

Light It Up 4 HD Information Package

Contact Information

The Huntington Society of Canada
151 Frederick Street Suite 400
Kitchener, Ontario N2H 2M2
www.huntingtonsociety.ca

Sobia Khan
Communications Coordinator
1-519-749-7063 ext 130



This package has been designed to assist your organization in promoting the Huntington Society of Canada’s #LightItUp4HD campaign during Huntington Disease Awareness Month in May 2017. Please use this information, as well as the attachment materials, to post on your website or throughout your social media channels.

What is the Huntington Society of Canada?

The Huntington Society of Canada is a not-for-profit charitable organization which raises funds to deliver individual and group counselling service to support individuals and families living with Huntington disease (HD) and to fund medical research to delay or stop the progression of the disease. The Society also works with health and social services professionals to enable them to better serve people living with HD.

Our national office is located in Kitchener, Ontario, we have offices servicing every province and territory as well as over 40 volunteer chapters across Canada.

What is Huntington disease?

Huntington disease (HD) is an inherited brain disorder. HD causes cells in parts of the brain to die: specifically the caudate, the putamen and, as the disease progresses, the cerebral cortex. As the brain cells die, a person with Huntington becomes less able to control movements, recall events, make decisions and control emotions. The disease leads to incapacitation and, eventually, death (generally due to other health complications).

For more information, and to access various programs and resources dedicated to HD, please visit our website at www.huntingtonsociety.ca.

A great way to introduce Huntington disease to your audience is through our public service announcement launching May 1, 2016. Please see attached materials to share with your local community. As this PSA hasn't officially launched yet, please keep all materials confidential until then.

Purpose and objectives of the campaign

Light It Up 4 HD across Canada in May 2017.

On May 4, 2015, Jamie – a volunteer from the Huntington Society of Canada (HSC) – was instrumental in lighting up the CN Tower to raise the visibility of Juvenile HD (in purple) and HD (in blue) and Huntington Disease Awareness Month, held each May.

When the sun set on May 4th, hundreds of thousands of Canadians saw the CN Tower lit up in purple and blue. And our HD community lit up with pride.

Thanks to Jamie's enthusiasm, and at the urging of our HD families and volunteers, we are helping them to expand “LightItUp4HD” all across Canada by lighting up buildings, monuments and statues during the month of May. Last year, we were joined by international countries including Spain, Ireland and the United States.

For so many years, HD has been kept secret in families, due to stigma and discrimination. This “LightItUp4HD” campaign is a wonderful opportunity for those with HD to raise awareness, make connections, get support from their communities, and move forward with pride and dignity.

We have invited our sister organizations from around the world to join in this movement. Scotland, Ireland, and the United States, are just some of the countries working with us to #LightItUp4HD during the month of May 2017.

Working with our volunteers, we have put together an impressive list of places that will be lighting up 4 HD in May 2017, representing every province and territory in Canada, and we expect the list to continue to grow as enthusiasm spreads for our light up campaign.

Please visit www.lightitup4hd.com to stay up-to-date on confirmed sites.

To watch a video featuring last year's sites, visit: <https://youtu.be/LNGOR1sstb0>

What #LightItUp4HD means for the HD community

For the HD Community, this campaign is about increasing awareness for Huntington disease in Canada. The more people understand the disease the more they can accept those who are impacted and extend support. The month of May is particularly designated as Huntington Disease Awareness Month.

Social Media Content Bank

The following sample social media messages can help get you started. Feel free to customize to suit your organization's voice. Add photos and graphics (we have attached some for your use) to make your social media content more appealing.

Facebook:

- May is Huntington Disease Awareness Month. In honour, we will be lighting up (insert site) on (insert date). Talk to your neighbour about HD and help educate Canadians on what HD is. For more information, visit www.huntingtonsociety.ca.
- Ever wondered what Huntington disease is? Watch this powerful public service announcement from the Huntington Society of Canada and share to raise awareness during #HDAwareness month this May. Look out for blue and purple lights at (insert site) on (insert date) as we #LightItUp4HD

Twitter:

- May is Huntington disease awareness month. We're going to #LightItUp4HD on (insert date) at (insert site). Learn more about HD at www.huntingtonsociety.ca.
- #HDAwareness month is the perfect time to learn about Huntington disease. We're supporting @HuntingtonSC and will #LightItUp4HD on (insert date).
- Join us in celebrating #HDAwareness month with @HuntingtonSC. See us #LightItUp4HD at (insert site) on (insert date).

Please encourage members of your local community to share on social media and tag any posts/pictures pertaining to the sites with the hashtag: #LightItUp4HD

*Tag Huntington Society of Canada on Facebook, Twitter and Instagram.

Please direct any questions or comments to Sobia Khan at skhan@huntingtonsociety.ca.