

Donor Report

Huntington Society of Canada

Soci t  Huntington du Canada

“How wonderful that nobody need wait a single moment before starting to change the world.”

Anne Frank (1912-1945)

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

Thanks to your generosity and vision, we were able to invest just over \$1.1 million in our New Pathways and Navigator research programs this year.

New Pathways and Navigator Research Programs

The applications we received for our Navigator and New Pathways programs, from both established scientists and up-and-coming investigators, speak to the success of our funding strategy and the growing excitement surrounding HD research. From these impressive submissions, we selected the following projects to fund.

New Pathways – Dr. Jeff Carroll, Western Washington University, Washington

While HD is always caused by a mutation in a specific gene, it’s not clear what the normal role of this gene is. Dr. Carroll believes that future therapies for HD will be improved by probing this mystery. A surprising result from one of Dr. Carroll’s mouse studies suggests that the HD gene may be playing a role in DNA repair. Meanwhile, a huge study of human HD patients suggest that variations in genes involved in the DNA repair process can actually change the age at which people experience HD symptoms.

Dr. Carroll and his team propose to investigate in much greater detail whether the HD gene is involved in specific DNA repair pathways, and if so, how. If their initial findings are validated, it could suggest several new and exciting approaches to HD treatment.

Navigator – Dr. Christopher Pearson, The Hospital for Sick Kids, Toronto

HD is one of more than 40 genetic neuromuscular/neurodegenerative diseases caused by mutations in repeated DNA sequences. If you think of a gene as though it were a sentence such as “THE CAT ATE THE FAT FAT RAT”, a repeat mutation would be “THE CAT ATE THE FAT FAT FAT FAT FAT RAT”. In affected tissues, the number of repeats gets progressively larger as the patient ages, making symptoms worse. The repeats can also expand when a parent passes the gene onto their children.

Dr. Pearson’s team has a collection of compounds that can bind to the repeat sequences or to the unusual structures that the repeats can form. They plan to screen this collection to see which ones can stop or reverse the trend of longer repeats, thereby slowing the progression of the disease or reducing the severity of symptoms.

Research, cont'd.

Accelerating Discoveries and Partnering with Brain Canada

After launching in 2015, for funding in 2016, our partnership with Brain Canada established a \$2-million research initiative to fund innovative “virtual networks” that connect clinicians, scientists and patients.

This year's recipient, of the HSC-Brain Canada Grant, is Dr. Simonetta Sipione from the University of Alberta. She will be collaborating with several other Alberta researchers and a colleague at the Université de Montréal to examine the link between HD and gangliosides — a group of molecules that are important for healthy brain function.

Preliminary data shows that using the GM1 ganglioside to treat HD mice dramatically improves the symptoms of the disease and slows down the neurodegenerative process. Dr. Sipione and her team will expand this work, looking at the changes created by GM1 treatments both in HD mice and in samples from human patients with HD. They will also determine whether gangliosides in human blood and spinal fluid can be monitored to provide accurate information about HD progression.

Be Brave, Be Bold, Be Ready: Laying the Foundation for Successful Clinical Trials

In 2012, the HD Consortium was created to bring together clinicians, researchers, HSC staff and family representatives in a first-of-its-kind collaboration to build a national HD clinical trials strategy. On April 25, 2016, the Consortium met to discuss the newly created HD Recruitment Strategy, aimed at increasing the number of HD clinics and clinical trial sites in Canada and the number of Canadian participants.

This meeting included three new organizations with expertise to help us fast-track our efforts: N2 (Network of Networks), a national alliance of clinical research networks and organizations; Clinical Trials Ontario, which works to improve Ontario's clinical trials environment and attract clinical trial investment to the province; and Innovative Medicines Canada, the national voice of Canada's pharmaceutical industry.

N2 and HSC Host a Clinical Trials Webinar

The more people who enroll in clinical trials, the faster potential treatments can get to the market. Together, N2 and HSC are presenting a webinar on October 1, 2016, designed to take the mystery out of clinical trials, using HD as an example. The webinar will feature a clinician who conducts trials, a study coordinator who will explain the process step by step and a participant who will share her experience. Please help spread the word and join the webinar on October 1, 2016. Register at www.clinicaltrialswebinar.ca.

BE BRAVE · BE BOLD · BE READY CLINICAL TRIALS



Join HSC and N2 (Networks of Networks) for a clinical trials webinar on Saturday, October 1st, 2016.

This introductory webinar will focus on clinical trials and their significance, meeting a clinician to discuss participating in a clinical trial, which clinical trials are currently in progress and how you can get involved.

There will also be dedicated time for questions and answers.

FEATURED SPEAKERS: DR. OKSANA SUCHOWERSKY

Professor of Medicine, Medical Genetics & Pediatrics, Toupin Research Chair in Neurology, Director of Clinical Genetics at the University of Alberta
& A CLINICAL TRIAL PARTICIPANT

As this is a free event, please register early to secure your spot. Registration is open until September 25th.



Visit www.clinicaltrialswebinar.ca to register.
Visit www.itstartswithme.ca to learn more about clinical trials.



Advocacy

Ending Genetic Discrimination

For many years the Canadian Coalition for Genetic Fairness — chaired by HSC's CEO, Bev Heim-Myers — has been strongly advocating for legislation to protect genetic information. Now, Bill S201, An Act to Prohibit and Prevent Genetic Discrimination, is moving to second reading in the House in late September. Bev and other coalition members continued to meet with MPs over the summer to rally support. The response was positive, and we are cautiously optimistic the bill will move forward, ending genetic discrimination in Canada.

Toronto International Film Festival (TIFF)

Taking place along King Street West between Peter and University Street, in Toronto, Ontario, the 11 day festival attracted over 500,000 moviegoers of all ages. CCGF and HSC broadcasted the HSC Do You Really Want To Know? commercial. This unique opportunity was presented to charities at a significantly reduced price and was aired 440 times during the festival. TIFF is expected to bring in 5,400 industry delegates (from 80 countries), 1,200 journalists and hundreds of movie stars.

Family Services

Understanding Behaviour

Announcing the newly updated *Understanding Behaviour in Huntington Disease!* This publication gives families and caregivers valuable insights and strategies for dealing with the behavioural symptoms of HD — often the most troubling part of this disease. Many thanks to the John M. & Bernice Parrott Foundation and the Huntington's Disease Society of America for helping make this publication available to HSC to include the Canadian content and make it accessible to the HD community.

Growing Our World-leading Youth Mentorship Program

Our Youth Mentorship Program has proven to be a resounding success, earning praise from mentors, mentees, parents and international HD organizations. To meet demand from youth seeking mentors, we expanded the program this spring, training a group of six new volunteers to support their younger peers.

Enhancing Outreach

Our Family Services team frequently give presentations about HD to families, long-term care staff, healthcare professionals and the public. To make that job easier, HSC launched a series of HD 101 modules this past spring. These customized PowerPoint presentations cover various aspects of HD, complemented by video interviews with different people touched by the disease. We are also updating our factsheets — posted to our website — that provide up-to-date information. They can be accessed at www.huntingtonsociety.ca/hd-fact-sheets-articles.

Expanding Services

Families in New Brunswick and in Kingston, Ontario and the surrounding area now have more access to the services they need. We recently boosted the number of hours allocated to our Family Services professionals.

Investing in Professional Development

Professional development ensures our Family Services team stays current on all the latest HD developments. With generous support from the Charles Johnson Family Fund, we organized a session this past spring on hospice, palliative care and medical assistance in dying, giving our team the knowledge they need to help families facing end-of-life choices.

Connecting Our Community

YPAHD Champion's Challenge

Our youth chapter, Young People Affected by Huntington Disease (YPAHD), launched the first-ever Champion's Challenge. Between May and October, YPAHD members will be organizing fundraisers across the country, including bottle drives, online auctions, yoga and yard sales. The challenge continues until the National Conference, where we will be presenting awards for most dollars raised, most donors and most unique event.

Huntington's Disease Society of America (HDSA) Convention and National Youth Alliance (NYA) Day

This year, we once again provided funding for two YPAHD members to attend the HDSA Convention in Baltimore, as well as the NYA Day held the preceding day. Our representatives came back energized and filled with ideas to enhance our National Conference & YPAHD Day and increase youth involvement nationally and internationally.

Corey Janke, our Southwestern Ontario Resource Centre Director, also attended the convention, networking with colleagues from HDSA and the Australian Huntington Disease Association and bringing back valuable information to share with the Family Services team.

HDYO Camp

This year's HDYO camp near Washington, DC attracted 50 youth from the ages of 15-25, including six Canadians. HSC was part of the staff of 10 who organized age-specific discussions about family, friends, relationships, genetic testing, grieving and loss. Special guests included genetic counsellors, HD researcher Dr. Jeff Carroll who shared his family story of HD and the latest news in HD research and Lysle Turner, the youngest South African to climb Mount Everest and did so to raise awareness about HD. There was also lots of opportunity for fun, including paddle boarding, campfires, canoeing, swimming, archery and other traditional camp activities. HSC continues to support and commit to HDYO helping us to maximize our comprehensive support to youth dealing with HD.



Believe
Transforming Tomorrow Together

Learn with us at HSC's 2016 National Conference in
Halifax, Nova Scotia on Nov 4&5 2016.

Register now at huntingtonsociety.ca/conference

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Gearing Up For Halifax: National Conference 2016

Join us for an exciting weekend this fall at the HSC National Conference in Dartmouth, Nova Scotia, hosted by the Halifax Chapter.

We have lined up an all-star array of presenters. They include inspirational speaker Dr. Terry Kelly, totally blind since age two, who will inspire us to live in gratitude by embracing our talents, abilities, and remembering that everyone has a purpose. Using personal anecdotes peppered with humour, songs, and audience participation, Terry will encourage us to develop our own strategies for living and working happily and healthily, relative to where Huntington disease (HD) is in our life.

Jay Ingram, the Real Scientific Influencer: Powerful Personage. Jay's keynote will explore the influence of Nancy Wexler, well-known in the HD community for her involvement with a study group in Venezuela that discovered the location of the gene that causes HD. Using Nancy's story as the foundation, Jay will discuss how a powerful personage, such as Nancy, can influence the course of science.

Researchers Dr. Ray Truant and Dr. Tamara Maiuri will discuss newly discovered insights into why having 36 or more CAG repeats leads to HD. Meanwhile, perennial conference favourites Dr. Jeff Carroll and Dr. Ed Wild, editors of HD Buzz, will host an interactive session on the latest developments in HD research.

Fundraising & Awareness



Launched in early September, our newest capital campaign aims to raise \$3 million: \$1.5 million to help researchers build on recent advances and expand clinical trials and \$1.5 million to ensure all Canadians affected by HD have access to the services they need. It's an ambitious goal, but we're already one third of the way there, thanks to our passionate supporters.

HSC is thrilled to partner with Chloe Angus, globally recognized designer, who has collaborated with Hadia Artist Clarence Mills to create a Spirit Button Wrap with a unique Dragonfly motif. The Dragonfly is the symbol of the *Believe: Transforming, Tomorrow, Together* campaign.

Huntington Disease and Juvenile Huntington Disease Awareness Month

Each May, volunteers and staff make special efforts to educate Canadians about HD. Barb Marshall wanted to raise awareness about HD, so she put her creativity and sewing talents to work. The result was a bold, beautiful blue and purple lapel ribbon — blue for Huntington disease and purple for juvenile HD — that has raised nearly \$2,000.

Meanwhile, Jo Zadorsky, a dye artist and owner of Costa Nada in Stouffville, Ontario, teamed up with her husband, Grant Ivens, brand marketer and owner of Say What! Communications, to create a #cureHD tie-dye t-shirt. They launched it at Stouffville's TEDx talk in April.

Fundraising & Awareness, cont'd.

Light It Up 4 HD

In 2015, a volunteer inspired Canada's HD community when he arranged to light up the CN Tower in blue and purple for Huntington Disease Awareness Month. This year, HSC volunteers took the campaign nationwide, lighting up 16 landmarks from coast to coast and spreading the word on social media using the hashtag #LightItUp4HD. The idea went global as well, turning landmarks in Ireland, Scotland and Spain blue and purple.



NEW: Public Service Announcement (PSA) Campaign

Thanks to a number of volunteers, HSC launched a new PSA campaign this year focusing on raising awareness. This powerful campaign tells compelling stories of each participant, how they are impacted by HD and what their message of hope is for the HD community and beyond.

Our new PSA videos can be found at www.huntingtonsociety.ca.

Huntington Disease
is a fatal, hereditary brain disorder.

IT IS LIKE experiencing the symptoms of Alzheimer's, Parkinson's and schizophrenia – simultaneously.

Huntington disease
AFFECTS GENERATIONS.

LEARN MORE
cureHD.ca
1-800-998-7398

Huntington Society of Canada
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Huntington Society of Canada
HUNTINGTON
Soci t  Huntington du Canada

HUNTINGTON DISEASE is a fatal, hereditary brain disorder

EVERY CHILD born to a parent with HD has a 50% chance of sharing the same fate

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 connected to HSC, 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.