

# A Professional Order for Genetic Counsellors in Quebec

A request for the Office des Professions to consider the creation of a new professional order for this growing group of health professionals.

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Submitted on behalf of the QAGC membership

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## Summary statement

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Genetic counsellors are uniquely trained allied health professionals who communicate extremely complex and sensitive information to a patient population that is often ill-equipped to determine whether the counselling they receive is accurate or appropriate. While there is a clear recognition within the profession as to the training that a genetic counsellor should have, there is no measure currently in place to regulate who uses this title in Quebec. For these reasons, amongst others, we are submitting this document, urging the Office des Professions to work with us to create a professional order to regulate the use of the title “genetic counsellor” in Quebec in order to provide protection to the public.

Genetic counsellors are a small group in Quebec but the numbers are increasing quickly and there is great potential for growth given the current situation in the field of medical genetics. In 2001 and in 2004 requests to the Office were denied due to the small number of genetic counsellors at the time. Since then, the number of genetic counsellors in Quebec has more than tripled. The Collège des médecins de Québec (CMQ) has recommended that genetic counsellors seek to be regulated by a professional order<sup>1</sup> and several documents submitted to the Quebec government in the past 15 years call for regulation of medical genetics practices in the province<sup>2</sup>, with one specifically recommending that genetic counsellors be regulated through a professional order<sup>3</sup>.

The field of medical genetics continues to expand rapidly in Quebec and elsewhere in the world. Research is identifying new genes and new technologies that allow for expanded clinical testing, which in turn leads to new challenges in interpreting often complex genetic test results and in communicating the implications of those results to patients and their relatives. In this environment, it will become increasingly important that those providing genetic counselling have adequate training to avoid conveying inappropriate or inaccurate information to patients. Restricting the use of the title “genetic counsellor” to those with the appropriate training and establishing a professional order to regulate the profession would provide much-needed protection for the public.

It should be noted that while there are no professional orders or equivalent regulation for genetic counsellors in Canada, more and more states in the United States are requiring licensure of genetic counsellors as a means of providing protection to the public. Both the American Society of Human Genetics (ASHG)<sup>4</sup> and the National Society of Genetic Counselors<sup>5</sup> (NSGC) have issued statements supporting licensure as a means of regulating the profession and protecting the public from harm.

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<sup>1</sup> *Personal communication between the CMQ and representatives of the QAGC, 2006.*

<sup>2</sup> *Conseil de la santé et du bien-être, La santé et le bien-être à l'ère de l'information génétique – enjeux individuels et sociaux à gérer (Québec : Gouvernement du Québec, 2001), p. 71.*

<sup>3</sup> *Commission de l'éthique en science et en technologie, Les soins de santé « personnalisés » : prudence et balises, (Québec : Gouvernement du Québec, 2014), p. 73.*

<sup>4</sup> *American Society of Human Genetics, « ASHG Issues Statement Supporting Licensure of Genetic Counselors,» Press release, September 10 2015, <http://www.ashg.org/press/201509-gc-licensure.html>*

<sup>5</sup> *National Society of Genetic Counselors Advocacy: State Licensure for Genetic Counselors, accessed May 23 2016; <http://nsgc.org/p/cm/ld/fid=16>*

All of these changes have prompted us to relaunch efforts into creating a professional order here in Quebec. We submit this document in the hope that it will provide sufficient evidence that this small but rapidly growing profession should be regulated in order to protect the public. We will start with a brief overview of the profession, including the historical roots and some of the recent developments that have shaped where genetic counsellors work and the roles they play in healthcare in Quebec today. We will then provide a more in-depth look at the current situation in Quebec, including the current numbers of genetic counsellors working across the province, the training and certification requirements that are currently in place, and the risks to the public that will exist for as long as this profession remains without an order.

# Introduction to the profession of “genetic counsellor”

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## ***The origins of the profession***

It is impossible to speak of the origin of the profession of genetic counsellors without first acknowledging the origin of the field of medical genetics. This clinical field began to firmly take root in Quebec and across North America in the 1950s with researchers and physicians working in laboratories and hospitals to learn about the causes of hereditary diseases, providing diagnoses to patients with such hereditary diseases, and conveying information with regards to the impact of such diseases for the individual affected and their family members. Ultimately this gave rise to a new specialty for physicians, who became known as medical geneticists.

In the 1960s and 1970s the demand for the services of medical geneticists grew exponentially. This demand stemmed from the availability of more and more clinical genetic tests, the advances in prenatal diagnosis and the start of newborn screening programs for inborn errors of metabolism. As a result, the medical genetics services as they existed at that time could not cope with the demands and the need for a new profession grew. At this time it was acknowledged that conveying information about a genetic diagnosis was not a medical act per se and could as such be performed by someone other than a physician. In Quebec, and elsewhere, this created a new role for a “genetic counsellor”, someone who did not have a medical degree but who was entrusted to convey information about genetic risk to patients and their families.

The title of “genetic counsellor” stems from the term “genetic counselling” that was first used by Dr. Sheldon Reed in the 1950s to describe the process of conveying information about genetic diseases to individuals at risk<sup>6</sup>. In 1974 Dr. Clarke Fraser, a medical geneticist from Montreal, proposed a definition of genetic counselling that was later adopted by the American Society of Human Genetics and is still widely used today<sup>7</sup>. However, while this definition accurately describes genetic counselling as a communication process, it fails to address the psychosocial support that is an integral component of all genetic counselling encounters. As such, it is slowly being replaced by the one put forth by the National Society of Genetic Counselors in 2006. This definition now stands as the cornerstone for the services provided by those who are trained as genetic counsellors.

“Genetic counseling is the process of helping people understand and adapt to the medical, psychological and familial implications of genetic contributions to disease. This process integrates the following: (1) Interpretation of family and medical histories to assess the chance of disease occurrence or recurrence; (2) Education about inheritance, testing, management, prevention, resources and research; (3) Counseling to promote informed choices and adaptation to the risk or condition.”<sup>8</sup>

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<sup>6</sup> Sheldon Reed, *Counseling in Medical Genetics* (Philadelphia : Saunders, 1955).

<sup>7</sup> American Society of Human Genetics Ad Hoc Committee on Genetic Counseling (1975). *Genetic counseling*. *Am J Hum Genet*, 27 240–242.

<sup>8</sup> Robert Resta et al., « A New Definition of Genetic Counseling: National Society of Genetic Counselors’ Task Force Report, » *Journal of Genetic Counseling* 15, no. 2 (2006): 77.

In the early years those fulfilling the role of 'genetic counsellor' were individuals with an interest in genetics who had a nursing or Bachelor of Science degree and who received on-the-job training. However, it quickly became clear that a more in-depth and specialized training both in the manifestations of genetic disease and techniques of psychosocial support would be necessary to allow genetic counsellors to be able to work more autonomously and thereby improve the services available to patients and their families. Thus was born the Master's level training for genetic counsellors at Sarah Lawrence College in the United States in 1969, followed by the first Master's level training program in Canada at McGill University in Montreal in 1985. It is now widely recognized that all genetic counsellors should have Master's level training in genetic counselling and should update their education throughout their careers.

*Other key dates in the growth of the profession of genetic counsellors:*

- 1990 Incorporation of the CAGC-ACCG (Canadian Association of Genetic Counsellors / Association canadienne des conseillers en génétique)
- 1998 First Canadian certification examination offered by the CAGC-ACCG - previously certification was only available through the American certification boards
- 2001 Utah becomes the first State in the United States to pass legislature requiring licensing of genetic counsellors
- 2003 Incorporation of the QAGC-ACCGQ (Quebec Association of Genetic Counsellors / L'Association des conseillères et conseillers en génétique du Québec)
- 2006 Creation in Quebec of an official title of employment 'genetic counsellor' with associated salary scale
- 2006 Publication of a code of ethics for genetic counsellors in Canada by the CAGC-ACCG.
- 2012 Canadian certification is formally recognized by the American Board of Genetic Counselors (ABGC) as sufficient to be a qualified supervisor for students attending an ABGC-accredited program in genetic counselling
- 2012 CAGC-ACCG adopts the knowledge-based and practice-based core competencies to establish practice standards for genetic counsellors in Canada, replacing the previous Scope of Practice.
- 2015 Canadian certification is recognized as sufficient for registration to work as a genetic counsellor in Europe
- 2016 As of April, 18 States in the US have laws requiring licensure for genetic counsellors, with 3 more in the process of finalizing legislation for licensure

***The role of a genetic counsellor***

Today the provision of genetic counselling is seen as an integral part of medical genetics throughout the world, especially when a genetic diagnosis is suspected or confirmed. It is strongly suggested that anyone undergoing genetic testing of any kind receive genetic

counselling before consenting to the test. Genetic counselling is a recommendation on all genetic test reports from certified laboratories, whether the result is positive, negative, or a variant of uncertain significance. It is also recommended in conjunction with newborn screening and prenatal screening programs across North America. It is recommended for anyone undergoing predictive genetic testing at both the pre- and post-test stages. Finally, any well-designed research project that will involve contacting participants with relevant genetic test results will recommend genetic counselling when results are confirmed and reported. All of this means that there is a great demand for the services of genetic counsellors at this time.

As suggested by the definition of genetic counselling provided in the previous section, genetic counsellors are trained to communicate with patients, families, physicians and others with regards to any hereditary condition for which partial or complete information is available while providing support and anticipatory guidance and helping each individual to make the choices that are best for them, in the context of their own personal circumstances.

A genetic counsellor is trained to approach each session as a unique situation and to modify his or her approach based on the needs of the specific individual. A genetic counsellor should be able to review the relevant medical literature, synthesize the information relevant to each particular session, convey that information in a clear and concise manner, explore risks and options with their patients, remain non-directive in the counselling approach, and recognize that each patient's needs will be different depending on the reason for the encounter, the individual's stage of life, their culture, their social status and/or religious beliefs, their current emotional status, and so on.

### *Genetic counsellors in a clinical setting*

Given the historical roots of the profession, it is only natural that the majority of genetic counsellors continue to work in a clinical setting. Most genetic counsellors work as part of a multidisciplinary team that provides medical genetics services in many different clinical settings (e.g. prenatal, paediatric, or adult clinics; clinics focused on general genetics, or specialty clinics such as metabolic or hereditary cancer clinics). These teams most often include a medical geneticist, whose role in diagnosing genetic disorders is complementary to the role of a genetic counsellor. However, in some situations a counsellor will work directly with other specialists such as neurologists, oncologists or maternal-fetal medicine specialists.

The services that a genetic counsellor provides will often depend on the specific workplace and the approach of the team in that setting. In all settings the genetic counselling encounter will involve a one-on-one meeting between the genetic counsellor and an individual, or a group of individuals, to discuss genetic risk based on family history, medical test results and/or genetic test results.

The individuals who may benefit from meeting with a genetic counsellor include the following:

- ◆ Couples who are planning a pregnancy and who have a personal and/or family history of an inherited condition, a history of infertility or recurrent miscarriages, or a consanguineous relationship;

- ◆ Pregnant women and their partners with a known risk for a genetic condition, an abnormal ultrasound finding or an abnormal result from a prenatal screening or diagnostic test;
- ◆ Parents of a newborn with an abnormal newborn screening result or a congenital malformation, parents of children with a known or suspected genetic condition, or with developmental delay or behaviour abnormalities, including autism spectrum disorder;
- ◆ Adults with a personal and/or family history of an inherited condition, or with a history of cancer or neurological condition that is suggestive of an inherited predisposition, who want to learn about their personal risk and/or risks to relatives.

In some situations the genetic counsellor may meet with patients being evaluated by a medical geneticist for investigation of a possible genetic diagnosis. The role of the genetic counsellor in these situations may include collecting information about the medical and family history and providing preliminary information about potential risks to the family. In some circumstances the medical geneticist may also empower the genetic counsellor to coordinate preliminary testing on their behalf as well.

More often a genetic counsellor will meet with patients and/or relatives once a genetic diagnosis has been established. In this context the discussion will centre on the diagnosis and an evaluation of the risks for the individual and for other relatives (pregnancy, siblings, more distant relatives, etc...) based on the medical literature describing the condition as well as the specifics in the particular family, including the family history and genetic test results available. Genetic counsellors will discuss any tests available to help confirm or modify a person's risks and will explore the advantages, disadvantages and limitations that may come into play.

In the United States and in the rest of Canada, more and more clinical genetic counsellors are working outside of the medical genetics clinics. Instead, they are working directly with other specialists, including oncologists, neurologists, cardiologists, ophthalmologists, and others, and providing them with a much needed clinical genetics expertise. While most clinical counsellors in Quebec continue to work directly with medical geneticists, it is anticipated that Quebec will eventually follow this same trend, opening new employment opportunities for genetic counsellors and a streamlining of care for patients.

#### *Genetic counsellors in research*

Many genetic counsellors work in research positions and it is likely that the research setting will continue to provide employment opportunities for genetic counsellors in the future since a genetic counsellor's training hones skills that make them valuable members of any research team. For some genetic counsellors research is their primary focus. For others, their position may include both research and clinical responsibilities. It is important to point out that many clinical positions start out as research-funded positions that are later converted to a more permanent, clinical position. Genetic counsellors in a research setting may be involved in writing research grants, coordinating research projects, recruiting patients, collecting and analyzing data, writing scientific manuscripts and presenting research findings at scientific meetings. The recruitment of patients may involve encounters similar to those described in a clinical setting, although the focus of the discussion would be different.

### *Genetic counsellors in education*

Genetic counsellors are often involved in education at many different levels. In general, genetic counsellors strive to educate both the lay public and non-genetics medical professionals about genetic counselling and other aspects of hereditary disease. As a result, genetic counsellors may be involved in presentations at schools, public organizations, support groups, hospital rounds, medical conferences and so on. More specifically, some genetic counsellors are hired directly by a university or another organization to fulfill an educator role. As one local example, both Master's programs in Quebec employ a genetic counsellor as the director or co-director of the program. These programs also rely on genetic counsellors working in clinical and research settings to provide student supervision in a clinical setting for their trainees to gain hands-on experience and this is often written into the genetic counsellor's work contract as part of their official duties. In addition genetic counsellors may teach didactic coursework, supervise or review student research projects, and become involved in the selection process for new trainees being admitted into the genetic counselling Master's programs. Genetic counsellors may also be involved in training medical students, residents or fellows on rotation in their department and in providing education to colleagues, either about genetic counselling itself or any genetics-related topics.

### *Genetic counsellors in laboratories and in private industry*

The past decade has seen some major technological advances that have allowed for rapid expansion in clinical genetic testing services. More and more laboratories in the US and Canada, whether publicly or privately funded, are hiring genetic counsellors. These genetic counsellors may have a direct laboratory role, helping with data analysis and interpretation and generating reports, or a supportive role in verifying test requests and communicating with referring physicians for clarification or responding to questions from medical professionals or patients about testing or results. Alternatively, some genetic counsellors are involved in business development and sales, travelling and representing their company and raising awareness about the test services being offered. Genetics counsellors' unique set of skills in critical thinking and communicating complex information to a range of audiences make them highly valued members of these teams.

### ***Current statistics for genetic counsellors in Quebec***

As of May 2016, there are 55 genetic counsellors employed in Quebec, with 43 working in public clinical positions, 2 in private clinical positions, 1 in a clinical management position and the remainder employed in various other settings including research (3), industry (3), education (1), government (1) or support/advocacy group (1). Several genetic counsellors hold positions that combine clinical, research and/or education roles. A few hold more than one position, such that they work both in the public and private sectors.

By region, the majority of genetic counsellors work in the Montreal area (47). Four work in Quebec, one in Sherbrooke and three in Chicoutimi. Most genetic counsellors work at University Hospital Centres (CHUs) with a minority at smaller hospitals. A number of major hospitals in Quebec do not have genetic counsellors on site.

Today's numbers represent a 224% growth in the number of genetic counsellors since 2004, when there were only 17 counsellors in the province. However, this still only provides a single clinical genetic counsellor per 200,000 or more individuals (based on the 2015 Quebec population of 8.264 million<sup>9</sup>). By comparison, the province of Ontario employs 145 clinical genetic counsellors in the public sector for a population of 13.8 million, which gives 1 per 95,000 individuals (based on Ontario population in 2015<sup>10</sup>).

It is important to mention that genetic counsellors are not the only health professionals providing genetic counselling to patients in Quebec. As would be expected, medical geneticists often provide genetic counselling while evaluating and diagnosing patients. While they may not receive the same depth of training with regards to the nuances of genetic counselling as a genetic counsellor receives, their specialist training does include a genetic counselling component. Outside of genetics clinics, other health professionals in Quebec may also provide so-called genetic counselling to their patients. This is a different situation because nurses, general practitioners and non-geneticist specialist physicians are unlikely to have received adequate training in genetic counselling and are unlikely to have the appropriate knowledge and skill set to provide comprehensive genetic counselling effectively and without risk to the patient and/or their family members.

### **Future Projections**

Several Quebec government publications have highlighted a need for more genetic services in general and genetic counsellors in particular:

« Le réseau connaît actuellement une pénurie de ressources humaines dans le domaine du conseil génétique. On compte en effet à peine plus d'une quinzaine de conseillères en génétique au Québec...C'est en ce qui a trait au nombre de conseillères en génétique que le Québec est moins favorisé, surtout par rapport à l'Ontario. Il est manifeste que l'Ontario compte sur le travail des conseillères pour assister les médecins dans leur tâche. »<sup>11</sup>

Recommandations de « reconnaître le conseil génétique comme élément indispensable du service génétique, et de développer et renforcer les équipes multidisciplinaires de soins en donnant priorité au conseil génétique. »<sup>12</sup>

« ...on a signalé au Conseil, d'une part, qu'il y a un manque flagrant de ressources et de personnel formé à ce chapitre et, d'autre part, que les facultés de médecine ont d'autres priorités. La formation professionnelle en génétique des médecins, des médecins spécialistes et d'autres professionnels de la santé est jugée inadéquate par plusieurs. »<sup>13</sup>

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<sup>9</sup> Statistique Canada, tableau 051-0001: Estimations de la population, selon le groupe d'âge et le sexe au 1er juillet, Canada, provinces et territoires, annuel, CANSIM, consulté le 23 mai 2016, <http://www.statcan.gc.ca/tables-tableaux/sum-som/l02/cst01/demo02a-fra.htm>

<sup>10</sup> *Ibid.*

<sup>11</sup> Santé et services sociaux. *L'organisation des services de génétique au Québec – plan d'action 2005-2008*, (Québec : Gouvernement du Québec, 2005), p. 5, 12.

<sup>12</sup> *Ibid.*, p. 19

<sup>13</sup> Conseil de la santé et du bien-être. *La santé et le bien-être à l'ère de l'information génétique – enjeux individuels et sociaux à gérer*. (Québec : Gouvernement du Québec, 2001), p. 21.

« Au Québec, de plus en plus d'hôpitaux se dotent d'un service de conseil génétique. Toutefois, bien qu'un programme de formation soit proposé aujourd'hui dans certaines universités, l'offre tarde à suffire à la demande et les services sont parfois méconnus de la population. »<sup>14</sup>

« Au fur et à mesure que les soins de santé personnalisés deviendront pratique courante, ils feront partie de la première ligne, mais les médecins ne pourront interpréter tous les tests. Ainsi, de plus en plus de professionnels de la santé vont être amenés à faire du conseil génétique sans être nécessairement formés pour le faire. Cette nouvelle réalité s'ajoute à la nécessité de disposer d'un nombre suffisant de conseillers en génétique suffisamment formés pour répondre à la demande. Le conseil génétique pour bien informer les gens représente donc une avenue à ne pas négliger. »<sup>15</sup>

This fits with the overall global view that the field of medical genetics is becoming more and more relevant in the clinical setting and that additional resources will be needed in the coming years. Most projections suggest that there will be an ongoing increase in the demand for genetic counsellors in the next 10-20 years and that this will result in job creation in many settings including clinics, research, education, laboratories and industry. This growing demand for genetic counsellors is already clearly evident in the United States, with far more job postings than can be filled by the current capacity of the training programs for genetic counsellors.

“The field of genetic counselling is growing rapidly and was recently named a “Hot Concentration” for healthcare jobs by US News and World Report. There are now more than 2,000 genetic tests available, and with that comes an increased need for genetics experts. Since 2006, the number of genetic counsellors (in the US) has grown 75%”<sup>16</sup>

“Employment of genetic counselors is projected to grow...much faster than the average for all occupations...Ongoing technological innovations, including lab tests and developments in genomics, are giving counselors the opportunities to conduct more types of analyses. ...Most growth over the next 10 years for genetic counselors is expected to be in hospitals.”<sup>17</sup>

These projections are based on several factors, including:

1. The rapid expansion of current knowledge about genetic and genomic concepts and the application of this knowledge to a clinical setting;
2. The growing number of genetic tests available and the specialty training required to appropriately choose the best testing algorithm for each individual/family;

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<sup>14</sup> *Commission de l'éthique en science et en technologie. Les soins de santé « personnalisés » : prudence et balises, (Québec : Gouvernement du Québec, 2014), p. 44.*

<sup>15</sup> *Ibid., p. 45.*

<sup>16</sup> *Jennifer Malone Hoskovec, « Genetic Counseling: A Rapidly Growing STEM Career, » National Society of Genetic Counselors, 17 juin 2014, <http://nsgc.org/p/bl/et/blogid=53&blogaid=204>.*

<sup>17</sup> *United States Department of Labor, Bureau of Labor Statistics, « Occupational Outlook Handbook, » <http://www.bls.gov/ooh>.*

3. The increasingly complex interpretation of genetic test results and the subtle concepts that must be conveyed to the individual/family as part of the discussion surrounding genetic testing;
4. The public's increasing awareness of the role of their DNA in influencing their health and increasing demands for testing/answers;
5. The emergence of direct-to-consumer testing and the likely need for counselling surrounding these test results;
6. The expansion of programs for prenatal and newborn screening and the growing interest in personalized medicine.

Within Quebec it is clear that more and more physicians, including specialists and general practitioners, are ordering genetic tests in their daily practice. Many are then struggling with the interpretation and communication of results to their patients and must then refer their patients for genetic counselling about these results. Currently, some patients are tested appropriately while others are not. Some are given correct information about their test results by their physician but for others the information is often incomplete or inaccurate. Some patients must wait months or even years to meet with a genetics specialist to learn more about their results. Others are never referred and only learn years later of the potential risk to themselves and their relatives. This situation reflects not only the reality in terms of current demands for genetic services, but also highlights the anticipated need for growth and expansion in the coming years. It is likely that genetic counsellors will play an important role because, as the WHO stated, their training is less lengthy and less costly than training a physician:

« Dans quelques pays, notamment aux Etats-Unis d'Amérique et au Canada, le conseiller en génétique constitue une profession à part entière. Ces conseillers ont reçu une formation postuniversitaire poussée en génétique et en conseil psychosocial, mais ne sont pas médecins. La formation de ces conseillers est exclusivement axée sur les besoins des individus et des familles du fait de la part importante réservée au conseil. Elle est moins longue et moins coûteuse que ne le serait le fait de former des médecins. Il convient d'encourager dans tous les pays la mise en place de programmes de formation au conseil génétique... »<sup>18</sup>

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<sup>18</sup> D.C. Wertz, J.C. Fletcher et K. Berg, « Les problèmes éthiques rencontrés en génétique médicale » (Genève : Organisation Mondiale de la Santé, 2001), p. 21.

# Required knowledge and training for genetic counsellors

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## **Core Competencies for Canadian Genetic Counsellors**

In 2012, the Canadian Association of Genetic Counsellors (CAGC) adopted two sets of core competencies to establish practice standards for genetic counsellors across Canada. The Knowledge-Based Competencies and Practice Based Competencies together serve as a platform for practice guidelines, training curricula, certification requirements, maintenance of competency, re-entry to practice and other quality assurance initiatives for genetic counsellors in Canada. These documents replace the original Scope of Practice that had been created in 1994 in conjunction with the establishment of certification standards for Canadian genetic counsellors.

The **Knowledge-Based Competencies** for Canadian Genetic Counsellors<sup>19</sup> reflect the continuing evolution of the profession of genetic counselling and the rapidly expanding field of medical genetics. They represent the core knowledge a practicing genetic counsellor must master, subdivided into 9 areas:

1. Epidemiology, Population, and Basic Human Genetics
2. Clinical Genetics
3. Molecular Genetics
4. Cytogenetics
5. Biochemical Genetics
6. Cancer Genetics
7. Genetic Screening
8. Prenatal Diagnosis
9. Genetic Counselling

A genetic counsellor is expected to master not only the scientific and medical knowledge associated with each of these areas of training, but also the cultural, social, legal, ethical and psychological implications within each area.

The **Practice Based Competencies** for Canadian Genetic Counsellors<sup>20</sup> describe the integrated skills, attitudes and judgment that genetic counsellors require in order to perform the services and duties that fall within the practice of the profession responsibly, safely, effectively and ethically. They centre on three domains:

1. Counselling and communication
2. Genetic expertise
3. Professionalism and ethical practice

Within these three domains lies the framework for an individual to work as a genetic counsellor. As a brief summary, a genetic counsellor is expected to demonstrate an ability to analyze

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<sup>19</sup> See the CAGC Knowledge-Based Competencies for Canadian Genetic Counsellors: [https://www.cagc-accg.ca/doc/knowledge\\_based\\_competencies\\_final\\_french\\_translation%20-%20june%2026%2C%202012.pdf](https://www.cagc-accg.ca/doc/knowledge_based_competencies_final_french_translation%20-%20june%2026%2C%202012.pdf)

<sup>20</sup> See the CAGC Practice Based Competencies for Genetic Counsellors: <https://www.cagc-accg.ca/doc/cagc%20practice%20based%20competencies.pdf>

scientific information critically and to communicate professionally and clearly with any audience, to work effectively as part of a healthcare team, to respect diversity whether it be cultural, spiritual, physical, cognitive, political or sexual, to provide counselling that is not directive and to be aware of and apply other principles that guide genetic counsellors as medical practitioners including issues of privacy, informed consent, confidentiality, discrimination, self-determination, equality, trust, respect, beneficence, honesty, and empathy.

The knowledge- and practice-based competencies are intended to be used in conjunction with the **Code of Ethics** for genetic counsellors that was established by the CAGC in 2006, along with one's professional judgement. The Code of Ethics<sup>21</sup> specifically outlines the expectations of ethical conduct of genetic counsellors with respect to patients, to society, to colleagues and to themselves. In brief, the code of ethics states that a genetic counsellor should respect the autonomy of their patients and approach each session with honesty and integrity and without prejudice, that a genetic counsellor should work to promote equal access to services and should utilize self-care practices to foster well-being for themselves and their colleagues.

While a genetic counsellor's degree of expertise in these competencies will vary depending on their own level of experience and individual practice setting, it is expected that every genetic counsellor possess these competencies as a minimum requirement for practice.

Core competencies for genetic counsellors have also been defined in other jurisdictions that are sometimes useful to counsellors working in Canada. In the United States, the NSGC has outlined the core skills of genetic counsellors<sup>22</sup> and the ABGC has established the practice-based competencies required of a practicing genetic counsellor<sup>23</sup>. This documentation serves as the foundation for licensure at the State level. In Europe, the situation differs depending on the country. As two examples, in the UK, the registration board defines the code of conduct and scope of practice for genetic counsellors whereas in France the title and role of the genetic counsellor were defined by government legislation, under the "Code de la santé publique", in 2004.

### ***Training programs and requirements***

The minimum training requirement to work as a genetic counsellor is a Master of Science degree in genetic counselling. These specialized training programs integrate a core didactic curriculum to establish a foundation of genetic and medical knowledge with extensive practical learning via clinical and laboratory rotations supervised by genetic counsellors and other medical professionals. Most of the training programs are 2 years in length and also include a research component; however not all programs require a formal thesis for graduation.

There are currently 4 training programs in Canada: McGill University, Université de Montréal, University of Toronto and University of British Columbia. Admission is highly competitive, with only 18 students currently admitted per year across the country. There are also over 30 training

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<sup>21</sup> See the CAGC Code of Ethics for Canadian Genetic Counsellors (2006) : <https://www.cagc-accg.ca/doc/code%20of%20ethics%20e-070628.pdf>

<sup>22</sup> See the NSGC Core Skills of Genetic Counselors: <http://nsgc.org/d/do/433>

<sup>23</sup> See the ABGC Practice-Based Competencies: [http://www.abgc.net/docs/Practice%20Based%20Competencies\\_Aug%202006%2010-29-09.pdf](http://www.abgc.net/docs/Practice%20Based%20Competencies_Aug%202006%2010-29-09.pdf)

programs in the United States that attract Canadian students and that also provide trained genetic counsellors to the Canadian workforce.

Students applying to the genetic counselling training programs typically have a science background, many with an undergraduate degree or even a prior Master's degree in Science, usually majoring in biology or human genetics and often with a minor or sub-specialization in psychology. Occasionally students apply with a different background such as a degree in nursing, psychology, or medicine. While a specific undergraduate degree is not necessary to enter most of the genetic counselling programs, key coursework in biochemistry, human genetics, embryology, psychology and /or statistics are typical requirements. In addition, applicants are expected to have worked or volunteered for a significant amount of time in a setting providing crisis counselling and/or psychosocial support to adults.

Once students are enrolled, their didactic coursework covers a wide range of topics such as core principles of human genetics, application of genetic principles to medical genetics, practice of clinical genetics, risk assessment and communication, psychosocial aspects of genetic counselling, philosophy of genetic counselling and consideration of the ethical, legal and social principles that guide the practice, public health principles and general information on the delivery of healthcare, as well as teaching and research methodologies.

This coursework is complemented by the clinical rotations that expose students to a wide range of clinical settings where genetic counselling takes place. There are core rotations in general genetics (paediatric and adult settings), prenatal genetics, and cancer genetics as well as exposure to a variety of specialty clinics that may differ depending on the training program (e.g. multidisciplinary clinics for cleft lip/palate, skeletal dysplasias, neurofibromatosis, neuromuscular conditions, inborn errors of metabolism). Students progress through rotations lasting 4 to 8 weeks in the different areas, actively involved with patients from the beginning of their training, completing the tasks that their level of training permits and building on their clinical skills as they gain exposure. These rotations are closely supervised by a genetic counsellor, who will debrief with students after each clinic. Feedback sessions with the supervisor is seen as an integral part of the learning process, is targeted to the student's training level, and aims to ensure that the student develops the core competencies required to practice as a genetic counsellor by the end of their training program. Successful completion of the program requires that the student demonstrate competence in both the didactic and practical aspects of their training.

#### *Accreditation of training programs*

While it is recognized that accreditation of training programs can provide an assurance of the quality of the training received, currently there is no Canadian accreditation body for training programs in genetic counselling. However, most of the Canadian training programs for genetic counsellors have sought accreditation through the American accrediting body.

Genetic counselling programs in the United States and Canada were initially evaluated and accredited by the ABGC, but this task is now under the control of a new organization called the Accreditation Council for Genetic Counseling (ACGC). Graduation from an accredited program is a requirement for eligibility to sit the ABGC certification examination, and plays a role in determining eligibility to sit the CAGC certification examination, as outlined in the following section. Accreditation of genetic counselling programs is based on the affiliation and structure of the program, its direction and its resources for both teaching and clinical supervision, its curriculum and its policies for admission and evaluation of students. The current accreditation

requirements were implemented for all programs on June 1, 2014<sup>24</sup>. Accreditation is granted for a finite period and must be renewed as specified by the ACGC. Currently, there are 32 American programs and 3 Canadian programs (McGill University, University of Toronto and University of British Columbia) that are accredited by the ACGC.

## **Certification**

Certification or eligibility to become certified is currently a requirement or a strong recommendation for genetic counsellors seeking to work in most clinics in Canada and in the United States. Currently in Quebec, the job title 1539 for genetic counsellors requires a Master of Science in genetic counselling. Most recent postings for positions in the province have requested certification or eligibility for certification; however, some stated that certification was preferable but not essential and rarely, a position was described without any mention of certification.

Certification is achieved by passing a board examination. Canadian genetic counsellors are often certified both in Canada (by the CAGC) and in the United States (by the ABGC), in part because CAGC certification only became available in 1998 and genetic counsellors trained prior to this were encouraged to sit the American certification examination. The practice of dual-certification persisted beyond 1998 because one of the requirements for program accreditation was to have ABGC-certified supervisors. It was only in 2012 that the accreditation body accepted that CAGC certification was sufficient for accreditation purposes. This may reduce the number of Canadian genetic counsellors seeking ABGC certification; however, ABGC certification is still a requirement to work in the United States and, while most Canadian employers ask for certification, many currently recognize both the ABGC and CAGC credential. Therefore, having both CAGC and ABGC certification can afford a Canadian genetic counsellor the flexibility to work in either country.

The ABGC certification examination is open to graduates of MSc genetic counselling programs accredited by the ACGC and is offered twice a year. The Canadian examination was initially offered every 3 years, but as of 2007 it has been offered on a biennial basis. The examinations have been validated and the questions are based on the respective core competencies of each organization.

There are two pathways by which a genetic counsellor may apply for the CAGC examination. The first pathway is for graduates from a MSc genetic counselling program that is accredited by the ACGC. This process is streamlined because the programs have already undergone a rigorous evaluation process to achieve accreditation. The second pathway is for graduates of a non-accredited program and requires that the genetic counsellor provide a curriculum vitae as well as a detailed description of their training program (course content, clinical rotations, professional activities). Regardless of the pathway used, the genetic counsellor must also submit a logbook detailing their involvement (during training) in 50 genetic counselling cases, letters of recommendation and their transcripts and proof of graduation<sup>25</sup>.

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<sup>24</sup> See the ACGC Standards of Accreditation for Graduate Programs in Genetic Counseling: <http://gceducation.org/Documents/Standards%20Final%20approved%20Feb%202013.pdf>

<sup>25</sup> See the CAGC Certification Handbook 2017 Examination: <https://www.cagc-accg.ca/doc/CertificationHandbook2017Updatedforonline.pdf>

Genetic counsellors who pass the Canadian examination can use the English title “Canadian Certified Genetic Counsellor (CCGC)” or the French title “Conseiller ou conseillère en génétique agréé canadienne (CGAC)”. The title and credential associated with the ABGC certification is “Certified Genetic Counselor (CGC)”.

#### *Maintenance of certification*

Once certified, a genetic counsellor must maintain certification through a process of continuing education, applying for renewal of certification every 5 years for ABGC<sup>26</sup> and every 10 years for CAGC. The process is similar for both CAGC and ABGC. The counsellor can either opt to re-write the examination after this time period or can choose to submit proof of sufficient continuing education credits by the end of the time period<sup>27</sup>. These credits can be accrued through attendance at recognized conferences and other educational forums (continuing education credits, CECs) and through employment as a genetic counsellor, supervision of students and/or teaching didactic coursework (continuing practice credits, CPCs). In Canada, a total of 150 credits are required over the 10-year period, with a minimum of both CPCs and CECs.

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<sup>26</sup> Formerly ABGC certification was valid for a period of 10-years. Counsellors who were certified in 2007 or prior are still on the 10-year program but as of 2017 all counsellors will be re-certifying every 5 years.

<sup>27</sup> See the CAGC Recertification Protocol, updated February 2016 : <https://www.cagc-accg.ca/doc/Recertification%20Protocol%202016%20English.pdf>

# Aspects of the work that pose a potential risk to the public

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We have outlined the specialized skills that a genetic counsellor must have and the training requirements for developing those skills and maintaining the knowledge required to practice. Now we will address directly the aspects of the profession that could harm the public if not practiced as outlined in the code of ethics and competencies published by the CAGC.

## ***Autonomy in the workplace***

Clinical genetic counsellors work closely with medical geneticists or other physicians but they perform many of their roles with a **high degree of autonomy** and are rarely directly supervised during patient encounters. This autonomy is critical in ensuring that genetics departments, with limited resources available, can provide adequate and timely service in the face of an ever increasing demand. By working autonomously, the counsellor can meet with individuals in an appropriate setting and with the time necessary to provide appropriate genetic counselling, and will also have the time to follow-up with the family in terms of discussing test results, meeting with relatives at risk and/or responding to any emerging concerns or questions that the family may have. This in turn allows the medical geneticist to concentrate on cases requiring diagnostic evaluation, which improves access to both types of genetics professionals. It is highly appropriate that genetic counsellors work autonomously given the specialized training that they receive before entering the workforce and the continuation of their education on the job. The autonomy associated with the profession highlights a need for regulation to ensure that those using the title of 'genetic counsellor' truly have the competence to provide appropriate and comprehensive genetic counselling.

As the core competencies demonstrate, genetic counsellors are trained to provide all aspects of genetic counselling autonomously and they are also trained to recognize and respect the boundaries of their scope of practice (eg. recognition that making a diagnosis or ordering medical tests are medical acts and restricted to medical doctors).

- ◆ A genetic counsellor generally does their own independent case preparation, including research into the impact of a genetic test result, the medical management that might be recommended based on that result, any additional testing options, and calculating any relevant recurrence risks to be discussed with their patient. The counsellor typically meets with the physician they are teamed with prior to a counselling session and is often the one recommending a particular approach based on their case preparation. Depending on the level of experience of the genetic counsellor and the nature of the team dynamic, the discussion with a physician prior to seeing the patient may be brief or extensive. Cases that are more focused on management often require more discussion with the physician to outline the plan and testing options to be discussed with the patient, whereas cases focused more on family counselling and recurrence risks may only require brief review.
- ◆ Once in the room with the patient, the counsellor is typically alone to discuss all of the relevant topics and to provide appropriate psychosocial support. While the physician remains available should issues arise, they are almost never called into a genetic

counselling session, in part because of the competence of the genetic counsellors but also due to a recognition that this division of labour is essential in order to optimize patient care and to allow for the physician to see their own patients who need a medical genetics evaluation rather than genetic counselling alone.

- ◆ When a session is complete, the genetic counsellor typically writes their own chart notes and letters. Whether the letters are co-signed by the physician will depend on the specific institution, the specific circumstances of a case, and/or the degree of trust that develops between a particular physician and counsellor. In most cases a co-signature is required when a letter is outlining a new diagnosis or new medical management recommendations as these go beyond the scope of practice of a genetic counsellor, whereas a letter that is focusing on outlining recurrence risks and reproductive options may only be signed by the genetic counsellor as these tasks fall well within the core competencies.

Beyond this routine degree of autonomy, sometimes medical acts may be informally delegated to a genetic counsellor by the physicians they work with, either on a case-by-case basis or more formally through inter-professional protocols within their institution, typically done in order to facilitate the flow of patient care within the clinics. This again speaks to the degree of trust between genetic counsellors and the physicians they work with. It also speaks to the ever-increasing degree of autonomy with which a genetic counsellor may practice and it can sometimes blur the lines between the scope of practice of a genetic counsellor and medical acts that they should not be performing unless specifically delegated.

- ◆ While a genetic counsellor cannot order genetic tests per se, they will often propose a particular test or testing algorithm to the physician with whom they work based on the counsellor's review of the case file and the literature. After discussing this with the physician, the counsellor will autonomously carry out the plan, discussing the test options with their patient, obtaining informed consent, filling out the necessary paperwork, directing the patient to provide the necessary biological samples and ultimately calling the patient with the results and discussing the implications.
- ◆ Genetic counsellors in Nova Scotia work with delegated medical functions, approved through the province's College of Physicians and Surgeons in order to increase efficiency by recognizing and optimally using the training and skill set of the genetic counsellors within the healthcare system.
- ◆ As of now, Nova Scotia remains the only province with such delegated medical functions, although in other provinces there may be institutional-level protocols in place. As one example, in order to streamline an ever-increasing demand to provide a genetics evaluation for relatively common conditions such as hearing loss, developmental delay or autism spectrum disorders, the MUHC medical genetics department has developed inter-professional protocols that are initiated by the medical geneticist to allow a genetic counsellor to work independently to carry out the pre-approved algorithm, including ordering specific genetic tests in a step-wise manner.

## ***Ability of public to judge competence***

The **competence** of the individual representing themselves as a genetic counsellor will be difficult for most patients to judge. First of all, genetic counselling by definition centres on a discussion about often complex genetic concepts and unfortunately many individuals come to their counselling sessions with no knowledge of what to expect and without any frame of reference to help guide them as to whether the information being provided is accurate and complete. Although genetics is being incorporated into secondary-level biology courses in Quebec, retention of health relevant information is limited and thus the majority of the general public does not have a working knowledge of medical genetics.<sup>28</sup>

- ◆ A competent genetic counsellor will at some point in the session with a patient ascertain the level of background genetics knowledge that the patient has, and will typically include a “genetics 101” discussion to make sure that they are starting from the same reference point. Using terms like “chromosomes” or “variants of uncertain significance” without this framework can result in a lack of understanding or worse, a misunderstanding.

Second, many patients do not anticipate the “counselling” aspect of genetic counselling. Contracting to reach a mutually agreed-upon agenda, checking in with patients regarding their comprehension and well-being, and providing anticipatory guidance are all integral aspects of the services provided by a genetic counsellor. Yet these might not be missed by a patient if they are not provided, because the patient wouldn’t even know to expect these.

- ◆ The manner in which genetic information is conveyed, and the support that patients feel they received is as important as the information itself. Many patients have told genetic counsellors about their dissatisfaction with encounters with other health professionals who tried to provide them with genetic counselling. Many patients share their satisfaction after an encounter with a trained genetic counsellor, often mentioning the attention and support that they received at a time when they were learning about a genetic diagnosis or when they needed to make a difficult decision.
- ◆ What is not said in a genetic counselling session can be as important as what is said. Overwhelming a family with too much information about a new diagnosis is not beneficial and will likely lead to confusion and misunderstanding later on. Again, a trained genetic counsellor learns to look for verbal and non-verbal cues to evaluate how a patient is managing the information and then will adapt the session accordingly. Even more importantly, a counsellor will prepare for cases knowing that they must plan for this possibility and then actively work with the patient to decide what can be accomplished in the session.

Third, there are ethical considerations at play with respect to genetic testing that genetic counsellors are trained to recognize and respond to should the need arise. Patients are not usually aware of the historical moral or ethical debates or the literature that may support certain decisions based on the ethical principles that guide our society. Therefore, they may be unable to recognize when the ‘wrong’ thing is being done.

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<sup>28</sup> According to the Public Health Agency of Canada, 60% of adults and 88% of seniors in Canada are not health literate : <http://www.phac-aspc.gc.ca/cd-mc/hl-ls/index-fra.php>

Some of the more common ethical dilemmas that are encountered in a clinical setting include:

- Requests for genetic testing in minors
- Requests for reproductive sex selection
- Obtaining informed consent from minors
- Obtaining informed consent from individuals with intellectual disabilities
- Instances of genetic discrimination
- Conflicts that can arise between a sense of duty to warn family members of a risk vs. the need to respect each individual's privacy and autonomy
- Conflicts surrounding discovery of non-paternity and when and how to disclose such information
- Questions surrounding a sense of duty to recontact patients if new information becomes available and the difficulties that this presents, both ethically and logistically
- Questions about equal access to care and using resources responsibly
- The blurring lines between research and clinical testing

### ***Intimacy of relationship between genetic counsellors and their patients***

Those meeting with genetic counsellors are often in a vulnerable state, whether learning about a new genetic diagnosis in the family that threatens their desire to have more healthy children, dealing with a pregnancy at risk or consulting because of a recent diagnosis of a potentially hereditary disease in themselves or a close relative, to name just a few examples. Each of these situations will lead to a discussion about highly personal information. The relationship that develops between the genetic counsellor and their patient is often intimate and always involves support being provided by the counsellor to the patient in one form or another. In order for that support to be well-received, the genetic counsellor must build trust and rapport with their patient and the patient in turn must feel comfortable enough to discuss often sensitive and delicate information with the genetic counsellor. The counsellor must also consider the dynamics between those present during a session. Often patients come with close or extended family members or even friends who act as a support person, which is encouraged and important, but may change what can be discussed openly. There are times when a genetic counsellor may need to ask one or another individual to step out of the room to facilitate a discussion.

- ◆ Many patients walk into sessions with genetic counsellors without an understanding of why they were referred. They must depend completely on the counsellor to explain why they are being seen, what genetic counselling is and how the session will progress.
- ◆ The genetic counsellor will typically begin a session with a process called contracting, reaching a mutually agreed-upon agenda for the session with their patient. This allows the patient to have a say in what is or is not discussed at a particular session, and also hopefully starts the process of building rapport and trust. This is important in all genetic counselling encounters, but is particularly vital when discussing such sensitive topics as termination of pregnancy, non-paternity, or the imminent death of a child due to a genetic condition. The patient must trust that they can express their emotions and their beliefs with the genetic counsellor without being judged and without being directed towards any particular decision.

## **Confidential information**

All medical professionals deal with confidential information. Access to medical records is an integral part of caring for patients and respecting the regulations in place to control access to those records is a well-recognized principle in healthcare. However, when dealing with hereditary conditions there are added layers of complexity that must be recognized and respected because the information that we must access, and that we must document, can have implications not only for an individual's own health but also for the health of their relatives.

- ◆ Genetic counsellors may meet with members of an extended family over a period of months or even years. Knowing what information can be divulged to each family member, and ensuring that there is permission to share genetic test information is a very important part of the process. While some families openly share information with one another, in other families there may be complex dynamics that lead to a lack of open communication, or even an express desire not to share information with certain family members. Genetic counsellors work with families to decide how best to share risk information with relatives and generally encourage families to share the information themselves. It is rare that a genetic counsellor would breach confidentiality since it is typically hard to prove imminent harm in genetic conditions that often are not fully penetrant.
- ◆ It is often necessary to access records from family members in order to provide accurate genetic counselling for an individual. Genetic counsellors are trained to obtain appropriate authorization before reviewing records, whether the records are readily accessible through their own institution or need to be requested from an external source. In many areas of genetics, it is vital to obtain comprehensive records in order to assist in a genetics evaluation as any small detail may provide the key to a genetic diagnosis. At other times a request may be restricted to a particular imaging result or a genetic test result. In some circumstances, more than records are required. In hereditary cancer clinics, in particular, it is often necessary to obtain tissue samples or tumour blocks and to perform initial testing on those samples, which may be from the person consulting in medical genetics, or may be from a relative, alive or deceased.
- ◆ The family history that is routinely collected as part of a genetics evaluation will often have third party information that may be privileged. This applies equally to the chart notes that a genetic counsellor writes in order to document family history and the review of relatives' records and results necessary to provide ongoing care for the patient. As such these documents must be handled carefully in the medical record.
- ◆ In addition to third-party information, a genetic counsellor's chart note can often contain sensitive information such as a couple's feelings about a termination of pregnancy, or whether non-paternity may be an issue or their preferences in dealing with a palliative care situation for their child. Genetic counsellors also routinely inquire about and document whether a woman took drugs or alcohol during her pregnancy, whether she has had miscarriages or terminations of pregnancy in the past, and whether she or her partner have children with other partners. There are many considerations here, including when and how to ask such questions, respecting that a couple may not wish to divulge this type of information to others, and how to document the responses to avoid divulging highly confidential information that could potentially damage social ties in the future, for

example if an adult accesses their pediatric file and reads sensitive information that their parents disclosed during a genetic counselling session years before.

- ◆ Genetic tests can reveal information that was not the object of the testing. A patient may unexpectedly face the knowledge of non-paternity, or a health risk for themselves or others in their family. These situations require great sensitivity to confidentiality as each patient will choose to handle this information in their own way.

## Risk of serious harm to the public with lack of regulation

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The potential harm that could ensue if genetic counselling is not handled appropriately and provided by trained genetic counsellors who are certified to have the required core competencies to act in accordance with the practice guidelines may be very serious in some circumstances and less serious in others. The harms that are outlined below highlight not only medico-legal issues but also ethical and financial issues that could potentially arise without a professional order to regulate the profession.

### ***Wrongful birth***

One of the more obvious potential harms is that a couple is not given available information that would have impacted their decision about whether or not to become pregnant, or whether to continue or terminate an existing pregnancy. Either of these situations could result in the birth of a child with a serious condition that either results in an early death or in lifelong physical and/or intellectual disability. While some couples would embrace these challenges, others would not, and if the couple felt that they were misled or misinformed they could view this as a wrongful birth and a serious harm inflicted upon them by the person who provided the genetic counselling. Potential implications include:

- ◆ Immediate psychological distress as the couple faces a situation they didn't ask for, and that they would have tried to avoid if they had been given all of the facts. Ongoing distress as the couple faces any number of challenges, from decisions about palliative care or adoption/placement of the child to dealing with judgement from society, friends and family to coping with the daily grind of doctor's appointments and school meetings as they try to provide for their child or the grief that comes with the loss of a child.
- ◆ Loss of employment has been described by patients who are raising a child with a genetic condition because the parent is missing too much work to go to doctor's appointments.
- ◆ Divorce or separation has been documented as being more common amongst couples who have a child with a disability or a significant medical condition.
- ◆ Financial ramifications, for example with metabolic disorders where experimental therapies may be the only hope but are not covered by medicare and are rarely covered by private insurance.
- ◆ Lawsuit if the couple opts to pursue this avenue to seek compensation.

A trained genetic counsellor will take a detailed family history, will ensure that test results are interpreted accurately, and will discuss all relevant information and options with a couple so that the couple is empowered to make the best decision for them, no matter what that decision may be. Regardless of personal beliefs, a genetic counsellor will outline all options and will explore the couple's comprehension of the risks being discussed and their feelings about a potential

termination of pregnancy or the possibility of raising a child with a disability or losing their child at a young age.

### ***Wrongful termination of pregnancy or sterilization***

Another fairly obvious potential harm is essentially the opposite situation to the one just described, that a couple terminates a pregnancy based on the information they were provided or because they felt coerced in some way. Or that an individual decides to take permanent measures to avoid a pregnancy because of their perception of the risk, or again, because they felt coerced. Either way, a very permanent and difficult decision is made that will have lifelong ramifications, whether psychological, physical, or both. If that decision was based on incomplete or inaccurate information, an individual may consider this to be a harm inflicted upon them by the health care provider.

- ◆ Genetic counsellors have reported anecdotally that they have met with a woman who has already had a tubal ligation because she was “told to” or because she was told “there was no chance they could ever have a healthy baby”. The counsellor never truly knows what the woman was told in the past but, upon review of the file, they often have to disclose that the genetic risk would in fact have been 25 or 50%, depending on the mode of inheritance of the condition, and not the 100% they had previously been quoted. Genetic counsellors have witnessed women experiencing extreme distress upon learning that they had a 50 or 75% chance of having a healthy baby but that this is no longer an option for them. A meeting with a trained genetic counsellor, prior to making such decisions, could have led to a very different and more satisfying outcome for some of these women.
- ◆ Genetic counsellors also report meeting with parents of adolescent children with intellectual disabilities who ask to have their child sterilized to avoid the difficulties in dealing with puberty, menstruation and/or their developing sexuality. Such a request must be handled carefully, with a discussion including not only the short-term advantages perceived by the parents but also the minor’s rights and the long-term medical, social, ethical and legal consequences. A genetic counsellor’s training is highly suited to explore such concepts with the parents, and their code of ethics would lead them to seek additional help in addressing such requests.
- ◆ Another anecdotal account from a genetic counsellor describes a consanguineous couple who were double first cousins and told the genetic counsellor that their doctor told them they would never have normal babies when in fact the risk increase for this couple was 6-7%. Luckily this couple sought a second opinion, but others make irreversible decisions such as separation or avoiding having children altogether, which may not be culturally and socially acceptable.
- ◆ The thought of a wrongful termination of pregnancy is a terrible one, not only for the couple but undoubtedly for the health professionals involved as well. While any decision to terminate a pregnancy may be regretted by a couple, a wrongful termination implies that they could have avoided the decision completely, or would have made a decision to continue the pregnancy if they had been presented with facts that were available but were not discussed with them. A trained genetic counsellor would provide a thorough review for the couple, consulting with other experts as needed, to ensure they have complete

diagnostic and prognostic information, would take the time to explain any complex information and ensure a proper understanding, and would explore the couple's impressions and reactions and help them to make the decision that is best for them without being directive.

### ***Inappropriate surgical interventions or management recommendations***

The provision of genetic counselling will often involve a discussion about recommendations for medical management as well as any preventive measures that the individual may want to consider in an effort to reduce risks for certain health complications. Since many genetic disorders are very rare, there are not always established guidelines and the genetic counsellor must rely on what is available in the literature in order to try to determine the best information to provide to their patient. In general a competent genetic counsellor would recognize that this aspect of genetic counselling should involve a discussion with a medical geneticist or another specialist physician, who may be able to make additional suggestions in terms of management and prevention for the particular condition based on their medical expertise. But accounts exist where individuals have received genetic counselling from other healthcare providers and have then faced psychological and potential medical harm because they followed what may have been inappropriate recommendations.

- ◆ An anecdotal account from a genetic counsellor describes an individual who was found to have a variant of uncertain significance (VUS) on BRCA1/2 testing. This individual was not given their result by a genetic counsellor and it was not possible to confirm exactly what they were told by their health professional. The individual opted for bilateral mastectomy and oophorectomy, a management option available to women at high risk of breast and ovarian cancer associated with a pathogenic variant in BRCA. Future communication between the genetic counsellor and the patient's relatives revealed that the individual did not seem to know the difference between a VUS and a known pathogenic variant. Whether this knowledge would have changed the patient's surgical decisions is not known, but in some cases it certainly could. Counselling about a VUS is frequently performed by genetic counsellors and is quite challenging due to the complexity of the information being discussed and the subtle distinctions that must be made clear to the patient.
- ◆ It is worth elaborating here on the fact that interpretation of results and their implications is an integral part of the process of genetic counselling. Such interpretation is more and more complex as clinical testing is expanding more quickly than our knowledge and ability to accurately interpret results. Variants of uncertain significance pose a particular challenge to those trying to provide genetic counselling who are not trained as genetic counsellors or medical geneticists. One must assess and weigh the available data on a variant with the patient's clinical and family history to try to determine its likely significance for that particular patient and then determine the appropriate medical management. When the significance is truly uncertain, it is possible that no conclusion will be drawn. The patient must understand that knowledge could change in the future and be encouraged to remain in contact to learn of any changes or updates that could impact management.
- ◆ Genetic counsellors working in clinics testing for adult-onset conditions with debilitating and devastating symptoms must be particularly careful to assess for potential suicidal

ideation amongst their patients. In addition, discussions about new diagnoses or risks for health issues must be handled delicately and with a consideration for the patient's well-being. Checking in with patients and determining when enough information has been disclosed in a particular session is an important aspect of genetic counselling. Follow-up sessions, either in person, by phone, or by letter can be arranged and are a far better alternative than overwhelming a patient during a first encounter regarding a positive test result. In addition, anticipating complex psychological reactions to genetic test results and exploring with a patient how they might prepare themselves before they even do the genetic test can set the stage for a better discussion about those results and reduce the likelihood of major psychological trauma and/or suicide attempt. The practice guidelines for genetic counsellors include recognizing signs of distress beyond what is typical and knowing when to refer to an appropriate expert.

- ◆ One anecdotal account from a genetic counsellor describes a person who was tested outside of a genetics clinic for cystic fibrosis because of a family history and being told they were "not a carrier of the familial mutation". This person went about their life and their reproductive plans, reassured that they were not a carrier of this condition and therefore not at risk to have an affected child. They later met with a genetic counsellor for another reason and the counsellor, upon reviewing their file, recognized that the wrong test had been done - a panel of common cystic fibrosis mutations was run, but the familial mutation was not on that panel. The patient's carrier status was therefore in fact still unknown.
- ◆ Genetic counsellors communicate medical information to other health professionals within the scope of their practice, and often co-write medical management letters with the physicians they work with. Someone with a lack of competence could convey the wrong information, leading to mismanagement of the patient's medical follow up, either with too much surveillance or with inappropriate surgeries or interventions being discussed, or with too little care provided and potentially missing a significant health risk.

### ***Harm to relatives***

Most healthcare professionals are trained to treat the patient in front of them. However, when dealing with hereditary conditions it is essential to recognize that any information provided to an individual may impact other family members. While the primary duty may be to the individual in the clinic, it is vital to think about risks to relatives and explore options on how to convey that risk to them in an appropriate manner. By failing to consider the risk to other relatives there could be a potential for serious harm.

- ◆ For example, taking a 3-generation pedigree is standard of care in genetics clinics. Genetic counsellors are trained to interpret the information provided, to know when to address a potential risk for a hereditary condition, and to know when to request medical records to verify reported information. Failing to identify relatives at risk and informing an individual denies them the opportunity to inform that relative and denies that relative the opportunity to seek out their own information so that they can make an informed decision.
- ◆ One genetic counsellor reports seeing pregnant women who were not aware that having a nephew with an X-linked genetic disorder posed a potential risk to their own children. In

many centres boys with Duchenne muscular dystrophy are well-followed in terms of medical management but their parents are not often referred to a genetic counsellor to discuss the risks to their future children, as well as to those of their relatives.

- ◆ Taking time to explore options to share genetic test results with relatives, which can be difficult in some families, is important and can help the individual actually go through with the disclosure that could potentially save, or change, the lives of their relatives. In facilitating this process, the genetic counsellor will often use a range of counselling techniques to help their patient work through whatever difficulties they perceive. The counsellor will also recognize that each relative has both a right to be informed and a right not to know. In some cases a genetic counsellor will help by providing a neutral letter that can be shared with relatives so that they can each then decide if they want to seek out additional information.
- ◆ Relatives who feel they should have been informed may experience psychological distress and may feel that they were denied a right to make informed decisions about a particular risk. They may also be faced with a perceived wrongful birth situation, or they may have avoided having children their whole life based on a perceived risk, only to learn that genetic testing could have confirmed if they were truly at risk or not. They may face their own health risks and feel that some preventive measure might have been possible if they had been informed earlier.

### ***Inappropriate testing of a minor***

The issue of whether to test a minor or not, in particular for genetic information that will not have implications in childhood, has long been debated in the context of both predictive and carrier testing. A large body of literature exists on the ethics surrounding genetic testing in minors and it is generally accepted that such testing should not be done unless it would change medical management in childhood. This respects the child's right to make their own decision about testing when they are old enough to give their own informed consent.

- ◆ Genetic counsellors often meet with parents to discuss testing for their children and in some cases those parents may strenuously disagree with the stance of not testing the child. While these conversations may be difficult, the genetic counsellor's training provides the framework for the discussion so that parents can begin to understand the ethical principles at play and move beyond their own needs to consider the needs and rights of their child.
- ◆ There are many anecdotal instances where parents whose children were not tested through the genetics clinic will later approach a different health professional, not a genetic counsellor or a geneticist, who agrees to test the child with little discussion or thought of the implications. This child, who may test positive, now has no choice but to grow up knowing this information and dealing with any psychological distress, changes in parenting styles, or discrimination that may come from those results.

## ***Insurance or employment discrimination***

The potential issue of genetic discrimination is not regularly discussed by other health professionals with their patients prior to doing genetic testing. Many feel that with a socialized healthcare system in place it is not necessary to discuss such risks. However, discrimination does occur and currently there is no protection in Canada against genetic discrimination. The NSGC and the CAGC have issued statements against genetic discrimination, showing how relevant this topic is and how necessary it is to protect the public.<sup>2930</sup> While no legal protection is in place, the risk can be minimized by informing the public and, in particular, informing those undergoing genetic testing so that they can make an informed choice. Genetic counsellors are trained to recognize this risk and to discuss it with all of their patients, although this is typically more relevant in the context of pre-symptomatic or predictive testing. Unfortunately in other clinic settings this topic is rarely discussed, and as clinics get busier and busier, with less and less time spent on informed consent, key issues like this one may be omitted altogether, either from lack of awareness of the issue or because of the time constraints.

- ◆ Genetic counsellors have heard from patients who have been denied all forms of insurance in Canada (medical, life, long-term disability, travel and mortgage) based on genetic test results that in some cases do not pose any risk for health complications for that individual (e.g. carrier status for cystic fibrosis, an autosomal recessive condition) and in other cases pose only a potential risk for health issues (e.g. breast cancer predisposition). If a person undergoes genetic testing without having been informed of this potential risk, then they could suddenly be faced with unexpectedly high insurance premiums or, in some cases, being denied insurance altogether.

## ***Psychological distress***

Genetic counsellors, like all health professionals, are guided by the core principles of medical ethics: beneficence, non-maleficence, autonomy and justice. The genetic counselling interaction is rather unique in that it integrates the communication of core medical knowledge with a process of non-directive counselling to support a patient in their decision-making process. In addition, the information and its psychosocial impact do not affect only the individual in front of them, but also their family members – their children, their siblings, their parents. Genetic counsellors must balance the core ethical principles in the care of every family. Otherwise there are serious risks for psychological distress, potentially suicidal ideation, social stigmatization, crises of faith and strained social relationships.

- ◆ Consider the situation where genetic counselling is being provided in a setting where a child is in the room with the parents and the genetic counsellor must ask questions that may be inappropriate to discuss in front of a child, or documenting information in the child's file (in a pediatric setting) that the child can access as an adult, leading to distress for child and/or parents and a breach of confidentiality and trust. Such topics could range from non-paternity to asking about consumption of drugs or alcohol during pregnancy to

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<sup>29</sup> National Society of Genetic Counselors, "Nondiscrimination position statement", June 1, 2011, <http://nsgc.org/p/bl/et/blogaid=32>

<sup>30</sup> Canadian Association of Genetic Counsellors, "The public needs to be protected from genetic discrimination", press release, December 13, 2012, [https://www.cagc-accg.ca/doc/cagc%20gd%20press%20release%20final\\_v2.pdf](https://www.cagc-accg.ca/doc/cagc%20gd%20press%20release%20final_v2.pdf)

questions about an undisclosed adoption or the use of assisted reproductive technologies. They could also involve asking the parents how they feel about terminating a pregnancy with the same condition as the child in the room, or providing distressing information about the child's health risks without first checking to see if the child is aware of the condition, if the parents have discussed anything with them yet and if the parents feel the child is ready to learn more.

- ◆ One anecdotal account comes from a family who were fortunate to meet with a trained genetic counsellor to discuss their child's diagnosis of neurofibromatosis. The genetic counsellor used their training to contract and ascertain that the child knew the name of the diagnosis but that the parents were not yet prepared to speak to the child directly about the diagnosis due to their young age. During contracting, it was agreed that the child would step out of the room with a guardian while the counsellor met with the parents. Some of the topics discussed included the timing of disclosure to children with genetic conditions, the level of information that is appropriate at different ages, the resources available to help the parents discuss the diagnosis with the child, and the child's access to the internet, which could result in the child seeking their own information if the parents withheld too much for too long. This approach avoided a breach of the parents' trust, a potential psychological harm in discussing too much too quickly with the child, a potential psychological harm if the parents withheld information for too long from the child, and a potential distress if the child searched the internet for neurofibromatosis and found incomplete or inaccurate information.
  
- ◆ As stated previously, counselling in a group setting, either with multiple family members or with strangers with a similar indication for counselling also requires a genetic counsellor to carefully handle what is discussed to avoid any breaches of confidentiality or trust.
  
- ◆ Another anecdotal account from a genetic counsellor describes meeting with a separated couple being tested for cystic fibrosis carrier status because their daughter was found to have two mutations. The genetic counsellor provided information, including the potential for mutations to be in cis or trans orientation (on one allele or on two different alleles), and explored whether non-paternity could be an issue for this family during the test consent process since this would impact the results. The woman was tested first and neither mutation was identified, which made it likely the father would have both in a cis orientation and that both he and his daughter were carriers of cystic fibrosis. Since the man lived in another province testing was coordinated by sending a letter asking that he be tested specifically for the 2 particular mutations found in the child. The next call to the counsellor was from the woman who was extremely distraught because her ex-partner had received his result from those who arranged the testing, with no genetic counselling provided, and because neither mutation was found he was cutting off child support because he took this as proof that he was not the child's father. Ultimately, the counsellor was able to review the man's results and determine that the wrong test had been ordered, a panel test that did not include either of the mutations found in the child. The counsellor directed the local clinic to order the correct test and discussed the error with the couple, encouraging them to await this result before making any decisions. The man did in fact carry the two mutations, which not only provided him and his new partner with information about potential risks to their children, but also removed any doubt of paternity. While this couple experienced harm in terms of psychological distress and additional stress on already tenuous social ties, ultimately the fact that a trained genetic counsellor

was involved likely diminished what could have been a much more difficult situation. In the end both parties were satisfied with the information provided and were frustrated that the wrong test had been done, the only aspect of this that could not be directly managed by the genetic counsellor, despite her efforts to guide the other clinic in ordering the appropriate test.

- ◆ Genetic counsellors have countless anecdotal stories about patients who arrive for a counselling session and begin by quoting misinformation that they received from other healthcare professionals. Consider also the patients who are receiving information without context, or without appropriate psychological support. It cannot be known whether the patient misunderstood or whether the healthcare professional actually provided the wrong information. It is possible that the way the information is conveyed plays a role in comprehension and a trained genetic counsellor, who can take the time to fully explore the information with a patient and who can provide a psychosocial support framework during the discussion, will be better able to ensure that patients understand what is being discussed and can make informed decisions based on that understanding.

### ***Harm that can come from a lack of informed consent, or informed refusal***

A consent, or a denial of consent, that is not informed can have serious repercussions for the patient, including a decision not to proceed with a test or procedure without fully understanding the ramifications, or vice versa, to opt to do a test or procedure and receiving results later that were not wanted and that the patient is ill-equipped to handle due to their circumstances.

- ◆ A genetic counsellor recognizes that it is vital to explain to a patient being offered certain genetic tests that the test could reveal non-paternity, could identify an unexpected health risk for the person being tested with associated risks for relatives, or could report back a result whose significance is uncertain. Each of these circumstances can lead to an increase in anxiety and frustration in the patient, and can potentially lead to discrimination. This is why an informed consent process is so important.
- ◆ Genetic counsellors often meet with patients regarding results from tests ordered in other departments and it is rare that they are aware of any of the possible outcomes of such testing. Restricting genetic counselling to those trained to understand the importance of such concepts would help to protect the public from such harm.
- ◆ Obtaining informed consent must be an active process that involves checking in with patients to make sure they have understood what was said to them, that they have asked their questions, and that they voluntarily give authorization to proceed. Certain patients, whether for cultural reasons or for their confidence in the medical system, assume that they must sign any consent form and will often do so blindly if they are allowed.

### ***Unequal access***

Demand for genetics services is increasing every year, with more and more genetic tests available, and more and more value being perceived by the public in terms of knowing about their genetic risk factors in a context of provision of more personalized health care. Alongside

the medical geneticists, genetic counsellors play a pivotal role in making sure that the appropriate genetic tests are ordered, that members of the public understand what genetic testing can and cannot provide, and that those seeking the services of a genetic counsellor feel supported and listened to throughout the process and have a good understanding of the genetic risks to their offspring and other relatives and the options available to them, including any current limitations to our understanding. If the number of genetics professionals in the province cannot match the demand, and without any regulation of who can use the title of genetic counsellor, there is a growing risk that untrained persons will be providing genetic counselling. They will not be able to appropriately handle the inherent complexity and this will ultimately lead to more and more harm to the public.

- ◆ In the current system with a lack of regulation in terms of who provides genetic counselling and who can represent themselves as a genetic counsellor, some patients in Quebec are receiving care from an appropriately-trained and competent genetic counsellor while others are receiving care from other individuals who are likely excellent healthcare providers but who lack the specialized training that genetic counsellors receive. This exposes some of the public to all of the harms previously mentioned. This is happening in part because of the limited availability of genetic counsellors in Quebec, forcing patients to seek information elsewhere and perhaps discouraging health professionals from referring to genetics services knowing how long the wait may be. This is also happening because of a lack of awareness of the potential dangers associated with untrained individuals trying to provide genetic counselling.
- ◆ A professional order would provide recognition for the profession, would legitimize the competence of the genetic counsellors who become members of the order, and would hopefully give others a reason to stop and consider whether they are truly capable of providing genetic counselling to their patient or whether they should refer to a medical genetics clinic. This would also hopefully lead to more uniform access to genetic counselling across the province of Quebec.

### ***Financial harm for the patient directly, or to the public in general***

Studies have clearly shown that when genetic counsellors are involved in choosing genetic testing algorithms for patients, there is an increase in efficiency both in terms of cost and turnaround time to getting results.<sup>31</sup> This is vitally important in a publicly-funded healthcare system.

- ◆ Genetic counsellors are trained to be able to differentiate one lab test from another. A genetic counsellor will consider whether the test should target a single gene or cover multiple genes at once, as well as the appropriate technology to identify the mutation in question. The genetic counsellor is also trained to distinguish between a test that is targeted to particular mutations common in a population versus a more comprehensive test and to know which one is better suited to a particular patient. The genetic counsellor will also systematically compare different laboratories offering the same or similar tests in

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<sup>31</sup> C.E. Miller et al., "Genetic counselor review of genetic test orders in a reference laboratory reduces unnecessary testing," *American Journal of Medical Genetics Part A* 164, 5 (2014).

order to find the most cost effective option that will provide the optimal results. They will also check for local testing before considering out-of-province or out-of-country options.

- ◆ Another potential financial harm recently came to light when several patients disclosed to their genetic counsellor that they had been directed to seek out international genetics labs themselves and pay for testing out-of-pocket if they wanted to find out more about the genetic basis of their condition, or their child's. They were given documentation that they shared with the counsellor that gave some information about the condition, the potential genetic causes, and a list of labs where testing was available. They reported never to have been told that they could also be tested through a medical genetics clinic and that typically the costs would be covered by medicare. There was certainly no mention of this on the documentation they were provided. These families sought genetic counselling because they paid for testing themselves (often \$1000 or more) and had received a result that mentioned that the result should be discussed with a genetic counsellor. Upon review, all of the testing could have been covered by medicare and, in one case, it turned out that the test they paid for was not the optimal test that would have been recommended and this family had to undergo additional testing to complete the evaluation.

# Moving towards a professional order for genetic counsellors

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There is currently no mode of regulation for genetic counsellors in Quebec or elsewhere in Canada, but in the United States more and more states are licensing genetic counsellors and in France their legislature legally recognizes the genetic counsellor as a professional and provides protection of title as well as exclusivity of practice.

As a profession, Canadian genetic counsellors have already developed a code of ethics as well and competencies that could be converted into a scope of practice as would be required in the context of a professional order. We also have access to four Canadian training programs, two of which are in Quebec, and have established that a Master's in genetic counselling is the minimum necessary requirement to work as a genetic counsellor. Certification is also available through a Canadian exam that is offered in both French and English. Whether certification should become a minimum requirement will require further discussion, but many genetic counsellors feel that this credential should be required, certainly for all future employment.

Within Quebec, we have the support of the majority of genetic counsellors in Quebec to pursue the creation of a professional order. We gave a webinar in 2015 that was well attended and we also led a discussion at the 2015 annual general meeting of the QAGC that ended with a majority vote to support the submission of this document. We also have the encouragement from many of our medical geneticist colleagues and have informed both the CMQ and the Association des médecins du Québec (AMGQ) of our intent to relaunch this process. Finally, we have long-standing support from the CMQ, the CAGC and the NSGC to try to establish a professional order.

Currently within our profession we rely on our certification exams, our competencies and our code of ethics to ensure that those trained as genetic counsellors have the training and the abilities required to do their job in a professional manner. We cannot prevent others from using the title of genetic counsellor without the training, or verify that the so-called 'genetic counselling' provided by those without this training is accurate and complete. A professional order and title protection, as well as certain delegated medical acts, would go a long way towards protecting the public from harm.

Self-regulation through a professional order is the method of choice in Quebec for providing protection to the public and regulating professionals in most allied health professions. We feel that the public would benefit from this mechanism being implemented for genetic counsellors as well. We feel that the training involved in becoming a genetic counsellor and the types of skills and personalities that genetic counsellors often have would be well suited to the day-to-day running of a professional order and in handling any complaints made against those working under the title of genetic counsellor.

We have considered whether we could try to fit within an already established professional order but upon reviewing the scopes of practice and mandates of a number of professional orders, we do not feel that this would be possible given the highly specialized nature of our profession. We hope that this document has highlighted just how specialized our profession is in terms of our work with genetic disease, with families as our patients, and with short-term patient-centered counselling at the core of our work. We are not physicians nor are we nurses. We do provide counselling, but we are not psychologists and do not infringe on their exclusive medical acts.

We work with pregnancies, but we are not midwives. We work with individuals struggling with their sexual identity, but we are not sexologists. And while we are not trained for any of these professions and do not present ourselves as such, nor do any of these professionals have the training to be genetic counsellors.

We do feel that it may be possible to share some resources with a larger, pre-existing order, as a means of financial savings. We note that certain orders have a shared website and headquarters but still retain their individuality. As a small group we would welcome an opportunity to keep the costs of running a professional order to a minimum. We would welcome the Office's suggestions as to which order we might pair up with in such an arrangement.

In terms of running a professional order, our hope is to use volunteers for as many of the positions in the Order as possible and, as a small group, to keep to the absolute minimum the number of positions to fill. Our profession has run on volunteerism from the beginning and we have reason to believe that most, if not all, counsellors in Quebec would participate in this endeavour as much as possible. All of the accomplishments for genetic counsellors to date have been achieved through volunteer work, including the CAGC competencies and code of ethics.

We are aware that the financing of a professional order will be a burden given how few counsellors there are in Quebec at the moment. As stated previously, we are prepared to be paired with another professional order in order to share some of the overhead costs for the headquarters and website. In many ways we can compare ourselves to the Midwives who had similar numbers (56 according to their website) when work began on the creation of their professional order. Many of us have worked closely with midwives and recognize a similar level of risk to the public from lack of regulation for our own profession as theirs. We hope that the Quebec government will be in a position to help genetic counsellors establish their professional order, as they did for the midwives and other orders. We must be honest in stating that without financial subsidization, the professional order dues would likely be prohibitive for Quebec genetic counsellors now and in the near future.

## Conclusion

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Genetic counsellors across Canada are feeling pressure to protect the public. While each province works towards regulation, such as the professional order system in Quebec, the CAGC is evaluating whether other options exist at the national level that could serve as temporary measures aimed at providing some reassurance to a nervous public. It is clear, however, that regulation of genetic counsellors needs to move forward at the provincial level in order to offer the best protection to the public.

In 2010, a lawyer who has since started working closely with the Genome Centre and the Medical Genetics Department of the McGill University Health Centre submitted his thesis work that was based on research into whether or not genetic counsellors in Quebec should be regulated by a professional order. While we may not agree with all of his descriptions of the role of a genetic counsellor, we do applaud his conclusion, which was that genetic counsellors meet all of the conditions for a professional order and that the small number of counsellors should not prevent the creation of an order.

« Quant à la nécessité de créer un ordre professionnel, il n'y a aucun doute que le conseiller en génétique répond aux exigences prévues au Code des professions pour une telle reconnaissance. De plus, la création d'un tel Ordre professionnel...est une condition sine qua non d'une reconnaissance législative dans le Code des professions. Il est vrai que les conseillers en génétique ne sont pas nombreux au Québec, mais cela ne devrait pas être un obstacle à la création de leur ordre professionnel. À titre d'exemple, les sages-femmes ont leur propre ordre professionnel au Québec et elles ne sont que 131. »<sup>32</sup>

In 2014, a report from the Commission de l'éthique en science et en technologie recommended that the Office des professions regulate genetic counsellors through the creation of a professional order in recognition of the fact that health professionals providing genetic counselling need to be sufficiently trained in order to provide accurate information and interact appropriately with patients with hereditary conditions.

« Considérant que les professionnels de la santé doivent être suffisamment formés en génétique pour conseiller, informer et traiter de façon appropriée les patients aux prises avec une maladie à composante génétique, la Commission recommande (recommandation n° 4): Aux ordres professionnels et aux universités québécoises d'inclure dans leurs cursus destinés aux futurs professionnels de la santé une formation en génétique suffisante; Aux ordres professionnels d'offrir à leurs membres un perfectionnement continu en génétique; À l'Office des professions d'encadrer la profession de conseiller en génétique. »<sup>33</sup>

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<sup>32</sup> Ma'n Hilmi Mohammad Zawati, « La responsabilité civile des conseillers en génétique au Québec et les conséquences juridiques de la non-reconnaissance: vers un encadrement juridique? », Mémoire présenté à la Faculté des études supérieures en vue de l'obtention du grade de Maîtrise en droit (LL.M.), Août 2010.

<sup>33</sup> Commission de l'éthique en science et en technologie. Les soins de santé « personnalisés » : prudence et balises, (Québec : Gouvernement du Québec, 2014), p. 45.

These recommendations in combination with the government recognition since 2004 of a need to expand and better manage genetic services in Quebec, serve as evidence that the pressure to create a professional order for genetic counsellors is not only coming from within the profession, but from without as well.

What has changed from 2001 to now that makes us think a professional order should be reconsidered? First, the growth in the number of counsellors in the province and the projections that suggest continued growth in the future. Second, the recent changes to the legislation that have enabled other medical professionals to have “delegated or dedicated medical acts”. Third, the above recommendations from outside parties to regulate our profession. Fourth, the increase in anecdotal reports from patients to genetic counsellors about their dissatisfaction with the so-called genetic counselling they had received outside of the Medical Genetics services, from health professionals who were not trained as genetic counsellors and who were not mandated to follow our code of ethics or our competencies.

In conclusion, genetic counsellors are skilled specialists who are often working autonomously in clinical situations with access to highly confidential information and meeting with vulnerable clientele who are generally not in a position to judge if the person with whom they meet is a trained and qualified genetic counsellor or not, or if the information being conveyed is incomplete or even erroneous. In terms of protecting the public, the creation of a title with salary scale in Quebec was a good beginning. The creation by the CAGC of a code of ethics and practice- and knowledge-based competencies to be used as a scope of practice was another important step. But we must continue to move forward in regulating the profession of genetic counsellors in Quebec through the creation of a professional order.

We thank you for your consideration.

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