

Huntington Society of Canada 2023/2024 Annual Report

STORIES of **HOPE**



Governance



Executive

Mack Erno – Chair

Brynne Dalmao – Past Chair

Diane Tullson – Vice Chair

Bob Scriven – Secretary

Cindy Rainsford – Treasurer

Vision

A world free from
Huntington disease.



Mission

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

HSC Board Directors

Geneviève Bélanger
(Société Huntington du
Québec Representative)

Megan Burd
(YPAHD Representative)

Ron Muller

Andrew Wright

Heidi Bredenholler-Prasad

Lise Munsie

Dillon Sookbir

Malay Matalia

David Morin

Etienne Murgues

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Board Chair Note

Mack Erno

It's a pleasure to write this note once again as Chair of the Board of Directors for the Huntington Society of Canada (HSC) – this society is very near and dear to me.

I was so pleased that my time as Board Chair overlapped with part of our 50th anniversary year, 2023. What a wonderful milestone to celebrate together. You'll read more about the various important initiatives we launched as part of our golden anniversary, but I just wanted to highlight briefly how this is a special achievement that reflects what it is all about - a truly wonderful community of amazing folks.

In our world, community and family are practically interchangeable. I feel like our community members are family. And families look after each other. It's one of the best things about our Huntington disease (HD) community. Their caring spirit and kindness always inspire me and leave me in awe of the strength and resilience shown by those around me.

Another inspiration is HSC's National Conference. I am a huge fan of conference and was excited to see it return as an in-person offering in November 2023. Seeing the looks on people's faces when experiencing the magic of conference for the first time was one of my favourite aspects of the whole event.



Reconnecting, sharing, learning – that's what conference is all about. The 2023 offering, held in stunning Niagara Falls, with so much help from the amazing Niagara Chapter, was a huge hit and I know I left inspired to do more. It was extra special to celebrate 50 years of HSC with so many familiar and new faces for HSC – but the icing on the cake was being able to celebrate with one of our Society's founders, Ariel Walker and her family. What a legacy of 50 years!

The past year saw many successes and milestones for HSC and I am confident our next fiscal year will be just as impactful and caring. It is an honour to serve on the HSC board for all of our stakeholders - my chosen family for life, the HD community.

Hope to see you down the trail.

Mack Erno
HSC Board Chair

Letter from the CEO

Shelly Redman

I am excited to present our latest Annual Report, covering our Fiscal Year from April 1, 2023 to March 31, 2024. This publication is a chance to reflect on our journey over the past year and look forward to the future with renewed energy and determination.

We have made incredible progress together over the past year. From specialized support for those affected by Huntington disease (HD) to groundbreaking research, each achievement comes from the power of our community. Your dedication and generosity have made this possible, and I want to express my deepest gratitude for your ongoing support.

Within these pages, you'll find evidence of resilience, hope, and forward momentum. You'll read about the innovative research projects we've been able to fund, thanks to your generosity. You'll also hear how individuals and families have been touched by our specialized Family Services team, showing the importance of our mission and the impact we're making together.



But our work is far from over. As we celebrate our accomplishments, we also recognize the challenges ahead. That's why we're more committed than ever to accelerating our efforts, expanding our support services, and advocating for those affected by Huntington disease. Together, we can continue to make a difference and move closer to a future free from the challenges of this disease.

I want to take this opportunity to thank every one of you. Whether you've donated, volunteered, shared your story, or lent a listening ear, your contributions have made a difference in the lives of so many. It's because of you that we can face the future with hope and determination.

A handwritten signature in black ink, appearing to read 'S. Redman', on a yellow background.

Shelly Redman
CEO, Huntington Society of Canada

Family Services

Our Family Services team is the heart of HSC, responsible for delivering our mission to improve the quality of life for those living with Huntington disease. Here are the many ways the Family Service team Resource Centre Directors (RCDs) help to counsel the community, educate the public, and connect those in need with specialized services.

The Family Services Team in Action

2738
active files

f Closed Facebook group grew by another **5%**. We now have **413** members!

In-person services continue to grow:

2x the number of case consultations in long-term care facilities

RCDs attended 268 HD clinic appointments **(10% increase)**

30% increase in home visits **(total of 463 home visits)**

Ways to connect with HSC social workers:



RCDs continue to provide telephone support with **an increase of 22%** in phone meetings with community members



Emails are also a means to connect with HSC social workers. We saw an **8% increase** in the number of emails last year (4624 to 4996)



increase in self-referrals and clinic referrals to HSC services thanks to the new Add.Me link



Referrals to community services have **increased by 9.6%**

Support Groups



★ Virtual Carers Groups:

AB - Provincial group
 BC - Provincial groups
 BC - Vancouver
 MB - Provincial group
 ON - Kingston/Belleville drop ins
 ON - Provincial group for spouses/carers
 ON - Ottawa and Eastern ON

● In-Person Carers Groups:

BC - Victoria
 ON - Niagara Region

■ Virtual Mixed Group

NB/NL/NS - Atlantic Education series

▲ Virtual Group: People with HD

BC - Provincial
 BC - Victoria
 MB - Men with HD

National Virtual Groups:

At-Risk/Gene +: 4 groups
 Parents of people living with HD: 2 groups



We had a 30% increase in attendees to support groups last year



HSC offered **24 support groups** (both virtual and in person) and regional, provincial and national groups.

The groups connected carers, people with HD, people living at-risk or who are gene positive or parents of someone with HD.

The groups also included social offerings where folks could **connect for coffee and meet community members online.**

Fact Sheets

The Family Services team updated **3** fact sheets accessible on our website and via our Strength & Knowledge newsletter, delivered right to your inbox.

- Living At-Risk
- Exercise and HD
- Depression and HD

Want to sign up to receive a new fact sheet every three months?

Here's the link: www.huntington-society.ca/enewsletters/

The Youth and Young Adult Mentorship Program welcomed **8 new individuals last year. We now have **23 matches** across the country!**

Spotlight on Education

RCDs offered the following online sessions for carers in various areas across Canada:

HD and Cognition: Everything You Need to Know: New Brunswick/ Nova Scotia, PEI/ NL.

Important Things to Know About Life & Health Insurance: National.

Care for Today, Hope For Tomorrow: An Overview of the Genetic and Clinical Features of HD: New Brunswick/Nova Scotia, PEI/ NL.



2023 National Conference & YPAHD Day

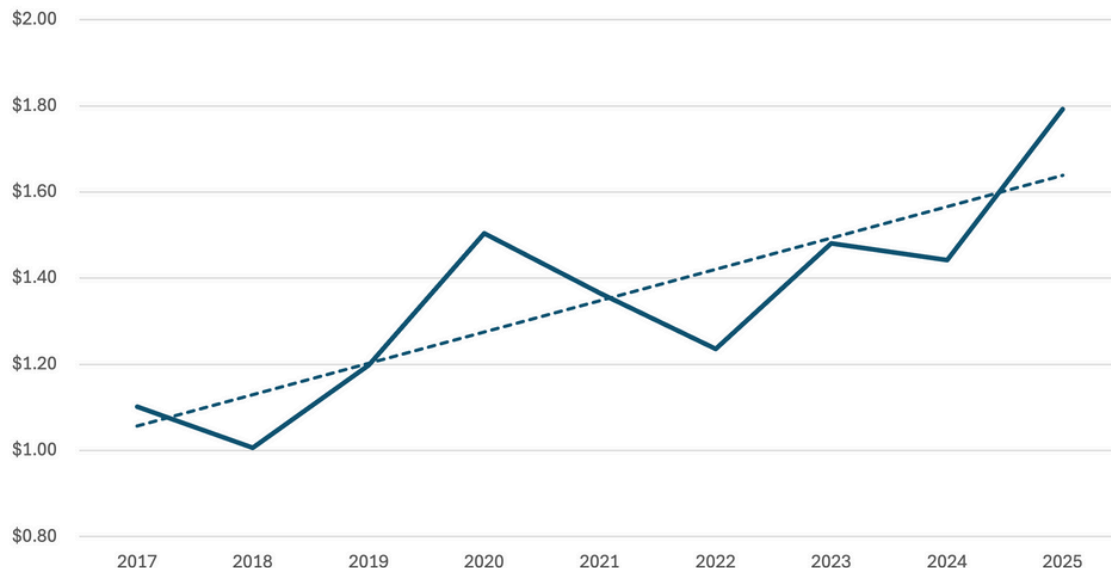
National Conference RCD educational sessions (provided by 6 RCDs):

- HD 101
- A World of Possibility: Exploring Programs Available to Youth in the Huntington disease Community
- Navigating Transitions to Care Homes

2023 YPAHD Day educational sessions offered by 4 RCDs:

- Self Care and Coping Strategies
- Navigating Relationships
- Improving Quality of Life Through Healthy Living and Exercise
- Grief in a Virtual World

Annual Family Services Program Budget (in \$C m)
(Incl. Staffing, Outreach, Education)



Since 2017, HSC has increased its annual budgeted commitment to Family Services programs by an average of 6.25%, from a base of \$1.1 million in fiscal 2016-17 to a planned expenditure of \$1.8 million in fiscal 2024-25. During the pandemic, annual budget allotments to Family Services programs reflected HSC's commitment to ensure staffing levels continued to meet increased need despite restrictions to in-person outreach and related travel. Post pandemic, annual resource commitments reflect a return to pre-pandemic levels of in-person outreach and related travel.

Quote Wall

Hear from the community about how the Family Services team benefits individuals and families:



"We share experiences that help to make me aware what to expect and how to cope..."



"The level of trust and security created by the RCD and members facilitated difficult personal discussions. The 'I've been there' and 'I got an idea' response from the group have helped to keep me living independently much longer than I never thought possible."



"I really enjoyed connecting with other people who have HD. It's really helpful to hear other people's experiences and tips about managing HD."



"It was a feeling of belonging with others who understand what is happening with open hearts."



"Our group allows us to be open and sincere with each other. I appreciate that we have that available to us!"



"Please continue offering these. As a family member I am very grateful."



"Enjoyed the camaraderie."



"The people that were in it sharing their stories make you feel not so alone in this journey."

Research and Strategic Partnerships

HSC is committed to supporting excellent, peer-reviewed research by investing in the most promising fundamental and clinical research opportunities in Canada. We will continue to build a strong foundation for HD research in Canada and partner with individuals and families affected by HD to find answers and support them on every step of their journey.

Funding HD Research

In the summer of 2023, thanks to your investment in HD research, HSC's Navigator Program funded two research grants, awarding \$150,000. We have funded Canadian scientific research with direct and immediate relevance to HD for over 20 years.

20 Years of HSC's Navigator Awards

32 Navigator awards given

19 Researchers funded

15 Institutions funded

Total amount funded:

\$4,393,205

Navigator projects funded this year



Cheryl Arrowsmith

HTT-RNA interaction dynamics as a target of therapeutic intervention

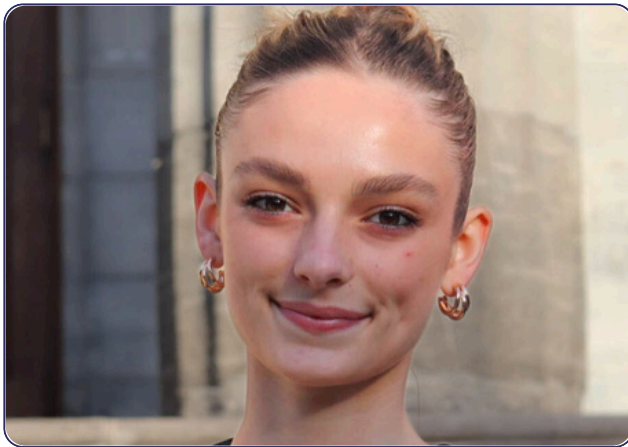


Michael Hayden & Chris Kay

Determining the role of somatic instability, RAN translation, and RNA toxicity as mechanistic drivers of CAG-CCG modifier variants in the HD Brain

Undergraduate Student Summer Fellowship

We believe that by engaging the next generation of scientists, we can make significant strides in understanding HD and developing new treatments. This past fiscal year we launched an undergraduate research program. This program provides students with the opportunity to conduct hands-on research under the guidance of experienced faculty members. By doing so, students gain valuable experience in scientific inquiry, critical thinking, and problem-solving, while contributing to our understanding of Huntington disease. In 2023, HSC selected four researchers to receive this fellowship, jumpstarting their research endeavors through the study of HD pathology with \$20,000 in funding.



Rylee McDonald, McGill University

How mutations in the HTT huntingtin gene alter the constituents of the huntingtin transport complex and contribute to HD



Etienne Sellar, University of Guelph

Modelling the human blood-brain barrier to understand the contributions of different cell types to barrier integrity



Justin Alvarado, McMaster University

The role of ATM kinase in HD and its therapeutic potential



Tess Leavitt, University of British Columbia

Assessment of CAG repeat instability in HD brain tissue with modifier variants

HD-COPE

HD-COPE is a globally recognized program co-founded and jointly operated by the Huntington Society of Canada (HSC) and the Huntington's Disease Society of America (HDSA). This collaborative effort unites HD patient advocacy organizations to give families affected by HD a direct voice in clinical research.

The purpose is to enhance the quality of all aspects of the clinical trials process through worldwide representative input from persons living at-risk, or with HD, their family members, care partners, and youth. Together, HSC and HDSA organize and facilitate these crucial conversations between industry partners and community volunteers, ensuring comprehensive and representative feedback from the HD community.

6 Years of HD-COPE

11 Countries represented by volunteers

24 Total industry engagements

Our Advocacy Efforts

Member of the Canadian Brain Research Strategy (CBRS). The CBRS is a pan-Canadian effort to develop a national research strategy for brain and mental health.

Active participant in the Best Medicines Coalition (BMC), a national alliance of patient organizations with a shared goal of equitable and consistent access for all Canadians to safe and effective medicines that improve patient outcomes.

Strategic managing partner of HD Coalition of Patient Engagement (HD-COPE), communicating the international HD community's experiences and needs to regulators, industry, and researchers.

HSC CEO is co-chair of the governing council of Neurological Health Charities Canada (NHCC), a coalition of organizations that represent people with neurological diseases, disorders and injuries in Canada.

Board Director of the Health Charities Coalition of Canada (HCCC), working alongside more than 20 major charities on advocacy efforts (Shelly Redman).



Chapter Development and Events

2023 National Conference and YPAHD Day

HSC was proud to host our first in-person conference since 2018 with more than 250 attendees. From Nov. 17 to 18, the community gathered in beautiful Niagara Falls, ON to connect, learn, and support one another. We also offered a virtual experience for those not able to attend.

Our keynote speakers for the HSC 2023 National Conference featured this stellar lineup:

- HD advocate Charles Sabine
- HD Researcher Dr. Ray Truant
- HD experts HDBuzz
- HD crusader Nora Guthrie

Each keynote address engaged, informed, and left everyone feeling hopeful and energized! There was even dancing and more than a few tears and laughs.

Popular breakout sessions included:

- Exploring your spirituality during illness
- Insights into the HD protein molecule
- Art-making as therapy
- From bench to bedside: How HD basic research feeds the clinical trial pipeline
- Navigating transitions to care homes



Smile File

Here's what our conference attendees had to say about their experience:



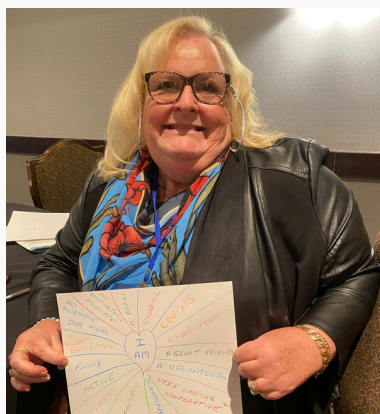
"I have attended 4 conferences - this conference was by far the best in every instance."



"My husband, who is HD positive, came back changed by this conference - mainly because of Charles Sabine, but really because of the whole conference. He met with folk who are more symptomatic than him, he had a one-on-one with Charles Sabine at the pub, and he was inspired by all of it. He now is telling his friends more about HD."



"As always, I come away feeling hope. I always feel 'refreshed' from seeing all the people that I know from all over who are in the same boat as me. We cope together."



"Made me feel good about the contribution that I do make to the HD community. Inspired me to continue with that work (chapter executive, amaryllis sales, public speaking with HealthPartners to raise awareness)."



YPAHD Day

We had 78 youth attending YPAHD (Young People Affected by Huntington disease) Day on Thursday, November 16, reaching more of our younger demographic than ever.

Some of the sessions offered included:

- Navigating relationships
- Improving quality of life with healthy living and exercising
- Grieving in a virtual world
- Journaling for self care

YPAHD Speaks About Their Favourite Part of YPAHD Day



“Re-connecting with old friends & connecting with new people. It is very important to have these friendships in our community. To have a network to lean on when you need them, and to be able to support them in return in their time of need, is something that is truly special in our unique community.”



“I loved to see lots of new faces and first-time YPAHDers. It was a great day full of information and building connections with others in the community.”

2023 Conference Award Winners

Ariel and Ralph Walker Founders' Award

Recipient: Jim Pollard

Brighter Futures Award

Recipient: Shaunacy De Jong

Milestone Communications Award

Recipient: Vancouver Island and Gulf Islands Chapter of BC (VIGI)

Dean Crain Memorial Award

Recipient: Bunny Clark, Celine Payne

Milestone Fundraising Award

Recipient: Southern Alberta Chapter

Chair's Award

Recipient: James Walters

Michael Wright Community Leadership Award

Recipient: Clare Gibbons

Maike Zinabou Award

Recipient: Abigael Delos Santos
(first time being presented)

National Award of Merit

Corporate Recipient: Shaw Communications
Volunteer Recipient: Keely McCoy

Dorothea Smith & Stan Edwards Award

Recipient: Sharon Haig, Stephen Hurst

HSC Chapter and Active Area Highlights

The HSC chapters are the heartbeat of the organization and the community. Their commitment to connecting those affected by HD and providing social, educational, and fundraising efforts is inspirational. These hardworking volunteers give their knowledge, time, passion, and energy, and we want to highlight these unsung heroes.

Here are just a few milestones from the past fiscal year:

PEI Chapter

The **PEI Chapter** raised just under \$8,000 via their 2023 walk. Throughout May, approximately 60 community members in four walking groups walked 7059.56 km – fabulous teamwork!

Sarnia Active Area

The **Sarnia Active Area** became a chapter in **September**! This energetic group has already launched several community- and capacity-building initiatives.

Newfoundland Active Area

The **Newfoundland Active Area** roared back into **action this year** with a re-energized executive posting to social media, holding a wonderful walk and online auction, and organizing a fundraising bake sale at Memorial University.

New Brunswick Chapter

Our **New Brunswick Chapter** worked closely with the NB RCD to deliver meetings and events that bring the community together.





Niagara Chapter

The **Niagara Chapter** celebrated their hard work at **a fabulous conference** – all of the great feedback is a testament to how hard this amazing team worked.

Camrose Chapter

The **Camrose Chapter** brought back their **fabulous golf tournament** and reminded everyone why it's a must-attend event.

Southern Alberta Chapter

The **Southern Alberta Chapter** raised over **\$78,000** via their casino volunteering – fabulous work!

Vancouver Island and Gulf Islands Chapter

The **Vancouver Island and Gulf Islands Chapter** made the papers with their fundraising and awareness efforts.

Young People Affected by Huntington disease

YPAHD (Young People Affected by Huntington disease) elected a new executive in November and the team is hard at work hosting more Facebook Live Chats and engaging youth.

To every person involved in a chapter or active area, you are making such a difference in the lives of people affected by Huntington disease. The days are long, the weeks are busy, but as every year ticks over we see the leaps you have taken forward. The funds raised, connections made, and social networks opened will never be forgotten.



OUR VOLUNTEERS MAKE A WORLD OF DIFFERENCE

As we reflect on the past year's accomplishments, we want to highlight the incredible dedication of our volunteers.

Your commitment to organizing these events has been the key to our ongoing progress and offerings.

With your passion and warmth, you've brought communities together, encouraged generosity, and made a tangible difference in countless lives. From the bottom of our hearts, we extend a heartfelt thank you for your invaluable contributions.



Fundraising Events

Over the past fiscal year, HSC's fundraising events surged into full swing. With over 80 events this past fiscal, HSC's events are beginning to bounce back to their pre-covid numbers. From walks to galas, community events raised critical funds (\$1,173,783), supporting family services and research efforts. This revenue represents 23.8% of HSC's total revenue this fiscal.

New events for 2023-24 included:

Winnipeg World Police/ Fire Games
July 28 to August 6, 2023

Winnipeg Darts Tournament
August 12, 2023

Targa Newfoundland Tarmac Rally
September 14 to 21, 2023

Toronto Golf Tournament
September 30, 2023

Peterborough Curling for HD
March 2, 2024

Sarnia Music Bingo
March 17, 2024

Lab tour at the University of Toronto
with Dr. Rachel Harding
March 30, 2024

2023 Huntington Heroes National Walk

The Huntington Heroes National Walk rallied communities across Canada once again for a common cause: supporting those affected by Huntington disease.

Beyond the funds, the walk fostered a sense of solidarity and hope, reminding us of our collective capacity to make a difference. To all who participated, volunteered, sponsored, and supported, your dedication is deeply appreciated. Let's continue walking together, united in our mission to create a brighter future for everyone affected by Huntington disease.

Light it Up 4 HD 2023

#LightItUp4HD was a huge success in 2023! For the first time, we illuminated more than 100 Canadian sites during the campaign. More than 400 #lightitup lawn signs were distributed around the country, increasing awareness about HD and Juvenile HD.

Many others printed out our template to place in windows to further share our message of shining a light on Huntington disease and Juvenile Huntington disease.

549 participants registered



With matching, over

**\$400,000
RAISED**



increase in participants
from last year

Development

50th Anniversary Wrap-up

The Route 50: Driving Hope Forward anniversary campaign celebrated HSC's incredible accomplishments over the past 50 years while bringing a renewed vision to HSC's mission of research and care. We are so grateful to the community for renewing their commitment to HSC and the future of HD support in Canada by helping achieve our funding goals.



50th Campaign At-a-Glance

\$3 million funding
goal reached



Funded HSC
Research Chair at
Western University

Garden of Memories
Memorial segment reaching

125% of set goal



62 new monthly donors

through the 50 for 50
campaign achieving

124% of target



Engaged
community
and donors

Garden of Memories Memorial Campaign

To celebrate 50 years and pay tribute to those who have gone before us, in June 2023 HSC established a new memorial giving program, providing an opportunity for community members to pay tribute to their loved ones.

Inspired by co-founder Ariel Walker's tribute to the late Ralph Walker, HSC designed the campaign around the image of Ariel in the Garden of Memories with the option of having honoured loved one's names appear in the garden. The Garden of Memories became a beautiful and thoughtful tribute to loved ones who have passed. The donations gathered make it possible to support current families living with HD.

To everyone who donated in memory of a loved one, thank you. We hope you see your love and commitment reflected in this memorial campaign and can gain some solace knowing that your gifts make a difference in the future of individuals and families facing HD.

50 for 50 Monthly Donor Campaign

Monthly donations are the backbone of HSC's giving program and allow us to plan to offer ongoing support. In honour of HSC's 50th anniversary we set the goal of 50 new monthly donors via the 50 for 50 monthly giving program.

The campaign brought in 62 new monthly donors, exceeding the set goal by 124%. These monthly donations, which ranged from \$10/month to hundreds of dollars monthly, make it possible for HSC to fund continuous support and research.

A big thank you to our 62 new monthly donors! We hope you know how important monthly donations are – they enable us to plan future programs, secure in the knowledge that there is funding to meet current and future needs.



HSC Research Chair at Western University

The HSC Research Chair held at Western University started as a vision to make a difference in the future of HD research in Canada by funding an Endowed Chair at Western University's Schulich School of Medicine and Dentistry. This new opportunity solidified HSC's commitment to research and was a major segment within the 50th Anniversary campaign. Western University matched donations up to 1.5 million dollars and HSC launched their giving with an investment from the Ralph Walker Fund, and then began the campaign to fundraise for the remaining amount.

This segment allowed HSC to build new relationships with researchers and staff at Western University and provided research-oriented major donors the opportunity to make a tangible difference. The \$3-million chair position was fully funded in April 2023, thanks in large part to a handful of HSC major donors who made generous commitments.

Thank you to our donors for accelerating the landscape of HD research in Canada.

HD Centres for Clinical and Research Excellence (CARE)

HSC's vision is to bridge the gap between people affected by HD and specialized care through internally accredited clinical hubs called the Centres for HD Clinical and Research Excellence (CARE). Our number one goal is equal care for all Canadians.

These centres will expand access to HD-experienced clinical care, counselling, and other community and health services with a multidisciplinary health team. Family planning information, counselling, involvement in clinical trials and carer resources will be offered.

The Centres for HD CARE will better position Canadian sites to act as hubs for clinical trials, expanding access to Canadians. The proposed model is the first of its kind in Canada and includes an in-depth community assessment. This will identify gaps and help us better understand the needs of minority or hard-to-reach populations, as well as to inform the next steps in development.

We are working very hard to launch this program and look forward to future updates.





GRANT AND FOUNDATION SUPPORT

Ontario
Trillium Foundation



Fondation Trillium
de l'Ontario

An agency of the Government of Ontario
Un organisme du gouvernement de l'Ontario

AQUEDUCT
FOUNDATION

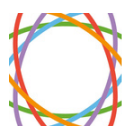
Disclaimer: A grant project
was funded by the Government
of Canada's Community
Services Recovery Fund.

THE
WINNIPEG
FOUNDATION 
For Good. Forever.



Foundation

SickKids®
FOUNDATION



ONTARIO
BRAIN
INSTITUTE

INSTITUT
ONTARIEN
DU CERVEAU

HSC is proud to be
a member charity
of HealthPartners

 HealthPartners
PartenaireSanté

\$321,485.40
IN GRANTS

THE WINDSOR FOUNDATION

The Charles Johnson
Charitable Fund

Amaryllis Campaign

The annual HSC Amaryllis campaign raises funds to support our Family Services team and their programming, as well as critical HD research. This fundraising initiative supports our community and inspires hope, year after year.

22,452
bulbs sold

♥ **\$10,167**
in donations

Revenue:

\$286,000

over **\$6 million** raised since the start of the Amaryllis campaign



Photo Festival:
58 submissions

Top Sellers:

137
cases

Heather Dodds
Southern Alberta Chapter

100
cases

Valerie Nabb
Ottawa Chapter

69
cases

Corrine Bees
British Columbia Chapter

62
cases

Larry Campbell
Camrose Chapter



Quotes About This Inspirational Campaign



MARY STOCKS, NOVA SCOTIA

"For quite a few years now I have been buying your wonderful Amaryllis bulbs and giving them away as Christmas gifts. The Huntington Society is something I dearly support and always will."



ANNE SZEPLABI

"I wasn't sure what to expect when I received my first Amaryllis plant for Christmas. I am amazed that it bloomed so quickly."



KARINA L., BRITISH COLUMBIA

"After my father's death a couple of years ago with HD, a trip from BC to Nova Scotia with my mom coincided with the HD Amaryllis campaign, and we purchased and shared a few bulbs with our East Coast family.

This year, the HOPE was spread coast to coast, as Mom ordered a box and shipped these bulbs to family and friends across the country.

WOW!! Planting and observing their development brought joy to all, while sharing photos, stories, and laughs together throughout the weeks was PRICELESS. We will be participating again next year, expanding the group and spreading more HOPE and awareness of HD."



MAUREEN OLSON

"My niece gifts us with an amaryllis every Christmas. She has Huntington disease in her family. We are happy to support her in this campaign and also in the annual Huntington disease walk."

We'd like to thank everyone who supported the 2023 Amaryllis Campaign. The efforts of everyone in our community made this year's campaign a success.

HSC Social Media: Raising Awareness, Reaching People

On social media, we share great chapter and volunteer success stories, research updates, educational offerings, and helpful tips. All that goes towards raising awareness, fundraising, and educating about Huntington disease. But which topics and photos really caught the eye? Here are the top 10 posts for the fiscal year for Facebook and Instagram. If you don't already follow our feeds, join the conversation today and stay up-to-date with HSC and HD.



1

Top 10 Facebook Posts

1. Holidays and HD in Virgin River

Our community loved reading about the holiday episodes of Virgin River, Netflix's hit show featuring Denny, a young man facing HD (played with compassion and grace by Canadian actor Kai Bradbury).

2. Amaryllis Alert - They're Here!

It was the post that floral enthusiasts had been waiting for – the launch of the Amaryllis Campaign, aka the star holiday offering from HSC.

3. Garden of Memories - Celine Payne

This emotional post featured Celine Payne (President of YPAHD and the Sarnia Chapter) remembering her mother, who passed due to complications from Huntington disease. This quote was particularly impactful: "We didn't go a day without knowing how much she loved us."



3



4



6

4. YPAHD Day Wrap-Up - Group Photo

People loved seeing the group photo from 2023 YPAHD Day in Niagara Falls. Our youth were buzzing with inspiration, motivation, and the wonderful feeling of being connected.

5. Day Before 2023 National Conference

The photo of the HSC Team and Niagara Chapter prepping for an unforgettable weekend at HSC's 2023 National Conference in breathtaking Niagara Falls drew a lot of attention as people were excited for conference!

6. Huntington Disease Adventure Documentary

People were excited to learn about the adventure documentary detailing HD advocate Dimitri Poffé's story "The Present", showing at the Vancouver International Mountain Film Festival (VIMFF).



7

7. Nora Guthrie at the 2023 National Conference

There's no question – Nora Guthrie was the star of 2023 Conference and the reaction to the post outlining her session supported those sentiments. Her program followed Woody Guthrie's journey with HD and his wife Marjorie's relentless efforts.

8. Sarnia Receives Chapter Status

The community showed lots of love to Sarnia for receiving official chapter status on Sept. 17 at a social and educational event. We are so happy for their chapter status and appreciative of their hard work.



8

9. Team Virgin River

People loved the idea of walking on Team Virgin River to raise funds and awareness for people affected by Huntington disease.

10. One Day to YPAHD Day Launch

Excitement was buzzing on YPAHD Day eve. Our youth (aged 14-35) were getting ready for a day full of learning, connecting, and sharing with workshops, discussions, and limitless possibilities!

Top 10 Instagram Posts

1. Who Gets HD - Animated Video

Viewers were delighted to see another installment of our popular animated educational video series. This video focuses on explaining the genetic connection to the disease as well as the different types of Huntington disease.

2. Rare Disease Day - Rare to Care

This message resonated with our community: Today, on Rare Disease Day, we're united in putting the CARE in RARE diseases like Huntington disease, spreading hope, awareness and support across Canada.

3. HSC Research Chair - Video

With the HSC Research Chair at Western University, the community was thrilled to learn, via a video, how we're securing funding for generations to come and attracting brilliant minds to unravel the mystery of a meaningful treatment for HD.

4. What Causes HD - Animated Video

Another animated video featured in the top 10. This one explains the role of mutant huntingtin protein in HD.

5. Amaryllis Campaign - Video

The video of a blooming amaryllis reminded everyone that this successful fundraiser inspires hope from coast to coast.

6. YPAHD Day - Wrap-up Video

Hope and inspiration for our YPAHD Day attendees shone through in this video recapping all the great education and connection opportunities.

7. Virgin River - New Season

Readers loved watching the new season of Virgin River and appreciated the sensitive portrayal of Huntington disease in Denny, one of the show's main characters.

8. Conference Day 1 - Wrap-up Video

This video capturing some of the highlights of the first day of 2023 Conference, full of reunions, learnings and support, was a big hit with our Instagram crowd.

9. Why Conference is Great - John Stainsby Video

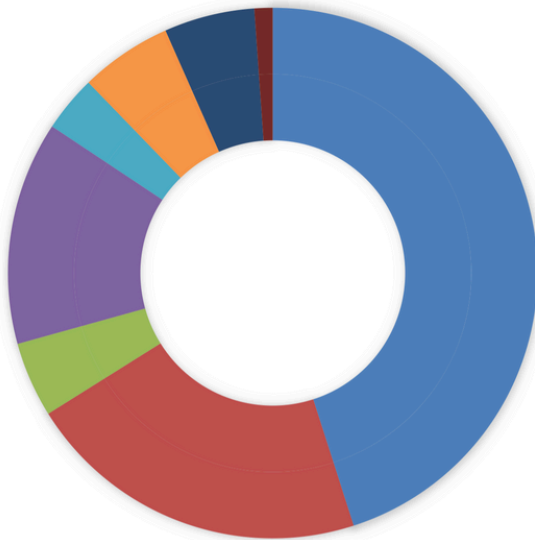
People loved hearing John Stainsby, President of the HSC Niagara Chapter, explain why conference is a great opportunity for the Huntington disease community - and why Niagara Falls is the perfect host location!

10. YPAHD Day 2023 - Resilience Video

Our thanks to talented YPAHD exec member Megan Robertson for making this beautiful video highlighting the resilience of our youthful community members.



SOURCE OF FUNDS 2023-24



- Donations 45.1%
- Bequests & Memorial Giving 21.0%
- Grants 4.6%
- Fundraising - Chapter & Events 13.6%
- Fundraising - Charity Gaming 3.4%
- Fundraising - Amaryllis Revenue 5.6%
- Investment Income 5.5%
- Other Income 1.1%

USE OF FUNDS 2023-24



- Family Services 36.9%
- Development 14.3%
- Public Awareness and Education 14.2%
- Volunteer Support 10.6%
- Administration 11.4%
- Research 7.4%
- Fundraising Expenses 5.2%

Our 2023/24 Donor List is available on our website: www.huntingtonsociety.ca/donor-recognition/

Statement of Financial Position

March 31, 2024, with comparative information for 2023

	General Fund	Capital Asset Fund	Endowment Fund	Ralph Walker Research Fund	2024 Total	2023 Total
Assets						
Current assets:						
Cash (note 2)	\$ 572,499	\$ -	\$ -	\$ -	\$ 572,499	\$ 584,986
Investments (note 3)	-	-	1,841,573	593,391	2,434,964	3,492,867
Accounts receivable (note 4)	230,775	-	-	-	230,775	165,611
Interfund receivable (payable)	188,077	-	-	(188,077)	-	-
Prepaid expenses	94,267	-	-	-	94,267	143,143
	1,085,618	-	1,841,573	405,314	3,332,505	4,386,607
Capital assets (note 5)	-	163,308	-	-	163,308	55,593
	\$ 1,085,618	\$ 163,308	\$ 1,841,573	\$ 405,314	\$ 3,495,813	\$ 4,442,200
Liabilities and Fund Balances						
Current liabilities:						
Accounts payable and accrued liabilities (note 6)	\$ 104,802	\$ -	\$ -	\$ -	\$ 104,802	\$ 299,887
Deferred revenue (note 7)	165,839	-	-	-	165,839	198,802
	270,641	-	-	-	270,641	498,689
Deferred lease inducement	3,054	-	-	-	3,054	6,715
	273,695	-	-	-	273,695	505,404
Fund balances:						
General Fund	811,923	-	-	-	811,923	367,244
Capital Assets Fund	-	163,308	-	-	163,308	55,593
Endowment Fund	-	-	1,841,573	-	1,841,573	1,790,204
Ralph Walker Research Fund	-	-	-	405,314	405,314	1,723,755
	811,923	163,308	1,841,573	405,314	3,222,118	3,936,796
Commitments and subsequent event (note 12)						
	\$ 1,085,618	\$ 163,308	\$ 1,841,573	\$ 405,314	\$ 3,495,813	\$ 4,442,200

*These statements are extracted from the audited financial statements for the year ended March 31, 2024. The full set of audited financial statements is available on our website.

Statement of Operations

Year ended March 31, 2024, with comparative information for 2023

	General Fund	Capital Assets Fund	Endowment Fund	Ralph Walker Research Fund	2024	2023
Revenue:						
Donations	\$ 3,080,272	\$ -	\$ -	\$ 342,547	\$ 3,422,819	\$ 2,023,613
Chapter and volunteer fundraising revenue (note 8)	1,170,601	-	-	3,132	1,173,733	1,063,173
Grants	96,178	139,999	-	1,732	237,909	53,770
Investment income	95,223	-	-	90,566	185,789	140,734
Change in fair value of investments	-	-	51,369	48,856	100,225	(67,510)
Other income	57,650	-	-	-	57,650	38,149
	4,499,924	139,999	51,369	486,833	5,178,125	3,251,929
Expenses:						
Family services (note 9)	1,621,879	-	-	-	1,621,879	1,503,178
Development (note 9)	627,105	-	-	-	627,105	414,300
Public awareness and education (note 9)	624,496	-	-	-	624,496	281,737
Chapter and volunteer support (note 9)	464,501	-	-	-	464,501	377,964
Administration (note 9)	454,147	-	-	-	454,147	576,468
Research (notes 9 and 10)	20,000	-	-	305,274	325,274	382,702
Chapter and volunteer fundraising expenses (note 8)	230,193	-	-	-	230,193	204,123
Amortization	-	45,208	-	-	45,208	20,889
	4,042,321	45,208	-	305,274	4,392,803	3,761,361
Excess (deficiency) of revenue over expenses before funding of Huntington Society of Canada Research Chair	457,603	94,791	51,369	181,559	785,322	(509,432)
Funding of Huntington Society of Canada Research Chair (note 10)	-	-	-	1,500,000	1,500,000	-
Excess (deficiency) of revenue over expenses	\$ 457,603	\$ 94,791	\$ 51,369	\$ (1,318,441)	\$ (714,678)	\$ (509,432)

*These statements are extracted from the audited financial statements for the year ended March 31, 2024. The full set of audited financial statements is available on our website.

Treasurer's Letter

I am pleased to present this report to the membership and stakeholders of the Huntington Society of Canada (HSC) for the fiscal year ended March 31, 2024.

For the twelve months ended March 31, 2024, HSC recorded a \$785,322 operating surplus (before the one-time impact of the funding of the Huntington Society of Canada Research Chair (\$1.5 million). The organization had strong fiscal results in 2023/24 and the Board is focused on ensuring that the organization stays financially strong.

HSC revenue for this fiscal year is \$1,926,196 higher than the previous fiscal year. Donations increased \$1,399,206 due to the successful 50th anniversary and other fundraising campaigns. Chapter and volunteer fundraising increased \$110,560 mainly due to successful sporting events. Grant revenue increased \$184,139 due primarily to the receipt of a capital grant to update HSC's IT infrastructure. Other revenue categories increased \$232,241 reflecting higher investment income, improved valuation of invested assets, and conference sponsorships.

Expenses were \$631,442 higher than fiscal 2022/23. Our spending is tied to strategic initiatives and we saw increased expenditures in public awareness and education, as well as community and family support.



Our National Conference was held in November 2023, which contributed \$233,169 in additional expenditures to this fiscal year. Family Services expenses increased \$118,701 from the previous fiscal due mainly due to the return of in-person meetings and pre-pandemic client visits and travel. Chapter and volunteer support expenditures increased \$86,537 due to severance costs and increased travel. Public awareness and education expenditures increased \$342,759 over previous fiscal due to the National Conference and increased activity in support of the 50th anniversary. Development expenditures increased \$212,805 due to the 50th Anniversary Gala and increased activity in support of the 50th anniversary fundraising campaign.

Administration expenses were \$122,321 lower than previous fiscal mainly due to lower contractor expense. Research expenditures were \$57,428 lower due to reduced major award activity.

We had a clean audit report this year and continue to work with KPMG to streamline audit processes and ensure segregation of duties and appropriate internal controls.



As mentioned above, the one-time impact to operating surplus of the funding of the Huntington Society of Canada Research Chair is seen in the current year statements. We are excited to see the future impact on HD research of these funds raised in the Ralph Walker Fund, which established a perpetual endowed fund at the University of Western Ontario. Terms of the fund are outlined in the footnotes to the operating statements in this annual report.

Many thanks to HSC's Chief Financial Officer, Doug Woodburn, and the Finance staff as we continue to see improvement in reporting and communication.

Congratulations to the HSC staff team on a successful year. I look forward to continuing to work with the dedicated volunteers, management team, and dynamic Board. Thank you to our donors, chapter members, and stakeholders for your ongoing support! We are looking forward to another strong year in 2024.

Cindy L Rainsford, CPA, CMA
HSC Board Treasurer



CONTACT

1-800-998-7398
info@huntingtonsociety.ca

WEBSITE

Huntington Society of Canada
www.huntingtonsociety.ca

LOCATION

20 Erb St. W - Suite 801
Waterloo, ON N2L 1T2

Charitable Registration Number: 11896 5516 RR0001