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Calgary Insurance Case Underscores Need for Genetic Privacy Protection

(Kitchener, ON) September 30, 2013 – The [Canadian Coalition for Genetic Fairness](#) today cited the dramatic case of a Calgary resident who nearly died in a fire as demonstrating the long overdue need for genetic fairness legislation in Canada. An article in the [National Post](#) which details the decision by the Alberta Court of Appeal stating that this individual must undergo genetic testing to determine the level of damages to be paid out by a private insurance company is a gross intrusion of the private sector into the privacy of an individual's own health information and genetic code.

Canada is one of the few developed countries to have not addressed genetic discrimination and privacy issues through legislation and or regulation. The Canadian Coalition for Genetic Fairness has been calling for legislation to address this situation for several years that to date has not yet been enacted federally or at the provincial level in Canada. Each person's genetic information is private and should not be used to discriminate against them. "When will legislation catch up and protect this very personal information? The precedent this sets is frightening for all Canadians," says Bev Heim-Myers, Chair of the Canadian Coalition for Genetic Fairness.

This is why the Canadian Coalition for Genetic Fairness is leading the charge when it comes to genetic fairness in Canada. The Coalition wants to educate Canadians that genetic discrimination is a reality in Canada. Anyone could have sequences in their DNA that can lead to diseases like Huntington's, Parkinson's, Alzheimer's, vision loss and many others. Canada is the only G8 country that does not protect its citizens against genetic discrimination.

On April of 2013, the Honourable James S. Cowan QC, Leader of the Opposition in the Senate introduced a comprehensive Bill in the Senate to end genetic discrimination in Canada. Many countries, including the United States, United Kingdom, Germany and many other EU countries, have taken important steps towards eliminating genetic discrimination. Canada has fallen behind. Now, more than ever, Canada needs to support a genetic non-discrimination bill as we are seeing the negative effects that a lack of genetic protection has for Canadians. "Our practices in commerce, science and health must keep pace so people are protected from incomplete information and inappropriate usage," says Heim-Myers, asking "who among us has perfect genes?" and pointing out that, "Everyone is at risk."

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The Canadian Coalition for Genetic Fairness (CCGF/CCEG) is a coalition of organizations dedicated to preventing genetic discrimination for all Canadians. The Coalition is deeply concerned about discrimination against individuals based on their genetic make-up. We are united to educate Canadians about genetic discrimination and to influence governments both federal and provincial, and other relevant organizations to create change. CCGF/CCEG currently represents 18 hereditary genetic diseases in Canada.

Huntington disease is a debilitating brain disorder that is fatal and incurable. About one in every 7,000 Canadians has HD and approximately one in every 5,500 is at-risk of developing the disease. Many more are touched by HD whether as a caregiver, a family member, or a friend. Huntington disease is devastating for both the body and the mind. The symptoms, which may include uncontrollable jerking movements and relentless cognitive and emotional impairment, usually present between the ages of 30 and 45, and gradually worsen over the 10-25 year course of the disease. Eventually they lead to total incapacitation and death. The [Huntington Society of Canada](#) is the founding organization of the Canadian Coalition for Genetic Fairness and is a respected leader in the worldwide effort to end Huntington disease.

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