

SPRING



ISSUE 166

HORIZON



Shelly Redman
CEO, HSC

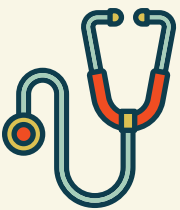
CEO COLUMN

50 years.

What an amazing legacy Ralph and Ariel Walker created from a single vision and a great deal of heart, along with so many other hardworking and caring individuals, families and supporters.

As part of this 50th milestone, we have launched our bold new campaign **ROUTE 50: Driving Hope Forward**. As part of this initiative we have set goals that we believe will truly help us to achieve **HSC's** mission: to improve the quality of life for those affected by Huntington disease.

Here's how we plan to deliver on our mission:



Expand support for all people in Canada affected by Huntington disease (HD) by enhancing social work services and support resources via our proposed Centres for HD CARE (Clinical And Research Excellence).



Support an endowed chair in Huntington disease research at Western University's Schulich School of Medicine & Dentistry. Every dollar raised up to 2.5 million will be matched by our generous partners at Western University.

Our 50th Anniversary campaign goal is to raise a minimum 3 million dollars to fund these exciting new initiatives in research and care – and we have already raised \$750,000 – that is amazing! If you would like to donate: **ONLINE** huntingtonsociety.ca/hsc50 **PHONE** 1-800-998-7398 Ext. 121 **MAIL** 20 Erb St W, Suite 801 Waterloo, ON N2L 1T2

To help achieve our campaign goals, we asked for volunteer solicitors and were overwhelmed by the response. We now have 13 members sitting on the volunteer fundraising cabinet chaired by Board Director Andrew Wright, working diligently to reach our goals.

Thank you to these amazing volunteers. I am overjoyed to be with the Huntington Society of Canada (HSC) as we celebrate this special milestone and I look forward to what the future holds. I am thankful to be sharing in these celebrations and passionate projects with you, our wonderful Huntington disease community. Thank you for joining us on the journey.

ARIEL VIEW

Can you believe it's the 50th anniversary of **HSC**?

When I think about those early days, one fundraiser comes to mind. Can you guess which one? It was the ten years of hosting increasingly elaborate garage sales at the original site of HSC, 136 Blair in Cambridge.

These garage sales became a not-to-be-missed tradition and were more than just a fundraiser. They provided camaraderie and human connection. Our friends helped us organize the event and the whole community pitched in by donating items, running the event, or purchasing goods. It was a great way to get to know people while also raising awareness for **HSC** and Huntington disease (HD).

We had reporters come out to interview Ralph, and the newspapers sent out photographers too. It seemed that everyone knew about our garage sales. In fact, one year the city bus driver for the route that went by the house stopped the bus right there. He announced to his passengers that he visited our garage sale every year and that he had to go take a quick look, holding up traffic as he did so. I believe he returned after his shift. That's just the way it was in a small town.

We first offered a garage sale in 1976. I remember the year because we went out west to meet families affected by HD in 1974 and out east for the same reason in 1975. That's how I tend to remember timelines, based on those formative trips. We

advertised by putting an ad in the paper, a notice in the church bulletins, a sign on the yard and via word of mouth. We used to get a fair amount of traffic passing by the house before they made a different thoroughfare so that helped reach a lot of people. The day of the garage sale was always quite



Ariel Walker
CO-FOUNDER, HSC

a social time. We'd have the coffee and donuts out and the neighbours would come over to visit. One neighbour was sitting in an easy chair for sale and had to get up because someone wanted to buy it. We had such a variety of goods to sell, from exercise equipment to games, and an extensive book section. The furniture

was quite wonderful – I remember an antique secretary-style desk going for \$600! Both of our kids worked every single garage sale, selling goods, and my mother, mother-in-law and Ralph's aunt worked hard making sandwiches and cookies to keep all of the volunteers going. Everyone came out and supported us. Even our cat Willie got involved, greeting everyone and testing out each chair for sale.

I hope this type of involvement continues in all of the communities across Canada. My advice is to do whatever is most comfortable for you and your community, and it will be successful along with bringing joy.



“ Dear **HSC**, My husband has HD and he needs more help to do the day-to-day stuff. He also refuses to accept help from anyone but me. I am feeling drained, overwhelmed and I don't know how long I can keep this up. Is this what caregiver burn-out is like? ”

Dear Spouse,

HD affects the family in many ways, and this could include burnout for family carers. We know that HD progresses, so it is important to start discussions early and to plan for the ever-changing symptoms and life transitions. Here are a few helpful hints to get you started:



TAKE CARE OF YOURSELF

Identify opportunities that “recharge your batteries” or “fill your cup.”

They will help you to stay both mentally and physically fit. These can be simple activities!

If you need inspiration, you can visit the **Huntington Society of Canada (HSC)** website and read our **Caring for Carers and Families With HD** Fact Sheet for suggestions:

hsc-link.com/caring-carers-families-hd



BE KIND TO YOURSELF

These are normal reactions to challenging circumstances.

Building a support team early on, including family, friends and health care workers can help. This support team can also help to break the isolation that carers experience. Join a support group, as talking to others may help to create a shared understanding and break isolation.

You can access information on current virtual and in-person support groups by connecting with your **Regional Family Services Team** member:

hsc-link.com/family-services-team



EDUCATE YOURSELF

HSC's website has a variety of information on HD and its progression.

You can also ask any questions you have to the members of the **Regional HD Clinic Team**:

hsc-link.com/hd-clinics-canada

Remember, in working towards your own wellness, you can be the best advocate and care provider that you can be for the person with HD in your life. These strategies can go a long way to help you to continue to feel hopeful and strong.

CHAPTER



HAPPENINGS

1. BC

The BC Chapter hosted their Annual General Meeting on September 29, 2022 as per gaming regulations. The chapter also lands as one of **HSC's** top 3 chapter sellers of Amaryllis nationwide.

2. ALBERTA

Congratulations to Mack Erno, **Peace Country Chapter**, for his successful climb of Mount Babcock in Tumbler Ridge, BC, as part of the Emperors Challenge. Mack has a history of setting personal challenges for himself in an effort to inspire donations for the annual Ride 4A Cure event in Grande Prairie. Mack and his two children raised nearly \$10,000 online as part of the overall 2022 Ride 4A Cure totals. The **Camrose Chapter** was also the recipient of funds from a lemonade stand hosted by a young relative of one of the chapter members.

A big thank you to the **Southern Alberta Chapter** for their hard work on this year's Amaryllis

campaign. The chapter remains the top seller nationwide with 133 cases sold!

Edmonton Chapter President Greg Taylor was able to meet with Annie during her visit to Alberta this past November to start plans for succession, as well as stronger youth engagement for the chapter.

3. SASKATCHEWAN

We are excited to welcome Morley Ellis as President of the **Saskatchewan Chapter** following the resignation of June Nichol in 2022. Morley's mother founded the chapter (as the Saskatoon Chapter), and Morley is looking forward to building on her legacy as he grows the efforts of the chapter throughout the province.

4. MANITOBA

The **Manitoba Chapter** hosted the 27th Annual Indy Go-Kart Race on September 11. Neat coincidence - the event raised over \$27,000!

The HD500 Snowmobile Ride, scheduled for February 10-11, features riders travelling more than 500 km on their snowmobiles over the weekend. This is one of our biggest events nationwide!



▲ A young relative of one of our **Camrose Chapter** members demonstrates great HD community spirit!



▲ Enjoying another wonderful **Winnipeg Indy!**

5. ONTARIO

The **London Chapter** hosted their first Indy Go-Kart Challenge in at least 7 years on September 18. It was great to welcome back this spirited event!

The **Barrie Chapter**, who received official status designation the same week that the pandemic struck in 2020, hosted a social gathering on September 24 as part of their strategy to re-engage and rebuild post-pandemic. The event was hosted at a local pub and had a great turnout, including one new family. We are excited for what comes next for the area.

In September, the **Niagara Chapter** and **Peterborough Chapter** each hosted their golf tournaments. The combined fundraising total of both

tournaments is over \$15,000. Speaking of the **Niagara Chapter**, the group also hosted a bottle drive on January 21 and collected empties around the region.

The **Toronto Chapter's** New Year social took place on January 14. The group had a great turnout with lots of new faces present, and the event provided an

opportunity to discuss upcoming events and initiatives for 2023. Speaking of new faces, the chapter recently welcomed Lena Premack to their executive as Social Media Coordinator.

We are happy to report that Bunny Clark has returned as President of the **Durham Region Chapter** after a brief hiatus and is working on plans for the annual Walk to Cure event in Bowmanville.

The **25th Annual Trap Shoot for Huntington disease** took place Saturday October 22, 2022 at the Rondeau Rod and Gun Club in Chatham. 25 years is a momentous milestone and we wanted to highlight the deeply positive impact it has

had, led by a wonderful volunteer, Dave Ulch.

6. ATLANTIC CANADA

Volunteers and community members gathered on a cool but wonderful day for the Coachman's Cove Walk in western Newfoundland on August 20. Volunteers are thrilled to report that online fundraising alone increased about \$1600 over last year.

With support from a former BC Chapter President, the **Newfoundland Chapter** attended a volunteer fair at Memorial University in January.

▼ Celebrating the **25th Annual Trap Shoot for Huntington disease**



The group has a number of great ideas for rebuilding this chapter.

The **PEI Chapter** had impressive growth in their Amaryllis sales this year, with Sharon Moyse selling 31 cases – awesome!

PRESIDENTS GATHERING

We were excited to welcome Chapter Presidents to **Toronto** on February 10-12 for a weekend of training and strengthening our work in local communities. As part of the agenda, attendees had an opportunity to participate in an open discussion with **HSC's** CEO, Shelly Redman, as well as to learn about a variety of topics from our staff team including budget, sponsorship strategies, media relations, and event and succession planning.



▲ So happy that the **London Indy** is back!

▼ **RILEY & ERIK** attend their first YPAHD Day in **Calgary**



YPAHD



DAY

On November 26, we were thrilled to be able to host our first in-person national event of the year, with 48 youth attending Young People Affected by HD (YPAHD) Day in **Calgary** and **Toronto**.

We interviewed two participants who were first-time attendees to get their impressions on the gathering and the community.



▲ **PARKER & JUDE** at Toronto's YPAHD Day

Jude Levesque, AGE 30
LONDON, ONTARIO

"My best friend is a member of the Huntington disease community, and I wanted to come with him to this event to learn more about the disease itself and the community it surrounds. Some of my favourite aspects were meeting the very tight-knit community who were nothing but kind and welcoming to me from the moment I arrived. I enjoyed the very thorough presentations that explained the disease and its effect on families/friends, as well as within the community itself. I found it very helpful and quite informative.

One of the biggest things I took away was the possible time from showing symptoms to the date of death. Within this group, those who shared their experiences noted a lifespan of 10 to 15 years after being diagnosed and showing symptoms. I could not believe how fast it started to form in these specific family cases. It's hard to hear but makes the need for a supportive community all the more compelling."

"I attended YPAHD Day to be part of the **Huntington disease (HD)** community. It's important to hear from others in a similar situation so I can learn from them and see where I can help in the larger community. My favourite part of YPAHD Day was the welcoming, energetic people who also attended. I was nervous when I first signed up, but after getting to know everyone that anxiety washed away and I was able to fully enjoy the experience. It was neat how the event felt like a weekend retreat, with no distractions, just deep internal work.

One key point I learned was that everyone affected by HD has a different experience, but they all support and give really good advice despite everyone going through a hard thing. My brother Riley also attended. He's on the left in this photo and I'm on the right."

Erik Barrett, AGE 20
CALGARY, ALBERTA

▼ **Our Calgary YPAHD Day crew**



Thank you Erik & Jude for sharing your experiences.

We hope you continue to participate in YPAHD and **HSC** initiatives. You're part of the family, now!



▲ **YPAHD Day attendees in Toronto**

WHAT TO **WATCH**, **READ** & **DO**

There's so much happening in the **HSC** universe.



WATCH

Every single National Virtual Conference session from November 2022 is available for viewing on our YouTube channel:



youtube.com/@huntsoccanada



READ

Check out some of our recently updated fact sheets on the website:

🔗 [Caring for Carers and Families With HD](https://hsc-link.com/caring-carers-families-hd)
hsc-link.com/caring-carers-families-hd

🔗 [End-of-Life Care for People with HD](https://hsc-link.com/eol-care-people-hd)
hsc-link.com/eol-care-people-hd

🔗 [End-of-Life Options for People with HD](https://hsc-link.com/end-life-options-people-hd)
hsc-link.com/end-life-options-people-hd

🔗 [We Are Here to Help - Fact Sheet](https://hsc-link.com/help-fact-sheet)
hsc-link.com/help-fact-sheet

🔗 [Juvenile HD - Fact Sheet](https://hsc-link.com/juvenile-hd-fact-sheet)
hsc-link.com/juvenile-hd-fact-sheet

🔗 [Genetic Testing and HD - Fact Sheet](https://hsc-link.com/genetic-testing-hd-fact-sheet)
hsc-link.com/genetic-testing-hd-fact-sheet

🔗 [Interested in Clinical Trials?](https://hsc-link.com/interested-clinical-trials)
hsc-link.com/interested-clinical-trials



DO

MARCH 1

Registration opens for the National Walk
hsc-link.com/2023-national-walk



MAY 23

Registration opens for the National Conference in Niagara Falls, Nov. 17-18
hsc-link.com/2023-national-conference



MAY

Huntington Disease Awareness Month, featuring LightItUp4HD and the National Walk
hsc-link.com/2023-light-it-up-4-hd



MAY 27 - 28

National Virtual Walk weekend – if you are walking in your own community, walk on this weekend with all of us across the country!

NEW FAMILY SERVICES
TEAM MEMBERS



We're pleased to introduce you to some of the new staff members on our Family Services team.



Maryam
Chamani Fard
RESOURCE CENTRE
DIRECTOR (RCD)

not an area of study that appears on most social workers' CVs, but it makes for a wonderfully diverse background. It was while pregnant that Maryam decided to follow her lifelong passion for helping others. She went back to school to pursue a degree in Social Work, describing how throughout her life she has always been motivated to give back whenever and wherever possible.

Since her career change, Maryam has worked within a variety of community and court settings and has provided support to both youth and adults. Maryam has also facilitated support groups and educational sessions on a variety of topics related to immigration and family violence.

"My practice is very client-centred and trauma-

On July 4, HSC welcomed Maryam Chamani Fard, registered social worker, as the new Resource Centre Director (RCD) in **Southern ALBERTA**, covering the area south of Red Deer and Red Deer itself.

Maryam has a Master's degree in Agricultural and Environmental Economics – maybe

informed," says Maryam. "I decided to take the role at **HSC** because from the very first interview I knew that the organization shared this philosophy of social work. HSC's goals of advocating for the community to receive required services and support also really resonated with me."

Maryam sings the praises of the entire Family Services team, and the support offered even though all members are in different geographic locations, calling such connection crucial for the internal network as well as the broader audience.

This newsletter article provides Maryam with an opportunity to share a message with the Huntington disease (HD) community. "My message for everyone is that I've seen how complex HD is, and how it manifests in different ways for every individual, family member and caregiver," she says. "It can be very lonely. Please reach out so that we can support you and understand the gaps. I advocate for every single person with their varying needs."

Maryam is deeply committed to the cause. In fact, she mentions that her job is very personal and spills over into her leisure time by choice. "I'm always educating myself – I find myself reading about trauma, HD and genetics in my spare time."

What does she do for a break? "Even though I'm relatively new to winter activities, I love them! I adore skating on the lake with my kids and then coming inside to do crafts."



Welcome to **HSC** and the HD community, Maryam!



Ana Paret
RESOURCE CENTRE
DIRECTOR (RCD)

Back in balmy April, Ana Paret became the Resource Centre Director (RCD) for **Southwestern ONTARIO**, including Kitchener-Waterloo, Guelph, Sarnia, London and Grey/Bruce regions.

Ana has had a varied career path; working in corporate administration services (specifically in accounting for the retail real estate sector) Ana didn't feel inspired by her work. Craving a deeper connection to clients, she started her own business offering career coaching and resume services. This led her to continuing her education at University of Waterloo where she gained an Honours BA in Social Development specializing in Social Action/Social Justice and Social Work. At this time, personally she found herself being a caregiver to her elderly parents, particularly her mom, who was diagnosed with Parkinson's disease. "As I navigated life as the primary caregiver, I found gaps in services and sought out resources, advocating for my parents' needs, and supporting them through their journey, which led me to continue my studies and develop my career as a social worker."

Ana has worked in the long-term care sector, for the Alzheimer Society of Waterloo Wellington as their First Link Coordinator/Rural Social Worker, and then for Home and Community Care Support Services as a Hospital Care Coordinator.

Ana has some specific goals for her role at **HSC**, including:

- Offering education sessions to long-term care homes and community partners, such as local police officers or lawyers, to build awareness of HD. CMHA has also shown interest in partnering with us to learn more about HD.
- Advocating for the voices that are not heard or understood. With HD being a rare disease, not many people are aware of its complexities. Education and knowledge sharing can deliver clarity and understanding.
- Collaborating with community partners to develop complementary ways to support mutual clients. For example, working with the local hospice to develop a workshop series on a topic such as complex grief.

Throughout all of her work, Ana values meeting her clients where they are. "Sometimes the most important service I can offer is to hold space with them until they are ready to move into the next step of their journey."

In terms of her personal life, Ana is loving and creative. She recently visited Italy and became an aficionado on all things tiramisu. Ana is also a mixed media artist and had one of her pieces featured in her local art museum in Kitchener, where it was purchased by a collector! She loves to knit scarves and finds Zentangling a fun and relaxing way to de-stress. Ana also has a message for the community:



"In the midst of the most challenging of journeys, hope can be found, although it may not be in the way we expect it. Reach for those moments of hope. I want you to ask questions, advocate and build knowledge about HD. Get support - you don't have to be alone or isolated. Make connections through our support groups and community. (hand over heart) I am honoured to walk alongside you in your journey. I am here for you, please reach out."



Muna Young
**RESOURCE CENTRE
DIRECTOR (RCD)**

Muna Young, Resource Centre Director (RCD) for **Central ONTARIO**, will be marking her one-year anniversary with HSC just as the organization celebrates its 50th.

Muna is a registered social worker and has a Bachelor's degree in Social Work, along with 18 years of experience in addictions, child protection and adoptions. She has worked with a variety of individuals in multi-disciplinary settings including those involving children, youth, couples and families. "A constant theme in my experience has been working with families – my passion," Muna notes. "That's a good crossover with the Huntington disease (HD) community, but at the same time,

every family is different. It's not one size fits all." Muna has also facilitated many support groups and educational sessions on many different topics.

Muna whole-heartedly believes being a helping professional is her distinct privilege. "I really enjoy following the care of people long term, and supporting them in their most intimate moments," she says. "I'm here to meet those affected by HD when they are vulnerable and need me the most."

Muna found out about the role at HSC through a good friend, who thought it would be a perfect fit – and she was right. "The whole experience of working with individuals and families facing HD has been enlightening and inspiring," she says. "It's an isolating disease, and I want every single person to know that they are worthy of support – at-risk, gene negative, caregiver – everyone."

Outside of her professional life, family is paramount to Muna. During her free time, Muna spends time with her children, and is especially fond of tobogganing in the winter and being by the water in the summer. She also confesses to relying on UberEats (we're with you on that one, Muna).

Living in Niagara Falls, Muna is particularly excited about HSC's upcoming National Conference in November. "I can't wait to share the beauty of this amazing place in person."



WHAT TO EXPECT SUPPORT



FROM A VIRTUAL GROUP

Now that **HSC** has expanded offerings to include virtual support groups, we wanted to provide some insight on how they work.

WHAT ARE VIRTUAL SUPPORT GROUPS?

Virtual support groups consist of a small number of people, usually capped at eight, who meet regularly (often once or twice a month) with one or two of **HSC's** Family Services Team members via Microsoft Teams, an online meeting platform. The facilitators offer presentations and guide discussions, while participants can share their experiences and ask questions.

The purpose of the support groups – indeed, the benefits of attending one – are to provide a social and supportive setting where participants can build connections and talk about issues specific to Huntington disease (HD). "The groups are client-focused, open-minded and non-judgmental," says Corrina Masson, Family Services Worker with **HSC**. "We make the group what the participants want it to be."

HOW TO GET INVOLVED WITH A SUPPORT GROUP

The Family Services team conducts a phone call with each person interested in the virtual group to ensure that it will work for them. It provides a soft entry to the process. It also helps with understanding what is required to participate, for example, a computer, tablet or cell phone with a camera and a microphone, internet access, and a private room from which to participate to preserve the confidentiality of the group.

HOW DO THEY WORK?

Groups are based on a common theme, such as a group for caregivers in a certain geographic region. Other offerings might include a national group for parents, or for individuals at risk or positive for the gene mutation that leads to the progression of HD. Interested participants can contact their local Resource Centre Director (RCD) to find out if there are any virtual support groups taking place that meet their needs. The full list of Family Services team members is here: hsc-link.com/family-services-team. If you are not yet connected with Family Services, you can use this confidential form and a member of the team will get back to you: hsc-link.com/contact-form.

Co-facilitators often run the groups in tandem, which is helpful if one RCD is leading the discussion while another is available to offer support on topics from tech challenges to emotional reactions. Having a co-facilitator is also helpful if a participant in the caregiver group, for example, needs a few moments with the camera and microphone off to attend to a matter or if they need to leave altogether. The second facilitator can check to make sure that everything is okay.

RCDs are still available for 1:1 needs and other matters.

Happy one-year anniversary, Muna – we'll see you in Niagara Falls.

WHAT ARE THE BENEFITS?

In terms of content, the support groups provide insight into other people’s experiences. Members and leaders suggest ideas and tools that others can implement. Although HD is unique in how it presents, at the same time, being able to talk to others in a similar situation can provide a tangible sense of relief in being able to share, especially because some scenarios are certainly common to people affected by HD.

Another benefit is that groups tailored to carers differ from clinics, which focus on the individual with HD. Caregiver support groups are designed to meet the needs of the carers, with the intent to recognize that this is a family disease.

“The longevity of HD can be wearing for a caregiver,” says Rozi Andrejas, RCD for Toronto and area. “It is important to recognize what burnout, components of self-care, and anticipatory grief look like. Carers might need treatment assistance from a professional. It’s okay to seek support.”

There also tends to be variety in the groups, both in terms of what comes to the surface as well as life stage. Groups are there to support families for whom HD is a new diagnosis as well as to hold space for those who have been living with the disease for a while. There are no costs, only a time commitment from the comforts of your home, encouraging everyone to try a virtual group as a means of broadening your support network.

“We hear gratitude and appreciation from the new families for the support from others who have been where they are,” says Rozi. “It means a lot to facilitators and group members alike to give back in a positive way and provide meaning to the journey.”

SECRETS TO SUCCESS FOR SUPPORT GROUPS

It takes a bit of time to achieve a group that is comfortable talking about the issues and emotions associated with HD, but that comfort definitely becomes established and is one of the highlights of the experience.

“There can be an apprehensive energy when the group first meets, especially because members are talking to people they’ve never met,” says Corrina. “But then the engagement really starts to help with the loneliness that can be associated with HD. There aren’t always a lot of opportunities to have this kind of discussion in everyday life.”

Corrina mentions that there are some ground rules for successful and supportive groups. Members agree on the importance of:

- Being kind and respectful
- Waiting their turn to speak
- Gently providing space
- Listening to others
- Providing support and not judgement
- Maintaining privacy and confidentiality

Having an open-minded approach to topics that do or don’t gain traction, and allowing the conversation to flow and the group to evolve, are key aspects for both facilitators and members to embrace. The result is a group that is cohesive and caring.

A CARER’S PERSPECTIVE

Greg Taylor from Edmonton has been participating in **HSC** support groups since the late 80’s and mid-90’s, when they were in person. Greg is caregiver to his wife, who has HD, along with two of her siblings. His wife’s mother had HD, as did four out five of her siblings, so Greg and his wife witnessed caregiving for that generation as well. “I really enjoyed the in-person groups, and I hope that is an option one day. Yet, on the other hand, the virtual format has allowed the group to open up to all of Alberta, whereas before we only drew from the Edmonton area,” says Greg. “Plus, saving travel and time away makes participating possible. Caregiving is difficult, but I can usually join the virtual group and be at home as needed.”

Greg mentions how helpful it is to talk to others in the same situation, noting that if he can help anyone else by sharing ideas, there is a feeling of satisfaction. “I would say that talking to others who are dealing with HD, like you, can help to reduce anxiety. The psychological effects on a person affected by HD can wear down the caregiver. Many of the topics we discuss in the group deal with helping to support your relationship with your loved one who is affected by HD. I find the emotional aspects tend to be the hardest for caregivers to deal with - their loved one’s frustration and anger coupled with the rapid swings in emotions.” Greg encourages anyone considering a virtual support group to just try it. “Some people, especially those new to HD, are looking for a silver bullet. It has yet to be found. I’ve been around HD since the 1980’s and I continue to search for answers. There are tools and programs available to help. The best coping strategies I’ve gleaned are from the individual caregivers in the HD support groups. Test the waters – the virtual support group might not be the right fit today but it could be in the future.”

A PARENT’S PERSPECTIVE

Jennifer Hawn joined the pilot of the virtual support group for parents of children with symptomatic HD. “It was important to me that this support group addressed my very specific situation – being a caregiver to my daughter, who is in her 20’s, and who has Juvenile HD,” says Jennifer. “The virtual format was extremely important. I simply could not have participated if it was in person because at the time I was caring for my daughter 24/7, working full-time remotely, and also raising my daughter’s daughter.” Jennifer’s daughter is now in a long-term care home, and discussing that process with the group was very helpful for Jennifer. “I think it made some other participants more aware of the situation, and how soon they’d need to research options and get on waiting lists,” Jennifer says. “I definitely learned some new things as well. Participants were great to offer ideas about who to reach out to.”

Jennifer says that the specific nature of the group helped her not to feel so alone as a caregiver. She recommends it to anyone considering participating, noting that the shared experiences of the group can make discussing tough topics, like moving to long-term care, less scary. She also wants people to know that the facilitators of the virtual meetings excelled at helping participants to join the online platform as well as troubleshooting any issues that came up along the way. “Not everyone is comfortable speaking, but listening is beneficial, too – there’s no pressure to contribute. However, it does seem that opening up and sharing stories is therapeutic,” says Jennifer. “We enjoyed the presentations, but really what the group most liked was being able to talk, ask questions of each other, and support everyone.”

NEXT STEPS

If you are interested in learning more about a virtual support group that is right for you, please contact your local Family Services team member by referring to this list: hsc-link.com/family-services-team or filling out this form hsc-link.com/contact-form.

Help is here, and the HD community is strong.

▼ **MEGAN** & her mom **JENNIFER**. Jennifer participated in the National Parenting support group



▲ **MEGAN** & her daughter **NYOMI**

COMMUNITY



MESSAGE



Alexander Maxan,
PhD
HSC RESEARCH LEAD

Dear members of the Huntington disease (HD) community,

As I continue my first year as Research Lead for **HSC**, I am eager to share with you the strides we at **HSC** have taken to assist the HD community across Canada on the research front.

While we have certainly made some progress in our understanding of this devastating disease, and the development of potential treatments, I must admit that the news was not all positive. As you probably know, several clinical trials have been discontinued over the last year. Despite this, we continue to remain optimistic and remind ourselves that even in discontinuation we learn more about these potential treatments and why they might not have worked. All data is useful. That being said, we remain deeply committed to supporting research in an attempt to develop treatments for HD. We are fortunate to have a talented and dedicated community of researchers, clinicians, and patients who are working tirelessly to achieve this goal.

Along with guidance from our volunteer Research Council, I have been working hard to support research efforts through our NAVIGATOR and Clinical Fellowship programs. The Navigator awards support research scientists across the country, while the Clinical Fellowship award aims to address the shortage of neurologists treating HD patients across the country. I have also been attending research conferences and webinars to stay as up-to-date as possible on research efforts around the world. I am then able to share these developments with community members at events such as conference, YPAHD day, and our virtual support groups.

HSC's Research Council consists of leading HD research scientists with expertise in various areas of investigation who volunteer their time and expertise to aid our organization. They help analyze and prepare recommendations about applications received to our NAVIGATOR research program, and provide advice on how we approach all new HD-related developments. And so, for all of the time and effort they have put into assisting **HSC** in our research endeavors over the past year, I would like to issue a very special thank you to our current council volunteers: **Dr. Mahmoud Pouladi** (University of British Columbia), **Dr. Rachel Harding** (University of Toronto), **Dr. Tam Maiuri** (McMaster University) and **Dr. Tiago Mestre** (University of Ottawa).

I know that the journey towards treatment developments can be a difficult and uncertain one, and I want to express my sincere gratitude to each and every one of you for your perseverance and commitment to this cause. Your dedication is truly inspiring, and it gives me hope for the future. But we must also remember that we are not alone in our journey. As a community, it is important that we continue to lean on each other for support through the tough times, to keep our heads held high, and our eyes bright and full of wonder.

Even though it may not always seem that way, every step we take is a step in the right direction.

Together, we can make a difference.

While the road ahead may be long and challenging, I am confident that by working together, we will ultimately be able to make a real difference in the lives and futures of those affected by Huntington disease. Thank you all for your support thus far. This is a commitment we will take on together.

Dr
Mahmoud
Pouladi
HSC
RESEARCH
COUNCIL

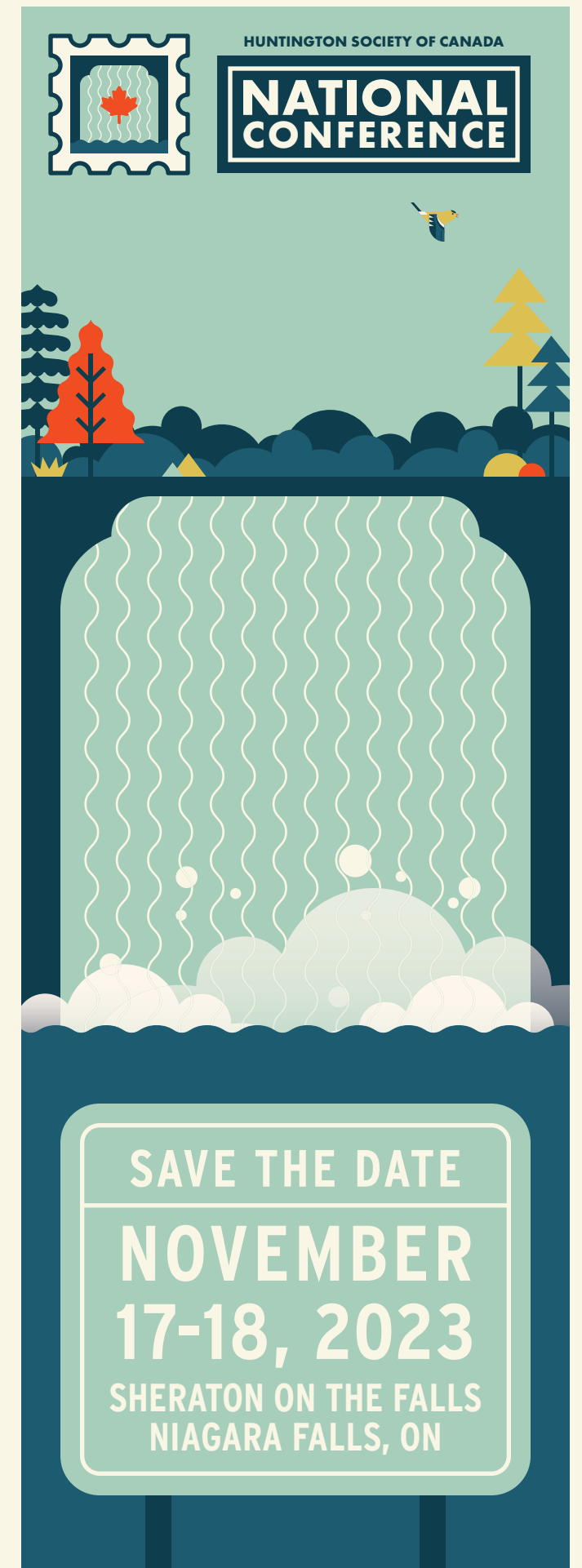


Dr
Rachel
Harding
HSC
RESEARCH
COUNCIL

Dr
Tam
Maiuri
HSC
RESEARCH
COUNCIL



Dr
Tiago
Mestre
HSC
RESEARCH
COUNCIL



HUNTINGTON SOCIETY OF CANADA NATIONAL AWARD RECIPIENTS



We were excited to present the National Awards at our National Virtual Conference November 12-13, 2022. Our recipients shared some words of thanks via video and **HSC** representatives across the country presented their awards in person.

ARIEL & RALPH WALKER FOUNDERS' AWARD

Dr. Mark Guttman

BRIGHTER FUTURES AWARD

Mackenzie Remillard

DEAN CRAIN MEMORIAL AWARD

Peterborough Chapter

Rob Laycock

Southern Alberta

Hope Run Committee

DOROTHEA SMITH & STAN EDWARDS AWARD

Valerie Nabb

June Nichol

MICHAEL WRIGHT COMMUNITY LEADERSHIP AWARD

Mack Erno

MILESTONE COMMUNICATIONS AWARD

Barrie, ON Chapter

MILESTONE FUNDRAISING AWARD

Manitoba Chapter

NATIONAL AWARD OF MERIT

CORPORATE

Dream Casters Edmonton

VOLUNTEER

Sharon & Chuck Gera

Glenn Groves is the definition of commitment. Laid up in hospital with the long-term effects of Covid and pre-existing lung disease, the long-time Ingersoll resident nonetheless sold 12 cases of Amaryllis.

Sadly, his own health struggles were not the greatest challenge he faced last Amaryllis season. Glenn's wife Donna passed away this past December, 29 years after being diagnosed with Huntington disease (HD).

The family knew nothing about HD before the diagnosis. Corey Janke, **HSC's** current National Social Worker and then social worker for the region, encouraged them to join the London Chapter. Glenn has fond memories of the Indy Go Kart and is tickled that Jacki Skinner brought the event back in 2022. Glenn even served as President for 7 years, and Donna attended meetings as well, until she progressed further with HD.

Glenn's real passion has always been for the Amaryllis campaign, claiming it was a commitment he could honour even as shift work made other chapter initiatives challenging. "The Amaryllis campaign was something I needed to get involved in, and to make others aware of," says Glenn. "I am passionate about getting funds to Family Services and research – wherever the dollars need to go, and I just hope that other families can be supportive."

This year, as Glenn lay in hospital, his 12 cases of Amaryllis were at his home. Glenn praises his community choir for their amazing support.

Before he took ill, he gave a presentation about HD to the Rotary Club and the choir. "It was very well-received," he says.

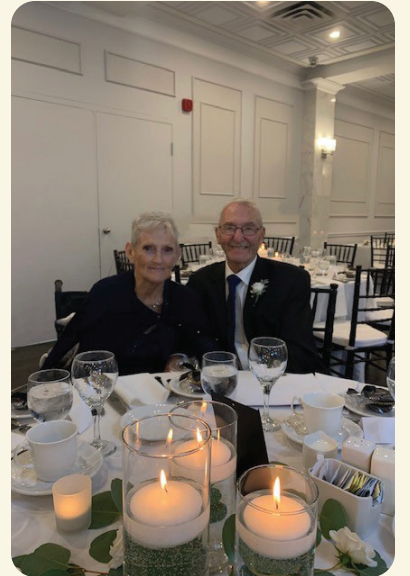
Glenn has been a member of the choir for 10 years, so he says that most are well aware of HD, but he wanted to make sure that the new members understood the reason for his passion. Staff at the Ingersoll Services for Seniors, where Donna's PSWs worked, were also very generous in ordering.



With the help of Glenn's son Darcy, a fellow choir member collected the orders and money for Glenn and brought the Amaryllis to the choir's Christmas concert for distribution. Glenn contacted friends to sell the remaining bulbs and Darcy helped deliver those, as well. It's a family labour of love. "Donna is gone but the journey hasn't ended," says Glenn.

"I have two sons and four grandkids. We go on the best we can." His message to the community? "Make it a day-by-day journey. Take advantage of the support that **HSC** can provide."

Glenn provides a final beautiful thought.



▲ **DONNA & GLENN GROVES**
in September 2022 at their
granddaughter's wedding, two
months before Donna passed and
just before Glenn went into hospital

"Here in the hospital I look at the pictures my son sends me of my Amaryllis blooming at home, and it really does inspire me. It makes me hopeful. That's what we have – hope."

A WALK THROUGH TIME

Since its inception, the **Huntington Society of Canada** has always been an organization with volunteers at the forefront. So it should come as no surprise that volunteers have inspired some of **HSC's** most impactful fundraising campaigns and events.

THE DREAM OF ONE VOLUNTEER

One of the biggest fundraisers that volunteers support annually is the National Walk, and it all started with one volunteer in Corner Brook, NL.

Doreen Janes first joined the organization as a volunteer in the late 1970s. She continuously planned fundraising events and made big waves across the society with her infectious spirit and drive to volunteer and give back. For years, every edition of Horizon had some mention of Doreen and her tremendous contributions. On June 13th, 1982, Doreen held a run-a-thon and raised \$622. Little did she know that this would be the first run of many that would take place in the decades to come.

THE TREND CATCHES ON

There were a couple of volunteers and chapters in the first few years who caught on to Corner Brook's success and began planning walks of their own.

Beatrice Gray launched an annual walk across Cumberland County, NS that grew in distance and participation as the years went on. There were also a few other early adopters in Nipissing, ON and Bonne Bay, NL.



▲ 2014 TUMBLER RIDGE, BC Walk

But it wasn't until the early 2000s that the idea of a fundraising walk really gained traction. From coast to coast, volunteers began to plan walks for **HSC** and it became clear that walks were here to stay. As efforts grew, HSC began branding the walks as a way to create consistency across the country and the Huntington Heroes theme emerged. This theme celebrates the everyday heroes amongst us who fearlessly face Huntington disease every day.

THE BIRTH OF THE NATIONAL VIRTUAL WALK

Today, we still champion the Huntington Heroes theme as we organize fundraising



▼ 2011 SASKATOON Walk



▲ 2014 OTTAWA, ON Race Weekend



▲ 2014 NEW BRUNSWICK Gathering & Walk

of the National Virtual Walk upon us, community members can also walk in their own areas but as part of a collective national team. This is a bonus for those in remote communities without a nearby walk event, allowing them to participate and make a difference from their own communities. The impact these events have is remarkable. Since 2010, **HSC's** walks have been some of the biggest revenue generators in the organization.

THE 2023 NATIONAL WALK

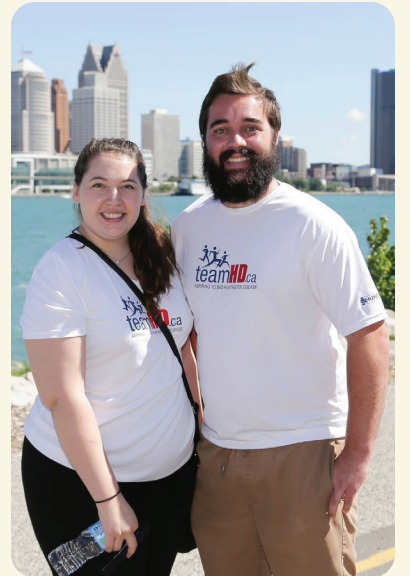
The National Walk is heading into its third year and promises to be another amazing opportunity to connect hundreds of individuals across the country and raise much-needed funds for research and support services for those affected by Huntington disease.

We hope to have more participants than ever this year and the years to follow.

If you'd like to get involved, May is Awareness Month for Huntington disease and the National Walk is a major highlight. Local walks take place throughout the month, culminating in a virtual walk with everyone walking together on the same weekend, May 27-28, across the country.



It's amazing to see what an incredible impact one individual and a great idea can have! From a single volunteer in Corner Brook, NL to a nationally led and championed effort by hundreds of volunteers across Canada, we can truly say that every action, big and small, has a huge impact.



▲ 2017 WINDSOR, ON Walk



REGISTER AT

🔗 hsc-link.com/2023-national-walk

DONATION



DOLLARS

2022 was a wonderful year for donation dollars and we are truly grateful for everyone who contributed.

We saw 1624 new donors join our community from January 1 to December 31, 2022 – thank you! We had 331 amazing unique monthly donors and their giving increased by 6.78% - this fabulous consistent commitment allows us to plan for continuous delivery of services.

Thank you to everyone who contributed! In 2022 we had...

1624

NEW DONORS Join Our Community

331

Amazing Unique **MONTHLY DONORS**

6.78%

Increase In **GIVING**

Interested in learning about Legacy Giving and Estate Planning? Check out the presentation on the topic from our National Virtual Conference on our YouTube channel here:



youtube.com/watch?v=u9t2Y5m_ZBU

NEW WAYS TO CONTACT OUR FAMILY SERVICE TEAM

Are you looking for support
resources or information on
Huntington disease (HD)?

HUNTINGTON
Société Huntington du Canada

CONTACT ME

Thank you for reaching out to the Huntington Society of Canada. In order to best answer your questions, please complete the following information and a member of our Family Services team will get back to you.

First Name *

Last Name *

Gender *

Choose... v

Date of Birth (YYYY-MM-DD) *

ONLINE

hsc-link.com/contact-form

PHONE

1-800-998-7398

hsc-link.com/family-services-team

LOOKING FOR UP-TO-DATE INFORMATION?

For the latest on Huntington disease
research, support services, education
and events, sign up now for our
e-mails.

hsc-link.com/sign-up-newsletter

Choose your topics – you'll only
receive news YOU can use. Sign up
now and don't miss another update.

ROUTE 50
DRIVING HOPE FORWARD



HUNTINGTON SOCIETY OF CANADA
50TH ANNIVERSARY

MEET



MARNIE



Marnie Engel
HSC'S VOLUNTEER
SPECIALIST

Marnie Engel, **HSC**'s new Volunteer Specialist dedicated to supporting the community, explains that the spirit of volunteerism is in her blood, having grown up in a family very involved in Rotary Club.

"Volunteering was very much a part of my family culture, and I'm thrilled to continue my work in the field," Marnie says. "Since I started with **HSC** in early September, my focus has been on supporting and strengthening the recruitment, screening, training and recognition of volunteers going forward."

Marnie joins the Development team with eight years of experience coordinating volunteers with Hospice Niagara, where she contributed to growth and worked towards accreditation of the volunteer program, as well as training volunteers to support individuals in challenging times and circumstances of life.

Marnie will apply this experience to structuring the **HSC** volunteer programs. Marnie will create a framework for the volunteer program, including policies and procedures on risk assessment, code of conduct and confidentiality.

"I'm in the process of building the foundations with these pieces," Marnie explains. "I am also available to help Chapters access volunteers in the community, and use creative ways to find new help via students or volunteer resource centres."

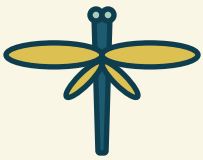
Marnie is a mom to two teenage sons, and the wife of a chef – making the oft-heard refrain "what's for dinner?" one of her favourites, filled with possibility. Marnie looks forward to sharing her passion for people and her skills in connection as furthers **HSC**'s commitment to supporting volunteers nationwide.

Her message for the community?

"Quite simply, we're invested in you."

Welcome to **HSC**, Marnie!

VOLUNTEER



SPOTLIGHT



Taylor Crain
HSC VOLUNTEER

You may remember Taylor's father, Dean Crain, as a force to be reckoned with in the Huntington disease (HD) community.

Now Taylor is making a difference in his own way. A graphic designer by trade, Taylor started volunteering for **HSC** for the LightItUp4HD campaign in early 2022, designing a new logo and providing other graphic design help.

Since then, he has also worked on the design elements for YPAHD Day, as well as the program for the National Virtual Conference in fall 2022, volunteering his time for a cause close to his heart.

"I wanted to volunteer for HSC, but at first I wasn't sure what to do," Taylor says. "Then I realized that I have a unique skill that I enjoy doing, and I know that there

are usually many more design needs than a non-profit organization has time or budget for, so I got in touch to see if I could help."

It's a generous offer from a busy designer; Taylor works full-time in Vancouver for the modern furniture e-commerce site Article and has his own freelance business. Born in Richmond, B.C., he obtained a Visual Arts degree with a major in photography from UBC Okanagan in Kelowna and then received a graphic design diploma from Emily Carr University of Art and Design.

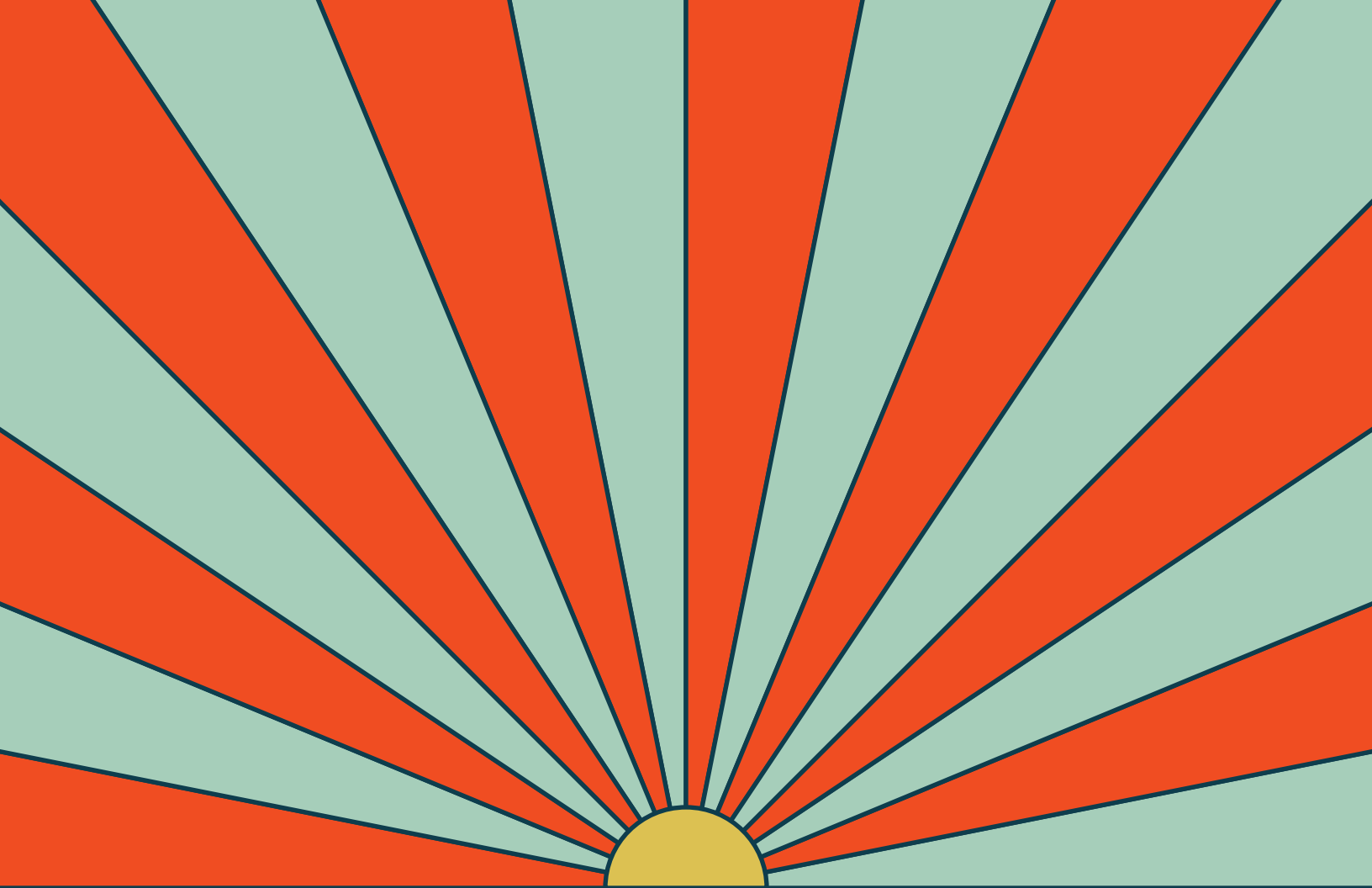
"I was quite young when my father was in the later stages of Huntington disease," says Taylor. "I couldn't fully comprehend what was going on. Now that I'm older, I've been learning more about tests and trials on the horizon – it's an exciting time. There were limited options when my dad was alive – these new possibilities would have been unfathomable to him."

Taylor says that he absolutely loves giving back in appreciation for all that the community and **HSC** does for those affected by HD. When asked what he would tell someone considering volunteering, he says, "Don't worry if the traditional volunteering roles don't seem to be a good fit for you. My dad used to be very involved in an HD running group, but I've followed my own path and now help design logos, graphics and publications for HSC. Think about what makes you unique – what you bring to the table – and it will work out."



▲ BELOVED COMMUNITY
MEMBER DEAN CRAIN
(top) & SON TAYLOR
CRAIN (bottom), circa 2001

Thank you for all that you do, Taylor.
We really appreciate your skills and willingness to help.



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