



State of Wisconsin


LEGISLATIVE REFERENCE BUREAU

RESEARCH APPENDIX - **PLEASE DO NOT REMOVE FROM DRAFTING FILE**

Date Transfer Requested: 11/27/2006 (Per: TKK)





Appendix A

 The 2005 drafting file for LRB 05-3151

has been transferred to the drafting file for

2007 LRB 07-0760

 This cover sheet, the final request sheet, and the final version of the 2005 draft were copied on yellow paper, and returned to the original 2005 drafting file.

 The attached 2005 draft was incorporated into the new 2007 draft listed above. For research purposes, this cover sheet and the complete drafting file were transferred, as a separate appendix, to the 2007 drafting file. If introduced this section will be scanned and added, as a separate appendix, to the electronic drafting file folder.

2005 DRAFTING REQUEST

Bill

Received: **06/03/2005**

Received By: **phurley**

Wanted: **As time permits**

Identical to LRB:

For: **Alberta Darling (608) 266-5830**

By/Representing: **david volz**

This file may be shown to any legislator: **NO**

Drafter: **phurley**

May Contact:

Addl. Drafters:

Subject: **Occupational Reg. - prof lic**

Extra Copies:

Submit via email: **YES**

Requester's email: **Sen.Darling@legis.state.wi.us**

Carbon copy (CC:) to:

Pre Topic:

No specific pre topic given

Topic:

Genetic counselors

Instructions:

See Attached

Drafting History:

<u>Vers.</u>	<u>Drafted</u>	<u>Reviewed</u>	<u>Typed</u>	<u>Proofed</u>	<u>Submitted</u>	<u>Jacketed</u>	<u>Required</u>
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/P1	phurley 07/21/2005	wjackson 08/18/2005	chaugen 08/18/2005	_____	lnorthro 08/18/2005		

FE Sent For:

<END>

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Received: 06/03/2005

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By/Representing: david volz

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FE Sent For:

<END>



Wisconsin Genetic Counselor Network
11221 W. Greentree Road, Milwaukee, WI 53224
Phone: (414) 266-2031 Fax: (414) 266-1616

Genetic Counselor Licensure Fact Sheet

Who are genetic counselors?

Genetic counselors are allied health professionals who provide medical services - including information, risk assessment, management recommendations and support - to families or individuals who may be impacted by a particular genetic condition or health concern. They receive extensive training in medical genetics and psychosocial counseling through accredited training programs usually at the Master's degree level. **The American Board of Genetic Counseling certifies genetic counselors.**

Why is NOW the time to enact licensure of genetic counselors?

The completion of the human genome project has led to an explosion in our understanding of the genetic contribution not only to rare conditions, but to *common* diseases which impact each and every Wisconsin family such as cancer, heart disease and diabetes. This expansion of genetic knowledge is anticipated to influence medical care related to *all* aspects of human health and disease within the next decade. However, there exists an ever-widening gap in the ability of both the lay public and primary health care providers to understand and apply these advances in the safest, most beneficial and most economical way. Genetic counselors are uniquely qualified health care providers with the training and expertise to ensure that Wisconsin citizens receive the advantages genomic medicine has to offer, with the least likelihood of negligent application. Unless action is taken now, the citizens of this state will be vulnerable to the influence of profit-driven technology without the benefit of knowing which care providers are best qualified to help guide related health care decisions.

Why is licensure of genetic counselors important for the people of Wisconsin?

Without licensure of genetic counselors, the health care community and people of Wisconsin are without means to identify appropriate providers of genetic services and information. Currently, there are no state regulations in place to prevent inadequately trained individuals from calling themselves genetic counselors and attempting to practice as such. Examples of potential harm resulting from unregulated practice include:

- Inappropriate or unnecessary use of costly genetic testing
- Misinformation regarding genetic risk for disease or lack thereof
- Misunderstanding of the implications of genetic test results, which may result in:
 - * Unnecessary medical treatment and/or procedures
 - * Failure to provide potentially life-saving treatment, screening and prevention strategies
 - * Irreversible decisions regarding childbearing and pregnancy

Licensure is the *only* avenue that will permit Wisconsin citizens and their health care providers to easily identify practitioners qualified to provide proficient genetic counseling and ensure appropriate application of genomic medicine.

Currently, three other states, Utah, Illinois and California have enacted legislation allowing for licensure of genetic counselors. Fourteen other states are actively engaged in applying for licensure, and the National Society of Genetic Counselors, as well as other medical societies is strongly in support of licensure efforts. Wisconsin has a tradition of excellence in biotechnology - please join us in ensuring that Wisconsin citizens will not be left behind in the application of this technology for the improvement of their health and well-being.

LuAnn Weik, MS, CGC – President
Dawn Allain, MS, CGC – Vice President
Peter Levonian, MS, CGC - Secretary

Criteria For Evaluating Need To Draft A Regulatory Legislative Proposal

CRITERION ONE: Regulation should address the single purpose of promoting the general welfare of the consumer of services. Please respond to the following questions:

1. Has the public been harmed because this profession/service entity has not been regulated?

Yes No

2. What constitutes harm? Please list examples:

Harm caused by untrained individuals attempting to provide genetic counseling includes:

- * Inappropriately undertaking costly genetic testing;
- * Misinformation regarding genetic risk (or lack of risk);
- * Misunderstanding of the implications of genetic information (e.g., family history, test results, etc.) which can lead to
 - unnecessary medical treatment and/or surgery
 - lack of prevention or disease monitoring strategies
 - irreversible reproductive decisions
- * Avoidable fear, anxiety and guilt.

3. To what extent has the public's economic well-being been harmed? Is the harm widespread or isolated? Please explain.

Inappropriate and unnecessary genetic testing contributes to increasing societal health care costs in general. Individual consumers have also been held personally responsible for the costs of genetic testing which was not medically indicated. Provision of costly health interventions based upon inaccurate interpretation of genetic information can have dire economic effects. For example, it is much more costly to treat advanced colon cancer in someone with a genetic predisposition than it is to correctly identify high-risk individuals and perform regular colonoscopy evaluations. Recently, genetic testing for cystic fibrosis carrier status has been initiated on a widespread basis for all couples currently pregnant or anticipating a pregnancy. It has been documented that non-genetic medical practitioners have incorrectly interpreted these test results, leading to unnecessary prenatal test procedures (amniocentesis), which are costly and infer a risk for pregnancy loss (Redman JB et al., 2003). Licensing of genetic counselors would reduce costs as their clinical expertise allows them to critically evaluate the appropriateness and utility of genetic tests

4. Is potential harm recognizable or remote? If yes, provide examples to support answer.

Most genetic counselors' main responsibilities involve patient care. As with any health care provider, inappropriate or inaccurate medical care could potentially harm any of the patients with whom an unlicensed genetic counselor has contact. One example of incorrect counseling and test interpretation is found in the New England Journal of Medicine (Giardiello, FM et al., 1997). This article highlights the likelihood of harm when non-genetic physicians misinterpret genetic testing information. The authors of this study surveyed 177 patients who underwent genetic predisposition testing for Familial Adenomatous Polyposis, (FAP), an inherited condition that leads to the development of colon cancer early in life. This cancer can be prevented with appropriate surgical intervention, so accurate interpretation of test results is crucial. Eighteen percent of the patients studied underwent genetic counseling prior to genetic testing and these patients received accurate interpretation of their genetic test results. Of the remaining 145 patients, who did not receive genetic counseling, 30% were given the wrong test interpretation because caregivers incorrectly interpreted inconclusive test results as meaning that the patient definitely did not have an FAP mutation. The consequences of this misinterpretation are potentially devastating, since these individuals would have thought they were no longer at risk for colon cancer and were likely to stop potentially life-saving endoscopic screening.

Harm may occur if practitioners do not elicit complete family history information. This was demonstrated in a study in the Journal of Perinatology, which assessed the adequacy of genetic risk assessment among primary care providers (Cohn GM. et al., 1996). This study found that in 35% of the 378 cases studied, significant genetic risk was identified in a subsequent genetic

consultation that had been missed by the referring physician. Failure to identify significant genetic risks may lead to inappropriate medical management, physical injury, death or psychological distress. The concern for harm has already been recognized by the general medical-legal community as evidenced by the cost of malpractice suits against non-genetic physicians for failure to inform patients of heritable risks to themselves or their offspring (Pelias MZ and Shaw MW, 1992 and Deftos LJ, 1998).

Genetic counselors provide risk assessment by obtaining and interpreting medical and family histories together with results of medical tests. Genetic counselors communicate this information to health care providers and patients that may influence medical management decisions. Genetic counselors are knowledgeable about the intricacies of genetic risk factors, provide education and psychosocial support, recommend testing, provide test interpretation, all of which prevent harm and ensure that patients receive comprehensive health care services.

5. To what can the harm be attributed?

a) Lack of knowledge

It is extremely difficult for persons outside of the profession to keep abreast of the explosive growth in genetic knowledge. An unqualified provider's lack of awareness of genetic advances may deprive patients of valuable information and medical options. For example, one study found that 57% of clinicians did not recognize that a patient with multiple relatives affected with breast cancer on her father's side should be considered at increased risk for breast and ovarian cancer (Hayflick SJ et al, 1998). Furthermore, most medical professionals have little training in medical genetics and are familiar with only the most common genetic disorders. A survey of U.S. Medical schools revealed that the average medical student was exposed to only 29 hours of didactic coursework in medical genetics (APHMG, 1998). While nearly 70% of allied health professionals surveyed reported discussing genetic issues with clients, even though 80% had no formal genetics training (Lapham et. al, 2000). As a result, few medical professionals understand the natural history of most genetic conditions; the complexity of genetic tests; or the interpretation and implications of test results. Clinical genetic knowledge is rapidly expanding into common complex disorders (such as cancer). The expansion of genetics into the care of common disorders will only make it more difficult for the busy clinician to stay informed about genetic advances relevant to their practice.

Often these issues of harm apply not only to the patient but also to extended family members. Since genetic counselors are the most knowledgeable about genetic developments and already utilize family systems methodologies, ensuring that these practitioners are licensed would be the most effective way of minimizing harm to the public.

b) Lack of skills

Licensing genetic counselors may alleviate death, significant morbidity, and psychological distress. Genetic counselors identify families at risk for genetic disorders, investigate the medical problem present in the family and analyze inheritance patterns. Genetic counselors also interpret information about the disorder, provide recurrence risks, review available options with both health care providers and the family, and provide case management and psychological support services. Unskilled care in any of these areas may lead to increased medical, psychological and financial harms as exemplified by the following case discussions:

1. Licensed genetic counselors can reduce harm, including stillbirth and death, by taking a thorough family history and identifying potentially heritable conditions. For example, a genetic counselor may note a family history of strokes and deep venous thromboses, leading to the discussion of a possible genetic clotting abnormality such as Factor V Leiden mutations. Women with a Factor V Leiden gene mutation have an increased risk for pregnancy complications including miscarriage, placental abruption, preeclampsia, and stillbirth. They may also experience blood clots during and after pregnancy. If an expectant patient were recognized to have a Factor V Leiden gene mutation and either a poor obstetric history or another clotting

111 abnormality anti-clotting therapy would be recommended through the duration of pregnancy and
112 a short time thereafter to reduce the risk for these serious complications. The counselor would
113 also recommend that the patient alert her first-degree relatives to their 50% risk for carrying the
114 same genetic clotting problem so that appropriate precautions can be taken during their
115 pregnancies.
116

117 2. Genetic counselors communicate risk information regarding genetic conditions to individuals
118 and their family members. This information is based on a thorough assessment of the family
119 medical history and interpretation of genetic test results. Patients and their physicians use this
120 genetic information to make medical decisions. Unskilled health care providers may inadequately
121 collect family history, inaccurately assess risk and incorrectly interpret diagnostic evaluations.
122 These errors lead to detrimental decisions by depriving patients of valuable information and
123 medical options. For example, patients may undergo unnecessary preventive surgery (such as
124 mastectomy) if an unskilled provider misinterprets results of DNA tests for genetic susceptibility
125 to breast cancer. Misinterpretation of these test results could also falsely reassure a patient
126 leading them to neglect to obtain recommended cancer screening. Lack of appropriate screening
127 could lead to the unfortunate circumstance of advanced stage, incurable cancer.
128

129 3. Individuals affected by genetic conditions often face serious social and psychological challenge. At
130 minimum, parents may feel guilty or stigmatized when they pass on defective genes to their children. If
131 testing is done without appropriate preparation and informed consent, more harm than good can easily
132 result. Individuals undergoing pre-symptomatic genetic testing, such as for Huntington disease (HD),
133 may experience overwhelming anxiety regarding their at-risk status and the impending threat from the
134 disease process itself. HD is associated with a variety of medical and non-medical symptoms. Often the
135 disease presents with alteration of mood, memory and thought processes, with onset typically occurring
136 in the thirties or forties. Children who are themselves at 50% risk, grow up with confused and
137 misguided perceptions of "what is wrong with mommy?" Their psychological burden is immense.
138 Presymptomatic testing without adequate attention to this burden is disastrous. Timing is everything.
139 The time to identify the problem in "mommy" is not two weeks before her daughter's wedding without
140 any forewarning, reeducation, appreciation of her own genetic risk or attention to years of
141 misperceptions as recently occurred in one patient. Genetic testing does not just impact the individual,
142 it affects the whole family. Unsuspecting new members like fiancés and future generations are also
143 impacted. In the case cited above, "mommy" and daughter were merely sent for labs to rule out
144 Huntington disease. Their health care provider never mentioned HD, much less all the issues that go
145 with it. The daughter came home from her honeymoon to her mother's positive test result. Blood was
146 immediately drawn on her, again without any preparation or understanding or true informed consent.
147 She tested positive. She had grown up dealing with her mom's "craziness". She was robbed of her
148 childhood, as all of her life she had to be the adult. Now this was her, and her unsuspecting husband of
149 just one month had lost his entire family. This couple was referred for genetic counseling after the
150 results were complete, after the damage had been done. The couple was devastated by the news.
151 Overwhelmed by the nightmare that had been her childhood, they left the clinic never to return again.
152 This is not informed consent or quality medical care. Genetic counselors receive unique training
153 permitting them to anticipate and mitigate psychological harms associated with genetic conditions and
154 genetic testing. They are able to recognize premorbid clues and assist patients in making healthy
155 decisions about the timing of testing, such that the need for additional medical therapy and treatment is
156 minimized.
157

158 4. Skilled genetic counselors can also reduce costs by using their training and experience to
159 critically evaluate the appropriateness and utility of genetic tests in order to reduce unnecessary
160 and/or redundant testing. For example, in a Wisconsin institution a pediatric neurologist ordered
161 a surgical nerve biopsy on a child, to rule out the genetic condition spinal muscular atrophy. Had
162 this neurologist contacted a genetic counselor, they would have learned that there is a diagnostic
163 genetic test, which can be performed on a simple blood sample. This genetic test is highly
164 accurate and less expensive than a surgical biopsy and would have avoided the need to put a
165 small child through a surgical procedure. Another more troubling example is the use of junk

166 science to sell a product to a vulnerable patient population like those at increased risk for cancer.
167 For example, a Wisconsin nutritionist referred a patient to a commercial company for genetic
168 testing to determine the type of nutritional supplements, which would reduce her risk of cancer.
169 This company promotes their tests in order to sell their products and is listed on the quackwatch
170 website (Barrett, 2004). Not surprisingly, the results of her testing found her to be lacking in
171 many nutrients which posed increased risks for many cancers (according to their interpretation of
172 the causal relationship between nutrient levels and cancer risks), which the company said, could
173 be ameliorated by many of their products. She now takes half a dozen or so unnecessary, costly
174 supplements to help reduce cancer risks.

175
176 As illustrated by the examples above, it is obvious that appropriately trained and licensed genetic
177 counselors are likely to ensure that clinical genetic services are provided with the least risk for
178 medical, psychological and financial harm to the public.

179
180 **c) Lack of ethics**

181 Genetic counselors receive training in legal, ethical and social principles pertaining to the delivery of
182 genetic services, as well as training in professional ethics and values. Genetic counselors adhere to a code
183 of ethics specifying the counselor-client relationship be based on values of care and respect for the
184 client's autonomy, individuality, welfare and freedom. The primary concern of genetic counselors is the
185 interests of their clients. The Code of Ethics of the National Society of Genetic Counselors states that
186 genetic counselors strive to:

- 187 • equally serve all who seek their services
- 188 • respect their clients' beliefs, cultural traditions, inclinations, circumstances and feelings
- 189 • enable their clients to make informed independent decisions, free of coercion, by providing or
190 illuminating the necessary facts and clarifying the alternatives and anticipated consequences
- 191 • refer clients to other competent professionals when they are unable to support their clients,
192 maintain as confidential any information received from clients, unless released by the client
- 193 • avoid the exploitation of their clients for personal advantage, profit or interest.

194
195 There has been well-documented research which indicates that other health care professionals are more
196 likely to provide directive counseling (i.e., making the patient's decision for them), thereby not allowing
197 for the client to base decisions upon their own value based system.

198
199 **d) Other**

200
201 **6. Can potential users of the service be expected to possess the knowledge needed to properly**
202 **evaluate the quality of the service?**

203 _____ Yes X No, Why not?
204

205 The majority of consumers do not possess the comprehensive knowledge or experience necessary to
206 evaluate whether a genetic counselor is competent. The extent of the public's knowledge of genetics is
207 limited and often skewed by media resources. Given the rapid pace of genetic discoveries using advanced
208 DNA technology, it is difficult for an individual not trained in genetics to understand information about
209 their unique condition. Information about any one condition is rapidly changing and highly specialized,
210 requiring ongoing education to be able to interpret new tests and data.

211
212 In addition, many potential genetic counseling clients are not aware of the availability or the scope of this
213 service. State regulation of the profession will help increase public awareness of genetic counseling
214 services. State regulation will also provide potential consumers with assurances of competency.

217 **CRITERION TWO: The functions and responsibilities of individuals working in the**
218 **occupation shall require independent judgment and action based on a substantive body of**
219 **skill and knowledge.**

220 The questions to be raised in regard to this criterion have to do with autonomy and
221 accountability.

222
223 **1. What is the extent of autonomy of work?**

224 Significant autonomy is required to carry out the professional responsibilities of a genetic
225 counselor. Autonomous activities of genetic counselors include, conducting individual genetic
226 risk assessments and patient counseling sessions; providing genetic consultative services for
227 other medical specialties, laboratories and HMOs/insurance companies; collaborating with
228 multidisciplinary teams in patient management; providing education on genetics topics for lay
229 and professional groups; supervising training of genetic counseling students; and coordinating
230 research.

231
232 **2. Is there a high degree of independent judgment required?**

233 The role of a genetic counselor demands a high degree of independent judgment. Genetic
234 counselors must be able to collect and interpret a detailed family history, determine under what
235 circumstances genetic testing is appropriate, and research genetic conditions. They are
236 responsible for interpreting information for patients and referring clinicians, analyzing medical
237 records for relevant information and understanding the results and implications of a genetic test
238 result. Genetic counselors must also judge how a genetic condition might impact medical care of
239 the patient and/or family, determine the impact of the genetic situation on the patient's
240 psychosocial well-being, advocate for patients within the healthcare system, and provide
241 recommendations regarding medical management and referral to appropriate medical specialties.

242
243 **3. How much skill and experience is required in making these judgments?**

244 Provision of genetic counseling services requires a unique and comprehensive set of skills.
245 ~~Through the genetic counselor certification process, the American Board of Genetic Counseling~~
246 ~~(ABGC) has developed and promulgated a set of competencies intended to demonstrate that~~
247 ~~genetic counselors possess a solid set of core skills (Appendix A).~~

248
249 A genetic counselor's technical skills demand knowledge of the following:

- 250
- 251 • ~~Human genetics~~, including cytogenetics, Mendelian and non-Mendelian inheritance,
252 biochemical genetics, molecular genetics, population and quantitative genetics, human
253 variation and disease susceptibility, embryology and teratogenicity.
 - 254
 - 255 • ~~Clinical genetics~~, including an understanding of a broad range of genetic diseases, indications
256 for and methods of genetic diagnosis, including physical assessment, dysmorphology, clinical
257 syndromology, and laboratory studies, indications for and methods of prenatal diagnosis,
258 family history and pedigree analysis; and use of the medical/genetics literature.
 - 259
 - 260 • ~~Methods of genetic testing~~, including indications, limitations, and methodology of cytogenetic,
261 molecular and biochemical testing.
 - 262
 - 263 • ~~Patient interviewing~~, counseling theories, and practice, including, individual social and
264 psychological development and dynamics, family dynamics, crisis intervention, psychological
265 and social assessment and intervention, grief/bereavement counseling, cross-cultural issues.
 - 266
 - 267 • ~~Legal, ethical, and social principles~~ pertaining to the delivery of genetic services.
 - 268

- 269
- Health care delivery systems, including, principles of public health and the role of genetics in public health, health care service organization and financing, community, regional and national resources, insurance reimbursement issues.
- 270
- 271
- 272
- Research methods, including, an understanding of clinical and laboratory research methodologies and protocols, an understanding of quantitative and qualitative methods of social science research.
- 273
- 274
- 275
- 276

277 ABGC-accredited genetic counseling training programs are also required to provide graduates with additional competencies in the following areas:

278

279

- Communication skills – eliciting all appropriate and relevant information regarding family, medical, pregnancy, developmental, social and psychosocial history. This includes the ability to convey medical information (verbally and in writing) regarding genetics, genetic testing, diagnosis, treatment, etiology, and prognosis, to clients with a variety of educational, socioeconomic and cultural backgrounds. Genetic counselors must be able to provide the same information to other health professionals. In addition, they must be able to plan, organize and conduct public education programs in genetics and genetic counseling.
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- Critical-thinking skills - the ability to assess and calculate genetic and teratogenic risks. The ability to assess and evaluate genetic, medical, social and psychological factors in order to make accurate diagnoses and provide case management and/or refer clients to other local, regional, or national resources. The ability to identify sources of additional information in the medical and social science literature, and from on-line resources.
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- Interpersonal, counseling, and psychosocial assessment skills - the ability to establish rapport with clients, identify concerns and priorities, respond to emerging issues, and apply a range of counseling techniques. Includes the ability to facilitate and promote client decision-making in an unbiased, non-coercive manner.
- 294
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- Professional ethics and values - the ability to advocate for clients, and act in accordance with recognized ethical and legal principals. The ability to identify and pursue options for continued professional growth, as well as collaboration with other health professionals.
- 299
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304 Genetic information is becoming increasingly complicated with almost daily advances in human genetics. The Human Genome Project is revolutionizing our understanding of medicine and the role of genetics in disease and health. Working with these complex changes is recognized and embraced by genetic counselors. They provide a valuable skill in translating these discoveries into current clinical practice both for the practitioner and the public.

305

306

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310 **4. Do practitioners customarily work on their own or under supervision?**

311 The scope of their clinical practice, combined with their unique skills and training enable genetic counselors to work independently to accomplish the responsibilities of their profession. Genetic counselors consult on an as needed basis with designated medical supervisors. The level of supervision varies with the practitioner setting and institutional requirements.

312

313

314

315

316 **5. If supervised, by whom, how frequently, where, and for what purpose?**

317 Genetic counselors are indirectly supervised. A physician with specialty training in the area in which the genetic counselor is employed provides medical supervision. Supervision is similar to that experienced by advance practice nurses or physician assistants in that supervision is not required for routine completion of responsibilities, but rather for unusual or complex patient presentations.

318

319

320

321

322

323 **6. If the person is infrequently, or unsupervised, to whom is he/she accountable? To whom**
324 **is the supervisor accountable?**

325 Only genetic counselors who are in private practice are truly unsupervised. Therefore, they are
326 not accountable to any institutional body. Genetic counselors who are not directly supervised by
327 medical personnel are accountable to their institutional administrator.

329 **CRITERION THREE: The public cannot be effectively protected by means other than regulation.**
330 **This criterion can be viewed in two stages:**

331 **1) Can existing problems be handled through strategies on the part of the applicant group?**

332 The applicant group has no structure or power to police or monitor issues to protect the public. Only
333 through licensure can the scope of practice be specified and performed legally by licensed individuals. In
334 addition, only licensure provides the authority to take disciplinary action should the licensee violate
335 provision of the law or rules in order to assure that the public health, safety and welfare will be well
336 protected. Licensure would be particularly useful because the activities of the genetic counseling
337 profession are complex, require specialized knowledge and skill and independent decision-making.

339 **a) Has the occupational group established a code of ethics? To what extent has it been**
340 **accepted and enforced?**

341 The National Society of Genetic Counselors (NSGC) is an organization that furthers the professional
342 interest of genetic counselors, promotes a network for communication within the profession, and deals
343 with issues relevant to human genetics. Under the leadership of the NSGC, the establishment of a code of
344 ethics has guided the professional conduct of genetic counselors, but there is no means of enforcement or
345 censure (Appendix B). The NSGC has the Ethics Subcommittee, which serves as consultant to its
346 membership at large as well as the NSGC Board of Directors. This self-initiated process allows genetic
347 counselors a forum for discussion and evaluation of clinical and professional ethical dilemmas through
348 the lens of the NSGC Code of Ethics.

350 **b) Has the group established complaint handling procedures for resolving disputes between**
351 **practitioners and the consumer? How effective has this been?**

352 No

353 **c) Has a non-governmental certification program been established to assist the public in**
354 **identifying qualified practitioners?**

355 The American Board of Genetic Counseling (ABGC) and the American Board of Medical Genetics
356 (ABMG) prepares and administers examinations to certify individuals who provide services in the
357 medical genetics specialty of genetic counseling and accredits training programs in the field of genetic
358 counseling. ABGC and ABMG require re-certification every 10 years demonstrated by examination or
359 accrual of continuing education credits. A directory of all certified genetic practitioners is available
360 through the ABGC and the ABMG websites; however, most consumers are unaware that these certifying
361 bodies exist.

363 **2) Could the use of existing laws or existing standards solve problems?**

364 **a) Use of unfair and deceptive trade practice laws**

365 **b) Use of civil laws such as injunctions, cease and desist orders, etc.**

366 **c.) Use of criminal laws such as prohibition against cheating, false pretense, deceptive**
367 **advertising, etc.**

368
369 Existing laws, whether trade, civil or criminal, do not protect the consumer from unqualified
370 practitioners as no legal scope of practice has been defined and standards for professional
371 conduct have not been legally established for genetic counseling services. Licensure will provide
372 a specified scope of practice, which may only be performed legally by licensed individuals.
373 Licensure also provides the authority to take disciplinary action should the licensee violate
374 provision of the law or rules. Licensure also assures that the public health, safety, and welfare
375 will be reasonably well protected against unqualified practitioners. Finally, licensure has the
376 advantage of using professional standard of care to allow the use of genetic counselors to be the

377 experts rather than laypersons whom have insufficient knowledge to judge when harm may have
378 incurred.

379
380 Current laws fail to address the scope of practice of a genetic counselor and the necessary
381 training and credentials. While some laws address violations related to unethical practice and
382 unfair and deceptive trade practices, consumers still do not know who is qualified and who is
383 not. In addition, the current situation leaves the minimum standards for genetic counseling
384 services undefined, so there is little recourse for issues of malpractice or for policing negligent,
385 incompetent or outdated practice by professionals within the field.

386
387 To take advantage of current civil remedies at law, one must first appreciate that one has been
388 harmed. Most people have neither the education nor the life experience upon which to make this
389 judgment. Without knowledge or experience, judgments concerning incorrect interpretation of
390 family history or inappropriate/incomplete counseling are not possible. Frequently the family is
391 not aware that sub-optimal care was provided, that additional medical options or tests existed, or
392 that inaccurate or incomplete genetic information was given. Civil law is rarely used as recourse
393 for consumer protection against inappropriate or inaccurate genetic services.

394
395 Licensure is a well-recognized process upon which consumers depend to define the standards of
396 qualification, education, training and experience necessary to provide a service.

397
398 **CRITERION FOUR Benefits of regulation should outweigh potentially adverse effects.**

399 **1) What are the potential BENEFITS?**

400 **a) How will regulation help the public identify qualified services?**

401 Genetic counseling is a relatively small, new and emerging profession. As such, many
402 consumers, including the public and other health care providers, are unaware of the depth of
403 training and scope of practice involved in genetic counseling. This lack of awareness prevents
404 consumers from being able to recognize individuals who are qualified genetic counselors. In
405 contrast, "licensed professional" is a designation well recognized by the vast majority of
406 consumers. Licensure will thus permit health care institutions, health care professionals, and
407 Wisconsin citizens to easily and clearly identify who is qualified to provide genetic counseling.
408 Despite the increasing sophistication of consumers in the evaluation of their own health care, the
409 exponential rate at which genetic knowledge is expanding precludes even the most savvy
410 consumer or their primary health care provider from recognizing the potential benefits and harms
411 inherent in genetic information and/or testing.

412
413 **b) How will regulation assure that practitioners are competent?**

414 Licensure of genetic counselors will require certification either by the American Board of
415 Genetic Counselors (ABGC) or the American Board of Medical Genetics (ABMG). The
416 certification process ensures that a genetic counselor has been adequately trained, meeting
417 established standards of knowledge in genetics and clinical skills. Certification requires
418 possession of a graduate degree through an accredited genetic counseling training program. To
419 achieve certification, a genetic counselor must also demonstrate significant experience in a range
420 of clinical settings. By requiring ABGC/ABMG certification, licensure will thus ensure that
421 practicing genetic counselors meet the highest level of standards within the field. In addition,
422 licensure requirements will include obtaining continuing education units (CEUs), which is also a
423 component of re-certification by the ABGC. Temporary licenses may be required for graduating
424 genetic counseling students who have not yet completed the board examination (currently offered
425 once every two years).

426
427 **c) What assurance will the public have that the individuals credentialed by the state
428 have maintained their competence?**

429 Licensure will require genetic counselors to obtain CEUs to ensure that they remain current with
430 new scientific discoveries, clinical protocols, and available technologies. This is especially
431 critical in the field of genetics, which continues to evolve at a prodigious rate. A genetic

432 counselor that does not keep up with the latest knowledge can be medically, psychologically and
433 financially harmful to consumers. Genetic counselors certified prior to 1996 have certification
434 that is not time-limited and hence they are not required to obtain CEUs or re-certify every 10
435 years. Without licensure requiring continuing education units, these individuals may not remain
436 current in this rapidly changing field.

437

438 Therefore, licensure will provide uniform certification requirements and ensure all those
439 practicing genetic counseling obtain essential continuing education. By allowing for legal
440 oversight, state regulation of this profession will protect the delivery of quality services to
441 consumers seeking genetic counseling expertise.

442

443 **d) How will complaints of the public against the practitioners be handled?**

444

445 The Department of Occupational and Professional Licensure will handle complaints and
446 disciplinary action as they have in other regulated allied health care professions. A "Genetic
447 Counselors Examining Board" should be created in part to assist the department in reviewing
448 complaints concerning the unlawful or unprofessional conduct of a licensee and advise the
449 DOPL in its investigation of public complaints.

449

450 **e) Will licensure increase the availability of services and decrease costs?**

451

452 It is our firm belief that the number of practitioners will increase with state licensure, as the profession of
453 genetic counseling will become increasingly recognized as a medical subspecialty. Genetic information
454 obtained through physicians is frequently associated with a higher cost for the service and limited in
455 scope. By increasing the utilization of genetic counselors through licensure, more patients will have
456 access to high quality, comprehensive services, billed at much lower costs than a standard physician
457 appointment. Licensure may also serve to expand coverage for genetic counseling and related genetic
458 testing for insured patients, as well as increase access to these services by under- or uninsured portions of
459 the population. Licensure of skilled genetic counselors is anticipated to further reduce health care costs,
460 as their training and experience allow them to critically evaluate the appropriateness and utility of genetic
461 tests, thereby reducing unnecessary, redundant, and potentially harmful testing.

461

462 **f) What is the impact of this action on consumer choice? Are choices increased, or
463 maintained, or limited?**

464

465 Licensure will serve to make genetic counselors more visible and assist the public and health
466 care providers in identifying a proficient genetic counselor. Currently consumer choice is
467 extremely limited by lack of awareness of what constitutes appropriate genetic counseling. By
468 increasing the recognition of the genetic counselors as medical specialists and increasing access
469 to qualified genetic counselors, licensure will significantly enhance consumer choice.

469

470 **2) What are the potential ADVERSE EFFECTS?**

471

472 **a) Will the occupational group control the supply of practitioners?**

473

474 The number of genetic counseling training programs around the country is what currently
475 limits the supply of qualified genetic counselors. Licensure of genetic counselors in the state of
476 Wisconsin is not anticipated to have any negative impact on such programs. Indeed, licensure of
477 genetic counselors may well serve to facilitate the development of additional genetic counseling
478 training programs within the state. Licensure will, however, limit the ability of those not trained
479 in such programs to practice genetic counseling, thereby protecting the consumer from lower
480 quality care.

480

481 **b) Will regulation act as an entry barrier?**

482

483 No. Any genetic counselor that is ABGC or ABMG certified or a graduate with active candidate
484 status will be eligible for licensure. Entry into the profession itself, via accredited training
485 programs, will not be impacted.

484

485 **c) Will regulation prevent the optimal utilization of personnel?**

485

486 No. Regulation is anticipated to improve the utilization of qualified genetic counselors, by
487 improving recognition of the profession and increasing the employment of genetic counselors by
488 health care facilities.

489

490 **d) Will regulation increase the cost of services to the consumer? Consider: License**
491 **fees, bonding costs, record keeping**

492 The cost of services to the consumer is not expected to increase with licensure. It is not expected
493 that licensure fees will, in any way, be passed on to the consumer. Licensure fees will be paid by
494 the practitioner, are not anticipated to be financially burdensome to genetic counselors, and
495 should be adequate to cover the cost of maintaining the regulation.

496

497

498 **e) Will stringent and/or additional educational requirements increase the cost of entry into the**
499 **occupation and subsequently increase the cost of the service?**

500 No. Licensure requirements will not change the cost of entry into the occupation via
501 accredited training programs. Certification by the ABGC/ABMG and continuing education units
502 (CEUs) are costs already incurred by the majority of genetic counselors. Although genetic
503 counselors certified prior to 1996 are not currently required to obtain CEUs, most still attend the
504 related educational conferences, and the percentage of genetic counselors falling into this
505 category will continue to decrease. At this time, given that the training and certification that will
506 be required for licensure as a genetic counselor is already in place, no increase in consumer cost
507 of these services is anticipated.

508

509 **f) Will regulation decrease availability of practitioners?**

510 No. It is anticipated that licensure will only increase the availability of genetic counselors and
511 improve access of consumers to qualified genetic counseling services.

512

513 **DO THE BENEFITS MORE THAN COMPENSATE FOR THE POTENTIALLY**
514 **ADVERSE EFFECTS?**

515

516 It is clear that the anticipated benefits of licensure of genetic counselors far outweigh any
517 potential adverse effects. Licensure of genetic counselors in the State of Wisconsin will increase
518 the availability of related services to consumers, insure that consumers are receiving the most
519 appropriate care, and decrease the documented harm to consumers incurred by inaccurate genetic
520 information or test interpretation. In addition, licensure of genetic counselors will lead to lower
521 health care costs overall by reducing the number of inappropriate genetic tests ordered and
522 increasing appropriate screening and care of at-risk individuals. Licensure will also provide for
523 the ongoing education of other health care professionals. As genetics continues to play an
524 increasingly important role in medicine, the ability of the consumer to access and identify a
525 qualified genetic counselor will become of paramount importance to the public's health and well
526 being. Without our state government assuming a role, the public is at risk for harm.

527

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- 558
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559 **Appendix A:**

560



Required Criteria for Graduate Programs in Genetic Counseling Seeking Accreditation by The American Board of Genetic Counseling

561

562 **Specific Requirements for Accreditation in Genetic Counseling**

563 **Domain I: Communication Skills**

564 1. Can establish a mutually agreed upon genetic counseling agenda with the client.

565 The student is able to contract with a client or family throughout the
566 relationship; explain the genetic counseling process; elicit expectations,
567 perceptions and knowledge; and establish rapport through verbal and
568 non-verbal interaction.

569 2. Can elicit an appropriate and inclusive family history.

570 The student is able to construct a complete pedigree; demonstrate
571 proficiency in the use of pedigree symbols, standard notation, and
572 nomenclature; structure questioning for the individual case and probable
573 diagnosis; use interviewing skills; facilitate recall for symptoms and
574 pertinent history by pursuing a relevant path of inquiry; and in the course
575 of this interaction, identify family dynamics, emotional responses, and
576 other relevant information.

577 3. Can elicit pertinent medical information including pregnancy, developmental,
578 and medical histories.

579 The student is able to apply knowledge of the inheritance patterns,
580 etiology, clinical features, and natural history of a variety of genetic
581 disorders, birth defects, and other conditions; obtain appropriate medical
582 histories; identify essential medical records and secure releases of
583 medical information.

584 4. Can elicit a social and psychosocial history.

585 The student is able to conduct a client or family interview that
586 demonstrates an appreciation of family systems theory and dynamics.
587 The student is able to listen effectively, identify potential strengths and
588 weaknesses, and assess individual and family support systems and
589 coping mechanisms.

590 5. Can convey genetic, medical, and technical information including, but not
591 limited to, diagnosis, etiology, natural history, prognosis, and
592 treatment/management of genetic conditions and/or birth defects to clients with a
593 variety of educational, socioeconomic, and ethnocultural backgrounds.

594 The student is able to demonstrate knowledge of clinical genetics and
595 relevant medical topics by effectively communicating this information in
596 a given session.

597 6. Can explain the technical and medical aspects of diagnostic and screening
598 methods and reproductive options including associated risks, benefits, and
599 limitations.

600 The student is able to demonstrate knowledge of diagnostic and
601 screening procedures and clearly communicate relevant information to
602 clients. The student is able to facilitate the informed-consent process.
603 The student is able to determine client comprehension and adjust
604 counseling accordingly.

605 7. Can understand, listen, communicate, and manage a genetic counseling case in a
606 culturally responsive manner.

607 The student can care for clients using cultural self-awareness and
608 familiarity with a variety of ethnocultural issues, traditions, health
609 beliefs, attitudes, lifestyles, and values.

610 8. Can document and present case information clearly and concisely, both orally
611 and in writing, as appropriate to the audience.

612 The student can present succinct and precise case-summary information
613 to colleagues and other professionals. The student can write at an
614 appropriate level for clients and professionals and produce written
615 documentation within a reasonable time frame. The student can
616 demonstrate respect for privacy and confidentiality of medical
617 information.

618 9. Can plan, organize, and conduct public and professional education programs on
619 human genetics, patient care, and genetic counseling issues.

620 The student is able to identify educational needs and design programs
621 for specific audiences, demonstrate public speaking skills, use visual
622 aids, and identify and access supplemental educational materials.

623 **Domain II: Critical-Thinking Skills**

624 1. Can assess and calculate genetic and teratogenic risks.

625 The student is able to calculate risks based on pedigree analysis and
626 knowledge of inheritance patterns, genetic epidemiologic data, and
627 quantitative genetics principles.

628 2. Can evaluate a social and psychosocial history.

629 The student demonstrates understanding of family and interpersonal
630 dynamics and can recognize the impact of emotions on cognition and
631 retention, as well as the need for intervention and referral.

632 3. Can identify, synthesize, organize and summarize pertinent medical and genetic
633 information for use in genetic counseling.

634 The student is able to use a variety of sources of information including
635 client/family member(s), laboratory results, medical records, medical
636 and genetic literature and computerized databases. The student is able to
637 analyze and interpret information that provides the basis for differential
638 diagnosis, risk assessment and genetic testing. The student is able to
639 apply knowledge of the natural history and characteristics/symptoms of
640 common genetic conditions.

641 4. Can demonstrate successful case management skills.

642 The student is able to analyze and interpret medical, genetic and family
643 data; to design, conduct, and periodically assess the case management
644 plan; arrange for testing; and follow up with the client, laboratory, and
645 other professionals. The student should demonstrate understanding of
646 legal and ethical issues related to privacy and confidentiality in
647 communications about clients.

- 648 5. Can assess client understanding and response to information and its implications
649 to modify a counseling session as needed.
- 650 The student is able to respond to verbal and nonverbal cues and to
651 structure and modify information presented to maximize comprehension
652 by clients.
- 653 6. Can identify and access local, regional, and national resources and services.
- 654 The student is familiar with local, regional, and national support groups
655 and other resources, and can access and make referrals to other
656 professionals and agencies.
- 657 7. Can identify and access information resources pertinent to clinical genetics and
658 counseling.
- 659 The student is able to demonstrate familiarity with the genetic, medical
660 and social-science literature, and on-line databases. The student is able
661 to review the literature and synthesize the information for a case in a
662 critical and meaningful way.

663 **Domain III: Interpersonal, Counseling, and Psychosocial Assessment Skills**

- 664 1. Can establish rapport, identify major concerns, and respond to emerging issues
665 of a client or family.
- 666 The student is able to display empathic listening and interviewing skills,
667 and address clients' concerns.
- 668 2. Can elicit and interpret individual and family experiences, behaviors, emotions,
669 perceptions, and attitudes that clarify beliefs and values.
- 670 The student is able to assess and interpret verbal and non-verbal cues
671 and use this information in the genetic counseling session. The student is
672 able to engage clients in an exploration of their responses to risks and
673 options.
- 674 3. Can use a range of interviewing techniques.
- 675 The student is able to identify and select from a variety of
676 communication approaches throughout a counseling session.
- 677 4. Can provide short-term, client-centered counseling and psychological support.
- 678 The student is able to assess clients' psychosocial needs and recognize
679 psychopathology. The student can demonstrate knowledge of
680 psychological defenses, family dynamics, family theory, crisis-
681 intervention techniques, coping models, the grief process, and reactions
682 to illness. The student can use open-ended questions; listen
683 empathically; employ crisis-intervention skills; and provide anticipatory
684 guidance.
- 685 5. Can promote client decision-making in an unbiased, non-coercive manner.
- 686 The student understands the philosophy of non-directiveness and is able
687 to recognize his or her values and biases as they relate to genetic
688 counseling issues. The student is able to recognize and respond to
689 dynamics, such as countertransference, that may affect the counseling
690 interaction.
- 691 6. Can establish and maintain inter- and intradisciplinary professional relationships
692 to function as part of a health-care delivery team.
- 693 The student behaves professionally and understands the roles of other
694 professionals with whom he or she interacts.

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Domain IV: Professional Ethics and Values

1. Can act in accordance with the ethical, legal, and philosophical principles and values of the profession.

The student is able to recognize and respond to ethical and moral dilemmas arising in practice and seek assistance from experts in these areas. The student is able to identify factors that promote or hinder client autonomy. The student demonstrates an appreciation of the issues surrounding privacy, informed consent, confidentiality, real or potential discrimination, and other ethical/legal matters related to the exchange of genetic information.

2. Can serve as an advocate for clients.

The student can understand clients' needs and perceptions and represent their interests in accessing services and responses from the medical and social service systems.

3. Can introduce research options and issues to clients and families.

The student is able to critique and evaluate the risks, benefits, and limitations of client participation in research; access information on new research studies; present this information clearly and completely to clients; and promote an informed-consent process.

4. Can recognize his or her own limitations in knowledge and capabilities regarding medical, psychosocial, and ethnocultural issues and seek consultation or refer clients when needed.

The student demonstrates the ability to self-assess and to be self-critical. The student demonstrates the ability to respond to performance critique and integrates supervision feedback into his or her subsequent performance. The student is able to identify and obtain appropriate consultative assistance for self and clients.

5. Can demonstrate initiative for continued professional growth.

The student displays a knowledge of current standards of practice and shows independent knowledge-seeking behavior and lifelong learning.

725
726

Appendix B

national society
of genetic
counselors, inc.



727
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Preamble:

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730

Genetic counselors are health professionals with specialized education, training, and experience in medical genetics and counseling.

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The National Society of Genetic Counselors (NSGC) is an organization that furthers the professional interests of genetic counselors, promotes a network for communication within the profession, and deals with issues relevant to human genetics.

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With the establishment of this code of ethics the NSGC affirms the ethical responsibilities of its members and provides them with guidance in their relationships with self, clients, colleagues, and society.

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NSGC members are expected to be aware of the ethical implications of their professional actions and to adhere to the guidelines and principles set forth in this code.

745

Introduction:

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A code of ethics is a document which attempts to clarify and guide the conduct of a professional so that the goals and values of the profession might best be served. The NSGC Code of Ethics is based upon relationships. The relationships outlined in this code describe who genetic counselors are for themselves, their clients, their colleagues, and society. Each major section of this code begins with an explanation of one of these relationships, along with some of its values and characteristics. Although certain values are found in more than one relationship, these common values result in different guidelines within each relationship. No set of guidelines can provide all the assistance needed in every situation, especially when different relationships appear to conflict. Therefore, when considered appropriate for this code, specific guidelines for prioritizing the relationships have been stated. In other areas, some ambiguity remains, allowing for the experience of genetic counselors to provide the proper balance in responding to difficult situations.

760

Section I: Genetic Counselors Themselves

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Genetic counselors value competence, integrity, dignity, and self-respect in themselves as well as in each other. Therefore, in order to be the best possible human resource to themselves, their clients, their colleagues, and society, genetic counselors strive to:

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1. Seek out and acquire relevant information required for any given situation.
2. Continue their education and training.
3. Keep abreast of current standards of practice.

- 772 4. Recognize the limits of their own knowledge, expertise, and therefore competence in any
773 given situation.
774
775 5. Be responsible for their own physical and emotional health as it impacts on their
776 professional performance.
777

778 **Section II: Genetic Counselors and Their Clients**

779
780 The counselor-client relationship is based on values of care and respect for the client's
781 autonomy, individuality, welfare, and freedom. The primary concern of genetic counselors is the
782 interests of their clients. Therefore, genetic counselors strive to:

- 783
784 1. To serve clients without regard to race, sex, sexual orientation, age, religion, genetic status
785 or socioeconomic status.
786
787 2. Respect their clients' beliefs, cultural traditions, inclinations, circumstances, and feelings.
788
789 3. Enable their clients to make informed independent decisions, free of coercion, by providing
790 or illuminating the necessary facts and clarifying the alternatives and anticipated consequences.
791
792 4. Refer clients to other competent professionals when they are unable to support the clients.
793
794 5. Maintain as confidential information received from clients, unless released by the client or
795 disclosure is required by law.
796
797 6. Avoid the exploitation of their clients for personal advantage, profit, or interest.
798

799 **Section III: Genetic Counselors and Their Colleagues**

800
801 The genetic counselors' relationships with other genetic counselors, genetic counseling students,
802 and health professionals are based on mutual respect, caring, cooperation, support, and a shared
803 loyalty to their professions and goals. Therefore, genetic counselors strive, individually and
804 through NSGC, to:

- 805
806 1. Foster and protect their relationships with other genetic counselors and genetic counseling
807 students by establishing mechanisms for peer support.
808
809 2. Encourage ethical behavior of colleagues.
810
811 3. Recognize the traditions, practices, and areas of competence of other health professionals
812 and cooperate with them in providing the highest quality of service.
813
814 4. Work with their so that clients receive the best possible services.
815

816 **Section IV: Genetic Counselors and Society**

817
818 The relationships of genetic counselors to society include interest and participation in activities
819 that have the purpose of promoting the well-being of society. Therefore, genetic counselors
820 strive, individually and through NSGC, to:

- 821
822 1. Keep abreast of societal developments that may endanger the physical and psychological
823 health of individuals.
824
825 2. Participate in activities necessary to bring about socially
826 responsible change.

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3. Serve as a source of reliable information and expert opinion for policymakers and public officials.

4. Keep the public informed and educated about the impact on society of new technological and scientific advances and the possible changes in society that may result from the application of these findings.

5. Adhere to laws and regulations of society. However, when such laws are in conflict with the principles of the profession, genetic counselors work toward change that will benefit the public interest.

Adopted 1/92 by the National Society of Genetic Counselors, Inc.

Hurley, Peggy

From: Volz, David
Sent: Friday, June 03, 2005 3:22 PM
To: Hurley, Peggy
Subject: FW: Licensure of genetic counselors



GC Licensure Fact
Sheet FINAL....



Licensure
FINAL.doc

-----Original Message-----

From: deborah.wham@aurora.org [mailto:deborah.wham@aurora.org]
Sent: Monday, April 18, 2005 1:39 PM
To: Volz, David
Subject: Licensure of genetic counselors

Hi Dave-

Per our conversation today, here is our application document and a fact sheet explaining a bit about the genetic counseling profession. In addition, if you would like more info on genetic counseling itself, go to www.nsgc.org, which is the National Society of Genetic Counselors website.

As we discussed we have the support of the DRL via Chris Klein as well as the Wisconsin Medical Society. Thanks for your help, and I look forward to hearing from you.

(See attached file: GC Licensure Fact Sheet FINAL.doc) (See attached file:
Licensure FINAL.doc)

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8/19

PRELIMINARY DRAFT - NOT READY FOR INTRODUCTION

7-21-05
D-note ✓

Gen

1 AN ACT ...; relating to: licensing genetic counselors and granting rule-making
2 authority.

Analysis by the Legislative Reference Bureau

This is a preliminary draft. An analysis will be provided in a later version.

The people of the state of Wisconsin, represented in senate and assembly, do enact as follows:

3 SECTION 1. 440.08 (2) (a) 37m. of the statutes is created to read:
4 440.08 (2) (a) 37m. Genetic counselor: November 1 of each odd-numbered year;
5 \$60.

6 SECTION 2. 448.015 (1g) of the statutes is created to read:
7 448.015 (1g) "Genetic counseling" includes identifying a family or individual
8 at risk for genetic disorders, analyzing inheritance patterns of genetic disorders,
9 providing information to individuals or families regarding recurrence risks,

1 available options for treatment or planning, providing information to physicians or
2 other medical care providers, providing case management services to families or
3 individuals, and providing psychological and social support to families or individuals
4 who are at risk for genetic disorders.

5 **SECTION 3.** 448.015 (1k) of the statutes is created to read:

6 448.015 (1k) “Genetic counselor” means an individual who practices genetic
7 counseling.

8 **SECTION 4.** 448.02 (1) of the statutes is amended to read:

9 448.02 (1) LICENSE. The board may grant licenses, including various classes
10 of temporary licenses, to practice medicine and surgery, to practice genetic
11 counseling, to practice perfusion, and to practice as a physician assistant.

History: 1975 c. 383, 421; 1977 c. 418; 1981 c. 135, 375, 391; 1983 a. 188 s. 10; 1983 a. 189 s. 329 (5); 1983 a. 253, 538; 1985 a. 29; 1985 a. 146 s. 8; 1985 a. 315, 332, 340; 1987 a. 27, 399, 403; 1989 a. 229; 1991 a. 186; 1993 a. 105, 107; 1995 a. 309; 1997 a. 67, 175, 191, 311; 1999 a. 32, 180; 2001 a. 89.

12 **SECTION 5.** 448.03 (1) (d) of the statutes is created to read:

13 448.03 (1) (d) No person may practice genetic counseling, attempt to do so, or
14 make a representation as authorized to do so, without a license to practice genetic
15 counseling granted by the board.

16 **SECTION 6.** 448.03 (2) (b) of the statutes is amended to read:

17 448.03 (2) (b) The performance of official duties by a physician, genetic
18 counselor, or perfusionist of any of the armed services or federal health services of
19 the United States.

History: 1975 c. 383, 421; 1977 c. 164; 1979 c. 317; 1985 a. 29; 1987 a. 40, 399; 1989 a. 31, 229; 1991 a. 23; 1993 a. 105, 107, 490; 1995 a. 27, 201; 1997 a. 67, 175, 311; 1999 a. 32, 180; 2001 a. 89.

20 **SECTION 7.** 448.03 (2) (c) of the statutes is amended to read:

21 448.03 (2) (c) The activities of a medical student, respiratory care student,
22 genetic counseling student, perfusion student, or physician assistant student

1 required for such student's education and training, or the activities of a medical
2 school graduate required for training as required in s. 448.05 (2).

History: 1975 c. 383, 421; 1977 c. 164; 1979 c. 317; 1985 a. 29; 1987 a. 40, 399; 1989 a. 31, 229; 1991 a. 23; 1993 a. 105, 107, 490; 1995 a. 27, 201; 1997 a. 67, 175, 311; 1999 a. 32, 180; 2001 a. 89.

3 **SECTION 8.** 448.03 (2) (d) of the statutes is amended to read:

4 448.03 (2) (d) Actual consultation or demonstration by licensed physicians,
5 genetic counselors, or perfusionists or certified respiratory care practitioners of other
6 states or countries with licensed physicians or perfusionists or certified respiratory
7 care practitioners of this state.

History: 1975 c. 383, 421; 1977 c. 164; 1979 c. 317; 1985 a. 29; 1987 a. 40, 399; 1989 a. 31, 229; 1991 a. 23; 1993 a. 105, 107, 490; 1995 a. 27, 201; 1997 a. 67, 175, 311; 1999 a. 32, 180; 2001 a. 89.

8 **SECTION 9.** 448.03 (2) (k) of the statutes is amended to read:

9 448.03 (2) (k) Any persons, other than physician assistants, genetic counselors,
10 or perfusionists, who assist physicians.

History: 1975 c. 383, 421; 1977 c. 164; 1979 c. 317; 1985 a. 29; 1987 a. 40, 399; 1989 a. 31, 229; 1991 a. 23; 1993 a. 105, 107, 490; 1995 a. 27, 201; 1997 a. 67, 175, 311; 1999 a. 32, 180; 2001 a. 89.

11 **SECTION 10.** 448.03 (3) (g) of the statutes is created to read:

12 448.03 (3) (g) A person who is not licensed to practice genetic counseling by the
13 board may not designate himself or herself as a genetic counselor, use or assume the
14 title "genetic counselor," or use any other title, letters, or designation that represents
15 or may tend to represent the person as a genetic counselor. This paragraph does not
16 apply to any of the following:

17 1. Any person employed as a genetic counselor by a federal agency, as defined
18 in s. 59.57 (2) (c) 1., if the person provides genetic counseling services solely under
19 the direction or control of the federal agency by which he or she is employed.

20 2. Any person pursuing a supervised course of study leading to a degree or
21 certificate in genetic counseling under an accredited or approved educational
22 program, if the person is designated by a title that clearly indicates his or her status
23 as a student or trainee.

1 3. Any person practicing genetic counseling under a temporary license issued
2 under s. 448.04 (1) (cm), if the person is designated by a title that clearly indicates
3 that he or she is practicing under a temporary license.

4 **SECTION 11.** 448.04 (1) (cg) of the statutes is created to read:

5 448.04 (1) (cg) *License to practice genetic counseling.* A person holding a license
6 to practice perfusion may practice genetic counseling.

7 **SECTION 12.** 448.04 (1) (cm) of the statutes is created to read:

8 448.04 (1) (cm) *Temporary license to practice genetic counseling.* The board
9 may, by rule, provide for a temporary license to practice genetic counseling for a
10 person who satisfies the requirements of s. 448.05 (4) but who has not passed an
11 examination under s. 448.05 (6). The board may issue a temporary license for a
12 period not to exceed one year and may renew a temporary license annually for not
13 more than 5 years. A person who holds a temporary license may not practice genetic
14 counseling unless the person is under the supervision and direction of a licensed
15 genetic counselor at all times while the person is performing genetic counseling. The
16 board may promulgate rules governing supervision by licensed genetic counselors.

17 Cross Reference: Cross Reference: Cross Reference: See also ch. Med 22, Wis. adm. code. Cross Reference:

18 **SECTION 13.** 448.05 (4) of the statutes is created to read:

19 448.05 (4) **LICENSE TO PRACTICE GENETIC COUNSELING.** An applicant for a license
20 to practice genetic counseling must supply evidence satisfactory to the board that he
21 or she has successfully completed an educational program in genetic counseling
22 recognized by the board and that he or she is certified to practice genetic counseling
23 by the American Board of Genetic Counselors or the American Board of Medical
24 Genetics.

25 **SECTION 14.** 448.07 (1) (d) of the statutes is amended to read:

1 448.07 (1) (d) No registration may be permitted by the secretary of the board
2 in the case of any physician, genetic counselor, or perfusionist who has failed to meet
3 the requirements of s. 448.13 or any person whose license, certificate, or limited
4 permit has been suspended or revoked and the registration of any such person shall
5 be deemed automatically annulled upon receipt by the secretary of the board of a
6 verified report of such suspension or revocation, subject to the licensee's or
7 permittee's right of appeal. A person whose license, certificate, or limited permit has
8 been suspended or revoked and subsequently restored shall be registered by the
9 board upon tendering a verified report of such restoration of the license, certificate,
10 or limited permit, together with an application for registration and the registration
11 fee.

12 History: 1975 c. 383, 421; 1977 c. 29, 131, 418; 1979 c. 162; 1987 a. 27, 264, 399; 1991 a. 39; 1995 a. 245; 1997 a. 175; 1999 a. 180; 2001 a. 89.

12 **SECTION 15.** 448.13 (1r) of the statutes is created to read:

13 448.13 (1r) Each person licensed as a genetic counselor shall, in each 2nd year
14 at the time of application for a certificate of registration under s. 448.07, submit proof
15 of completion of continuing education requirements promulgated by rule by the
16 board.

17 **SECTION 16.** 448.40 (2) (bm) of the statutes is created to read:

18 448.40 (2) (bm) Establishing the scope of the practice of genetic counseling and
19 establishing continuing education requirements for renewal of a license to practice
20 ~~perfusion~~ ^{genetic counseling} under s. 448.13 (1r).

DRAFTER'S NOTE
FROM THE
LEGISLATIVE REFERENCE BUREAU

LRB-3151/Pdn

PJH:.....

WYJ

David Volz

Please review this preliminary draft to ensure that it is consistent with your intent and that it contains all of the provisions you want. If the draft is satisfactory, let me know and I will write an analysis and prepare the draft for introduction. If you need further changes, please let me know.

Peggy Hurley
Legislative Attorney
Phone: (608) 266-8906
E-mail: peggy.hurley@legis.state.wi.us

DRAFTER'S NOTE
FROM THE
LEGISLATIVE REFERENCE BUREAU

LRB-3151/P1dn
PJH:wlj:ch

August 18, 2005

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Legislative Attorney
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PRELIMINARY DRAFT - NOT READY FOR INTRODUCTION

1 **AN ACT to amend** 448.02 (1), 448.03 (2) (b), 448.03 (2) (c), 448.03 (2) (d), 448.03
2 (2) (k) and 448.07 (1) (d); and **to create** 440.08 (2) (a) 37m., 448.015 (1g),
3 448.015 (1k), 448.03 (1) (d), 448.03 (3) (g), 448.04 (1) (cg), 448.04 (1) (cm), 448.05
4 (4), 448.13 (1r) and 448.40 (2) (bm) of the statutes; **relating to:** licensing
5 genetic counselors and granting rule-making authority.

Analysis by the Legislative Reference Bureau

This is a preliminary draft. An analysis will be provided in a later version.

The people of the state of Wisconsin, represented in senate and assembly, do enact as follows:

6 **SECTION 1.** 440.08 (2) (a) 37m. of the statutes is created to read:
7 440.08 (2) (a) 37m. Genetic counselor: November 1 of each odd-numbered year;
8 \$60.
9 **SECTION 2.** 448.015 (1g) of the statutes is created to read:
10 448.015 (1g) "Genetic counseling" includes identifying a family or individual
11 at risk for genetic disorders, analyzing inheritance patterns of genetic disorders,

1 providing information to individuals or families regarding recurrence risks,
2 available options for treatment or planning, providing information to physicians or
3 other medical care providers, providing case management services to families or
4 individuals, and providing psychological and social support to families or individuals
5 who are at risk for genetic disorders.

6 SECTION 3. 448.015 (1k) of the statutes is created to read:

7 448.015 (1k) “Genetic counselor” means an individual who practices genetic
8 counseling.

9 SECTION 4. 448.02 (1) of the statutes is amended to read:

10 448.02 (1) LICENSE. The board may grant licenses, including various classes
11 of temporary licenses, to practice medicine and surgery, to practice genetic
12 counseling, to practice perfusion, and to practice as a physician assistant.

13 SECTION 5. 448.03 (1) (d) of the statutes is created to read:

14 448.03 (1) (d) No person may practice genetic counseling, attempt to do so, or
15 make a representation as authorized to do so, without a license to practice genetic
16 counseling granted by the board.

17 SECTION 6. 448.03 (2) (b) of the statutes is amended to read:

18 448.03 (2) (b) The performance of official duties by a physician, genetic
19 counselor, or perfusionist of any of the armed services or federal health services of
20 the United States.

21 SECTION 7. 448.03 (2) (c) of the statutes is amended to read:

22 448.03 (2) (c) The activities of a medical student, respiratory care student,
23 genetic counseling student, perfusion student, or physician assistant student
24 required for such student’s education and training, or the activities of a medical
25 school graduate required for training as required in s. 448.05 (2).

1 **SECTION 8.** 448.03 (2) (d) of the statutes is amended to read:

2 448.03 (2) (d) Actual consultation or demonstration by licensed physicians,
3 genetic counselors, or perfusionists or certified respiratory care practitioners of other
4 states or countries with licensed physicians or perfusionists or certified respiratory
5 care practitioners of this state.

6 **SECTION 9.** 448.03 (2) (k) of the statutes is amended to read:

7 448.03 (2) (k) Any persons, other than physician assistants, genetic counselors,
8 or perfusionists, who assist physicians.

9 **SECTION 10.** 448.03 (3) (g) of the statutes is created to read:

10 448.03 (3) (g) A person who is not licensed to practice genetic counseling by the
11 board may not designate himself or herself as a genetic counselor, use or assume the
12 title “genetic counselor,” or use any other title, letters, or designation that represents
13 or may tend to represent the person as a genetic counselor. This paragraph does not
14 apply to any of the following:

15 1. Any person employed as a genetic counselor by a federal agency, as defined
16 in s. 59.57 (2) (c) 1., if the person provides genetic counseling services solely under
17 the direction or control of the federal agency by which he or she is employed.

18 2. Any person pursuing a supervised course of study leading to a degree or
19 certificate in genetic counseling under an accredited or approved educational
20 program, if the person is designated by a title that clearly indicates his or her status
21 as a student or trainee.

22 3. Any person practicing genetic counseling under a temporary license issued
23 under s. 448.04 (1) (cm), if the person is designated by a title that clearly indicates
24 that he or she is practicing under a temporary license.

25 **SECTION 11.** 448.04 (1) (cg) of the statutes is created to read:

1 448.04 (1) (cg) *License to practice genetic counseling.* A person holding a license
2 to practice perfusion may practice genetic counseling.

3 **SECTION 12.** 448.04 (1) (cm) of the statutes is created to read:

4 448.04 (1) (cm) *Temporary license to practice genetic counseling.* The board
5 may, by rule, provide for a temporary license to practice genetic counseling for a
6 person who satisfies the requirements of s. 448.05 (4) but who has not passed an
7 examination under s. 448.05 (6). The board may issue a temporary license for a
8 period not to exceed one year and may renew a temporary license annually for not
9 more than 5 years. A person who holds a temporary license may not practice genetic
10 counseling unless the person is under the supervision and direction of a licensed
11 genetic counselor at all times while the person is performing genetic counseling. The
12 board may promulgate rules governing supervision by licensed genetic counselors.

13 **SECTION 13.** 448.05 (4) of the statutes is created to read:

14 448.05 (4) LICENSE TO PRACTICE GENETIC COUNSELING. An applicant for a license
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16 or she has successfully completed an educational program in genetic counseling
17 recognized by the board and that he or she is certified to practice genetic counseling
18 by the American Board of Genetic Counselors or the American Board of Medical
19 Genetics.

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25 be deemed automatically annulled upon receipt by the secretary of the board of a

1 verified report of such suspension or revocation, subject to the licensee's or
2 permittee's right of appeal. A person whose license, certificate, or limited permit has
3 been suspended or revoked and subsequently restored shall be registered by the
4 board upon tendering a verified report of such restoration of the license, certificate,
5 or limited permit, together with an application for registration and the registration
6 fee.

7 **SECTION 15.** 448.13 (1r) of the statutes is created to read:

8 448.13 (1r) Each person licensed as a genetic counselor shall, in each 2nd year
9 at the time of application for a certificate of registration under s. 448.07, submit proof
10 of completion of continuing education requirements promulgated by rule by the
11 board.

12 **SECTION 16.** 448.40 (2) (bm) of the statutes is created to read:

13 448.40 (2) (bm) Establishing the scope of the practice of genetic counseling and
14 establishing continuing education requirements for renewal of a license to practice
15 genetic counseling under s. 448.13 (1r).

16 (END)