

HORIZON

RESEARCH • SERVICE • EDUCATION

No. 155

Spring 2018

Huntingtin-Lowering Results Raise Optimism

Latest Updates About Clinical Trials From the CHDI Conference

By Julie Stauffer

In 1993, scientists made headlines when they announced the discovery of the HD gene. Twenty-five years later, we're now seeing the fruits of that breakthrough. Instead of testing whether drugs developed for other diseases might help HD, investigators are now testing drugs specifically designed to address the root cause of Huntington disease.

So when researchers presented the results of the Ionis Phase I/IIa huntingtin-lowering trials at the CHDI Huntington's Disease Therapeutics Conference in March, it was standing room only.

The first, crucial goal of any clinical trial is making sure a potential treatment is safe. Mission accomplished, according to Britain's Dr. Sarah Tabrizi, the lead investigator in the Ionis trial. According to the data she presented, the Ionis drug doses were well tolerated with no safety concerns.

Not only that, the study revealed that higher drug doses reduced the level of huntingtin protein in the cerebrospinal fluid by 40 to 60 percent. In earlier studies using animal models, that level of reduction created some improvements in symptoms. These results leave researchers like Vancouver's Dr. Blair Leavitt feeling very optimistic. "If this change in animals led to improvement in their symptoms, hopefully we'll see the same results in people," he says. Dr. Leavitt is the principal investigator for the Ionis trial site in Vancouver and he enrolled the first ever human subject in a huntingtin-lowering trial in September of 2015.

It is expected that later this year, a Phase III study spearheaded by Roche will test that hypothesis. The multinational drug company licensed the Ionis drug in December, so they'll be able to put their considerable resources into designing and running

the pivotal trial, which will involve hundreds of patients in more than a dozen countries.

Meanwhile, two more huntingtin-lowering trials are currently underway. PRECISION-HD1 and HD2 are testing drugs developed by Wave Life Sciences that specifically target RNA that is associated with production of the mutant huntingtin protein (unlike the Ionis drug, which targets both the normal and the mutant protein).

However, not everyone with the HD gene also carries the genetic targets for the Wave drugs. According to Wave's Mike Panzera, who shared the company's latest data at the CHDI conference, approximately 64 per cent of gene-positive people are candidates.

Dr. Mark Guttman's Toronto-area clinic was the first site in the world to launch PRECISION-HD1 and HD2, with no hiccups to date. "It's going smoothly," Dr. Guttman reports. "We started dosing in November, and what I can say is that people are tolerating the medication well."

The University of Montreal will also be a clinical trial site and are also expected to begin soon.

None of these advances would be possible without the HD community. When Dr. Tabrizi thanked the Ionis trial participants – "the true HD research heroes" – who volunteered to test the drug despite many unknowns, the audience at CHDI broke into spontaneous and sustained applause.

Now, says Dr. Leavitt, we need people to continue raising dollars for research and participating in whatever studies they are eligible for. "This is a collaborative endeavour," he says. "The scientists and the doctors can't do it alone."

Want to get involved?

Visit www.huntingtonsociety.ca/hd-clinical-trials to see which clinical trial sites are currently recruiting volunteers.



Get ready to #LightItUp4HD in May 2018

To see a list of confirmed sites visit: www.lightitup4hd.com



For more on Light It Up For HD Awareness, see the story on page 3.

Save the Date for
HSC 2018 National Conference

Be Brave • Be Bold • Be Ready

Believe

Kelowna, British Columbia
November 2 & 3, 2018

INSIDE

Note from the CEO page 2

2018 Spring Events Calendar page 7

Save the Date:
2018 HSC National Conference..... page 10

Join the RaceHD Team..... page 12

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.

Editors:

Tiffany Nobes
Jeffrey Hoffman

Associate Editor:

Laurie Williams

Layout: Real World Graphic Design

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

Huntington Society of Canada
151 Frederick St., Suite 400
Kitchener, ON N2H 2M2

Tel: 519-749-7063
Toll Free: 800-998-7398

Email: info@huntingtonsociety.ca
Web site: www.huntingtonsociety.ca

Charitable Registration Number:
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Note from the CEO

As I enter the eve of my retirement from HSC I reflect back at the amazing year we have had to date and the activities planned to the end of our fiscal year in June.

With the unfaltering support from our many volunteers across Canada and a dedicated staff team we will execute more than 80 events over the next couple of months including our Light It Up for HD Awareness, where we light up the world in close to 100 locations, with blue and purple – the HD colours.

We launched HD-COPE and had our first international meeting in London, England in February. Industry and Pharma now have a reliable source of experts in our family member participants to reach out to, to better understand the lived experience of dealing with HD and to accurately inform early protocol development for clinical trials. The voice of our community is respected and is being heard.

Our Amaryllis Campaign was a huge success this year. I am still getting photos from my family and friends that are amazed at the stunning, vibrant blooms that seem to never stop.

We are finalizing our plans for the 2018 HSC National Conference. The Kelowna Chapter is working hard alongside our Chapter Development team to make this one of our best conferences to date. You will see our lineup of featured speakers later in this issue, they are impressive. And yes, Jeff and Ed are returning to share their knowledge, fun and lay language research updates that we have come to depend on.

We are all encouraged by the clinical trials addressing the root cause of HD. Hope looms large as we leap over the safety hurdles of the huntingtin-lowering trials.

The Genetic Non-Discrimination Act remains the law. Your genetic test information is protected by this legislation. While the Quebec Government is appealing the law, we have been granted intervenor status and will continue to ensure this worthy, and critical, legislation is upheld for all Canadians.

It is business as usual and we continue to work hard to make a difference for the HD community. Our CEO search team comprised of board members is also working hard to find the next CEO to lead HSC. The Chair of our Board, Brenda Nowakowski, states, "We do not take this task lightly and are proceeding with due diligence and the utmost care, to ensure the right leader is found." Until that leader is found I will stay as CEO. Initial interviews are underway and it has been my pleasure to work with the search team to help inform their process towards a positive outcome.

Thank you for helping us be the best that we can be.

Bev Heim-Myers
CEO, Huntington Society of Canada



Are you a supporter of the Huntington Society of Canada? Interested in getting more involved?

HSC is now accepting applications to its Board of Directors for vacancies beginning in 2018 and 2019. This national board includes 15 directors from across the country who combine enthusiasm for the work of the Society with expertise in one or more areas of business including law, fundraising, finance, communications, strategic planning, media and human resources. If you, or someone you know, is interested, please let us know. There is a process that we follow, and expertise

that we are looking for, but it starts with your interest. Forward your CV and Letter of Interest outlining your skills and experience to:

Huntington Society of Canada
151 Frederick St., Suite 400
Kitchener, ON N2H 2M2
Attention: HSC Board

All nominations received by May 15, 2018 will be considered.



Huntington disease research news.

**In plain language.
Written by scientists.**

For the global HD community.

Go to www.HDBuzz.net to see what the Buzz is all about!



Light It Up For HD Awareness

By Tiffany Nobes

Get ready, Canada, because another May lit up in blue and purple is coming your way!

Throughout the month of May, buildings and monuments across Canada will be lighting up in the HD colours – blue (for Huntington disease) and purple (for Juvenile Huntington disease) – once again to raise awareness.

This movement is made possible by volunteers like Melissa Kozak, who worked tirelessly to canvas local sites to #LightItUp4HD. Melissa helped to coordinate the campaign by reaching out to past volunteers and sites to participate again in 2018, as well as new sites to gain more participants.

“I’m so excited to be part of Light It Up for HD this year,” says Melissa. “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. 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.”

Our volunteers are so creative! When there isn’t a monument or building to light up, they look for other ways to raise awareness.

Bunny Clark from Oshawa, ON organizes five flag raisings in her area every year to contribute to May Awareness. “In this area we don’t really have places that can ‘Light It Up’ for us,” says Bunny. “But we still want to raise that awareness so we have the HSC flag flying at administrative buildings every year. The Mayors and Councillors engage personally by reading the proclamation aloud for onlookers, declaring May as HD Awareness Month.”

Meanwhile Rich Wheeler from Pasadena, Nfld has gotten his friends and neighbours involved by lighting up their own homes with blue or purple porch lights. Last year, Rich’s local hardware store even sold out of blue and purple lightbulbs because of the overwhelming support.

This May, head out to a lit up site or flag raising or replace your outdoor bulbs like the folks in Newfoundland! Make sure to take photos and let the world know how you #LightItUp4HD.

Visit www.huntingtonsociety.ca/may-awareness to see a full list of events near you!

Adding Amaryllis to Your Spring Checklist

By Josh Martin

Spring is in the air. That means it’s time to pack away the winter woollies, open up the windows – and place your orders for the 2018 Amaryllis campaign! Year after year, this flagship fundraiser continues to be incredibly successful. In 2017, more sellers than ever joined the campaign, while many Chapters increased their orders from previous years.

The result was a team of veterans and newcomers who sold more than 20,000 kits and raised well over \$120,000 for HSC. “We couldn’t have done it without such a wonderful, committed volunteer force coast to coast,” says Jeff Hoffman, HSC’s Director of Development and Marketing.

Their efforts also put smiles on faces across the country, as buyers got to experience what makes these flowers special. We are constantly told that our bulbs – specially grown for us in Holland – produce blooms that are larger, hardier and more vibrant than any others on the market.

We had another amazing crop of submissions to our Amaryllis Photo Festival this year, including

the winning photos above sent to us by Melissa Craftchick and Theresa Case.

These blooms do more than bring a splash of colour to homes and offices in the depths of winter. They also bring hope, raising vital funds for the HD cause. “It’s more than another great flower. It’s a way to make a difference in somebody’s life,” says Jeff.

Jeanne Hagey agrees. Our Amaryllis seller in Ontario likens the growth of the flower to the progress we’re making toward a cure. “Like the research, the plant grows in spurts,” she says. “[Today] research is in the ‘pregnant’ stage like the buds, ready to burst.”

It’s early-bird contest time! Place your order before the end of June for your chance to win Julie Lawson-Timmer’s book Five Days Left and a Kindle. 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.

Jacquie Lingard’s Legacy of Support

By Josh Martin

Jacquie Lingard was braced for the results when her first husband, Barry, took the genetic test in 2002. From their own research and what they knew about his father’s illness years earlier, they knew HD was a definite possibility. However, nothing could truly prepare the Chatham, Ontario couple for the road ahead. “You don’t know the enormity of the disease when you first get the results,” she says.

As her husband’s symptoms progressed, Jacquie handled each episode as best she could. Fortunately, she found much-needed help in a nearby HSC support group, which quickly became her lifeline.

“We would hash things out amongst each other and find ways to deal with certain issues. It was just an amazing group,” she says. “I can’t say enough about the London Chapter and what it did for me and our family and all the other HD families that I knew.”

Since Barry’s passing, Jacquie has moved to Calgary, Alberta to be close to her two daughters. However, she stays in touch with the friends she made through that Chapter, and they continue to support each other despite the distance.

As far as Jacquie is concerned, that kind of network is something everybody affected by HD should have. That’s why she chose to include a legacy gift in her will to HSC.

“It’s not a huge amount,” she says. But she’s happy knowing it will go toward helping the HD community – whether that’s improving care for patients, funding the latest research advances that give her hope, or creating more support groups like the one that helped her so much as she navigated the enormity of HD.

If you’d like to learn more about including a gift to the Huntington Society of Canada in your will, contact Jeff Hoffman at 1-800-998-7398 ext. 125 or jhoffman@huntingtonsociety.ca.

HD-COPE: Bringing the Voice of Patients to Clinical Trials

By Julie Stauffer

When Shaunacy takes her mom to a specialist's appointment, she has to drive three hours each way. Over the years, the young caregiver has missed many classes and clocked thousands of kilometres to make sure her mom gets the care she needs.

Now, Shaunacy is helping pharmaceutical companies understand the lived experience of HD when they're developing clinical trials. Last fall, she joined the Huntington Disease Coalition for Patient Engagement (HD-COPE), a newly launched joint initiative between the Huntington Society of Canada (HSC), the Huntington Disease Society of America (HDSA) and the European Huntington Association (EHA).

According to HSC's CEO, Bev Heim-Myers, it's crucial to design clinical trials in a way that makes it less of a burden for volunteers to participate, to enable recruitment and ensure retention in clinical trials. To do that, they need to consult the experts: the people who face Huntington disease every day. That's why HD-COPE was established.

In February, Shaunacy packed her bags for HD-COPE's first official meeting held in London, England. She was joined by 19 others including

caregivers, people with HD and individuals who are at-risk or carry the HD mutation from across Canada, the U.S. and Europe. In the coming years, the coalition plans to include members from other countries around the world.

To help them demystify clinical trials, day one included a trip to the labs of HD researchers Dr. Sarah Tabrizi and Dr. Ed Wild to hear about the current huntingtin-lowering trials. Later, neurologist Bernhard Landwehrmeyer briefed the group on clinical protocol evaluation and ethical considerations. They also met with representatives from the European Medicines Agency to find out how the agency evaluates drugs in Europe.

The group learned how and why clinical research is done, what good research looks like, what pitfalls to avoid, and how to be an effective intermediary between families and the drug makers. Dr. Wild believes asking informed questions will be critical as more and more companies aim to develop HD treatments in the coming years. "To me, the most important role of HD-COPE is speaking truth to power," he says.

For Shaunacy, the weekend was eye-opening. In the past, she'd wondered why clinical trials take so long and why there are so few sites involved. Now, she says, she realizes just how much thought goes into designing clinical trials to ensure researchers get the best possible data.

It was eye-opening for drug company executives as well. The HD-COPE team spent an entire day with Roche executives – the first time the pharmaceutical company has consulted with patients this early in the drug development process. "Everybody was there to learn," says Bev.



coalition for patient engagement

"Voices were heard and acknowledged. It was an amazing, collaborative experience."

Jenna, another member of the Canadian HD-COPE contingent, agrees. "It's fantastic to be able to interact with these people and know them by their first name and be able to share your story and to know that they're listening," she says. "I think that this is really the start of something that's going to be quite strong and quite powerful."

For more information about HD-COPE, visit www.huntingtonsociety.ca/HDCOPE.



Genetic Non-Discrimination Act (GNA) Update

For now, the Genetic Non-Discrimination Act (GNA) remains law and your genetic test information is protected. It is a criminal offence for a service provider or anyone entering into a contract with you to require or compel you to take a genetic test or to provide your results of a genetic test. The GNA also makes it a criminal offence for a service provider or anyone entering into a contract with you to collect, use or disclose your genetic test results without your explicit written consent. Service providers or parties entering into a contract with you, include but are not limited to, insurance providers, landlords, adoption agencies, employers, schools and more. The act sets out a maximum penalty of a fine of \$1 million or possible imprisonment up to 5 years.

The Quebec Government referred the GNA to the Quebec Court of Appeals and they are challenging the constitutionality of the legislation. There are

others that support Quebec's position including the Attorney General of Canada, Attorney General of BC and the Canadian Life and Health Insurance Association (CLHIA). The Canadian Coalition for Genetic Fairness (CCGF) and the Canadian Human Rights Commission have been given intervenor status to support the GNA, and the Chief Justice of Quebec has also appointed an amicus (impartial advisor) to support the legislation. We will continue to fight for the GNA during the Quebec appeal and (if necessary) the Supreme Court of Canada. Timing for the oral arguments at the Quebec Court of Appeal will be determined in the fall of 2018.

What does this mean for you? At this point in time, the GNA remains law and your genetic test information is protected by the prohibitions stated above.

This historic law is a huge step forward and will enable all people living in Canada the opportunity to make informed life decisions regarding health and reproduction, without fear of genetic discrimination. This legislation also enables Canada to remain as a leader in genomic research. The HD community played a significant role in moving this mountain forward. We are doing everything we can, working with several incredibly dedicated stakeholders, to ensure the genetic test information for all people in Canada continues to have comprehensive protection provided by the GNA.

For the most up-to-date information, visit www.huntingtonsociety.ca/GNA.



Blocking Brain Cell Receptors Could Halt Huntington Disease

Drug Reverses HD Symptoms in Mice

By Julie Stauffer

Huntingtin-lowering drugs have been attracting plenty of headlines lately, with good reason. However, they aren't the only drugs with big potential to slow or stop HD.

For two decades now, Dr. Stephen Ferguson has been building up evidence that targeting a particular receptor on brain cell membranes might halt Huntington disease in its tracks. His latest studies, funded by HSC donors through our NAVIGATOR grants, are the most promising yet.

The University of Ottawa researcher focuses on mGluR5, a receptor we know is disrupted by Huntington disease. By using a drug called CTEP to block mGluR5, Dr. Ferguson and his team have produced dramatic improvements in mice with HD.

The investigators began by looking at motor symptoms. As mice with HD get older, they have more and more difficulty running across a horizontal ladder. They're slow, they pause frequently, and they make missteps. However, after being treated with CTEP, the mice navigated the rungs without hesitation. They also performed just as well as mice without HD on treadmill tests.

Even their cognitive symptoms improved. Typically, older mice with HD can't tell the difference between familiar objects and new ones. In contrast, the mice treated with CTEP easily identified new objects.

So what's going on? According to Dr. Ferguson, CTEP helps brain cells clear out the mutant huntingtin protein before it reaches toxic levels. When the researchers examined the mouse brains at the end of the study, they found far fewer clumps of mutant protein in the treated mice, and the clumps they did see were much smaller than in untreated mice. Most tellingly, there were fewer dead brain cells.

Dr. Ferguson believes the next step should be running clinical trials with basimglurant – a version of CTEP that can block mGluR5 in humans. Since the drug has already gone through safety testing for other diseases, pharmaceutical companies could move immediately into phase II testing.

"I think it has huge potential," says Dr. Ferguson. "I do believe that HD is one neurological disease that we're going to be able to find a meaningful treatment for."

For more up-to-date information about HSC donor-funded research, visit www.hdresearchnews.ca.

An Ariel View



In February, my brother Bruce passed away. Bruce loved his family and friends, as well as the New York Giants, the Toronto Maple Leafs and the Toronto Blue Jays – not to mention all kinds of movies, jokes and a glass of good Scotch.

He came down with pneumonia, and the last two and a half weeks were rough. He was just so agitated. He didn't want to be in the hospital, and he didn't understand a lot of what was happening. He's at peace now, that's all I can say.

We had the funeral on a Sunday, and then the next day I was scheduled for my knee replacement. I'm happy to say the surgery went really well, but the recovery is going to take many weeks. So I'm here at home with lots of time to reflect on life – and a long list of rehab exercises to do.

While I'm recuperating, I'm watching my Amaryllis grow. It's a bright spot in my life right now. And my goodness, is it growing! It has three stalks – two with four blooms and one with five – so I am quite thrilled.

I remember when the Society launched the Amaryllis campaign. It must have been back in 1985. In Newfoundland, Marion Janes had had a lot of success raising money by selling paperwhites, so the Society decided to make it a national campaign. We weren't sure if paperwhites were for everyone, so Ralph and the rest of the staff went to work to try to pick another flower to represent the Society.

I remember Ralph calling me at work after one of their Friday morning staff meetings and asking, "Ariel, do you know what an Amaryllis is?" Well, I didn't have a clue, but Ralph told me that when it blooms, it looks like the HSC logo. So that was it.

Of course, Ralph and I started selling them that year, and I've sold them ever since. These days, I get phone calls from people even before the cases arrive, asking me when the Amaryllis are coming. David Hobson, who writes the gardening column in our local paper, did a nice blurb about them three or four years ago, so even more people started calling.

The Society talks about how our Amaryllis campaign inspires hope, and we could all use a little hope in our lives, couldn't we?

The other thing that gives me hope right now is watching my grandchildren grow. The two oldest boys are in fields they love, and my oldest granddaughter is going into nursing, which I'm thrilled about. Hannah is in grade eleven and also thinking of a career in the medical field while Elisabeth, the youngest, loves horseback riding. It's just great seeing them so vibrant and full of anticipation for the future.

I get that same feeling when I meet all the bright young scientists who are working so hard to find a solution for Huntington disease. So while we all experience loss in our lives, we also have lots of reason for hope.

If you would like more information on the Amaryllis program, visit www.inspirehope.ca.

Did you know that you can

DONATE SECURITIES

to the Huntington Society of Canada?

Donating shares is an effective way to give to HSC. Any amount of securities can make a real difference.



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

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HealthPartners Celebrates a Milestone

For more than 30 years HealthPartners has been supporting families impacted by Huntington disease. HealthPartners helps businesses engage their employees by promoting wellness programs that create healthier workers, resulting in a healthier bottom line.

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.

As Canada was celebrating its 150th birthday, HealthPartners celebrated a milestone in dollars raised, surpassing the \$150 million mark. This amazing result has had a significant impact on people across Canada, including the Huntington disease community.

As a result of these significant milestones, HealthPartners produced a report that highlights 150 achievements that have advanced the

field of medical research. The report showcases the tremendous research being undertaken by researchers and scientists who are supported by the 16 member organizations, including the Huntington Society of Canada.

The ground-breaking work highlighted in this report can be viewed at www.healthpartners.ca.

iii HealthPartners
Charities At Work

Music and HD *By Tiffany Nobes*

From raising funds and awareness to serving as an effective therapy to letting people live their best lives, music has many benefits for the HD community.

Dr. Tamara Maiuri, researcher at McMaster University and trumpet player for Niagara-based band Eli and the Straw Man, has seen firsthand benefits music can have on people.

Tam's band, Eli and the Straw Man, has been using their music to raise funds and awareness for HD since they partnered with the Huntington Society of Canada in 2016 for an awareness tour across Canada. Since the tour, the band has performed five benefit concerts organized by local groups across Ontario, raising close to \$40,000. The band already has two more concerts confirmed for 2018 and hope to do more going forward. "For the band it's a great opportunity for us to do something helpful through our music, beyond just entertaining," says Tam.

Toronto musician, Peter Gray, was also familiar with using music in a way beyond entertaining, as it was a way for him to live his best life. Peter spent the majority of his life in Toronto, training

to be an actor as well as pursuing his true passions of singing and song writing when he was diagnosed with HD in 2001.

Whether it was through singing himself or writing songs, before his HD diagnosis or while symptomatic, music was always a way for Peter to continue living with hope.

For Vicki St. Amand, the music therapy that she receives at her long term care home in Waterloo, Ontario gives her hope too, as well as increased confidence.

When music therapist, Melissa Jessop, first started working with Vicki, Vicki insisted she would play an instrument in the background while Melissa sang. As the therapy has progressed, though, she now wants to sing lead on songs going forward and be more involved in the process.

Melissa believes that music is extremely effective in supporting Vicki's emotional expression. "With HD, the focus tends to be about a person's physical decline," says Melissa. "But we need to focus on the whole person including their mental well-being."

When Matthew Kliewer, Alberta-based musician, began to experience depression from various health issues and from the knowledge that he was at-risk for HD, he let the depression take over his life for nearly two years. When he found the courage to do something about the depression, he returned to playing guitar as he had played for the majority of his life previous.

For Matt, music goes beyond a hobby or pastime. "The benefits of playing an instrument or simply being creative are so valuable," he says. "It's a necessity [for the mind]."

Back in Niagara, Tam can see the benefits of music from all sides. "As a researcher, I can say music is a great way to exercise your body and brain. As a musician, our music is bringing awareness of HD to people who may have never heard about it," she says. "As someone who is at-risk for HD, though, I like to think music is helping me delay the symptoms if I do have it."

Join us at the 2018 HSC National Conference in November in Kelowna, BC for a presentation on music therapy for HD. For more information about Conference visit www.huntingtonsociety.ca/Conference.



Eli and the Straw Man



Peter Gray



Matthew Kliewer



Vicki St. Amand

2018 Spring Events Calendar: Coming to Your Neighbourhood Soon!

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

Walks



Wednesday, May 16

Wildflower Walk

Barrie, ON

www.hscevents.ca/WildflowerWalk

Saturday, May 26

Edmonton Walk

Edmonton, AB

www.hscevents.ca/EdmontonWalk

Saturday, May 26

Peterborough Walk

Peterborough, ON

www.hscevents.ca/PTBOWalk

Event Spotlight!

Sunday, May 27

5th Annual Durham Huntington Heroes Walk to Cure & Fun Fair

Oshawa, ON

Join the Durham Chapter as they celebrate their 5th annual walk with a new theme – Huntington Heroes! Come dressed as your favourite hero and enjoy a walk in the park followed by fun family activities including inflatables, vendors, wildlife rescue, face painting, balloon artists, ice cream truck, live music, a BBQ and special guests!

www.hscevents.ca/DurhamWalk

Saturday, June 2

Saskatoon Walk

Saskatoon, SK

www.hscevents.ca/SaskatoonWalk

Saturday, June 2

Exeter Hike of Heroes for Huntington Disease

Exeter, ON

www.hscevents.ca/ExeterHike

Saturday, June 2

Winnipeg Huntington Heroes Walk/Run

Winnipeg, MB

www.hscevents.ca/WinnipegWalkRun

Saturday, June 9

Lafleche Walk

Lafleche, SK

www.hscevents.ca/LaflecheWalk

Saturday, June 9

Windsor Walk

Windsor, ON

www.hscevents.ca/WindsorWalk

Saturday, June 16

Niagara Walk

Niagara Falls, ON

events@huntingtonsociety.ca

Saturday, June 23

Coachman's Cove Walk

Baie Verte, NL

www.hscevents.ca/BarkersBattle

Runs



Sunday, May 6

Toronto Goodlife Marathon

Toronto, ON

www.hscevents.ca/RaceHD

May 18 to 20

Scotiabank Bluenose Marathon

Halifax, NS

www.hscevents.ca/RaceHD

Saturday, May 26

Vernon Run

Vernon, BC

www.hscevents.ca/VernonRun

May 26 to 27

Tamarack Ottawa Race Weekend

Ottawa, ON

www.hscevents.ca/RaceHD

Sunday, May 27

Scotiabank Calgary Marathon

Calgary, AB

www.hscevents.ca/RaceHD

Saturday, June 9

10th Annual Southern Alberta Hope Run for HD

Calgary, AB

www.hscevents.ca/HopeRun

Sunday, June 24

10th Annual Toronto Run

Toronto, ON

www.hscevents.ca/TORun

Sporting Events



May 4 to 5

St. John's Volleyball Tournament

St. John's, NL

events@huntingtonsociety.ca

May 5 to 6

Lillooet Softball Tournament

Lillooet, BC

events@huntingtonsociety.ca

Saturday, May 12

Grand River Pins & Pizza

Kitchener, ON

www.hscevents.ca/GRBow

Saturday, May 12

Bowl for a Cure

Timmins, ON

events@huntingtonsociety.ca

Saturday, May 26

Zumbathon

Newmarket, ON

www.hscevents.ca/Zumbathon

Sunday, June 3

Golfapalooza

Niagara Falls, ON

www.hscevents.ca/Golfapalooza

Event Spotlight!

Saturday, June 23

PEI Go Kart Indy Challenge

Summerside, PEI

The Indy Go-Kart Challenge originated in Niagara Falls in 1996. Many groups still run this fundraiser throughout the year – including the PEI Chapter! Raise pledges and rev up your engines for another year of racing fun at the 21st Annual Indy Go-Kart Challenge! Fun for all ages and abilities. For more information about other Indy's near you, visit

www.huntingtonsociety.ca/events

www.hscevents.ca/PEIIndy

Saturday, July 14

Barry's Bay Beach Volleyball Tournament

Barry's Bay, ON

events@huntingtonsociety.ca

Other



May 1 to November 1

YPAHD Champion Challenge

National

www.hscevents.ca/YPAHD

May 7 to 12

Niagara Book Sale

St. Catharines, ON

events@huntingtonsociety.ca

Thursday, May 10

Sarnia Paint Nite

Sarnia, ON

events@huntingtonsociety.ca

Saturday, May 12

Windsor Eli and the Straw Man Concert

Windsor, ON

www.hscevents.ca/WindsorEli

Monday, May 14

Paint Nite

Halifax, NS

events@huntingtonsociety.ca

Thursday, May 24

Race for a Cure

Ottawa, ON

www.hscevents.ca/RaceForACure

Tuesday, May 29

BC Pub Trivia Night

Vancouver, BC

www.hscevents.ca/BCPubTrivia

Event Spotlight!

Month of May

3rd Annual Online Auction for HD

Saskatoon, SK

YPAHD member Lisa Pollock holds an auction every year to raise money for HD completely online through Facebook. Lisa gets donations from friends, family and community members, posts photos of the products on her Facebook event page and sets bid open and close times. In the past 2 years, Lisa has raised almost \$10,000!

events@huntingtonsociety.ca

June 23 to 24

100 Mile House Campout

100 Mile House, BC

events@huntingtonsociety.ca

Youth Resources: Empowering a New Generation

By Josh Martin

Growing up in Fortune, Newfoundland (population 1,400), Catherine Price understands how lonely it can feel dealing with HD. "I grew up completely isolated," she says. "I didn't know anyone else who had Huntington disease in their family."

That changed eight years ago when she tracked down our toll-free number and asked how she could get involved. That call introduced Catherine to YPAHD, our virtual youth chapter – a community of young people affected by HD who understood the challenges she faced and shared her enthusiasm for making a difference.

In addition to connecting digitally and via monthly conference calls, Catherine received funding to participate in events like YPAHD Day - HSC's annual, high-energy gathering of youth from across the country who come together to share, learn and form life-long friendships.

Those gatherings always leave Catherine inspired to take action, she says. Over the years, she has raised thousands of dollars and tons of awareness through HD walks, go-kart challenges, trivia nights

and more. "It's a great feeling to have that kind of impact," she says. "I feel like I'm contributing to something greater."

Lisa Pollock agrees. Each year, the YPAHD member from Weyburn, Saskatchewan raises thousands of dollars for HSC through her Facebook auction.

She also supports a younger peer through our world-leading youth mentorship program – a program that has earned a big thumbs-up from mentees, mentors and parents alike. As one mentee said in last fall's survey, "Having someone to talk to and get insight from is such a great way to feel the weight lift off my shoulders."

Lisa has also volunteered at the annual Huntington Disease Youth Organization (HDYO) camp. The five-day event brings together campers and counsellors from across North America for HD workshops, community-building and plenty of fun activities like archery, rope courses and paddle boarding.

Most recently, she has joined HSC's Saskatoon Chapter, using her social media savvy to boost the group's communication efforts. "The more I get involved, the more I want to do," she says.

Having worked for HSC for 25 years, our Southwestern Ontario Resource Centre Director, Corey Janke, is thrilled to see how much is available to youth today. Whether it's a 15-year-old thrust into the role of caregiver, a 21-year-old going through genetic testing or a 28-year-old considering starting a family, "We are giving youth information and tools they need at a younger age," he says. "We are also building a stronger overall community."

Like Catherine did eight years ago, the key is taking that first step to reach out. "It's definitely a great support system," she says. "It's almost like a little family."

These programs wouldn't be possible without the generous support of funders. Our heartfelt thanks go out to the Mark Mercier Foundation, the Edith Lando Foundation and the Pollard Foundation whose donations are giving youth the resources, support and opportunities they need to live their best possible lives.

For more information about the resources available to youth affected by HD, visit www.ypahd.ca

YPAHD Column



By Jaclyn Skinner, YPAHD President

As youth affected by HD, we're the next generation of this organization. But I also believe that by coming together to raise funds, increase awareness and support each other, we can also be the last generation that has to face this disease.

Last year, we raised over \$90,000 through our YPAHD Champion Challenge and local youth-led events. I am beyond excited to see what we can

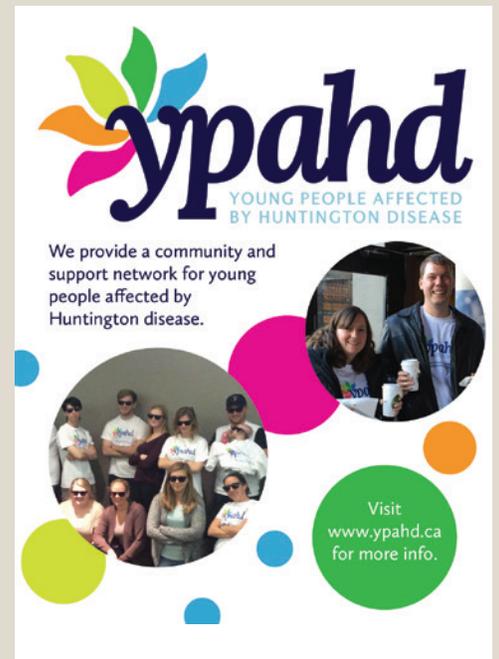
accomplish this year! There's no threshold on how big or small an event can be. Just pick an activity you enjoy – bowling, knitting mittens, etc. – and turn it into a fundraiser. Our online platform makes it simple to collect donations, and we have incredible people within YPAHD and HSC to help make your event a success.

Thinking about summer? There's still time to apply for a fully funded spot in this year's HDYO Camp in San Diego. Visit www.hdyo.org to apply! Whether you attend as a participant or a camp volunteer, I can tell you from personal experience that you'll return home feeling better and stronger, with an amazing community of support in your back pocket.

I'm also really looking forward to YPAHD Day in Kelowna, B.C. on November 1st. We've built the entire agenda around your feedback. There are going to be great sessions on relationships, genetic testing and more. And as always, you'll have loads of opportunities to connect, share and have fun.

We'll also be holding elections that day for YPAHD's 2019/2020 executive committee, so start thinking about nominating yourself or someone you know. You don't need any qualifications, and you'll get plenty of support from HSC and past executives like me. All you need is a passion for making a difference.

For more information about everything YPAHD-related, visit www.ypahd.ca. Want to chat with other YPAHD members? Email us at ypahd@huntingtonsociety.ca for details about our next conference call, happening on May 15th.



ypahd
YOUNG PEOPLE AFFECTED BY HUNTINGTON DISEASE

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

Visit www.ypahd.ca for more info.



A Heart for Volunteering

By Tiffany Nobes

For Nicole Patterson, Huntington disease (HD) has been a big part of her life since she was young. She watched it take her grandma's life when she was in the sixth grade, and soon after, Nicole learned her father also has the disease. Wanting to help in some way, Nicole volunteered with the Toronto Run for HD for a few years with her family. As her father's condition worsened, however, the family had to stay home more and volunteering fell on the back burner.

Now at school at the University of Waterloo, Nicole has returned to volunteering. This time, she's at

the HSC National Office in Kitchener. Nicole volunteers as often as her busy school schedule allows, helping with social media and website design.

"Volunteering with HSC is the perfect way for me to be able to do my part, while still being able to keep up with school," says Nicole. "It is an amazing opportunity to make a difference in people's lives. As we get closer to finding a cure, the hope that one day we can eliminate this disease is inspiring."

National Volunteer Week was April 15-21, where we took time to celebrate and thank all of our dedicated volunteers in the HD community! We appreciate the contributions of time and effort from all of our incredible volunteers. To learn more about volunteer opportunities, visit www.huntingtonsociety.ca/volunteer.

Paying it Forward with Pigs, Pittsburgh Penguins and Pinot Noir

By Josh Martin

When Principal Casey Brown suggested that the Grade 7/8s at Teepee Creek School donate 25 percent of the proceeds from their silent auction to HSC, it was a tough sell. After all, the small elementary school in rural Alberta relies on money from their Christmas fundraiser to pay for their year-end trip.

However, the 19 students that made up the class had been learning about "paying it forward," and this was a great opportunity to put the idea into practice. "We were talking about why it's important to do things for other people," says Casey. "It's a good quality that they need to learn for the future."

After a few class discussions and a presentation from Mack Erno – a member of the Teepee Creek community whose wife has HD – the kids were all

in. They got to work making up tickets, gathering donated items and organizing the event.

When the day of the Christmas Carnival arrived, the silent auction tables boasted 50 prizes, including three big-ticket items: a \$100 wine gift card, a signed hat from local Pittsburgh Penguin hero Carter Rowney, and even a pig.

The event raised a record-breaking \$1,308 – more than it ever had in 20+ years. Just as important, it taught the youth powerful lessons in helping others.

True to their word, the school presented Mack with \$327 for the Huntington Society of Canada. "It's pretty amazing," says Mack. "We feel like we have a whole community that's really come out and supported us."

Thank you, Miss Brown, and your generous Grade 7/8s!

youth MENTORSHIP program

Supporting young people across Canada facing everyday challenges of HD

Become a *mentee.*

Become a *mentor.*

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

For more information, visit: www.huntingtonsociety.ca

The Huntington Society of Canada is a proud supporter of



HUNTINGTON'S DISEASE YOUTH ORGANIZATION

To learn more please visit www.hydo.org

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Save the date:

2018 HSC National Conference

November 2 & 3, 2018

Join us for an exciting weekend this fall at the 2018 HSC National Conference hosted in partnership with the Okanagan Chapter. We are pleased to invite you to be brave, be bold, be ready and believe in Kelowna, British Columbia on November 2 and 3. To accommodate all attendees, this year's Conference will be held at the Delta Hotel by Marriott Grand Okanagan Resort in Kelowna, BC.

Conference Featured Presentations Include:

Huntingtin-Lowering Therapy: A Promising Step Forward



Presented by Dr. Blair Leavitt, HD Researcher at UBC

Therapies designed to decrease the amount of disease-causing mutant huntingtin protein in Huntington Disease are promising and are currently being tested in human studies. The results of a recent clinical trial of huntingtin-lowering antisense oligonucleotide (ASO) showed this treatment to be safe and well tolerated. Current trials administer huntingtin-lowering agents directly into

the cerebrospinal fluid (CSF). Thanks to a three-year \$950,000 grant from the HSC and Brain Canada, Dr. Blair Leavitt and his team will advance this research by exploring less invasive, and more efficient ways of delivering gene-silencing treatments.

Protecting the Hearts and Lives of Caregivers in the HD Community



Presented by Peter Rosenberger, Author, Radio Host, and Caregiver

Without question, the physical, emotional, and financial stress weighs heavy on those who care for a loved one with HD, and can be one of the most challenging journeys faced by any caregiver. Although no solutions exist for them, there are ways for HD caregivers (and those living with HD), to lead a calmer and healthier life. Drawing upon his own caregiving journey for more than three decades, author and syndicated

radio-host, Peter Rosenberger, helps to safely lead fellow caregivers through many of the difficult and lonely places that caregivers know all too well.

I Just Showed Up



Presented by Yvonne Heath, RN, Radio & Television Host, and Author of 'Love Your Life to Death'

"I don't know what to do!" "I don't know what to say!"

Have you ever said these things or felt this way when it came to grief, death or dying? Me too. But we can do better and we should do better. We have to grieve, but we can also choose to Just Show Up for ourselves and others, so we can live

our best lives – no matter what – with the good, the bad and everything in between!

Where's the Silver Lining? HD Drug Progress 25 Years after the Gene



Presented by Dr. Ed Wild and Dr. Jeff Carroll, HD Researchers and Founders of HDBuzz

It's been 25 years since the genetic basis of Huntington disease was discovered. Ed and Jeff haven't been HD researchers quite that long, but they've long described HD as the most curable incurable disease because we know what we have to do to prevent and treat it. A new era of drug trials is underway, targeting the known cause of HD. Together we'll find out how they're going, and what's next.

For more information about Conference, visit www.huntingtonsociety.ca/conference.



Be Brave • Be Bold • Be Ready

Believe



Lighten the Load with a Reverse Gift List

By Julie Stauffer

Mack Erno has a wife with HD and two young kids. He also has lots of friends and neighbours who say 'if you ever need anything, let us know.' "It's a genuine offer," Mack says. "But at the same time, you kind of go, 'where do I begin?'"

Bernadette Modrovsky, our Northern Alberta Resource Centre Director, has a suggestion: make a list. Specifically, a reverse gift list.

The idea is simple: jot down all the small, manageable tasks other people could take on that would free up some time in your day. Perhaps they could pick up your prescription at the pharmacy, or shovel your driveway, or cook dinner once a week.

Next, make a list of the folks who have offered to help – or might offer to help in the future – and start matching. Perhaps Susan from your Synagogue enjoys cooking, or Kevin down the street has a snowblower. Bingo: you've created a support network.

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.

If you feel guilty about asking for help or think it's a sign of weakness: don't. You can't be a good caregiver if you don't take care of yourself, Bernadette says. A free hour here and there gives you the time you need to recharge.

On top of that, you're actually doing your friend or neighbour a favour. "If you're allowing me to do something for you, it's making me feel good," Bernadette explains. "It's the gift that keeps giving."

Mack starts musing about the things he could put on his list. Perhaps someone could take Amanda into town for grocery shopping, when driving becomes more difficult for her. Or they could come by once a week for a coffee and a chat.

"I'll always be her main support person," he says. "But maybe there are little things that would lessen the load." And that's exactly the idea.

The Huntington Society of Canada's NAVIGATOR research program is supported by the following funds:

Family Fund Partners: Barrett Research Fund; Bloom Family Fund; Rick and Norma Brock Fund; The Kelly Bumstead Family Fund; Chaplin Family Fund; Cranston-Dorr Family Fund; Annie J. Cutler Memorial Fund; Barbara Dorr Research Fund; Goodman Family Fund; Irwin Family Fund; Lembit and Karen Janes Fund; McArthur Family Fund in memory of Megan McArthur; Reklitis Family Fund; Garth Shuster Family Fund; Skene/Stevens Family Fund; Skeoch Family Fund; Sterling Family Fund; Wright Family Fund in memory of Helen-Mary Wright; Yeung Family Fund; Neuman Family Fund; Laura's Hope Fund; Zantingh Family Fund; The Lingard Family Fund; Grange John Taylor Fund; The McGregor Norm Fund; Diane Kuzyk Family Fund; The Mark Atkinson Family Fund

To apply for the Navigator research program, please visit www.huntingtonsociety.ca/navigator-research-program



Champion of Hope: Janet Longpre

By Josh Martin



At HSC, we're lucky to have many monthly donors whose regular contributions give us funds we can count on. However, few of these Champions

of Hope can boast a track record as long as Janet Longpre's. "I'm the type of person that when I start something, I don't stop," she says.

With more than four decades of monthly giving to her name, that seems like an accurate claim.

Janet began donating in the early 1970s, after meeting Ralph and Ariel Walker in her hometown of Edmonton. Her father-in-law had passed away from HD, leaving her first husband, Bert, at risk. Eager to help however she could, she joined the Edmonton Chapter alongside its founders John and Diane Kuzyk.

After Bert passed in 1984, an autopsy revealed he had inherited the HD gene. Many years later, their daughter Shelley also tested positive for the disease, reinforcing Janet's commitment to the HD cause. "I'm praying for a treatment for my daughter and for all the future people affected," she says.

Together with her second husband, Emile, Janet backs up those prayers with concrete action. The couple laces up their sneakers each year for the Walk to Cure HD and they help guests place their bets at the Chapter's popular casino events. Janet also sells Amaryllis to her friends at the local ten-pin bowling alley (where she has been racking up strikes and spares for nearly half a century!).

More than 40 years since making her first gift to the Society, Janet remains as committed as ever. "I will keep on for as long as I can, for as long as I'm living," she says. "Hopefully I live long enough to hear that there definitely is a treatment!"

If you'd like to become a monthly donor like Janet, call us at 1-800-998-7398 or visit huntingtonsociety.ca/monthly-giving.

Join the RaceHD Team!

By Tiffany Nobes

As the sun was rising on October 22, 2017, the Wright Runners were already awake and ready to run as a team in the Scotiabank Toronto Waterfront Marathon and raise awareness for Huntington disease.

Awareness wasn't all the team raised, though. The Wright Runners also raised over \$25,000 for HD!

The Wright Runners raised these funds and participated as part of RaceHD, the Huntington Society of Canada's National Race Team that participates in races across Canada and the United States.

To be a part of RaceHD, participants register through the race's official website, then return to the Society's official fundraising page to sign up as a RaceHD team member. From there, participants get the chance to personalize their page with a custom message and send their page link to potential donors. The concept of this process is considered a 'piggy back event'.

"Piggy back 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 restraints of their own."

Participants don't just enjoy these types of events for the ease of planning; they also enjoy the sense of being part of a team and getting together with people for one cause.



"I think it's a great way to raise money," says Susan Wright, past HSC board chair and Wright Runners team member. "In terms of time spent compared to money raised, it's definitely worth it. It is also a great opportunity for my big family to get together!"

You shouldn't let the term 'race' scare you, though, as many of the events RaceHD participates in include 5K/10K walks or runs and kids' marathon options in addition to the standard marathon and half marathon distances.

"Several members of my family are runners," says Susan. "That's why this type of event appealed to us as a group. But not all of us are runners, and lots of us strolled our way over the finish line."

If you aren't interested in participating in the actual races by walking or running, many races also offer the option for charities to set up cheering booths. Booth participants dress up in their HD swag and cheer on other RaceHD members while raising awareness.

The Halifax Chapter did just that in May 2017 as part of the Scotiabank Blue Nose Marathon's 'Blue Nose Boogie' challenge. Not only did the group have fun and raise awareness for HD, they were also given the chance to win \$500 if they were the booth that cheered the loudest.

No matter how you choose to participate, through walking, running, cheering or donating, RaceHD is a great team to join and has people coming back year after year.

"Our family had a blast," said Susan. "We will definitely be participating again this year!"

The next RaceHD event is the Toronto Goodlife Marathon on May 6! For a full list of races near you and to sign up, visit www.hsevents.ca/racehd.

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. We partner with the Huntington Society of Quebec. Their resources can be found at www.huntingtonqc.org.

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. Nous travaillons également en étroite collaboration avec la Société Huntington du Québec, vous pouvez visiter leur site Web à : www.huntingtonqc.org.