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Inspiring Canadian woman raises awareness for Huntington disease

(Kitchener, ON) May 20, 2014 – Colleen Edwards, an inspiring Canadian, raises awareness for Huntington disease (HD) for the Huntington Society of Canada (HSC). Huntington Disease Awareness Month is in May, the Society highlights the reality of genetic discrimination in Canada and how it affects those who have the genetic potential for Huntington disease, Alzheimer’s, vision loss and other diseases.

When Colleen Edwards’ dad was diagnosed with Huntington disease (HD) in 2007, the family was floored. They knew something must be causing his unsteadiness and mood swings, but a fatal, incurable neurodegenerative illness? It was hard news to swallow, made even harder by the fact that because HD is genetic, Colleen and her sisters have a 50 percent chance of inheriting it.

The potential ripple effects were staggering. Aunts. Uncles. Cousins. Her twin girls, only a year old. “You can’t even wrap your head around the implications,” she says. “It’s like someone’s playing Russian roulette with your family tree, and every second person is going to get a bullet.”

Faced with that risk, Colleen decided to go through genetic testing and discover exactly what she was up against. With her husband Derek by her side, Colleen opened the envelope that held her results: she also carried the gene.

She might have wanted to curl up under the covers and cry, but as a mother of two baby girls, Colleen knew that wasn’t an option. Instead, she decided that she was going to do everything she could to create awareness, raise money and help others affected by this disease. “We have to let some good come of this somehow,” she says.

Colleen and her family got involved with the Huntington Society of Canada (HSC), organizing fundraising hikes, raising awareness and serving on the executive of the Society’s B.C. Chapter. Both she and Derek signed up for research trials, Derek serving as part of the control groups.

“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.”

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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 G7 Country that does not protect its citizens against this form of discrimination.

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.

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.

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