



Spring 2016 Donor Report

Huntington Society of Canada

Soci t  Huntington du Canada

“The things you do for yourself are gone when you are gone, but the things you do for others remain as your legacy.”

Kalu Ndukwe Kalu

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

Research

Accelerating discoveries

Last year, Brain Canada matched the generous \$1 million donation from an anonymous donor. In November 2015, partnering with Brain Canada, we launched the Brain Canada/ HSC \$2 million multi-investigator research initiative to fund innovative “virtual networks” that connect clinicians, scientists and patients.

By fostering collaborations both within the Huntington community and across different neurodegenerative diseases, these networks will generate innovative thinking and expedite discoveries. We have gathered together an impressive international peer review panel of experts and hope to extend funding before the end of June 2016.

Funding leading-edge research

This year we received a record 27 letters of intent for our New Pathways and NAVIGATOR grants, many from new researchers entering the HD field. The significant increase over previous years reflects a growing recognition that HD breakthroughs will hold the answers for many other neurodegenerative diseases. The most promising applicants will be invited to submit full proposals, and we will be announcing our funding decisions by the end of June.

Be Brave, Be Bold, Be Ready: Laying the foundation for successful clinical trials

The easier it is for clinicians to set up and run clinical trials, the faster we can learn which potential HD treatments are effective. On October 5, 2015, HSC convened more than 20 researchers, clinicians, researchers and families from the HD community to finalize a Huntington Disease Preparation Guide for Clinical Trials in Canada and an HD specific Clinical Trials Readiness Checklist. The event also marked the launch of a new mentorship program for HD clinicians. The first of its kind in Canada, the program matches new clinicians with more seasoned ones who can help guide them through the complicated process of leading a clinical trial.

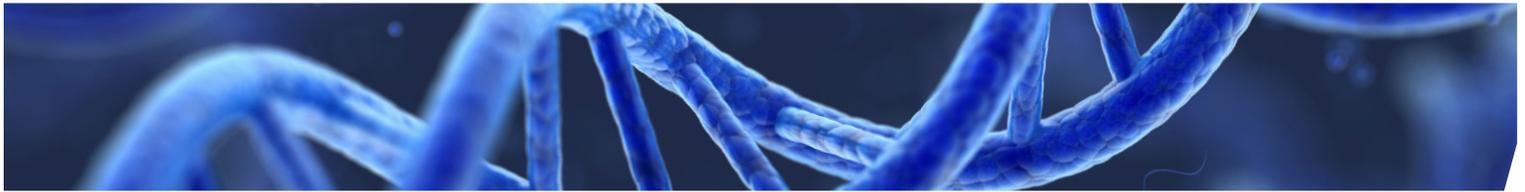
To keep the momentum going, we are now planning our fourth clinical readiness meeting. Taking place on April 25, the event will focus on participant-centred clinical trial recruitment strategy and begin to look at how we can streamline the start-up process. Once again, we will be inviting families to the table, since the success of clinical trials depends on the participation of people who are impacted by HD. We will also include representatives from Clinical Trials Ontario and N2 (a cross-Canada organization of clinical research networks) the pharmaceutical industry, Innovation Medicines and CHDI to share our work with the wider clinical trials community and tap into existing knowledge.

Advocacy

Ending genetic discrimination

Bill S-201, a bill to outlaw genetic discrimination, died when the federal election was called last fall. Now genetic fairness is back on the political agenda, thanks to the tireless work of Senator James Cowan, the Canadian Coalition for Genetic Fairness (chaired by HSC's CEO, Bev Heim-Myers) and the HD community. Senator Cowan re-tabled Bill S-201 on December 8, 2015, and it is currently being reviewed by the Senate Standing Committee on Human Rights. Bev testified in front of the Committee on February 17, presenting more examples of genetic discrimination that keep pouring into our office.

Given the speed at which this version of Bill S-201 is moving forward and the signs of support from senators of all political stripes, we are cautiously optimistic that this time, the bill will move forward to the House.



Family Services

Enhancing outreach

A big part of the job of our family services team is educating families, long-term care staff, healthcare professionals and more. Our new HD 101 modules, now ready to roll out across the country, will make that job easier.

The modules consist of customizable PowerPoint presentations on various aspects of HD, along with video interviews featuring the perspectives of different people touched by the disease: a person diagnosed with HD, a caregiver, a couple with an HD-positive spouse and a person who has tested gene-negative. Meanwhile, new templates for introduction letters and standardized presentation request forms will help streamline the booking process.

Youth

Growing our world-leading Youth Mentorship program

This April, we will be holding our third round of mentor training, preparing a new group of youth to support their younger peers. The first of its kind in the world, the program has become the gold standard that other organizations now use as a model. Growing interest in the program speaks to its success. All of our mentors from our first two rounds of training have been matched with mentees. However, it is feedback like the following that really tells us we are making a difference:

"My son keeps a lot of his feelings inside ... It took time for my son and his mentor to connect, but now I know he finally has someone (other than our immediate family) to talk to and this is a BIG deal."

Providing much-needed resources for kids

To support younger children affected by Huntington disease, HSC funded a new interactive online platform called HDYO Land. Created in partnership with the international non-profit Huntington's Disease Youth Organization (HDYO), the website fills an important gap by helping kids learn about HD in a positive, age-appropriate way. To learn more, visit www.en.hdyo.org/kid

Connecting Our Community

National Symposium 2015

On October 17, 2015, approximately 300 participants from across the country joined our 2015 National Symposium, a 20 per cent increase over the previous year. Through teleconferencing, attendees were able to participate at one of 13 sites or live-stream the event at home.

Our theme focused on clinical trials, with pre-recorded presentations from Dr. Mark Guttman, Director of Toronto's Centre for Movement Disorders, and Dr. Joe Giuliano, Director of Clinical Operations at CHDI. Dr. Giuliano was on hand to answer live questions, as was Paul McCann, research study coordinator at the University of Alberta's Department of Neurology.

Teleconferencing offers a cost-effective way to connect our community. Judging by the feedback we've received from participants and the significant growth in attendance, this is a model that families appreciate, allowing them to take part wherever they might live.

Expanding YPAHD Days

In the past, HSC has held YPAHD Days in conjunction with our biannual National Conference. However, youth told us that once every two years wasn't enough. That's why we hosted our first-ever Regional YPAHD Day in an off conference year, on November 21, 2015, gathering together young people affected by HD in Calgary, Toronto and Halifax.

Over the course of the high-energy day, participants connected with each other, learned about the latest research and took part in roundtable discussions on everything from mentorship to grief, caregiving, fundraising and genetic testing. For many participants, it was their first HSC event, but bonds formed fast.

"It's helped me be more positive in my life," said one participant. "Such a great weekend with amazing people," said another. Among the highlights was a teleconference session with gene-positive HD researcher Dr. Jeff Carroll. "He's such an inspiration to all of us," one YPAHD member told us.

Gearing up for Halifax: National Conference 2016

Every two years, we gather families, researchers, healthcare professionals and other members of the HD community to connect, share and learn at our National Conference. Plans are now in full swing for the 2016 event, to be held in Halifax on November 4th and 5th. Dr. Jeff Carroll and Dr. Ed Wild from HDBuzz and Dr. Ray Truant and Dr. Tamara Maiuri, from McMaster University, are slated to attend. It is sure to be another powerful event, and we warmly invite all members of the HD community to join us.



Save the Date!

November 4 & 5, 2016

HSC 2016 National Conference

It's never too early to start thinking about the 2016 HSC National Conference. Hosted by the Halifax Chapter of the Huntington Society of Canada, we invite you to join us in Halifax, Nova Scotia on November 4 & 5 so we can transform, tomorrow together. This year's conference will be held at the Holiday Inn Halifax Harbourview in Halifax, NS. For more information or to register, contact us at 1-800-998-7398 or email us at events@huntingtonsociety.ca or visit www.huntingtonsociety.ca

Conference Featured Speakers Include:



Dr. Ed Wild,
MRCP, PhD

Ed is a Clinician Scientist at UCL Institute of Neurology, London, and a Consultant Neurologist at the National Hospital for Neurology and Neurosurgery. Ed

studied medicine at Cambridge University and has worked in neurology since 2005. He now leads a team at UCL's Huntington's Disease Centre focusing on clinical trials of new HD treatments and studying cerebrospinal fluid to understand HD. He has authored 6 books and over 40 peer-reviewed scientific publications. Since 2009, he has been collaborating with Dr. Jeff Carroll to make HD research news accessible to the global HD community through HDBuzz.



Dr. Ray Truant

Dr. Truant has been with McMaster University since 2000. He has been the recipient of the CIHR New Investigator Award 2001-2006 and is a Fellow of the Howard Hughes

Medical Research Institute, Duke University 1996-1999. Dr. Truant achieved his PH. D in Toronto, at the C.H. Best Institute of Biomedical Research and is supported by CIHR and CHDI Inc. His career to date includes over fifty career manuscripts. Dr. Truant was a recipient of the Queen Elizabeth II Diamond Jubilee Medal for public service in 2012, and is now a full Professor at McMaster University and Chair of the Scientific Advisory Council for the HSC, as well as, External Scientific Advisor for HDBuzz.net.



Dr. Jeff Carroll,
PhD

Jeff Carroll is a scientist studying HD as an assistant professor at Western Washington University. As a post-doctoral fellow in the lab

of Marcy MacDonald at Massachusetts General Hospital, Harvard Medical School, he completed his PhD under the supervision of Michael Hayden at UBC in Vancouver. His research is focused on understanding the links between metabolism and CAG-expansion in the huntingtin gene. As well as conducting research, Jeff is a member of an HD family and himself carries the mutation which causes the disease. Jeff also co-founded and serves as co-editor-in-chief of HDBuzz.net with Dr. Ed Wild.



Dr. Tamara Maiuri

Dr. Tamara Maiuri is a research scientist and postdoctoral fellow in Dr. Ray Truant's group at McMaster University in Hamilton, Canada. Prior to joining the Huntington

disease field, Tamara obtained her PhD from the Medical Biophysics Department at the University of Toronto where she studied the cell biology of cancer-related genes. Her work in the Truant lab focuses on the normal biological functions of the huntingtin protein in hopes of understanding how they may be disrupted upon inheritance of the mutant huntingtin gene that causes HD, and how they may be restored by small molecule drug candidates.



Jay Ingram

Co-host of Discovery Channel's science show, Daily Planet, for 16 years, science broadcaster and writer Jay Ingram has earned two ACTRA Awards over the course of his career, including

one for Best Host. He has also hosted The Talk Show, a series about language, for which he won a Science in Society Journalism Award. For his efforts to popularize science, Jay was awarded the Sandford Fleming Medal from the Royal Canadian Institute in 1984 and the Royal Society of Canada's McNeil Medal for the Public Awareness of Science in 1997. In 2000, Jay was awarded a Michael Smith Award for Science Promotion by the Natural Sciences and Engineering Research Council of Canada. Jay has also written 13 books, including many bestsellers, and is the 2015 recipient of the Walter C. Alvarez award for medical writing given by the American Medical Writers Association. He is currently a columnist for Canadian Wildlife magazine.

For further details on the 2016 HSC National Conference, visit www.huntingtonsociety.ca/events

Fundraising & Awareness



Transforming Tomorrow Together

This spring, HSC will be launching Believe: *Transforming Tomorrow Together*, our new fundraising campaign. Thanks to our passionate supporters, more than \$1 million in early donations have been raised. In total, the campaign aims to raise \$3 million. Half of those funds will help researchers build on recent advances and expand clinical trials, while the other half will help ensure all Canadians affected by HD have access to the services they need. Although it's an ambitious goal, we're confident our supporters will step up to the challenge.

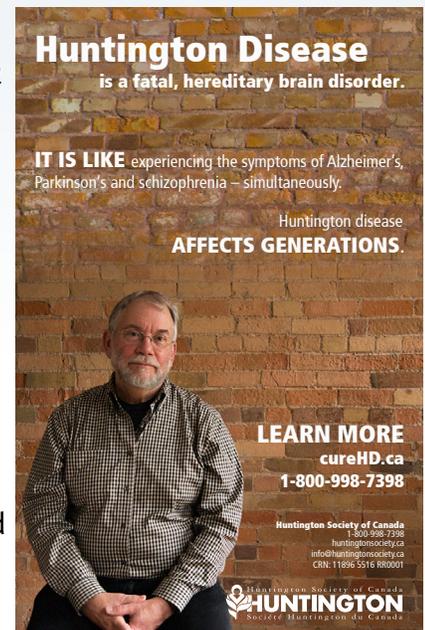
Huntington Disease and Juvenile Huntington Disease Awareness Month

This May, a new series of public service announcements (PSAs) will put the spotlight on Huntington disease and Juvenile Huntington disease. The powerful PSAs feature people from the HD community talking about how the disease impacts their lives, what they fear and what they hope for the future. PSA campaigns can significantly increase awareness as broadcasters will allow charities air time to promote their cause. This year, our campaign features volunteer members of the HD community to help raise our profile. We also partnered with local musical group Eli and the Straw Man, from the Niagara region, in Ontario, who have a connection to our community. Here is a sneak peek at HSC's new campaign which will fully launch in May during Huntington disease awareness month.

Meanwhile, volunteers across the country are stepping forward to #LightItUp4HD, arranging to have landmarks in their community lit up in blue & purple for Huntington disease and Juvenile Huntington awareness month. Our volunteers have some incredible ideas, similar to the #LightItUp4HD and the PSA campaigns, we have a volunteer in B.C. who is working to raise awareness by making blue and purple lapel ribbons in support of HD. These ribbons will be distributed nationwide to television stations asking hosts to wear them during the month of May.

Be sure to watch for our PSA campaign, our #LightItUp4HD sites and our blue and purple ribbons. Our volunteers will be sharing our outreach successes on social media in hopes of making a significant impact on Canadians.

The Society is extremely grateful to all of our volunteers who agreed to participate in this year's campaign. It is a true testament to the commitment and dedication of our community that members of the HD family would participate in a national public service campaign, share their stories, and help light up Canada in blue and purple during the month of May.



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.