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Ontario Father-Daughter Duo Take on Huntington Disease *Celebrating National Volunteer Week: April 23-29, 2017*

(KITCHENER, ON) April 20, 2017 – Volunteers are at the heart of the Huntington Society of Canada (HSC). Our volunteers tell a powerful story of caring people who pull together to improve the quality of life for Canadians impacted by Huntington disease (HD). To celebrate National Volunteer Week (April 23-29), the Huntington Society of Canada is honouring the volunteer work of father-daughter duo John and Brynne Stainsby and the impact they have made in the HD community.

Brush your teeth. Comb your hair. Volunteer. Brynne Stainsby grew up in a house where giving back to the community was just expected. That isn't surprising when you've got a dad like John. "In every aspect of his life, he was such an example of putting others first," says Brynne. "That was always what I saw."

After his mom was diagnosed with Huntington disease (HD) in the early 90s, John wasted no time getting involved with the Huntington Society of Canada's Niagara, Ontario chapter. And when he also tested gene-positive in 1994 for the fatal, degenerative brain disease, those efforts became all the more important.

Inspired by the strength and camaraderie he saw in the HD community, John became a stalwart of the organization, spearheading fundraisers, serving as the chapter's president and spending several years on HSC's national board. "That's the way I like to deal with it: knowing what's happening and being involved and helping out where I can," he says.

Brynne, in turn, became the founding president of Young People Affected by HD (YPAHD), the Society's national youth chapter. Nearly a decade later, the group has grown by leaps and bounds, hosting events across the country and offering peer support. Meanwhile, Brynne has also been a fearless champion for genetic fairness, sharing her story to ensure all Canadians have legal protection from discrimination.

Individually, John and Brynne have made impressive contributions. But just watch what happens when you put them together. For the past 10 years, the father-daughter duo have run half-marathons together, raising thousands of dollars for the HD cause.

Brynne admits there have been plenty of times she's finished a race exhausted, sore and ready to hang up her running shoes. But then she reminds herself how lucky she is. "I get to run, and that's a pretty huge gift," she says. "And I get to run with my dad, and that's a bigger gift."

From April 23 to 29, Volunteer Canada and the Huntington Society of Canada celebrate Canada's 12.7 million volunteers during National Volunteer Week (NVW). This year marks the 76th year Volunteer Canada has been recognizing the hardworking volunteers that make a difference in Canada. It has grown to be the largest celebration of civic participation in Canada. Help us celebrate National Volunteer Week 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 (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 dealing with Huntington disease across Canada.

Volunteer Canada (www.volunteer.ca)

Involved Canadians build strong and connected communities to create a vibrant Canada. Volunteer Canada provides national leadership and expertise on volunteerism to increase the participation, quality and diversity of volunteer experiences. Since 1977, Volunteer Canada has worked closely with a network of more than 200 volunteer centres across Canada, over 1200 Volunteer Canada members, charitable and nonprofit organizations, businesses, educational institutions, and government departments.

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