

# HORIZON

RESEARCH • SERVICE • EDUCATION

No. 165

Spring 2022

## HD Hockey Classic Debuts May 14

This May, Huntington disease Awareness Month will see a classic rivalry play out on ice.

Announcing...  
the **Huntington Disease Hockey Classic!**

Mark your calendars – on Saturday, May 14, 2022, the Huntington Society of Canada (HSC) will face off against the Huntington's Disease Society of America (HDSA) in this inaugural event!

These two organizations will be coming together to raise much-needed funds and awareness to support individuals and families facing Huntington disease (HD) across North America. This Canada vs. USA charity hockey game will feature former professional and collegiate players battling it out for bragging rights – all for an incredible cause.

The puck will drop at 1:30 p.m. (EDT) during HD Awareness Month at RWJBarnabas Health Hockey House in Newark, New Jersey, home of the New Jersey Devils. This will be a fun-filled event for the entire family that will include intermission contests, entertainment, raffles, player meet & greets, special guests and much more!

Here's how you can get involved:

1. Attend the event live! Make a vacation of it and cheer for Team HSC in person.
2. Take in the game from the comfort of your own home via the free livestream. Put on your HSC clothing and cheer our Canadian team to victory. You could even organize a watch party in your community to raise the roof with support for Team HSC.
3. Make an assist for Team HSC. Your donation will help us reach our goal to raise funds that will go directly to providing much-needed resources for families impacted by Huntington disease (HD) throughout Canada.

Donate, buy tickets, and get all of the details via our HD Hockey Classic webpage here: <https://www.huntingtonsociety.ca/hd-hockey-classic/>

Go Canada! Go Team HSC! 🇨🇦



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# HORIZON

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*Horizon* is the newsletter of the Huntington Society of Canada. Issued two times a year, its purpose is to convey information to individuals with Huntington disease and their families, health care professionals, friends and supporters.

Huntington disease (HD) is a hereditary, neurodegenerative illness with physical, cognitive and emotional symptoms. Symptoms vary from person to person and at different stages of the disease but may include involuntary movements and difficulty with focus and thought. Symptoms usually appear between the ages of 35 and 55, and gradually worsen over the 10-20 year course of the disease. But HD can also appear in youth (under 20 years – Juvenile HD) or older adults (Late Onset HD). As yet, there is no meaningful treatment.

The Huntington Society of Canada (HSC) is a national non-profit charitable organization founded in 1973 to help individuals with Huntington disease and their families.

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**Layout:** Real World Graphic Design

*Horizon welcomes your comments, ideas and suggestions for future articles.*

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## Message from the CEO



After so very long, I see hope on the horizon for the movement toward some kind of normalization. That won't be a return to exactly how everything was before the pandemic, as new events, partnerships and progress have revealed themselves and we continue to evolve and grow with our new reality.

I have to say, I am so looking forward to seeing community members in person and being a part of these exciting opportunities.

My first in-person event in almost two years – my first ever since starting as CEO of HSC – will be to drop the puck at the HD Hockey Classic in New Jersey on Saturday May 14. If you haven't heard about this fantastic event yet, I urge you to read the front-page article dedicated to the topic. It promises to be an amazing display, whether you can travel to New Jersey to attend in person, or plan to have a watch party at home and take in the action via the free livestream feed.

It's wonderful to see in-person events returning, even as we apply the learning from two years of virtual and hybrid events to our slate of offerings moving forward. We live in a different time now, and the success of our second virtual conference in February has illustrated that there is a place for both in this super connected world of ours.

Spring is a time for renewal, and hope, too. It's a phase of fresh starts, and togetherness. Speaking of get-togethers, wouldn't it be great to meet up with some friends and family for a spring BBQ (if you can do so safely) feasting on truLOCAL products? We'll be offering another campaign with the company, which delivers local meat, poultry, fish and seafood products directly to your door (available in BC, ON and AB). Ordering is online, and a portion of the proceeds goes to HSC, so your order stocks your freezers, benefits local, high-quality food producers, and supports research and Family Services here at HSC. Check out the article about partnership with truLOCAL in this issue of *Horizon*, as well.

So, as we anticipate seeing more of each other, let's have some fun. Make plans to attend a local Huntington Heroes Walk, or join our National Virtual team. Watch or attend the HD Hockey Classic. Participate in Awareness Month – you can check out some of the buildings and structures lighting up in blue for HD and purple for Juvenile HD across Canada, and the world. Let's look forward to these special moments and celebrate each touchpoint together as a community. 🌟

Shelly Redman  
CEO

**Huntington Society of Canada**



# National Virtual Conference 2022

For the second year in a row, the Huntington Society of Canada (HSC) held a successful National Virtual Conference (#HDCon22) taking place February 26 and 27, 2022. The tagline of the conference was "one community, united in caring", and we certainly saw that sentiment expressed throughout the course of the two days! Conference allowed us to once again come together as a community virtually and connect with others who understand the struggles that HD presents.

*"I feel like I have new friends and connections for this journey as a caregiver, and also a clearer understanding of the status of research to eliminate or delay the onset of HD. All this new information and my increased feeling of confidence due to all these new supports will help me support my whole family and my health care team." - Conference attendee*

Our speakers provided valuable information to attendees, connecting them with knowledge, hope and resources to help with their daily lives. Sessions encompassed a variety of topics for caregivers, individuals at risk for Huntington disease (HD), and those positive or negative for the gene mutation that causes HD – a huge learning opportunity for all. Some standouts included Dr. Ray Truant, Angie Dale and Elaine Sanchez, to name just a few.

Here are some incredible stats from the conference:

- Over 1000 registrants (570 registered + 441 additional viewers)
- People tuned in from 9 countries internationally
- 48% of people attended conference for their first time ever

In the end, we feel our attendees summed up conference the best as they shared their experiences:

*"Encouraging, fact-based information for dealing with all aspects of the disease was really helpful."*

*"Gained new knowledge from Jimmy's HD 201 talk. The first speaker showed there was still hope and research ongoing. Clinical trial session valuable as I may take part in one, one day. It was good hearing from the HD clinic teams. The last speaker was wonderful and heartfelt! It was also great to be able to chat with participants and have questions answered. And it felt great to be able to give my thanks to the researchers/HD clinic staff/HD staff for everything they are doing for HD families."*

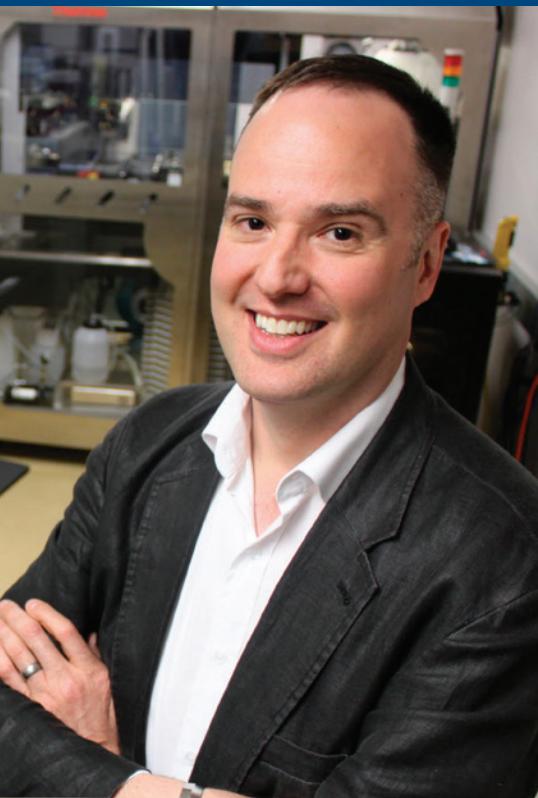
*"Raised renewed hope of eventual treatment arising from ever-improving research knowledge."*

*"It brought me closer to my daughter who has HD. It was something we could do together."*



Thank you to everyone who attended, spoke or volunteered at this year's conference. We invite you to watch the recordings of the conference sessions on our YouTube channel at <https://www.youtube.com/user/HuntSocCanada>. 📺

Keynote speaker Dr. Ray Truant



Closing speaker Elaine Sanchez



HSC Events Coordinator Kelsey Laidlaw



# Canadian Virtual Hospice Resources on Grief and HD

*"Grief is a constant companion through illness."*

International grief expert Dr. Ken Doka's words were the foundation for the Canadian Virtual Hospice's new free online module "Grief as Illness Progresses: Dementia, ALS, MS, Parkinson's, and Huntington disease."

"Many people don't realize that feelings of grief often begin with the diagnosis of a serious, life-limiting illness," says Shelly Cory, Executive Director of Virtual Hospice, whose mother died of ALS in 2018. "With progressive neurodegenerative diseases, it can feel like a relentless march of losses. We are grateful to Huntington Society of Canada for partnering with us to provide this resource for families and caregivers."

The Canadian Virtual Hospice ([www.virtualhospice.ca](http://www.virtualhospice.ca)) is a charitable not-for-profit that provides online support and personalized information about advanced illness, palliative care, loss and grief to people living with illness, family members, and people working in healthcare, totalling over 2.4 million visitors each year.

Recently, the organization expanded its award-winning MyGrief.ca platform to include a series of new online modules. Module 20 offers information and support for people who are caring for others living with progressing neurodegenerative illness including Huntington disease (HD), Alzheimer's disease, other dementias, amyotrophic lateral sclerosis (ALS), Parkinson's disease, and multiple sclerosis (MS). HD is clearly identified as well as being the focus of a few chapters.

"I was asked to review the module on progressive neurodegenerative diseases, including Huntington disease, and I was really impressed by how well it was done," says Angèle Bénard, National Director of Family Services with HSC. "I am pleased to be able to link to it from the Loss and Grief section of our HD Booklets and Publications webpage. This



allows members of our HD community to more easily access this excellent resource. Plus, this module will be available in French."

The resource was designed to help family, friends and others affected by the illness understand and care for themselves as they grieve. It was developed in collaboration with national grief specialists and people who have grieved losses while someone they care about is living with a progressive neurodegenerative illness.

According to the module:

*"If you are caring for someone with an illness that gradually impairs brain and body function, you continually witness and share in the person's losses while also experiencing your own. When these losses combine with the demands of caregiving, they contribute to unique challenges that can impact your grief, which may have begun when the person was diagnosed and continued as their disease progressed."*

Canadian Virtual Hospice notes that you may be providing care to your spouse/partner, a parent, a sibling, or a friend. You may be a full-time caregiver, or you may be providing care as your circumstances allow or you may be a family or friend living at a distance. You may have other caregiving responsibilities, such as parenting children or caring for another family member. You may be experiencing a range of thoughts and feelings that can change as time passes, and you may be feeling alone or isolated in your grief.

The module includes a chapter about grieving after death. It is recommended that you review eight Grief Basics modules found at MyGrief.ca, including:

1. Understanding grief
2. How has this loss affected my family and me?
3. Moving through grief
4. Making sense of intense emotions
5. Managing difficult situations
6. Caring for yourself
7. Do I need more help and where do I find it?
8. When life starts to get better

There is also a series of relationship modules that can help you understand how the loss affects you as a spouse, an adult child, a parent, a sibling, or a friend.

## As you read through the module(s)

Whether you are reading the content while the person is living with illness or some time after death, revisiting the resources often is recommended, as you may only be able to absorb so much at any one time. What you find helpful may change over time.

As you read the modules, you may have strong emotions or feel uncomfortable. It's okay to step away from it for a while, or it might help to talk with the Family Services team at HSC or a trusted family member or friend. We hope you find the resources helpful during the grieving process.

HSC would like to thank the Canadian Virtual Hospice for providing a safe space and giving a voice to those grieving a progressive neurodegenerative illness.

Find the Module here: <https://www.huntingtonsociety.ca/hd-booklets-and-publications/> or at <https://mygrief.ca/mod/lesson/view.php?id=1035>

Find the entire series here: <https://mygrief.ca/>

For French, visit: <https://mondeuil.ca/>

For more information on the Canadian Virtual Hospice, visit: [www.virtualhospice.ca](http://www.virtualhospice.ca)



## MODULE 20

As illness progresses:  
Dementia, ALS, MS,  
Parkinson's, or  
Huntington Disease

# YPAHD Column



**By Doug Mallock,  
outgoing YPAHD President**

It's hard to believe how quickly time goes. The YPAHD Executive took our roles at the 2018 National Conference in Kelowna. It was the first time since YPAHD formed in 2008 that we had a truly national executive, with representatives from Vancouver Island to Newfoundland!

We had amazing plans, from a social media campaign to recognize some of the incredible youth supporting HSC across Canada, to youth-focused education and presentations throughout the year, beyond YPAHD Day. We were able to achieve many of our original goals and continue to grow YPAHD – a chapter that is so important to the youngest members of the HD community as they navigate some truly tricky times in their lives.

While our term was meant to wrap up in 2020, Covid had other plans, and the YPAHD membership agreed to support us for another term while we navigated how the pandemic affected our work. We were able to introduce Facebook Live Chats to engage more youth outside of our meetings, and in November 2021, hosted a virtual YPAHD Day. While the names of the members remained the same, our executive experienced a lot of personal change since November 2018 – I welcomed my first child just a few months ago, as did our YPAHD Vice-President!



**Photo taken of the newly elected executive in 2018 at the Kelowna Conference. L-R: Catherine Price (Youth Board Rep, NL), Doug Mallock (YPAHD President, NB), Katie DeLargie (YPAHD Secretary, ON), Caleb Harding (YPAHD Vice-President, BC) and Lisa Pollock (YPAHD Social Media Coordinator, SK). Not pictured, Mackenzie Remillard, YPAHD Youth Engagement Coordinator, MB, elected to the Executive in 2020.**

In March, we hosted an election for the 2022-2024 YPAHD Executive and I'm pleased to list the results here:

**YPAHD President: Caleb Harding**

**YPAHD Vice-President:  
Celine Payne**

**Social Media Coordinator:  
Taylor Van Beest**

**Youth Engagement Coordinator:  
Mackenzie Remillard and Parker Van Beest**

Non-elected Positions:

**Past President: Doug Mallock**

**HSC National Board of Directors  
Youth Representative:  
Catherine Price**

Like the outgoing executive, the new YPAHD Executive has many plans for the future. I encourage you to visit [www.ypahd.ca](http://www.ypahd.ca) or find YPAHD on social media to meet the new executive and share your thoughts about what you'd like to see happening for YPAHD in the coming months.

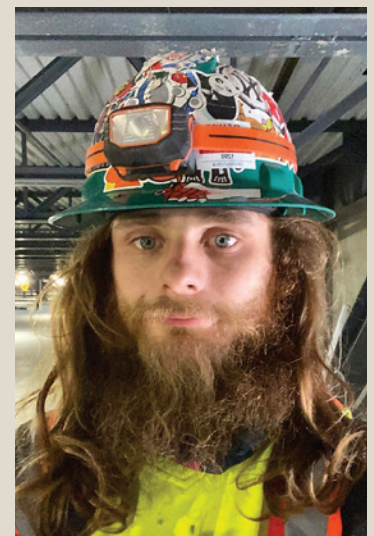
And to those who served alongside me for the last three-and-a-half years, thank you – I had so much fun working with you, deepening our friendships, and learning from all of you. I'm so proud of what we were able to achieve together! 🐾



**YPAHD President Caleb Harding (BC)**



**Vice-President Celine Payne (ON)**



**Youth Engagement Coordinator Parker Van Beest (ON)**



**Social Media Coordinator Taylor Van Beest (ON)**



**Youth Engagement Coordinator Mackenzie Remillard (MB)**



**Q** Dear HSC, I am not eligible to participate in Huntington disease (HD) clinical trials at this time. Are there any other research opportunities for me?

**A** Great question! Clinical trials tend to get a lot of attention and excitement because they are associated with finding a potential treatment for HD. However, in order to move the science forward, we need information from families in the HD community at many stages of scientific research, not just a trial that focuses on a treatment. So where or how could someone participate in research if they are not eligible for a clinical trial? Here are a few options that could be available for multiple members of a family affected by HD:

### 1. Observational studies:

Your involvement in observational studies (e.g., Enroll-HD or Join-HD) helps researchers (globally!) better understand the disease and its progression. The data collected helps to improve the standards of care for individuals affected by HD, and ultimately the development of effective treatments. These studies include registries that collect experiences and medical information from family members of those affected with HD. By participating in these types of studies, you can learn more about HD and become familiar with some of the types of assessments used in clinical trials.

### 2. HD Biobank – Tissue Donation:

The gift of human samples (blood and tissue donations) along with medical and family history details are an invaluable resource for researchers worldwide. The HD Biobank is a proud custodian of these samples. With the support of families affected by HD, samples are collected, stored, studied, and shared with research collaborators who are working tirelessly to understand and treat HD.

### 3. Research (surveys) on lived experience:

Understanding the impact of HD on various life choices is also important. You may be invited to share your story, or your lived experience. When you choose to do so, you add your voice to others to help shape services and increase awareness about life with HD. (currently we have a survey on predictive testing available on our website: <https://www.huntingtonsociety.ca/predictive-testing-survey/>).

I would encourage you to reach out to your HSC Family Services team member or to your regional HD clinic to discuss the options available in your area. HSC provides a list of current research opportunities on our website: <https://www.huntingtonsociety.ca/hd-clinical-trials/>.

# HealthPartners

HealthPartners connects Canadians to 16 of our most trusted health charities, including the Huntington Society of Canada, a founding charity partner of HealthPartners.

At HealthPartners, our goal is to create a healthier Canada by supporting life-saving research, support services, education, and advocacy for those affected by over 400 chronic diseases and major illnesses.

Over the course of our partnership, the Huntington Society of Canada has been a prime example of a HealthPartners member charity through their immense support and notable engagement.

"I cannot think of conferences that are more inspiring," says Eileen Dooley, HealthPartners CEO, who specifically recalls being invited to and attending many of the Huntington Society of Canada's conferences, and the immeasurable hope and encouragement that they bring. "Being there to experience the care firsthand, talking to people about their life experiences, and hearing the optimism that's generated as they listen to researchers talk about new study leads is an absolutely phenomenal experience." Through the Huntington Society of Canada, HealthPartners supports those affected by the disease in fostering courage and providing a sense of hope.

HealthPartners is grateful to the Huntington Society of Canada for the work that they do on behalf of Canadians in every community across the country. By coming together, we change the outcome and contribute to a healthier Canada. 🌱



Eileen Dooley, CEO of HealthPartners

# iii HealthPartners

Charities At Work

# Huntington Disease Awareness Month and Huntington Heroes National Walk

Once again this May during Huntington Disease (HD) Awareness Month, Huntington Heroes across Canada will participate in the National Virtual Walk to raise funds to support our HD community!

The Huntington Heroes theme celebrates the everyday heroes that make up the HD community – caregivers, professionals, and those at-risk or living with the disease who are compassionate, courageous and committed to support.

This year we are encouraging participants to walk throughout the month of May to reach our target goal of 4000 km logged by our community. We know we can do it by making walking a habit and encouraging friends and family to join.

There are two ways to participate. Details for both are on the National Walk website at <https://p2p.onecause.com/hscnationalwalk/home>

- 1) Check to see if local volunteers are hosting **in-person events near you**. Details are on the events page of the walk registration website.
- 2) Sign up to walk, run, or roll as part of the **National Walk team** throughout the month of May.

Both initiatives go towards our goal to walk 4000 km as a community, fundraising and increasing awareness along the way! All donations and contributions made to this event before June 30th will be matched by an anonymous donor dollar for dollar.

This year, we turned to the community to help us design an impactful t-shirt for our walk. Thank you to our winner Emmanuel R. for the amazing design that will be featured on all 2022 National Walk T-shirts. To receive one, choose the “register for the T-shirt” option on the National Walk Page (shirts will be shipped out in June to wear at events throughout the year).

The Huntington Heroes National Walk is about coming together all across the country to walk for a common goal. This national effort helps us to raise our voices even louder, and spreads our message even farther, as we build awareness for HD.

Stay tuned to HSC social media and our emails for more exciting announcements about the Huntington Heroes National Walk and Huntington Disease Awareness Month, May 2022. 🍀



LEARN MORE: [P2P.ONECAUSE.COM/HSCNATIONALWALK](https://p2p.onecause.com/hscnationalwalk)



**HUNTINGTON HEROES  
NATIONAL VIRTUAL WALK**



# North York General Hospital Huntington Disease Clinic

*For this next article HSC interviewed Clare Gibbons, Genetic Counsellor and Clinic Manager of the North York General Hospital (NYGH) Huntington Disease (HD) Clinic.*

## Tell us a bit about the NYGH HD Clinic.

Our multi-disciplinary clinic was established in 1995, around the time that genetic testing first became available, with access to genetics, neurology, psychiatry and social work services (the Huntington Society of Canada [HSC] social worker). Dr. Philippe Rizek, neurologist, and Dr. Alan Fung, psychiatrist, have been working in the clinic for many years and so have a lot of expertise caring for patients with HD.

When Dr. Guttman from the Centre for Movement Disorders retired last summer, he approached our clinic to take over the care for the patients in his clinic. We had been providing care for about 200 patients and, with the transfer of the patients from Dr. Guttman's clinic, our patient volume doubled. This increase in volume posed a real logistical challenge, but we were very fortunate to have neurologist Dr. Ragini Srinivasan come from the Centre for Movement Disorders clinic to join the NYGH clinic. She already knew many of the patients who transferred from Dr. Guttman's clinic so this was very helpful for the transition.

## What has changed about the clinic?

Our HD clinic used to be on Wednesdays but we now have clinic on Tuesdays and Thursdays in order to handle the increase in volume. Covid has had the biggest impact on running the clinic and the services available. Many of the consultations shifted to virtual appointments. We found that for

some consultations the virtual format worked well; patients appreciated having certain appointments, like genetic counselling, from the comfort of their own home. Of course, some patients prefer in-person visits, and certain aspects of the neurology appointment require a physical examination to assess the signs and symptoms properly. Ultimately, the future of the NYGH HD clinic will likely include a blend of virtual and in-person assessments and appointments.

## How has the transfer of patients worked? Are you accepting new patients?

Dr. Guttman's clinic reached out to as many patients as they could asking permission to transfer their files to us. They couldn't connect with everyone, so if you were a patient of Dr. Guttman's or know someone who was and have not yet been called by the North York Clinic, please call our medical secretary Samantha Persichilli at 416-756-6128 so that we can reconnect with you. We are also accepting referrals from outside of the clinic for new patients; just have your family doctor refer you.

## What can you tell us about the genetic counselling and testing offered at NYGH?

The NYGH team of genetic counsellors provide counselling to individuals considering having predictive testing to determine if they carry the gene mutation that leads to HD. The genetic counsellors also meet with people who are at risk for HD, or who have tested positive, to talk about their reproductive options. Our genetic counsellors spend a lot of time keeping up to date on the latest in HD care and research so are well positioned to answer a variety of questions.

## What HD research is ongoing at the NYGH clinic?

We have been involved with ENROLL HD for a number of years. The ENROLL HD participants from the Centre for Movement Disorders are being transferred to our clinic. We are also enrolling new participants into this study. We have completed enrollment for KINECT HD2, which was a clinical trial investigating a new medication to treat chorea (involuntary, jerky movements). SHIELD HD participants from the Centre for Movement Disorders transferred to our clinic and they will complete the study at NYGH. We are hoping to start a number of new trials in 2022, as well as assisting our patients to learn about trials that are being conducted in other clinics.

## What message would you like to share with the HD community?

It can feel challenging for people and their families to have to explain HD to health care providers who do not know about the disease. We want individuals and families facing HD to know that the NYGH clinic provides specialized HD services so they have a place to go where everyone knows about HD. We also work closely with the HSC Family Services team (social workers) so patients and their families also benefit from a continuity of support and care from clinic to community. We are committed to treating HD patients, supporting families and promoting research.

Here's a list of our team members so that you can see how many people are dedicated to this clinic and to amazing patient care:

Dr. Philippe Rizek, Neurologist  
Dr. Ragini Srinivasan, Neurologist  
Dr. Wai Lun Alan Fung, Psychiatrist  
Dr. Melanie Bedford, Clinical Geneticist  
Dr. Marjan Nezarati, Clinical Geneticist  
Clare Gibbons, Clinic Manager, Genetic Counsellor, Research Coordinator  
Kristen Miller, Genetic Counsellor  
Gillian Owens, Genetic Counsellor  
Julia Su, Genetic Counsellor  
Mala Singh, Research Coordinator  
Rebecca Solmito, Research Assistant  
Susan Akbaroghli, Research Coordinator  
Samantha Persichilli, Medical Secretary  
Nadia Mandarino, Receptionist

For more information, visit:  
[www.nygh.on.ca/genetics-clinical-services](http://www.nygh.on.ca/genetics-clinical-services)



## Event News: Event in a Box

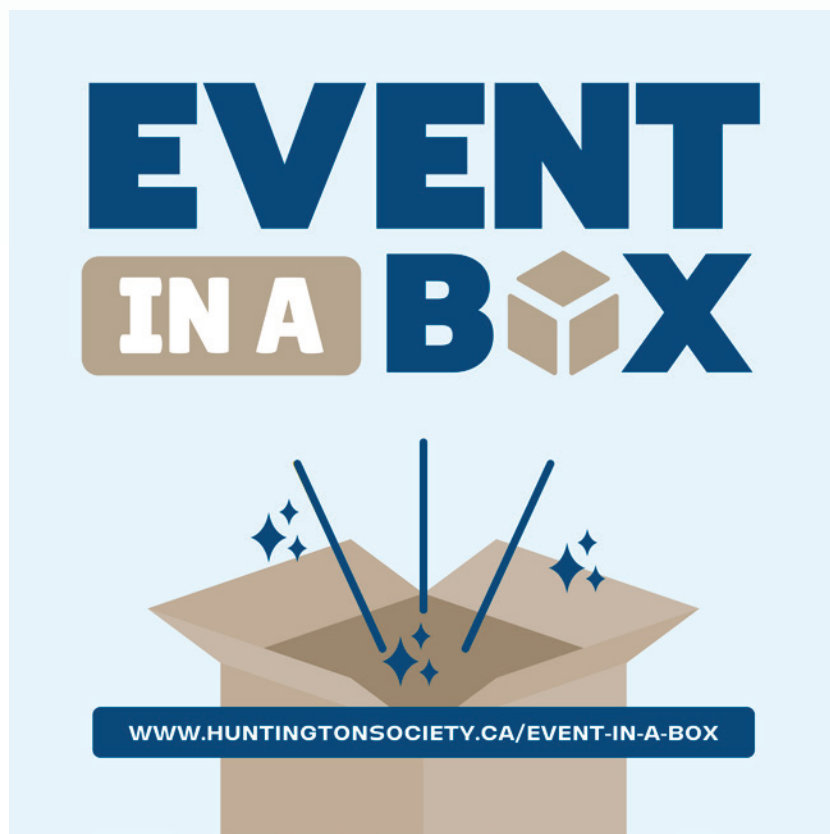
Event in a Box is a great resource for those looking to plan a fundraiser for the Huntington Society of Canada (HSC) but don't know where to begin. Step-by-step instructions for how to plan different types of events are included; it's a great way to get off the starting line. Whether an initiative is big or small, every dollar counts and goes towards funding innovative research as well as Family Services for those affected by Huntington disease (HD).

Online auctions have proven to be very successful and well received, and are perfectly suited for a virtual format. You can reach out to local businesses for donated items, create a Facebook page to display the items, and increase engagement and traffic to the page. "Online auctions are great because everybody gets something out of it! Businesses receive promotion and increased visibility to new audiences. Buyers reap the rewards of new and exciting items that they might have purchased anyways, and HSC benefits from donations to go towards our services. It's really a win-win," says Kelsey Laidlaw, Community Events Coordinator for HSC.

A number of individuals from New Brunswick to British Columbia have planned successful online auctions raising thousands of dollars for HSC. Karen Barrett, a volunteer in NB, held her first-ever online auction in 2020 as a way to fundraise while not being able to meet in person and raised over \$2,000.

"I think it went well!" says Karen. "It came together relatively quickly and people were very generous."

The Camrose Chapter decided to host an auction in 2021 in lieu of other in-person events and members raised over \$14,000 – wow. For all the tools, tips, tricks and resources you need to run an online auction, check out the Event in a Box webpage for details (<https://www.huntingtonsociety.ca/event-in-a-box/>). You can also reach out to our events team for support at [events@huntingtonsociety.ca](mailto:events@huntingtonsociety.ca). Do-It-Yourself for donations just got even easier! 📦



## An Ariel View

*By Ariel Walker,  
HSC Co-Founder*



My focus for this article is about two very important tenets in times of upheaval: trust and connection.

In terms of hardship, whether from political strife or the life-changing diagnosis of Huntington disease (HD), trust is important. It can seem overwhelming to be one person against so many challenges, and the reason it seems overwhelming is that it is! One versus many is too much. However, having a trusted team to help you face road bumps makes it easier to share the burden. I deal with adversity by having faith in people with a lot more knowledge and understanding than I possess and trusting the process. Trust your neighbours to be there for you. Definitely trust the care team you have assembled, if you or a loved one are facing HD. Trust the researchers and scientists as they pursue leads and search for a way to treat or delay the progression of HD. Trust the Huntington Society of Canada (HSC) to represent and uphold the interests of the HD community in many avenues.

When you trust in others, you don't feel so alone. Another aspect of not feeling alone is to reach out to HSC or a local chapter to get involved in meetings, groups or events. My recommendation is not to isolate yourself, as that can be very frightening. And if you are in the position to reach out and support others, please do so to make sure they don't feel so alone. Sometimes it might feel like you are giving all the time and not getting any connection back, but then you might receive a wonderful phone call that truly brightens your week.

That happened to me right before Christmas. Someone asked to purchase two Amaryllis from me, but I had been sold out for weeks. I called Rachel Thompson, our Amaryllis Coordinator at National Office, and it just so happened that she had a few left and that she could drop them off at my house. She mentioned that she was going to be in the area anyhow, dropping off another order. We got to chatting and I learned that the other drop-off was for the son of a dear friend of mine! I had watched him grow up and had attended his wedding, but hadn't seen him for a long time. Well, once he learned about this he offered to pick up his Amaryllis at my house, and that out-of-the-blue visit was absolutely wonderful! These connections truly leave a lasting impression.

On the subject of taking the time to call, visit, or write to someone, my mother always said, "You'll never know how much good you've done for someone." I agree with her, and so I encourage you all to both reach out and provide connection and receive it as well with gratitude. 🙏

We recognize that some of the content in the following piece might be difficult to read. Our role at HSC is to support, educate and provide community resource options to families throughout all phases of the Huntington disease journey. To that end, with articles like the one about Virtual Hospice Services and a family's story in choosing Medical Assistance in Dying, our goal is to offer information. Support is available through the HSC Family Services team. You can find the national list of social workers at this link (<https://www.huntingtonsociety.ca/family-services-team-list/>).

# Brenda Porter and Gerry Gray: Choosing MAiD

*This article is a Q&A with Brenda Porter, volunteer with the Huntington Society of Canada (HSC) Prince Edward Island (PEI) Chapter, detailing her partner Gerry Gray's experience with Medical Assistance in Dying (MAiD).*

## Can you tell me why Gerry pursued MAiD?

Gerry had always spoken of assisted death from the year 2000 when his brother Peter was diagnosed with Huntington disease (HD). When Gerry was diagnosed a few years later and his own body and mind started to deteriorate, he began to consider it in a more concrete way.

## How did you find out information? Were there any organizations or resources that were particularly helpful?

We were able to access information online (via HSC) and from the neurology clinic and Barbara Horner, the HD social worker in Halifax. In addition, our family doctor helped us to make connections with the MAiD doctor here in Charlottetown. We also had a key appointment with a visiting neurologist who explained very clearly what the decision-making steps in the MAiD process would be.

## What was the process like when meeting with MAiD representatives?

All of the professionals with whom we met were wonderful. They were understanding, patient, and so compassionate. At no point did anyone

try to influence Gerry one way or the other. The process was explained clearly, and we always felt supported emotionally. We also always had wonderful support from our HD social worker from HSC, Barb. We met four or five times with the MAiD doctor and once with a second doctor who confirmed that Gerry was eligible for MAiD. Finally, we had unbelievable emotional support from the visiting neurologist mentioned earlier. He was in email communication almost daily. This was particularly important for me, actually.

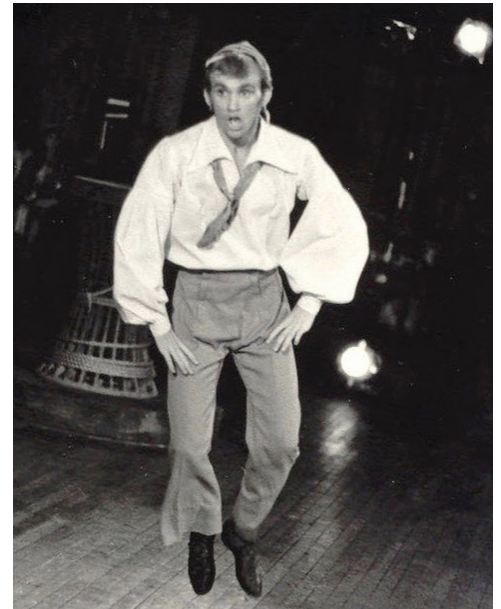
## How did Gerry feel once he made his decision?

Gerry was so afraid of MAiD. He was also terrified of moving into a long-term care home (which was going to happen very soon). But he knew very well what lay down the road for him with HD. Gerry had great dignity and bravery. He was devastated by what was happening to his body (he had been a professional dancer for many years and was still dancing in two adult dance classes until a few months before his death). Once he had come to his final decision, he never wavered. He was frightened but calm and determined to cheat HD of what it had in store for him.

## Once he reached his decision, how did you both live the final months of his life?

The decision was only made three-and-a-half weeks before his death. Gerry's mental competence was slipping very quickly, and he had to make the decision while doctors could still confirm that he was mentally competent. Once the date was set, the two of us walked together every step of the way. Gerry had no immediate family left, and I have no family here on PEI. We decided not to tell anyone that his death date was set, primarily because we didn't feel that it was fair to place that burden of knowledge on friends. Also, we did not want the complications of folks trying to dissuade Gerry from his decision or becoming emotional when they knew they were seeing him for the last time. It was just the two of us until the final three days (when we told two of our closest friends here).

And we made our 'bucket list'. We identified places we wanted to revisit, walks that we wanted



Gerry doing the Sailor's Hornpipe dance

to take, restaurants that we especially enjoyed, favourite meals at home (including fresh pan-fried haddock and PEI potatoes for his last dinner). We listed special friends that we wanted to see and have quality time with – either over dinner, for an evening together, or an afternoon visit on the patio. And we listed photos of our travels that we wanted to look at again and passages from our travel journals to re-read. Once the 'bucket list' was made, we had something special to look forward to every day. We also filled some of the 'spare' time by re-watching Downton Abbey, right from the beginning!

## What were his last days like? His special, final night?

Really, they were not greatly different from the previous days. Of course, there was a 'counting down', but neither of us said that aloud. There were lots of hugs.

One very special thing happened the day before his death. To put this in context, Gerry and I led a Scottish and English Social Dance group for almost 20 years. Many in that group are good friends. As Gerry was – in his heart and soul – a dancer,

*Continued on page 11.*



Gerry during the 2020 HD Walk  
(photo by Doug Gallant)

# Choosing MAiD

*Continued from page 10.*

I contacted six of our closest friends in the group and asked if they would like to get together at our regular venue to do some of Gerry's favourite dances. They knew nothing but that it would be a chance to dance together. The women in the group clamoured for a chance to dance with Gerry (he was delighted). Despite the fact that his feet and legs were not doing what he wanted them to, he knew where he had to be and he got there. He was in his element and even gave us a couple of pointers along the way. At the end of 90 minutes he was exhausted, but what a triumphant evening it was! After we got into bed, we talked about it a bit. I asked him to consider that not many people get to choose what they would do on their final evening. I told him how incredibly brave he was and how proud of him I was. We had a nice hug and turned out the light. It felt as if all was ready.

## When did he pass away?

Gerry passed away at home, in his favourite chair, with his dancing shoes on, on September 16, 2021, at 5:45pm. He reminded the doctor that he had been "no ordinary dancer", and I played a live recording of him dancing his famous hornpipe as he went peacefully to sleep.

## How have you been doing since then?

It has been one day at a time. I have been so fortunate that my close friends rallied around immediately. They have provided such support, as have family members from a distance. The amazing tributes to Gerry that were shared, the stories that were told, the photographs unearthed, all helped me to remember Gerry without HD. 'Snippets' of him appear every day and, of course, there is sadness. But there is also celebration of a dignified, vital, kind man with an infectious laugh whom many loved.

## What are your plans for working with the PEI chapter and the Huntington Heroes Walk?

We are trying to keep our wee Chapter alive. The plan is to have perhaps two very casual get-togethers this year to get caught up and to plan for fundraising projects. A very special project for us is the Huntington Heroes Walk (linked with the National Walk) that will be in honour of three members of our PEI HD family whom we lost in the past year. I will also work to keep the lines of communication open between HSC and our members, especially with regard to pointing folks to supports that are available on their journey with HD.

## What does it mean to you to be involved in raising awareness for Huntington disease?

Quite simply, I am doing this for Gerry. I absolutely know that he would want me to, and it will give me joy to continue his advocacy. 🌟



Gerry's professional head shot



Brenda and Gerry in dance costumes (2014)



## New Board Director Marg Romanow

Marg Romanow is from Regina, Saskatchewan and joined the Huntington Society of Canada Board of Directors in September 2021. Marg is a Registered Nurse and previously worked in the Intensive Care Unit (ICU) and the Cardiac Care Unit (CCU). Because of back injuries, she took a desk job working for the Nurses Union addressing pension, benefits and disability appeals.

Marg has dedicated her career to being an advocate for those with health and disability issues.

Marg has been on a number of Boards and was granted the ICD. D designation by the Institute of Corporate Directors. This designation represents a lifelong commitment to excellence in the boardroom and helps directors be better at what they do. Marg found her way to the Huntington Society of Canada because she was interested in serving on another Board; her interest was piqued by the HSC position as it relates to a number of health issues.

"I wish to utilize my Board experience to address Governance matters. I believe that Boards are key to organizations and proper structure and protocols are vital for engaged and productive work," says Marg. "I commend the Huntington Society for organizing initiatives to support individuals and families affected by this disease and to improve their futures."

Welcome to the Huntington Society of Canada Board of Directors and to the broader Huntington disease community, Marg. We are so fortunate that you have been generous enough to donate your time and expertise. 🌟

# Sharon Gera, Amaryllis Volunteer

*Editor note: Chuck and Sharon Gera live in Burlington, ON, where Sharon volunteers to sell Amaryllis. This is her story as written by Chuck.*

Our family's introduction to Huntington disease (HD) came as a complete shock almost ten years ago. Sharon's family had no known history, and to this day, we can only speculate, as there was no apparent evidence of symptoms in either of her parents or their siblings. Both parents passed away before any symptoms of HD began to appear. To date, none of her cousins or their children have had cause for concern.

This past Christmas Eve, Sharon celebrated her 70th birthday. She is the second oldest of six siblings, three of whom are sisters and all four of the girls are in varying stages of HD. Moreover, our daughter, a young mother, also carries the HD gene. Her daughter does not. Sharon's struggles with Huntington disease are significantly different from those of her sisters, two of whom currently receive home care and experience considerable movement and communication difficulties.

Balance issues are becoming more frequent and challenging for Sharon. However, her major concerns extend to those in both the cognitive and emotional areas. Sharon's increasing decline in personal drive and motivation have become more pronounced, magnified by the loss of her driver's licence and the independence and enjoyment she derived from driving.

From the outset, Sharon has been determined to gain as much information about HD as she could. To that end, she began attending the national conferences (four at last count), and was eager



Sharon's family, from left to right: Sharon, Raymond MacDonald, Anne Veenendaal, and Joyce Marton in front.

to attend the Niagara conference, had Covid not forced postponement. We have attended both local group support and caregiver meetings since her diagnosis.

She was encouraged to get involved with the sale of Amaryllis flowers through Robert Schellenberg ("Schelly"), whose late wife had HD, and who has remained actively involved in distributing the plants. Schelly has been an ongoing source of inspiration for Sharon. She has been open and engaged when she is able to talk about HD with others. She doesn't see herself as a victim, but rather sees an opportunity to inform others and increase awareness about a disabling disease that is scarcely known to most.

For Sharon, who has difficulty initiating and communicating her thoughts through conversations, selling Amaryllis is not in her comfort zone. For her to go out into our community, knock on doors, and encourage strangers to purchase a plant is a formidable task. However, it has been a goal that is personally rewarding for her, because her comfort level increases when she is able to talk about her disability and the importance of fundraising for HD research. She has undeniably been able to share her message. This year, arguably her most difficult time in getting herself motivated, has been her most rewarding. Sharon has been selling the plants for the past five years or so and she has averaged about 60 sales each season. This year has been the most successful by far.

This year, Sharon sold more than 100 Amaryllis flowers – nine dozen in total. Her efforts have reaped benefits beyond the sales. Her niece, whose mother is facing considerable challenges, decided to get involved with sales this year. Our neighbour, a recently retired teacher who worked with 'special needs' children, used the Amaryllis in her classroom and the youngsters watched it grow and eagerly recorded their daily observations. It proved to be a terrific motivator for the little ones.

As difficult a time as we currently face with Covid and its variants, and as hard as it is becoming for her to stay motivated, Sharon made the effort this year and it has paid dividends. She was actively involved, followed up on sales, and looked after all of her financial responsibilities.

I write this as an opportunity both to recognize my wife for her accomplishments in selling Amaryllis, and to highlight her determination to deal with her HD in a manner that is helpful and beneficial to her.

I am proud of her efforts and she is my personal 'Huntington Hero'.

Chuck Gera 🌱





## Huntington Society Partners With truLOCAL

Opening the bold, distinctive black and white truLOCAL package of frozen meat products is like opening a present on your birthday. The box is meticulously packaged with dry ice; each beef, chicken or fish/seafood product is individually shrink-wrapped. The best part? All products are from local food producers and the purchase of a package supports Family Services programs and research in the field of Huntington disease (HD).

"It was so hard to decide between all of the packages, but I chose both a chicken and a BBQ package and my mom ordered the surf and turf. I can't wait to order more in the spring for BBQ season," says Shelly Redman, CEO of the Huntington Society of Canada (HSC). "For years I've committed to purchasing local meat from Ontario farmers, and that has always meant a

lot to me. Now with this fundraiser we can all support multiple local farmers while also investing in support services and research for Huntington disease."

The campaign was initially slated to run in Ontario, Alberta, and B.C. from January 20 to February 20, but as the momentum continued to build, it was extended to February 28. Based on the success of the initial offering, HSC plans to run a second campaign in late spring/early summer to keep everyone's freezers well-stocked for cottage weekends and backyard BBQs.

The truLOCAL story started as an idea between Ontario entrepreneurs Marc LaFleur and Greg Quaile who saw a need to bring supply chains close to home. The pair appeared on the popular

TV show Dragons' Den to pitch their business, and soon the Dragons were competing to provide backing. You can view the original pitch and the update here: <https://www.cbc.ca/dragonsden/m-pitches/trulocal>. They landed a deal with Michelle Romanow and at the end of 2020, they sold the company for 16.7 million dollars. The new truLOCAL owners continue to value supporting local farmers and food producers as well as giving back to the community.

You can give back, too! Stay tuned to our e-blasts and social media channels for the launch of our next campaign, just in time for the warm weather.

For more details about truLOCAL, visit: <https://trulocal.ca/>

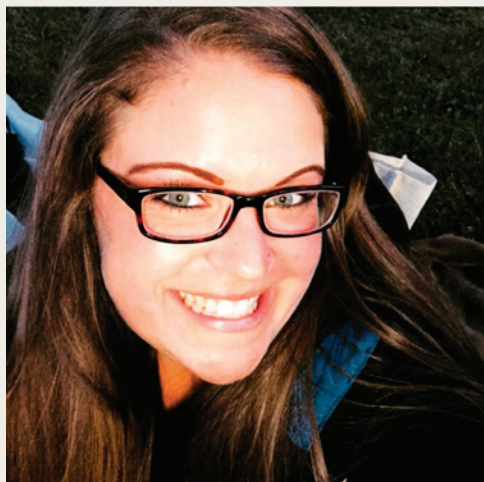


truLOCAL co-founders Marc Lafleur (left) and Greg Quaile (right)



# How to Engage Your Community Virtually

As the world begins to re-open, many members of the Huntington Society of Canada (HSC) community are excited for the opportunity to gather in-person once more for meetings and events. Mindful that uncertainty and discomfort about in-person events linger, it will be important to incorporate learnings from recent years as we offer virtual or hybrid ways for connection and showing support.



**Southern Alberta Hope Run Committee Organizers (top – bottom):** Brittany VanNorman, Rachelle Turk, Jenna Marsh

“What remains essential is that we are offering a variety of opportunities for individuals to engage with the cause in a way that is comfortable, accessible, and meaningful,” notes Annie Vanexem, Senior Manager, National Events & Chapter Development.

## BC Chapter Experience

The BC Chapter, based in Vancouver, found that sweet spot of success in the virtual arena. When Covid struck, the chapter switched their monthly meetings and annual walk to a virtual format. To participate, individuals simply turned on their computers or devices in the comfort of their own homes, cutting out travel time from people’s busy lives. Chapter President Lesley Nantel shares that through virtual meetings and events, individuals from all across British Columbia were able to participate. As such, the chapter is now considering continuing with virtual monthly meetings, only meeting in person on a quarterly basis, and moving the walk to a hybrid format to allow individuals to walk together in Vancouver, or remotely wherever they are. To keep everyone feeling a part of the event, no matter their location, the group intends to live stream from the event on social media, as well as to host activities such as raffles or auctions both online and in-person.

## Reducing Barriers Using Technological Tools

Many chapters and groups across HSC are using tools like Zoom and Google Meet to host group or one-on-one meetings. Several chapters, including the Toronto Chapter and YPAHD, also leveraged Facebook to share content as it happened with Facebook Live during the pandemic. Offerings included virtual lab tours with HD researchers and chats with community members sharing their HD experiences. “The Facebook Live chats, and eventually virtual YPAHD Day, allowed us to assemble several guest speakers or experts in the same ‘room’ without any associated costs such as meeting space and travel,” says Caleb Harding, newly elected President of YPAHD. Like many groups hosting virtual activities, Caleb notes the virtual format reduces barriers, not only from an accessibility or travel perspective but also for those who are more introverted or private, and therefore not as comfortable with attending an in-person event.

## Communication and Promotion

In addition to being a platform for educational events, social media tools are well known for their ability to promote events and activities. Whether through social media, websites, emails, or good old-fashioned phone calls, providing

clear information in advance helps everyone feel comfortable. For virtual events, this may mean sharing links and tutorial information. In the case of in-person or hybrid events, this extends to communicating safety precautions and procedures. Vern Barrett, Manitoba Chapter President, took this approach with several events his chapter was able to host in-person last year. “By providing clear communication about what we were doing to keep everyone safe, along with the venues’ protocols, we were able to instill confidence while respecting everyone’s diverse comfort levels with Covid,” Vern comments.

## Community Building

After promoting an initiative, the next focus is community building on the day of the event. Playing icebreakers, having a common goal to work on at a meeting, using designated hashtags on a social media channel, or participating in virtual activities are all effective. The most successful events are those that plan a virtual experience for their participants, as was the case for the BC Walk and the Southern Alberta Hope Run. These events used Facebook (and Instagram) Live to stream concerts, entertainment and kick-off videos from the event committee. The initiatives also used online tools to track distances and offered prizes for achievements like top fundraisers. The Southern Alberta Hope Run committee notes that partnering with the National Virtual Walk allowed them to focus their efforts on the online auction at their virtual run. “All of the media was ready for us, so all we had to do was share the event on social media to encourage participation and fundraising,” says Rachelle Tuck, a member of the Hope Run committee.

We continue to learn more about the uses of ever-evolving technology for virtual events and have seen that these tools help create a breadth of offerings for those looking to connect and support the HD community, whether by simply meeting and connecting, learning together, or raising funds. Ultimately, it is our goal to improve the experience so everyone feels comfortable in the virtual space.

There is certainly no replacement for the community building and connection of an in-person event or meeting, but we continue to be excited and amazed by the creativity that virtual and hybrid initiatives create. In addition, there are multiple benefits to breaking down barriers for attendance by offering different formats. There are so many more opportunities to get involved and connect. If you are interested in attending or organizing an event, meeting or other activity for HSC, please contact [events@huntingtonsociety.ca](mailto:events@huntingtonsociety.ca) 🌐

#NVW2022

# LET'S ALL CELEBRATE CANADA'S VOLUNTEERS



**NATIONAL VOLUNTEER WEEK**  
**APRIL 24-30, 2022**



## National Volunteer Week

*by Annie Vanexem, Senior Manager,  
National Events and Chapter  
Development*

Volunteers are the heart of the Huntington Society of Canada (HSC). The dedication and commitment of volunteers founded this organization, and despite the ways we continue to grow and develop over the years, our success is still driven by the hard work of volunteers nationwide. National Volunteer Week in Canada occurs every year at the end of April and it is a great time to reflect on how vital volunteers are to the work we do.

This year's National Volunteer Week theme is "Volunteering is Empathy in Action" and we feel this keenly at HSC. Our volunteers truly care about each other, the community and HSC.

As Volunteer Canada reflects through their National Volunteer Week campaign, the empathy, compassion and generosity of volunteers creates connected communities and builds a stronger Canada. This is equally true at HSC. Our volunteers support more than 20 local chapters and groups across Canada, with a core of 150 leadership volunteers, and many more who support the initiatives of these chapters and groups.

These groups and chapters fill a multitude of roles at the local level that help HSC extend our reach and resources. For example, chapters and individuals plan, organize, and assist at fundraising events. During the pandemic, these events, along with other volunteer-led fundraising such as the Amaryllis campaign, accounted for a quarter of HSC's overall fundraising dollars.

Locally, volunteers are also responsible for a variety of awareness initiatives including petitioning local monuments and sites to light up in blue and purple every May as part of LightItUp4HD (also led and started by volunteers), and requesting flag raisings and proclamations by local municipalities. Chapters and groups of volunteers support education initiatives such as information tables and presentations.

At the national level, we are blessed by the generosity and heart of our fourteen board members who hail from all corners of Canada and bring a breadth of experience and expertise to the governance of HSC.

Volunteers are also responsible for informal social support – the type that happens organically when together with like-minded individuals, whether at a chapter meeting, education event, fundraiser, or social activity. This support is a wonderful example of the compassion and empathy that National Volunteer Week highlights this year.

When we talk about support, we must also recognize our network of youth mentors across the country. These volunteers connect one-on-one with other youth affected by Huntington disease (HD) to help them navigate the complexities of the journey. Youth mentors exemplify empathy and compassion as they provide youth with positive role models in the HD community, prevent isolation, and help prepare youth for the challenges they face.

When thinking about the heart of HSC volunteers, another special group is the hundreds of volunteers nationwide who participate in observational studies and clinical trials to further research into treatments and a better understanding of HD. While HSC does not manage observational studies and clinical trial volunteers (each trial takes this on individually), HSC and the broader HD community benefit greatly from the time and bravery of these volunteers.

We cannot say enough good things about the many ways that individuals across Canada, and the world, give back to HSC and the HD community. Over the course of National Volunteer Week, we are able to shine a spotlight on a few of the volunteers who bring heart to HSC. While we are only able to recognize a handful through these profiles, we truly appreciate every single volunteer that makes our organization so great. Your generosity, compassion, and heart is what helps us to improve the quality of life for those affected by HD every day. 🌍

# LEGACY GIVING



Huntington Society of Canada  
**HUNTINGTON**  
Société Huntington du Canada

## Legacy Giving

“What will my legacy be?” is a question that crosses many people’s minds when thinking about their future. Many of our community members know about making an impact on Huntington disease (HD) through involvement in clinical trials and HD research, but did you know you can leave a lasting legacy on HD through a legacy gift to HSC?

Legacy gifts are future planned gifts to HSC arranged through your estate. Legacy gifts ensure you will have a lasting impact on HD, and your contribution guarantees HSC will have continuous funds to fulfill our commitment to supporting families, educating communities, and funding research. Such a commitment is also a great way

to acknowledge the impact HSC has had on your or your family’s lives. Talking about end-of-life decisions can be difficult. To get started planning your legacy, consider the following:

- Talk to your loved ones about your estate wishes. If HSC has had an impact on your life, and you’d like HSC to be recognized in your estate, discuss these wishes with your family. Remember, there is no minimum threshold for legacy giving.
- Reach out to HSC’s development team. There are many ways a legacy gift can be designated to HSC and we are here to help discuss your options and find the right fit for you and your family.
- Set an appointment with your lawyer and financial planner. An estate lawyer can work with you to

advise you on the best financial setup for your estate. When you are pleased with the proposal, ensure you meet with your lawyer to update your will.

Estate giving is a large contributor to HSC’s success. This article is the first in a series about estate planning and legacy giving. Be sure to look out for more legacy giving information in our next issue of Horizon, where we discuss the financial benefits estate giving can have on your estate.

For more information, please contact Manager of Development Rachel Thompson at [rlthompson@huntingtonsociety.ca](mailto:rlthompson@huntingtonsociety.ca), 519-749-8491, ext. 134, 1-800-998-7398 📞