

“Success is the sum of small efforts, repeated day in and day out.”
Robert Collier

For four decades, the Huntington Society of Canada (HSC) has striven for excellence by providing practical help for families dealing 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

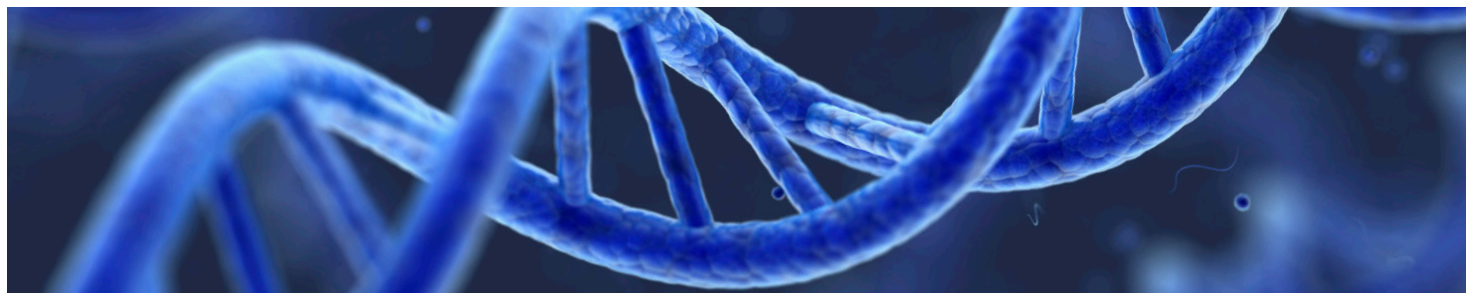
Be Brave, Be Bold, Be Ready

This year will see the launch of clinical trials for five potential HD treatments, including highly promising gene-silencing drugs. Participation in clinical trials is critical to move treatments for Huntington disease forward. To make sure as many people as possible know about these trials, we continue to raise awareness through HSC’s newsletters, website, social media, events and the National Conference. Our goal is to make clinical trial information easily accessible to those that are interested. We have recently had discussions with other global HD organizations, clinicians and pharma to work together and enhance access to clinical trial information.

At the same time, we are ensuring that clinicians across the country are research-ready. In partnership with Canada’s Research-Based Pharmaceutical Companies (Rx&D), we organized another highly successful roundtable discussion last October, bringing together investigators and clinicians from across the country to share information and create a strong foundation for clinical trials in Canada.

Filling the research pipeline

As clinical trials progress, we continue to strategically fund Huntington disease research. In January, we launched our 2015 New Pathways and Navigator research programs. In answer to our call for Letters of Intent, we received numerous submissions from across Canada and globally. By the end of February we will invite the most promising research proposals to submit a fully detailed research application. The HSC Research Council will make funding recommendations based on a complete peer review process of all full proposals submitted. This process will happen prior to the end of June.



Advocacy

Pushing forward for genetic fairness

Last fall, HSC's Chief Executive Officer Bev Heim-Myers was invited to testify at the Bill S-201 hearings. Bill S-201 is a comprehensive bill to prevent and end genetic discrimination in Canada. The Senate Standing Committee on Human Rights heard evidence supporting Bill S-201 and the importance of protecting genetic test information in Canada, for all Canadians. Fear of genetic discrimination is a barrier to many Canadians when considering participation in clinical trials that could lead to treatments for HD and other genetic diseases.

We continue to work closely with the Prime Minister's Office and the Ministry of Justice to help them realize the commitment in the 2013 Speech from the Throne, to end genetic discrimination by insurers and employers based on genetic test information. The hope is that a solution will be presented prior to this current session of Parliament ending. We are optimistic that in 2015 our federal government will take action to end genetic discrimination in Canada.

Services

Strengthening our team

Once again, the HSC National Conference provided a wonderful opportunity to bring our Family Services Team together. For new hires, the pre-conference Family Services Training Day was the first chance to meet their colleagues from across the country and gain insights from our seasoned veterans. Thanks to the close bonds forged at events like these, every team member has the support of a national network to help them provide the best possible services to families.

HD Education



This spring, in partnership with the ALS Society of Alberta, we will be creating a series of educational modules aimed at health-care professionals and long-term care staff. We would like to extend our sincere thanks to the Beta Sigma Phi Sorority (Calgary and Area) for providing the funds to make this project possible. When our Family Services Team are invited to give in-service educational sessions, this ready-to-use material will save them significant preparation time. The presentations and manuals will be developed and tested in our Southern Alberta Resource Centre and then rolled out to the rest of Canada.

Youth

Training more mentors to meet demand

Our new Youth Mentorship Program has proven to be a resounding success, earning praise from mentors, mentees and parents alike. Now we are busy expanding the program to meet demand. In the coming months, we will train six new mentors to give their younger peers the support they need.

Making connections

YPAHD Day, the 2014 pre-conference event hosted by Young People Affected by Huntington Disease (YPAHD), attracted 40 youth from across the country and was very successful. Each time we provide forums for youth to come together, they tell us how valuable the experience is. That is why we will be creating more opportunities for face-to-face connections in the coming years. We will also provide more youth-focused supports through Family Services.

2014 National Conference

Providing hope and perspective

Winnipeg's Holiday Inn Airport West was filled to capacity with conference attendees. We sold out and then squeezed in still more who wanted to come: people with HD, people at-risk, family members, young people, caregivers, researchers, clinicians and medical professionals, from Victoria to St. John's.

The biggest buzz came from our session on impending clinical trials. However, there were plenty of sessions to choose from, covering research, care, planning, testing, genetic discrimination and more. Every speaker was well received. In the conference evaluations, no speaker rated less than "very good."



The conference attracted new families as well as many familiar faces. For half, it was their first or second HSC conference. As well, youth were out in force both at the pre-conference YPAHD Day and at the conference itself.



Almost everyone reported coming away with a greater understanding of genetic fairness and the ability to talk to people about HD. Perhaps most importantly, they left inspired and optimistic. "This conference has shown that we are united and if we all stand tall, we will make a difference," said one participant. "Leaving with some hope and perspective. Cannot wait for 2016," said another.

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 reach out to families who are not yet connected to HSC, continue to support and advocate for families from coast to coast, invest in world-class research, and play a leadership role in the international Huntington's community.

With your help, we are continuing to improve the quality of life for people with HD, cultivating strength and resilience in the Huntington's community and providing substantive reasons for hope by investing in globally recognized research leading to treatments that will slow or stop Huntington disease.