

HORIZON

RESEARCH • SERVICE • EDUCATION

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Spring 2019

Roche Trial Moving Forward

Six Canadian Sites Involved in Pivotal Phase III Trial

By Josh Martin

As we described in our last issue of *Horizon*, earlier trials that wrapped up in 2017 showed the huntingtin-lowering drug, RG6042, is initially safe and that higher doses reduce the level of huntingtin protein by 40 to 60 per cent. Now, Roche aims to find out whether the drug can actually slow HD progression and determine the long-term effects of lowering huntingtin. If the trial proves successful, RG6042 could become the first treatment available that addresses the root cause of HD.

Canada's Clinical Trial Contributions

Roche plans to recruit 660 participants for their GENERATION HD1 study — a pivotal Phase III clinical trial to test the effectiveness of the huntingtin-lowering drug RG6042 — at sites around the world. Six of those sites are here in Canada:

- Centre for Huntington Disease at the University of British Columbia in Vancouver
- University of Alberta in Edmonton
- Centre for Movement Disorders in Toronto
- Ottawa Hospital
- Centre Hospitalier de l'Université de Montréal
- True North Clinical Research in Halifax

The number of Canadian sites is no accident, says HSC's CEO Robin Markowitz, pointing to the Society's clinical readiness roundtables and the depth of research expertise in this country. The other key difference-maker is the HD community. "It's incredibly courageous for people to come forward and be part of clinical trials," says Robin. "They're the unsung heroes, stepping up for the betterment of everyone."

Not everyone with HD is eligible to participate in GENERATION HD1 — and that's deliberate. "It's a very select group," says Dr. Mark Guttman from the Centre for Movement Disorders in Toronto. "Roche has been very clear that they want to have the best scenario to be able to answer a very clear question: Is this medication going to work and is it safe?"

Important Changes to GENERATION HD1: Fewer Lumbar Punctures!

In March, Roche announced a key change to GENERATION HD1. Originally, the trial involved monthly spinal injections called lumbar punctures. Moving forward, however, participants will only receive injections every second month.

Roche made the change after reviewing data gathered from the open-label extension of the Phase I/IIa study for RG6042. In this extension, participants who completed the Phase I/IIa study have continued to receive RG6042: some have been receiving the drug monthly; some, every other month.

An analysis of the data suggests the less frequent dosing is enough to lower the levels of the huntingtin protein. Roche now plans to divide participants into three groups. One group will receive RG6042 every two months. Another group will receive a placebo every two months. The third group will get injections every two months, alternating between the drug and the placebo. In all cases, neither the volunteers nor their doctors will know whether they're receiving the drug or the placebo. There will be a brief pause in recruitment for GENERATION HD1 while the new study design is approved.

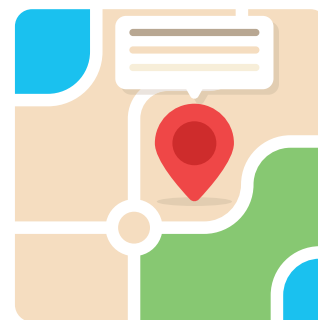
Getting the Answers We Need

Meanwhile, the new HD Natural History study will complement what we're learning from other studies. The 15-month observational study seeks to further understand how levels of the mutant huntingtin protein naturally change over time. To do that, participants will undergo a number of tests and receive four lumbar punctures to take cerebrospinal fluid samples over the course of the study.

Unlike GENERATION HD1, there is no drug involved in this study (although Roche hopes to offer RG6042 to participants who complete the study). Because of this, researchers will be able to compare disease progression between untreated patients and those receiving RG6042. To draw meaningful conclusions from those comparisons, researchers need volunteers

Find Clinical Trials in Canada

The Huntington Society has created a NEW interactive map, listing clinical trial sites across Canada.



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

who match participants as closely as possible in age, gender, CAG repeat lengths and more.

The study will include up to 100 participants, with early symptomatic HD, at up to 17 global sites. Two of those sites are in Canada: Dr. Guttman's clinic in Toronto and the Centre for Huntington Disease at UBC. In January, Roche announced that the first sites had opened and the first volunteer enrolled was a Canadian.

Full Steam Ahead

Now, the goal is to get all the trial and study sites up and running as quickly as possible. "After so much preparation, it's incredibly exciting to finally see this next phase get underway," says Robin. "Roche's choice to run six clinical trials in Canada highlights the high caliber of our doctors and scientists, as well as the high level of engagement within the Canadian HD Community."

For more information about clinical and observational studies in Canada, visit

www.huntingtonsociety.ca/hd-clinical-trials.

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HORIZON

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Horizon is the newsletter of the Huntington Society of Canada. Published throughout the 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 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



For Huntington disease awareness month we've never had such good news to share. Today there are several clinical trials underway in Canada for treatments that could slow or stop the progression of HD: Roche's GENERATION HD1 trial, Wave's Precision HD-1 and HD-2 trials, and Vaccinex's SIGNAL trial for VX15/2503 (read more about it on page 4).

Across the country, our amazing volunteers will be spreading that message, as well as raising flags, making proclamations and lighting up local landmarks in blue and purple. They're educating Canadians who aren't familiar with HD and reaching families affected by HD who haven't connected with us yet.

Our chapters are planning all kinds of fundraising events as well, from walks and runs to art shows, concerts, bowling nights and book sales. The Huntington Society of Canada relies on the generosity of donors – and the passion, commitment and drive of the volunteers who organize these events.

There's no question that volunteers are the lifeblood of our organization. It's truly amazing what they accomplish, and I can't thank them enough. And awareness and fundraising aren't the only ways they contribute.

In February, I had a chance to meet the HD-COPE volunteers who are helping pharmaceutical companies understand HD. As a result, the trials will be designed with further understanding of how to best capture the vital data from those affected by HD.

I also want to acknowledge all the courageous people who are stepping forward to volunteer in observational studies and clinical trials. Each month, they're undergoing a battery of tests and – in the

case of the Wave and Roche trials – they're also receiving lumbar punctures. Their contributions will benefit the entire HD community.

While we wait for the results from those trials, HSC is not sitting still. We've announced that Dr. Ragini Srinivasan is the 2019 recipient of our new clinical fellowship, designed to attract bright young neurologists to the field of HD research. We've also redesigned our biannual Symposium (now renamed the Community Education Forum) to better meet the needs of our community.

Instead of live-streaming national presentations, we're recording them so that local chapters can present them on the date of their choosing, together with local programs reflecting local interests. Don't miss our sessions with two global leaders in HD research: Dr. Michael Hayden and Dr. Ed Wild. (Visit www.huntingtonsociety.ca/CEF for a site near you.)

Meanwhile, when we undertake our strategic planning this spring, we'll be looking at what new resources we can create and how we can better advocate for families. We're also planning for the day when meaningful therapies become available, laying the groundwork now for drug access.

Since I joined the Society last summer, I've had the chance to speak with many of you. You've helped me understand just how complex a disease this is and how much support families need. I'm listening! What strikes me most from my conversations with the HD community is your belief in a better future. I share your belief — and together, we will achieve it.

Robin Markowitz

Robin Markowitz
CEO, Huntington Society of Canada



We provide a community and support network for young people affected by Huntington disease.



Visit
www.ypahd.ca
for more info.



HSC Community Education Forum (formerly Symposium)

The Huntington Society of Canada invites you to attend its annual Community Education Forum for presentations on research and caregiving.

HEARTS FULL OF

hope

Visit us at
huntingtonsociety.ca/CEF
for a list of dates and
locations near you!

Hearts Full of Hope

The world of HD research moves quickly and can often be confusing. That's why every other year HSC provides a live forum where patients and carers can meet and learn about the most recent updates in HD.

This year, the HSC Community Education Forum (formerly Symposium) will take place in more than 20 locations across Canada from April to November. Families will learn about current clinical trials as well as what is in the pipeline.

Presentations will include Huntington Disease Research Updates from Dr. Ed Wild, How to Manage Expectations for Clinical Trials with Dr. Michael Hayden and local HD experts who will present on a variety of topics. The forums also offer families invaluable opportunities to network with each other and to have their questions answered by leading professionals specializing in HD.

"We are so fortunate to have leading HD clinicians and researchers who work closely with us to host events such as the Community Education Forums," says Robin Markowitz, HSC CEO. "Their support enables us to provide current information in this increasingly changing landscape."

Understandably, the HD community's excitement is palpable right now because there is hope for treatments that target the root cause of HD. Many of our families have expressed that for the first time that they can recall, they have hearts full of hope.

"All these research breakthroughs provide hope," says Greg Taylor, Edmonton Chapter President and organizer of the Edmonton Community Education Forum. "Hope is the fuel that moves us forward towards the goal of a meaningful treatment. By being united with others affected by HD and being focused on a common goal, we gain strength to persevere."

The Community Education Forums offer local groups across Canada the chance to gather together to connect with one another in a safe environment. Care strategies are shared, research updates are heard and connections are made. Due to the isolation that can accompany HD, many of our community members value this event to see each other again. Especially if they are a group that doesn't meet regularly.

"Given that the National Conferences are every two years, the community education forums are a great way for people in the community to catch up with each other and on the latest and greatest in HD research," says Steven Beatty, organizer of the Barrie, Ontario, Community Education Forum. "Getting together face-to-face can be so beneficial because you learn you're not alone and you get that real sense of family."

And for some groups, this could be the first time they will have an opportunity to get together.

"This is the first time that we have a specific resource centre for Mississauga and Halton," says Ekta Hattangady, new Resource Centre Director for Halton/Peel, Ontario and organizer of the first Mississauga Community Education Forum location.

"We are hoping that this means more awareness for service providers and the general community. This will in turn improve the experience of families when they try to access services."

Visit www.huntingtonsociety.ca/CEF for more information and a full list of participating sites.

Join our Champions of Hope...

GIVE MONTHLY.



Giving a monthly donation is an easy way to make a big impact.

Visit www.huntingtonsociety.ca/monthly-giving or call us at 1-800-998-7398 for more information.



An Ariel View

By Ariel Walker, Co-Founder of HSC



I am excited for HD Awareness Month in May. It's wonderful to see all the activities going on across the country – all the flag raisings and events and things lit up in blue and purple. I would also like to say thank you to everyone who will share their stories to create a better understanding of HD.

Education and awareness have always been a big part of the Huntington Society's mission. Back when we started, there was so little information available, even for medical professionals. When I was in nursing school, they only mentioned HD once, in a class about rare diseases. Meanwhile, the general public knew almost nothing.

One of the first things we did after creating the Society was to print brochures with a list of HD symptoms and our contact information, so people could get in touch. I still have a copy somewhere! We wrote to hospitals and we held meetings. And whenever we could, we did media interviews.

Thank goodness we lived in a small town, because the local newspaper was always looking for things to print. I think Ralph must have been interviewed by them at least once a year, and every time an article was published, new people called us. I remember after one article appeared, we got calls from three different local families with HD. None of them knew each other, and we didn't know them – and Galt was just 30,000 people back then!

That's why May awareness is so important. Even with the amount of information available online these days, speaking up and organizing events always reaches new families and educates people who might not know about HD. Anything you're able to do to raise HD awareness in May, or any month, makes a difference.

I hope you'll also be able to come to HSC's Community Education Forum – what we used to call the Symposium. I just finished recording my video messages for it. The theme is Hearts Full of Hope, and I know it's going to give lots of hope to lots of people when they hear Dr. Michael Hayden and Dr. Ed Wild talking about clinical trials.

This year, it's going to be held on different dates all across the country, so make sure you check the website for details. I'm so excited to see all the places that will be hosting it. There are big cities, of course, but also communities like Quispamsis in New Brunswick, Bowmanville in Ontario and Conception Bay North in Newfoundland.

Just getting together with other families at an event like the forum is powerful. Often, someone comes to their first event and goes home energized to do something. It doesn't matter where you live – it only takes one person to bring a group together, create momentum and educate their community.

That's how the Society has grown from our kitchen table into today's phenomenal organization: individuals all across Canada, each making a difference.

I think about all those hearts full of hope and I get a little teary. Together, we've come so far – and we're going to keep going.

For more information on the Community Education Forums and to find a location near you, please visit www.huntingtonsociety.ca/CEF.

Testing for the Gene Takes a Team

You know that HD is in your family and that you are at-risk of having HD. You've decided you want to get a genetic test to see if you are gene positive or negative for HD.

In every situation, the decision to undergo genetic testing is a personal decision.

Additionally, anyone considering genetic testing is strongly encouraged to take part in genetic counselling. The goal of genetic counselling for HD is to help individuals better understand the impact of the testing results. There is no fee for genetic counselling or testing (if deemed appropriate) as it is covered by provincial health insurance.

HSC's Family Services Team often provides support for individuals by being a part of the genetic counselling meetings.

"In Saskatchewan the process is very collaborative between the genetic counsellor and myself," says Erin Stephen, Saskatchewan Resource Centre Director. "When an individual makes an appointment with the genetic counsellor, the counsellor asks if they would like the HSC Family

Services Team member to be a part of the appointment. If they say yes, I attend the first appointment to meet them, give them more information about HD and how I can support them."

While the process isn't as streamlined as this in every area, it's important to know that the option is always available for an HSC Family Services Team member to be at those appointments with you; you just have to ask.

"It is your right to have the family services worker included," says Erin. "Even if they do not give you this option initially, you can ask the counsellor for them to be included or contact the family services worker directly and ask them to attend."

Having a Family Services Team member part of these meetings is important to ensure the person being tested has all of the information about HD and knows the resources available to them. This also helps to establish a relationship with their HSC support staff, no matter the test outcome.

"It's important we meet no matter what the test results are, because even a negative test result can

bring up questions," says Rhonda Romolock, British Columbia Resource Centre Director. "As HD is a genetic disease, someone in their family has it, and it's a way for people impacted to know that we can support them and their family now and in the future. It can be easier for people to reach out if they've met you in person."

Even if the individual attends the genetic counselling sessions and decides they do not want to follow through with being tested, Family Services Team members are still available to them for support in the future.

"Whether you test gene positive or negative, or choose not to be tested, we are with you," says Natasha Kulolj, Southwestern Ontario Resource Centre Director. "Whether you are affected by HD, or are caring for someone who is, resources and services are available to best support you."

If you are considering genetic testing and would like a Family Services Team member to be a part of your genetic counselling meetings, visit www.huntingtonsociety.ca/family-services-team to find a team member near you.

Jamming the Signal: New Drug Takes Aim at Reducing Brain Inflammation

By Julie Stauffer

Today, clinical trials for huntingtin-lowering drugs have generated lots of excitement. But there's another approach in Phase II trials that also has the potential to slow or stop HD.

The biotechnology company Vaccinex is currently testing a drug called VX15/2503. This antibody targets the semaphorin 4D protein: a signalling molecule that sets off a chain of events leading to brain cell inflammation. Ultimately, that inflammation causes brain cell death. By knocking out that signal, researchers believe we could stop the process before damage occurs.

VX15/2503 has been proven safe in patients with multiple sclerosis, and it has shown very promising results in animal models of HD. Now, the phase II SIGNAL trial is assessing the safety, tolerability and effectiveness of VX15/2503 in HD, focussing on people in the stages just before or after a clinical HD diagnosis.

Across North America, 240 participants have signed up at 35 sites, including Vancouver and Edmonton.

It's a big commitment. For a year and a half, these volunteers will receive monthly IV infusions of either the drug or a placebo. They'll have regular bloodwork done and undergo MRIs, EEGs and movement tests.

On top of that, they'll go through an intensive battery of cognitive tests, including pattern matching, facial recognition, symbol identification and more.

According to Paul McCann, who is coordinating the study at the Edmonton site, it's one of the most intense clinical trials he's been involved with. Despite the challenge, the HD community has stepped up in a big way. "I love working with them. They are a special group," he says.

Now that the SIGNAL study is fully enrolled, the last tests are expected to be completed in summer 2020. After that, it will likely take at least another six months to analyze the data before we find out the results.

As with any clinical trial, there's no guarantee the drug will be effective. "We're still trying to find out, do these things actually work?" says Paul. "They're still experimental."

Whatever the outcome, each new trial represents progress. And with more trials on the horizon, Paul feels optimistic about the road ahead. "This is very exciting for us," he says.



Observational Studies: A Key Piece in the Research Puzzle

By Josh Martin

Observational studies may not make headlines as often as clinical trials for potential treatments like huntingtin-lowering drugs. But make no mistake, they play a critical role in HD research by deepening our understanding of the disease. "If we don't have participants in these types of studies, then clinicians will operate in the dark," says Charles Victor, a senior director at Ontario's Institute for Clinical Evaluative Services.

Some studies – like ENROLL-HD or Roche's new HD Natural History Study – are monitoring how HD progresses. In HDClarity, researchers are collecting cerebrospinal fluid from participants to measure how the level of huntingtin protein changes as HD advances, assessing whether we can use it as a "biomarker" that reflects disease progression. Meanwhile, the upcoming FuRST 2.0 study aims to assess the effectiveness of a new rating scale to assess early symptoms of HD.

Studies like these offer crucial insights, accelerating the discovery of new interventions. They also provide a very clear picture of how HD normally progresses, so researchers can figure out whether the drugs being tested in clinical trials are actually working. That's particularly important for a slow-moving disease like HD, where the changes from month to month and year to year can be subtle.

Observational studies will also continue to make a difference if and when treatments become available. Clinical trials run for a relatively short period of time with a relatively small group of patients who meet very specific selection criteria, Charles explains. Once the drug is approved, observational studies let researchers monitor its effects over the long term in a larger, more diverse population so they can make sure it's safe for all the patients who take it.

According to Charles, developing an effective treatment means using a variety of approaches. "At the end of the day, research is really a spectrum," he explains. "Clinical trials are absolutely critical," he says, "but so are observational studies."

The greater the number of people who participate in observational studies, the more data researchers will have – and the more insights they can gain. To learn more about how you can get involved, visit www.huntingtonsociety.ca/hd-clinical-trials.

Partners in Health, Partners in Hope

Through workplace campaigns with both the public and private sectors – and through the generous support from donors – HealthPartners provides support to their 16 charity partners to improve the health and quality of life of Canadians and to advance life-saving and life-changing research.

For more than 30 years, HealthPartners has been supporting families impacted by HD. HealthPartners helps businesses engage their employees by promoting wellness programs and offering information sessions by the 16 charities.

In Canada, we have over 30 volunteers across the country that are affected by HD who take part in these HealthPartners events.

Simon from British Columbia has volunteered recently by giving presentations on what HD is and how it affects him. Most notably, he has spoken at events held by the Royal Canadian Mounted Police (RCMP), border services in the airport and border services through the marines.

"Because there is no cure or treatment for HD, my life literally depends on raising awareness and funds," says Simon. "There's no telling what the next dollar amount is that we will need or who that next person will be to make a discovery, so spreading the word is imperative."

Not only do these speaking opportunities help volunteers to share their stories, raise awareness and gain new experiences, but they also help businesses to have employees who better understand diseases and causes in their communities.

"The feedback from donors, employees and workplaces is clear: those who can share their own experience with chronic disease in our workplaces inspire, humble

and move employees to donate," says Eileen Dooley, CEO of HealthPartners. "HealthPartners relies on our health-charity members to provide speakers who demonstrate the impact of a donor's gift. HealthPartners is grateful to all those volunteers who give so generously of their time and their passion to help us engage employees in workplaces."

But sometimes, these presentations even help the employees personally.

"After one of the presentations, someone in the audience that had Multiple Sclerosis emailed me," says Simon. "She said that she related and connected with my story and just wanted to say thank you because my story touched her. And that's the goal. To make those connections, to move those in the audience to donate that portion of their paycheck to the HD cause or to fundraise for HSC."

For more information about HealthPartners, visit www.healthpartners.ca. To volunteer to speak at HealthPartners events, email info@huntingtonsociety.ca.

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hdfactsheets.ca

Raising Awareness and Growing Amaryllis

Corry Stark teaches grade six at Robert W. Zahara Public School in Sexsmith, Alberta and is a volunteer for the Huntington Society of Canada's Peace Country Chapter. As a recent class project, Mrs. Stark had her students make bags that included an information card about HD and a blue lightbulb for them to use to raise awareness in May (HD Awareness Month). As part of the project, Mrs. Stark gave the students more information about HD, including telling them about the annual Amaryllis campaign. After learning more about HD, many of her students then purchased an Amaryllis bulb from her, including one of her students named Avery.

Every day after school since learning about HD, Avery went home and asked his mom, Cheryl, if they could buy a bulb.

"Avery has the green thumb in our family," explains Cheryl. "He has other plants that he grows too and was so excited to get an Amaryllis."

So the family purchased a bulb, planted it and took care of it. It didn't take long for the flower to grow tall and display four beautiful blooms.

When it first bloomed, Avery ran to show his mom, and they took a picture of him with the flower to send to Mrs. Stark. Mrs. Stark then sent the photo to HSC to be entered into the annual Amaryllis photo festival.

That image (pictured right) went on to win the contest with the most votes ever – 144 at final count! This is three times more votes than the usual winning photos.

"It felt pretty good to win the contest," says Avery. "But my favourite part was watering and measuring it every day."

It's already time to start ordering your bulbs for 2019! Place your order before the end of June and you will be entered into our early-bird contest. 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.



(above) Amaryllis Photo Contest Winner, Avery

(left) Natalie, from the Toronto Chapter

(below left) Team Members from Dr. Ray Truant's Laboratory at McMaster University



SAVE THE DATE FOR
YPAHD Day

**November 16
2019**

Individuals aged 14-35 are invited to join us for the **Young People Affected by Huntington disease (YPAHD)** one-day conference featuring presentations, discussions and the opportunity to build connections!

HALIFAX
NOVA SCOTIA

TORONTO
ONTARIO

CALGARY
ALBERTA



2019 Spring Events Calendar: Coming to Your Neighbourhood Soon!

For a full listing of events near you, visit www.huntingtonsociety.ca/events.

Walks



Friday, April 26

Wawota Walk

Wawota, SK

www.hscevents.ca/WawotaWalk

Sunday, April 28

Wiswell Family Architectural Gems Walk & Social

Toronto, ON

www.hscevents.ca/GemsWalk

Saturday, May 4

Edmonton Walk

Edmonton, AB

www.hscevents.ca/EdmontonWalk

Wednesday, May 22

Wildflower Walk

Barrie, ON

www.hscevents.ca/WildflowerWalk

Saturday, May 25

Peterborough Walk

Peterborough, ON

www.hscevents.ca/PTBOWalk

Sunday, May 26

Durham Walk to Cure & Fun Fair

Oshawa, ON

www.hscevents.ca/DurhamWalk

Saturday, June 1

Saskatoon Walk

Saskatoon, SK

www.hscevents.ca/SaskatoonWalk

Saturday, June 1

Exeter Hike of Heroes for Huntington Disease

Exeter, ON

www.hscevents.ca/ExeterHike

Event Spotlight!

Saturday, June 1

Winnipeg Huntington Heroes Walk/Run

Winnipeg, MB

The Huntington Heroes theme acknowledges the everyday heroes that make up the HD Community – caregivers, professionals, and those at-risk or living with the disease who never stop fighting. Come to the event dressed as your favourite hero – superheroes, musicians, athletes, service people; it is not just about superheroes, but all heroes! Join others in the Winnipeg community and walk, run or stroll for HD. Stick around after the walk/run for free breakfast, face painting and massage therapy!

www.hscevents.ca/WinnipegWalkRun

Saturday, June 8

Lafleche Walk

Lafleche, SK

www.hscevents.ca/LaflecheWalk

Saturday, June 15

Niagara Picnic in the Park

Niagara Falls, ON

www.hscevents.ca/NiagaraPicnic

Runs



Sunday, May 5

Toronto GoodLife Marathon

Toronto, ON

www.hscevents.ca/RaceHD

Saturday, May 25

Vernon Run

Vernon, BC

www.hscevents.ca/VernonRun

May 25 to 26

Tamarack Ottawa Race Weekend

Ottawa, ON

www.hscevents.ca/RaceHD

Sunday, May 26

Scotiabank Calgary Marathon

Calgary, AB

www.hscevents.ca/RaceHD

June 6 to 9

Scotiabank Bluenose Marathon

Halifax, NS

www.hscevents.ca/RaceHD

Saturday, June 8

Southern Alberta Hope Run

Calgary, AB

www.hscevents.ca/HopeRun

Golf



Sunday, June 2

Golfapalooza

Niagara Falls, ON

www.hscevents.ca/Golfapalooza

Monday, June 10

Peel Police Charity Golf

Guelph, ON

www.hscevents.ca/PeelCRBGolf

Event Spotlight!

Saturday, June 15

Camrose Golf Tournament

Camrose, AB

Join us for Camrose's 11th Annual Golf Tournament. This fun-filled day includes 18 holes of Texas Scramble, good food, a silent auction, prizes and fun! Your admission includes your golf, your cart, a hot dog lunch and a BBQ dinner following the tournament. You won't want to miss the return of this event!

www.hscevents.ca/CamroseGolf

Other



April 18

Paint Night Fundraiser for HD

Oshawa, ON

events@huntingtonsociety.ca

April 30-May 4

Niagara Book Sale

St. Catharines, ON

events@huntingtonsociety.ca

Wednesday, May 1

Halifax Art Show

Halifax, NS

events@huntingtonsociety.ca

Saturday, May 11

Grand River Pins & Pizza

Kitchener, ON

www.hscevents.ca/GRBowl

Saturday, May 11

Bowl for a Cure

Timmins, ON

events@huntingtonsociety.ca

Saturday, May 11

Orangeville Vendor Sale

Orangeville, ON

events@huntingtonsociety.ca

Saturday, May 25

Sauble Beach Concert for a Cure

Sauble Beach, ON

www.hscevents.ca/SaubleBeachConcert

Thursday, June 27

Race for a Cure

Ottawa, ON

www.hscevents.ca/OttawaRace

July 1 to August 31

London Jays Raffle

Ontario-wide

www.hscevents.ca/LondonJaysRaffle

Saturday, July 20

Barry's Bay Beach Volleyball

Barry's Bay, ON

events@huntingtonsociety.ca

Event Spotlight!

August 23 to 25

10th Annual Ride 4 a Cure

Grand Prairie, AB

We can't wait for you to join us to celebrate the 10th year of this event! If you love nature, community, and supporting a great cause, this event is perfect for you. In the last 9 years, the event has expanded in participants, supporters, and even the weekend surrounding the day of the trail ride. There are so many ways to participate and be involved through the weekend!

www.hscevents.ca/HDRide



Family Planning with HD: Adoption

When Erin and her husband were 31 years old they decided to start a family. Shortly after sharing the exciting news with her parents, they were told something unexpected. There was speculation that her grandmother might have had Huntington disease (HD), meaning that Erin and her father may be at-risk of having the disease.

A short eight months after learning about the possibility of HD running in her family, Erin found out through genetic testing that she was gene positive.

Despite this news, Erin and her husband were still determined to start their family. After one year of trying to conceive naturally, the couple spent two and a half years trying assisted reproductive technologies including In Vitro Fertilization (IVF) with Preimplantation Genetic Diagnosis (PGD). None of the options the couple tried worked, as Erin was suffering from an unexplained infertility.

After taking a year off to consider their options, the couple decided to try adoption. Erin's biggest fear was that they would get turned down because of her gene positive status. But she knew the only thing they could do was try.

They decided to try private adoption in Ontario. Private adoptions are when birth parents choose a couple to become the parents of their child. Potential adoptive parents create a life profile book about themselves. They can make a connection with birth parents through word of mouth or an adoption lawyer. Applicants must register with individual lawyers who hold on to a copy of their life-books. The books are shown to birth parents looking to make an adoption plan for their child.

As with any adoption, there are various other steps the couple must complete. These include parenting classes (in Ontario called PRIDE training) and a home study which involves interviews with a social worker, home visits and the submission of finances. These steps are to ensure they are adequately prepared for the parenting roles.

Almost six years after they decided to start a family, Erin and her husband received a call. A baby had been born the day before and they were chosen to be her parents!

"After such a long, exhausting journey, it all happened so quickly," says Erin.

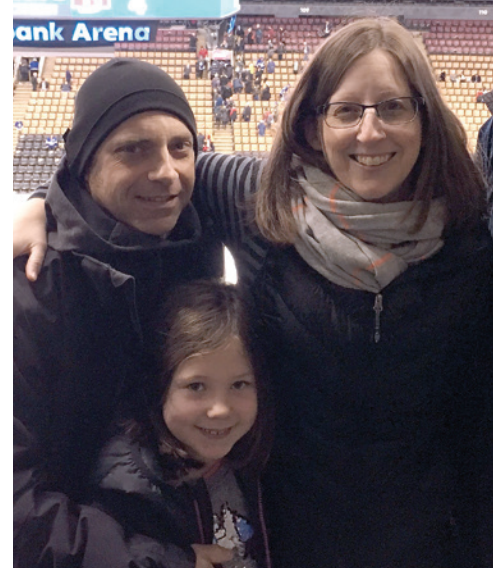
They were able to bring their new baby home when she was just 10 days old.

"The process is intense," says Erin. "But it was worth it."

For couples affected by HD who are considering starting a family, Erin recommends talking to your partner and trying not to let other people's opinions get in the way.

"You and your partner are the only ones who can make this decision," Erin emphasizes. "Everyone will bombard you with their suggestions but, all that matters is that you are both comfortable with what you decide to do."

This is the first in a three-part series about Family Planning and HD. Stay tuned to future editions of Horizon for information on natural conception and IVF and PGD. To discuss family planning options, you can reach out to the Family Services Team member in your area for more information and



resources. You can find a list of our Family Services Team at this link

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

Probing the Details of the Huntingtin Protein

By Julie Stauffer

Current huntingtin-lowering trials may hold plenty of potential, but we don't want to put all of our eggs in one basket. That's why HSC continues to invest in other promising HD research.

Last year, we awarded a two-year, \$150,000 NAVIGATOR grant to Dr. Cheryl Arrowsmith, a professor of medical biophysics at the University of Toronto and a chief scientist at the Structural Genomics Consortium, who is developing a detailed 3D model of the huntingtin protein.

By figuring out its exact shape, right down to the level of atoms, she and post-doctoral researcher Rachel Harding can gain new insights into what the normal version of the protein does and what goes wrong in the mutant version.

It's challenging work. Because huntingtin is much bigger than most proteins in the human body, it forms a very complex three-dimensional shape. To examine it, they'll use cryo-electron microscopy, a revolutionary new technology for looking at large proteins. Once they've nailed down the bigger picture, they'll use high-resolution X-ray crystallography to zoom in on the details of key areas.



Dr. Cheryl Arrowsmith (left) and Dr. Rachel Harding

According to Dr. Arrowsmith, there's growing evidence that normal huntingtin might be involved in fixing the DNA damage that naturally occurs in our bodies over time. That's why she and Dr. Harding will also look at how huntingtin interacts with DNA and different repair molecules. "It will go a long way to try to help understand how this very elusive protein is behaving," she says.

What they learn, they'll share. Researchers typically don't reveal their data until they publish it in a scientific journal. However, Dr. Harding is taking the radical step of publishing all her experimental results in an online blog at www.labscribbles.com. Once they've figured out the exact structure of huntingtin, they'll make it available in a public database.

Research is a long, slow, painstaking process, but this "open science" approach will speed up the pace of discovery. "By sharing the information sooner, it should accelerate science," says Dr. Arrowsmith. "Anything we can do to make things move more quickly will help."

YPAHD Column



**By Doug Mallock,
YPAHD President**

Mark your calendars! We're hosting this year's regional YPAHD Day on November 16 in three locations: Halifax, Toronto and Calgary. Registration opens May 1, and the deadline for funding applications is June 26.

If you are between the ages of 14 and 35 and want to learn more about HD, meet people in the HD community or get some support, you'll want to sign up. We'll have social events on the Friday night, a full day of sessions on the Saturday and a whole lot of amazing people. The programming and speakers will vary from site to site, and we try to cater to the particular interests of each group.

One of the great things about these events is how they fire people up. We've seen a lot of young people inspired to do stuff at the local level, and it's nice to see people giving back to the community. For example, one fellow raised over \$500 for HSC doing a bottle drive after attending YPAHD Day last year. That's a lot of bottles.

Another opportunity in 2019 for HD youth is the HDYO Camp. It takes place from August 11 to August 15. For more information on HDYO Camp visit www.hdyo.org.

HDYO Camp and our regional YPAHD Day here in Canada are going to be awesome events. The more the merrier, so take the risk and sign up — I promise you won't regret it.

If want to learn more about YPAHD, email us at ypahd@huntingtonsociety.ca or visit www.ypahd.ca. We're here to give you the resources and support you need.

Youth Resources Impact Families

Rollie Remillard doesn't pretend to know what his kids are going through. His wife is gene positive for Huntington disease (HD) and both his 18-year-old son and 15-year-old daughter are at-risk for HD themselves.

That's why when he heard about the Young People Affected by Huntington Disease (YPAHD) Chapter and the Youth Mentorship Program at the 2014 HSC National Conference in Winnipeg, Rollie and his family decided to find out how to get his kids involved.

Since then, both of his kids have been to the Huntington Disease Youth Organization (HDYO) Camp in California and have attended multiple YPAHD Days and conferences.

YPAHD is a virtual chapter of HSC that helps youth think about and discuss things like genetic testing, family life, dating with HD and more. This group gives young people someone to relate to, talk to and lean on. The group has a monthly virtual meeting by phone and has a one-day conference every year.

Both of Rollie's children are also mentees in the Youth Mentorship Program, a nationwide mentoring program that provides youth mentees with personalized attention from a mentor. The goal of the program is to offer young people the opportunity to connect with a mentor who will be able to provide them with valuable support at critical points in their lives. The mentor volunteers are also from families affected by HD, allowing them to better understand and connect with the mentees.

"These programs are amazing," says Rollie. "It gives them the opportunity to talk to someone one-on-one who knows what they're going through. And not just with their mentor but with the whole chapter of youth from across Canada."

These programs have helped his kids to better understand their circumstances and how to keep living life to the fullest. Both kids are now also holding volunteer positions with the Manitoba Chapter and continue to stay involved.

"Having them a part of these programs has positively affected our family quite a bit," Rollie reflects. "Our family is very open and we talk about a lot, but there are just some things they need to talk about with someone who knows what they're going through. They now know they aren't alone."



Hannah, Rollie and Mack Remillard

For more information on resources available to youth affected by HD, visit www.huntingtonsociety.ca/youth.

youth MENTORSHIP program

Supporting young people across Canada facing everyday challenges of HD

Become a **mentee.**

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

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One for All and All for Awareness

May 31, 2018 marked the final day of a record-setting HD Awareness Month.

Leading up to the month of May, volunteers all across the world were tirelessly canvassing and promoting the upcoming month of awareness in every way they could. They wrote letters to request city proclamations, emailed countless buildings to add more Light It Up 4 HD sites to our roster, and visited local city officials to convince them to raise the HSC flag.

In 2019, we're hopeful to expand even more through all the different awareness initiatives.

"Light It Up is a very important campaign – a wonderful opportunity each May to inform our communities about Huntington disease," says Deanna Ryan-Meister, organizer of Light It Up 4 HD for the Halifax Chapter. The Halifax Chapter was the first group to secure a building for this year's Light It Up campaign. "2019 will be our 4th year participating in Light It Up, with the illumination of Halifax City Hall in blue from May 29-31. Our event grows each year and we anticipate an even bigger crowd in support this year."

Recognizing May as HD Awareness Month through official proclamations, flags flown proudly, and blue and purple lights shining brightly brings much-needed education to communities about HD. It also acts as a signal to those affected by HD that there is hope and that across the country and around the world, we are united in this fight against HD.

"I love the idea of Light It Up because it's something that has the ability to unite all of us affected across the country and even across the world," says Melissa Kozak, National Light It Up 4 HD volunteer. "I can be looking at a monument that's been lit up in Toronto, and know that my sister is looking at another monument that's been lit up in Vancouver."

This May, head out to a flag raising or lit-up building to show your support and share your photos using #LightItUp4HD. For a full list of events near you, visit www.huntingtonsociety.ca/may-awareness.

Genetic Non-Discrimination Act (GNDA) Update

By Bev Heim-Myers, Chair, Canadian Coalition for Genetic Fairness

The hearing at the Quebec Court of Appeals regarding the Genetic Non-Discrimination Act (GNDA), took place on December 11 and 12, 2018.

Supporting the Genetic Non-Discrimination Act were lawyers representing the Canadian Coalition for Genetic Fairness (CCGF) and the Canadian Human Rights Commission. Arguments were presented in favour of the GNDA being a valid exercise of Parliament's criminal law power. The court appointed an Amicus (a voluntary impartial adviser to a court of law) who also argued in favour of the GNDA.

Legal representation for the Quebec Attorney General, the Canadian Life and Health Insurance Association (CLHIA) and the Attorney General of Canada argued against the GNDA being a valid exercise of Parliament's criminal law power. (BC's Attorney General also intervened against GNDA but did not verbally present arguments in court.)

Although not unexpected, on December 21, 2018, the Quebec Court of Appeal unanimously took the view that the GNDA is not a valid exercise of Parliament's criminal law power. The Quebec Court of Appeal did not express an opinion on the GNDA's ultimate validity or invalidity – that would have been beyond the scope of the question referred to them. Courts do not issue declarations of invalidity in references; they just provide advisory opinions on the questions referred to them – however, this opinion does put the Genetic Non-Discrimination Act at risk.

The Canadian Coalition for Genetic Fairness filed a notice of appeal, as the appellant, referring the Quebec Court of Appeal's decision to the Supreme Court of Canada (SCC). The notice of appeal was accepted, as of right, in mid-January.

As of the time of this publication, the Attorney General of Canada, Attorney General of Quebec, Attorney General of BC and the Attorney General of Saskatchewan have each filed a notice of intervention.

The CCGF Factum (Statement of Facts) was submitted in March to the SCC. Currently we are working with our lawyers to ensure we meet all the future timelines for our next steps as we prepare to defend the GNDA at the SCC, for all Canadians. The tentative date for the hearing is in early October, 2019.



It is important to remember that the GNDA is currently still law, but it is at risk. Please connect with your Attorney General's provincial office and the Attorney General of Canada. Let them know that a pan-Canada federal law to protect genetic test information is important to you and to the health and well-being of all Canadians. Make sure your voice is heard.

More information and updates on the Genetic Non-Discrimination Act and the appeal process can be found at www.ccgf-cccg.ca.

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**2020 Huntington Society of Canada
National Conference**

The Many Forms of Family Service

By Josh Martin

After 15 years as Resource Centre Director for P.E.I. and Nova Scotia, Barb Horner understands that serving families takes many forms. One day, she might be sending someone fact sheets about genetic testing. The next, she's driving from Halifax to Charlottetown for a home visit. A week later, she's at a long-term care facility educating staff about how to support residents with HD. "I'm the go-to person for a lot of families and individuals," she says.

The health professionals at Halifax's multidisciplinary HD Clinic also benefit from Barb's close ties with the community they serve. "Because I'm the one that is doing outreach, I can help determine when folks should be seen at the clinic," she explains.

You'll find that same kind of service from HSC's other 20 Family Service Team members across the country. Take Shelley Thiele, our new Resource Centre Director for Southern Alberta. After leading programs in other organizations for several years, Shelley was eager to return to her social worker roots and help people more directly.

Within a week of starting her new job in January, Shelley was helping a family understand information they got from their doctor, providing resources and connecting them with other families affected by HD. "This allows you to give back and make an impact in such a significant way," she says.

As a member of Southern Alberta's HD community, Terry Berngards has seen that impact firsthand. "Having access to a Resource Centre Director gives myself, my friends, my family and even many professionals peace of mind," she says. "I live alone and don't drive so having a social worker available is comforting. They are also an essential part of my clinical trial experience and in creating my future plans."

Whatever support you need, our Family Services Team is here to help. Visit www.huntingtonsociety.ca/family-services-team for the complete list.

We are very thankful to the many donors who support families impacted by HD. We also recognize the Cambridge and North Dumfries Community Foundation, the Windsor Foundation and the Community Initiatives Fund for their generous support.

Piggybacking Your Way to the Fundraising Finish Line

For some people, event planning can be a fun experience. For others, event planning can seem like a daunting task that discourages them from fundraising at all.

But it doesn't have to be a large task to undertake! Piggyback events can allow someone to fundraise with minimal planning frustrations.

"Piggyback events are essentially events that are already planned by an outside party and require minimal effort from volunteers other than fundraising," says Annie Vanexem, HSC's Manager of National Events and Chapter Development. "These types of events are great for the HD community because our volunteers are often facing time constraints of their own."

And piggyback events are catching on with our community! More and more events are popping up where fundraising is an added bonus to an already planned event.

Comedy Nights



Many comedy clubs across Canada team up with charities to host nights where cover fees are donated back to the organization. Some comedy clubs will also allow you to set up a silent auction or information booth to raise even more awareness and funds.

Since the comedy club already has their venue and all their comedians, the planning is minimal for the volunteers, often a matter of simply selling tickets.

"The venue was very cooperative and supportive," says Adam Johnstone, organizer of the Halifax Comedy Night fundraiser. "It made for a very easy and stress-free partnership."

Paint Nites



Paint Nites were originally established in 2012 but are really starting to catch on now – especially as fundraisers! Many areas have their own Paint Nite artists that put on these events where people sign up, pay a fee and gather at a local venue on a specified day. Attendees then paint a specific image that the artist walks you through step-by-step, and you get to keep your painting at the end of the night.

To turn this into a fundraising opportunity, volunteers contact their local hosts to coordinate a night where the proceeds from that event are donated back to HSC.

"I wanted to host an event that I would want to go to, so that I knew what interest is out there," says Courtney Farr, organizer of the Newfoundland Paint Nite fundraiser. "And with my busy schedule, Paint Nites were great because after you make the initial contact with Paint Nite, all you have to do is sell tickets."

Facebook Fundraising

Philanthropy has finally met technology with the release of Facebook fundraising. In Canada, you now have the option to "Support Nonprofit" when you create a new post. You simply click the option and type in the Huntington Society of Canada. You can set fundraising goals and add your reasons for supporting.

While many are using this feature to raise funds for charities on their birthdays, some volunteers are getting creative and adding a challenge aspect to it.

Just Do It!



HD Smash Fest was a competition Jennifer Thompson created at her work in Oshawa, Ontario, where five supervisors volunteered to get a pie in the face. She went around with buckets with their names on them and whoever had the most money in their bucket by event day was the one to get the pie smashed in their face.

"I really liked that it was simple," says Jennifer. "We have a big walk every year in May, but this smaller fundraiser gives me momentum in the off season to keep fundraising."

Whether you enjoy event planning or not, it has never been easier to start fundraising for HSC.

To start planning your piggyback event, contact events@huntingtonsociety.ca.

The HSC Volunteer Factor

One of our strongest assets is our dedicated volunteers. The Huntington Society of Canada was built by volunteers and continues to thrive because of the ongoing support of volunteers.

Across the country we have more than 150 leadership volunteers, plus many more supporting our events, fundraising and awareness. Here are the stories of just a few of our dedicated volunteers.

Lisa Pollock, Saskatchewan



Lisa got involved with HSC in 2013, just one year after she discovered she was at-risk for HD. She connected with her local chapter and got involved. For Lisa, the connections she made are what has kept her volunteering ever since.

"When I learned I was at-risk for HD, I felt very isolated and alone," says Lisa. "By volunteering, I felt this instant sense of community and belonging. These people have a different understanding than those who are in my life day-to-day and that was important."

Lisa is now the Social Media Coordinator for the Saskatoon Chapter, the Social Media Coordinator for Young People Affected by HD (YPAHD) and a

youth mentor. But for Lisa, the flexibility of the roles is key.

"I work as a teacher, have a young daughter and serve on a variety of committees in my community," she explains. "Flexibility is necessary for me to volunteer and these roles allow me to fit it in my schedule on my time."

Khalilah Alwani, British Columbia



In 2004, Khalilah moved to Victoria, BC to attend college. The next year her mother joined her in the move as well. At the time, her mom was experiencing the early stages of HD. The pair got involved in the local HD community, attending chapter potlucks, social events, educational events and fundraising through the annual Amaryllis campaign and other events.

Over the years, Khalilah has continued to be involved with the HD community in a variety of ways. Most recently, Khalilah has taken on a new leadership role with the chapter, and is working with other Chapter members to transform the group with new energy and ideas.

Other than her role in the chapter, Khalilah is involved in the HD community in other ways through health education programming. She works as a nutritional

educator and is very passionate about how nutrition can improve the health and quality of life of families affected by HD. She has provided nutritional programming at YPAHD Days and started a community kitchen project in Victoria for people affected by HD.

"There are so many ways to be of service in your community," says Khalilah. "If you follow your interests, passions and skill sets, you can find where there are gaps that you can help fill and have fun while doing it."

The Hope Run Planning Committee, Alberta

For approximately five years now, Rachelle and her friends have entered a team in their local run in Alberta. They gathered donations, added team members and attended on the event day. After the 2017 run, the group of friends offered to help plan in 2018 and from then on became the "Hope Run Planning Committee".

The committee is made up of 5 individuals: Rachelle, Jenna, Brittany, China and Ashley. All have their own life commitments including work and spouses but all also enjoy certain aspects

of event planning that, when brought together, makes them a dream team.

"We're a really collaborative group," says China. "Everyone works on every task and helps each other."

And seeing the results of their efforts in 2018, where they doubled the amount raised in 2017 and had over 200 attendees, helps them stay motivated to keep going.

"Seeing the impact we're able to make through how many people came out and how much money we raised feels incredible," says Brittany. "It's helped us continue that momentum into 2019."

National Volunteer Week (NVW) was April 7-13 and was a time to celebrate and thank our dedicated volunteers. Volunteer Canada's theme this year was "The Volunteer Factor – Lifting Communities". The Volunteer Factor celebrates and recognizes the exponential impact of volunteers and how they lift our communities.

To learn more about volunteering with HSC, visit www.huntingtonsociety.ca/volunteer-in-my-community.



Thank you

On behalf of families living with 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 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 Huntington disease community and providing substantive reasons for hope. If you have questions, story ideas or comments about *Horizon* or the Huntington Society of Canada, please contact us at info@huntingtonsociety.ca or call us at 1-800-998-7398.

The Huntington Society of Canada 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.