

ISSUE 170

SPRING 2025

HORIZON

THE HUNTINGTON DISEASE AWARENESS MONTH ISSUE

THE HUNTINGTON SOCIETY OF CANADA'S MAGAZINE



CEO LETTER

Shelly Redman

As the days grow warmer, May brings a special energy to our Huntington disease (HD) community - it's Huntington Disease Awareness Month! It's a time for us to shine a light on our mission, our community, and the incredible impact we have together.

This May, our fundraising community walks will take place across the country, uniting families, friends, and supporters to take strides for HD. These events are not just about raising funds; they're about building connections and showing the strength of our small but mighty community.

We'll also celebrate Light It Up 4 HD, a beautiful initiative that sees landmarks across Canada glowing in blue and purple to honour those impacted by Huntington disease and Juvenile Huntington disease. If you spot a lit-up landmark near you, take a moment to reflect on the difference we're making together.

And let's not forget Volunteer Appreciation Week, held the last week of April! Our volunteers are the heart of what we do - giving their time, energy, and passion to further our mission. To all of you who volunteer, please know how deeply valued you are.

We may be small compared to other health charities, but our dedication and collective impact are anything but.

Every step we take, every light we shine, and every moment we dedicate to this cause brings us closer to a brighter future for families living with HD.

Thank you for everything you do.
Together, we're unstoppable.

Warmly,

CEO, Huntington Society of Canada

AN ARIEL VIEW

Ariel Walker

Spring is the season of new hope and new beginnings. We have the opportunity to hold events after a winter pause (save for the HD 500 Snowmobile Event in Winnipeg, bless you hardy souls) and appreciate the warm weather. The spring event I am most excited about is our National Walk held all over the country in May.

I have to admit, when I attended our first walk in Riverside Park in Cambridge back in the day, I was nervous. But our chapter volunteers and community were so welcoming and supportive, always greeting everyone with a friendly smile and a sense of camaraderie. This remains true to this day.

Attending a National Walk event is like reconnecting with old friends, even if it's the first time you've ever met them.

There is a shared understanding and common goal: raising vital funds for support services and research for all those affected by Huntington disease.

May is also Huntington Disease Awareness Month. Raising awareness means helping those affected by HD feel less isolated. It means that people are listening. Many people are hesitant to talk about how HD has impacted their lives, families, and relationships. I understand that. This is why raising awareness about HD is so important. We can help make them feel more comfortable when sharing their story.



Raising awareness also means creating a kinder world for those affected by HD as more people come to understand what is involved in the disease, how to support them, and what they need from all of us.

This May, I hope you will reconnect with old friends or meet them for the first time at a National Walk event. Or perhaps you will mark HD Awareness Month by sharing or listening to stories about people's experiences with Huntington disease. In whatever way you participate – thank you. We come together as one community so that no one faces HD alone.

Ariel



Dear HSC

My teenage daughter and I will be travelling this spring for a weekend in Banff, Alberta. My daughter will be doing most of the driving due to my HD symptoms. Are there any tips you could recommend for travel?

Dear Traveller,

Taking time with your family while travelling is an exciting, memorable endeavour. Please read the following tips to help make your trip smooth sailing.

Considerations when travelling:

1. Learning about the hotel or campsite in advance can help you plan for common needs.
2. **Consider how busy or crowded the destination might be.** Make sure it offers accessibility features like ramps, elevators, and parking for physical needs. Make a checklist of what to pack to be as prepared as possible.
3. Stick to your regular routines for eating, sleeping, exercise, and rest. Bring snacks for the trip.
4. Inquire if the destination can accommodate special dietary requests if required.
5. Make sure to take frequent stretch breaks.

More resources for travellers:



"Travelling with HD" Fact Sheet
hdfactsheets.ca



Printable "I have HD" Wallet Card
[huntingtonsociety.ca/
hd-identification-cards/](http://huntingtonsociety.ca/hd-identification-cards/)

If you are taking medications, please review the following:

1. Before the trip, consult your healthcare team about your travel plans.
2. You may want to consider a letter from your healthcare provider, explaining the impact of HD and the supports you may need for your travel destination.
3. Keep medications in original labeled bottles or a pharmacist-prepared blister pack. Carry your pharmacist's contact information in case of emergencies.
4. In advance, ask your pharmacy what a contingency plan could be, if medications are lost or refills are needed, while travelling. Confirm if there is a pharmacy nearby.
5. Use a medication reminder system or phone alarms to stay on track during routine disruptions.
6. Consider a medical ID bracelet or carrying a HD wallet card to ensure first responders have access to important medical information.

After the trip

Upon your return, take the opportunity to learn from your travels. **Debrief on what worked and what did not.** For example, would an organized trip with a group itinerary work better in future? Would it be helpful to be in an environment where there is always a place to rest, like a cruise? Would travelling with other friends/family be a good choice to provide respite breaks for carers?

Key takeaway

Remember to relax and enjoy this time with your loved one. **Patience is the most important thing to remember.** As you embark on your next adventure, embrace the possibilities, celebrate each milestone, and enjoy travelling. Let your journey reflect your unique strengths and inspire others along the way!

Family Services Updates



A Note from **Sheri Mayhew**,
HSC's New National Director
of Family Services

I am thrilled to step into the National Director of Family Services role at the Huntington Society of Canada and to have the opportunity to serve this incredible community in a new capacity. Working as the Resource Centre Director within Eastern Ontario has been deeply rewarding, and I am so grateful for the relationships we've built and the impact we've made together.

I want to express my heartfelt thanks to Angèle Bénard for her exceptional leadership and dedication, which has left an inspiring legacy. I am excited to collaborate with the community, chapters, families, and individuals affected by Huntington disease across Canada, alongside our dedicated Family Services Team. I can't wait to see what we can achieve together!



HSC Welcomes Brooke Hurley, Resource Centre Director for Southwestern Ontario

HSC would like to extend a very warm welcome to Brooke Hurley, the new Resource Centre Director (RCD) for Southwestern Ontario.

Brooke is a registered social worker with 20 years of experience supporting seniors and their families in the community as well as in the hospital system. For over 10 years Brooke worked as a social worker with the Alzheimer Society, providing support to individuals and their care partners through supportive counseling, support group facilitation, assisting with navigating the healthcare system, and connecting families with community supports.

She has extensive experience supporting individuals through grief and loss as well as challenging life transitions.

Brooke is looking forward to sharing her knowledge and skills with the HD community. Brooke will be based out of London, Ontario, where she has been living for the past 16 years with her husband and beagle, Ally McBeagle. Brooke is a passionate dog mom who can often be found hiking with Ally or curled up on the couch watching a good show. She enjoys being active and is a retired fitness and spinning instructor. Brooke loves to travel - anything from a nice beach in the Caribbean to exploring Europe.

You can connect with Brooke via email bhurley@huntingtonsociety.ca or phone: 1-800-998-7398, ext. 200.

We are lucky to have you, Brooke!

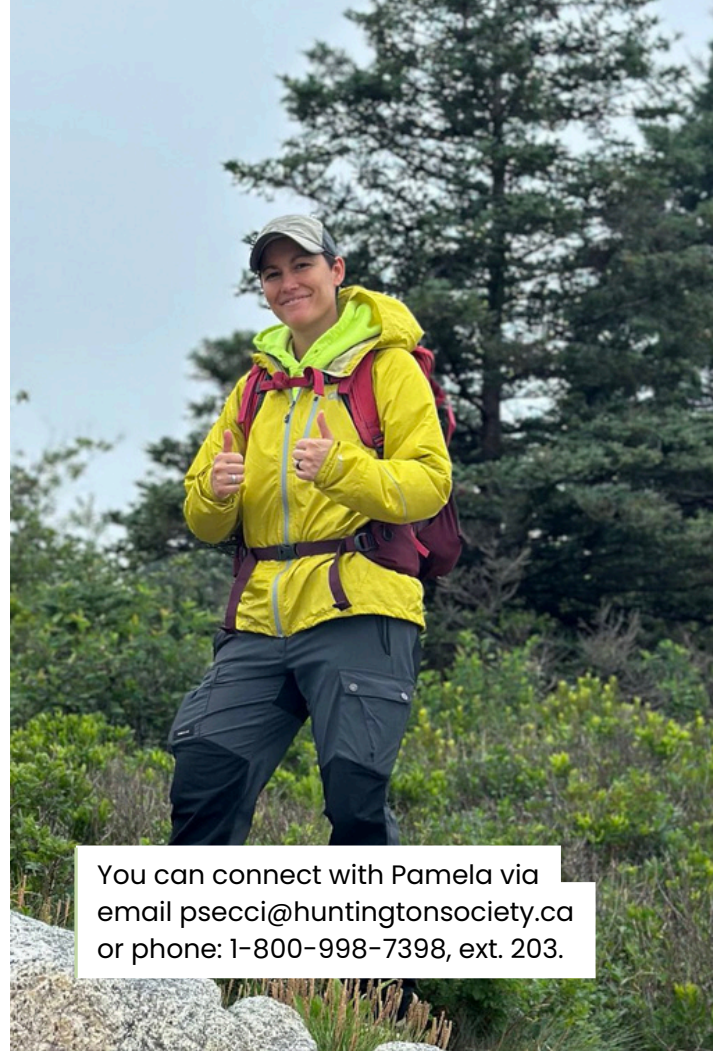
Welcome Pamela Secci, Resource Centre Director for Nova Scotia and PEI

We are delighted to welcome Pamela Secci to HSC in the role of Resource Centre Director (RCD) for Nova Scotia and PEI.

Pamela started her social worker career in the U.S. working with adults living with severe schizophrenia, addiction, trauma, and homelessness. After moving to Nova Scotia, she provided counseling services across the country to individuals presenting with a variety of challenges including relationship issues, depression, anxiety, workplace stress, grief and loss, and parenting concerns. Pamela has experience providing support to autistic youth and adults, as well as career counseling services. Using a neuro-affirming and trauma-informed approach, Pamela is looking forward to connecting with the Huntington disease (HD) community.

When she's not outdoors hiking and camping, Pamela enjoys reading, crafting, and cooking. Pamela loves to travel. She has yet to explore Manitoba, Saskatchewan, and the Canadian territories.

We're happy to have you on board, Pamela!



You can connect with Pamela via email psecci@huntingtonsociety.ca or phone: 1-800-998-7398, ext. 203.

Welcome Stephen Martyn, Resource Centre Director for East Central Ontario

HSC is pleased to announce that Stephen Martyn joined the organization in the role of East Central Ontario Resource Centre Director on February 3, 2025.

Stephen has dedicated his career to child welfare, working in various capacities including child protection worker and director of services. He is a Registered Social Worker and holds a Master of Social Work degree from Dalhousie University, a Bachelor of Social Work from the University of British Columbia, and a Bachelor of Political Science from Western University.



"My commitment to supporting children and families has shaped my empathetic and compassionate approach to advocacy and social work," says Stephen. Stephen is also a part-time professor at Fleming College in the Social Service Worker program, where he shares his knowledge and experience with the next generation of social service professionals.

Outside of his professional work, Stephen enjoys spending time with his family and giving back to the community through volunteer efforts.

You can connect with Stephen via email smartyn@huntingtonsociety.ca or phone: 1-800-998-7398, ext. 207.

We are so happy that you have joined us, Stephen!



Jill, Ollie the Octopus, and the beautiful west coast of Newfoundland

Mission Connection: RCD Jill Ford's Cross-Newfoundland Outreach

| By Jill Ford, Resource Centre Director for Newfoundland & Labrador

When starting work with the Huntington Society of Canada as the Newfoundland and Labrador Resource Centre Director (RCD) in March 2024, my first goal was to reach as many people as possible within my province. I decided to plan a cross-provincial trip to meet with families in person. I was able to accomplish this, and I also met with some long-term care staff and local clinics along my way, forming connections and providing education on Huntington disease (HD).

I believe that we need to try to reach as many people as we can, which means providing services to rural communities.

Part of the reason for this trip was because I want people to feel connected to our organization and the HD community.

—> Covid had a tremendous impact on community connections. We now need to integrate the technology we have been using to connect virtually with in-person touchpoints. **No one needs to face Huntington disease alone.**

This was my first time away from home in a long while, so my son Wesley wanted me to have a little buddy for the trip. He presented me with Ollie the Octopus. To capture my experiences from a few stops along our route, I snapped a photo of Ollie the Octopus at various locations so that you and Wesley could come along for the ride.

My route started in St. John's and went all the way to Stephenville, so from the east coast to the west coasts of NL.

During my trip, I met so many amazing folks, clients, families, and healthcare workers, all affected by HD in some capacity. This trip truly solidified my decision to join the Huntington Society of Canada - **I witnessed firsthand the strength of the HD community and feel honoured to be able to work alongside our wonderful members.**

The dedication of family, friends, and healthcare providers to loved ones and patients is truly inspiring. My outreach also allowed me to connect, support, network, navigate, provide resources, and spread awareness about HD.

My overall goal for this trip was to make sure people are aware of our services, to introduce the role of RCD for NL, and to connect with me as the person filling this role.

My final message is that you are not alone on this journey. I hope that I can continue to be a resource for you all.



Building Natural Supports and Relationships: One Key to Staying Ahead of the Curve

| By John Lord

As part of a family living with Huntington disease (HD), I know full well what it means to 'stay ahead of the curve.' Our family tries to anticipate future changes and act before these changes become a problem or, even worse, unmanageable. For example, my partner, who has HD, and I moved from a three-story townhouse to an apartment on one floor to ensure her safety.

Staying ahead of the curve also means cultivating the support and connections you need to remain in your community and maintain your quality of life. Our family has found that building natural supports and relationships is one key to enabling this to happen. 'Natural supports' refer to the assistance that flows from social networks, including family, friendships, neighbourhood contacts, religious affiliations, and connections with community groups. Natural supports are voluntary and unpaid.

Research has shown that when people engage natural supports, they tend to be healthier and happier.¹

Building natural supports can be a challenge for families with HD. Many families become isolated and disconnected from family and friends. In the early years of our HD experience, we brought our children and siblings together to reflect and plan with us. We decided that we needed to be intentional about building natural supports. This has turned out to be one of the most important decisions we made in our HD journey.



For us, being intentional about building natural supports has included three main areas:

- 1. Inviting friends, family, and neighbours to take on specific tasks.** My partner now has five different people walking with her, every Monday to Friday. A sibling stays overnight regularly.
- 2. Building a neighbourhood supportive community.** Every community has people who are kind and ready to help their neighbours. We have built a neighbourhood supportive community, where people meet on a regular basis and support each other as needed. Naturally Occurring Retirement Communities (NORC) are a great example of neighbour connections.²
- 3. Creating a Support Circle of caring family and friends.** Support Circles meet on a regular basis and provide both emotional and practical support. We have also found our Circle to be a valuable vehicle for problem-solving and planning.³

Building natural supports takes time, energy, and a belief that people will commit to be part of your journey. Not everybody will, and there will be disappointments along the way.

Many people, however, are honoured to be asked and find their participation to be very meaningful.

Natural supports work best when they are complementary to a robust formal system of community-based care. When these work together, the person with HD is well supported and primary caregivers receive the respite they deserve.



John Lord is a social researcher and writer and the primary caregiver for his partner with HD. His most recent book is *Aging and Elder Care: Time for Transformation* (Captus Press), which explores formal and informal systems of care. He also has an extensive list of resources and articles on his website: www.johnlord.net

End Notes

¹ Susan Pinker (2014). *The Village Effect: How Face-to-Face Contact Can Make us Healthier and Happier*. Toronto: Vintage Canada.

Vivek Murthy (2020). *Together: The Healing Power of Human Connection in a Sometimes Lonely World*. New York: Harper Collins.

² The NORC Innovation Centre <https://norcinnovationcentre.ca/>

³ John Lord and Peggy Hutchison (2017). *Pathways to Inclusion: Building a New Story with People and Communities*. Concord, ON: Captus Press.



Chapter Happenings

| Spring events are here!

Alberta

- The Southern Alberta Chapter will host their Hope for a Cure Run/Walk on June 7. This year's walk is 80's themed and will take a look at all the progress HSC has made over the past 40 years.

CHAPTER HAPPENINGS



Manitoba

- The Manitoba Chapter raised **\$42,000** from their Annual HD500 Snowmobile Ride. They were featured on their local radio station this year and were able to spread awareness about this event and HD.

Ontario

- Barrie Chapter President Jo Kaattari is hosting a giant Book Sale on May 10.
- The London Chapter is back after a brief hiatus. Welcome to Marvin and Gloria Wideman who are leading the charge!
- The Niagara Chapter will hold their second Cornhole Tournament on July 19 after a successful launch last summer.

Atlantic Canada

- The Newfoundland Chapter held their first ever mini-golf event on March 23. We look forward to more fun events this spring.



Address Change

We have moved! Our new address is **375 Hagey Blvd., Suite 114, Waterloo, ON N2L 6R5.**

Don't worry, we have mail forwarding activated in case you send anything to our previous home.



YPAHD Day 2024

On November 9, we welcomed 68 youth from the national Young People Affected by HD (YPAHD) Chapter in Mississauga for an incredible day of fun, friendship, and education. This was the first time YPAHD Day was held in one city as an individual conference, and we were thrilled to have everyone together in one space! Our youth heard from researchers, met their RCDs, shared stories, asked questions, and created lifelong memories – some featuring the amazing social event solving escape-room style puzzles at BRKFREE! We can't wait to see you at YPAHD Day 2025!

Raise the Dough: HSC Pizza Fundraiser

This past January, the National office partnered with a local Domino's Pizza franchisee to Raise the Dough for HD. 50% of the proceeds of each pizza purchased were donated to HSC over the course of 5 days, with over \$500 raised!

Now we're excited to carry out this fundraiser across the country and we're looking for some pizza connectors to get things started - **it's as easy as 1,2,3:**

1. Reach out to your favourite pizza franchise
2. Publicize the deal to family and friends – social media works great for this!
3. Make it a pizza night for a good cause!

The beauty of this fundraiser is its simplicity. It's a great offer that everyone in the community can enjoy while also contributing to a great cause! Plus, there's always a night where schedules make pizza night music to the entire family's ears.

Scan here to find all the resources you need to get this started in your community!



huntingtonsociety.ca/pizza-fundraiser/



[Register for the
National Walk](#)



2025 NATIONAL HUNTINGTON HEROES WALK

The month of May means it's Huntington disease Awareness Month and the National Walk is back! Across Canada, walks are taking place throughout the month to raise funds for support services and research and to provide connections within the community.

Local and Virtual Walks

Local walks are a great way to raise awareness in your community and make an impact at the ground level. Also offered is the National Virtual Walk, which allows members in remote areas to participate as part of the National team, bringing the walk right to your home. The Virtual Walk takes place one weekend, May 24-25, when the national community walks individually but stands together to achieve a common goal: raising funds and awareness for HD.

We truly appreciate everyone who walks, fundraises, donates, shares our messages, and provides support for one another.

Plus, once again we have an Awareness Month match – so if you have been thinking about donating, **now is the time because those dollars are automatically doubled!**

Our Impact in 2024

Our amazing community raised \$208,000 during the national walk last year, which was doubled to a total of \$416,000 thanks to a match by a generous donor. We thank everyone for their participation and are excited to see new faces this year. Thanks to those who walked, ran, fundraised, volunteered, and spread the word. You all make such a difference.

Rep Your Cause: T-shirts & Hoodies are Back!

Once again this year you can purchase Walk T-shirts or crewnecks, or HD Awareness month T-shirts or hoodies online and have them delivered directly to your doorstep in time for your local event or the month in general: huntingtonsociety.sellfy.store/



We can't wait to walk alongside all our Huntington Heroes this May!



Huntington Disease Awareness Month: Light It Up for HD

Prepare for a month-long light show of blue and purple this May with #LightItUp4HD 2025, HSC's brightest campaign around!

Every year buildings, structures, and landmarks across the world light up in blue for HD and purple for Juvenile HD, opening the door for conversation and education about Huntington disease.

Last May, we saw 56 Canadian locations and 158 sites spread across 12 countries light up in blue and purple. After illuminating just over 200 sites across the globe in 2024, we aim to focus on the Canadian sites nearest and dearest to our communities for 2025.

We would like to thank James Walters, the first-ever #LightItUp4HD volunteer, for his continuous efforts in making the campaign shine.

To keep up with all the sites illuminating in your area, visit the #LightItUp4HD website: (huntingtonsociety.ca/2025-light-it-up-4-hd/)



RaceHD

RaceHD is HSC's National Running Team that allows you to participate in any marathon, race or walk across Canada while raising funds for HD! With no experience necessary, there's a run for everyone. Trying out a half or full marathon this year? Sign up to fundraise for your favourite cause – the Huntington disease community! Check out a few of your options and spend your 2025 feeling good, while doing good:

May 4: Toronto Marathon

May 4: Georgina Spring Fling Marathon

May 4: Vancouver Marathon - RUNVAN

May 11: Sporting Life 10k

May 16-18: Emera Blue Nose Marathon (Halifax)

May 25: Calgary Marathon

May 24-25: Tamarack Ottawa Race Weekend

June 15: Manitoba Marathon

June 22: Vancouver Half Marathon

June 25: Kawartha Sun Run
(Fenelon Falls - new in 2025)

Aug. 17: Edmonton Marathon

Oct. 10-12: Royal Victoria Marathon (Victoria)

Oct. 18-19: Toronto Waterfront Marathon

Oct. 25: Niagara Falls International Marathon



Join RaceHD today!

www.p2p.onecause.com/racehd/home



RaceHD Team Member: Parker Van Beest

Parker has been involved with HSC and chapter events for as long as he can remember; in fact, he used to go to events when he was younger with his mom, who had Huntington disease. Parker's involvement began with his local London Chapter, which is in the process of being revitalized. He is also on the Executive Committee for YPAHD (Young People Affected by Huntington disease).

—→ Last year, Parker participated in RaceHD for the first time with his wife, Kalene. His favourite part about RaceHD is the connection to his local community. Parker reminds us that “every person adds to the community” and that it’s “one small action” to participate. RaceHD allows everyone of all abilities to participate however they can. He emphasizes that it’s not just running a marathon that makes a difference, but rather collecting online donations, fundraising in your community, and connecting with each other, too.

Participation in community events is important to Parker.

Since his mother’s passing, he continues to participate however possible to honour everything she did. **“I don’t want it to go to waste. I want to help it grow,” he says. “This is part of my journey, and my kids’ journeys.”**

What motivates Parker during these long runs? The community members with signs and candy! He loves seeing the community chipping in to show support and raise awareness. Parker says he always feels nervous beforehand, but with even strangers cheering him on, he’s reminded that he’s helping to make a difference. Thank you, Parker, for all that you do!

Help HSC Continue to Offer Services

We are currently navigating uncertain economic times, which can feel unsettling. While the future is unpredictable, taking proactive steps can provide stability and peace of mind.

Here are some key strategies to help you prepare.

1. **Stay informed but avoid panic** - Keep up with economic news, but don’t make rushed decisions out of fear.
2. **Take care of your mental health** - Stress can impact decision-making, so find ways to manage anxiety (exercise, meditation, hobbies).
3. **HSC is here to help!** Reach out to the Family Services team if you need support.

How you can help HSC navigate economic uncertainty

It’s not easy to admit, but we need your help. The economy makes it challenging to offer support services and continue to fund exciting research that could lead to the end of Huntington disease research – we can’t stop now!

Pledge your support to protect HSC’s services!



Scan here for our giving page and help HSC and the HD community make it through these uncertain times – together.

huntingtonsociety.ca/yes-i-want-to-donate/





Dr. Melanie Alpaugh

Dr. Shaun Sanders

Dr. Dale Martin

Navigating Hope for the HD Community: New HSC-Funded Research Moves the Dial

| By Jo Kaattari

The Huntington Society of Canada (HSC) has awarded the 2024 Navigator Research Program grant to Dr. Shaun Sanders (Lead Investigator, University of Guelph), Dr. Melanie Alpaugh (Co-investigator, University of Guelph), and Dr. Dale Martin (Co-investigator, University of Waterloo).

This new research project is an exciting collaborative study between the Huntington Society of Canada, the University of Guelph, and the University of Waterloo. The title of the project is DLK as a Novel Therapeutic Target to Treat Huntington Disease. You can learn more about this research by visiting: www.huntingtonsociety.ca/navigator-program/.

One of the goals of the Navigator Research Program is to provide a platform for the future recruitment of outstanding investigators to Huntington disease (HD) research.

With this talented team of researchers, HSC is well on its way to accomplishing this goal.

For families facing Huntington disease, research resides in the realm of our dearest hopes. This makes us deeply interested in why people who are not impacted by this devastating disease choose to be involved with our small but mighty community. These three young researchers have diverse (and impressive) academic backgrounds and interests, but they all share the common bond of having a passion for HD research and our community.

**And now, let's meet these
dedicated researchers.**

Dr. Shaun Sanders

Dr. Shaun Sanders completed her undergraduate degree at the University of British Columbia and then started a job as a technician at Dr. Michael Hayden's lab at the Department of Medical Genetics at UBC. She was immediately entranced with the world of HD and found the community-driven approach at the Hayden lab compelling.

Dr. Sanders enjoyed bringing the research to life by making HD connections, inviting families facing HD for lab visits, and participating in fundraising walks with the local chapter.

Dr. Sanders attained her PhD at the Hayden lab and knew she wanted to devote her career to Huntington disease research.

Now working at her lab at the University of Guelph, Dr. Sanders is invested in her career in HD research. She notes that it certainly never gets boring; she loves learning new things and being on a journey of continual discovery. She greatly values the fact that HD research tends to have a strong collaborative approach among researchers. Developing links with the Huntington disease community is a key part of the research process.

"My original plan had been to go to Europe to do my PhD. But after engaging with the HD community and other HD researchers, I immediately knew that that researching Huntington disease was where I wanted to be."

– Dr. Shaun Sanders

"Huntington disease really touched me, and it became something I just wanted to keep working on and trying to understand so that I could be part of helping others."

– Dr. Melanie Alpaugh

Dr. Melanie Alpaugh

Dr. Melanie Alpaugh received her undergraduate degree and PhD from the University of Alberta. From her undergraduate experience, Dr. Alpaugh knew she was interested in studying the brain, but she hadn't narrowed down her specific area of research.

Then, Dr. Alpaugh attended several lectures by Dr. Simonetta Sipione, a Huntington disease researcher. Dr. Alpaugh was fascinated with HD research and joined the Sipione lab to complete her PhD.

Through learning more about the disease and meeting families facing HD, Dr. Alpaugh knew she wanted to spend her career in this field of research.

Dr. Alpaugh now works at the University of Guelph. She finds HD research to be a very positive experience. Dr. Alpaugh enjoys problem solving and continuous learning, and HD research always offers something new and different. She greatly values engaging with the HD community and working with young graduate students and benefiting from their energy and enthusiasm.

Dr. Alpaugh feels fulfilled when she goes to work each day and has the possibility of improving the lives of others. She knows that even if HD researchers don't achieve the results they want as quickly as they'd like, collectively, the research is helping to build knowledge that will benefit others.

Dr. Dale Martin

Dr. Dale Martin attained his PhD at the University of Alberta. One aspect of his research was related to Huntington disease, and through this experience, he became acutely interested in HD. This interest resulted in him reaching out to Dr. Hayden's lab and, upon finishing his PhD, Dr. Martin joined the team there. Dr. Martin describes benefitting enormously through interacting with the HD community and experiencing the diverse and collaborative research occurring at this dynamic lab. Dr. Martin also has research experience with ALS, and he seeks to learn more about potential common therapies for the two diseases.

Dr. Martin now works at the University of Waterloo where he and his team conduct multiple research projects. Due to the restrictions in place during the pandemic, research initiatives and connections with the HD community were hampered for several years. Dr. Martin is delighted to now be working in a time of multiple projects, enhanced collaboration, and a great deal of synergy in the HD research community.

He also highly values the opportunity to connect with and learn from the HD community via community events and conferences.

Dr. Martin noted that in recent years HSC has put a strong focus on funding research – in fact, in 2025, HSC will fund up to FOUR projects under the Navigator Research Program.

"It's an exciting time to be an HD researcher in Canada. The number of HD investigators, complemented by this next generation of HD labs, has reached a critical mass in Canada. And now with such strong support from the HSC Navigator program, I'm excited to see what the next round of funding will bring to the HD community."

– Dr. Dale Martin



A Tradition of Guelph Gryphon Good Luck

The University of Guelph campus features a prominent statue of their mascot, a mighty gryphon. There's a long tradition of students patting the gryphon's beak for good luck. HSC's CEO Shelly Redman met with the research team at the University of Guelph last autumn. They all gave the good luck charm a go, patting the gryphon's beak for luck and hoping for a magical HD research breakthrough.

Families facing HD lean into that hope, and are patting the gryphon's beak, metaphorically, right alongside!



A note from the writer

As a family affected by Huntington disease, many days are hard, but sometimes days are bright and hopeful! For me, a day of hope happened recently when I had the honour of interviewing this research team. For families affected by Huntington disease, research resides in the realm of our dearest hopes, and it was profoundly inspiring to speak with these three young and brilliant researchers who are deeply committed to HD research and our community. THANK YOU ALL SO MUCH!

- Jo

Jo Kaattari is a researcher/writer and President of the HSC Barrie Chapter.

Edmonton Chapter Scores Big with Casino Fundraiser

The Edmonton Chapter once again knocked it out of the park with their casino fundraising initiative held July 30-31, 2024, at Starlight Casino in West Edmonton Mall. We caught up with casino chairperson Aislinn Macquire to chat about this wonderful event, which leaned on the big hearts of community volunteers to up the ante.

“Thanks to everyone who volunteered their time, the event saw 20 incredible volunteers and six new faces help cover four eight-hour shifts,” says Aislinn. “Each shift required between six and 12 volunteers and some of them were helping until 3:30 in the morning!” Aislinn credits Greg Taylor, Edmonton Chapter President, with championing volunteer motivation, even providing helpers with transportation to the late-night Count Room shift.

The volunteers worked hard to make the event happen, and the returning volunteers even took on more responsibilities to make the event a success.



Aislinn says, “This year we had some volunteers who had only ever previously been in the Count Room make the leap into the longer, more difficult positions. I was really proud of everyone, and it was so encouraging to see our community come together to make this happen!” She also notes the recent influx of involvement in the Edmonton Chapter from the younger generations, something the Chapter was previously concerned about. Aislinn says, “I think we're starting to see that involvement now and it's definitely exciting for the chapter.”

Overall, the night was a major success and **raised over \$80,000 for the HD community!** Thank you to all the volunteers who helped make this special event happen.

Twelve-Year-Old Emma Writes Children's Book about Huntington Disease

On a cold snowy night in December, 12-year-old Emma Wajswasser from Toronto stood behind a table at her elementary school's holiday market. Her family was there with her to celebrate the launch of her children's book *Bloopy the Alien Learns about Huntington's Disease*. Emma was at the market to publicize her book, and she was also raising awareness about Huntington disease (HD). The table was filled with Amaryllis plants for sale and information about HD including brochures, stickers, and pens that people could take with them.

Every visitor to the booth was impressed that she had written a book at such a young age.

Each person asked, "What is Huntington disease?" Emma described the symptoms of HD and then explained why she had written the book: **her grandpa is living with the disease.**

Emma said, "A lot of people don't know what HD is or how to act around people with HD. I just wanted to teach them how to treat him properly."

The night was a big success.

"Lots of teachers purchased books and the principal bought a bunch of copies for the library. My teacher even asked me to read it for the class. It has been really great seeing people in the community liking it."

Emma and her mom worked on the book for over a year. After writing the text for the story, Emma sketched out the pictures she envisioned for each page. She then worked with an illustrator to bring the ideas to life. Emma and her mom also sent in photographs of her family as inspiration for the characters. After going back and forth with the illustrator to get everything just right, the book was finally ready.

"I have always been a big reader and writer. I just really love books, so this was a really fun thing to do."





The book is bringing a lot of happiness to her family, especially her grandpa. Before the launch, Emma was happy to take a day off school to go visit her grandpa, who lives two hours away, to show him the book.

“We went up to see him a couple of months ago and I said, ‘I have a surprise for you’. We got out the book and I started reading it to him and he got all teary-eyed. The two words he says the most are very good. So, he just kept saying, very good, after every page.”

Since its launch, Emma has sold over 100 copies of her book and even received some wonderful endorsements from the community.

“Armed with a bag of Goldfish crackers, love for her grandpa, and her understanding of HD, Emma introduces an alien to her grandfather in a way that connects them as instant friends. A fun story well told! Congratulations, Emma!” Jimmy Pollard, Huntington disease educator and author of Finding Nana’s Smile

Emma has big plans for her future writing career. She is currently writing a chapter book about one of her favourite topics, dinosaurs. She also plans to continue her advocacy work by writing more books about Bloopy the Alien.

“I want to research and write about another rare disease family. Then Bloopy can come and learn about their disease the same way he learned about HD.”



About the Bloopy the Alien Learns About Huntington’s Disease:

When Bloopy the alien comes to Earth to learn more about humans, he meets Emma and her family. He quickly wonders why Emma’s grandpa is behaving so differently. In this heartwarming story, Emma teaches Bloopy about having empathy and understanding for people living with a rare disease. Bloopy the Alien Learns About Huntington’s Disease is available for purchase on Amazon.

DATES FOR IN-PERSON COMMUNITY WALKS:

May 10

- Lockport River's Edge Run
- Belleville Walk
- Ottawa Walk

May 11

- Toronto Walk

May 24

- Newfoundland Walk
- Edmonton Walk
- London/Exeter Walk

May 25

- Sarnia Walk
- 28th Annual BC Walk
- Durham Walk
- New Brunswick Walk

May 31

- Niagara Lake-to-Lake Challenge
- PEI Walk
- Saskatchewan Walk
- Sauble Beach 5K
- Hamilton Walk

June 7

- 17th Annual Calgary Hope Run
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To find more events near you, go to:

<https://www.huntingtonsociety.ca/events/>

Thank you so much for your support!

