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National Media Contact:

Christina Steinmann 519-749-8491 Ext. 130

csteinmann@huntingtonsociety.ca

Do You Really Want to Know about Genetic Discrimination in Canada?

(Kitchener, ON) April 30, 2014 – May is Huntington disease Awareness Month and the Huntington Society of Canada (HSC) is raising awareness by sharing their public service announcement (PSA) campaign, “Do You Really Want to Know?” which exposes the reality of genetic discrimination in Canada. The campaign highlights the reality of genetic discrimination in Canada and how everyone in is affected!

To download the “Do You Really Want to Know?” newspaper ads, radio ads, and view the commercials or brochure, please visit the Society’s Media Centre [HERE](#).

“Genetic research is big business in which Canada has invested billions of dollars. There are substantial benefits to genetic research,” says Bev Heim-Myers, CEO of the Huntington Society of Canada and Chair of the Canadian Coalition for Genetic Fairness. “Without it we would not have been able to identify diseases like the Huntington, Cystic Fibrosis or Breast Cancer genes, which are leading to promising new therapies. However, without protection, people may be reluctant to come forward for treatment, to benefit from early detection and to participate in clinical trials.”

Anyone could have sequences in their DNA that can lead to diseases like Huntington’s, Parkinson’s Alzheimer’s, Diabetes and vision loss. Today, there are over 3,000 genetic tests available to Canadians but being tested may put the individual at-risk for genetic discrimination. Canada is the only G8 Country that does not protect its citizens against this form of discrimination.

“Our practices in business, commerce and in the home must keep pace so people are protected from incomplete information and inappropriate usage,” says Heim-Myers. “Who among us has perfect genes?” she points out. “Everyone could be at-risk.”

This is why the Huntington Society of Canada is leading the charge when it comes to Genetic Fairness in Canada. May is Huntington Disease Awareness Month and the Society wants to educate Canadians because genetic discrimination is a reality in Canada.

The Society wishes to applaud the efforts of the Honourable James S Cowan QC, Leader of the Opposition in the Senate who, on February 5, 2014, took Bill S-201 to a second reading in the Senate to end genetic discrimination in Canada. The purpose of Bill S-201 is to address specific issues that are preventing many Canadians from benefiting from extraordinary advances in medical research. Though other countries, including the United States, the United Kingdom, Germany and

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many other EU countries, have taken important steps towards eliminating genetic discrimination, Canada has fallen behind.

This Bill will help to bring the necessary level of protection to Canadians, aiming to ensure that genetic information is used properly without fear of repercussion. This would ensure that genetic information is used for health and research purposes only.

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 the only G8 country that does not protect its citizens against genetic discrimination.

Huntington disease (HD) 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. HD causes cells in specific parts of the brain to die. As the disease progresses, a person with Huntington's become less able to manage movements, recall events, make decisions and control emotions. The disease leads to incapacitation and, eventually, death.

The Huntington Society of Canada is a respected leader in the worldwide effort to end Huntington disease. HSC is the only Canadian health charity dedicated to providing help and hope for families dealing with Huntington disease across Canada.

For more information contact: Christina Steinmann

Phone number: Christina Steinmann 519-749-8491 Ext. 130

Email: csteinmann@huntingtonsociety.ca

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