

FOR IMMEDIATE RELEASE

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“Shedding Light” on Huntington Disease in Canada and Around the World

(Kitchener, ON) May 1, 2019 – May is Huntington disease (HD) Awareness Month and volunteers are spreading the word, educating Canadians about the disease and how they can help the thousands of Canadian families affected by this devastating disease, through several movements.

Since 2015, volunteers from across Canada have been illuminating various buildings, monuments and statues during the month of May to raise the visibility of HD and Juvenile Huntington disease (JHD) with blue and purple lights, respectively. Thanks to the enthusiasm of the HD community and the many HD volunteers, “LightItUp4HD” will be coming to a site near you!

“After having the CN Tower lit up in 2015, I was asked by the Huntington Society of Canada (HSC) what I would like to see become of this,” says James Walters, Founder of the Global Huntington Association and the LightItUp4HD initiative. “I said I would love to see more buildings across Canada illuminated in 2016. And my Canadian Huntington’s family did not disappoint! In May 2016, Canada was awash in blue and purple. Then, in 2017 members of our worldwide Huntington disease families stepped up and joined us in our quest to bring HD and JHD out of the shadows and into the light.”

Volunteers have reached out to HD organizations from around the world and have invited them to “LightItUp4HD”. Along with almost 50 sites in Canada (and counting), Australia, England, Ireland, Scotland, Northern Ireland, Norway, Spain and Wales are just some of the countries working to “LightItUp4HD” this May. Many cities here at home have also made proclamations to declare May as HD Awareness Month. In most cases, this is coupled with a flag-raising event outside the local city hall or civic centre.

The HSC hopes that this month’s events will help to educate Canadians about the disease and its impact - so that they are more likely to extend support. Together with its fantastic base of volunteers, the HSC invites Canadians to learn more about Huntington disease and Juvenile Huntington disease.

“Today, we as a global family are stronger than ever,” adds Walters. “I’m humbled by the tireless efforts of thousands of our JHD/HD families, volunteers and organizations who put in endless hours promoting our cause. I’m also thankful to the HSC for allowing me to this opportunity to express my heart felt thanks to each and everyone who has joined us for #LightItUp4HD.”

For a comprehensive list of participating sites, visit <https://www.huntingtonsociety.ca/may-awareness/>.

– 30 –

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 Huntington disease. HSC is the only Canadian health charity dedicated to providing help and hope for families dealing with Huntington disease across Canada. Learn more at www.huntingtonsociety.ca.

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