

SUMMER 2023



ISSUE 167

HORIZON





SHELLY REDMAN

NOTE FROM THE CEO

Happy 50th birthday to the Huntington Society of Canada (HSC), and the entire supportive community!

We are halfway through this celebratory year, and there have been so many amazing initiatives in the Huntington disease (HD) arena to recognize.

In keeping with the halfway theme, we are thrilled to have made it past the halfway mark in our Route 50: Driving Hope Forward fundraising campaign.

Our goal is 3 million – we have raised nearly two million dollars!

That means we have solidified the funding for the Huntington Society of Canada Research Chair, held at Western University. This is fabulous news. We can't wait for the recipient of the endowed chair position to be selected so that they can begin work.

This milestone also signals a shift from fundraising for the research chair and now focusing on the groundwork for the Centres for HD CARE (Clinical And Research Excellence). The first step is a needs assessment; we are eager to move forward in this important project that will bring HD-specialized care close to everyone.

Spring events were back with so much positive energy and it was wonderful to be able to gather again. These events are not just great fundraisers – they're also important community builders. Forging connections and strengthening bonds are incredibly important outcomes.

Family Services offerings continue to bring education and information to our community where and when they need it the most. We were proud to offer a virtual webinar and fact sheet about insurance options for families facing HD. We heard from many of you that this information was particularly needed and we were pleased to be able to provide such targeted resources.

New for the 50th year are two special fundraising campaigns. We have relaunched our memorial giving campaign as the HSC Garden of Memories. I hope many of you will find comfort in being able to honour a loved one who has passed. We are also seeking 50 new monthly donors for our 50th year. Monthly donors truly are the unsung heroes of the funding model. Without them, we would not be able to plan programs and services. Their consistent contributions make it possible for us to provide continuous support – we are so grateful.

Coming up soon is our National Conference – in person! I can't wait to meet many of you and dive into some fantastic programming and social events. This truly has been a golden year and I am so pleased to be able to share it with you, our amazing community. I'm energized to face the second half of this year with motivation and drive to reach our goals with the support of this amazing community.

Here's to another half century of care!

Shelly Redman
CEO

AN ARIEL VIEW The Garden of Memories

I'd like to welcome you to the Huntington Society of Canada (HSC) Garden of Memories, a place where love and remembrance live on.

Today, I invite you to become a part of this journey by supporting the Huntington Society of Canada. With your generous memorial gifts, we can nurture hope and make a lasting impact on the lives of those affected by Huntington disease (HD).

HSC is dedicated to providing support, education, and advocacy for individuals and families touched by Huntington disease.

The Garden of Memories is a new memorial initiative made possible by your donations in honour of a loved one.

In return, we will plant a flower in the digital Garden of Memories in their honour. With your support, the garden will come alive with vibrant blue and purple blooms, representing HD and Juvenile HD.

Help us nurture the Garden of Memories. Your donation, no matter the size, will provide vital resources, support programs, and innovative research, enabling us to empower individuals living with Huntington disease and their families.

Your contribution can help fund educational workshops, carer support programs, and research breakthroughs that bring us closer to a meaningful treatment for Huntington disease. Together, we can plant compassion and hope, ensuring that no one faces the challenges of Huntington disease alone.

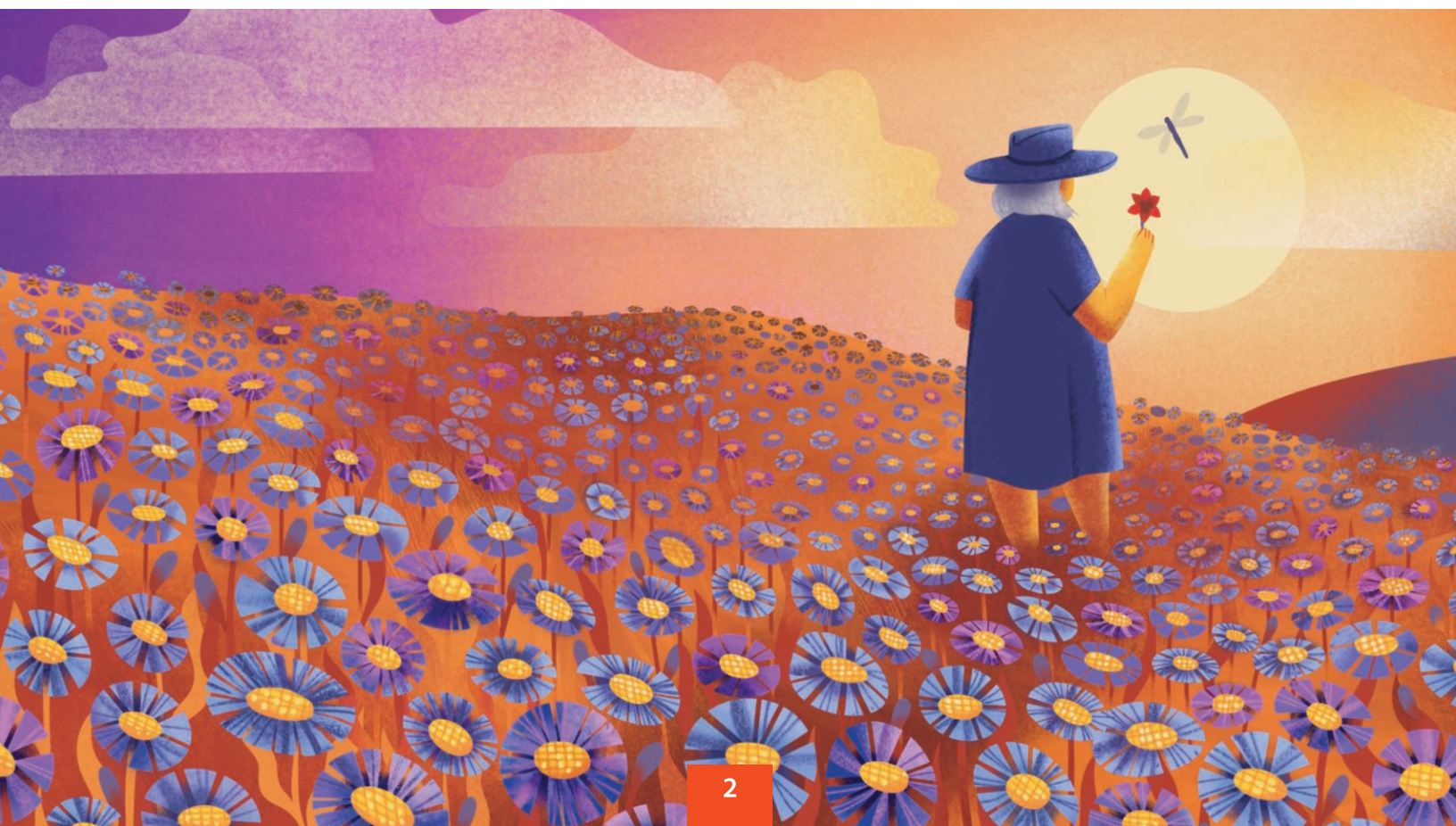
This is a very special campaign for me. Not only am I featured in the illustration – yes – that's me! – so too is Ralph (my late husband and co-founder of HSC), in the form of a dragonfly, a very special symbol for me.

I plan to make a donation in memory of Ralph, whom I feel everywhere, but especially in the beauty of nature. I know he would be so moved by this campaign. It's a beautiful tribute to all of the people taken far too soon from their loved ones.

I would be so appreciative if you could join us in creating the Garden of Memories, where every flower represents a life touched and a memory cherished.

Let's bring this magical garden to life!
www.huntingtonsociety.ca/garden-of-memories/

Ariel



DEAR HSC

Dear HSC,

For a few years, I attended the HD clinic with my grandfather, and now I go with my dad. The HSC social worker is often there during the appointments, but I never felt the need to connect with them until now. As things are changing with my dad and I am thinking about my own risk of HD, I think I would like to connect with the HSC social worker in my area. Where do I start?

Great question! There are many ways in which the Huntington Society of Canada (HSC) social workers can be reached. Here are some links and phone numbers that can help you reach them:

- As you mentioned, HSC social workers attend HD clinic appointments and you can connect with them there.
- HSC social workers also participate in local chapter events; you may run into them there as well!
- You can also find the list of social workers (and their phone numbers/emails) on our HSC website here:
www.huntingtonsociety.ca/family-services-team-list/
- If you are unsure as to which social worker covers your area, you can submit your question at the self-referral link here:
<https://contactme.cloud/form/huntingtonsociety>
- If phone is easier, you can also call our HSC toll free number 1-800-998-7398 and ask for the social worker in your region.

Please remember, should you be looking for the youth and Young Adult Mentorship Program, you can also use these links to reach out. We look forward to connecting with you!



YPAHD UPDATE

Shine a Light

As part of May Awareness Month, the YPAHD Chapter challenged youth to #ShineALightonHD. One of the YPAHD Executive members even posted a glow stick dance!

Monthly Drop-in Google Meets

Missing that feeling of community and support? YPAHD has you covered! They're hosting monthly drop-in Google Meets where you can all come together, chat, and support each other. These virtual hangouts happen Sundays at 4:00 p.m. Eastern time. Mark your calendars for these upcoming dates: July 9, Aug. 13, Sept. 10, Oct. 15, Nov. 12, and Dec. 10.

If you have any ideas for topics to cover, head over to YPAHD's Facebook page and drop them a message or comment.

Can't wait to see your lovely faces there!



YPAHD DAY: Thursday November 16 (pre-conference)

Listen up, folks! YPAHD Day is coming up on Thursday, November 16, and it's all happening in beautiful Niagara Falls, Ontario. Get ready for a day filled with connections, learning, and support. It's the perfect opportunity to meet other incredible individuals affected by HD, share experiences, and create lasting memories. Don't miss out on this fantastic event! Limited funding is still available. Register now at www.huntingtonsociety.ca/ypahd-day/.

YPAHD is here to support and uplift our amazing Huntington disease community, especially youth aged 14-35. Let's shine a light on HD together by sharing our stories, attending those awesome Google Meets, and joining the excitement on YPAHD Day. We're in this together, and together, we'll make a difference! **Stay strong, stay connected, and keep spreading the love!**



WHAT TO WATCH, READ, DO

There's a lot of helpful content in our learning library, as well as loads of things to do. Here's what to watch, read and do.



WATCH:

- Our new animated video “What is Huntington disease” is on our YouTube channel: www.youtube.com/watch?v=hZbDc5Rs_Cc
- The Netflix show *Virgin River*, featuring a character with Huntington disease, returns Sept. 7
- The show *911 Lone Star*, shown above with Chad and Rob Lowe, features a Huntington disease storyline and returns in the fall.
- Check out our video about the Centres for HD CARE (Clinical And Research Excellence) on our YouTube channel here: www.youtube.com/watch?v=w_qRB8zH3AY
- Learn more about the HSC Research Chair at Western University via our video on YouTube: www.youtube.com/watch?v=jfu7OJUbzZg



READ:

- Our latest fact sheet, “Important Things to Know About Health and Life Insurance”: www.huntingtonsociety.ca/wp-content/uploads/2023/04/HSC-Life-and-Health-Insurance-Tips.pdf
- Our 2023 National Conference Program to decide on sessions, should you be attending: www.huntingtonsociety.ca/wp-content/uploads/2023/05/Registration-Package-Final.pdf



DO:

- Register for YPAHD Day and Conference: Early Bird deadline is Aug. 31: www.huntingtonsociety.ca/conference/
- Saturday July 22: 18th Barry’s Bay Volleyball in Ontario
- Saturday Aug. 20: 8th Annual Coachman’s Cove Walk in Newfoundland
- Saturday Aug. 26: 13th Annual Ride 4A Cure in Peace Country, Alberta
- Sunday Sept. 10: 8th Annual Golfapalooza in Niagara, Ontario
- Sunday September 10: 28th Annual Winnipeg Indy in Manitoba
- Saturday September 23: 4th Annual Thanksgolfing in Peterborough, ON
- Sunday September 24: London Indy in Ontario
- Saturday September 30: Toronto Drive for a Cure Golf Tournament
- Thursday November 16: YPAHD Day in Niagara Falls, ON
- Friday November 17 to Saturday November 18: National Conference in Niagara Falls, ON



CHAPTER HAPPENINGS



ALBERTA

- The **Edmonton Chapter** hosted their first in-person Wellness event since the spring of 2019 on April 16. Attendees were impressed by guest speakers on research, genetic testing, and youth mentorship.
- The **Southern Alberta Chapter** hosted their casino on April 11 and 12, with support from Alberta Gaming and a committed group of volunteers who worked the casino floor over two full days. Casino events in Alberta raise an average of \$60,000 each year!
- The **Camrose Golf Tournament** took place on June 17. The event sold out several months ago. Golfers took part in 18 holes, a hot dog lunch, bbq dinner, silent auction and more. More importantly, it was the first time the chapter has been able to host the tournament after a few years of not being able to connect. So great to see this event in action again! Neveah, aged 8, set up a lemonade stand in support of HSC as a part of Northern Alberta's Lemonade Day on June 17.

SASKATCHEWAN

- The **Saskatchewan Chapter** was thrilled to host Jimmy Pollard April 12 and 13 for the first "HSC Pollard Tour" since the fall of 2019.
- Individuals in Regina and Saskatchewan, as well as two long-term care facilities, were able to learn about the physical and cognitive aspects of HD.

ONTARIO

- The **London Chapter** hosted a social and educational event on April 23 to bring together chapter members for a day of learning and camaraderie. Attendees enjoyed guest speakers, including a virtual presentation from Jimmy Pollard, a hands-on activity, potluck lunch, and social time.
- Co-President Jo Kaattari of the **Barrie Chapter** once again hosted her amazing Wildflower Webinar on May 8. Participants were delighted by for a virtual tour of the "greatest show on earth" - beautiful spring wildflowers blooming in Ontario's forests!



Huntington Heroes Walk

ONTARIO

- The **London Chapter** hosted the London/Exeter Walk on May 27. The event takes place in a small town outside of London and is always well attended. This year saw several new faces – welcome!
- The **Toronto Chapter's Walk** on May 14 was a great success. Participants had a wonderful time connecting and chapter members had the chance to meet Chapter President Natalia Marnica's 3-month-old daughter Isabel. The event included an online auction, live DJ, snacks, refreshments, as well as a (temporary) tattoo booth, "Tats 4 HD", inspired by conversations had at the Presidents Gathering in February!
- The **Niagara Chapter's Lake-to-Lake Challenge** was hosted by Ron Culp, who was recently elected to Vice-President for the chapter. Ron's wife Janice co-hosted the fabulous event, which took place May 13. The event raised \$9094!
- The **Sarnia Walk** took place on May 27 and area rep Celine Payne spent many hours on local radio promoting the event. Way to raise funds and awareness! On the same day, further north along the Lake Huron coast, Shaunacy De Jong organized an amazing Sauble Beach walk enjoyed by an energetic and supportive community.
- The **Ottawa Chapter's Walk** made its mark on May 13. A small but mighty crew came out for one of the chapter's first in-person walks. Typically, this group participates in the Tamarack Ottawa Race Weekend, but had branched off with virtual walks during the pandemic, and chose to host their own small event this year. Congratulations!
- The **Durham Chapter's Walk to Cure** launched into action on May 28. Historically, the chapter has called this event a walk "and fun fair" and it's easy to understand why. This year's event included tethered hot air balloon rides, silent auction, kids' activities, face painting, Smiling Faces Equestrian Centre, Animal Guardian Society and some furry friends, Durham Regional Police Services Forensics Vehicle, Bowmanville Fire and Sparky the Fire Dog, live entertainment, bouncy castle, and more! Thanks to a partnership with the **Peterborough Chapter** that came about at the Presidents Gathering, attendees also enjoyed donated hamburgers, veggie burgers and hot dogs.





MANITOBA

- The **Winnipeg Walk** had another fun-filled day on June 3. This wonderful event partners with the local runners club to further awareness and fundraising opportunities.

B.C.

- The **Vancouver Chapter's Walk** took place on May 7. Attendees enjoyed a silent auction, door prizes, 50th anniversary merchandise and live entertainment. Thanks to generous sponsors, the silent auction included tickets to Shania Twain, Matchbox20, and Luke Combs concerts.
- The **Vancouver Island and Gulf Islands Chapter** hosted their first fundraising walk after a long hiatus. Hedley Cullen, President, and Events Coordinator Susan Nickerson committed a number of hours to media relations and awareness generating around the walk, as well as their #Lightitup activities for the month. The result was a great article published in The Lookout, a community newspaper for CFB Esquimalt. On May 27, over 30 people attended the Walk in Esquimalt, and the group was able to raise lots of great awareness for the cause.

ALBERTA

- The **Edmonton Walk** was back in person on May 27. A great time was had by all!
- **Southern Alberta** had a wonderful 15th Annual Hope Run in Calgary on June 10. This year's event included an online silent auction and raffle table, family registration prices, and even dog registration that included a Hope for a Cure bandana for the four-legged friends in attendance!

SASKATCHEWAN

- The **Saskatchewan Walk** took place on May 27 in Saskatoon. Volunteers and participants from across the province came together for a day of connection and fun including breakfast foods, pizza, and a silent auction.
- Walkers took to **Lafleche** on June 10, followed by lunch and wonderful community connection.

ATLANTIC CANADA

- Members of the **PEI Chapter** scheduled their annual Walk in Bonshaw Provincial Park for June 3. The event was postponed due to weather, but the chapter held an intimate breakfast to connect instead - way to make the most of a bad situation!
- The **Newfoundland Chapter** hosted their walk event on May 27 at Quidi Vidi Brewery. The unique venue wasn't the only stellar aspect of the event – proceedings also included live music, a silent auction and tons of fun.
- The **New Brunswick Chapter** celebrated community at their walk May 27 at the Stepping Stone Senior Centre in Fredericton. It was wonderful to see some new families come out to support the HD cause. Amazing job!

#LightItUp4HD

#LightItUp4HD 2023 was a huge success! For the first time, we illuminated more than 100 Canadian sites during the campaign. In another first, we distributed 400 #LightItUp lawn signs around the country.

Visit the #LightItUp4HD website to see the full list of sites that were illuminated in your region, and across Canada in May.

A big thank you to our two National Volunteers, Keely Crawford McCoy and Tavleen Kaur, for their great work in making #LightItUp4HD a huge success in Canada this year. Hats off as well to the original #LightItUp4HD volunteer James Walters, who helps motivate the international efforts every year, as well as pulling together images and videos. Hooray to Taylor Crain, our amazing graphic design volunteer for another standout logo this year.



MEET THE NEXT GENERATION OF HD RESEARCHERS

The future is looking bright for Huntington disease research. The Huntington Society of Canada, thanks to generous donations from the community, is funding four summer research positions.

The student fellowship program has two goals:

1. To attract the brightest young scientists into the field of Huntington disease (HD) research
2. To facilitate meaningful HD research to pinpoint the biological mechanisms underlying HD pathology

The four fellowships offer undergraduate university students across Canada the opportunity to pursue an HD research project conducted over a 12-week period between May and September. Fellowship recipients, working under the supervision of senior HD scientists, are working on projects that are focused and achievable in a short timeframe, yet helpful in guiding future HD research.

And now – here's your starting lineup!

Justin Alvarado

Justin Alvarado is a recent graduate of the Honours Biochemistry program at McMaster University. He completed his 4th-year thesis project in the Truant Lab, becoming inspired by the drive and collaboration between the lab and the Huntington disease (HD) research community. Justin will complete his Masters degree in the Truant Lab, investigating the role of ATM in HD and its therapeutic potential.

Justin also enjoys playing guitar, weightlifting, running, and, most of all, playing and coaching soccer! Says Justin, "I am extremely excited to get to work this summer and beyond grateful for the support from HSC."



Tess Leavitt

Tess Leavitt recently graduated from Queen's university with a Bachelor of Science in Kinesiology with honours. For the past two summers, she has worked as a student researcher at the Centre for Molecular Medicine and Therapeutics at the University of British Columbia with a strong focus on Huntington disease research.

"I look forward to continuing this research this summer. I am extremely passionate about scientific molecular research and patient-centred care." Tess was born and raised in Vancouver, BC and loves spending time outdoors, sewing, and playing sports.

Rylee McDonald

Rylee is a fourth-year Bioengineering student at McGill University. Her passion for biomedicine and design has flourished over the course of her degree and throughout her participation in various extracurricular activities. After learning about recent developments in the field of neurodegenerative research in class, she became very interested in contributing to the field.

"Although I have not been impacted by Huntington disease directly, I am inspired by the work done and supported by the Huntington Society of Canada. I very much look forward to this summer experience," says Rylee. In her research with Professor Adam Hendricks at McGill University, she will work to uncover how mutations in the HTT huntingtin gene alter the constituents of the huntingtin transport complex and contribute to Huntington disease.

Etienne Sellar

Originally from Oakville, Ontario, Etienne recently earned his Honours BSc degree in Neuroscience from the University of Guelph. His grandfather's experience with the later stages of Alzheimer's disease helped Etienne realize the importance of studying and finding better treatment options for neurodegenerative diseases. Etienne completed an undergraduate research project in Dr. Alpaugh's lab looking at the effects of environmental stressors on protein misfolding.

Etienne says, "Thanks to the HSC award this summer, I will continue to work under Dr. Alpaugh's supervision to study human blood-brain barrier models. Specifically, we will look at the proteins and types of cells involved in this barrier and how they change to form a less functional barrier in Huntington disease models."

We can't wait to see what discoveries await this gifted group.



SOUTHERN ALBERTA POOL FUNDRAISER



The 2nd Annual Huntington disease Hope for a Cure Pool Tournament Fundraiser held on May 13 was an incredible success. Six teams took home cash prizes and enjoyed a 50/50 draw, donated food and pizza, and a live broadcast of the event. Our heartfelt gratitude goes to organizer Georgios Zigopoulos and all the individuals involved in making this event possible.

And now, let's hear from the organizer himself, Georgios:

"A huge thank you to everyone who attended and contributed to the fundraiser. Your support and generosity resulted in raising just over \$32,000, including the donation matching by an anonymous donor for spring HSC fundraising events. These contributions have made a significant impact in raising awareness and funds for Huntington disease. I am so grateful for your overwhelming support.

Big kudos to the players who participated in the tournament. Your skills, enthusiasm, and sportsmanship created an unforgettable experience for everyone involved.

Thank you, as well, to the venues and staff who hosted the tournament. You provided such a welcoming and enjoyable atmosphere that contributed greatly to the event's overall success. Your help means the world to us.

Special thanks go out to our amazing volunteers and tournament directors, Larry Walper, Stephanie Toy, Wendy Bruntjen, and Tara Johnson-Ouelette. Your hard work behind the scenes, from organizing logistics to selling tickets and ensuring a smooth flow of the tournament, was key to making this event a resounding success.

With everyone's support, we have taken a step forward in supporting research and support services for Huntington disease.

Let's continue to build on this momentum! I encourage everyone to keep supporting the cause in any way possible. Whether it's raising awareness about the disease or helping to grow an event, every contribution counts. Together, we can make a lasting impact. Thank you."

Hats off to Georgios Zigopoulos for organizing this incredible event, and to all who played a part in its success. We look forward to future fun events as we continue our journey toward a world free from Huntington disease. Great work, everyone!



Happy Retirement!

Bernie Modrovsky

- Resource Centre Director (RCD) in Northern Alberta – retired at the end of March 2023. Bernie had been with HSC since 2014 and was well-loved for her contagious laughter and caring and empathic ear!

Marilyn Mitchell

- (RCD in East Central ON) retired at the end of June. Marilyn had been with HSC since 2012, when she took on the (at the time new) East Central ON Resource Centre Director role. Her calm and compassionate approach will be greatly missed.

Marthe Gautreau

- Out on the east coast, Marthe Gautreau (RCD in New Brunswick) retired at the end of June. Marthe worked with HSC since 2001, starting as a Family Services Worker, then taking on the new NB Resource Centre Director role in 2017. We will miss Marthe's loving and energetic care, as well as her wonderful photos!

Gioia Levesque

- Family Services Worker in Windsor, ON has retired after over three decades of work with HSC. Thank you for all you have done for the families in southern ON, Gioia.

Bernie, Marilyn, Marthe and Gioia, we wish you well and much happiness on this new adventure you are about to begin!

Moves & New Roles

Rhonda Romolock

- Former RCD in BC - has moved to Edmonton... and so she will be staying with HSC and has assumed the Northern AB RCD role. We are so happy that Rhonda is able to continue to be part of the HSC team!

Corrina Masson

- Family Services Worker [FSW] in Vancouver) is now RCD for Vancouver and area.

Jennifer Aikens

- (FSW for Victoria) has accepted the NEW RCD role for Victoria and Vancouver Island.
- We are also recruiting for another NEW RCD role. This new role will provide services to the HD community in the BC Interior (including Fraser Valley, the Okanagan and the northern parts of BC).

Ana Paret

- RCD for Southwestern ON, will be providing support, advocacy and education to the individuals and families affected by HD in the Windsor/Essex regions.

Congratulations to everyone on these exciting life changes!

TRANSITIONING TO CARE HOMES

Transitioning to a long-term care home, also called a nursing home, continuing care facility, and residential care home (depending on where you live in Canada) can be challenging. While most people prefer to stay in their homes, the increasing care needs of someone with Huntington disease (HD) can become more than what their spouse, partner or family can provide.

Navigating Transitions to a Care Home

At our upcoming National Conference Nov. 17-18 in Niagara Falls, ON, Huntington Society of Canada (HSC) Resource Centre Directors (RCDs) Sheri Mayhew and Muna Young will present a session focusing on this topic.

You and your family may not be at this stage of the HD journey, but these resources are here for you. It can be helpful to consider options available and plan over time as this can offer a bit of control over a situation and disease in which we have little control.



Sheri Mayhew



Muna Young

As you consider what may work for you and your family:

- **Be Proactive:** Preparation for a care home could include conversations with family and friends. Planning also includes a variety of considerations, and your local HSC Resource Center Director (RCD) can help you identify areas to explore.
- **Build Your Team:** Establish a support system that includes both formal and informal support, such as friends, family, and healthcare professionals.
- **Determine the "Right" Time:** Supports, such as the regional HD multidisciplinary team and RCD, can help the person with HD and the family determine when is the right time to engage in the transition to a care home. The RCD can also help you to connect with the community resource that will process the care home application.
- **Funding Eligibility:** Care home costs and subsidies vary by province in Canada. The health care professionals assessing your care needs, often called case managers, will explain the costs and funding options available. Contact the community case manager to determine your eligibility.





- **Recent care home options:** Learn about the most up-to-date long-term care options in your area. This may help to promote a positive view of the long-term setting and services offered. By visiting the potential care homes, you can observe how each operates. Engage in open conversations with the person with HD (and the family) about how the care homes may best address their needs.
- **Utilize Respite Services:** Most provinces offer respite services. These services help to provide care on a short-term basis in a care home. They may also help to prepare the person with HD and their family for the transition into a care home.
- **Navigating the emotions of change:** Many emotions, such as grief, anxiety and relief, can surface, associated with the new living arrangements as the person with HD moves into a care home. Share your emotions with family and friends, talk to others in similar situations, and access emotional support services.
- **Family Involvement:** Stay involved, consider visiting regularly, establish a communication point person at the care home, personalize personal space, and encourage staff education on HD. Creating a Life/Memory Book can help staff understand the person's life story.

When transitioning to a care home, please remember that the staff members are an important support that can develop special bonds with the person with HD and their family. The RCDs are available to support the care homes' ability to meet the needs of the person with HD. This is done by providing education and consultation to the person with HD, the family and the staff.



For more information, HSC has a fact sheet entitled **Transitioning to Long-term Care** that you can read here: www.huntingtonsociety.ca/wp-content/uploads/2020/10/Transitioning_to_LTC-Factsheet-Oct-2020.pdf.

You can also contact HSC's Resource Centre Directors (RCDs).

First time contacting the Family Services team?
Use this link: contactme.cloud/form/huntingtonsociety

Otherwise, you can look up your RCD's contact information here: www.huntingtonsociety.ca/family-services-team-list/

For further guidance, visit provincial ministry of health websites, or connect with HSC chapters and support groups. These resources can provide valuable information and insights from others who have gone through the transition to care homes.



**WILL YOU
SIGN UP
TO BE ONE
OF OUR
50 FOR 50?**

CAN WE COUNT ON YOU TO BE ONE OF THE **50 FOR 50**? WE'RE CELEBRATING OUR 50th ANNIVERSARY, AND INSTEAD OF GOLDEN TRIBUTES, WE WANT SOMETHING EVEN BETTER: **HOPE!**

You know that Huntington disease (HD) is a devastating genetic condition that affects approximately 1 in every 7,000 Canadians. Its impact is profound. HD affects people's minds and bodies, and emotions, often making it hard to move, speak, and do things on their own.

Tasks that many of us take for granted become incredibly challenging for those with HD. Current treatments can only manage the symptoms, leaving us determined to find a more meaningful solution. But we can change that with your help. We need 50 new monthly donors to shake things up and make a difference in the HD world.

We've profiled **2** amazing monthly donors on this page. Read about why they feel compelled to help. We already have **11** new monthly donors – that's a move in the right direction!

When you donate to the Huntington Society of Canada, you're making a big impact. Your support helps fund a research chair in Huntington disease at Western University. That means we'll get closer to understanding this condition and finding a treatment that really works. Not only that, but your donation also helps create the Centres for HD CARE (Clinical And Research Excellence) in Canada. That way, folks affected by HD can get the specialized care and support they need, no matter where they are.

This is a big moment for us, and we want you to be a part of it. Together, we can bring hope to those living with HD. No amount is too small, so please consider donating today. Just visit our website to learn more and become one of the 50 for 50. Let's make a real difference together!

Thanks for considering being one of the 50 for 50. Happy 50th to everyone.

Two Amazing Monthly Donors!



Elaine Cooper, Moncton, New Brunswick

It was an easy decision to donate initially to the HSC when my youngest brother-in-law, Ben, was finally diagnosed with Huntington disease.

Ben lost a series of jobs and his marriage ended. He had two children. Eventually, Ben moved to a group home. My husband helped in finding one that was a good fit. My eldest daughter and I took Ben to the small support group meetings, even after I moved to my present home in 1991. My daughter continued to be involved in meetings after she moved out west until her military husband had out of country postings.

Ben's diagnosis explained what had been the matter with his father, who died of an aneurysm after years of strange behaviours.

Ben died at 49, his daughter at 28, and his son at 45.

My husband had predictive testing as soon as it was available - the best Thanksgiving gift we've ever had - and one of his brothers has been tested. So far, we believe that no one else in the family has developed the disease.

I was fortunate in meeting Ralph Walker early in this saga and, in appreciation of his and his wife's commitment, decided to begin donating, eventually doing so monthly.



Ron Sandalack, Regina, Saskatchewan

The reason that I support the Huntington Society of Canada with monthly gifts is primarily my involvement with being a caregiver from late in the 1990s into the mid-2000s. My late wife Judy was diagnosed in the mid-1990s and eventually passed on in early 2010.

We were both actively involved with the Northern Alberta Chapter during the 1980s and well into the 2000s. It was during this time I became aware of the terrible effect Huntington disease had on the family and friends of those facing the disease.

My small contribution alone will not do much to alleviate those effects. However, as a national effort led by HSC and involving thousands of others like me, perhaps we can make a difference.

50th CAMPAIGN UPDATE

Centres for HD CARE and HSC Research Chair at Western University

The theme of our 50th Anniversary is Driving Hope Forward. And one of the forces helping propel progress further is partnership.

Partnership is a concept well known to HSC and the Huntington disease (HD) community.

This year is the 30th anniversary of the scientific publication detailing the discovery of the expanded gene that leads to the progression of Huntington disease.

That giant step forward in HD research was made possible by the efforts of international partners, all working together and sharing information.

But it couldn't have been done without the partnerships with individuals and families living with Huntington disease, who donated blood samples and detailed family history to fill in the missing pieces of the HD puzzle.

HSC Research Chair at Western University

The Huntington Society of Canada Research Chair, held at Western University, provides the opportunity for another leap forward in our understanding of HD, as well as our fervent hopes for finding a way to stop or slow the progression of HD.

This is why we are so thrilled to have raised over 1.9 million towards the 50th Anniversary Campaign, and how honoured we are to work with such an esteemed institution as Western University. Once again, a partnership will be the key to hope and a brighter future.

HSC's vision is a world free from HD. We know what causes HD. We know where the mutation takes place.

With more research, like the type afforded by this research chair, we know we can take the next step and stop the progression of the disease.

As our knowledge in the field continues to expand, we will also deliver on HSC's mission, which is to improve the quality of life for those affected by HD.

That's why we're here. To make a difference in the days of people who are living with this disease.

We've been doing this for 50 years. We have a renewed focus on supporting research and providing support services in the field of Huntington disease. All with the goal to deliver on our mission.

So thank you. Thank you to our donors, for giving so generously. Thank you to Western University, for matching these donations and providing a home for the chair. Thank you to the community for raising funds, awareness and spirits.





CENTRES FOR HD CARE (Clinical And Research Excellence)

Now that the focus of the 50th Anniversary Campaign has shifted towards the Centres for HD CARE, we'd like to tell you more about them.

- We have a vision to bridge the gap between people affected by Huntington disease (HD) and specialized care.
- These clinical hubs will address unmet needs in HD-related health care services across Canada, and specifically in hard-to-service segments of the Canadian population.
- They will expand access to HD-experienced clinical care, counselling and other community and health services with a multidisciplinary care team.
- The centres will offer a variety of services and supports for youth, whether they are at risk, positive, or negative for the gene expansion that leads to the progression of HD.
- Family planning information, involvement in clinical trials, and carer resources will also be available.
- When we find a treatment for HD, the Centres for HD CARE will be there, ready to accommodate individuals living with HD for the chance at a higher quality of life.

The Centres for HD CARE is a bold vision with the goal to make sure that specialized care – and hope – are available on everyone's doorstep.

Don't forget to check out our video about the Centres for HD CARE featuring London Chapter President Jackie Skinner.

Here's a look behind the scenes on filming day!

HUNTINGTON SOCIETY OF CANADA

2023

NATIONAL
CONFERENCE



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/learn-about-hd/youth/youth-mentorship-program/](http://www.huntingtonsociety.ca/learn-about-hd/youth/youth-mentorship-program/)**

UP FOR A CHALLENGE?

You can fundraise for HSC if you are participating in a non-HSC-related race or marathon, such as the Toronto Waterfront Marathon in October, using our RaceHD platform! Various distances available!

If you're participating in a race that you don't see listed, email us at events@huntingtonsociety.ca



p2p.onecause.com/racehd

Volunteer Spotlight: Morley Ellis

Morley Ellis, of Moose Jaw, Saskatchewan, is following in his mother's footsteps. Carol Ellis founded the Saskatchewan Chapter because Morley's grandma, his father's mother, was diagnosed with Huntington disease (HD). The family struggled to find information on HD, and Carol was motivated to start the chapter to help people with the disease. In October 2022, Morley took up the reins as president of the Saskatchewan HSC Chapter following the retirement of long-time leader June Nichol.

Growing up in Lafleche, Saskatchewan, Morley had a lot of exposure to HD. His father's grandmother died from HD complications in her early 70s.

"Throughout the years we have had numerous aunts, uncles and cousins being diagnosed with HD," says Morley. "It's tough to wrap your head around it. It feels so damn unfair."

Now his father, who has HD, is in a care home. His mom passed away in 2005, and Ariel Walker attended the funeral. "I remember my mom making pajamas for Ariel and Ralph's kids," Morley says.

Morley has vivid memories of his mother's involvement in the Saskatchewan Chapter. He recalls tagging along to chapter meetings and fundraisers. "I remember one fundraising supper in Regina. Mom made pumpkin pies for the whole event – that made a big impression on me!"

Morley is full of praise for the rest of the small but mighty Saskatchewan Chapter. "My mom made lifetime friends in the HD community and I hope I can do the same. It is such a strong group, full of hope. And more than anything, I want to make my mom proud of me."

The chapter holds telephone meetings as they are scattered across Saskatchewan. Indeed, when Morley wants to see community members in person, it involves a lot of driving. "One week I drove 4 hours to Prince Albert, then to Saskatoon and Regina, home to Moose Jaw, and down to Lafleche."

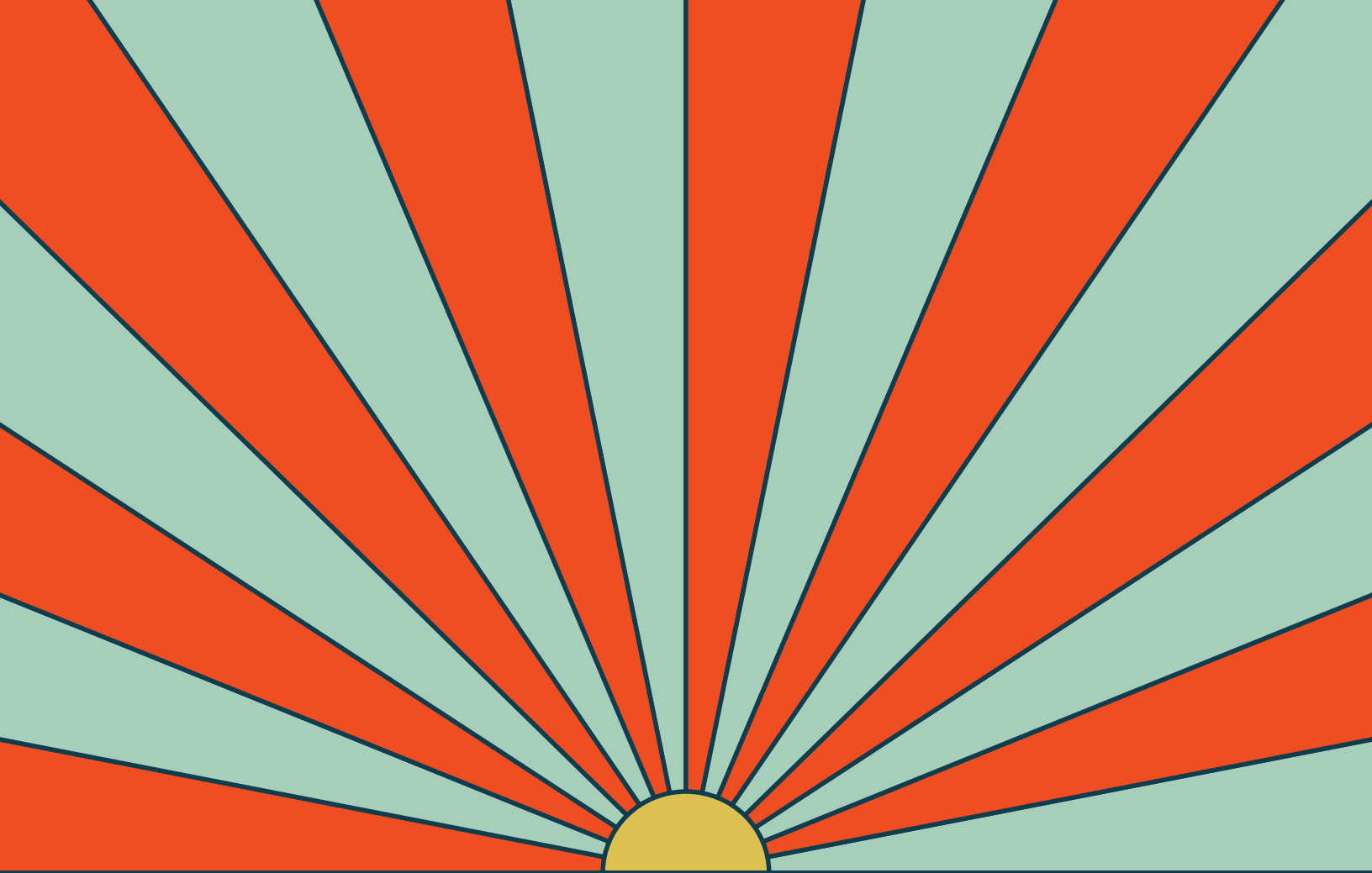
Morley is used to the commitment of being a volunteer. Previously, he was on town council and coached kids' hockey. "With volunteering, when everyone is focused on the same outcome, it can be truly fulfilling." He adds, "It's nice to help people."

In 2010, Morley underwent genetic testing, but he didn't access the results immediately. Then, in 2019, they were looking for people with HD to be participants in clinical trials. Morley wanted to volunteer, and that involved finding out his genetic test results – which are positive for the gene mutation.

"I chose to accept my diagnosis and cope by truly joining in with the HD community. It's the greatest extended family I could have." Morley is also a carer, visiting his father in the care home and helping him with various activities. Morley's wife has multiple sclerosis, so he assists her as well.

Morley's unwavering optimism and commitment to volunteering is an inspiration to everyone. His final message to the community is similarly uplifting. "I hope that when the 100th anniversary of the Huntington Society of Canada rolls around that Huntington disease will just be a footnote – and it will truly be a celebration."





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