

More Than Medicine: A Holistic Approach to Wellness

By Josh Martin

Tell Kathryn Kimmins you want to join her yoga class and she might laugh in your face. Don't take it personally. She wants you to laugh in hers too. "Laughter yoga is a unique combination of laughter, exercise, deep yogic breathing, clapping, stretching and childlike play," says the Hamilton, Ontario instructor.

Sound strange? Suzanne Csordas thought so too when she first met Kathryn at an HSC picnic last year. Things started innocently enough: a few stretching and breathing exercises got the group of nearly 40 people warmed up. But then they were asked to start laughing with each other. "In the beginning you felt absolutely ridiculous," Suzanne recalls.

Before long though, genuine grins, giggles and guffaws started to emerge from the forced laughter. In no time at all, the grassy field was booming with the sound of hearty belly laughs. "It was just so satisfying," says Suzanne. "We were so joyful."

However, the chuckle fests do more than help relieve stress and give people a chance to socialize in a silly way. According to Kathryn, one minute of laughter is the equivalent of 10 minutes on a rowing machine. After a session of laughter yoga you will feel like you have done a full cardiovascular workout, she says.

That is especially important for people affected by HD, with more and more evidence showing that you may significantly delay the onset of symptoms by staying physically, mentally and socially active.

As a therapeutic recreation specialist, Bev Farrell could not agree more. "In therapeutic recreation, we are taught how important it is to have meaningful activities in your life," she says. As she explains, there is a lot of research that shows that people who are socially connected and take part in meaningful activities have greater resilience.

Bev's seated tai chi sessions were a hit at last year's Ontario HD retreat. Participants gathered outside on a beautiful sunny day as Bev led them through a series of fluid movements intended to stretch the body, improve circulation, strengthen their core and control their breathing. An ancient form of martial art, tai chi is as physical as it is meditative, engaging and relaxing both muscles and mind. And because she modifies the exercises so they can be done in a seated position, people with balance issues can still participate without the worry of falling.

The importance of investing in holistic wellness is gaining traction beyond the Huntington's community. Case in point: Parkinson Alberta's Buchanan Centre in Edmonton. Slated to open in the summer of 2014, this \$5 million facility is a model for active and healthy living that is generating a lot of buzz.

The idea behind the Buchanan Centre is simple: "The longer we can keep clients healthy, mobile, feeling good and living well, the better day-to-day life is going to be," says Brandi La Bonte, Community Relations and Communications Coordinator at Parkinson Alberta.

In addition to providing educational resources and information, the 9,000-square-foot building will be home to a myriad of social and physical programs for both patients and families, including dance, music, art, massage, yoga, tai chi and cooking. From extra-wide hallways to caregiver respite areas, the Buchanan Centre is being designed from the ground up to be a hub for living well with Parkinson's and other movement disorders.

Of course, not everyone lives near Edmonton, which is why the state-of-the-art facility will be equipped with video cameras and virtual tools. This will allow anyone, from any location, to enjoy guest speakers, for example, or watch how-to videos.

Because Parkinson's shares similarities with other neurological diseases, Parkinson Alberta is actively looking to collaborate with other groups like HSC who could also benefit from their programming. "The opportunity for partnership is going to be amazing," says Brandi.

Whether you are laughing yourself silly, losing yourself in an ancient martial art, or whipping up an easy-to-swallow banana smoothie at the Buchanan Centre's kitchen, remember: participating in meaningful activities is a key part of holistic wellness.

You'll find laughter yoga videos and links to local clubs at www.laughteryoga.org. The Taoist Tai Chi Society offers health recovery classes in many communities; for listings, visit www.taoist.org. And, of course, your HSC Family Services Staff can point you to wellness programs and activities in your area.

Healthy Liver, Healthy Brain?



Jeff Carroll

By Julie Stauffer

Jeff Carroll still remembers how nervous he felt applying for a Huntington Society of Canada fellowship as a first-year PhD

student, still wet behind the ears. "When you first start out, you are pretty sure no one is ever going to pay you to do science," he says.

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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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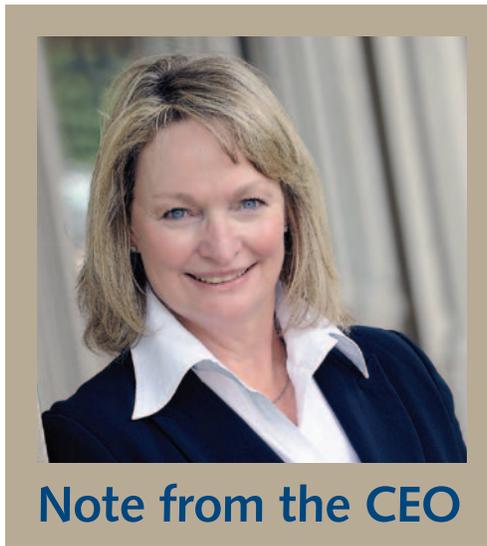
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Happy New Year and warm wishes to you and your family. As we begin 2014, I want to take an opportunity to reflect on our collective accomplishments and anticipated successes to come.

In November, we launched our new website: a fresh online face for the Society. If you have not had a chance to visit recently, please take a look at www.huntingtonsociety.ca. You will find a wealth of news, information and resources, all easier to access than ever before.

Also in November we welcomed six new members to our Board of Directors: Mack Erno, Dr. Kathryn Todd, Brenda Wasylow, Marie-Claude Foisy (HSQ Rep.), Jonathan Genest-Jourdain, Dan Tremblay. Collectively, they bring an incredible range of skills and experience, and I look forward to their advice and insights in the months ahead.

On the services front, our first cohort of youth mentors completed their training this past fall and are being matched with younger peers. I am very excited to see the launch of this groundbreaking program, which gives youth growing up in families affected by HD invaluable one-on-one support.

Meanwhile, over 200 participants across the country attended our Fall Symposium. For

the first time, families had the choice of taking part at one of our teleconference sites or from home via high-speed Internet. It is the perfect example of how the Society is leveraging technology to reach out and connect with families wherever they may live.

Last fall saw research advances as well. We have had incredibly positive feedback from our clinical trial readiness roundtable: Be Brave, Be Bold, Be Ready. Thanks to the generous support of Canada's Research Based Pharmaceutical Companies (Rx&D), we were able to bring together clinicians, researchers and scientists this past September. The full-day workshop was a resounding success, attracting new and seasoned clinicians alike to share best practices for accelerating the pace of clinical trials in Canada.

As we build on these successes in the year ahead, we will continue to be guided by the strategic plan we established last spring. Our priorities include expanding services to families, especially in rural and remote areas, and continuing to invest in high-impact research, like Dr. Ray Truant's recent insights into the structure of the HD protein.

We will also take advantage of the awareness generated by our 2013 Public Service Announcement (PSA) Campaign and our efforts to end genetic discrimination. We continue to champion the federal government for identifying genetic discrimination as a problem in the Throne Speech 2013, and for showing the leadership required to make ending this a priority. We extend our appreciation to the Honourable Senator James Cowan, Leader of the Opposition for his work on re-tabling Bill S-201, a comprehensive genetic non-discrimination bill, and we continue to work with our allies to create similar provincial legislation in Ontario and Alberta.

None of this is possible without your support. Thank you to our volunteers, donors and staff who make this Society such a powerhouse. Together, we will achieve even more in 2014.



Bev Heim-Myers
CEO and Executive Director

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

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Huntington's 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!

2014 World Congress on Huntington Disease: When Samba and Science Collide

By Josh Martin



Michelle Muller

While most students were settling into a new school term in September, 25-year-old Michelle Muller was packing her bags and heading south. Her destination:

Rio de Janeiro, Brazil. Although the promise of sunny skies and a cerveja or two on the beach would be enticing enough, Michelle had a more compelling reason to go: the 2014 World Congress on Huntington Disease (HD).

As a grad student working in Dr. Blair Leavitt's lab at the University of British Columbia's Centre for Molecular Medicine and Therapeutics (CMMT), Michelle has focused her research on HD. Attending the four-day event went beyond academics. "When I come to these conferences, it is different than being another student in the lab," she says. That is because in addition to being a young HD researcher, Michelle is also from a HD family, giving her a unique perspective.

The scientist in her gobbled up the sessions that showcased some of the groundbreaking work going on right now. From rocketing an HD protein into space (yes, space) so we can better understand its structure, to studying high-prevalence populations in remote areas of Venezuela, there was a lot of research for Michelle to absorb.

As someone from a HD family, who understands HD, it was the sessions about caring for individuals and families that really made an impression on her, whether it was Dutch care facilities providing HD patients with speaking software to communicate in late stages of the disease or activity-based support groups in Chile. "It is always inspiring to hear about what is happening. It gives you hope and motivation," Michelle says.

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A Successful First Step: Be Brave, Be Bold, Be Ready.

By Cyndy Forsyth

On September 9, 2013, a group of researchers, clinicians, HSC staff and Canada's Research Based Pharmaceutical Companies (Rx&D) from across Canada came together to carve a new path. The goal, to work together to develop a comprehensive national Huntington disease clinical trial strategy in Canada and ensure best practices are shared.

Currently, Huntington disease clinics in Canada work independently without a formal mechanism in place to connect clinicians and share best practices. This, coupled with the Huntington disease community expressing confusion with how the clinical trials process works and whether they should participate, sparked the Huntington Society of Canada to take action. As part of the 2012 five-year strategic plan, HSC identified a critical need to develop a national Huntington disease clinical trial strategy complete with the structure and implementation steps required to ensure Canada is prepared.

"We need to anticipate the very real possibility of effective treatments reaching the final phase of clinical trials over the next three to five years. To ensure those treatments are approved as quickly as possible, we need

strategies in place to recruit trial participants," says Bev Heim-Myers, CEO and Executive Director of the Huntington Society of Canada.

"The Society plays a key role in bridging the relationship between researchers and individuals by educating Canadians on the importance of the clinical trial process; how they can get involved; and why their participation is so crucial," Heim-Myers continues, "The urgency lies in educating as many people as possible, including efforts in rural and culturally diverse communities, and ensuring clinicians have sustainable mechanisms in place to support the process."

The Be Brave, Be Bold, Be Ready, strategy is a groundbreaking approach and is carving a new path for the research community. It is an opportunity for clinicians, the Huntington Society of Canada, and Canada's Research Based Pharmaceutical Companies (Rx&D) to partner in the outreach efforts to encourage participation in clinical trials.

To learn more about clinical trials in Canada, go to www.huntingtonsociety.ca and see our new Fact Sheet on Clinical Trials.

A Mentor's Perspective

By Stephanie Rees

The new HSC Youth Mentorship Program is designed to support young people across Canada who face the everyday challenges of growing up in a family affected by Huntington disease. HSC has committed to offering a nationwide mentoring program that provides youth with one-on-one time and attention with a volunteer mentor who will receive ongoing support from

HSC Family Services Staff. The pilot stage of this program has begun and the first training weekend was hosted in Toronto in September.

I didn't find out that my mother had HD until I was 18, and that was only because a relative told me. My parents wanted to protect me and my little brother by keeping it a secret until we had both finished high school.

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Healthy Liver, Healthy Brain?

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But HSC's Research Council recognized the potential of the bright young investigator in Michael Hayden's, University of British Columbia, lab. They granted him a Landmark Graduate Award to study caspase enzymes in a mouse model of Huntington disease (HD). When Jeff heard the news, it was like he'd just won a Nobel Prize. He ran into Dr. Hayden's office shouting "I got funded!" Dr. Hayden was just as enthusiastic. "He jumps up and gives me a big hug like he won the Nobel Prize too," Jeff laughs.

The grant kick-started a highly successful research career. Jeff went on to: earn a PhD; obtain federal and provincial funding; land a post doctorate research position in the Harvard lab of Dr. Marcy MacDonald (one of the researchers who discovered the HD gene in 1993); publish more than a dozen papers to date; and accept an assistant professorship in behavioural neuroscience at Western Washington University.

This is fitting that his first grant as an independent researcher should come from HSC. Earlier this year, Jeff received a \$140,000 NEW PATHWAYS grant to examine liver cells in HD mice.

Yes, liver cells. Although we think of HD as a brain disease, researchers have found the mutant huntingtin protein in cells from every part of the body they have looked at. As Jeff's postdoc work with HD mice revealed, while the mutant protein severely affects metabolism in brain cells, it affects metabolism in liver cells even more. Is there a link? Jeff suspects so.

"One of the jobs of the liver is to keep your brain alive in between your meals," he explains. Brain cells need a constant source of sugar to function, but they have no cellular machinery for making it themselves. That is where the liver comes in. Between meals, the liver slowly converts your body's fat into sugar and releases it into the bloodstream, providing vital sustenance for the brain.

That is why Jeff believes that liver problems in HD might contribute to brain cell death. To back up his hunch, he points to a recent German study that revealed liver problems in gene-positive people, problems that show up before any neurological symptoms of HD.

"In my mind, anything that happens before disease onset is interesting because it might contribute to disease onset," he says. Jeff is planning to compare metabolism in liver cells from normal mice and HD mice, trying to identify key steps in the process that could serve as targets for treatment. If his theory is correct, the right liver drugs could slow or stop brain damage in HD.

Even if it turns out that liver problems are not linked to brain problems, there are still very compelling reasons to investigate them. A malfunctioning liver often leads to weight loss which is a serious problem for many people with HD, he explains. Finding the right liver drugs could help prevent that debilitating symptom. It is exciting research, he says, and he is thrilled that HSC has chosen to support it. "It is a big vote of confidence that smart people think you have good ideas," he says.

A Mentor's Perspective

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It was really tough. The relative who told me didn't have all the facts about HD, so I went to the Internet, which can be a really scary place. I think the hardest part was seeing the changes in my mother, the depression, the memory loss, the lack of motivation and not being able to explain the reason to my brother. And of course I had to deal with the fact that I was at risk. It's a lot to take on at that age, when you're trying to sort out what your next step is in life.

Through the Huntington Society I found a few informal mentors who helped me when I was going through decisions about genetic testing and family planning. It makes a real difference to have that support.

My husband is my rock. I was dating him when I found out about HD and it did not stop him from marrying me. Even so, I don't know that he really, truly understands what I'm going through on a bad day. That's why it was so good to connect with people who had been through similar experiences.

This is why I signed up to be a youth mentor: because I wish I could have had a mentor when I was younger. Becoming a mentor is my way of giving the next generation the kind of support I needed.

In September, HSC hosted a mentor training weekend and it was amazing. There were seven of us from all over Canada. I already knew many of them from Young People Affected By Huntington Disease (YPAHD) day at the 2012 National Conference in Toronto, so it was great to reconnect. We all have different experiences, so we all bring something different to the table, and I think that will make the mentor team very strong.

We covered a lot over the weekend. We discussed our roles and responsibilities as mentors, gaining trust, and about suicide



intervention and self-harm. Confidentiality was another big issue, especially with Facebook. We spent a lot of time role-playing different scenarios.

I think having this kind of program is important because not all kids want to go to their parents with questions or concerns. A mentor is somebody who you can talk openly to, who isn't that much older than you and who isn't part of the family. I also feel mentorship is a two-way street. I have a lot to give to a mentee, but I think that I can learn and grow from their experiences as well.

I left the training weekend feeling very excited about the program and looking forward to getting matched with a mentee.

The Huntington Society of Canada is now accepting mentees (a person who is guided by a mentor)! If you are interested in finding out more, contact our Mentorship Program Coordinator, mentorship@huntingtonsociety.ca or contact the Society at 1-800-998-7398.

New Website for the Huntington Society of Canada

Since its inception, the HSC website has been a hub of communication providing valuable information to those affected by HD and their families, donors, volunteers, researchers, professionals serving the HD community, and the general public.

With over 45,000 visitors per year, HSC is recognized globally for our role in educating individuals about HD and the services the Huntington Society of Canada provides. This new website provides easier access to engage our readers, leverage our partnerships, further develop grassroots relationships, and effectively tell our story.



HSC launched the new website in November 2013 and invites visitors to explore its new content. The new website has been designed to provide the ultimate user-friendly experience with improved navigation and functionality throughout, allowing visitors to access detailed information and videos with ease.

The site includes extensive information to help visitors understand Huntington disease (HD), HSC services available and the latest research news. Created with the user experience in mind, the website uses the latest technology so it is compatible with today's browsers and mobile devices.

In addition to helping make the site easy to browse, new social media tools are also included. They are front and centre for those who wish to participate in the conversation and share information quickly and easily. On the HSC website, visitors can also stay informed with the latest news and latest research news, as we connect directly with HDBuzz.net.

This new website means that visitors can now benefit from a more comfortable and engaging online experience that is easier to navigate and share with others. This website is a result of talking with our community over the last 5 years and gaining valuable feedback.

We invite you to visit the new HSC website and provide us with your feedback by posting a comment on our Facebook page or email us directly at info@huntingtonsociety.ca.

An Ariel View ...with Norma and Bob Stevens

I thought it would be fun to give some of our long-serving volunteers a chance to share a few of their favourite HSC memories. This time, I asked past B.C. Chapter presidents Norma and Bob Stevens to reflect on some of their highlights over the years.

Marjorie Guthrie's visit, in the early 70s, was definitely a catalyst for getting the B.C. Chapter going. Doris Bersea and Ralph Walker had been trying to start a group here, so they invited Marjorie to come to Vancouver. A bunch of us got busy spreading the word and convinced about 25 people to come out to the basement of Doris' church to hear Marjorie speak.

It was a great meeting. Marjorie sat on the edge of the stage with her shoes kicked off, swinging her elegant legs, and just talked from her heart about her husband Woody and their experience with HD. It really fired people up, and as a result of that we got a Chapter going almost immediately, one of the first in Canada.

We held our monthly meetings in that same church basement on 41st Avenue. It meant a great deal to be able to get

out and talk to people who were dealing with the same issues. The Chapter continued to grow and flourish. By the mid-80s, Dr. Maurice Bloch was hired to run B.C.'s first HD Resource Centre.

We helped Dr. Bloch organize the inaugural therapeutic retreat in Squamish. That first year there were 27 participants and maybe five or so volunteers. A girl from Ireland named Bernie Moran joined us as one of the volunteers. She was working in B.C. at the time and had just found out she had HD in her family. She was a delightful girl, but she and Norma got their wrists slapped because they skipped out one night for a beer. Years later, we came across Bernie's name on the Internet. Would you believe she would go on to found the Huntington's Disease Association of Ireland? I guess we impressed her!

Getting Dr. Michael Hayden involved was another big win. Ralph was looking for people for his medical advisory board and after a private lunch or two and a bit of arm-twisting, we managed to convince Michael to move to Vancouver. He went on to create the Centre for Molecular Medicine and Therapeutics at UBC, and a lot of his important work in HD is still being carried on by people that he trained.



The Society really has seen wonderful growth over the past 40 years, but its number one strength remains the same: people. We have brought together all kinds of good people over the years (too many to name!) and a lot of us remain close friends to this day.

To celebrate our 40th anniversary, we are collecting memories of the Society's impact over the years. If you have a story you that you'd like to share, email us at info@huntingtonsociety.ca. We will interview you, write the article and you will be able to review it before we share with our readers.

Ariel Walker

Celebrating our Healthpartners Volunteers

As a member of Healthpartners, an alliance of 16 national health charities that raise funds for workplace giving programs, the Huntington Society of Canada is actively involved in the campaign through our incredible volunteer network across Canada. In celebration of Healthpartners 25th anniversary, the Society is profiling

two volunteers from Alberta who are dedicated to helping the Society, as well as Healthpartners. Our heartfelt thank you goes out to all HSC volunteers. You do an incredible job!

To read about Tara and Kim and other Healthpartner volunteers visit www.healthpartners.ca.

Healthpartners: Making a difference in your community everyday
 Healthpartners is 16 of Canada's Health charities working together to transform the health of Canadians by raising funds exclusively through workplace giving. 87% of those you love are likely to be diagnosed with the major illnesses represented by Healthpartners. You can make a difference for as little as \$10 a pay. With your help, we can improve the health of people like Tara who is receiving help right in her community from The Huntington Society of Canada.



HUNTINGTON & Tara
 Tara Johnson Ouellette was 20 when her mother, Janice, was diagnosed with Huntington disease. For Janice, it was a death sentence: researchers haven't yet found any treatment for this degenerative brain disease. Meanwhile, Tara faced a 50/50 risk of carrying the same fatal gene. In the months that followed, both women cried themselves to sleep each night.

As Janice's physical, cognitive and behavioural symptoms rapidly worsened, Tara became her caregiver. At the same time, she went through the emotional wringer of genetic testing. Tara doesn't know how she would have gotten through that period without the support and services of the Huntington Society of Canada. "It's your lifeline," she says. "It's literally your lifeline."

Today, Tara wants to ensure that everyone coping with neurological diseases like Huntington's, Parkinson's, ALS and Alzheimer's gets the help they need. "That's why I feel so passionately about Healthpartners and what it can do," she says. "I know at the end how it helps our families in all of our organizations."

Please feel free to contact us. We look forward to hearing from you in the near future. www.healthpartners.ca




Healthpartners: Making a difference in your community everyday
 Healthpartners is 16 of Canada's Health charities working together to transform the health of Canadians by raising funds exclusively through workplace giving. 87% of those you love are likely to be diagnosed with the major illnesses represented by Healthpartners. You can make a difference for as little as \$10 a pay. With your help, we can improve the health of people like Kim who is receiving help right in her community from The Huntington Society of Canada.



HUNTINGTON & Kim
 Yes, two car accidents have left Kim Wedgerfield with brain damage and a spinal cord injury. Yes, she has Huntington disease, a fatal neurodegenerative disorder that slowly destroys muscle control, memory and speech. And yes, she worries that her son has a 50% chance of inheriting the genetic disease.

But Kim also has medals from seven world triathlon competitions, plus one heck of a positive attitude. "I'm going to try to live every single day of my life and enjoy it, try to be the best human being I can and give back as much as I can," she says.

Kim credits the Huntington Society of Canada (HSC) with providing resources and connecting her to other people living with Huntington's. "It's just so important to have that contact," she says. "We're able to laugh and cry and get angry and be happy and support each other as best we can."

HSC also funds promising research into treatments — research that Kim says gives her hope for the future.

Please feel free to contact us. We look forward to hearing from you in the near future. www.healthpartners.ca




Healthpartners 25th Anniversary National Volunteer Award

Healthpartners National Volunteer Award is awarded to an outstanding volunteer for their work and dedication during the 2012 Government of Canada Workplace Charitable Campaign (GCWCC). It is the largest and most generous workplace campaign having raised

over \$100 million dollars for Healthpartner members in the past 11 years.

Congratulations to Vern Barrett who was awarded the Healthpartners 25th Anniversary National Volunteer Award for Manitoba.



Kristen Pachet, Muscular Dystrophy Canada, Healthpartners co-chair in Manitoba; Heather Carroll, Heart & Stroke Foundation of Canada, Healthpartners co-chair in Manitoba; Vern Barret; Eileen Dooley, Executive Director of Healthpartners.

2014 World Congress

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Finally, as a young person, the chance to travel to an exotic location, enjoy Brazilian barbeques, and dance the night away at a samba nightclub made the new stamp in her passport all the more worthwhile. The best part about attending conferences like this? "Meeting people of course," she says. "It was a really positive experience because I always make more lifelong friends."

Back in B.C., Michelle is wrapping up her Masters in Neuroscience and making future plans. Whatever the future holds, she is eager to keep learning and living life to its fullest.

To read more about the 2013 World Congress on Huntington Disease go to HDBuzz.net

Enroll!
 Updates from the Enroll-HD global community



Save the Date!

2014 HSC National Conference

Join us on October 24 & 25, 2014
Holiday Inn, Airport West, Winnipeg, MB

“On behalf of the Winnipeg Chapter, we extend an invitation, to our entire HD community, to join us in Winnipeg – the heart of the continent!”

Come to Manitoba, let us show you our friendly hospitality. You will have a great time.”

Vern Barrett, Host Chapter President

Embracing our Strength

our future
our vision
our story

Our Story

Family is at the heart of our community. Our families, researchers and volunteers tell a powerful story of caring people who pull together to improve the quality of life for Canadians impacted by Huntington disease (HD). Hosted by the HSC Winnipeg Chapter, this two day Conference will be filled with inspiration and education: offering families affected by HD the information they need; informing medical professionals of the most up-to-date care practices; and presenting cutting edge information on recent HD research and the future of HD treatments.

Our Vision

Families living with HD, donors, volunteers, clinical staff, researchers, and students will find the conference experience inspiring, engaging and informative. This is an opportunity to come together to network, learn more and be mutually supportive.

Our Future

Featuring prominent HD researchers, Dr. Ray Truant, Dr. Jeffrey Carroll and Dr. Ed Wild, this year's conference will highlight the latest research findings and their meaning. Don't miss Dr. Ray Truant's presentation on his discovery that mutant protein causes the HD protein to fold into a different shape than a typical protein and what that potentially means to the HD community. *Dr. Ray Truant is an Associate Professor in the Department of Biochemistry and Biomedical Sciences at McMaster University in Hamilton, Ontario.*

We welcome back Dr. Jeffrey Carroll and Dr. Ed Wild who, with their unique presentation styles, will explain complicated scientific research and answer questions at the end of each day. *Dr. Jeffrey Carroll is an Assistant Professor of Neuroscience in the Department of Psychology at Western Washington University. Dr. Ed Wild is a Clinical Lecturer in Neurology at UCL Institute of Neurology, Queen Square, London UK, and an Honourary Specialist Registrar in Neurology at the National Hospital for Neurology and Neurosurgery.*

Young People Affected by Huntington Disease (YPAHD) Day

October 23, 2014

Calling all youth! Join us for the 2nd YPAHD Day, a gathering point for Canada's youth affected by HD, a day created by youth, for youth. Look forward to an exciting day, planned by a dynamic team of youth volunteer leaders, filled with thought-provoking discussions, information, support, and fun!

Do you know of a young person interested in attending YPAHD Day 2014?

For more information contact us at ypahd@huntingtonsociety.ca

Funding is available for travel assistance for those who qualify. Please contact us for more information.

What's New

Be Brave, Be Bold, Be Ready National HD 101 Clinical Trial Workshop

October 23, 2014

HSC will host a Be Brave, Be Bold, Be Ready National HD 101 Clinical Trial Workshop and is extending an invitation to those researchers, scientists and clinicians who are interested in learning from one another and building momentum for clinical trial readiness. This workshop is designed to continue the discussions on developing a national strategy and implementation steps to ensure Canada is prepared for HD clinical trials. This workshop will bring clinicians in Canada together to discuss the mechanisms to share best practices and transfer knowledge. We encourage all those connected to the HD community to talk to their health care professionals and promote this groundbreaking workshop planned for the 2014 HSC National Conference.

Our Strength Is Our Grassroots Community

By Julie Stauffer

Since its earliest days, HSC has been driven by volunteers. Today, that is still the case. Chapters across the country create awareness, support local families, and raise more than a million dollars for research and services annually.

How do Chapters get started anyway? It all boils down to vision, determination, good planning, and a healthy dose of fun.

In the small community of Courtenay/Comox on North Vancouver Island, Rick Fischer and Ruth Weber wanted the support that a Chapter would bring. Rick is in the mid-stage of HD, while Ruth's husband recently started showing symptoms.

The duo is working hard to raise awareness and generate interest among local families. Rick, a talented amateur photographer, organized an exhibit of his work last year and donated the proceeds to HSC. Seventeen people attended an information night in May. And while turnout was low at Ruth's August BBQ, she held a successful meet and greet in November. Both Rick and Ruth are looking forward to 2014 and building upon their successes.

That perseverance is important when you are trying to get a group off the ground, according to Devin Bonner, HSC's Manager of Chapter Development. "It does not happen overnight," he says. "It takes time and patience." According to Devin, energy within each local Huntington's community naturally goes in cycles.

In Sudbury, for instance, the Chapter is currently on an upswing, thanks to Rita Deschene. Rita remembers her aunts holding HSC fundraisers when she was growing up. Now, she is keen to do the same, inspired by the energy and ideas she encountered at the 2012 National Conference.

Over the past year, Rita has spoken about genetic testing on CBC radio, organized a very successful fundraising night at a local billiards hall that attracted folks from the HD community and wider communities alike, raising just under \$3,000. In the fall, she spearheaded a gas card raffle that brought in approximately \$1,500.

There is now an official HSC Chapter in Sudbury. Rita started this chapter as a small group working with Angèle Bénard, HSC's Northern Ontario Resource Centre Director, to build a core team and decide what activities they want to undertake. "It is meeting people where they are at," says Angèle. "They are building from the ground up."

Meanwhile, in B.C.'s Okanagan region, one of HSC's newest Chapters is proving just how much a core group of six people can accomplish. Over the past year, this team of firecrackers has organized a run, dance and silent auction, partnered with the local lacrosse team to raise money, and attracted significant media attention. There is no question, though, that the highlight of 2013 was being selected as the Charity of Choice of the five-day Interior Provincial Exhibition, an event that attracts 150,000 people. The Okanagan Chapter organized squadrons of

volunteers decked out in TeamHD t-shirts to staff a booth, put together a parade float, and help out at the 4H auction and the rodeo. Altogether they raised \$38,200, more than double their first year revenue.

Chapter member Laurie Williams credits their supportive hometown of Armstrong, where HD is quite visible and everyone believes in helping their neighbour. "We get amazing support from our community," she says.

Of course, the Chapter deserves a lot of the credit too. This is a group that believes in strategic planning, open, honest communication and having a good time. "We believe that people want to be part of something good and part of something fun," Laurie explains.

Clearly, it doesn't take a lot of people to make a big impact. "Inevitably, these initiatives start with one or two people who say, 'I will find a way to make this happen,'" says Maribeth Meijer, HSC's Director of Family Services and Community Development.

The best part? You are not alone. If you would like to start a Chapter in your area or reinvigorate an existing one, HSC's Chapter Development team would be happy to help. Together they can work with you to assess your ideas and discuss the different opportunities available.

To start a Chapter, host an event or learn more about how Chapters at HSC work, contact us at events@huntingtonsociety.ca or 1-800-998-7398.

HSC's Grande Dame of Fundraising

By Julie Stauffer

Meet one of the Society's best fundraisers. Over the course of nearly three decades, this tall, flamboyantly attractive grande dame has brought in millions of dollars to support HD research, services and education. We are talking about Amaryllis, of course: the hugely popular bulbs we sell each year.

While the campaign is almost as old as the Huntington Society itself, its momentum just keeps growing. "It is in many ways our best goodwill ambassador," says HSC's Development Manager, Jim Martin. "People love it." He credits their perennial appeal to the burst of colour they create in the depths of winter. "It's at just the right time of year for something big and bold and beautiful," he says.

Although the price of each kit increased slightly to \$15 this past fall to cover the rising

costs of production and transportation, we are happy to announce that we had another successful year.

Social media helped to drive some of those sales. Facebook and a successful "Rafflecopter" were used to introduce our Amaryllis to a wider circle of people. However, our biggest kudos are reserved for our passionate and dedicated sellers. "The campaign would not succeed without our volunteers," says Jim. "Many folks have been doing this from the very beginning."

Thank you to everyone, old and new, who sold Amaryllis bulbs last year and to the thousands of purchasers across the country.

Stay tuned for the launch of our 2014 campaign in May! Can't wait until then? Head over to www.inspirehope.ca and plant a virtual bulb.



YOU SUPPORT
Huntington Society of Canada
HUNTINGTON
Société Huntington du Canada

YOUR AMARYLLIS INSPIRES HOPE!
Support the fight against Huntington Disease.

Your purchase supports families affected by Huntington disease (HD) in your community and across Canada. Thank you!

Please visit: www.inspirehope.ca or call 1-800-998-7398

Make An Impact



Make An Impact – Our work is funded primarily by donations, whatever you can give makes a difference.

In Phase two of the Huntington Society's Grassroots to Mountaintops 40th Anniversary Campaign the Campaign Cabinet extends an invitation to donors who wish to contribute by making a donation of \$40, \$400 or \$4,000 in honour of 40 years.

The campaign will officially close at the 2014 National HSC conference in Winnipeg, Manitoba so if you have been thinking of donating, now is the time. Every person who donates will be listed on the Society's new website and be included in the 2013/2014 HSC Annual Report (unless you choose to donate anonymously).

Why donate? Because you are with us every step of the way. Each and every day, your support is igniting action in research, family services, education and advocacy. You strengthen our resolve and renew our passion to make lives better for HD families. You make a tremendous difference. Your gifts help Canadians in your community and across Canada who are confronting HD.

How your gift can help:

- \$40 will pay for 1 hour of counselling for someone who has been diagnosed with Huntington disease.
- \$400 will fund 10 support group sessions to help individuals and families affected by HD to cope with the complexity of managing isolation and depression often associated with HD.

- \$4000 will send several individuals with HD to a retreat and also provide respite care for their caregivers.

You allow us to invest in the most promising avenues of research. You help alleviate symptoms through advancement in treatments. You nurture families in all stages of HD through our Family Services program. You are a voice on the critical issue of genetic discrimination. You support our education programs to assist more Canadians to learn more about HD. Thank you!

Your dollars in action!

1 Invest in world-class research that will lead to treatments to slow and prevent Huntington disease

2012-2013 Accomplishments

- A review of the impact of HSC research funding was completed. Our external expert concluded that HSC has received an excellent return on our investment in HD research
- Attendance at HSC's 2012 National Conference increased by 35 per cent over the previous Conference
- Eight medical sites in Canada are now participating in research.
- HSC received a \$10,000 grant from Rx&D and hosted a clinical trial readiness roundtable with experts from across the country

Focus moving forward

- Continue to build a critical mass of HD research in Canada that will lead to treatments for HD, while encouraging global collaborations
- Continue to forge strong connections to individuals and families living with HD to ensure a strong base for potential clinical participation
- Enhance clinical research in Canada by influencing a successful made-in-Canada model

2 Continue to advocate for families and individuals living with HD and enhance the services we provide them

2012-2013 Accomplishments

- The B.C. Social Worker position was added at the BC HD Resource Centre in Vancouver to expand services to individuals with HD across the province.
- HSC met with genetic fairness champion Senator James Cowan to discuss Bill S-201,

the most comprehensive piece of genetic discrimination legislation proposed in Canada.

- HSC opened the East Central Ontario Resource Centre in November 2012.
- HSC met with the federal Privacy Commissioner, presented at the Privacy Commissioners Summit, and met with Alberta's Finance Minister and Justice Minister.
- HSC attracted significant media coverage of genetic discrimination.

Focus moving forward

- Maximize our connections with HD families and individuals
- Lead efforts to end genetic discrimination

3 Increase the awareness of HD and HSC

2012-2013 Accomplishments

- HSC completed a new communications strategy
- The new PSA campaign was launched, attracting considerable attention
- Resource gaps were identified and HSC developed a schedule to update and create new brochures and fact sheets
- Approximately 10,000 volunteers across Canada contributed to fundraising and awareness

Focus moving forward

- Effectively tell HSC's story
- Create opportunities for stakeholders and interested parties to become involved in the Society

4 Demonstrate leadership locally, nationally and globally

2012-2013 Accomplishments

- HSC's CEO continued to hold executive positions with the Canadian Coalition for Genetic Fairness, Health Charities Coalition of Canada and the International Huntington Association

Focus moving forward

- Increase global collaboration with HD service providers and organizations
- Explore opportunities for joint projects with other service providers (e.g., cultural organizations, First Nations, other neurological disease groups)

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Make An Impact

continued from page 9

5 Strengthen the focus on young people (pre-teens, teens, young adults) affected by HD and enhance the services we provide them

2012-2013 Accomplishments

- HSC created a permanent position on the Board of Directors for a youth representative
- The YPAHD president sits on the Board of the Huntington's Disease Youth Organization (HDYO)
- The policy and procedure manual for our Youth Mentorship Program was developed and the recruitment of mentors began
- Our team worked with youth in the HD community to develop and launch a website that will serve as a hub for resources, events and community building

Focus moving forward

- Educate and advocate for youth-specific concerns and initiatives
- Train mentors and roll out the mentorship program
- Increase the number of youth affiliated with HSC

6 Ensure financial and organizational stability, effectiveness and excellence

2012-2013 Accomplishments

- HSC met the expense management targets for 2012/13. The Society attracted four new major donors, experienced growth, and revenue from the grassroots fundraising events exceeded HSC's targets
- HSC enlisted the services of a chartered accountant consultant to identify operational weaknesses and help increase efficiencies
- HSC became a member of Imagine Canada in May 2013, a key step toward accreditation
- Overall the 2012 National Conference was rated very highly

Focus moving forward

- Achieve or exceed revenue growth targets
- Set the example for organizational stability, effectiveness and excellence
- Retain and nurture a high-performing team

Now, we need to keep the momentum going. For more information on the Grassroots to Mountaintops 40th Anniversary Campaign or to contribute in any way, email us at info@huntingtonsociety.ca or call 1-800-998-7398.

New PSA Campaign

By Cyndy Forsyth

Last May, the Huntington Society of Canada launched a new Public Service Announcement (PSA) campaign called, "Do You Really Want to Know?" in conjunction with Huntington Disease Awareness Month. The campaign highlights Huntington disease (HD) and why HSC is leading the charge for genetic fairness in Canada. This campaign has put genetic discrimination on the national stage through the print and television media.

The campaign educates Canadians on when genetic discrimination occurs, when people are treated unfairly because of actual or perceived differences in their genetic information that may cause, or increase the risk of developing, a disorder or disease. The campaign also informs Canadians on how genetic information is complicated and should not be used against anyone.

"Genetic research is big business in which Canada has invested billions of dollars. There are substantial benefits to genetic research," says Bev Heim-Myers, CEO and Executive Director of HSC and the Chair of the Canadian Coalition for Genetic Fairness (CCGF). "However, without protection against genetic discrimination, there are people who are reluctant to come forward for testing, to benefit from early detection and to participate in clinical trials."

Please support this initiative by calling or writing your Senator. Let them know this is important and you want genetic discrimination to end. The Canadian Coalition for Genetic Fairness has the updated information regarding legislative initiatives, including sample letters people can use to contact their political representatives and a complete list of Senators, MP's and MPP's.

To view the entire campaign go to www.huntingtonsociety.ca and view the Media section PSA Campaign which includes the brochure, poster, newspaper advertisements, and TV commercials.

The Huntington Society of Canada is the founding organization of the Canadian Coalition for Genetic Fairness (CCGF). CCGF is dedicated to preventing genetic discrimination for all Canadians.

HSC Symposium – From the Lab to Your Home

On October 26, over 200 participants across the country joined together for HSC's latest National Symposium. This year's event focused on two equally important topics: Predictive Testing & Genetic Counselling and The Process From Research Discovery to the HD Population (the process from discovering potential treatments and the steps to have them tested and ready for the HD population).

Meghan Ferguson, a genetic counsellor from the Maritime Medical Genetics Services in Halifax, was one of the guest speakers. Meghan provided an enlightened presentation on what to expect and some of the questions to ask before and during the testing process.

The second portion of the Symposium was dedicated to understanding the research discovery process and what it takes to get treatments to the HD population. HSC's CEO,

Bev Heim-Myers, was joined by Dr. Oksana Suchowersky and Dr. Simonetta Sipione as they explored the different phases of the discovery process, the phases of clinical trials and what exactly has to happen in order for a treatment to be approved in Canada.

Overall the National Symposium was a success that attracted many new families and earned high scores from participants. Over 200 Canadians tuned in to this year's event which included an option to participate from the comfort of home. Chapters used the event as an opportunity to get together, and ten sites across the country complemented this year's event with their own programming.

To view the presentation in its entirety please go to www.huntingtonsociety.ca and click on Symposium.

Speaking His Truth: Ken Gane

By Julie Stauffer

Five years after his HD diagnosis, Ken Gane is ready to speak up: about living with a fatal brain disease, about the overdose that put him in hospital for three months and about letting go and finding peace in the moment.

Ken has always been driven to help people. Over the years he served as a personal support worker, a counsellor, and a youth worker assisting young people with fetal alcohol syndrome. However, Huntington disease led to his career ending in his early 40s.

It started with telltale jerking movements. At first Ken ignored them, convinced he hadn't inherited his father's Huntington's gene. But when the diagnosis came, he knew exactly what it meant, having watched his father become more and more incapacitated by HD. "It's tough when you see someone deteriorate like that," he says.

Perhaps that's what was in Ken's mind when he swallowed the fistful of drugs last fall. Maybe, he just wanted to take something that would solve his sleeplessness. Or his antidepressants might have triggered suicidal thoughts — a possible side effect during the first few months of treatment. He doesn't know; he can't remember anything leading up to that moment.

When his sister Lorraine found him in the kitchen, surrounded by pill bottles, he couldn't speak coherently. By the time the paramedics wheeled him into the emergency department, he was having seizures.

Ken spent several days in a coma and several weeks on a ventilator. Things went from bad to worse when he developed pneumonia. After that came kidney failure brought on by the antibiotics prescribed to treat the pneumonia.

For a long time it was touch and go. His family visited him every day, stringing up prayer flags around his room. Neighbours rallied to help, while people around the world prayed for him.

Throughout it all, says Lorraine, Ken showed amazing strength and courage. "He just agreed to keep going, agreed to the procedures," she recalls. "What I saw in him was so inspiring."

Slowly, that determination helped him turn things around. He got off the



ventilator. He took his first steps after lying motionless in the ICU for a month. Eventually, he was able to remove the feeding tube, and his hemoglobin level started to increase. On December 24th, his doctors decided he was well enough to spend Christmas dinner at home with his family. "That was huge," says Lorraine. Finally, on January 15th, he was discharged.

Three months after the ordeal ended, Ken's life has changed. He still has HD, of course, but he is walking a couple of hours a day, rebuilding the muscles that wasted away in hospital. These days, he relies on brain exercises and meditation to cope with his bouts of anger and agitation. Instead of lashing out, he's learning to relax and let things go.

He has also regained a sense of purpose. During his stint in hospital, he discovered that he could make a difference for the other patients around him: sometimes by talking with them, sometimes just by being there. "You can always help, no matter what kind of condition you're in," he says.

At the same time, he recognizes the value of reaching out for support, whether it's from family, friends, professionals or even strangers. No matter where you go, he says, there's always help, you just have to ask for it.

Most of all, he has come to accept what is. "This is what I've learned in hospital: surrender to the moment," he says. "I think our spirit wants us to learn and grow. It's always teaching us things in the moment, and I think it's up to us to stop and listen."

It's a simple lesson, but profoundly powerful. Now Ken wants to share it with others. And, by telling his story, he's doing exactly that.

If you have a story to share please contact us at info@huntingtonsociety.ca or call us at 1-800-998-7398. It is inspirational stories like Ken's that help everyone.

Celebrating Our Heroes

Dr. Mark Guttman and Francine Robert

By Josh Martin

Francine Robert still remembers the first HD client she saw, back in 1989. He was 22 years old. "When I saw this young man in the community living at home with HD and the challenges he was facing, it just broke my heart," the North Bay genetics nurse recalls. "I swore that I would help him."

Back then, HD patients in this high-prevalence region went without specialized care. With no Neurologist with Huntington's expertise within 350 kilometers of North Bay, local family doctors felt overwhelmed trying to provide the complex care this disease demands.

So in 1995, Francine and HSC co-founder Ralph Walker invited Dr. Mark Guttman, a Toronto-area neurologist, to speak at an HD Family Day event in North Bay. "They were a bit sneaky," Dr. Guttman recounts. "They said, 'since you're coming here, can you see some patients?'" The Northern HD Clinic was born. Since then, Dr. Guttman has been returning to North Bay every six months to offer his expertise.

From day one, the clinic has been a uniquely collaborative effort between Dr. Guttman, Francine and HSC's Northern Ontario Resource Centre Director. The entire team made up of a doctor, nurse and social worker, sit down with each client to discuss and address their needs. Between Dr. Guttman's visits, the rest of the team follows up with families and makes home visits.

More recently, thanks to telemedicine, the clinic's reach has expanded to include all corners of underserved northern Ontario, from Sault Ste. Marie to the First Nations community of Attawapiskat, perched at the edge of James Bay. The ability to connect remotely means that Dr. Guttman can be sitting in his office in Toronto while seeing a patient in a nursing home in Elliot Lake, hundreds of kilometres away. It also means that Francine can participate from North Bay while family members teleconference in from yet another location. "We create the feeling that everybody is in the same room," says Dr. Guttman.

Whether making a house call to someone in Sudbury, seeing a patient at the bricks-and-mortar clinic in North Bay or discussing treatment options with family members in Moose Factory over video conference, this small but mighty team has helped expand HD support to remote communities for nearly two decades. "There's not a challenge that cannot be met, that we cannot work through, if we work together," says Francine.

And together, they remain committed to making a difference in Northern Ontario. "The reality is people with Huntington's don't live in urban areas necessarily, and we need a way of connecting with them to provide care, to open the door for them to get involved in research, and to give them hope as well," says Dr. Guttman. "This is what it's all about: providing service and hope to people."

Making a Difference: Unexpected Successes: Small Towns Coming Up Big

This past year saw some amazing success stories from unexpected places. In Pincher Creek, AB, population 3,600, local volunteers hiked up a mountain and came down with approximately \$25,000. In Baie Verte, NL, population 1,400, volunteers gathered for what they thought would be a walk with an intimate group of friends and family, and ended the day raising \$10,700. In Pierson, MB, population 250, a group of dedicated volunteers engaged their community for a run, and raised almost \$17,000.

Cas Main-Freeman and several people from her team of caregivers, known locally as Team Cas, attended the 2012 National Conference in Toronto. "I was so inspired attending the Toronto Conference last fall and couldn't stop sharing that energy with anyone who would listen when I returned to Pincher Creek," says Bev Everts, a member of Team Cas. Just months after the Conference, they connected with HSC's Chapter Development team and started to plan an event.

What better way to celebrate the 40th Anniversary Grassroots to Mountaintops campaign than to climb a mountain! The support from Pincher Creek and surrounding areas was overwhelming. What started as a small group of people hiking up Corner Mountain with a goal of raising \$3,500 and increasing awareness, became 200 people making the 2,254 metre climb and raising an amazing \$25,000. "It was so awesome to see the spirit and compassion of our community come together this weekend," adds Bev. Before the event was over, Team Cas was already making a list of things to do for the 2014 Climb for Huntington's, and are excited to add to this year's success!

Susan Fitzgerald phoned the Chapter Development team with a desire to plan a walk and run to raise funds for the Huntington Society of Canada. She didn't know exactly what to expect, but had the will and desire to start something from nothing. Utilizing HSC's online fundraising tools, Susan was able to engage friends and family across Canada to

join her in supporting the event. Receiving fundraising incentives and give-aways from HSC, Susan was able to increase awareness in Western Newfoundland while raising a total of \$10,700. Not only does Susan plan to host her walk annually, but participants in her event have decided to host a second fundraising and awareness event, showing that Susan's run truly was a spark plug for her community.

After previously participating in the Winnipeg Run for HD, Terri Alphonso and Cindy Horrigan decided that in 2013 they wouldn't make the 4 hour drive, instead they would plan something closer to home in Pierson, MB. On June 14, the first annual Sprint into Summer was held. "We were blown away by everyone's generosity, excitement, and participation," says Terri. Adopting a 'pay-to-run' structure, the event had over 90 participants and close to 250 additional supporters for the BBQ. Terri and Cindy tell the story of Shannon Lee, a woman who

committed to shaving her head if she raised over \$800. Shannon started the day with \$20, by the time the run came she was up to \$590, and at the finish line she was over \$1,200 and her head was shaved right then and there! The community support was incredible; a combination of run registrations, pledges, and generous donations brought the event total to approximately \$17,000! Building on the success of this year, Terri and Cindy have plans for a 2014 event and promise that it will be bigger and better!

Small towns across Canada are making a huge difference in the mission of the Huntington Society of Canada. Are you interested in fundraising and increasing awareness in your home town? Give HSC's Chapter Development team a call, and let us show you how we can help!

To contact HSC Chapter Development Team email us at events@huntingtonsociety.ca or at 1-800-998-7398.



Pincher Creek, AB: Cas on a horse



Pincher Creek, AB: Group at top of Corner Mountain



Pierson, MB: Tania Kyle-Robinson, Terri Alphonso, Jody Jacobson



Baie Verte, NL

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's community.

With your help, we are continuing to improve the quality of life for people with HD, cultivating strength and resilience in the Huntington's 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.