

HORIZON

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No. 153

Fall 2017

Another \$950,000 investment from the Huntington Society of Canada and Brain Canada could make gene-silencing even more effective

By Julie Stauffer

Now, thanks to a three-year \$950,000 grant from the Huntington Society of Canada and Brain Canada, Dr. Blair Leavitt and his team can advance research into gene-silencing. According to the University of British Columbia's Dr. Blair Leavitt, gene-silencing (otherwise known as huntingtin lowering therapy) offers a promising way to slow or stop Huntington disease (HD). By using anti-sense oligonucleotides (ASOs) to prevent the HD gene from producing huntingtin protein, this approach targets the disease right at its root.

Dr. Leavitt has been involved in IONIS-HTT_{Rx}, the Phase I/IIa clinical trials that are testing ASOs in humans. We won't know the initial results of those trials until later this fall, but based on animal studies, Dr. Leavitt is optimistic.

"ASOs are incredibly effective," he says. "If you can get them to the correct cell, they work very well."

The trick is getting them where they need to go. The IONIS trial uses intra-thecal injections to deliver ASOs into the cerebrospinal fluid that bathes the spinal cord and the brain. However, animal studies suggest that when researchers use this approach, not as much of the ASOs reach the deep brain structures that are most affected by HD.

So, while clinical trials in humans continue, Dr. Leavitt is already looking for more effective delivery methods. "We have brought something all the way from the test tube to the patient," he says. "Now we are going back to the lab and saying, 'How can we make this more efficient? How can we make this better?'"

He hopes to answer that question with a \$950,000 grant from the Huntington Society of Canada and the Brain Canada Foundation.

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Get the scoop on all the latest developments at HSC's 2017 National Symposium

By Julie Stauffer and Josh Martin

There is a touch of giddiness these days within the Huntington disease research community, and with good reason. For starters, there has been an explosion of clinical studies and trials over the past few years, with plenty of others in the pipeline. What is more, a growing number of these trials are examining drugs that might slow or stop HD, rather than just treat the symptoms.

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AGM Notice



Notice is hereby given of the 2017 Annual General Meeting of the Huntington Society of Canada.

Date: Saturday, October 21, 2017

Time: 11:30 AM EST

Place: Holiday Inn Toronto International Airport
970 Dixon Road, Toronto, ON, M9W 1J9

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

Living, Loving and Letting Go

How one Winnipeg man has chosen to dance with the HD elephant

By Julie Stauffer

For years, Jarem Sawatsky lived with the "elephants" of Huntington disease (HD): his fears that he had inherited the fatal gene that killed his mother and that he would slowly lose control of his body and mind. Most of all, he worried that he would hurt his wife and twin daughters the same way his mother had hurt him.

Jarem did inherit the huntingtin gene, and in 2014 he started showing symptoms. That is when he

decided he had to deal with his elephants and, in his words, to dance with them.

He is the first to admit that waltzing with five-tonne beasts is not easy. It takes faith, humour and the willingness to fail and try again. But the former professor of peace and conflict studies believes that letting go of fears opens up a whole lot of space for joy and love.

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Pictured: Jarem Sawatsky

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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.

Editors:

Cyndy Moffat Forsyth
Sobia Khan

Associate Editor:

Laurie Williams

Layout: Real World Graphic Design

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

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

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

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

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Note from the CEO

It has been a very busy few months at the Society with fundraising events taking place from coast to coast, research proposals being funded, lighting up the world for HD, Bill S201 being given Royal Assent and year end demanding a detailed focus by our finance team.

It was a thrilling moment on May 4, when Bill S201 was given Royal Assent making the Genetic Non-Discrimination Act, law. This would never have happened without our community and many champions coming together to do the right thing and protect genetic test information for all people living in Canada. Although some members of the insurance industry are adapting to this new reality, others continue to push back and oppose the law. We are prepared to ensure this law stays for all Canadians.

May, June and July presented a very busy event season. Over 60 events were held in 12 short weeks with the hard work and commitment of hundreds of volunteers and supported by our Chapter Development team. I had the opportunity to attend a few events including the 10th annual Vernon Run/Walk that was organized by our Okanagan Chapter and upcoming hosts of the 2018 National

Conference. We have a lot to look forward to in 2018 with this dedicated and hard working group of community members hosting the Conference.

Our communications team truly influenced lighting up the world for May awareness. This initiative, started by HSC, has truly grown in popularity. Globally, 99 locations participated during May awareness to light it up for Huntington disease. As far away as Australia, our global connections joined in to increase awareness for HD by proudly displaying our colours.

We are at a very exciting time in HD research. This year, Drs. Stephen Ferguson and Lynn Raymond are the recipients of our Navigator Awards. Where research has come so far, we still need to better understand the underlying mechanisms for mutant huntingtin and the research of Dr. Ferguson and Dr. Raymond will help move that forward. We have also funded our second team as a result of the HSC-Brain Canada partnership. Dr. Blair Leavitt and his multi-disciplinary team have been awarded close to \$1million over the next three years for their work in exploring novel treatment delivery strategies for HD.

Be sure to mark October 14, 2017 in your calendars. Our National Symposium is booked for that day. Across the country, community members will be meeting to hear about clinical trials, what hasn't worked and what clinical trials are going forward in Canada. Don't miss this opportunity to hear from our experts, many of whom are from local sites and will bring local care strategies and local resources to those who are attending from the community. Also, our youth conference, YPAHD Day, is scheduled for November 18, 2017. You can read more about both events in this edition of *Horizon*.

Finally, our Believe Campaign has resulted in over \$2 million in commitments for the next few years. From the launch of the Chloe Angus designed HSC Dragonfly Spirit Wrap to the dedicated funds our esteemed Campaign Cabinet have secured, we are experiencing a very successful campaign.

Recently our local MP, Raj Saini, paid a visit to our Kitchener office. He was so impressed at how much HSC, given our modest size, has achieved. Thank you, to all of you, for your support and commitment to making us the best that we can be. Together we are moving mountains.

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For the global HD community.

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global community
www.enroll-hd.org



Finally A Step Closer to Genetic Fairness For All Canadians



By Bev Heim-Myers

The year 2017 has been an exciting year in our journey to protect genetic test information.

On May 4, 2017, Bill S201 received Royal Assent and was passed into law. Now, the Genetic Non-Discrimination Act (GNA) protects the genetic test information of all people living in Canada. In addition to the GNA, the Canadian Human Rights Act has been amended to add Genetic Characteristics, and amendments to the Canadian Labour Code will add an extra layer of protection for employees of federally-regulated industries.

The GNA's prohibitions apply to providers of goods and services and anyone entering into or continuing a contract with an individual. This would include (but not be limited to) employers, landlords, schools, insurers etc. In all situations, businesses are not allowed to require a person to take a genetic test or to disclose the results of a previous or future genetic test. The GNA also prohibits providers of goods and services, and anyone entering into or continuing a contract with a person, from collecting, using or disclosing the person's genetic test results without that person's written consent.

Canada stepping forward to protect genetic test information was a long-awaited success story for all Canadians. Needless to say, it was disappointing when our Minister of Justice, Wilson-Raybould, indicated that after the parliamentary process took place, she would ask Cabinet to refer this legislation to the Supreme Court of Canada. As of July 2017, that has not yet happened. The Quebec government, however, adopted the decree directing their Minister of Justice to file a reference before the Court of Appeal on May 31st. As of July 2017, a reference had been filed.

It has been a very long journey to protect genetic test information in Canada. Huntington Society of Canada began this journey almost 10 years ago and formed the Canadian Coalition for Genetic Fairness. Hours and hours of meetings with our decision makers, presentations to interested parties, participation on panel discussions, testifying at hearings, sharing the stories from our communities and working with many champions, has finally resulted in legislation to protect genetic test information anywhere in Canada. The voices of Canadians have been heard by the majority of our MPs and they did the right thing by protecting our genetic test information.

The insurance industry has aggressively pushed back on protecting genetic test information from day one. In the other G7 countries that protect genetic test information, the insurance industry thrives. The industry will also continue to thrive in Canada. It is important to note that the industry still has access to family medical history information, which has been enough for all other jurisdictions. It is sad and unfortunate that even after the best constitutional experts in Canada supported Bill S201 and we witnessed democracy at its best with the passing of Bill S201, the Cabinet, the Quebec Government and the insurance industry continue to fight this human right for all Canadians.

For now, we celebrate and thank all of the champions that helped pass legislation to protect our genetic test information. The GNA is law – your genetic test information is protected.

To ensure you are up-to-date on genetic fairness in Canada follow @GeneticFairness on Twitter and @FightingGeneticDiscrimination on Facebook, or learn more at <http://ccgf-cceg.ca/en/home>

An Ariel View



A few months ago, Bev called to tell me the Society wanted to rename the walk organized by our local Grand River chapter. She said they wanted to change it to the "Founders Walk to Cure HD" as a tribute to Ralph and me. I felt very humbled and very honoured. You know, I still have a hard time getting my head around how much this organization has grown since we started it around our kitchen table all those years ago.

Walks were not a big part of the Society's fundraising efforts in the early days. Back then, we did garage sales, fashion shows and hoop-a-thons. And the Indy, of course, that really took off across Canada.

Over the past few years though, I have had the pleasure of participating in several walks organized by our local chapter. I remember showing up at one of the first, in Waterloo, and I just could not get over the number of people that came. It was heart-warming to see them all.

For me, the best part of walks is the camaraderie. I am a bit of a social butterfly, and I love the chance to renew old friendships and to meet some new people. We are like a big family: everyone is very welcoming, friendly and inclusive. Whether you are young or old, have HD or just want to show support, these events are accessible to everyone. It is a great opportunity to connect with other families who are affected by the disease and get support from the HD community.

Plus, the organizers look after us so well. Last year, it was a cold, wet day, but everybody was laughing and having a heck of a good time. There were prizes and draws and wonderful pizza as well.

So don't be afraid to come out and join me at the Founders Walk to Cure HD this September. If you're too far away, you could organize your own Walk to Cure HD – after all, that is how the Indy, the Amaryllis Campaign, the garage sales, fashion shows, runs... well come to think of it, that is how everything started, one person with one idea. We are hoping for good weather, but as you know, we will have a wonderful event despite what Mother Nature chooses to give us.

If you are in Ariel's area, join her on Saturday, September 16th, 2017 at Riverside Park in Cambridge, Ontario for a one- or five-kilometre walk, plus activities for the whole family. To get more details and to register, visit www.hscevents.ca/FoundersWalk or if you would like to start your own Founders Walk to Cure HD contact us at events@huntingtonsociety.ca or call 1-800-998-7398.

The year's must-attend youth event is just around the corner

By Julie Stauffer and Josh Martin

A year ago, Caleb Harding was gearing up for his first YPAHD Day (Young People Affected by Huntington Disease) and National Conference, unsure what to expect when he arrived in Halifax. "I would be lying if I said that I wasn't nervous," the University of Victoria student admits. "It can be intimidating to attend a conference full of strangers to talk about a serious and sometimes scary topic."

However, it didn't take long for the butterflies to dissipate when he sat down to breakfast with other youth. "It was just a very welcoming environment," he recalls. "You felt at home immediately."

Today, Caleb isn't just excited about this year's regional YPAHD Days, he is busy organizing them as part of the youth chapter's executive committee. On November 18th, dozens of young people will gather in Kelowna, Toronto and Moncton to equip themselves with new tools and connect with other youth affected by Huntington disease.

There will be no shortage of exciting things to talk about. From the latest research developments to unique care strategies, attendees will sink their teeth into the most up-to-date HD information.

YPAHD Day will also feature sessions on grief and guilt, led by trained HSC social workers. The reality is, HD comes with a lot of loss: whether it is the death of a loved one, changing relationships or the fact that mom or dad cannot do the things that other moms or dads do. Then there is the impact of genetic testing. People who test positive often struggle with the loss of hopes and dreams, while people who test negative may find they are hit with survivor's guilt.

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Pictured: Caleb Harding

"Sometimes it is hard to share that within your family," says HSC's Director of Family Services and Community Development, Angèle Bénard, who will be guiding the discussion at the Moncton session. YPAHD Day offers a safe space to discuss those experiences with other youth.

Meanwhile, roundtable sessions will let participants ask whatever pressing questions are on their minds, from whether to get tested, to how to tell a boyfriend or girlfriend about HD, to what family planning options are available.

And while there will be plenty of opportunities to share personal experiences, there's never any pressure. "We do not make people talk if they do not want to," YPAHD President Jackie Skinner promises.

Participants will also come away with practical strategies for looking after themselves. Across the country, we have lined up workshops on mindfulness and holistic nutrition, exercise, and the healing power of music.

Plus, world-recognized HD researchers will be on hand to chat about new breakthroughs. In Kelowna, the University of British Columbia's Dr. Lynn Raymond will provide the latest updates on clinical trials. In Toronto, Dr. Mark Guttman from the Centre for Movement Disorders will talk about how the global HDClarity study is investigating biomarkers to track HD progression and measure whether treatments are working. Meanwhile, in Moncton, Dalhousie University's Dr. Eileen Denovan-Wright will talk about the benefits and risks of cannabis for people with HD.

Of course, there will be no shortage of fun either. This is a group that likes to laugh, play games and



indulge in some crazy dancing. For those who wish to take part, our pre-event social night on Friday kicks things off with bowling in Toronto, working through an escape room in Kelowna and feasting on a steak dinner in Moncton.

Most of all, YPAHD Day provides a chance to connect with people that "get it." That is something Jackie tells every YPAHD newbie. "For the first time, you are going to go somewhere and say 'my mom or dad or my sister or whoever has Huntington disease and it sucks,' and nobody is going to look at you and go 'what's that?'" she says.

Caleb agrees. His trip to Halifax last year taught him about the magic that happens when this community comes together face-to-face. "Laughing with them and just sharing stories and getting to know them, you began to understand that everybody had this shared connection, this shared journey," he says.

This is a place where you will find instant friendship, immediate acceptance and no end of support. "I don't think anyone has all the answers," Caleb says. "But at least you have that group to draw on to help you along your own way."

Be part of YPAHD Day 2017! We welcome everyone from the age of 14 to 35. (Participants younger than 18 must bring a parent or guardian.) To register, visit www.huntingtonsociety.ca/ypahd-day, email events@huntingtonsociety.ca or call 1-800-998-7398. The fee is \$120, or \$200 including a shared hotel room. Sign up before November 3rd!

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.

A gift for other people's grandchildren

By Julie Stauffer

For 23 years, Stephen Hurst nursed his wife Glenda until she passed away from Huntington disease in 2008. Now, two of his daughters have developed the disease. "I had no idea how long and hard it was going to be," he says. "It just cuts a swath that's so deep, it consumes you."

Despite that, he counts himself lucky in a number of ways.

One, for finding Janet-Rose: the live-in caregiver who helped him look after Glenda and later married him. Two, for the social workers, resources and peer support that HSC provided as he and Janet-Rose grappled with the challenges of HD. And three, for the fact that both his grandchildren were born without the fatal gene.

Learning that two of his daughters have HD was tough, and he and Janet-Rose know the coming years will get tougher. But while they support Stephen's daughters, they will also continue contributing to the Huntington disease community.

When Stephen was a young father and husband, he relied on the advice of others ahead of him on the HD journey. Now, as a Huntington disease veteran, he feels an obligation to make sure other families don't face the disease alone.

The pair has volunteered in the P.E.I. chapter for decades – Stephen as president, Janet-Rose as secretary – while Stephen also served for seven years on the Society's National Board. Janet-Rose was also recently recognized for her volunteer efforts with HSC National Conferences at the 2016 National Conference in Halifax with the National Award of Merit. Today, they continue to be top

fundraisers for the chapter's Amaryllis campaign and Indy Go-Kart Challenge.

Their support won't stop there. Stephen and Janet-Rose have also included a gift for the Society in their wills, despite the fact HD won't touch their own grandchildren. "We could step back and say 'hey, we're done,'" says Janet-Rose. "[But] there's so many other people out there that need help."

It's a decision that makes Stephen feel good about the future amidst the chaos HD is currently causing in his family. "I'm a long-term thinker," he explains. "I wanted to leave a gift that could help generations that come behind us."

For more information about legacy giving and how you can impact future generations please contact Jeff Hoffman at 1-800-998-7398 or jhoffman@huntingtonsociety.ca.

Living, Loving and Letting Go

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Jarem shares the wisdom he has acquired in *Dancing with Elephants*, a 224-page book published earlier this year aimed at anyone dealing with an incurable illness.

One of his key messages is the importance of living in the moment. "I need to be careful not to get caught up in the past, yearning for the life I had," he explains. "I also need to be careful not to get caught up in the future, mourning the life I will not have."

To do that, he draws on lessons learned from luminaries like Buddhist monk Thich Nhat Hahn and mindfulness expert Jon Kabat-Zinn. However,

one of his best teachers has been Kobi, a golden lab they got as a puppy in 2015. "Having a dog, even a poorly trained puppy, is minute-to-minute mindfulness training in happiness," he says.

Part of living in the moment entails celebrations, and plenty of them. If they involve food, even better. When he tested positive for HD, Jarem and his wife threw a "Movers and Shakers" party and invited all their friends. Today, rarely a week goes by without some special dinner or get-together.

Meanwhile, he invited six people from their church to create a formal 'circle of support,' ensuring his wife and daughters do not have to bear that burden alone. Many people want to offer support, he says, and the circle offers a tangible way to do that.

Jarem does not sugar-coat the reality of HD: "It is a slow train wreck of a disease," he says. Although he cannot change that reality, he can change how he frames it and that means not thinking of HD as a battle. After all, he says, when you are fighting a fatal disease, you are ultimately going to lose and use up energy that you could be using to create love and joy. That is why he has chosen to see dealing with Huntington disease as a dance. Like any physical dance, learning how to do it involves plenty of practice and, inevitably, plenty of missteps.

Perhaps the wisest advice in the book comes from a colleague's wife, who has Parkinson's: "When you stumble, just make it part of the dance."

For more advice on dancing with elephants, consult your HSC Resource Centre Director at www.huntingtonsociety.ca or order a copy of Jarem's book please visit www.jaremsawatsky.com/dancing-elephants.

Building a house to last

By Josh Martin

After Mark Atkinson was diagnosed with HD in 2015, he and his wife Rebecca soon realized their existing home wasn't going to cut it as his symptoms progressed. Their two-storey house had lots of narrow stairs, closet-sized bathrooms and a sunken living room that became increasingly problematic as Mark's chorea and balance got worse. Meanwhile, the cramped quarters were a recipe for frayed nerves and spikes in anxiety, especially when their eight-year-old daughter, who is on the autism spectrum, had noisy play dates over.

So, with the support of family, their occupational therapist and a design-savvy aunt, the Atkinsons got to work designing a three-bedroom bungalow outside Fredericton. Completed last November, every detail of their new home takes Mark's current and future needs into account.

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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

Giddy'up! The benefits of therapeutic horseback riding

By Josh Martin

For most people dealing with the symptoms of Huntington disease, horseback riding doesn't spring to mind as a practical pastime. Between the balance problems and the involuntary movements, climbing onto the back of a thousand-pound animal might seem like a recipe for disaster.

Think again, says Heather Mackneson.

Heather is the executive director of Pride Stables: a charity in Kitchener, Ontario that offers therapeutic horseback riding lessons to people with disabilities, including those with Huntington disease. Since 1973, the organization has been improving the lives of its participants with its empowering approach.

Each year, the team at Pride Stables helps hundreds of kids and adults with cerebral palsy, spina bifida, autism and other conditions, get in the saddle. With 29 therapy horses, five qualified instructors, year-round classes and nearly 400 volunteers, the program is one of the largest of its kind in Canada.

During lessons, safety is paramount. Trained leaders guide the horses around the arena and outdoor riding area, while volunteers walk alongside the rider to prevent falls and ensure everybody gets the most out of their experience. "We really look at the person not through the eyes of 'what is wrong with you?'" says Heather. "It is how can we help the horse make a positive difference in your life?"

For people with HD, that positive difference is often physical. A horse's gait mimics that of a human's, and the swinging, repetitive motion can improve balance, posture and coordination. A rider must also constantly react to the horse's movement, strengthening muscles, mobilizing the joints and increasing range of motion. Meanwhile, the animal's higher body temperature can help to relax tight muscles.

Therapeutic riding provides many emotional and psychological benefits as well. According to Heather, the experience gives participants a feeling of freedom, control and accomplishment. "Not only are you getting exercise," she says. "But it's



Pictured: One of the founding members of the Grand River Chapter, Mitch de Beus can vouch for the therapeutic benefits of the horseback riding program at Pride Stables.

also things like getting outside, doing something independently."

Nor is it just the riders who reap the rewards. Heather sees very special friendships develop between the horses, the riders and the volunteers. "I have been here 20 years. It is just a fantastic way to see people benefiting," she says. "You see the smiles."

Want to try therapeutic riding? The Canadian Therapeutic Riding Association at www.cantra.ca has a list of members across the country. However, Heather notes that many programs don't belong to CTRA, so it is also worth googling for local options.

Gene-silencing

continued from page 1

The ambitious project brings together world-class researchers from three different institutions to assess the feasibility of injecting ASOs into the bloodstream; it's being done in close collaboration with Dr. Michael Hayden, the Hayden lab, and his colleagues who pioneered pre-clinical work that contributed significantly to the use of ASOs for gene silencing in HD.

Because blood vessels wind their way throughout the brain, this approach could potentially reach deep brain structures better than spinal injections and be less invasive for the patient.

However, the investigators must overcome two major problems to make blood-borne delivery work. One, ASOs tend to break down in the bloodstream. Two, the brain is protected by a special barrier that stops just about everything except sugar and oxygen from moving from the blood into the brain.

That is where two scientists from the National Research Council of Canada (NRC) come in. Dr. Danica Stanimirovic and Dr. Abedelnasser Abulrob are world-renowned experts at developing nano-carriers that can transport drugs across this blood-brain barrier. As part of the project, the pair will be engineering several different carriers specifically designed to deliver ASOs.

They will start with a lipid capsule that encloses the ASOs, preventing them from breaking down in the bloodstream. Next, they will attach antibody fragments that act as a security pass, letting the capsule (and its contents) pass through the barrier. Once it reaches the other side, the lipid capsule will merge with brain cell membranes, releasing the ASOs directly into the cell.

If all this unfolds as the researchers hope, it will represent a major milestone for Huntington disease therapy, Dr. Abulrob says.

He and Dr. Stanimirovic will send the most promising versions of their nano-carrier to UBC in Vancouver, where Dr. Leavitt and the UBC team will test them in mice, and to the Oregon Health and Science University in Portland, where Dr. Jodi McBride will test them in larger animal models.

Drs. Leavitt and McBride will examine several different things: which type of carrier works best, how much of the drug reaches the target areas of the brain and whether injecting ASOs into the bloodstream is more effective than injecting them into the cerebrospinal fluid.

The final phase of the research project focuses on biomarkers. Research suggests that the level of huntingtin protein in the cerebrospinal fluid reflects huntingtin levels in brain cells. Dr. Leavitt will fine-tune ways to measure these levels.

He and Dr. McBride will then compare them with ASO penetration and Huntington disease symptoms in their animal models, creating a more sensitive and accurate way to assess whether gene-silencing therapy is working.

"I am really excited to be a part of this project. It is the quintessential example of bringing together people who have amazing expertise," says Dr. McBride. "It is going to be quite a powerful collaboration."

The results will help enhance the effectiveness of ASOs, taking a promising therapy for HD and making it even better. Potentially, it could also pave the way for treatments of other genetic brain diseases, including specific types of epilepsy, Parkinson's and Alzheimer's.

"If we succeed in demonstrating that we can do this, that has the potential to open up the field tremendously," says Dr. Stanimirovic.

The funding for this research comes from a \$2 million partnership between the Huntington Society of Canada and the Brain Canada Foundation. The goal is to create multidisciplinary, multi-investigator networks that maximize the opportunity for discovery and expedite the translation of discoveries to effective treatments. To learn more, visit www.huntingtonsociety.ca.

A Historic Huntington Disease Awareness Month

By *Sobia Khan*

Every May, the Huntington Society of Canada (HSC) recognizes Huntington Disease Awareness Month and this year was no different. The Huntington disease (HD) community comes together to raise awareness, make connections, get support from their communities, and move forward with pride and dignity. Throughout May 2017, we were involved in a host of activities and events. Keep reading to see what we got up to!

Our volunteers are amazing – they dedicate their time and efforts toward the HD cause year-round and this month we profiled the work of some across Canada. From organizing runs in support of HD research and services, like Beka Pottery and Ellie Smith have done, to starting a chapter in a local region (way to go Bunny Clark!), being involved with the local chapter for more than 15 years (Judy Harding really has been with us that long) and finally all the way to using unique talents, such as modelling, to promote the cause – the way Kathryn Jordan has done. These volunteers are truly unmatched. Thank you for being part of the family.



#LightItUp4HD is an awareness initiative started in 2015 by a volunteer and it has been going strong ever since. This year we expanded even further, bringing the grand total of sites lighting up in blue for HD and purple for JHD (Juvenile Huntington disease) worldwide to 99! Thanks again to our amazing volunteers and community members, partner organizations and families, who banded together to compile a very impressive list of sites including Niagara Falls, the Kelpies in Scotland, Spinnaker Tower in England and more!

Over on the east coast, our very own Rich Wheeler is once again on a mission to set the bar a little higher! Not only did he light up his house in blue, he encouraged the rest of his neighbourhood and community to do so as well – until the hardware store ran out of their stock of blue lights! Now people all over are lighting up their homes in support. He also organized what originally was to be an awareness-only fitness event (called WorkItOut) that turned into a fundraising hit by raising over \$8,000!



Pier Paolo Lisarelli Photography @ www.pplimages.com

On May 18, 2017, in a historic meeting that was the first of its kind, Pope Francis met with and addressed Huntington disease families in Vatican City. In doing so, he became the first world leader to recognize the devastating plight of those living with and affected by HD. Pope Francis was joined by families, researchers, foreign dignitaries and celebrities from across the world. The event was coined the 'HDdenomore' initiative (pronounced 'Hidden No More') to raise awareness of HD, bring HD families together, and generate action to end the stigma and shame around the disease that has persisted for generations.

HSC's 2017 PSA Campaign, "What is HD?", aims to spread the word about HD and JHD to the general public. During the month of May, we launched our TV and radio ads on several local outlets across the nation to raise awareness with the general public, many of which are still airing. The ads were

accompanied with testimonials from our community, including YPAHD President Jaclyn Skinner and Peterborough Chapter President Heath Sterling. We invite you to share these ads in your region so we can get every possible outlet engaged in HD awareness year-round!



Started in 2016 by Barb Marshall, you may have seen these beautiful hand-crafted ribbons across social media or at a chapter event. This year, these ribbons were available for fundraising at chapter events and individuals could also request them. In 2017, her campaign raised \$1896 with all proceeds going to the Huntington Society of Canada.



On May 18th, another event new to HSC took place in Vancouver, BC. The Chloë Angus Design Studio partnered with HSC for an event where participants could design their own dragonfly button wrap. These spirit wraps feature a beautiful dragonfly, created by Haida artist Clarence Mills, which is a symbol of both HSC's Believe campaign and a symbol of change, transformation and swiftness in Haida culture. Proceeds from the wraps go to HSC; HD has a special place in Studio owner Chloe Angus' heart, as her mother was diagnosed two years ago.

To purchase a Dragonfly Button Wrap or to learn more about #Lightitup4HD or to donate to Barb's Ribbons of Hope visit www.huntingtonsociety.ca.

2017 Fall Calendar of Events



Indys

Sunday, September 10

Winnipeg Indy Go-Kart Challenge

Headingley, MB
info@hdmanitoba.ca

Sunday, September 10

Windsor/Essex Indy Go-Kart Challenge

Windsor, ON
pjb8man@hotmail.com

Sunday, September 24

Halifax Indy Go-Kart Challenge

Halifax, NS
jimrussell@eastlink.ca



Walks

Sunday, September 10

BC Walk to Cure HD

Vancouver, BC
britishcolumbiahd@gmail.com

Saturday, September 16

Founders Walk to Cure HD

Cambridge, ON
hdgrandriver@gmail.com

Looking to get involved?

To volunteer, participate, or for event ideas, please contact us at 1-800-998-7398 or email us at events@huntingtonsociety.ca



Runs

Sunday, October 15

Niagara Falls International Marathon

Niagara Falls, ON
www.hscevents.ca/teamhd

Sunday, October 22

Toronto Scotiabank Waterfront Marathon

Toronto, ON
www.hscevents.ca/teamhd

Wednesday, December 27

Toronto Resolution Run

Toronto, ON
events@huntingtonsociety.ca



National

Saturday, October 14

HSC National Symposium

Victoria, British Columbia
Kelowna, British Columbia
Edmonton, Alberta
Calgary, Alberta
Saskatoon, Saskatchewan
Winnipeg, Manitoba
London, Ontario
Guelph, Ontario
Toronto, Ontario
Barrie, Ontario
Peterborough, Ontario
Kingston, Ontario
Ottawa, Ontario
Halifax, Nova Scotia
Quispamsis, New Brunswick
St. John's, Newfoundland
www.huntingtonsociety.ca/symposium

Wednesday, October 18

HSC National Symposium

Thunder Bay, Ontario
www.huntingtonsociety.ca/symposium

Saturday, November 18

Regional YPAHD Days

Toronto, Kelowna & Moncton
www.huntingtonsociety.ca/ypahd-day



Other

Saturday, September 30

A Night to Flourish Gala

Calgary, AB
events@huntingtonsociety.ca

Tuesday, October 3 to Monday, October 9

Niagara Book Sale

St. Catharines, ON
events@huntingtonsociety.ca

Wednesday, October 18

Paul Paone 3-on-3 Basketball Tournament

Niagara Falls, ON
events@huntingtonsociety.ca

Friday, October 20

Niagara Trivia Night

Niagara Falls, ON
bit.ly/NiagaraTrivia

Saturday, October 21

Victoria Halloween Dance Fundraiser for HD

Victoria, British Columbia
bit.ly/VictoriaHalloweenDance

Sunday, October 29

Haunted Halloween's Eve Gala

Vancouver, British Columbia
events@huntingtonsociety.ca

Tuesday, November 7 to Saturday, February 24, 2018

Toronto Sports Getaway Raffle

All Ontario
events@huntingtonsociety.ca

November 2017 (Exact Date TBC)

Ottawa Family Christmas Concert

Ottawa, ON
events@huntingtonsociety.ca

Spotlight:

Eli and the Straw Man



Eli and the Straw Man are a contemporary indie roots rock band from Niagara Falls. In 2016, the band partnered with the Huntington Society of Canada for a tour to spread

awareness about Huntington disease. Shortly after the tour, the London Chapter of the Huntington Society of Canada proposed a partnership for a benefit concert. The band has since performed 3 more benefit concerts led by volunteers and Chapters in Ontario, including Niagara Falls, Oshawa, and Kitchener. The group also released their first album, and pursued another awareness tour in 2017. In just over six months, the band has helped raise over \$30,000 towards research and support services with HSC. Band member, Tam Maiuri, comes from a family that is impacted by HD and works at McMaster University in an HD research lab led by Dr. Ray Truant. If you'd like Eli and the Straw Man to perform a benefit concert in your area, contact events@huntingtonsociety.ca.

YPAHD column

By Jaclyn Skinner, YPAHD President

What do a lemonade stand, yoga session and ice fishing derby have in common? They are all examples of how young people affected by HD are taking action!

Since YPAHD's members are literally all across the country, it is hard to get together to do fundraising events like other chapters do. That is why we launched the HD Champion Challenge last year and invited youth to create their own fundraisers. It gives everybody an opportunity to do something as big or small as they want and collectively move mountains!

Our members have organized bottle drives, golf tournaments, walks, Facebook auctions and everything else under the sun. This year's Challenge runs until November, so there is still time to help us reach our \$25,000 goal. Just follow the links at www.huntingtonsociety.ca/events to find out more.

I love these digital tools, but nothing beats meeting face-to-face. As I write this, I am getting ready to volunteer at the HDYO camp near Washington, D.C. It's an incredible experience, bringing together about 50 youth from all over North America. We do typical summer camp activities like swimming, paddle boarding, canoeing and campfires, but we also explore HD-related topics like genetic testing, family dynamics and relationships.

The best part is feeling an instant bond with everyone. Last year I cried my eyes out when I



Jaclyn Skinner, YPAHD President

left because I fell in love with so many of the campers. I felt so inspired, I wanted to come back and change the world.

I see those same bonds happening at our annual YPAHD Day: it's like creating a second family that helps you get through some of the toughest stuff of your life. I honestly don't know where I'd be without the people I've met through YPAHD!

This year we are holding YPAHD Day in Kelowna, Toronto and Moncton on November 18th. If you haven't registered yet, sign up at www.huntingtonsociety.ca/ypahd-day.

Are you under 35 and interested in being a part of the YPAHD Chapter? Contact ypahd@huntingtonsociety.ca to be added to our mailing list, or find us on social media.

Amaryllis 2017: Growing strong

By Josh Martin

HSC's annual Amaryllis Campaign is underway, and with more than 50% of the kits already sold, we are well on our way to achieving our goal of \$115,000. So what is the secret behind this fundraiser's success year after year?

For many, it is the fact that HSC's signature flower makes a perfect gift. Not only do the vibrant blooms make homes brighter during the dreary winter months, they also help make the future brighter by raising vital funds for HD research and for family services across the country.

Meanwhile, we see a lot of green thumbs drawn by the quality of our amaryllis. "They love the plant itself and recognize that our bulbs are some of the best that they can find out there," says Jeff Hoffman, HSC's Senior Manager, Development.

Of course, seeing is believing. Our Amaryllis Photo Festival, back again this year by popular demand, features shot after shot of stunning flowers in bloom submitted by proud growers across the country.

The campaign also attracts many businesses. Some give amaryllis kits as client gifts, while others organize growing challenges within the office. "They find it is a fun way to team-build, raise some energy and give back to the community in a positive way," says Jeff. "It is a nice way to bring in some cheer just before the holidays."

But the biggest reason why the Amaryllis Campaign flourishes? Our awesome HD community. For more than three decades, we have been blessed with passionate and hardworking sellers. In malls, workplaces and communities from coast to coast, dozens of seasoned veterans and enthusiastic newcomers are generously volunteering their time and talent.

"It is successful because of all of their energy and their dedication," says Jeff.

Join their ranks! To order your kits 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.

Congratulations to Jeanne from South River, Ontario, the winner of our Amaryllis Early Bird Contest! Jeanne received a Kindle e-book reader and a copy of *Five Days Left*, Julie Lawson Timmer's critically acclaimed novel.

Did you know that you can

DONATE SECURITIES

to the Huntington Society of Canada?

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



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



YOUTH MENTORSHIP PROGRAM

For more information, visit:
www.huntingtonsociety.ca



Transforming Tomorrow Together

Only 25% to go to reach \$3 million

The Believe: Transforming, Tomorrow, Together Campaign Cabinet is optimistic that the goal will be reached by 2018

The goal: \$3 million over 2 years

Officially launched in November of 2016, the Believe: *Transforming, Tomorrow, Together* campaign has reached a milestone. The campaign cabinet was pleased to announce in June 2017 that they were 75% to goal with \$2.34 million committed to date.

The campaign's main focus is a vision of a future where HD no longer ravages the mind and body. In order to make that happen, HSC's Believe campaign focuses on two key areas.

\$1.5 million for discovery research

These dollars will help scientists build on important recent discoveries to find treatments more quickly – treatments that reverse, slow or prevent the progression of HD.

\$1.5 million to increase services to families, individuals and youth

Everyone affected by HD deserves to have access to services and clinical trials. The Believe campaign will ensure we have the capacity and tools to support all families who are affected by HD, including those in rural and diverse communities.

The campaign's goals are simple, but the impact will be profound. Let's transform, tomorrow, together.

To learn more about the campaign and how to make your contribution, please visit us at www.huntingtonsociety.ca/believe-transforming-tomorrow-together.

HSC's 2017 National Symposium

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"I am really excited by this," says Dr. Mark Guttman, who heads up Toronto's Centre for Movement Disorders. "This is what we have been hoping to do since I started doing the clinical research program into Huntington disease in the early 90s."

To help the HD community understand how far potential treatments have come and where research goes next, the Huntington Society of Canada (HSC) has assembled an all-star cast of Canadian researchers for the 2017 National HSC Symposium. Join HSC on October 14th for insights from Dr. Guttman (Toronto), the University of British Columbia's Dr. Blair Leavitt, the University of Alberta's Dr. Oksana Suchowersky and McMaster University's Dr. Tam Maiuri.

One of the clinical trials that will be discussed is IONIS-HTRx, the Phase I/IIa trial for a gene-silencing drug developed by Ionis Pharmaceuticals. The company doesn't expect to release the results until the end of this year, but according to a June press release, there have been no safety issues to date. As a result, Ionis is giving all participants the option to continue taking the drug.

"That is wonderful news," says Dr. Leavitt. "As far as we can tell, things are looking very, very positive."

Meanwhile, Dr. Guttman will be involved in trials for a different gene-silencing drug developed by WAVE Life Sciences. Unlike the IONIS trial, this anti-sense oligonucleotide targets only the disease-causing component of RNA, not the normal part. Like the IONIS study, this is a Phase I/IIa study for a small number of participants who meet the specific criteria.

Nor is gene silencing the only promising way to treat HD. Dr. Suchowersky is part of a team that is currently conducting HSC-funded trials in the lab on GM1, a substance that has reversed Huntington disease symptoms in mice. GM1 is present in healthy nerve cells, and may be depleted in the brains of individuals with HD. Her clinic is also involved in the LEGATO-HD trials for laquinimod, a drug that dials down the brain's inflammation response. Because inflammation can exacerbate brain cell damage, keeping it in check could slow the progress of HD.

The more options, the better. Not all drugs may work in all patients, and a combination of drugs may work better than a single therapy.

However, getting a treatment to market takes time. "We are not sure whether it will benefit the people that are already affected by Huntington disease," says Dr. Suchowersky. "But hopefully we will have treatments for the next generation."

For example, the current IONIS trial aims to test safety. It will take many more studies to judge whether gene silencing works. If it does prove effective, scientists will still need to tweak the drug formulation, delivery mechanism, dosage and more.

"Ultimately, we want the most effective therapy with the least potential for side effects and the least invasiveness for the patient," Dr. Leavitt explains. That is why he is currently leading an ambitious study to look at better ways to deliver gene-silencing drugs (see article on page 1).

To judge the success of any therapy, investigators need a sensitive way to measure HD progression. The global HDClarity study aims to assess whether the level of huntingtin protein in cerebrospinal fluid accurately reflects the progression of the disease. Meanwhile, Dr. Suchowersky and her colleagues in Montreal and Calgary are conducting similar assessments of GM1 both in blood and cerebrospinal fluid.

Of course, not every study delivers the results researchers hope for. We have seen several clinical trials called off in recent years, including Amaryllyis, 2CARE and PRIDE-HD. So were those efforts a waste of time? Not at all, says Dr. Maiuri.

In her presentation, Dr. Maiuri will help explain why these trials ended early and discuss how the path to scientific breakthroughs includes false starts and wrong turns. Every so-called "failure" gives us valuable information, opens up new pathways and brings us one step closer to success.

She understands how agonizingly slow that process can seem for families dealing with Huntington disease: her mother has HD, and Dr. Maiuri herself is at-risk. But when she looks forward, she feels nothing but optimism. "Things are accelerating now," she says. "I think we are going to see many exciting potential therapies."

Find out what is happening, where clinical trials go from here and how you can play a role at HSC's National Symposium on Saturday, October 14th. Come to one of the 18 sites across the country, or live-stream the research presentations from home. Get all the details and reserve your spot at www.huntingtonsociety.ca/symposium.

Making a difference: Lightning in a bottle

By Josh Martin

When Emily returned home from the 2015 YPAHD Day in Calgary, the then 12-year-old was fired up to take action. She wanted to help HD researchers find a cure for the disease that killed her grandfather and will one day afflict her gene-positive dad. So, the Regina girl set out to raise money.

"Teachers are always saying one person can always make a difference, and I wanted to be that one person who could really try to make a difference for people with Huntington disease," she says.

The question was how.

That is when Emily remembered the bottle drive her school had done for the Terry Fox Foundation. Why not use the same approach to collect funds for HSC? So last year, she and five of her friends put on YPAHD t-shirts, grabbed some Huntington Society brochures and started knocking on doors.

By the end of the day, they had loaded her uncle's truck and trailer with a mountain of empty bottles. When they brought their haul to the local recycling plant, they discovered they had raised over \$450. "We were all really happy," she says.

Buoyed by the success of their first attempt, Emily set an ambitious goal of raising \$1,000 in 2017. "Nothing's impossible," she figured.

She was right.

Emily pulled out all the stops, creating an online fundraising page and distributing paper pledge sheets to friends and family. Meanwhile, her cousin encouraged her to write a letter to the local RONA store. Each month, the home improvement retailer has popcorn available to customers and employees with a donation collection identifying which charity the proceeds go to and thus donating the proceeds to a charitable cause. The bottle drive fit the bill nicely, and both the RONA stores in Regina and Saskatoon got on board.

The campaign was a roaring success. Altogether, Emily collected more than \$3,400: triple her original target. Looking ahead, she hopes to do multiple bottle drives next year and get more RONA stores across Saskatchewan involved.



Her advice for other youth interested in contributing to the cause? Get your friends involved, don't underestimate yourself, and most of all, have fun. "Go for it," she says. "Even if you raise a hundred dollars, it will help a lot."

To create an event of your own to raise awareness or to raise funds, the Huntington Society of Canada has a team dedicated to supporting your ideas. Contact us at events@huntingtonociety.ca or call 1-800-998-7398 to learn more.

Powerful story triggers powerful response

By Josh Martin

Dr. Tam Maiuri admits she hesitated when we asked her to be the face of our spring donor appeal, especially because it involved video interviews. "Oh man, I hate cameras!" she says.

However, because the Huntington disease cause means so much to her both personally and professionally, she chose to confront her camera fears. The story she told was powerful.

As a molecular biologist, Tam is in the lab every day, working with Dr. Ray Truant's team to find a cure for Huntington disease. But her connection goes deeper than that. Tam's mother has Huntington disease, and if Tam used her microscope to look at her own cells, there's a 50 per cent chance she would find the same genetic mutation. If she did, it would mean her two children would also be at-risk.

Tam's contributions do not stop when she hangs her lab coat up for the night. The band she plays in, Eli & the Straw Man, regularly puts on benefit concerts to raise money to help families impacted by HD. "The guys in the band love it," she says. "They feel like they are doing something worthwhile [and] meaningful."

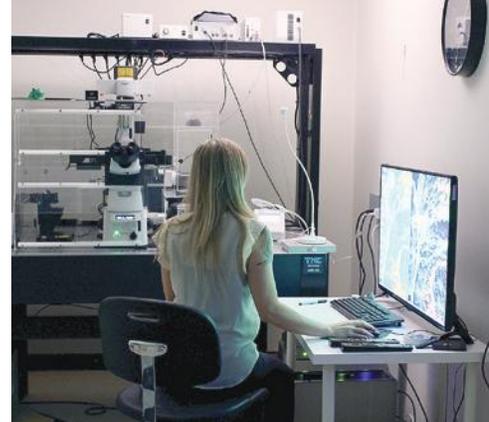
Tam's story struck a chord. Across the country, Canadians dug deep to support the Society's work. Better still, an anonymous donor matched those contributions dollar for dollar.

The Huntington Society's direct donors are having a real impact. Whether it is funding HD research in labs like Tam's, increasing services like the recently opened Resource Centre in New Brunswick or expanding outreach into remote communities, these funds are vital.

"These things cannot happen without the support of our generous donors," says Jeff Hoffman, HSC's Senior Manager, Development. "These campaigns are really a huge success because of their ongoing commitment year after year. Our heartfelt thanks goes out to Tam for sharing her story, to our matching donor who enabled us to double our impact and to everybody who played a part in making our spring donor appeal such a wonderful success."

Now, we are gearing up for a new campaign this fall, offering more opportunities to make a difference. Watch your mailbox!

Learn more about how you are impacting the entire HD community with your support and how the Huntington Society of Canada reports on our strategic outcomes at <https://www.huntingtonociety.ca/donor-reports-and-strategic-plan-results/>



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Celebrating Our Heroes

Greg Shwaga

By Josh Martin

On July 10th, Greg Shwaga set out on a 700-kilometre hike from one side of Saskatchewan to the other, raising more than \$16,000 so far and a heck of a lot of awareness. A few days before his epic walk, we sat down with him to talk about his motivations, his training regimen and what he was looking forward to on the road ahead.



Embarking on the long-distance hike was a deeply personal decision for the 46-year-old school principal. Greg's mother-in-law passed away from HD last year, while his sister-in-law has also tested gene-positive. Furthermore, there's a 50/50 chance his wife Val and her two brothers will develop the fatal disease as well.

That threat creates an ever-present cloud over Greg, Val and their two children. "It changes your perspective," says Greg. "You're no longer looking at life as being something you do until you're 80. It's maybe something you do until you're 40."

To prepare for the journey, Greg squeezed in 16-kilometre hikes several times a week around their hometown of Vanguard, Saskatchewan. He stocked up on bug spray and moleskin for blistered feet. Meanwhile, his daughter, wife, son, stepfather and sister decided to take turns driving a pilot vehicle (that also served as a support vehicle) provided by Knight Nissan in Swift Current.

Logging 30–50 kilometres each day is no small challenge, but Greg had a few things to keep him motivated. As a history teacher, he was excited to follow in the footsteps of early Prairie settlers. Meanwhile, having so many supporters rooting for him – including his students, who surprised him with a \$2,000 donation, put some pep in his step.

Most importantly, it was the chance to raise awareness about HD. Indeed, when it comes to supporting his family, no distance is too great. "If you just slowly chip away at it, it doesn't seem to be that big of an obstacle," he says.

"I think it is impressive and inspiring that this busy principal and dad would dedicate a portion of his summer holidays to do this," says Greg's sister-in-law Glenda Rowein. "I know families who are impacted by HD across the province are cheering him on."

To send Greg your congratulations on an amazing achievement, visit the Huntington Society of Canada's facebook page at www.facebook.com/HuntingtonSC. Although his walk is over, you can still make a donation by visiting bit.ly/GregSKwalk.

Building a house to last

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To reduce the risk of falling, they built a thick half-wall around the basement stairs and installed handrails and grab bars. The open-concept home is also wheelchair-ready, with wide hallways and lower light switches, countertops and shelving. The induction stove features controls at the front instead of the back so Mark won't have to reach across hot burners, while a ramp makes it easier to get from the garage to the house.

Accommodating Mark's cognitive and emotional symptoms was also important. A large whiteboard known as "command central" now keeps track of therapy appointments, medication information and task lists. The larger house also ensures that family members have more privacy, including a soundproofed basement so their daughter can play without bothering her dad.

"[The] guest bedroom down there works great for sleepovers so giggling girls can be giggling girls," says Rebecca. It can also be converted into a caregiver's suite, should the family require live-in help down the road.

A good location was another priority. Their new digs are less than 10 minutes away from a pharmacy, their daughter's school, a trail system full of accessible walking paths, and their aunt, who often stays with them while Rebecca runs errands.

Sweating every detail took a lot of effort. But for the Atkinsons, it was worth it. "We love it, it works incredibly well for our needs," says Rebecca. "Everyone is much happier."

To learn more on how you can implement ideas to help cope with the symptoms of HD visit the Huntington Society of Canada's resources page at <https://www.huntingtonsociety.ca/hd-fact-sheets-articles/> or if you have a good idea that is worth sharing contact us at info@huntingtonsociety.ca so we can share with the HD community.



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.