HORIZON

RESEARCH • SERVICE • EDUCATION No. 156 Fall 2018

Phase III Trials for Huntingtin-Lowering Drug Set to Launch

Latest updates about clinical trials and other research initiatives

By Julie Stauffer

In his Toronto clinic, Dr. Mark Guttman is busy juggling several HD studies and gearing up for more on the horizon. "We've hired a couple of new staff and we're trying to be ready for all these new and exciting projects," he says.

As he prepares, he can't help thinking about what Ralph Walker told him decades ago, when neurologists had very little to offer patients with HD. "It doesn't matter," Ralph had said. "We need you to be there for the people because they need hope."

Today, as huntingtin-lowering drug trials and other research get us closer than ever to meaningful HD treatments, Dr. Guttman is glad he took Ralph's advice.

Roche RG6042 (formerly known as IONIS-HTTRx)

As we reported in the last issue of Horizon, Ionis' 13-week Phase I/IIa trial has been completed. The study demonstrated that their drug was initially safe and that higher doses reduced huntingtin proteins by 40 to 60 per cent.

The next step is for Roche, the multinational biotech company that licensed the Ionis drug last year, to announce details of the Phase III clinical trial shortly.

This global study aims to answer several key questions. What are the effects 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?

In the meantime, researchers continue to collect data from Phase I/IIa volunteers who all now have access to the drug, regardless of whether they received the real drug or the placebo during the trial.

Roche is also committed to conducting smaller, targeted studies including a "natural history" study to further understand the role of mHTT and disease progression in the absence of any active treatment. This small study is in the planning stages and not yet open or enrolling.

Wave PRECISION HD-1 and HD-2

Back in Toronto, Wave Life Science's PRECISION HD-1 and HD-2 trials continue to run smoothly at Dr. Guttman's clinic. "Things are going well," he says. "People are tolerating the medication. There are no problems that we've seen."

Like the Roche treatment, Wave's two drugs – WVE-120101 and WVE-120102 – are administered into the cerebral spinal fluid via lumbar puncture. Unlike Roche, they leave normal huntingtin protein unaffected, targeting just the mutant huntingtin by binding to specific bits of DNA that about two-thirds of gene-positive people carry.

In July, Dr. Guttman acquired an ultrasound machine to help make the lumbar punctures even faster and easier for patients. He's now teaching other neurologists how to perform the cutting-edge spinal tap procedures.

Meanwhile, he is still enrolling volunteers with early-stage HD who live within a 1.5-hour drive of his clinic. Participants will receive a total of

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HSC 2018 National Conference
Kelowna, British Columbia
November 2 & 3, 2018

Be Brave • Be Bold • Be Ready

Believe

www.huntingtonsociety.ca/conference

INSIDE

HORIZON

ISSN 0827-7605

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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Introducing HSC's New CEO

I chose a career in the not-for-profit sector because I wanted to give back and create meaningful change. Over the past three decades, I've worked for some great organizations including Kids Help Phone, Osteoporosis Canada, Lymphoma Canada and more. What I discovered in the process is that the people involved in the charitable sector are exceptional.

Nowhere is that more true than in the HD community.

Since I joined HSC in July, so many people have reached out to wish me well and to offer support. I've been impressed not only by your warmth but also by your strength and determination. The board, the staff, the researchers and the volunteers are all so hopeful, so committed and so passionate.

Before I took on this position, I was told HSC punches above its weight internationally. That's clearly evident. Thanks to the vision of HSC's founder, Ralph Walker, we have created an exciting area of HD research here in Canada, as well as a network of world-class clinicians. We are a leader in serving families, and our trailblazing youth programs are flourishing.

Internally, this organization is in excellent shape, thanks to the hard work of the staff, the board and my predecessor, Bev Heim-Myers, who has done so much for the HD community.

It's also clear to me just how much our Chapters make possible. Across the country, HSC volunteers are doing incredible work to raise money and public awareness. That's even more remarkable when I think about what so many of you are coping with. To me, the resilience of families affected by HD embodies what human beings can do at their best.

I'm fortunate to be joining HSC at an incredibly exciting time. With Wave's Phase I/II clinical trials underway and Roche's Phase III trials moving forward soon, we're closer than ever to having effective treatments for HD. When that day arrives – and I believe it's a question of when, not if – it's going to transform the lives of people impacted by HD. It's also going to transform the entire field of neuroscience.

In the meantime, we need to continue making smart investments in research and providing vital support to people with HD, people at-risk and the caregivers who give so much. We also need to plan for the day when treatments are approved, making sure that they are available and affordable to everyone who needs them.

In the coming months, I'm looking forward to meeting many more of you. I'm making time to visit clinics and research labs and take part in fundraising events. Of course, I'll also be at the HSC National Conference in Kelowna this November, and I warmly invite all of you to join me there. Our staff and volunteers have been working hard to create another top-notch event you won't want to miss. And whether or not you're able to come, I'd love to connect, so don't hesitate to reach out at any time at 1-800-998-7398 or rmarkowitz@huntingtonsociety.ca.

It truly is a privilege to join this organization and to serve the needs of families affected by HD across Canada.

Robin Markowitz
CEO, Huntington Society of Canada

HD BUZZ

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

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

AGM Notice

Notice is hereby given of the 2018 Annual General Meeting of the Huntington Society of Canada.

Date: Saturday, November 3, 2018

Time: 11:00 AM PDT

Place: Delta Hotel by Marriott Grand Okanagan Resort

1310 Water Street, Kelowna, BC V1Y 9P3

Please visit www.huntingtonsociety.ca or contact us at info@huntingtonsociety.ca or 1-800-998-7398 for further details.

Picnic Power: The Therapeutic Benefits of Bonding over Burgers

By Josh Martin

Never underestimate the power of a hotdog and a bag of chips. Just ask the families who attended our Family Services barbeque in Vancouver last June. Held in the city's beautiful Queen Elizabeth Park, the event drew more than 30 members of the local HD community for an afternoon of picnicking, prizes and plenty of good food.

Open to all ages, the get-together attracted people with HD, their families and friends, while HD researcher Nick Caron served burgers and hotdogs from behind the grill. Some attendees stuck close to the tables loaded with brownies, sliced watermelon and jugs of iced tea. Others took advantage of the sunny Sunday weather, strolling through the park's rose garden or taking in live entertainment at the nearby amphitheater. "People seemed to really enjoy themselves," says British Columbia Resource Centre Director, Rhonda Romolock, who organized the gathering.

The barbeque is just one of many social events HSC's Family Services team offers throughout the year. Across the country, our staff organize everything from potlucks and bowling nights to Christmas socials and meetups at local coffee shops with help from local volunteers and Chapter members.

Though informal, these events offer important therapeutic benefits, allowing families to recharge and enjoy a few hours of carefree socializing with people who understand the world of HD. "It creates an atmosphere where people don't have to be afraid or feel like they have to explain what's happening if their loved one is symptomatic," says Angèle Bénard, HSC's Director of Family Services and Community Development. "They can just be who they are."

Furthermore, social events are a great way to introduce people to the Society. For some newcomers, joining a formal HSC support group or booking a one-on-one session with one of our social workers can feel intimidating. Get-togethers like Rhonda's picnic, on the other hand, let folks connect with our Family Services team in a much more relaxed environment. "It's very non-threatening," says Rhonda. "I've got a nametag on just like everyone else."

On top of that, families get to know each other better. Throughout the day, Rhonda saw people having wonderful conversations, discovering shared connections and trading tips. Those moments of bonding have a lasting impact. As Rhonda was packing away leftovers once the event wrapped up, she noticed two of her guests continuing to chat. "I think we're just going to hang in the park for a bit more," they told her.

Mission accomplished.

If you haven't connected with us yet, we'd love to hear from you! Visit www.huntingtonsociety.ca/family-services-team to find the Family Services professional nearest you, and let's chat about how we might be able to help.

Genetic Fairness Update

By Bev Heim-Myers, Chair of Canadian Coalition for Genetic Fairness (CCGF)

CCGF/CCEG

Things are slowly heating up with the Genetic Non-Discrimination Act (GNA) and the Quebec referral to the Quebec Court of Appeals.

Over the last few months I have been working closely with lawyers Bruce Ryder in Toronto and now William Colish in Quebec, to move our legal documents forward. Senator Cowan and Barbara Kagedan, even though retired, continue to support and educate regarding the GNA.

Recent Activity:

- August 2017 – CCGF granted intervenor status in the matter of the Reference of the Government of Quebec concerning the constitutionality of the GNA. CCGF will support the GNA along with the Canadian Human Rights Commission. The Attorney General (AG) of Canada, AG of British Columbia and the Canadian Life and Health Insurance Association (CLHIA) have all also been granted intervenor status, but will challenge the GNA.
- April 2018 – Doug Mitchell appointed Amicus for GNA – he will support the legislation
- April 2018 – Affidavits submitted to Quebec Court of Appeals
- May 2018 – Paper published in Canadian Medical Association Journal (CMAJ) – Authors: Dr. Yvonne Bombard and Bev Heim-Myers
- June 2018 – CCGF Factum submitted to Quebec Court of Appeals

Next Steps

- Verbal arguments will be scheduled during the week of December 10, 2018 at the Quebec Court of Appeals in Montreal.
- Until further notice, the GNA is law in Canada and the genetic test information of all Canadians is protected. We are working with the provinces to influence the strengthening of provincial Human Rights Acts and Provincial Labour laws, to include the protection of genetic test information provincially. This is not mandatory given the robust GNA, however, it will offer options in the future for individuals who have been discriminated against.

Champion of Hope: Kristina Vandervoort

By Josh Martin

Gordon Moss took his last breath on January 2, 2017 with his wife Kristina Vandervoort by his side and his son Erik holding his hand. Their bedside presence surprised no one. Kristina and Erik had visited Gordon in the care facility every night for years leading up to his gentle passing.

The family's journey with HD, however, was not peaceful. Gordon's HD symptoms started to show long before his diagnosis in 2002. His personality changed and he made some bad decisions.

Then came the diagnosis of HD – a disease they knew nothing about. "It was so frightening," Kristina recalls. "It was such a shock."

For help, they turned to HSC. The BC Resource Centre offered vital information. Support groups equipped them with valuable coping and caregiving skills. Meanwhile, their Resource Centre Director was always just a phone call away. "They had my back," Kristina says. "I couldn't have done it alone."

Now Kristina has all of our backs. Since 2009, her monthly donations have supported HSC's work. For her, it's a simple, hassle-free way to help other families like hers cope with a horrible disease. What's more, it helps fund vital HD research and helps our advocacy efforts around genetic fairness. "I believe in what the Society is doing," Kristina says. "It's invaluable work."

Monthly contributions give HSC a revenue stream they can count on. It also puts the Society in a better position to quickly respond to opportunities that arise. Kristina's donations aren't big, she admits, but as she points out, "If a lot of people give just a little, it adds up."

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

The HealthPartners: Working to End Chronic Disease and Keep Canadians Healthy

Health matters to everyone. And because nine out of 10 Canadians are impacted by a major disease or chronic illness during their lifetime, our goals at HealthPartners are twofold: to help eliminate chronic disease and to keep Canadians healthy. Working with our 16 national health charities as partners - including the Huntington Society of Canada - we raise funds through targeted workplace giving campaigns. One example is the Government of Canada Workplace Charitable Campaign (GCWCC) which raises money for the important work our partners do. HealthPartners provides workplaces with the tools they need to be healthy.

Think of HealthPartners as an educator, ambassador and connector. We educate employees and workplaces on the benefits of healthy living practices, through resources like our innovative Small Steps Program (healthpartners.ca/smallsteps). And, by connecting employees with our member charities, we ensure that employees benefit from the many services and programs offered right across the country.

HealthPartners

Charities At Work

Our work is making a real difference!

The donations that HealthPartners raise for the Huntington Society of Canada through the GCWCC and other workplace giving campaigns benefit the one in 1,000 Canadians who are impacted by HD. Whether it is from counselling services and support groups that improve quality of life, or from the HD clinics that enhance service delivery or from research that leads to better treatments, HealthPartners is helping to provide the funds for those services.

"HealthPartners has provided me with an opportunity to share my personal story, in person and on local radio, raising awareness of HD," says Valerie Nabb, volunteer of the Ottawa Chapter of the Huntington Society of Canada. "HealthPartners raises funds which support ongoing HD research that is currently giving the HD community – including myself – great hope."

The GCWCC campaign launches in September. To date, HealthPartners has raised over $150 million for its member charities. The generosity of public servants who support the work of HealthPartners cannot be understated; through every workplace campaign, HealthPartners is helping to improve the lives of Canadians living with diseases like HD.

Phase III Trials

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four injections of either a placebo or the real drug, starting with low doses that gradually increase over the course of the study. As a Phase Ib/IIa study, this trial is designed to test the safety and tolerability of the drugs in humans, not their therapeutic benefits.

A second Canadian site is expected to launch soon. There are also international sites that are participating. Around the world, Wave aims to enroll a total of 48 people for each of their two studies.

Observational studies

As the process of clinical trials moves forward, observational studies remain as important as ever, providing data to judge the effectiveness of potential drugs like RG6042 or WVE-120101 and WVE-120102.

For example, more than 15,000 people from 18 countries have now joined Enroll-HD, which monitors how HD develops in patients over time. Researchers will cap the study at 20,000 participants, while people with more advanced symptoms will graduate to a less-demanding "Enroll-HD lite" protocol.

Finally, to help identify and assess HD biomarkers, the HDClarity study aims to collect cerebrospinal fluid (CSF) from people with pre-symptomatic Huntington disease. Over 300 samples have already been collected from around the world. Now, researchers want to up that figure to 1,200 patients participating. They're also planning to add neuroimaging in 2019 in select sites through HDClarityImaging. Through MRI and other techniques, they hope to correlate changes in huntingtin levels in CSF to physical changes within the brain.

Want to learn more and find ways to get involved? Visit www.huntingtonsociety.ca/hd-clinical-trials.

Eye-catching Aprons, Superstar Sellers

By Josh Martin

Last year, April Heppleston returned home to Morinville, Alberta from HSC's Symposium with her heart filled with hope and her arms filled with Amaryllis kits. The novice seller had no difficulty finding buyers for that first case, and April and her daughter Tabitha quickly ordered more. Loading them into their van – along with some eye-catching aprons – they headed to Christmas markets around Edmonton.

Although the Hepplestons don't have HD in their family, they've discovered many personal connections. The mother of Tabitha's high school friend died from HD at the age of 40. The wife of April's friend recently entered full-time care with the disease. Meanwhile, April's son Adam learned that HD ran in his colleague's family. Now, they've adopted HD as their cause – and Amaryllis offered the perfect way to raise funds.

"I'm not much of a runner," Tabitha admits. But selling bulbs once a year? No problem. "It's an easy fundraiser," she says.

In their first year, she and her family raised more than $1,000 at three different Christmas markets. Tabitha's five-year-old daughter, Primrose, proved a master salesperson, tugging at the sleeves and heartstrings of prospective customers and asking "Have you got your Amaryllis?"

According to Jeff Hoffman, HSC's Director of Development and Marketing, our signature fundraising campaign sells out year after year because of volunteers – like the Hepplestons – from coast to coast. "That's how it started, and that's still what makes it successful today," he says.

For April, supporting the campaign is an obvious choice. "I don't feel I'm being selfless in the slightest," she says. "We're all one human family, and nobody escapes illness and hardship."

This fall, the Hepplestons will be hitting their local markets once again – and with enthusiasm for the HD cause as vibrant as their pink, green and orange aprons, they'll be hard to miss.

Amaryllis kits are available until the first week of December! To order yours or learn more about becoming a seller, call us toll-free at 1-800-998-7398, email amaryllis@huntingtonsociety.ca or visit www.inspirehope.ca.

An Ariel View

Looking back at old HSC newsletters recently, I found a writeup (below) of the 1977 Conference and Annual General Meeting (AGM) that we held at Sunnybrook Hospital in Toronto. That must have been one of the very first ones, although back then we called it a "weekend workshop," not a conference.

The fee to join the Society was only $5 — can you imagine? — and there couldn't have been more than 75 people there, tops. When our treasurer spoke at the AGM, he told us our annual income in 1976/77 was $39,000.

So much has changed since then. When I went to the World Congress in Vancouver in 2009, there were 650 people and we filled all the ballrooms in the hotel. I thought, holy cow! And what is our annual budget now? Over $4 million?

However, a surprising amount has stayed the same over the last four decades. Back in 1977, people came from across the country to attend the conference. We had presentations on patient and family services, a workshop on fundraising, and an update on the latest research. Right from those early days, the research was always the most popular because it gave us hope.

I remember how much work Ralph would put into organizing each conference, getting all the details just right to make sure everything ran smoothly. All the 'i's had to be dotted and all the 't's had to be crossed so that everyone who came had a good experience. Today, our staff and our volunteers work just as hard to make these events a success.

Whether they're big or small, conferences are just so crucial. Sure, it's much easier to get information about HD now, with the Internet and email and wonderful things like HDBuzz, but you still can't beat getting together face to face. It's a chance to meet other families, hear directly from researchers, get your questions answered and find out what other Chapters and volunteer groups are doing. Most importantly, you realize that you're not alone.

The research updates are still my favourite part. It's so encouraging to hear about the studies and clinical trials and to see so many bright young investigators choosing to focus on HD. There's all kinds of energy in the room, and you just soak it up and take it home with you.

That's why I'm looking forward to this year's conference in Kelowna: to reconnect with old friends, meet new people and come away inspired by the latest research developments. I know I'm going to leave feeling hopeful. Hope to see you there!

For more information about this year's Conference in Kelowna, BC visit page 10!

A 1977 HSC article about one of the first ever Conference and AGMs.

ANNUAL MEETING AND WEEKEND WORKSHOP

March 25-27 was a busy weekend at Sunnybrook Hospital, Toronto, for those attending the annual meeting and the workshops arranged for Chapter leaders. Everyone who had paid the $5.00 membership fee received a notice of the annual meeting. Workshops included Fund Raising, with Mr. Michael McFarland, Director of Publicity, Canadian Rehabilitation Council for the Disabled, as the leader, and Patient and Family Services led by Mrs. Verne O'Neill, a public health nurse, and Mrs. Margaret Strecker, a social worker with the Hamilton District of the Ontario Ministry of Community and Social Services.

Saturday morning included a Research presentation by Dr. Rory Fisher, Head, Dept. of Extended Care, Sunnybrook Hospital, Toronto, and Dr. Kenneth Lloyd, Acting Head, Dept. of Psychopharmacology, Clarke Institute of Psychiatry. These gentlemen explained the research being carried on at their respective hospitals.

The financial report presented by Mr. Gordon Hazzard, our national treasurer, showed a gross income of $30,264. for 1976, and a balance at the end of the year of $39,036. I have plenty of extra copies of the Annual Report, which are available on request from Box 333, Cambridge (Galt).

A pleasant session on Sunday morning heard reports from each of the Chapters represented. A brief summary of Chapter activities for the period October 1976 - March 1977 is included later in the Newsletter. We were delighted to have Doreen Dyrnes from Edmonton, Ann Kotello from Winnipeg, Mary and Claude David from Montreal, Barbara and Wayne Martin from Stirling, Ontario, plus several representatives from the Chapters in Windsor, London, Hamilton and Toronto attend the Weekend.

A Happy Retirement for Sue Campbell

After close to 19 years with the Huntington Society of Canada, Sue Campbell, HSC's Donations Coordinator, made the decision to retire in July 2018 and began her full-time career as a new grandmother.

Sue made a difference for families impacted by Huntington disease. Sue cared deeply about everything she did, had a critical knowledge about our community, and provided valuable insight and knowledge as we connected with our supporters.

Our ability to maintain strong relationships with our donors and keep them involved in our work is something that Sue played a significant role in. She ensured that we efficiently and accurately engaged with that group. During her time at HSC, Sue processed countless donations and saw the fundraising program evolve and moved right along with that growth.

Sue will miss the organization and community but is proud of her time spent with the Society. "Working at HSC has truly been a rewarding journey. Along the way I have worked with and met many wonderful people," she says. "I'm honoured to have been part of an exceptional organization that works so tirelessly for families."

Sue has had a real impact in her time with us and the entire Society is so excited for Sue and her family as she takes on her next journey.

Congratulations on your retirement, Sue!

Reaching More Families than Ever

By Josh Martin

In January, Maike Zinabou sat down with a young couple. The husband had just tested positive for the Huntington disease gene, and the pair were eager to learn as much as they could about HD. "They felt that knowing was power," says our West Central Ontario Resource Centre Director, who spent almost two hours answering questions and putting that test result into perspective.

Every week, people contact our family services team across the country for the first time to learn more about our Family Services Program. Sometimes it's a referral from a neurologist or geneticist. Other times, people find our information online and either call or email.

Whatever their situation – at risk, gene-positive, early or late-stage HD – HSC's Family Services team offers understanding, information, connections and support. We're also available to help caregivers and family members. "I think we really make a difference in people's lives," says Maike.

Now, thanks to generous funding from the John Deere Foundation of Canada, the Community Initiatives Fund, the Manitoba Community Services Council, the Sifton Foundation and the Windsor Foundation, we're able to support them better than ever.

"I'm always excited to get phone calls from new families so that we can let them know that we are here and there's lots that we can do," says Saskatchewan Resource Centre Director, Erin Stephen.

That includes making referrals to movement disorder clinics, in-home care and other community support programs. We also provide up-to-date fact sheets, videos and other resources, as well as educate staff at care facilities and other groups through in-service presentations.

Our support groups provide a safe space to talk and share ideas. In Winnipeg, for example, Manitoba Resource Centre Director, Marla Benjamin, regularly welcomes new caregivers and people with HD to the monthly meetings she runs. "When you can reach out to others, it helps to alleviate the burden of being all alone," she says.

In many cases, we can even come by for a home visit to better understand a family's needs, help parents explain HD to their children or just develop a relationship over coffee. "The key," says Director of Family Services and Community Development, Angèle Bénard, "is that our clients choose what help they want and when."

"Where would they like to start? What do they feel are the important issues right now?" she says. "They can get as engaged as they would like, or they might decide to take a step back for a while and then reconnect further down the road. And that's okay."

"For me, it's about building relationships with people," says Barb Horner, Resource Centre Director for Nova Scotia and Prince Edward Island. While you may not need support right now, making connections early means that when you need to reach out later, you're not contacting a stranger. "What we all offer is a consistent source of support that's always going to be there for folks," she says.

Thank you to our generous funders

The Windsor Foundation

Community Initiatives Fund

MCSC
MANITOBA COMMUNITY SERVICES COUNCIL INC.

Sifton Foundation

John Deere Foundation of Canada

2018 Calendar of Events: Coming to Your Neighbourhood Soon!

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

April 15 to September 8

Newfoundland & Labrador Resort Getaway Raffle
Newfoundland & Labrador
www.hscevents.ca/NLResortGetaway

Saturday, September 8

8th Annual Grand River Founders Walk
Cambridge, ON
www.hscevents.ca/FoundersWalk

Sunday, September 9

Winnipeg Indy Go-Kart Challenge
Headingley, MB
www.hscevents.ca/WinnipegIndy

Sunday, September 9

21st Annual BC Walk
Vancouver, BC
www.hscevents.ca/BCWalk

Sunday, September 9

17th Annual Essex Indy Go-Kart Challenge
Windsor, ON
www.hscevents.ca/EssexIndy

Saturday, September 15

New Brunswick Summer Gathering & Walk
Fredericton, NB
www.hscevents.ca/NBWalk

Saturday, September 15

2nd Annual Eli and the Strawman Benefit Concert
London, ON
www.hscevents.ca/LondonEli

October 2 to 6

Niagara Book Sale
St. Catharines, ON
events@huntingtonsociety.ca

Saturday, October 13

21st Annual Trap Shoot
Chatham, ON
events@huntingtonsociety.ca

Saturday, October 13

Simcoe Muskoka Run/Walk to Cure HD
Barrie, ON
www.hscevents.ca/SimcoeMuskoka

Sunday, October 14

Niagara International Marathon
Niagara Falls, ON
www.hscevents.ca/RaceHD

October 16 and 24

Paul Paone Basketball Tournament
Niagara Falls, ON
events@huntingtonsociety.ca

Friday, October 19

Halifax Comedy Night
Halifax, ON
events@huntingtonsociety.ca

Friday, October 19

3rd Annual Niagara Trivia Night
Niagara Falls, ON
events@huntingtonsociety.ca

Sunday, October 21

Toronto Scotiabank Waterfront Marathon
Toronto, ON
www.hscevents.ca/RaceHD

October (Date TBD)

A Haunted Hallows Eve Gala
Vancouver, BC
events@huntingtonsociety.ca

Thursday, November 1

YPAHD Day
Kelowna, BC
www.huntingtonsociety.ca/YPAHD-Day/

November 2 and 3

National Conference
Kelowna, BC
www.huntingtonsociety.ca/Conference/

Saturday, December 29

Resolution Run
Toronto, ON
events@huntingtonsociety.ca

Springing into Fundraising Action

The summer break brings a time for cottages, vacations, and lots of time to relax and recharge – things HSC's incredible community of volunteers deserve after the Spring events season! The season runs from April 1st to June 30th, with nearly 60% of all HSC events occurring in these 3 months alone.

Volunteers from Vancouver to St. John's helped organize over 80 fundraising and awareness events – one of the busiest events seasons we have on record!

"It is always inspiring to see the calibre of events, and the remarkable results, that are entirely led by local volunteers nationwide", says HSC's Manager of Chapter Development, Annie Vanexem "This Spring, the network of volunteers, organizers, donors, sponsors and attendees contributed over $500,000."

The lineup of events was very diverse – from first-time events like the Wildflower Walk in Barrie and the Pub Night in Camrose, to milestone events like the 10th Annual Calgary Hope Run and the 20th Annual Toronto Architectural Gems Walk, and this season's most popular events – paint parties and bowling nights!

Leaving a Lasting Legacy

By Jim Wiswell (written by Jen Love)

It's the people, the social connections, the sense of family. To me, that's what is so special and remarkable about the Huntington Society of Canada. And I've felt that way every day since 1994 when I tested positive for HD and connected with the Society and the Toronto Chapter. They are part of our family. My partner Ellen and I give, volunteer and access support we need from our HSC social worker together.

And when it came time for us to do our Wills about 10 years ago, we made the decision together to remember the Society. We've seen for ourselves the incredible progress the organization has made over the years, and we want to be part of the Society's story forever. It's a story of collaboration, a story of shared values and an absolute dedication to helping families every single day in every single way.

What do we hope for the future? We hope that our gift will make life better for the next generation, for our nieces and nephews. We hope that our gift provides comfort, care and hope to families. And we hope that our gift, combined with others, invests in the most promising research.

Here in Toronto, our social worker Rozi is very good at assessing the future. She keeps us informed about what we can expect and she is also here to help us adapt to the changes this illness brings. Through Horizon and HDBuzz, I also feel informed about research, and ways that I can be involved. It's this idea of assessing the future that makes us feel confident and proud to remember the Society in our Will.

Jeff Hoffman, Director of Development and Marketing, would like to extend his deep gratitude to Jim and Ellen 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.

YPAHD Column

By Jaclyn Skinner, YPAHD President

This November brings elections for a new YPAHD executive, and the end of my term as president. I'm so proud to have served as YPAHD president for the past four years. Seeing how far we've come is something I'll cherish forever.

Our numbers have grown incredibly. We've created a world-renowned mentorship program that gives youth across the country one-on-one peer support.

We've started holding regional YPAHD Days during non-Conference years, because going two years without seeing each other is way too long. More youth are leading events and Chapters than ever. And lots more!

I'll be wrapping up my final term as president at YPAHD Day in Kelowna this fall, where we're on track to have a record number of participants. This year, we're making it a really open forum for YPAHDers to share their stories and learn from each other's experiences about topics like family planning, relationships and genetic testing.

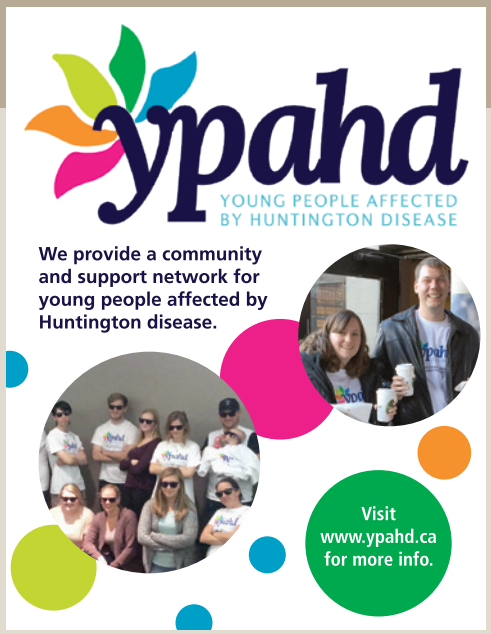
We'll also be holding elections – live and online – for the YPAHD executive. You can learn more and nominate someone (including yourself!) by visiting ypahd.ca. Of course, that's not the only way to get involved.

One thing I've learned is that little things make a big difference, whether it's sharing your story, listening to someone who needs help or holding your first small fundraiser. You don't have to change the world in a day – but participating in YPAHD can change your life.

Being president showed me that helping people is what I'm supposed to do. In August, I moved to Nashville to do a Master's in social work, which includes interning at the Huntington Disease Centre of Excellence to help them build their own YPAHD-inspired youth program.

YPAHD has been an incredible experience. I want to thank everybody who supported me and all the young people in this organization. I know that the folks coming up through YPAHD today are going to make this virtual Chapter even stronger.

It's going to be awesome to watch.



Catherine Price: Jumping in with Both Feet

By Julie Stauffer

Catherine Price wants to be clear: joining YPAHD does not mean you have to attend conferences across the country and continent, become a mentor, launch several fundraisers in your hometown, collect nearly $45,000 for research and services, join the YPAHD executive and get recognized in the Canadian parliament. That just happens to be the path she took.

When Catherine moved away to university eight years ago, she decided she wanted to do something about the disease that her grandmother had. So, as we described in the last issue of *Horizon*, she found the Society's website, dialed the phone number listed and said "Hey, I want to get involved."

Our office staff told her about YPAHD, the organization's national youth Chapter. Before she knew it, Catherine was heading off to the Huntington's Disease Society of America convention, together with other YPAHD members. For the first time in her life, she was meeting other people who were affected by HD.

At first, she felt a little overwhelmed. Then she felt compelled to make a difference. When she arrived back in St. John's, she launched a walk for HD. "I wanted to find a way to give back," she explains. "Funding can make a huge impact on research and family services." As a result, she earned HSC's Dean Crain Memorial Award in 2012 and was publicly acknowledged by her MP in the House of Commons.

After five years of walks, Catherine decided to change it up. She organized a trivia night, an Indy go-kart event and, most recently, a province-wide travel raffle.

Meanwhile, when we put out the call for volunteers to join our youth mentorship program in 2013, Catherine stepped up to support a younger peer. For the past four years, she has also served on the YPAHD executive.

Somehow, she has also found time to attend HSC conferences here in Canada and HDSA events in the U.S., as well as facilitating sessions at our annual YPAHD Day. With each event, she has developed new friendships and strengthened her sense of purpose.

"What I do isn't just for my family," she says. "It's about everyone that I've met that's affected by HD."

In Celebration of Gabe

By Tiffany Nobes

Gabriel (Gabe) Murchison was a lovable 11-year-old who was always giving or receiving hugs, hanging out with his friends and having an impact on the students and teachers at Saint Rose School in Saint John, NB. Even when Gabe was having a bad day, he went out of his way to brighten everyone else's.

Gabe passed away in February 2018 after a courageous battle with Juvenile Huntington disease (JHD).

In late April 2018, a girl from Gabe's Grade 5 class approached their teacher, Mr. Brian Bordage, and suggested the Grade 5 classes do something to honour Gabe. Mr. Bordage did some research of his own and discovered that May was HD Awareness Month. When he told the students, the class erupted in conversation and the ideas started flowing.

Mr. Bordage's class, with the help of Mrs. Suzanne Wilson's Grade 5 class, all decided to think of things that Gabe loved and aligned fundraisers to his interests including pajama days, superhero days, sock hops and ending with a huge breakfast by donation for the whole school featuring Gabe's favourite food – pancakes!

Through all of their events, the Grade 5 classes raised over $1,000 for HD research and support services. The Saint Rose School Staff Fund contributed to the total of donations. The classes encouraged the whole school to participate and also received support from the surrounding community through donations of butter, syrup and pancake mix for the big breakfast finale.

"As staff, we could do nothing but support all of the students' ideas," says Mr. Bordage. "How could we not? They received absolute support from all the other grades as well. It really brought the whole school together."

When the two classes began planning, they only had one goal: to celebrate Gabe and his life. Through hosting all of their events, though, they gained a sense of pride and accomplishment and were able to come to terms with Gabe's passing.

Thank you, Mr. Bordage, Mrs. Wilson, the Grade 5 students, Principal Mrs. Victoria Moseley-McAllister and Vice-Principal Mrs. Shari Carey at Saint Rose School for your generosity!

youth FACTS

- 24% of all events from July 2017 to June 2018 were youth-led
- Youth-led events have raised close to $95,000 from July 2017 to June 2018
- In 2017, 8 of 20 official Chapters had a President or Vice-President that was a youth

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youth MENTORSHIP program

Supporting young people across Canada facing everyday challenges of HD

Become a *mentee.*

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

For more information, visit: www.huntingtonsociety.ca

2018 HSC National Conference

Conference Highlights

Thursday, November 1

YPAHD Day
Join us for a day of education, peer support and fun specifically designed for young people (under the age of 35)!

Community Development Night
Representatives of HSC Chapters and active areas are invited to join the HSC Chapter Development team for an evening of idea sharing and training.

Friday, November 2

Resource Fair
Drop by the tables to learn about a variety of services and resources available to, and within the HD community.

Keynote Speakers & Workshops
Hear from the HD community and talented speakers during the Friday presentations. Workshops available include:

Animal Assisted Therapy Workshop
Learn from the experts how to incorporate canine, equine and animal therapy into your care strategy.

Finding Comfort in Discomfort: Supporting Grieving Children Workshop
Ever wondered how to talk to your child/youth about HD? Build strategies with Tara Noble!

Using Social Media to Raise Funds and Awareness Workshop
Our panel of HD community members share how you, too, can use social media for good.

Welcome Social Hosted by the Okanagan Chapter
Our host Chapter looks forward to welcoming you to a Kelowna landmark, the Laurel Packinghouse, for a dinner and social, introducing you to the flavours of the Okanagan.

Murder Mystery Dinner & Show Hosted by YPAHD
This youth-only (35 years and under) event offers the chance to come enjoy dinner at the "Teen Idol Awards". Rub shoulders with the likes of Justin Bebre, Taye Swiftly and Poppy Razzi.

Saturday, November 3

Resource Fair
Drop by the tables to learn about a variety of services and resources available to, and within the HD community.

Keynote Speakers & Workshops
Hear from the HD community and talented speakers during the Saturday presentations. Workshops available include:

No Surprises! Arranging Our Days and Homes for HD's Cognitive Challenges Workshop
In a new talk, Jimmy Pollard walks us through accommodations for the cognitive challenges of HD.

Building Your Chapter/Volunteer Group Workshop
Looking for ways to start or grow a Chapter in your area? Ask our panel how!

The Music Connection Workshop
Learn from music therapist, Catherine Staples, how music can be incorporated in your care.

Annual General Meeting
Gather to vote on important items of business and elect the next National Board of Directors.

Closing Banquet Awards Ceremony
Celebrate another outstanding conference and the leaders in our community with dinner and awards, followed by dancing!

The HSC National Conference gives the HD community the opportunity to socialize with professionals and others affected by HD.

This year's Conference offers presentations on research, caregiving strategies, event planning and more!

Join us at the beautiful Delta Hotel by Marriott Grand Okanagan Resort - the only hotel that could fit our ever-growing Conference!

November 2-3 will be a weekend full of world-class speakers that you won't want to miss.

Kindness, Companionship and Conference in Kelowna!

By Tiffany Nobes

This November 2nd and 3rd, HD community members from across Canada will gather for an invaluable opportunity to connect the individuals impacted by HD with the professional teams that dedicate their lives to the research, caregiving and treatment of HD.

Attendees aged 14-35 will have the opportunity to kick off the Conference with their own one-day youth-led Conference, YPAHD Day, on Thursday, November 1st with all youth-specific topics.

The first official day of Conference on Friday, November 2nd will be filled with informative sessions on caregiving, animal therapy, research, skills building and more! Mingle and meet new people at one of two social dinners that night.

On Saturday, November 3rd, attendees can look forward to valuable information being shared about grief/guilt, self-care, music therapy and of course – more research updates! We look forward to seeing everyone later on that day at the closing banquet and awards ceremony.

The diverse line-up of topics this year comes from community requests and interests – you asked, we listened!

"This year's program includes some of the usual suspects, like workshops on research, or care strategies, but we also listened to feedback and have added a track of workshops on community development like raising awareness in your community," says Annie Vanexem, Manager of National Events and Chapter Development. "We hope that you will be pleased with the agenda, and that it won't be too hard to decide between some of the sessions!"

Hosted in partnership with the Okanagan Chapter, this Conference will be held in the beautiful area of Kelowna, British Columbia.

To accommodate all attendees, this year's Conference will be held at the Delta Hotel by Marriott Grand Okanagan Resort.

"We are so excited to partner with the incredibly strong Okanagan Chapter, and to enjoy the stellar surroundings of the Delta Grand, the only hotel in the region that could fit our ever-growing Conference," says Vanexem. "While this isn't HSC's first time hosting a Conference at a Delta property, it certainly will be a treat for those in attendance as we are right downtown, and overlooking the water."

While we are excited to welcome you to a weekend full of world-class speakers addressing the topics of breaking research, current clinical trials and much more, the Okanagan Chapter is excited to welcome you to the place they call home.

"We are so excited to welcome you to our home region of the Okanagan," says Dan Middleton, Chapter President of the Okanagan Chapter. "Whether you have traveled far or near, this is your first conference or one of many, we hope that you enjoy your stay in Kelowna and this conference becomes one to remember."

For a proper introduction to the area, the Chapter will be hosting a welcome social at the Laurel Packinghouse, a Kelowna landmark where fruit had been received and processed prior to distribution for over 50 years!

HSC has been looking forward to the Conference for the past two years and we are so excited to see everyone all together again. Thank you to the Okanagan Chapter for all of their work preparing for such a fabulous weekend!

There is still time to register for this year's National Conference! For more details including the full schedule, registration information and more visit www.huntingtonsociety.ca/conference.

Huntington Heroes Sponsor HSC National Conference

By Tiffany Nobes

Thanks to the generous support of our sponsors, people will travel from across Canada this November to come to Kelowna, BC for the HSC National Conference.

For some attendees, they may have just discovered HD in their family and this will be their first HD-related event. For other attendees, this may be the event they most look forward to every other year. For everyone, it will be a valuable opportunity to learn about the latest research, discover new caregiving strategies and connect with people who know exactly what they are going through.

The bi-annual Conference is an important chance for people affected by the disease all across Canada to come together, share, offer support and learn.

This weekend would not be possible without the generous contributions and support of our sponsors. Because of our sponsors we are able to offer the Conference to the community as a safe place to learn, grow and connect. We are so grateful to our sponsors for believing in the HD cause and choosing to support such a vital opportunity for the HD community. You truly are our Huntington Heroes!

The Huntington Society of Canada would like to extend our deepest thanks to the 2018 HSC National Conference sponsors:

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Jimmy Pollard: A Huntington Hero for 30+ Years

By Julie Stauffer

In 1986, Jimmy Pollard was working in a nursing home just outside of Boston, running programs for residents with neurological problems. One day that June, the home received a referral for a young woman with HD. "We rejected her," Jimmy recounts. "Just like so many nursing homes did. Just out of ignorance."

That might have been the end of the story, but the young woman's mother refused to take no for an answer. She called, she wrote, and through gentle persistence she persuaded the home to take her daughter. That decision marked the start of Jimmy's long career in the HD field.

Caring for their first resident with HD came with many challenges, but her mother provided plenty of coaching. Through trial, error and perseverance, the staff figured out what worked and what didn't. Word of their success quickly spread through the local HD community. Before they knew it, they had 15 people with Huntington disease – and with each new resident, they acquired a little more experience in the best ways to handle the disease.

That's when Jimmy got a call from Canada. HSC's Ralph Walker had caught wind of the growing expertise in the Massachusetts nursing home and, in typical Ralph fashion, he wanted to ensure that knowledge was shared. Soon, Jimmy was speaking with groups across North America and around the world.

Ralph's other big goal was to produce a series of publications. Back in those pre-Internet days, the only information about HD available outside of medical journals was found in a few slim brochures – brochures that got photocopied and re-photocopied and passed from hand to hand. Ralph envisioned three cornerstone publications: a guide for physicians, a guide on dealing with the behavioural aspects of HD and a caregiver's guide to the advanced stages of the disease.

To write the caregiver's guide, he lined up a team of experts, and Jimmy was head of the list. Today, two decades after its publication, Jimmy still sees people showing up at his talks with their dog-eared copies, asking for an autograph.

Caregiving with compassion

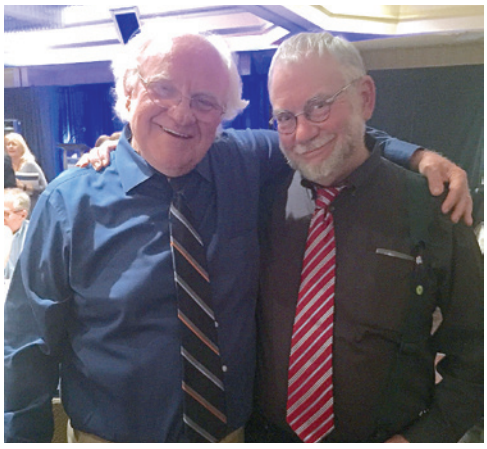
Jimmy has lost track of all the presentations he's made over the years. When he stopped counting over a decade ago, the total was more than 300. At every talk he gives – including a recent series in B.C. – he tells families that someone with advanced HD is still the person you've loved and shared your life with, despite the "mask" that HD creates.

Of all the insights he's gained about caring for someone with HD, the single most important one is to slow down. As HD progresses, it takes people longer to retrieve and process information. That's why it's crucial to give them time to respond to one question before you ask another. Even a seemingly simple question like "what do you want for dinner?" forces them to recall and consider all kinds of possible choices.

"A lot of the outbursts come [from] an accumulation of frustration with people going too fast for them or throwing too much stuff at them," Jimmy explains.

Finally, he emphasizes that even in the advanced stages of the disease, people with HD can still find pleasure in each day. "They value their life. They see quality in it," he says. "They still have fun." And as Jimmy has proven for the past 32 years, the right caregiving strategies can maximize that quality of life.

If you're coming to our National Conference in Kelowna in November, don't miss Jimmy's "No Surprises" talk on how to make life a little easier for people with HD by creating a predictable environment. Visit page 10 for more details on the Conference and how to register.



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.