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Last year was a whirlwind surrounding our 50th anniversary. We celebrated the incredible accomplishments by the Huntington Society of Canada (HSC) over the past 50 years, while bringing a renewed vision to HSC's mission of research and care. The Route 50: Driving Hope Forward campaign closed with:

- 3 million funding goal reached
- Garden of Memories Memorial segment surpassing the goal by 25%
- 62 new monthly donors through the 50-for-50 campaign

Thank you for your support. We are excited to see the impact of this funding and programming in the years ahead. Now, onto the new year, because for HSC, our fiscal year begins April 1.

You'll read more in this issue about exciting new additions to the 2024 National Walk. I'd also like to celebrate a few different events that are new or returning. As you read this, I'm likely in Calgary attending the Southern Alberta Chapter's fundraising gala. I am thrilled that this special event has returned. The theme is A Night to Flourish: Blooming Hope and Connecting Pieces. Many thanks to the organizers for their tireless efforts bringing this inspirational event back. Also in Calgary is the 3rd annual HD Hope for a Cure Pool Tournament and fundraiser May 12-14 - it's become a powerhouse event delivering on fun AND funds.

In other event news, our newly minted Sarnia Chapter got creative with a Music Bingo fundraiser, and the Manitoba Chapter battled stubborn Mother Nature to fundraise for the HD500 event in February, although the snowmobile ride had to be cancelled.

These successes would not be possible without the work of our outstanding volunteers. You've received this issue of Horizon during a special week: Volunteer Appreciation Week is April 14-20. There's nothing quite like this mutually beneficial relationship. We are so grateful to our amazing volunteers, and studies show that volunteering is incredibly important for wellbeing and leading a purpose-driven life. Stay tuned as we advertise specific volunteer openings.

Volunteers are an important part of our 2024-2027 Strategic Plan, which you can find on our website. It's a roadmap to continued excellence and we hope you'll see your needs and contributions reflected.

It's going to be another productive and fast-paced year, and we couldn't do it without you! Thank you for your participation in this beautiful Huntington disease community.

CEO, Huntington Society of Canada



AN ARIEL VIEW

Ariel Walker

In my last column I wrote about the Garden of Memories campaign, honouring loved ones who have passed. I want to extend a special thank you to those who contributed to the campaign, bringing our dear ones close to us. It is so special to think that the money generated from the campaign in their memory goes to help the Huntington disease community and families of today. March 22 was the 22nd anniversary of Ralph's passing, and this Garden of Memories campaign makes me feel close to him.

It's hard to believe that it has been 50 years since Ralph and I started HSC at our kitchen table - and now look at the exciting new achievements of the past year. We've established the HSC Research Chair at Western University and are now supporting new undergrad HD researchers. The enthusiasm of the community is just as strong as it was when we first started. Thank you so much for your contributions, whether financial or time.

Now, there is one group that is essential to the ability of HSC to keep going, and that's volunteers. What they do, and what they have always done, are beyond a doubt the most important actions of the past five decades. Even though I'm getting on in years, I'm still volunteering, and I won't give that up for a while - that's how important volunteering is. There are people I've known in the HD community for 50 years who are still contributing - it can be done.

What does it mean to contribute? You don't need to donate a massive sum. You don't need to commit thousands of hours. Everyone's volunteering looks different to them and has its own special impact.

I remember one community member, a nurse originally from England, who always bought three Amarylles from me. Her health worsened and she couldn't get around easily, so I delivered the kits to her. I always looked forward to that delivery because we had a good chat every time; in fact, I would plan my day to allow for that time to connect. I genuinely enjoyed these visits, and they were uplifting for her, too. She has since moved to the Maritimes and I've lost touch, but that's an example of a contribution and connection specific to her situation.

This community is its own family, from the health care workers to the researchers, the staff to the volunteers, all working together toward the end goal, which is to make life better for those affected by Huntington disease. It's the work of a special kind of family and it is phenomenal. Thank you everyone for all your unique contributions. They make everything possible.

Ariel

Dear HSC

How does HSC advocate for members of the Huntington disease (HD) community?

As Huntington disease is considered a rare disease, it does not always “fit” into the community or health care service lists. Individuals and families may face exclusion from services that would make their journey through HD a little easier. Since its creation over 50 years ago, HSC has advocated on multiple levels for the needs of individuals and families affected by HD to ensure they have a voice and access to supports and services needed.



On a national level, HSC has advocated in collaboration with other genetic conditions for protection against genetic discrimination for people living in Canada. In 2017, the Genetic Non-Discrimination Act (GNDA) became law in Canada. The GNDA makes it illegal for any person to require someone to undergo or share the results of a genetic test to enter into a contract or agreement (you can learn more about the GNDA here: www.huntingtonsociety.ca/gna/)

HSC also partnered with HD and movement disorders clinics across the country to ensure that the HD community was ready once clinical trials became available. HSC collaborated with various community members to ensure that researchers and pharma understood the realities of living with HD and the importance of finding a meaningful treatment for HD.

Our advocacy work extends to collaborating with other charities as part of specialty organizations. Our CEO Shelly Redman is the co-chair of the governing council of Neurological Health Charities Canada (NHCC), a coalition of organizations that represent people with neurological diseases, disorders and injuries in Canada. Shelly also sits on the Board of Directors of the Health Charities Coalition of Canada (HCCC), working alongside more than 20 major charities on advocacy efforts.

Regionally and locally, HSC social workers advocate for individuals and families to ensure they have access to services needed as HD progresses. The Canadian Association of Social Workers provides a guiding principle for advocacy in social work: “social workers advocate for the rights of all individuals, families, groups and communities to be free from oppression, exclusion, racism and discrimination”.

This can include access to day programs, transportation, assistive devices, housing, or income support. Each region has a variety of program options, and the regional HSC social worker is best equipped to understand the service landscape, criteria and the contact persons that may be helpful in accessing those services.

Most often, we start with education about HD. As we work to advocate on behalf of individuals and families, awareness of Huntington disease grows. HSC Chapters also raise awareness about HD, and you can connect with them here: www.huntingtonsociety.ca/chapters-near-you/). To learn about how HSC social workers could help you or your family, please reach out here: <https://contactme.cloud/form/huntingtonsociety>)

Finally, Community Education Forums (CEF) are back! These free, online webinars offer education on different topics in HD research and care. We hope you can attend!

October 19, 2024: Jim Pollard
February 1, 2025: HDBuzz

Volunteer Profile: Sébastien Heins



Sébastien Heins remembers vividly when his family's Huntington disease journey began. As a teenager, he recalls watching his mother acting oddly, moving her foot uncontrollably while drinking her morning coffee. He would ask her to stop, and she couldn't.

This loss of control - and subsequent learning how to take control back - became the central theme of his solo theatrical production *No Save Points*. Opening in June 2023 to rave reviews, it was produced by Outside the March, Starvox, and Modern Times, in partnership with the BMO Lab and Hilltop Games. Sébastien began working on the play in 2019 and started to develop it in earnest in 2020. No stranger to the stage, he debuted at age 10 in *The Lion King* and has performed for 20 some years, including at the National Theatre School of Canada and the Stratford Festival.

"I wanted to write a play that was about my mom having Huntington disease. It's about losing control and taking back control."

No Save Points uses the concept of audience participation and video games to provide input into the actions of the main character, known simply as "Son".

"When I started writing I found I couldn't put myself in the play. The story of my mom - my family - dealing with HD was too emotional. I couldn't use the first person. By creating the character of Son, I found I could more fully develop the storyline and play the role as I have done throughout my career. The difference is - that role is me."

Sébastien raised \$7000 for HSC through audience donations and selling merchandise at the play and is very grateful for the support. For him, it's making good on a promise he made at YPAHD Day 2022 to raise money doing what he does best, which is writing, developing and performing in creative productions.

Sébastien is grateful to YPAHD for the interpersonal support and to HSC for the numerous educational resources he accessed, which have all helped Sébastien support his mother and her HD progression.

One of his key takeaways from the entire process is about motivation and quality of life, which can be applied to facing HD as an individual or a caregiver. "It's about continuing to find a purpose with the time that we have. That's where you focus your energy. That's where you find and use your potential. Whether you volunteer, provide care, or focus on living the best life you can, do it with purpose, and the benefits will multiply."



Meet the New RCDs

Since our last issue of Horizon, we've welcomed four new Resource Centre Directors (RCDs) and said Happy Retirement to Elaine Smith, our former RCD for Newfoundland/Labrador.

Meet the new team members here.

Denise Mazerolle: RCD for New Brunswick

Denise joined HSC on July 10 as a bilingual registered social worker who brings experience in a variety of school, community and health care settings. Denise started her career a registered nurse, and has since completed a Bachelor of Social Work – she looks at it as a “different way to get to the bedside”. After living in Fredericton for school, she decided to make it her permanent home after meeting so many wonderful people and enjoying the vibe of the bilingual capital city. Denise has truly enjoyed working with Keely McCoy, the NB Chapter president, recognizing that the social aspect is so important to decrease isolation and increase capacity. Denise loves the RV life and summer sees her enjoying the campground with her partner. She can be found giving guitar lessons to her neighbours and enjoying nature.

Jill Ford: RCD for Newfoundland/Labrador

Jill is a registered social worker who has worked with a variety of individuals experiencing trauma, grief, mental health issues, crisis, substance use disorder, or have been in conflict with the law. Her experience includes working at Legal Aid NL, Labrador Grenfell Health Hospital and at Children, Senior and Social Development. Jill provides a client-centred approach and has extensive experience in mental health counselling, assessments, crisis intervention, group facilitation, workshops and presentations. Jill looks forward to sharing her advocacy skills with the Huntington disease community. Jill started on March 15, based in St. John's, and will be available 25 hours per week.

Quinn Mykyte: RCD for BC Interior

Quinn Mykyte has been providing support, advocacy and HD education for the BC Interior and North since August 21. Quinn is a registered social worker and completed her Bachelor of Social Work at the University of the Fraser Valley. Quinn's extensive experience includes engaging community stakeholders, conflict resolution, substance use issues and supporting children and families facing multiple challenges.

“Being adaptive, empathetic and providing ongoing support is crucial in providing effective support to people with HD and their caregivers.”

In her spare time Quinn enjoys yoga and dance fitness class. Her favourite places to go are Mexico and Disneyland. Quinn is on maternity leave with her third child. We look forward to her return!



Tarak Ahmed: RCD for East Central Ontario (including Barrie, Simcoe, Peterborough and Durham regions)

Tarak joined HSC on Jan. 15 from University of Toronto, where he supervised the counselling team. Tarak has both Bachelor and Master degrees in social work and is excited to be in what he calls an impact position in a close-knit community.

“It's not what we don't have. It's how we find happiness with what we do have.”

Tarak has already noticed the powerful benefit of being exposed to the amazing resilience of the Huntington disease community. In his spare time, Tarak loves being with family, fishing with his grandfather, going on adventure trips with his brother, and swimming with his two-year-old daughter. Growing up in the 90s, Tarak had fun with video games and still enjoys relaxing with his Nintendo Switch, playing Mario Kart and Donkey Kong.





YPAHD 2024-2026 Executive

The 2024-2026 Young People Affected by Huntington disease (YPAHD) voted in their new executive at YPAHD Day 2023. **Meet this exciting new team here.**

Celine Payne: President

Celine Payne is the YPAHD president. She is from Sarnia, ON and just turned 31. Celine's mother had HD and sadly passed away due to complications of the disease in 2019 at age 48. Celine has two brothers who are at-risk, one who tested positive and one who tested negative. Celine tested negative for the gene mutation that leads to HD.

Celine attended her first YPAHD Day in 2017 in Toronto and this lit the flame for her to start diving into fundraising and creating the Sarnia Chapter. Celine has been working hard to raise funds and awareness ever since that first YPAHD Day almost 7 years ago and she has no plans to stop!

Taylor Van Beest: Vice President

Taylor is the current YPAHD vice president. She is 28 years old and from a small town in southwestern Ontario. Taylor attended her first YPAHD day in 2015 and since then has always been involved with YPAHD to some extent. Taylor is excited to serve YPAHD in a new capacity and grow with all the members.

Parker Van Beest: Co-Youth Engagement Coordinator

Parker is one of YPAHD's youth engagement coordinators. He was born and raised in London Ontario and is turning 30 in a few months. He recently started a family. He enjoys running, doing jiu jitsu and hanging out with family. He is in the process of completing his electrical apprenticeship. Parker attended his first YPAHD day in 2018 in Kelowna and since then he has been doing everything in his power to help. After attending his first YPAHD day, he just wanted to get involved in any way. It is his second term as youth engagement coordinator. Parker is excited to serve another term on YPAHD's executive.



Nicole Verwey: Co-Youth Engagement Coordinator

Nicole comes from an household affected by HD and has known about HD all her life. She attended her first YPAHD day in 2017 and has been involved ever since. When she's not in the classroom, she's taking care of her son. She is excited to be on the exec as the youth engagement coordinator.



Hannah Remillard - Social Media Coordinator

Hannah Remillard is 20 years old and lives in a small town called Otterburne, which is located in Manitoba. She first became involved with YPAHD at the Winnipeg conference. She is excited to join as the Social Media Coordinator for YPAHD as she already has some experience being the Social Media Coordinator for the Winnipeg Chapter. Hannah grew up affected by HD and has been her mom's primary caregiver since she was 14 years old.



Megan Roberston Burd: Youth Board Representative

Megan comes from a family affected by HD and created a documentary in 2011 about the struggles of HD. During this time, she connected with HSC for a quote and has been volunteering ever since. She can be seen behind a camera at HSC conferences and creating YPAHD videos. She joined the YPAHD exec in memory of her late Uncle Dale.



Top 5 National Walk Tips and Facts

It's almost May, and that means it's time for the 2024 Huntington Heroes National Walk. May is Huntington disease Awareness Month, and the walk is the star of the month.

Dollars are doubled:

We have a match, which means for every dollar you fundraise or donate, the amount and your impact automatically doubles - wow!



Walk Where You Live:

We have lots of options to walk. If you live close to an in-person walk, be sure to check it out! Or you can move at home as part of our virtual team.

Team Virgin River and Team YPAHD Join the Lineup:

This year we have Team Virgin River, in honour of the character Denny on the show who is facing Huntington disease, and Team YPAHD (Young People Affected by Huntington disease). Both teams promise to be powerhouses!



New Shirts for 2024:

Our walk and awareness shirts for 2024 are STYLISH! Choose from a blue walk T-shirt, Awareness Month T-shirt or sweatshirt, or Team Virgin River sweats or tees.



Events Fund Support Services:

Donations from the walk, and all the other amazing community events, cover the cost of the Family Services team providing support services for individuals and families living with Huntington disease - talk about **IMPACT**.



Register, buy a shirt, or donate today!

Find all the walk information online at www.huntingtonsociety.ca/nationalwalk/

One Degree of Separation

With Huntington disease, resources are important to answer the many questions individuals and families facing Huntington disease have after learning about risk, a diagnosis, and the journey beyond. The hope that news of recent developments and community initiatives brings is vital.

That means we want to make sure we are connecting with everyone who is affected or who knows someone who is facing Huntington disease. This one degree of separation community is our priority. You are the ones we want to reach with education, opportunities and information.

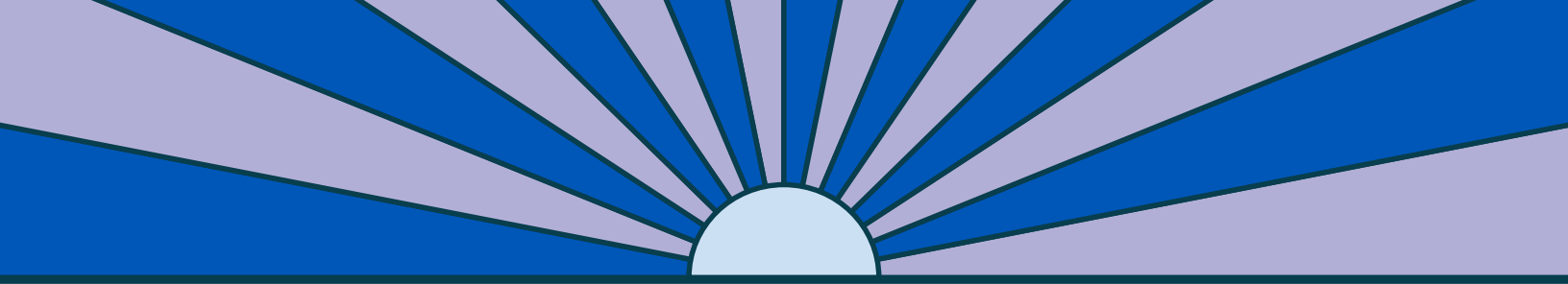
This brings us to two questions:

1. Are we connected with everyone in Canada who is affected by HD?
2. How can we communicate with this population?

We're asking everyone to resubscribe to our email communications, even if you already receive information from us. We also want to know the type of information you wish to receive. You can fill in the slip enclosed in the paper copy of Horizon or go to our website at: www.huntingtonsociety.ca/newsletters/

Next - who are we missing? Do you know someone who would benefit from learning about recent developments in research, care and education? Please share the e-mail sign-up with them, or forward them emails and have them sign up for their own news.

Help us share HD-specific news with those who will benefit the most - thank you!



Your 2024 In-Person Walks

See you at one of our fun + family-friendly walks!

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| SATURDAY MAY 11 | Lockport, Manitoba |
| SATURDAY MAY 11 | Belleville, Ontario |
| SATURDAY MAY 11 | Ottawa, Ontario |
| SUNDAY MAY 12 | Toronto, Ontario |
| THURSDAY MAY 16 | Barrie, Ontario |
| SATURDAY MAY 25 | Niagara, Ontario |
| SATURDAY MAY 25 | Edmonton, Alberta |
| SATURDAY MAY 25 | Quidi Vidi, St. John's, Newfoundland |
| SATURDAY MAY 25 | Fredericton, New Brunswick |
| SATURDAY MAY 25 | Bonshaw Provincial Park, PEI |
| SATURDAY MAY 25 | Saskatoon, Saskatchewan |
| SATURDAY MAY 25 | Esquimalt (Vancouver Island), British Columbia |
| SUNDAY MAY 26 | Vancouver, British Columbia |
| SUNDAY MAY 26 | Bowmanville, Ontario |
| SUNDAY MAY 26 | Hamilton, Ontario |
| SUNDAY MAY 26 | Sarnia, Ontario |
| SATURDAY JUNE 8 | Calgary, Alberta |
| SATURDAY JUNE 15 | London, Ontario |

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