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Local Volunteers Work to “Shed Light” on Huntington Disease

(CALGARY, AB) April 29, 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 in Southern Alberta and the many HD volunteers, “LightItUp4HD” will be coming to a site near you!

For so many years, HD has been kept secret in families due to stigma and discrimination," says Heather Dodds, president of the Southern Alberta Chapter. “HD Awareness Month is an opportunity to bring attention to the disease but also to make connections, garner support from Canadians and move forward with pride and dignity.”

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.

In Alberta, the following sites are showing their support for the HD Awareness movement:

- 8th Ave. Canopy Lights (Stephen Avenue), Calgary: May 3
- Calgary Tower, Calgary: May 3
- McMahon Stadium, Calgary: May 3
- Olympic Plaza, Calgary: May 3
- Reconciliation Bridge, Calgary: May 3
- South Pointe Toyota Dealership, Calgary: May 3
- Telus Spark Centre, Calgary: May 3
- ATB Place, Edmonton: May 3
- Art Gallery of Alberta, Edmonton: May 3
- High Level Bridge, Edmonton: May 3
- Sexsmith Gazebo, Sexsmith: May 3
- Teepee Creek Stampede Grounds, Sexsmith: May 3

Many cities across Canada 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 Southern Alberta Chapter has worked with the City of Calgary to plan such an event for May 3 at 12 p.m., at the courtesy pole (north side of the Municipal Plaza). All are welcome to attend and support the HD community.**

Continuing the awareness celebrations into June, local volunteers will also be hosting some fun events! The 11th Annual Southern Alberta Hope for a Cure Run and Walk will be taking place on June 8 at Bowness Park, Calgary and the Scotiabank Calgary Marathon Bag Check, named for the Huntington Society Canada and organized/supported by chapter volunteers, will happen on May 26. More information can be found by visiting www.huntingtonsociety.ca/events/#alberta. Both events will raise funds for family services support and cutting edge research into a treatment for HD.

The Huntington Society of Canada (HSC) hopes that May'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.

"I love the idea of Light It Up because it's something that has the ability to unite all of us affected across the country and even across the world," says Melissa Kozak, national Light It Up 4 HD volunteer. "I can be looking at a monument that's lit up in Toronto and know that my sister is looking at another monument that's lit up in Vancouver. It's so very heartwarming."

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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. Learn more at www.huntingtonsociety.ca.

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