



**ANNUAL REPORT**  
**2019 - 2020**

HOPE • BELIEVE • INSPIRE

## Mission

The Huntington Society of Canada (HSC) is a not-for-profit charitable organization that raises funds to deliver individual and group counselling services to support individuals and families living with Huntington disease (HD) and to fund basic research to delay or stop the progression of the disease. HSC also works with health and social services professionals to enable them to increase their understanding of HD and better serve people living with HD.

## Vision

HSC aspires to a world free from HD and maximizes the quality of life of individuals living with this disease by:

- delivering services;
- enabling others to understand the disease; and
- furthering research to slow and prevent HD.

Family is at the heart of our community. Our families and volunteers tell a powerful story of caring people who pull together to improve the quality of life for those living in Canada who are impacted by HD.

The good news is, with recent medical breakthroughs, many researchers and scientists believe that once we are successful in stopping the progression of HD we will also find the answers to many other neurological diseases. Your valued support is helping to bring us closer to this goal.

## Huntington Disease Facts

- HD is a hereditary, neurodegenerative illness with physical, cognitive and emotional symptoms.
- A child born to a parent with HD has a 50 per cent chance of sharing the same fate.
- 1 in every 7,000 Canadians has HD while 1 in every 5,500 Canadians are at-risk for HD.
- Currently, there is no known cure for HD.



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*Front and Back Cover Images: 2019 Muskoka Walk - Barrie, ON.*



# Message from the CEO and Chair

In many respects, this has been twelve months of transition for the Huntington Society of Canada (HSC). In September 2019, after more than two decades in Kitchener, ON we moved our national office to Waterloo, ON. The following month, we said goodbye to Chief Executive Officer (CEO), Robin Markowitz, and welcomed back Bev Heim-Myers, who served as interim CEO while the HSC board of directors undertook an executive search. Then, as we approached the end of our fiscal year (March 31, 2020), COVID-19 struck and lockdown began in Canada.

HSC's staff and volunteers took all these changes in stride. Even when we were forced into a new world of virtual operations, we kept our eyes squarely on HSC's vision: aspiring to a world free from Huntington disease (HD) and maximizing the quality of life of individuals affected by HD.

And over the past year, we did that in many ways.

There's no question that COVID-19 affected our operations in mid-March, but we adapted quickly. Our national office team began working remotely, while our family services team (which has always delivered some support from a distance) extended virtual services as best they could.

In addition to serving more than 3,900 active files across the country through traditional methods, our family services team piloted new initiatives. For example, in July 2019, we launched our closed Facebook support group; providing a safe, moderated space to share stories, ask questions and access resources.

We also laid the groundwork for online support groups that we will continue to roll out in 2020-2021. As a result, families and individuals will have more ways to connect with others in the HD

community and get information — wherever they live and whenever they need it.

Our youth initiatives also continue to grow. In November, 83 Young People Affected by HD (YPAHD) gathered in Calgary, AB, Toronto, ON and Halifax, NS, marking our largest Regional YPAHD Days event yet. More than a third were first-time attendees. Meanwhile, since 2014, 48 young people also continue to receive peer support through our popular Youth and Young Adult Mentorship program.

In 2019, we launched a highly successful new format for our Community Education Forums (CEFs). More than 500 participants attended one of 23 local events from coast to coast or took part in our virtual CEF to learn more about the latest developments in research and clinical trials.

And, with several potential drugs to treat HD now being tested, there was plenty to talk about. Thanks to HSC's work to build capacity for clinical trials in Canada, this country is a major site for GENERATION HD1, PRECISION-HD1, PRECISION-HD2 and SIGNAL, as well as a host of observational studies.

HSC continued to invest in lab bench research as well, through our NAVIGATOR research program, which helped to fund Dr. Francesca Cicchetti's cutting-edge work on gene-editing CRISPR technology. Meanwhile, we launched our clinical fellowship program in 2019 to equip a new generation of neurologists with the skills and knowledge to advance clinical research.

We also continued to advocate for genetic fairness. After the Cour d'Appel du Québec (Québec Court of Appeal) gave its opinion that the Genetic Non-Discrimination Act (GNDA) is



unconstitutional in December 2018, the Canadian Coalition for Genetic Fairness (CCGF) appealed to the Supreme Court of Canada (SCC). A hearing took place in October 2019. While the decision was not made public until after the fiscal period to which this annual report covers, our efforts over the past year did indeed pay off. We would be remiss if we failed to acknowledge that in July 2020, the SCC upheld the constitutionality of the GNDA. This decision effectively protects the privacy of genetic test results for all people living in Canada. HSC is sincerely appreciative of the efforts of Bev Heim-Myers, as chair of the CCGF, who has been actively involved with this process from the beginning.

Due to COVID-19, HSC couldn't host the international meeting of the HD Coalition for Patient Engagement (HD-COPE) in Toronto, ON in March, as planned. Instead, we found virtual ways for this group to continue providing valuable input into the design of clinical trials.

Because the pandemic struck very close to the end of our fiscal year, it didn't have a significant impact on our 2019-2020 finances. However, the crisis will undoubtedly affect our bottom line in 2020-2021. Lockdowns and physical distancing measures forced us to cancel a number of the fundraising events that drive so much of our revenues, while the economic slowdown has affected many of our donors. We have adjusted our budgets, but COVID-19 creates many unknowns in the coming year.

One thing we do know is that the HD community meets every challenge with extraordinary resilience and determination. When the pandemic turned our organization upside down, the strength of our team became clearer than ever. As we wrap up 2019-2020, we'd like to say a heartfelt thank you to each and every one of you.

To our donors and sponsors, as always, we are

deeply grateful for your ongoing support. Your generosity and commitment make our work possible. Likewise, a huge thank you to our volunteers across the country who raise so much of the funds we rely on and who made May 2019 our most successful HD awareness month ever.

To our chapters, board members and local volunteers — we're so appreciative of your time and efforts. The same is true for our dedicated staff, who regularly go above and beyond their job descriptions. A special thank-you must go to Bev Heim-Myers, for returning to HSC with an open heart and helping to steer the ship in the midst of a global health crisis which none of us could have predicted.

We salute our Canadian HD-COPE volunteers and everyone who has stepped up to take part in clinical trials and observational studies. And we extend our thanks to all the healthcare professionals working to improve care and the researchers who provide us with more hope than ever before that meaningful treatments lie within our grasp.

Much is in flux right now, but as we enter this new era of clinical research and a new phase of HSC's evolution, we have many reasons to move forward with optimism and excitement.



*Shelly Redman*

**Shelly Redman**

Chief Executive Officer

Huntington Society of Canada



*Mack Erno*

**Mack Erno**

Chair

Huntington Society of Canada

# Governance

Hailing from all corners of Canada, the Huntington Society of Canada (HSC) board of directors currently meets twice a year and is responsible for governing the organization. This includes HSC’s mission and strategic planning; policy development; stewardship of resources; and accountability to members, donors and the public.

HSC board directors serve a two-year term, and may stand for re-election for two further two-year terms. A few vacancies occur each year, since members’ terms are staggered. Nominations for these positions are recommended to the membership by the governance and nominating committee of the board.

One seat on the board is reserved for a representative of the Huntington Society of Québec, while another seat is reserved for a representative of Young People Affected by HD (YPAHD), our virtual youth chapter.

The election of the board of directors takes place at each Annual General Meeting of the members, with an emphasis on recruiting individuals that can bring specific expertise to the governance of HSC.

## HSC Executive

- Mack Erno** . . . . . Chair
- Brynne Dalmao** . . . . . Vice-Chair
- Sean Dewart** . . . . . Secretary
- George Halatsis** . . . . . Treasurer
- Brenda Nowakowski** . . . . . Past Chair

## HSC Board Members

- |                        |                           |
|------------------------|---------------------------|
| <b>Cameron Barrett</b> | <b>Geneviève Bélanger</b> |
| <b>Billy English</b>   | <b>Dr. Mark Guttman</b>   |
| <b>Brenda Mason</b>    | <b>Catherine Price</b>    |
| <b>Dr. Ray Truant</b>  | <b>Diane Tullson</b>      |
| <b>Andrew Wright</b>   |                           |

# Canadian Coalition for Genetic Fairness



The Canadian Coalition for Genetic Fairness (CCGF), chaired by former Huntington Society of Canada (HSC) CEO, Bev Heim-Myers, comprises a group of organizations dedicated to preventing genetic discrimination against individuals, based on their genetic test information. CCGF advocates (at the federal, provincial and territorial levels) to create positive changes for the Huntington disease (HD) community and all Canadians.

You may recall that in May 2017, the Genetic Non-Discrimination Act (GNDA) received Royal Assent and



passed into law. Prior to that date, Canadian law did not protect the genetic test information of Canadians. Parliament enacted the GNDA pursuant to its criminal law power as a response to expert evidence that showed some Canadians avoided taking genetic tests, despite knowing about their potential health benefits. The GNDA empowers all people living in Canada with the chance to make informed decisions regarding health and reproduction, without fear of genetic discrimination.

A hearing at the Cour d'appel du Québec (Québec Court of Appeal) regarding the GNDA, took place on December 11 and 12, 2018.

Arguments in support of the GNDA were presented by lawyers who represent both the CCGF and the Canadian Human Rights Commission (CHRC), stating that it is indeed a valid exercise of the Parliament of Canada's criminal law power. The court appointed an Amicus (an impartial adviser to a court of law), who also argued in favour of the GNDA.

Conversely, legal representation for the Québec Attorney General (AG) the Canadian Life and Health Insurance Association (CLHIA) and the AG of Canada argued against the GNDA being a valid exercise of the Parliament of Canada's criminal law power. British Columbia's AG also intervened against the GNDA, but did not verbally present arguments in court.

On December 21, 2018, the Québec Court of Appeal unanimously took the disappointing, yet expected, view that the GNDA is not a valid exercise of the Parliament of Canada's criminal law power.

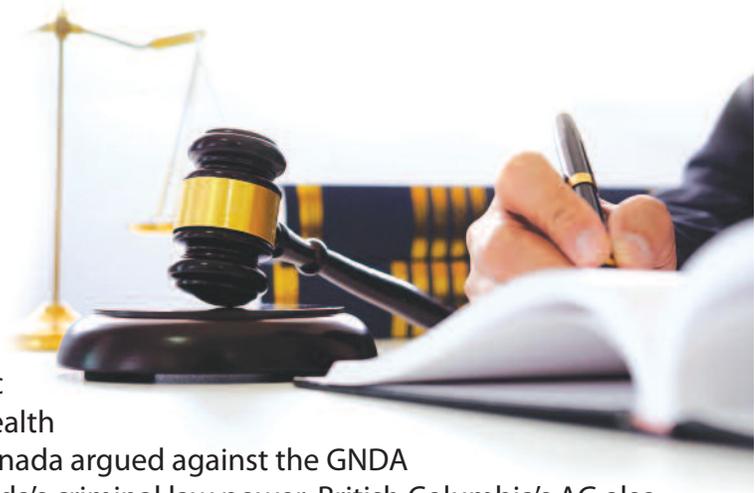
The Québec opinion did not overturn the GNDA, but did put the GNDA at risk.

In response to the opinion of the Québec Court of Appeal, CCGF filed a notice of appeal referring the decision to the Supreme Court of Canada (SCC).

Bev Heim-Myers attended the hearings at the SCC in October 2019 and was joined by Senator Jim Cowan (ret.), and his former Senior Policy Advisor, Barbara Kagedan, both of whom have been very engaged with this file. Their historical knowledge and guidance proved to be invaluable. Of course, the CCGF legal team also attended and presented CCGF's perspective very succinctly.

While outside the fiscal period to which this publication refers, it is important to note that on July 10, 2020, the SCC did, in a 5-4 vote, rule that the GNDA is indeed constitutional. Therefore, it does remain law. This favourable decision is extremely reassuring and illustrates that the SCC recognizes the necessity for the pan-Canada protection of genetic test information by supporting the GNDA in this country.

***CCGF thanks our team of lawyers, Senator Cowan and Barbara Kagedan for their hard work on this file, on behalf of all people living in Canada.***



# Family Services

Huntington disease (HD) is a progressive neurodegenerative condition, and as such, there are many junctures in the challenging disease journey. Whether an individual remains at-risk, provides care for an individual with HD, has tested positive for the HD gene mutation (or has tested negative within a family of individuals who are at-risk), finding appropriate support is crucial. The Huntington Society of Canada (HSC) is committed to providing that help.

Be it through links to genetic or HD clinics, advice to help with daily living and independence in the early stages of HD, or legal and financial support for the difficult decisions taken as the disease progresses, at HSC it is a priority to offer reliable resources — and develop new ones — that will make the journey easier to navigate.

## The Family Services Team

In order to provide responsive services to the 1 in 7,000 Canadians who have HD and the 1 in 5,500 Canadians who are at-risk of inheriting the HD gene mutation, the HSC family services team covers all geographic areas of Canada, except Québec (the Huntington Society of Québec provides HD support and education to those living in that province). The team includes the national director of family services, the family services and research coordinator, the national social worker, 14 resource centre directors (RCDs) and five family service workers (FSWs), who effectively expand the reach of HSC's resource centres. Within the team, there are 19 registered social workers, one recreational therapist and two registered psycho-therapists — all with a combined 266.5 years of experience, enabling the team to skilfully serve the HD community.



## Online Support



It is important for anyone anywhere in the country to have access to the help they need. Consequently, HSC offers support groups from coast to coast. However, with Canada's expansive geography, some members of the HD community may not have access to a local group. In other cases, work or other carer responsibilities may prevent individuals from attending a meeting — or some people simply may not feel ready to meet in person.

That's why HSC created two new virtual ways to connect.

In June 2019, the HSC closed Facebook group was launched, which offers a safe space online for the HD community in Canada to connect and get resources. Whether an individual has HD themselves, is at-risk or cares for someone with the disease, they are welcome to join. The Facebook group already has nearly 300 members, with more registering every day. The national social worker serves as a moderator for the group, reviewing and accepting appropriate requests to join, monitoring group activity, addressing any issues that might arise and sharing HD resources as appropriate.

Meanwhile, HSC's national social worker is also facilitating a pilot virtual support group for people at-risk of HD. As with traditional support groups, meetings are held at a specific date and time. In this case, however, individuals will participate via online video conferencing. The series focuses on a different topic each session.

Thanks to these new opportunities, you can now connect with the HD community wherever you live and whenever you need to!



## In-Person Support

While virtual support may increase access to HSC services, it is important to maintain the more traditional touch points. In the 2019-2020 fiscal year, 3,910 individuals and families affected by HD were served by the family services team. There were 121 support group sessions offered.

The family services team hosted a further 20 drop-in opportunities for community members. For more information on the services provided to the HD community over the last year, please refer to the box at the bottom right of this page.

## Factsheets

HSC also continues to issue new factsheets and revise existing ones as new information is learned. Over the last year, four factsheets have been updated while one original factsheet was created.



In early 2019, HSC received a grant from Heritage Canada to help offset the costs of translation of 30 factsheets into French. The funding came through the "Support for Interpretation and Translation Program" (SIT), a subcomponent of the Official Languages Support Program.

The availability of French language factsheets will help HSC expand outreach efforts in French speaking communities across Canada, including New Brunswick, Québec, Northern Ontario, Manitoba, Saskatchewan and Alberta. HSC will use the factsheets at educational events and in individual and group counselling sessions. They will also serve as a resource to assist healthcare professionals (including doctors at genetics clinics and staff at long-term care facilities) in working with individuals with HD.

All 30 factsheets are posted to both the English and French HSC websites.

## Youth and Young Adult Mentorship Program

In 2013, HSC launched its Youth and Young Adult Mentorship Program (YYAMP), and since then, the organization has conducted five rounds of training and now has mentors in almost every province. Over the last 12 months, seven new mentors were trained, meaning that a total of 32 mentors are helping their younger peers face the day-to-day challenges of growing up in a family affected by HD.

Interest in the program continues to grow, with 30 mentees signed up across the country. Since 2014, 48 matches have been made (some ended, some ongoing) and three mentees have graduated to becoming mentors themselves.

The steady growth of this internationally-recognized program points to its success, as do the testimonials received from participants and parents.

## FAMILY SERVICES STATISTICS

- 788** Clinic appointments attended by RCDs
- 83** Genetic appointments attended by RCDs
- 121** In-services provided to 1249 attendees
- 214** Information sessions provided to community members and service providers
- 890** Case conferences coordinated to ensure appropriate community services
- 588** Service collaborations with community and regional services to ensure community needs are being met
- 638** Referrals for genetics, HD clinic support and info on HD clinical trials
- 1,841** Home and community meetings (phone, in person)
- 1** Virtual social coffee time with HSC's closed Facebook group members

## Professional Development

The family services team continues to listen to the HD community about the issues that can cause anxiety and concern. As such, the group is committed to ongoing learning, and over the past year have participated in professional development opportunities around: Medical Assistance in Dying (MAiD); Kairos Blanket Exercise (a unique, participatory history lesson developed in collaboration with Indigenous Elders, knowledge keepers and educators that fosters truth, understanding, respect and reconciliation among Indigenous and non-Indigenous peoples); Mental Health First Aid (Mental Health Commission of Canada); and Seating Matters (wheelchair considerations).

Going forward, the family services team will continue to explore specialized service and support opportunities, as well as unique delivery methods that will better serve the HD community.

*Thank you to all of the generous organizations who made our family services program possible this year:*



Cambridge & North Dumfries  
Community Foundation



Community  
Initiatives Fund



JOHN DEERE  
FOUNDATION



OTTAWA  
COMMUNITY  
FOUNDATION

*The Windsor  
Foundation*

THE  
WINNIPEG  
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## Clinical Trials Updates

Today, a number of drugs with the potential to alter the course of Huntington disease (HD) are undergoing clinical trials. Canada is at the forefront of many of these trials, thanks to the depth of research expertise across the country and the many courageous volunteers who have stepped forward to participate.

## Observational Studies

Observational studies are key to understanding how HD normally develops and progresses. Without this baseline information, researchers can't determine the effectiveness of their potential treatments. Several observational studies were underway in Canada during the 2019-2020 fiscal period. These include ENROLL-HD, HDClarity, FURST 2.0 and Roche's 15-month Observational Natural History Study.

## Roche – GENERATION HD1

In this Phase III trial, Roche is assessing whether their huntingtin-lowering drug can slow the progression of HD. After a brief pause last spring, the trial restarted with welcome changes. Instead of monthly lumbar injections, participants now receive them every two months. This is due to the fact that results from an earlier 15-month open label study indicated that the less-frequent regimen is just as effective at lowering mutant huntingtin levels — and much less demanding on patients.

Roche's drug, formerly known as RG6042, now goes by its new generic name, Tominersen. Researchers already know Tominersen is effective at stopping cells from producing the huntingtin protein that causes HD. Now, GENERATION HD1 is assessing whether that also slows the progression of the disease.

Roche wrapped up recruitment in April 2020. Today, 791 volunteers are participating in GENERATION HD1 at 100+ sites around the world, including Vancouver, BC, Edmonton, AB, Toronto, ON, Ottawa, ON, Montréal, QC, and Halifax, NS. Despite the COVID-19 pandemic, trials have continued wherever local guidelines allow.

## Wave – PRECISION-HD1 and PRECISION-HD2

Wave Life Sciences is running two parallel Phase Ib/IIb trials — PRECISION-HD1 and PRECISION-HD2 — to test the safety, tolerability and effects of two huntingtin-lowering drugs. These therapies target just the disease-causing form of huntingtin, leaving the normal version unaffected.

In December 2019, Wave released early results from the PRECISION-HD2 trial, showing the drug is safe and can successfully lower mutant huntingtin in the spinal fluid by 12 per cent. However, it's important to remember that Wave's trials are at an earlier stage than Roche's and the doses are also significantly lower: 16 milligrams in the PRECISION-HD2 study versus 120 milligrams in GENERATION HD1. Now that the drug has been proven safe at a low level, Wave has added a 32 milligram dose to both its trials.

Currently, 14 sites in five countries are currently taking part in the PRECISION studies. Recruitment is ongoing at all three Canadian sites: Edmonton, AB, Toronto, ON and Montréal, QC.

## Vaccinex – SIGNAL

United States drug developer Vaccinex is taking a different approach to tackling HD. Instead of targeting the protein that causes the disease, Vaccinex is looking further downstream. The company has developed an antibody called VX15/2503, which targets a key signaling protein in brain cells. This protein sets off a chain of events that leads to inflammation and, ultimately, cell death. VX15/2503 is designed to stop that response, blocking the signal that neurons send out.

In animal studies, the drug reduced cognitive symptoms of HD. Meanwhile, an initial human trial with 19 volunteers showed the drug was safe and significantly boosted the amount of glucose taken up by brain cells — a measure that the cells are working normally. Now, Vaccinex is testing the safety, tolerability and effectiveness of their antibody in a Phase I/IIa trial called SIGNAL.

SIGNAL is running at 30 sites across North America, including Vancouver, BC, Edmonton, AB, and Montréal, QC. Three-quarters of the 265 participants have completed the 18-month trial, and Vaccinex hopes to have all testing completed by the end of summer 2020.

# Research Dollars in Action

## Funding Groundbreaking Advances in the Lab

CRISPR gene-editing technology made headlines around the world when it was developed eight years ago. Now, researchers are applying that technology to Huntington disease (HD). Thanks to a \$150,000 NAVIGATOR grant, Université Laval's Dr. Francesca Cicchetti and her colleagues in Wales, UK and Boston, MA, are developing a way to remove the extra CAG repeats found in the mutant version of the HD gene.

They're using a harmless virus to transport a tiny pair of molecular scissors and a guide into brain cells of mice with HD. There, with the help of the guide, the scissors snip away the excess CAGs. By turning the mutant gene into the healthy version, Dr. Cicchetti and her team aim to stop cells from creating the disease-causing huntingtin protein.

Initial tests in HD mice show that CRISPR can improve movement and cognitive symptoms. Now, this two-year NAVIGATOR grant is funding a new set of experiments to see whether it reverses HD damage at a cellular level.

The investigators will also test the approach in pre-symptomatic HD mice to see if the promising treatment can prevent the onset of the disease.

In 2019, the Huntington Society of Canada (HSC) also provided a second year of NAVIGATOR funding for the University of Toronto's Dr. Cheryl Arrowsmith, who is deciphering the three-dimensional structure of mutant huntingtin protein. The results promise to yield important insights into how mutant huntingtin behaves, paving the way for new disease-fighting drugs.



Dr. Francesca Cicchetti



Dr. Cheryl Arrowsmith



Dr. Ragini Srinivasan



Dr. Fabricio Pio

## Clinical Fellowships: Training the Next Generation of HD Specialists

In 2019, HSC launched a pilot program to attract bright young neurologists to the HD field. With the support of the Manning and Beckham families and our generous base of donors, HSC was able to provide \$60,000 Clinical Fellowships to Drs. Ragini Srinivasan and Fabricio Pio — offering them exposure to clinical research and hands-on training in the diagnosis and management of HD.

Working under the supervision of Dr. Mark Guttman, Dr. Srinivasan sees patients at the Toronto Centre for Movement Disorders and in the Ontario towns of North Bay, Sturgeon Falls and Sudbury, where Dr. Guttman makes regular trips to serve families in the north of the province.

On the research front, Dr. Srinivasan is conducting physical and cognitive assessments for participants in the Enroll-HD study. She's also assisting with the lumbar punctures in the Roche and Wave huntingtin-lowering trials, testing drugs that have the potential to alter the course of HD.

Meanwhile, Dr. Fabricio Pio's journey began in Brazil, where he received his medical doctorate in 1996. He practised as a neurologist there for many years, interspersed with research stints and clinical fellowships in Ontario and Alberta.

Now, he's applying his clinical and research skills as a part of Dr. Blair Leavitt's team at the University of British Columbia's Centre for Huntington Disease. Already, his support has helped accelerate ongoing clinical trials, initiate new ones and make life easier for trial participants.



# Chapter Development and Community Events

## Community Events

Huntington Society of Canada (HSC) chapters and active areas are comprised of families and volunteers who provide each other with support and companionship on a local level while raising funds and awareness for HSC. In 2019-2020, another recognized chapter was created in Barrie, ON, bringing the total to 27 chapters and active areas across the country. Thanks to generous donor support of these events, local families affected by Huntington disease (HD) are able to come together to build community, social networks, provide and receive emotional support, and create a sense of pride.

The last twelve months have seen HSC volunteers extremely busy, with 153 events held across the country from April 2019 to the end of March 2020. It is estimated that these fundraisers drew upwards of 12,000 participants and attendees.

As always, variety is the key to attracting participants with varying interests and abilities and because of this, the chapter development team is always supporting volunteers with new ideas that can potentially tap into the interests of a wide variety of individuals. Events in the 2019-2020 year included go-kart races, hikes, trivia nights, concerts, snowmobile rides, comedy nights, walks, runs, paint nights, golf tournaments, trail rides, volleyball tournaments, bowling and even a trap shoot! Community events were responsible for raising over \$1.2 million for HD awareness, services and research over the fiscal period.

The HSC chapter development team also continues to engage through various other speaking engagements. In 2019-2020, staff attended and spoke at over 60 events including five chapter Christmas parties, 48 chapter meetings or gatherings (17 of which were attended in-person), seven fundraising and educational events, and the Toronto Young People Affected by HD (YPAHD) Day.

The switch to the new fiscal year (April 1 to March 31) has been advantageous for the chapter development and community events team. Much of the revenue from fundraising events comes in during the spring months and the previous fiscal year meant that this revenue also came in towards the end of the fiscal term. This made budgeting for the department difficult. Because of the new fiscal period, the chapter development team is better able to assess revenue and expenses in order to budget for the next fiscal period.





# Hearts full of Hope

## 2019 Community Education Forums

With over 23 Community Education Forums (CEF) completed across Canada in 2019, the Huntington Society of Canada (HSC) wishes to thank our sponsors for ensuring the success of each event. *Without the generous support of Roche, uniQure, Vaccinex and Wave Life Sciences, the 2019 CEF program would not have been possible.*



uniQure



WAVE<sup>™</sup>  
LIFE SCIENCES

Every other year, HSC provides a live forum in multiple venues wherein families and individuals affected by Huntington disease (HD) and carers can meet to learn about the most recent updates in HD, network with other members of the community and, perhaps most importantly, have the opportunity to have their questions answered by leading professionals who specialize in HD.

In 2019, the HD community's excitement was palpable, because 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".

Final reports show 490 attendees across 23 CEF sites from Vancouver, BC to St. John's, NL. This exceeds the original goal of 300 attendees at 20 sites. A further 32 people participated in the Virtual Day forum in November, with participants from Mexico, Italy, Argentina and the USA, as well as Canada. Therefore, the final total participation for 2019 is 522 people, a 26 per cent increase over 2017 (the last year the Community Education Forums were held).

In addition to our sponsors, HSC extends a special thank you to Drs. Michael Hayden and Ed Wild for their pre-recorded videos and to HSC co-founder, Ariel Walker for her participation in the video. HSC also thanks George Yohrling of the Huntington's Disease Society of America for his keynote presentation and participation in the livestreamed Virtual Day. Thank you as well, to each local "in-person" presenter across the country, and the HSC family services team members and chapter volunteers who organized CEFs in their communities.

HSC is looking forward to continuing to offer educational opportunities to the community in the future.



# Young People Affected by Huntington Disease (YPAHD) Day

As a chapter of the Huntington Society of Canada (HSC), Young People Affected by Huntington Disease (YPAHD) aspires to a reliable treatment for Huntington disease (HD). YPAHD helps youth think about and discuss topics such as genetic testing, family life and dating and supports them in their unique journey. This group provides young people with peers they can relate to, talk to and lean on. The support system can be incredibly important during this stage in life.

YPAHD strives to:

- provide a community and support network for young people affected by HD;
- increase public awareness thereby enabling others to understand the disease;
- raise funds to deliver services for those living with HD;
- further research in order to slow and prevent HD; and
- listen to and advocate for the needs and goals of young people affected by HD through the communication mechanisms provided by HSC.

In 2012, YPAHD created a one-day youth conference (YPAHD Day). Every other year, these conferences are held regionally in Western, Central and Eastern Ontario. YPAHD Day attendees appreciate the fun activities and opportunity to meet other youth who understand their situation, as well as helpful education and support. Regional YPAHD Days first took place in 2015.

*"YPAHD day has been a great support for myself, my partner and my siblings. In a world where you feel alone, these young people show connection, support and hope for our families and futures. It's a place where we can learn and open up to others that understand the complexity of the disease. It brings me courage for my family's future. It brings me support for how I'm feeling and how I'm dealing with HD. It brings me hope for the future of the community. I'm building skills on how to deal with this disease and for that I am forever grateful."*

On Nov. 16, 2019, young people between the ages of 14 and 35, affected by HD gathered at three locations across Canada to learn and inspire one another. The line-up of local social activities and educational



workshops planned by YPAHD representatives and local chapter members was impressive and included topics from research, to care, as well as subjects that matter to youth, specifically. All workshops, breakfast, lunch and coffee breaks on Nov. 16, along with a social activity on Nov. 15, were included with registration.

Funding was available for young people to attend the location nearest to them, simply by filling out an application form, available online. HSC was able to fund 75 youth, in some way, to attend this year, with 37 per cent of overall attendees coming for their first time.

Final reports show 83 attendees (including five staff) across three sites (Calgary, AB, Toronto, ON and Halifax, NS). This represents a 22 per cent increase over the 2017 Regional YPAHD Days, and a 14 per cent increase over the 2018 Conference YPAHD Day.

Of these numbers, 45 youth attended the Toronto YPAHD Day (53 per cent of total attendance). This represents a 25 per cent increase over the 2017 Toronto YPAHD Day. The Calgary YPAHD Day saw a 32 per cent increase over 2017, with 28 youth in attendance. The Halifax YPAHD Day had 10 youth in attendance, with HSC exploring options for the future of YPAHD Days in Atlantic Canada.

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FOUNDATION

*The Huntington Society of Canada sincerely thanks our YPAHD Day sponsors.*

# 2019 Huntington Disease Awareness Month



Huntington disease (HD) Awareness Month in 2019, was, by all accounts, one of the most successful ever.

Since 2015, volunteers from across Canada have been working to illuminate various buildings, monuments and statues during the month of May to raise the visibility of HD and Juvenile Huntington disease (JHD).

Thanks to the enthusiasm of the HD community and many volunteers, the 2019 campaign saw a record number of participating sites, worldwide. In Canada, 55 sites participated in #LightItUp4HD, while another 114 international buildings, monuments and other structures lit up in blue for HD and/or purple for JHD. In addition, nearly 60 sites from the virtual world “Second Life” lit up, thanks to the advocacy of an avatar within the HD community.

An international total of 169 sites participated – nearly 50 more than in the previous year. This included the following countries: Australia, Cyprus, England, Germany, Ireland, Northern Ireland, Mexico, Norway and Spain. A number of cities and municipalities across Canada also made proclamations to declare May as HD Awareness Month. In most cases, this was coupled with a flag-raising event outside the local city hall or civic centre.

As well as posts on social media, with much engagement, the campaign also generated several media stories in print, television and radio – with a news release issued at the beginning of the month and also in wrap-up. The estimated reach of each of these stories means that the campaign is able to reach those who may not be familiar with HD.

Thanks to chapter volunteers across Canada and international partner organizations, #LightItUp4HD continues to increase awareness.



# 2019 Amaryllis Campaign

For over 30 years the Amaryllis has been the signature flower of the Huntington Society of Canada (HSC). This annual fundraising and awareness campaign continues to inspire hope from coast to coast, with over 20,000 bulbs blooming across Canada each year. The beautiful, long-lasting, Amaryllis never fails to attract attention.

Each kit arrives packaged in a lovely gift box, which contains one high-quality Orange Sovereign bulb, growing instructions, soil, a planting pot, a plant stake and a saucer.

Where flowers bloom so does hope. Our Amaryllis volunteers work diligently to sell bulb kits to help raise vital funds for Huntington disease (HD) research, and HSC services and programs. In short, each kit sold means we are a step closer to finding a treatment for HD.

HSC supporters purchased 21,132 Amaryllis bulbs throughout the 2019-2020 campaign, raising awareness in homes, workplaces, and communities coast-to-coast across Canada. Funds raised through Amaryllis are used to fund world-class research focused on finding treatments for HD, build a strong foundation for Clinical Trials Canada and provide much-needed support to families through the family services program. Funding also impacts youth through our Youth and Young Adult Mentorship Program and Young People Affected by HD (YPAHD) chapter.

Since 1985, HSC's dedicated Amaryllis volunteers have raised well over \$5.5 million in support of HD. We are looking forward to another successful campaign this year.



# Financial Health - Treasurer's Report

I am pleased to present this report to the membership and, indeed, all stakeholders of the Huntington Society of Canada (HSC) for the fiscal year ended March 31, 2020.

The past twelve months have been transitional for HSC. We welcomed back a familiar face as interim CEO, while your board of directors undertook an extensive search for the next CEO to guide the organization through some very challenging, yet hopeful times for our community and our families.

The fiscal year ended on the heels of the declaration of a world-wide pandemic.

Even in the waning weeks of the financial year, we began to see and experience the impact of COVID-19. However, I remain optimistic in that we continue to see you — our community and stakeholders — remain determined to ensure that HSC is financially able to deliver much-needed programs, as we work towards our core vision of a world free from Huntington disease (HD).

With the shift in our fiscal year in 2019, we drew several comparatives to better understand how we had performed against our mission and values. While we had several very good years where revenue exceeded \$4 million, this latest fiscal ended with revenues just shy of \$3.8 million. This represents a drop in revenue of about 12-15 per cent over prior comparative periods. However, we remained determined to fund the programs critical to our community.



We invested just short of \$1 million in research and we increased our spending in family services from \$1.2 million to \$1.3 million (again, over prior comparative years). The assets of the organization are strong at \$3.8 million and our research fund continues to exceed \$1 million, even with our very important investment in this area.

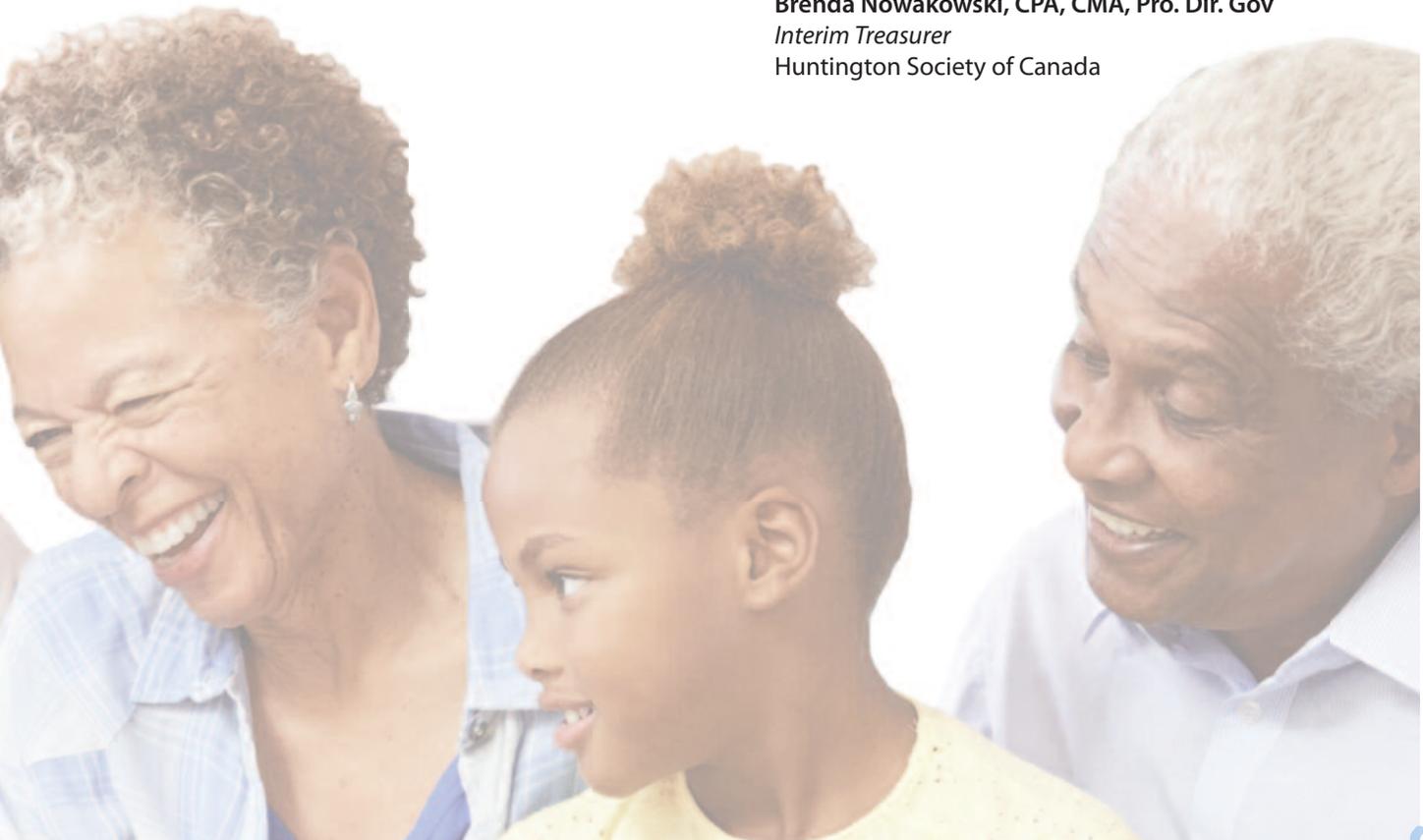
While we are reporting a \$286,000 deficit for the year ended March 31, 2020, we continue to manage revenue and, more importantly, expenditures to ensure HSC remains financially strong into the future. Just as importantly, we remain committed to our mission of improving the lives of those affected by HD. Our spending is tied to very strategic initiatives and I cannot thank our many volunteers and dedicated staff enough for their hard work, diligence and continued encouragement and financial support.

That support is more important now than it has ever been. While COVID-19 will remain clearly on our radar, we are in the throes of exciting and promising research and clinical trials that are addressing the root causes of HD. This research continues to provide promising results as more biotech and pharmaceutical organizations explore different treatment options for those impacted by HD.

Optimism and belief are the foundation upon which we will continue to take the next steps closer to a world free from HD. We will continue to manage with purpose and fiscal responsibility as our guiding principles.



**Brenda Nowakowski, CPA, CMA, Pro. Dir. Gov**  
*Interim Treasurer*  
Huntington Society of Canada



# Statement of Financial Position\*

March 31, 2020, with comparative for 2019

|  | 2020                | 2019                |
|--|---------------------|---------------------|
| <b>Assets</b>                            |                     |                     |
| Current assets:                          |                     |                     |
| Cash                                     | \$ 870,424          | \$ 1,007,463        |
| Investments                              | 2,642,350           | 3,037,917           |
| Accounts receivable                      | 134,130             | 30,111              |
| Prepaid expenses                         | 99,161              | 96,150              |
|  | 3,746,065           | 4,171,641           |
| Capital assets                           | 77,032              | 19,600              |
|  | <b>\$ 3,823,097</b> | <b>\$ 4,191,241</b> |
| <b>Liabilities and Fund Balances</b>     |                     |                     |
| Current liabilities:                     |                     |                     |
| Accounts payable and accrued liabilities | \$ 160,818          | \$ 80,163           |
| Deferred revenue                         | 309,305             | 489,841             |
|  | 470,123             | 570,004             |
| Deferred lease inducement                | 17,699              | -                   |
|  | 487,822             | 570,004             |
| Fund Balances:                           |                     |                     |
| General Fund                             | 298,552             | 582,573             |
| Capital Assets Fund                      | 77,032              | 19,600              |
| Endowment Fund                           | 1,755,311           | 1,887,916           |
| Laura's Hope Fund                        | 18,780              | 17,847              |
| Ralph Walker Research Fund               | 1,185,600           | 1,113,301           |
|  | 3,335,275           | 3,621,237           |
|  | <b>\$ 3,823,097</b> | <b>\$ 4,191,241</b> |

\*These statements are extracted from the audited financial statements for the year ended March 31, 2020.  
The full set of audited financial statements are available upon request.



# Statement of Operations\*

Year ended March 31, 2020, with comparative information for the nine month period ended March 31, 2019

|   | General Fund        | Capital Assets Fund | Endowment Fund      | Laura's Hope Fund | Ralph Walker Research Fund | Total year ended March 31, 2020 | Total nine month period ended March 31, 2019 |
|---|---------------------|---------------------|---------------------|-------------------|----------------------------|---------------------------------|--|
| <b>Revenue:</b>                                     |                     |                     |                     |                   |                            |                                 |  |
| Donations   | \$ 1,356,483        | \$ -                | \$ -                | \$ -              | \$ 503,592                 | \$ 1,860,075                    | \$ 974,488                                   |
| Grants  | 178,328             | -                   | -                   | -                 | 431,237                    | 609,565                         | 536,617                                      |
| Chapter and volunteer fundraising revenue           | 1,273,497           | -                   | -                   | -                 | 3,558                      | 1,277,055                       | 753,164                                      |
| Investment income                                   | 58,610              | -                   | -                   | 933               | 33,594                     | 93,137                          | 93,076                                       |
| Change in fair value of investments                 | 23,321              | -                   | (117,605)           | -                 | (53,035)                   | (147,319)                       | 3,360  |
| Other income  | 93,212              | -                   | -                   | -                 | -                          | 93,212                          | 91,499                                       |
|   | 2,983,451           | -                   | (117,605)           | 933               | 918,946                    | 3,785,725                       | 2,452,204                                    |
| <b>Expenses:</b>                                    |                     |                     |                     |                   |                            |                                 |  |
| Research  | 68,445              | -                   | -                   | -                 | 846,647                    | 915,092                         | 438,927                                      |
| Family services                                     | 1,343,180           | -                   | -                   | -                 | -                          | 1,343,180                       | 991,916                                      |
| Public awareness and education                      | 321,007             | -                   | -                   | -                 | -                          | 321,007                         | 350,421                                      |
| Chapter and volunteer support                       | 170,182             | -                   | -                   | -                 | -                          | 170,182                         | 122,843                                      |
| Development   | 388,691             | -                   | -                   | -                 | -                          | 388,691                         | 291,112                                      |
| Chapter and volunteer fundraising expenses          | 250,944             | -                   | -                   | -                 | -                          | 250,944                         | 245,044                                      |
| Administration                                      | 672,232             | -                   | -                   | -                 | -                          | 672,232                         | 412,418                                      |
| Amortization  | -                   | 10,359              | -                   | -                 | -                          | 10,359                          | 5,006  |
|   | 3,214,681           | 10,359              | -                   | -                 | 846,647                    | 4,071,687                       | 2,857,687                                    |
| <b>Excess (deficiency) of revenue over expenses</b> | <b>\$ (231,230)</b> | <b>\$ (10,359)</b>  | <b>\$ (117,605)</b> | <b>\$ 933</b>     | <b>\$ 72,299</b>           | <b>\$ (285,962)</b>             | <b>\$ (405,483)</b>                          |

\*These statements are extracted from the audited financial statements for the year ended March 31, 2020. The full set of audited financial statements are available upon request.

# Quick Facts



153

Community Events  
Across Canada



12,000

Event  
Participants



27

Chapters and  
Active Areas



21,132

Amaryllis  
Bulbs  
Sold



23

Community  
Education  
Forums



3

Regional  
YPAHD Days



83

YPAHD Day  
Attendees Across  
Canada



2

Clinical  
Fellowships  
Awarded



121

Support  
Group  
Sessions



3,910

Open  
Individual  
Files



14

Resource  
Centres



169

Sites Lit Up for  
Huntington Disease  
Awareness



1

Virtual  
Community  
Education Forum



522

Community  
Education Forum  
Attendees



266.5

Years of Combined  
Experience Across  
the Family Services Team



3,280

Facebook Followers  
and 3,351 Facebook  
Page Likes



1

Fantastic, Engaged  
and Inspiring HD  
Community!





**TO VIEW OUR 2019-2020 DONOR LIST,  
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20 Erb St. W., Suite 801  
Waterloo, ON N2L 1T2  
1-800-998-7398