

HORIZON

RESEARCH • SERVICE • EDUCATION

No. 163

Spring 2021

Huntington Heroes National Virtual Walk Headlines Awareness Month

Spring is most definitely in the air, putting some pep in our step... and that's a good thing, because it's time to get excited about the National Virtual Walk! The event headlines May Awareness Month, which will be full of lots of other fun and informative initiatives, including Light It Up 4 HD.

It likely comes as no surprise that we couldn't count on being able to hold large, in-person events across the country because of COVID-19. "Because COVID" has become the reason for so many changes, the slogan should practically go on a T-shirt. But no – we have a much better T-shirt for you, and that's the one associated with the Huntington Heroes National Virtual Walk.

Once again this year we invite Canadians to register, fundraise and walk in their own neighbourhoods on May 29-30 as part of the Huntington Heroes National Virtual Walk. Sign up here: <https://p2p.onecause.com/hscnationalwalk>.

There are some local chapter events scheduled, that, although virtual, allow participants to walk as part of a team and take part in specific initiatives and activities. You can look for local events on the National Virtual Walk page. And if those days don't work for you, feel free to walk when convenient for you – that's the beauty and flexibility of a virtual event.

"Although pivoting away from large gatherings means fewer hugs, the decentralized approach allows people to participate no matter where they live," says Kelsey Laidlaw, Community Events Coordinator with Huntington Society of Canada. "There are still wonderful opportunities to connect with others from the Huntington disease (HD) community and raise broader awareness; these events just look slightly different."

Lesley Nantel, president of our Vancouver chapter, agrees. "With the 2020 virtual event, we were able to reach a lot of people that maybe wouldn't

have participated normally," she says. That included one woman from a small community in Northern B.C. Until she heard about the walk, she didn't realize anyone else in the province had HD.

At the National Office in 2020, our team pulled out all the stops to preserve as much of the energy and camaraderie of traditional walks and runs as possible. We provided lawn signs that folks decorated with streamers and balloons to raise awareness. We ran a costume contest looking for the best-dressed superhero. We shared warm-up and cool-down videos led by our amazing volunteers Natalie Marnica and Patsy Szabo.

Meanwhile, local chapters put their own stamp on things. In B.C., that included a 24-hour online auction, door prizes during a Facebook Live event, and a pre-recorded performance by Canadian country/rock band Taylor-Rae and the Backseat Drivers. "It was awesome," says Lesley. "Everybody was very adaptable and very creative."

All told, participants raised more than \$176,000 for HD research and family services in 2020 – a sum matched by an anonymous donor – and clocked a staggering 2,200 kilometres. Wow! Thank you to everyone who stood together by walking alone. As always, we owe this success to your hard work and generous support and hope that we can go even bigger and better with our 2021 offerings.

May Awareness Month and the Huntington Heroes National Virtual Walk accomplish so many goals. The funds raised from the National Virtual Walk go to support education, research and counselling. Awareness Month initiatives will reach out to inform, educate and engage with a wider audience than ever before, connecting them to the cause and the community. Light It Up 4 HD shows just how much spirit and hope the HD community has. We invite you to follow us on our social media



channels and sign up for our e-newsletters for the latest on all of these initiatives.

These are unique times. We're asking everyone to dig deep to once again find the energy, rekindle the spirit, and make May Awareness Month 2021 and the Huntington Heroes National Virtual Walk more enthusiastic, generous and beloved than ever before.

"With this organization and this community, it really is one big family," says Kelsey. "So whether we're walking alone or not, we're still all in this together." 🌍

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HORIZON

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

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

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

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

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Message from the CEO



Like organizations everywhere, the Huntington Society of Canada has been forced to change the way we operate because of the challenges of COVID-19. It's been truly amazing to see how our community has responded. People – from community members to donors – really stepped up, and it's because of your support that we have had a successful year. This engagement has made me really excited about what we can achieve. After learning so much from COVID-19, I'm incredibly hopeful for a strong and powerful year.

Our volunteers and staff have worked hard to pivot fundraising and educational events from in-person to online. We're learning as we go, but we've had some incredible successes. The upside of this shift is being able to reach more people than ever before, via initiatives such as our first-ever Virtual National Conference and the interactive, online platform we'll be using to bring you informative sessions, opportunities to reconnect, and a blissful absence of travel hassles. Plus, we are able to offer the conference for free, removing any financial hurdles. If you haven't signed up yet, be sure to do so at: <https://inevent.com/en/HuntingtonSocietyofCanada/HSCVirtualNationalConference/form.php>

We'll also be continuing with strong, impactful offerings with our National Virtual Walk – starring all of your Huntington Heroes – occurring on May 29-30. Why not sign up now at: <https://p2p.onecause.com/hscnationalwalk>. You'll be able to read more about these initiatives in separate articles in this issue.

Embracing new ways of doing things has been a constant theme for the past year and will also shape our new fiscal year, starting April 1. I think of it as a time to reset and start off on a strong footing moving forward. It truly is our time to shine with a positive outlook.

People can also continue to support the Society just by buying things they normally would through our new FlipGive campaign. (If you haven't signed up yet, you can read all about it further into the magazine.) Our Development team has even more projects in the works, so stay tuned.

To all the people that have supported us, I can't thank you enough. COVID-19 has been tough. Our team has done an incredible job providing much-needed support to our community despite the pandemic. In fact, working virtually has helped us serve people we couldn't reach with more traditional models.

When I joined the Society last summer, everyone told me how special this organization is. It really is true. I've seen so much resilience and hope and sense of community over these past months. Despite the pandemic, the future has never looked brighter. 🌟

Shelly Redman
CEO

Huntington Society of Canada



We're Social!



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HD BUZZ

Huntington disease research news. In plain language. Written by scientists. For the global HD community.

Visit hdbuzz.net to see what the buzz is all about!

VIRTUAL NATIONAL CONFERENCE



Virtual National Conference: HDCon21

David Bowie once famously sang about "Changes," and that's certainly been the theme of the past year. We had planned for our biennial National Conference to take place in November 2020 in Niagara, but because of COVID-19 restrictions, we had to make the challenging decision to cancel. That was tough, because we know how much everyone was looking forward to the National Conference; in fact, all 350 available conference spots had been claimed, and excitement was building. But in the fall, given governmental announcements that a second wave of the virus was in full swing, we couldn't reschedule. HSC simply couldn't support any mass in-person gatherings so far in advance.

But, as they say, when one door closes, another door opens. The realities brought about by the pandemic necessitated trying new things, embracing technology like never before, and going virtual. Our conference, HDCon21, is going online and into the homes of our HD community: a free conference, with no geographic hurdles, available to more participants than ever before.

Kicking off on Friday March 26 with a brief welcome session, HDCon21 continues on March 27 at 1 p.m. Eastern Time. Motivational speaker Chris Koch delivers the keynote

address to launch the speaker sessions for our Virtual National Conference. Despite being born without arms and legs, Chris grew up like any other small-town kid – playing road hockey, causing mischief at school, and helping out on his family farm. Neither he nor his family treated his disability like a tragedy, and instead used it to fuel his dreams. Chris loves sharing his story and spreading his message of: "If I Can..." An avid traveler, marathoner, and farmer, his presentation reflects his full life. Simply put, Koch says: "If I can do what I've done so far in my life, what's stopping others from doing the same?"

Other sessions, some from speakers near and dear to the community already, include:

- Genetic Fairness – Bev Heim-Meyers
- Easy But Difficult Accommodation in Cognitive Care – Jim Pollard
- Medical Assistance in Dying – Judith Wahl
- Navigating Relationships – YPAHD Panel
- HD Research Q&A – HDBuzz Panel, including Dr. Leora Fox, Prof. Ed Wild and Dr. Rachel Harding
- Forest Therapy – Ronna Schneberger

This stellar line-up is sure to make for a conference full of fascinating

information, compassionate discussion, and thoughtful ideas. And, for attendees who want to watch concurrent sessions, no longer do you have to try to be in two different places at one time. Sessions will be available to watch on-demand after the conference.

We also know that a big draw of our National Conference is reuniting with the community, making new friends, and re-connecting. Although the hugs will be virtual, there will still be plenty of time and opportunity to catch up during the social sessions in virtual chat rooms.

We're proud of what we've been able to accomplish, making our first ever Virtual National Conference an event that gives the HD community an opportunity to connect, learn and grow through this time of isolation. We're committed to exceeding expectations with the interactive experience and continuing to share experiences. We can't wait to join together once more as a community at HDCon21. Be sure to register for yourself at: <https://inevent.com/en/HuntingtonSocietyofCanada/HSCVirtualNationalConference/form.php>

THANK YOU!

Thank you to our sponsors for their generous support of the 2021 Virtual National Conference.





Q “I’m noticing there are a lot of Clinical Trials going on and I want to get tested. Where do I start?”

A The decision to be tested for the Huntington disease (HD) gene mutation is such an intensely personal choice. We would suggest first connecting with your local Huntington Society of Canada (HSC) Family Services (FS) team member. They can help connect you with a genetic counsellor to discuss whether predictive testing is right for you at this time in your life. A conversation with someone who is familiar with the process of predictive testing may bring forward choices and considerations new to you, and ensure that you are as fully informed as possible in making your decision.

Regarding clinical trials, if your motivation to be tested is to be able to participate in research, did you know that you don’t actually have to be tested for the HD gene mutation in order to participate? Observational studies like Enroll HD can keep your genetic status private while adding your information into the research database. Keep in mind that even if you do go for predictive testing, it will not guarantee that your profile will fit the criteria of studies or trials that are currently enrolling participants in your area. Your local FS team member can connect you with a research coordinator near you to provide more information on current studies and clinical trials. This information is also available on our national website here:

www.huntingtonsociety.ca/clinical-trial-locations/

The contributions of those who have participated in research toward HD treatments have been and continue to be a wonderful gift to the research community, while providing hope for families affected by HD. Each study brings us closer to a more promising future. Should you wish to proceed with the predictive testing process, you can contact your nearest FS team member here:

www.huntingtonsociety.ca/family-services-team-list/

Thank you for your questions! 🌱

HealthPartners Column

For this issue of *Horizon*, HealthPartners has shared a news release based on a national study concerning the effects of the pandemic, as follows. Although the statistics tell of a chronic disease shadow pandemic, the silver lining is that Canadians see health charities as ideal partners for collaborative solutions.

A national poll conducted in January 2021 found 66% of those with chronic disease and major illness have faced some level of difficulty in accessing care and treatment for their illness since the beginning of the pandemic. While diagnostic, screening and treatment delays are worsening Canadians’ physical health outcomes with chronic disease, data suggest that it is also deteriorating their mental health and that of their caregivers.

As a result, one in three (34%) have turned to support programs and services (outside the healthcare system) that they did not use prior to the pandemic and are relying more on intermediate services, like those offered by health charities as they await treatment. 64% said they are likely to access more health charities services even after the pandemic is over.

In response to the findings, Eileen Dooley, CEO of HealthPartners, says, “We know that 87% of Canadians are likely to be affected by one or more chronic diseases or major illnesses throughout their lifetime. The impact of COVID-19 on these Canadians – and their families and caregivers – cannot be understated. The threat of the virus itself, coupled with difficulties in accessing services, diagnoses, and supports – at the same time that health charities have seen major losses in funding – is contributing to significant challenges to Canadians living with chronic disease and their caregivers.”

“Canadians overwhelmingly see health charities as an ideal partner for a collaborative solution,” said David Coletto, CEO of Abacus Data. “Ninety-one per-cent of Canadians want to see the federal government work with health charities to help navigate and solve the immediate strains on the healthcare system caused by delays to treatments and services.”

HealthPartners and its member charities are calling on the government of Canada to ensure that Canadians living with chronic disease – and their caregivers – have the support they need during the crisis and beyond. The organisation is also calling upon Canadians to support those they love by supporting their #HealthChampionsCan initiative.

More information on the findings of the report, and the #HealthChampionsCan campaign and the public opinion research can be found online at: www.healthchampionscan.ca 🌱

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Charities At Work

YPAHD Column: Mackenzie Remillard



Mackenzie Remillard

Mackenzie Remillard of Niverville, Manitoba is just 20 years old, but he's already been an active member of the Huntington disease community for years. Currently the Youth Engagement Coordinator on the YPAHD Executive committee, Mackenzie has also been active in the Youth Mentoring Program as both a mentor and a mentee.

Mackenzie remembers vividly the 2014 HSC Conference in Winnipeg, where he attended both Youth Mentorship time slots. He knew then that he wanted to be a part of that program, and in 2019 took part in training in Toronto to become a Youth Mentor. He hasn't been matched with a mentee yet, but is ready to provide the support and compassion that has been offered to him by the Huntington community.

"YPAHD is such an amazing group," he reflects. "We only see each other once a year, at YPAHD Day or HSC's Conference, and yet we're so close and those events really help bring us all together. Whenever I encounter troubles, I have at least 20 people to reach out to for guidance."

That support was present in abundance when he joined the YPAHD executive in September 2020. Even though he's a fair bit younger than the rest of the members, they have welcomed Mackenzie with genuine warmth and respect. He feels like he's been a part of the team for a long time, noting that the other executive members are keen to listen to his ideas and views.

Mackenzie is committed to get more people involved and to raise awareness about Huntington disease. "The Huntington community has done so much for me," he concludes. "I want to reach more people and to have them benefit from the same support system." 🌱

An Ariel View

*By Ariel Walker,
HSC Co-Founder*



Thank goodness for spring! With longer days and the wonderful return of warmth and new growth, it seems fitting that there are also so many new initiatives coming our way. Some are long-standing offerings, like HSC's Conference and the National Walk, that look a bit different this year. They've gone virtual to allow for participation in spite of a pandemic that hopefully is nearing its finish.

Such opportunities to participate mesh well with my philosophy to keep busy, allowing for a sense of accomplishment every day. Participating in, and even helping out (virtually) on these HD community initiatives offer the chance to achieve those goals – and it feels good.

Recently, I embarked on a project to stay busy and preserve some family heritage. I went through my stuff – inventory, let's say – and started recording where it was purchased, or if it was a family item. This way I can pass the information along to my children so they'll understand the stories behind the pieces. I have a piece of china from my father's mother, whom I never had a chance to meet because she died when I was very young. It means a lot to me to have something that belongs to her, and to know that my children will as well. The whole process certainly has been a walk down memory lane, with both chuckles and sadness along the way.

In looking over the pieces that belonged to my mother, I could just see that humorous glint in her eye. She passed along her mischievousness to me, and I guess that's become part of my survival strategy. I just try to find something to giggle at every day, even when there's not much that would be considered humorous. During that deep freeze in February I made it a point to continue to reach out to my community. One day the snow plow driver was passing and I thought, "Well, I've never chatted with him." I gave him a big grin and a wave and he responded with an even greater smile and a warm "Good morning!" Reaching out and trying to smile through it all – it really makes a difference.

We're heading into new seasons, and new times, and I hope you'll join me in finding ways to chuckle, connect, and take it a day at a time. 🌱

THANK YOU!

Many thanks to our sponsors for their support of our three-part Community Education Forum.



From the Lab Bench to the Board: Ray Truant's Commitment to Accelerating HD Research

Few people know the huntingtin protein better than biochemist Ray Truant. He began analyzing the structure of this hugely complex molecule when he joined McMaster University in 1999. In the two decades that followed, his lab has achieved breakthrough after breakthrough – most recently, showing that normal huntingtin plays a key role in DNA repair.

Although his work focuses on fundamental science, Dr. Truant never loses sight of the people it will help. “My end goal in all of this – in my career – is to get something that’s going to make a difference in the clinic,” he explains.

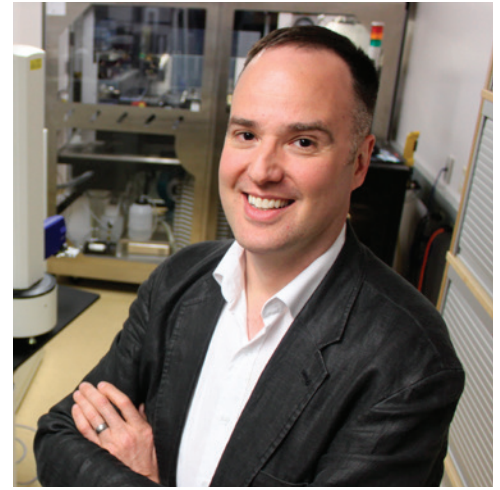
That’s why he got involved with the Huntington Society of Canada (HSC). In 2007, when Dr. Harry Robertson decided to retire as chair of HSC’s Research Council, Dr. Truant stepped up to take his place. He’s been serving on the Council – and as an officer of HSC’s Board of Directors – ever since.

Volunteering his time just makes sense, he says. In his own lab, he focuses on one part of the HD puzzle. Through HSC, he’s helping support research at every stage of the pipeline.

The most obvious way is through grants. HSC funds “high risk, high reward” projects that give investigators the results they need to get longer-term funding from national agencies like CIHR and NSERC and that help young scientists enter the HD field.

He also sees big payoffs from the clinical trial readiness roundtables we launched in 2013 and the clinical fellowships we currently offer young neurologists. Today, Canada is a leader in clinical research, with trials and observational studies running at seven sites across the country. Meanwhile, HSC’s work for genetic fairness laws means Canadians can now undergo the testing required to participate in clinical trials without fear of discrimination.

But according to Dr. Truant, the smartest thing HSC has done since he joined the Board is invest in youth. Through YPAHD, the international HDYO initiative, and our world-leading mentorship program, the Society has provided crucial support to young people and created an influx of fresh energy into the organization. “It was more wildly successful than we thought it would be,” says Dr. Truant. In fact, some of



Dr. Ray Truant

those youth are now working in his lab, inspired to choose a career in HD research.

With effective treatments now a real possibility, that research has never been looked more promising. What currently excites Dr. Truant are the genome-wide association studies showing that several genes can modify the age of HD onset. This explains why two people can have the same CAG count, but one person begins showing symptoms 30 years later than the other. Now we just need to figure out how to control those genes. “Nature is telling us it’s possible,” he explains. “It’s a fixable problem.”

Pharmaceutical companies see that potential. Today, they’re investing in HD research because they believe successful treatments will open the door to treatments for Alzheimer’s, Parkinson’s and other neurodegenerative diseases.

But how we work is just as ground-breaking as the results we get. Scientists in other fields can learn a lot from the collaborative nature of HD research, says Dr. Truant. When he switched from the brutally competitive world of HIV research, investigators he didn’t know readily shared material and insights, and at his first conference, geneticist Dr. Nancy Wexler welcomed him with a big hug.

Today, he figures half his friends come from the HD community, making his work even more meaningful. “I don’t have any genetic motivation from my family’s perspective,” he says. “But I definitely have an emotional involvement. This is 20 years of my life’s work so far.”

Two decades in, that involvement hasn’t wavered. Read Dr. Truant’s paper on page 7 in this issue of *Horizon* about research in HD and the application to other neurodegenerative diseases. 🌱



Dr. Ray Truant's Laboratory

Breakthroughs and Hope: How HD Research is Opening the Door to Understanding Other Neurodegenerative Diseases

How does research pertaining to a rare neurodegenerative disease like Huntington disease (HD) impact other, more common neurodegenerative diseases like Alzheimer's disease (AD), Parkinson's disease (PD) or Lou Gehrig's/Amyotrophic Lateral Sclerosis (ALS)?

Usually, with the common forms of AD, PD or ALS, there is no known cause – it is non-genetic neurodegeneration. This makes drug development and clinical trials very difficult, as there are no good tests or biomarkers for any of these diseases. This means that in a clinical trial, doctors cannot know why different patients have these diseases, they just know they do. Huntington disease is a monogenic disease: mono: one cause, genic: caused by one and only one gene. In HD clinical trials, we know with 100% certainty why the patient has HD and we can even predict approximately when in their lifetime they will start to get HD. This means we can trial drugs not only in those sick with HD, but importantly, also in those who have yet to get sick with HD - this isn't possible with non-genetic neurodegeneration. We can even measure how much mutant huntingtin there is within a patient.

Does Huntington disease have anything in common with AD, PD, and ALS, or is it very different?

Dementia can occur in both HD and Alzheimer's. Like Parkinson's and ALS, movement disorders can also occur in HD. For decades, the diseases were thought to have very different causes; however, in 2015, a breakthrough in HD research led to a fundamental new understanding of why these diseases all have an onset later in life. This type of study, and thus the results generated, could only have been performed with a monogenic disease like HD.

What changed in 2015?

Due to the vast network of closely tied patients and academic and foundation research teams working collaboratively, together with social support from agencies like the Huntington Society of Canada (HSC), we were able to enroll more than 16,000 HD patients and families not yet affected in a massive study that revisited the genetics of this population and led to the discovery of the huntingtin gene in 1993. The study asked a simple question: why do some people with the exact same number of CAG DNA expansions in huntingtin get sick earlier or later in life? What other genes matter?

Since around 1992 it was thought, for all forms of neurodegeneration, that the diseases were caused by misfolding proteins: mutant huntingtin, beta amyloid, tau, SOD, etc. However, no drug trying to address this mechanism of disease was ever developed.

The answer offered up by studying from HD genetics focussed on DNA damage. Differences between people's disease came down to how they were able to repair DNA damage over time via normal brain metabolism. Another important discovery from the Hayden group at UBC in 2019 was that just a few base pairs of DNA can affect age of onset of HD by decades. This indicates it is possible to affect the age of onset for Huntington disease, and likely these other diseases, by decades; nature has proven this is possible, it just needs to be "tuned" with drugs.

By 2017, it was discovered that huntingtin is a DNA damage repair protein that overlaps in a pathway seen in another rare disease: ataxia telangiectasia mutated, or ATM. The damage is being carried out by reactive oxygen species - the by-product of the brain's high level of energy use. At rest, the brain alone is using over 50% of the body's total energy, and as with any "burning", there are harmful by-products that need to be removed. These by-products are seen to be elevated in ALS. In ALS, SOD enzymes are supposed to remove reactive oxygen. In HD, huntingtin is supposed to fix DNA damaged by reactive oxygen.

In 2017, another rare neurodegenerative disease, AOA-Ataxia, was discovered to be caused by a defective DNA repair protein, and a long list of neurodegenerative disease proteins are now known to be involved in the repair of DNA. This is critical over age 50, but not earlier, which is why these diseases are extremely rare in younger people.

What is at the leading edge of research now?

In 2018, the Dawson Group (Drs. Ted and Valina) at Johns Hopkins published a massive study in Parkinson's disease related to DNA repair that is hyperactive in that disease. Now, in collaboration with the Truant lab in Canada at McMaster University, the same pathway is seen affected in Huntington disease, and seen in Alzheimer's disease. The genetics study of 2015 and work from 2017-2020 have uncovered new targets for these diseases, many of them already developed targets

in cancer research. A 2018 study from the Truant lab led to the discovery of a drug lead that has a direct effect on mutant huntingtin protein. A few years earlier, it was discovered to be a drug lead in Parkinson's disease. This is now a HD-PD effort in the California biotech, Mitokinin.

These new gene targets identified in HD are now able to be "tuned" by an exciting new class of drugs called antisense oligonucleotides, or ASOs, which led to the first successful treatment of spinal muscular atrophy (SMA) in children. Once a 2-3 year death, or a shortened lifetime in a wheelchair, children with SMA who receive treatment are now riding bikes.

How is HSC supporting these exciting developments?

Since 1973, the mandate of HSC has been holistic: social and emotional support of individuals and families, education of the broader community on HD, clinical care, advocacy for protection of genetic information (now a law in Canada), support of research, support for training young doctors through clinical fellowships, and a clinical trials preparedness program developed years before clinical trials were even a possibility. This has pushed a small research community from a small country to the forefront internationally, with Canada being the first country to hold clinical trials for new HD ASO drugs. Trial recruitment was efficient, because our community of patients and families was engaged, educated and clearly understood the importance of their participation. Patient dropout, common in any trial, is rare in HD trials. And HSC has shared their preparation templates with other disease charities. Trials are being planned for HD gene positive people before they will get sick, using new sophisticated digital tracking technology that will provide massive amounts of real time data to show how a drug is working. This could not be done by supporting just one of the pillars of the HSC, it has to be done well across all the pillars equally.

As we are now in a new era of HD clinical trials, we no longer have to rely on models of disease. We are now getting data from real people with a neurodegenerative disease with drugs that precisely target the cause of that disease. This means the movement towards a future featuring a therapy will be in leaps instead of small steps. This is a first for human neurodegenerative diseases, and with HSC's efforts, we can pave a road forward for application to much more common forms of neurodegeneration. 🌱



Give back
with

FlipGive



Supporting the Cause While You Shop

Imagine supporting the Huntington Society of Canada (HSC) every time you pump gas, pick up groceries, shop online or grab a double-double from Timmies — all at no extra cost to you. With FlipGive, you can.

The shopping platform has partnered with major retailers across Canada who have agreed to offer cash-back rewards in the form of donations to HSC. Today, the growing list of companies includes Walmart, Amazon, Indigo, Loblaws, Esso, Nike, Under Armour and many more.

The best part of this campaign is that we're not asking our supporters to dig into their own pockets. All you have to do is continue buying the things you would normally — just do it through the FlipGive website or app (available on iOS and Android) to generate donations for HSC. Those contributions are made by the retailer, not the customer, and you don't pay anything additional at checkout.

There are two ways to shop. Most retailers offer e-gift cards that can be purchased directly and securely through FlipGive. Simply call up your e-gift card on your phone and the cashier can scan it from the screen just like with e-coupons and other electronic barcodes. Or you can apply the e-gift card at checkout if you're shopping online. In other cases, you can select the retailer's website from the FlipGive platform. As long as you get there via FlipGive, the Huntington Society will benefit from your online purchases.

"I've found it really easy to use, especially for monthly expenses like gas and groceries," says Shelly Redman, HSC's CEO. "I pre-load my account for gas purchases and set it to re-load automatically. At Sobey's, I'll load an estimated amount for groceries onto an e-gift card and pay that way."

Anybody can participate. Here's how to get started:

1. Visit <https://try.flipgive.com/hsc>
2. Click on your chapter (if you don't have a chapter, choose who you would like to support)
3. Click "Join This Team"
4. Create a free account

5. Contribute to HSC by selecting participating retailers in the FlipGive platform

For example, if you purchase a \$100 Sobey's e-gift card through the app, the Huntington Society will receive a \$3 donation. "It sounds like small amounts individually, but all those little percentages really add up," says Shelly, pointing to the Huntington disease (HD) community's cross-Canada reach.

The new fundraising initiative is truly a win-win proposition. For participating retailers, it's an opportunity to advertise, drive more sales and meet their philanthropic goals. For the HD community, it's a way to support the cause while shopping for gifts, food, books and other products they would be purchasing anyway. And for chapters, it's an easy way to raise funds, especially since the pandemic makes event organizing more difficult. In fact, here are two more ways to raise money even faster, and it's a wonderfully simple process:

1. With your first purchase through FlipGive you get a \$5 bonus donation for the chapter.
2. Once your chapter raises \$20 through FlipGive (not including the first purchase bonus), both the chapter and HSC get a bonus \$50 donation (\$100 total). That's a significant amount of free money!

When we launched this campaign last fall, we challenged chapters to see who could raise the most money through FlipGive until the end of March. We've had a great response, with many folks using the platform while they did their Christmas shopping. "It's something that the chapters are appreciative of, I think, because it's not having to ask people for money out of their pockets," says Shelly.

Thank you to everyone who registered for FlipGive. The friendly competition between chapters wraps at the end of March. To see the results, please stay tuned to our social media channels.

Don't stop using FlipGive — your purchases continue to earn us money! If you haven't signed up yet, visit <https://try.flipgive.com/hsc>, and be sure to share the link with your family and friends. 📢



GIVE BACK
with

FlipGive



Karen Koester's Magical Amaryllis Touch

For Southern Alberta Chapter Amaryllis Coordinator Karen Koester, the amaryllis flower represents perseverance. It's an apt analogy for a campaign and community that faced the unexpected challenges of 2020. And yet, like the flower that blooms without fail, the chapter once again had a banner year - the best since 2009.

Karen and the Southern Alberta Chapter sold 129 cases of amaryllis, amounting to \$23,220, not including associated donations, which likely added thousands more.

"We weren't sure how Covid would affect our sales, but it seemed to have a surprisingly positive impact. People had more time at home and typical holiday shopping was difficult. Amaryllis to the rescue!" says Karen. "We all know (and now more 'new' people know, as well) that they make a great gift and our saying is: once you buy one and watch it bloom, you're hooked! Next year you'll be back and buying a couple more for friends and family."

When asked about how to mimic the success her chapter achieves, Karen has a variety of suggestions, including:

- **Use your networks and target people you know:** In the past, people sold at their workplaces, or to sports teams or other organizations they

were involved with. Gift a flower to a dentist or a school secretary and then ask to put up a flyer in their public spaces.

- **Spark a competition:** Karen once gave an amaryllis to one person in an office. This sparked a multi-year office tradition with management gifting an amaryllis to each employee. An "amaryllis competition" ensued, with employees naming their plants, playing music for them, and even using blankets or fans to keep the temperature just so. The gifting of the amaryllis and the competition extended to a second office. That one plant that Karen gifted led to four cases being purchased every year – and a lot of fun team building. This year competitions even thrived online.
- **Build community:** Community works in two ways. First, it helps to have a whole team working to sell the amaryllis. Karen emphasizes that she doesn't do it all herself – it is a team effort. Second, sharing an amaryllis bulb with someone else builds community, spreads beauty, and will likely result in a "reaping what you sow" benefit as more people want to share the love.
- **Advice for Newer Chapters:** Karen suggests that newer chapters could devise a plan with a core group of volunteers, each reaching out to

their own personal network of friends, family and coworkers. Within the core, dividing responsibilities often works well. For example, one individual could take on initial delivery and distribute the cases to others (using a spreadsheet to track who got what and when). Another could act as the campaign treasurer to track the money. Perhaps another could approach a few local businesses for sales or to display a poster. Another could compile a contact list of people with email and phone numbers. It feels like a huge job, but splitting the campaign into tasks would make it feel more manageable for a new chapter.

Looping back to the idea of perseverance, Karen marvels at the beauty of the amaryllis flowers and the high quality of the bulbs. "They're so easy to grow – it's always wonderful to hear about someone's experience growing them for the first time, because they don't know what to expect from this little bulb," she comments. "And then this amazing plant blossoms – it really reminds me of the people in the HD community. It's a kind of unexpected happiness and enjoyment, whether from a plant or from life."

Build a team, build a community. Gift an amaryllis, gift beauty. Spread the joy, spread the love. We can't wait to see what 2021's Amaryllis Campaign delivers! 🌷



Karen in front of the many amaryllis plants sold by the team



Stephenville, Newfoundland



St John's, Newfoundland



Cabot Trail, Nova Scotia

Gas Left in the Tank: Rving Across Canada with Huntington Disease

Sitting on the stony beach in Stephenville, Newfoundland, Marcel Gassner and Cheryl Winters watched the sun go down over the Gulf of St. Lawrence. Nearby, a group of local musicians sang and strummed guitars around a bonfire. For the B.C. couple, it was a high point on their two-month journey.

But their epic adventure was only halfway done. Many more incredible experiences awaited them on the long drive home to Princeton, B.C.

One month and more than 6,000 kilometres earlier, Marcel and Cheryl were busy loading their 1988 Chevy Vanguard motorhome with supplies. They had just spent \$1,700 on new tires, batteries and mechanical work. Still, they had their doubts. Their past camping trips in the Kootenays and Vancouver Island were one thing. But driving thousands of kilometres across Canada? Marcel wondered if the 30-year-old RV was up to the task.

Truth be told, he wondered the same thing about himself.

In 2012, Marcel tested positive for Huntington disease (HD). He was 45, the same age as his father when he was diagnosed. Although Marcel knows everybody's disease progresses differently, his dad's death at age 60 is a daily reminder of his own ticking clock and a powerful motivation to "get on with the meaningful stuff before it's too late," as he puts it.

With his balance, movements and other symptoms getting worse, Marcel and Cheryl decided if they were going to take their trip of a lifetime, it was now or never.

So, on July 3, 2019 – the day after Marcel's annual appointment at the University of British Columbia's Centre for Huntington Disease – they boarded their ancient, 10,000-pound house on wheels and headed for the Trans-Canada Highway.

Their aim was to revisit some of the places where Marcel had been posted during his 14-year air force career and discover new parts of the country. If the Vanguard broke down, well, they'd get as far as they could and then fly home.

Amazingly, the motorhome held up. Sure, the fridge stopped working whenever it rained. And yes, they started losing heater fluid somewhere along Quebec's Gaspé Peninsula, forcing them to make a pit stop in New Brunswick to replace the heater core – a three-day process. "It was such an old vehicle, they couldn't find the parts anymore," Marcel recalls. "They had to sort of jerry-rig something into there to make it all work."

Marcel and Cheryl did great as well, despite spending day after day together in cramped quarters, manoeuvring the 27-footer through narrow city streets and navigating unknown terrain.

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RVing Across Canada

...Continued from page 10

Marcel even handled the massive crowds of tourists at Niagara Falls — something that would normally send his level of anxiety skyrocketing. In the end, the thrill of the adventure outweighed any bumps on the road they encountered.

Preparations made a big difference. Before heading out, they made sure they had sufficient health insurance and a three-month supply of Marcel's medication. They also invested in a good GPS system, which eliminated a lot of stress.

Meanwhile, discussing what they wanted to see and do ahead of time helped prevent disagreements. "Plan and talk about your expectations of the trip, but be prepared for spontaneity — and the occasional breakdown," Cheryl advises couples with similar ambitions.

They certainly packed a lot in. They marveled at the big skies of Saskatchewan and the tides at Hopewell Rocks in the Bay of Fundy. They took in butterfly sanctuaries in PEI and puffin colonies in Newfoundland. They hiked and swam and sampled local beers. And they celebrated Marcel's 52nd birthday on the southern shore of the St. Lawrence.

Then there were the people. Everyone they met was incredibly nice, from fellow RV'ers in Wal-Mart parking lots and campgrounds to the mechanics at the OK Tire in Campbellton, New Brunswick who let Marcel and Cheryl camp on their property while they waited for parts to arrive. "They were just so kind and hospitable," says Marcel.

Two months after their adventure began, the couple pulled their faithful motorhome back into their driveway in Princeton, B.C. All told, the trek added nearly 19,000 kilometres to the odometer and many wonderful memories to their lives — memories that Marcel has documented in words and photos on their crosscanadawithHD.ca blog.

Looking back on the experience, Marcel couldn't be happier. As much as he discovered about Canada, he also discovered a lot about living with HD. Like the RV, it turns out he's tougher than he thought. "I'm not as anxious. I'm not as afraid anymore to do a lot of things," he says. "You can deal with more than you think you can."

Since their excursion, Marcel and Cheryl have sold the motorhome and moved to Nanaimo to be closer to family. But the avid campers aren't done travelling yet. Marcel would love to return to many of the places they visited, while plans are in the works to visit northern B.C. and the Yukon with Cheryl's family.

Whatever else they end up doing — and however long they have left to do it — they're grateful for the opportunity to enjoy this trip of a lifetime together. "It's a trip that I think every Canadian should take to see how big our country is and how diverse and how wonderful the people," says Cheryl.

"It's so worth it," Marcel agrees. "There are just so many beautiful places." 🌍



Cape Sable Island, Nova Scotia



Mosquito Creek, BC



Niagara Falls, Ontario

Donor Spotlight:

John Hickson

This donor spotlight features a piece written by John Hickson

In Memoriam

(My story of living with a wife with HD, and afterwards)

My first wife, Sylvia, and I immigrated to Canada from England in 1967 after I landed a job as a geophysicist with Imperial Oil in Alberta. In 1971, after our daughter was born, we were shocked to learn that Sylvia's mother had been diagnosed with Huntington disease (HD). She died a few years later.

At the time, there was very little information available about HD but because of its hereditary nature we decided to adopt our son. Looking to connect with others facing HD, we put an ad in the newspaper and had a meeting in Calgary. This started the Alberta chapter of the HSC, aided by Ralph and Ariel Walker. As many of you know, they drove across Canada on vacation with their tent trailer in tow, visiting fledgling chapters and families who had come together to help fight this awful disease. These were the early days of HSC.

Eventually a chapter was also started in Edmonton, and Sylvia was the Southern Alberta Chapter leader for many years. We raised money for research and increased awareness of HD

through various chapter functions. We kept up to date with the latest developments, sharing information and providing morale support. That "take action" approach helped me deal with the fact that Sylvia and my daughter were at risk for developing the disease with no way to test, cure or control it. As a family we tried to live as optimistically as possible, and enjoy what we had at every moment, but it was not always easy with Sylvia's increasing mood swings.

Sylvia was diagnosed with early HD symptoms in the late 80s. Her diagnosis was confirmed when they discovered the HD gene in 1993. I was working on global projects for Exxon in Texas at the time. Our daughter was also tested and is mutation-negative, so our ongoing family is finally free of HD. Sylvia was relieved as she felt a lot of unwarranted but understandable guilt that she had passed on the HD gene to our daughter.

In 2000, I retired early from Imperial Oil to take care of Sylvia at home. We had moved to Vancouver Island to be nearer to our daughter and friends for support as well as for treatment advice from Michael Hayden at UBC. Our son lives in the UK. We didn't want to face Calgary winters, especially with Sylvia's increasing movement



Sylvia Hickson

disorders, which led to her eventually needing a wheelchair. I was able to get care aides to help with Sylvia's home care. Sylvia died in 2005. She is one of HSC's Shining Stars and there is a Sylvia Hickson Family Fund.

After Sylvia's death, I travelled extensively and continued to support HSC and the local Victoria chapter. I married again in 2013 to my wife Jean, a widow and neighbour whom I met at church. We continue to travel and visit our extended families. Jean has brought me a great deal of comfort after living a life involving HD.

Because of efforts by organizations such as HSC, knowledge and treatment of HD have come a long way since the early 1970s. Even though my family is no longer at risk for HD, I continue to support HSC through "in memoriam" donations in the hope that a cure will be found soon, and others will not have to go through the anxiety that we did. The "in memoriam" donations increase awareness of HD because HSC sends sympathy cards to the families of the deceased (from any ailment), advising them that a donation has been made in the name of their loved one. I explain to the family that HD was the disease from which my first wife died and that HSC is the main charity that I support. These donations fund research to find a cure for HD and help families who are suffering as a result of HD – two of my ultimate goals. 🙏



John travelling in S.E. Asia in 2017

YOUR SUPPORT MATTERS!

We need you. Quite simply, we need your time, energy and financial support. We need this to continue being able to offer Family Services programs to the Huntington community, from individual and group counselling to educational resources and mentoring youth. The research that is happening is too important to stop; real progress is being made. We're asking for help, from a one-time donation to ongoing giving to support the Huntington community of researchers, patients, caregivers and families. Can you make a difference? Will you help us? Pick your path below:



Make a Financial Donation

Choose whatever method works best for you. For any questions, reach out to: rstjules@huntingtonsociety.ca

Online:

www.huntingtonsociety.ca/yes-i-want-to-donate/

Phone:

1-800-998-7398

Mail:

20 Erb St. W, Suite 801
Waterloo, ON N2L 1T2, Canada



Volunteer

Please visit

www.huntingtonsociety.ca/volunteer-in-my-community/

to see how we can work together to improve the lives of people impacted by HD.



Leave a Gift in Your Will

A gift in your will provides future support for the Huntington community. To find out more, visit

www.huntingtonsociety.ca/legacy-giving/



BECOME A MONTHLY DONOR

Make an impact by joining our Champions of Hope and becoming a monthly donor. Our support programs and research are ongoing to meet the needs of the Huntington community, which is why we're counting on you for consistent support. Becoming a monthly donor reduces our administrative fees so that more of your contribution will reach these key areas of focus: our community members and everyone touched by Huntington disease.

To become a monthly donor, please visit: www.huntingtonsociety.ca/monthly-giving/

B.C. and Yukon Online Carer Group

For many people, a support group offers a safe and supportive forum. Indeed, the goal of a support group is to provide an opportunity for people to share experiences, and feelings, as well as learn about coping strategies and self-care. So when the pandemic swept across the country – and the world – and made it challenging to hold such meetings in person, HSC tried to be innovative with how to best support the HD community.

Since the pandemic began, the Family Services Team has transitioned to providing individual and group support across Canada via online formats. Some of these new groups will continue in a virtual format after in-person meetings can start again. Corey Janke, HSC's National Social Worker, offers a national At risk online group and there is a Facebook Support group that is private and can be accessed only by participants.

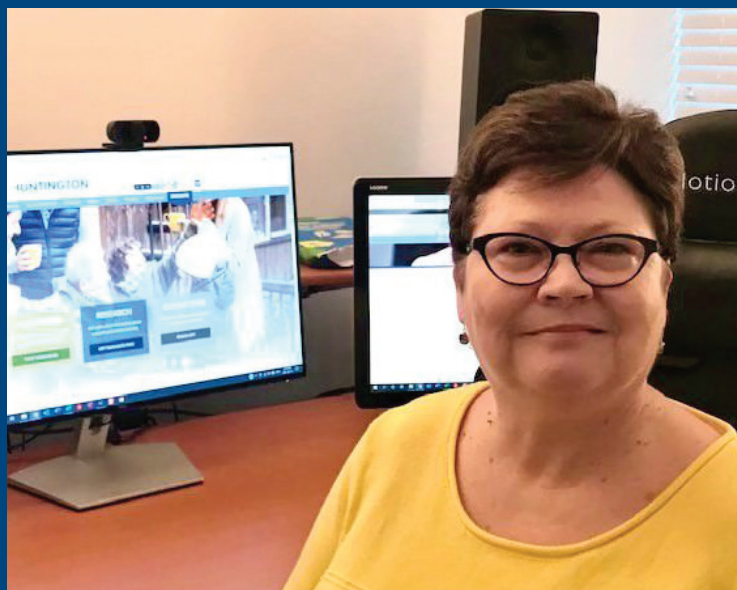
Another online offering that enjoyed great success was the new online carer support group for B.C. and the Yukon, run by Rhonda Romolock, Resource Centre Director (RCD) for the area. "One benefit of going online was being able to reach people throughout B.C. and the Yukon who don't usually have access to in-person support groups because of their location," Rhonda notes. "Others may have been benefiting from accessing supports in their area, but with the online format they can share HD-specific experiences, increase their knowledge about HD and its progression, and learn about other topics fundamental to caregiving."

"One of the positives of the remote group is no travel," Rhonda says. "Also, with the progressive nature of HD, it can become increasingly difficult for the carer to leave home. A virtual offering allows the carer to be available in case they are needed, while still benefiting from the support group."

Rhonda confirms that they are very careful about issues of confidentiality, such as ensuring the group members have a private location in their homes while joining the sessions. She talks with potential participants about hopes and expectations to make sure the group is a good fit.

"The idea of a support group can be intimidating for some," says Rhonda. "We stress that any participant should merely share what they want to share and that passing is okay, too. Sometimes people like to process a session and reach out for added support, and the group leaders are available for this."

Rhonda adds that another benefit of a support group is building a relationship with an HSC Family Services worker, so if individual counselling, links to resources, or advocacy is needed, participants have an increased comfort level in accessing services. And it goes both ways –



Rhonda Romolock

Rhonda says that if she notices during a virtual support session that a topic has affected a participant in a certain way, she can connect later and check in.

"It was great to see how quickly everyone connected and shared their experiences, even though they had never met before," Rhonda says. "We talk about some challenging issues, but there can still be laughter and finding things we are grateful for," Rhonda says.

One of the benefits of a support group is hearing first-hand from others what has helped. Carers report feeling understood and less lonely and isolated. Rhonda also stresses the importance of having this safe space to discuss experiences caring for someone with HD.

The B.C. and Yukon Carer Group consisted of six structured sessions, with the possibility of continuation, and the Family Services Team is continuing to work on what service offerings will look like for the remainder of the year and also post-pandemic.

Stay tuned for continued offerings from HSC's Family Services Team. Or, if you'd like to join a B.C. Carer Support Group, contact Rhonda at romolock@huntingtonsociety.ca or 604-604-822-7195. 📞

Thank You!

On behalf of families living with Huntington disease (HD), thank you for your continued partnership and generous support. The HD community makes the difference as the Huntington Society of Canada (HSC) reaches out to families not yet connected to the organization. HSC is committed to supporting and advocating for families from coast to coast, investing in world-class research and playing a leadership role in the international HD community. With your help, HSC is continuing to improve

the quality of life for people with HD, cultivating strength and resilience in the HD community and providing substantive reasons for hope. If you have questions, story ideas or comments about *Horizon* or HSC, please contact HSC at communications@huntingtonsociety.ca or call 1-800-998-7398.

HSC is committed to reaching out to as many Canadians as possible. Should you wish to explore the French side of the HSC website, select the

Français option at the top right hand corner of the website www.huntingtonsociety.ca.

La Société Huntington du Canada a pour mission d'éduquer et d'aider autant de Canadiens que possible. Si vous souhaitez explorer la partie française de notre site Web, veuillez cliquer sur l'option française en haut à droite de la page suivante : www.huntingtonsociety.ca. 🌐