

HORIZON

RESEARCH • SERVICE • EDUCATION

No. 159

Fall 2019

Clinical Trials: More Momentum Than Ever

By Julie Stauffer

Newly Published Data Reinforces Efficacy of Huntingtin-Lowering Drug

Last year, spirits were high when Ionis Pharmaceuticals announced results of their Phase I/IIa clinical trial. According to the top-line data, their antisense oligonucleotide (ASO) drug was initially safe and could lower levels of the protein that causes Huntington disease (HD). Now, more detailed results published in the *New England Journal of Medicine* reinforce those conclusions.

According to the University of British Columbia's Dr. Blair Leavitt, who co-authored the article, all of the key measures in the Phase I/IIa trial – imaging, blood work and clinical evaluations – left researchers very comfortable with moving forward.

They also found the ASO was effective at lowering huntingtin protein levels in the fluid that bathes the brain and spinal cord. "As you increase the dose of the ASO, the levels of the abnormal protein in the spinal fluid went down. And higher

doses had a greater effect than lower doses," he says. "So that was all really fantastic news."

Best of all, they found the ASO could lower huntingtin to levels that improved Huntington's symptoms in animal models. "We had a target," Dr. Leavitt explains. "We wanted to knock the mutant huntingtin down in the spinal fluid around the levels of 40 to 60 per cent. And that's exactly what we got."

Generation HD1 Back Up and Running with Fewer Lumbar Punctures

Now, drug giant Roche has picked up the ASO baton. In a Phase III trial called Generation HD1, they're aiming to answer the crucial question: Does lowering huntingtin slow the progression of HD in humans?

Roche launched Generation HD1 at the beginning of 2018 but paused it briefly due to results from Gen-Extend. Gen-Extend is an open label extension of the earlier Ionis Phase I/IIa trial, where participants continue to take the drug. It revealed that having lumbar injections every two months, rather than every month, is just as effective at lowering the huntingtin protein.

Based on those results, Roche restructured Generation HD1 with less frequent injections of the drug. "Obviously, that's better for everyone," says Dr. Leavitt.

Now it's back up and running in almost 100 sites around the world, including Vancouver, Edmonton, Toronto, Ottawa, Montréal and Halifax. In total, Roche aims to recruit 660 participants worldwide – and Dr. Mark Guttman, a neurologist at Toronto's Centre for Movement Disorders suspects they'll have no trouble reaching that target.

Note: Anyone with questions around participation in clinical trials should connect with their neurologist to see what options are available to them.

Wave Results Expected by End of Year

In Edmonton, Dr. Oksana Suchowersky is the latest researcher to join Wave Life Science's Precision-HD1 and HD2 trials. These Phase I/IIa trials are testing ASOs that specifically target the mutant form of the huntingtin protein – unlike the Roche/Ionis ASO, which lowers both the normal and the mutant forms of huntingtin.

Although the trials have unfolded a little more slowly than initially planned, there are now 14 sites in five countries taking part, including Toronto, Montréal and Dr. Suchowersky's clinic in Edmonton.

Wave expects to release results of Precision-HD1 and HD2 by the end of this year, revealing whether the drugs are safe and can reduce levels of mutant huntingtin. They are also preparing to launch an open label extension for participants who have completed the initial trial.

SIGNAL Tests a New Approach to Treating HD

The U.S. drug developer Vaccinex is using a different strategy to tackle HD. Instead of targeting the protein that causes HD, they're looking further downstream.

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

WE'RE MOVING!

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Message from the CEO



As a community, we have a lot to be proud of. Our May Awareness initiative is a great example. Your efforts resulted in extensive media coverage, dozens of flag raisings and proclamations, and more than 50 landmarks across Canada lit up in blue and purple. I am always appreciative of anyone who organizes fundraisers and courageously tells their stories to raise awareness about this disease – in May and throughout the year.

While we work to tell our stories and raise awareness, we're also leading the charge in clinical trials. In Canada, we continue to punch above our weight, with an impressive number of sites testing huntingtin-lowering drugs right now – six locations running Roche's Phase III trial, three for Wave's Phase I/IIa trial, and three sites testing Vaccinex's antibody which targets brain cell inflammation.

Drug developers understand this is really fertile ground. We have world-class neurologists in Canada, and the Huntington Society of Canada (HSC) has done an incredible job laying the groundwork for clinical trials. But first and foremost, the HD community has stepped up as eager participants, ready to help move the science forward.

Today, everybody wants to know more about trials. It's easy to understand why. We've entered a whole new era of HD research, with potential treatments that could slow or stop the progression of the disease, not just treat the symptoms. In response, more and more drug developers are entering the field. The most recent example is Novartis, one of the biggest pharmaceutical companies in the world.

I'm sure these developments are one reason why our Community Education Forums (formerly Symposium) have been so popular. Drs. Ed Wild and

Michael Hayden do a wonderful job unpacking the latest research updates. We've also been getting great feedback about the event's new model, which allows chapters to host a forum when it works best for them. If you haven't attended one yet, I encourage you to visit our website to find a location near you or to join us online for our virtual forum on November 2, 2019.

As we get closer to treatments, more people are reaching out to HSC for information and support. That's why we recently launched two new ways to serve the HD community. Our HSC Closed Facebook Group offers a safe online space to connect and find resources. Meanwhile, we're piloting a virtual support group for people at-risk for HD that allows participation from anywhere in Canada.

We're also in the final stages of developing HSC's strategic plan for the next five years. We want to continue supporting clinical trials, find new ways to reach underserved communities, invest further in youth and engage in advocacy initiatives that will make a real difference to families. We'll be presenting our proposed plan to the Board of Directors later in September, and I can't wait to share it with you once it's approved.

During my first year with HSC, what's impressed me most is how willing the HD community is to get involved. I think that commitment is what sets our community apart – and it's also what gives me great hope looking forward.

Robin Markowitz

Robin Markowitz

CEO, Huntington Society of Canada



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

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

Clinical Trials

...continued from Page 1.

Because the molecules of mutant huntingtin protein don't fold the way normal huntingtin does, they stick together in clumps. Eventually, these clumps reach toxic levels within the brain's neurons.

When that happens, the neurons send out a signal to surrounding cells called astrocytes, switching them from their normal function of taking up glucose to red-alert, inflammatory mode. It's this inflammatory response that leads to HD symptoms.

Vaccinex's VX15/2503 drug is designed to stop that response, blocking the signal that neurons send out.

In animal studies, the drug reduced cognitive symptoms of HD. Meanwhile, a small-scale human trial that wrapped up in 2017 demonstrated the drug was safe. And despite the fact that the trial involved only 36 volunteers, researchers saw significant results.

Patients who received the drug had higher levels of glucose than patients who received a placebo, suggesting that VX15/2503 was blocking the inflammatory response and allowing astrocytes to continue their normal function.

"There was a very large difference in glucose uptake," says Dr. Maurice Zauderer, Vaccinex's President and CEO. "We were very excited."

Now a larger-scale Phase II trial at 30 sites across North America – including Vancouver, Edmonton and Montréal – is examining whether once-a-month IV infusions of the drug can reduce HD symptoms. And unlike other clinical trials for potential HD treatments, SIGNAL is also testing VX15/2503 in gene-positive participants who haven't yet developed symptoms.

The trial is fully enrolled, with the last patient visit to take place next June. After that, Vaccinex will get busy analyzing the results. If VX15/2503 proves effective, it won't just be great news for the HD community. As Dr. Zauderer points out, the drug could potentially be used to treat other neurodegenerative diseases that involve toxic clumps of protein, such as Alzheimer's, ALS and Parkinson's.

"We hope that this could really bring benefit to patients," says Dr. Zauderer.

For more information on clinical trials near you, go to www.huntingtonsociety.ca/clinical-trial-locations.



An Ariel View



By Ariel Walker,
Co-Founder of HSC

It used to be most of the folks who came to HSC chapter meetings or conferences were in their 40s or 50s. Now we're seeing so many young people getting involved, and it's just phenomenal.

It started at the Charlottetown conference in 2008, when Young People Affected by Huntington Disease (YPAHD) was launched. They came out with their energy and their optimism and their Gangnam Style dancing. Oh my gosh! I used to say going to the HSC National Conference doubled your enthusiasm, but seeing all those youth triples it. They're dynamos.

The next year, Katie DeLargie gave her talk at the World Congress on HD in Vancouver, BC. She was only 13 at the time, but she stood up in front of 700 people to speak about her Dad's diagnosis and what that meant for her family. Her story really made people think about the impact of this disease on youth.

That's why I was so excited when HSC launched the Youth Mentorship Program in 2013. It's often so much easier to talk about things with a peer than with your parents. And now there are camps and YPAHD Days and the international HDYO website as well. Ralph would be thrilled.

In fact, it was one of Ralph's students who prompted us to start HSC. She walked into the guidance office one day and asked, "Does anyone know anything about Huntington disease?"

Ralph did. His cousin had married a gal from a family affected by HD. The doctors had told her she couldn't inherit the disease because it only affected males, so they went ahead and had four children. Unfortunately, she did develop HD and it progressed very quickly. She died when her youngest child was just a toddler.

We wanted to get the correct information out there at that point, but we had just started our own family and had our hands full. Then a few years later, along came this student whose Dad had been hospitalized with HD. Ralph came home that night and said, "You know, we really need to do something." So we did. We launched HSC, and all kinds of people across the country stepped up to help.

Now we have a new generation stepping up. They're supporting each other, raising money, speaking up and taking on leadership roles. Some of them have even chosen careers in HD research.

Ralph would be over the moon to see we're leaving our legacy in such capable hands. He truly would.





Genetic Non-Discrimination Act Update

By Bev Heim-Myers

Chair, Canadian Coalition for Genetic Fairness

Prior to May 2017, the genetic test information of Canadians was not protected. On May 4, 2017, the Genetic Non-Discrimination Act (GNDA) received Royal Assent and was passed into law. This historic law, which passed third reading in the House of Commons by a vote of 222 to 60 in May 2017, enabled all people living in Canada the opportunity to make informed life decisions regarding health and reproduction, without fear of genetic discrimination. This legislation also enabled Canada to remain as a leader in genomic research and has already helped to alleviate the fears of Canadians, thus encouraging participation in genomics research and clinical trials.



In late 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. It is important to note that the Québec Court of Appeal just provided an advisory opinion on the specific questions referred to them, however, this opinion does put the GNDA at risk.

The Canadian Coalition for Genetic Fairness (CCGF) filed a notice of appeal, as the appellant, referring the Québec Court of Appeal's decision to the Supreme Court of Canada (SCC). The notice of appeal was accepted, as of right, in mid-January. That means that the CCGF will be the appellant as this case moves to the SCC.

The Attorney General of Canada, Attorney General of Québec, Attorney General of BC and the Attorney General of Saskatchewan, each filed a notice of intervention. The Canadian Life and Health Insurance Association, Canadian Human Rights Commission (CHRC), Privacy Commissioner of Canada (PCC) and Canadian College of Medical Geneticists (CCMG) have also applied for leave to intervene. The CHRC, PCC and CCMG all support the position taken by CCGF. All parties that applied to intervene were given intervener status.

The hearing at the SCC is currently scheduled to take place on October 10, 2019.

Today, the Genetic Non-Discrimination Act is still law, but it is threatened. The CCGF will continue to work with our team of lawyers to ensure that the GNDA stays as law to protect the genetic test information of all people living in Canada.

For more information and updates on the Genetic Non-Discrimination Act and the appeal process, visit www.ccgf-cceg.ca.



Q ...as my husband's movement symptoms get worse, he's finding it harder to feed himself. How can I make meal times easier, without taking away his independence?

A HD symptoms often lead to up-ended saucepans, dropped forks and broken plates. These splatters and spills can fray your nerves and leave both of you feeling frustrated.

Striking the right balance between maximizing independence, minimizing daily cleaning tasks and keeping everybody safe isn't simple. Every case is different, and it's a moving target because HD symptoms change over time. However, there are a number of ways to make meal times more manageable.

Your doctor may be able to offer medications that help with the movement symptoms. An occupational therapist can also offer practical strategies – whether it's a placemat that stops plates from sliding, weighted utensils to help control involuntary movements or cups with large handles to reduce spills. Meanwhile, if cooking is becoming too big a burden, consider stocking the freezer with ready-to-go meals or taking advantage of community programs like Meals on Wheels.

The best way to start is to contact your HSC Family Services worker (visit www.huntingtonsociety.ca/family-services-team-list/ for contact information). Together, you can discuss your specific needs and zero in on concrete options that are right for you.

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

Editing the HD Gene

By Julie Stauffer

When Francesca Cicchetti heard molecular biologist Vincent Dion describe his gene-editing achievements at a conference, she knew they needed to collaborate. "I was just so excited by this potential treatment that I ambushed him after his talk," says the HD expert, laughing.

For more than 20 years, Dr. Cicchetti has worked at the forefront of HD research, studying the disease in animal models at the Université Laval. Meanwhile, Dr. Dion has been applying the CRISPR technology that first made global headlines in 2012.

CRISPR consists of three tools that, together, let scientists tweak genes in a way that wasn't possible before. An enzyme called Cas9 nickase serves as a pair of tiny scissors, cutting DNA. A molecular guide specifically designed to bind to the target gene shows the scissors where to cut. And to get that machinery into the cell, researchers package it in a harmless virus that acts like a courier.

"Is CRISPR really as revolutionary as what is being claimed?" asks Dr. Dion, who recently joined the University of Cardiff. "The answer is yes. It changes everything."

Over the past few years, he has developed a CRISPR-Cas9 system that removes extra CAG repeats from the HD gene. Once Cas9 cuts out the genetic stutter, the cell's repair systems stitch the two ends of DNA back together. Bingo, you've got a normal gene that no longer makes the disease-causing huntingtin protein.

There are challenges, of course. The biggest is making sure Cas9 doesn't cut other genes by mistake – especially because the results are permanent.

Initial tests in Dr. Cicchetti's mice were very promising. Injecting CRISPR-Cas9 into mice with Huntington disease symptoms created improvements in movement and cognitive behaviour.

Those results convinced HSC's Research Council to fund follow-up experiments. In June, HSC awarded Drs. Cicchetti and Dion a two-year, \$150,000 NAVIGATOR grant. Together with Vanessa Wheeler, a collaborator at Massachusetts General Hospital, they'll focus on three goals.

First, they'll scrutinize the impact at the brain cell level to see whether gene editing reverses the damage caused by HD.

Next, they'll try to improve the efficiency of the editing system ("coming up with version 2.0," as Dr. Dion puts it).

Finally, they'll test whether treating mice before they develop symptoms can prevent the onset of HD.

If they're successful, the approach would need to be tested in larger animals to investigate the longer-term consequences before human trials become possible. And because changing DNA creates permanent effects, they need to tread very carefully. "I suspect that there's going to be a few failures before we can see some of the successes," Dr. Dion cautions.

Currently, CRISPR-based therapies are being evaluated in 25 different clinical trials, focussing on everything from hereditary blindness to blood disorders. "Targeting the DNA itself with these new approaches is very, very exciting," says Dr. Cicchetti. "We've entered a completely new era."



Francesca Cicchetti's initial tests of the CRISPR-Cas9 system in mice are yielding promising results.

Community Education Forums: Filling Hearts Full of Hope

By Josh Martin

When the Southern Vancouver Island chapter needed a volunteer to organize their local Community Education Forum (CEF), Khalilah Alwani stepped up. For her and her mother – who has HD – the event will be a great opportunity to get the latest research updates and connect with other members of the HD community. Meanwhile, she's looking forward to increasing awareness about HD with long-term care providers and other local stakeholders. "It also just contributes to a wider sense of community building," she says.

In the past, under the name "Symposium", these forums have been streamed live from a central location. This year, however, HSC pre-recorded the keynote speakers, giving groups the freedom to choose when and where to host their own events. In the first presentation, Dr. Michael Hayden explores the different components of a clinical trial and what we can realistically expect in the years ahead. In the other video, Dr. Ed Wild discusses how current clinical trials are going and what's next in this new era of HD research.

"It was very easy," says Resource Centre Director, Marthe Gautreau, who organized two forums in New Brunswick in the Spring. "All I had to do is bring my laptop and put my memory stick in and there it was."

Marthe also invited a social worker and clinical trial coordinator to speak to participants. Other forums have included Q&As with local neurologists and experts in nutrition, self-care, disaster preparedness and more. The line-up at upcoming forums this Fall is equally diverse, including popular speakers like Yvonne Heath and Jimmy Pollard.

So far, the new format has been well received. "Folks are saying they're getting a much better understanding of the research," says Annie Vanexem, HSC's Manager of National Events and Chapter Development. "We're also seeing that there are a lot of new faces in the rooms."

Several sites across the country have already hosted Community Education Forums and this Fall, another 16 are scheduled to take place, including Khalilah's on October 19, 2019 at the Victoria Public Library.

A huge thank you goes to our sponsors – Roche, Wave Life Sciences and uniQure – who have made these CEFs possible. "We've been able to make the event bigger and broader than ever before through their support," says Annie.

Visit www.huntingtonsociety.ca/cef to find and register for a forum near you. Can't attend in person? Join our virtual CEF on November 2, 2019. This live version will include different presentations, so consider participating even if you've attended a local forum.



Online Groups Offer More Ways to Connect

By Josh Martin

Today, you'll find HSC support groups from coast to coast. However, not everyone has a group nearby. In other cases, work or carer responsibilities may prevent folks from getting to a meeting. Meanwhile, some people may not feel ready to meet in person.

That's why HSC has created two new virtual ways to connect.

In June, we launched our Closed Facebook Support Group, which offers a safe space online for the Canadian HD community to connect and get resources. Whether you have HD, are at-risk or are caring for someone with the disease, you're welcome to join. The Facebook group already has over 200 members, with more registering every day.

"It's going really, really well," says HSC's National Social Worker, Corey Janke. "Within the first day of people joining up, there was story sharing, there were questions being asked, there were people documenting their journey and getting a lot of support back from fellow members."

Corey and Halton/Peel Resource Centre Director, Ekta Hattangady, serve as moderators for the group. Together, they review and accept appropriate requests to join, monitor group activity and address any issues that might arise.

Meanwhile, Corey is also facilitating a pilot Virtual Support Group for people at-risk of HD. As with traditional support groups, meetings are held at a specific date and time. In this case, however, individuals will participate via online video conferencing. The six-meeting series starts in September, with discussions focused on a different topic each session.

Thanks to these new opportunities, you can now connect with the HD community wherever you live and whenever you need it. "We want to be able to break down any barriers that people may experience to receive the support they need," says Corey. "I'm extremely excited about the opportunity to offer this."

To join the Facebook group, visit www.huntingtonsociety.ca/closed-facebook-support-group. To sign up for the Virtual Support Group, contact Corey Janke at cjanke@huntingtonsociety.ca or 519-800-1587 or speak to your local Family Services representative.

Thank you to all of the generous donors who make our Family Services program possible, including the following organizations:



The Windsor Foundation



Clinical Fellowship: Training the Next Generation of HD Specialists

By Julie Stauffer

Meet newly minted neurologist Dr. Ragini Srinivasan: part of a new generation of medical professionals keen to learn more about HD. The McMaster graduate is the first recipient of a one-year, \$60,000 clinical fellowship from HSC designed to attract bright young neurologists to the HD field and expose them to clinical research.

Under the supervision of Dr. Mark Guttman, Dr. Srinivasan is seeing patients at the Toronto Centre for Movement Disorders and in North Bay, Sudbury and Sturgeon Falls where Dr. Guttman makes regular trips to serve families in northern Ontario.

On the research front, she's conducting physical and cognitive assessments for participants in the Enroll-HD study. She's assisting with the lumbar punctures in the Roche and Wave huntingtin-lowering trials, testing drugs that have the potential to alter the course of HD. "It's a whole new experience for me," she says. "It's

certainly something that I don't think I would ever have had exposure to otherwise."

She's even getting involved outside the clinic, participating in the Toronto chapter's annual GEMS Walk to raise money for HSC.

Since Dr. Srinivasan began working with patients affected by HD last November, what has struck her most is the sense of community she sees and the opportunity to develop long-term relationships with patients and their families.

And while Dr. Guttman has taught her a lot, he's not the only mentor she has encountered through the HSC fellowship. "There's so much I learn looking at families, whether it's spouses that are coming and supporting their loved ones or children that are coming in with their parents," she says. "You learn so much about what compassion is."

Over the course of the next few months, Dr. Srinivasan looks forward to gaining more experience in managing HD and helping people



Dr. Ragini Srinivasan is the recipient of a one-year, \$60,000 clinical fellowship from HSC.

through their journey with the disease. "I'm so grateful for this opportunity," she says. "It's such an incredible community to be involved in."

As for Dr. Guttman, he hopes to see the clinical fellowship program continue after this pilot year wraps up. As more potential treatments reach the stage of clinical trials, we need more professionals equipped to run those trials and, one day, administer the treatments that could slow or stop HD.

"I think we need lots of new neurologists becoming involved, and I hope this will be a catalyst," he says.

2019 Fall Events Calendar: Coming to Your Neighbourhood Soon!

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

NATIONAL EVENTS

Dec. 1 – 31

Holiday Hustle

Canada-Wide

Join one of the many winter races in your area this year and fundraise for HSC for a chance to win fun prizes! Check out all the races listed at www.hscevents.ca/HolidayHustle. If you don't see a race listed you would like to participate in, contact us at events@huntingtonsociety.ca.

COMMUNITY EVENTS

BRITISH COLUMBIA

Sunday, Sept. 15

Huntington Heroes Walk to Cure HD

Vancouver, BC

www.hscevents.ca/BCwalk

Oct. (Date TBC)

Vancouver Halloween Party

Vancouver, BC

events@huntingtonsociety.ca

ALBERTA

Saturday, Sept. 14

Tools for Resilience

Red Deer, AB

www.hscevents.ca/RedDeerSocial

Nov. (Date TBC)

Frock Box Clothing Fundraiser

St. Albert, AB

events@huntingtonsociety.ca

Saturday, Nov. 16

YPAHD Day

Calgary, AB

www.huntingtonsociety.ca/YPAHD-day

SASKATCHEWAN

There are currently no fundraising events planned in Saskatchewan. If you are interested in planning a fundraiser this Fall, please email events@huntingtonsociety.ca.

MANITOBA

Sunday, Sept. 8

Winnipeg Indy Go-Kart Challenge

Winnipeg, MB

www.hscevents.ca/WinnipegIndy

ONTARIO

Saturday, Sept. 7

Grand River Founders Walk

Cambridge, ON

www.hscevents.ca/FoundersWalk

Sunday, Sept. 8

Essex Indy Go-Kart Challenge

Windsor, ON

www.hscevents.ca/EsssexIndy

Sunday, Sept. 15

Starting a Chapter Info Session

Sarnia, ON

events@huntingtonsociety.ca

Sunday, Sept. 22

Toronto Huntington Heroes Run

Toronto, ON

www.huntingtonsociety.ca/TORunforHD

Saturday, Sept. 28

Peterborough Golf Tournament

Peterborough, ON

www.hscevents.ca/PTBOgolf

Friday, Oct. 18

Niagara Trivia Night

Niagara, ON

www.hscevents.ca/NiagaraTrivia

Saturday, Oct. 19

Chatham Trapshoot

Chatham, ON

events@huntingtonsociety.ca

Muskoka Walk

Barrie, ON

www.hscevents.ca/SimcoeMuskoka

Sunday, Oct. 20

Toronto Scotiabank Waterfront Marathon

Toronto, ON

www.hscevents.ca/RaceHD

Niagara International Marathon

Niagara Falls, ON

www.hscevents.ca/RaceHD

Mon. Oct. 21 – Sat. Oct. 26

Book Sale

St. Catharines, ON

events@huntingtonsociety.ca

Tuesday, Oct. 22

Paul Paone 3-on-3 Basketball Tournament

Niagara Falls, ON

events@huntingtonsociety.ca

Nov. 1, 2019 – Feb. 29, 2020

Toronto Sports Getaway Raffle

Ontario-Wide

www.hscevents.ca/SportsGetawayRaffle

Saturday, Nov. 16

YPAHD Day

Toronto, ON

www.huntingtonsociety.ca/YPAHD-day

Saturday, Nov. 23

5K Pub Run

Toronto, ON

events@huntingtonsociety.ca

Sunday, Dec. 29

Resolution Run Toronto

Toronto, ON

www.hscevents.ca/ResolutionRun

ATLANTIC CANADA

Sunday, Sept. 22

Huffin' Puffin Marathon

St. John's, NL

www.hscevents.ca/RaceHD

Grand Bay-Westfield Paint Party

Grand Bay-Westfield, NB

www.hscevents.ca/NBPaintParty

Tuesday, Sept. 24

Support and Information Sharing Session

Halifax, NS

events@huntingtonsociety.ca

Saturday, Oct. 6

New Brunswick Family Gathering and Walk

Fredericton North, NB

www.hscevents.ca/NBGathering

Friday, Nov. 1

Halifax Comedy Night

Halifax, NS

events@huntingtonsociety.ca

Saturday, Nov. 16

YPAHD Day

Halifax, NS

www.huntingtonsociety.ca/YAPHD-day



#LightItUp4HD Receives a Boost from the Aurora Borealis

By Josh Martin

When Craig Morgan's phone started beeping at 2 a.m., the avid photographer grabbed his camera and headed for the headframe of the old McIntyre mineshaft in Timmins, ON. According to his meteorological app, the aurora borealis would be putting on a show. The headframe – now a historical landmark the City of Timmins illuminates after dark – would create a great foreground.

However, instead of the usual white illumination, the headframe was lit in blue and purple, thanks to the efforts of local HD advocate, Lynn Walker. After Craig posted his photos online, Lynn reached out to explain the significance of the colours and the international #LightItUp4HD campaign.

This year, a record 169 sites around the world turned blue and purple, including 55 sites across Canada – from the B.C. Parliament Buildings on Vancouver Island to Government House in St. John's – during May Awareness month. May Awareness 2019 activities also included numerous flag raisings, proclamations, newspaper articles, television interviews and radio PSAs about HD. And clearly, it has made an impact.

Like many people, Craig had never heard of HD before. So Lynn told him how her Dad had passed away from the disease and now, two of her brothers are in long-term care. For Craig, it was a big eye opener. As he posted on his blog, "That's the beauty of awareness campaigns, it makes people aware!"

To support the cause, he donated a framed print of the Northern Lights photo (for auctioning off as a fundraiser). It now hangs on a wall of a business in King City, ON, where it continues to grab attention. "I really hope this image I took will somehow create more awareness and really bolster the efforts to get a cure for this disease," says Craig.

Thank you to Lynn, Craig and the countless other volunteers who helped raise awareness for HD in May!



McIntyre Headframe: Timmins, ON.
Photo: Craig Morgan



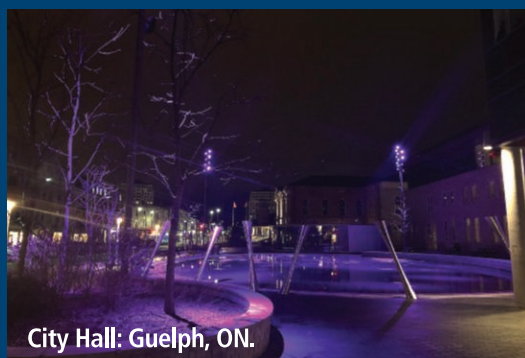
Elizabeth Quay: Perth, Western Australia.



Second Life Virtual World.



Reconciliation Bridge, Calgary, AB.
Photo: Michael Long



City Hall: Guelph, ON.

Government of Canada Charitable Campaign Set to Launch

By Eileen Dooley
CEO, HealthPartners Canada

At some point in their lives, 87 per cent of Canadians are likely to be affected by a chronic disease. Donations to HealthPartners directly help 16 of Canada's most trusted health charities, including HSC, which all work to prevent chronic disease and to care for those affected by it. With our members and partners, we work to reduce chronic disease, improve the health and well-being of employees, and connect employees in workplaces to our health charities.

Canadians are among the world leaders of scientists who are conducting leading-edge research as the search for effective treatments for HD continues. For everyone within the HD community, a treatment for HD cannot come soon enough. The good news is that several very promising drugs are undergoing clinical trials right now, and even more are being planned. HealthPartners is proud to have contributed to the success of this research through 30+ years of partnership with HSC.

If you know federal government employees, they can support HSC and HealthPartners through the Government of Canada Workplace Charitable Campaign (GCWCC), which raises money for the important work our member charities do. Through workplace campaigns like the GCWCC, HealthPartners raises funds to support ongoing HD research, which is currently giving the HD community great hope. I was so inspired by hearing about the research advances at the HSC Conference last November and I've been following updates on the research and clinical trials occurring all over the world. At HealthPartners, we are inspired and pleased to be able to help.

The GCWCC campaign launches in September. To date, HealthPartners has raised over \$179 million for our member charities. Again, if you know a federal public servant, please take a moment to thank them for their generosity and remind them that every donation to HealthPartners helps improve the lives of Canadians living with diseases like HD.

iii HealthPartners

Charities At Work

YPAHD Column



By Doug Mallock, YPAHD President

We've got some great sessions lined up for YPAHD Day 2019 and we're just adding the final bells and whistles. So whether you're new to HD or you've been coming to these events for years, join us in Calgary, Toronto or Halifax on November 16, 2019.

As usual, we'll kick things off on Friday night with social activities (if you're at the Halifax Paint Nite, you can admire my artistic skills – no one does stick men as well as I do!).

On Saturday, we're running an HD 101 session as well as presentations on genetic testing, family planning, the latest research, how to organize a fundraiser with impact, and more. We've booked some expert speakers! But, we also know you don't want to just sit in a chair all day and listen. That's why we'll have lots of time for questions and discussions, as well as ice-breakers and hands-on workshops like yin yoga, mindfulness and drumming, depending on the location you attend.

Most importantly, you're going to meet people who know what you're dealing with. At YPAHD Day, you really do create friendships that last a lifetime.

Another place to make those friendships is HDYO Camp. As I write this, I'm getting ready to head off to California, along with several other youth from across Canada. Thank you to HSC for providing some of the funding that makes this camp possible!

Finally, I want to give a shout-out to all the youth across the country who contributed to May Awareness this year. #AskMeAboutHD went big on social media, proving that sharing authentic stories is a really powerful way to raise money and awareness.

Together, we're #InItToEndIt.

If you're 14 to 35, come join us at YPAHD Day. Register at www.huntingtonsociety.ca/ypahd-day by November 1, 2019. Funding applications will be accepted from Sept. 3 – Sept. 30, 2019. For more information, visit the link above.

HSC would like to extend our deepest thanks to our 2019 YPAHD Day sponsors:

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NYA Day: Buoyed up in Boston

By Josh Martin

Brittany was pretty bleary-eyed when she showed her passport to the Canadian customs official. Running on three hours of sleep will do that to you. "It was worth it," the 33-year-old from Pine Lake, AB insists.

Brittany, whose mother passed away from HD in 2016, was one of two young Canadians HSC sent to participate in the Huntington's Disease Society of America's National Youth Alliance (NYA) Day and Annual Convention, the world's largest event for families affected by HD. Held June 27–29, 2019 in Boston, MA, the busy three days featured sessions on research, self-care, testing positive, relationships and more. A gala and talent show rounded out the agenda.

For Nicole – HSC's other youth delegate – NYA Day felt like coming home to family. "You walk in and everyone is just so happy and energetic and hopeful and positive and welcoming," she says. "You feel like you can be yourself. You don't need to put on a face or put on an act."

Having attended YPAHD Day, HDYO Camp and the HSC National Conference in Kelowna, BC last year, Nicole understands the value of connecting with others from the HD community. During one session, she found herself being comforted by someone she had met just two minutes earlier as Nicole told the group about testing gene-positive last year. "Having that support and someone to lean on is just amazing," she says.

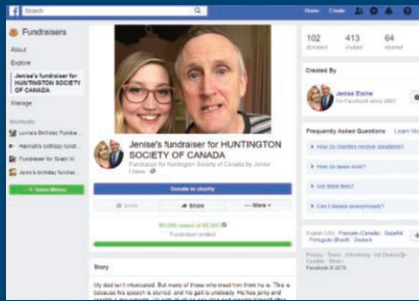
Seeing so many others who haven't let their test results hold them back also made a big impact. "It was definitely inspirational," says Nicole.

Meanwhile, both Brittany and Nicole have been actively involved in a slew of HD fundraisers over the years – including walks, runs, paint nights and comedy events – and Boston was an opportunity to exchange ideas and get fired up all over again. "It was really great to be able to go on behalf of Canada and share what we're doing and learn from them," says Brittany. "I felt really motivated and inspired by the people I met."

Nicole agrees. "I'm coming back [with] so many ideas for my chapter," she says. "I just can't wait to share them all."



Brittany (L) and Nicole say their NYA Day experience has given them many great ideas to take back to their chapters.



Facebook Fundraiser Goes Viral

By Josh Martin

To post or not to post? Jenise L. wrestled long and hard with that question, debating whether to share her HD story during May Awareness Month. But then she started seeing other personal stories popping up on her social media feed with the hashtag #AskMeAboutHD.

"My dad isn't intoxicated. But many of those who meet him think he is," her Facebook post begins. Jenise goes on to explain that her father, Steve, has HD. She describes his symptoms and his indomitable spirit. She then reveals that she is also gene positive. "One day I will struggle to speak, to walk, and to think," she writes. "But right now, I still have those abilities. I have the chance to be an advocate."

Originally, she only intended to use her story to raise awareness. But after sharing it, a prompt from Facebook invited her to turn her post into a fundraiser for HSC. Jenise agreed, and the website automatically generated a fundraising page for her. "It was really simple," she says.

With no idea what reaction to expect, Jenise set her initial goal at \$1,000. She reached it within a few hours. So she upped it to \$2,500, and the donations kept flooding in — many from complete strangers touched by her story — as more and more people shared the post. "I was blown away," she says.

In the end, Jenise raised \$6,000. "It was such an amazing feeling," she says. "There's definitely power in everyone's individual story."

Thank you, Jenise, for having the courage to speak up!

Grow a Brighter Future

It's that time of year again! We are very excited to kick off the 2019 Amaryllis Campaign. Our goal this year is to sell over 20,000 bulbs and we are hoping that, together, we can achieve this and inspire hope in as many lives as possible!

The Amaryllis is the signature flower of HSC. We have Amaryllis volunteers across the country who sell bulb kits to help raise vital funds for our programs in research, services and education. Every year, around 20,000 Amaryllis bulbs bloom from coast to coast, inspiring hope for a world free of Huntington disease (HD). Since 1985, HSC's dedicated volunteers have raised more than \$5 million in support of HD.

"This campaign is one of our biggest fundraisers of the year," says Bruce Mackenzie, HSC's Senior Manager, Development. "The HSC staff love seeing how enthusiastic our volunteer sellers are. In fact, it's very inspiring to witness the support through sales too!"

Amaryllis kits are priced at \$15. Each kit is packaged in a lovely gift box, which contains one high-quality Orange Sovereign bulb, growing instructions, soil, a planting pot, a plant stake and a saucer. They come in cases of 12 kits and are shipped across Canada.



Orders can be made at any time, with delivery dates from October to December.

You can plant your bulbs immediately when you receive them or you can store them in a cool, dry place. Many people like to give them out as holiday gifts! Gorgeous orange-red blooms will appear approximately 6-8 weeks after planting.

Each kit we sell brings us a step closer to finding a treatment for HD and supporting another family with HD. Every Amaryllis bulb blooming in someone's home or business holds the promise of a world free from this disease.

"We would all like to see the sales record broken this year," adds Mackenzie. "We think it can be done!"

Happy Trails, Paul!

By Josh Martin

As HSC's Resource Centre Director for Eastern Ontario since 1991, Paul Klodniski has been a tireless champion for the HD community. Now, as he transitions into a new chapter in his life, we want to wish him our very best.

Over the years, Paul collaborated closely with the HD clinic in Ottawa. He worked hard to educate long-term care providers about the disease and created valuable resources, including fact sheets and a booklet on grief and loss. He also enjoyed a great relationship with the local chapter and drew on his experience as a counsellor to provide support groups that made a real difference in the lives of people with HD, their families and carers.

"Paul has become a pillar for the HD community in Eastern Ontario," says Corey Janke, HSC's National Social Worker.



Paul Klodniski (seated), HSC's Resource Centre Director for Eastern Ontario, is set to retire in coming weeks.

He proved equally invaluable for his HSC colleagues across the country, who regularly turned to him for advice and support. Unfailingly considerate, Paul was always happy to help. "He's really been a mentor for a lot of the other Family Service Workers," says Corey.

On behalf of the entire HD community, thank you, Paul, for your dedication and service. We're going to miss your calm, thoughtful presence!

Family Planning with HD: IVF with PGD

Offering Hope With a Risk of Heartbreak

By Julie Stauffer

Stephanie Rees and her husband, Derek, always dreamt of having children. But Stephanie carries a reduced-penetrance gene for HD. That means her symptoms likely won't show up until later in life – or perhaps never. However, her children could inherit the full-blown version of the HD gene.

For the southern Alberta couple, in vitro fertilization with preimplantation genetic diagnosis (IVF with PGD) seemed like the perfect way to make sure the disease stopped with Stephanie.

The process begins like standard IVF. After hormones are used to stimulate a woman's egg production, the eggs are collected and then fertilized in the lab. What's different is the next step: before the doctor transfers one of the resulting embryos into the woman's womb, they're screened to find one that doesn't carry the HD gene.

As laboratory director and preimplantation genetic testing coordinator at Atlantic Assisted Reproductive Therapies in Halifax, NS, Dr. Megan Dufton uses the process to help couples avoid passing along genetic diseases like HD. "We take great pride in helping them have the families they want," she says. "We feel fortunate and honoured to help them make their families."

While the promise is big, she does note that couples need to go in with their eyes wide open.

IVF with PGD isn't cheap: each cycle costs approximately \$20,000, plus travel and hotel expenses if you're coming from out of town (doing it when you're younger saves money, says Dr. Dufton, because less medication is required, and that's a big part of the price tag).

It's also time-consuming. The entire process can easily take 12 months from the initial meeting to confirmation of pregnancy – or the news it didn't work.

Plus, the entire experience is physically and emotionally exhausting. The daily hormone injections used to stimulate egg production can cause mood swings. "I [snapped at] a couple of people in the mall," Stephanie admits. And that's on top of the stress of clinic visits, wondering whether it will work and trying to keep up with all the other responsibilities of daily life. "It can feel very isolating at times," says Derek. "We didn't have a lot of close friends or anything that had gone through it."

For many couples, the costs are worth knowing their baby will never have to worry about developing HD.

"We see really excited patients when they see the baby's heartbeat for the first time," says Dr. Dufton.

But the other thing to keep in mind is that the results aren't guaranteed. IVF with PGD is a numbers game: how many eggs can be harvested, how many can be successfully fertilized, how many of the resulting embryos develop, and, of course, how many of those embryos don't carry the HD gene.

In Stephanie and Derek's case, their first round of IVF with PGD resulted in an ectopic pregnancy – a dangerous condition where the baby starts growing outside the womb. They had to terminate the pregnancy. Their second attempt also ended in disappointment when the embryo didn't implant. Many months, \$35,000 and plenty of tears later, they decided to call it quits.

According to Dr. Dufton, if the woman is under the age of 36, they'll typically end up with six to eight embryos for genetic testing. On average, half of those will be gene-negative. If there is an embryo to transfer, the chance it will result in a successful pregnancy is roughly 70 per cent.

That can mean going through multiple rounds of IVF with PGD before you end up with a baby – or decide to pursue other options.

Because the odds get smaller the older you are, Dr. Dufton suggests doing IVF with PGD now and freezing the embryos if you're not ready to have a baby right away. But as Stephanie and Derek discovered, even younger couples like them face a risk of failure.

The Alberta couple definitely don't regret trying. But if you do opt to go this route, they say, know what you're getting into. "I hope our story can bring a sense of realism," says Derek.

Have some serious conversations up front. How much time and money can you afford to spend? How much stress and grief are you prepared to deal with? And if it doesn't work, what's most important to you: having children that are biologically yours or having children who don't carry the gene?

After a lot of soul-searching, Stephanie and Derek ultimately decided to conceive naturally and hope that treatments will be developed by the time their children grow up. Today, they're the proud parents of five-year-old Clara and six-month-old Hazel, and the struggles they went through to create their family have left them with a stronger relationship than ever.

"There was a ton of loss and heartache," says Stephanie. "But they are worth it. And whether they



While IVF with PGD didn't work out for Stephanie and Derek Rees, it does prove to be a viable family planning option for many couples affected by HD.

are at risk or not, we have two beautiful girls that will hopefully see a treatment in their lifetime."

Stephanie and Derek Rees have shared their story at YPAHD Days. Stephanie is also a mentor with the HSC Youth Mentorship Program (for more information on this, contact mentorship@huntingtonsociety.ca or call 1-855-253-0215).

This is the second in a three-part series about family planning and HD. In the next issue of Horizon, watch for an article on natural conception. For more family planning information, contact your local Family Services team member.

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Celebrating Our Heroes:

Vern Barrett, Shaunacy De Jong and Rachel Harding

By Josh Martin

For nine years, HSC's Manitoba chapter has organized a Walk/Run to Cure HD, most recently under the "Huntington Heroes" branding. This year was their most successful one ever, thanks in large part to a story in the Winnipeg Free Press featuring chapter president Vern Barrett and his wife, Ellen. After the story appeared, online pledges skyrocketed.

At the event itself, Winnipeggers came out in force. Smitty's Pancake House provided a free hot breakfast. City volunteers painted faces and made balloon animals. A DJ donated his services, while members of the firefighters' union handed out Gatorade. Meanwhile, local massage therapists were on hand to ease aches and pains.

More than 130 people participated. Some came with dogs and strollers, others with skateboards. Some sported superhero costumes. "There was a lot of fun happening," says Vern, the chapter's long-time president. "People didn't want to leave."

Those participants raised \$37,994 (at time of print) for HSC, which was doubled thanks to an anonymous donor who matched all donations made across Canada in the Spring.

But for Vern, the value of these events goes far beyond dollars. "It's like family coming together," he says. "And after it's over, people have all sorts of connections and memories and commitment to the cause and to each other."

Shaunacy De Jong – whose mom has HD – also experienced the power of community recently. In May, she and her sister hosted a fundraiser for HSC in Sauble Beach, ON. The small-town concert boasted four bands, plenty of pulled pork sandwiches and a heap of raffle prizes and auction items donated by local businesses, including Blue Jays tickets, homemade quilts, beach-themed gift baskets and more.

Almost 300 people showed up to dance the night away, raising just over \$15,000 and a whole lot of awareness about HD in the process. "Oh my gosh. I was so overwhelmed," says Shaunacy. "It was quite incredible to see the community come together."

Dr. Rachel Harding knows firsthand the difference these fundraisers make. As a researcher exploring the biochemistry of huntingtin proteins, her work with the Structural Genomics Consortium depends on grants from organizations like HSC.

After meeting families at HSC's National Conference in Kelowna, BC last year, Rachel wanted to do more to connect with the people that make her work possible. In April, she invited members of the HD community to tour her lab at the University of Toronto. Later that month, she volunteered with the Toronto chapter's annual GEMS Walk for Huntington disease. And in September, she and her two fellow researchers will be lacing up their sneakers for a fun run to support HSC.

"Having that connection with the patient group is really important," she says. "When we're spending the money from the grant, you have to remember that this has all been raised through people doing sponsored walks and bake sales and running marathons and doing 5K fun runs and everything else."

Thank you to everyone who has contributed to fundraising events throughout the year! Your efforts allow us to serve families and fund ground-breaking research. Interested in hosting a fundraiser in your community? Contact events@huntingtonsociety.ca.



Vern Barrett.



Shaunacy De Jong (R) and her sister Shelby.



Dr. Rachel Harding.

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.