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Local Okanagan Volunteers Make a Global Impact on Huntington Disease Awareness

(KELOWNA, BC) October 27, 2017 – This past September, four friends and their partners from Kelowna, BC walked across the Camino de Santiago Trail to raise global awareness for Huntington disease (HD). Ellie Smith, Marlene Boone, Ann Young and Isla Van de Laar all trekked 800 kilometres for over a month.

Their expedition started September 5, 2017 in Spain where the Camino de Santiago Trail is located. They brought the bare essentials including their HD t-shirts, buffs with the HD logo and information cards for those who wanted to learn more, all while walking over 20 kilometers a day.

The group decided to do the hike to raise awareness for HD in support of Smith, who has seen many family members die from the disease. “She’s tireless, and she’s upbeat,” Young says. “She somehow puts a positive spin on it all and does what she can to make people aware, and how can you not follow that?”

The four friends walked several kilometers a day all while enduring hard trails from hiking over the Pyrenees Mountains. They walked long and hard all while sparking up conversations from other hikers about their t-shirts and buffs. They knew that they were creating awareness for Huntington disease one step at a time.

Once their journey had come to an end, the four friends were overly thrilled by accomplishing this adventure together. They were even greeted at the end of the journey by a very special visitor. “We were honored to have the Mayor of Santiago de Compostela welcome us at the end of the trail,” says Smith. “It feels good to have all the work that is being done for Huntington disease awareness and research by both Spain and Canada acknowledged. It wasn’t always easy but it was well worth it and far exceeded our expectations. It was an incredible adventure that we’ll remember forever.”

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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. Huntington disease is often described as having the symptoms of Alzheimer’s, Parkinson’s and ALS – simultaneously. 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 find a meaningful treatment for HD. HSC is the only Canadian health charity dedicated to providing help and hope for families dealing with HD across Canada. HSC aspires for a world free from Huntington disease. For more information about HD and HSC visit www.huntingtonsociety.ca.

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