



A Message from CEO

Shelly Redman

When we told Amaryllis coordinator Sharon Gera that she'd be on the cover of this issue of Horizon, her response was immediate and heartfelt: "Why me?"

We were the ones surprised then.

Why not you, Sharon? You are a tireless advocate, a creative and dedicated fundraiser, and a steady, generous volunteer. You raise awareness and bring beauty and hope to our community. You are exactly the kind of person who should be on the cover.

The truth is, Sharon represents something much bigger than herself. She reflects the strength, kindness, and unwavering spirit of our entire Huntington disease community. Every one of you is extraordinary.

Why not any of you? The caregivers, families, researchers, and individuals living with HD who inspire us every day. The youth raising their voices. The volunteers who show up again and again. The donors and walkers and advocates who fuel our mission. You remind us that no one is alone, and no effort is ever small.

It's Sharon on the cover this time, but it could just as easily be any one of you. Each of you brings something special. Each of you is in our hearts every second.

It is truly an honour – one of the greatest honours of my life – to share your stories, to witness your courage, and to walk beside you.

With deep gratitude,

Rodm

Shelly Redman CEO, Huntington Society of Canada

An Ariel View

When facing a challenge, you need people in your corner. Huntington disease is a greater challenge than most and requires support in abundance.

Support can look different for everyone. But the support groups offered by HSC, as well as getting involved with chapters, are a great place to start.

One of my most meaningful support group experiences occurred shortly after Ralph died. I was on a trip with friends to Newfoundland, which happened to line up with a support group meeting held by our Newfoundland chapter. I wasn't sure if I wanted to go to the meeting. With the grief from Ralph's passing, it felt too close to home. But in the end, I decided to go.

Throughout the meeting, while everyone was chatting, a man who was symptomatic got closer and closer to me, like he had something to tell me. Finally, when we were knee-to-knee, he told me his story. He wanted to thank Ralph and me for founding the Huntington Society of Canada. The chapter had become like a family to him, for which he was thankful, since he had very little support.

As his HD progressed, he found himself struggling at work. With 10 months left until his retirement, his friend, who happened to be his neighbour, would help him complete the work he could not do. If it wasn't for her, he said as he pointed to her across the room, he would have had to quit and would have had no money whatsoever.

Hearing those words made me realize how important HSC, our support groups, chapters, and volunteers are to people. The one thing Ralph wanted was to provide that connection and support. I still tear up when I think about that man at the chapter meeting and his friend.



Connection and support are available thanks to our amazing chapters, volunteers, and community members. I'm overwhelmed by the amount of work our volunteers and chapter leaders do. It is so important. If it were not for all of you, those affected by HD would not have the support they need.

Thank you. I urge everyone to tap into the support offered. It makes a difference.

Yours in Friendship,



Ariel Walker

Co-founder, Huntington Society of Canada



p.s. Check out the many different support groups on offer here:

www.huntingtonsociety.ca/ support-groups

Dear HSC: Exercise & HD

Dear HSC,

I am interested in starting an exercise routine. As a person with HD, how can physical exercise benefit me, and what should I be aware of when starting?

Warmly, Ready to Take the First Step

Dear Ready to Take the First Step,

What a great goal!

Studies have shown that staying physically, mentally, and socially active can improve the quality of life for people with HD. With some planning and setting realistic expectations, you can engage in a safe and beneficial physical exercise plan. Small changes to daily activity levels can make a significant difference, so don't feel pressured to take on too much at once.

If interested in a fitness class, connect with the instructor to learn about modified movements. Exercise also releases endorphins – your body's natural pain relievers and mood boosters – offering an instant lift in positivity. Free or discounted access to accessible parks across Canada provides a wonderful opportunity to enjoy nature while staying active.

Remember, safety first! Before starting, consult your doctor, who may refer you to a physiotherapist. A physiotherapist familiar with HD can offer education and a tailored program to suit your needs.



If you require additional information or local resources, contact your local Huntington Society Resource Centre Director for assistance.

It may be easier to start and stay motivated when you have an exercise plan in place. Build movement into your daily routine and involve friends and family whenever possible. Try selecting two or three simple movements to begin with. This makes them easier to learn, remember, and maintain over time.

Every little step counts. Enjoy your exercise journey!

Family Services Welcomes & Goodbyes



Kim McMullin: New Resource Centre Director for Eastern Ontario

We are thrilled to welcome Kimberly (Kim) McMullin BA (Psych), BSW, RSW, to the Family Services team at the Huntington Society of Canada (HSC). Kim is our new Resource Centre Director (RCD) for Eastern Ontario, including Ottawa, Kingston, and Belleville areas! She started with HSC on March 31, 2025.

Kim is a Registered Social Worker with more than a decade of experience in community healthcare. She has a Bachelor of Arts in Psychology and a Bachelor of Social Work from Carleton University. Kim looks forward to sharing her experience in community rehabilitation, neurorehabilitation, neurodiversity, chronic pain, and complex mental health.

"I am so honoured to be the new Resource Centre Director for Eastern Ontario and to have the opportunity to collaborate with everyone working towards our collective goal of supporting clients, families, and communities affected by Huntington disease," says Kim. "I am excited to develop my skills, knowledge, and understanding of Huntington disease and nonprofit organizations and I am grateful for the opportunity to contribute to such meaningful work. I look forward to getting to know everyone!"

Outside of her professional life, Kim is passionate about her family and adventure, enjoying cycling, scuba diving, travel, and home renovations.

You can reach Kim at 1-800-998-7398, ext. 132, <u>kmcmullin@huntingtonsociety.ca</u>. We're happy to have you on board, Kim!

Happy retirement to Corey Janke, who devoted 33 years to HSC on the Family Services team, most recently as National Social Worker. We wish you the best in your exciting next chapter, Corey!



HSC Expands Our Child, Youth, and Young Adult Offerings



We are excited to announce the development of new offerings within HSC that address the growing needs of children, youth, young adults, and families accessing our services. This focus expands on our existing programs, including Young People Affected by Huntington disease (YPAHD) and the Youth and Young Adult Mentorship program, by extending services to those under the age of 14, our previous entry point.

"We are thrilled with HSC's new investment in meeting the needs of our youngest community members," says Shelly Redman, CEO of HSC.

"We know that HD impacts everyone in the family, and now we will be able to offer support to children facing this disease, whether it affects their parent, grandparent, sibling, or even themselves."

Winnie Diverlus joined the Huntington Society of Canada on August 18, 2025, as HSC's Child and Youth Care Practitioner. In this new role, she will develop and lead a Child, Youth, and Young Adult Program at HSC to support young people and their families in meaningful ways. She will also facilitate groups, build community partnerships, keep track of progress, and guide and enhance the Youth Mentorship Program to help youth learn, connect, and grow.

Winnie has spent over 10 years developing programs that empower people to feel capable, connected, and understood. With experience ranging from Montessori classrooms to grassroots organizations, Winnie's focus includes creating welcoming and inclusive communities. Her skills extend to group facilitation, program evaluation, and child development.

"I am truly honoured to play a role in supporting continuity of care for our vulnerable children and youth facing the challenges of HD," Winnie says.

You can reach Winnie at 1-800-998-7398, ext. 212, <u>wdiverlus@huntingtonsociety.ca</u>. Welcome to HSC, Winnie!



Creating Connection Through Art:

How Jaclynn Phillips is Supporting the Huntington Disease Community with Art Therapy

Each month, through the soft rustle of magazine clippings, the quiet scratch of pencil on paper, or the gentle brush of paint across canvas, something remarkable unfolds.

Jaclynn Phillips, an artist and HSC Resource Centre Director for Vancouver and Lower Mainland Region, British Columbia, leads a virtual art therapy support group for people affected by Huntington disease (HD). In this group, creativity becomes a lifeline – a way to navigate the emotional, physical, and relational challenges of a rare and complex disease.

Jaclynn's group is called the BC HD Community Art Therapy Support Group, and it's open to anyone impacted by HD: individuals who are at-risk, gene-positive, diagnosed, or caring for someone with the disease. It's an inclusive space grounded in compassion, therapeutic insight, and the belief that healing can come from making art — even if you've never picked up a paintbrush before.

"You don't need any art skills to participate," Jaclynn says. "In fact, artists might find it more challenging because the focus is on the experience, not the outcome. The art is a vehicle – it's not the destination."

A Support Group Like No Other

What sets Jaclynn's group apart is the way she blends her background in both fine art and social work. Jaclynn has a diploma in art therapy and a Bachelor of Social Work plus a minor in Fine Art from the University of Calgary. She is now completing her Master's in Social Work at Wilfrid Laurier University. Her professional background includes work in palliative care, mental health support, dementia care, crisis intervention, and long-term care, including facilities supporting individuals with neurodegenerative diseases like HD. Across all these roles, she's integrated creativity into her care, because she's seen firsthand how powerful it can be.

The HD art therapy group meets online, allowing Jaclynn to connect with participants across the province. Each session has a different theme that's connected to a personal or emotional skill: resilience, self-advocacy, identity beyond diagnosis, or regulating emotions, for example. Jaclynn guides the group through a creative activity that helps explore that week's concept.

"We might talk about adapting to change, and the art activity reflects that," she explains. "Every session includes time for sharing and debriefing. I ask, 'How was that for you?' and we talk about how what happened in the art process relates to what's happening in life. It's amazing what people discover."



The Power of Process

Jaclynn emphasizes that art therapy isn't about producing masterpieces. Often, the constraints of the activity (using only one colour, drawing without lifting the pen, or creating something out of found objects) can make people uncomfortable at first. "That's the point," she says. "We're often dealing with discomfort in real life. These sessions help us learn how to sit with that, work through it, and discover something new."

In one popular activity, participants create collages using magazine cutouts Jaclynn has prepared. Despite the randomness of the materials, the end results are always fascinating, expressive, and surprisingly cohesive. Another week might focus on monochromatic painting or continuous-line drawing, which leads to abstract, contemporary-looking pieces that reflect participants' internal experiences.

Jaclynn uses all kinds of media, including clay, photography, acrylics, and even gold glue. Her upcoming session at the 2025 Huntington Society of Canada National Conference features a Kintsugi-inspired project. Kintsugi is the Japanese art of repairing broken pottery with gold, emphasizing the beauty of flaws and the resilience of mending. Participants will paint and break their pots, then reassemble them with gold glue. "It's such a powerful metaphor for living with HD," Jaclynn explains. "We're not the same as we were, but that doesn't mean we're broken. We're transformed. The cracks tell a story, and they're beautiful."

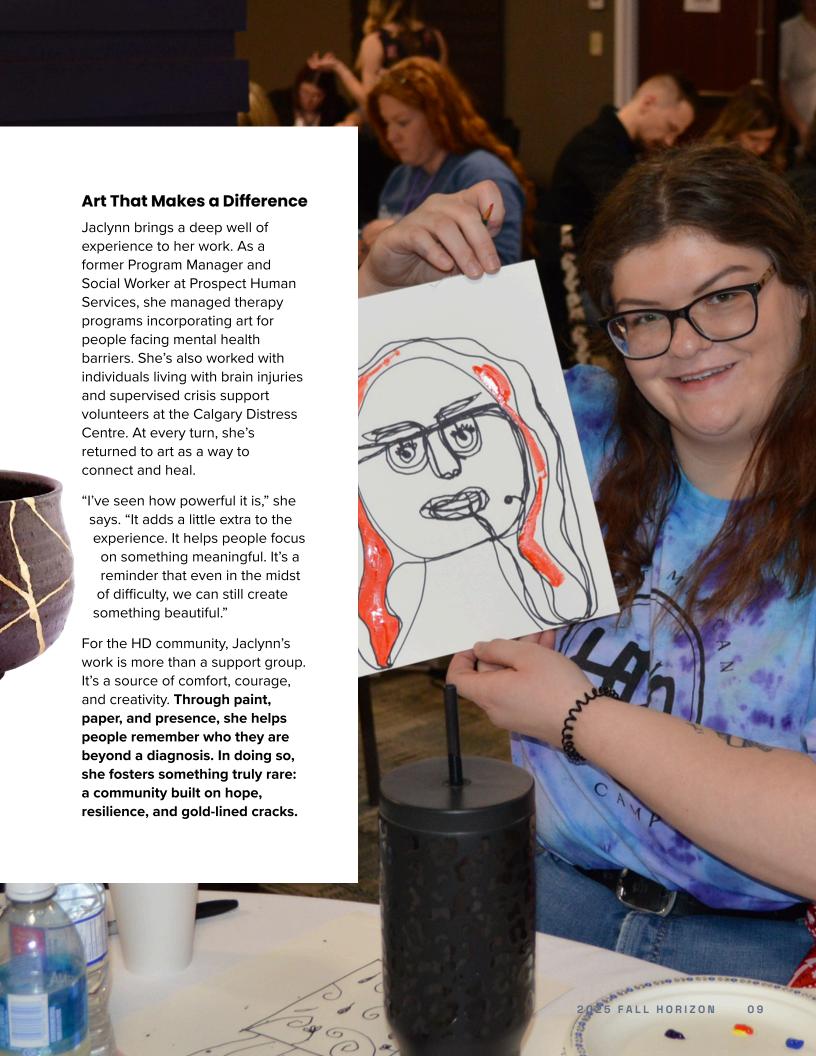
Building Community, One Session at a Time

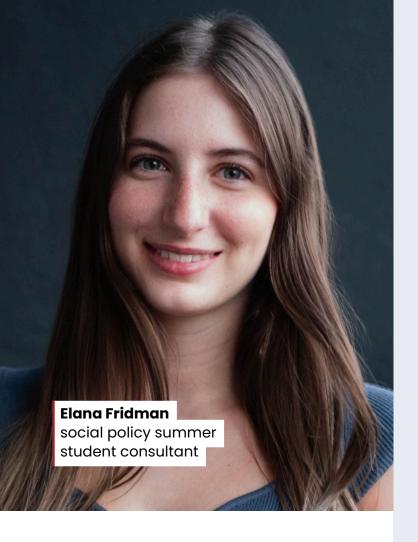
In addition to her support group, Jaclynn has facilitated large-scale sessions for the HD community, including at the 2024 YPAHD (Young People Affected by Huntington Disease) Day. While large groups don't always allow for in-depth debriefing, Jaclynn still sees incredible value in the shared experience. "Even a simple compliment, such as 'I like your piece,' can make someone feel seen. That's the power of art in community."

She's passionate about how art therapy intersects with advocacy and social justice, particularly in rare disease communities. "When we make art together, we're creating awareness. We're telling our stories. We're making space for our experiences to be understood."

Jaclynn sees a future where HD art therapy groups might meet in person. "That would be amazing," she says. "We'd get to connect even more deeply. But for now, virtual sessions allow me to reach people across B.C. who might not otherwise have access to this kind of support."

The group is capped at 14 participants to ensure everyone has time to engage and share. There's often a waitlist, a sign of just how meaningful these sessions have become. "People show up. They stay. They grow," Jaclynn says. "And they take what they learn in the session into their lives."







Kick-starting HSC's Advocacy Strategy

This past summer, HSC had the pleasure of hosting Elana Fridman as our social policy summer student consultant, funded by the Canada Summer Jobs program. Elana graduated from Queen's University (Kingston, ON) with a bachelor's degree in health sciences. She has recently been accepted to medical school in Ireland.

To begin development of HSC's HD Advocacy Strategy, Elana connected with HSC staff, healthcare professionals, and HD community members to understand the challenges facing those affected by Huntington disease.

Here's what Elana was able to achieve in eight weeks:

- 36 interviews conducted
- Mix of community members, genetic counsellors, neurologists, HSC staff, volunteers, and many more
- 44 survey responses collected

Early themes include the need for education, as well as a shortage of clinicians, and obstacles surrounding caregiving and long-term care.

Elana analyzed the data and produced a final report that lays the groundwork for an Advocacy Framework reflecting the community's needs.

Our gratitude to all who participated! Best of luck to Elana – although our time together was brief, Elana made a big impact!



Centres for HD CARE

We're excited to update you on our progress around the Centres for HD CARE (Clinical and Research Excellence). For Phase One, we are partnering with the Centre for Community Based Research (CCBR), based at the University of Waterloo. There's a strong Huntington disease connection to CCBR – the institute was founded by John Lord, HD care expert, HSC Conference speaker, and a caregiver with lived experience in a family facing HD.

Phase One (of three overall phases): This initial phase focuses on conducting a comprehensive gap analysis so we can better understand the specific challenges and barriers individuals face when accessing HD care.

Phase 1 includes:

- Literature review
- Forming a steering committee composed of community members with lived experience facing HD
- · Ethics review
- Stakeholder interviews
 - Care professionals, community members, rural and remote stakeholders, Huntington Society of Quebec (HSQ)
 - Key Funding partners
- Analysis
- Final Report and National Forum

Thank you to everyone who has supported us on our quest to provide hubs of clinical expertise in Huntington disease care, especially in underserved regions. Your support brings us one step closer to launching the Centres for HD CARE.

Results of Federal Election Advocacy Campaign

Last April, we asked for your support by writing to your local candidates in the federal election in support of a renewed National Neurological Health Survey via the website www.brainhealthmatters.ca.

We are excited to share the results of this online advocacy campaign:

669 personalized letters sent to candidates across Canada

418 total candidates reached

103 candidates were reached by more than one constituent

40 candidates received letters from three or more people

36 letters were sent in French

17 candidates received 4 or 5 letters – these have high follow-up potential!

One newly elected candidate from Calgary Confederation (Corey Hogan) replied saying they would like to meet with the constituent!

Thank you so much for your support in asking the federal government to make neurologic health a priority.







For more National Conference information, visit

https://site.pheedloop.com/event/hscconference2025

Presenting... HSC's 2025 National Conference and YPAHD Day

HSC 2025 National Conference

We're excited to welcome you to the 2025 National Conference taking place on Friday, October 31, to Saturday, November 1, at the Toronto Westin Airport Hotel in Mississauga, Ontario.

Here you'll find connection with a group of people who know what it is like to be affected by Huntington disease.

You'll learn the latest updates from the growing field of Huntington disease research – from the scientists themselves!

Experts will share helpful and specific information on caring for someone with HD, navigating the HD journey, raising awareness, and moving the dial on advocacy.

The keynote speakers will leave you inspired, hopeful, and ready to return home with new knowledge and insight to share with your community and apply to your situation.

People say conference is magical – we can't wait for you to experience it for yourselves.

YPAHD Day

YPAHD (Young People Affected by Huntington Disease) Day returns on Thursday, October 30 in Mississauga, Ontario. This youth conference provides the perfect opportunity for community members aged 14-35 to gather inperson and meet other incredible youth affected by HD. The day will offer opportunities for youth to share their experiences, strengthen their support network, and learn about a variety of topics. Get ready to laugh, learn, and create unforgettable memories that will last a lifetime.



Find out morebout YPAHD Day by visiting:

www.huntingtonsociety.ca/ ypahd-day/

HUNTINGTON SOCIETY OF CANADA













2025 Huntington Heroes Walk Highlights

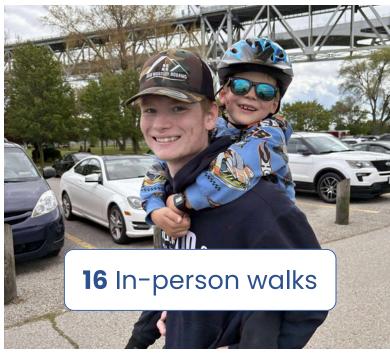
- The Durham Chapter welcomed new organizers sure to make former president Bunny Clark proud. Nicole Verwey, Jerry Johnston, and Tyler Paul created a successful event that left participants beaming. They are already busy planning their future events.
- The Toronto Chapter far exceeded their fundraising goal this year, raising almost three times their original goal! New team Westminster Funeral & Reception Centre helped knock it out of the park.
- The Belleville Active Area held another fantastic event uniting friends, family, and community. Every participant contributed to the energizing spirit and left the event feeling inspired.



- The London Chapter once again held their walk in Exeter, bringing together a wonderful group of fundraisers and introducing some new organizers. CEO Shelly Redman was pleased as punch to attend and had a fantastic day celebrating with the community.
- The Sarnia Chapter had yet another successful walk, featuring festive face painting, friendly pups, and inspirational HD spirit. The chapter was thrilled to welcome new and returning attendees, whose attendance made for an incredible day filled with community support and connection.
- The Saskatchewan Chapter saw participants travelling from far and wide for their walk along Meewasin Trail in Saskatoon. Due to wildfires, organizers closely monitored air quality the morning of the walk, taking extra precautions to ensure a safe and memorable experience. Conditions stayed favourable, and a record-high number of participants had a wonderful day gathering and celebrating the walk with some pizza.









- The Edmonton Chapter hosted their annual walk in the park with a heartwarming addition, partnering with people living with HD from the local hospital. Residents were pleased to get out and enjoy the beautiful day alongside chapter volunteers.
- The Sauble Beach Walk organizers saw 44 participants attend their walk in May. Although a tad chilly, this dedicated team brought together a fantastic group of participants to walk and raise awareness for HD in their community.
- The Hamilton Walk crew held their event at Confederation Beach Park with 13 attendees. Together, this small but mighty group surpassed their goal to fundraise \$5600. Congratulations on your huge accomplishment, Hamilton!
- The Windsor / Essex fundraising walk celebrated the new season in Kingsville, ON, on September 7 with wonderful spirit!











Walk This Way: How Lori Anne Webb Smashes Fundraising & Awareness Goals

Twenty years ago, Lori Anne Webb hadn't even heard of Huntington disease, let alone realized it ran in her family. Now, the Nova Scotia fundraiser has turned her magic touch to the annual HSC Huntington Heroes Walk, racking up both dollars and steps for a cause very close to home.

Lori Anne's mother was diagnosed in 1996 with Huntington disease after a car accident.

"My mom was in her 70s, but she wasn't showing symptoms," Lori Anne says. "After her car accident, the neurology tests showed Huntington disease."

It came as a shock, as the family was unaware of anyone else with HD. After investigating, they realized that Lori Anne's maternal grandfather had HD, although he died from cancer, and several cousins were also affected.

In 2010, Lori Anne's sister was diagnosed. She turns 69 in November and is now in a care home. "I'm her person," Lori Anne says. "For medical, legal, financial issues – it's me."

Then, in 2019, Lori Anne's brother was diagnosed with Huntington disease, too.

"It had already been really tough watching my mom go through Huntington disease, and then my sister, and finally my brother's diagnosis."

"Next, Covid hit, and it was so hard to do anything."

But one day in 2021, Lori Anne received an email from HSC about the National Walk going virtual. "I thought – that's something I can do!" Lori Anne collected about \$1000 in pledges and walked close to 10 km in her community with a friend in her Covid bubble.





In the fall of 2021, Lori Anne required surgery to replace a heart valve.

And yet, 7 months after open heart surgery, she asked her doctor if she could participate in the 2022 Huntington Heroes Walk.



The answer? "Go for it!". And she did, walking 20 km in one day at the cottage surrounded by family, friends, and other cottage-goers. She raised almost \$2400. In 2023, she again walked 20 km at the cottage with her friends and family, gathering \$3000. In 2024, her total climbed to \$3790, and the cottage tradition was firmly entrenched.



"I'm thrilled to have raised \$15,000 over my five years of walking for the Huntington Society of Canada," Lori Anne says. "My advice to anyone looking to raise money for Huntington disease is to keep increasing your goals – you can do it!"

In 2025, Lori Anne switched it up and joined the PEI Chapter for their walk at Bonshaw Hills National Park on Saturday, May 31, raising \$4770. Lori Anne's husband placed a donation box at his business and raised \$500 to support her efforts. Even though Lori Anne participated in the walk, her cottage group wasn't forgotten. "My cottage friends and family insisted that I walk at least 10 km with them the weekend before PEI, which we did with great pride!"

Lori Anne mentions how much the Huntington Society of Canada's Resource Centre Directors support her family. "They have both been amazing advocates for my family."

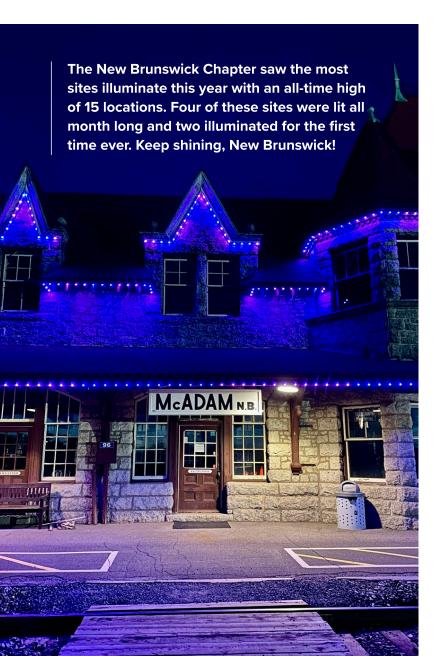
Lori Anne says she was welcomed with open arms by the PEI Chapter and plans to join their walk next year, too. "The PEI group is small and mighty," Lori Anne says. "That's why we use social media to help raise funds and awareness for the cause — it's a wonderful force for good, and people have been so generous and encouraging of the cause."

Lori Anne's Tips for Successful Fundraising

- The dollar-to-dollar match is a huge driving force. When people express regret that they can't give more, it's great to be able to remind them that every amount is automatically doubled.
- Posting weekly to social media helps me achieve my goals! I always get a few pledges after doing so, and people tell me they are proud of what I am doing.
- Providing updates on my progress helps people see that I am close to achieving my goal.

 I give myself a good 3 months to fundraise to make sure I can make it to the finish line!
- The incentive prizes (T-shirts and hoodies) aren't the reason I fundraise, but they are nice, and they help raise awareness, so that's a bonus. I wear them often, and with great pride!
- Remember that by raising awareness and funds, we are making a difference! That's motivation to go out and try to have a goal to reach when fundraising. Be consistent in your efforts to achieve it!

Thanks for these tips, Lori Anne – you're a pro and we are so grateful for your efforts!



Light It Up 4 HD Spotlight

In 2025, HSC's goal for the #LightItUp4HD campaign was to highlight the sites that mean the most to our communities. In Canada, we saw 79 awe-inspiring sites light up over the month of May, illuminating alongside more than 12 countries.

The PEI Chapter also saw a remarkable turnout with 10 sites illuminating for HD. All but one were lit for several days over the course of the month, and many are repeat participants, lighting up for HD year after year. A small but mighty community, PEI loves to shine!





It's been eight years since Rachelle Tuck, Brittany Van Norman, and Jenna Scott (Marsh) took over as the Southern Alberta Chapter's Hope for a Cure Run & Walk organizers. For several years before organizing, they each attended the event with their families – something they will continue to prioritize in the future. Then, they were presented with the opportunity to organize the popular and successful fundraiser.

This launched a period of deep involvement with the chapter, as Rachelle, Brittany and Jenna volunteered their time, energy, and expertise in a variety of ways. Organizing the event allowed them to explore new ideas, get creative, and learn from their experiences. Every year, the trio spent upwards of 10 months leading up to the event day planning how to make every year better than the last.

"We have all been really motivated by the impact we've been able to make by planning this event. It can be hard to believe how much money we're able to raise. It has been really special seeing the community grow and make this event annual for their families. It is very inspiring every year," says Rachelle.

"My favourite memory was from our 14th Annual Hope for a Cure Walk, which had a Family Reunion theme. It was our first in-person event after COVID, and the energy was so special – like a true homecoming. Seeing families, friends, and long-time supporters reconnect in person after being apart for so long was incredibly emotional."

"There was laughter, tears, and this shared sense of hope and resilience that reminded me why we do this every year. It truly felt like a reunion – not just of people, but of community spirit. That day made all the planning worth it."

Now it is time for Rachelle, Brittany, and Jenna to pass the torch. The powerhouse organizers are hopeful the next volunteers will continue to bring passion to the event and encourage them to have fun with it.

"Thinking outside of the box and doing things you find exciting allows you to make the event your own."

They are excited to see what the future holds, with new leaders and ideas. Thank you, Brittany, Jenna, and Rachelle, for all your hard work over the last eight years, and congratulations on your accomplishments.

Play to Your Passion

Want to help fundraise, but not sure where to start? We find that when people start with a personal interest, wonderful events follow! Here are a few hobbies that could pivot into engaging fundraisers:

- Hiking
- Yoga, Zumba, or line dancing
- Baking try a pie contest!
- Knitting, crocheting, quilting, sewing, or needle-point – it could be a stitch-a-thon
- Biking hit the trail or country roads
- Photography offer mini sessions or host a contest
- Trivia
- Cornhole
- Pickleball
- Geo-caching
- Snowshoeing, skiing, or snowmobiling
- Nature interpretation
- Gardening imagine a garden tour!
- Wreathmaking, flower-arranging
- Pottery, or making candles/soap
- Nature journalling or forest bathing

Reach out to your local chapter or the HSC Events team (events@huntingtonsociety.ca) to discuss your idea. They'll be able to support you with event planning and the next steps for an exciting and successful event.







Creative Events for Much-Loved Pastimes

- The Peace Country Chapter held its 16th Annual HD Ride 4A Cure in TeePee Creek this past August. Past Board Chair Mack Erno was thrilled to see new and returning participants attend the event, running, walking, and riding, all abuzz with the camaraderie of this unique fundraiser. He is already looking forward to next year's HD Ride.
- The Manitoba Chapter recently held its 30th Annual Indy Go-Kart Challenge in Headingley. A day everyone looks forward to, attendees of all ages had an eventful day of racing and celebrated with prizes. Thanks to everyone who made this monumental Indy a huge success!
- The Young People Affected by HD (YPAHD)
 Chapter enthusiastically hosted their second annual tattoo fundraiser in London, ON. Youth from across the province attended and received flash tattoos to raise funds and awareness for HD, and HSC CEO Shelly Redman got her very own dragonfly tattoo the logo for YPAHD.
- On March 8, the Peterborough Chapter held its second annual Curl to Cure HD event in Selwyn.
 Open to everyone from seasoned skips to firsttime sweepers, the event was a perfect blend of challenge and fun for the whole family.

Events like these, which appeal to the community's interests, forge deeper connections, inspire new ideas, and create memorable moments for everyone.





The Camrose Chapter held their 13th annual golf tournament on Sunday, June 21. They saw over 140 attendees at the Silver Creek Golf Course near New Norway. Golfers were eager to participate in both the silent and live auctions to snatch up incredible prizes donated by local businesses in Camrose. After a successful day on the course, everyone in attendance enjoyed a BBQ dinner and celebrated another wonderful event held by the Chapter.

More Than Just a Tournament - a FUNdraising event

The 10th Annual Golfapalooza HD Classic in Niagara

The Niagara Chapter has a long tradition of organizing golf tournaments to raise funds for Huntington disease, as well as encouraging camaraderie and connection!

History of the Niagara Chapter's Golf Tournaments

The golf tournament legacy began in 1994, when it was first organized by Lamberta (Bert) Sauder, a longtime volunteer with the Niagara Chapter. After Bert's passing, her daughter Gail and Gail's husband Neil DeKoning continued the tournament in her honour as "The Bert Sauder Memorial Golf Tournament" until 2014. Gail and Neil are also longtime members of the Niagara Chapter. Gail is the secretary, and Neil was heavily involved as an Amaryllis Coordinator for years, as well as treasurer.



RUN
2025 FALL HORIZON
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In 2007, Bert's daughter Lynn (Gail's sister), and her husband, Rick Miner, embarked on a 10-year run organizing a couples golf tournament until 2017.

When Barb Eade, John Stainsby and Jim Heywood got together in 2016 to talk about the continuance of a 23-year Niagara Chapter tradition of organizing golf tournaments to raise funds and awareness for HD, they knew they wanted to attract golfers from all over the region (new and experienced) and for the tournament name to be fun! They decided on The Niagara HSC Chapter Golfapalooza – HD Classic.

Adding Palooza = Adding Fun

Along with the traditional tournament experience, the planning team infused a little "palooza" into the day. Each year, there is a colour or pattern theme, such as neon or argyle. Cart snacks, door prizes, and items for raffles and auctions change each year. The event features team photos with funny props and signs, and teams can choose playful names like "The Fore Fathers," "Tee Totalers," or "Putt Pirates," to name just a few.

Games on the Course

On the course, players come across friendly foursome or individual challenges like "Golf Trivia," "Puttapalooza," or "Wheel of Fore-tune," where each player spins the wheel and performs the task they land on, such as "Blindfolded Drive", "Playing the Hole with Just One Club" or doing "5 Jumping Jacks."

Raising Fun and Funds for the Cause

Last year, the tournament raised \$9,000. This year, Golfapalooza took place on September 7 at Willodell Golf Club of Niagara. The planning team hopes to reach their goal of \$10,000.

This year marks Barb and John's final year running this spirited and successful event.

"After a fun decade of organizing
Golfapalooza, we're looking for someone new to take on the leadership role," says Barb.

"We're excited about the fresh perspective our next organizer will bring to the event."

Making a Difference for Decades!

The total number of years of both golf tournaments, with a stretch of two a year, totals 40 years of FUNdraising, playing a great sport for a great cause!







B.C.'s Lesley Larsen-Nantel takes her dad on one last motorcycle ride

By Erin Paterson

When Vancouver, BC's Lesley Larsen-Nantel visits her dad, Dan Larsen, at his care home, they sit outside on the patio when the weather is nice. They often hear the roar of a Harley motorcycle in the distance.

"I could tell my dad misses being on a motorcycle," Lesley says. "My dad was an avid rider. My brother and I grew up on the back of his bike, going on bike and camping trips. Sometimes there would be fishing rods across the handlebars," she remembers fondly.

Dan's passion for motorcycles inspired Lesley to get her dad out for one last ride.

It had been over eight years since his last bike ride. The idea started as a way to get her dad some wind therapy and create memories. It quickly turned into something more.

"We thought, why don't we have other people come along?" So, Lesley and her dad opened it up to other bikes as well as classic car enthusiasts.

"We wanted people to be with like-minded folks who know bikes and understand the freedom of being on a bike. At the last minute, it turned into a fundraiser. The biker community is incredibly supportive."





On the day of the ride, Sept. 8, 2024, 30 bikes showed up. Most of the people didn't even know Dan. A couple who owned a motorcycle towing company volunteered their time to drive the pilot car and block traffic. The scenic route took them from the Barnes Harley-Davidson in Langley to the Dewdney Pub in Mission.

Lesley's dad didn't quite understand what was happening or that everyone was there for him, but when he saw the bikes, he said, "I want to ride, I want to ride."

"Most of his words are slurred now, but that was as clear as day," Lesley says. "When he was on the bike, he looked at ease. He was nice and calm, and in his element."

Even after all these years, Dan remembered how to be on a bike. He still knew what to do.

After the ride, Lesley helped her dad, who uses a wheelchair, look at the numerous bikes and classic cars in the parking lot. They capped off the celebration by enjoying beer and burgers at the pub.

At the time of writing, Lesley is planning another bike ride with a bigger fundraising element. If her dad's health permits, she would love to get him on a bike again, but it might have to be a bike with a sidecar or a classic car instead.

Beyond this fundraiser, Lesley is determined to carry on her father's legacy. She has a bike and plans on getting her license to allow her to carry on the tradition of biking in her family.





About the author:

Erin Paterson is an author, speaker, and Huntington Disease advocate. She founded Lemonade Press to help amplify voices from underrepresented medical communities and has published four books about HD.



By Jo Kaattari



It's sometimes said that you don't choose the books you read – they choose you. In two Canadian communities, books not only found us, but also led to fundraising, Huntington disease (HD) awareness, creativity, community building, and more.

Two families affected by HD, in two provinces, had one great idea – to create "Mystery Books" to raise funds for the Huntington Society of Canada (HSC). Mystery Books are gently used books that are carefully wrapped and decorated to ensure the book is a beautiful surprise. Clues to the book's genre and content are included, along with a bookmark and a tea bag.

Shauna Warren, from Pasadena, Newfoundland, and Jo Kaattari, from Barrie, Ontario, with the help of their family and friends, both created Mystery Books to raise funds for HSC.

Shauna's beloved aunt, Kim Childs, was an avid reader who owned many books. When her aunt went into long-term care due to Huntington disease, Shauna and her uncle, Greg Childs, wanted to use these books to raise funds for HD in Kim's honour.

Shauna came up with the idea of selling Mystery Books at a Christmas Craft Fair in Pasadena. Shauna created 83 Mystery Books for the fair with the help of her young daughter, Hannah. To Shauna's great surprise, people flocked to her booth, and her Mystery Books quickly sold out!

There were additional benefits. People were pleased to see Huntington disease promoted in their community, and a great deal of awareness was raised. People were highly supportive, and many book donations were received for Shauna to make more Mystery Books in the future.

Speaking of the future, Shauna plans on selling Mystery Books at the same Christmas Fair again in 2025, and she may expand to attending a fair in the neighbouring community of Corner Brook.

"It was wonderful to honour Aunt Kim by using her books to create awareness of HD and raise funds to support the work of the Huntington Society of Canada," Says Shauna.

Jo Kaattari and her husband, Steve Wells, held a Book Sale of Hope for HD in Barrie in May 2025. They collected over 600 used books and lived in a bookish fortress all winter (being book lovers, they didn't mind in the least!). As part of her "winter blues" therapy, Jo also made 40 Mystery Books. The Book Sale of Hope went very well, but it was the Mystery Books that quickly sold out.

Other benefits of holding the Book Sale of Hope included meeting other HD families, creating community, and embracing the kindness of family, friends, and strangers who donated books... lots of books!

Instead of holding a large used book sale next year, Jo and Steve plan to sell Mystery Books at several community fairs. They found that Mystery Books are more manageable and profitable as a fundraiser than used books, and the fun of making Mystery Books is good for the soul.

Jo and Steve knew there would be leftover books, due to the incredible generosity of donors, so they plan to donate surplus used books to prison inmates, women's shelters, and Little Free Libraries. There have been many heartwarming offshoots from this one fundraiser!

Shauna and Jo plan to keep in touch and share strategies and ideas for creating and selling mystery books. Who knows what other ideas they may come up with as they wait for the books to work their magic!

"What a joy to create beautiful Mystery Books that raised funds for HD research and family services AND brought fun, creativity, and good into the world," says Jo.









Celebrating Retirement for a Very Special Volunteer:

Nancy Murphy

In January, Nancy Murphy retired after a 45-and-a-half-year career with McGee Fencing Ltd. in Gloucester, Ontario (Ottawa area). Nancy is also a long-time volunteer with the Ottawa Chapter of the Huntington Society of Canada and has achieved great success with fundraising events.

Nancy became involved with the Huntington Society of Canada when her mother-in-law, who was in her early 60s, was diagnosed with Huntington disease. Nancy's husband, Dan, was diagnosed in his late 30s and passed away six years ago this fall. Her oldest son was diagnosed at the age of 25.

"My son, age 37, is in the late stages of HD now, struggling every day," she says. "I had to get involved and do what I could to raise money, keeping a little bit of hope that someday we will find a cure."

Nancy also inspires others to donate money to the HD cause, such as fencing supply company Master Halco, which has been one of McGee Fencing Ltd.'s suppliers since 1997. Nancy asked Michelle and Derek, managers at the Toronto/Ontario Master Halco location, to sponsor a prize for the 2024 Murphy Golf Tournament, to which they generously agreed. In 2025, they upped the ante. Every year, each branch selects a charity close to their hearts to benefit from the Master Halco Gives Back program, in which a portion of the branch's sales is donated to the chosen charities.

"I have been working with Master Halco for 28 years, ever since they opened. We've got to know each other quite well, and they know about my life challenges as a caregiver and working full time," Nancy explains. "A couple of weeks before I was to retire, they told me they had chosen the Huntington Society of Canada – in my honour – as the charity they wanted to benefit from the Master Halco Gives Back program. Best retirement news ever."

Across all branches, the program raised over \$310,000 in 2024, bringing the total over the last 4 years to just over \$1 million!



"I know that our region raised \$3298.22 to go to HSC," says Nancy. "It's great news. I was so happy when they told me that. I hope it will have a big impact."

"My retirement after 45.5 years was not an easy decision, but my son needed more care than I was giving him, and as each day seemed to get a little worse, I knew it was time. Looking back, I don't know how I did it. More help is needed to relieve the caregivers so they can have even a small amount of free time. We are not in the process of burning out, we **are** burnt out."

Despite these challenges, Nancy has always prioritized fundraising for HD. Just this past year, she organized or assisted with the following initiatives:

Huntington Heroes Walk: Carp Fairgrounds, May 4 (Murphy Family)

"I made 8 dozen muffins, bought some water, created some signage – and there you have it. Instant walkathon! We raised over \$8300 - an overwhelming result!"

4th Annual Murphy Golf Tournament: Timber Run Golf Club, (Ottawa Area), June 14

This event sold out in 3.5 hours, with 144 golfers at the beautiful Lanark Highlands Timber Run Golf Club.

"At least 75% of the participants were related to our family. It might not be a day of skill, but it is always a social, fun-filled day," Nancy laughs.

The golf tournament was started by Nancy's niece, Amy Murphy Kingham, Nancy's nephew, Reed Murphy, and Reed's wife, Teasha and they continue to be the organizers – Nancy helps. It's in honour of Amy and Reed's dad, Jeff (brother to Nancy's husband Dan), who also has Huntington disease. "It's so important to see a younger generation help out to raise money to find a cure."







Ottawa Area Amaryllis Coordinator

Nancy's longest volunteer stint has been as one of the Amaryllis Coordinators for the Ottawa area. "Don't ask me how many years I've been doing this – I've been doing it so long, I forget!" she explains. "I know 68 cases and 812 plants went through my door last fall. It's a huge job, keeping track of the orders and waiting on pick-ups. But it is very rewarding."

A Lifetime of Dedication to Career, Community, and Cause

Nancy gives so much, even as the demands on her time and energy continue to increase. Everyone who knows Nancy is impressed and motivated by her commitment to raising funds and awareness.

"It's not easy," Nancy says. "But I am blessed to have a loving and supportive family who are always there, and the best of friends and neighbours a person could ask for, to help us through this battle."

Nancy, you are an inspiration! Thank you for all you do!

Has Nancy's story started you thinking about the different ways in which you can contribute?



To see if your employer offers a financial donation to match yours, visit: www.huntingtonsociety.ca/double-your-donation/

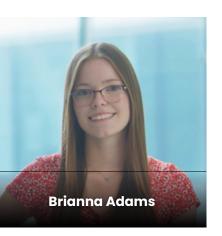
You can also see if your employer will make a monetary donation when you volunteer for a charity like HSC.

Inspired to start your own event? Contact <u>events@huntingtonsociety.ca</u> with your questions and ideas!

2025 HSC Student Fellowship Awards in Huntington Disease Research

Together with our partner, Brain Canada, we are honoured to announce the recipients of the 2025 HSC Student Fellowships. These student awards are partially funded by the Canada Brain Research Fund (CBRF), an innovative arrangement between the Government of Canada (through Health Canada) and Brain Canada Foundation.

Here are the student researchers tackling Huntington disease challenges. The future is bright!







Brianna Adams - Memorial University, St. John's, Newfoundland

Brianna Adams started her fourth year in the Behavioural Neuroscience program at Memorial University in September. She is fascinated by the brain, particularly neurodegenerative diseases like Alzheimer's, Parkinson's, and Huntington disease.

"The fact that there are still no cures for these illnesses has driven my passion to contribute meaningfully to this field," says Brianna. "I currently work in several neuroscience research labs exploring the biological and behavioural mechanisms behind these diseases."

Brianna hopes to become a neurologist, working alongside other researchers and clinicians to develop treatments that change lives. She enjoys studying, learning new things, and problem-solving. Beyond academics, she loves spending time with friends and family, walking her dog, Sasha, crafting, and volunteering with organizations like Ronald McDonald House Charities.

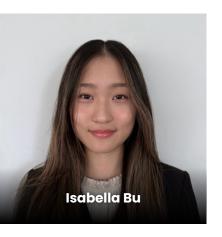
Alexandra Bérubé Ebacher - Université Laval, Québec City, Québec

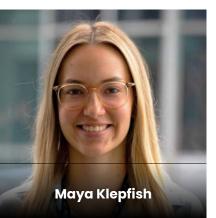
Alexandra Bérubé Ebacher studies medicine at Université Laval, having chosen this program due to a deep desire to help others and benefit society. Outside of school and research, one of her greatest passions is sports, especially volleyball.

"I am intrigued by research, largely due to my analytical nature. I enjoy reflecting deeply on questions that remain unanswered," she says. "Neurology fascinates me because so many mysteries in the field persist. I am sincerely grateful for this fellowship and look forward to working on Huntington disease."

Christiana Lammers – University of Guelph, Guelph, Ontario

Christiana Lammers is currently studying Bio-Medical Science at the University of Guelph. This summer, she conducted Huntington disease research in the Alpaugh lab, investigating a pro-degenerative neuronal pathway and its impact on HD. Christiana hopes to become a neurologist and make a difference in the lives of people facing HD.









Isabella Bu – University of Western Ontario, London, Ontario

Isabella Bu entered her second year of Medical Sciences at Western University in September. This summer, she worked with the Stathopulos Lab to investigate how S-nitrosylation of MCUb may disrupt mitochondrial calcium regulation in Huntington disease.

Isabella is passionate about tackling challenging questions surrounding the molecular basis of disease and hopes to contribute meaningfully to both biology and human health through her work.

Maya Klepfish – McMaster University, Hamilton, Ontario

Maya Klepfish is in her final year of her undergraduate degree at McMaster University, majoring in Molecular Biology and Genetics Research with Co-op. She recently completed her undergraduate thesis project in the Truant Lab, focused on DNA damage in Huntington disease patient-derived cells and optimizing a new technique for tracking live huntingtin protein. Maya's passion for researching genetic disorders stems from a high school project on Friedreich's ataxia, and she has since researched MECP2 duplication syndrome and Huntington disease. When she's not at the lab, Maya enjoys hiking, trying new cafes, and exploring interior design.

Yusra Kureshi – University of Waterloo, Waterloo, Ontario

Having just finished the last term of her undergraduate degree in Biochemistry, Yusra Kureshi is excited to start research in improving the delivery of therapeutics for Huntington disease. Yusra plans to pursue a Master's degree soon.

"I am continually in awe of how science can forever change lives," Yusra says. "I hope to one day work in developing gene therapeutics for debilitating human diseases."

Outside of science and research, Yusra loves to crochet and build 1000-piece puzzles of her favourite Van Gogh paintings.

Fatma Slim – University of Ottawa, Ottawa, Ontario

Fatma Slim is an undergraduate student in the Honours Bachelor of Health Sciences program at the University of Ottawa. She is currently completing a neuroscience research internship at the CHU de Québec – Université Laval, where she works on blood-brain barrier models using iPSC-derived cells. Outside of academics, Fatma practices karate.

"Discipline is something I grew up with through karate, and it continues to shape the way I approach challenges in both research and daily life," Fatma says. "I am passionate about biomedical science and eager to contribute to Huntington disease research through this fellowship."



Shannon Pulido – Memorial University, St. John's, Newfoundland

Shannon C. Pulido Román is a Behavioural Neuroscience student at Memorial University of Newfoundland with plans to pursue a double major in Human Biosciences.

"My interest in Huntington disease research developed at a young age. My best friend's late mother had HD, and I had the privilege of assisting in her care with the guidance of her family," says Shannon. "Witnessing the profound effects of the disease on both my best friend's mother and her loved ones had a lasting impact and continues to inspire my research aspirations. This experience has solidified my commitment to understanding and finding solutions to neurodegenerative diseases."

Shannon worked with Dr. Matt Parsons this summer. She is interested in exploring the underlying mechanisms of DNA damage and somatic expansion in HD.

2025 Clinical Fellowship: Dr. William Leduc



The Huntington Society of Canada is pleased to announce the recipient of the 2025 Clinical Fellowship, Dr. William Leduc.

Dr. Leduc completed medical school and neurology residency at the Université de Sherbrooke.

He began his fellowship in movement disorders at the University of Calgary in July, receiving comprehensive clinical training in Huntington disease. He participates in both clinical management and ongoing clinical trials. Upon completion of his subspecialty training, Dr. Leduc plans to return to Montreal to begin his practice as a movement disorder specialist.

What is the Clinical Fellowship Program?

The Clinical Fellowship enables more neurologists to have an HD practice in Canada by encouraging promising young doctors to specialize in Huntington disease. This will help ensure that the day-to-day management of HD is accessible and available to all Canadians.

Welcome, Dr. Leduc, to the Huntington disease community. We are so pleased you have decided to focus your work in this area.

Thank you to our supporters for making this Clinical Fellowship program possible.



It wouldn't be fall without the signature burst of orange and red blooms that mark the Huntington Society of Canada's beloved Amaryllis Campaign. This year, we're thrilled to kick off our 2025 campaign with just as much enthusiasm, and even more hope!

Amaryllis Details

- We have 24,000 bulbs ready to go across Canada
- They're sold in cases. One case contains 12 kits and costs \$204
- Each kit includes an Orange Sovereign bulb, soil, pot, saucer, and instructions
- All bulbs are shipped from September 24th to December 4th, so your delivery arrives just in time for cozy autumn planting and festive holiday décor, and gifting
- Individual kits are available through regional Amaryllis sellers. Find their information here: www.huntingtonsociety.ca/amaryllis-area-sellers/



Region	Order Deadline
Newfoundland & Labrador, Yukon	October 24
Manitoba, Saskatchewan, Alberta	November 21
British Columbia, Quebec, Ontario, Atlantic Provinces	November 27

Be sure to order early to meet the deadlines and avoid shipping in cold weather! When our Amaryllis supplier says it's too cold to ship, they're looking out for the health of the bulb and its ability to produce a beautiful bloom. Some years, we must close orders earlier than anticipated due to severe weather, so order early! Amaryllis bulbs store beautifully in a cool, dry environment, so you can keep them healthy while you wait to gift or grow these beautiful blooms.

Amaryllis: Steeped in History & Hope

This campaign continues a tradition stretching back to 1985, when local chapters turned flower fundraising into a national movement. Just like those early days, each blooming bulb symbolizes hope and funding essential services for families and advancing research.

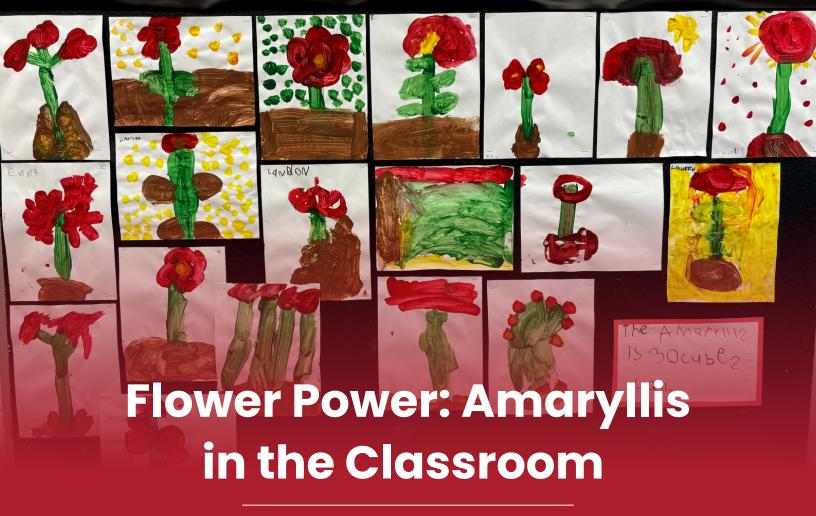
How to Get Involved

- Order online now at www.inspirehope.ca
- Email amaryllis@huntingtonsociety.ca or cchristophersen@huntingtonsociety.ca
- Call 519-749-8491 ext. 126 to chat with Camilla, our Amaryllis coordinator

Whether you're a longtime supporter or a first-time purchaser, your contribution makes a tangible difference. One case means twelve stunning flowers and twelve steps toward better lives and brighter futures.

Let's watch every bloom spark hope where it's needed most. Order your kits early, gather your friends and family, and let's make 2025 our most beautiful and impactful campaign yet!





Amaryllis plants truly inspire hope, and now they also lend their floral superpowers to fostering learning in kindergarten students at Sacred Heart of Jesus Catholic Elementary School in Burlington, Ontario.



It all began with Diane Durran, a neighbour to Chuck and Sharon Gera, powerhouse Amaryllis sellers in the Burlington area.

"Diane is a dear friend of Sharon's, and so very supportive of her struggle with Huntington disease," says Chuck.

Every year, Diane supports the Huntington Society of Canada by purchasing many Amaryllis. She gives them out as gifts to friends and former colleagues.

Two of these colleagues, Sonya Bresolin and Andrea Morton, are current classroom educators. For the past few years, they have used Amaryllis as an engaging and effective teaching tool.

Each year, students complete activities centred around the growth of the Amaryllis plants, including:

- · Charting growth using various math skills
- Creating daily journal entries via language skills
- Incorporating the Amaryllis as a basis for art activities
- Observing the daily Amaryllis growth

Some of their children talk about wanting to help those with Huntington disease.

"I was an elementary educator for over 35 years, and I am so impressed by the classroom work undertaken by these educators and, especially, by their young students," says Chuck. "I wanted to share their story because I felt the experiences of these children in the classroom could help increase community awareness of HD and the Amaryllis campaign."

HSC would like to thank Diane Durran and Chuck and Sharon Gera for their support with the Amaryllis campaign and raising awareness, Sonya Bresolin and Andrea Morton for their unwavering and compassionate dedication to education, and to the students, parents, and administration of the Sacred Heart of Jesus Catholic Elementary School for providing permission to be featured.

Sharon Gera is on the cover of this issue.











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