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## **May Is Huntington Disease Awareness Month And Toronto Woman Is Climbing A Rocky Road For Huntington Disease**

(KITCHENER, ON) May 8, 2017 – Kathryn Jordan thought she was prepared to get the results of her genetic test. She had done her homework on Huntington disease (HD). She knew she had a 50/50 chance of inheriting the fatal neurological disease. She had watched a documentary again and again about a young woman — like her — undergoing the testing process. Despite all that, she broke down when she learned she carried the HD gene — the same gene that killed her mother when Kathryn was just six years old.

Kathryn’s memories of those early years are spotty. She remembers sitting in her mom’s lap, being hugged and told stories. She recalls going go-kart racing to raise money for the HD cause.

She remembers the darker moments as well. Her mom’s moodiness. All the medications. How her mom spent so much time in bed in the final months. After that came dealing with the grief and trauma of losing her mother, the rifts that created within her family and her own fears of carrying the gene. “It’s been a rocky road,” she acknowledges. “A really rocky road.”

Getting support from the Huntington Society of Canada (HSC) helped Kathryn navigate that difficult terrain. “They were there when I needed them,” she says. “When it felt like nobody was.” Meanwhile, attending the Society’s national conference introduced her to other youth affected by HD. Walking into a room full of people who shared her experiences shattered her sense of isolation. “It was amazing,” she says. “We connected so deeply.”

Now 26, Kathryn is making the most of life. She volunteers. She’s carving out a career as a model. She has a loving boyfriend and dreams one day of having children — dreams buoyed by the hope that current advances in HD research will produce treatments before her own symptoms develop.

Kathryn is also raising awareness about HD. She knows that Huntington disease may one day take away her ability to speak. But until then, she’s determined to use her voice to tell Canadians about the disease that has impacted her life so profoundly.

The month of May carries a particular significance because it’s Huntington Disease Awareness Month. During this time, volunteers are hard at work raising awareness about Huntington disease, a rare genetic disorder that causes brain cells to die. A person with HD becomes less able to control movements, recall events, make decisions and control emotions. The disease leads to incapacitation and, eventually, death.

“It is the dedication and support of people like Kathryn that are the fabric of the Huntington Society. Volunteers who go above and beyond help us grow, achieve impactful results and reach our goals,” says Bev Heim-Myers, Chief Executive Officer of the Huntington Society of Canada. “We are incredibly fortunate for people like Kathryn and the thousands of volunteers who stand beside us and make us the best that we can be.”

### **About Huntington Disease**

Huntington disease (HD) is an inherited, 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. Huntington disease is devastating for both the body and the mind. The symptoms, which may include uncontrollable jerking movements and relentless cognitive and emotional impairment, usually present between the ages of 30 and 45, and gradually worsen over the 10-25 year course of the disease. Eventually they lead to total incapacitation and death.

### **About the Huntington Society of Canada**

The Huntington Society of Canada (HSC) is a respected leader in the worldwide effort to end Huntington disease (HD). HSC is the only national health charity dedicated to providing help and hope for families dealing with HD across Canada. HSC aspires to a world free from Huntington disease. For more information about Huntington disease and the Huntington Society of Canada visit [www.huntingtonsociety.ca](http://www.huntingtonsociety.ca).

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