2024 FALL ISSUE



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## Welcome to the Fall issue of Horizon!

It promises to be an exciting season full of new and returning initiatives.

I want to start by thanking and saying goodbye to our seven Summer Research students. Thanks to additional funding from the Canada Brain Research Fund (CBRF), an innovative arrangement between the Government of Canada (through Health Canada) and Brain Canada Foundation, we were able to add to the program that started last year. You'll read more about each student later in this issue.

I'm also excited to announce that the 2025
National Conference will be in Toronto!
Additional details will follow, so make sure
you're subscribed to all our communications
channels to learn more. YPAHD (Young People
Affected by Huntington Disease) Day is inperson this November in Mississauga – we
know this is such a meaningful time for our
youth chapter and we are thrilled to be able to
offer the gathering.

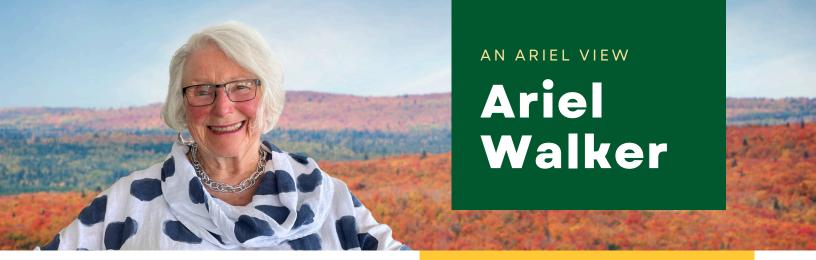
Fundraising events return with all your favourite golf tournaments, Indy Go-Kart events, and the Chatham Trapshoot. New this year, HSC Presents the Greg Morton Comedy Tour. Greg was a semi-finalist in America's Got Talent in 2019. Judge Howie Mandel said, "I can't believe there isn't a banner with your name on it in Vegas," and called him a one-man variety show. Originally from Woodstock, Ontario, Greg is thrilled to be representing and supporting the Huntington Society of Canada and the Huntington disease community.

Fall also means that Amaryllis are here! I love this campaign – what's not to like about gifting beautiful blooms ready to go in stunning gift boxes? It's as much a treat to give these wonderful symbols of hope as it is to receive them.

If you are looking for any details on these initiatives, please visit our website at huntingtonsociety.ca! Enjoy the season.

Tham

CEO, Huntington Society of Canada



There's a fundamental truth in our society: people like to be acknowledged.

My mother always used to say, "You don't know how much good you can do just by saying hello to a stranger." True to her word, she did that, even when shopping in downtown Hamilton. She would say good morning to every person she passed as if she were in the small communities of her youth. In return they would stop, pause, and then return the "hello" with a surprised smile.

Greeting people and taking the time to acknowledge them is something I have always done. After yet another stop for a quick chat while out and about, my daughter used to joke, "Are you going to add them to your Christmas card list, too?" But you know what, both my daughter and my son now do the same thing as adults. They take the time to greet people, check in and truly see them, not just pass by in a flurry of busyness and tunnel vision. It's about valuing people, which goes a long way to improving everyone's outlook.

There's one group I value so deeply and want to acknowledge – the hardworking chapters of the Huntington Society of Canada (HSC). If it hadn't been for them, HSC would not have survived.

Here are just a few of the wonderful things chapter members do:

- Offer their expertise
- Hold amazing events
- Raise money
- Support each other
- Have fun, all at the same time

I marvel at the efforts and achievements of the chapters.

And the smaller chapters or active areas are just as important as the larger, more established groups. I know how hard it is to start a small group and hope it grows and continues to flourish.

The first step is the hardest when volunteering, whether for a chapter or a cause in general. But I hope you will commit yourself to volunteering in any way you can, especially with our wonderful, hardworking chapters.

So, to all our amazing chapters and active areas, big and small – THANK YOU. We couldn't fund research and offer support services without you.

I may not see you in person every day, but I see you in my heart always.

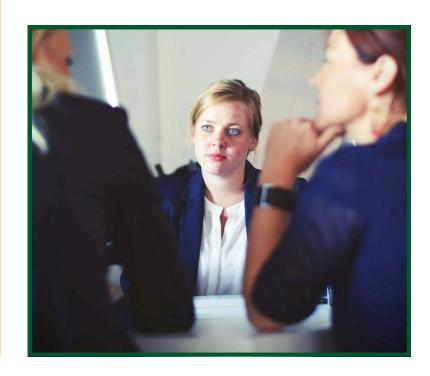
Ariel

# Dear HSC: Considerations During Separation & Divorce

#### "Dear HSC.

My spouse and I are in the process of separation, and we plan to divorce. What are some considerations specific to HD that we need to keep in mind?"

Divorce is not easy for any couple or family. Should a life-limiting genetic disease like Huntington disease (HD) come into play, here are some suggestions:



#### 1. Seek legal advice

Across Canada, there are lawyers who specialize in family law, including separation and divorce, who can provide legal advice. If your budget is restricted, you can connect with community legal aid clinics, where lawyers volunteer their time to provide free (or discounted) legal services. Please note that each province has its own guidelines and criteria for legal aid.

#### 2. Property & housing considerations:

During separation and divorce, the process could include decisions about property and division of assets. Consider where everyone will live. Will the current housing be adaptable as HD progresses?

#### 3. Power of Attorney & wills

You may need to update the Power of Attorney for property and care, as well as wills if your current spouse is the person identified.

#### 4. Custody of minor children

Even if someone has been diagnosed with HD, this does not mean they automatically lose custody of minor children. There may be options to include various supports to help the HD-affected parent to care for the children during separation or following a divorce.

#### 5. Financial and future planning

Are you both still working? Will there be extended healthcare benefits to cover the costs of prescriptions and other healthcare needs? How will these change after the divorce? Consider life insurance and beneficiaries.

These are just a few considerations to keep in mind. If you are unsure where to start, you can also contact the HSC Resource Centre Director in your area for available legal services: (https://www.huntingtonsociety.ca/family-services-team-list/).

Remember, every family situation is unique, so finding the legal services that will support you through this process is important.





### **Chapter News**

We are excited to bring you recent news from our amazing chapters & volunteers!



## Young People Affected by Huntington Disease (YPAHD)

YPAHD held its first in-person event of the year. The Tats for HD event partnered with a local tattoo shop in London, ON to offer HD-related tattoos at an affordable price with a portion of the proceeds going to HSC. Great work, YPAHD!

#### Southern Alberta Chapter

The Southern Alberta Chapter has been busy this spring with an amazing roster of events. From the Flourish Gala in April (raised over \$78,000) to the Pool Tournament in May and the Hope Run in June (raised over \$70,000), the chapter has been working hard! Wooden puzzles from Stumpcraft with custom artwork from local artist Michelle Austen are available for sale, with some proceeds going to HSC. Purchase on:

https://www.stumpcraft.com/products/blooming -hope-by-michelle-austen or locally by contacting Wendy Bruntjen at wenbrunt@gmail.com

#### **London Chapter**

The London Chapter held the London/Exeter Walk on June 15 with a great turnout and over \$10,000 raised – that's a considerable achievement for the small but mighty chapter.

#### **Camrose Chapter**

The Camrose Chapter has been hard at work with a variety of successful offerings such as their Online Auction, BBQ and shop for a cause event raising over \$25,000!

#### Peterborough Chapter

Big shout-out to the Peterborough Chapter for hosting their social and info night on June 22. They were able to connect with new families and old friends alike.

#### **Niagara Chapter**

The Niagara crew just keeps getting more and more creative, with cornhole and trivia as recent event options!



## **Huntington Heroes National Walk**

The 2024 Huntington Heroes National Walk raised \$209,000. With the match, that's \$418,000!

#### **Manitoba Chapter**

The Manitoba Chapter welcomed a wonderful new partnership with the Running Room for their walk this year. They pivoted to a new location and breathed new life into the event with amazing sponsorship and community buy-in. Fantastic work!

#### **Barrie Chapter**

Barrie's walk looked like a turn through a Group of 7 painting! This chapter has a special affinity for nature and the photos are gorgeous.

#### **Ottawa Chapter**

On May 26th, family and friends gathered to support the Murphy Family as they face Huntington disease. Over 100 people attended, including three Huntington's heroes, all in various stages of the disease, who enjoyed the outing.





#### **Belleville Active Area**

Congratulations to the Belleville group for their largest walk to date - a very successful outing with the mayor and fire department in attendance!

#### **Durham Chapter**

2024 marked the last walk organized by former Durham President Bunny Clark as she moves down the highway to Belleville. We have no doubt the Durham crew will pick up the reins and make Bunny proud with walks in the future. Thank you for all you have done for the Durham Chapter, Bunny!

#### **CHAPTER DEVELOPMENT & EVENTS**

### **Fall Events**

You don't want to miss a fantastic lineup of fall events. Check out our website and social media channels for how to participate.

SUNDAY, SEPT. 8	Winnipeg Indy
SUNDAY, SEPT. 8	Golfapalooza in Niagara
SATURDAY, SEPT. 21	Peterborough Golf Tournament
FRIDAY, OCT. 4	Toronto Golf Tournament
SATURDAY, OCT. 19	Chatham Trapshoot
TBD	London Indy

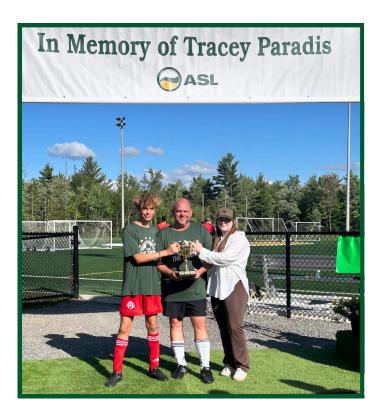
#### Here's the schedule for the Greg Morton Comedy Tour:

WEDNESDAY, SEPT. 18	Sarnia
THURSDAY, SEPT. 19	London
SATURDAY, SEPT. 28	Ottawa
FRIDAY, OCTOBER 4	Peterborough
FRIDAY, OCT. 25	Newmarket
SATURDAY, NOV. 2	St. Catharine's – 2 shows
FRIDAY, NOV. 29	Sudbury



More details on our website! Scan here to purchase tickets

## **Event Spotlight: ASL Agrodrain** 5th annual tournament



This was the 5th time ASL Agrodrain has hosted a soccer tournament, made up of 12 teams from the company and various subcontractors from the Ottawa area.

There were 180 participants raising over \$70,000, with close to \$200,000 raised to date. The team "The Farm" (made up of ASL employees) won this year.

It was an especially poignant time as the tournament was dedicated to Tracey Paradis, wife of Jonathan Paradis, one of the event's co-organizers. Tracey was affected by Huntington disease and passed away from other causes earlier this year.

Tracey's two teenage children attended this year in honour of their mom, with her son playing on the winning team.

Thank you ASL Agrodrain and supporters for making this tournament such a success and for raising funds to help families facing HD, just like Tracey.

#### CALL FOR VOLUNTEERS



We are looking for volunteers in the Peterborough area to help the chapter with everything from events to fundraising and social togetherness.

Visit our website to fill out the volunteer application form and join a great team!

#### **VOLUNTEER** SHOUTOUT

Community member and musician Tyler DeLargie performed across Ontario during May (HD Awareness month), raising money and spreading awareness about HD.

## Meet the New RCDs

We're excited to have some new faces in our Family Services team. Here's our intro to our newest Resource Centre Directors (RCDs), Jaclynn and Pamela. We hope you'll give them a warm welcome!



Jaclynn started at HSC on May 15. Learn more about her here!

#### Where did you go to school?

I earned my bachelor's degree in Social Work with a minor in Fine Art from the University of Calgary. Currently, I am pursuing a master's degree in Social Work at Wilfrid Laurier University.

#### Where else have you worked?

My most recent role was working as a Program Manager/Social Worker at a not-for-profit called Prospect Human Services, which supported individuals with mental health barriers. I managed multiple group therapy programs that incorporated art as a therapeutic tool. Additionally, I provided short-term counseling and outreach support as a Social Worker.

Alongside that role, I casually facilitated virtual group art therapy classes at a not-for-profit that supports individuals with traumatic brain injury due to concussion.

Previous to that, I worked at the Calgary Distress Centre as a phone room supervisor, where I supported the volunteers with crisis intervention and suicide prevention.

I also worked at Alberta Health Services as a Social Worker in palliative care and at a long-term care facility specializing in neurodegenerative diseases, including Huntington disease. Additionally, I gained valuable experience working as a recreational therapist in a dementia care facility—a role I particularly enjoyed.

Throughout my career in the human services field, I have consistently sought to incorporate art into my practice whenever possible.

Lower Mainland Region

#### What is interesting about this role?

This role aligns perfectly with my past experiences and skill sets. I am excited to once again work with a population similar to those I served years ago. From that experience and my first few months with the Huntington Society of Canada, I have witnessed the strength, resilience, and supportiveness of our clients and families. This is both inspiring and motivating in my work. Additionally, I am eager to collaborate with the team at the UBC HD clinic and the national HSC Family Services Team to further educate myself about the disease and gain a deeper understanding of the medical, social, and emotional aspects.

#### What do you like to do in your spare time?

I spend the majority of my time rock climbing, and recently moved to Squamish BC so I can climb outdoors frequently. I also love creating art and have a pottery wheel at home that I make ceramics on often. I also love to create linocut prints.

#### What is your message for the community?

I am thrilled to join you as a social worker at the Huntington Society of Canada. My journey has led me to work with various populations, and I am excited to bring my experiences and skills to support you. In my short time here, I have already seen the incredible strength, resilience, and support within this community, which inspires and motivates me every day. I look forward to working closely with each of you, learning more about your stories, and providing the assistance and advocacy you deserve.



## Meet the New RCDs



Pamela Jacobson

RCD for BC Interior

Pamela is covering Quinn Mykyte's parental leave. She started on May 1. Here are a few facts and fun tidbits about Pamela!

#### Where did you go to school?

I completed my Social Work degree at Thompson Rivers University in Kamloops, BC, and became a Registered Social Worker in 2019.

#### Where else have you worked?

I have worked with the Y Women's Shelter for women and their children leaving abusive relationships. I also worked with high-risk youth at AXIS Family Resources. I did my practicum at Royal Inland Hospital, and I worked with ASK Wellness for over 14 years as a Coordinator and Team Lead for Mental Health and Addiction Services.

#### What is interesting about this role?

The RCD role is interesting as it gives me the opportunity to advocate for and support people living with a life-threatening disease that can manifest itself in different ways and at different times. I have had experience working with people who have trauma and am honoured to use my skills and experience to help those who live with Huntington disease.

## What do you like to do in your spare time?

My spare time is filled with spending time with my four grandsons, who are the light of my life. I have three grown daughters who have become great human beings, and I am so proud to be their mom. I have a Yorkie-cross, Indy, who is smart and kind. We walk and hike every day together. Kayaking with my friends on warm days is incredible and I read all different genres of books. I have a passion for cooking diverse foods and my favourite right now is making different dishes for my grandkids. I have travelled extensively around the world and have done volunteer work overseas. My favourite travel partner is my father, who used to be in the Navy and loves the ocean.

#### What is your message for the community?

My message for the community is to live in the moment because we can't change the past and the future will bring itself to each of us in different ways. Hold onto each moment and to each other. Choose to be kind and be grateful for the little things, as this is the key to bringing happiness into our lives.

The **HSC National** Conference returns to **TORONTO** in Fall 2025 Stay connected for all of the upcoming details!

We also say Happy Retirement to Barb Horner, RCD of Nova Scotia & PEI for 20 years. Enjoy your leisure time, Barb - you have earned it.



## **HSC Funds New HD Research Meet the Summer Research Students**

It's the second year of the HSC Student Fellowships and we have grown! This year, thanks to support from the Canada Brain Research Fund (CBRF), an innovative arrangement between the Government of Canada (through Health Canada) and Brain Canada Foundation, and the Huntington Society of Canada, we funded 7 summer students.

This summer, promising young researchers, each granted \$5000, focused on projects with the potential to reverse, stop or slow the progression of Huntington disease (HD). Read on to find out more about their research and where they are from.

#### **HSC FUNDS NEW HD RESEARCH - MEET THE SUMMER RESEARCH STUDENTS**



Anthony Dang
University of Waterloo
(Ontario)

Anthony Dang recently graduated with a B.Sc. (Honours) in cooperative biochemistry at the University of Waterloo. During that time, he worked on neurodegeneration research with Dr. Dale Martin. Previously, they discovered new potential inhibitors of acyl-protein thioesterase 1 (APT1). Throughout the summer Anthony worked on testing and improving these inhibitors. Because they may clear out toxic mutant huntingtin, these drugs could become promising new treatments for Huntington disease.

**Title of research:** Computationally Driven Design and Biochemical Characterization of Improved APT1 Inhibitors as Therapeutics for the Treatment of Huntington Disease



Isabel recently completed her Bachelor of Health Sciences in biochemistry at McMaster University and her fourth-year thesis in the Truant Lab (HD research). She continued to work in the lab as a research assistant over the summer. During her free time, she enjoys going on hikes, playing piano and travelling. Isabel enjoys contributing to research in Huntington disease and thanks the Huntington Society of Canada for their support!

**Title of research:** Analysis of N6FFA levels in HD human cells and knockout lines by the use of immunofluorescence and expansion microscopy



Gabriel Gonzales Vargas

University of Guelph
(Ontario)

Gabriel graduated from the University of Guelph in biomedical sciences with a minor in neuroscience. He is thrilled to take his first steps into the HD research community. Gabriel has always been interested in studying human health but discovered his passion for understanding neurological disorders while at university, learning about the human brain and its structures and functions, and is still eager to learn more. Gabriel is very grateful for the support of family, friends, and professors in pursuing this goal.

"With the additional support of the HSC this past summer, I am hoping to successfully launch my research career and am so excited to work alongside passionate, like-minded people."

**Title of research:** Understanding the interactions between hypertension and HD

#### **HSC FUNDS NEW HD RESEARCH - MEET THE SUMMER RESEARCH STUDENTS**



From the beginning of her academic journey, Christiana has been deeply fascinated by the molecular mechanisms of neurodegenerative disorders, particularly in Huntington disease. Recognizing the need for more research in this area, she began volunteering as a laboratory assistant in her second year of studying behavioural neuroscience at Memorial University of Newfoundland. This summer, she worked with Dr. Matthew Parson on the research project "Atypical NMDA Receptors in Huntington's Disease." Her work aims to uncover new treatment pathways to protect brain cells and slow disease progression. Outside of research, Christiana enjoys reading, crocheting, and solving puzzles - she likes to keep her mind active and enjoys constantly challenging herself.

**Title of research:** Atypical NMDA receptors in Huntington's disease



Jenni Nguyen University of British Columbia Jenni is a graduate of the Department of Biological Sciences at Wellesley College and will be pursuing an MSc in Cell and Developmental Biology at The University of British Columbia under the supervision of Dr. Mahmoud Pouladi. Jenni is interested in the development of therapeutics for neurodegenerative disease, and has conducted research on diseases such as ALS, Alzheimer's, and Huntington disease.

Title of research: Investigating a putative modifier of HTT toxicity using cellular assays



Mikaela Perron is an undergraduate student at the University of Manitoba. She earned a bachelor's degree in health sciences with a minor in psychology. Mikaela has always had a passionate interest in science. In high school, she led dissection demonstrations and experiments involving fire at science fairs! At the University of Manitoba, Mikaela volunteered as a peer mentor to first-year students where she shared her passion for research and encouraged the students to pursue their interests. Outside of the lab, Mikaela enjoys extracurricular activities and has a black belt in Tae Kwon Do.

**Title of research:** Trace the origin of the somatic repeat instabilityrelated cellular phenotype in HD

#### **HSC FUNDS NEW HD RESEARCH - MEET THE SUMMER RESEARCH STUDENTS**



As a 3rd year student studying pharmaceutical sciences at the University of British Columbia, Ashleen discovered a passion for scientific research last summer while working as a research assistant in Dr. Michael Hayden's Molecular Biology lab. The experience developed valuable skills and sparked her interest in genetic research. This summer, Ashleen worked on her project, 'Characterization of HD Brain Tissues with Loss-of-Interruption (LOI) Modifier Variants.' Outside the lab, Ashleen enjoys cooking and exploring British Columbia's natural beauty, which provides her with relaxation and inspiration. Although she has not been impacted by Huntington disease directly, Ashleen is thrilled to contribute her efforts to the Huntington Society of Canada.

**Title of research:** Characterization of HD Brain Tissues with Loss-of-Interruption (LOI) Modifier Variants

## **2024 Clinical Fellow**Dr. Falen Fernandes

One of HSC's goals is to ensure each Canadian with HD receives appropriate medical attention, drug treatment, support services, continuous care, educational resources, respect, dignity, help, and hope. One way we are pleased to help is through the Clinical Fellowship program. This initiative encourages promising young clinicians to pursue clinical training in HD and eventually have an HD practice in Canada.



Dr. Fernandes is originally from Toronto, Ontario. She completed her Honours Bachelor of Science at the University of Toronto, graduating with First Class Honours and Distinction. She completed her medical training at the University of Limerick in Ireland and came back to Canada for her Neurology residency at Memorial University of Newfoundland and Labrador. She is excited to begin her Movement Disorders Fellowship training at the University of Calgary, with a special focus on Huntington disease.

Welcome, Dr. Fernandes!

## **Volunteer Spotlight**

**Kaylee Fraser**, Winnipeg Manitoba





"I believe that there is a cure out there somewhere, and it lies in research and science. As so many people do, I dream of a future without HD for anyone. I do believe that it is possible, if not for me, then eventually for a future generation."

It was while on a long canoe trip at summer camp, with ample time for quiet thought, that Winnipeg's Kaylee Fraser realized Huntington disease (HD) was always going to be a part of her life. "It was hard because that's something that I know a lot of people don't understand," she says.

Kaylee had only found out that HD ran in her family five years earlier when she was 12 years old. Since then, she has been volunteering and raising money for the Huntington Society of Canada (HSC). She credits her parents with setting a good example in terms of becoming involved with the community. Their living room is filled with Amaryllis every November, which they sell to raise funds, and her family and friends participate in the national walk co-hosted by the Manitoba Chapter.

"We like to help and are glad to have the support of our friends who come out and support us with everything we do. Of course, a lot of it is my parents but I like to do my part as well."

Indeed, it was Kaylee who came up with the fabulous idea of raising money and awareness for Huntington disease at her high school's annual improv night. She approached her drama teacher, Allison Perlov, who eagerly agreed to help. "Ms. Perlov brought it up to the class and everybody was so supportive. To be part of such a good community feels truly amazing."

On the night of the performance, her family was in the crowd, holding back tears.

Kaylee and her friends at Fort Richmond Collegiate put on an amazing show full of laughter and spoke to the crowd about Huntington disease, raising \$260. There are already plans to repeat the event next year.

"A big thanks to everyone on the team and in the improv program. None of this would have happened without their incredible support and the awesome show. Whether on stage or off, this is such a wonderful group," Kaylee says. "An extra big thank you to Ms. Perlov for her incredible support and for being so open to making this work. The improv and drama programs wouldn't be the same without her."

Next year Kaylee will graduate from high school and plans to go to university. Although still undecided, she is considering English, Journalism, or Photography. One thing is for certain, though - she knows she will always keep improv in her life.

When asked about what motivates her to get involved, Kaylee says, "I don't want anyone else to have to think about what a future with HD looks like."

She has accepted that HD will always be a part of her life and raising funds for research is one way she finds hope for the future.

# Social Justice and HD: Youthful Inspiration



When Gr. 7 student Isaac Young learned of his class assignment concerning social justice, one cause immediately came to mind: Huntington disease (HD).

Unbeknownst to his mother Muna Young (HSC RCD for Central Ontario), Issac described HSC and HD to his three group members. They all agreed that Huntington disease is a cause that does not get enough recognition, and the group decided to raise awareness about it within their community via the assignment.

They were tasked with researching the topic, educating other people, and coming up with reasonable solutions to the social injustices faced by the community. The process of preparing the project was eye-opening.

"They learned how challenging HD is not only for the person who has symptoms, but also for their family, friends, and caregivers," says Muna.

"They were really impacted by the realization that when you love someone with HD, you slowly lose pieces of them right in front of you."

They put together the display board and slideshow with information from the HSC website. A few days before they were scheduled to present the project at the school's social justice fair Isaac approached his mom.

"Isaac wanted to complete the work independently and did not tell me about it until it was nearly finished," says Muna. "He decided to let me know about the project because he felt it would benefit from some additional resources for the display. He also asked me to attend the event to help answer community questions, which I did."



Isaac and his classmates from their Niagara Falls, Ontario elementary school presented their project on May 9 to about 500 students, teachers, and community members attending the event.

"The experience was amazing. The attendees were really engaged and interested in learning about HD." says Isaac.

"Even though HD can be sad, doing this project helped the team realize that you never have to face HD or any challenge alone. It helped Isaac understand how important it is for me to show up to work every day and do what I do as part of the HSC team," says Muna.

"They were also very touched to hear me describe how despite the challenges caused by HD, the community is beautiful, supportive, and full of people living incredible lives."

Doing the project prompted Isaac to think about his future and the possibility of going into science to help find a cure for HD. "He wants to lessen the pain, heartbreak, and loss people in the HD community face," says his mom.

Thank you, Isaac and team, for your incredible work on this meaningful project



# Amaryllis: It's About Blooming Time

It's the campaign that many of our community members have been asking about since June! Even as the summer blazes, those in the know are dreaming of their gorgeous Amaryllis blooms set against a backdrop of wintry snow, golden candles, and green garland.

These faithful floral devotees also know how perfect it is to shop and gift Amaryllis. The gift box draws oohs and aahs, and once you've grown one Amaryllis, you just can't stop.

We're excited to open sales early this year to make sure everyone receives their Amaryllis in time for the winter holidays.



## **Colder Weather Order and Shipping Dates**

Amaryllis bulbs can be tender and don't like the cold! To make sure they don't freeze, we have revised our shipping cut-offs. We want to make sure that every bulb produces a gorgeous bloom. Same-week orders cannot be processed. Please plan around these deadlines as we cannot extend them. HSC must receive orders as listed below.

Key Dates	
AUG. 27	Amaryllis orders open
SEPT. 25	First possible delivery date
OCT. 22	Last possible order date YK and NFLD (delivery date Oct. 30)
NOV. 21	Last possible order date  AB, SK, and MB  for delivery Nov. 29
NOV. 27	Last possible order date (for BC, ON, QC, NS, NB and PEI only) for delivery Dec. 4 or 5

#### How much does each Amaryllis cost?

Each Amaryllis bulb costs \$17. A case of 12 Amaryllis bulbs is \$204. Shipping is \$14 per order if 6 or fewer cases are shipped. Shipping costs have risen to meet the rising shipping costs HSC incurs. If more than 6 cases are ordered, shipping is free.

#### Where can I buy Amaryllis?

#### Here's how to purchase a case:

#### Via our website:

(www.huntingtonsociety.ca/amaryllis-campaign/)

Call or email National Amaryllis Lead Camilla Christophersen at 519-749-8491 ext 126 or amaryllis@huntingtonsociety.ca

#### Where are the Amaryllis delivered?

The case or cases of Amaryllis will be delivered right to your door. Unfortunately, orders smaller than a full case of 12 cannot be shipped directly to your door.

#### When will the cases be delivered?

When you place your order, you can select from our available delivery dates so you know when it will arrive. If there are any changes to your delivery date, you will be notified.

#### How can I buy a single Amaryllis kit?

If you would like to purchase fewer than 12 flowers, a list of sellers by area can be found on our website along with their contact information.

## FAQ

#### How do I grow the Amaryllis?

Instructions will be included with your Amaryllis on planting and growing directions.

If you have any other questions, please contact Camilla at 519-749-8491 ext 126 or amaryllis@huntingtonsociety.ca



#### **Fun Facts**

- Did you know that the Netherlands is the worldwide hub for growing Amaryllis? They produce around 15 million bulbs per year!
- The longest-living Amaryllis was reported to have lived for 75 years!
- The name Amaryllis is derived from the Greek word Amarysso, which means 'to sparkle'!

## Amaryllis Sellers: Gwenda and Trina Klein



Gwenda and Trina Klein are not only a dynamic mother-daughter duo from Saskatchewan – they are also champion Amaryllis sellers for the Huntington Society of Canada (HSC).

Gwenda and Trina are passionate about selling Amaryllis to help raise money for Huntington disease (HD) research and Family Services. For them, the Amaryllis campaign has always been about inspiring hope, supporting family, and raising awareness.

Gwenda has been involved from the very beginning of HSC's Amaryllis fundraising campaign – she has been selling Amaryllis kits since 1986, almost 40 years ago!

Gwenda knew that HD was present in her husband's family. While attending family gatherings, she noticed several of her husband's aunts, uncles, and cousins had involuntary movements – the physical symptoms of the disease.

Gwenda also noticed another important characteristic - they were happy people.

Their hope inspired Gwenda to sell Amaryllis kits to help find a meaningful treatment for Huntington disease. Gwenda says, "I just knew I wanted to help. They are my family. This mattered."

Through the years Gwenda, and later Trina, continued to participate in the Amaryllis campaign each year.



#### Then, HD hit even closer to home.

First, Gwenda's father-in-law, Lloyd, was diagnosed with HD. Next, in 2018, Gwenda's husband (and Trina's dad), Dale Klein, also received an HD diagnosis.

Finally, Trina decided to undergo genetic testing in 2021 and learned that she, too, is gene positive.

But did this news derail this family's Amaryllis campaign? No! Gwenda and Trina knew that more hope, more research, and more support services were needed now. With courage and determination, they tripled their sales of Amaryllis kits, participated in Light It Up for HD awareness activities, and registered for HSC webinars and conferences to learn and connect. Trina also held a very successful fundraising Walk for HD.



#### Gwenda and Trina know that selling Amaryllis kits is a community effort.

Over the years, friends and family have demonstrated their support by purchasing Amaryllis kits. Gwenda also developed other creative ways of reaching out to the local community. She donated Amaryllis kits to their family doctor, pharmacist, and local church to raise awareness. Their priest put several Amaryllis plants in front of the altar at Christmas, which sparked community interest. Gwenda, alongside her nieces who are teachers, connected to several schools to sell Amaryllis kits and raise awareness about HD. As well, Trina sells kits at her workplace and to her friends. They both use the personal touch to sell Amaryllis kits. As Gwenda says,

"I phone them up, I tell them why it's important to buy an Amaryllis, and they say YES."



Trina finds motivation from the Amaryllis campaigns, saying, "When the Amaryllis plants grow tall, strong, and unstoppable, it reminds me of the strength and resiliency of the HD community."

Gwenda and Trina want to remind the HD community that the Amaryllis is a symbol of hope and a way to remember that no one walks alone.

"We have each other - our HD family."



## **YPAHD DAY**

is taking place in **Mississauga, ON** this November!



Get your funding application in **NOW.** 

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## YOUTH MENTORSHIP

- Are you a youth affected by Huntington disease?
- Would you like to connect with a mentor?



Find out more about the HSC Youth Mentorship program