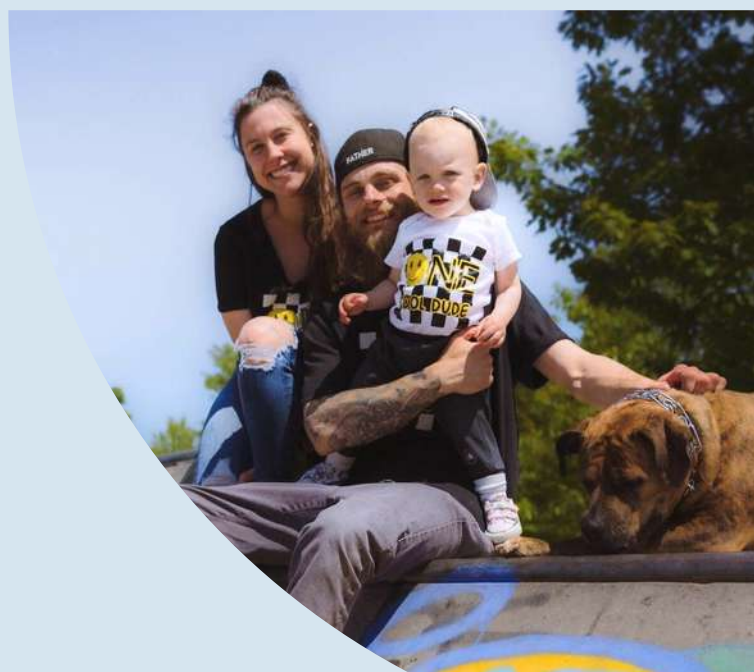

2022/2023

ANNUAL REPORT



**HOPE
BELIEVE
INSPIRE**

Governance

Vision:

A world free from Huntington disease.

Mission:

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



The Huntington Society of Canada (HSC) Board Directors

Geneviève Bélanger (*Huntington Society of Québec Representative*)

Catherine Price (*YPAHD Representative*)

Mack Erno (*interim*)

Ron Muller

Diane Tullson

Andrew Wright

Marg Romanow

Gregory Kocik

Heidi Bredenholler-Prasad

HSC Board Executive

Brynne Dalmao – Chair

Bob Scriven – Secretary

Cindy Rainsford – Treasurer

TABLE OF CONTENTS

Governance	01
Board Chair Note	03
Letter from the CEO	04
Family Services Report	05
HSC Research Report	11
National and Community Events	13
Light It Up 4 HD 2022	17
Chapter Development	18
YPAHD Day	21
Fall 2022 Virtual Conference	22
2022 Amaryllis Fundraising Campaign	23
Monthly and Memorial Giving	26
Raising Awareness via Social Media	27
Treasurer's Report	30
Statement of Financial Position	31
Statement of Operations	32

2022/2023



BOARD CHAIR NOTE

Brynne Dalmao

What a privilege it has been to be Board Chair to lead off the Huntington Society of Canada's 50th Anniversary.

It's been a wonderful year full of many firsts befitting a golden milestone. Here are a few that shine particularly brightly.

University of Western HSC Research Chair Announcement

I was incredibly fortunate to visit Western University to celebrate the announcement of our HSC Endowed Research Chair. We had the opportunity to tour the labs and meet with a number of dedicated scientists at Western. They shared so much of their knowledge and hope with us – it was truly inspiring.

This Huntington disease (HD) research opportunity is going to make meaningful differences in the lives of those affected by HD. To me, this has been one of the most memorable highlights in the history of HD research since the identification of the gene. It has given me such meaningful, substantive hope to know that there is a team at such a prestigious university, integrated within the Schulich School of Medicine and Dentistry, dedicated to HD research. The Research Chair position will foster and inspire research for generations to come.

Centres for HD Clinical And Research Excellence (CARE)

I continue to be so inspired by this community and the support we have already seen for the 50th anniversary campaign. Our Centres for HD CARE will be groundbreaking and I am so proud of everyone who has worked so hard to bring this model forward. These clinical hubs will truly make a difference for individuals and families affected by HD.

Connecting In Person

It has been amazing to connect at in-person events again, including the Toronto and Durham walks, and meeting in person as a Board for the first time since 2019. I look forward to seeing and chatting with so many more of you at our National Conference in November!

My Gratitude to You All

As always, my immense gratitude goes to all of the volunteers (both in the community and on our Board) and dedicated staff who have achieved so much in our first 50 years since Ariel and Ralph set us all along this amazing path... and, of course, I can't wait to see what the next 50 will bring!

Here's to a fabulous 2022-23 and many more milestones and achievements to come.

LETTER FROM THE CEO

Shelly Redman



Three quarters of the way through this past fiscal, we celebrated a huge milestone in the history of the Huntington Society of Canada – our 50th Anniversary. I am so proud of our collective commitment and unwavering dedication to the cause that brings us together.

When I look back at the past 50 years, I'm filled with admiration for the incredible strength and resilience of our community. We've faced so many challenges along the way, and we've never given up on our mission to create a better future for those affected by Huntington disease. Together, we've weathered storms and overcome obstacles, always believing that we can make progress and create a world where Huntington disease is no longer a threat. In this Annual Report, we've tried to capture the essence of our journey over the past year. It's a celebration of the strides we've made in research, support, and education. But more than that, it's a tribute to the incredible people like you who have stood by our side, offering your unwavering support and kindness.

When you flip through the pages of this report, you'll find tidbits that fill your heart with hope, courage, and strength. You'll read about the groundbreaking research we've been able to fund thanks to your generous contributions. And you'll see the faces of individuals and families whose lives have been touched by our collective efforts, reminding us why we all work so hard, and give so much.

This Annual Report isn't just about looking back; it's about looking forward, too. We've laid out some big goals for the coming years. It's a roadmap that will guide us toward a brighter future, one where we can say that Huntington disease doesn't hold power over anyone's life.

As we celebrate our 50th anniversary, I want to express my deepest gratitude to each and every one of you. Whether you've donated, volunteered, conducted research, cared for someone, or have been personally affected by Huntington disease, your contribution is priceless. It's your caring dedication that has brought us this far, and it will continue to drive us forward.

Let's embrace this incredible milestone and let it ignite our passion and commitment even more. Together, we'll write the next chapter in our amazing journey—a chapter filled with hope, progress, and, ultimately, a world free from Huntington disease.



With heartfelt thanks
and warmest regards,

A stylized, handwritten signature in blue ink that reads "Shelly Redman".

Shelly Redman
CEO, Huntington Society of Canada

Family Services Report



HSC's Family Services team provides emotional support, education and advocacy to people affected by Huntington disease (HD). Offering a variety of support from individual and group counselling to sharing information on strategies for coping and for care, this is the front-line team truly making a difference in the quality of life of those facing HD.

The Return of In-Person Visits

The big story of the year is the return of in-person visits by the Resource Centre Directors (RCDs) because of COVID restrictions lifting. Specifically, for 2022/23, compared to 2021/22, there was a:

85.5%

INCREASE IN CLINIC VISITS (IN-PERSON)

16%

INCREASE IN CASE CONFERENCES WITH SERVICE PROVIDERS (IN-PERSON)

264%

INCREASE IN HOME VISITS

In total, Family Services provided 8144 direct services for the year, **an increase of 12%!**

People seeking support and information also use virtual means. There was a 195% increase in indirect services, with 5023 connections. These included:

15%

INCREASE RE: INDIVIDUALS NEW TO THE HD COMMUNITY REACHING OUT

Often these contacts were looking for information about options for genetic testing, clinical trials and support services available

6%

GAIN IN CLOSED FACEBOOK GROUP MEMBERS

This online community is open via permission only due to privacy

6%

INCREASE IN THE NUMBER OF TELEPHONE CALLS CONDUCTED BY RCDS

3%

RISE IN NEW CLIENTS

Overall Services Increased





“The people that were in it sharing their stories makes you feel not so alone in this journey.”

“We share experiences and that helps to make me aware of what to expect and how to cope, as I am new to this disease.”

“Wow, getting the opportunity to share stories with other folks that are living similar situations was a highly enriching, insightful and grounding experience for me.”

“The group was really great. The facilitators were knowledgeable, welcoming, kind and supportive. I can't express how valuable this experience was for me and I am so, so grateful.”

“They were fantastic facilitators! They created a safe and inclusive space for sharing that let us participate as much or as little as we wanted or needed. The resources shared will be helpful beyond these sessions. I learned about myself and the small changes I can make to regain some balance I've lost in the last year. Thanks so much this was a valuable experience for me.”

Support Groups Grew and Flourished

In-person support groups returned. These specific groups ran throughout the year:

- Carers group
- Mixed groups that include persons with HD, those at-risk, those with the gene mutation, and carers
- Groups specific to persons with HD

Virtual support groups continue to be a good option for many people who do not live close enough to attend an in-person support group or who appreciate the flexibility when balancing work, school, and/or caregiving. Virtual support groups include those specifically designed for:

- Carers
- Persons with HD
- Parents of those with HD
- At-risk and Gene +
- Social “coffee chats”

Comments from participants in our support groups are included in the boxes to the left. Have a read to learn what it is like from their perspective.



Educational Sessions Provide Information and Raise Awareness

The Family Services team offers a variety of learning opportunities for both community members as well as health care professionals. Here's a look at those learning connections:

On April 22, 2022, Jim Pollard presented **Cognitive Symptoms of HD and What You Need to Know** at an Atlantic Canada virtual Lunch and Learn with 70 registrants.

On Aug. 31, 2022, Dr. Eleff presented a hybrid session in Charlottetown **entitled Care for Today, Hope for Tomorrow: An Overview of Clinical and Genetic Features of HD** with 60 people registered.

RCDs participated in **Grand Rounds**, which provides an opportunity to provide medical education on patient care. Specifically: An HD physician/specialist and an RCD present the medical problems, symptoms, etiology and treatment of a particular patient or group of patients living with HD to an audience consisting of doctors, pharmacists, residents, and medical students.

2022 YPAHD Day sessions offered by RCDs included:

- After the Test
- Survivor's Guilt
- Emotion and Mood Changes
- Grief and Loss

2022 Fall Virtual Conference RCD Education sessions:

- Family Planning
- HD101
- This is Me: Capturing and Sharing Memories



Fact Sheets

...

The Family Services team updated 5 fact sheets accessible on our website and via our Strength & Knowledge newsletter, delivered right to your inbox.

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

www.huntingtonsociety.ca/sign-up-for-our-e-newsletters/

Care Home Presentations

- RCDs share information with care facilities who have residents living with various symptoms and later stages of HD. Some are approaching or are in the end stages of the disease and no longer able to care for themselves
- RCDs speak with everyone involved in resident care including nursing staff, management, kitchen staff, physiotherapists, occupational therapists, recreational therapists, and janitorial staff
- Staff most often need help understanding the progression of the disease and how to help the resident best manage their everyday activities, also called "activities of daily living." These activities include bathing, dressing, grooming, using the toilet, eating, and moving around—for example getting around using a walker or wheelchair
- Those affected by HD have specific needs for meals, transportation and communication, making it important for all staff to partake in the presentation to understand the disease and its progression
- RCDs leave behind HSC educational material to provide a valuable resource for staff



Spotlight on Education in the Atlantic

This year the Atlantic Canada RCDs offered a series of well-attended online sessions for caregivers in the area, covering the following topics:

- Overview of HD
- Building Your Team & Community Resources
- Challenges, Life Transitions & Planning for the Future
- Moving through Stress, Grief & Guilt
- Self-Care

New Ways to Connect with Family Services

In January 2023, the Family Services team added a new way for people looking for HD resources to connect.

The **contact me link** captures all requests for information and support: contactme.cloud/form/huntingtonsociety.

Individuals can fill out the confidential form and a member of the Family Services team will get in touch.

What is This Link For?

This link is to capture all types of requests, including information on:

- Clinical trials and HD clinics
- Genetic testing
- General HD topics
- How to request an education session
- How to become connected to a Family Services worker
- How to join a support group
- Other support/resources questions

One Toll-free Number

This year we also implemented one toll-free number for all of the Family Services Team: 1-800-998-7398.

Entering extensions, found on our website, connects callers directly with the RCDs.



Research Report

2022 HSC National Conference Presentations

This past fiscal, HSC wanted to express our commitment to advancing our research expertise and infrastructure, especially as part of our 50th anniversary, by introducing our research lead, Alexander Maxan. So far, we believe we have shown we can support considerable growth in our research offerings for years to come. Here's a look at the HSC Research Lead's 2022 Conference sessions.

Alexander and Angèle Bénard, National Director of Family Services, presented "How HSC Supports Research in Canada," focusing on:

HSC's involvement in clinical trials as well as non-drug trial, HD-related studies.

Ongoing efforts to support researchers and clinicians across the country to grow our network of academics studying mechanisms of disease and those providing clinical support.

Alexander moderated two other sessions:

1. The dedicated HD research scientists that make up HSC's Research Council came together to answer all of the audience's burning questions about HD research including clinical and observational research and studies
2. Dr. Blair Leavitt graciously provided an update and scientific breakdown of HD clinical trials in Canada with a focus on huntingtin-lowering therapies

Research Dollars in Action

GOAL: To enhance the well-being of individuals impacted by Huntington disease (HD)

ACTION: Fund innovative research

IMPACT: Supporting researchers at different career stages exploring a wide range of topics within the field

HSC Research Chair at the Schulich School of Medicine & Dentistry

GOAL: To advance patient care outcomes and accelerate life-changing research in HD

ACTION: Western University and HSC have partnered to create an endowed research chair that will pave the way for accelerated advances in HD research

IMPACT: This faculty position will enable a world-class leader in neurodegenerative research to focus on finding new ways to prevent, identify and treat Huntington disease

One of the key advantages of a research chair position is the ability to attract top talent to our organization's umbrella. This position will also serve as a magnet for experienced and respected researchers, who are bringing with them a wealth of knowledge, expertise, and connections.

By recruiting these individuals, we are able to expand our research capabilities, develop new research projects, and build our reputation as a research-funding leader in our field.

We are also excited about the research assistants, postdoctoral fellows, PhD, Master's and undergraduate students who will be thrilled to work alongside this prestigious chair and other researcher collaborators. They will help manage data, conduct literature reviews, and perform other essential research tasks.

This role will bring in a number of fresh faces whom we will be able to target with our research funding initiatives, allowing us to profile and showcase HD research efforts here in Canada. The chair will serve as a bridge between our organization and other research groups, facilitating joint research projects and sharing resources. **This will not only expand our research reach, but also increase the impact of our work.**



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.

2022 Navigator Research Program Recipient:

Cheryl Arrowsmith, PhD: University of Toronto

Project Title: HTT-RNA interaction dynamics as a target of therapeutic intervention

Project goal: Evidence is accumulating for a role of the huntingtin protein in processes involving genetic material in our cells. Their lab has been able to show that huntingtin protein interacts with a certain type of genetic material, termed RNA, directly. Dr. Arrowsmith and team aim to identify the pathways by which huntingtin interacts with the specific RNAs and characterize them using a variety of biochemical and cellular methods. They have used cutting-edge microscopes to visualize huntingtin protein at high resolution. Building on this work, they now want to visualize how huntingtin protein interacts with specific RNAs. Their results will provide insight into how both normal and mutant huntingtin proteins interact with RNA in cells to regulate key processes involved in the health and HD-mediated death of neural cells. If they can understand how these interactions occur, then they can develop strategies to avoid or rescue the effects of human huntingtin for potential treatment.



National & Community Events

Events from April 2022 – March 2023

Thanks to our incredible and resilient community, we began to see events coming back in person this year. We had over 25 events take place in person, a huge increase over the number of in-person events offered during the pandemic. Thank you to all of our event organizers and volunteers for continuing to push on and fundraise for HSC. Your can-do spirit helped to raise \$556,191, 52% of HSC's overall fundraising revenue this fiscal.

25 IN-PERSON EVENTS
\$556,191 TOTAL FUNDS RAISED





Here's what happened in May 2022 for the Huntington Heroes National Walk, part of Huntington disease Awareness Month!

HUNTINGTON HEROES NATIONAL WALK

430 NATIONAL WALK PARTICIPANTS

\$202,000 RAISED

\$404,000 including the
match from our
generous donor

Together, we walked over

8,500km

during the month of May, more
than double our goal of 4,000 km!

That's like walking across the country
from Victoria to St. John's, stopping
at all the chapters along the way



Participants sported T-Shirts designed by Manitoba's
Emmanuel R., winner of our t-shirt design contest



**IMPORTANT CAUSE
AND COMMUNITY**

Event Spotlight



2022 ASL Agrodrain Soccer Tournament

A big thank you to ASL Agrodrain for hosting their soccer tournament in support of the Huntington Society of Canada. The event saw Ottawa-area companies registering teams to join the tournament and raised **over \$40,000**.



HD Hockey Classic - HDSA x HSC

On May 14, 2022, the Huntington Society of Canada (HSC) partnered with the Huntington's disease Society of America (HDSA) to put on the first ever HD Hockey Classic in New Jersey.

The two organizations came together to raise much-needed funds and awareness to support individuals and families facing Huntington disease (HD) across North America.

This Canada vs. USA charity hockey game featured collegiate and former professional players battling it out for bragging rights. While the game was in the US, HSC offered Canadians the opportunity to stream the game online, as well as to enter the chuck-a-puck contest virtually and receive an HSC-branded hockey puck as a memento.



2022 PEI Huntington Heroes Walk

Although the PEI Chapter does not have an official President, Area Representative Brenda Porter did an exceptional job organizing this incredible group of individuals to walk together in memory of several important chapter members who passed away in the last year.

KEY ACHIEVEMENTS:

- Over **\$8,600** raised
- **35 individuals walked more than 3,000 km** throughout the month of May
- That's **80% of the national distance goal** of 4,000 km

"The distance goal was a great way to connect the HD community on the island and has generated energy that has been lacking in our chapter for some time."

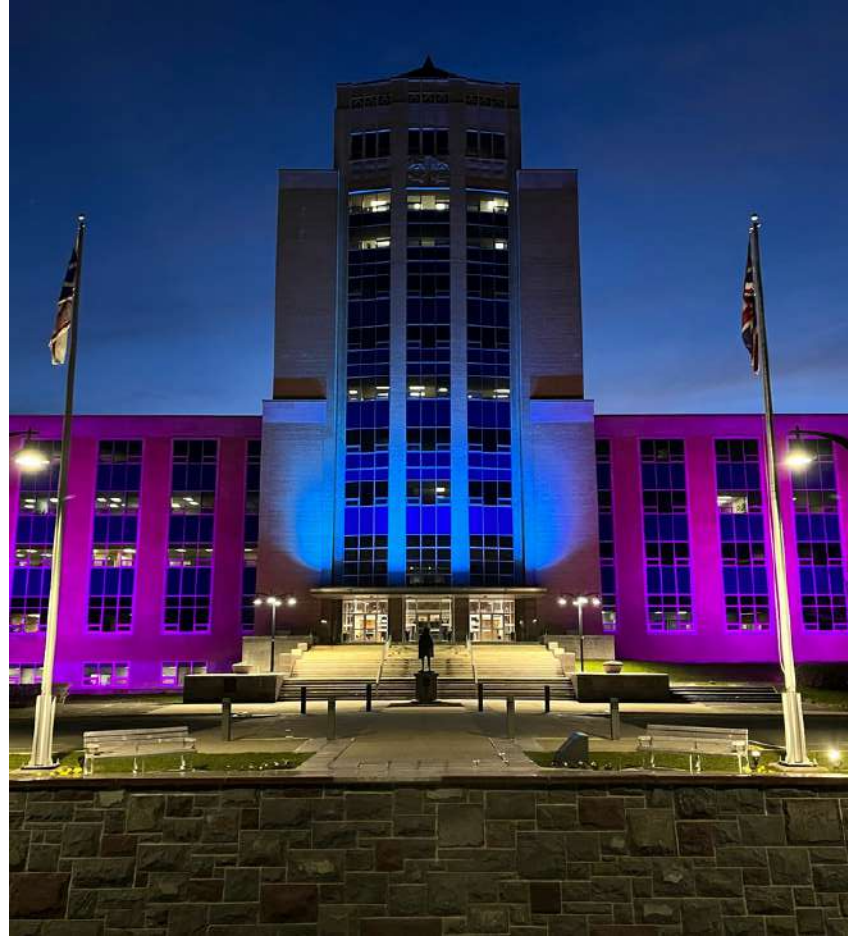
- Brenda Porter, PEI Area Rep

Nevaeh's Lemonade Stand

Nevaeh, aged 7, from Camrose, AB, held her first lemonade fundraiser for HSC. She raised over \$1,100 and donated 50% of her profits to the Huntington Society of Canada. Thank you Nevaeh for all your hard work!

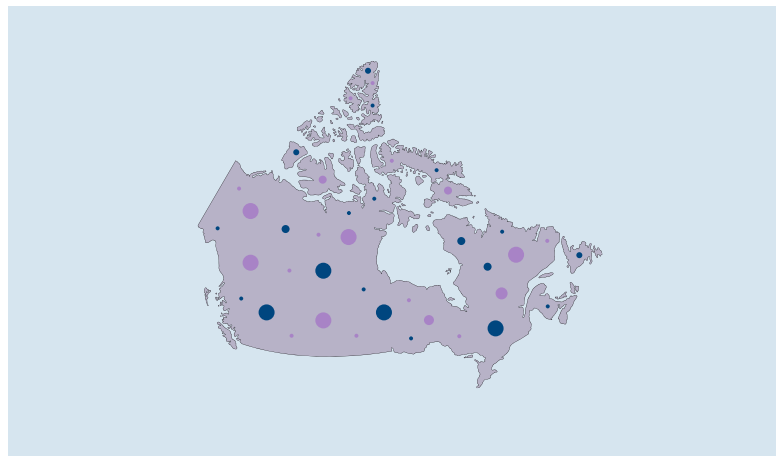


Light It Up 4 HD 2022



The 2022 Light It Up 4 HD campaign broke records! This yearly tradition sees buildings and structures around the world light up in blue and purple to raise awareness for Huntington disease and Juvenile Huntington disease.

Thank you to everyone who helped confirm sites and snapped photos. We had 250 sites worldwide in 13 countries including two new additions, India and Italy.



83 SITES RAISING AWARENESS FOR HD

In Canada, we had 83 sites! This is a huge increase over our previous highest year of 56 sites, and for the first time ever, includes a site in every province and one territory.

Our gratitude, as always, to volunteer James Walters who founded the campaign and continues to drive the efforts each year in Canada and around the world. We also thank National Light It Up 4 HD volunteer Ellie Gibbard for her efforts in confirming so many of our Canadian sites.



250 SITES IN 13 COUNTRIES

Chapter Development

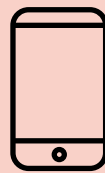


This fiscal saw a revitalization of many of our chapters that had been limited in their activity during the pandemic.

As of February 2023, 19 Chapters and Active Areas had restarted their activity, including 7 Chapters that identified a new President or Area Representative to support the rebuilding.

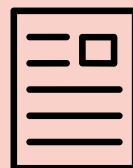
HSC's Chapter Development team saw this year as an opportunity to rebuild connection and communication amongst the chapters as well.

The Chapter Development team launched a new support strategy and resources to assist the chapters, including:



A regular schedule of calls for Chapter Presidents featuring feedback opportunities and training on topics pertinent to chapters, including:

- Confidentiality Best Practices for Chapters
- Social Media Best Practices for Chapters



A monthly newsletter uniquely prepared for Chapter Presidents, the Presidents Periodical.

- This resource provides valuable updates from the National Office team, celebrates chapter successes, and offers further resources to support the efforts of chapters.



Presidents Gathering

In February 2023, HSC hosted the first-ever Presidents Gathering as part of the support strategy. Created in response to feedback from the chapters, the event brought 15 chapter representatives together in Toronto for two days of intensive training and development. The event also served to build connections and collaboration between staff and Presidents nationwide. Several chapters met each other for the first time and formed alliances to strengthen their capacity to support local communities.



"It was all so well done. I appreciated the chance to "meet" all of HSC staff in person or virtually and learn more about them. Each session was so informative and well organized and presented. It was great to hear from a variety of staff. Lovely to meet HD volunteers from all across Canada and what different Chapters were doing. Very inspirational!"



"I will be taking all of the information I learned and bringing it back to my community. I am filled with more drive now to pick things up where they left off pre-COVID."

"It helped us redefine our goals and how we are operating. Gave us ideas and new things to implement at our upcoming events. We decided to make our next event bigger than we had originally planned and there is a new energy moving forward."

Stories from the Chapters

Saskatchewan Chapter

A big thank you goes to our dear friend, June Nichol. Over the summer, June made the often-difficult decision to step back from her long-standing role as President of the Saskatchewan Chapter after almost 20 years. June will remain involved with the chapter but handed the reins over to the next generation in Saskatchewan. Together with the team at HSC, the chapter's new President Morley Ellis hosted a goal-setting session and prepared for an educational session with Jim Pollard and in-person walks in Saskatoon and Lafleche.

South Vancouver Island Chapter

Many changes are happening on Vancouver Island! The former South Vancouver Island Chapter elected Hedley Cullen as President and identified an opportunity to improve inclusivity with a name change; they are now the Vancouver Island and Gulf Islands Chapter. After a hiatus over the pandemic, Hedley's new energy is already attracting support, including identifying a new Events Coordinator, and holding an in-person Walk in May 2023 – the first chapter-led fundraiser in the region since 2017.

Toronto Chapter

The Toronto Chapter has been busy this year identifying new members from a variety of sources, thereby rebuilding their chapter after the pandemic and preparing for the return of some in-person events next fiscal. The chapter welcomed a new Social Media Coordinator and a new Communications Coordinator. New Vice-President Mandy Urbach also stepped into an interim President role while Chapter President Natalie Marnica takes some time off with her new baby.



YPAHD Day



Hear from the youth attendees:

“

“Attending YPAHD Day helped me connect to the HD community and learn from others who are in a similar situation to me. It's a very heavy topic that made me cry talking about it a year ago, but having these hard conversations in a supportive environment has helped me think more clearly about HD and bring awareness to it in my community.”

”

“I've attended a bunch of YPAHD days and even this time around I found myself learning new things about myself and about the community. The ability to hear people's experiences that are totally different from mine is eye-opening! It really shows how different our journeys may be but also how even though we experienced different journeys, we are still together in this fight. Nothing compares to in-person interactions. I found the virtual YPAHD days hard to sit behind a computer and listen. When you're in person you can see and feel the emotions behind what people say.”

HSC's youth chapter, Young People Affected by Huntington disease (YPAHD), had a wonderful year getting together in-person.

Regional YPAHD Days 2022

On November 25 and 26, YPAHD Day made its return in both Calgary and Toronto. Not only was this HSC's first in-person event since gathering restrictions began to ease, but it was also the first time the youth were able to gather and learn since November 2019.

YPAHD Day is a one-day conference designed specifically for youth affected by HD (14-35 years of age). Youth from across the country gather to learn about HD topics with a youth-oriented lens and strengthen the support systems that help them to thrive in their HD journey.

The 2022 event drew 51 attendees including 20 first-time attendees. Youth appreciated being able to connect with each other and HSC once again, hearing about research, and the normalization of HD – an experience not often felt in their day-to-day lives.

Fall 2022 Virtual Conference: Research, Care, Connection and Learning



NOVEMBER 12 AND 13 2022

3rd National Virtual Conference

42% first-time attendees

More than **600** individuals registered to participate

Gaming aspect with hidden codes leading to fun prizes

Relaunch of National Awards program after a 4-year hiatus, providing some well-deserved recognition to our chapters, volunteers, businesses and HD professionals

Sessions available on our YouTube Channel

From Our Community:

"As the wife and matriarch of the family, I am committed to learning as much as I can about HD, the research, trials etc. to share the hope with my family. The conference this year did just that. The guest speakers did a great job in managing expectations regarding the length of time this could take; however, to see and hear about the ongoing trials and a promise of more to come was the most uplifted I have felt in some time. It was great to be able to share that with others."

"Conference has greatly inspired us - as have all previous conferences. We've been topped up with care and love; very suitable practical education; informed about all of our Society's efforts and a wide variety of very engaging topics and discussions; reconnected with old friends and plugged into new connections. Thanks for it all! Each successive conference builds on the foundations laid at previous conferences and becomes the new best conference ever. Thanks."

Session Highlights

- HDBuzz
- Community Celebration
- Ask the Scientists Anything
- This is Me: Capturing and Sharing Memories

2022 Amaryllis Fundraising Campaign

"I bought my Amaryllis flower many years ago when I was the first social worker here in Newfoundland for HSC, and it still blooms! It always warms my heart and reminds me of the resilience of the many folks I had the sincere privilege of working with back then."

*Wilma MacInnis, inaugural NL social worker,
whose Amaryllis has bloomed for 16 years*



"This is Colin, who is in a nursing home and in late-stage Huntington disease. When we ask him to smile this is what he does every time. Thank you for all the support HSC gives to families. It is much appreciated and although we don't have a lot of money, I wanted to support this cause."

Maria Coles, whose husband Colin has HD

"It was so much fun to be able to contribute to your great cause and have so many of my clients share their blooms with me. My friend so beautifully gift-wrapped the box that my clients did not want to open it but I spelled it out for them that they had to! My dining room and car were quite full. It was a fun experience, too, for my clients with children as they helped them through the process."

Margaret Young Ping, Kitchener Real Estate agent



Runner-up of the 2022 Amaryllis Photo Contest

"This is a picture of my hero - my papa, Glen Campbell, who passed away from Huntington disease on November 8, 2022. At the age of 83, he refused to stop walking until he took his last breath. RIP."

Jennifer Judge

"These are my two grandkids with their Amaryllis supporting HSC and Huntington disease. Natalie's plant has 8 blooms on it and Cole's has 4. For the past 3 years I have bought a plant for the two of them. They really enjoy watching them grow. Natalie's plant with the 8 blooms is the most blooms I've ever seen on any of our plants in the past years.

Larry Campbell is a friend of ours and I always order from him. Larry's wife Kathy was also a friend of ours - she passed away in 2010 from Huntington disease. All of our family has supported HSC for many, many years by always buying our plants from Larry. Every year as I watch my plant grow, I think of Kathy and the many struggles that she faced with HD. Supporting HSC is a very worthwhile cause. Because Natalie had such a beautiful plant this year, I took pictures of the kids to enter into your contest."

Susan Terway



Total # of Amaryllis sold

25,128

Gross Revenue

\$304,982

**80 photo festival
submissions**
and 996 votes

6 million

raised to date through
amaryllis campaign

"Our Aunt Marj had the great idea of getting each of our six cousins an Amaryllis bulb to plant in honour of our great-grandfather, Henry Neuman, and our two uncles, Peter and John Neuman. We named our plants and measured them each week. We sent pictures to each other and shared stories about growing the plants. The money helps with Huntington Society research and we get to share memories of our relatives. It was lots of fun and we hope to do it again next year!"

The Neuman Family:

Brayden, Jackson, Oli, Josh, Elliott and Mae



Winner of the 2022 Amaryllis Photo Contest

"This year we purchased three Amaryllis. We have many family members who have been diagnosed with Huntington disease. It is on both my mother's and father's side. I have grandparents, aunts, uncles and cousins who have been diagnosed. We love supporting this very important cause! These are twins Eli and Isaac showing off their beautiful Amaryllis plants!"

Mindy Felgate



"I was surprised to see mine was a unique colour this year - I had to share. My mom has been selling Amaryllis for over 35 years. I've had one each year almost my whole life. When I think of them, I instantly smile - I think of family. Their gorgeous blooms brighten the day of so many from coast to coast, spreading hope and awareness and raising money. It's about creating that yearly tradition of planting, watching them grow and bloom and trying so hard to not let them fall over!"

Trina Klein



Monthly and Memorial Giving



Memorial Giving

\$120,393 and 1099 memorial donations honoured 308 different individuals.

Monthly Giving

\$132,037 came from 327 monthly donors, with an average gift of \$33.65.

50

Why We Are Monthly Donors – Testimonials from the Community

“My long-term girlfriend is positive for the gene repeats, though thankfully remains symptomless for the time being. Her family has been torn apart by the disease, with the entire family tree ravaged by Huntington disease. I have another friend, as well, whose mother has been dealing with symptoms for years, and has avoided testing so far. I donate to both support them and others who are going through similarly tragic, or worse, circumstances.” – *Ryan Z Walters*

“I support the Huntington Society monthly because the staff at HSC, and my local support group, have kept me going through difficult times for the last twenty-five years. I donate to help all the Huntington's families across Canada to have the services they need, and to help fund research in the hope that one day no one will have to experience this disease.” – *Janet Slade*

Raising Awareness via Social Media

Social media is a great tool to raise awareness about Huntington disease. Here are the top 10 posts for the fiscal year for Facebook and Instagram. Not a follower? Search us up and add your support to sharing our message with Canadians from coast to coast to coast.



2

Top 10 Facebook Posts

1. HD Gratitude Day, March 23: Followers loved adding their support to a day that expresses gratitude to the international partners, researchers, and the generous families for working together on the ground-breaking work that led to the 1993 discovery of the CAG repeat mutation that causes Huntington disease.



3

2. Light It Up 4 HD Lawn Signs: We offered lawn signs for Light It Up 4 HD – and wow – did you ever respond! Love the enthusiasm.

3. Amaryllis Photo Contest Voting Opens: The ever-popular Amaryllis Photo Contest opened voting with many keen supporters.

4. Community member Rich Wheeler's CBC story: Rich Wheeler shared his story of being a carer to Ruby, who is affected by Huntington disease (HD).



4

5. International Huntington Disease Awareness Day May 15, 2022: An updated informational video "What is HD" reached many viewers.

6. Rare Disease Day: On Feb. 28, 2023, HSC shared a post about Rare Disease Day and the statistic that HD affects 1 in 7000 Canadians.

7. Research Funding News Flash – Research Chair at Western University:

News that HSC's generous donors had committed funds to support an endowed chair in Huntington disease research at Western University's Schulich School of Medicine & Dentistry was well received.

8. Early Onset Dementia and HD video:

Community member Tim Irwin talks about advocating and raising awareness in this video about Huntington disease and early onset dementia.

9. 25th Chatham Trap Shoot for HD:

On Saturday October 22, Chatham had their 25th Annual Trap Shoot for Huntington disease at the Rondeau Rod and Gun Club and it was a huge success! You loved the great photos and commitment to the cause.

10. Factual Friday – Conversation: On Feb. 10, HSC shared the following Factual Friday post that struck a chord with many: Did you know that... Huntington disease affects a person's ability to start a conversation. The person may not 'strike up' a conversation but may enjoy the discussion if someone else starts it.



7



9

- HSC's Snapchat account reactivated to use filters for in-person YPAHD Days – total of over 20 uses and 484 views
- LinkedIn helped us find the brightest employees and volunteers

Other social media news



Top 10 Instagram Posts

1. HDSA and HSC at the HD Hockey Classic in May

2022: There was a friendly wager on the outcome of the game. This reel shows what HSC had to do to make good!

2. International Huntington Disease Awareness Day

May 15, 2022: This updated informational video "What is HD" was also successful on Instagram.

3. YPAHD Day video: The past two years have been rough for the HD community. However, if there is one thing this community knows how to do...it is rise. Thank you Megan R. for putting this creative piece together!

4. Early Onset Dementia and HD video: Tim Irwin's education, advocacy, and personal experience in this video about Huntington disease and early onset dementia did well on the platform.

5. Presidents Gathering Reel: Thanks for the love shown to the "Put these sunglasses on and pose video."

6. Rare Disease Day: On Feb. 28, 2023, HSC shared a post about Rare Disease Day and the statistic that HD affects 1 in 7000 Canadians.

7. Community member Rich Wheeler's CBC story: Rich Wheeler gave an account of being a carer to Ruby, who is affected by Huntington disease (HD).

8. HD in Real Life: Community member Natalie Marnica shared her story about her family's experiences with HD.

9. HD Gratitude Day, March 23: IG viewers showed lots of support to the day that expresses gratitude to the international partners, researchers, and the generous families for working together on the ground-breaking work that led to the 1993 discovery of the CAG repeat mutation that causes Huntington disease.

10. Genetic testing for HD article: The link to an article describing the author's experiences with genetic testing for Huntington disease in the USA, where services are different from here in Canada, still struck a chord.



Treasurer's Report



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, 2023.

For the twelve months ended March 31, 2023, HSC recorded an (\$509,432) operating loss. Deferral of some fundraising efforts until next fiscal (the exciting 50th anniversary year) as well as higher expenses in several areas when compared to previous fiscal resulted in the loss. In spite of this result, we continue to ensure that the organization stays financially strong.

HSC revenue for this fiscal year is \$20,705 lower than the previous fiscal year. While donations increased \$247,759 and Chapter and volunteer fundraising increased \$63,677, we did see a drop in grant revenue of (\$23,613) as well as lower government funding (\$347,257) with the termination of COVID funding (CEWS). Expenses were \$827,063 higher than fiscal 2021/22. Our spending is tied to strategic initiatives and we are seeing increased expenditures in research as well as community support.

Expenditures for research increased \$151,978 over previous fiscal and are a factor of the number and quality of grant applications received. Family Services expenses increased \$205,096 from previous fiscal as outreach and staff development activity begin to recover to pre-COVID levels.

Administration expenses were \$241,528 higher than previous fiscal mainly due to \$279,000 in one-time severance and contractor expenditures as we align the organization for the future. Chapter and volunteer fundraising expenses were \$104,175 higher as was expected with expanded in-person fundraising events and the gradual return to pre-COVID activity.

We had a clean audit report this year and you will note that the revenue qualification has been removed from the report this fiscal. As the use of cash continues to decline in favour of credit cards or on-line payments, we have been able to eliminate the qualification.

You will also see our funding for the Huntington Society of Canada Research Chair at Western University reflected in Note 11 – Commitments of the Financial Statements. Our continuing investment in research has taken a step forward.

Welcome to Doug Woodburn, HSC's Chief Financial Officer, who started with the organization in March 2023. Under Doug's leadership, we are already seeing improved reporting processes and fiscal controls for HSC.

Having joined the HSC Board in March 2023, I look forward to continuing to work with the dedicated volunteers, management team and Board. The future will be exciting as HSC continues to expand research and family services. Our focus on fiscal responsibility will endure. Thank you for your ongoing support! We are looking forward to a strong 50th anniversary year in 2023.

Cindy L Rainsford, CPA, CMA
Treasurer

Statement of Financial Position

March 31, 2023, with comparative information for 2022

	General Fund	Capital Asset Fund	Endowment Fund	Ralph Walker Research Fund	2023 Total	2022 Total
Assets						
Current assets:						
Cash	\$ 584,986	\$ -	\$ -	\$ -	\$ 584,986	\$ 1,049,091
Investments	-	-	1,790,204	1,702,663	3,492,867	3,411,882
Accounts receivable	165,611	-	-	-	165,611	78,283
Interfund receivable (payable)	(21,092)	-	-	21,092	-	-
Prepaid expenses	143,143	-	-	-	143,143	84,959
	872,648	-	1,790,204	1,723,755	4,386,607	4,624,215
Capital assets	-	55,593	-	-	55,593	68,696
	\$ 872,648	\$ 55,593	\$ 1,790,204	\$ 1,723,755	\$ 4,442,200	\$ 4,692,911
Liabilities and Fund Balances						
Current liabilities:						
Accounts payable and accrued liabilities	\$ 299,887	\$ -	\$ -	\$ -	\$ 299,887	\$ 82,734
Deferred revenue	198,802	-	-	-	198,802	153,572
	498,689	-	-	-	498,689	236,306
Deferred lease inducement	6,715	-	-	-	6,715	10,377
	505,404	-	-	-	505,404	246,683
Fund balances:						
General Fund	367,244	-	-	-	367,244	766,949
Capital Assets Fund	-	55,593	-	-	55,593	68,696
Endowment Fund	-	-	1,790,204	-	1,790,204	1,824,045
Ralph Walker Research Fund	-	-	-	1,723,755	1,723,755	1,786,538
	367,244	55,593	1,790,204	1,723,755	3,936,796	4,446,228
Commitments						
	\$ 872,648	\$ 55,593	\$ 1,790,204	\$ 1,723,755	\$ 4,442,200	\$ 4,692,911

*These statements are extracted from the audited financial statements for the year ended March 31, 2023. The full set of audited financial statements is available on our website.

Statement of Operations

Year ended March 31, 2023, with comparative information for 2022

	General Fund	Capital Assets Fund	Endowment Fund	Ralph Walker Research Fund	2023	2022
Revenue:						
Donations	\$ 1,844,959	\$ -	\$ 500	\$ 178,154	\$ 2,023,613	\$ 1,775,854
Chapter and volunteer fundraising revenue	1,053,660	-	5,000	4,513	1,063,173	999,496
Investment income	82,083	-	-	58,651	140,734	196,307
Grants	7,000	-	-	46,770	53,770	77,383
Change in fair value of investments	-	-	(39,341)	(28,169)	(67,510)	(198,096)
Other income	38,149	-	-	-	38,149	421,730
	3,025,851	-	(33,841)	259,919	3,251,929	3,272,674
Expenses:						
Research	60,000	-	-	322,702	382,702	230,724
Family services	1,426,113	-	-	-	1,426,113	1,221,017
Public awareness and education	255,501	-	-	-	255,501	249,163
Chapter and volunteer support	262,388	-	-	-	262,388	158,213
Development	381,036	-	-	-	381,036	301,547
Chapter and volunteer fundraising expenses	204,123	-	-	-	204,123	168,021
Administration	828,609	-	-	-	828,609	587,081
Amortization	-	20,889	-	-	20,889	18,532
	3,417,770	20,889	-	322,702	3,761,361	2,934,298
Excess (deficiency) of revenue over expenses	\$ (391,919)	\$ (20,889)	\$ (33,841)	\$ (62,783)	\$ (509,432)	\$ 338,376

*These statements are extracted from the audited financial statements for the year ended March 31, 2023. The full set of audited financial statements is available on our website.





Our 2022/23 Donor List is available on our website



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

