



Spring 2014 Donor Report

Huntington Society of Canada

Soci t  Huntington du Canada

“Energy and persistence conquer all things.” – Benjamin Franklin

For four decades, the Huntington Society of Canada (HSC) has strived for excellence, 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

Funding breakthroughs in HD research

Not one, but two HSC-funded researchers made headlines in recent months, proving once again that your support is getting us ever-closer to life-changing treatments.

In December, University of Western Ontario researcher, Dr. Stephen Ferguson, announced that blocking a specific glutamate receptor, mGluR5, in the brains of Huntington disease mice created a dramatic impact on motor symptoms. This NAVIGATOR-funded breakthrough could carve a path to treatments that reduce symptoms, not just in HD but also in Parkinson’s and other movement disorders. What makes this even more exciting is the fact that the FDA has already approved mGluR5-blocking drugs for other diseases, significantly speeding up the clinical trials process.

Meanwhile, McMaster University researcher, Dr. Ray Truant, was able to deliver big news of his own recently. Thanks, in part, to a NAVIGATOR grant, his team discovered that the huntingtin protein “bends” differently in a person with the HD mutation compared to someone without it. As a result, we now have a deeper understanding of how the disease works and, by extension, should be able to identify effective treatments. HSC funds excellent research and each year we receive many exemplary research proposals. Unfortunately, we are not in the economic position to fund all of the high-calibre, fundable proposals. That is why one of our key priorities going forward is to raise more money for research, so that no promising proposal goes unfunded.



Advocacy

Be Brave Be Bold Be Ready: HD Clinical Trial Preparation

On January 29, 2014, over 20 researchers, scientists and clinicians from across Canada joined HSC and Canada's Research-Based Pharmaceutical Companies (Rx&D) to further discuss the urgent need to ensure that we have research-ready clinics and clinical trial participants. Our goal is to ensure that future treatments get to Canadians as soon as possible.

HSC plays a key role in bridging the relationship between researchers and individuals by educating Canadians on the importance of clinical trial readiness; how they can get involved and why their participation is so crucial. Since the first meeting in September, HSC has been able to attract additional participation from interested clinicians and researchers. The Society has completed a preliminary survey of HD clinics across Canada, and although a more detailed survey is required in order to track the data collected, this preliminary survey provides a base of information that will inform our process.

Over the next year, depending upon funding, the consortium proposes to implement a comprehensive national HD clinical trial strategy. Engaging current HD clinicians across Canada and encouraging participation in HD clinical trial research will be the focus.

Making genetic fairness a reality

On October 16, 2013, Governor General David Johnston made history when he announced "Our Government will... prevent employers and insurance companies from discriminating against Canadians on the basis of genetic testing." Those words, part of the Speech from the Throne, signalled an unprecedented commitment from our leaders to make genetic fairness a reality in Canada.

To help move that agenda forward, we have been meeting with key stakeholders such as the Canadian Human Rights Commissioners, the Federal Privacy Commissioner's office and the Ontario Genetic Secretariat. At the federal level, Senator James Cowan re-tabled his non-discrimination bill, S-201. In Ontario, MPP Mike Colle tabled Bill 127, which aims to add genetic characteristics to the province's human rights code. Meanwhile, the Alberta government decision makers are discussing what genetic fairness may look like in Alberta.

Change is in the air. HSC is rallying the support of all Canadians, urging them to raise their voices so that together we can put an end to genetic discrimination in Canada.

Services

Delivering the best care possible

Each and every day our Family Services team provides vital support to families dealing with HD. Thanks to your support, we have been able to expand services, review the impact and convert two positions, established a year ago, from contract to permanent: the Social Worker position in B.C. and the Resource Centre Director position in East Central Ontario.

We have also continued to invest in the skills and knowledge of that team. At our semi-annual training session last fall, Diana Tikasz from Compassion Fatigue Solutions delivered an engaging workshop on acknowledging, understanding and dealing with the emotional toll that comes from constantly caring for others. Not only does this add value for our Family Services staff, they can also model and share these valuable lessons with caregivers in the HD community. This training benefits our clients, both directly and indirectly, maximizing the impact of your investment.

Partnering with doctors, genetic counsellors and other experts in the community, who give generously of their time and expertise, we have begun to update many fact sheets and to create new resources addressing priority topics. You will find all the latest resources on our website, including the basics of HD, intermediate alleles, genetic testing, multi-disciplinary clinics, and driving with Huntington disease.

Serving our youth

The Youth Mentorship Program component of Family Services is up and running, making HSC a world leader in supporting young people affected by HD. Last fall's intensive training weekend brought together a group of young people from across Canada, keen to serve as our first group of volunteer mentors. We are now in the process of pairing them with mentees, individuals from young teens to early twenties. HSC is reaching out to youth and parents to inform them of this new and exciting opportunity for support.

This pilot program offers youth one-on-one support from an experienced peer who understands what it means to grow up in a family affected by Huntington disease. In addition, our Youth Mentorship Coordinator provides support by touching base with mentees monthly and conducting an annual review with both them and their parents. We are also keeping mentors at the top of their game through ongoing teleconference training and support throughout the year.

These efforts add up to a unique program designed to help youth cope with the challenges they may face, providing positive role models, and breaking down the sense of isolation that many young people dealing with HD feel. For more information on HSC's Youth Mentorship Program call 1-855-253-0215 or visit Learn About HD at www.huntingtonsociety.ca.

Finding fresh ways to connect

November marked the launch of our new website: on time and under budget! It is a fresh online face for the Society, full of news, information and resources and is easier to access than ever before. If you have not had a chance to visit recently, please take a look at www.huntingtonsociety.ca.

Meanwhile, over 200 participants across the country attended our highly successful Fall Symposium. The event featured genetic counsellor, Meghan Ferguson, discussing the process of predictive testing, while two prominent HD researchers, Dr. Oksana Suchowersky and Dr. Simonetta Sipione, explained the road to clinical trials. For the first time, families had the choice of taking part at one of our Symposium site locations or in the privacy of their home via the web. It is the perfect example of how the Society is leveraging technology to reach out and connect with families wherever they may live. To view the October 26, 2013 Fall Symposium video go to www.huntingtonsociety.ca under the Media tab and click on Hear Our Video Stories.

Thank You

On behalf of families living with HD, thank you for your continued partnership and generous support. 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 disease community.

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