



2014

ANNUAL NEWSLETTER



Canadian Association of Genetic Counsellors Association Canadienne des Conseillers en Génétique



MESSAGE FROM THE CHAIR

This is our third annual newsletter and we are pleased to provide you with updates on projects undertaken by our dedicated CAGC member volunteers in the past year.

In 2013, CAGC continued to improve communications for our membership and the public. We issued a press release about our Position Statement on Genetic Discrimination, which coincided with the reading of a private member's bill in Parliament about the same topic. On the social media front, we joined Twitter and saw a significant growth in our Facebook posts and followers. In addition, we are in the process of revamping our website to make it friendlier for both members and the public. We are hoping that all of these efforts in communications will increase awareness of our professional organization as we continue to work toward our mission.

I hope you will see from this newsletter the exciting work that our members have engaged in during the past year. Interest in our profession continues to grow each year, as both the healthcare professions and the public see the value of genetic counselling expertise. We have big goals and foresee tremendous opportunities to contribute to the fields of healthcare, policy, and research in the years ahead. CAGC's strength lies in the passion of our members to continually improve our practice in helping Canadians utilize genetic information and technology.

Sincerely,

Julie Rutberg, MSc, CGC
2013 CAGC President

MISSION STATEMENT

The mission of the Canadian Association of Genetic Counsellors is to promote high standards of practice, encourage professional growth and increase public awareness of the genetic counselling profession in Canada.

2014 BOARD OF DIRECTORS

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CANADIAN CERTIFIED GENETIC COUNSELLORS: QUALIFIED AND COMPETENT GENETIC COUNSELLING SERVICE PROVIDERS

The Canadian Association of Genetic Counsellors (CAGC) Certification Board is committed to ensuring that members of the Canadian public are receiving genetic counselling services from health care professionals with a standard level of knowledge, skills, attitudes, and judgement. Genetic counsellors granted the credential CCGC (Canadian Certified Genetic Counsellor) and/or its French equivalent CGAC (Conseiller(ère) en génétique agréé(e) du Canada), have demonstrated these standard knowledge and practice competencies.

CAGC CODE OF CONDUCT

For the past two years, the CAGC Task Force for the Professional Development of Genetic Counsellors in Canada has been developing a Code of Conduct for Canadian genetic counsellors. Whereas a professional body's Code of Ethics focuses on ethical principles by which we abide, a Code of Conduct shifts the focus onto behaviours that promote professionalism. Our goal has been to create a Code of Conduct for Canadian genetic counsellors that provides clear, illustrative guidance regarding expected professional conduct. It is grounded in the principles laid out in the CAGC Code of Ethics and Core Competencies. When incorporated into daily practice, the Code of Conduct is expected to minimize risk of harm to the client and contribute to excellence in professional practice. The proposed Code of Conduct focuses on five targeted behaviours – respecting autonomy and diversity, protecting personal health information, practicing competently, acting professionally, and maintaining personal well-being. We look forward to sharing it with the greater membership and assimilating their feedback.

Look for the **CCGC** –
Canadian Certified Genetic
Counsellor – designation for **quality**
and **competence**
in genetic counselling.

THE CAGC AND GENETIC DISCRIMINATION LEGISLATION IN CANADA

In December 2012, the CAGC published a Position Statement on Genetic Discrimination (the full statement can be found on the [CAGC website](#)). In May 2013, in light of some new legislative progress around genetic discrimination, the CAGC issued a [press release](#) in order to highlight our Genetic Discrimination Position Statement and our organizational support

WHAT IS A GENETIC COUNSELLOR?

Health professional with specialized training and experience in the areas of medical genetics and counselling who:

- Provides individuals and families with information on the nature, inheritance, and implications of genetic conditions to help them make informed medical and personal decisions
- Helps people understand and adapt to genetic conditions including seeking appropriate medical management and surveillance
- Provides supportive counselling and connects people to resources

for the development and implementation of legislation to protect the Canadian public from the unfair use of genetic test results or family history information.

As is outlined in our statement, Canada is currently the only G8 country that does not have laws in place to protect the public from the misuse of its citizens' genetic information. However, there is significant progress being made. In large part due to the lobbying efforts of the Canadian Coalition for Genetic Fairness (CCGF), the lobbying commissioner has recommended that there be anti-discrimination legislation in Canada.

In 2013 Libby Davies, the Member of Parliament for Vancouver East, BC sponsored the private member's bill calling to amend the Canadian Human Rights Act to add genetic characteristics as prohibitive grounds for genetic discrimination. In 2014, Senator James Cowan, Liberal leader in the Senate, sponsored the second reading of Bill S201- An Act to Prohibit and Prevent Genetic Discrimination.

The Office of the Privacy Commissioner of Canada has recently issued a statement on the use of genetic test results by life and health insurance companies recommending that life and health insurance companies refrain from asking genetic testing questions until this information can be shown to be necessary and effective. The Prime Ministers office has officially supported the Privacy Commissioner's recommendation.

Bill S201 has now been referred to the Standing Senate Committee on Human Rights. A hearing has been scheduled in Ottawa for late October 2014. We are pleased to report that the CAGC will be represented at the October hearing by Clare Gibbons, former CAGC president and Julie Rutberg, Past President I. The CAGC is excited that progress is being made to help protect Canadians from genetic insurance discrimination and are thrilled to be playing a vital role in this initiative.

2013 CAGC ANNUAL EDUCATION CONFERENCE A HUGE SUCCESS

The 2013 CAGC Annual Education Conference (AEC) was held in Toronto in November 2013. Attended by an astounding and unprecedented 210 delegates, it was a huge success! The conference kicked off with an inspiring keynote address from fashion photographer [Rick Guidotti](#). He captivated the room with his photography and stories of the beauty in genetic diversity. The Scientific Planning Committee filled the week with an incredible educational program, back-to-back practice specific workshops, abstract sessions, plenary talks, and joint symposia with the Canadian College of Medical Genetics (CCMG). Other events included a screening of the award-winning documentary [65 RedRoses](#) at the Toronto International Film Festival (TIFF) Bell Lightbox (sponsored by [Centogene](#)), the annual CAGC banquet held at a restaurant in the hip King Street district, and a fun week-long photo scavenger hunt.

Mark your calendars!

The 2014 AEC will be held in Vancouver, B.C., from November 5 – 8, 2014. The Short Course will be on November 4th on the topic of Clinical Integration of New Technologies. For more details on the upcoming conference please visit <http://cagcconference.ca>.



LEXIGENE: A UNIQUE CAGC TOOL FOR YOUR PRACTICE

Lexigene is the English-French genetic counselling lexicon funded by the CAGC that was launched in 2011. We are proud to announce that as of June 19, 2014, Lexigene is now registered as a CAGC trademark at the Canadian Intellectual Property Office. Trademarking Lexigene in Canada ensures that the CAGC maintains intellectual property over Lexigene. The process of trademarking Lexigene at the United States Patent and Trademark Office is still underway.

JOIN CAGC ON FACEBOOK AND TWITTER!

Over the past year, the number of "likes" for the CAGC Facebook account have more than doubled from 160 to almost 400. We are receiving posting suggestions every month from genetic counsellors and the public about events or articles that matter to them.

The CAGC Facebook page isn't the only thing generating a buzz. Accompanying the launch of the [@CAGC_ACCG](#) Twitter account, genetic counsellors lit up Twitter with the [#CAGC2013](#) hashtag during the Toronto AEC. With the help of the social media workshop facilitated by Allison Janson Hazell ([@alliejanson](#)) and Christine Davies ([@CHDavies1](#)) many attendees were added to the ranks of tweeting genetic counsellors. Today, [@CAGC_ACCG](#) has over 300 followers and counting.

If you would like to post content on the CAGC Facebook page or Twitter, message the Facebook Page directly or email cagcsocialmedia@gmail.com.

New terms are also still regularly being added to the website by the Lexigene team. Bookmark Lexigene for future reference (www.lexigene.com) and send us your ideas through the feedback page!

Are you on Twitter? Follow us @Lexigene_CAGC to get updates on what is new with Lexigene!

REVAMPED CAGC WEBSITE: RESOURCES AT YOUR FINGERTIPS!

The CAGC is pleased to announce the release of our new website (<http://www.cagc-accg.ca/>). This site's design is modern and streamlined, with a more

user-friendly navigation. As well, the site is bilingual, with almost all public content available in both of Canada's official languages. Changing the website's language is accessible via a quick click in the upper right corner.

The site boasts a "Find a Genetics Clinic" feature, searching for a clinic based on name, city, province or speciality, allowing interested parties to find the nearest clinics for referrals, or the clinic closest to family members in other provinces to facilitate inter-provincial care. As well, the new website allows interested organizations to upload job postings or information regarding events that may be of professional

interest to the membership. The site also hosts important information regarding genetic counselling in Canada, such as the CAGC's Code of Ethics, Code of Conduct, and Practice and Knowledge Based Competencies, as well as articles about Assisted Reproduction, and Genetic Testing and Screening.

Keep an eye open for even more great features coming soon to the website! We hope that this updated site will allow you to easily find information regarding genetic counselling in Canada.

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(905) 847-1363

WEBSITE:
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GENETIC COUNSELLING AWARENESS WEEK 2013: GENETICS IN THE MEDIA!

In November 2013, genetic counsellors across the country participated in the CAGC's 4th annual Genetic Counselling Awareness Week (GCAW). With many radio, television and news interviews, it was clear that many counsellors took advantage of the Genetics in the Media theme! Many genetic counsellors also provided the world with updates via Facebook and Twitter. The following groups were acknowledged for their efforts:

Best YouTube Video winner was North York General Hospital, Toronto, as their video received over 800 views during GCAW. The video is available at <http://www.youtube.com/watch?v=x38ELQ7-p7s>

Most Attended Event winner was SickKids Hospital, Toronto, as talks to elementary schools reached over 240 students. With events being held each day during the week, they reached an estimated 500 people!

The runner-up was Vancouver Children's and Women's hospital whose short film screening had great attendance.

Best Media Outreach winners were Sudbury and Ottawa as genetic counsellors were featured in television and radio interviews as well as publications in the popular press.

In 2014, Genetic Counselling Awareness Week will take place between November 16-22.