



FOR IMMEDIATE RELEASE

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***NEW INDUSTRY CODE ON GENETIC TESTING ADOPTED BY LIFE AND HEALTH INSURERS
LEAVES CANADIANS EXPOSED***

(Kitchener, ON) Friday, September 26, 2014 – On Thursday, September 25, 2014, the Canadian Life and Health Insurance Association (CLHIA) released a new Industry Code on Genetic Testing Information for Insurance Underwriting for all of its member life and health insurance companies. This new industry code does not address the concerns of Canadian who fear discrimination by insurance companies due to their genetic make-up.

“Insurance companies continue to be a barrier to individuals proactively seeking their own personal and private genetic information,” says Bev Heim-Myers, Chair of the Canadian Coalition for Genetic Fairness and CEO of the Huntington Society of Canada. “Genetic information can help individuals make informed decisions. It is unacceptable that Canadians risk discrimination by insurance companies if they wish to obtain their personal genetic information. This is unacceptable and stands in the way of Canadians being proactive about their own health.”

The facts:

- Anyone could have sequences in their DNA that can lead to diseases like cancer, Huntington’s, Parkinson’s Alzheimer’s, diabetes, or vision loss. Today, there are over 3,000 genetic tests available to help Canadians manage their health through early diagnosis, prevention and treatment. These tests come with an unexpected risk for Canadians as there are no protections against genetic discrimination and no provisions to protect an individual’s private, personal, complicated, and often misunderstood, genetic information.
- Genetic research is very promising and progressing rapidly. Canada has invested billions of dollars to better understand and advance this science. Without this investment, we would not have been able to identify genes that are leading to promising new therapies. However, without protection, people may be reluctant to come forward for diagnosis and treatment, to benefit from early detection or to participate in clinical trials.

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- Canada is the only G7 country that does not protect its citizens against this form of discrimination. All other G7 countries protect genetic test information and have taken important steps towards eliminating genetic discrimination. Canada has fallen behind. In Canada, science has outperformed legislation.
- 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, health and research must ensure that personal complicated genetic information is used for the benefit of all Canadians. Who among us has perfect genes? Everyone could be at-risk.
- There is recognition from all three Federal parties that this is an urgent issue.
- The Prime Minister has acknowledged the need to act in the federal government's last Speech from the Throne in which they committed to end genetic discrimination by insurance companies and employers.

ABOUT THE COALITION FOR GENETIC FAIRNESS

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 16 hereditary genetic diseases in Canada. www.ccgf-cccg.ca/en

Members of CCGF/CCEG include:

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
The Centre for Israel and Jewish Affairs	Individual Members
Spina Bifida and Hydrocephalus Association of Canada	



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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