

HORIZON

RESEARCH • SERVICE • EDUCATION

No. 161

Spring 2020

2020 Huntington Society of Canada National Conference Postponed

Given the ongoing uncertainty that COVID-19 presents, especially economic impact to the Huntington Society of Canada (HSC) and our community, we have made the difficult decision to postpone our National Conference. This year, we were all set to gather at the conference on Nov. 13 and 14 in Niagara Falls, ON. Given our inability to predict potential restrictions we may face in November, we felt it would be best, instead, to meet in 2021 when we can fully celebrate our successes and each other.

We will keep everyone informed as to the new 2021 date for the National Conference as soon as we have more details.

We know that this event provides our community with an important opportunity to gather and learn from some of the best, innovative minds influencing Huntington disease (HD) care and research. Postponing the conference is

disappointing for all of us. That said, there is no reason why we cannot gather in "virtual" safety.

In lieu of conference, we are pleased to offer three virtual Community Education Forums (CEFs) over the next year. Once COVID-19 restrictions have been lifted, as with past CEFs, our chapters and local volunteer-led groups will be invited to host in-person viewing parties of these livestreams. Alternatively, you may opt to watch the livestream from the comfort of your own home.

We are working on confirming topics and speakers and cannot wait to share the line-up with you. Stay tuned to www.huntingtonsociety.ca/cef for full details.

If you have questions, please reach out to the HSC events team at events@huntingtonsociety.ca or review HSC's website www.huntingtonsociety.ca/covid-19-a-message-from-our-ceo/.



Due to COVID-19 concerns, the 2020 HSC National Conference will be rescheduled for Fall 2021.

Details will be shared at a later date.

COMMUNITY EDUCATION FORUM
2020-2021 SEASONAL SERIES



May 30, 2020
Nov. 14, 2020
Feb. 27, 2021

www.huntingtonsociety.ca/CEF



INSIDE

Latest Clinical Trial Results	page 3
COVID-19: What is HSC Doing?	page 4
Champion of Hope: Steven Beatty.	page 6
Paul Manning: A Quiet HD Hero	page 7
Youth Corner	page 10

HORIZON

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Horizon is the newsletter of the Huntington Society of Canada. Issued three 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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Message from the CEO



Spring always feels packed with energy and promise – and this Spring, there is plenty for the Huntington disease (HD) community to be excited about.

As you will read in this issue, the initial results from Wave Life Sciences' PRECISION-HD2 trial show their drug can lower the huntingtin protein. Meanwhile, early results from Roche's open label extension are also promising.

Here at national office, we also have a lot going on. Our staff are currently hard at work projecting results for our year-end and developing our budget for 2020.

Sadly, as we prepared to host the annual Huntington Disease Coalition for Patient Engagement (HD-COPE) meeting, which would have taken place in Toronto in March, recommendations around preventing the spread of COVID-19 meant we collectively made the decision to cancel the event this year (you can read more on page 4 about what HSC is doing amid the COVID-19 outbreak). Typically, the HD-COPE group comes together each year to learn about clinical research and to share their lived experiences with the pharmaceutical companies that are developing and testing potential treatments.

Of course, we have also been busy gearing up for May awareness this month. The success of this annual campaign relies on our phenomenal chapters and volunteers across the country. While public gatherings and flag raisings are discouraged, I would like to thank everyone who is working to #LightItUp4HD, #ChalkItUp4HD or #StringItUp4HD, sharing their personal stories and organizing virtual fundraisers. Shining a spotlight on HD – and the incredible progress towards treatments – pays off in so many ways. Your efforts bring in dollars to support families and fund research. They help new families learn about

the disease and what the Huntington Society of Canada (HSC) offers, and they also create understanding among Canadians from coast to coast.

As mentioned on page 1, due to COVID-19 concerns, we have postponed our National Conference until 2021. In the meantime, our chapter development team is working on bringing you a series of virtual Community Education Forums (CEFs). Stay tuned to our website for details on those.

Time has passed so quickly these past few months, and it has been an honour to be back. Every day, especially during these unprecedented times, I'm reminded how courageous, creative, resilient and strong our community is. Thank you for all you do – and for welcoming me "home" – it has been a wonderful visit!

Bev Heim-Myers
CEO (Interim)
Huntington Society of Canada

Late Breaking News

Huntington Society of Canada Announces New Chief Executive Officer

The Huntington Society of Canada (HSC) board of directors has named Shelly Redman as the organization's new chief executive officer. Shelly will assume her new role effective May 25, 2020.

Shelly has a strong track record of informed engagement and empowering leadership in the not-for-profit health and wellness sector, as well as a comprehensive understanding of the health care system. Shelly has worked directly with individuals and families impacted by Huntington disease (HD) and understands their needs, the importance of research and the value of HSC's grassroots community and volunteers.

"Shelly is a strategic executive and dedicated advocate who brings proven leadership to the role at a critical time for HSC," says Mack Erno, chair of the HSC board of directors. "Her organizational leadership experience and extensive clinical experience as a nurse practitioner will ensure our organization continues to advocate for the needs of those affected by HD in Canada. On behalf of the board of directors, I am very excited to welcome Shelly to the HSC team."

Look for a profile on your new CEO in the Fall 2020 issue of Horizon.

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Latest Clinical Trial Results: More Huntingtin-Lowering Success

By Julie Stauffer

It's official: we now have two drugs proven to lower the levels of the mutant huntingtin protein that causes Huntington disease (HD). Although, there is still much to learn about side effects, effective doses and length of time and frequency at which the treatment is needed to be effective.

In 2018, clinical trial results showed that Roche's RG6042 (now referred to as tominersen) could reduce the levels of huntingtin in humans. Now, Wave Life Sciences' WVE120102 has also proved successful. At the end of 2019, they announced initial results from their PRECISION-HD2 phase 1b/2a clinical trial.

Not only did WVE120102 lower huntingtin, the results also followed the classic dose-response pattern that researchers look for, where higher doses create greater effects. At the highest dose, it reduced mutant huntingtin levels in the cerebrospinal fluid by 12.4 per cent.

"I'm very pleased," says Dr. Mark Guttman, whose Toronto clinic is involved in the Wave studies. "This is what we were hoping for."

Wave hasn't yet examined the performance of their other huntingtin-lowering drug, WVE120101, currently being tested in their PRECISION-HD1 trial. Those results are expected later this year.

Upping the Dose

One of the challenges of designing clinical trials is deciding what doses to test. To ensure the safety of trial volunteers, Wave started low, testing doses of two, four, eight and 16 milligrams in both PRECISION trials. Those doses revealed no serious side effects. The most common issues were headaches and procedural pain, which affected roughly the same number of patients receiving the placebo as those receiving the drug.

Wave has now added a 32 milligram dose in both PRECISION trials to see if they can achieve greater huntingtin reductions. If it proves safe, they will include this higher dose in the open label extension study offered to volunteers who complete the clinical trial.

It's important to remember that these are just preliminary findings, and we won't get full results until later this year. Both PRECISION-HD1 and PRECISION-HD2 are still recruiting at their three Canadian sites: Edmonton, AB, Toronto, ON and Montréal, QC.

As WAVE's chief medical officer, Michael Panzara, said in his letter to the global HD community last December, "All of us at Wave are enormously grateful to the PRECISION-HD clinical trial participants and their families. We recognize the personal sacrifices made by each and every family involved in these trials. Their participation along with the support of the entire HD community are critical to advancing the scientific and medical understanding required to defeat this devastating disease."

Roche Expands GENERATION HD1 and Announces Early Open Label Extension Results

Right now, scientists don't know how much we need to reduce mutant huntingtin to slow the progression of HD. Roche's GENERATION HD1 trial aims to provide some answers. It's assessing whether tominersen can reduce the movement and cognitive symptoms of HD and improve patients' ability to handle daily tasks around the house.

On April 20, 2020, with 791 people with manifest HD from around the world (18 study sites) recruited into the Phase III GENERATION HD1 study, Roche has reached approximately 99 per cent of the targeted 801 participants. Given the dynamic situation with COVID-19, Roche decided to close recruitment at 791 participants, globally, in order to avoid additional pressure on



clinical trial sites who were screening potential participants. Roche is confident that this number of patients is sufficient to provide the information required to thoroughly assess the benefit-risk profile of tominersen in manifest HD.

This decision also enables the GENERATION HD1 study to continue to progress within planned timelines.

If you have any questions about clinical trial participation, please contact your regional HD clinic team.

Meanwhile, the company has continued to offer tominersen to volunteers from the earlier phase 1b/2a clinical trial. Recently, Roche announced results from this open label extension. The big news here is that giving patients the drug every two months was just as effective at lowering huntingtin as giving it every month – and it created fewer side effects.

FIND
CLINICAL TRIALS
IN CANADA

The Huntington Society of Canada has an interactive map listing clinical trial sites across the country.



To learn more and find locations near you,
visit www.huntingtonsociety.ca/clinical-trial-locations

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Two Different Approaches to Lowering Huntingtin

Both Wave and Roche have designed drugs to lower the mutant huntingtin protein that causes HD. But the two companies are taking slightly different approaches.

Roche's tominersen drug lowers levels of both the normal huntingtin protein and the mutant version. Wave's two drugs, WVE120101 and WVE120102, take an "allele-selective approach," lowering just the mutant huntingtin protein.

Right now, it is not known which approach will be safer or more beneficial over the long term. For that, more trial results are needed.

HealthPartners Elects New Directors at Annual General Meeting

By Eileen Dooley
CEO, HealthPartners Canada

I hope you will join me in welcoming three new directors to the HealthPartners board: Mary Ann Butt, senior vice president for Heart & Stroke (Nova Scotia, Prince Edward Island and Newfoundland and Labrador); Robert Eardley, senior director (ret.), Air Canada; and Allan Smofsky, a Toronto-based health benefits consultant.

"We are very much looking forward to working with these new directors," says HealthPartners board chair, Debra Lynkowski. "All three are passionate about helping HealthPartners fulfill our vision of building healthy workplaces, healthy Canadians and healthy charities."

In the health charity sector, we rely on having boards of directors who are committed, connected and caring – and focused on providing support for those living with chronic disease and major illness. At HealthPartners, we are most fortunate to have a combination of directors who have been nominated by our member charity partners and members-at-large who come from government, the private sector and the charitable sector.

We changed our board structure two years ago to allow us to grow and succeed in a rapidly changing environment. Our board of directors is composed of six nominees from HealthPartners member organizations as well as the five external directors from the public and private sectors mentioned above. In order to ensure the engagement of our member charity partners we also created a HealthPartners Members' Council, consisting of one representative from each of our 16 national health charities. I am pleased to say that the Huntington Society of Canada (HSC) has been a strong supporter of HealthPartners and our governance structure, and we are delighted to welcome Ian Foss, national director of development at HSC as your representative.

I truly believe that together we have the ability to enhance our support for all our member charities in Canada, which has included HSC for over thirty years.

iii HealthPartners

Charities At Work

COVID-19: What is HSC Doing?



Important Information from Your CEO

Our thoughts and prayers are with you and your loved ones during these uncertain times. Like so many, I have a heavy heart as I learn each day about the new impacts COVID-19 is having on communities across the country and around the world. At the Huntington Society of Canada (HSC), we continue to monitor this situation closely.

Let me take a moment to summarize some of the things we are doing to keep you connected – and safe.

In light of recent developments and the latest advice from the federal government, provincial government and local public health agencies, HSC has made a number of decisions to prioritize the health and safety of our staff, our community and their families.

Recently, we have adapted face-to-face meetings to virtual and for now, we have cancelled or postponed any planned international or domestic travel.

Our professional team of social workers are adopting virtual options for any gatherings planned and where they cannot offer the program via an online medium outreach, teleconference is still an option.

HSC is already skilled and experienced at delivering online services. We will keep you posted of any moves to virtual support as they become known, whether that be via videoconferencing, phone or email. We thank you in advance for your patience and understanding as we work to expand our capacity for staff to deliver more support online.

With respect to larger and mass gatherings, HSC was prepared to host the international meeting of the Huntington Disease Coalition for Patient Engagement (HD-COPE) in Toronto in March. However, as mentioned on pages 2 and 13, due to COVID-19 concerns we collectively made the decision to cancel the meeting. This is a sad but necessary outcome. The HD-COPE team continues to work diligently to find alternative ways to connect the international group.

Our chapter development team is working hard to assess how COVID-19 will affect event planning across Canada and rescheduling our National Conference for 2021. We are pleased, in the meantime, to offer virtual Community Education Forums (CEFs), as highlighted on page 1.

In terms of day-to-day operations, given direction from federal and provincial governments and the Region of Waterloo Public Health Unit, the decision was made to close the Waterloo office and have all staff work remotely, as per government guidelines.

We took these precautionary measures in light of the developing COVID-19 situation. The well-being of our staff, our stakeholders and their families is a primary concern. We also acted with the health and safety of the broader HD community in mind.

We will continue to monitor and follow provincial and federal guidelines closely, and respond appropriately. For further updates as they become available, please go to our website at www.huntingtonsociety.ca or Facebook page at www.facebook.com/HuntingtonSC/. Should you have any specific questions, please email us at communications@huntingtonsociety.ca.

These are indeed extraordinary circumstances and we thank you for your patience and understanding. We wish our HD community a healthy and safe time in the coming weeks and months.

Please remember that we will remain accessible to you during this time of disruption. Together, we will take care of one another.

Sincerely,

Bev Heim-Myers
CEO (Interim)
Huntington Society of Canada

Genetic Non Discrimination Act Update

By Bev Heim-Myers

Chair, Canadian Coalition for Genetic Fairness

The Canadian Coalition for Genetic Fairness (CCGF) comprises a group of organizations dedicated to preventing genetic discrimination against individuals, based on their genetic test information. CCGF advocates (at the federal, provincial and territorial levels) to create positive changes for the Huntington disease (HD) community and all Canadians. The Huntington Society of Canada (HSC) and the HD community have led this advocacy.

You may recall that in May 2017, the Genetic Non-Discrimination Act (GNDA) received Royal Assent and passed into law. Prior to that date, Canadian law did not protect the genetic test information of Canadians. Parliament enacted the GNDA pursuant to its criminal law power (as a response to expert evidence that showed some Canadians avoided taking genetic tests, despite knowing about their potential health benefits). The GNDA empowers all people living in Canada with the chance to make informed decisions regarding health and reproduction, without fear of genetic discrimination.

In December 2018, the Cour d'appel du Québec (Québec Court of Appeal) gave its opinion that the GNDA does not constitute a valid exercise of Parliament's criminal law power. The Québec opinion did not overturn the GNDA, but did put

the GNDA at risk.

In response to the opinion of the Québec Court of Appeal, CCGF filed a notice of appeal referring the decision to the Supreme Court of Canada (SCC).

As reported in the Winter 2020 edition of Horizon, I was privileged to attend the hearings at the SCC in October 2019 and was joined by Senator Jim Cowan (ret.), and his former senior policy advisor, Barbara Kagedan, who continue to remain very engaged with this file. Their historical knowledge and guidance remain vital as we move forward. Of course, the CCGF legal team also attended and presented CCGF's perspective very succinctly.

At this stage, it is important to know that the GNDA continues to remain as federal law and genetic test information remains protected for people living in Canada. Again, as soon as we are advised of the opinion of the SCC (sometime in 2020), we will be sure to update you.

CCGF thanks our team of lawyers, Senator Cowan and Barbara Kagedan for their continuing hard work on this file, on behalf of all people living in Canada.



An Ariel View

By Ariel Walker,
HSC Co-Founder



There is still snow outside my window right now, but I hope by the time this reaches you, Spring will be in full bloom.

My son, Matthew, and my granddaughter, Hannah, helped me trim back my overgrown bushes over the summer, so I am looking forward to seeing them bloom this year, as well as all my usual hyacinths, daffodils, tulips and hostas. The garden has certainly changed since Ralph and I moved here 50 years ago, when there was nothing but weeds!

The Huntington Society of Canada (HSC) has changed so much as well. Bev invited me to see the new offices earlier this year. Oh my goodness, they really are gorgeous! There is a lot of glass to let the light in, and the setup is much more open and spacious than the workspace on Frederick Street, which was starting to get very cramped.

When I visited, I also had a chance to meet some of the new staff. Bev asked me to tell them a bit about the history of HSC. At one point, I had everybody crying when I talked about the sacrifices we made in the early days.

When Ralph gave up his teaching job to work full time as HSC's executive director, he took quite a cut in salary. However, we believed in what we were doing, and our parents were very supportive. They had big vegetable gardens, and I remember canning and freezing all sorts of goods to help keep our bills down. And for several years, Ralph and I didn't get any new clothes.

Now look at where we are. I guess both gardens and organizations grow and evolve!

Some of those changes have been hard. Over the years, we have said goodbye to a lot of wonderful people: staff and volunteers, doctors and researchers and generations of families. But we've also said hello to so many new folks who bring the same spirit of enthusiasm and determination that has made HSC such a success.

And, my gosh! What a difference we are creating. I have been reading about the results of all the huntingtin-lowering clinical trials, and it really feels like we are entering a new era. It is just so exciting. I am sure we are going to be hearing all about that at one of the Community Education Forums happening throughout this year. I hope you will take part!

Champion of Hope: Steven Beatty

By Josh Martin

Although Steven Beatty knew Huntington disease (HD) was in his family, he felt confident he had dodged the genetic bullet. After all, his dad was symptom-free well past the age when Steve's two uncles had died of it. But then, in 2015, his dad's health started failing.

Steve decided to get tested, just in case. "I really thought I was going to be negative," he recalls. Instead, the genetic counsellor told him, "It's not the result we were hoping for."

It wasn't just his world that was upended. The results suddenly threw the lives of other untested family members into flux. His two kids. His sister. His nephew. His dad's daughter from a second marriage. "It was just like dominos falling," says Steve. "I had no idea what to do next."

Steve's mom, Susan Van Aarsen, and his step-dad, John, responded by volunteering with their local

Huntington Society of Canada (HSC) chapter in London, ON. Susan served as chapter president, coordinated support groups and organized silent auctions, benefit concerts and flag raisings. Susan also initiated the Eli and the Straw Man Benefit Concerts after HSC promoted the band's awareness tour. London's was the first, and when Susan shared its success at the 2016 National Conference, many other chapters followed suit thereafter.

Sadly, John died last October, following a long fight with cancer. Two days later, Susan also passed away. It was a devastating blow for the family and a real loss for the entire HD community.

Today, Steve is continuing their legacy – and forging one of his own. "I've really committed myself to doing everything I can to spread the word and raise money," he says.

After getting his genetic test results in 2015, the Victoria Harbour, ON resident reached out to HSC to find a local support group. After discovering that the closest chapter was an hour and a half away, he volunteered to start one closer to home.

Steve now organizes regular meetings for the fledgling Barrie chapter of HSC. Last year, they hosted a Community Education Forum and their second annual 5k Fun Run/Walk in the Fall along the Barrie waterfront. For Steve and his wife, connecting with other families who are going through similar experiences has made a big difference.

Steve has also written *In-Between Years: Life After a Positive Huntington's Disease Test*, with all proceeds going to HSC. So far, the project has raised thousands of dollars and plenty of awareness.

As the title suggests, the book is about the years following genetic testing but before symptoms begin to take hold. It explores how every stumble or misplaced purse brings a jolt of fear that that the disease has arrived. It talks about caring for loved ones with HD and wondering how long it will be before it's your turn. And it discusses practical considerations, like breaking the news to other people, making choices about having children, planning ahead and participating in clinical trials.

Throughout the book, Steve emphasizes that life doesn't end with a diagnosis and that there is incredible support to be found within the HD community. Most of all, *In-Between Years* is about hope. "I talk a lot about the advancing science and what an exciting time it is with the research," he says.



Steven Beatty (left) is joined by Barrie–Springwater–Oro-Medonte MPP, Doug Downey at the Muskoka Walk last October. The group was presented with a note of congratulations on their 2nd annual event, on behalf of the Government of Ontario.



Steve was officially diagnosed with symptomatic HD last summer, after movement and mental health symptoms began to surface. Although the diagnosis forced him to retire early from his job as a registered nurse, he's grateful for the extra time he gets to spend with his wife, their seven-year-old daughter and their five-year-old son. "I'm making sure that I'm spending all the time that I can with them," he says. "I'm just trying to focus right now on looking after them and just being the best that I can for as long as I can."

To learn more about *In-Between Years* and to order your copy, visit www.inbetweenyearsbook.com.

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2. Newsletters
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Q ...My family member lives outside of Canada and needs to get information on Huntington disease (HD) and the support services in their area. Is there anyone that can help them?

A The Huntington Society of Canada (HSC) is recognized as a world leader in Huntington disease (HD) information and support services, and as a Canadian organization, we can only support those affected by HD who are living in Canada.

However, our website contains reliable and up to date information that is accessible to download and can be viewed anywhere there is internet access: www.huntingtonsociety.ca

Here in Canada, for those living in the province of Québec, la Société Huntington du Québec (SHQ) is also available for support and resources: www.huntingtonqc.org

HSC has many international partners that are available to provide information, resources and support to individuals and families affected by HD.

In the United States, individuals can reach out to the Huntington's Disease Society of America (HDSA): www.hdsa.org

For research updates, HDBuzz is a website that

provides easy to understand clinical trial and research information from around the globe - in multiple languages: www.hdbuzz.net. You can also read more about this in the article on page 12.

For questions from or about youth from a family affected by HD, the Huntington's Disease Youth Organization (HDYO) is another great international resource: www.hdyo.org

Families can also visit the International Huntington Association (IHA) website to see a map that lists the locations, and contact information, for HD associations around the world: www.huntington-disease.org/findyournationalorganization

And, as always, should a person be unsure where to start, they can reach out to HSC via email at info@huntingtonsociety.ca and our team will be happy to connect and point them in the right direction.

Got a question you'd like to ask Dear HSC? Email it to us at communications@huntingtonsociety.ca

Paul Manning: A Quiet HD Hero

By Josh Martin

Brilliant. Gentle. Generous. These are just a few of the descriptors peppered throughout the obituary of Paul Manning, who died from Huntington disease (HD) on January 2, 2020. "He was just the kind of person most people would like to meet," says his wife, Jane Manning.

Those qualities helped Paul follow in his father's footsteps as a successful civil engineer, becoming one of the largest independent contractors in British Columbia (BC). Unfortunately, he got more than career inspiration from his father. In 2013, Paul discovered he had HD. The family was floored. Paul's dad died in 1991, and no one knew he carried the fatal gene.

Paul took each day as it came. He refused to wallow in self-pity, feeling that many people faced more difficult challenges. He also never wanted others to feel bad about his deterioration, doing his best to make people feel comfortable. "That was Paul: the consummate gentleman and kind soul to the end," says Jane.

As the disease progressed, he struggled with angry outbursts and other uncharacteristic behaviour. Meanwhile the physical symptoms made it difficult for him to enjoy two of his greatest passions: fishing at the Hakai Land and Sea Fishing Club and skiing in Whistler, BC, where he and Jane first met.

Jane and their son David were undeterred. They organized fishing trips, enlisting friends and family who helped Paul get in and out of the boat, held his rod and baited his hooks. Meanwhile, thanks to Whistler's world-renowned adaptive ski program, Paul got to carve the slopes one more time with the aid of special equipment and trained professionals. "It was just one of those glorious days," says Jane.

Paul and Jane always believed in giving back. Over the years, they supported the arts, education, healthcare and the Tong Louie Family YMCA in South Surrey, BC. As well, Jane served on the board and as campaign co-chair for the Peace Arch Hospital Foundation in White Rock, BC, helping raise \$15 million for an expanded emergency room.

When Paul was diagnosed, that generosity extended to the Huntington Society of Canada (HSC). Paul wanted to do everything he could to contribute to finding a cure. He had spent his life building bridges, tunnels and hydroelectric projects throughout BC and Alberta – and now he wanted to help build a better future for the HD community.

The duo quickly became important allies of HSC. Jane served as a cabinet member for our Believe capital campaign that raised close to \$3.5 million. She was also the driving force behind the Dragonfly Spirit Button Wrap initiative, selling gorgeous shawls designed by Clarence Mills and created by her niece, Chloë Angus, to raise money and awareness for HD.

Paul and Jane also started the \$30,000 Manning Doctoral Student Fellowship to encourage young scientists to focus on HD. And in 2018, they teamed up with another family to establish the Manning Family and Beckman Family University of British Columbia (UBC) Huntington Fellowship. The three-year commitment of \$100,000 per year funds a clinical research fellowship at the Centre of Huntington Disease at UBC, Jane and Paul's alma mater. Currently, Dr. Fabricio Pio holds that fellowship, supervised by Dr. Blair Leavitt (read Dr. Pio's story on page 9).

Paul's support went beyond financial contributions. When clinical trials for new huntingtin-lowering treatments were announced at UBC, he didn't hesitate to sign up. He even agreed to donate his brain to science after he died, helping Dr. Leavitt, Dr. Pio and other HD researchers gain valuable insights into the disease. "Paul was always humble and liked to fly under the radar," says Jane. "But I think he'd be glad that he was a pioneer at such an important time."





Huntington Heroes Theme Gives HD Events a Family-Friendly Boost

By Josh Martin

Dogs in capes. Kids in masks. Grown men decked out as their favourite superheroes. Since the Huntington disease (HD) Hike in Exeter, ON adopted the Huntington Heroes theme, Lindsay Groot has seen many great costumes. But for the event's organizer, nothing beats the time her husband showed up dressed as a nurse. "He was me," says Lindsay, who works as a nurse and has tested positive for the HD gene. "His hero."

For decades, HD walks and runs have been a cornerstone of Huntington Society of Canada (HSC) fundraising efforts. Annie Vanexem, HSC's senior manager, national events and chapter development, wanted to create an even bigger impact by giving them a family-friendly theme. In 2016, Huntington Heroes was born, offering fun for all ages that broadens the appeal beyond the running community and families directly impacted by the disease.

Although Exeter has a population of only 4,600, their 13th annual HD Hike last year attracted roughly 250 people and raised \$35,000 – which was doubled thanks to an anonymous donor. And while many came to tackle MacNaughton Trail, others came for the live music, face painting, bouncy castle, splash pad and mascots like Dora the Explorer, followed by a train of pint-sized fans. "People that maybe don't want to walk can hang back and just have their coffees and donuts and socialize," says Lindsay. "It's just a really fun day."

Last year, several other chapters used the Huntington Heroes theme for the first time. For some, it was as simple as adding Huntington Heroes messaging to promotional flyers and

social media content, encouraging participants to come in costume.

"It was really the national office staff who encouraged us," says Corinne Bees, who spearheaded the BC Walk to Cure HD in Vancouver's Olympic Village Square last September. "We needed a new theme or some pizzazz to get more people out."

Volunteers handed out multi-coloured superhero masks and sold T-shirts with space to write the name of your personal hero, which proved very popular. For Corinne, it was a chance to honour her sister Diane Kuzyk – an HSC stalwart who founded the Northern Alberta chapter. On the day of the walk, she brought laminated stories about Diane and wore them around her neck for people to read. "My sister has been a really strong person," she says. "And determined."

A musician, juggler and balloon artist were also on hand to entertain the 200 or so people who came out. White Spot – a BC institution – served up burgers. In the end, the Vancouver chapter shattered their fundraising goal, raising just over \$42,000.

For Kristin Johnston, incorporating the heroes theme into the Toronto HD Run last September was easy and added lots of fun to the day. "It worked out really well," the event co-organizer says. "We're very happy with the results."

A DJ amped up the energy level, while a bouncy castle, glitter tattoo artist and 1K run for kids dressed in superhero outfits kept the children entertained. Not to be outdone, many of the adults sported Batman or Superman shirts, and a team of 25 or so came dressed in matching

"Incredibles" costumes.

To reward those efforts, raffle tickets were handed to anyone who wore a costume. That included an HD researcher, who gave Annie a confused look after she gave him a ticket. "Well, you're wearing a lab coat," she explained. "So, you're already an HD hero."

Kristin was keen to celebrate other real-life heroes as well. She reached out to the Toronto Police, who went above and beyond by bringing a 1960s-era police cruiser to the event. "That was a pretty big attraction for kids and families," she says.

In total, the Toronto run raised nearly \$36,000.

The Manitoba chapter also surpassed their 2019 targets with their first hero-themed Walk/Run to Cure HD. It turned out to be their most successful year ever, raising about \$74,000 with the help of the same anonymous donor who matched donations at the Exeter hike. "It was an amazing event for all of us," says organizer Vern Barrett. "There was a lot of energy."

This year, Annie is keen to help more chapters tap into that energy with the Huntington Heroes theme. "It's been really fun," she says. "And we're seeing the revenue results associated with it."

Despite event adjustments due to COVID-19, many of our events are already open for donations, including the Winnipeg Walk and Exeter Hike of Heroes and your support is matched dollar for dollar until June 30! Find these events and more to support at www.huntingtonsociety.ca/events.

2020 Spring Calendar of Events: Coming to Your Neighbourhood Soon!

Note: In light of COVID-19, events and event dates are subject to change. For the most current information, and to find event websites to show your support, visit www.huntingtonsociety.ca/events.

NATIONAL EVENTS

Ongoing

RaceHD
Canada-Wide
p2p.onecause.com/racehd



BRITISH COLUMBIA

Postponed until Fall 2020

BC Walk
Vancouver, BC
p2p.onecause.com/bcwalk

Tuesday, July 14

Hunting Fore a Cure Golf Tournament
Langley, BC
Cancelled.
Donations may still be made at
p2p.onecause.com/huntingforeacure

ALBERTA

Fri., Aug. 28 – Sun., Aug. 30
Ride 4A Cure
Grand Prairie, AB
p2p.onecause.com/ride4acure

SASKATCHEWAN

Saturday, Sept. 19

Saskatoon Walk
Saskatoon, SK
p2p.onecause.com/saskatoonwalk

ONTARIO

Saturday, June 6

Manny's Century Ride for HD
Ayton and Southampton, ON
Solo Ride – fundraiser only.
p2p.onecause.com/centuryride

Saturday, Sept. 26

Hunt for a Cure Casino Night
Ashton, ON
Contact Chloe at
chloebrownlee@gmail.com



Sunday, Sept. 27

Durham Walk
Bowmanville, ON
p2p.onecause.com/durhamwalk

ATLANTIC CANADA

Fri., Nov. 6 – Sat., Nov. 8

Bluenose Marathon
Halifax, NS
p2p.onecause.com/racehd

VIRTUAL EVENTS

Fri., June 5 – Sun., June 7

Winnipeg Walk
Anywhere in Canada!
p2p.onecause.com/winnipegwalk

Saturday, June 27

Calgary Hope Run
Anywhere in Canada!
p2p.onecause.com/hoperun



Training the Next Generation of HD Clinicians

By Julie Stauffer

Dr. Fabricio Pio's fascination with the brain goes back many years. "I always thought there was so much to discover," he says. "And I'm quite a curious person." So, after finishing medical school in his native Brazil in 1996, he did a residency in neurology and set up a practice.

He worked as a neurologist there for many years, interspersed with research stints and clinical fellowships in Ontario and Alberta. In 2018, he joined Dr. Blair Leavitt and the research team at the Centre for Huntington's Disease (HD) at the University of British Columbia (UBC) – first as an observer and then as a clinical fellow, learning how to conduct assessments on patients with HD.

He is also learning how to run clinical trials like Roche's GENERATION-HD, Vaccinex's SIGNAL study, HDClarity and a new one called KINECT-HD, which is testing a treatment for chorea. Dr. Pio loves the team he works with. "They are just fantastic. It's a great environment," he says. Meanwhile, he is impressed with the families affected by HD he has met and their willingness to participate in research.

But what really gets him fired up are the advances in science. "There is so much research going on and so much excitement with the new developments," he says. "I feel very privileged in many ways to be able to be part of the research studies that perhaps will change lives."

It's all thanks to a clinical fellowship generously funded by the Beckman and Manning families (see page 7 to learn more about Paul Manning and his legacy). The three-year program is designed to equip more neurologists with the skills to run clinical trials as more potential treatments for HD are developed.

In the case of the Centre for HD, Dr. Pio's support has made it possible to recruit more participants for existing clinical trials and to launch new studies. "It cannot be emphasized enough how important it is for us to train the next generation of HD researchers," says Dr. Leavitt. "This fellowship opportunity has enabled us to train an excellent new HD clinician and to bring them into the fight against HD."

That is exactly what the fellowship has done for Dr. Pio, inspiring him to pursue a career in HD research. "I want to continue to work in this field. I find it very, very exciting," he says. "It's about hope. That's what excites me the most."

The Centre for HD and Dr. Leavitt would like to thank and acknowledge the leadership and support of the Beckman and Manning families, which has made this fellowship possible.



YPAHD Column



By Doug Mallock, YPAHD President

Spring is here and what an unusual time it brings for this great planet we call home. As many of you know, the COVID-19 outbreak has affected Huntington Society of Canada (HSC) event planning (see page 9 for more). That means the postponement of our National Conference and Young People Affected by Huntington Disease (YPAHD) Day as it was planned. I know that this will disappoint many in the community, but the

Huntington Society of Canada (HSC) leadership has done the right thing in an effort to keep us all safe. I for one am glad that HSC has taken proactive steps to protect the HD community as well as its awesome staff. I know they continue to work hard on our behalf and thank them for adapting their business operations so quickly to continue to provide the services our community relies on.

Having said that, we'll still hold virtual elections for the YPAHD executive team on Nov. 12. You can nominate yourself or someone else and vote online, so it's super easy. It's a pretty satisfying gig, giving you the chance to shape the future of YPAHD. Keep your eye out for the call for nominations, and don't be afraid to take that first step.

On HSC's youth mentorship front, the organization trained a new batch of mentors in the Fall, to help mentees through the day-to-day struggles of being affected by HD. If you're a young person looking for support, contact Erin at mentorship@huntingtonsociety.ca or 1-855-253-0215.

YPAHD is all about connections – whether it's through monthly conference calls, social media, amazing events like YPAHD Day or one-on-one mentoring. If you're not involved yet, what are you waiting for?

youth MENTORSHIP program

Supporting young people across Canada facing everyday challenges of HD

Become a *mentee.*

Become a *mentor.*

Connecting youth with an adult mentor from a family with HD for valuable support

For more information, visit:
www.huntingtonsociety.ca

From Fearful to Award-Winning Fundraiser

By Josh Martin

Last November, when the South Saskatchewan chapter of the Association of Fundraising Professionals handed out their annual awards, Outstanding Individual Volunteer went to Lisa Pollock.

For the 33-year-old, it marked a milestone in a journey that began eight years ago. That's when the death of her grandmother revealed that Huntington disease (HD) lurked in her family. Lisa suddenly found herself – and her 14-month-old daughter – at risk of inheriting a fatal disease. She felt alone, afraid and confused.

But then the elementary school teacher connected with the Huntington Society of Canada (HSC). She started participating in the Saskatoon chapter's annual Walk to Cure HD. She became a youth mentor, volunteered at Huntington's Disease Youth Organization (HDYO) camps and joined the Young People Affected by Huntington Disease (YPAHD) executive team as the youth chapter's social media coordinator (Lisa is also the social media coordinator for the Saskatoon chapter).

The connections Lisa has made with other young

people affected by HD have changed everything. "I have this feeling of a brand new family that I've created," she says. "It creates this fire in us to want to do more."

For Lisa, that included ramping up her fundraising. She remembers lying awake in bed, trying to think of ideas. "Everyone has something to bring to the table," she says. For her, that was social media savvy.

She created an online auction on Facebook, featuring donations that range from baked goods to barn-wood mirrors. The wildly successful event now raises thousands of dollars for HSC each year. "It became so much bigger than I ever anticipated," she says.

Having that work recognized was a big honour, but the biggest honour was realizing how many others she has touched. "More people than I ever imagined," Lisa says.

Today, she feels overwhelmed by hope, thanks to clinical research and a new sense of community. And through her fundraising and volunteer work, that hope keeps growing.



Lisa Pollock has deservedly received the Outstanding Individual Volunteer award from the South Saskatchewan chapter of the Association of Fundraising Professionals.

Mini-Putt Meet-Up: Mack Remillard Connects Manitoba Youth

By Josh Martin

Mack Remillard remembers watching his aunt's health deteriorate as her Huntington disease (HD) progressed. A couple of years after she passed away, his mom also started showing signs of the disease. Although the 19-year-old has tested gene-negative, his younger sister remains at risk.

For Mack, dealing with all that was an isolating experience, especially living in St. Malo, MB: population 1,227.

Then he attended Young People Affected by Huntington Disease (YPAHD) Day at the 2014 Huntington Society of Canada (HSC) National Conference in Winnipeg, MB. Connecting with other youth was transformative. "It's given me more support than I've ever had," he says. "It also showed me how I can be more involved as a young person in my community."

But he noticed that besides his sister and two cousins, there were few participants from Manitoba at the event. To help change that, Mack stepped up as the Manitoba chapter's first youth coordinator in 2018.

Last September, he and his girlfriend set up a table at the chapter's annual Indy Go-Kart Challenge, inviting youth to take part in a free mini-golf tournament. The recruitment strategy worked. Over the course of the day, four youth signed up, tackled the mini-putt course and won YPAHD swag. Most importantly, they connected.

Four might not seem like a lot – but it's a start, says Mack. Looking ahead, he envisions organizing other social events like bowling, bringing in speakers to talk about HD and inspiring youth in Manitoba to fundraise. "We want to make a change," he says. "I hope that we keep growing the little group we have now."



Mack Remillard (pictured, left, with his girlfriend Teaghan), became more actively involved with YPAHD after attending YPAHD Day in Winnipeg, MB in 2014.



Feeling the Buzz

By Josh Martin

When Dr. Jeff Carroll's mom was first diagnosed with Huntington disease (HD), he discovered there was a lot of misinformation online. What credible information did exist often required an advanced degree to decipher. So when he decided to pursue a career in HD research, he was determined to make the results more accessible to families hungry for information.

He got his opportunity at the 2009 HD World Congress in Vancouver, BC. Each evening, he and Dr. Ed Wild hosted a "nightly news report," moderated by veteran TV journalist Charles Sabine. Together, they would translate the day's complex gobbledegook into digestible explanations. Charles even had a bell he would smack whenever one of them got too technical. The audience loved the humour – and they loved learning what was happening in the world of HD science.

Inspired by the experience, Drs. Wild and Carroll launched the website www.HDBuzz.net (HDBuzz) in 2011. The regularly updated website features clear explanations of the latest HD breakthroughs, details of upcoming clinical trials, podcasts and videos about new discoveries and a glossary of terms to help visitors to the website understand everything from anti-sense oligonucleotides to zinc-finger nucleases.

Over the past decade, the stream of HD research has become a flood, but readers can count on HDBuzz to highlight the most important advances and explain how they move us closer to effective treatments.

To remain completely impartial, HDBuzz receives no money from drug companies. Instead, it relies on funding from the Griffin Foundation and HD organizations around the world— including the Huntington Society of Canada (HSC). "HSC's really



Drs. Ed Wild (left) and Jeff Carroll are the founders and driving force behind the popular website www.hdbuzz.net. It has become one of the most reliable resources for the HD community in terms of scientific news – which is broken down into plain words and delivered in 19 languages to anyone around the world.



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!

been a key part of making HDBuzz successful," says Dr. Carroll.

Today, the team of editors includes McMaster University's Dr. Tamara Maiuri and the University of Toronto's Dr. Rachel Harding, while a network of translators make the content available in 19 languages. The site attracts more than 37,000 monthly visits, and kudos keep pouring in.

Readers say HDBuzz helps them turn something terrifying into something more manageable. And each new post gives them more reason for hope. "The journey from 'new to HD and terrified' to 'empowered HD warrior' seems to be much quicker nowadays," says Dr. Wild. "Partly, that's because of reduced stigma, improved support and the power of social media – but I like to think we have played a small part."

In recognition of their efforts, Drs. Wild and Carroll received the Michael Wright Community Leadership Award at the HSC National Conference in Toronto, ON in 2012. The award is in recognition of unique contributions to the HD community in the areas of clinical leadership, family support and community development.

To check out HDBuzz, visit www.hdbuzz.net. If you're new to the world of HD research, click on the "start here" button for a helpful overview.



COVID-19: What Does it Mean for Patients with HD and Families Affected by HD?

Extracts from HDBuzz.net, April 6, 2020

COVID-19, short for coronavirus disease 2019, has taken the world by storm in almost every sense – many people have been infected with the SARS-CoV-2 virus, it's created shopping pandemonium in stores, and many people are isolated at home. But behind that frenzied storm, scientists around the world have been working tirelessly to move research forward at an unprecedented speed so that we can understand the virus and develop a treatment or vaccine.

A key question for many in the Huntington disease (HD) community right now is: Am I, or is my loved one, at greater risk for COVID-19 because of HD? The answer to that is – it depends. On its own, having the genetic mutation that causes HD doesn't make anyone more or less susceptible to COVID-19 than someone without HD.

What would make an individual with HD more susceptible to COVID-19 is if they had any underlying conditions that put them in the "high-risk" category. Those can be as obvious as having asthma or being a smoker. But this can also include individuals with HD who are symptomatic since we know that swallowing, clearing secretions from the lungs, and self-understanding of limitations can be impaired by HD.

To stay safe and healthy we should all continue doing what the WHO recommends – wash our hands regularly for 20 seconds with hot water, clean surfaces with a disinfectant, and practice social distancing. Social distancing means only coming in contact with members of your household and only going out for essential things, like an essential job, grocery store run, or to get medication from the pharmacy. Everyone should also remain vigilant for the symptoms of COVID-19, which include fever, a dry cough, shortness of breath and fatigue.

Some patients with HD at particularly high risk may need to isolate themselves even more strictly. You should seek advice from the above sources and your health provider if you are concerned.



HD-COPE Meeting Cancelled

By Josh Martin

The Huntington Disease Coalition for Patient Engagement (HD-COPE) serves as an important voice for families affected by Huntington disease (HD). The international team – including five Canadians – consists of carers and individuals who are at-risk, gene-positive or gene-negative. This year, the HD-COPE team added participants from Africa, China and Australia.

Each year, they meet with pharmaceutical companies to share their lived experiences with HD, helping ensure clinical trials consider the unique needs of patients and their carers. That's crucial, because if participating in a trial is too difficult for volunteers, they drop out, delaying the assessment of potential treatments.

This year the Huntington Society of Canada (HSC) was prepared to host the international meeting in Toronto, ON. Unfortunately, due to COVID-19 concerns, it was collectively decided that the meeting should be cancelled. The HD-COPE team continues to work diligently to find alternative ways to connect the international group.

When HSC teamed up with the European Huntington Association (EHA) and the Huntington's Disease Society of America (HDSA) to launch HD-COPE in 2017, nothing like it existed. Today, it is more important than ever, as a growing number of potential treatments reach the stage of clinical trials.

According to HSC's interim CEO, Bev Heim-Myers, HD-COPE represents the gold standard for incorporating the voice of patients into drug trial design. "This is an amazing program," she says. "I'm a real believer that if you bring the right people to the table, you get the right outcomes."



HSC Working to Provide Resources for ALL of the HD Community

Heritage Canada Grant Helps HSC to Translate Factsheets to French Language

In early 2019, the Huntington Society of Canada (HSC) received a grant from Heritage Canada to help offset the costs of translation of 30 factsheets into French. The funding came through the "Support for Interpretation and Translation (SIT) Program", a subcomponent of the Official Languages Support Program.

"It's important that as many people as possible from the Canadian Huntington disease (HD) community feel that they can access the information they need in either official language," says HSC's national director of family services, Angèle Bénard. "By translating the bulk of our factsheets, we're taking a step in the right direction."

The SIT Program assists organizations in providing bilingual services, and supports the availability of an increased number of documents in French and English. Eligible applicants must be Canadian not-for-profit organizations.

The availability of French language factsheets will help HSC expand outreach efforts in French speaking communities across Canada including New Brunswick, Québec, Northern Ontario, Manitoba, Saskatchewan and Alberta. HSC will use the factsheets at educational events and in individual and group counselling sessions. They will also serve as a resource to assist healthcare professionals (including doctors at genetics clinics

and staff at long-term care facilities) in working with people with HD.

"HSC's factsheets play an essential role in the organization's outreach efforts and communications strategy and are a central means of communicating information to our members and the general public about all aspects of the disease and the services we provide," says Rachel Thompson, HSC's development coordinator. "The grant has allowed us to effectively build the resource capacity at HSC."

As of April 2020, all thirty translated factsheets are posted to the English HSC website at www.huntingtonsociety.ca/hd-fact-sheets/. You can also find them as downloadable PDFs on the French HSC website at www.huntingtonsociety.ca/language/fr/fiches-dinformation/

The factsheets are available for members of the organization and the Canadian public, including those living with HD, family members, caregivers, and members of the medical community. They will be available in hard copy from HSC staff at HD resource centres across Canada.

"Thanks to Heritage Canada, we now have more resources available in French," adds Thompson. "We plan to seek out additional funders for translation services in the near future, so that we can better serve the Francophone HD community going forward."

Leaders in the HD Community: Jonathan Genest-Jourdain

By Josh Martin

On the northern shores of the St. Lawrence River – more than 600 kilometres east of Québec City, QC – Jonathan Genest-Jourdain runs a busy law office in his hometown of Uashat-Maliotenam. After earning his law degree from Université Laval in 2004, he launched his career as a lawyer in this remote Innu community.

A few years later, Jonathan found himself defending a client with Huntington disease (HD) who had ended up on the wrong side of the law. “He was acting erratically because of the disease,” Jonathan explains. Jonathan brought in doctors and specialists to ensure the judge understood the illness behind the man’s criminal behaviour.

Sadly, it’s not an isolated case. While about one in 7,000 Canadians are affected by HD, that figure is 50 times higher in Uashat-Maliotenam. More than one in 200 residents in this community of 4,000 have been diagnosed with the disease, and potentially hundreds more carry the mutant gene.

In 2011, Jonathan interrupted his legal career to enter politics. He was elected as the Member of Parliament for Manicouagan as part of the NDP “orange crush” and appointed Deputy Critic for Aboriginal Affairs and Northern Development.

Jack Layton wasn’t the only one keen to tap into his expertise. In 2013, Huntington Society of Canada (HSC) CEO, Bev Heim-Myers, invited him to join HSC’s board of directors. Jonathan accepted, serving on the board for six years. “I was a bit intimidated at first,” he admits, recalling the group of world-renowned experts sitting around the table.

However, he brought important perspectives to the table as an Innu and lawyer who understood what it meant to live in an isolated community hit hard by HD, addiction, depression and other issues. “I did my best to bring forward all those social aspects,” Jonathan says.

Back in Uashat-Maliotenam, support for the HD community has been improving. The Société



Huntington du Québec (SHQ) has been training local healthcare professionals and offering respite programs for caregivers and a genetic counsellor has developed a series of web-based videos about HD in French and Innu.

Meanwhile, the local band council opened a residential facility specializing in HD in 2015, with support from the federal government, Montréal’s Hôpital Notre-Dame and other partners. The first of its kind in Canada, Le Centre Shakashtueu can accommodate eight Innu patients.

It also supports the broader HD community, offering caregiver resources, evaluations for mobility and swallowing, advice from nutritionists and kinesiologists and more. Meanwhile, researchers and specialists from McGill University travel to the community to conduct tests and check-ups each year.

Today, Jonathan continues to be involved in the HD cause. Serving on the HSC board and serving his clients has taught him a lot about the disease. He’s also seen just how much progress researchers have made towards treatments.

But what impresses him most is how the people affected by the disease – the families, the youth involved in Young People Affected by Huntington Disease (YPAHD), the volunteers – work together to support each other. “That’s something to witness, the solidarity,” he says. “L’esprit combattant, as we say in French.”



WE NEED YOU!

**ARE YOU A SUPPORTER OF
THE HUNTINGTON SOCIETY OF CANADA?
INTERESTED IN GETTING MORE INVOLVED?**

HSC is now accepting applications to its Board of Directors for vacancies beginning in 2020 and 2021. This national board includes 15 directors from across the country who combine enthusiasm for the work of HSC with expertise in one or more areas of business including law, governance, fundraising and development, finance, media/communications, strategic planning, science and research and human resources.

Forward your CV and Letter of Interest, outlining your skills and experience to:
HSC Board of Directors
Huntington Society of Canada
20 Erb St. W., Suite 801
Waterloo, ON, N2L 1T2
Or email: jgulka@huntingtonsociety.ca

All nominations received by May 20, 2020 will be considered.

JOIN THE HSC BOARD OF DIRECTORS



COMMUNITY EDUCATION FORUM
2020-2021 SEASONAL SERIES

May 30, 2020

Huntington Society of Canada
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Amaryllis Unboxed

Behind the Scenes of HSC's Biggest and Longest-Running Fundraiser

By Julie Stauffer

As the last cases of Amaryllis shipped last Fall, and the Huntington Society of Canada (HSC) accounting department added up the final totals for the 2019 campaign, across Canada, more than 20,000 bulbs bloomed in all their deep red-orange glory. Now, at national office, development coordinator (and coordinator of the Amaryllis campaign), Rachel Thompson, is gearing up for Amaryllis 2020.

Pulling together HSC's biggest and longest-running fundraiser will be a 12-month job, says Rachel, who joined HSC in March. Here's a behind-the-scenes glimpse of what's involved in bringing Amaryllis bulbs to your door.

January to March

While scores of Amaryllis photos are brightening up our social media feeds, Rachel is sitting down with our bulb supplier to assess the previous year's campaign. How was the quality of the bulbs? Did the distribution go smoothly? What could be improved? Rachel will review the design of the boxes and decide if anything needs to be tweaked.

This year, she's considering adding a small brochure about Huntington disease (HD) to each kit. "A lot of these bulbs are sold to families and individuals who understand HD, but a lot of them are not," she points out. Why not seize that opportunity to boost awareness?

Meanwhile, in the Netherlands, bulb producers are busy in their greenhouses. Growing Amaryllis is a

lengthy process. Each bulb takes a full three years before it's large and firm enough to be harvested!

April to June

Once spring arrives, HSC starts focusing on early-bird orders. Anyone who puts in an Amaryllis order by July 1 gets entered in a draw. "Everybody likes a little contest and an opportunity to win," Rachel explains. And we offer some great prizes. Last year, our winner took home a Kindle device and a copy of Julie Lawson Timmer's HD-inspired novel *Five Days Left*.

Spring is also the time HSC picks its bulb supplier, agrees on pricing and signs a contract. For the last 15 years, we've worked with Van Noort Bulb Company in BC. "It's awesome that we can be a part of it," says Tessa Wood, an administrator at the bulb and perennial wholesaler. "We feel really excited that we get to partner with the Huntington Society of Canada."

July to September

Across the ocean, Amaryllis growers are digging up the bulbs and cleaning them scrupulously. Before the bulbs can leave the Netherlands, they must be scrutinized by the Canadian Food Inspection Agency to make sure they're completely free of soil that might carry plant diseases.

Once they receive approval, the bulbs are trucked to Belgium and then loaded onto ships for a two-week transatlantic voyage to Montréal, QC. Then they hit the highway – some destined for Van Noort's facilities in St. Catharines, ON and some to their headquarters in Langley, BC.

When they arrive, Van Noort staff at each location swing into action, setting up production lines where teams of five check the quality of the bulbs and start the big job of assembling more than 25,000 kits.

October to December

Back at national office, the campaign shifts into high gear. In early October, HSC sends its first, massive order to Van Noort. But that's just the beginning.

HSC staff continue to field orders from volunteers right through to November. Some orders come by phone, some by fax and some by email. Some volunteers pay for their cases up front, while others wait until they've sold them. "We try to make it as easy as possible," says Rachel.

At Van Noort, the deliveries start going out to every province and territory. Shipments are made from the beginning of October until the first week of December.

Not all the bulbs make it to the delivery trucks. Tessa admits she buys some for herself. "I love them so



Thanks to Dutch supplier Van Noort Bulb Co. and volunteer sellers across the country, HSC reached its bulb-selling goal again in 2019!

much!" she says. "My husband asks me, 'aren't you supposed to be selling those, not taking them home?'"

Of course, volunteer sellers are busy as well! Some have already lined up friends, neighbours and co-workers who want a kit or two. Others set up tables in malls, office lobbies or craft shows.

Amaryllis are an easy sell. "What else can you buy for \$15 that is a really lovely gift?" Rachel asks. And you don't need a green thumb to make them bloom. "These bulbs grow anywhere, anytime, anyhow," she says.

Volunteers agree. Each year, the campaign grows a little more. People who bought one kit last year want a couple the next year. Sellers who ordered two cases last year now order three. And that excites Rachel. "I don't think we're anywhere near where we can be with this campaign," she says as she starts setting 2020 targets. "I think this has the potential to be even bigger."

Gearing Up for the 2020 Amaryllis Campaign

Spring is in the air. That means it's early-bird contest time for the 2020 Amaryllis campaign! Place your order before the end of June for your chance to win Julie Lawson-Timmer's book *Five Days Left* and a Kindle device. Don't know exactly how many kits you'll need or when you want them delivered? Don't worry! Give us your basic order information, and we'll connect with you in the Fall to firm up specifics. To get started, visit www.inspirehope.ca, email amaryllis@huntingtonsociety.ca or call us toll-free at 1-800-998-7398.

Be sure to send us your 2020 Amaryllis photos as well! Just email us at amaryllis@huntingtonsociety.ca or use #HSCAmaryllis on social media.



We had another amazing crop of submissions to our Amaryllis Photo Festival this year, including the winning photo above sent to us by Erin P., featuring her daughter, Emma doing some quality control on her Amaryllis bloom. The picture won the vote by a landslide. Well done, Erin and Emma!

Thank you to everyone who made the 2019 Amaryllis campaign a success!

COVID-19 Brings New Era for HD Awareness

May is Huntington disease (HD) Awareness Month and by all accounts, it is shaping up to be one of the most unusual years for the campaign ever, thanks to the worldwide COVID-19 pandemic. Since 2015, volunteers from across Canada have been working to illuminate various buildings, monuments and statues during the month of May to raise the visibility of HD and Juvenile Huntington disease (JHD).

Thanks to the enthusiasm of the HD community and many HD volunteers, “#LightItUp4HD 2019” saw a record number of participating sites, worldwide. In Canada, 55 sites participated in #LightItUp4HD, while another 114 international buildings, monuments and other structures lit up in blue for HD and/or purple for JHD. Last year, an international total of 169 sites participated – nearly 50 more than in 2018.

But the measures in place to prevent the spread of COVID-19 in 2020, unfortunately mean towns and municipalities are discouraging public gatherings (flag raisings) and simply don’t have time for additional paperwork – like filing #LightItUp4HD requests. While we may not knock it out of the park as we had hoped this year, any site that does come on board is a site

gained during “unusual times”. We are asking people to keep up the good work with their asks throughout May, while realizing it may not be a priority at the municipal level.

What you might consider is doing something at the residential level, during self-isolation. Why not encourage people to hang posters in their windows supporting HD awareness month? How about purple or blue porch/Christmas lights? HD ornaments in a tree in your front yard – or sidewalk chalk! Send messages of support to the HD community any way you can – from your home. We can still make HD Awareness Month a success – even if it’s virtual – in May 2020. And, we can #ChalkItUp4HD and #StringItUp4HD at home!

Thanks to James Walters, Founder of the Global Huntington Association and the #LightItUp4HD initiative, national #LightItUp4HD volunteer, Carolyn McKinney, chapter volunteers across Canada and international partners, #LightItUp4HD does continue to gain interest and increase awareness and in 2021 it will be back to hopefully set the bar at new levels. Don’t forget to send your creative ideas and pictures to us at the HSC national office via communications@huntingtonsociety.ca!



Thank You!

On behalf of families living with Huntington disease (HD), thank you for your continued partnership and generous support. Our community makes the difference as we reach out to families who are not yet connected to the Huntington Society of Canada (HSC), continue to support and advocate for families from coast to coast, invest in world-class research, and play a leadership role in the international Huntington disease community. With your help, we are 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 us at info@huntingtonsociety.ca or call us at 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 our website, select the Français

option at the top right hand corner of our 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.