



Huntington Society of Canada

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FOR IMMEDIATE RELEASE

Local Not-for-Profit Organization Fights for Genetic Fairness
A campaign launch to make genetic fairness a reality in Canada

KITCHENER (September 13, 2013)- The Kitchener chapter of the Huntington Society of Canada is launching a campaign to fight for genetic fairness. The organization is hosting a series of presentations at post-secondary institutions in the Waterloo Region through September to October about the issues of genetic discrimination. Currently, the government does not protect Canadians from having their genetic information shared without consent.

The Huntington Society wants to change that. A petition will be held to support genetic fairness, in hopes to pass a bill that prevents insurance companies or employers use the results of a genetic testing against individuals. The goal is to collect 1,500 signatures by the end of the year. The petition will then be forwarded to Kitchener-Waterloo MP Peter Braid to take the issue to the Parliament.

The term ‘genetic discrimination’ describes individuals who have been denied their civil rights because they tested positive or has a family history of a genetic disorder. Genetic disorders can include Huntington Disease, ALS, Parkinson’s and certain cancers among others. Kitchener resident Jaclyn Skinner, who has a family history of Huntington Disease, knows the importance of educating people about genetic discrimination: “They need to be more aware of how they can help to make that illegal. We are a small and mighty group and we are not going to stop supporting, fund-raising and helping our community.”

The Huntington Society of Canada is a not-for-profit organization that supports finding a cure for Huntington Disease. Founded in 1973, they provide information about HD and services like support groups for families who suffer from HD and raise funds for researchers.

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Fact Sheet on Genetic Discrimination and Campaign

- The government does not regulate genetic testing. Because of this, it is difficult for individuals to gauge accuracy of the results.
- Canada currently does not protect citizens from their genetic information being shared without consent.
- Genetic disorders are disorders that run in the family. These disorders include but not limited to Huntington Disease, Parkinson's and certain cancers.
- Huntington Society of Canada is a member of [Canadian Coalition for Genetic Fairness](#), an organization that fights for genetic fairness in Canada.
- Genetic discrimination can hinder the livelihood of Canadians who are at risk of genetic disorder. They may be denied life insurance or lose their job because they were tested positive of an unfavourable genetic disorder.
- A study published in [Nature Reviews Neurology](#) reveals that 30% of 233 participants have faced genetic discrimination in the workplace due to genetic test results.
- [A study from University of British Columbia](#) has shown that 40% of Canadians have faced genetic discrimination even though they did not undergo genetic testing. Canada currently does not have a legislation that protects citizens from genetic discrimination. The Huntington Society hopes to change that with this petition.
- The campaign will run from September to late December.
- Presentations will be made at post-secondary institutions around the Waterloo Region about genetic discrimination.
- Stories will be delivered by those impacted by Huntington Disease and genetic discrimination.
- The public who attends the presentation is encouraged to sign a petition in support of genetic fairness.
- At the end of the campaign, the petition will be presented to MP Peter Braid.



Additional Information

Speaker Bio: Jaclyn Skinner



Jaclyn Skinner is a local Kitchener woman who has a family history of Huntington Disease. She has been aware of this disease and how it seriously affects the victims and their families all her life. When her mother was diagnosed positive of Huntington, she knew that she now had 50/50 chance of inheriting the gene. Since then, she decided to become more active in the HD community, to educate herself on the illness and to help others who are affected. There are five members in her family who have been diagnosed with HD. Skinner has chosen to not undergo genetic testing at this point in her life. She believes she is emotionally not ready to hear the results, good or bad. She fully understands the frustration with genetic discrimination and it is an issue she thinks about on a daily basis. Skinner has been working for the Huntington Society the last five years to support finding a cure for HD and fight to make genetic discrimination illegal in Canada. She is available for interview if you are interested in writing a feature story about her.

Pictures:



Huntington Disease is a neurological disorder that eventually leads to an individual's physical and psychological deterioration. They are left completely helpless as they become unable to control their motor skills and emotional state.

Photo credit: Corbis Images



Individuals at risk of inheriting a genetic disorder can face discrimination by insurance firms, at their work environment and/or from family and friends.

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