

HORIZON

RESEARCH • SERVICE • EDUCATION

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The Latest Scoop on Treatment Trials

By Julie Stauffer

"This is a super-exciting time in research for HD," University of British Columbia's (UBC) Dr. Blair Leavitt told the 400-plus people who tuned into our National Symposium last October. He wasn't exaggerating. Our panellists provided the latest scoop on different clinical trials for potential Huntington disease (HD) treatments currently underway.

Dr. Oksana Suchowersky from the University of Alberta talked about the human proof of concept studies for GM1, a substance that has reversed HD symptoms in mice, and the clinical trials for Laquinimod, an anti-inflammatory drug that could reduce HD symptoms.

Dr. Leavitt discussed the IONIS phase one trial that has focused on proving the safety of a huntingtin-lowering drug in humans. Meanwhile, Dr. Mark Guttman described the trials for another huntingtin-lowering drug that are starting in his Toronto clinic (see article on page 4).

According to the panellists, these studies are a testament to Canada's strong, involved HD community. "None of us could do clinical research without you," Dr. Guttman said.

Nor is physically being involved in a trial the only way to contribute. Dr. Leavitt highlighted the importance of fundraising and, looking forward,

patient advocacy. "We're going to need the community to help push our governments, not just to fund the research but to fund these treatments as they become available," he predicted.

Will all – or any – of these potential treatments prove effective? HD researcher Dr. Tamara Maiuri emphasized that if there's one thing we've learned from unsuccessful trials, it's that humans are not mice, and what works in the lab won't necessarily translate into clinical success.

That said, every trial gives us valuable information that moves us forward.

Today, Dr. Maiuri is thrilled to see more than 13,000 people participating in Enroll-HD, a global observational study that tracks people through the different stages of Huntington disease. "This is the best way to accelerate drug discovery," she said. "When it comes to studies, there is power in numbers."

After Symposium, Dr. Maiuri reflected on just how much progress researchers have made over the past decade. "I came away from the whole experience feeling even more hopeful than before," she says.

Missed it? Watch the video presentations and download the summaries at www.huntingtonsociety.ca/symposium.

Breaking News:

On December 11, 2017 Ionis Pharmaceuticals announced that the HTRx drug has successfully lowered the harmful huntingtin protein in spinal fluid, the drug is safe and well tolerated. This announcement is promising and gives us substantive hope that the treatment is near.

The Canadian HD Community has been leading the charge. Canadians are a part of this clinical trial helping us all to get to this important point in our history.

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November 2 & 3, 2018



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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 is a hereditary brain disorder which has devastating effects on both body and mind. The symptoms, which may include uncontrollable jerking movements and relentless cognitive and emotional impairment, usually appear between the ages of 35 and 55, and gradually worsen over the 10-20 year course of the disease. 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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Bev Heim-Myers, CEO, Announces Her Retirement From HSC

The Huntington disease community in Canada, and globally, has never been in a better position to realize the dream of a "world free from Huntington disease."

For close to eight years, Bev Heim-Myers has brought passion and purpose to HSC, leading us to this important point in our organization's history.

Under Bev's guidance, the work of the Society has grown. More families are now served by our amazing network of social workers and research funding has increased, including our two million dollar research partnership with Brain Canada.

Through Bev's leadership of the Canadian Coalition of Genetic Fairness, an individual's genetic test information is now protected, and her work has resulted in the Huntington Society of Canada being recognized as a global leader in the clinical trial readiness space.

Bev assembled a team of the best and brightest, not only across the Society but through worldwide HD connections, increasing awareness, resources and vital partnerships.

Bev will continue to lead the Society until the end of May, 2018. The Board of Directors has formed a search committee which will be led by Past Chair, Susan Wright.

Bev will be missed, although I believe she will never be far away supporting us as we continue to move forward. We are so happy for Bev, as she makes the transition into retirement to spend more time with her family and her five little grandchildren.

At the Huntington Society of Canada, it is business as usual. The staff are busy supporting families, working with all our Chapters and volunteers, planning for the 2018 National Conference, raising awareness and more support, and preparing for our next set of research investments.

On behalf of the Board of Directors of the Huntington Society of Canada, thank you Bev. We have achieved so much and come so far. You have made a true difference in the lives of families impacted by HD, both in Canada and globally. There is so much hope as we look to the future, and you have made that future brighter for all of us.

Brenda Nowakowski (Wasylow)
Chair, Board of Directors
Huntington Society of Canada



Huntington disease research news.

In plain language.
Written by scientists.

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Note from the CEO

What an incredible journey!

Eight years ago I had the distinct pleasure of meeting Dan Devlin and the late Stephen Gould. Stephen was Chair of the HSC Board at the time and Dan was the Vice Chair. They were leading the search for a new CEO for the Society. After several interviews, including one with most of the Board members in attendance, I wasn't sure if I would be offered the position but I was sure I was going to do something for the HD community and the Society. I was hooked and ready to learn more. As good fortune would have it I was offered the position of CEO and I have never looked back, only forward.

Over the last eight years together we have achieved incredible momentum and success. Our success has not come without challenges however, the commitment, resilience and focus of staff, the HSC Board and the HD community has led us on a journey that few of us dared to dream.

The team is stronger than ever, our systems are efficient and our financial stability is the envy of many organizations our size. This does not happen because of one person, it happens because a team of people believe that it can.

With the Genetic Non-Discrimination Act receiving Royal Assent on May 4, 2017, all Canadians are protected against genetic discrimination, because you and HSC believed it could happen. Our Board had the wisdom to know we could lead the initiative, our community had the courage to tell their stories and our partners in the Canadian Coalition for Genetic Fairness, the scientific and medical communities and Senator Cowan, believed that we would help make a difference.

Clinical trials addressing the root cause of HD are here. Canada was the first clinical site to be approved for the WAVE precision trial. The first dose was given to a courageous trail blazer in Toronto. The Ionis huntingtin lowering trial has completed phase one and it continues to move quickly. These promising trials are exciting and give us substantive hope that the solution is near. Our research investments have guided global thinking and our partnership with Brain Canada has resulted in significant investments in HD research in Canada.

HSC has been recognized locally, nationally and globally for our genetic fairness initiative, clinical trial readiness preparation, youth mentorship program and creating a forum through HD-COPE to give HD families a global voice at the table of future clinical trials. We truly punch above our weight. We could never have achieved this much if only a few believed we could do it, we all believe we can do it.

When I started this journey I was quoted in the Fall 2010 Horizon as follows, "Sometimes the universe

just comes together and this is the time for the Society to grow beyond where we have come from in order to evolve to where we are going. Together we will make that happen." Together we have made it happen.

It has been a true honour and a privilege to have been given the opportunity to lead this "small but mighty" organization. Together we have made a difference in our community and many others. The momentum will continue because it is driven by you, a community of committed, resilient, focused individuals working to positively change the history of HD and make HD history.

Working with the HD community has been the gift of a lifetime and I will never veer far from the cause. I can only hope that you feel I have given back to you a fraction of what you have given to me. Thank you for believing in me and the vision. Thank you for the incredible journey.

Bev Heim-Myers
CEO, Huntingtin Society of Canada

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A Wave of Excitement: More RNA Lowering Drugs Start Trials

By Julie Stauffer

As Dr. Mark Guttman described in his Symposium presentation in October, two more potential HD treatments have reached the point of clinical trials, and his Toronto clinic is the first in the world to be testing them.

Wave Life Sciences has developed two closely related drugs – WVE-120101 and WVE-120102 – that are designed to stop cells from making the mutant huntingtin protein that is thought to be toxic to the brain.

Like the IONIS-HTTRx trial, Wave's PRECISION-HD trials are testing drugs that "shoot the messenger" – targeting the messenger RNA (mRNA) that translates the HD gene and leads to the production of mutant huntingtin protein. By reducing the messenger, these drugs aim to stop the disease in its tracks or prevent it from developing in the first place.

However, unlike the IONIS drug, the Wave drugs target only the RNA that is associated with the abnormal CAG repeat, leaving the normal part

untouched. (People with HD have both because they inherit two versions of the gene: a mutant version from one parent and an unaffected version from the other.)

That selectivity might prove to be an advantage, since the normal huntingtin protein does important things in the cell – although exactly what, we're not quite sure, yet.

Targeting just the mutant mRNA isn't easy, but the scientists at Wave have found a sneaky way to do it by zeroing in on specific bits of DNA often found with the mutant gene. They call these bits SNP1 and SNP2.

WVE-120101 is designed to bind to SNP1 close to the mutant mRNA, while WVE-120102 binds to SNP2. When that happens, it prompts the cell to use an enzyme to destroy the mRNA-drug complex.

The catch is that only two-thirds of people with the HD gene also have these SNPs. And, even if someone has one of those SNPs, it may be in a place where the drug physically won't fit. That

means unlike the IONIS drug, the Wave drugs will only work for some patients.

Right now, Dr. Guttman is screening potential participants for these phase Ib/IIa trials. There's a long list of criteria they need to meet to be eligible. They have to be in the early stages of HD, under the age of 65, and otherwise in good health. They have to live within a 90-minute drive of the clinic, and they have to have one or both SNPs in the right location.

On top of all that, they have to be available for a battery of tests and a series of seven lumbar punctures. "It's very intensive," says Dr. Guttman. "It's certainly not for everybody."

This is just the first study, however. If the drugs prove safe, he says, there will be more opportunities to get involved. "It's exciting," he says. "This is what we've been waiting for."

For more information on all the clinical trials taking place across Canada, visit www.huntingtonsociety.ca/hd-clinical-trials.

From the Living Room to the Boardroom: Brenda Nowakowski (Wasylow), Agent of Change

By Josh Martin

Brenda Nowakowski's involvement with HSC began in a small living room with Ralph Walker. She was 21 years old, and Ralph had travelled to Saskatoon to drum up support.

Brenda didn't need much convincing. Her mother had HD, and the fatal disease would eventually take her sister and brother as well. At risk herself, she welcomed any opportunity to help. "I am not a victim if I'm contributing," she reasoned. "I can choose to be an agent of change."

Since then Brenda has sold Amaryllyis, volunteered at Indy events and organized fundraisers – including the very first Saskatoon Walk to Cure HD, which raised more than \$25,000. She also served on the Saskatoon Chapter executive, joined the cabinet of two major fundraising campaigns for HSC and raised awareness everywhere she went. Brenda is also the Vice President of Finance at JNE Welding in Saskatoon.

Testing negative for the HD gene has only intensified her commitment to the HD community. Since 2003, Brenda has served on the National Board of Directors, stepping into the role of Chair last October.

Contributing to the cause gives Brenda optimism. She cites the flurry of breakthroughs that have happened since she first sat down with Ralph all those years ago. "At times it has been like drinking from a fire hose in terms of the speed of change," she says. "We have come a long way, and I have never felt more hope than I do today."

As Board Chair, she aims to help keep that momentum going. "Those people who have come before me have built an incredibly stable and formidable ship," she says, pointing to all the champions working in HSC's National Office, in local Chapters, on the Board and in research labs across the country. "I am honoured to be part of what I believe is one of the strongest organizations in the world."



Going to Court to Protect Genetic Fairness

By Julie Stauffer

Last May, the Genetic Non-Discrimination Act (GNA) received royal assent – and for a few brief hours, we celebrated that landmark achievement. The next day, however, the federal cabinet said they would refer the new law to the Supreme Court.

Two steps forward, one step back.

The cabinet hasn't followed through on that yet, but as we described in the last issue of Horizon, the Quebec government has decided to challenge the new law. If the Quebec court rules against the GNA, the case will automatically go to the Supreme Court of Canada.

Bev Heim-Myers, CEO of the Huntington Society of Canada and Chair of the Canadian Coalition for Genetic Fairness (CCGF), believes this move is probably driven by the insurance industry – and that's simply not acceptable. "We should not overturn this law and put the interests of the insurance industry above the interests of all Canadians," she says.

Rest assured, we're taking action. The CCGF has been granted official intervenor status so that we can argue why the court should uphold a law

that received all-party support and the backing of Canadians across the country.

The Canadian Human Rights Commission will also argue in favour of upholding the current law, but British Columbia's Attorney General and the Canadian Life and Health Insurance Association will take the other side.

We're working with our lawyer in Quebec to prepare for our 90 minutes of oral arguments this fall. If the case ends up going to the Supreme Court, we'll continue our vigorous advocacy there. "We are not going to give this up," says Bev. "This is much too important for all Canadians."

In the meantime, what does this mean for your genetic test information?

Right now, the GNA is law, and that protects your genetic test information, no matter where in the country you live.

If the law ends up being overturned – something we'll be working very hard to prevent – any test results you get between now and then will probably stay protected, according to the experts we've talked to. Unfortunately, that's not one hundred percent guaranteed.

As a measure of protection, we're suggesting healthcare providers put a note on your file with the date of the results and instructions not to share them with anyone without your explicit written consent.

Ultimately, every person who is considering genetic testing will need to decide for themselves whether now is the right time to go ahead.

"This is far beyond the interests of the insurance industry," says Bev. "They have survived in other jurisdictions. The GNA is about protecting your genetic information from employers, landlords, schools or anyone who chooses to use it against you."

For now, your genetic test information is protected. Help keep it that way! Let your MP and the Prime Minister know how important this is to you. Write them a letter to ask them to honour Canada's new Genetic Non-Discrimination Act and protect the interests of Canadians across the country.



An Ariel View



Well, the first Founders Walk to Cure HD here in Cambridge has come and gone. I may be slightly biased, but I think it was a huge success. Of course, it's just the name that is new. The Grand River Chapter has been organizing an annual walk for several years, and let me tell you, they are seasoned pros. They did just a superb job. The weather was perfect – a welcome change from the heavy rains we got the year before – and we had a great turnout.

There were little kids, teenagers, young couples and oldies like me. Best of all, I saw so many people I didn't know, which means more people are getting involved. And the energy was unbelievable.

Before the walk got underway, they invited me to say a few words. I shared my dragonfly story, and how the dragonfly had become an important symbol for me and the HD community

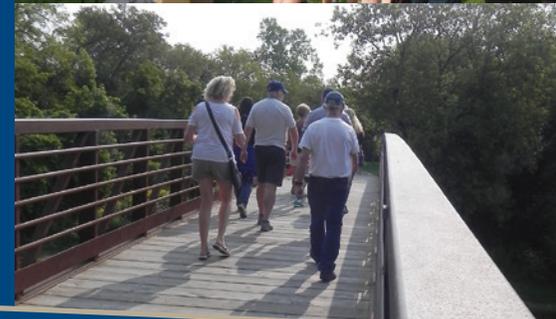
(see Horizon, Spring 2017 for the full story). I think I might have prompted a few tears in the audience.

Bryan May, our local Member of Provincial Parliament, was there and shared a few remarks of his own. He talked about the importance of hardworking, caring volunteers to the success of organizations like ours.

I couldn't agree more. Watching this community come together year after year – to see familiar faces and to meet new people – is just so heart-warming. That close camaraderie is one of the things that makes this such a great organization.

From day one, Ralph and I worked hard to instill that sense of family within the Society. (Many of you will remember Ralph's habit of writing little, personal notes to our donors and volunteers.) That feeling is still there, and I think that is just phenomenal.

Meanwhile, the impact of this group is also phenomenal. The Founders Walk in September raised almost \$24,000. Multiply that by the number of fundraisers our Chapters and volunteers organize each year across the country, and you really start to see the power of this incredible community!



Mentor/Mentee Meetups

YPAHD Day was all about connecting. For some of the participants in our Youth Mentorship program, it was also a very special opportunity to finally meet face to face. Meanwhile, HSC's new Youth Mentorship Coach, Corey Janke, was busy recruiting potential newcomers. In Kelowna, program coordinator Erin Stephen also spread the word.

Since we launched the program in 2012, we've matched 40 individuals across the country as mentees and trained mentors. With our fourth training session scheduled for March, those numbers are sure to go up, giving more youth the chance to use their experience and knowledge to support their younger peers.

That support is making a difference. In a survey we conducted last fall, a whopping 100 percent of the mentors, mentees and parents who responded told us the program fills a big need.

Want to get involved? Contact us at mentorship@huntingtonsociety.ca or call 1-855-253-0215.



YOUTH MENTORSHIP PROGRAM

For more information, visit:
www.huntingtonsociety.ca

YPAHD Day 2017

By Julie Stauffer

Inevitably, there are some heavy moments when youth dealing with HD get together for Young People Affected by Huntington Disease (YPAHD) Day. But there is also a huge amount of energy and optimism.

"They're laughing, they're having a good time," says Annie Vanexem, HSC's Manager of Chapter Development. "They're learning what they need to learn and asking the questions they need to ask, but they're doing it with a very light-hearted approach."

All told, 76 youth aged 12 and up registered for our YPAHD Day events in Kelowna, Toronto and Moncton last November – a 26 percent increase over 2015. For almost half, it was their first YPAHD Day ever.

They learned about grief and guilt, social media savvy and the latest news on clinical trials. They enjoyed board games and escape room adventures. Most of all, they connected.

"The biggest highlight for me was meeting so many amazing people who knew exactly what I was talking about," says 25-year-old Nicole from Whitby, ON, a first-time participant.

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YPAHD Day - Toronto



YPAHD Day - Moncton



YPAHD Day - Kelowna

For that, we can thank our sponsors: Kindred Home Care, McLean Group and SickKids Foundation. "More than 80 percent of our youth wouldn't be able to attend without funding," says Bev Heim-Myers, HSC's CEO. "By supporting YPAHD Days, our sponsors make a direct impact on the lives of young people growing up in families affected by HD."

Most importantly, that impact lasts far longer than a single weekend. "I feel more positive about HD and for the future of this disease," says 17-year-old Rachel from Nanaimo, BC. Courtney from Saint John, NB agrees. "[It] made me feel like I wasn't alone and that there was hope."

Couldn't attend last year – or already itching for your next YPAHD fix? Mark your calendars: YPAHD Day 2018 will be held on November 1st in Kelowna, right before our National Conference. Hope to see you there!

YPAHD Column



By Jaclyn Skinner, YPAHD President

The 2017 YPAHD Day events in Kelowna, Toronto and Moncton were incredible!

Over the years, I've been to many YPAHD Days. What always strikes me is how there are no barriers. You form an immediate bond with your fellow participants because when you walk in, everybody gets it. There's no elephant in the room that needs explaining. Instead, you've got a safe space to share your experiences. Plus, the workshops and speakers always offer practical information and tools.

However, I think the biggest benefits happen after you go home. You leave with a whole group of people you can call upon when you need them. We had a slew of first-timers signed up this year, and it's great to know they now have this fantastic support network they can turn to. As YPAHDers, we're only a phone call, text or email away.

Last August, I got to see that support in action when I, along with 4 other Canadians, volunteered at the 2017 Huntington Disease Youth Organization Camp near Washington, D.C. It was such an amazing experience to see the courage these kids have. I left energized to do everything I absolutely can to make sure that I'm part of the last generation that knows what this disease can do.

I'm not alone, judging by the number of youth who fundraised for our 2017 Champion's Challenge, or through their local Chapters. We had youth from across the country organizing walks and runs, trivia nights, fishing derbies, selling mittens or popcorn, participating in half-marathons and marathons, running bottle drives, lemonade stands, yoga events and more to raise funds for the HD cause. Online, the Champion's Challenge raised nearly \$6,000, but overall, youth in 2017 raised over \$92,000!

It's so motivating to be surrounded by all these strong and hopeful individuals pushing their boundaries to make a difference. I can't wait to see what we can achieve in 2018!

Raising Money for Mentorship Magic

By Josh Martin

Donations to HSC support everything from cutting-edge research to caregiver support groups. Last fall, our fundraising appeal highlighted how those contributions support a world-leading initiative: HSC's Youth Mentorship program.

We shared Shaunacy's story: a 21-year-old from small-town Ontario, who spent her childhood helping her mother through mood swings. The moods would be difficult at times for Shaunacy and her sister to keep up with. It wasn't until a few years ago that her mother was diagnosed with HD.

For Shaunacy, it was an isolating experience. "None of your friends are affected by it," she says. "I didn't know anyone else that was suffering from HD, especially coming from such a small town."

Then HSC's social worker Corey Janke told her about the Society's Youth Mentorship program. Before long, she got paired with her 32-year-old mentor, Natalie.

Like Shaunacy, Natalie grew up in a home affected by HD and spent much of her 20's as the primary caregiver for her grandfather and mother. Looking back, she wishes she had someone to lean on along the way. "It's very challenging to go through this disease process alone," says Natalie.

Over time, the two got to know each other through email, texts and FaceTime. Some days, Natalie would give Shaunacy advice on navigating the healthcare system and finding the right kind of support for her mother. Other times, they would talk about the pros and cons of genetic testing. And some days, they would simply shoot the breeze and share a few laughs.

Today, Shaunacy has graduated university, is now a registered nurse and the feelings of isolation have faded. "It was like, oh my gosh, I'm not alone," she says. "She knew exactly what I was going through."

Shaunacy and Natalie have a simple message to donors: your dollars help us live better.

Thank you, Shaunacy and Natalie for sharing your story – and thank you to all our donors who make transformative initiatives like the youth mentorship program possible!

If you haven't made a contribution yet, it's not too late. Just go to

www.huntington society.ca/yes-i-want-to-donate.

One Extra Push: Sharing Amanda's HD Story

By Josh Martin

As a video content creator for Shared – an Ottawa-based marketing company – Amanda Munro is no stranger to the camera. However, she's not usually the one in front of it. That changed recently when she chose to tell her HD story for a powerful awareness video.

The video was Shared's CEO, Jordan Nabigon's, idea – a way for his company to support an important cause that could have a large impact. Amanda held nothing back,



Amanda Munro and her Mom.

talking openly and honestly about how her mother's HD has affected her family. "It's coming from somewhere that's very real and raw," she says.

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Completing the Camino: 800 Kilometres of HD Awareness

By Josh Martin

As the sound of bagpipes grew, so did Ellie Smith's excitement. This was it. After 34 days, she had reached the end of the 800-kilometre pilgrimage along the Camino de Santiago through France and Spain. When she and the other members of "TeamHD" entered Santiago's town square last October, there were plenty of hugs to go around. "People were screaming and yelling and jumping around, and it was just so joyous," recalls Ellie.

The journey had been a magical one for the eight friends from Armstrong, British Columbia. Spectacular sunrises greeted them each morning as they began their daily march through medieval towns, across mountains and along old stone fences bordering vineyards and fields of grain.

Of course, it wasn't without its challenges. Sleeping in bunk beds in a dorm room with 20 other pilgrims made privacy tricky. The lack of veggies at meals left them desperate for a real salad. Meanwhile, walking 24 kilometres a day resulted in plenty of blisters, shin splints and a few lost toenails. "At the end of every day, you really wanted to get rid of that 20 pounds off your back and kick off your boots," says Ellie's friend Isla Van de Laar.

Still, it was well worth it. Whether it was listening to nuns singing in a church, finding themselves in a sun-dappled eucalyptus forest or discovering the deeply personal reasons behind another pilgrim's journey, there was no shortage of powerful experiences.

The trip was also a chance to raise awareness about HD. The group jumped at every opportunity, handing out information cards, explaining the

significance of their "TeamHD" buffs and sharing how HD has affected Ellie's family. What struck Ellie most was how few people had heard of the disease. "There is not enough awareness of what HD is," she says.

After reaching Santiago, the group met with members of the Huntington Society of Spain and the town's Mayor, who welcomed them and commended all the work that is being done for the HD cause. "They were so thankful for Canada and what we've done in regards to HD," says Ellie.

Today, Ellie, Isla and the others are keen to remember the lessons the Camino taught them: the importance of appreciating what you've got, leaning on your team and simply putting one foot in front of the other. "It was just every day, step by step, that we did it," says Isla. "And every day I found joy."

To learn more about their journey, visit www.huntingtonsociety.ca/blog.

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Breaking News:

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There is still much to do and learn. We have compiled resources and information about this announcement on our website. You can find all the up to date information at www.HDLoweringTrials.ca.

We are so thankful to all of the brave volunteers who signed up and committed to this trial. This is very promising for the HD community and sets us up for an exciting 2018. For our family members, if you have specific questions about participation in clinical trials, we recommend that you speak with your clinician. As more information is made available, we will continue to update you.

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

Visit www.ypahd.ca for more info.

A Transformed Tomorrow? Believe it.

By Josh Martin

Throughout our Believe campaign, we've talked a lot about "transforming tomorrow together." As we close in on our \$3 million goal for research and services, it's exciting to think what that transformation might look like for the HD community.

For a teenager, it could mean getting the peer support she needs, thanks to more funding for our Youth Mentorship program. For a couple living in a remote part of the country, it could result in more visits from a family service worker. And for researchers in the lab, a new grant could be the key to a treatment breakthrough.

However, we don't need a crystal ball to see the difference these dollars will make. The recently opened HD Resource Centre in New Brunswick is a direct result of the Believe campaign, giving more families in the area access to the support they need.

The benefits of the campaign go beyond dollars and cents. Believe has allowed us to build new relationships with a number of first-time funders from corporations and foundations. "The new donors are excited about what they're funding," says Jeff Hoffman, HSC's Director of Development and Marketing. "But we've also been able to grow the knowledge and awareness around Huntington disease."

We couldn't have come this far without our incredible campaign cabinet – volunteers who have come together from across the country to lend their expertise and open doors to prospective donors.

With their leadership, we've raised \$2.4 million to date. And with a year left before the campaign officially wraps up, tomorrow keeps looking brighter and brighter. "We're close to pushing this right over the top," says Jeff.

If you'd like to help us fund more research and increase services to families – or know an individual or organization that does – call us at 1-800-998-7398 or email info@huntingtonsociety.ca.

Accelerating Clinical Trials in Canada

By Josh Martin

PRECISION-HD. IONIS-HTTRx. LEGATO-HD. Open HART. Canadians have never had more opportunities to take part in clinical trials for potential HD treatments – and for that, the HD Clinical Trials Consortium can take a hefty dose of credit.

The Consortium was first convened in 2014 to connect clinicians, share best practices and maximize the opportunities for people affected by HD to participate in clinical trials. Since then, we've developed a preparation guide, a readiness checklist and a mentorship program to help clinicians hit the ground running whenever new clinical trials are launched.

"We are seen as leading the charge when it comes to being ready for clinical trials," says Bev Heim-Myers, HSC's CEO. By sharing our tools widely, we're also helping the global HD community and providing an example that other disease groups can follow.

Our 2017 meeting brought together close to 30

clinicians, family members, researchers and other stakeholders from across Canada, including HSC. At the top of our agenda was developing a decision guide to help patients decide whether to participate in clinical trials – and if so, which ones.

We're also anticipating the day when HD treatments become available, and we want to make sure that everyone who can benefit from them gets access. "We need to start to advocate for that now," says Bev.

Meanwhile, the Consortium experience has taught us just how much patient voices add to clinical

discussions. That's why HSC has teamed up with the European Huntington Association and the Huntington's Disease Society of America to launch the Huntington's Disease Coalition for Patient Engagement (HD-COPE).

"This globally recognized initiative will ensure the HD community voice is heard by regulators, industries and researchers in a coordinated, timely manner," says Bev.

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.

Daryl Cook: A Supporter Since Day One

By Julie Stauffer

When Daryl and Gord Cook married in 1964, not much was known about HD. However, they did know that Gord had a 50/50 chance of developing the disease that was slowly killing his mother. So the couple made a conscious decision. "We were going to live life to the fullest and have the best time we could for as long as we could," says Daryl. "And we did."

They also did everything they could to support the HD cause. When they read about a researcher at the University of British Columbia – Dr. Tom Perry – who was trying to find a treatment, they started sending him cheques.

A few years later, Ralph and Ariel Walker founded the Huntington Society of Canada, so the Cooks started making donations to HSC as well.

Unfortunately, it turned out that Gord had inherited the fatal HD gene. When his symptoms became more challenging, the Society was

there to help: arranging home support and later educating staff at Gord's long-term care facility. Meanwhile, Daryl started attending HSC's local caregiver support group.

Gord passed away in 2013, but Daryl continues to contribute to the Society, hoping to see a cure – or at least treatments – for the disease that took away her husband.

She writes annual cheques and has been selling Amaryllyl for almost a decade. She has also included a gift to the Society in her will. "It was a way of continuing the donations that we'd made over all those years," she explains. "It probably isn't going to be very much at the end, but whatever it is, what better place could it go?"

Considering leaving a gift to the Huntington Society of Canada in your will? Contact HSC's Director, Development and Marketing, Jeff Hoffman at 1-800-998-7398 ext. 125 or jhoffman@huntingtonsociety.ca to learn about the different options.

Providing our Family Services Team With the Tools They Need

By Julie Stauffer

HSC Family Services Worker Tim Bayliss regularly gets calls from long-term care facilities across British Columbia's interior. They have a resident with HD, they explain, and they need some help. Could he come give an in-service presentation?

Absolutely, he says – and he reaches for one of HSC's educational modules.

Our Family Services team spends a huge amount of their time educating long-term care workers, health professionals, families, Rotary clubs, law enforcement officers and more. In fact, according to HSC's Family Services Director, Angèle Bénard, they gave a total of 150 presentations across the country last year alone.

So we wanted to make their job a little easier. Thanks to the generosity of the Beta Sigma Phi sorority in Calgary, we've been able to develop more than a dozen different educational modules. The topics range from diagnosis and different

aspects of caregiving to Juvenile HD, clinical trials and end-of-life care.

Not having to create their own presentations saves our team all kinds of time. Our modules incorporate PowerPoint decks, handouts and videos featuring people with HD, caregivers, spouses and others talking about their experiences.

Tim's go-to module for educating long-term care staff is HD 101. Many have never encountered HD before, and his presentation inevitably triggers a few "a-ha" moments and lots of animated discussion. Suddenly, staff realize that their resident's obsessive behaviour or temper outbursts aren't a sign that she's deliberately being difficult.

"They can see their resident in a different light," Tim explains. "It clicks in that this is part of their disease process."

In Winnipeg, Resource Centre Director Marla Benjamin has pulled up slides from the modules during one-on-one sessions with her clients, because the helpful visuals make information about CAG counts easier to digest. She has used them in support group meetings, schools, community presentations and personal care homes.

Meanwhile, Marla can be confident that she's working with reliable and up-to-date information. "It's easier not to have to dig up stuff all the time," she says.

Of course, she'll give the presentation her own flavour. She'll emphasize some points and skip over others, depending on her audience and how much time she has. When she's doing in-services, she also likes to include stories or photos about the resident with HD, so staff can see the person behind the disease.

When she first joined the Society two years ago, she also used the modules to educate herself about HD. "It was wonderful to have a set of tools that I could use to learn," she says.

For Tim, the biggest value is how the modules help long-term care staff improve quality of life for their residents with HD. "I think it helps them understand the disease and all the ins and outs and what's involved and how they can work better with their resident," he says. "It's a good tool, for sure."

Thank you to Alberta's Beta Sigma Phi Sorority and the ALS Society of Canada, who partnered with us to develop these modules. We'd love to put them to use in your community! To arrange a presentation, just contact your local Resource Centre Director or Family Services Worker.

HSC's Family Services Team Presents

HD EDUCATIONAL MODULES

Module presentations can be scheduled through your local Family Services team member.

For a complete list, visit:
huntingtonsociety.ca/family-services-team

Thanks to the BETA SIGMA PHI Sorority in Alberta for their generous funding of this project.

Contact Us At: 1-800-998-7398

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

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



One Extra Push

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In her interview, Amanda described the heartache that comes with losing her mom bit by bit. "She just changed as a person altogether, and every day it gets worse and worse," she says.

She acknowledged the toll caregiving has taken on her dad. "He's a hero to me for it, but it's hard to see," Amanda says. She also talked about being at risk and wondering what lies in her future.

Although Jordan knew about Amanda's connection to HD, most of her co-workers did not. So when it came time to pre-screen the video at the office, it really struck a chord. "There was no way I could know how powerful it would be until we watched it," says Jordan.

As for Amanda, it means the world to work for a company that supports the Huntington disease cause.

Amanda concludes her video by saying, "They're so close to finding a cure... you just want to go and give them that one extra push, because really that's all they need." Thank you to Amanda and to the generous folks at Shared for helping make that push.

Now it's your turn. Watch the video for yourself at www.oneextrapush.ca and share it widely!

The Unstoppable Amaryllis

By Josh Martin

The Amaryllis is a hardy plant. Just ask Daryl Cook, who tossed her 2016 bulb into the compost heap once the blooms were long gone. Fast-forward to the spring when a friend noticed something curious growing behind the forsythia. "I look, and the Amaryllis is blooming like crazy," Daryl says. (See page 9 to learn more about this long-time HSC supporter.)

Just like the flower, our Amaryllis fundraiser also has real staying power. Thirty-three years on, the campaign continues to pick up steam. In 2017, volunteers sold more than 20,000 bulbs to raise over \$120,000 for the Society. We're seeing many veteran sellers upping their orders and a slew of newcomers stepping forward. "It's still going so strong with this extremely passionate, energetic community," says Jeff Hoffman, HSC's Director of Development and Marketing.

That community never ceases to impress us. We have supporters who buy kits and ship them to friends and family across Canada as holiday gifts. We have volunteers who set up tables in the mall and sell Amaryllis to local supporters. We even have sellers who schedule their vacation around the campaign, ensuring all their kits are pre-sold before they go on holiday. "It's really just this amazing volunteer group that makes this such a successful campaign," says Jeff. "It's kind of sewn within the fabric of the community itself."

Indeed, thanks to our sellers, HSC's signature flower has become as much a part of the holiday season as candy canes and mistletoe for many Canadians. Today, people across the country look forward to watching the plants grow and blossom, the gorgeous orange flowers brightening homes and offices as the mercury dips and the days get shorter.

Thank you to everyone who bought Amaryllis, sold them to co-workers and friends, planted them and grew the symbol of hope this past year. Together, we continue to make this a vibrant tradition, and we're looking forward to your support again in 2018!

Be sure to check out all the gorgeous photos on our Facebook page (www.facebook.com/HuntingtonSC/photos) – and don't forget to share your own at www.inspirehope.ca/!



Amaryllis 2016 Photo Winner Marilyn Lightfoot



Amaryllis 2016 Photo Winner Judy Stevenson



Amaryllis 2016 Photo Winner Kayly E.

HealthPartners Helps Improve Lives of Canadians – Including Families Impacted by HD

Together with the Huntington Society of Canada, HealthPartners plays an active role in the lives of families impacted by HD.

Family is at the heart of the Huntington Society of Canada, one of 16 national health charities working with HealthPartners to transform the health of Canadians. HealthPartners' member charities are right there for families, linking the people we know and love who are impacted by a major disease or chronic illness – that's 87% of all Canadians – to local programs and services.

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

To date, HealthPartners has raised over \$150 million for its partner health charities. We are so thankful to all the donors who support HealthPartners and the 16 national health charities. Your support is making a true difference by funding leading HD research and is supporting families all across Canada.

To learn more about HealthPartners please visit www.healthpartners.ca.

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Charities At Work

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Chapter Champions: Passing the Torch, Brightening the Flame

By Josh Martin

From hosting fundraising walks to doing media interviews to making presentations at Rotary clubs, our Chapters are a driving force behind the Society. “We’re a small organization,” explains Annie Vanexem, HSC’s Manager of Chapter Development. “We couldn’t do what we do without them.”

Leading these groups are passionate volunteers like Jim Russell. Since Jim took on the presidency of the Halifax Chapter in 1995, their Indy fundraiser alone has raised more than \$280,000 for the Society. However, Jim understands the importance of renewal, and today, he has passed the president’s torch to Shirley Smith.

Jim leaves big shoes to fill, but he is quick to point out that although he served as president for many years, taking on a leadership role doesn’t have to be a long-term or time-consuming commitment. “It doesn’t take a huge amount of work through the course of the year, and you can usually do it on your own time,” he says.

“Nor will you be doing it alone,” says Annie. In her role, she not only supports Chapter events but also helps groups with things like finding new volunteers, creating succession plans and ensuring a smooth transition for new executives. She also runs the recently launched New President Orientation program, which includes a handbook for new leaders and regular calls to answer questions and share ideas.

Brynne Stainsby and Natalie Marnica have appreciated that support since becoming co-presidents of HSC’s Toronto Chapter last February. “Oh my gosh, they’re phenomenal,” Brynne says. “You are so well supported.”

For Brynne, getting involved with the Toronto Chapter Executive seemed like a natural progression from her work with YPAHD, where she served as founding president. Meanwhile, she and Natalie are excited to bring new perspectives and ideas to the table.

In addition to adding new fundraisers to the calendar like yoga classes and comedy nights, the co-presidents are also trying out new tactics to reach more people. That

includes everything from recruiting a savvy volunteer to be their social media coordinator to live-streaming Chapter meetings on Facebook for folks who can’t make it in person. “We really put a big kick on bringing a new energy [and] trying to reach out to people in different ways,” Brynne says.

Rob Campbell also recognizes the importance of outreach and Chapter growth. As the president of the Camrose, Alberta Chapter for the past four years, Rob describes their group as small but mighty – and much appreciated. “I know how important this Chapter is to our community, how much it means to the families,” he says.

Each year, they host barbecues, sell Amaryllis and organize a golf tournament that has raised over \$430,000 for HSC over the past 10 years.

But relying on the same, few local families affected by HD for everything can be a challenge – especially if the demands of caregiving limit their availability to volunteer. “Everyone works so hard to keep it going,” Rob says. “By involving more people, it will help us deal with all of our different priorities.”

To help make that happen, Annie facilitated a strategy session on growing the group. Together, they came up with a novel idea to expand the boundaries of the Chapter, rotating meetings through different communities to reach more families in the surrounding areas. “It allowed us to sit back and look at some things from outside the box,” Rob says. “I can already tell people were more energized.”

Back in Nova Scotia, Jim sees that kind of strategic thinking as the key to ensuring that Chapters continue to thrive. He’s optimistic about the future under Shirley’s new leadership and hopes she gets as much out of the experience as he did. “I’m absolutely glad I did it,” Jim says. “I’ve met some wonderful people over those 22 years for sure, and I’ve enjoyed my involvement tremendously.”

Want to get involved in your local Chapter? Contact Annie at avanexem@huntingtonsociety.ca or 1-800-998-7398 ext. 127.



Jim Russell



Brynne Stainsby



Rob Campbell

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.