

FOR IMMEDIATE RELEASE

(Waterloo, ON) April 27, 2020 – May is Huntington disease (HD) Awareness Month around the world. While especially challenged in 2020, Canadian volunteers are working to spread the word, educate the public and let them know how they can help the thousands of people living in Canada who are affected by this disease. And those volunteers are getting creative.

Typically, the HD community is able to boast a truly international collaboration of supporters working to have structures such as bridges, stadiums, statues, bridges and landmark buildings and other monuments #LightItUp4HD (in blue for HD and purple for juvenile HD, respectively). The challenge arises this year due to federal and provincial government guidelines – in Canada and across the globe – around physical distancing and working remotely. Whereas in a normal situation, volunteers would be encouraging flag raisings and the lighting of structures to mark the month, the banning of public gatherings has dramatically affected ambitions in that area. As well, most municipalities are working with skeleton crews and simply do not have the staff in place to handle the administrative paperwork around #LightItUp4HD requests.

“It’s extremely disappointing,” says James Walters, Founder of the Global Huntington Association and the #LightItUp4HD initiative. “Last year, we had 55 sites in Canada and a total of 169 around the world participating in the #LightItUp4HD movement. We had hoped to break that record this year, but it’s just not possible with COVID-19 guidelines in place.”

Still, the Huntington Society of Canada (HSC) is asking its community and supporters to do what they can to raise awareness. Rather than public monuments and buildings, the organization is encouraging anyone who would like to participate to string blue and purple lights in trees, replace their porch bulbs with blue or purple ones, create sidewalk or driveway art using chalk or even make ornaments and posters at home that can be hung in front yard trees and home windows.

HD awareness month is a time when the organization is able to focus on bringing awareness to a devastating but little-known disease and encourage donations from a larger pool than the typical donor base. It’s a time to share stories, fundraise and celebrate the collective hope that a therapy for HD will be available in the not-too-distant future.

“While we are forced to scale down in 2020, we are as determined as ever to raise awareness,” adds Walters. “We’re thinking outside of the box now – and that’s our silver lining! So please, #LightItUp4HD, #StringItUp4HD or #ChalkItUp4HD – show your support in any way you can.”

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Huntington disease (HD) is a hereditary, neurodegenerative disease with no cure. 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.

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