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***Youth Go Digital to Tackle Fatal Family Disease***

(VICTORIA, BC) February 14, 2017 – Most university students have worries: paying rent, passing exams, finding that crucial first job. Third-year University of Victoria student Caleb Harding faces all of those, plus a few more.

In 2012, his mother was diagnosed with Huntington disease (HD), a fatal neurodegenerative illness. In the coming years, Harding learned, she will gradually lose the ability to walk, to speak and to swallow.

But the bad news didn't end there. Because HD is genetic, there's a fifty percent chance that Harding will suffer the same fate. And whether he inherited the fatal gene or not, he faces the risk of genetic discrimination when he tries to launch his career.

"My potentially having Huntington disease is such a cloud over me that I can't control," says the 22-year-old political science student.

For three years, he grappled with those issues alone. Then, thanks to the generous support of the B.C.-based Norgaard Foundation, he received funding to attend the Huntington Society of Canada's (HSC) National Conference in Halifax, Nova Scotia last fall.

For the first time, he met other youth who knew exactly what he was going through. "That was huge, finding that community," Harding recalls. And those peers were taking action. As part of Young People Affected by HD (YPAHD), HSC's youth chapter, they were raising money for research, supporting their peers and working to end genetic discrimination in Canada.

Inspired, he volunteered to serve as their social media coordinator. Now, he is using tweets, texts and other digital tools to raise vital awareness and funds. He's especially keen to make sure every young person, like him, has access to the information they need.

"Young people who have questions about HD are probably not going to go and talk to their doctor about them," he explains. "If anything, they're going to go online and they'll go on social media."

Although Harding's future is uncertain, one thing is clear: HSC's youth programs are making a powerful difference. "Without sounding too cheesy, me being involved in that conference did change my life," says Harding.

### **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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