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Submitted to: [webform_submission:values:contact]

Name: Ellie Gibbard

Email: <u>lightitup@huntingtonsociety.ca</u>

Telephone:

Subject: Light it Up for Huntington Disease

Comment or question:

Hi there,

My name is Ellie and I am a national volunteer with the Huntington Society of Canada (HSC). I am reaching out on behalf of HSC for the annual #LightItUp4HD 2022 campaign to see if you would be willing to help us raise awareness for Huntington disease (HD) this year by lighting up the Town of Okotoks in blue and/or purple for one or more days in May 2022 for HD Awareness Month.

HD is a genetic brain disorder that affects a person's ability to control their movements, recall events, make decisions and control their emotions. HD is often described as having ALS, Parkinson's and Alzheimer's all at the same time. Sites across Canada are helping us raise awareness for HD and Juvenile HD by lighting up in blue and purple, respectively.

This year we want to reach more people so those affected can be better supported. For many years, HD has been kept secret in families because of stigma and discrimination and the #LightItUp4HD campaign is a wonderful opportunity for those with HD to raise awareness, connect and gain support from their communities.

If you are willing and able to light up the Town of Okotoks in blue and/or purple for one or more days in May 2022 to help us raise awareness for HD we would be thrilled. I ask that you kindly let me know either way of your decision to participate in this campaign.

I have attached an Information Package with some additional background on HD.

If I can answer any questions or provide additional information, please let me know. Additionally, if there is a separate contact with whom I should be coordinating this with, please do not he sitate to reach out!



#LIGHTITUP4HD 2022 Information Package







CONTACT US

The Huntington Society of Canada 20 Erb St. W.
Suite 801
Waterloo, ON N2L 1T2
www.huntingtonsociety.ca

For all #LightItUp4HD inquiries, please email: mwarwick@huntingtonsociety.ca

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 2022. 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 (HSC) is a not-for-profit charitable organization with the mission to improve the quality of life for those affected by Huntington disease (HD). We will address our mission through:

- Overseeing and facilitating excellent support services
- Providing access to the best and most up-to-date educational resources
- Increasing national and global awareness
- Advocacy
- Investing in promising research.

Our national office is located in Waterloo, ON and we have resource centres servicing every province and territory as well as 27 chapters and active areas across Canada.

What is Huntington disease?

Huntington disease is a genetic brain disorder with physical, cognitive and emotional symptoms. HD causes cells in parts of the brain to die.. As the brain cells die, a person with Huntington becomes less able to control movements, recall events, make decisions and manage emotions. HD is often described as having ALS, Parkinson's and Alzheimer's disease all at the same time. A child born to a parent with HD has a 50% chance of having the gene mutation that will lead to the progression of Huntington disease. Currently, there is no known cure for HD..

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

What #LightItUp4HD Means for the 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 extend support to individuals and families facing HD. The month of May is designated as Huntington Disease Awareness Month.



Campaign History

In 2015, James W. – 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 4 that year, **hundreds of thousands of Canadians** saw the CN Tower lit up in purple and blue, and our HD community lit up with pride.

Purpose and Objectives of the Campaign

We want to see all provinces #LightItUp4HD across Canada in May 2022.

Thanks to James' enthusiasm, and at the urging of our HD families and volunteers, we are expanding **#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**, **Germany**, **the USA**, **Cyprus** and **Australia**.

For so many years, HD has been kept secret in families, due to stigma and discrimination. The **#LightItUp4HD** campaign is a wonderful opportunity for those with HD to raise awareness, make connections, receive 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.

Working with our volunteers, we are putting together an impressive list of places that will be lighting up 4 HD in May 2022, **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 <u>www.lightitup4hd.com</u> to stay up-to-date on confirmed sites.

To watch a video featuring last year's sites, visit: https://youtu.be/pirztjb4boA





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.

Facebook:

- May is Huntington Disease Awareness Month. In honour of the month, we will be lighting up (insert site) on (insert date). Talk to your neighbours about Huntington disease (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 video from the Huntington Society of Canada and share to raise awareness during #HDAwarenessMonth this May. Look out for blue and purple lights at (insert site) on (insert date) as we #LightItUp4HD

Twitter:

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

