

## 2020 "#LightItUp4HD" Shines Brightly in May

## FOR IMMEDIATE RELEASE

(Waterloo, ON) June 4, 2020 – May was Huntington disease (HD) Awareness Month and despite challenges brought about by the COVID-19 pandemic, sites around Canada and the world again lit up in support. Since 2015, volunteers from across Canada have been working to illuminate various buildings, monuments and statues during the month of May to raise the visibility of HD and Juvenile Huntington disease (JHD).

Thanks to the enthusiasm of the HD community and many HD volunteers, "LightltUp4HD 2019" saw 42 sites participate, worldwide. In Canada, 19 sites participated in #LightltUp4HD, while another 23 international buildings, monuments and other structures lit up in blue for HD and/or purple for JHD. The impact of COVID-19 on the initiative (in 2019, an international total of 169 sites participated) may have meant less sites were able to come on board, but hope continues to flourish in the HD community.

"When lockdown started, we began to hear back from sites that they weren't in a position to participate this year – for various reasons" says James Walters, Founder of the Global Huntington Association and the LightItUp4HD initiative. "So, we counted each site in 2020 as a small victory in strange times."

Walters and other HD volunteers across Canada – such as National #LightItUp4HD Volunteer, Carolyn McKinney reached out to HD organizations from around the world and invited them to "LightItUp4HD". Along with the 19 sites in Canada, the following countries also participated: Australia, Cyprus, Germany, Ireland, Spain and the USA. Calgary, AB Mayor, Naheed Nenshi, also made a proclamation to declare May as HD Awareness Month in that city. In most cases, flag raisings (public gatherings) were cancelled in order to comply with COVID-19 measures, although Guelph, ON, Sudbury, ON and Chatham, ON raised flags in a safe manner or residentially. Members from the HD community also lit up their own homes in blue or purple, strung lights or drew sidewalk art with chalk.

"Each year, in addition to the sites we ask to participate, I continue to hear from new HD ambassadors around the world who want to be part of #LightItUp4HD," adds Walters. "It's not just creating awareness, it's also fostering more relationships within the HD community – and that's a powerful thing."

Thanks to Walters, McKinney, chapter volunteers across Canada and international partners, #LightItUp4HD continues to increase awareness and in 2021, hopefully the bar will be set at levels higher than the records set in 2019.

For a comprehensive list of participating sites and to view a video montage of 2020 site pictures, please visit <a href="https://www.huntingtonsociety.ca/lightitup4hd-2020/">https://www.huntingtonsociety.ca/lightitup4hd-2020/</a>.

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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 Huntington disease. HSC is the only Canadian health charity dedicated to providing help and hope for families dealing with Huntington disease across Canada.

## For More Information:

Lianne (Lia) Appleby Communications and Marketing Manager 519-749-8491, ext. 130 lappleby@huntingtonsociety.ca

