

ISSUE 172

SPRING 2026

HORIZON



THE GET INVOLVED ISSUE

THE HUNTINGTON SOCIETY OF CANADA'S MAGAZINE

A Message from the CEO **Shelly Redman**

Welcome to Horizon, Spring 2026 – **the Get Involved issue**. These pages are bursting with stories of how Huntington disease community members are stepping up to participate in a variety of advocacy, care, research, and fundraising initiatives.

From an amaryllis superseller to an educator/singer-songwriter, these inspirational people remind us that “Where there’s a will, there’s a way.” You’ll hear about community members dedicating their time and energy to advocacy work and research trials, and we’ll also highlight the award winners from our Gala Dinner back in the fall.

We recognize that there are many ways to participate beyond fundraising. In this issue, you’ll learn how to get involved in everything from research to awareness activities like Light It Up 4 HD.

Speaking of fundraisers, spring is a very special time for the HD community, because May is HD Awareness Month, and this year, there is an impressive roster of fundraising walks. These events are such a wonderful display of dedication, generosity, and togetherness. It’s one of my favourite times of year, and I hope you can take part in the joy of an in-person walk. Check the list of events on our back cover.

In this community, **we are all advocates. We are all the voice of a disease and a community.** We are moving into an exciting time of real change, and I’m so grateful to share it with you.



Shelly Redman | CEO, Huntington Society of Canada





An Ariel View

| Ariel Walker, HSC Co-founder

I am working on this column on a snow day spent with my daughter and son-in-law – that record snowfall in January. She suggested I hunker down with them for the duration, and we've had a great time playing cards and board games. Many of them are the same games I played with my kids, and they're as fun as ever. My son takes care of the snow at my house in Cambridge, and pops in for a nice visit each time he does.

These connections are more important than ever.

I read an article recently that stated, **"Loneliness is the new smoking,"** citing the health risks of not connecting with people.

And yet, life happens. Relationships change. People age, move away, and the relationships you once had with peers, co-workers, or your kids' friends and families might shift.

When this happens, I hope you will heed this advice and make sure you fill the friend void. Your new friends might not be the same age as you – and that's wonderful. I encourage you to step outside your comfort zone for new activities or friend groups - like HSC's new male caregivers support group! Or maybe you'll invite the neighbours over for coffee. Maybe you'll start a book club!

On the recommendation of Jimmy Pollard, I'm reading an amazing book right now by Dr. Anne Young called **Disorderly Movements: A Neurologist's Adventures in the Lab and Life**. In this memoir, she describes her laboratory experiences identifying new neurotransmitters and their receptors. The book also discusses her life with husband and collaborator Jack Penney and their involvement in identifying the Huntington disease gene with neuropsychologist Nancy Wexler, whose autobiography **My Life, My Science: Pursuing a Cure for Huntington's Disease** was also recently published. Your book club could all read these fascinating books and discuss them – snacks are encouraged!



I hope the snow days are over for a while, but maybe you can spend a fun Sunday afternoon playing games with neighbours, joining a walking group in preparation for the Huntington Heroes National Walk, or trying Chair Yoga. You could get involved with a research study or patient advocacy group, or perhaps try your hand at writing and recording music. Those topics and experiences are covered in this issue of Horizon, so please keep reading.

Reach out, get involved, and feel a part of something – your health will thank you!

Ariel



Dear HSC: Dental Care

Dear HSC,

I'm experiencing uncontrolled movements that are making it difficult to hold my toothbrush and impossible to floss. I'm worried that it's having an impact on my ability to look after my teeth. What can I do to prevent problems?

Uncontrolled movements are common in Huntington disease and can make it hard to hold a toothbrush, floss, open your mouth wide, or stay still while cleaning your teeth. This can raise the risk of sore gums, loose teeth, and cavities over time. Some people with HD find it harder to keep up with daily self-care in general, so needing extra help with brushing and flossing is very normal and not your fault.

There are tools that can make cleaning your teeth much easier. **Electric or suction toothbrushes, water picks, and air flossers** work well when your hands are shaky, and these dental tools can clean better than regular floss. **Use fluoride toothpaste every day** to help protect your teeth. If your mouth feels dry because of medication, xylitol gum or toothpaste can help and will lower the chance of cavities. **Try not to eat at least 30 minutes before going to bed**, because your mouth makes less saliva when you sleep, and food left on your teeth can cause decay. **Seeing your dentist every six months** is also very important.

You do not have to manage this alone. An occupational therapist can show you easier ways to brush and floss, help set up simple daily routines, and suggest safe positions so you do not get too tired or choke. At dental visits, tell the staff about your movements and any problems you are having so they can help you feel more comfortable. You might also think about bringing a caregiver or support person if that helps. With the right tools and support, you can protect your teeth and keep your mouth healthy.



For more information read our **“Dental Care and HD”** Fact Sheet

Visit hdfactsheets.ca for more Fact Sheets on a variety of HD topics

Centres for HD CARE Update

We're excited to share an update on the Centres for HD CARE. We're in the needs assessment stage, working with the **Centre for Community Based Research (CCBR)** on a national research project that looks at gaps in access to specialized care for people affected by Huntington disease.

Some key research questions are:

How is clinical care currently being accessed by people living with HD?

What are the challenges and gaps in care experienced in different Canadian cities, rural areas, and regions?

Based on the above, what considerations should shape the proposed Centres for HD CARE?

These research questions and the design of the project will be guided by HSC, CCBR, and the project steering committee.

Your contributions have made a real difference. Thank you to:

- Vern Barrett
- Greg Childs
- Morley Ellis
- Sharon Haig
- Lesley Nantel
- Celine Payne
- Hannah Remillard

National Survey and Focus Groups

This needs assessment research includes:

1. A national survey to hear directly from people living with Huntington disease and their caregivers to better understand the challenges faced in accessing specialized care

- English and French available
- Open to all Canadians living with HD and their caregivers (including those in Quebec)
- Developed with input from the steering committee

2. Focus groups and interviews with the following groups:

- People with HD
- Caregivers
- Healthcare providers
- Potential funding partners
- Staff and the board of HSC and HSQ

3. Two rural and remote communities for focus groups:

- Northern BC (with facilitation help from Quinn Mykyte, RCD for Fraser Valley, Interior & Northern BC)
- The Uashat community in Northern Quebec (with facilitation help from local elders and social workers)

Result and Vision

These results will help guide the development of multidisciplinary Centres for HD CARE across Canada. The vision for these Centres is to expand access to HD-experienced clinical care, counselling, and other community and health services through a multidisciplinary health team.

Thank you to everyone for your participation so far. We are excited by our progress and keen to share more updates.



Creating Pathways of Support for Youth in the HD Community

By **Winnie Diverlus**, Child and Youth Practitioner, HSC



Just a few weeks into my new role, I attended my very first Young People Affected by Huntington Disease (YPAHD) Day and the 2025 HSC National Conference. Aside from the YPAHD executives, I hadn't met anyone yet, and I felt the happy kind of nervousness that comes from new beginnings. There were so many friendly faces eager to introduce themselves. From the small group sessions to the creativity behind group art therapy, and then a wonderful social night at BRKFREE, I had a front-row view of the emotions, imagination, and critical thinking of this incredible young demographic.

The weekend wrapped up with the gala, where well-deserving recipients received their awards. The dance floor became a therapeutic space filled with old-school favourite music – nostalgia was running high! The conference reminded me why these spaces matter; they serve as lifelines of belonging and understanding.

My overall experience with YPAHD Day and conference reinforced my commitment to this one goal: **every program we develop should aim to serve with care, inclusivity, and impact.**



Being There for Youth

As a Child and Youth Practitioner, an important part of my role is being available when youth need support, often in partnership with our local Resource Centre Directors (RCDs). Whether they're looking for information, guidance, or a safe space to talk, I'm here as part of the wider HSC support network. When young people connect with me, my focus is on helping them feel heard, supported, and grounded as they navigate the challenges and transitions that come with facing Huntington disease (HD).

Here are some specific programs I am excited to offer:

First young adult in-person group

My support extends into group spaces, including support groups and our new in-person youth group pilot in the Halton and Hamilton regions. Running on the last Wednesday of each month until June 2026, this group aims to create inclusive and supportive opportunities for connection, learning, and community-building.

Youth Mentorship Program (YMP)

The YMP has been a cornerstone of youth support at HSC for over a decade, connecting young people with mentors who understand, listen, and encourage. These relationships have made a meaningful difference for youth navigating HD. Have you thought about being a mentor? If you've ever considered sharing your experience and perspective, I'd love to hear from you. Your involvement can make a real difference in the lives of youth.

Youth engagement and connection

I am currently supporting youth across a broad range of needs within the HSC community. A key priority is increasing engagement and creating opportunities for meaningful participation. Central to this work is ensuring that youth voices inform programming, with intentional efforts to involve young people in shaping initiatives that reflect their needs, interests, and lived experiences.



HSC core offerings

Youth and families can explore a variety of psychoeducational resources through the HSC website and social media channels, including information about HD, upcoming webinars, and ways to connect with the YPAHD chapter. These resources offer youth the chance to learn at their own pace, deepen their sense of belonging, and stay connected to a community of peers who understand their experiences.

Looking ahead

I envision a future filled with meaningful ways for youth to engage, grow, and feel supported through a blend of one-to-one connections, group programs, psychoeducational resources, and mentorship. Let's continue building spaces where youth feel connected, empowered, and understood within the HSC community.

How to Connect

Youth and families can connect with me directly by email at wdiverlus@huntingtonsociety.ca or by phone at **1-800-998-7398**, ext. **212**. My working hours are Monday-Friday, 8:30 AM to 4:30 PM ET.

I look forward to continuing to support the children, youth, and young adults in the HD community!



How You Can Get Involved in Huntington Disease Research & Awareness

| By **Dr. Alexander Maxan, PhD** | Director of Research and Partnerships, HSC

Huntington disease (HD) impacts an estimated 5 to 7 thousand Canadians, while thousands more live at risk. For many of our country's families who are directly or indirectly affected by HD, the journey may feel isolating and overwhelming, as no cures or treatments exist.

However, over the past few years, we have seen rapid advancements and a changing landscape in the drug development sector, with recent breakthroughs in clinical and preclinical research studying:

- gene therapies
- antisense oligonucleotides (ASOs)
- small molecules targeting DNA repair mechanisms

Many of the companies working on these potential future therapies rely on feedback and input from HD community members to design clinical trials that test therapies.

They need to know what to expect from families affected by HD when it comes to study participation, willingness to participate, and what would be ideal for those affected.

Whether it is through participating in a landmark observational study like **Enroll-HD**, contributing your thoughts via patient engagement coalitions such as **HD-COPE**, or exploring **clinical trials** yourself, community involvement has never been more vital to the process. By volunteering your time and getting involved, individuals and families in Canada and beyond can help drive faster innovation in the field of HD research and solutions.

Here are some ways you can act and **turn your personal experience into collective progress.**



Part I: Enroll-HD

Enroll-HD is the world's largest observational study for families affected by HD, with over 22,000 participants globally. It is a **large, ongoing database that tracks individuals affected by HD over their lifetimes** to learn how the disease progresses while collecting:

- clinical data
- biospecimens
- health info

This is done to help understand HD progression, identify biomarkers, and support future trials. No experimental drugs are involved, but it does require annual visits (1-2 hours) to your local participating clinic. These visits involve:

- neurological exams
- cognitive tests
- surveys
- optional blood/urine samples

There is no cost, and the data is anonymized, so even if you do not want to know your gene status, it will not be shared with you or your clinicians.

This study is open to anyone 18 and older from a family affected by HD (affected, at-risk, or gene-negative). Enroll-HD has been highly promising for foundational research.

The data collected has enabled **over 100 studies on HD progression**, and the anonymized data, which may be shared with researchers from around the world, has contributed to **hundreds of publications related to HD**.



If you are interested in participating, **please contact a local site via**

enroll-hd.org/find-an-enroll-hd-site/

Part II: HD-COPE

HD-COPE (Huntington's Disease Coalition for Patient Engagement) is a global initiative launched in 2018 and currently managed collectively by the Huntington's Disease Society of America and the Huntington Society of Canada.

The goal of HD-COPE is to amplify HD community voices in clinical research. This process provides input to drug developers, regulators, and researchers from around the world to improve trial design, recruitment, and relevance. HD-COPE creates the opportunity for you to tell scientists what parts of HD matter most to you, and how they have affected your families.

If sharing your thoughts on research is important to you, **we are happy to welcome new people with HD experience** (affected, at-risk, caregivers, or gene-negative) to join our volunteer team, to whom we provide training on drug development. Previous experience with HD clinical trials is an asset, but it is not necessary to participate. Interest in HD research and learning more about these processes is what we consider to be most valuable, as this group is not for clinical trial recruitment, but to aid in the design and operation of research studies.

To apply, please reach out directly to HSC's Alexander Maxan via email at amaxan@huntingtonsociety.ca.

Part III: Clinical Trial Participation

Participating in clinical trials represents one of the most direct and impactful ways for individuals and families affected by HD to contribute to the development of new therapies.

These studies test potential treatments, ranging from first-of-its-kind gene therapies to symptom management options, through carefully controlled phases to evaluate safety, tolerability, and efficacy.

In Canada, participation is facilitated through a network of specialized HD clinics and research sites, often located in major cities such as Toronto, Vancouver, and Montreal.

To find recruiting trials, access the **HD Trialfinder** tool on HSC's website.



If you are interested in learning more about the **trials happening around the world**,

you can search clinicaltrials.gov directly for "Huntington's Disease" with filters for "Recruiting."

Always verify the latest status directly through the resources above, discuss risks/benefits with your HD specialist, and consider informed consent. Your involvement could help speed up the trial's recruitment, data collection, and accelerate our understanding of what potential therapeutics could benefit HD symptoms in the future.

Every Contribution Matters – Start Now

In addition to contributing to our scientific understanding of HD, getting involved with HD research and awareness also helps to turn your personal experiences into powerful drivers of change and can fuel hope for a future without HD. Observational studies, patient coalitions, clinical trial participation, and volunteering all raise awareness - every step matters and has an impact. The momentum is real and growing. Whether you're at-risk, gene positive, a caregiver, or simply passionate about making a difference in a community that could use all the help it can get, your participation will help drive us forward. Start today, and reach out to your HD specialist, your local RCD, or HSC national staff to ask how you can help get involved. The future looks brighter than ever.



HSC Chapter & Events News

The fall and winter season brought back fan-favourites and new events alike! We want to extend a heartfelt thank you to all participants for supporting our journey to raise awareness for HD, and to the event organisers for all your hard work and accomplishments.

The Snow family held their **first annual Snow Family's Run for Huntington disease** on August 16 in Scarborough, ON. In honour of their father, Bill, who was diagnosed with HD over ten years ago, Nick and Brooke Snow reached out to HSC for support in planning a 5k run/walk in their community. Together with 52 of their friends and family, they **fundraised over \$6,500** and chatted with several passersby about HD. Congratulations to the Snow family on a successful first event.

The **Southern Alberta Chapter** celebrated its fifth annual **Hope 4 a Cure Pool Tournament** on January 23 to 25 in Calgary. Over 60 players participated, making the competition fierce and the stakes high. Participants won a grand prize payout and several prizes donated by local businesses. Thank you to all players. We look forward to a rematch next year!

In Sept. 2025, the **Ottawa Chapter** and **Kim McMullin, RCD for Eastern Ontario**, hosted an in-person education event featuring Dr. Mestre (Neurologist) and Dr. Abe (Neuropsychiatrist) from the Movement Disorder Clinic at The Ottawa Hospital. Kim described the day as a rare chance to have the community come together in one space. About 50 people attended, including the hospital's genetics team (Dr. Diamond and Stella MacDonald), along with members of Kim's caregiver support group and their families.



Manitoba's weather held on strong to allow for another incredible **HD500** event held by Brett Mitchell and the **Manitoba Chapter**. A team of snowmobilers participated in the 13th annual 2-day trek from Lockport to Bird Lake and back, raising funds and awareness for HD along the way. Whether they rode in memory of a loved one or simply supported a meaningful cause, participants had an eventful ride and **raised over \$45,000**. Way to go, Manitoba crew!

The **Vancouver Chapter** held a public tour of Dr. Michael Hayden's lab at the Centre for Molecular Medicine and Therapeutics at the University of British Columbia in Vancouver on September 25. Dr. Hayden is one of the world's leading HD researchers, and community members were thrilled to see and learn more about where HD research takes place.

Spring Events

Our chapters sprang into action with some exciting events for the season!

On March 4, the **Sarnia Chapter** launched a new doubleheader event! They hosted **Refined Fun for a Cause**, a family-friendly charity takeover event at Refined Fool Brewing Co., followed by Piece by Piece for HD. The event included booths from local vendors, mini-games, colouring contests, and a puzzle competition – fun for the whole family!

The **Peterborough Chapter** hosted its **3rd annual Curl to Cure HD** bonspiel on March 7 at Lakefield Curling Club. Highlights included lunch, prizes, and all the fun we've seen from this wonderful event over the past few years!

The **Newfoundland Chapter** has a few events on the docket for the St. John's region, including **mini-golf, trivia night, and two blind date with a book sales**. Keep an eye on the Huntington Society of Canada - Newfoundland Chapter Facebook page for event dates and details. www.facebook.com/HSCNL

Have an idea for an event in your area?

Reach out to

events@huntingtonsociety.ca

for support on getting started.

2026 Huntington Heroes National Walk



We are proud to host the National Walk again this May and hope you will join us at a local event in your area. There are several walks throughout the year, all offering a fun, family-filled day of support, connection, and awareness (**see the back cover of the magazine for our in-person walks this year**). Can't make it out in person, but still want to fundraise? Register for the **National Virtual Walk**, taking place May 30 to 31, and walk anytime, anywhere in support of HD.

Check out p2p.onecause.com/hscnationalwalk for more details.



Thank you to everyone who participates, fundraises, volunteers, or spreads the word – you truly all make such a difference! Let's make 2026 another incredible year.

Light It Up 4 HD

Light It Up 4 HD will make its return this May, illuminating sites and landmarks across the country in blue for HD and purple for Juvenile HD. In 2025, HD community members in more than 12 countries gathered around blue and purple illuminations to celebrate HD Awareness Month. **Canada saw a total of 79 sites illuminate** over the course of May.

#LightItUp4HD shines a light on a disease that's been kept in the shadows for far too long. It provides a chance for individuals and families across the globe to come together to raise awareness and show support for those affected by HD and JHD.



Check out lightitup4hd.com for daily updates on sites illuminating in your area. We encourage you to take photos of your local sites to see them in the annual wrap-up video.



To submit your photos to a shared community album, use this link (<https://albums.memento.com/LightItUp4HD2026/view>) or email them directly to LightItUp4HD2026@submit.memento.com for automatic upload.



Celebrating National Social Worker Month

Thank you for helping us celebrate National Social Work Month by engaging with our social media posts throughout March. **HSC's social workers play an essential role in supporting individuals and families affected by Huntington disease**, and we are deeply grateful for the compassion, expertise, and dedication they bring to our community every day. Your support in recognizing their impact helps us highlight the important work they do.



YPAHD Day

Youth Affected by Huntington Disease (YPAHD) Day was held on Thursday, October 30, in Mississauga, Ontario, leading into a fantastic National Conference weekend. The day included 56 youth aged 14 to 35. **Nearly half attended for the first time.**

Youth learned about topics like caregiving, self-care and coping skills, family planning, and navigating different relationships, among many more.

Afterward, they attended BRKFree for an evening of fun, where the new YPAHD executive team was announced.

Meet the new 2026–2028 YPAHD Executive:

President: Hannah Remillard

Vice President: Mackenzie Remillard

Youth Board Representative: Erik Barrett

Youth Engagement Coordinators: Ashley Drewelow, Lorraine Pearson, Nicole Verwey (to 2027)

Social Media Coordinator: Jen Carter

Please join us in thanking the outgoing executive team, **Celine Payne, Taylor Van Beest, Parker Van Beest, and Megan Burd**, for everything they have contributed to YPAHD these last few years. Thank you! And don't worry, you can still find them at YPAHD Day, local chapter events, or even HSC Board meetings!



Stay tuned for details on
YPAHD Day 2026.

2026-2028 YPAHD Executive

From left to right: Jen Carter, Ashley Drewelow, Mackenzie Remillard, Hannah Remillard, Lorraine Pearson, Erik Barrett

2025 HSC National Conference Highlights

HSC's 2025 National Conference took place Thursday, Oct. 30, to Saturday, Nov. 1. Thank you so much to our sponsors, volunteers, chapter delegates, speakers, and attendees for building a culture of shared learning.

We believe that the highlights from conference are best expressed by the participants themselves – **here are a few words of feedback from those who attended.**

“Considering that it was Halloween weekend and there were two Blue Jay World Series games, with the 7th ongoing during the dinner, I thought that the organizing committee did a wonderful job acknowledging the attendees as well as a die-hard fan base at the dinner. You pulled it off and did a great job! The meal was excellent, as was the wait staff of the hotel.”



“For my wife, the conference is always a 'reunion' of sorts as she regards these get-togethers as second family members. She is comfortable knowing that everyone in attendance is aware of HD and has an understanding of living with it and caregiving for it.”



“Meeting new people at YPAHD Day and conferences, whether family members, patients, or neuroscientist/patient advocacy leaders like Dr. Maxan, is the best reason I have for why our HD events are so special and important. Seeing that other people are experiencing the same grief as you or advocating for you/your family, or simply wanting to learn about something (HD) that they weren't previously connected to, shows me that our community is growing and that its continued growth is so important.”



2025 HSC National Conference Highlights

"It felt easier to talk to any session's speakers after the fact, with all of them attending the Halloween event and Awards Gala. Getting to talk directly with someone so knowledgeable, yet who treats you (HD community members) as a complete equal and wants to hear your story, is very special."



"I enjoyed all the sessions I attended, including the ones about HD-COPE, Law enforcement, and HD, and fundraising."

"Seeing some old friends was the best part of conference. For those of us who have been "in the game" for 20 or 30 years, it was so nice to share some laughs and tears."



"My favorite part of the conference was, hands down, connecting with so many new people. I left with a new bestie, and we have big plans to make an impact together in the next few years!"

"Best part was meeting other families, making more connections, and knowing that you're not alone."



Huntington Society of Canada **Awards Winners**

On Saturday, November 1, at the Awards Gala on the last night of the HSC 2025 National Conference, we honoured and celebrated the deserving recipients of our community awards.

And the winners are....

National Award of Merit – Volunteer

Recipients: Gwenda & Trina Klein
from Saskatchewan

National Award of Merit – Corporation

Recipient: Deer Bridge Plumbing and Heating (Calgary, Alberta)

Maike Zinabou Award

Recipient: Nicole Nadeau-Frechette,
from Winnipeg, Manitoba

Milestone Award for Awareness

Recipients: PEI Chapter

Milestone Award for Fundraising

Recipients: Newfoundland Chapter

Michael Wright Award

Recipient: Dr. Rachel Harding,
University of Toronto

Dorothea Smith and Stan Edwards Award

Recipients:

- Nancy Murphy, Ottawa
- Larry Campbell, Camrose, AB

Dean Crain Award

Recipients:

- Brett Mitchell from the
Manitoba Chapter
- Greg Taylor, Edmonton AB

Brighter Futures Award

Recipients: Carly Judd, Toronto, ON

Chair's Award

Recipients: Wendy Bruntjen and
Tara Johnson-Ouellette

Ariel & Ralph Walker Founders' Award

Recipients: Vern and Ellen
Barrett (Winnipeg, Manitoba)



**For a detailed list of award
recipients please visit:**

<https://tinyurl.com/ycy5w6u8>



Diane Tullson, Rachelle Tuck
 (Southern AB Chapter President, accepting the National Award of Merit Award for a Corporation awarded to **Deer Bridge Plumbing and Heating**), **Shelly Redman**



Diane Tullson, PEI Chapter
 (Awareness Award), **Shelly Redman**



**Diane Tullson, Newfoundland Chapter
(Fundraising Award), Shelly Redman**



**Diane Tullson, Brett Mitchell
(Dean Crain Award winner), Shelly Redman**





Vern and Ellen Barrett
(Ariel and Ralph Walker Founders' Award)

Congratulations to all our winners! Your dedication and spirit are an inspiration to everyone in the Huntington disease community!

Thank You to our Conference Sponsors:



We are a Community of Caregivers

| By Erin Paterson

Erin Paterson published this article on December 16, 2025, via LinkedIn. She reached out to HSC to ask if we could republish it in this issue of Horizon, and we replied with a resounding “yes!”

As I sat down in the plush green chair across from my therapist, I knew we were going to spend much of the day’s session talking about the stresses of being a caregiver. I didn’t want to talk about the endless hours I dedicate to my dad’s care, but rather, my frustration that few people in my life understand the amount of effort it takes, both mentally and emotionally. This lack of understanding and acknowledgement has left me feeling extremely angry and alone. I know I am not the only one who feels this way.

Being a caregiver is hard.

For most of us, there is more than one person with Huntington disease in our family. A dad, an uncle, an aunt, a brother, a sister, and three cousins. All those people need to be cared for at some point in their lives. When someone sadly passes away, there is often someone else in the family whose symptoms are progressing. Maybe there are a handful of years when no one needs intense caregiving, and we can embrace the moment of calm, but oftentimes, there is never a break.

We are a community of caregivers.

To the gene-positive caregivers who are taking care of a loved one and have the added pressure of witnessing what their own future will hold: Your gene status adds an extra layer of anxiety and fear to being a caregiver, but it also makes you a damn good one. You know what is going to happen to you, so you make sure to treat your loved ones as you would want to be treated.

You model that to your own children because you know they will most likely be your caregivers one day, too. That is a hard reality to face. You hope your kids will stick around and care for you in your time of need, but also wish they didn’t have to bear that burden.

To the gene-negative caregivers who are living with survivor’s guilt, who look at their loved ones suffering with HD and think, *Why them and not me?*: Even though some people tell you that you are “one of the lucky ones,” it doesn’t feel that way because often your experiences and emotions are dismissed. You may believe you don’t have the right to complain. But you are overwhelmed by the magnitude of the need in your family. You decided to stay and support your loved one, and the emotional burden on you is just as great as it is on anyone else in the community.

To the caregivers whose gene status is unknown, for whom life can be emotionally fraught, with the tasks of caregiving constantly reminding them of their risk: Every trip to the store for supplies, every phone call that comes in, and every decision that needs to be made is a reminder that you might have inherited the gene. Sometimes you second-guess your decision not to get tested, and you wonder if it would be easier just to know your status. But despite all of that, you are there helping your loved one through this time in their life.

And finally, **to the young caregivers** who are navigating all of the monumental decisions that come with being a teen or young adult, who are also going home at the end of the day and taking on the role of being a caregiver for a parent who has HD: You may be helping your parent shower, paying the bills, cooking dinner, and watching out for your siblings.

You are living a life that is impossible for your peers to even comprehend, and it can be hard to figure out where you fit in anymore.

To those of you who have stepped up to be caregivers, I see you and all the work you are doing. I understand how hard it is. I know it can feel endless and like you have lost yourself. I know you have a tremendous amount of compassion for your loved one with HD, and you feel guilty complaining about it. But your feelings and emotions are valid. Just because you complain about it sometimes doesn't make you a bad caregiver.

You are doing a wonderful job. **Your loved one is living a better life because of YOU!**

Being a caregiver is the greatest act of love.

Erin Paterson is an author, speaker, and Huntington's Disease advocate. She founded Lemonade Press, a publishing company focused on empowering underrepresented medical communities by helping them write and share their own journeys in inspiring anthologies. She has published four books, including *All Good Things* and *Huntington's Disease Heroes*.



Tam Maiuri's stepdad and mom, Gerry Poirer with his late wife, Vicki Poirer



Sébastien Heins and his parents, John and Shella



Corinne Napier with her mom, the late Mae Brown



Do Something: Stories, Songs, & Mental Wellness

By **Greg Shwaga** – Teacher, Aspiring
Musician, and Mental Health Advocate



Editor's note: Greg Shwaga is the principal of Vanguard Community School in Vanguard, Saskatchewan. In the fall of 2025, he offered to donate the revenue from three of his original songs, *Breaking*, *Six Strings*, and *Here*, to HSC. The songs were inspired by his wife's experience with Huntington disease. Please consider purchasing or streaming his music to support the HD community:
<https://distrokid.com/hyperfollow/gregmshwaga/light-on-the-dark-side>

Greg's mission didn't stop there.

What follows is the literature supporting a teacher workshop he presented in November 2025 – powerful words, all Greg's own, asking the community to fight mental health struggles with positive action.

Hello, everyone. Thank you for coming and for joining me in this presentation about stories and songs relating to mental health and wellness. My name is Greg Shwaga. I teach here in the Chinook School Division. I grew up on a farm near Yorkton, Saskatchewan, and I've been teaching for 32 years.

I spent four years teaching on a reserve in Bella Bella, British Columbia — about as far west and as isolated as you can go in Canada. Then I spent three years at Calgary Academy in one of the richest neighborhoods in Calgary, maybe in all of Canada. After that, I taught for two years in Granisle, British Columbia. Granisle was an interesting and sad place to teach. The school was built for 400 students during the time of active molybdenum and gold mining. By the time I was there, there were only about 50 students in the school and the town had gone from 2000 to about 400 residents. Reminders of past glory were omnipresent.

The rest of my teaching career (23 years) has been spent in Vanguard, Saskatchewan, as principal of Vanguard Community School. I'm married to Val, who was also a teacher but is no longer teaching. We have two kids: Jessalyn, a teacher in Maple Creek, Saskatchewan, and Seth, who is finishing his final year of engineering at the University of Saskatchewan and is a master corporal in the 38 Canadian Brigade Group, a reserve unit of the Canadian Armed Forces.

How did I end up sharing songs, telling stories, and connecting all of this to mental health and wellness? A few things sparked my interest.

First, I believe I have a naturally melancholic/thoughtful disposition. One time, a parent asked me why I always looked at the ground when I walked, as if the weight of the world was on my shoulders. The reality is, sometimes it really does feel like that, not just for me but for everyone.

Second, Huntington disease has had a major impact on my life. It's caused by a faulty HTT gene that creates a mutant protein, which slowly kills the brain. Symptoms typically start between the ages of 30 and 50, progressing through mental impairments and movement disorders. It's fatal, inherited dominantly — each child of someone with HD has a 50% chance of getting it. I watched my mother-in-law die from it. **My wife and her siblings all inherited the gene.** Huntington disease also causes anosognosia, meaning early on, people may not even realize they have symptoms. Everyone around them is affected.

Third, my work in schools has shown me, anecdotally at least, that mental health issues are increasing among students and likely adults in general; so much so that it has now become a priority for Saskatchewan Education and school divisions.

Fourth, a personal loss: one year ago, my best friend, my childhood buddy, and best man at my wedding, passed away. He struggled with his mental and physical health from a young age. He could lift others up, but he couldn't lift himself. His loss made me deeply think about why some people get stuck in valleys and never come out?

All of these experiences led me to a simple guiding principle: **do something**. But what? I broke it down into three pillars: do something for **someone**, do something for your **community**, and do something for **yourself**.

Songwriting became part of this journey. I learned to play guitar later in life, in my late 20s, around the time I became principal at Vanguard. When I was in a dark place, I'd write songs — sometimes just to force myself to learn a chord progression, other times as a form of expression. Over the decades, the songs I wrote became a reflection of my life and my journey with mental health. Writing songs was **doing something for myself**, even if I didn't realize it at the time.

The song Stay Sad came from a frustrating experience with a parent. I felt like giving up, but instead, I wrote the song. In a way, it trapped the sadness in music so I could move forward.

Doing something for someone has health benefits. Just five minutes of research shows that helping others boosts serotonin, dopamine, and oxytocin, lowers blood pressure, increases lifespan, and reduces stress. It's difficult to help others when you are thinking about yourself. I started thinking about how Huntington disease affected my wife and her siblings. I tried to see the world from their perspective. This reflection inspired a song called Breaking, which I initially didn't plan on sharing, but after my friend's death, I realized it could, perhaps, help others too.

Doing something for your community has benefits as well. Research shows community involvement enhances mental health by creating a sense of connection and purpose.

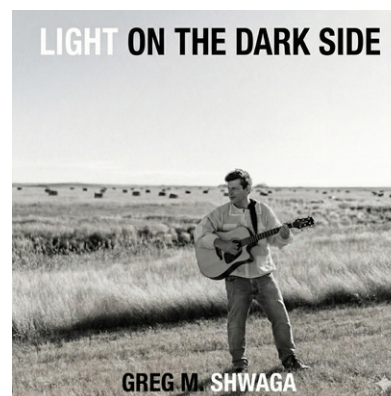
In 2017, I walked across Saskatchewan to raise money for the Huntington Society of Canada. **Seventeen days, a marathon a day for 11 of 13 days, raising \$30,000.**

What began as a personal journey turned into a community effort when sponsors joined in. It was an incredible peak. But life brings valleys too: after the walk, I developed Bell's Palsy, battled bronchitis, our family pet was killed, my daughter went to university, and Huntington disease once again made its presence known in our family. Life is always a series of peaks and valleys.

In the summer of 2023, I found myself in a deep valley again. Playing my guitar, as an escape yet again, I realized I always have these six strings — and feelings. That moment inspired the song Six Strings, which helped me climb out of the valley.

To summarize: mental illness is prevalent. It's real. We've all been in valleys. The way - and maybe the only way - to respond is this: do something. Do something for someone, for your community, and for yourself. The key to doing something, I believe, is the aggregation of marginal gains — small, frequent actions that, over time, make a big difference. Whether it's walking to school a kilometre a day, carrying a 15-pound dumbbell, or eating something from your garden every day, small, consistent actions add up.

Do something. Something for someone, something for your community, and something for yourself. **Start small. Keep going. Every action counts.**



Purchase or stream *Light on the Dark Side* by Greg M. Shwaga

For Corinne Bees, Finding a Cure for HD Hits Home

| By Kerry Gold

Corinne Bees had been heavily impacted by Huntington disease (HD) long before she'd even heard of the disease.

As a child, the Edmonton-born Corinne and her sisters, Diane and Joan, had endured their mother's constantly erratic behaviour. Her mother was a caring, loving person who'd invite children from the local orphanage over for dinner. But she'd also have outbursts or do something Corinne describes as "wildly irrational", such as sending her to school in a ripped dress.

"You just didn't know who she was going to be," says Corinne.

When Corinne was 15, her mother suddenly moved to Vancouver, leaving her, her sisters, and their dad behind in Edmonton, returning home for the rare visit. Corinne recalls seeing bruises and cuts on her mother's arms and being baffled by her mother's alarming behaviour. By her 20s, Corinne would visit her mom in psychiatric hospitals in Vancouver and Edmonton. By the time her mother died in 1965, Corinne had a husband and two children, and craved answers. An autopsy revealed the truth: her mother had Huntington disease. By 1967, Corinne had started to notice that her aunt was also behaving strangely. After her aunt died two years later, her uncle shared that she had Huntington disease. Eventually, Corinne and her sisters put together that the disease had been passed down from their mother's father. Out of four children, three had inherited the disease.



And so, Corinne's HD journey began. Spurred on by her mother's diagnosis and wanting to make the most of life, Corinne, a teacher, moved with her family to Africa for two years.

Back in Vancouver by 1969, she began the relentless pursuit of learning everything she could about the disease, connecting with others who were impacted, and fundraising for research to stop HD from harming other families.

Corinne has been an integral member of the HD community going back to 1979, when she used to print a newsletter on HD topics on an old Gestetner machine. She has sat on the Vancouver Huntington Society Chapter since the 1980s. Her sister Diane and her husband started the Alberta chapter.

Corinne achieves record amaryllis sales in B.C., typically anywhere from 660 to 816 bulbs a season. Her fundraising efforts reflect a desire to connect with others. Corinne, who is 85 and enduring mobility issues due to a bad knee, will drive across Vancouver to deliver a single bulb. Those transactions often turn into conversations about other Huntington disease journeys. Corinne finds the stories about women who've given up on the idea of having children out of fear of passing the gene along particularly touching because of her own experience.

She always wanted to have more children, but the spectre of the disease destroyed those plans. Terrified of passing the disease on to future children, by 1970, Corinne had already decided to have a tubal ligation.

"It was the hardest thing I've ever done in my life."

The disease has affected her in other ways, too. Simply getting older became terrifying, and she dreaded hitting age 40, the age her mother started showing symptoms. So, she channeled her defiance and independence instead, and at age 40, got her master's in education.

In her early 60s, predictive testing for the disease became available, and so she was tested. The results showed a CAG repeat of 36, meaning she may or may not show symptoms. Despite the testing, her uncertainty and fear continued.

Her beloved sister Diane came to Vancouver around the same time to undergo predictive testing, too. **When she picked her up from the airport, Corinne saw the same familiar movements in Diane that she'd seen in their mother.**

"I could tell just by the way she reached down to get her suitcase," recalls Corinne.



"I remember coming home and crying and saying to Bill, 'Diane's got Huntington's.' Diane was my absolute favourite person in the whole wide world."

Diane died from the disease during Covid, at a time when Corinne couldn't visit her. Two out of four of Diane's daughters have tested positive for HD. Corinne's other sister, Joan, is 90 years old and, like Corinne, is not showing any signs.

"I was born an optimist," says Corinne. "My father drilled into us that we should not give up, no matter how bad it gets. I read a lot. I feed the birds every day. I love seeing my grandchildren for dinner each week. I am intensely grateful for the small things in life."

Kerry Gold has been a member of the Huntington Society of Canada Vancouver Chapter for 12 years and is a caregiver for her ex-spouse, who has HD.

Building Rare Disease Connections – A First Step in Advocacy

| By Erin Paterson

This past fall, approximately 180 people from different rare disease communities attended the Canadian Organization for Rare Disorders (CORD) conference in Ottawa, Ontario. Among them were three representatives from the Huntington disease community, Valerie Nabb and Allison Bush from the Ottawa Chapter, and me, Erin Paterson. Conference attendees were there to share their experiences, make new connections, and collaborate on addressing issues that impact all rare disease communities.

One subject came up repeatedly: **the need for new drugs to be approved in Canada and for them to be accessible to all patients who need them, across the entire country.**



Tom Kmeic and Erin Paterson

“Our single biggest takeaway was that there are significant systemic challenges in the Canadian health care system, especially as it relates to rare diseases and to approval and funding of new drugs. The system appears cumbersome, time-consuming, antiquated, and designed for a different era. We are keen to find some way we can help make a difference,” says Valerie.

Shortly after the conference, Allison joined the Provincial Rare Action Group (PRAG), an organization focused on helping address some of these issues with the federal government.

“There are so many opportunities to learn from other disease communities, especially the ones that have been effective in getting treatments covered, such as the cystic fibrosis and spinal muscular atrophy communities,” says Allison.



Erin Paterson, Allison Bush, Valerie Nabb, and Beth Vanston from PRAG

We all agreed that attending the conference was invaluable. Not only was it inspiring to meet so many passionate advocates, but we also gathered valuable information and left with the feeling we are all in this together.

While in Ottawa, I was also invited to attend the Rare Champions breakfast on Parliament Hill, which was sponsored by three members of parliament. I met with Tom Kmiec, who is the Deputy Speaker of the House of Commons as well as the MP for Calgary Shepard, Alberta. I spoke with him about Huntington disease and gave him a copy of some of the books I have published about HD and other rare diseases. He seemed very engaged and interested in our stories.

How You Can Get Involved

If you are interested in getting involved in advocating for the Huntington disease community, the **Provincial Rare Action Group (PRAG)** is seeking volunteers and would greatly benefit from more representatives.

Learn more by contacting
provincialactiongroup@gmail.com

or check out their **Facebook group**:
<https://m.facebook.com/groups/1932087307635065>



Kathy Thauberger: My mom, my hero who wears a Huntington's cape

| By Jennifer Judge

My mom was born in 1963, the eldest of three children with two younger brothers. When her parents divorced, she chose to live with her dad. He was her hero - generous, positive, and accepting of everyone. Even on hard days, he lived life as if it were great, and he always had her back. That spirit shaped my mom deeply.

At sixteen, she dropped out of high school to follow her dream of becoming a hairstylist. Each day, she bussed an hour and a half each way to school, proving her determination. She became an exceptional stylist, known not just for her talent but also for the warmth she gave others, making her clients feel seen, cared for, and beautiful.

Not long after, tragedy struck when her middle brother died in a car accident. The loss was devastating, but like her father, she carried on with strength and resilience, always holding her family close to her heart.

As a mother, she was a fighter. She left an unhealthy marriage and, later, found true love with her perfect match, my stepdad, her very own Prince Patrick, who served in the Canadian Air Force. He provided the life, unwavering support, and stability our family needed. Together, they built a home filled with love, guidance, and encouragement. My mom poured herself into raising three children, always guided by his steadiness and care.

When my brother was diagnosed with autism, she became his fiercest advocate, driving him over an hour each way to therapy, determined to give him the best chance at success. She succeeded. When I struggled with mental illness, which was later understood to be connected to HD, she fought for me, too, making choices no mother should ever have to make. She succeeded again. My younger sister, the middle child, grew up strong under their guidance and became a psychologist, dedicating her life to helping children with autism. That strength came directly from my mom and the love, discipline, and support of my stepdad.

In 2016, Huntington disease entered our lives. My grandfather began falling and injuring himself, and my mom refused to accept not knowing why. She researched tirelessly, asked questions, and pushed for answers until a doctor finally diagnosed him with Huntington disease. **True to her proactive nature, she chose to get tested herself and learned she, too, was positive. I would later receive the same diagnosis, and today my mom and I share this journey together - an “adventure,” as we call it - with her as my greatest example of courage.**

My mom is now part of history. She became the **very first Canadian participant** in a groundbreaking gene-targeted therapy trial for Huntington disease.

Today, she is in the third stage of the trial. This has meant endless medical appointments, traumatic spinal taps, long hours in MRI machines, and countless blood draws.



She put down her scissors four years ago, finding her new purpose, saying this trial is now her full-time job. Even while facing cardiovascular challenges and the scare of a breast lump, she never wavered. Her focus has always been on this trial - not for herself alone, but for me, for our family, and for the rest of the world.

My mom's story is one of resilience, sacrifice, and love. She has shown me what it means to face Huntington disease with dignity and to transform struggle into hope. HD may have changed our path, but it cannot take away our strength, our bond, or our love for life. Because of her, I believe in a brighter future for all families facing Huntington disease.

And just like her dad, when she falls or drops something, she gets back up with a smile, and then says the words: “I feel great.”

I love you mom.

Jennifer Judge is a member of the Ottawa Chapter of the Huntington Society of Canada.

DATES FOR IN-PERSON COMMUNITY WALKS:

May 9

- Winnipeg, MB
- Belleville, ON
- Ottawa, ON

May 17

- Sarnia, ON

May 23

- Edmonton, AB
- Regina, SK
- St. John's, NL
- Grand Falls-Windsor, NL

May 24

- Fredericton, NB
- Bowmanville, ON
- Exeter, ON
- Vancouver, BC

May 30

- Saskatoon, SK
- Bonshaw, PEI
- Waterloo, ON

May 31

- London, ON

June 6

- Lafleche, SK
- Calgary, AB



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