

# 2021/2022

## HUNTINGTON SOCIETY OF CANADA

# ANNUAL REPORT



HOPE  
BELIEVE  
INSPIRE

**The Huntington Society of Canada (HSC) is a not-for-profit charitable organization that raises funds and awareness, all with the goal to support individuals and families facing Huntington disease (HD).**

## **VISION**

A world free from Huntington disease.

## **MISSION**

To improve the quality of life for those affected by Huntington disease.

We will address our mission via:

- The oversight and facilitation of excellent support services
- Providing access to the best and most up-to-date educational resources
- Increasing national and global awareness
- Investing in promising research
- Advocacy



## **VALUES**

**COMPASSION**

**INTEGRITY**

**ACCOUNTABILITY**

**INCLUSIVENESS**

**COLLABORATION**

**LEADERSHIP**

**EMPOWERMENT**



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2021/2022

# Brynne Dalmao

## Board Chair Note

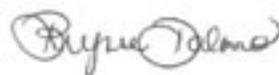
Looking back on the past fiscal year, I feel a sense of optimism as the world has started to emerge from pandemic mode.

Engaging in activities provides such a renewed sense of community. It has been wonderful to see people attend events in person again, and to witness the remarkable success of these endeavours. I am overwhelmed and thankful to all of the chapters, volunteers and donors for the amazing generosity and support they continue to show. This display of unity is truly energizing; it gives me a fresh sense of hope.

From a governance standpoint, the Board of Directors is always working to make sure we are creating and following a strategic plan that is accessible to all community members across the country. There is such a sense of unity within the community and support for one another – we are unique in how we band together. We see that sense of connection in everything, from our fundraising efforts providing support across the country, to the clinicians, scientists and researchers collaborating. The mutual benefit for everyone feels so refreshing and hopeful!

I have always found our mission statement, to improve the quality of life for those affected by Huntington disease, to be empowering. This core statement highlights that help is available to all people affected by Huntington disease. No matter how remote or tiny your community, the entire community still benefits from collective fundraising, services offered, and support. That sharing of resources is more important now than ever before.

The fiscal year 2021/22 was a positive and successful year. It is exciting to have these wins and milestones achieved to celebrate. I am certain that the next year will continue to be energizing and empowering for our unique, generous and united community.



**Brynne Dalmao**

*Chair*

Huntington Society of Canada



# Shelly Redman

## Letter from the CEO

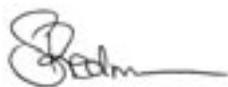
Our fiscal year 2021-2022 was a year of thriving even while the pandemic continued. We had an educational first Covid year, pivoting and being thrown head first into the world of virtual programming and work. We came out of that first year successfully, and this past year showed how wonderful the entire community continues to be.

From volunteers to donors, staff and families, everyone contributed at such a high level. A new routine was established. I was so impressed by people's willingness to continue to adapt and adopt new ways of doing things. Without the strength of the individuals and teams working together, our year would not have been so successful.

You will have a chance to read more details about some of the outcomes we were able to achieve in 2021-22. I would like to highlight a few here as well:

- We offered our second National Virtual Conference and our community participated in greater numbers than ever before
- Our Family Services team piloted new specialized online support groups and online educational sessions for social service and health care providers
- Some chapters and volunteers were able to offer a handful of in-person fundraising events, in spite of dealing with the challenges of Covid
- We had a record-breaking Amaryllis campaign, selling 25,320 bulbs and inspiring hope throughout Canada

Thank you, everyone, for an amazing year. We truly went from surviving to thriving. Given the community's inspirational response to challenges, I am filled with confidence and excitement for the year ahead.



**Shelly Redman**

CEO

Huntington Society of Canada





## Governance

### HSC Executive

*Brynne Dalmao – Chair*  
*Cameron Barrett – Vice-Chair*  
*Mack Erno – Past-Chair*  
*Sean Dewart – Secretary*  
*Anne Brace – Treasurer*

### HSC Board Members

*Geneviève Bélanger*  
*(Huntington Society of Québec Representative)*  
*Genevieve Giroday*  
*Brenda Mason*  
*Ron Muller*  
*Catherine Price (YPAHD Representative)*  
*Marg Romanow*  
*Patrick Thauberger*  
*Diane Tullson*  
*Andrew Wright*

Hailing from all corners of Canada, the Huntington Society of Canada (HSC) board of directors currently meets four times 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.

# Family Services

The Family Services team at the Huntington Society of Canada plays a crucial role in delivering our mission, which is to improve the quality of life for those affected by Huntington disease.

The team does so by delivering excellent support services and providing access to the best and most up-to-date educational resources. In so doing, the HSC social workers offer tools, strategies and resources that can help individuals and families navigate the Huntington disease landscape.

Here is a look at the numbers for 2021/2022 in the various categories of support and program offerings.

## Individual Supports

In 2021/22, the Family Services team met the increased demand for telephone calls and meetings, requests for services, and information needs:

- **HD clinic appointments:** the number of clinic appointments attended by the Family Services team has remained the same with a continued shift to virtual appointments (53% virtual and 47% in person)
- **Telephone calls and meetings:** 23% increase in phone contacts with HD community members
- **Anonymous requests for HSC services (people and service providers who do not have a service file):** Increased by 57% (424 requests)
- **New persons who opened a file with HSC Family Services:** 15% increase since last year (329 individuals)

**Top areas for requests included information on Huntington disease, Family Services supports and education, genetic testing and clinical trials**





## Group Supports

The Family Services team continued to offer new and innovative programming to meet the diverse needs of the community. These included:

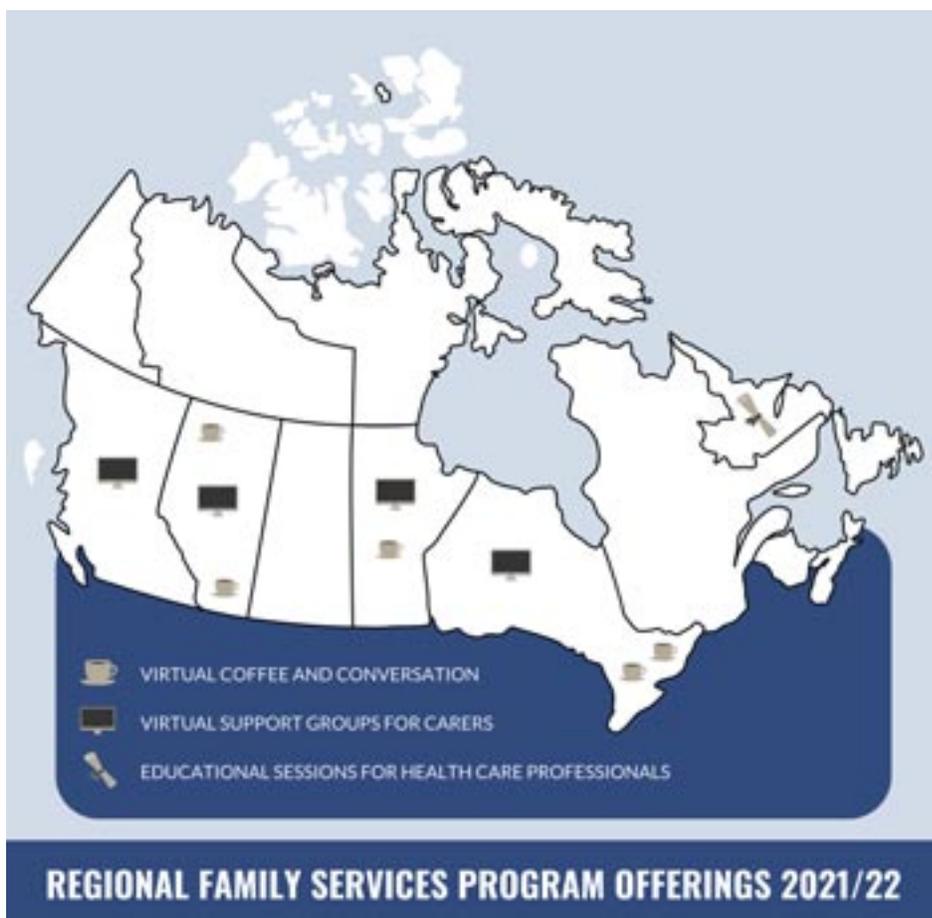
### New Provincial Virtual Groups

- In BC, Family Services ran a pilot virtual group for **partners of individuals who had tested positive for HD**. Topics included HD 101, clinical trials, family planning, and emotional changes
- The **Central ON Carers** closed group featured Toronto and East Central ON participants

### New Social Virtual Groups

These regions connected for virtual coffee and conversation:

- Alberta: North and South
- East Central ON: Peterborough and Durham regions
- Manitoba
- Eastern ON: Ottawa, Kingston and Belleville regions



## Continuing Successes

Family Services at HSC continued several support groups due to continued need and interest.

- Virtual Support Groups for Carers in BC, AB, MB and ON
- Interest in the At Risk/Gene Positive Group (national) increased yet again. Family Services offered a series in the fall of 2021 and again in the spring of 2022. With increased demand, it required two groups to meet the needs. Our national social worker offered different groups, one in Eastern and one in Western Canada.

**In early 2022, the Family Services team conducted a pilot of a new national virtual group specifically for parents of those with HD. This closed group met for 8 sessions and discussed HD 101, future planning and decision-making, grief and guilt, coping and self-care.**

## Using Social Media to Connect

There was a 13% increase in closed Facebook group members. It now has 370 members. The closed Facebook group is a private and secure forum, where families affected by Huntington disease can connect with others 24/7.

## Education

The Family Services team continued to deliver on our mission by providing and facilitating top-tier educational opportunities, including:

- National: **Advance Care Planning** with Dr. Heyland: 166 registered
- Provincial: **Ontario Disability Support Program**: 66 registered
- Sessions for service providers:
  - i. **Psychiatric considerations of HD** with Dr. Eleff (Atlantic Provinces) : 23 attendees live
  - ii. **Cognitive Considerations of HD** with Jimmy Pollard (Atlantic Provinces) : 70 registered

**At the National Virtual Conference in February 2022, the Family Services team presented the session HD 101 as well as Relationships and Boundaries. The team also moderated both the Community Services Panel and the HD Clinic Panel.**





# Research Dollars in Action

Our mission at HSC is to improve the quality of life for those affected by Huntington disease (HD). One of the ways that we address our mission is by investing in promising research.

This past fiscal was an exciting time for funding research projects in the field of Huntington disease. The field is diverse and we were pleased to participate in different topics and with researchers at varying stages of their careers.

## **Navigator Research Program**

The Navigator Research Program has been providing funding to support HD researchers since 2003 with awards up to \$75,000/year for 1-2 years.

### **Goals of the Navigator Research Program Include:**

- Funding for Canadian scientific research of direct and immediate relevance to Huntington disease
- To provide a platform for the future recruitment of outstanding investigators to HD research
- To facilitate research collaboration nationally and internationally
- To support research which is relevant to other neurodegenerative disorders as well as HD

## 2021 Navigator Research Program Recipients:

**Blair Leavitt, MD:** University of British Columbia

**Project title:** Design and evaluation of an epigenetic therapeutic strategy for Huntington's disease treatment

**Project goal:** This work will improve our understanding of how chemical changes to DNA (called DNA methylation) control the amount of huntingtin protein produced by brain cells. The project will look at controlling these DNA methylation changes as a new way to selectively lower mutant huntingtin levels and to potentially treat Huntington disease.

### Dr. Leavitt Bio

Dr. Leavitt is a full Professor in the Department of Medical Genetics & the Department of Medicine, Division of Neurology (Associate) at the University of British Columbia. Dr. Leavitt completed his medical degree at McGill, medical internship at Columbia-Presbyterian, and neurology residency at Cornell and Harvard. While in Boston, he completed a basic neuroscience research fellowship at Harvard Medical School and Children's Hospital of Boston. Blair is a consulting neurologist and Director of Research at the UBC Centre for Huntington's Disease. A scientist and physician, Dr. Leavitt's time (both clinical and research) is dedicated to developing new treatments for genetic brain disorders such as Huntington's disease

**Mahmoud Pouladi, PhD:** University of British Columbia

**Project title:** Investigating the impact of mutant huntingtin on human oligodendroglia.

**Project goal:** Mutant huntingtin, the protein that causes Huntington disease (HD), is present in the majority of cells that make up the brain. Recent evidence shows that mutant huntingtin interferes with the work of oligodendrocytes, a type of brain cell that helps different parts of the brain communicate.





Some studies have suggested that this disruption of oligodendrocytes is partly to blame for the clinical symptoms that develop in patients with HD.

The objective of this research project is to investigate the ways in which oligodendrocytes are affected by the HD mutation (and the mutant huntingtin protein it encodes) and to develop possible ways to treat them. These studies could lead to new ideas about how to treat HD.

### **Dr. Pouladi Bio**

Dr. Pouladi is an Associate Professor of Medical Genetics at the University of British Columbia (UBC). Dr. Pouladi obtained his Bachelor of Science (summa cum laude) majoring in Molecular Biology, followed by a Masters degree in Immunology, both from McMaster University. He completed his PhD in Medical Genetics with a thesis titled "Assessment of novel therapeutic approaches in the YAC128 mouse model of Huntington disease" as well as postdoctoral training at UBC. He has been the recipient of a number of awards and distinctions including the Canadian Institutes of Health Research Brain Star Award, the British Columbia Innovation Council's Ripples of Hope Award in Biotechnology & Entrepreneurship, and the Michael Smith Health Research BC Scholar.

### **Health Care Capacity Study Poster Project**

Huntington Society of Canada was proud to participate in a research poster presented at the HSG conference in the fall of 2021 for the Health Care Capacity Study in collaboration with Roche and clinics across the country.

The title of the poster is *Current HD health care capacity and anticipated gaps for intrathecal disease modifying therapy provision in Canada.*

The study concluded that access to multidisciplinary care for patients with HD is inequitable across

Canada. There is little additional capacity in the Canadian healthcare system to support the administration of a new HD therapy.

More information about the publication of the article will follow. We are committed to the collaboration with this research team, adding to knowledge and insights for future planning in the field of Huntington disease care.

## **2022 Clinical Fellowship in Huntington disease**

In September 2021, the Huntington Society of Canada announced the creation of a stable, long-term program to train a new generation of neurologists with expertise in treating patients with Huntington disease in Canada. The new Clinical Fellowship program provides the opportunity for post-residency training for one year (\$80,000). The program will run for five consecutive years, beginning July 1, 2022. The goal is to add five new Huntington disease neurologists in Canada over the next five years.

The Clinical Fellowship Award is administered by HSC through a national competition adjudicated by an expert panel.

The new Clinical Fellowship award was made possible via a donation by Dr. Mark Guttman and his wife, Lesley Simpson. Dr. Guttman, who retired at the end of August 2021, is one of the leading neurologists in the country specializing in Huntington disease, in both research and clinical fields. There is a shortage of neurologists in Canada trained to manage HD patients and their families. Without a dedicated initiative to stimulate interest in the field of HD, the shortage of neurologists with expertise in HD care will only continue or worsen. Dr. Guttman's goal with creating this program was to help fill that gap. A key feature of this program is that recipients be permitted and planning to work in Canada for the long term.





## Predictive Testing Survey

HSC funded the Predictive Testing survey with Principal Investigator Dr. Blair R. Leavitt from the University of British Columbia. HSC is working in collaboration with the Centre for Huntington Disease at University of British Columbia to help determine the effects of clinical trial results on predictive testing uptake via an online survey of individuals affected by Huntington's disease.

The survey aims to help decision makers and healthcare providers (including clinicians, genetic counsellors, and HSC) better prepare for a potential surge in predictive testing requests. This preparation will in turn improve the quality of care.

The survey is open to people living at risk for the HD gene mutation, those who have recently undergone predictive testing, or those who have chosen to postpone the process. One of the goals of the survey is to discover factors affecting individuals' decisions to access predictive testing or not.

# YPAHD Day

November 13, 2021 saw the first-ever virtual version of the popular Young People Affected by Huntington disease (YPAHD) Day. This one-day youth conference provided opportunities for learning and interaction, including social time to help connect youth with others in similar situations.

“Going virtual for YPAHD Day allowed for youth engagement among participants who, in a normal year, would be attending the events in three separate provinces. As well, the virtual format reduced the barrier to entry and provided a sense of anonymity for those wishing,” says Caleb Harding, President of YPAHD. “We were fortunate to have a slate of fantastic speakers and round table discussions. We are excited to see how we can incorporate a virtual component in YPAHD Days to come.”

Speakers provided thought-provoking, educational sessions on the following topics:

- Relationships
- Genetic Testing
- Family Planning
- Research
- Life after YPAHD (getting involved with other HSC chapter/volunteer opportunities)

“Saturday, November 13th was a day filled with learning, connection, and support. The event had almost 100 registrants with over 50% being new to YPAHD Day – AMAZING!” Kelsey Laidlaw, Event Coordinator, HSC.

**The Huntington Society of Canada is proud to be investing in youth, providing mental health support and opportunities for engagement.**



# National Virtual Conference



On February 26 and 27 2022, HSC hosted our second annual National Virtual Conference and it was a huge success. More than 1000 individuals registered to watch. Of those who registered, 48% stated that it was their first time attending an HSC conference. The two-day conference featured sessions with topics ranging from research to caregiving.

## Highlights included:

- Dr. Ray Truant's Keynote address: What Clinical Trials Taught Us and How HD Therapeutic Development is Accelerating in 2022
- Dr. Fung and Angie Dale: Survivor's Guilt
- Elaine Sanchez's Closing Plenary Session: Finding Hope, Humour and Heart in Caregiving

Many of the sessions are available to watch on our YouTube channel .

## From Our Community

Our participants had wonderful feedback to share about our National Conference's positive impact:

From a caregiver:

"I feel like I have new friends and connections for this journey as a caregiver, and also a clearer understanding of the status of research to eliminate or delay the onset of HD. All this new information and my increased feeling of confidence due to all these new supports will help me support my whole family and my health care team."



From an individual facing Huntington disease:

“Gained new knowledge from Jimmy's HD 201 talk. The first speaker showed there was still hope and research ongoing. The clinical trial session was valuable as I may take part in one, one day. It was good hearing from the HD clinic teams. The last speaker was wonderful and heartfelt! It was also great to be able to chat with participants and have questions answered. And it felt great to be able to give my thanks to the researchers/HD clinic staff/HD staff for everything they are doing for HD families.”

Loving the community support:

“I liked feeling like I was part of a community and that all my feelings and experiences with HD were understood. It was nice to be learning instead of educating. The speakers all did a great job but I really loved the presentations about boundaries and the final one about humour.”

About the benefits of a virtual option:

“Keep doing this National Conference and please make sure that there is always a virtual option for the fullest participation possible for those who are unable to travel.”

# Chapter Development and Volunteers

For the fiscal year 2021/22, virtual meetings were the continued focus for chapters. Despite these limitations due to Covid, our chapters and volunteers persevered and adapted to the circumstances. Here are some of the year's success stories:

**New Beginnings in Belleville:** An individual in Belleville hosted a virtual educational session to start the wheels turning on forming a chapter in Belleville/Kingston

**Fresh New YPAHD Executive:** The YPAHD Chapter elected a new executive in March after the previous executive was approved to extend their term because of Covid

**Dawn of a New Era:** The end of the fiscal saw energy and connections returning within the chapters and our team - we start the new fiscal with exciting new initiatives that will only serve to strengthen the work we do nationwide!



## We Our Volunteers Because They:

 <b>RAISE AWARENESS</b>	 <b>PLAN EVENTS</b>	 <b>LEAD CHAPTERS</b>	
 <b>ARE SPEAKERS &amp; PRESENTERS</b>	 <b>SHARE THEIR STORIES</b>	 <b>SELL &amp; ORGANIZE AMARYLLIS</b>	
 <b>RAISE FUNDS</b>	 <b>PROVIDE SUPPORT</b>	 <b>ARE MENTORS</b>	
 <b>MAKE LIGHT IT UP 4 HD HAPPEN</b>	 <b>GOVERN OUR BOARD</b>	 <b>COORDINATE MEETINGS</b>	

# Community Events



Strength. Adaptation. Perseverance. Hope. When we reflect on another unsettled year due to Covid disrupting the in-person meetings and activities that chapters thrive on, these are the qualities that stand out and inspire the entire community.

We still had a great event season with many chapter- and volunteer-led events raising money for HSC. Here is how our wonderful chapters and volunteers managed the challenge.

## Adapting to Virtual Formats

- Some events went virtual, such as many of our walks/runs joining the National Virtual Walk to continue despite gathering restrictions
- The Camrose Chapter switched to an online auction, which took the place of their Annual Golf Tournament and raised over \$14,000

## In-Person Events

- A variety of events continued to run in person when safe to do so, including these highlights – there were many others:
  - > Peterborough Golf Tournament
  - > HD500 in Manitoba, which returned after running virtually in 2021
  - > The Coachman’s Cove Walk in Newfoundland proceeded in person in August 2021 - participants enjoyed the uplifting sense of community stemming from face-to-face events

## New Events

- We also had a number of new events pop up to help fill the gaps, such as:
  - > Niagara Chapter’s online auction, an event the chapter has never run before
  - > Runners supported HSC with their fundraising efforts, like Parker Van Beest, who dedicated his runs to HSC and helped raise funds and awareness for the cause
  - > Liz and Bobby’s Ultra-marathon – read more in the mini story below!
- We are so inspired by the can-do attitude exhibited by our chapters and volunteers, proving that **where there’s a will there’s a way**

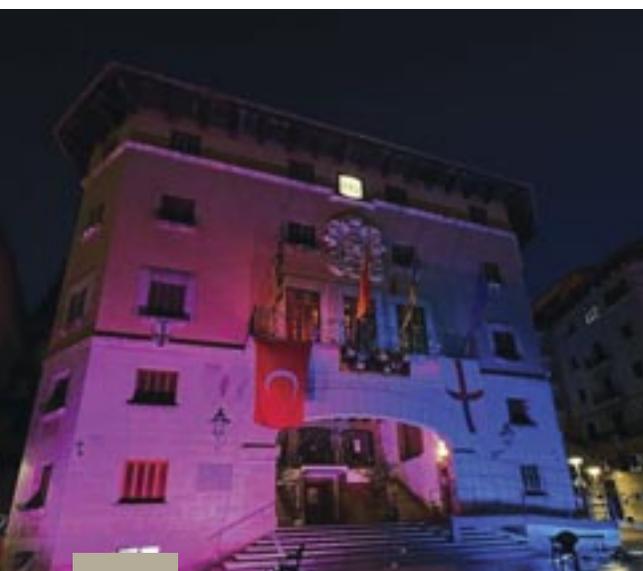
Thank you so much volunteers, participants and donors across Canada for making these events a success, raising funds, awareness and spirits.

### **Fundraiser Spotlight: 100 km Ultra Hike for Huntington disease**

**Bobby Jinkinson and Liz Hobbs took more than 130,000 steps in the Ottawa region in support of Huntington disease. Together they ran an ultra marathon – that’s 100km! This fundraising initiative on behalf of Huntington Society of Canada raised \$11,000. Amazing!**



# Huntington Disease Awareness Month



Huntington disease Awareness in May 2021 once again looked different from years past. It was virtual – and it was wonderful! Here are a few goals we shattered in our quest to raise funds and awareness for HD.

## **Light It Up 4 HD 2021 Reached Around the World**

- Light It Up 4 HD is a global phenomenon that sees buildings and structures lighting up in blue for HD and purple for Juvenile HD.
- These stunning visual displays offer a significant opportunity to have a conversation about HD – its impact, symptoms, and what it's like for an individual affected by HD and their families – as well as what can be done.
- In 2021, we had a **record-breaking year for Light It Up 4 HD with 172 sites participating, 39 in Canada and 133 internationally!**

Thank you to all of the volunteers who worked tirelessly to liaise with sites to light up and for taking photos to share with our community.



### HD Awareness Month = Spirit Month

- In another year of firsts, 2021 marked the inaugural spirit month for HD Awareness Month
- Our social media channels and email communications featured different themes each week, from “Fill Your Feeds with Blue and Purple” to “HD Spirit @ Home” to help us raise awareness for HD
- We saw unprecedented levels of engagement as our community grew in numbers and reach reacting to posts, videos, photos and emails
- This helped increase education about HD and bolstered our fundraising efforts, all with the goal to support those facing HD with Family Services as well as to continue to fund research to treat the root cause of the disease





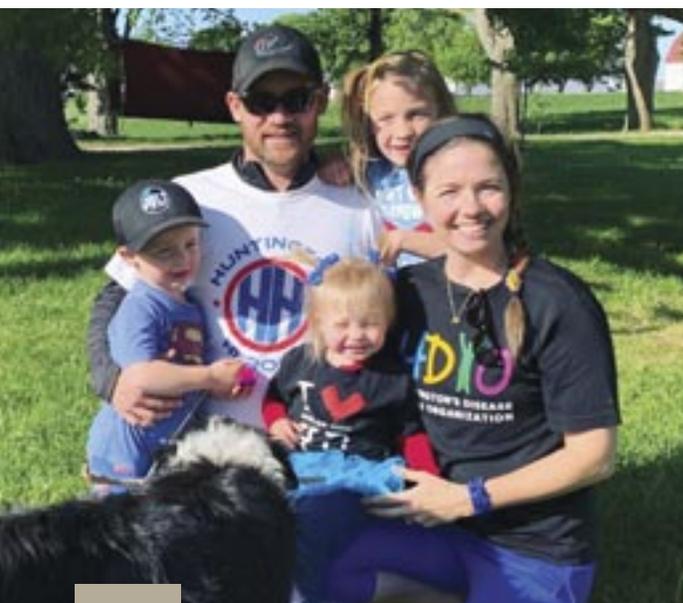
**HUNTINGTON HEROES  
NATIONAL VIRTUAL WALK**

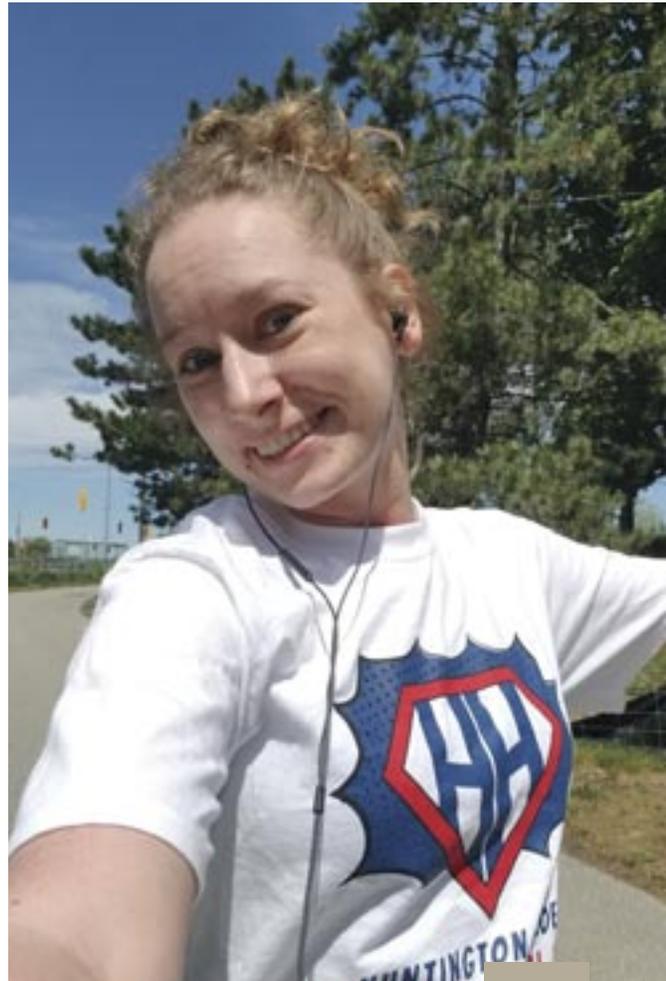
## 2021 Goal Exceeded!

- The 2021 Huntington Heroes National Virtual Walk was an amazing success, raising more than half a million dollars!

**We collected over \$250,000,  
exceeding the \$213,000 goal.**

- That amount was matched dollar for dollar by an anonymous donor – it was a tremendously wonderful boost for HD research and the provision of Family Services for individuals and families affected by HD
- We also had more participants than ever before. The event took place May 27-28, 2021 and was our first year walking all on the same weekend
- 16 regions offered local, virtual programming for the walk, with a national virtual option for those without a chapter or group near them – think music, prizes and more!





**Thank you everyone  
for your donations  
and participation!**



# Amaryllis Campaign

The 2021 Amaryllis Campaign truly lived up to its tag line and inspired hope for the entire community, thanks to the amazing efforts of our volunteers, chapter coordinators and community members.

**Together,  
we sold 25,320 Amaryllis bulbs.  
Thank you so much to everyone  
for this huge success.**

This fundraising allows HSC to support Family Services programs and invest in promising research. The successful campaign also represents a way for the community to come together in blossoms and hope.

## **Did you know?**

**If you placed all 25,320 Amaryllis gift boxes next to each other, they would equal the length of 38.6 football fields! That is a tremendous amount of flowers, matching the incredible efforts and courage of our community. Imagine being surrounded by that beauty.**



One of HSC's most beloved traditions is the Amaryllis Photo Festival. In January 2022, we received 113 submissions to the photo festival and 896 votes.

There were so many amazing entries but one standout caught everyone's heart.

**The winner was Hildi Banting from Victoria, B.C. for the photo of her mother.**



"I'm submitting a photo of my mom with her Amaryllis. This may not be the cutest photo, or the most magnificent specimen, but it could just be the most heartwarming photo.

Holding this beautiful amaryllis plant is my very dear mom....99.9 years of age, completely blind and living in a care home in Winnipeg, Manitoba. Mom has always loved flowers, and as her sight was diminishing, we would choose brightly coloured florals with lovely fragrances to help her appreciate their beauty. Today she uses her senses of touch and smell as well as our descriptions to help her visualize the blossoms. My mom can't see these cheery red blooms and the full beauty of this amaryllis plant, but she touches it with gentleness, love and appreciation, and hopefully it provides a bright spot of beauty for the staff assisting her each day.

The morning of January 6 was our last visit as I was flying back to Victoria, BC later that day. As I sat beside her, I suddenly decided to take this photo as a remembrance of our special visits together. How beautiful she looked gently holding this brightly coloured Amaryllis. Had I known at the time about the photo contest, I might have straightened the plant or tried to maximize other aspects of the photo. However, it was merely taken as a remembrance of our love.

That same afternoon Covid shut down all visitations in the care home. I don't know if the other buds bloomed, or if anyone shared its ongoing beauty with my mom, but on that day a beautiful memory was created... thanks to this one Amaryllis plant.

The Amaryllis... something so beautiful! Huntington disease... so devastating. Huntington disease has wreaked much havoc and pain in the family (and extended family) of my dear childhood friend. Wishing you all the best in your ongoing research for a cure."

Hildi Banting Victoria, BC



**Thanks again to everyone involved in the entire campaign. We look forward to 2022 with a goal of selling 27,000 bulbs – we can do it!**

# Treasurer's Report

In the twelve months ending March 31, 2022, the country has gone through additional Covid waves and continued uncertainties that accompanied this time. HSC has weathered these storms with resilience and creativity. Overall, HSC remains in a strong financial position. Core revenues are increasing, expenses are being well managed, and our reserves are holding well.

During the fiscal year, donation revenue increased by 5% and chapter fundraising activity increased by a whopping 34% as we saw some returns to normal activities. Grant revenues fell by about 71% since we found that many foundations focused their resources on Covid-related needs. We believe that our overall grant strategy remains focused and relevant to our mission and that these revenues will rebound in 2023. We continued to receive government funding through the CEWS program in the amount of \$347,257 (reported under other income). This amount is down from the 2021 amount of \$651,237, but remains substantial nonetheless.

Expenses have remained in line with revenues and have demonstrated management's focus on managing these items in challenging times. The exception to this is our expenditures on the research portfolio which have been much lower than we would like. These investments in ongoing research have been declining, or low, for a number of years, for a variety of reasons – partially due to the challenge of attracting suitable research grant applications. HSC did an in-depth review of

research investments during 2022 and has identified a number of ways that our approach to research funding could be improved. We will be making announcements about this as the plans are finalized and as we go forward with our plans for a 50<sup>th</sup> Anniversary Campaign.

You will also note that our audit report this year is somewhat different from prior years. Earlier, our auditors have given a qualified report with respect to revenue completeness because of our receipt of cash donations. As the use of cash continues to decline in favour of credit cards or on-line payments, we have been able to eliminate the revenue qualification for the 2022 fiscal year. Since the qualification was still in place last year, it is still referenced in the Auditor's report. This is very common among not-for-profit organizations as many, if not most, have been able to transition away from the audit qualification as we have done.

Finally, congratulations to the management team for demonstrating strong financial controls and leadership again in 2021/22. As I step away from the Board this fall, I am honoured to have been able to work with such dedicated and committed individuals on the HSC staff and Board.



Anne Brace, Treasurer

# Statement of Financial Position

March 31, 2022, with comparative information for 2021

	General Fund	Capital Asset Fund	Endowment Fund	Ralph Walker Research Fund	2022 Total	2021 Total
<b>Assets</b>						
Current assets:						
Cash	\$ 1,049,091	\$ -	\$ -	\$ -	\$ 1,049,091	\$ 1,021,918
Investments	-	-	1,824,045	1,587,837	3,411,882	2,986,532
Accounts receivable	78,283	-	-	-	78,283	259,832
Interfund receivable (payable)	(198,701)	-	-	198,701	-	-
Prepaid expenses	84,959	-	-	-	84,959	77,529
	1,013,632	-	1,824,045	1,786,538	4,624,215	4,345,811
Capital assets	-	68,696	-	-	68,696	67,673
	\$ 1,013,632	\$ 68,696	\$ 1,824,045	\$ 1,786,538	\$ 4,692,911	\$ 4,413,484
<b>Liabilities and Fund Balances</b>						
Current liabilities:						
Accounts payable and accrued liabilities	\$ 82,734	\$ -	\$ -	\$ -	\$ 82,734	\$ 137,909
Deferred revenue	153,572	-	-	-	153,572	153,686
	236,306	-	-	-	236,306	291,595
Deferred lease inducement	10,377	-	-	-	10,377	14,037
	246,683	-	-	-	246,683	305,632
Fund balances:						
General Fund	766,949	-	-	-	766,949	560,275
Capital Assets Fund	-	68,696	-	-	68,696	67,673
Endowment Fund	-	-	1,824,045	-	1,824,045	1,929,091
Ralph Walker Research Fund	-	-	-	1,786,538	1,786,538	1,550,813
	766,949	68,696	1,824,045	1,786,538	4,446,228	4,107,852
Commitments						
	\$ 1,013,632	\$ 68,696	\$ 1,824,045	\$ 1,786,538	\$ 4,692,911	\$ 4,413,484

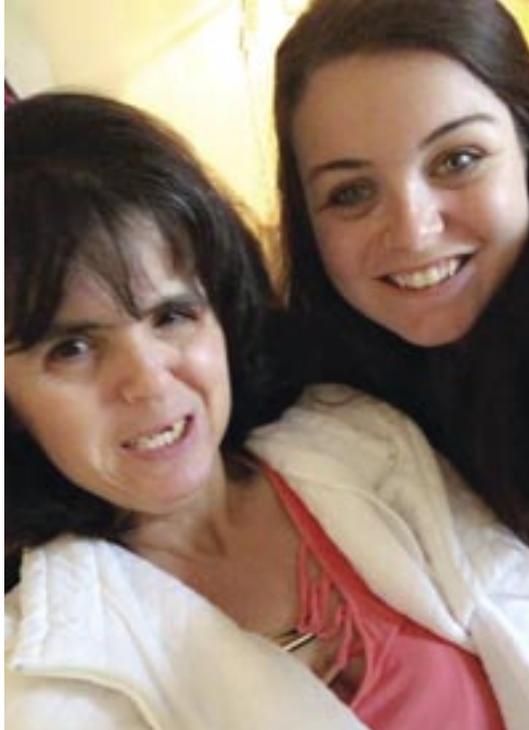
\*These statements are extracted from the audited financial statements for the year ended March 31, 2022. The full set of audited financial statements is available on our website.

# Statement of Financial Operations

March 31, 2022, with comparative information for 2021

	General Fund	Capital Assets Fund	Endowment Fund	Ralph Walker Research Fund	2022	2021
<b>Revenue:</b>						
Donations	\$ 1,348,407	\$ -	\$ 5,000	\$ 422,447	\$ 1,775,854	\$ 1,691,339
Chapter and volunteer fundraising revenue	992,656	-	-	6,840	999,496	743,321
Investment income	118,962	-	-	77,345	196,307	142,139
Grants	75,670	-	-	1,713	77,383	265,494
Change in fair value of investments	-	-	(120,046)	(78,050)	(198,096)	294,543
Other income	421,730	-	-	-	421,730	820,912
	2,957,425	-	(115,046)	430,295	3,272,674	3,957,748
<b>Expenses:</b>						
Research	36,154	-	-	194,570	230,724	580,243
Family services	1,221,017	-	-	-	1,221,017	1,187,710
Public awareness and education	249,163	-	-	-	249,163	235,914
Chapter and volunteer support	158,213	-	-	-	158,213	192,625
Development	301,547	-	-	-	301,547	301,186
Chapter and volunteer fundraising expenses	168,021	-	-	-	168,021	139,524
Administration	587,081	-	-	-	587,081	531,084
Capital assets fund expenses	-	18,532	-	-	18,532	16,885
	2,721,196	18,532	-	194,570	2,934,298	3,185,171
<b>Excess (deficiency) of revenue over expenses</b>	<b>\$ 236,229</b>	<b>\$ (18,532)</b>	<b>\$ (115,046)</b>	<b>\$ 235,725</b>	<b>\$ 338,376</b>	<b>\$ 772,577</b>

\*These statements are extracted from the audited financial statements for the year ended March 31, 2022. The full set of audited financial statements is available on our website.



# HD Facts and Figures

EACH CHILD OF A PARENT WITH HUNTINGTON DISEASE HAS A 50% CHANCE OF HAVING THE GENE MUTATION THAT LEADS TO THE PROGRESSION OF HD

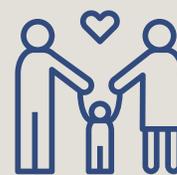
# 50%

**MALES AND FEMALES HAVE THE SAME RISK OF INHERITING THE DISEASE**  
HD OCCURS IN ALL PARTS OF THE WORLD



**SIGNS AND SYMPTOMS USUALLY APPEAR BETWEEN THE AGES OF**

# 35-55



EVERY PERSON LIVING WITH HD **WILL EXPERIENCE SYMPTOMS AND PROGRESS IN A DIFFERENT WAY**



**A DIAGNOSIS IN OLDER ADULTS, AFTER THE AGE OF 60, IS CONSIDERED LATE ONSET HD AND HAPPENS IN ABOUT**

# 10%

 OF TOTAL CASES

**WHEN HD IS DIAGNOSED IN YOUTH UNDER THE AGE OF 20, IT IS CONSIDERED JUVENILE HD OR JHD**  
JHD MAKES UP **ABOUT 10%** OF TOTAL CASES AND TENDS TO FOLLOW A MORE RAPID PROGRESSION







#### WEBSITE

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*Our 2021/22 Donor List is available on our website*