

HORIZON

RESEARCH • SERVICE • EDUCATION

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Memories are Made of This

8 tips for retaining and recalling information when you have HD

By Josh Martin

As Huntington disease (HD) progresses, it can feel as if someone has shuffled your mental filing system. Manitoba Resource Centre Director, Marla Benjamin, hears it all the time. "I've got a fog in my head," one client will tell her. "I know there's all these pieces and I just can't put them together," says another.

Everything is still there, but finding the information you want can take a frustratingly long time. Unlike Alzheimer's disease, where those mental files are actually lost, Huntington disease damages parts of the brain responsible for retrieving existing information and storing new information.

"Patients lose their ability to be able to multitask, often at the time when they are dealing with growing children, caring for their aging parents, and keeping up with daily routines such as shopping, not to mention their employment. This puts them into a very challenging, often anxiety-producing situation. Making decisions as to what aspect of all of these important things in life to start

to back away from is never easy," says Dr. Douglas Hobson, Professor of Neurology at the University of Manitoba.

That means seemingly simple tasks like making a sandwich, remembering why you popped out to the grocery store or learning how to use the new DVD remote become increasingly difficult.

Fortunately, there are a number of strategies that can help you put the mental puzzle pieces together, like these tips from Marla and her predecessor at the Manitoba Resource Centre, Sandra Funk.

Use organizational tools. Place a large monthly calendar in a central location to organize family events and appointments, and use daily planners and to-do lists to help keep track of your schedule. Consider colour-coding your calendar entries and to-do lists: for example, one colour for appointments, another for household chores, and another for family events. Pill organizers can help you keep track of your medications. Finally, get into the habit of writing lots of notes. Even if you never look at them later, just writing them can help you remember.

Create environmental clues. Add physical reminders to your surroundings to trigger your brain. For example, put everything you need to take with you in the morning on a table next to the door. Place post-it notes or signs around the house, such as a note on the door reminding you to lock it when you leave.

Leverage technology. There are gadgets for everything. Use them! Take advantage of tools like timers for meal preparation, kettles that shut off automatically and alarms on your watch, computer or smartphone for reminders.

Develop routines. Habits are very sticky. Whether it is placing your keys in the same spot by the door or following the same shower-shave-breakfast routine each morning, the more you can establish a predictable structure now, the easier it will be to recall down the road.

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SAVE THE DATE: HSC National Conference November 4th-5th, 2016!

Join us for an exciting weekend this fall at the HSC National Conference hosted by the Halifax Chapter! We are pleased to invite you to Halifax, Nova Scotia.

Conference Keynote Speakers include the usual suspects: Dr. Jeff Carroll and Dr. Ed Wild from HD Buzz, and Dr. Ray Truant, Chair of the HSC Research Council. This year we are pleased to introduce a new researcher, Dr. Tamara Maiuri, and a special guest speaker, Jay Ingram, a science broadcaster and writer.

Before the conference officially begins, YPAHD Day – a day created by and for young people affected by HD (YPAHD) – will be held on November 3rd. This day will be full of fun, networking, and information, with age appropriate streams for youth as young as 12. Join us in November as we transform tomorrow together!

The HSC Conference committee is working hard to make the 2016 Conference a success! For more information and to volunteer, please contact us at 1.800.998.7398 or email us at volunteer@huntingtonsociety.ca



Transforming Tomorrow Together

Our new campaign aims to raise an additional \$3 million to invest into discovery research so that researchers can build on recent advances. Our goal is to find treatments that reverse, slow, or prevent the progression of HD, faster and ensure we reach out to remote communities in Canada expanding our services reach every individual and family in Canada.

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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 30 and 45, and gradually worsen over the 10-25 year course of the disease. As yet, there is no meaningful treatment.

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

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Note from the CEO

In January, before we had begun sending out invitations to speakers for our national conference, I received an email from Dr. Jeff Carroll. He said he had been asked to speak at another conference in November, but he knew we would be holding ours that same month, and he wanted to make sure he did not miss it.

To me, that is what makes this Society special. We have such an incredible sense of community and commitment, and nowhere is that more clear than at our biannual conference.

I warmly encourage everyone to join us in Halifax on November 4th and 5th to reconnect, to meet new people and to learn from one another. (Rest assured, Jeff Carroll will be there, along with Ed Wild, Ray Truant, Tamara Maiuri and special guest, Jay Ingram, science broadcaster and writer, as well as many other wonderful speakers.) This is a conference you do not want to miss!

Of course, the conference is just one example of how our community comes together.

Recently, our focus has been on assessing proposals for the new "virtual networks" that we are funding in partnership with Brain Canada. The goal of these networks is to connect clinicians, scientists and patients to implement innovative research and expedite discoveries. Not only will they foster collaborations within the HD community, they will also create links to researchers investigating other diseases such as Parkinson's and Alzheimer's. This is an exciting time to be involved in HD research in Canada, and I am proud of how our community is leading the way.

At the end of April, we will be holding our fourth Be Brave, Be Bold, Be Ready: HD Clinical Trials Readiness meeting, convening clinicians, researchers and study coordinators from across Canada to share best practices. As we did in the fall, we have invited family representatives to the table, since the success of clinical trials depends on

the participation of people from the HD community. The value they bring to the table is helping us shape our national HD clinical trial strategy.

Following this meeting, we will launch our new public service campaign to increase awareness of HD and the Huntington Society of Canada, just in time for Huntington disease awareness month. We are incredibly fortunate to have many volunteers from our community participate in this new campaign. You will see some familiar and some new faces on this year's campaign, all of whom have spent countless hours assisting us in ensuring our message was powerful enough to capture the attention of Canadians who need, and want, to know about HD.

Meanwhile, we are gearing up for our next round of mentor training, ensuring more youth affected by HD have an older peer they can turn to for support.

Speaking of youth, a high school student recently asked me why Canada is the only G7 country that doesn't protect genetic information. It's a question that I ask myself every day. I am thrilled to see Senator James Cowan reintroduce Bill S-201, a bill that aims to prevent and prohibit genetic discrimination. Both Senator Cowan and I are cautiously optimistic that this year, his bill will pass.

Finally, we launched our new campaign, Believe: Transforming Tomorrow Together. Our goal is to raise \$3 million to fund more research and ensure that all Canadian families affected by HD have access to the services they need. Given the strength and commitment that characterize this community, I have no doubts that we will succeed. Thank you for your ongoing support. Like Jeff Carroll's, your commitment provides an incredible sense of community and it is through your efforts that our community grows in strength and numbers.

Bev Heim-Myers
Chief Executive Officer



Huntington disease research news.

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

For the global HD community.

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Lab Scribbles

Radical “open notebook” experiment promises to speed up HD discoveries

By Josh Martin

Behind every polished and peer-reviewed article that appears in a scientific journal lies a mountain of raw data, failed experiments and inconclusive results. Normally those messy details stay tucked away on computer hard drives or in overflowing filing cabinets. Not so with Rachel Harding’s work.

The Huntington disease (HD) researcher at the University of Toronto has traded her coffee-stained notebook for a public blog: www.labscribbles.com. As she helps decode the structure and function of the huntingtin protein, she will be uploading all her raw data and initial musings online. “This will be one of the first open lab notebooks that I am aware of for medical research,” she says.

Rachel’s work is part of a unique collaboration between the Cure Huntington’s Disease Initiative (CHDI) Foundation and the Structural Genomics Consortium (SGC), a not-for-profit partnership that includes nine pharmaceutical companies and more than 200 academic researchers around the world. Both organizations have agreed not to file for patents on anything that

comes out of their collaboration, as well as committing to make all their data – and their biochemical materials resulting from their collaboration – freely available to the broader research community.

In doing so, they are breaking new ground. Most medical researchers keep a tight lid on their results until publication. But Rachel sees huge benefits from open-access science, chief among them attracting more investigators to the Huntington disease field and speeding up the pace of discovery. “Rather than squirrelling away all data and not sharing it and competing with each other, it makes a lot more sense that we all work together,” she explains.

Dr. Ray Truant agrees. “This will give a unique first-person perspective on scientific discovery in real time, and let the public see the trials and tribulations of doing benchtop research; as well as get a real sense of the challenges and dedication that comes from these individuals on the front lines of drug discovery,” says the McMaster University biochemist, who chairs the Huntington Society of Canada’s Research Council.

A collaborative approach is especially valuable when it comes to understanding the huntingtin protein. Although scientists tracked down the HD gene in 1993, we still do not understand the function of the protein it produces. That is a mystery Rachel aims to shed light on.

Right now, she is working to pin down the overall shape of huntingtin. In the coming years, she will delve into greater detail, working out the interactions between individual atoms to develop a precise 3D model. That knowledge will give us insights into how the normal huntingtin protein operates and what goes wrong in the disease-causing version.

However, the size and complexity of the huntingtin protein makes it a tough nut to crack. “It’s not going to be an easy task,” Rachel predicts. “It’s a very, very big protein.” By sharing her work in progress, she hopes to attract insights and feedback from other investigators and encourage them to build on her results. “Having that network of collaborators is going to push things further, faster,” she says.

Down the road, that knowledge could lead to new targets for HD treatments. “The ultimate goal is to get effective drugs to patients in the shortest possible time,” says Robi Blumenstein, president of CHDI.

Don’t have a PhD in biochemistry? Rachel plans to preface each blog post on Lab Scribbles with an easy-to-understand summary of the day’s experiments, methods and results, so you can follow her progress without wading through technical jargon. To see her notes, visit www.labscribbles.com.

The Power of Connection

By Josh Martin

For some members of the Huntington disease (HD) community, connecting means sipping coffee and swapping strategies at a support group. For others, it is feeling the buzz of a national conference. And for many of our youth, it’s seeing a friendly text from their mentor when they need it most. Whatever form it takes, facilitating connections between families has always been one of the most important things we do at the Huntington Society of Canada (HSC).

No two HD journeys are the same. Every family dynamic is different, each person with Huntington disease experiences different symptoms, and every stage of the disease brings its own set of unique hurdles. However, members of the HD community share many similar emotions and challenges and

that means there are other people you can turn to who understand what you are going through.

One way to connect is through an HSC support group. Led by trained facilitators, these confidential meetings allow you to share stories and strategies, vent frustrations and draw strength from people who face the same struggles. “They don’t have to explain what the disease is,” says Angèle Bénéard, HSC’s Director of Family Services and Community Development. “It’s almost like, OK, I can breathe and just be me.”

For some people, connecting during one of HSC’s information nights or symposiums is a better fit. These events give people the chance to learn the latest information about HD and gain valuable skills. One session might focus on clinical trials, another on navigating the long-term care system.

And thanks to things like videoconferencing, we are finding ways to bring in national speakers and to connect families who cannot make it in person.

HSC’s National Conference takes things to a whole new level. This year, families, doctors, researchers and other experts will converge in Halifax on November 4th and 5th to meet old friends, make new ones, find out about the latest breakthroughs and get inspired by what others are doing across the country.

Fundraisers also help bring people together. Whether it is meeting up with friends to sell amaryllis, putting the pedal to the metal at an HD Go-Kart event or lacing up your running shoes for the annual Run for Huntington Disease, we offer many ways to connect with each other while making a difference.

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Making the Move:

How to successfully manage the transition to long-term care

By Julie Stauffer

Richard King did not want to move into long-term care. His mother, Marilyn, did not want him to leave. But Richard was falling more frequently, and after Marilyn had her hip replacement, she struggled to support him when he stumbled.

That is when their local Huntington Society of Canada (HSC) Resource Centre Director suggested the time had come. At first Marilyn resisted. "I didn't see it," she says. "You don't even know things have changed because you're dealing with it on a daily basis."

Ultimately, however, they faced facts. She and Richard reluctantly packed up his things and moved him to a nearby facility.

Because HD symptoms worsen gradually, it is easy to think you can keep managing at home. According to Angèle Bénard, HSC's Director of Family Services and Community Development, there are certain situations that should prompt a move.

The first situation is physical risk to the person with Huntington disease (HD) or other members of the family, like the Kings faced. The second is exhaustion. As a person with HD requires more help, caregivers can reach the point where they simply do not have the physical or emotional resources to keep up, especially if they are also

juggling a job and household responsibilities.

In addition, some folks choose to move before their HD symptoms become too advanced so that it is easier to adjust to their new environment. In Richard's case, moving when he could still communicate clearly gave staff the chance to get to know him better.

Angèle suggests visiting facilities and discussing choices well in advance to give everyone time to prepare. (Because many facilities have waiting lists, this increases the chances of getting into your home of choice.)

When moving day arrives, a few strategies can help smooth the transition. First, make the new space familiar. Richard has covered his walls with Egyptian paintings and photos from his trip to the pyramids. He has a large-screen TV to watch his favourite shows, and Marilyn brings their pet Sheltie, Sarah, to visit at least once a week.

If communication is difficult, a "life book" can give staff insights into the person behind the disease by describing his or her interests, career and family.

You may need to work with the facility's staff to establish appropriate routines. A 40-something resident with HD may not be happy going to bed at 8:00 pm, for example. Giving them a pair of headphones can allow him/her to watch TV without disturbing the other residents.

Finally, recognize there will be a grieving process for everyone in the family. The person with HD may be angry or anxious, and emotions may be expressed through behaviour. Meanwhile,



caregivers often experience a complex mix of relief, guilt and loss of purpose when they are no longer on call 24 hours a day.

Talk through and share those emotions, Angèle says, or use art or music to express them. It also helps to focus on the benefits that long-term care provides. The person with HD can take advantage of the facility's programs and stimulation, while caregivers can enjoy quality time with their loved one without worrying about meals, laundry, cleaning and other chores.

Marilyn admits the house feels empty without Richard. In her heart, however, she knows they made the right decision, and she could not be happier with Richard's facility. "It's a marvellous home," she says.

To learn more about transitioning into a long term care facility or how to start the conversation, talk to your HSC Resource Centre Director as every situation is unique. For a list of the HSC Family Services team, visit www.huntingtonsociety.ca.

Memories are Made of This

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Break it down. When learning something new, break the information or instructions into bite-sized chunks. Write the steps down and give yourself lots of time to practice them. Patience and repetition are key to getting new information to stick.

Avoid distractions. Need to make dinner? Switch off the TV. Trying to listen to a phone call with other conversations going on around you? Take it to a quiet bedroom. Reducing distractions helps your brain focus on the task at hand.

Adopt a healthy lifestyle. Regular exercise isn't just good for your body, it also benefits your brain. So hit the gym, head over to the pool or just take

a walk around the block. A diet rich in fruits and vegetables and lots of water can also sharpen the mind, while drugs and alcohol will dull it. Finally, treat your brain like a muscle and keep it fit with activities like reading, playing card games, doing puzzles and socializing with friends.

Go easy on yourself. When those puzzle pieces refuse to snap into place, it is easy to feel frustrated, angry or scared. Unfortunately, those feelings can further gum up the brain, making it even harder to recall information. Instead of getting wound up, take a deep breath and show your brain a little compassion.

This is just a sampling of strategies on improving memory. For more resources and ideas, talk to your neurologist or Resource Centre Director. For a complete list of Resource Centres in Canada visit www.huntingtonsociety.ca

Tips for Caregivers and Family Members

Incorporating cues into your questions makes it easier for someone with HD to find answers. So instead of asking "When is your dentist appointment?" ask "Is your dentist appointment this morning or this afternoon?" When you need to communicate something, break it into chunks and wait until you're sure one piece has sunk in before you move on to the next.

Believe



Transforming Tomorrow Together

By Julie Stauffer

HSC's Senior Manager of Donor Relations, Danielle Havelka, is packing her bags for a cross-country tour to meet with potential donors. Her message: together we can change the future of HD. Her goal: to raise \$3 million for *Believe: Transforming Tomorrow Together*, HSC's new campaign.

You only need to look at all the recent clinical trials and breakthroughs in Huntington disease research to see the difference that donations can make. "Things are moving so quickly right now," Danielle says. "We are on the brink of discoveries that will transform lives."

Already, early donations have begun rolling in, and Danielle couldn't be more excited. "Out of the gate we already have \$500,000 raised for this campaign," she says. "I'm absolutely thrilled."

Now we need to keep that momentum going.

Believe: Transforming Tomorrow Together aims to raise an additional \$1.5 million to invest into discovery research so that researchers can build on recent advances. Our goal is to find treatments that reverse, slow, or prevent the progression of HD, faster.

And as Danielle points out, it is not just the HD community that will benefit. HD research may hold important clues for other diseases like Parkinson's and Alzheimer's, making this a cause that all kinds of people have a stake in supporting.

In conjunction with raising \$1.5 million for research, we are also aiming to raise \$1.5 million to increase accessibility to support and services for the HD community. Although HSC has an excellent network of resource centres and family service workers across the country, we are still not reaching all the families in Canada affected by HD.

Every child, individual, and family deserves a safe place to land. More dollars will enhance our capacity to ensure everyone touched by this disease gets the support they need. We will use this funding to enhance our youth mentorship programs, expand outreach, develop new multidisciplinary clinics and continue advocating for genetic fairness. In particular, we will target services for young people, families in rural and remote areas, and under-served multicultural communities.

Help us make this campaign a record-breaking success. Spread the word, connect us with potential donors and keep the conversation going. Together, we can transform tomorrow.

For more information, visit the campaign page at www.huntingtonsociety.ca or contact us at 1-800-998-7398 or info@huntingtonsociety.ca.

An Ariel View

With Chris Taylor

As a change of pace, I have invited a few of the Society's stalwarts to share some of their favourite HSC memories. This time our contributor is Chris Taylor from Advance Printing. Chris recently merged his company, Highland Printcraft, a company the Society has relied on for many decades, with Advance Printing.



I know the Huntington Society through our family business, Highland Printcraft. My great-grandfather started the company. My grandfather worked there and so did my dad, and I started doing deliveries when I was 15.

At that time, the Huntington Society of Canada's office was on Water Street in downtown Cambridge, and it was up this big flight of stairs. I have to admit I did not always look forward to carrying all the printing deliveries up those stairs, but I was always impressed with how much was going on with all the staff and volunteers. It felt like there was a story going on in every room.

And of course there was Ralph Walker. Ralph made quite an impression on me, as I know he did on so many others. He was a really warm guy, and he was so kind to me. After all, I was just a kid who made deliveries. Ralph always took the time to ask how I was doing and was genuinely interested in what I was up to. None of our other customers did that; to them I was just a supplier, but Ralph, he treated me like a friend. And when I looked at the Society's publications, I could see just how many people he touched and the impact he made not only in Cambridge, but nationally and internationally. He was an impressive guy.

Later, when I was working on the printing presses, I'd see him come down to the shop and talk with my dad. My whole family loved him. You have all these influences as you're growing up, and for me, Ralph was one of the significant ones.

I was there for his funeral after he passed away. People came from across the country, and it was standing room only in the church. It was incredible. I looked at that and thought, "This was a life well-lived." It helped inspire me to volunteer for different causes and to try to bring a warmth and human connection to my business relationships. To me, that's what Ralph embodied.

A lot has changed over the years. It is just crazy the way the Huntington Society has grown. I remember when they moved their office to Kitchener in the early 2000s. They worried that it would be harder for us to work together because of the distance, but when I found out the new building had an elevator, I said, "Yes! This is going to work!"

Printing technology has changed a lot too. Earlier this year, I helped Ariel put together some HSC publications for her grandchildren's scrapbooks, and it really took me back. I remember printing most of them myself. At that point, we just had one and two-colour presses, and because they were three-colour jobs, I would have to run them through multiple times.

It's been over a year since Highland merged with Advance Printing, but we still work with the Society. Although it is a business relationship, it is so much more than that to me. To this day, the Huntington Society of Canada feels like family to me. I feel like I am a part of the HD team working to keep Ralph's legacy alive and ensuring those who are affected by HD have the services they need. It has been a privilege to be associated with such a valuable organization.

Have a story to tell about your involvement with HSC? We are collecting memories of the impact the Society has made over the years. Please share your story with us. Email us at info@huntingtonsociety.ca or call us at 1-800-998-7398. We will interview you, write your story and share it with our readers.



“I Am So Glad I Have You to Talk to” HSC welcomes the latest batch of youth mentors

By Josh Martin

A mentor’s phone vibrates on her nightstand. The text reads, “HEY, CAN WE TALK?” The possible conversations that follow are as diverse as the people in HSC’s Youth Mentorship program.

One young mentee might feel overwhelmed, having only recently discovered he is at-risk for Huntington disease (HD). A teenager might need to vent about her mother’s progressing symptoms. A young adult could find herself wrestling with questions of genetic testing and having babies.

Youth affected by HD face many challenges, and our mentors are there to support them. Comprehensive training equips mentors with the knowledge and active listening skills they need to offer mentees an empathetic ear. “[It’s] not telling somebody what they should or shouldn’t do, and

it’s not giving advice,” says Program Coordinator Erin Stephen. “It’s having a conversation, it’s about getting them the resources they need.”

Trust lies at the heart of those conversations. That is why our training puts so much emphasis on confidentiality. Unless someone’s health or safety is at risk, mentees can be assured that their interactions with mentors will stay between them. Not even Erin is privy to personal details about conversations. Although she holds regular check-ins with mentors, she uses that time to answer questions and make sure mentors can direct mentees to the right resources.

Interest in the program is growing steadily, with events like HSC’s expanded Young People Affected by Huntington disease (YPAHD) Regional Days that are helping to spread the word. In response, we are completing our third round of training later this month, welcoming a new set of mentors into the fold who are now ready to be matched. With mentors hailing from all walks of life and all corners of Canada, there is lots of room to welcome new mentees.

And they are having an impact. As one young person recently put it to their mentor: “Who would I talk to if you weren’t here for me?”

“That’s how I know we’re on the right track,” says Erin.

If you’re 12 years old or over and you would like to connect with a mentor who knows what it’s like to grow up in a family affected by HD, or if you know someone who would benefit from this program and want to learn more, contact us at 1-855-253-0215 or mentorship@huntingtonsociety.ca.



**YOUTH
MENTORSHIP
PROGRAM**

For more information, visit:
www.huntingtonsociety.ca

The Power of Connection

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The list goes on. The youth mentors provide peer-to-peer support for young people from HD families across Canada. The family services workers regularly get behind the wheel to visit clients in their homes. Meanwhile, the annual retreats forge strong bonds of friendship and show participants just how brightly they can shine. “Providing people with HD the opportunity to connect with other people that are living a similar experience is incredibly powerful,” says Jenna Shea, whose mother participated in a therapeutic retreat. “I cannot thank you enough for giving her this opportunity.”

The HD journey is a hard one, but you do not have to face it alone. There is strength in numbers and comfort in togetherness. That is why HSC will continue to do whatever they can to facilitate connections with this amazing community.

To participate in a HSC program or to connect with the HD community contact us at info@huntingtonsociety.ca or visit our website at www.huntingtonsociety.ca to learn more about support groups, events and information sessions offered by the Huntington Society of Canada.

Enroll!
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Disclosing Your Diagnosis

When – and how – do you tell your employer you have HD?

By Julie Stauffer

Cst. Mike Neill looked okay on the outside. Inside, though, Huntington disease (HD) was starting to take a toll on his short-term memory. The police officer knew it was no longer safe to be out on patrol. “This is not a place you can make mistakes,” he says. The time had come to tell his employer.

It is a decision that many people with HD have to face. And while Mike’s story had a happy ending – “I couldn’t have asked for better understanding,” he says – not everyone fares so well.

That means thinking through a lot of things before sitting down with your boss.

Assess your options

The first thing to consider is timing. Tell your employer too early and you risk getting passed over for promotion or even being asked to leave. Wait too long and your performance may start to slip. If your employer does not know the reason, you could find yourself out the door.

Next, assess your situation. How well can you still do your job? Fatigue, poor balance or difficulty walking might not be a big problem if you have a desk job, but they could pose a serious risk on a construction site. Meanwhile, planning, memory and concentration problems could be big liabilities in a fast-paced multi-tasking environment.

If HD is starting to interfere with your performance, one option is to take early retirement or go on long-term disability leave. That is great for folks who are happy to say sayonara to the 9-to-5 grind. However, before you pack it in, take a hard look at your finances. What kinds of benefits could you collect if you left today? Would working another six months, for example, make a big difference?

Others love the meaning that work provides, and many simply cannot afford to call it quits. In that

case, could you continue to perform your current job with a few accommodations? For example, would tweaking the physical environment make it easier? Would it help to work different hours or take more frequent breaks? Are there some responsibilities that could be modified?

If performing your current job is no longer feasible, could you switch to a different position within the same organization?

Mike knew he would not be happy sitting at home on the couch, but active patrol was no longer possible. That is why he chose to take a desk job. “I still enjoy coming to work,” he says. “It’s not police work, but at the same time, it’s stuff at the division that’s got to be done.”

Prepare for your conversation

Once you have thought through the different options, plan how you are going to break the news of your disease.

Chances are your employer knows very little, if anything, about HD, so rehearse a few key points. Mention that HD is a progressive disease, and there will come a time when you can no longer do your job, but emphasize that it progresses slowly.

Describe the symptoms you currently have, and how that affects your performance. At the same time, describe all the capabilities you still have.

While many employers will be supportive, it is smart to know your rights. Check your provincial employment standards and read through your employment contract. If you are unionized, talk to your union rep.

After your conversation, jot down a few notes about what you discussed just in case you are let go.

Develop an exit plan

Ultimately, no matter how accommodating your employer is, at some point your HD symptoms will force you to call it quits. That is why it helps to have an open discussion in advance with your healthcare team, family and employer so that everyone can recognize the time when it comes – and you can say goodbye with dignity.

Every situation is unique. We urge you to have a discussion with your HSC Resource Centre Director regarding your employment and your plan. We are here to help. For a list of the HSC Family Services team, visit www.huntingtonsociety.ca.

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Family Fund Partners: Barrett Research Fund; Bloom Family Fund; Rick and Norma Brock Fund; The Kelly Bumstead Family Fund; Chaplin Family Fund; Cranston-Dorr Family Fund; Annie J. Cutler Memorial Fund; Barbara Dorr Research Fund; Goodman Family Fund; Irwin Family Fund; Lembit and Karen Janes Fund; McArthur Family Fund in memory of Megan McArthur; Reklitis Family Fund; Garth Shuster Family Fund; Skene/Stevens Family Fund; Skeoch Family Fund; Sterling Family Fund; Wright Family Fund in memory of Helen-Mary Wright; Yeung Family Fund



Events Calendar 2016: Coming to your neighbourhood soon!

April

April 19 – 23

Niagara Book Sale

St. Catharines, ON
Fairview Mall

Semi-annual fundraiser, Tuesday to Friday 9:00am to 9:00pm, & Saturday 10:00am to 4:00pm. Jewelry, puzzles and CD/DVDs are always needed. For more information or to volunteer, call Gail at (905) 892-6024 or email gaildekoning@gmail.com.

April 24

18th Annual Architectural Gems of Toronto Walk

Toronto, ON

Starting location: Northeast corner of Carlton & Sumach in downtown Toronto. Registration 1:00pm, walking tours 2:00pm, social gathering 3:30pm at Peartree (507 Parliament Street). For more information, call Jim at (416) 809-2469 or email gems@hdtoronto.org.

Web: <https://secure.e2rm.com/registrator/startup.aspx?eventid=189859>

April 24

Walk for a Cure

Wawota, SK

For more information, please contact Joanne Corkish at (306) 739-2237.

May

May 14

Score ONE for the TEAM

Peterborough, ON
Peterborough Sport and Wellness Centre

Join us for the 8th annual Score ONE for the TEAM, 3 on 3 Basketball Tournament! Teams of 3 or 4 can register for the 18-team competitive division or 6-team recreational division. For more information, email score.one3on3@gmail.com.

Web: <http://score-one-for-the-team.com/>

May 14

A Night To Flourish

Calgary, AB
Sheraton Cavalier, 2620 32 Avenue NE

Hope for HD. Tickets \$125 featuring dinner, silent auction and a cash bar along with an impactful speaker discussing the latest in HD research. For tickets or more information, call Tara at (403) 861-5730.

May 14 – May 15

Leduc Barbecue

Leduc, AB

Enjoy some great food in support of Huntington Society of Canada! 10am to 4pm at Canadian Tire.

For more information, contact Joan jcallum@hotmail.com

May 19

5th Annual Race for a Cure

Ottawa, ON – Rideau Carleton Raceway

Join us at Canada's fastest 5/8 mile track for a fun night at the races including horse racing, a buffet dinner, silent auction and a chance to play the slots! For more information, please contact Sharon Haig at sharon.haig@sympatico.ca.

Web: <https://secure.e2rm.com/registrator/TicketingWelcome.aspx?eventid=193424>

May 27

4th Annual Sprint Into Summer

Pierson, MB – Pierson Firehall

Pre-register or register on event day after 4:30pm for this 5K or 10K walk/run. We will start at 6pm with a BBQ to follow. Fun family event! Contact Terri Alphonso (306) 339-7990 or leeterri@hotmail.com or Cindy Horrigan (306) 482-8151 or cindy@goodlandsenviro.com.

Web: <https://secure.e2rm.com/registrator/LoginRegister.aspx?eventid=193641>

May 27

Zumbathon

Newmarket, ON – The Move Fitness and Dance

\$20 in advance or \$25 at the door. Just come and enjoy, no pledges needed! Please email pszabo@kubota.ca for details or visit our website below.

Web: <https://www.facebook.com/events/690104044452635/>

May 28 & 29

Ottawa Race Weekend

Ottawa, ON

Here is your opportunity to join TeamHD and walk, run, or push someone in a number of road events, over a variety of distances, in downtown Ottawa while raising funds for HD. For more information, contact Sharon Haig at sharon.haig@sympatico.ca

May 28

Edmonton Walk to Cure HD

Edmonton, AB – Rundle Park, Site 5

The Walk is held at Edmonton's wonderful Rundle Park, in the northeast part of the river valley. Registration begins at 1:00pm, Walk begins at 2:00pm. No dogs please. Please contact Debbie at (780) 456-6886 or taylor3@telus.net for more information.

Web: <https://secure.e2rm.com/registrator/startup.aspx?eventid=189996>

May 28

Golfapalooza Classic 9-hole Tournament

Niagara Falls, ON
Niagara Falls Golf Course

10:00 a.m. shotgun start. \$50 for golf, cart, lunch, and prizes. Fun for all skills and interests! For more information, contact Barb Eade-Stainsby at beadestainsby@gmail.com or (905) 562-8939.

May 28

10th Annual Walk to Cure Huntington Disease

Peterborough, ON
City Hall

Registration starts at 9:00am. The Walk continues down George Street to Del Crary Park for BBQ, Bouncy Castle, games and prizes for kids. For more information, call Rob Laycock at (705) 202-1045 or email info@hdpeterborough.org

May 28

9th Annual Run to Finish Huntington Disease

Vernon, BC
Kin Beach Park

Options include 1 km walk, 5 km walk or run. Registration 9:00am, Run 10:00am. Food, fitness and fun with friendly people in a beautiful setting. For more information, call Dan at (250) 808-8072 or email hscokanagan@yahoo.ca.

May 29

Walk to Cure Huntington Disease

Bowmanville, ON
Bow Memorial Park

Registration starts at 10:00am. The Walk starts at 11:00am and is followed by lunch and entertainment in the park! For more information, call Bunny Clark at (905) 723-5262 or email durhamregionhd@gmail.com.

May 31

Light it Up 4 HD

Kelowna, BC
Spirit of Sail at foot of Bernard Ave on the Waterfront

Join us as the fiberglass Spirit of Sail sculpture is lit up blue for HD and Juvenile HD Awareness. Contact Laurie Williams (250) 546-9681 or lauriepwilliams@telus.net for more information.

Web: <https://www.facebook.com/HSCOkanagan>

June

June 4

10th Annual Hike for Huntington's

Exeter, ON
McNaughton Park

Hosted by the Knights of Columbus. Registration at the Pavilion at 9:30am. Hike starts at 10:00am. BBQ lunch to follow. Lots of fun activities like face painting, splash pad and bouncy castle! NEW this year – dress as your favourite hero! For more information, contact Herman at (519) 235-1558 or email Lindsay at lindsay.muller.13@gmail.com

June 4

Walk to Cure Huntington Disease

Lafleche, SK
Club 50, 181 Main Street

10:30am Registration, Walk at 11:00am, lunch and social to follow. Contact Marg at (306) 472-5756 or Betty-Ann at (306) 472-5766 for more information.

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.

June 4

Walk to Cure HD

Winnipeg, MB
Assiniboine Park, Conservatory Area
10 km run, 5 km run, or 5 km walk. On-site registration 8:00am, Start 9:30am. Pancake breakfast free for all participants. For more information, contact info@hdmanitoba.ca.
Web: www.hdmanitoba.ca



June 4

8th Annual Saskatchewan Walk to Cure HD

Saskatoon, SK
Meewasin Trail, University of Saskatchewan
Registration 9:30am, Walk 10:00am. For more information, call June at (306) 997-2052.



June 5

21st Annual Golf Tournament

Brandon, MB
Glen Lea Golf Course
Shotgun start at noon, 3 divisions of 2 teams, mens/ ladies/mixed. For more information, call Sandy at (204) 724-0534.



June 11

6th Annual Hope for a Cure for HD

Waterloo, ON
Waterloo Park
Join the Grand River Chapter, TeamHD, and the 2016 Running Challenge. Run for a reason!
Registration 9:30am, Run 10:00am, 5 km run/walk. For more info, email hdgrandriver@gmail.com.



June 18

Camrose Golf Tournament

New Norway, AB
Silver Creek Golf Course
For more information, please contact Rob Campbell at rcampbell@educ-county.com.



June 23-25

Niagara Barn Book Sale

Ridgeville, ON
377 Canboro Road
Something for everyone, including fill-up a bag for \$5! For more information, call Gail (905) 892-6024 or email gaildekoning@gmail.com.

June 26

Run for Huntington Disease

Toronto, ON
Wilket Creek Park
Options include a 10 km run, 5 km run, and a 5 km hike. Registration 8:00am, 10 km run 10:00am, 5 km hike 10:05am, 5 km run 10:15am. For more information, call (647) 238-6294 or email run@hdtoronto.org.



JULY

July 16

13th Annual Beach Volleyball Tournament for HD

Barry's Bay, ON
Barry's Bay Public Beach, Lakeshore Drive
Entry \$100 per team. For more information or to register a team, contact Melissa at (613) 756-3060 or melissamcquey@hotmail.com.

August

August 27

7th Annual HD Ride 4 a Cure Trail Ride

Grande Prairie, AB
Bring your horse, jump in a wagon, or just come down for a drink and dance the evening away! For more information, call Mack at (780) 897-8048 or email mack@jadecash.com.
Web: www.peacecountryhd.ca

September

September 11

Hike 4 Huntingtons

North Vancouver, BC
Lower Seymour Conservation Reserve
Registration 8:30 am, Entertainment & warm-up 9:15 am, Hike 10 am, BBQ 11 am. For more information, contact britishcolumbiahd@gmail.com or (604) 682-3269 ext. 6159.
Web: www.hike4huntingtons.ca



September 11

Indy Go-Kart Challenge

Mississauga, ON
Join us for a great day of family fun! Check in begins at 8:30am and racing goes from 9:30am to 11:00am. For more information, contact 1-800-998-7398 or events@huntingtonsociety.ca.



September 11

Indy Go-Kart Challenge

Winnipeg, MB
Thunder Rapids Fun Park, Headingley
Enter your family/team of up to 6 people for a great day full of fun and prizes! For more information, contact Vern at (204) 694-1779 or vbarrett@mts.net.
Web: www.hdmanitoba.ca



September 11

Indy Go-Kart Challenge

Windsor, ON
Zap Zone Family Fun Centre
Join us for a great day of family fun! Check in begins at 8:45am and racing goes from 9:30am to 11:30am. For more information, contact Paul at thebatemans@sympatico.ca or (519) 322-5924.



September 17

Niagara Chapter Couples Golf Tournament

Welland, ON
Pelham Hills Golf Club
1:00 p.m. start. Includes golf, cart, lunch, dinner and prizes. For more information or to sponsor a hole, contact Lynn or Rick at rminer2@cogeco.ca.



September 18

Chris Clayton Memorial Indy Go-Kart Challenge

Langford, BC
All Fun Raceway at Western Speedway
Join the South Vancouver Island Chapter for their first annual Indy Go-Kart Challenge! Registration begins at 8:00am, Go-Karting will be from 9:00am to 11:00am, and will be followed by a BBQ and prize presentations. For more information, contact Shena at (250) 516-6664.



October

October 2

Indy Go-Kart Challenge

Kartbahn
Halifax, NS
The Halifax Chapter will be having our 20th Indy Sunday Oct. 2 2016 at Kartbahn in Bayers Lake Park in Halifax. We look forward to building on the quarter of a million dollars raised for HSC since 1997. For more information, contact Jim at (902)576-5660 or email jimrussell@eastlink.ca.



October 19

Paul Paone 3-on-3 Basketball

Myers Secondary School
Niagara Falls, ON
For more information, contact John Stainsby (905) 562-8939 or stainsbyjohn@gmail.com

October 30

Niagara Marathon

Run between U.S.A and Canada over the Peace Bridge as part of TeamHD! For more information contact Judy Harding (905) 354-5744 or judyharding@cogeco.ca



Legend				
	TeamHD	golf tournament	Go-Kart Indy	HD Run/Walk

Be Brave, Be Bold, Be Ready: HD National Clinical Trials Readiness initiative.

By Cyndy Moffat Forsyth

On April 25th, the HD Consortium will meet for the fourth time in four years, to continue their focus on building a national HD clinical trial strategy. This meeting will centre on how to streamline the HD clinical trial start-up process in Canada and how we can work together with organizations like the Networks of Networks (N2) and Clinical Trials Ontario to help facilitate the change required to increase clinical trials in Canada. The meeting will include the results of the HD National Clinical Trials Recruitment Strategy, how to increase the number of HD clinics and clinical trial sites in Canada, and our Clinical Trials Mentors and Mentees, who will report on their progress to date, how the program is developing and what the next steps are for the program.

Over the past four years, HSC and the HD Consortium have been working hard to develop tools to help encourage clinicians to participate in Clinical Trials. Together, we have developed tools such as an HD Clinical Trials Checklist, an inventory of HD clinics across Canada, and an HD Clinical Trial map locator (found on the Huntington Society of Canada's website).

A major milestone was recently met with the publication of the National HD Preparation Guide for Clinical Trials in Canada. Partnering with clinicians from across Canada, HSC and the HD Consortium, we developed an HD preparation guide for clinical trials focused on a participant-centred approach. With input from clinicians, study coordinators, medical professionals and family representatives, the guide is a comprehensive overview of what is involved in starting an HD clinical trial. The preparation guide is available to all HD Consortium members and includes a participant-centred approach to recruitment and retention.

This first-of-its-kind collaboration is taking HD clinical trials to a whole new level, based on a national all-inclusive approach which includes family representation at each meeting.

The guide is available in hardcopy and on the Huntington Society of Canada's website to clinicians working with HD patients and who are interested in learning more about participating in HD clinical trials research. Contact info@huntingtonsociety.ca or call 1-800-998-7398.



Helping National Office Hum

By Josh Martin

Our dedicated staff and volunteers keep HSC's National Office humming. For some time now, participants in the Region of Waterloo's Experience Matters program have been key members of that team. Each year, the employment-training program arranges short-term placements in our office with volunteers like Lauren Singroy, who has spent several months with us.

Lauren was a huge help during her placement, handling everything from updating our donor databases, responding to phone calls, to developing a presentation for the previous HSC National Conference. By providing an extra set of hands around the office, the program helps keep our administrative costs as low as possible. Furthermore, it's a wonderful opportunity to get more people from outside the HD community involved in our mission.

The program is a chance for participants like Lauren to gain valuable references, job skills and real world work experience, all while supporting an important cause. "Everybody was just so welcoming and the atmosphere was so conducive to learning," says Lauren. "I felt really good being able to give back."

We're happy to report that after completing the Experience Matters program, Lauren secured a full-time job with Economical Insurance, thanks in part to her stint at HSC.

Leaving a Profound and Lasting Impact

By Cyndy Moffat-Forsyth

"Volunteers are the roots of strong communities. Just like roots are essential for trees to bloom, volunteers are essential for communities to bloom. Thanks to volunteers, our communities grow strong and resilient. Even the tiniest volunteer effort leaves a profound and lasting trace in a community, much like tree rings that appear over time." – Volunteer Canada

National Volunteer Week in Canada takes place April 10-16, 2016. This year, along with Volunteer Canada, we are celebrating the 12.7 million Canadian volunteers who are the roots of our strong community. The Huntington Society of Canada (HSC) is very grateful to all of the volunteers who chose to spend their time, skills and talents in making a difference locally, provincially and nationally.

National Volunteer Week is a time to express gratitude for what our volunteers do and for the enormous impact they have on HD families and HD research across Canada.

Join us in celebrating National Volunteer Week! Nominate a volunteer for a national award. Our awards will be presented at the HSC National Conference November 4 & 5, 2016 in Halifax, Nova Scotia.

The Huntington Society of Canada would like to thank each and every one of our volunteers across the country. We deeply appreciate your hard work & dedication. To nominate a volunteer for a Huntington Society of Canada National Award email us at info@huntingtonsociety.ca or call us at 1-800-998-7398 and we will guide you through the process.

NATIONAL VOLUNTEER WEEK

April 10 - 16, 2016

Volunteers are the roots of strong communities



Lighting It Up Across Canada (and Around the World!)

by Julie Stauffer

Think big. Think really big. This May, we have found a whole new way to create awareness about Huntington disease – one that combines spotlights, projectors and tens of thousands of LED bulbs with provincial landmarks from coast-to-coast.

Introducing #LightItUp4HD.

Last year, Jamie Walters discovered that volunteers had arranged to light up buildings in the U.S. in blue and purple: blue for HD and purple for juvenile HD. Inspired, he asked the CN Tower to follow suit.

They said yes, and on May 2, 2015, Canada's most iconic structure was illuminated in blue and purple. That single act reached 37,000 people around the world, thanks to the magic of social media, not to mention thousands upon thousands of Torontonians who passed the tower that night.

That, in turn, inspired us. This year, the Huntington Society of Canada is working with volunteers from across Canada to light up landmarks, all the way from B.C. Place in Vancouver to Halifax City Hall.

Imagine buildings, statues and monuments from sea-to-sea bathed in blue and purple throughout the month of May. Now imagine how much hope, awareness and visibility that could generate.

"We are trying really hard to get at least one place in each province," says Christina Steinmann, HSC's Communications Coordinator (who will be watching the results from home in May, as she is off on maternity leave).

But we are not stopping there. We are also reaching out to Huntington's organizations in Scotland, Ireland, Europe, and the US to make this a truly global event.

The campaign has generated all kinds of enthusiasm. Suggestions have poured into the HSC national office, while volunteers have stepped up to contact local landmarks. For a list of confirmed sites, visit our website at www.huntingtonsociety.ca and check the page often as more requests are in the works.

One of the volunteers who stepped forward is Allison. As soon as she saw last year's photos of the CN Tower, she knew she wanted to be involved. "It's just a great way to catch people's attention and start a conversation," she says.

To make the request process as easy as possible for volunteers, Allison helped pull together a package of information posted at www.huntingtonsociety.ca/lightitup4hd-may2016/.



Get ready to #LightItUp4HD in May 2016 as we illuminate monuments across Canada (and internationally!) for HD awareness month.

To see a list of confirmed sites, and for more information, visit: www.huntingtonsociety.ca

We are aiming to create a big splash on social media with #LightItUp4HD 2016, as well as attract the attention of traditional media. According to Allison, it is the HD community that will enjoy the greatest benefit. "You see buildings are being lit up around the world and I think it makes families feel more connected," she says. "You know other people are going through the same things."

Help us make this a global success. Share the buzz on social media. Check www.huntingtonsociety.ca to see what is happening near you. Then head out, take photos and let the world know what #LightItUp4HD is all about.

Double Your Donation



Give by **June 30th, 2016** and your gift will be matched dollar for dollar. Thanks to a generous donor, all gifts made in the spring campaign will have double the impact.

Visit huntingtonsociety.ca to get involved.

Are You a Supporter of the Huntington Society of Canada?

Interested in getting more involved?

HSC is now accepting nominations to its Board of Directors for vacancies beginning in 2016 and 2017. This national board includes 15 directors from across the country who combine enthusiasm for the work of the Society with expertise in one or more areas of business including law, fundraising, communications, strategic planning, media and human resources. If you, or someone you know, is interested, please let us know. There is a process that we follow, and expertise that we are looking for, but it starts with your interest. Forward your CV and Letter of Interest outlining your skills and experience to:

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

All nominations received by April 30, 2016 will be considered.

HD Photo Exhibit the Hottest Ticket in Town

By Josh Martin

You know your event is going well when you start to worry you might exceed the venue's legal occupancy capacity. But that was not the only clue that Meghan Andrews' HD photo exhibit was a hit. If you cruised past the silent auction table, you would find heated bidding wars for the hockey tickets, yoga sessions, artwork and other items on offer. Meanwhile, the conspicuous absence of dry eyes in the room highlighted the powerful effect of the Toronto photographer's work. "The vibe was really amazing," said Meghan.

Hosted at Toronto's Gladstone Hotel in 2015, the November 12th opening of Huntington Disease: Trials and Triumph Gallery Exhibition launched a 12-day photo exhibit capturing the resilience of families affected by HD.

The event marked the culmination of a project two years in the making. In 2013, undeterred by her own HD symptoms, Meghan took time away from her professional photography business to embark on an arduous cross-Canada tour. She traveled from coast-to-coast, capturing portraits of families affected by Huntington disease. The gorgeous black and white pictures were published in September 2014 as a photo book that celebrates the strength, courage and positivity of the HD community.

Meghan would need her own strength and positivity as she scrambled to get the exhibition ready. Fortunately, a local PR firm offered their services pro bono, helping her with everything from securing the Gladstone to figuring out flower arrangements to booking media spots. "They were a godsend," she says.

Given attendees' enthusiastic responses, it seems the Gladstone Hotel was one of the hottest tickets in town that night. "What an amazing, inspiring exhibition!" said one commenter on the event's Facebook page. "Congratulations on a wonderful night honouring those battling Huntington disease," said another.



Around 150 people happily bought tickets, with all profits donated to the Huntington Society. The event raised more than \$11,000. However, just as important was the awareness it created. While the HD community was out in force, the buzz around the exhibit also attracted people with no connection to HD.

The project garnered great media attention, including a two-minute segment on CityTV and a live-to-air interview with CBC Radio. Meanwhile, Meghan's opening remarks at the gallery hit all the right notes. "Everyone loved the speech," she says. "Considering I hated public speaking in high school, I think I did really well."

After all the hard work, November 12th was a bit surreal for Meghan. The night marked a special milestone in her journey, a journey that has taken her across the country, into the homes of HD families, and now, into the hearts of the people lining up to see her work. "It was amazing to see the final product," she says. "I kept pinching myself."

Meghan's photo book Huntington Disease: Trials and Triumphs can be purchased online at <http://www.blurb.com/b/5738114-huntington-disease-trials-and-triumphs>. All proceeds go to the Huntington Society of Canada.



31 Years Old and Gorgeous as Ever

By Julie Stauffer

Our amaryllis campaign first took root three decades ago, when Huntington Society of Canada's volunteers began selling bulbs to raise funds for Huntington disease (HD) research and services in 1985. It has been growing strong ever since.

Last year, not only did we raise more than \$115,000, we sold out even faster than in 2014. "That is truly an amazing accomplishment," says campaign manager Jeff Hoffman.

You do not have to look far to find the reason for that success: our volunteers. Some have been selling amaryllis for decades, some have picked up the torch from a friend or loved one. Some buy a case for themselves because the kits make such great holiday gifts, while others buy it for their employees.

Want to contribute to this year's success? We have lots of resources available for first-time sellers (and for veterans as well). And do not think you need to be an extroverted sales pro to do the job. We have sellers who simply put up flyers in their condo and wait for the phone to ring. Some sell via social media. One gentleman set up a table in his seniors' home, while another volunteer got permission to email her coworkers and sold close to \$3,000 worth of amaryllis as a result. Jeff salutes every one of them.

"Since the beginning, it has been about a group of passionate, committed volunteers," he says. Thirty-one years later, that is still the case.

Online orders start in May at www.huntingtonsociety.ca. If you'd like to join the team, contact us at amaryllis@huntingtonsociety.ca or 1-800-998-7398.

Making a Difference

Telus: The Generous Giant

By Josh Martin

After spending close to a decade in the non-profit sector, Jennifer Kirner never thought she would end up at a massive corporation. Then again, not all corporations are like TELUS, recognized in 2010 as the most philanthropic company in the world.

Jennifer now works as a Senior Manager of Community Affairs for the telecommunications giant, overseeing charitable giving programs. "We are very committed to giving back to the areas [where] we live, we work and we serve," she says.

In 2015, TELUS, their team members and retirees, contributed more than \$43.98M and volunteered over 830,000 hours of service back to their communities. TELUS' annual campaign allows employees to make donations through their payroll system, which TELUS matches dollar-for-dollar, doubling the impact!

TELUS leaves staff free to choose the causes that matter most to them. Meanwhile, handling the donations through payroll makes it a cinch for employees, who receive all their charitable receipts on their T4. The program also gives charities like HSC an administrative break, since only a single receipt to TELUS is required.

The matching program is just one way TELUS gives back. For example, their Dollars for Doers initiative makes donations to employees' charities of choice for every 50 volunteer hours they rack up.

That giving philosophy has a number of perks for TELUS as well. More and more, socially conscious consumers are seeking out companies whose values align with their own. The same goes for suppliers and business partners. Finally, an appreciative workforce tends to go the extra mile. "Happy employees are productive employees," says Jennifer. "Especially when they are supporting things that they are passionate about."

To learn more about employee giving programs and how to approach your employer, email us at info@huntingtonsociety.ca or contact us at 1-800-998-7398. To learn more about how TELUS gives back, please visit telus.com/community.



Know Someone Who Goes The Extra Mile?

Why not nominate them for an HSC National Award?

Awards Will Be Presented At the 2016 HSC National Conference in November 2016

Nominations Submission Deadline – May 4, 2016

Please visit www.huntingtonsociety.ca for more information.

Your Opinion Matters

Provide your feedback on *Horizon*

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

The survey will remain open until May 31, 2016.

Access it here:

<https://www.surveymonkey.com/r/2016Horizon>

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

Save the Date!

November 4 & 5, 2016

HSC 2016 National Conference

It's never too early to start thinking about the 2016 HSC National Conference. Hosted by the Halifax Chapter of the Huntington Society of Canada, we invite you to join us in Halifax, Nova Scotia on November 4 & 5 so we can transform, tomorrow together. This year's conference will be held at the Holiday Inn Halifax Harbourview in Halifax, NS. For more information or to register, contact us at 1-800-998-7398 or email us at events@huntingtonsociety.ca or visit www.huntingtonsociety.ca

Conference Featured Speakers Include:



**Dr. Ed Wild,
MRCP, PhD**

Ed is a Clinician Scientist at UCL Institute of Neurology, London, and a Consultant Neurologist at the National Hospital for Neurology and Neurosurgery. Ed

studied medicine at Cambridge University and has worked in neurology since 2005. He now leads a team at UCL's Huntington's Disease Centre focusing on clinical trials of new HD treatments and studying cerebrospinal fluid to understand HD. He has authored 6 books and over 40 peer-reviewed scientific publications. Since 2009, he has been collaborating with Dr. Jeff Carroll to make HD research news accessible to the global HD community through HDBuzz.



**Dr. Jeff Carroll,
PhD**

Jeff Carroll is a scientist studying HD as an assistant professor at Western Washington University. As a post-doctoral fellow in the lab

of Marcy MacDonald at Massachusetts General Hospital, Harvard Medical School, he completed his PhD under the supervision of Michael Hayden at UBC in Vancouver. His research is focused on understanding the links between metabolism and CAG-expansion in the huntingtin gene. As well as conducting research, Jeff is a member of an HD family and himself carries the mutation which causes the disease. Jeff also co-founded and serves as co-editor-in-chief of HDBuzz.net with Dr. Ed Wild.



Dr. Ray Truant

Dr. Truant has been with McMaster University since 2000. He has been the recipient of the CIHR New Investigator Award 2001-2006 and is a Fellow of the Howard Hughes

Medical Research Institute, Duke University 1996-1999. Dr. Truant achieved his PH. D in Toronto, at the C.H. Best Institute of Biomedical Research and is supported by CIHR and CHDI Inc. His career to date includes over fifty career manuscripts. Dr. Truant was a recipient of the Queen Elizabeth II Diamond Jubilee Medal for public service in 2012, and is now a full Professor at McMaster University and Chair of the Research Council for the HSC, as well as, External Scientific Advisor for HDBuzz.net.



**Dr. Tamara
Maiuri**

Dr. Tamara Maiuri is a research scientist and postdoctoral fellow in Dr. Ray Truant's group at McMaster University in Hamilton, Canada. Prior to joining the

Huntington disease field, Tamara obtained her PhD from the Medical Biophysics Department at the University of Toronto where she studied the cell biology of cancer-related genes. Her work in the Truant lab focuses on the normal biological functions of the huntingtin protein in hopes of understanding how they may be disrupted upon inheritance of the mutant huntingtin gene that causes HD, and how they may be restored by small molecule drug candidates.

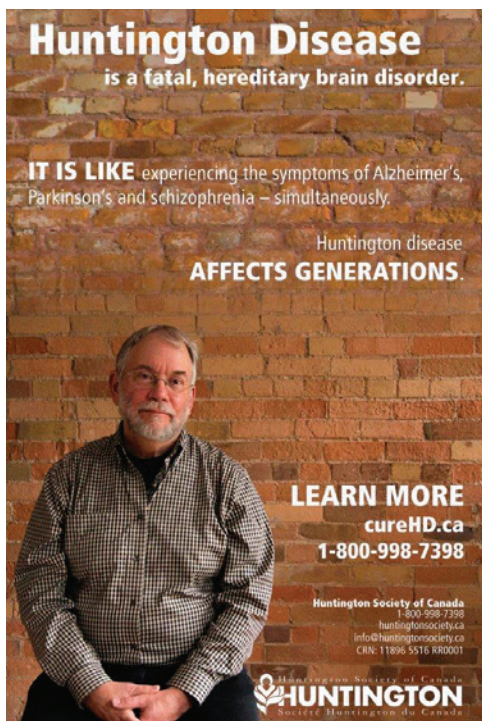


Jay Ingram

Co-host of Discovery Channel's science show, Daily Planet, for 16 years, science broadcaster and writer Jay Ingram has earned two ACTRA Awards over the course of his career, including

one for Best Host. He has also hosted The Talk Show, a series about language, for which he won a Science in Society Journalism Award. For his efforts to popularize science, Jay was awarded the Sandford Fleming Medal from the Royal Canadian Institute in 1984 and the Royal Society of Canada's McNeil Medal for the Public Awareness of Science in 1997. In 2000, Jay was awarded a Michael Smith Award for Science Promotion by the Natural Sciences and Engineering Research Council of Canada. Jay has also written 13 books and is the 2015 recipient of the Walter C. Alvarez award for medical writing given by the American Medical Writers Association. He is currently a columnist for Canadian Wildlife magazine.

For further details on the 2016 HSC National Conference, visit www.huntingtonsociety.ca/events



Increasing Awareness Takes Many Shapes

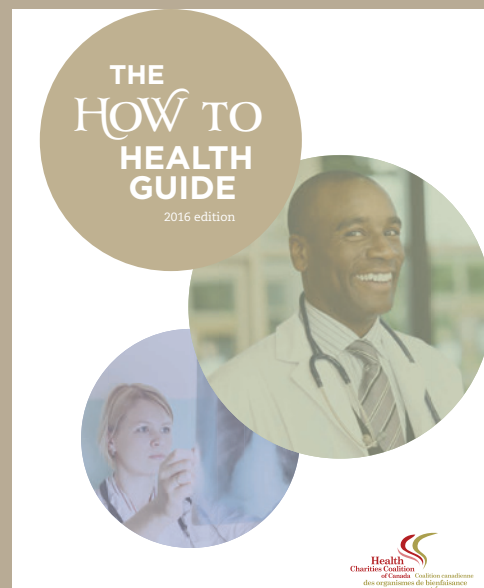
By Cyndy Moffat Forsyth

Raising Huntington disease awareness in Canada can sometimes feel like a daunting task. That is where public service campaigns can come in handy. Broadcasters across Canada open up their airwaves to help charities, like the Huntington Society of Canada, raise awareness for their causes. On May 1st, just in time for Huntington Disease Awareness month HSC will launch a new PSA campaign. The campaign features volunteer members of the HD community and partners with Eli and the Straw Man, a musical project made up of

seasoned musicians out of Canada's Niagara region, and fronted by songwriter, lead vocalist, and guitarist, Eli Maiuri.

The Society is extremely grateful to those volunteers who agreed to participate in this year's campaign. It is a true testament to the commitment and dedication of our community that members of the HD family would participate in a national public service campaign and share their stories.

Eli & the Straw Man is partnering with the Huntington Society of Canada and will be touring in the spring of 2016 to promote their album and to raise awareness about Huntington disease. To learn more about the 2016 tour, visit www.huntingtonsociety.ca and watch for our new campaign this May.



How To Health Guide

If you or someone you love and care for is trying to find health services, support or information for an illness or disease, there are actions you can take to help get the best possible care. Check out the How To Health Guide from the Health Charities Coalition of Canada by visiting www.huntingtonsociety.ca. It is posted on our resources page under the Family Services section.

Resurrecting hope:

Senator Cowan re-tables his genetic fairness bill

By Julie Stauffer

Last year, genetic fairness advocates were bitterly disappointed to see Bill S-201 gutted during Senate committee hearings. The bill, which aimed to outlaw genetic discrimination, then died when the federal election was called. But its author, Senator James Cowan, has not abandoned his efforts.

"Canada needs genetic fairness legislation," he says. Today, Canadians can scrutinize their DNA for a predisposition to hundreds of diseases, ranging from celiac disease to cystic fibrosis. In some cases, that knowledge opens the door to prevention and treatments. In the case of the HD gene, it can help you plan for the future and qualify you for clinical trials.

However, it also opens the door to discrimination.

"There is no protection against the use or misuse of genetic information," Senator Cowan explains. "Insurance companies can demand you take a genetic test to qualify, while employers can fire you because of your genetic status. This isn't just a theoretical problem," he says. "It's a real problem which affects all kinds of people."

That is why he re-tabled Bill S-201 on December 8, 2015 and this time, he is optimistic it will pass. The signs are promising. We have a new government in power, senators of all political persuasions are voicing support, and the Senate has a window of opportunity to move the bill forward before it gets swamped with government business.

If the bill becomes law, it will protect the privacy of your genetic test results, as well as your right to refuse to take a genetic test.



According to Senator Cowan, we could not have gotten this far without the sterling efforts of the Huntington Society of Canada's CEO, and Chair of the Canadian Coalition for Genetic Fairness, Bev Heim-Myers. Now, he says, we have to keep up the pressure.

To find out how you can support Bill S-201 and spread awareness about genetic discrimination, visit the Canadian Coalition for Genetic Fairness at www.ccgf-cceg.ca/en/take-action.

Celebrating Our Heroes

The Cream-Smeared Heroes at Hydro One

By Julie Stauffer

When you have spent 38 years with the same employer, your co-workers become family. So although Cindy Moore retired from Hydro One to care for her daughter, who has juvenile Huntington disease (JHD), her former colleagues did not forget her.

When they heard Cindy was raising money for Huntington disease research and services through a "Pie in the Face" challenge, they lined up to participate.

"It was definitely a no-brainer," says Emily Farrell, who worked with Cindy at Hydro One's office in Perth, Ontario. "We didn't think twice about wanting to help and show her our support."

On September 30, 2014, 17 employees and managers gathered outside the office, pie plates in hand and shower caps in place to protect their hairdos. One after the other, amidst gales of laughter, they smeared each other's faces in a massive cream pie chain reaction. One former staffer went even further, shaving his head to drive up the donations.

All told, this single one time event raised \$1,500. But their generosity did not stop there. Cindy's former union representative took it upon himself to contact Hydro One unions across Ontario, raising additional funds.

According to Emily, who sits on Hydro One's Charity Trust committee – that is simply the workplace culture at Hydro One. "We do really enjoy giving back to the community," she explains. "Most years we raise over a million dollars for local organizations."

Their latest fundraising initiative, initiated and introduced by fellow HD community member and Hydro One employee Jaclyn Skinner, is selling reusable water bottles and coffee tumblers, with a portion of the proceeds going to HSC. Between July and October 2015, sales added another \$2500 to Hydro One's contribution. When Cindy

stopped by the office for the annual Christmas party, she saw a water bottle on almost every desk.

"I was in tears," she recalls. "This awareness that has been raised and the amount of money that has been raised is beyond amazing." Altogether Hydro One has increased awareness and contributed funding through a variety of workplace events.

Hats off to everyone at Hydro One who supported their colleagues – and a great cause! We are very grateful for your support.



Donate2Celebrate!

More and more people are donating to celebrate special events such as birthdays, anniversaries, weddings or holidays in lieu of giving gifts. Each year, many people ask for donations to be sent to HSC in lieu of gifts and that number is growing. To help you direct donations for your special occasion, HSC is pleased to announce our Donate2Celebrate program.

It's quick and easy to participate. Follow these three simple steps.

1. Create an event on our celebration page.
2. Share your unique celebration link with your friends, family and social media contacts.
3. Watch your individual thermometer track the donations as they come in.

For more information, see our Donate2Celebrate page at www.huntingtonsociety.ca/Donate2Celebrate or call us at 1-800-998-7398.

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.