

ANNUAL REPORT

2024 → 2025



A YEAR OF PROGRESS & CONNECTION

CONTENTS

Welcome _____ 02

Research _____ 05

Family Services _____ 08

Community _____ 12

Development _____ 17

Measurement _____ 19



FROM YOUR CEO

BY SHELLY REDMAN

As I reflect on the past year, from April 1, 2024 to March 31, 2025, I'm filled with a deep sense of gratitude and pride in the Huntington Society of Canada community. This has been a year marked by meaningful progress, powerful connections, and unwavering hope.

One of this year's shining successes was our Amaryllis Campaign. Across the country, thousands of beautiful blooms brightened homes, offices, and community spaces, each one a symbol of hope and resilience. Thanks to your support, this campaign helped fund critical services for families and supported cutting-edge research.

Our National Huntington Heroes Walk also reached new heights this year, with inspirational participation and heartfelt stories from coast to coast. Across the country, people laced up their shoes and stepped up in honour of loved ones. Together, we raised essential funds to support research, advocacy, and family services, all while building a stronger sense of community.

On the research front, we continued to support groundbreaking Canadian studies. Thanks to your generosity, we're helping scientists get closer to treatments that could slow the progression of HD.

Personally, what has touched me most this year are the quiet moments—the emails from caregivers, the conversations with new families, the determination I see in every fundraiser, volunteer, and advocate. You remind me daily why this work matters.

As we look ahead, I am hopeful. With each dollar raised, each story shared, and each hand extended in support, we move one step closer to a future free of Huntington disease.

From the bottom of my heart, thank you for being part of this journey.

With heartfelt appreciation,



Shelly Redman
CEO, Huntington Society of Canada



FROM YOUR BOARD CHAIR

BY DIANE TULLSON

It's an honour to report on the year's highlights as Chair of the Board of Directors for the Huntington Society of Canada (HSC).

In November 2024, Western University biochemistry professor Patrick O'Donoghue was named the inaugural endowed Huntington Society of Canada Research Chair – the first of its kind in North America. Patrick is investigating the potential of transfer ribonucleic acid (tRNA) to accelerate life-changing treatments for Huntington disease (HD). Plus, since his appointment, Patrick has secured \$1.1 million in new funding to further and inspire HD research.

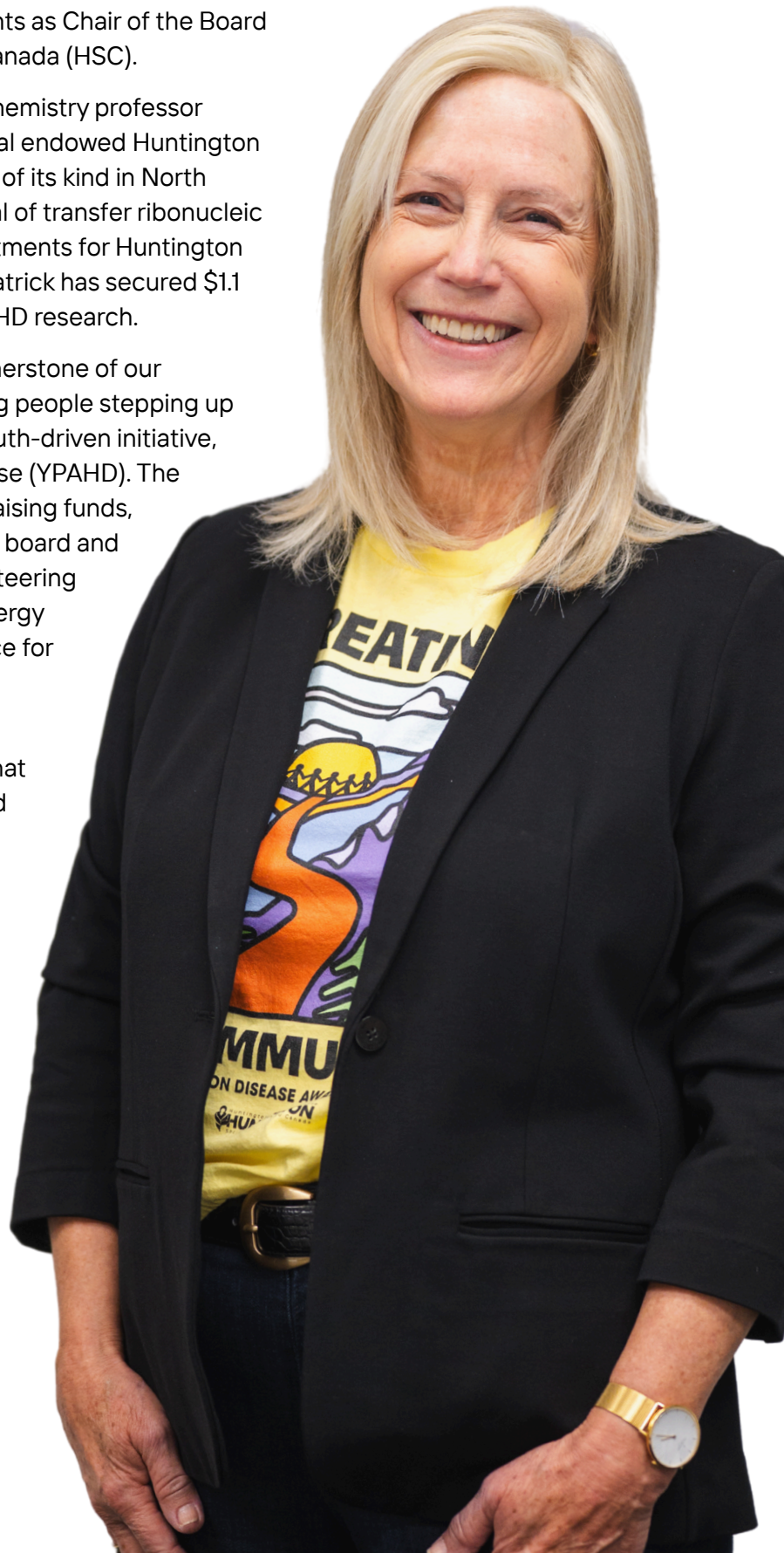
The HD community continues to be the cornerstone of our organization, and I'm heartened to see young people stepping up more than ever, notably in their own HSC youth-driven initiative, Young People Affected by Huntington Disease (YPAHD). The youth of our community are powerhouses: raising funds, mentoring HD youth, serving on the national board and chapters, advocating for patients, and volunteering in HD research studies. With their unique energy and perspective, YPAHD is a compelling voice for HD awareness here in Canada and globally. Watch one of their videos and be moved.

To our entire community - thank you for all that you do to lighten the lives of people affected by Huntington disease: in labs and clinics, support groups, care homes and your own homes; at head office, board meetings and chapter meetings; in garages stacked with amaryllis; and with your donations and compassion. I am so glad to be with you in this remarkable collaboration, and I look forward to our work in the coming year.

Warmly,



Diane Tullson
Board Chair, Huntington Society of Canada



2024-2025 HSC BOARD OF DIRECTORS

EXECUTIVE

Diane Tullson – Chair

Mack Erno – Past Chair

Lise Munsie – Vice Chair

Cindy Rainsford – Treasurer

Bob Scriven – Secretary

HSC BOARD DIRECTORS

Geneviève Bélanger

Heidi Bredenholler-Prasad

Megan Burd (YPAHD Representative)

Katrina Helal

Malay Matalia

David Morin

Ron Muller

Etienne Murgues

Dillon Sookbir

Gilles Tossing (HSQ Representative)

MISSION

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

VISION

A world free from Huntington disease.

VALUES

**Compassion; Integrity; Accountability;
Inclusiveness; Collaboration;
Leadership; Empowerment.**



RESEARCH

SPOTLIGHT: Huntington Society of Canada Research Chair at the Schulich School of Medicine & Dentistry, Western University



In November 2024, Patrick O'Donoghue, PhD, was appointed the inaugural Huntington Society of Canada Research Chair at the Schulich School of Medicine & Dentistry, Western University.

Goal of the HSC Research Chair

- To progress patient care outcomes and accelerate life-changing treatments
- To advance neurodegenerative research by focusing on innovative approaches to prevent, identify, and treat Huntington disease

Meet Dr. O'Donoghue:

2013: Patrick joined the Departments of Chemistry and Biochemistry at Western University, where he is currently a tenured Associate Professor.

2014 to 2024: Tier 2 Canada Research Chair in Chemical Biology

The O'Donoghue Lab

- Research in Patrick's lab focuses on genetic code evolution and engineering with applications in synthetic biology and medicine
- The Huntington Society of Canada Research Chair provides the unique opportunity to leverage Patrick's current research program to identify novel nucleic acid-based therapeutics for Huntington disease

This guaranteed and continued commitment to Huntington disease research is a landmark moment in Huntington disease research, in Canada and globally. Thank you to everyone who supported the campaign.





Navigator

After receiving 15 applications from 11 academic institutions across the country, HSC awarded the 2024 Navigator Research Award to:

- **Dr. Shaun Sanders**
(University of Guelph – lead investigator)
- **Dr. Melanie Alpaugh**
(University of Guelph – co-investigator)
- **Dr. Dale Martin**
(University of Waterloo – co-investigator)

Their research looks at stopping DLK, which may cause death signals in HD. This focus has shown promise in other neurodegenerative diseases. HSC and our supporters are thrilled to be able to fund the Navigator Research Award, enabling the study of this approach for Huntington disease.

HD-COPE

HD-COPE (Huntington's Disease Coalition for Patient Engagement) is a global coalition of HD family members providing direct input to researchers and drug developers to ensure the patient voice is central in HD research.

2024–2025 Highlights:

- 3** industry consultations conducted with HD-COPE input
- 2** Canadian regulatory advisory meetings attended
- 6** Canadian representatives actively engaged



1



2



3



4



5



6



7

Studentships

2024 marked the second year of the HSC Student Fellowships. Thanks to support from the Canada Brain Research Fund (CBRF), an innovative arrangement between the Government of Canada (through Health Canada) and Brain Canada Foundation, and the Huntington Society of Canada, 7 summer students focused on projects with the potential to reverse, stop, or slow the progression of Huntington disease (HD):

1. **Anthony Dang**, University of Waterloo (Ontario)
2. **Isabel Gibson**, McMaster University (Ontario)
3. **Gabriel Gonzales Vargas**, University of Guelph (Ontario)
4. **Christiana Kennedy**, Memorial University (Newfoundland and Labrador)
5. **Jenni Nguyen**, University of British Columbia
6. **Mikaela Perron**, University of Manitoba
7. **Ashleen Phandar**, University of British Columbia

Welcoming and supporting young researchers to the field of Huntington disease encourages continued interest and focus in the disease area, making the future bright!

Fellowships

Neurology Fellowship

Helps ensure each Canadian with HD receives appropriate medical expertise and treatment.

2024 Neurology Fellowship recipient: **Dr. Falen Fernandes**.



Multidisciplinary Fellowship

Expands multidisciplinary care across the country.

2025 Multidisciplinary Fellowship (Neuropsychiatry) recipient: **Dr. Caroline Dance**.



FAMILY SERVICES

Client Service

2479 client files

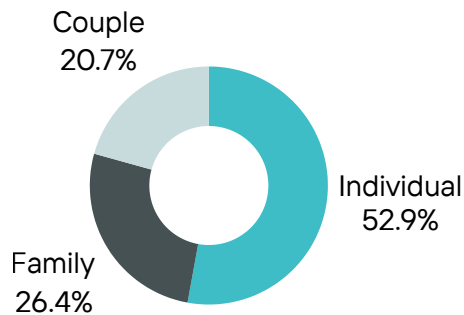
served by Resource Centre Directors (RCDs)

378 new clients

in 2024/25

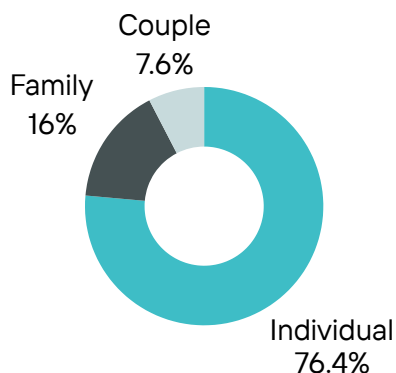
662

In-person Community Visits



789

Virtual Community Visits



RCDs are connecting with clients more than ever!

25% increase

in emails sent to clients

47% increase

in phone calls conducted with clients

18% increase

in virtual and in-person case conferences + client consultations with a professional

33% increase

in in-person community visits

61% increase

in virtual community visits

Genetics Clinics Appointments

137% increase

in the total # of in-person and virtual genetics appointments attended by RCDs





FAMILY SERVICES SUPPORT GROUPS

Participation

- RCDs facilitated **22 support groups (3 more than last year)**
- **355 participants**
- Two group types, support & social support
- Delivered virtually, in-person, or in a hybrid format

Audience

Groups can be for:

- **Carers** (persons caring for someone with HD)
- **Persons living with HD**
- **HD community** (persons affected by HD and their families)
- **French community** (Groupe MH nationale de soutien Communautaire)
- **Persons at-risk/gene positive**
- **Care partners** (spouse to an individual with HD)

Support Groups

Structured psychoeducational groups, providing both education and counselling support
Include:

- Guided discussions
- Resource sharing
- Help with developing coping strategies

Goals are to provide:

- Skill-building opportunities
- Knowledge
- Support
- Growth

Social Support Groups

Casual gatherings designed to:

- Reduce isolation
- Foster a sense of belonging
- Build connections

Goals:

- Inclusivity
- Strengthening social networks

SPOTLIGHT: Grief Café

Recognizing that HSC staff members are supporting individuals and families facing a neurodegenerative disease with no cure, the Family Services team launched the first in a series of Grief Cafés in March 2025, held every two months, led by Nova Scotia and PEI Resource Centre Director Pamela Secci.

The Grief Café offers a welcoming space where HSC staff can openly explore and discuss the complexities of death and dying. Its goal is to foster learning, professional development, and strengthen team connections amongst all staff members. Attending does not require expertise or grieving experience - Pamela welcomes and encourages the entire HSC team to attend. The first Grief Café explored death and burial traditions. Upcoming topics will include:

- pet loss
- death & burial traditions
- memorial activities
- religious and spiritual beliefs on death & dying
- legacy work
- types of grief

EDUCATION

61

education sessions delivered, both in-person and virtually

49% increase

in # of education sessions delivered since last year



RCDs facilitated YPAHD Day sessions on topics such as Supporting your Person, Genetic Testing and more

SPOTLIGHT: Raising Awareness about HD with Law Enforcement and Emergency Personnel

With the help from our Educator, in 2024, the HSC Family Services team created a Law Enforcement Education package containing:

1. Fact sheet
2. Infographic
3. PowerPoint presentation
4. Video

This entire package is designed to support the education of law enforcement and other emergency response personnel about Huntington disease throughout Canada, to be delivered by Resource Centre Directors.

Feedback from law enforcement and emergency personnel is that these resources have been very valuable.



"We are ultimately all affected by death and dying, and even more so with the population that we work with every day."



ADVOCACY

HSC Key Role: Advocacy for those affected by HD

We work to strengthen the voices of Canadians living with HD by building strong relationships within the community and using those connections to enhance our services. HSC advocates at international, national, and provincial levels to ensure the needs of those impacted by HD are heard.

Historical Advocacy

- The Canadian Coalition for Genetic Fairness (CCGF)

Current Advocacy

We contribute to the advocacy efforts of the following organizations and initiatives through participation in committees and boards:

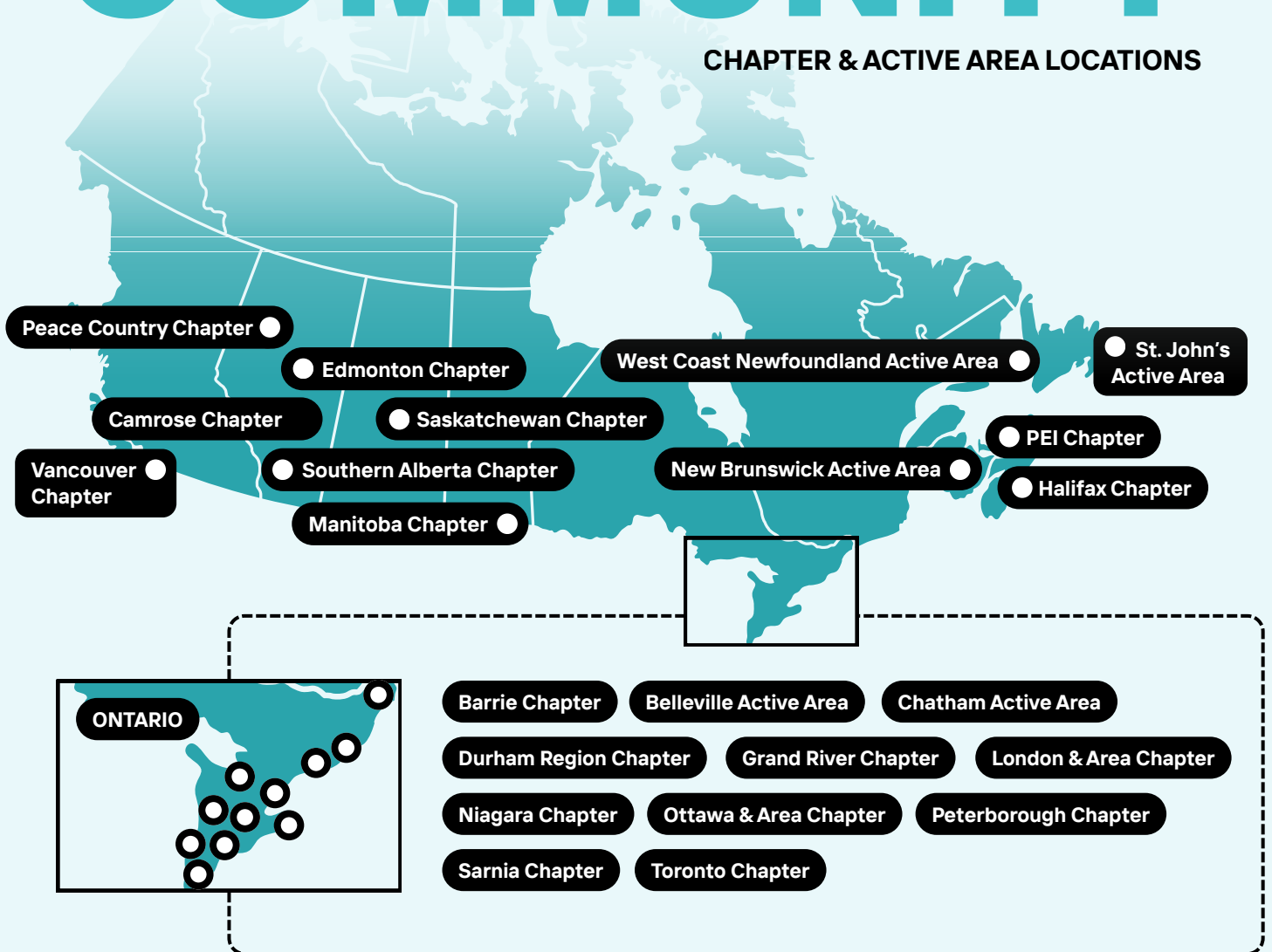
- Neurological Health Charities Canada (NHCC)
- Health Charities Coalition of Canada (HCCC)
- International Huntington Association (IHA)
- Medical Assistance in Dying (MAID) Roundtable

Future Advocacy

- Building an Advocacy Framework

COMMUNITY

CHAPTER & ACTIVE AREA LOCATIONS



Chapters

The HSC Chapter Facebook page redesign is complete, including:

- New chapter logos
- Designated event pages
- Provincial support group listings

The Chapter Facebook pages represent an accessible communications channel to welcome, inform, and include anyone interested in learning more about the community, chapter, or HD.



EVENTS

SPOTLIGHT: YPAHD Day

Young People Affected by Huntington Disease (YPAHD) Day took place on November 8-9, 2024, in tandem with the Family Services team training.

Highlights:

- Resource Centre Directors (HSC's psychotherapist and social workers) met with youth and formed meaningful connections
- Programming included art therapy, HD Jeopardy, and caregiver support
- Fabulous team-building activity at BRKFREE, a high-tech social entertainment venue



The Youth Speak: The Power of YPAHD Day

“Huntington disease can be incredibly isolating to deal with. Friends try to understand but often don't see the full picture. Family may see the full picture but are too close to it to help give you perspective. **So it is amazing to be able to come to YPAHD Day and build a community of support** for yourself made up of others who can appreciate what it is you are going through.”



“YPAHD allows me to connect with other youth affected by HD. Without YPAHD, I'd be feeling so isolated and alone, like no one understands, but YPAHD proves that isn't true.”



Night to Flourish Gala

Southern Alberta Chapter

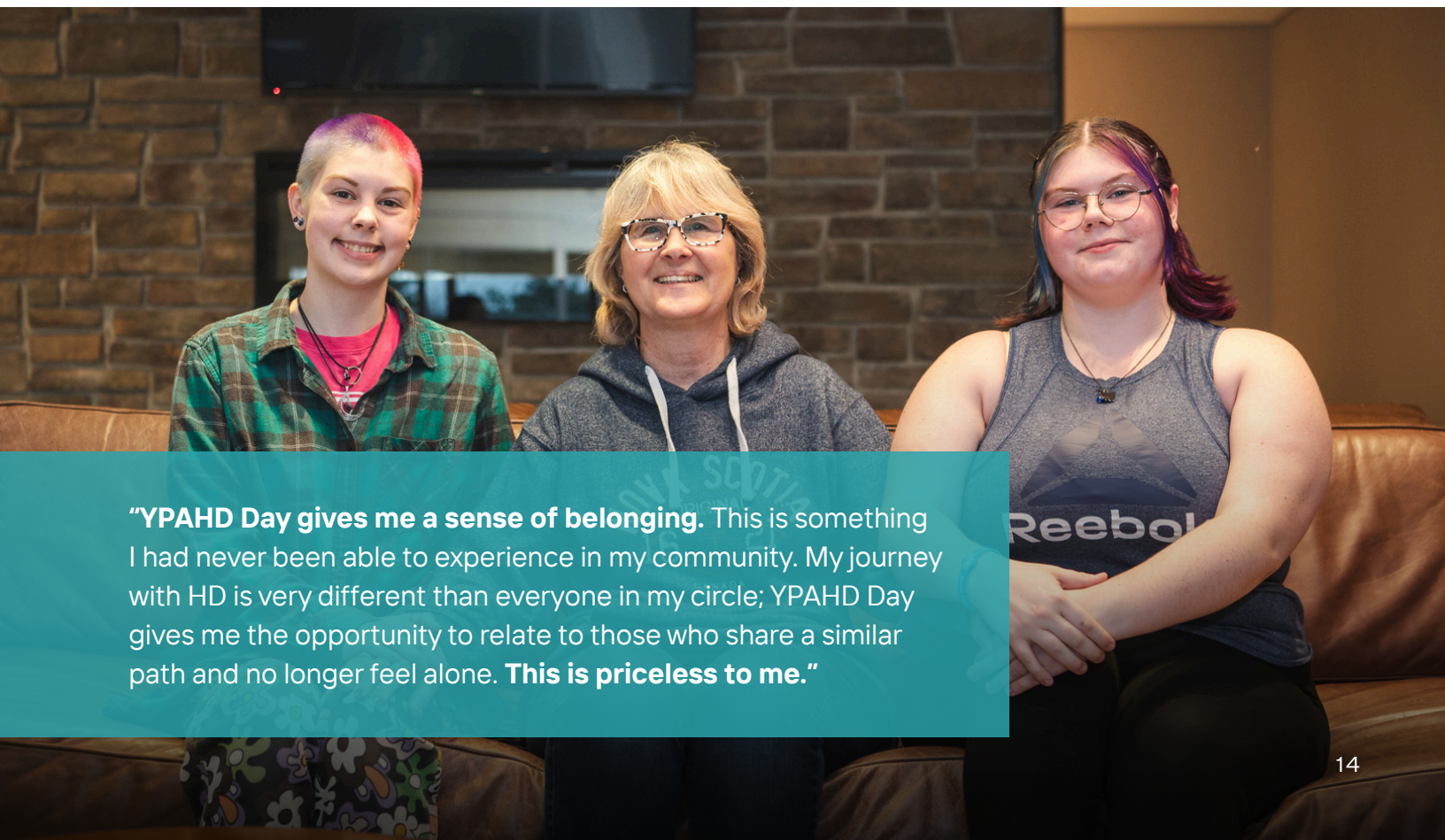
\$78,000

Raised for Huntington disease research and support services

Chapters Get Creative with New Fundraising Events

Our chapters have the touch when it comes to creative new fundraising events.

- **Niagara Chapter** gave the people what they love – cornhole! This new tournament was big on laughs and connection
- **Newfoundland Chapter** tapped into the Jeopardy craze for a fundraising trivia event – facts and fun!
- **Southern Alberta Chapter** added glamour to their Night to Flourish Gala, "Blooming Hope and Connecting the Pieces." **It raised an incredible \$78,000** for Huntington disease research and support services and featured a custom floral wood-cut puzzle as part of their fundraising efforts



"YPAHD Day gives me a sense of belonging. This is something I had never been able to experience in my community. My journey with HD is very different than everyone in my circle; YPAHD Day gives me the opportunity to relate to those who share a similar path and no longer feel alone. **This is priceless to me."**



SPOTLIGHT: 15th Annual Ride 4 A Cure – All Smiles in the Rain

Congratulations to the Peace Country Chapter on hosting the 15th Annual HD Ride 4 A Cure event on August 24. HSC Co-founder Ariel Walker and HSC CEO Shelly Redman attended this high-energy fundraiser with a variety of activities and entertainment.

Participants rode on horseback, in wagons, or used their own steam to travel the course. There was music, dancing, BBQ, and amazing prizes!

"We raised over \$60,000 in pledges alone. Add in the match from a generous donor, and this event will top \$120,000 - wow!"

- Mack Erno

past HSC Board Chair & Peace Country Chapter's President

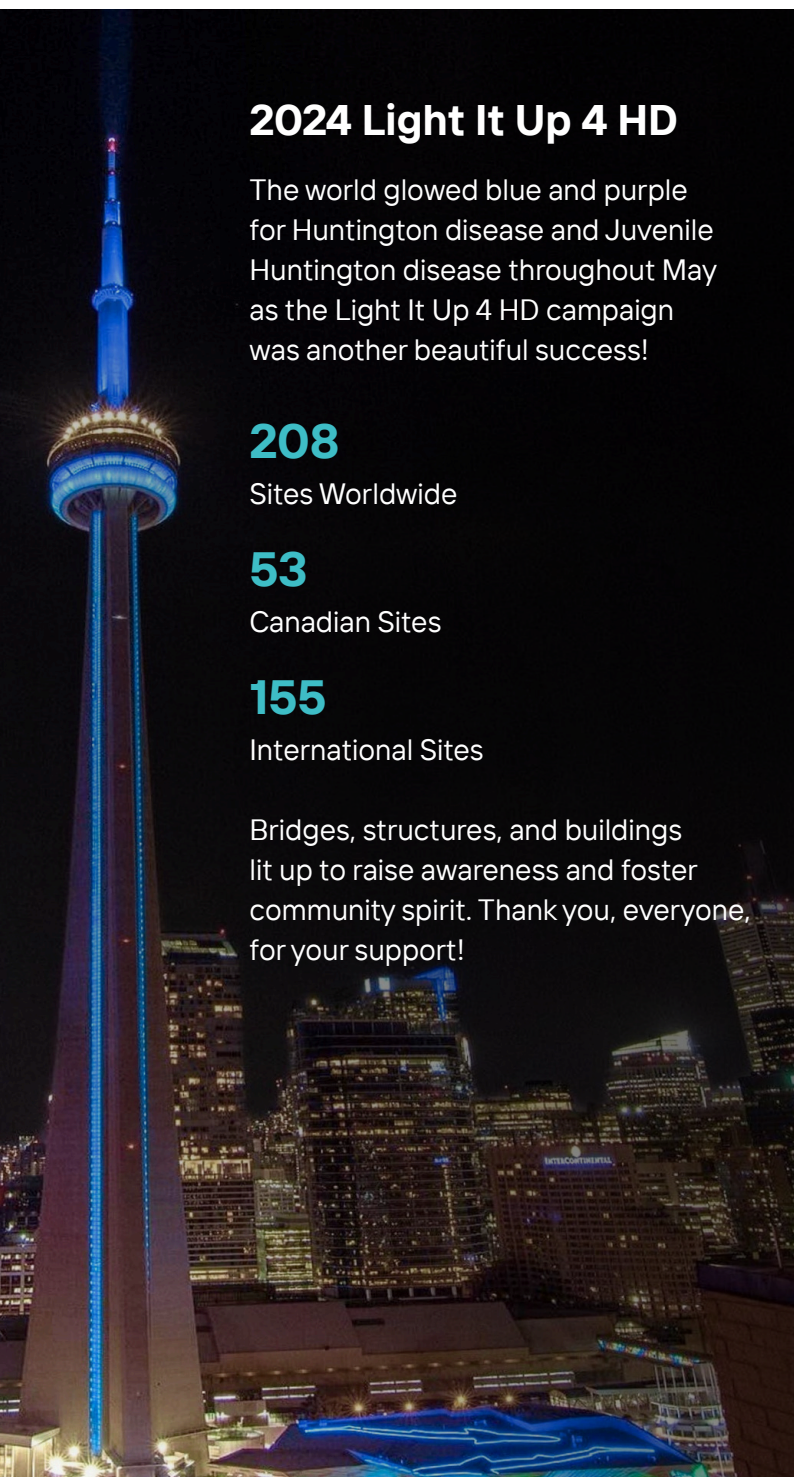




2024 National Huntington Heroes Walk

The 2024 Huntington Heroes National Walk raised \$209,000. With the match, that's **\$418,000**.

Special call-out to youth fundraisers, who accounted for more than \$30,000 of the funds raised!



2024 Light It Up 4 HD

The world glowed blue and purple for Huntington disease and Juvenile Huntington disease throughout May as the Light It Up 4 HD campaign was another beautiful success!

208

Sites Worldwide

53

Canadian Sites

155

International Sites

Bridges, structures, and buildings lit up to raise awareness and foster community spirit. Thank you, everyone, for your support!



Our Volunteers are All-Stars

To our amazing volunteers - thank you for everything you do! You make it all possible. You donate your research expertise, fundraising skills, and chapter enthusiasm. You give your time generously to sit on committees, share your stories, and organize events. You are supporters, mentors, connectors, and overall all-stars!

DEVELOPMENT

SPOTLIGHT: Another Successful Amaryllis Campaign

2024 marked an amazing Amaryllis season!

23,748

kits sold

\$295,034

in revenue

\$8,911

in donations

26

photo festival submissions

Thank you so much to everyone who purchased flowers, donated funds, or gave their time, energy, and passion to volunteering for the Amaryllis campaign as coordinators – we couldn't do it without you.



Valerie Nabb

Ottawa Chapter

Top Amaryllis Sellers

CHAPTERS:

155 cases	Ottawa Chapter Valerie Nabb & Nancy Murphy
126 cases	Southern Alberta Chapter Heather Dodds
81 cases	BC Chapter Corinne Bees
73 cases	Camrose Chapter Larry Campbell
70 cases	Winnipeg Chapter Vern Barrett
40 cases	Niagara Chapter Bev Traver
38 cases	Edmonton Chapter Greg Taylor

INDIVIDUALS:

32 cases	Corey Janke
30 cases	Chuck & Sharon Gera
25 cases	Ariel Walker



Lorraine Pearson

2024 Amaryllis Photo Festival Winner

HSC Sweepstakes

over \$4,800

raised in our first HSC National Sweepstakes, featuring a variety of artistic, entertainment, and experiential prizes.

Fall Match Campaign

\$55,600

in community donations with **\$50,000 in matching funds** - a successful fall match campaign.

HSC Board Gives Back

\$14,977

raised through the new board campaign for Giving Tuesday, "HSC Board Gives Back."



Monthly Giving

\$145,439

raised through monthly giving

up 6.1%

over the previous fiscal

378

monthly donors

8% increase

in # of monthly donors over the previous fiscal

GRANT AND FOUNDATION SUPPORT



AQUEDUCT
FOUNDATION

THE
WINNIPEG
FOUNDATION
For Good. Forever.

SickKids VS

ONTARIO
BRAIN
INSTITUTE

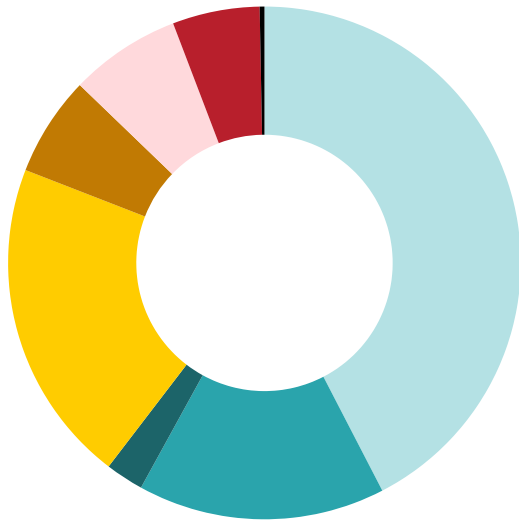
INSTITUT
ONTARIEN
DU CERVEAU

THE FITZHENRY FAMILY FOUNDATION

JEWISH FEDERATION
GREATER VANCOUVER

MEASUREMENT

Source of Funds



42.4% Donations

15.6% Bequests & Memorial Giving

2.4% Grants

20.5% Fundraising, Chapter & Events

6.3% Fundraising, Charity Gaming

7.0% Fundraising, Amaryllis Revenue

5.5% Investment Income

0.3% Other Income

Use of Funds



41.0% Family Services

11.7% Development

8.0% Public Awareness & Education

8.9% Volunteer Support

13.7% Administration

8.8% Research

7.9% Fundraising Expenses



Our 2024/25 donor list is available on our website: www.huntingtonsociety.ca/donor-recognition/

STATEMENT OF FINANCIAL POSITION

March 31, 2025, with comparative information for 2024

	General Fund	Capital Assets Fund	Endowment Fund	Ralph Walker Research Fund	2025 Total	2024 Total
Assets						
Current assets:						
Cash	\$ 802,313	\$ -	\$ -	\$ -	\$ 802,313	\$ 572,499
Investments	-	-	1,909,545	778,098	2,687,643	2,434,964
Accounts receivable	137,008	-	-	-	137,008	230,775
Interfund receivable (payable)	423,434	-	-	(423,434)	-	-
Prepaid expenses	144,690	-	-	-	144,690	94,267
	1,507,445	-	1,909,545	354,664	3,771,654	3,332,505
Capital assets (note 5)	-	89,945	-	-	89,945	163,308
	\$ 1,507,445	\$ 89,945	\$ 1,909,545	\$ 354,664	\$ 3,861,599	\$ 3,495,813
Liabilities and Fund Balances						
Current liabilities:						
Accounts payable and accrued liabilities	\$ 78,225	\$ -	\$ -	\$ -	\$ 78,225	\$ 104,802
Deferred revenue	183,388	-	-	-	183,388	165,839
	261,613	-	-	-	261,613	270,641
Deferred lease inducement	0	-	-	-	-	3,054
	261,613	-	-	-	261,613	273,695
Fund balances:						
General Fund	1,245,832	-	-	-	1,245,832	811,923
Capital Assets Fund	-	89,945	-	-	89,945	163,308
Endowment Fund	-	-	1,909,545	-	1,909,545	1,841,573
Ralph Walker Research Fund	-	-	-	354,664	354,664	405,314
	1,245,832	89,945	1,909,545	354,664	3,599,986	3,222,118
Commitments						
	\$ 1,507,445	\$ 89,945	\$ 1,909,545	\$ 354,664	\$ 3,861,599	\$ 3,495,813

*These statements are extracted from the audited financial statements for the year ended March 31, 2025. The full set of audited financial statements is available on our website.

STATEMENT OF OPERATIONS

Year ended March 31, 2025, with comparative information for 2024

	General Fund	Capital Assets Fund	Endowment Fund	Ralph Walker Research Fund	2025 Total	2024 Total
Revenue:						
Donations	\$ 2,355,875	\$ -	\$ -	\$ 189,483	\$ 2,545,358	\$ 3,422,819
Chapter and volunteer fundraising revenue	1,429,688	-	-	50,000	1,479,688	\$ 1,173,733
Grants	103,496	-	-	-	103,496	\$ 237,909
Investment income	115,072	-	-	36,232	151,304	185,789
Change in fair value of investments	-	-	67,972	21,938	89,910	100,225
Other income	14,895	-	-	-	14,895	57,650
	4,019,026	-	67,972	297,653	4,384,651	5,178,125
Expenses:						
Family Services	1,634,683	-	-	-	1,634,683	1,621,879
Development	465,651	-	-	-	465,651	627,105
Public awareness and education	318,799	-	-	-	318,799	624,496
Chapter and volunteer support	355,994	-	-	-	355,994	464,501
Administration	481,621	-	-	-	481,621	454,147
Research	2,500	-	-	348,303	350,803	325,274
Chapter and volunteer fundraising expenses	314,104	-	-	-	314,104	230,193
Amortization	-	64,613	-	-	64,613	45,208
	3,573,352	64,613	-	348,303	3,986,268	4,392,803
Excess (deficiency) of revenue over expenses before funding of Huntington Society of Canada Research Chair						
	445,674	(64,613)	67,972	(50,650)	398,383	785,322
Other income (expenses):						
Loss on sale of capital assets	-	(20,515)	-	-	(20,515)	
Funding of Huntington Society of Canada Research Chair (1)	-	-	-	-	-	(1,500,000)
Excess (deficiency) of revenue over expenses						
	\$ 445,674	\$ (85,128)	\$ 67,972	\$ (50,650)	\$ 377,868	\$ (714,678)

Note (1): On September 6, 2022, the Society entered into an agreement with The University of Western Ontario to make a gift on \$1,500,000 from funds raised in the Ralph Walker Fund to establish a perpetual endowed fund named the "Huntington Society of Canada Research Chair" to support research and other academic activities focusing primarily on the prevention, identification and treatment of Huntington Disease and secondarily on other neurodegenerative diseases. For financial statement purposes, the contribution is reported as a research expense on a separate line to highlight the one-time impact to operating surplus.

*These statements are extracted from the audited financial statements for the year ended March 31, 2025. 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, 2025.

For the twelve months ended March 31, 2025, HSC recorded a \$377,868 operating surplus. The organization again had strong fiscal results in 2024/25 and the Board is focussed on ensuring that the organization stays financially strong.

HSC revenue for this fiscal year was \$4.4 million which is a reduction of \$793,000 from the previous fiscal year. Donations decreased \$877,000 from prior year which was our 50th Anniversary year with related fundraising campaigns. Chapter and volunteer fundraising increased \$306,000 mainly due to higher gaming revenue and successful sporting events. Grant revenue decreased \$134,000 while Investment Income was lower by \$34,000.

We are grateful for our donor, chapter/volunteer community and stakeholders as they continue to support the important work of HSC!

Expenses were \$407,000 lower than fiscal 2023/24. Expenditures in most expense categories were consistent with prior year or were lower due to no conference expenses in this fiscal as well as no expenditures for 50th anniversary activities. HSC staff are continuing to steward to budget and examine controllable costs. Research expenditures were \$26,000 higher than prior year. Please note that Note 12 to the Financial Statements outlines commitments for operating lease and research payment over the next five years. Research commitments were added to this note as they are often multi-year commitments.

Administration expenses were \$27,000 higher than previous fiscal due to staffing at full complement. HSC staff continues to ensure the optimization of administration expenses.

Liquidity of HSC continues to improve. HSC cash balance increased to \$802,000 which is \$230,000 higher than prior year. Investments also increased to \$2.7 million from \$2.4 million prior year.

We had a clean audit report this year and continue to work to streamline HSC audit and reporting processes and ensure appropriate internal controls.

Many thanks to the Audit and Finance Committee of the Board for their dedication. Also thanks to HSC's Chief Financial Officer, Doug Woodburn and the Finance staff as we continue to see improvements in reporting and communication. In addition, the team completed several key projects which will result in efficiencies and cost savings in future years. These projects include the office move, new payroll/HR system, banking documentation updates, finance and risk policy refresh.

Congratulations to the HSC staff team on a successful year. I look forward to another strong year in 2025 working with the dedicated volunteers, management team and dynamic Board.



Cindy L Rainsford, CPA, CMA
HSC Board Treasurer



Huntington Society of Canada

375 Hagey Blvd., Suite 114, Waterloo, ON N2L 6R5

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

Charitable Registration: 11896 5516 RR0001