



## HSC National Conference 2014

Winnipeg, MB  
October 24 & 25, 2014

For more information  
or to register visit  
[www.huntingtonsociety.ca](http://www.huntingtonsociety.ca)

# Enroll!

Updates from the Enroll-HD  
global community



### Physician's Guide

HSC has published the 3rd edition of A Physician's Guide to the Management of Huntington Disease, with the assistance of HDSA.

For a copy please contact us at [info@huntingtonsociety.ca](mailto:info@huntingtonsociety.ca) or 1-800-998-7398.

# Strength & Knowledge

May 22, 2014  
Volume 7, Issue 3

## Brain and Tissue Donation

Many decisions we make on a daily basis are done instinctively, requiring very little thought or consideration. However, in preparation for future health changes, or times of emergency, it is important to discuss with family and friends what our thoughts and feelings are about issues of significance. Acting well in advance of these changes helps to ensure that our wishes are heard, can reduce stress and anxiety, and ensures we are in control of what will happen. Planning in advance will not only put us in control of major life decisions, it will save our family members from making these difficult decisions for us.

Strength & Knowledge (S&K) is a newsletter dedicated to caregivers and healthcare professionals to help guide individuals and families through the stages of HD (click here for our fact sheets on HD). This edition of S&K focuses on brain and tissue donations. From time to time, HSC is approached for information about brain and tissue donation. The process is complex and personal; for this reason HSC recommends you and your family seek professional advice (nurse, family doctor, social worker, etc.) as you create your advanced planning. HSC can provide you with the contact information for organizations in Canada that manage brain and tissue donations and provide support as decisions are made. However, we are not directly involved in the donation process.

Should this be something you wish to explore, you are encouraged to contact one of the 'Banks' below to receive the most up-to-date information.

### The Huntington Disease BioBank

#### University of British Columbia (UBC)

Centre for Huntington Disease, Room S179, 2211 Wesbrook Mall  
Vancouver, British Columbia, V6T 2B5  
Phone: 604-822-7738 or 604-822-7366

<http://www.cmmt.ubc.ca/outreach/hd-clinic/tissue-bank>

- 2 programs
- Blood and DNA donations
- Brain and tissue donations
- Serves as an invaluable resource for HD research
- Samples and clinical information are collected from consenting HD patients and other family members, both affected and unaffected
- Accepts tissue from across Canada

### Maritime Brain Tissue Bank

#### Dalhousie University, Department of Medical Neuroscience

Room 12D, Faculty of Medicine  
Halifax, Nova Scotia B3H 1X5  
Phone: 902-494-4130

<http://medical-neuroscience.medicine.dal.ca/brainbank.htm>

- Resource for researchers working to understand causes of dementia
- Not currently accepting tissue from persons with Huntington disease

### Douglas-Bell Canada Brain Bank

#### Douglas Institute

6875 LaSalle Boulevard  
Montreal, Quebec H4H1R3

Phone: 514-761-6131, ask for the Brain Bank

<http://www.douglas.qc.ca/page/brain-bank>

- Resource for research on neurodegenerative and psychiatric diseases
- Not able to accept tissue from outside the Province of Quebec



Please join us for another beautiful year of inspiring hope.

We are excited to offer a Tassimo Coffee Maker as our early bird prize. Submit your order before July 1, 2014 and you will be entered to win.

[Click here to enter.](#)

# Online Resources

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## **Huntington Society of Canada (HSC)** [www.huntingtonsociety.ca](http://www.huntingtonsociety.ca)

Our families and volunteers tell a powerful story of caring people who pull together to improve the quality of life of Canadians impacted by Huntington disease (HD). At HSC, we understand what you are going through, whether you have the disease yourself, are caring for someone with HD, are gene positive or are at-risk of inheriting HD.

We publish a variety of brochures, documents and fact sheets pertaining to HD. Check out the HD Healthcare Publications page to find publications like *A Physician's Guide*, a publication for doctors and nurses and other health care professionals; fact sheets on various topics including: Intermediate Alleles, Genetic Testing, Clinical Trials, Communication Tips, Strategies for Challenging Behaviours, Diet, Driving; and many more HD related resources.

## **Predictive Testing** [www.PredictiveTestingForHD.com](http://www.PredictiveTestingForHD.com)

If you are considering predictive testing for HD, this website provides information to help you make the decision that is right for you.

## **Do You Really Want To Know?** [www.doyoureallywanttoknowfilm.com](http://www.doyoureallywanttoknowfilm.com)

John Zaritsky, the film's director, is an Academy Award-winning and Emmy-nominated documentary filmmaker known for tackling difficult and serious subject matter in ways that personalize the stories, and yet draw attention to the issues. The results are deeply intimate and powerful portraits of ordinary people dealing with extraordinary life and death decisions and they often have a big impact on viewers.

## **HDBuzz** [www.hdbuzz.net](http://www.hdbuzz.net)

HSC is proud to be a founding funder and ongoing supporter of this international initiative. The cost-effective and one-of-a-kind service delivers the latest HD research news in easy-to-understand language and is helping spark interest in upcoming clinical trials.

## **Young People Affected by Huntington Disease (YPAHD)** [www.ypahd.ca](http://www.ypahd.ca)

A virtual chapter of HSC created by-youth-for-youth supports young people faced with challenges associated with HD. This online community provides support and networking opportunities for youth and connects them with HD initiatives in Canada and around the world.

## **Huntington's Disease Youth Organization** [www.hdyo.org](http://www.hdyo.org)

HSC is a founding funder of this online community, which brings together young people affected by HD from around the world. By pooling resources with other HD organizations to support HDYO, HSC is able to give youth a voice and deliver age-appropriate information and resources.



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