IN THE KNOW



In The Know (ITK) is the Huntington Society of Canada's monthly overview highlighting what is going on in the HD community. In an effort to ensure we notify the HD community of recent developments and up-to-date news, ITK is distributed on or about the 15th of every month.

NEWS

Join HSC in celebrating National Volunteer Week!

April 12-18 is National Volunteer Week! We would like to voice our sincere appreciation to all of our dedicated HSC volunteers. In honour of this week, we are highlighting the work of seven volunteers who, like many of our volunteers, have gone the extra mile. Click here to meet them.

CEO is recognized for outstanding efforts by HCCC

April 14, 2015



The staff and volunteers of the Huntington Society of Canada wish to extend their congratulations to Bev Heim-Myers, Chair of the Canadian Coalition for Genetic Fairness and CEO of the Huntington Society of Canada, who was recognized for her leadership role in Ending Genetic Discrimination in Canada. The Health Charities Coalition of Canada presented an Award of Distinction to Heim-Myers on April 14 at their meeting in Toronto. Click here for the full story.

D.I.Y. DNA: Genetic testing at home is risky business

Maclean's, March 23, 2015

On a midweek morning last month, Tim Cottee clicked shut his office door, woke his computer and girded himself for a piece of life-changing news. Weeks earlier, the 42-year-old executive at a Winnipeg financial services company had signed up with 23andMe, a California-based company that provides DNA testing and health information to Canadians over the web. Click here for the full article.

Home DNA tests may affect insurance, employment

CBC Marketplace, April 2, 2015

Curious about what your DNA might say about your medical future? Genetic tests may tell you if you are more likely to get sick, but taking the tests could expose you to risks you weren't expecting. Click here for the full article.

MLA Kerry Towle issues statement on Huntington disease to the Legislative Assembly March 19, 2015

Kerry Towle, MLA for Innisfail-Sylvan Lake, delivered a statement to the Legislative Assembly of Alberta last month in the words of her 18-year-old niece, Melinda Hunt, who was recently diagnosed with Juvenile Huntington disease. Click here to watch the video.

Genova delivers another hit

Waterloo Region Record, April 11, 2015

"Inside the O'Briens" is the story of a man named Joe, an Irish Catholic living in Boston. After a visit to the doctor it's not long before Joe receives his diagnosis — he has Huntington disease. Genova does an outstanding job of providing a compassionate story about Joe's life after this diagnosis. Click here for the full review.

Interview with HSC volunteer Bunny Clark

Durham Now, March 31, 2015

Illness and disease can be devastating, but when there's no cure it can leave you feeling hopeless. One Durham family is raising hope and awareness for a disease many don't know a lot about: Huntington's. Click here to watch the interview.

U of T engineering student showcase projects designed to solve local issues

CTV Toronto, April 10, 2015

Hundreds of University of Toronto engineering students showcased their projects on Friday that are designed to solve local issues and improve the lives of community members. One of the students who participated this year was first-year engineering student Michelle Samfira. Her group was one of eight teams that worked with the Huntington Society of Canada to engineer a special razor designed for those with muscle spasms. Click here for the full article.

A test will tell Bulldog Jake Dowell if he has Huntington disease

Hamilton Spectator, March 18, 2015

It's the little missteps that make Jake Dowell wonder. Are defencemen getting bigger and faster and tougher to beat? Or is it something more? Jake, a soon-to-be-dad, is at-risk for Huntington disease. Click here for the full article.

Angelina Jolie Pitt: Diary of a Surgery

New York Times, March 24, 2015

Two years ago I wrote about my choice to have a preventive double mastectomy. A simple blood test had revealed that I carried a mutation in the BRCA1 gene. It gave me an estimated 87 percent risk of breast cancer and a 50 percent risk of ovarian cancer. Click here for the full article.

Amaryllis Early Bird Contest: Order by June 30 for a chance to win a Fitbit!

It's that time of year again! HSC is kicking off its annual Amaryllis Campaign with an early bird contest! Amaryllis sellers that submit their orders by June 30, 2015 will have a chance to win a Fitbit activity tracker. This year, we will be offering two early bird prizes: one for our Amaryllis veterans and one for new sellers. Click here to learn more about our 2015 Amaryllis Campaign.

Join the Goodpin movement

Want to do some good and donate on the go? Join the Goodpin movement and support the causes you care about. The Huntington Society of Canada is pleased to offer Goodpin as a way to make donations from your iPhone and iPad. The app makes it easy to make donations from \$1 to \$200 and be social about it. Click here to learn more.

2015 North American HD Youth Camp

HDYO and HDSA are partnering this summer to host the first North American HD Youth Camp. The camp is open to anyone between the ages of 15 and 23 impacted by HD. Thanks to generous donations, the cost of camp, food and travel will be covered for all participants. This funding can support up to 40 young people to attend. The camp is located about an hour south of Washington DC. Click here to learn more.

National Advance Care Planning Day

April 16 is National Advance Care Planning Day. The purpose of this day is encourage Canadians to reflect on decisions made at the end of life and begin conversations with loved ones about their wishes for end of life care. Click here to learn more.

RESEARCH NEWS

Building a better mouse(trap): A new model of Huntington disease HDBuzz, March 16, 2015

Most research on Huntington disease is done using animal models that mimic the human disease. However, these models typically recreate only a few of the disease's symptoms, and there are some important symptoms that don't show up in any model at all. For the full article, click here.

Novel research technique suggests an antioxidant gene protects vulnerable neurons HDBuzz, April 6, 2015

Researchers have developed a new technique that allows them to screen for genes that could contribute to the progression of Huntington disease and other neurodegenerative disorders. For the full article, click here.

HD Clinical Trials: You can choose to play a role HSC is committed to updating the HD community about clinical trials taking place in Canada. Choosing

to participate in clinical trials is a personal decision. Genetic information is not protected in Canada and we recognize that some individuals at-risk may choose not to participate. If you would like to learn about clinical trials currently taking place in Canada, click here.

N2H 2M2 1-800-998-7398 info@huntingtonsociety.ca www.huntingtonsociety.ca Charitable Registration Number 11896 5516 RR0001

Huntington Society of Canada

151 Frederick St., Suite 400,

Kitchener ON

UPCOMING HSC EVENTS

There are a lot of exciting events coming up. Visit our website to see what is happening in your area! For upcoming events visit huntingtonsociety.ca/events





mentorship@huntingtonsocietv.ca OR Toll Free 1-855-253-0215



HSC's 2015

October 17, 2015

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