

The public needs to be protected from genetic discrimination

Toronto, Ontario, December 13, 2012 – The Canadian Association of Genetic Counsellors (CAGC) released their position statement on genetic discrimination. The CAGC believes that the public should be protected from genetic discrimination and that legislation is necessary to ensure this protection.

The potential for genetic discrimination remains relatively unknown to the general public. Genetic counsellors care for individuals and families with genetic conditions and so are in a unique position to witness genetic discrimination first hand. The potential for genetic information to be used unfairly against a large proportion of the general population will increase as the understanding of the genetics of common disease like heart disease and diabetes expands. In response to these concerns, the CAGC has developed a position statement on genetic discrimination (see attached). The position statement clearly outlines the organization's belief that the public should be protected from genetic discrimination and that legislation is necessary to ensure that this happens.

Canada is currently the only G8 country that does not have laws in place to protect the misuse of its citizens' genetic information. The United States, the United Kingdom, Germany and most of the European Union have already taken steps to enact laws to protect citizens against genetic discrimination. On October 1st, 2012, private member's Bill C-445 was tabled in the House of Commons by Libby Davies, the Member of Parliament for Vancouver East, BC. Bill C-445 calls for an amendment to the Canadian Human Rights Act to add genetic characteristics as prohibited grounds for discrimination. The CAGC supports and encourages the immediate development and implementation of legislation to protect the Canadian public from unfair use of genetic test results or family history.

To date, the frequency of genetic discrimination cases is not well known. In 2001, a case was reported that highlighted the potential of genetic information being used unfairly in the workplace. An American railway company performed genetic testing on their employees with carpal tunnel syndrome to assess whether their injury was work-related or whether it was due to a genetic predisposition (U.S. Equal Opportunity Commission v Burlington North Santa Fe Railway Co). The company tested their employees without fully disclosing the nature of the tests being performed and it was this lack of informed consent that formed the basis of the lawsuit brought against the rail company. The issue regarding the company's use of this genetic information and whether it constitutes genetic discrimination was not addressed by the lawsuit. Currently in Canada, there is no protection against this type of discrimination.

There are many potential ways that genetic information could be used to unfairly. For example, in the future, if genetic markers are discovered that slightly increase an individual's probability of sustaining a work place injury, a company may believe it is reasonable to require individuals to undergo this testing before they are hired. Governmental oversight regarding the use of genetic information is necessary to protect Canadians. The determination of how genetic information could be used should not be left to private industry.

The CAGC promotes increased public awareness of the issue of genetic discrimination in Canada and legislation that protects people from the unfair use of genetic information by employers, insurers and society. Canadians need to express their opinions about genetic discrimination in order to ensure the government takes appropriate action.

About the Canadian Association of Genetic Counsellors

The Canadian Association of Genetic Counsellors was incorporated in 1990 with the goal of promoting high standards of practice, facilitating and supporting professional growth, and increasing public awareness of the genetic counselling profession in Canada. The CAGC administers the Canadian Certification examination for genetic counsellors and provides continuing education opportunities for its members. CAGC is the leading voice for genetic counsellors in Canada and represents the primary source for issues relating to the genetic counselling profession in this country. For more information about the CAGC, or to find a genetics clinic in your area, visit the CAGC website at www.cagc-accg.ca/.

CAGC members available for interview on this subject:

Lacey Benoit, Saskatoon, SK, CAGC Genetic Discrimination Position Statement Committee

Susan Creighton, Vancouver, BC, CAGC Genetic Discrimination Position Statement Committee

Clare Gibbons, Toronto, ON, CAGC Genetic Discrimination Position Statement Committee, CAGC Past President II

CAGC member available for interview about the genetic counselling profession:
Jaspreet Sekhon-Warren, Vancouver, BC, CAGC President

For additional information, or to arrange an interview please contact the CAGC Secretary at: secretary@cagc-accg.ca



CAGC Genetic Discrimination Position Statement

The CAGC is opposed to genetic discrimination. Genetic discrimination is defined as the unfair use of genetic test results or genetic risk determined by family history.

Individuals should not be deterred from seeking genetic services, undergoing genetic testing or participating in genetics research out of concern for genetic discrimination. Individuals should not be coerced to undergo genetic testing by third parties. The decision to have genetic testing is a personal one and should be at the discretion of the individual.

Individuals should be protected from genetic discrimination by employers, insurers and society. The CAGC supports and encourages the immediate development and implementation of legislation to protect the Canadian public from unfair use of genetic test results or family history.

Énoncé de position de l'ACCG sur la discrimination génétique

L'ACCG s'oppose à la discrimination génétique. La discrimination génétique se définit comme l'usage injuste des résultats d'un test génétique ou des risques génétiques que révèlent les antécédents médicaux d'une famille.

Personne ne devrait se trouver à éviter de recevoir des services génétiques, d'avoir un test génétique ou de participer à un projet de recherche en génétique par crainte d'être victime de discrimination génétique. Personne ne devrait être forcé par un tiers à subir un test génétique. Le choix de se soumettre à un test génétique est une décision personnelle que seule la personne concernée doit prendre.

Toutes les personnes devraient être protégées de la discrimination génétique que pourraient commettre des employeurs, des assureurs et la société en général. L'ACCG appuie et encourage l'élaboration et la mise en œuvre immédiates d'une loi qui protège le public canadien de l'usage injuste de résultats génétiques ou des antécédents médicaux d'une famille.