Fall 2017

Donor Report

Huntington Society of Canada Société Huntington du Canada

"Dreams and dedication are a powerful combination."

- William Longgood

Huntington disease (HD) is a fatal, inherited neurodegenerative disease that slowly destroys both mind and body. For more than four decades, the Huntington Society of Canada (HSC) has strived for excellence by providing practical help for families grappling with HD and investing in research to slow and prevent this disease. Your leadership support toward the Huntington Society of Canada is an integral component of that excellence and tells a powerful story: a story of a community filled with caring people who pull together and change the reality of families living with HD.

RESEARCH

One gene, one cause, one disease
....and the research implications on other neurodegenerative diseases.

WHY RESEARCH HUNTINGTON DISEASE?

Huntington disease (HD) affects one in 5,500 Canadians, which some might consider rare. However, this means 6,000 Canadians and well over 25,000 people who are from families with HD are affected. HD is an age-onset neurodegenerative disease; this means the disease does not affect the individual until mid-life, with the exception of Juvenile Huntington disease which strikes during childhood. From the perspective of age-onset neurodegenerative diseases, these are not rare diseases and half the people in Canada over 65 are at-risk. As science and medicine have greatly impacted heart disease and cancer with prevention and treatment, researchers are now faced with the hurdle of neurodegeneration, compounded by the demographics of an aging population.

WHY SUPPORT HD RESEARCH IF YOU ARE NOT IMPACTED BY HD?

Common forms of neurodegeneration such as Alzheimer's and Parkinson's diseases are primarily caused by unknown reasons, and likely many different reasons, with a common outcome. This makes research extremely difficult because researchers do not know why most people have Alzheimer's and Parkinson's disease, and they are testing drugs in the people who have the disease for many different reasons. In addition, pre-clinical mouse research models of Alzheimer's and Parkinson's diseases poorly represent the human disease.

ONE GENE, ONE CAUSE, ONE DISEASE.

Huntington disease is caused by a CAG DNA mutation in the huntingtin gene. This is the only cause, and people with this expansion will develop the disease. Researchers have accurate genetic tests for HD, and have many accurate models of the disease where this one mutant gene will cause neurodegeneration. This means, in the process of drug discovery, researchers have very accurate cell systems and animal models. When clinical trials are started, researchers know exactly why each person in the trial has HD, and even how severe the disease will be. They even have tools now to accurately measure how much mutant huntingtin protein is in a person's spinal fluid.

RESEARCH cont'd

WILL HUNTINGTON DISEASE RESEARCH HELP PEOPLE WITH ALZHEIMER'S, PARKINSON'S AND OTHER FORMS OF NEURODEGENERATION?

In 2015, the Huntington disease research community published a massive genomic study to look for other genes that could affect the age of onset of HD from over 4,000 individuals who had HD. The list of genes in this study was then used by researchers in ataxia* research, and in 2016, it was found that similar genes affected the course of ataxias. The pathways uncovered in the HD study had significant overlap with known pathways affected in ataxias, Alzheimer's disease and ALS (Lou Gehrig's disease).

In 2016, a lead compound in HD drug development turned out to be relevant and under development for Parkinson's disease. Based on very recent research, HD researchers believe any therapy that is effective for HD will validate pathways to concentrate on for other forms of neurodegeneration, and even result in HD drugs that will impact other diseases.

Recent Huntington disease research, supported by the Huntington Society of Canada, shifted the research focus to a whole body approach in understanding the disease and looking for subtle changes outside the brain, which may be easier to understand than just focusing on the brain. This shift is now seen in Alzheimer's and Parkinson's diseases as the approach to studying these diseases is looking at the whole body.

In 2017, HD researchers also have the ability to perform genetics and whole genome analysis of clinical "outliers", people who have the disease far sooner and more severe, or far later and less severe than average, to understand secondary targets for drugs, and even effects of drugs already in use and how they may be able to influence neurodegeneration. The power in HD comes from studies like ENROLL-HD, in which data is being accumulated in over 14,000 people worldwide, either with the disease or who are at-risk of developing the disease, to track what is happening before people get sick, through to the onset of the disease, and the progression. Again, due to one gene, one cause, one disease, this data is extremely accurate.

Accumulative research dollars are pooled and disbursed once a year through the Society's Navigator research competition. Significant donor directed funding has been, and can be, transferred to a specific project within 10 business days ensuring research dollars are put into action as fast as possible.

The Huntington Society of Canada would like to extend its sincere appreciation to Dr. Ray Truant for authoring this article.

To learn more about HSC research investment programs visit www.huntingtonsociety.ca.

ADVOCACY

GENETIC DISCRIMINATION

Thanks to your generous donations, your essential and ongoing support has allowed HSC to continue leading the Canadian Coalition for Genetic Fairness (CCGF) activities over this past year. As a key strategic priority, you directly supported the efforts of HSC's CEO and Chair of CCGF, Bev Heim-Myers, in our efforts to end genetic discrimination in Canada. Canada now joins other G7 countries in protecting genetic test information.

The Genetic Discrimination Act became law on May 4, 2017, after receiving Royal Assent. HSC played a leadership role and the entire HD community should be very proud that our community members in all provinces and territories, now have their genetic test information protected.

For more detailed information, and for updates since May 4th, 2017, please visit http://ccgf-cceg.ca/en/.

FAMILY SERVICES

Over 15,000 individuals and organizations across Canada are supported by our Family Services team. This team delivers services from coast-to-coast, ensuring that individuals, families and organizations are educated about HD. Services include individual, couple and family support, advocacy for services where gaps are identified and support groups across the country. Thanks to donors like you, the Family Services team also provides youth specific services through a Youth Mentorship Program. This program connects youth growing up in a home with HD, with a HSC-trained young adult that can provide insight on how to navigate life choices in light of HD. This is made possible by the ongoing and continued support of our donors. Thank you.

UPDATING HSC'S EDUCATIONAL RESOURCES

HSC's Family Services team is launching new HD Educational Modules across Canada, thanks to funding provided by the Beta Sigma Phi Sorority in Alberta, Canada. Educational Modules include topics such as: What is Huntington Disease?, Living with a Chronic Illness, Caregivers Guide - overview, swallowing issues, emotions, movement, Law Enforcement, HD Clinical Trials, and Responsive Behaviours. Module presentations can be scheduled through your Family Services team member. For a complete list of HSC Family Services team members, please visit www.huntingtonsociety.ca/family-services-team.

The team has also updated several resources which are available on the HSC website. These include the following fact sheets: End of Life Care in HD, Juvenile HD, Eating and Swallowing, HD and Feeding Tubes, Living At-Risk of HD, and Cognitive Changes in HD.

To access HSC's informative, educational resources, please visit: www.huntingtonsociety.ca/hd-fact-sheets-articles.

YPAHD

2017 YOUNG PEOPLE AFFECTED BY HUNTINGTON DISEASE DAY (YPAHD DAY)

As part of our Youth Program, and through the support of donors like you, HSC holds YPAHD Day in conjunction with our biennial National Conference. Feedback from our youth community told us that every two years wasn't enough. This is why, since 2015, YPAHD Day has become an annual event. This year, YPAHD Day will be hosted on November 18, 2017 in Moncton, Toronto and Kelowna.

Over the course of the high-energy day, participants will connect with each other, learn about the latest research and take part in roundtable discussions and workshops about everything from mentorship to care strategies, grief and guilt, fundraising and genetic testing. YPAHD Day is a one-day opportunity for youth to learn from and inspire one another, as well as to see that they are not alone in their experience and build their own network of support.

To learn more about the 2017 YPAHD Day, please visit www.huntingtonsociety.ca/ypahd-day.

HSC 2017 NATIONAL SYMPOSIUM

Every other year, thanks to the generosity of our donors, people affected by Huntington disease (HD), medical professionals and support professionals across Canada come together for a one-day conference. Together, we learn, inspire one another, and offer support.

This year's Symposium will be held on October 14th, 2017. Working with volunteers from across Canada, HSC will host a variety of locations from coast-to-coast.

Participants will take part in two streamed presentations that will focus on learnings and new developments in the area of HD research, demonstrating how we can transform tomorrow together! In communities where local programming is added, further care strategies or regional research information will be provided. Individuals are also welcome to join the streamed presentations from home, providing an even higher level of accessibility to information.

To register for the 2017 Symposium, please visit www.huntingtonsociety.ca/symposium.

Thank You

On behalf of families living with HD, thank you for your continued generosity and partnership. Your donations make all the difference as we support families and youth from coast to coast, reach out to families who are not yet receiving much-needed support, invest in world-class research and play a leadership role in the international Huntington community.

With your help, we are continuing to improve the quality of life for people with HD, cultivate strength and resilience in the Huntington community and provide substantive reasons for hope.