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May Is Huntington Disease Awareness Month And Armstrong Woman is Determined to Find A Cure

(KITCHENER, ON) May 8, 2017 – Huntington disease (HD) has taken a lot from Ellie Smith’s family. It started with her father. As the neurological disease took its toll, the once strong, hardworking farmer from Armstrong, B.C. struggled with the simplest of chores. Ellie remembers when her dad discovered he could no longer fetch the mail. “He just sat at that mailbox one day and just cried because he could not open [it],” she says.

Over the years, Huntington disease has claimed the lives of Ellie’s dad, two brothers and a sister — and with them, the shared lacrosse games, backyard barbecues and hay rides her family enjoyed so much. Now, several other gene-positive loved ones are bracing themselves for the same fate. That includes Ellie’s niece, Angie: a talented artist who now struggles to hold a paintbrush.

After her diagnosis, Angie took action: organizing a hugely successful charitable run to support the Huntington Society of Canada (HSC). Ten years later, Angie’s passion has snowballed into a full-fledged chapter, bringing family, friends and the entire community together to raise money and awareness.

The impact is evident. Ellie remembers how her brother was once kicked out of a store because the owner mistook his motor symptoms for drunkenness. Today, thanks to their efforts to raise awareness, it’s a different story. “If you walk down the street in Armstrong, people will know what Huntington disease is,” she says.

While Angie now requires full-time care, Ellie continues to help the chapter thrive as its vice president. This year, their Run for HD celebrates its 10th anniversary (May 27, 2017), which has helped the small but mighty group raise more than \$130,000 for family services and potential treatments.

Between recent research breakthroughs and the passion of the Armstrong community, Ellie sees reasons for hope — and motivation to do more. “Let’s find that cure, let’s find something to slow this down, let’s find some way of helping these people that are afflicted with Huntington disease,” she says. “And until they find a cure or medicine to slow it down or stop it ... I will be there.”

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 Ellie 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 Ellie 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.

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