetic

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[5] Minutes of the Second Meeting of the Committee, June 9, 2010
[6] Minutes of the Orientation Meeting of the Committee, May 19, 2010
[7] Minutes of the Fourth Meeting of the Committee, August 18, 2010
[8] Minutes of the Third Meeting of the Committee, July 14, 2010
[9] Minutes of the Orientation Meeting of the Committee, May 19, 2010
[10] Minutes of the Third Meeting of the Committee, July 14, 2010
[11] Minutes of the Fourth Meeting of the Committee, August 18, 2010

counselors could not correct this problem because that nurse would be working under the delegation of a physician. [12]

Some committee members expressed doubt concerning the ability of the proposal to significantly add to the number of current practitioners in Nebraska, especially in rural areas of the State. The sixteen genetic counselors in the State are primarily located in Lincoln or Omaha, and licensure of these sixteen persons would be unlikely to significantly impact services in Nebraska. Also, there are not many genetic training programs nationally and none in the State. The applicants stated that there are 31 training programs across the United States. Concern was expressed that the training programs would not be able to graduate sufficient numbers of graduates to meet the demand for services in Nebraska. The applicants responded that licensure would provide assurance of quality of care, and could eventually improve access to care. [13]

The committee members discussed the merits of certification for genetic counselors versus licensure. They were informed that unlike licensure, which protects the title and restricts practice to practitioners meeting statutory requirements, certification only provides the benefit of title protection. The applicants stated that they prefer licensure because only licensure can handle the issue of unqualified practice. [14]

A committee member asked if there is any way to assess the impact of the proposal on access to the services provided by other health professions. The committee members were informed that because the term "genetic counseling" is not defined in law, it is difficult to ascertain the impact of this proposed licensure on the services of other health professions. If the applicant group does seek licensure, genetic counseling must be defined in the statutory version of its proposal and a scope of practice and a practice definition must be created. Creating a statutory definition would enable other professions that believe that they are able to practice genetic counseling to add this definition to their statute. It is common for the scopes of practice of licensed health professions in Nebraska to include generic language stating which health professions are to be exempted from their licensure requirements. [15]

The applicants stated that they are experts in assessing the likelihood that a client or a family member of a client could already possess or present with a similar or related serious illness or health condition later in life. They added that their expertise in genetic counseling exceeds that of most physicians simply because of their extended training. Typically, a client is referred to a genetic counselor by a physician. [16]

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[12] Minutes of the Third Meeting of the Committee, July 14, 2010
[13] Minutes of the Second Meeting of the Committee, June 9, 2010
[14] Minutes of the Third Meeting of the Committee, July 14, 2010
[15] Minutes of the Third Meeting of the Committee, July 14, 2010
[16] Minutes of the Second Meeting of the Committee, June 9, 2010

## COMMITTEE RECOMMENDATIONS

The members of the Technical Review Committee formulated their final recommendations on the proposal during their October 20, 2010 meeting. During this meeting, the committee members reviewed the testimony provided at the public hearing. They discussed and then applied the statutory criteria of the Regulation of Health Professions Act under Nebraska Revised Statutes, Section 71-6221. These four criteria and the committee recommendations are described below. When taken together, these four actions comprise the final recommendation on the entire proposal. The proposal must be supported on all four criteria for it to be positively recommended by the committee.

**Criterion One:**

**Unregulated practice can clearly harm or endanger the health, safety, or welfare of the public and the potential for the harm is easily recognizable and not remote or dependent upon tenuous argument.**

Dr. Schmidt moved and Mr. Keller seconded that the proposal satisfies criterion one. Voting aye were Keller, Liess, Riley, Schmidt and Stec. There were no nay votes. Dr. Tennity abstained. The motion carried.

**Criterion Two:**

**Regulation of the profession does not impose significant new economic hardship on the public, significantly diminish the supply of qualified practitioners, or otherwise create barriers to service that are not consistent with the public welfare and interest.**

Ms. Stec moved and Dr. Schmidt seconded that the proposal satisfies criterion two. Voting aye were Keller, Liess, Riley, Schmidt and Stec. There were no nay votes. Dr. Tennity abstained. The motion carried.

**Criterion Three:**

**The public needs, and can reasonably be expected to benefit from, assurance of initial and continuing professional ability by the state.**

Mr. Riley moved and Ms. Stec seconded that the proposal satisfies criterion three. Voting aye were Keller, Liess, Riley, Schmidt and Stec. There were no nay votes. Dr. Tennity abstained. The motion carried.

**Criterion Four:**

**The public cannot be effectively protected by other means in a more cost-effective manner.**

Mr. Keller moved and Ms. Liess seconded that the proposal satisfies criterion four. Voting aye were Keller, Liess, Riley, Schmidt and Stec. There were no nay votes. Dr. Tennity abstained. The motion carried.

**By virtue of these actions taken on the four criteria, the committee members recommended in favor of the proposal.**

After taking action on the four criteria, the committee members discussed and agreed upon the following ancillary recommendation.

**Ancillary Recommendation**

Mr. Keller moved and Mr. Riley seconded that the committee members recommend that the entry-level requirements for licensure be a Master's degree in an appropriate field as specified in the application and passage of the ABGC examination at the cut-score adopted by the State Board of Medicine and Surgery, upon the recommendation of the Genetic Counselor's Committee.

Voting aye were Keller, Liess, Riley, Schmidt and Stec. There were no nay votes. Dr. Tennity abstained. The motion carried.

## OVERVIEW OF TECHNICAL REVIEW COMMITTEE PROCEEDINGS

- The committee members met for the first time on May 19, 2010 for orientation to the review process and initial discussion on the proposal.
- On June 9, 2010, the committee members discussed the applicants' proposal and generated questions and issues that they wanted to discuss at the next meeting.
- The committee members continued their discussion on the issues raised by the proposal on July 14, 2010.
- On August 18, 2010, the committee members formulated their preliminary recommendations on the proposal.
- September 22, 2010 was the Public Hearing on the proposal.
- The committee members met on October 20, 2010 and finalized their recommendations on the proposal, including an ancillary recommendation.
- On December 1, 2010, the committee approved its report of recommendations and adjourned sine die.