



Donor Report

Huntington Society of Canada Société Huntington du Canada

“It always seems impossible until it’s done.”

Nelson Mandela (1918-2013)

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 to 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

Thanks to the generous support of our donors, the Huntington Society of Canada invests annually in HD research, clinical trial readiness and educating the HD community about the latest research findings. Your vital support allows us to ensure that more individuals are aware of HD research and other important HD clinical trial opportunities. One of the areas you directly support is the HD Clinical Trials map on the HSC website which provides current information about HD Clinical Trials in Canada. Thank you for funding this strategic priority.

HDCLARITY COMES TO CANADA

At the 2016 HSC National Conference, British neurologist Dr. Ed Wild spoke about the CHDI funded study, HDClarity. HDClarity aims to give researchers a more sensitive measure of HD progression — some kind of biomarker that reflects the changes happening inside brain cells.

Dr. Wild suggests that researchers look in the cerebrospinal fluid (CSF): the liquid that surrounds the brain and spinal cord. He is willing to bet that as HD starts to change the levels of certain proteins within brain cells, they will also see changes in the level of those proteins in the CSF. That is why he put together HDClarity. This new international study aims to collect samples of CSF from several types of volunteers: gene-positive people without any symptoms of HD, gene-positive people who have symptoms and people who are either gene-negative or have no family history of HD.

Dr. Mark Guttman at the Movement Disorder Clinic in Toronto is currently looking for HDClarity participants. At the University of Alberta, Dr. Oksana Suchowersky is overseeing site setup and Dr. Blair Leavitt in Vancouver will begin recruitment soon.

RESEARCH cont'd

By the end of 2017, Dr. Wild hopes to see a total of 30 sites up and running around the world. As the CSF samples flow in, the HDClarity team will use some of the precious fluid to measure the levels of huntingtin protein and see whether they could be an accurate biomarker for Huntington disease. They will also set some aside for other investigators who are conducting intriguing HD research.

Of course, the success of HDClarity depends on volunteers stepping forward. Dr. Wild calls these research participants "superstars." "They are all my personal heroes," he says. "They are the frontline in the fight against Huntington disease."

We'll take an in-depth look at HDClarity in the upcoming edition of Horizon. For more details on HDClarity, including a list of Canadian sites, please visit: www.huntingtonsociety.ca/clinical-trial-locations.

INTERNATIONAL COLLABORATION GIVES FAMILIES AFFECTED A DIRECT VOICE IN HD CLINICAL RESEARCH

The Huntington Society of Canada has teamed up with the European Huntington's Association, the Huntington's Disease Association (United Kingdom) and the Huntington's Disease Society of America to create a global coalition of leading patient advocacy organizations in order to unite and give families living with HD a direct voice in HD clinical research.

The purpose is to add quality to all parts of clinical development through patient representative input. The establishment of this collaboration is to avoid the present ad hoc work by mobilizing the patients from the HD community to be ready and skilled to contribute when needed. Patient input is urgently needed to speed up recruitment and decrease "drop-out" from clinical trials. This group will enable families affected by HD to be actively involved in the research process by being active partners with those who plan, manage, and carry out research.

By expanding patient involvement beyond participation in trials as subjects, the group seeks to ensure that public contributions enable research to be carried out 'with' or 'by' members of the community, rather than it being 'to', 'about' or 'for' them. Simply put, this group is putting the HD community at the center of HD research efforts in a manner consistent with global PPI (patient participation initiative) or 'patient-focused' efforts.

Your support is vital to ensure that, at a time when clinical research is being challenged to include the patient perspective, HSC is collaborating with global organizations to provide comprehensive support and access to the community to ensure that the HD patient experience is an established part of the clinical research process, rather than an ad hoc activity.

For more information about this initiative and the role of families affected by HD in clinical development, please contact info@huntingtonsociety.ca or 1-800-998-7398.

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. This is made possible by the ongoing and continued support of our donors, thank you.

NEW BRUNSWICK'S BIG BOOST: THE HSC RESOURCE CENTRE

Our strategic priority is to increase our services in new and remote areas. On January 16th, our newest HSC Resource Centre officially opened in Moncton, New Brunswick. Headed up by our long-time New Brunswick Family Services Worker, Marthe Gautreau, the new Centre dramatically increases support for families across the province and enhances outreach to the community and care facilities.

Previously, Marthe worked a limited number of hours a month. Now, she has regular office hours, allowing her to accomplish far more. Already, she has launched efforts to establish a formal HSC Chapter and to create three support groups in a province that currently has none. She has also begun conversations to resurrect a dedicated HD clinic, so that New Brunswick residents can access specialized HD multidisciplinary care in the province.

ADVOCACY

GENETIC DISCRIMINATION

Thanks to your generous donations, your critical and ongoing support has allowed us to take a leadership position in 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.

On February 14, 2017, Bill S-201 was debated in the House. In December 2016, the Bill was sent back to the House with unanimous support by the Standing Committee on Justice and Human Rights, as is, with a minor technical amendment. The debate began at 6:30pm and started with MP Randy Boissonnault, from Edmonton, tabling amendments that gutted all aspects of Bill S-201 except the amendment to the Human Rights Act. MP Boissonnault is a newly added member to the Standing Committee on Justice and Human Rights and was not present for the hours of testimony examined by many experts supporting the need for the robust protection that Bill S-201 provides for genetic test information. The insurance and actuarial industries also provided their expert opinions for consideration at the standing committee hearings.

Six others spoke that night, including MP Housefather, Chair of the Standing Committee on Justice and Human Rights, other standing committee members, MPs and Rob Oliphant. These six individuals expressed support for Bill S-201, as it stands. *continued page 4*

ADVOCACY CONTINUED

GENETIC DISCRIMINATION

Many also stressed the importance of Canada's legislation catching up to other western countries to protect genetic test information, so that Canadians can get lifesaving genetic tests without fear.

The 1st hour of debate continued until 7:30pm and the 2nd hour of debate will continue on March 7th the vote and 3rd reading will follow on March 8th.

MPs from all parties support Bill S-201. Bill S-201 is an appropriate robust solution for an important human rights issue and is also supported by the Chief Commissioner of Canadian Human Rights. Bill S-201 is not fully supported by the Liberal Cabinet Ministers (although it was stated that they agree in principle that genetic test information should be protected).

The insurance industry seems to feel it is their right to have access to genetic test information and they have lobbied strong and hard to keep that access. The body of evidence overwhelmingly supports robust pan-Canada protection of genetic test information, yet it seems that the influence the insurance industry holds over our federal and provincial governments has potential to negatively impact all Canadians.

We should all remember that this issue goes far beyond insurance. Protecting genetic test information will actually improve the health of Canadians as they make informed choices to diagnose, prevent and treat disease. Employers, adoption agencies, landlords and schools will not be able to use genetic information against Canadians if Bill S-201 is passed as supported by the Standing Committee on Justice and Human Rights.

If Bill S-201 is gutted, less than 10% of Canadians will have recourse if they experience genetic discrimination. The danger is that more than 90% of Canadians may think they are protected and they will not be.

Thank you for your continued efforts to contact our MPs reinforcing that it is critical to pass Bill S-201, as is. We are the voice of Canadians and that voice needs to be heard loudly.

Let your MPs know that you expect them to do the right thing; pass Bill S-201 as it stands with the Genetic Non-Discrimination Act (GNA), amendments to the Canadian Labour Code, amendments to the Canadian Human Rights Act and the technical amendment added by the Standing Committee on Justice and Human Rights. Genetic test information must be robustly protected now! To learn more about the Canadian Coalition for Genetic Fairness and to contact your MP visit <http://ccgf-cccg.ca/en>.

CONNECTING OUR COMMUNITY

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, we 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.

HSC 2017 National Symposium



For more information: huntingtonsociety.ca/symposium
To host a symposium location: events@huntingtonsociety.ca



If you would like to host a Symposium location in your community, or would like to sponsor Symposium, please contact events@huntingtonsociety.ca.

CONNECTING OUR COMMUNITY

2017 YOUNG PEOPLE AFFECTED BY HUNTINGTON DISEASE 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 two years isn'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 about everything from mentorship to caregiving, grief and guilt, fundraising and genetic testing. YPAHD Day is a vital opportunity for youth to learn from and inspire one another, as well as to see that they are not alone in their experience.

Watch for more information about the 2017 YPAHD Day in the Spring Horizon and at www.huntingtonsociety.ca/ypahd-day. Registration is expected to begin in May 2017.

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.

For more information on Huntington disease please visit www.huntingtonsociety.ca