

WINTER 2019 DONOR REPORT

A report to thank our incredible donors for their leadership and support to help families living with Huntington disease.

These 2018 highlights are possible because of our generous supporters.

 <p>40% INCREASE IN MENTEES AND MENTORS IN THE YOUTH MENTORSHIP PROGRAM</p>	<p>170 LEADERSHIP VOLUNTEERS ACROSS THE COUNTRY</p> 	 <p>OVER 3 MILLION VIEWS ON SOCIAL MEDIA</p>	 <p>RECORD-BREAKING ATTENDANCE AT THE 2018 NATIONAL CONFERENCE WITH OVER 310 PEOPLE IN ATTENDANCE</p>
<p>29 ACTIVE CHAPTERS AND AREAS ACROSS CANADA</p> 	 <p>FAMILY SERVICES TEAM SUPPORTS OVER 15,000 PEOPLE AFFECTED BY HD</p>	 <p>7 HD CLINICAL TRIALS CURRENTLY ACTIVE IN CANADA</p>	 <p>126 VOLUNTEER EVENTS</p>
 <p>OVER \$1M COMMITTED TO HD RESEARCH</p>	 <p>123 LIGHT IT UP 4 HD SITES INTERNATIONALLY 52 OF THESE SITES IN CANADA</p>	 <p>15 HUNTINGTON DISEASE RESOURCE CENTRES ACROSS CANADA</p>	 <p>10% INCREASE IN FAMILY SERVICES SUPPORT</p>  <p>20,000 AMARYLLIS BULBS SOLD ACROSS CANADA</p>

RESEARCH

The universal goal for international HD research is to find treatments that reverse, slow or prevent the progression of HD. The Huntington Society of Canada, HSC donors and HD Canadian researchers are a key part of this effort and the Society has a unique role to play.

The Huntington Society of Canada invests in the most promising basic and clinical research, leading to viable treatments for HD.

CANADA: A LEADER IN HD CLINICAL TRIAL RESEARCH

In December, Roche Pharmaceuticals announced the expected clinical trial sites for their Phase III GENERATION HD1 Study. This global study will enroll up to 660 patients with manifest HD at 80-90 sites in approximately 15 countries around the world.

In addition, there are currently six more clinical trials active in Canada for our community to participate in. Thanks to donor support, we have been able to create a way to clearly communicate these trials in an easy to use map at www.huntingtonsociety.ca/clinical-trial-locations.

It is exciting that Canadians can be a part of these trials and it is thanks to the caring, committed community willing to participate.

The Canadian Huntington disease community is committed to finding a meaningful treatment for HD. In Canada, the HD community is organized, active and engaged. The Huntington Society of Canada has close to 30 active Huntington disease Chapters in major cities and the surrounding communities all across Canada.

Our generous donors have also laid the groundwork for Canada to be known as a destination for clinical trials.

Donor support allowed for the creation of the Clinical Trials Consortium which first convened in 2015. Since then this group has worked together to connect clinicians, share best practices and maximize the opportunities for people affected by HD to participate in clinical trials.

Support from HSC donors helped to lay the foundation for these trials to take place, and this will only prove more beneficial in the future as more trials become available.

SUPPORTING OUR FAMILIES

The Family Services Team annually supports over 15,000 individuals across Canada. This team delivers support, education and advocacy services from coast-to-coast. Through their work, they are ensuring that individuals, families and organizations have a better understanding of HD and how it impacts the whole family. This is made possible by the ongoing and continued support of our donors. For a complete list of Family Services Team members, and to learn more about the support our Family Services Team provides, please visit www.huntingtonsociety.ca/family-services-program.



SUPPORT GROUP BEST PRACTICES GUIDE

Since the beginning, support groups have been a cornerstone of the Huntington Society of Canada, breaking down the sense of isolation so many families feel when they're living with HD.

Now, thanks to our generous donors, we're improving those services with our new Support Group Best Practices Guide. This new tool brings together the best ideas from our Family Services staff across the country, creating a one-stop resource where support group facilitators can find discussion questions, suggestions for guest speakers, up-to-date handouts, and more.

JIM POLLARD 2019 INFORMATION SESSION TOUR

Jim Pollard, the well-known HD presenter, is back by popular demand to complete an information session tour in Northern Ontario.

In April 2019, Jim will visit multiple locations in Northern Ontario presenting his favoured talk, "Hurry Up and Wait: Thinking about Thinking with HD", which includes a series of interactive exercises that stimulates and demonstrates how thinking with HD colours our interactions and challenges how we communicate with one another.

Thanks to our donor's support, Canadian HD community members will be able to benefit from Jim's insight.



2018 HSC NATIONAL CONFERENCE & YPAHD DAY

“Attending YPAHD Day and the HSC Conference has made such a difference in my life. It has made me feel less alone in the fight against HD. This Conference has touched so many lives.”

“Conference is the only place I have to connect with other people who know my struggle.”

“Conference has broadened the HD community. I am always meeting new people and am inspired by their stories.”

For many members of the Canadian HD community, the HSC National Conference weekend is one they start counting down to as soon as the last one ends. The Conference is a place where families can feel comfortable and at ease with their symptomatic loved ones, because everyone in the room understands what is happening. It's a place where knowing looks and comforting hugs are shared, and contact information is exchanged, in hopes of making someone else's journey just a little bit easier. It's a place to gather information and ask those questions that have been held onto for so long.

It's a place that wouldn't be possible without the dedication and generous support of our donors. Our donors make it possible to have so many incredible keynote speakers, worthwhile workshops and necessary resources. They allow us to fund a great number of community members and youth representatives from across the country to attend free of charge or at a reduced rate. Our donors believe in the impact that Conference has on our community.

In November 2018, over 300 people affected by HD gathered in Kelowna, BC for the annual Conference - our largest attendance yet. The weekend-long event kicked off with our Young People Affected by Huntington Disease (YPAHD) Day on the Thursday with our highest recorded attendance of youth to date. The group heard presentations on genetic testing, family planning, caregiving and relationships and walked away with life-long friendships.

Friday and Saturday were both full of engaging talks on caregiving and research, as well as several workshops on interesting topics such as cannabis, music and HD, social media, raising awareness and more.





2019 HSC COMMUNITY EDUCATION FORUMS: HEARTS FULL OF HOPE

Because of donors like you, every other year HSC is able to provide a live forum where community members and carers can meet to learn about the most recent updates in HD, network with other patients and perhaps most importantly, have the opportunity to have their questions answered by leading professionals who specialize in HD.

HSC is thrilled to announce our annual Community Education Forums. This year, the Huntington disease community's excitement is palpable, because, for the first time since the disease was identified by Dr. George Huntington in 1872, there is hope for treatments that target the root cause of HD. As many of our family members have expressed to us, for the first time that they can recall, they have "hearts full of hope".

Thanks to donor support, HD families are eager to learn more about the current clinical trials as well as what is in the pipeline. HSC's 2019 Community Education Forums will address community requests by providing presentations by HD clinicians and researchers.

HSC is most fortunate to work closely with leading HD clinicians and researchers across Canada. Their support enables HSC to provide accurate and current information in this increasingly changing landscape.

Presentations for the forum will include a talk from Dr. Michael Hayden, MB, ChB, PhD, FRCP(C), FRSC from British Columbia on Managing Expectations when it comes to clinical trials. Dr. Ed Wild, MRCP, PhD from London, England will also give an update on Huntington Disease Research Progress. Many sites will also offer local programming on a care topic, and have a live Q&A with a health care practitioner.

Formerly known as 'Symposium', since 2001, HSC's Community Education Forums have been successfully delivered at the Chapter level with the support of HSC staff and donors. They are anticipated to be in 20 different locations across Canada through April to November this year, with approximately 600 attendees.

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 receiving much-needed support, invest in world-class research and play a leadership role in the international Huntington community.

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



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