HORIZON

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Roche's Phase III Trial Set to Launch!

Global study will test whether huntingtin-lowering drugs slow down HD

By Julie Stauffer

Roche is set to launch the Phase III trial of RG6042 (formerly IONIS-HTTRx), called GENERATION HD1 in six expected sites across Canada. The sites expected to participate are in Edmonton, Vancouver, Ottawa, Toronto, Halifax and Montreal. This therapy is designed to lower the levels of huntingtin protein, including the mutant version that creates HD symptoms.

This follows the completion of the Phase I/IIa trial, which showed that RG6042 was deemed initially safe and that higher doses reduced huntingtin proteins by 40 to 60 percent.

Now comes the big question: can RG6042 actually slow the progress of HD? That's what the GENERATION HD1 trial aims to answer.

GENERATION HD1

"It's a very exciting time, and we're so proud to be leading this with you," says Dr. Lauren Boak, Global Development Team Leader at Roche at the 2018 HSC National Conference.

As a presenter at the Conference last fall, Dr. Boak explained that the Swiss pharmaceutical company has designed this study to get clear results as quickly as possible and to accommodate the needs of participants. It will also aim to answer key questions. What are the affects of lowering huntingtin over a longer period of time? Do any unexpected safety concerns emerge? And, of course, does sustained treatment slow or stop the progression of HD?

Altogether, Roche aims to enroll 660 individuals at up to 90 sites worldwide. Participants will be randomly assigned to one of three groups: one group will receive the drug monthly, one will receive a placebo monthly, one will alternate between the drug and the placebo.

Getting involved is a big commitment. Each month for 24 months, volunteers will spend a full day at a clinic undergoing assessments and getting a spinal injection called a lumbar puncture. Between visits, they'll wear a digital wristband that measures signs of HD.

To be eligible, participants must be 25 to 65 years old at the start of the study, with symptomatic HD. They also need a score of more than 400 on something called the CAG Age Product score: a calculation based on age and CAG count that predicts how quickly the disease is likely to progress.

That's important, Dr. Boak explained, because to assess RG6042, they need to test it on people whose symptoms would be expected to get measurably worse over the course of two years. At the same time, participants must score at least 70 out of 100 on a test of independence, meaning they can walk and speak and handle basic household chores.

Roche understands this excludes a lot of people affected by HD. However, Dr. Boak emphasized that the strict criteria are necessary to provide clear results as quickly as possible. "It's important that we design and get this right," she explained.

If the drug is effective, she said, it will be approved for a much broader range of people. Roche may at some point run future trials for other groups, including those with Juvenile HD and gene-positive individuals who haven't started showing clinical symptoms.

"We're going to continue to work and try and ensure that the best therapy gets to all HD patients," said the University of British Columbia's Dr. Blair Leavitt.

At the same time, it's important to remember that RG6042 aims to slow down the progression of HD – not to stop or reverse it. "When people come into these studies, they have to realize that they're not necessarily going to get a dose and then start seeing a symptomatic improvement," says Dr. Mark Guttman, who heads up the Centre for Movement Disorders in Toronto.

HD Natural History Study

In addition to GENERATION HD1, Roche is running an "HD natural history study." It will build on Enroll-HD and HDClarity, creating a more detailed picture of how huntingtin levels change over time without treatment.

The 15-month investigation will involve up to 100 volunteers between the ages of 25 and 65 in stage 1 or stage 2 HD. In Canada, UBC's Centre for Huntington Disease and Toronto's Centre for Movement Disorders will be enrolling volunteers.

Because this is an observational study, volunteers won't be receiving any drugs. Instead, they'll undergo a number of tests, including four lumbar punctures to take CSF samples, and they'll need to wear a digital device between clinical visits. Once finished, participants may be able to opt to receive RG6042.

For more information about HSC research visit www.hdresearchnews.ca

Find Clinical Trials in Canada

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

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

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HORIZON

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

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

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

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Message from the CEO

Happy New Year! Looking back over 2018, we have much to celebrate – and much to look forward to in 2019.

It was wonderful meeting so many of you last fall at our National Conference in Kelowna. I certainly wasn't the only newbie. Of the 313 participants - our biggest number ever - 49 per cent were first-timers. What impressed me most was the incredibly warm and supportive atmosphere. Whether you were coming for your first time or your fifteenth, you immediately felt embraced and involved. If you weren't able to attend Conference, many of the presentations featured this year were recorded and can be found at huntingtonsociety.ca/conference.

Not surprisingly, huntingtin-lowering trials were the big story of 2018. We saw the very positive results of the Phase I/IIa trials for Ionis-HTTRx (now known as Roche RG6042) and the continuation of Wave's PRECISION HD-1 and HD-2 trials. In November, Roche announced the sites for a new natural history study designed to learn more about the normal progression of HD, and in December announced the six expected sites of the Phase III GENERATION HD1 trial that are set to begin in the early new year.

It's no coincidence that both Wave and Roche have chosen to run clinical trials in Canada. It really speaks to the calibre of our doctors and scientists, who are leading the way in HD research.

It also speaks to the level of engagement within our community. I applaud the volunteers who have stepped up and continue to step up for research. Their bravery pushes us closer than ever to meaningful treatments. I'm also inspired by the Canadian volunteers serving on the HD Coalition for Patient Engagement (HD-COPE). This international group is helping pharmaceutical companies design trials that take into account the complex needs of people with HD.

Today, we have many reasons to feel optimistic about the prospect of meaningful treatments. However, we should also remember that trials are not therapies. The journey from clinical trials to commercially available treatments takes many years, and there is no guarantee the drugs currently being tested will prove effective. In the meantime, families dealing with HD continue to need support – and we're going to be there for them.

As I heard at the Conference again and again, dealing with HD is incredibly challenging, but the Society's support makes a world of difference. Now, as awareness of our programs and interest in clinical trials grow, our Family Services team is getting more calls than ever.

That's why we opened our new Halton-Peel Resource Centre at the end of August and why we're now looking at virtual ways to serve even more individuals and families.

That's all possible due to the generosity of new donors and long-time supporters who made our Believe campaign such a success, and I want to thank every one of you who contributed.

Since joining HSC last July, it's become very clear to me that people are the Society's greatest strength. As we move into 2019, I'm excited to work alongside our caring and committed families, volunteers, staff, board members, researchers and other members of the HD community. Together, we will continue to transform tomorrow.

Robin Markowitz

Robin Markowitz
CEO, Huntington Society of Canada

PLEASE TAKE OUR SURVEY

Providing information and services to you is a top priority for HSC. Your responses will assist us in evaluating *Horizon*, provide us with content ideas and help us identify areas for future improvement.

The survey will remain open until February 28, 2019.

Access it at www.horizonsurvey.ca

If you have any questions or comments, please contact us at 1-800-998-7398 or at info@huntingtonsociety.ca

New Research Rethinks the Root of Huntington Disease

By Julie Stauffer

For years, scientists have believed that a buildup of mutant protein kills brain cells, leading to the symptoms of HD. Now, new research from Dr. Ray Truant's lab at McMaster University suggests the buildup is just an effect of HD, not the cause.

According to Dr. Laura Bowie, who recently earned her PhD in Dr. Truant's lab, the real culprit is DNA damage.

There are a number of studies showing that DNA repair pathways have implications for Huntington disease, but recently there is evidence that the huntingtin protein is directly involved in DNA damage repair. The Truant lab believes that mutant huntingtin fails to do that job, so the damage accumulates. "That's a big problem," Dr. Bowie says.

The McMaster researchers believed the root of the problem might lie in a particular region of the protein - a region that undergoes a process called phosphorylation (an important mechanism by which the activity of proteins can be altered after they are formed) in normal huntingtin, but far less in the mutant version. If they were right, then finding something that could replicate the same amount of the process in mutant huntingtin should reduce HD symptoms.

To test the theory, Dr. Bowie screened more than 100 different compounds for promising candidates. The best compound was one called N6FFA.

Follow-up experiments confirmed that it could phosphorylate mutant huntingtin in a laboratory setting. So far, so good. The next step was testing it in mice. "A lot of stuff looks different in cell models," Dr. Bowie explains. "Animals are substantially more complex."

For help, they turned to Dr. Simonetta Sipione at the University of Alberta. "That's when it got really exciting," Dr. Bowie recounts.

Dr. Sipione looked at how N6FFA affected motor symptoms, measuring how long mice could stay on a mini-treadmill. Untreated HD mice fell off quickly, but the HD mice that received N6FFA hung on almost as long as their normal, healthy cousins. In another set of experiments, Dr. Sipione showed that HD mice treated with N6FFA showed fewer symptoms of anxiety than untreated mice.

According to Dr. Truant, we're a long way from testing this approach in humans. N6FFA doesn't have the kind of properties that translate well into drug form, although he's currently working with a biotech company to examine some promising N6FFA derivatives. Most importantly, the experiments with N6FFA have revealed an entirely new pathway to target HD - and potentially other neurodegenerative diseases as well.

For the latest HD research updates, visit www.hdresearchnews.ca.

An Ariel View

By Ariel Walker, Co-Founder of HSC

I've just got back from the 2018 HSC National Conference, and let me tell you, it was phenomenal. I came home from Kelowna absolutely glowing.

More than 300 people attended – the Society's biggest National Conference ever. There were 72 young people registered for Young People Affected by HD (YPAHD) Day, and what an energetic group they were! Their enthusiasm really set the tone for the weekend.

On Friday night, the local chapter put on a lovely banquet in a restored factory. I didn't know the two ladies who sat next to me, so we introduced ourselves. What a surprise to find out they were Jerry and Shirley Weber's daughter and daughter-in-law. Jerry and Shirley helped launch the Southern Alberta Chapter and did so much for the Society over the years. And Jerry, of course, was quite a character. Well, we had a great walk down memory lane that night.

The keynote speakers were great. On Friday, Peter Rosenberger gave a wonderful talk about caregiving: how important it is for caregivers to look after themselves, to get outside support and to have a sense of humour.

On Saturday, Yvonne Heath discussed the value of "just showing up." If someone is grieving, for example, just knock on their door and ask what you can do. Could you clean the house? Rake the lawn? Later, Dr. Mark Guttman from the Movement Disorders Clinic in Toronto was talking about Yvonne's message and he pointed out that's what Ralph, my late husband and co-founder of HSC, did: just showed up and did something.

In Mark's case, Ralph showed up at his door one afternoon to convince him to get engaged in the HD community. Really, that's the story of how HSC began. Now, here we are with chapters and social workers all across the country and so many exciting research advances.

On that note, I was delighted to finally meet Dr. Tamara Maiuri from Dr. Ray Truant's lab in Hamilton. She's one of the new generation of scientists who are giving us all these important insights into HD. I really enjoyed the workshop she and Dr. Jeff Carroll led called "Ask the Scientists Anything," where they stood up on stage and answered all our research questions.

It turns out that Tam's great-aunt was Dorothea Smith, one of the earliest members of the Society. Well, naturally I had to give Tam a hug! And I was thrilled to be able to give Tam's band, Eli and the Straw Man, the Ariel & Ralph Walker Founders' Award on Saturday night for all their incredible fundraising work.

There were so many hugs that weekend. I reconnected with old friends, and I also met lots of wonderful new people: chapter leaders, social workers and families who had never been to an HSC Conference before.

They say it takes a village to raise a child. Well, it feels like we've created a village – a village where everyone looks after each other and supports each other. I'm just so proud to see how many families the Society is helping and all the fantastic research we're funding.

HealthPartners

Charities At Work

HealthPartners Update

By Eileen Dooley, CEO of HealthPartners

"My heart is about to burst with hope," said Tammy, a first time participant at the HSC National Conference in Kelowna. Mine was about to burst with gratitude – having experienced the family orientation and generosity of spirit that characterizes the community of researchers, volunteers, staff and those directly affected by HD.

As the CEO of HealthPartners Canada – a collaboration of 16 of Canada's most trusted health charities (including HSC) – I've had the opportunity to learn about the work our charitable partners are doing to support Canadians diagnosed with chronic disease and to invest in research designed to find cures, treatments, diagnostic tools and ways to stop the progression of diseases such as MS, cancer, heart disease, diabetes, HD and others. And while I meet researchers, caregivers, those affected and their families, I rarely have the privilege to immerse myself in a community where they all come together – as I did at the HSC Conference.

The two-day event was a fantastic interplay between the latest research findings and inspirational plenary speakers, interspersed with conversations with families and researchers. I learned there are some exciting new clinical trials that have taken place and more that will soon be underway in Canada and around the world. I learned about the genetic component of Huntington disease and heard stories of entire generations in families that have the genetic mutation that will – inevitably – lead to the disease. I say inevitably at the moment. While there are still years of clinical trials and research into the efficacy of new drugs to slow the progression of the disease, there was a sense of cautious optimism that held sway throughout the event.

Most of all, I experienced the warmth of a close-knit team of researchers, families, staff and volunteers united in their desire to care for one another, to take care of one another and to take care of this disease. I am inspired to find more resources for the incredible work of the Huntington Society of Canada and the dedicated researchers – and the amazing families – it supports. Now I, too, am filled with hope on their behalf and a commitment to help them find more resources to aid them in this work.

For more information about HealthPartners, visit www.healthpartners.ca.

CCGF/CCEG

CCGF Update

By Bev Heim-Myers, CCGF Chair

The Genetic Non-Discrimination Act (GNA) hearings at the Quebec Court of Appeals were held in December. The Canadian Coalition for Genetic Fairness (CGGF) was given 90 minutes to make comments, which our lawyers worked hard to prepare for.

The Federal Attorney General, the Attorney General of British Columbia and the Canadian Life and Health Insurance Association were supporting Quebec's position to overturn the GNA. CCGF and the Canadian Human Rights Commission (CHRC) were supporting to keep the GNA intact for all Canadians. The court also appointed an Amicus (an voluntary impartial adviser to a court of law) who argued in favour of the GNA alongside CCGF and CHRC.

As of our publish date, we do not yet know the outcome and hope that it won't be long before we know the Quebec Court of Appeals recommendation.

The hearing was intense and our legal representation was excellent. Tough questions were asked by the judges and answered by our lawyers who focused on relevant details, expertise and clarity of the issue.

Where it was easy to get a little discouraged during the hearing I was reminded by one of the brilliant lawyers representing us that we are no less successful and the GNA legislation remains. We have achieved an amazing feat. It takes a village and the genetic test information of the village remains protected.

While there was no outcome results yet at publish date, frequently asked questions and answers about the GNA and a full update on the outcome of the hearings when we know it can be found at www.ccgf-cceg.ca/recent-updates.

Believe

Transforming Tomorrow Together

We Believed – and We Achieved!

By Josh Martin

When we announced at the 2016 HSC National Conference that we were aiming to raise $3 million in just two years, Vern Barrett wondered if we had bitten off more than we could chew. "It seemed like a daunting number," the Manitoba Chapter President and former HSC Board member admits. Still, he accepted the challenge and joined the Believe: Transforming Tomorrow Together campaign cabinet.

In the end, we didn't just hit our target; we flew past it. The final amount raised is close to $3.5 million – a transformative sum that will accelerate research discoveries, expand capacity for clinical trials and improve services for families and individuals.

Vern credits much of the success to the diverse and committed campaign volunteers across the country, as well as excellent support from staff.

He also points to a uniquely grassroots approach that set Believe apart from other capital campaigns. Although major donors played a vital role, it was the many smaller contributions that really pushed things over the top. "It's because of so many that we've been able to do this," says Jeff Hoffman, HSC's Director of Development and Marketing.

The latest research breakthroughs inspired many new organizations and individuals to step up. Meanwhile, the impact of our services – especially our youth programs – wowed other first-time donors. As a result, we're moving forward with a bigger base of support than ever.

"We just chipped away at it," says Vern. "It was a really astounding campaign."

HSC would like to thank everyone who was involved in the Believe campaign cabinet and those who made a donation to the cause. Your support has made a significant impact, helping us exceed our goal.

Cannabis and HD: Helpful or Harmful?

By Julie Stauffer

Across the country, Canadians are now legally using cannabis. But is cannabis a good idea for people who are symptomatic or carry the HD gene? "The short answer is we don't know," says neurologist and UBC researcher Dr. Lynn Raymond.

Scientists do know that the brain contains receptors for cannabinoids, the active chemical components in marijuana. The brain also makes its own cannabinoids, which are involved in motor learning, and contribute to developing brain circuits responsible for emotion and memory.

Intriguingly, levels of those natural cannabinoids and the receptors they bind to seem to be reduced in the early stages of HD. Evidence from in-vitro experiments and a few animal studies suggest that boosting activation of the receptors might help improve motor symptoms. Meanwhile, some individuals with HD have reported that cannabidiol (CBD) oil reduces their chorea.

However, the few, small-scale trials conducted in people with HD haven't replicated those results.

According to Dalhousie pharmacology professor Eileen Denovan-Wright, "There are no good human studies that indicate that cannabis or [its] components have a positive effect." Before we can draw firm conclusions, we need bigger, better-designed trials that run for more than a few weeks.

In the meantime, could it hurt to relax in the evening with cannabis? Potentially, says Dr. Raymond.

One major concern is the side effects from Tetrahydrocannabinol (THC), the chemical that creates the cannabis "high." Many studies have shown that THC can cause apathy, depression and psychosis – all symptoms that are already common in HD.

Some patients wonder about trying medicinal CBD oil to help reduce anxiety, help gain better quality sleep and/or perhaps reduce their motor symptoms. The THC levels in cannabidiol oil are quite low, so the side effects are fewer. However, Dr. Raymond cautions that using it floods the brain's cannabinoids receptors for several hours at a time, interfering with their natural function.

For gene-positive patients who choose to use cannabis, Dr. Raymond offers a few suggestions:

- Choose products with low levels of THC.
- Recognize that at this point, there are no strict guidelines governing testing and labelling of cannabidiol or THC content in oral products, so the effects on HD symptoms can vary from one batch to the next.
- Limit your use. Taking cannabis too frequently can create a rebound effect, increasing your levels of anxiety.
- Don't use cannabis if you're under 25, because studies have shown that it affects the development of the circuits in your brain.
- Tell your doctor(s), so they have the full picture and can learn from your experience.

Bidding Farewell to Members of the Board

By Tiffany Spencer

Hailing from all corners of Canada, the Huntington Society of Canada Board of Directors meets twice a year and is responsible for governing the Society. Each member of the board has specific expertise that is essential to the governance of HSC and we value each individual for their time, resources and dedication to the HD cause. This year, three members of the board are retiring:

Glenda Rowein

Glenda joined the HSC Board in 2011 and was appointed treasurer that same year. Glenda's professionalism and thoroughness provided sound fiscal oversight in a period of growth for the Society. Additionally, efficiencies and improvements to financial processes were seen under Glenda's term, including the change of the fiscal year end, which will provide for greater alignment of the budget cycle to the cash flow cycle. Glenda's duties as Treasurer included an active role on the Executive Committee, leading the Audit Committee, which she did with skilled knowledge, and adding value to the Investment Committee, ensuring the right questions were asked to enable understanding. It didn't stop there, however. Glenda also played an active role at the local level in Regina. She attended events and was instrumental in fundraising.

Susan Wright

Susan joined the HSC Board in 2010, serving as Chair from 2015 to 2017 and more recently as Past Chair. Susan's leadership, commitment and support were especially vital as HSC led key initiatives, such as clinical trial readiness, and advancing legislation to end genetic discrimination, all while providing more support to families across Canada. We also recognize Susan for her efforts leading the extensive and successful CEO search this past year. In true Wright family tradition, Susan has served HSC in multi-faceted ways. Over the last few years, Susan led the Wright Family Team in the Toronto Scotiabank Waterfront Marathon, raising significant funds for HSC.

Richard Taylor

Richard joined the Board of Directors in 2014 after several years of serving on the BC HSC Community Board. We are thankful for Richard's dedication to the HD community through both his work as a director and his efforts in Vancouver, engaging in substantial chapter work and special events support. Richard has always been very active with local fundraising efforts for HSC. We look forward to Richard's ongoing energy and relationship building skills supporting our community in BC.

HSC would like to extend our sincerest appreciation and thanks to Glenda, Susan and Richard for their leadership and support. You have each made a lasting impact on the Canadian HD community.

2018 HSC National Conference

By Tiffany Spencer

Keynote Presentation Summaries

Protecting the Hearts and Lives of Caregivers in the HD Community, with Peter Rosenberger

Without question, the challenges of serving as a family caregiver remain daunting for even the strongest of hearts. Although no solutions exist for them, there are ways for HD caregivers, and those living with HD, to lead a calmer and healthier life, and even a life containing beauty and joy, while dealing with the harsh and often grim circumstances of HD. Drawing upon his own caregiving journey through a medical nightmare for more than three decades, Peter used personal anecdotes and humour to deliver an important message: as a caregiver, you need to take care of yourself first. Peter shared that caregivers too often suffer from the three I's: they lose their independence, they become isolated and they lose their identity. Peter encouraged delegates to learn how to laugh at their situations and start to feel okay again.

Huntingtin-Lowering Therapy: A Promising Step Forward, with Dr. Blair Leavitt and Dr. Lauren Boak

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. Dr. Leavitt joined the Conference to speak specifically to the recent RG6042 (formerly IONIS-HTTRx) trials. He was quick to clarify that a trial this promising is a slow process, saying that it has taken 12 years of hard work to get this drug into people. He discussed the trial from the beginning, explaining that the very first thing they needed to discover was whether the trial was safe. Now that the trial has been deemed initially safe and well tolerated, the study can move on to the next phases. Dr. Lauren Boak, a representative from Roche, addressed the future of the trial, noting that Roche will be testing the differences between a monthly dose of the drug and a bi-monthly dose of the drug, as well as studying the role of mutant huntingtin protein in disease progression through an observational study. In the end, Dr. Boak stressed they are not doing this for the HD community; they are doing this WITH the HD community, and that collaboration has been the cornerstone of the program.

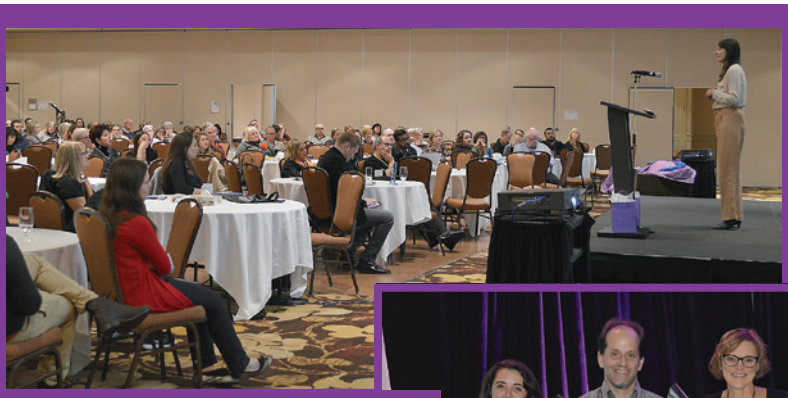
I Just Showed Up, with Yvonne Heath

We have to grieve, but we can also choose to Just Show Up for ourselves and others, so we can live our very best life - no matter what - with the good, the bad and everything in between. This was Yvonne's core message during her Saturday morning keynote. It is Yvonne's hope that one day the process of talking about the end of life will be normalized: when you turn 18, you make your end of life decisions because the best time to talk about, plan and prepare for grief is when you are young and healthy. She emphasized that end of life decisions should not be made at the end of life. Grief is hard enough to deal with, without trying to make decisions about someone's end-of-life wishes – she encouraged the crowd to make those decisions now as a gift to their families.

Where's the Silver Lining? HD Drug Progress 25 Years After the Gene, with Dr. Jeff Carroll

It's been 25 years since the genetic basis of HD was discovered. Dr. Jeff Carroll hasn't been an HD researcher quite that long, but he's 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, and Dr. Carroll describes 2018 as a "remarkably exciting year for HD research." One notable accomplishment includes one from the GEM-HD consortium which took data from participants in the Predict-HD study and registry and had the question "What affects the age of onset of HD?". Another significant advance was the new use of pig models in HD, because the pigs present the most common HD symptoms, including chorea, whereas mice do not demonstrate such symptoms. The Signal trial that is currently recruiting patients in Edmonton and Vancouver is another step in the right direction by being the only non-lowering trial run in Canada, advancing hope in another solution. Of course, the recent news with huntingtin-lowering trials is the most exciting of all. Dr. Carroll ended his presentation with obvious enthusiasm, saying "There are literally more companies trying to lower huntingtin than I have time to tell you about."

Visit www.huntingtonsociety.ca/conference to view recordings of the keynote presentations.



And the Award Goes to…

At every HSC National Conference, the weekend ends with the much anticipated awards gala. A time for delegates, researchers, staff and families to come together and celebrate all the accomplishments made in the last two years. Tears are shed, kind words are spoken, and momentum is gained. At the 2018 HSC National Conference Awards Gala, we celebrated the following people:

Dean Crain Memorial Award
Presented to Arlene Rowan and Geri Stewart

For extraordinary perseverance and leadership in carrying out the Society's mission through founding the Calgary Hope Run & South Vancouver Island Chapter respectively.

Dorothea Smith & Stan Edwards Award
Presented to Debbie & Greg Taylor

For demonstrating long-term commitment and leadership on behalf of people living with HD through their ongoing support of the Edmonton Chapter and walk.

National Award of Merit (Corporate/ Organization)
Presented to CIBC Charitable Foundation

For outstanding contributions to the HD community through their long-time support of the Youth Mentorship Program.

National Award of Merit (Volunteer)
Presented to Amanda Munro

For outstanding contributions to the HD community through being the face of the Shared Inc. awareness campaign and HSC fundraising campaign.

Milestone Award for Communications
Presented to the Halifax Chapter

For Chapters demonstrating outstanding achievement in communications through media, social media and awareness initiatives.

Milestone Award for Fundraising
Presented to the Grand River Chapter

For Chapters demonstrating outstanding achievement in fundraising through the development and growth of their Founders Walk and other fundraising initiatives.

Michael Wright Community Leadership Award
Presented to Heather Tomshak & Tyler Hoff AND Ellen Foster & Jim Wiswell

In recognition of unique contributions to the HD community in the areas of clinical leadership, family support, community and organizational development through support of the Grand Prairie Ride 4 a Cure and founding and leading the Toronto Architectural GEMS Walk.

Brighter Futures Award
Presented to Natalie Marnica

In recognition of a youth (35 years old and under) for outstanding achievement in meeting the HSC mission through leadership of her local Chapter, support of YPAHD, national involvement and fundraising.

Chair's Award
Presented to Lindsay Groot

In recognition of innovative and lasting contributions to the development of HSC through her PSA, national involvement and growth of the Exeter Hike of Heroes.

Ariel & Ralph Walker Founders' Award
Presented to Eli & the Straw Man band

In recognition of unique and lasting contributions to the development of HSC, and dedication to helping create a world free from HD through PSA and direct mail involvement, research and ongoing benefit concerts raising over $60,000.

2018 HSC National Conference

"Thank You" Will Never Be Enough

"Attending YPAHD Day and the HSC Conference has made such a difference in my life. It has made me feel less alone in the fight against HD. This Conference has touched so many lives."

"Conference is the only place I have to connect with other people who know my struggle."

"Conference has broadened the HD community. I am always meeting new people and am inspired by their stories."

For many members of the Canadian HD community, the HSC National Conference weekend is one they start counting down to as soon as the last one ends. The Conference is a place where families can feel comfortable and at ease with their symptomatic loved ones, because everyone in the room understands what is happening. It's a place where knowing looks and comforting hugs are shared, and contact information is exchanged, in hopes of making someone else's journey just a little bit easier.

It's a place to gather information and ask those questions that have been held onto for so long.

It's a place that wouldn't be possible without the dedication and generous support of our sponsors. Our sponsors make it possible to have so many incredible keynote speakers, worthwhile workshops and necessary resources. They allow us to fund a great number of community members and youth representatives from across the country to attend free of charge or at a reduced rate. Our sponsors, like Kindred Home Care, believe in the impact that Conference has on our community.

"The HSC conference is an incredible event where the Canadian HD community can gather, connect, and be educated on the latest HD research," says Billy English, Kindred Home Care CEO. "We are so proud to be a small part of bringing this incredible event to all those who attended."

The Huntington Society of Canada would like to thank all of our passionate sponsors for their support:

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SickKids FOUNDATION

DAVIDSON PRINGLE LLP LAWYERS

WAVE LIFE SCIENCES

Take it from the community… How did you feel about the 2018 HSC National Conference?

Rollie from Manitoba

To be honest, I'm sad that it is over! The 2018 HSC National Conference gave me the opportunity to learn lots of positive caregiving strategies, like taking care of yourself first and giving your loved ones time to process information. It was an incredible experience for my whole family – I don't know what my wife is going through or what my kids are going through, but we met a whole group of people who do and can help. It's a way to build an amazing support system, especially for my kids involved in YPAHD.

Keely from New Brunswick

Leaving the 2018 HSC National Conference, I felt refreshed, energized and overwhelmed with knowledge. It feels good to be able to absorb all the news on trials and bring the information home to my local community. The presentations were my favourite part – they were so insightful and it helped me to stay on top of what's happening in research. Even though it was my first Conference experience, I definitely built a network of friends who know what I'm going through.

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YPAHD Column

By Doug Mallock, new YPAHD President

In 2012, I hopped on a plane to attend my first YPAHD Day in Toronto. Until then, I had never met another family affected by HD. It was nerve-wracking going to an event where I didn't know anybody, but I returned to New Brunswick with a lot of life-long friends and a lot more optimism about the future.

This time, I returned home from Kelowna, B.C. as the youth chapter's new president. I've got big shoes to fill, but I'm looking forward to making a positive difference alongside our other new YPAHD executives, including Caleb Harding (vice president), Lisa Pollock (social media coordinator), Katie DeLargie (secretary) and Catherine Price (HSC Board representative).

YPAHD Day itself was a big success. We needed our biggest room ever to fit in all 72 attendees – from teens to people in their mid-30s. Almost half of them were first-timers, and it was exciting to see so many come out of their shells and get engaged. As usual, the weekend was jam-packed with informative workshops and plenty of fun.

It was apparent people left feeling invigorated and wanting to get more involved locally and nationally. As the YPAHD executive, we're available to help you out any way we can. In the coming months, we'll be planning for our regional YPAHD Days in November 2019, organizing fundraising events and gearing up for HDYO Camp this summer.

The new YPAHD executive

Finally, although we're reaching more people than ever, there's always room to grow. I encourage anyone who is considering getting involved with YPAHD to reach out. Taking that first step can be hard. But, like my boarding of that plane more than six years ago, it can also lead to connections and friendships that last a lifetime.

Ready to take that first step? Email us at ypahd@huntingtonsociety.ca.

Shaunacy's Journey from Searching to Sharing

By Julie Stauffer

When Shaunacy's mom got diagnosed with HD in 2014, the Ontario teenager had to turn to the Internet to understand what it meant. She didn't know anything about the disease or anyone else who had it. "We'll just have to suffer through with no support," she figured.

But then she discovered the Huntington Society of Canada.

Getting matched with a mentor from HSC's Youth Mentorship Program helped Shaunacy deal with her mom's difficult symptoms and navigate the process of getting her own genetic test. Later, at Huntington's Disease Youth Organization (HDYO) camp, she discovered a whole circle of peers who understood what she was going through and had her back. "That was an amazing experience," she says. "It was the most supportive group of individuals that I've ever met."

Soon, Shaunacy's involvement with HSC evolved from receiving support to providing it. In 2015, she and her sister organized their first HSC event – a BBQ and raffle that raised more than $8,000. This year, they're holding a benefit dance in May featuring four live bands, a raffle, a silent auction and plenty of food and drink, aiming to raise $10,000.

Shaunacy has also joined Huntington Disease Coalition for Patient Engagement (HD-COPE), a 20-person international advisory group that includes caregivers, people with HD and family members. Last year, Shaunacy travelled to London, England to learn about clinical trials: their processes, those involved in setting up a clinical trial and the important role that community plays in those clinical trials. The group also met with Roche to help shape its new clinical trials for huntingtin-lowering drugs.

It all adds up to a big sense of purpose. "I can only do so much for my mom," Shaunacy explains. "So becoming involved with HD-COPE and the Society and everything I can think of kind of fills that void, because I'm able to help other individuals."

On top of that, it has given her optimism. "It has definitely shaped me into a person who is more hopeful for the future," she says.

Today, Shaunacy is on the other side of Internet searches. In 2017, she launched a blog where she shares her experiences and thoughts on genetic testing, advocacy, relationships, grief and more. "If what I'm doing and what I'm sharing can help support somebody else, then of course I'm going to do it," she says.

The New Halton-Peel HD Resource Centre: Expanding Services for a Growing Community

By Josh Martin

A short drive west of Toronto lies Halton-Peel: one of the fastest-growing and most culturally diverse regions in the country. As the population in the area has increased, so too has the number of people affected by HD.

In response, we opened a new HD Resource Centre last August. Formerly served by social workers in our Toronto and West-Central regions, families in Halton-Peel now have a dedicated centre to call their own. At its helm is our newest Resource Centre Director, Ekta Hattangady. Angèle Bénard, HSC's Director of Family Services and Community Development, is pleased to welcome Ekta, a passionate, energetic and experienced social worker to the Family Services team!

In addition to her professional skills, Ekta has a deeply personal connection to neurological disorders. When she was 13, her mom was diagnosed with a genetic form of young onset dementia. Now, she plans on drawing on her experience caring for her mother to help youth and families in the HD community.

She's also keen to find ways to expand support to the diverse ethnicities that make up Halton-Peel's HD community. "Some cultures don't want to talk about it," Ekta says. "It's my role to remove barriers for people to access our services."

Working three days a week, Ekta has hit the ground running. You'll find her facilitating support groups, giving presentations at long-term care facilities, making home visits, fielding calls from families, and building community connections. She also provides social work support for patients at Dr. Mark Guttman's Centre for Movement Disorders.

Ekta says everyone she's met to date has been very welcoming, and she's looking forward to connecting with more families across the region. "We're here. We're available. Call us," she says. "I'm so invigorated to do this work."

Want to connect with Ekta? Call 1-833-584-3472 or email ehattangady@huntingtonsociety.ca. A full listing of Family Services team members across Canada can be found at www.huntingtonsociety.ca/family-services-team.

The Winnipeg Foundation and Ottawa Community Foundation Step Up to Help Make HD Support Groups Even Better

By Josh Martin

Since the beginning, support groups have been a cornerstone of the Huntington Society of Canada, breaking down the sense of isolation so many families feel when they're living with HD.

Today, more than two dozen groups from coast to coast give people with HD, carers, and at-risk individuals safe spaces to connect and learn from each other. They also offer an opportunity to develop stronger relationships with the local Family Services team members who run the meetings.

"I really think support groups are one of the best things we do at the Society, one of the best services we offer," says Paul Klodniski, our Resource Centre Director for Eastern Ontario.

Now, thanks to funding from The Winnipeg Foundation and the Ottawa Community Foundation, we're improving those services with our new Support Group Best Practices Guide.

This new tool brings together the best ideas from our Family Services staff across the country, creating a one-stop resource where support group facilitators can find discussion questions, suggestions for guest speakers, up-to-date handouts, and more.

We also consulted with other organizations and experts to develop facilitation guidelines, covering topics like how to structure sessions, create a safe and comfortable environment, and help participants navigate difficult topics.

"Why reinvent the wheel?" asks Angèle Bénard, HSC's Director of Family Services and Community Development. Thanks to our generous donors, the new guide combines HSC's in-house experience with international best practices.

For new members of the Family Services team, it will help them hit the ground running. For seasoned staff, it will cut down the time required to prepare for each session. Angèle also predicts the guide will lead to the creation of new groups across the country, giving more families the support they need.

"It will be wonderful to have a resource that is tried and true to go to," says Marla Buchholz, HSC's Manitoba Resource Centre Director. "That gives me the opportunity to spend more time on direct care to families."

"It's going to lead to a richer experience for my groups in Ottawa because it won't just be me contributing ideas, but all my colleagues," says Paul. "If I'm looking for ideas, this is going to be the first place I'm going to go."

Our heartfelt thanks go to The Winnipeg Foundation and the Ottawa Community Foundation for helping us meet the needs of individuals and families affected by HD. To find a support group near you, contact your local Family Services team member. A full listing can be found at www.huntingtonsociety.ca/family-services-team.

Christine's Story

By Christine Andrews (written by Jen Love)

My daughter Meghan tested positive for HD when she was 21. Once she recovered from the shock, she knew she wanted to get involved with the Society and dragged me along. For 12 years we were involved in fundraising, helping with events, and Meghan even created a photography book that tells stories from the HD community.

The support you get from just listening to each other's stories, and sharing your own, is so powerful. I walked into my first support meeting last year and walked out as Secretary of the Chapter. Everyone in this organization is so caring and helpful. Meghan is an artist, and there were a lot of people at her gallery opening who were from the HD community. They'd never met her, didn't know her, but they were there to support her.

That's my experience of the Huntington Society. Volunteers who step up and work hard. Good people who believe, like I do, in giving of themselves. Whole families getting involved, supporting each other, pulling together, caring for each other.

I was a nurse in Vancouver at the start of the AIDS crisis. It was running rampant before anyone knew what it was. It was a sure death sentence within a short amount of time. But today, people are

living with HIV, with good treatments, because of medical research and caring people who pulled together and looked to the future. People who decided to not just think about themselves but think about others.

We're here to help each other, in any way we can. I am fortunately in a position to help financially. My daughter will likely predecease me. If that happens, I want to make the same promise to her that I've made every single day of her life: what matters to you matters to me. Like my family before me, I've worked hard, saved up and I'm here to help future generations.

It's not easy but it's important to ask yourself: "Where do I want my money to go when I die?" I personally want it to matter. I want it to be part of my values. I want to support an efficient, effective charity that I know is doing great work. I give where I can see my impact, where I know what the charity is doing. It doesn't just feel good to give, it feels right.

Jeff Hoffman, Director of Development and Marketing, would like to extend his deep gratitude to Christine and all our dedicated and caring donors who have remembered us in their Wills. He would love to have a confidential conversation with you if you have any questions or would like more information. You can reach him at 1-800-998-7398 ext. 125 or jhoffman@huntingtonsociety.ca.

Keeping the Amaryllis Tradition Blooming in Stoughton, Saskatchewan

By Josh Martin

For more than a decade, the Amaryllis has been one of Shirley Coderre's go-to Christmas gifts. Although her family isn't impacted by HD, the Stoughton, Saskatchewan resident sees the flowers as the perfect way to spread cheer and support a good cause at the same time. "They bring a lot of joy to a lot of people," she says. "It's good for your recipients, it's good for people that are having to deal with HD."

For years, Shirley bought Amaryllis from her friend Bonnie. When Bonnie moved away a couple of years ago, Shirley didn't want to disappoint her loved ones who had come to eagerly expect their annual bulbs. So she contacted HSC and ordered a case.

Her friends and family were thrilled she did. A neighbour in town called Shirley each day to report how much her flower had grown, while Shirley, her mom and her daughters began competing to see who could grow the best bloom. (Shirley claimed that victory in 2017 with an Amaryllis that sported eight blooms at once, pictured to the right.)

She continued her lucky streak last year, winning our Amaryllis early bird draw and taking home a Kindle and a copy of Five Days Left by Julie Lawson Timmer.

Qualifying for those prizes isn't the only reason Shirley orders her Amaryllis kits early. It's also a great way to line up a bunch of Christmas presents before summer without having to step outside. "If you can get 12 gifts looked after [with] one email, that's pretty amazing," she says. "This has been my Christmas routine for 10+ years, and I don't plan to change it anytime soon."

Thanks to seasoned sellers and newcomers our 2018 Amaryllis campaign was another massive

success. We sold over 20,000 kits, totalling more than $120,000. "Our volunteers from coast-to-coast make a huge difference for the HD community each year," says HSC's Director of Development and Marketing, Jeff Hoffman. "We are so incredibly grateful to every one of them."

Check out this year's submissions to our Amaryllis Photo Festival at www.facebook.com/HuntingtonSC – and share your own by emailing amaryllis@huntingtonsociety.ca or using #HSCAmaryllis on social media.

30 Years of Flourishing and Fundraising

By Tiffany Spencer

For 30 years, Calgary has come together annually for the Southern Alberta Chapter's Night to Flourish Gala. A night filled with games, food, cocktails and socializing, all in support of the Huntington Society of Canada. But the event wasn't always solely in benefit of HSC.

In 1988, the Rotary Club of Calgary Olympic (RCCO) recognized that it was early days for many local charities and that they all needed a platform to bring the community together. So the fundraiser, then known as the Achieve Gala, was created in partnership with over 20 local charities including HSC. The event featured a program of more than 200 silent auction items and raised in excess of $250,000. Over the years momentum grew for each charity and some went on to do their own galas and events until HSC was the only one left, with RCCO hosting the event.

In the past five years, HSC has hosted the event alone, with RCCO still supporting as a sponsor. Over the years the gala has evolved, too. With the help of Ada Ballard, Stan Weber and Wendy Comtois, the gala has become a hugely successful – and unique – fundraiser.

"Over the years we've introduced more and more interactive components," says Tara Johnson-Ouellette, Southern Alberta Chapter President. "Games like *Crack the Vault, Diamond Dip, Rocks and Socks* and *Highs and Lows* make the gala fun and inviting."

Some years the group has also invited researchers to come and speak at the gala, to add an element of education to the night.

For the Southern Alberta HD community, the gala has given them the opportunity to learn about HD and even share their stories.

"One year our theme was predictive testing," says Tara. "Wendy shared her personal story in front of 150 to 200 attendees and other people were inspired to share their own stories. The gala gives people that chance to feel heard."

The event has been positive for HD and HSC as a whole by raising significant funds and bringing awareness to the disease through interviews with media. The gala offers a different version of fundraising than the usual walk or run. Even the sponsors and partnerships the gala has produced with companies like MP Energy (Gibson's) and Cardinal Coachlines (First Student) have made a great impact, with many sponsors utilizing the event as an employee night for their businesses.

"Without sponsor support, the event would have never happened," says Tara. "Thank you just isn't enough."

To honour the 30th year in 2018, the theme of the gala was "Rewind the Times". The Chapter teamed up with RCCO one final time and hosted the gala at the Canada Sports Hall of Fame with light refreshments and all the old favourite games as a tribute to years past. HSC's CEO, Robin Markowitz, attended to help celebrate 30 years of the successful event.

While 2018 is the final year for the gala in this format, Tara hopes this year has marked not an end, but a new beginning.

"We hope someone will take it over and give it a new perspective," she says. "Someone who has a new way of looking at it and can think outside of the box."

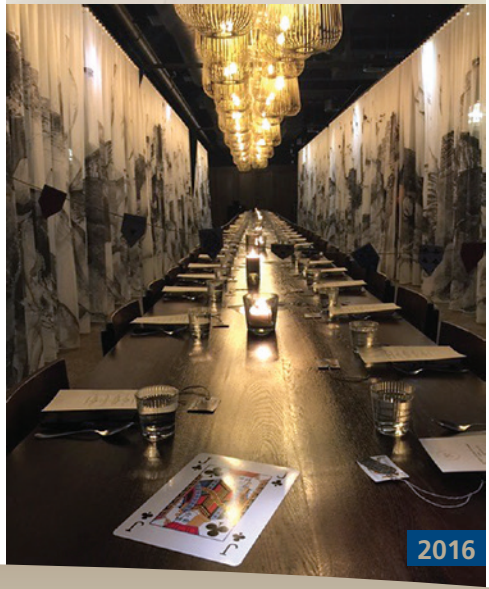
And thinking outside the box is exactly what made the gala so successful all these years.

"People kept coming back because it was different," explains Tara. "That's the key. Be different and stay different."

For more information on events near you or to plan your own event, email events@huntingtonsociety.ca.

2018

2015


2016

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.