“I’ve got a whole team on my side.”

May is Huntington Disease Awareness Month and Jaclyn wants to tell her story.

(Kitchener, ON) May 2, 2016 – “Huntington disease (HD) has always been part of my life. My grandma started showing symptoms when I was five, and since the disease is genetic, my mom has inherited the disease,” shares Jaclyn Skinner. Each child born to a parent with HD has a 50% chance of inheriting Huntington disease. “As soon as I found out about my mom, I wanted to find people who were like me and do everything I could to bring an end to this disease.”

Jaclyn is doing what she can. She is currently the president of the Huntington Society of Canada’s (HSC) youth chapter, Young People Affected by Huntington Disease (YPAHD). “It is a powerful group and it is refreshing to see how many people in my generation want to be part of changing the course of this disease and provide support to one another,” says Skinner. “Two years ago, I learned that I am gene positive. Huntington disease can change you physically and mentally, and my greatest fear is losing myself. I am a very independent person and it is really hard for me to ask for help. So knowing that this might be in my future is terrifying.”

Jaclyn credits her family for helping her through her diagnosis. “They are amazing. There is power in numbers, and I have a whole team on my side,” says Skinner “I will do whatever I can to change the course of this disease. I am part of the ENROLL-HD study, and I will continue to be actively involved in YPAHD and the Huntington Society of Canada. My greatest hope is that I will be part of the last generation that knows what this disease can do to a person. I really want to be the last.”

On May 1, 2016, the Huntington Society of Canada is launching a new PSA campaign: What is Huntington Disease? coinciding with Huntington Disease Awareness Month. For Jaclyn, participating in the new PSA campaign for the Huntington Society of Canada gives her strength and courage. “Lasting change is only possible if we work towards ending this disease together. People need to know that Huntington disease is horrible, that it impacts generations of families. The research that is being done now may create a ‘domino’ effect and provide answers to Alzheimer’s, ALS, Parkinson’s, and other neurological diseases. Seeing all the advances we’ve made so far, and knowing there’s more to come, that’s exciting to me and why I volunteer and push the Huntington message each and every day.”

“We are so fortunate to have individuals like Jaclyn in our community. Individuals who choose to get involved and want to make a positive impact,” says Bev Heim-Myers, Chief Executive Officer of the Huntington Society of Canada. “It takes courage to stand up for what you believe in and we are very grateful to Jaclyn for her commitment and dedication to helping increase awareness of Huntington disease in Canada.”

FOR IMMEDIATE RELEASE

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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 becomes 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 (HSC) 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 impacted by Huntington disease across Canada.

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