



FOR IMMEDIATE RELEASE

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Parliamentary Debate and Government Commitments on Genetic Fairness to Deliver Results in 2015

(Kitchener, ON) Tuesday, Dec. 16, 2014 – Speaking on behalf of all Canadians who are, or will be, impacted by genetic discrimination, Bev Heim-Myers, the Chair of the Canadian Coalition for Genetic Fairness and CEO of the Huntington Society of Canada, is calling for action.

The Prime Minister's commitment in the Speech from the Throne 2013, delivered on Oct. 16, 2013 by the Governor General, promised to "Prevent employers and insurance companies from discriminating against Canadians on the basis of genetic testing." Since 2013, Heim-Myers has worked with the federal government to find a solution to end genetic discrimination in Canada.

Heim-Myers testified at the Senate Standing Committee on Human Rights regarding Bill S-201, an act to prohibit and prevent genetic discrimination, last week. The Senate hearings on Bill S-201 wrapped up on Thursday, Dec. 11, 2014. The Senate will discuss the next steps for this bill after the holiday break in January.

When testifying at the Senate Standing Committee on Human Rights regarding the Bill, Heim-Myers addressed five key areas regarding genetic discrimination: the global response to genetic testing and use of information, the barrier that genetic discrimination plays to early detection and treatment, workplace discrimination, direct to consumer testing and the concerns raised by the Insurance Industry.

Heim-Myers testified, "When the Global Genome Project started, many countries, including Canada, engaged in a dialogue about where the genome project would lead. In Belgium, legislators and decision makers were informed by scientists and agreed that genetic information needed to be protected. Belgium (along with Austria, Denmark, Finland, Norway and the Netherlands) implemented explicit legislative provisions prohibiting the use of genetic testing information for insurance purposes."

Since that time, a series of countries have acted, including the UK, France and the United States. Canada is now the only G7 country that does not protect genetic information. "It is time for Canada to act", says Heim-Myers. "Science and technology have outperformed legislation; Canada needs to update outdated laws".

In her testimony, Heim-Myers cited the cases of Huntington disease (HD) where individuals from HD families cannot get life insurance unless they prove they do not have the genetic mutation.

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The Canadian Coalition for Genetic Fairness believes that genetic information is private, sensitive, complicated information that requires a high degree of protection. Heim-Myers, speaking on behalf of the Coalition, insists that, “It must be used to prevent illness and save lives – not be used against people. Not protecting genetic test information and allowing insurance companies and employers to use an individual’s most personal, complicated and not very predictable, genetic information, will have a lasting negative impact on the health and well-being of all Canadians.”

The Canadian Coalition for Genetic Fairness is calling on our policy-makers to make 2015 the year that genetic discrimination is ended in Canada.

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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 makeup. 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 17 hereditary genetic diseases in Canada and individual concerned citizens.

Members of CCGF/CCEG are:

ALS Society of Canada	Alzheimer Society of Canada
Canadian Cystic Fibrosis Foundation	CORD
The Foundation Fighting Blindness	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
Tourette Syndrome Foundation of Canada	Centre for Molecular Medicine and Therapeutics
Spina Bifida and Hydrocephalus Association of Canada	The Centre for Israel and Jewish Affairs
Canadian PKU & Allied Disorders	Individual Members

The Huntington Society of Canada is the founding organization of the Canadian Coalition for Genetic Fairness (CCGF). CCGF is dedicated to preventing genetic discrimination for all Canadians. Canada is currently the only G7 country that does not protect its citizens against genetic discrimination.

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For a full copy of Bev Heim-Myer’s speech or for more information, please contact:

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