

## 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

#### **Inside the O'Briens - Reading Group Guide**

If you are interested in a group study on *Inside the O'Briens*, this reading group guide includes an introduction, discussion questions, ideas for enhancing your book club, and a Q&A with author Lisa Genova. The suggested questions are intended to help your reading group find new and interesting angles and topics for your discussion. Click [here](#) for the full reading group guide.

#### **Congratulations Amaryllis Winners!**

Every year our trademark Orange Sovereign raises awareness and over \$100,000 for programs and services. To encourage early ordering, we offered a FitBit Flex Wireless Activity Wristband as our early bird prize. We are happy to announce our winners: Patti Clark, New Seller Draw and Jan Malcolm, Early Bird Draw. It is not too late to order Amaryllis! Click [here](#) to put in your order today.

#### **Canada Cares: A Celebration of Caregiving**

Canada Cares mandate is to say "thank you," and to elevate the role of family and professional caregivers. As a member of the HSC community we think that you may be able to help nominate some outstanding caregivers for this year's award. Caregivers who go above and beyond the call of duty to care for their loved ones deserve recognition, and that's where you come in. Deadline for nominations is September 18, 2015. To nominate a caregiver and to learn more about this program, click [here](#).

#### **Enroll-HD**

An Enroll-HD progress update from over the past month. You can learn more about the new Enroll-HD website, recruitment update and regional startup and enrollment updates for the clinical trials. Click [here](#) to view the new Enroll-HD website. To read the full newsletter, click [here](#).

#### **Ed Wild Ice Bucket Challenge and Pie in the Face Challenge for HD**

Neurologist and Huntington disease researcher does the Ice Bucket Challenge for ALS/MND, and the Pie in the Face Challenge for Huntington disease. To see the video click [here](#).

#### **IN THE NEWS:**

##### **Giving Back**

Vernon Morning Star, June 28, 2015

The Morning Star participated in the Run to Finish Huntington's walk/run at Kin Beach last month. Click [here](#) to view their Giving Back column, with photos from the event.

##### **Duncan woman with Huntington disease goes for one last motorcycle ride**

CHEK, June 21, 2015

It was a special day for a Duncan woman with Huntington disease. She wanted to go for one more motorcycle ride but because of the advanced stage of her disease she wasn't able to hold on by herself. Her mother put out an ad online for someone with a sidecar and the response was quick and exceeded any expectations. To watch the video, click [here](#).

##### **Preparing for the worst**

The Newfoundland Herald, June 27, 2015

Ruby Wheeler's Story: With an estimated 15 - 25 years left to live after the onset of the disease, Huntington's is one unforgiving illness. "When Ruby found out she had Huntington's, she knew what her sister was like and what was coming down the road for her. That's hard." - Rich Wheeler, Pasadena. For the full article, click [here](#).

##### **How at-home genetic testing could compromise privacy**

The Inside Agenda Blog, June 18, 2015

In June, Alison Turnbull of Toronto spit into a tube, sealed it into an envelope and dropped the package in the mail. In a month, after the scientists had spun her spittle and combed through the strands of DNA, she would receive an email telling her more about herself than she knew before. For the full article, click [here](#).

### RESEARCH NEWS

#### **Get Behind the Bus - Jeff & Ed at the HDSA Convention 2015**

July 4, 2015

A special edition presenting the audio recording of Jeff Carroll and Ed Wild's Research Forum presentation at the Huntington's Disease Society of America Annual Convention in Dallas in June 2015 - entitled 'Get Behind the Bus'. Big reasons to have hope, and the latest from drug research and clinical trials across the world. To listen to the podcast, click [here](#).

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#### **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](http://huntingtonsociety.ca/events)**

The Huntington Society of Canada is a proud supporter of



HUNTINGTON'S DISEASE  
YOUTH ORGANIZATION



For more information about the program, please contact the Youth Mentorship Coordinator:  
mentorship@huntingtonsociety.ca  
OR Toll Free 1-855-253-0215



**SAVE THE DATE**  
**October 17, 2015**

[huntingtonsociety.ca/symposium](http://huntingtonsociety.ca/symposium)

