

HORIZON

RESEARCH • SERVICE • EDUCATION

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Youth Rally Together for Support and to Learn More About a Disease that Impacts Them All

Often we say it takes a village, well in this case it takes a village of youth who are determined to create something special, something that will last, something that will bring support and strength. This past November, the youth Chapter of the Huntington Society of Canada, YPAHD, did just that; they rallied together to provide each other with strength and support. On November 21, 2015, youth from across Canada joined together to learn more about how they can create deeper ties to one another, offer each other support when times get tough and celebrate those phenomenal moments in life.

Since 2008, Young People Affected by HD (YPAHD), the youth Chapter of the Huntington Society of Canada, has hosted a one-day youth conference, attached to the HSC National Conference. Aly Hughes, of BC and a member of YPAHD since 2012, attended the first YPAHD Day in Toronto. "It was a bit intimidating," Aly remembers. "There were a lot of people. But it was interesting to hear different people's experiences with HD. I felt like my story was so similar to others, and I didn't feel like I was alone anymore."

Based on the overwhelming response, the Society decided to branch out and create YPAHD Regional

Days. "There is a need in the HD community for more education, greater support, and it's important to cultivate connections between youth and the HD community," says Angèle Bénard, Director of Family Services and Community Development.

Catherine Price, from Newfoundland, joined in on the fun this year as well, in Halifax. "I really wanted to connect with other people who were in the same kind of situation as myself," she explains. "That is what motivated me to get involved with YPAHD in the first place," and her experience paid off. Catherine is now a mentor and a YPAHD leader, helping others as they navigate their way through the HD journey.

When asked about the Regional YPAHD Days, President Jaclyn Skinner responded, "I'm really, really, excited about how this year's YPAHD Days went. I think we cannot underestimate the importance of connecting face-to-face as often as possible, to stay motivated, be inspired and to remember what, and who, we are fighting for. It's an incredible feeling, and I'm honoured to be a part of a group of such strong and hopeful young people who are so determined to change the HD world."

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Believe

HSC National Symposium 2015

On Saturday, October 17th the Huntington Society of Canada hosted the 2015 Yes, I Believe: National Symposium. Whether people joined from home via the Internet or attended one of the 13 sites across Canada, everyone learned more about the latest news of potential treatments, how drugs move from the lab bench to the medicine cabinet, and what you need to know to sign up as a study volunteer. This was one event that people did not want to miss.

What does this mean to me: A participant perspective.

President of YPAHD, Jaclyn Skinner interviewed neurologist Dr. Mark Guttman, from the Movement Disorders Clinic in

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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

It's always wonderful to kick off a new year with some great news. So, it is with great honour that I announce new funding for research – \$2 million for HD research: \$1 million from a very generous donor, matched dollar-for-dollar with a grant from Brain Canada.

Our challenge was to decide how we could create the biggest impact from these funds. We know treatments lie around the corner. However, when you're diagnosed with a fatal illness, every day counts. That's why we are launching a transformational research program to expedite effective HD treatments. It is an initiative that will break down silos, creating virtual networks that connect clinicians, basic scientists and the HD community.

Of course, we are continuing all our existing efforts to accelerate clinical trials. Last October, we held our third clinical readiness meeting, bringing together 22 clinicians, researchers and family members to accelerate the pace of clinical trials in Canada. Meanwhile, in October, our Fall Symposium on clinical trials attracted several hundred participants. Many joined us at one of 13 locations across Canada, while others participated online.

We followed that with our "I Believe" YPAHD Regional Days in November, held simultaneously in Calgary, Toronto and Halifax through videoconferencing links. It was the first time the event was held outside of our National Conference – but given the enthusiastic response, I promise you it won't be our last!

Finally, this fall also saw Canadians at the polls. Now, with the new federal government in place, we are gearing up to make genetic fairness legislation a reality in 2016.

Suffice to say, it's going to be a busy – but exciting – year! All of which could not be done without our dedicated community. Thank you for walking side-by-side with us; we are transforming tomorrow, together.

Bev Heim-Myers
Chief Executive Officer

The Unstoppable Pearces: Hanging in Together

By Josh Martin

On an adventure in the Rockies, the Pearce family came to a sign at the base of Whistler. Bob, Dorothy and their kids Christina and Tim took a moment to consider the warning, which advised tourists that there would be no reimbursement of charges if you chose to advance up the mountain in the cable cars. Dorothy expressed some doubts when Bob, Christina and Tim suggested she could climb Whistler and meet them at the peak. They kept going, all together, in the cable cars. If you know the unstoppable Pearces, that won't surprise you.

In college, Bob was part of the survey crew during the construction of the Dempster Highway from Dawson City to Inuvik, across the Arctic Circle. He flew small planes and ultralights – until crashing in a field made him reconsider



Dorothy, Tim and Christina Pearce

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Huntington disease research news.

In plain language.
Written by scientists.

For the global HD community.

Go to www.HDBuzz.net to see
what the Buzz is all about!

Meet the Courageous Leaders of our Community

Personal perspectives on getting involved in clinical trials



By Julie Stauffer

Tim Irwin

Today, there are six different clinical trials and observational studies running in Canada and more expected soon. That means plenty of opportunities to get involved in research, whether you're at-risk, gene positive or symptomatic.

Of course, deciding whether or not to sign up is a very personal choice. We talked to three participants about the pros, the cons and why they ultimately decided to step forward.

"For my children and my grandchildren"

Brampton's Pat AuCoin started signing up for research studies after she tested positive for the HD gene in 1994. Her motivation was simple. "It might maybe, just a tiny bit, help me," she says. "But my bigger concern would be helping my children and my grandchildren."

Over the course of half a dozen observational studies and clinical trials, Pat has undergone CAT scans, PET scans and MRIs. She has done all kinds of psychological tests and neurological tests and swallowed various pills.

Last year she finished 2CARE, a trial that involved taking eight coenzyme Q10 pills – "horse pills," she calls them – every day for five years. Not long after she finished, researchers announced they were stopping the trial early because the drug wasn't having an impact.

So when her neurologist asked if she wanted to join a new drug trial – Pride-HD – her first instinct was no. "I said 'whoa, whoa, I need time off here,'" she recalls. "I don't want to do any more

research." After she got home, however, Pat had second thoughts. She asked the clinic to send her the paperwork, she asked them questions and, last January, she signed up for the trial.

Pride-HD tests pridopidine, a drug that researchers believe might improve HD symptoms. And while Pat doesn't officially know whether she's taking a placebo or the real thing, she has noticed an impact. "It's improved my tremors," she says. "I've noticed my short-term memory has greatly improved, and I'm not wobbling when I'm standing up."

Stepping up to find answers

Tim Irwin has lost count of the number of trials and studies he has been involved in over the years. Whenever a study comes along that he qualifies for, he says yes.

Like Pat, he participated in the 2CARE trial – and was similarly disappointed when researchers pulled the plug early. "It was a bit of a bite in the you-know-what," he admits. "But this is why we do these things. We've got to figure out what doesn't work."

That's why he recently enrolled in LEGATO, which is looking at the effects of laquinimod on movements, memory problems and emotional disorders. "This could be it," Tim says. "This could be the one."

And if it's not, well, he'll just sign up for the next trial and the next one after that until we find effective treatments.

An Ariel View

With Inge Dodds



I have invited some friends to share their memories of the Society's early days. In this Memory Story, Inge Dodds, recalls a few personal moments of the past 42 years. Let me know if you enjoy these stories, I am certainly enjoying re-living some fabulous memories.

One of the couples I remember from the early years was the Dodds. Dr. Jack Dodds was a family physician in Streetsville, Ontario. His patients came to the Mississauga hospital where I worked, so we did rounds together on several occasions. Well, imagine my surprise when I saw him at a Huntington Society meeting. It turned out that his wife's family was impacted by HD, and his wife, Inge, became the Society's contact in Streetsville for many, many years. I've invited Inge to share some of her memories of those days.

My mother first started showing symptoms of HD when our family was living in Denmark. At that time we didn't know it was Huntington disease. My mother was adopted, and so of course her adopted family had no history of HD. It wasn't until we moved to Canada that she was diagnosed. That was in 1978, only a few years after the Walkers started the Society.

I remember we got in touch with Mr. Walker, and he very kindly came and talked with us. I can't say that he painted a rosy picture of the disease, because you can't, but he was very informative and kind.

I started holding meetings at my home for other families in the area. I think when you're dealing with something that changes your life the way HD does, it helps to talk to people with similar experiences.

I went to several conferences to hear about the research, since we couldn't turn to the Internet in those days. And for many years we organized a Huntington Society float in the Streetsville parade every summer to raise awareness.

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Meet the Courageous Leaders of our Community

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“If you don’t try, you’re not going to know”

Last year, Cindy Moore’s daughter Erin Wade was looking forward to joining a trial for a drug that might help control her movements. The 23-year-old had completed the screening and gone through all the paperwork – “over a hundred pages,” Cindy recalls. Then, on the day of her first appointment, she had a seizure that disqualified her.

“For each trial there is different criteria,” Cindy explains. “It can be based on the current drugs you take, your age, your CAG repeat count, what stage of the disease you are in, plus many more.” In order to be approved to participate you have to meet all the criteria that has been set forth for that particular trial.

She had to wait until she had gone six months without a seizure before she was eligible again. Those six months are now up and Erin is hoping to start the LEGATO study as soon as it begins running in Ottawa.

Laquinimod has already been tested for multiple sclerosis, with some promising results. Cindy realizes that’s no guarantee the drug will help Erin. But as she points out, if you don’t try, you’re not going to know.

Regardless of the outcome, participating in a trial means Erin will see an HD specialist more frequently and can call the clinic at any time if she has questions. “It’s kind of like having a whole team of doctors right beside you all the time,” says Cindy.

“We do have to be cautious,” says Angèle Bénéard, Director of Family Services and Community Development. “Not all clinical trials will be available in everyone’s immediate area. It’s best to check with your HD Resource Centre Director or with your neurologist”.

And if the drug does work, Erin can continue taking it without waiting for it to be approved by Health Canada, – a process that can take several years. This is not always the case as safety is the number one priority.

Going in with your eyes open

Each trial and study is different, but there are a few things you can count on. Lots of paperwork is a given. There may be a preliminary assessment that could involve CAT scans, MRIs, EEGs or blood work.



Cindy Moore and Erin Wade

The time commitment can range from one visit a year to one a week. Travel may also be required. In some trials, the drug company will cover travel expenses to ease the financial burden, but you’ll still need to decide whether you can afford the time required. There is lots to think about when considering participation – child care, travel, being away from work.

You also need patience. It takes time for study sites to recruit enough participants, and you may be waiting several months before researchers can draw any conclusions and report back on the results.

The bottom line

Clinical trials don’t come with guarantees. You might get the placebo, or you might get a drug that doesn’t work. Even if the drug does work, you might receive an ineffective dose. And, of course, there’s always the risk of side effects.

“You never know,” says Cindy. “But if we don’t do it, then we’ll never find a cure.” Tim agrees. Look at the numbers, he says. Because Huntington disease is relatively rare, researchers don’t have a big pool of potential participants to draw from. When you consider that each study has specific eligibility requirements, the pool shrinks even further.

That’s why Tim encourages everyone who qualifies for clinical trials to participate. “We really need you to step up,” he says.

Potential Clinical Trial Questions to Ask

Before you sign up for a trial, talk to your neurologist or trial coordinator to make sure you understand exactly what’s involved. Here are a few questions to get the conversation started:

- What impact do researchers think this drug could have on Huntington disease?
- What kind of tests and treatments are involved?
- What are the possible side effects?
- If I have questions during and after the trial, who can I speak to?
- Will the treatment prevent me from working or participating in regular activities?
- Where is the clinical trial located?
- How long will I be in the trial?
- How often will I have to come to the clinic?
- Do I continue to see my regular neurologist?
- What costs might I incur?
- If the results are promising, will I have access to the drug after the trial?

(Adapted from the National Cancer Institute)

*The Huntington Society of Canada (HSC) recognizes that some individuals at-risk for HD may choose not to participate in clinical trials, due to geographical location or because of genetic discrimination. Genetic information is not protected in Canada. Genetic test results can be used to the detriment of an individual by insurance companies and employers in Canada. The Society is advocating for genetic fairness in Canada; however, at this time, protection is not in place. Choosing to participate in clinical trials is a **personal decision**; the Society encourages those who are interested to consult with their HD Resource Centre Director or Family Service Worker to understand all aspects of this decision.*

To learn more about clinical trials please visit the Society’s website, www.huntingtonociety.ca. You will find a host of resources including an interactive map of clinical trial locations in Canada, questions to think about when considering a clinical trial and lots more. For those who are unable to participate in clinical trials visit Enroll-HD at www.enroll-hd.org. It is a resource for the entire HD community, including patients, families, patient advocates, clinicians and other healthcare professionals, researchers, and anyone else who has a connection to HD.

Continually Improving our Rural Reach

By Josh Martin

Elaine Smith's odometer gets a serious workout. As the HSC Resource Centre Director in Newfoundland and Labrador, criss-crossing the island to visit families in small communities involves some mega mileage. "The last trip I did, I traveled 1,800 kilometres," she says.

At HSC, we recognize that living in a remote area compounds the challenges of HD. Whether it's the debilitating sense of isolation, lack of access to neurologists and other healthcare professionals or the financial burden of driving hundreds of kilometres to participate in a clinical trial, many families living off the beaten path face barriers their urban peers might not.

That's why our family services team regularly gets behind the wheel. But to reach as many people as possible and maximize the impact of our family services dollars, it's crucial we find other, creative ways to serve rural and remote clients.

The World Wide Web

Thanks to the digital revolution, we can now engage individuals and families affected by HD through a host of electronic channels. The Internet is a perfect example. In addition to our website and electronic newsletters, HSC uses Facebook, Twitter and YouTube to ensure the latest and most relevant information is just a mouse click away.

That information is no longer only in English. We've been steadily adding French-language material to our website. Meanwhile, the Huntington Society of Quebec has worked with a genetic counsellor to develop online Innu-language material for a First Nations community on the north shore of the St. Lawrence River.

Digital technology is also bringing the HD community together in new ways, helping reduce the isolation many rural clients face. Take HSC's youth chapter, YPAHD, for example. Whether young people affected by HD are living on a farm in the Prairies or a First Nations community in Nunavut, they can now connect with each other from coast to coast to coast via this virtual group. HSC's Youth Mentorship program builds on this model, offering peer support through texts and Skype, regardless of geographic location.

Videoconferencing

In places like Northern Ontario and Saskatchewan, we're taking advantage of the increasing number of clinics and care centres that are now equipped with videoconferencing rooms. Using high-definition cameras and speakerphones, the

technology allows patients, staff and medical professionals to meet face-to-face over secure and private connections.

"That opened up a whole other door for me to be able to meet with families in different communities throughout Northern Ontario," says Family Services and Community Development Director, Angèle Bénard, who previously served as our Resource Centre Director for Northern Ontario.

Dr. Mark Guttman agrees. Thanks to Ontario's telemedicine program, the Toronto-area neurologist has been able to attend to HD patients in underserved areas from Sault Ste. Marie to Attawapiskat. Francine Robert, genetic nurse and clinic coordinator, HSC's Northern Ontario Resource Centre Director, local physicians or nursing home staff can all be included in the conversation. "The telemedicine program is very unique and wonderful," he says.

Community education

The need for Dr. Guttman's support highlights a common problem many remote communities face: access to service providers. The nearest neurologist can be hundreds of kilometres away, and the few doctors that are in the area often don't have much experience dealing with a rare disease like Huntington disease.

Continuity is another challenge. Short-term placements in rural and remote areas are common for medical professionals, which can mean a

revolving door of doctors and other care providers. "Unfortunately, the turnover rate is pretty high, so folks often have to start over," says Angèle. To help those professionals serve clients with HD better, HSC continues to develop educational packages and resources that can be offered through video-conferencing.

Old-school communication

Of course, not all rural and remote families have access to videoconferencing or even the Internet. And sometimes an old-fashioned phone call or face-to-face conversation over a cup of tea is still the best way to connect. That is why Elaine and the rest of HSC's Family Services Team continue to mail out information, pick up the phone and get behind the wheel.

Closing the gap

Expanding and improving service to rural, remote and First Nations communities is one of HSC's strategic priorities. We've made some great strides in the right direction, but we're keen to continue working with families and service providers to identify barriers and find solutions. "Share those ideas with us and let's see how we can build on that and what we can make happen," says Angèle.

Rural Outreach is high on our strategic agenda and we'd love to hear from you. Contact us at info@huntingtonsociety.ca or at 1-800-998-7398 about how we can improve our rural reach.

An Ariel View continued from page 3

As soon as the testing became available, I went. Finding out I was negative felt as though the curse I had been living with for so many years had suddenly been removed. I cried out of happiness.

Of course, the story didn't end there. I had four siblings, and my two younger sisters both developed HD. It was terrible to see them deteriorate.

They were such beautiful individuals, inside and out. Sigrid (Sisi) was an artist and Gudrun was a nurse. Gudrun kept working as long as possible. When she had to move into a nursing home, she would ride up and down the street on her adult tricycle and people would talk to her. After that, one niece and one nephew passed away from HD.

You deal with it the best you can; you take it in stride. I have been told I'm a very strong person, but it's not easy. Huntington disease is a heck of a disease. I'm relieved that no one else in our family will get it now, because my niece and nephew didn't have children.

I'm 86 now, and I stay connected to the Society by reading about the wonderful work the Society is doing and by continuing to support the Society financially. Our family has finally closed the door on Huntington disease, but I know other people aren't as lucky, which is why I stay connected.

Do you have a story to tell about your involvement with HSC? We are collecting your memories of the Society's impact 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.

The Unstoppable Pearces

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his choice of hobbies. Even with his feet firmly planted on solid ground, he still found ways to get into trouble, like the time he nearly electrocuted himself trying to fix their microwave oven.

Their daughter Christina has certainly never shied away from a challenge. As a child, she racked up merit badges as a Brownie and Girl Guide – badges that Bob painstakingly sewed onto her sash. Meanwhile, their globetrotting son Tim traveled the world during and after his engineering degree, pursuing his passion for photography in England, Japan, India and Africa.

However, as much as they accomplish individually, it's together as a family that the Pearces really shine. Whether it was Sunday church service, going out for dinner, a night at the movies or a March Break trip to Barbados, the close-knit family has always done things together.

Bob's HD diagnosis in 1991 didn't stop the family from grabbing life by the horns. From 1992 to 1995, Bob participated in a University of British Columbia drug study. They took advantage of the annual visits to the west coast, turning them into family vacations filled with adventures like orca watching and finding snow in July on Whistler's peak. "Getting the diagnosis does not mean that you have to give up," says Dorothy. "It just means that things have to get modified."

Later, Bob entered long-term care and couldn't come home for the holidays. So the family brought the holidays to him, and a new Christmas tradition was born at Sunnyside Home in Kitchener.

Bob passed away on November 4, 2014, but his never-surrender spirit lives on with his children. "He didn't let anything stop him," says Dorothy. "One of his big legacies is that he passed that attitude on to Tim and Christina."

Christina, now 37, and Tim, now 41, also have Huntington disease. However, that didn't prevent Tim from pursuing a fine arts diploma after his engineering degree. Or Christina, who finished her environmental science degree despite rapidly progressing symptoms that forced her into a care facility two years after graduation.

"Life goes on after diagnosis," says Dorothy. And for the Pearces, it goes on together. "It's not easy, but that's what we do – we hang in together," she says. Christina, who rarely speaks these days, echoes her mom. "We hang in together."

So when Bob passed away, there was no question of fully involving Christina in the funeral, despite the logistical headaches. As always, the Pearces found a way.

Wheelchair-accessible taxis were coordinated. Dorothy's sister Alice brought sandwiches so Christina could stay for both visitations and greet people from her chair. And when Christina insisted that she wanted to say her farewells on her own two feet, her mom and brother helped her stand next to the casket while she held her father's hand and kissed him goodbye.

At the next neurologist appointment, Christina's doctor asked about the funeral. Christina's response speaks volumes about how much it still means to her to be involved: "I was included," she said. "And it wouldn't be any other way," Dorothy adds.

Since Bob's passing, Christmas has moved to Christina's care facility, where last year, the staff helped transform the crafts room into a holiday hall. The family still makes frequent outings together, even if it's just down the road to the nearby McDonald's or shopping mall (where a stop at the Cinnabon is a must for Christina). Or they'll dig out DVDs and spend a low-key afternoon watching a few episodes of *Scrubs* or *Two and a Half Men*.

Dorothy, Tim and Christina continue to show that including people with HD in meaningful activities is possible with some effort and creativity. Indeed, whether it's exploring a mountain peak or facing a disease like Huntington's, the Pearce family seems to follow a simple rule: stick together, and keep going. "We can't go back in time, so we just have to show that life goes on," says Dorothy.

If you wish to learn more about ways to promote inclusion within your family, check out our Fact Sheets on the HSC website:
www.huntingtonsociety.ca/hd-fact-sheets-articles.



www.enroll-hd.org

The Politics of Genetic Fairness

The path to new legislation rarely runs smoothly. And that's certainly the case with genetic fairness legislation. When Parliament rose last June, it spelled an end to two genetic fairness bills: the government's Bill C-68 and the Senate Bill S-201.

Frustrating as it was to see those bills die, our efforts have achieved two important things: greater awareness of genetic discrimination in Canada and a strong political will to take action.

The proof? During the recent federal election campaign, the three main political parties all agreed to pass laws banning genetic discrimination. Now, with a new Liberal government in power, we'll be working closely with lawmakers to ensure it happens.

We have also gained new allies over the past months. "The scientific and medical communities are stepping up to the plate to support the protection of genetic information in Canada," says HSC's CEO Bev Heim-Myers. "We are all working together to move this forward."

Protecting genetic information is crucial. It ensures no one is denied insurance coverage or passed up for promotion because of their DNA. Furthermore, having that protection in place lets Canadians take advantage of individualized medicine tailored to their specific genetic makeup without fear of discrimination.

This year promises to be a big one for genetic fairness in Canada. Thanks to the support of the HD community and Canadians of all stripes, we've put this issue on the political radar. Now the time has come for political action. "We anticipate this will move quickly in the next while," Bev predicts.

*CCGF has launched a new website, www.ccgf-cccg.ca, complete with an area where you can submit your story of genetic discrimination to the Chair of the Coalition, Bev Heim-Myers. CCGF will protect your privacy and share your situation with our politicians to help them better understand what Canadians are going through. **Please submit your story today.***

Youth Mentorship: Paying it Forward

By Julie Stauffer

When Jenna Shea needed help, the Huntington Society of Canada was there for her. Now she wants to return the favour.

Growing up, Jenna had no idea that Huntington disease ran in her family. So when her mother had mood swings or couldn't cope with household tasks, no one realized it was a neurological problem.

Various forms of counselling and therapy made no difference. "I just thought I had a very challenging mother," Jenna says. It wasn't until Jenna acknowledged her mother's movement symptoms that she went online and discovered HD. In the process, she also discovered her local HSC social worker, Rozi Andrejas, who helped her family navigate the process of diagnosis and deal with all the implications.

Once her mom was stabilized, Jenna started thinking about the implications for herself. She was 28, in a serious relationship, and she and her partner were contemplating children. Did she want to find out whether she had the gene? Once again, Rozi was there. "She was really wonderful," Jenna says. "She really listened to what I was going through."

So when Rozi told her about the opportunity to become a youth mentor, Jenna jumped at the chance to give back. As a teacher, Jenna has seen how complicated home situations can hurt kids socially and academically – and how even one positive role model can make a huge difference.

"It's always nice to be able to bounce ideas or questions off of someone that can relate to what you're going through," she says.

Since completing a weekend of training in June, Jenna has been matched with a mentee and is looking forward to making that first connection. "I'm excited," she says. "I'm very excited."

According to program coordinator Erin Stephen, all of our first-round mentors have been matched with mentees, as have five of our eight second-round mentors. Now she's eyeing a new round of mentor training in 2016 to keep pace with the growing demand.



Jenna Shea and her mother

If you or someone you know would like more information about the HSC Youth Mentorship program, our program is expanding. If you would like to be a mentor or be matched with a mentor, contact us at mentorship@huntingtonsociety.ca or call the Youth Mentorship Coordinator at 1-855-253-0215.


Believe
Transforming Tomorrow Together

**Save the Date for
HSC 2016 National Conference**

**Halifax, Nova Scotia
November 4&5, 2016**

Youth Rally Together

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Meeting other people who understand Huntington disease through YPAHD is something Catherine really enjoys. "It's a huge relief to meet other youth affected by HD," she explains, "because you always think: 'Well, I grew up in rural Newfoundland, so I knew no one else who came from an HD family.' It was nice to know that you're not the only one going through it."

HSC's YPAHD Days had many different sessions covering different topics ranging from telling your friends at school about HD to family planning. "It was great to meet people, but also learn new things about HD research and the genetic component of Huntington's," remembers Catherine.

"I was just so excited to see familiar faces again," says Aly, remembering this year's YPAHD Days in Alberta. "Meeting new people and sharing our experiences with HD was such a joy."

Becoming involved in YPAHD can provide youth with a fun way to connect with their peers across the country, have their questions answered and learn more about HD. To learn more about YPAHD and how to become involved email us at info@huntingtonsociety.ca or visit www.YPAHD.ca.

HSC National Symposium 2015

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Toronto, Ontario, about what one can expect as a volunteer participant in a clinical trial or observational study. Dr. Guttman discussed who would be eligible for which trials, how the enrolment process works, how long an average visit takes and much more.

What does this mean for the HD community: The national and global perspectives.

After an extensive question and answer period, HSC's CEO Bev Heim-Myers chatted with CHDI's Joe Giuliano about the "bigger picture". Joe spoke of the trials currently taking place in Canada and around the world and what the scientific community is hoping to learn from them. Bev and Joe covered the latest developments, as well as how clinical sites are chosen and which pharmaceutical companies are showing an interest in HD.

Both sessions were greeted with lots of questions and lots of feedback. HSC extends its heartfelt thanks to Dr. Guttman, Jaclyn Skinner and Joe Giuliano for volunteering their time to provide the most up-to-date information possible.

Due to its popularity, videos from the symposium have been posted by HSC at www.huntingtonsociety.ca for members of our community who wish to learn more about the clinical trial process and why clinical trials are so important to our community. To learn more about clinical trials please visit the Society's website at www.huntingtonsociety.ca. You will find a host of resources including an interactive map of clinical trial locations in Canada, questions to think about when considering a clinical trial and lots more.

Believe 

Disability Tax Credit 101

Yes, you can qualify — without paying big fees to a private agency

By Josh Martin

Huntington disease takes a toll: physically, mentally, emotionally and yes, financially. That's why HSC Resource Centre Director Maïke Zinabou encourages her clients to apply for the Disability Tax Credit (DTC).

The DTC is a federal program for people with "severe and prolonged physical or mental impairments." It reduces the amount of income tax you pay by up to \$1,500 per year. If you don't pay income tax, you can transfer the benefit to an eligible caregiver such as a spouse or child. There are other good reasons to apply. For example, if a family member wants to set up a Registered Disabilities Savings Plan (RDSP), you must be eligible for the DTC.

There's no question that everyone with HD will qualify as the disease progresses, but it's up to your doctor to determine when you meet the criteria. Although you don't need to be in a long-term care facility, your doctor needs to be able to confirm that your condition significantly restricts you in several areas of your regular daily activities.

External agencies

Many of Maïke's clients have successfully qualified for the DTC. The relatively straightforward application — which has been streamlined in recent years — involves filling out one form yourself and having your doctor fill out a second one. "The process in itself is not difficult," says Maïke.

However, a slew of third-party agencies have popped up, offering to help you with your application... for a price. Luring clients with the promise of thousands of dollars, many of these companies then take a cut of 20 or 30 per cent of any credit you get.

If you're having trouble with the paperwork, steer clear of big-fee agencies altogether, advises Maïke. Instead, talk to a family member or an accountant, or give your HSC family worker a call. Alternatively, many non-profit organizations and established companies like H&R Block can also help for free or very modest fees.

Tips on applying

If you hope to claim the DTC with your next income tax assessment, you need to apply for the DTC before you file your annual tax return. Canada Revenue Agency takes up to eight weeks to decide whether you qualify, so get the ball rolling sooner rather than later.

The success of your application largely hinges on the information your medical practitioner provides. "Ask the physician for a half hour appointment at least, so there's really a good amount of time you can sit down and discuss it with them," suggests HSC Toronto Resource Centre Director Rozi Andrejas.

Finally, if at first you don't succeed, try, try again. If your family doctor doesn't feel you qualify this year, ask again next year, or consult your neurologist or your psychiatrist.

It's not too late

Wish you had taken advantage of this program sooner? In certain situations, the tax credit can be granted retrospectively for up to 10 years.

For more information about the Disability Tax Credit program, including forms and eligibility guidelines, visit www.cra-arc.gc.ca/disability or contact the HD Resource Centre Director in your area. For a complete list of HSC's Resource Centre Directors and contact information visit www.huntingtonsociety.ca.

Be Brave, Be Bold, Be Ready: HD Clinical Trials In Canada

By Cyndy Moffat Forsyth

Carving a new path to ensure the HD community is prepared for HD clinical trials is a strategic initiative of the Huntington Society of Canada. Playing a key role in bridging the relationship between researchers, clinicians and individuals, the Huntington Society of Canada is educating Canadians on the importance of the HD clinical trial process; how they can get involved; and why participation is so crucial.

This past fall, thanks to Canada's Research Based Pharmaceutical Companies (Rx&D) and Pfizer Inc., the HD Consortium, consisting of researchers, clinicians, HD family members and the Huntington Society of Canada, met to further the work of the National HD Clinical Trial Strategy.

For the first time, family representatives joined the discussion and along with the HD Consortium, took a

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Flower Power Hits \$5 Million

By Julie Stauffer

Selling out this year, \$115,000 was raised for research and services. And a whole lot of awareness created. Any way you measure it, our 2015 Amaryllis campaign was an outstanding success.

"I've been blown away," says our new development manager Jeff Hoffman, who joined the Society last August after 14 years at the Tim Horton Children's Foundation.

He credits a solid plan; the hard work of his predecessor, Jim Martin; and, most of all, a stellar team of Amaryllis sellers. "It's been such a positive group, such an amazing group," he says.

Throughout the campaign, Jeff connected with first-time sellers and veterans from coast to coast. Many, of course, are driven to raise dollars for a cause that lies very close to their heart. Some are carrying on a family tradition, taking up the torch from the generation before them. Others simply love the flower and say they can't find a better Amaryllis anywhere. Jeff welcomes them all.

He also applauds everyone who entered our second annual Amaryllis Photo Festival. If you need a hit of inspiration in the depths of January, head over to our Facebook or Instagram page for shot after shot of gorgeous blossoms.

Jeff isn't surprised this signature campaign has raised more than \$5 million over the course of its multi-decade history. "Everything I've come in contact with here at HSC has been about this amazing community who rallies around the individuals and the families that we're here to support," he says. "You can see that in full force – full bloom – with Amaryllis."

To view our Amaryllis Photo Festival or to sign up for our 2016 Campaign email us at amaryllis@huntingtonsociety.ca or call us at 1-800-998-7398. Learn how you can get involved.

Living Proof™ of Donations at Work

Since 1988, HealthPartners has raised more than \$135 million from Canadian workplaces to fund critical research, support programs, education and prevention initiatives that are revitalizing health and well-being in communities across the country. As a member, the Huntington Society of Canada continues to benefit from this partnership. Thank you to our many volunteers across Canada who sit on provincial councils, speak at educational sessions, or participate in Health Checks. Your continued support and efforts contribute significantly to the success of the HealthPartners and Huntington Society partnership.

Meet Manon Desbiens. She does not suffer from Huntington disease, but her mother, two of her sisters and her brother all died of the disease before age 60. For a long time, Manon's family had no idea that half of its members were afflicted with this neurodegenerative genetic disorder that affects muscle coordination and causes cognitive decline.

Then one day, the Huntington Society came into their lives. "I can't even begin to tell you how helpful those meetings were; learning about the research, gaining insight and receiving encouragement. Until then, we thought we were the only ones in this situation," says Manon.

HealthPartners and the Huntington Society have played an active role in the lives of the Desbiens family. "My sisters and brother went to the Huntington Society's HD retreat every year. For them, it was a very liberating experience. They always came back happy and fulfilled. And for us, the caregivers, these retreats offered us some respite so we could have a chance to recharge our batteries and take a break from all the responsibilities that weighed on us," continues Manon. "Your donations help. Thank you for your generosity."

"My name is Manon Desbiens and I am living proof that donating to HealthPartners works."

For more Living Proof of donations at work please visit www.iamlivingproof.ca.

Huntington Society of Canada is a proud member of HealthPartners. HealthPartners is a collaboration of 16 of Canada's most trusted health charities. To learn more about HealthPartners and how you can get involved contact us at info@huntingtonsociety.ca or 1-800-998-7398. Tell your friends and colleagues about HealthPartners, and how a workplace giving campaign can help strengthen successful businesses across Canada.

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

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



Believe: *Transforming Tomorrow Together*

HSC's new campaign will raise \$3 million to accelerate treatments and increase access to services

By Julie Stauffer

Until now, every person who tested positive for the HD gene knew what their future held. Today, we are preparing to rewrite that script.

As drug companies launch one new clinical trial after another and lab bench experiments create ever-more promising results, researchers are cautiously confident that we will soon have meaningful treatments for HD – treatments that reduce the symptoms of HD, postpone the onset or slow the progression of the disease.

For families, those treatments can't come soon enough. That's why HSC is launching our "*Believe: Transforming Tomorrow Together*" campaign this year. With your support our goal is to raise \$3 million to accelerate the pace of progress and increase our service reach across Canada.

HSC Senior Manager Donor Relations Danielle Havelka is confident we can reach our fundraising target in just two years. "Our donors believe in what we do. They are excited about the progress they see and they are optimistic about the future," she says.

We believe everyone deserves a safe place to land. To make this happen, these dollars will be invested in research to facilitate discoveries leading to a better understanding of treatments of HD, building capacity for more clinical trial sites, getting more clinicians involved and encouraging more families to step forward and participate. At the same time, these dollars will help us become more accessible to more people affected by HD in rural communities, and build capacity within our Family Services team. Things are moving quickly and we must keep up the pace to keep the momentum going.

With so many potential treatments in the works, we need to know our families are supported. As new discoveries may prompt more people to get tested, more people may come forward. To make sure we're ready, we'll also invest additional dollars in services for families and youth.

Today, we are on the cusp of discoveries that will transform the lives of everyone touched by Huntington disease and other diseases as well. "Things are moving quickly," Danielle says. "We truly believe that with your help, we can transform how HD impacts individuals."

We welcome your support! Make a donation or – just as importantly – help us connect with potential new donors. Contact us at 1-800-998-7398 or info@huntingtonsociety.ca.

Beta Sigma Phi Doubles Down on HD Education

By Josh Martin

As someone impacted by Huntington disease, Kim Wedgerfield has been a long-time supporter of the HD community. But that's not the only family she belongs to. For more than 25 years, she's also been a proud member of the Beta Sigma Phi sorority, and last year those two worlds collided at the blackjack table.

The sorority's Calgary chapter regularly teams up with a local casino to raise money for Alberta charities. That sounded like a great funding opportunity for HSC's Calgary Chapter, so the Huntington Society, along with ALS Society of Alberta, submitted a joint proposal to the sorority. The societies requested funds to update, enhance and expand our educational materials and create up-to-date, ready-to-go educational modules.

The casino campaign was another roaring success, and the sorority agreed to contribute \$15,000 to our project. "When it went through, I was so excited," says Kim.

Building blocks for better talks

Community education is a huge part of what we do at HSC, which is why equipping our staff and volunteers with up-to-date, consistent, ready-to-go presentation material is so important. To strengthen our outreach capacity, we hired a consultant to organize, update and create new audio, visual and print resources for both HSC and ALS.

The result? A toolbox of new and improved educational resources. New templates for introduction letters and standardized presentation request forms will help streamline the booking process. Meanwhile, updated PowerPoint presentations and backgrounders on a variety of topics provide users with the latest information that is easily updateable. "It's going to allow us to more quickly and more readily provide educational presentations," says HSC's Director of Family Services and Community Development, Angèle Bérard.

To bring the facts and stats to life, we also produced several new videos featuring interviews with a person diagnosed with HD, a caregiver, a couple with an HD-positive spouse and someone who's been diagnosed gene-negative. "It's like we're able to bring all those guest speakers with us to a presentation," says Angèle.

Versatility was another must. Speaking to a group of physiotherapists is quite different than presenting to law enforcement officials or long-term care providers. That's why we wanted a user-friendly way to create tailor-made presentations. Now, thanks to consistent styles and helpful checklists that spell out which materials are recommended for which audiences, custom-building presentations is a cinch for new, and seasoned, staff and volunteers.

Local initiative, national impact

From a return on investment perspective, these educational modules deliver real bang for their buck. While the project was funded as a community initiative in Alberta, HSC chapters from across the country will be able to take advantage of the new materials. Meanwhile, collaborating with ALS allowed us to share the costs of producing the content, while giving us the opportunity to foster an important partnership with a like-minded organization.

Finally, for our staff and volunteers, it means less time pulling together and updating material for a presentation and more time in the community, educating and empowering families, healthcare providers and service partners. "This is really an incredible opportunity," says Angèle. "It really expands our capacity."

We Remember

Stephen Gould



On June 3, 2015, the Huntington's community lost a staunch friend and ally. "Imagine the most intelligent, generous and kind individual you know and then double that and you would have Stephen," says his widow, Lila Gould. "He was off-the-charts smart, perceptive and an amazing leader in all facets of life."

Huntington disease didn't run in Stephen's family. Instead, he got involved because he watched his friend's mother suffer from the disease. That takes a special person, someone who gets involved and volunteers for decades because of a family friend.

Stephen served on HSC's Board for a decade, using his intelligence, insights and leadership to guide the Society through a sometimes-tumultuous period of transformation. During his tenure, we increased our revenues from \$1.5 million to \$3.5 million – and achieved a new level of professionalism and accountability – thanks in no small measure to his efforts.

"He made such a difference," says Vern Barrett,

who sat on the Board with Stephen. "The world has lost such a good person."

Several causes benefited from his generosity, including the Toronto Children's Breakfast Club, the Terry Fox Run and his children's schools. However, HSC always took centre spot. Even after his term as chair ended in 2011, he continued to advise the Society informally, take part in events like our annual Toronto casino and follow the latest research breakthroughs.

"He was fully committed to making life better for families dealing with HD. HSC is a better organization because of Stephen's dedication and expertise," says HSC's CEO, Bev Heim-Myers, who counted him as a mentor and guide. Stephen passed away far too early, but his legacy lives on.

Did you know honouring the memory of a loved one through a gift to the Huntington Society will create a lasting impression? To honour Stephen Gould or someone in your life, call 1-800-998-7398 or go to www.huntingtonsociety.ca.

Celebrating Our Heroes

Jamie Walters

Jamie Walters, HD Advocate

Jamie Walters is the lucky one: he didn't inherit the Huntington mutation that leads to Huntington disease, which killed his father. His siblings weren't so fortunate. One by one he watched them die of the complications of this fatal, progressive neurological disorder.

His youngest sister's death hit particularly hard. "It was at that point there that I basically sat on the floor and cried my eyes out," Jamie recalls. Eventually, though, the Canadian Navy veteran picked himself up and decided it was time to take action.

He knew it was too late to do anything for his dad and his siblings. However, he could help his two gene-positive nephews, as well as thousands of other families around the world impacted with HD.

Instead of dipping his toes in the water, Jamie jumped right in the deep end.

He joined the local chapter of the Huntington Society of Canada. Each year, you'll find him in front of the downtown mall in Guelph, Ontario, raising awareness and gathering pledges for the chapter's annual fundraising walk/run.

When the chapter needed a delegate to the Society's national conference, Jamie volunteered.

At the conference, he learned how researchers need more volunteers stepping forward to help test the potential treatments currently being developed. So when Jamie got home, he jumped on social media to start spreading the word.

The more people who sign up now, he explains, the faster we can start getting results from clinical trials.

As well as starting his own Facebook group (Be JHD/HD Aware), he serves as a Canadian advocate for the Florida-based Huntington's Disease Film Project, WeHaveAFace.org, and he is active in the international "We Wear Blue and Purple" movement that raises awareness about the disease.

"I'm one of those HD advocates," he says.

Most recently, Jamie hatched an ambitious plan to put HD on the public radar in a big way – a really big way. Thanks to his persistence, the CN Tower was lit up in blue and purple in May of 2015 to mark Huntington Disease Awareness month. The social media universe lit up as well, with 37,000 hits celebrating his achievement.

For the Society's next May Awareness campaign, Jamie wants to see lots more landmarks lit up across Canada and a million hits on social



media. Most importantly, he wants everyone to understand the meaning of all that blue and purple.

In his hometown of Guelph, he plans to set up a booth outside City Hall – lit up blue and purple, of course – complete with a big banner and plenty of brochures. In Toronto he'd love to have the CN Tower lit up on a day when the Blue Jays have a home game, so he can put a message about Huntington disease on the Jumbotron.

All that support doesn't leave many spare hours in the day, but that's fine by Jamie. "I know I'm making a difference," he says.

Why not join Jamie, the HSC Chapters and volunteers across Canada who are working to light up Canada for HD in May of 2016. Contact us at communications@huntingtonsociety.ca or call 1-800-998-7398 for more information on how to get involved in this inspiring event.

Making a Difference: June Nichol

By Josh Martin

Saskatoon's HSC Resource Centre Coordinator, Alice Gibson, was always on the lookout for new volunteers for the local chapter. So when she approached June Nichol, June made her a deal. "I promised her when I retired from teaching, she had me as a volunteer," she recalls.

Three years later, on June 29th 1998, the students said farewell to Principal Nichol. On June 30th, the phone rang. It was Alice, calling to collect on a promise.

June joined the Saskatoon Chapter executive that fall, and a year later she became president. Since then, she's helped raise crucial funds and awareness for HD, spearheading quilt raffles, Go Kart Indy events, walkathons and more. And, when fellow Saskatchewanian Carol Ellis stepped down from HSC's national board of directors, June took her place for six years.

She kept up that commitment even when her husband's HD got worse and she was forced to take over their beef farming operation. "What a learning curve that was," she laughs, describing frozen pipelines, wandering cattle and newborn calves that had to be bottle-fed.

When Bill became very ill, the learning curve continued as June figured out how to look after him at home. "It was probably the most moving and meaningful part of my life," she says, "caring for someone you love and giving back a small part of what he gave to me."

After nearly two decades of steadfastly supporting her local Chapter, June is keen on getting the next generation involved. Her advice to young people? You don't have to be extraordinary to make a difference – just show up and help out. "It's worth it," she says. "I



June Nichol (right) at Saskatoon Walk 2015.

think the most rewarding part is the sense of family," she explains. "I think it's the feeling that you're never alone, that when you're down, there's always someone to pick you up."

Know someone who is making a difference in your area? Help us thank them by highlighting their efforts. Email us at communications@huntingtonsociety.ca or call us at 1-800-998-7398. We'll make the process easy.

Be Brave, Be Bold, Be Ready: HD Clinical Trials In Canada

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360 degree look at HD clinical trials in Canada. By including family representatives, everyone benefits – ensuring everyone gets a voice.

As a result of that meeting, the Huntington Society of Canada has produced an information poster, and distributed it to HD clinics and HD neurologists, in Canada. This poster highlights the *Be Brave, Be Bold, Be Ready: Clinical Trial Location Map* found on HSC's website. The objective is to provide those impacted by HD, and health care providers that work with HD families, up-to-date information on HD clinical trials in Canada.

But the group did not stop there. The HD Consortium provided input on the new HD Clinical Trials Preparation Guide, which is designed for HD clinicians thinking of starting a HD clinical

trial. They also signed up for the HD Clinical Trials Mentorship Program, which matches seasoned clinicians with new clinicians, and agreed on the next steps.

What's on the horizon in 2016? The HD Consortium agreed to focus on two main objectives: streamlining the clinical trials start-up process for clinicians and developing a HD clinical trial recruitment strategy. It is also our intent to share what we have learned and developed with other HD organizations globally and other disease organizations, so that many can benefit from our work.

These are not easy goals, but the Consortium knows that we are carving a new path and we are doing so together.

The goal of the HD Clinical Trial Consortium is to assist clinicians, who are currently conducting HD clinical trials, and those who are thinking of participating in HD clinical trials in Canada, in order to maximize the clinical trial experience, address the requirements for a site to become research

ready, maximize the efficiency of the many study-related processes and encourage more clinicians to participate in HD clinical research in Canada. To learn more about HD clinical trials in Canada visit www.huntingtonsociety.ca.

Find Clinical Trials in Canada

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



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



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.