



EMBARGOED UNTIL
Friday, October 2 at Noon (EST)

New Group Lobbying Government for Genetic Discrimination Protections
Day on Parliament Hill of learning, education and action

(KITCHENER) September 24, 2009...Who has perfect genes? Genetic discrimination affects us all! The Canadian Coalition for Genetic Fairness/ Coalition Canadienne pour L'Equité Génétique (CCGF/CCEG) will be spreading the word about genetic discrimination on Parliament Hill on Tuesday, October 6th.

This day of learning, education and action will include a 10am press conference, a lunch and learn presentation with Yvonne Bombard and Trudo Lemmons, question period and visits with MPs, and an evening reception.

The Canadian Coalition for Genetic Fairness (CCGF) is an advocacy-based organization urging the Canadian government to develop and implement a "made in Canada" strategy designed to eliminate this form of discrimination, representing 14 member consumer organizations.

Groundbreaking advances in genetic testing have created a host of benefits and pitfalls for Canadians facing the possibility of a genetic disease or disorder. Being rejected for employment, losing a current job or being forced into a lower-paying position, or being denied essentials like mortgage, life and disability insurance are just a few of the fears faced by Canadians who undergo predictive tests.

Though other countries, including the United States, the United Kingdom, Germany and many other EU countries, have taken important steps towards eliminating genetic discrimination, Canada is falling behind. But CCGF/CCEG is working hard to bring a necessary level of protection to Canadians, aiming to ensure that genetic data is used properly without fear of repercussion. The new strategy would prevent employers and insurers from pushing applicants to take genetic tests or using genetic information or family histories for the purpose of assessing the applicant's risk of becoming a liability by being disabled at some point in future.

The issue is a critical one. As research advances, more and more is being discovered about the genetic origins of disease and disability, including who might get what disease some day. "Our practices in business, commerce and in the home must keep pace so people are protected from incomplete information and inappropriate usage", says Jo Anne Watton, Director of Individual and Family Services with the Huntington Society of Canada. "Who among us has perfect genes?" Jo Anne points out. "Everyone could be at risk"

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Interest in CCGF/CCEG has been growing at a steady rate with confirmed partnership from many organizations, including the ALS Society of Canada, Alzheimer Society of Canada, Canadian Cystic Fibrosis Foundation, CORD, Huntington Society of Canada, Kidney Foundation of Canada, Muscular Dystrophy Canada, Multiple Sclerosis Society of Canada, Osteoporosis Canada, Ovarian Cancer Canada, Parkinson Society of Canada, Spina Bifida and Hydrocephalus Association of Canada, the Centre for Molecular Medicine and Therapeutics, and the Tourette Syndrome Foundation of Canada. Other organizations are showing continued interest in joining the cause.

The Canadian Coalition for Genetic Fairness/ Coalition Canadienne pour L'Equité Génétique is a group of 14 organizations dedicated to establishing protections against genetic discrimination for all Canadians. Our mission is to educate Canadians about genetic discrimination and to influence federal and provincial governments, and other relevant organizations, to create positive change.

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