

HORIZON

RESEARCH • SERVICE • EDUCATION

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Pillars of the HD Care Community

By Josh Martin

It is hard to overstate the complexity of Huntington disease (HD) symptoms or the profound impact it creates on families generation after generation. For more than 20 years, three pillars of the HD medical community have addressed that complexity by pioneering multidisciplinary approaches. In doing so, they have created examples of excellence that are transforming care for patients and their families.

North York General Hospital's Multidisciplinary Huntington Disease Clinic

Joanne Honeyford remembers how HD care looked at North York General Hospital (in Ontario) before the multidisciplinary clinic started in 1994. A patient could see a neurologist on Monday, come back on Wednesday to see a psychiatrist in a different part of the hospital and meet another specialist the following week somewhere else entirely. "Before the clinic, it was more disjointed,"

the genetic counsellor recalls. "So we thought, how can we bring it all together to best meet the patients' needs?"

The answer was assembling geneticists, neurologists, a psychiatrist and genetic counsellors under one roof to provide holistic treatment and continuity of care.

Today, the clinic is a beehive of activity. It serves over 200 patients each year, some coming from as far away as Thunder Bay (1400 kilometres approximately a 15 hour drive). What's more, the hospital's molecular lab provides genetic testing for the entire province.

Recently, the team has also become involved in clinical trials. "I feel like together with the patients, we're a team, and we're trying to find a cure for this disease," says Clare Gibbons, who coordinates the clinic's research efforts. "There are some really exciting clinical trials in the pipeline, and when those come, we want an opportunity to be able to contribute."

UBC's Centre for Huntington Disease

Further west, Dr. Michael Hayden also recognized the value of a team approach, establishing the Centre for HD in 1996. HSC's Susan Tolley was there from day one, adding her expertise as the Director of the BC Huntington Disease Resource Centre. She informed families and professionals about HD, connected individuals to various resources and assisted individuals to create the highest quality of life for themselves and their families. She works alongside a team comprised of social workers, neurologists, psychiatrists, genetic counsellors and an ever-growing research team. "What we do together as a team for our B.C. families is greater than what we can do on our own," she says.

Initially, the clinic started as a once-a-month offering but quickly evolved to once a week in the face of growing demand. Today, it is ranked as the top multidisciplinary clinic in North America by the HDSA, drawing 300 patients a year (primarily from British Columbia and the Yukon but families from other Canadian provinces are seen at the clinic as well).

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Saluting Joanne Honeyford



After more than 20 years of service, Joanne Honeyford retired at the end of November from North York General Hospital's multidisciplinary HD clinic. As a member of the founding group that started the

progressive clinic, the genetic counsellor was there from the very beginning.

She was instrumental in implementing a multidisciplinary approach that improved the standard of care for her patients and also gave her the opportunity to know them on a much deeper level. "You establish a relationship, and

it can be quite a powerful bond," she says. "You celebrate their joys, you celebrate their losses."

Meanwhile, her clients taught her how to make the best of a situation and how to move forward. "It is quite a privilege to be able to follow people through such a long period of time and through such challenges," she says.

From all of us at the Huntington Society of Canada and the HD Community, thank you, Joanne, for the difference you have made in the lives of countless patients and families.

The Huntington Society of Canada is actively working with the medical community to establish more HD multidisciplinary clinics in Canada. For more information or to learn how you can help visit www.huntingtonsociety.ca

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HORIZON

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Horizon is the newsletter of the Huntington Society of Canada. Published throughout the year, its purpose is to convey information to individuals with Huntington disease and their families, health care professionals, friends and supporters.

Huntington disease is a hereditary brain disorder which has devastating effects on both body and mind. The symptoms, which may include uncontrollable jerking movements and relentless cognitive and emotional impairment, usually appear between the ages of 35 and 55, and gradually worsen over the 10-20 year course of the disease. As yet, there is no meaningful treatment.

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

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Note from the CEO

Happy New Year! Looking back at 2016, I am proud of how much we were able to accomplish. We have grown our revenue and achieved every one of our program objectives. Meanwhile, we have continued to increase our NAVIGATOR and NEW PATHWAYS funding, investing more than a million dollars in highly promising research projects.

Impressive as it is, that figure does not include the exciting research we are co-funding in partnership with Brain Canada. This past fall, we awarded Dr. Simonetta Sipione and her team a three-year, \$900,000 grant to build on her earlier discovery that gangliosides can reverse HD symptoms in a mouse model. We are now sitting down with Brain Canada to review proposals for a new wave of research funding this year.

Perhaps the most significant achievement of 2016 was the great strides we made toward genetic fairness. In 2008, when the Canadian Coalition for Genetic Fairness (CCGF) was first established, genetic discrimination was not on the government's radar at all. So when I was in Ottawa in October, it felt incredible to watch five MPs stand up in the House and speak so eloquently about the importance of Bill S-201. There is still work to be done, but I truly believe we will soon see the legal protection that Canadians need and deserve.

Of course, we also held our National Conference in Halifax in the fall, fuelled by good old East Coast hospitality. Our volunteers ensured everyone was warmly welcomed and enjoyed a wonderful time.

I was particularly thrilled to see so many new faces. About 40 percent of the people at the conference were first-time attendees, and based on the feedback we received, they had a fabulous experience. One individual told me how Huntington disease had left them feeling very

isolated, but now they know they are not alone. That is the power of this community.

We did some bold things at the 2016 Conference, including organizing a panel on assisted dying. This is a difficult topic, but our community members deserve to have a safe place to talk about the issue. Ultimately, each individual needs to make an informed choice, and I am proud that we were able to provide solid, reliable information from a variety of perspectives.

Our YPAHD members were also out in full force in Halifax. Every year, more young people join HSC's national youth chapter, while others sign up to support their younger peers in our world-leading youth mentorship program. When I see their energy and commitment, I feel confident our future is bright.

The aforementioned is not the only reason for optimism. When we launched our Believe campaign in 2015, we set a goal of raising \$3 million over the next three years: \$1.5 million for research and \$1.5 million for services. Just a few months later, we are already more than halfway to reaching that target.

Thank you for your continued support. We are now able to reach more people affected by HD than ever before. Most importantly, with numerous clinical trials underway, meaningful treatment options could soon be a reality. While that day cannot come soon enough, the future looks bright.

Bev Heim-Myers
Chief Executive Officer



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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!



\$900,000 grant could lead to key pieces of Huntington's puzzle

By Julie Stauffer

In 2012, the University of Alberta's Dr. Simonetta Sipione made global headlines when she announced that her lab had reversed the symptoms of HD in a mouse model, using a brain chemical called GM1.

GM1 is a type of ganglioside: natural chemicals that are abundant in the brain and that help brain cells communicate with each other. Earlier, Dr. Sipione and her team demonstrated that mouse models with HD have lower-than-normal levels of GM1. They followed that up by demonstrating that injecting GM1 into the brains of mice with HD could make their Huntington disease symptoms disappear.

Now, thanks to a three-year \$900,000 grant from the Huntington Society of Canada and Brain Canada, she is delving deeper, investigating exactly how GM1 creates those dramatic results. Understanding the mechanism in more detail will help them translate their discovery into potential treatments. "The more we know about how GM1 works, the easier it is going to be to move it to a clinical trial," she explains.

Over the next three years, Dr. Sipione will head up a multidisciplinary team of scientists and clinicians working on a variety of fronts. On one side, they will determine molecular changes that are triggered by GM1 in Huntington models, as well as how GM1 affects the communication among brain cells and neuroinflammation.

On top of that, a colleague will develop sophisticated methods to analyze gangliosides using mass spectrometry, increasing the researchers' ability to detect gangliosides in samples from individuals with HD.

But basic science is just one half of the ambitious project. The other half, headed up by University of Alberta neurologist Dr. Oksana Suchowersky, investigates whether the levels of gangliosides are decreased in blood and spinal fluid in individuals with HD, which could serve as a biomarker for HD progression.

Biomarkers are crucial to judge the effectiveness of any potential treatment – including GM1 – because they provide a clear, impartial way to quantify the progress of HD. According to Dr. Suchowersky, that could be difficult right now. "We have no easy way of measuring HD progression," she says. "While we have clinical scales such as the UHDRS [Unified Huntington's Disease Rating Scale], they're not very sensitive."

Because HD advances relatively slowly, the more sensitive the biomarker, the more quickly researchers can determine whether a potential treatment is helping or not. "What we are hoping to find is that GM1 and other gangliosides are an accurate measure," says Dr. Suchowersky.

That is where families with HD come in. At three centres across the country, Edmonton, Calgary and Montreal, Dr. Suchowersky and her colleagues will take blood samples from 80 people who carry the HD gene. That number includes some who have not developed Huntington disease symptoms, some in the early stages of the disease and some with moderate symptoms. The investigators will then compare those blood samples with samples taken from people who don't have the HD gene.

They will also take a second set of blood samples two years later to assess whether the GM1 levels have changed. Ideally, they hope to see a clear drop in GM1 and/or other gangliosides as the disease gets worse, while

levels stay steady in people without the HD gene. However, Dr. Sipione cautions that they may not observe significant changes over the course of the study, or they may discover levels vary too much from one person to the next to provide a useful measure.

That is why the investigators also plan to take samples of cerebrospinal fluid from patients at the Edmonton clinic and test them for GM1. It is a more invasive procedure than collecting blood: researchers have to insert a needle between the vertebrae of the lower back. But because cerebrospinal fluid bathes the brain, it provides a more accurate picture.

This research highlights the critical role that patients and families play in the research process. Meanwhile, Dr. Sipione emphasizes the importance of donors, large and small, in driving progress. "We are very grateful to the donors and the work that the Huntington Society of Canada – in this case with Brain Canada – [does] to promote research," she says.

Although important achievements don't happen overnight, each step brings us closer to treatments. "Translation of fundamental discoveries takes time and patience and lots of work," she explains. "It's a little bit like composing a big puzzle with hundreds of different pieces. Each piece matters. You can't complete the picture until you have all the pieces."

If all goes well, this particular project could add several crucial pieces to the puzzle.

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

Celebrating a quarter-century of service: Paul Klodniski

By Julie Stauffer

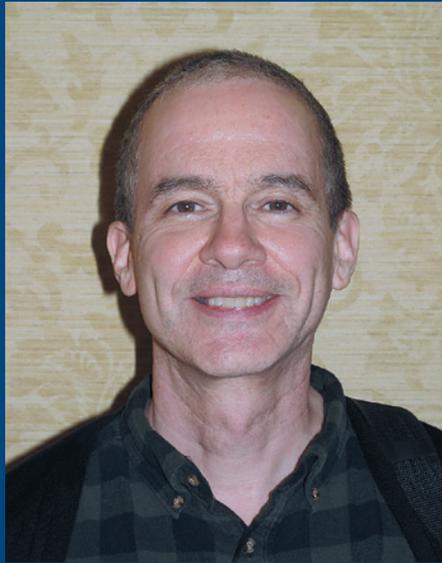
Paul Klodniski took a leap of faith when he left his position as a school board consultant in 1991 to head up the Eastern Ontario HD Resource Centre. But when he met Ralph Walker and the Society's staff, so welcoming and so determined to make a difference, he knew he had made the right choice.

In the 25 years since he joined the Society, one memory in particular stands out: the discovery of the Huntington disease gene in 1993. He still chokes up when he recalls the euphoria. His phone just kept ringing, and everyone within the Huntington community was filled with excitement and joy. "It was such a big leap forward," he says. "They realized what a fundamental change it was going to be for the science of the illness and the potential of finding some kind of treatment."

There have been many quieter triumphs over that quarter-century as well. Paul's greatest satisfaction comes from helping long-term care providers understand HD. Often when a resident with Huntington disease moves in, it is the first time the staff have encountered this complicated disease. As Paul has discovered, spending just a single hour briefing them about Huntington disease can make a big difference for that resident for years to come.

Paul also loves running the Ottawa support groups, helping clients navigate major challenges and making the road ahead a little smoother. However, he is quick to point out that he learns as much from them as he gives. "I always feel my families who are impacted by HD are my best teachers," he says.

When your work centres on a fatal illness, tough moments are inevitable. During those difficult



times, Paul's supportive Family Services colleagues make a world of difference.

Despite the challenges, the HSC veteran radiates energy and optimism. "I really feel like we are in a new golden era," he says, citing a host of reasons. He mentions the leadership of the Society's CEO, Bev Heim-Myers, and Angèle Bénéard, Director of Family Services, who has so capably stepped in to fill the shoes of outgoing Family Services Director Maribeth Meijer. An energized Ottawa chapter is organizing all kinds of activities. Youth across the country now have access to world-leading programs. Meanwhile, we are on the brink of seeing genetic fairness legislation in Canada.

Most exciting of all, Paul points to all the new research trials in progress, including several studies in Ottawa. "Stuff is happening," he says. "It just seems like the odds are in our favour."

Giving thanks to our sponsors: Clearwater Seafoods



By Julie Stauffer

For 40 years, Clearwater Seafoods has been supplying the world with premium, wild-caught seafood. The Nova Scotia company has grown from a two-man operation to one of the world's leading harvesters, processors and marketers of sustainably sourced seafood, employing 1,900 people around the world.

Clearwater believes in investing in the long-term health of our oceans, ensuring they continue to provide the shellfish so many of us enjoy. It also believes in investing in the health of communities where it operates.

Employees donate time to answer phones in the annual IWK telethon for children's and women's health, pick up debris from coastal shorelines in beach clean-ups each year and take part in countless events to raise funds for charitable causes.

Meanwhile, through Clearwater Cares, the company makes financial contributions to support organizations locally, nationally and internationally. This year, that included sponsoring HSC's National Conference in Halifax.

Clearwater's cofounder and chairman, Colin MacDonald, was inspired to support the conference after hearing about it from a close business associate. He was particularly interested in HSC's efforts to support youth affected by HD and also impressed by the Society's mandate and community involvement.

"We are proud to make financial contributions in support of community organizations, particularly those with a focus on children's health and welfare," says Diana Hanus, Senior Marketing Manager of Clearwater Seafoods. "The Huntington Society of Canada was a perfect fit!"

On behalf of the hundreds of families who attended our conference, thank you, Clearwater, for your generous support! To learn more about the Society's sponsorship opportunities, email us at info@huntingtonsociety.ca or visit www.huntingtonsociety.ca

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



Making a Difference

Stan Weber: torch-bearer for the cause

By Josh Martin

For Stan Weber, supporting the Huntington cause has been a family priority ever since his mother, Shirley, was diagnosed with the disease. His parents were a driving force behind the Calgary chapter, while his dad, Jerry, served on HSC's board of directors for many years.

Stan's support has taken the form of generous financial donations, including sponsoring fundraising events like the recent Camrose charity golf tournament. He has been a key supporter of the Society's capital campaigns, serving on the Road to Triumph cabinet in 2003 and contributing to our current \$3 million *Believe: Transforming Tomorrow Together* campaign.

And whenever we need to get folks – or flowers – from point A to point B, Stan has offered up the services of his school bus company, First Student Inc. Over the years, First Student has delivered hundreds of cases of amaryllis and transported dozens of campers to HSC's therapeutic retreats in B.C. and Alberta.



Although Stan's mother passed away several years ago, HD continues to affect his siblings and their children. He thinks of his brother who carries the gene. "I realized it was too late for my mother when she was going through it," he says. "But I am hopeful something will develop before it is too far along with him."

While he would love to see more support from the public sector to accelerate promising research, Stan knows that it's crucial for groups like HSC and the broader Huntington community to step up. "The reality is there is not enough research money available through the government funding," he says. "It takes some ground-up, grassroots support."

Stan is determined to keep up that grassroots support however he can, continuing to carry the torch passed on by his dad. "My father was always active with the Huntington community," he says. "As long as I am around, we will maintain that, and hopefully we can get the third generation active."

Do you know someone making a difference in our community? Email us at info@huntingtonsociety.ca and we will feature their outstanding efforts.

All in a day's work

By: Sobia Khan



Her family has dealt with Huntington disease for longer than she can remember and this past summer, Katie Ridpath found a new connection to HD as an intern at the Huntington Society of Canada's national office.

After her grandmother passed away in January, many local HSC chapters and volunteers met her family to say their goodbyes and give their condolences. "It was really touching that so many people came to support our family in our time of loss. Seeing that, it really pushed me to want to work with the organization and see what I can do to help better my family and the ones that are affected by HD," says Katie.

As a member of HSC, Katie worked primarily on the Development and Marketing team. She was able to lend her strengths and skills to many different aspects of the team including creating content and scheduling posts for our social media accounts, working on our blog, assisting with amaryllis promotions and providing fresh insight on the design of our website.

Katie's internship with us marked her first foray into the non-profit world. "It was an unbelievable opportunity. I learned so much not only about how an office works, but how certain aspects of running an office are dealt with differently because of the community the Society serves," says Katie.

Before joining us, however, Katie had quite a different view of internships. She notes that her role at HSC included an interesting mix of freedom and responsibility. "I thought it [internships] meant just assisting other people, with projects that they're already working on rather than having the freedom to do the projects that I did and have my own say and input on how we should do things."

Thanks for joining us over the summer, Katie. Your invaluable efforts make a difference in the community we serve.

If you are interested in participating in an internship with the Huntington Society of Canada, please reach out to us at info@huntingtonsociety.ca or call 1-800-998-7398.

A tradition of giving

By Julie Stauffer

Alberta resident Janet has played many roles over the course of her life. Cattle rancher. Teacher. Wife, mother, grandmother. And sterling supporter of the Huntington disease cause.

She and her husband knew nothing about HD when his sister was diagnosed with the disease. Not long afterwards, he also began showing symptoms.

They reached out to the recently established Huntington Society of Canada (HSC). The HD gene had not been discovered at that point, but through HSC, they learned about global research efforts to identify it.

Keen to contribute, Janet and her husband contacted Dr. Michael Hayden at UBC to see if her husband could donate tissue when he died. When he passed away on Christmas Day, Janet

undertook a two-hour drive through a raging blizzard to ensure his brain could help further Huntington disease research.

Janet has plenty of motivation to raise money for research. She buys amaryllis kits each year, makes an annual donation and supports events for the Society.

Adding HSC to her will was a natural next step. "It feels wonderful," she says. "My late husband always believed a treatment would be discovered" – and through her legacy, Janet is helping to realize his vision.

Thank you to Janet and the many Summit Society members who have chosen to include the Huntington Society of Canada in their will. Joining their ranks is easy. Call us at 1-800-998-7398 or visit www.huntingtonsociety.ca/legacy-giving for more details.

Saluting our Family Services Staff

By Julie Stauffer

Our social workers and resource centre directors are a special breed. As anyone within the Huntington disease community can testify, HD is a complex and challenging disease in so many ways. Our team rises to that challenge – and frequently goes beyond the call of duty – to help everyone within a family get the support they need to live their best life.

Here is a glimpse at how four different family service staffers across the country make a difference each day.

Tim Bayliss, Okanagan Kelowna & Area Family Services Worker since 2005

Tim Bayliss serves families in B.C.'s Interior, from Kamloops in the north to Penticton 200 kilometres south.

For anyone within the region who tests positive for the HD gene or receives an HD diagnosis, Tim is a local Family Services Worker. He is there to help them navigate a mass of difficult emotions and provide information on HD and on local service agencies.

"The Huntington Society is such a valuable resource for people with HD and their families because they know they are not alone in their journey," he says. "We are always there when they need us."

Although he cannot make Huntington disease go away, he can provide practical help as the disease progresses – filling in forms, arranging home care visits, connecting a family with a much needed service. For Tim, there is no one-size-fits-all approach. Everyone has different needs, he explains, and everyone responds to Huntington disease in different ways. That requires sensitivity. "I think it is important to meet people where they are at," he says. "They need to reach out in their own time, in their own kind of way."

He also recognizes that HD touches everyone within the family, so he is there to support every member.

Officially, Tim's position involves just 10 hours of work each month, but he had put in extra hours to cover the social worker position in Vancouver until the position was filled this past November. Nor does his commitment end with paid work. Tim frequently volunteers at the annual B.C. therapeutic retreat, volunteering his own time to help people in the early and mid-stages of the disease enjoy an empowering and inspiring break. He also keeps in contact with the Okanagan

Chapter and volunteers at the annual Walk/Run for HD in Vernon, BC. This gives him the opportunity to see families on a casual and fun basis.

"I have been very privileged just to be part of their lives and to help them in some way," he says.

Barb Horner, Nova Scotia & PEI Resource Centre Director since 2004

Barb Horner believes in giving 100 per cent to every client. Like Tim, she recognizes that every person and every situation is different, so flexibility is key. For Barb, that starts with scheduling.

"I am accessible whenever a family needs me to be," she says. "If a family can only meet me on a Saturday, I will meet on a Saturday. If it is in an evening, I will meet on an evening." And unlike so many of the professionals her clients deal with, Barb does not have a wait list. Whenever families need her, she will juggle her agenda so that she can respond.

In other cases, families may not be ready to connect – especially in the case of a recent genetic test or diagnosis. In that situation, she'll ask if she can add them to her mailing list and send an occasional newsletter. "It is trying to open that door to them so that they have a sense of who I am, what I do and that HSC is going to be here for them," she explains.

A big part of her job involves building networks across Nova Scotia and Prince Edward Island so that she can connect families to crucial services: housing, homecare, dieticians and more. In many cases, that doesn't simply mean passing along contact information. Barb has met with school guidance counsellors to ensure children get appropriate support and briefed new homecare workers to help them fully understand HD.

If she does not have answers, she will search them out. "We are doing our best to increase and improve quality of life for folks," she says. Ultimately, her goal is to give families peace of mind and a sense of security, knowing that they have the support they need to thrive.

Marthe Gautreau, New Brunswick Family Services Worker since 2000

For 16 years, Marthe Gautreau has been serving the entire province of New Brunswick. Initially, she was hired to work 10 hours a month. More recently, that got bumped up to 15. And when families need her, she has put in as much as 30 hours a month – on top of her full-time job with New Brunswick's Department of Social Development.

How does she keep up that kind of commitment? The families, she says. "They go through so much, and I find they have a lot of courage," she says. "They stay positive."

Marthe makes a point of meeting personally when she connects with a new family, even if that means a five-hour drive each way. "I find if I see their living surroundings and if I can do a face-to-face contact, it helps them and it helps me too," she explains.

She has organized annual Christmas parties – a chance for families to get together, enjoy some great food and take home a small gift.

One of her most important jobs is advocating on behalf of her clients. That might mean meeting with an employer to explain why a client needs to apply for long-term disability or ensuring her clients in long-term care get the time and assistance they need during meals.



continued from page 6

Sometimes that requires thinking outside the box. Right now, for example, she is puzzling over how to find a coach to help a particular client who struggles with the motivation to do occupational therapy exercises.

"For me, excellent service is if we can get to know our clients well, know what's important to them and try to get those services in place," she says.

Bernadette Modrovsky, Northern Alberta Resource Centre Director since 2014

Bernie Modrovsky describes herself as an advocate, a sounding board, an educator and a connector for families across Northern Alberta. A typical day might see her working with a psychiatrist to convince government funding agencies that a client should qualify for housing, helping another client on long-term income support get extra dollars for diet and introducing the idea of homecare to a third.

You can also find her helping a family member strategize the best ways to support a loved one recently diagnosed with HD and working with a long-term care facility to help a resident with HD get out occasionally to enjoy a show or play some pool.

This past winter, she ran a five-week caregiver support group focusing on grief and self-care. One of the best moments was helping the group compile a list of how they boost their resilience. It turned out to be an impressively long list, helping them realize that they have skills and knowledge to stay strong. "That was very, very powerful," Bernie says.

In all her work, Bernie brings patience, a sense of humour and strong beliefs in treating her clients the way she would want to be treated.

"There are lots of things [that] I cannot do anything about. I cannot stop the progression of the disease. There are times when I cannot get services for people," she says. But she can, as she puts it, walk the path with them, ensuring they do not feel alone.

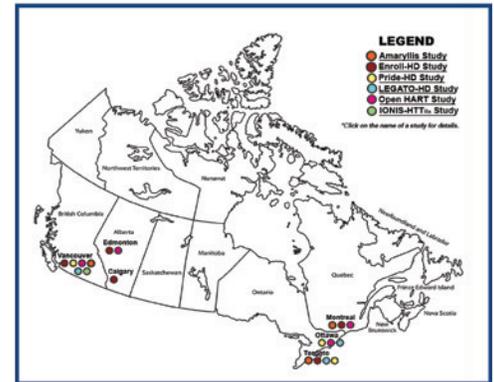
As a relative newcomer to the HD community, Bernie frequently draws on wisdom of her colleagues on the Family Services team. "They amaze me, the people I work with. They are so dedicated. They are such wonderful advocates," she says. "They are just very special people."

We could not agree more.

Has your Family Services Worker or Resource Centre Director made a difference for your family? We would love to hear. Email us at info@huntingtonsociety.ca or call 1-800-998-7398 and share your story.

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.

Electronic receipting now available from HSC

HSC donors now have the option of receiving electronic receipts! Help us reduce the cost of postage.

To sign up, contact us at: donations@huntingtonsociety.ca

HealthPartners Update

By Cyndy Moffat Forsyth

Eighty-seven percent of Canadians are likely to be diagnosed with a major illness. That comes with a heavy price: \$90 billion in treatment and lost productivity every year. The Huntington Society of Canada is proud to be one of the member organizations of HealthPartners, an organization committed to improving the health of Canadians.

HealthPartners raises funds for its 16 member organizations in a variety of ways, including the annual Government of Canada Workplace Charitable Campaign (GCWCC), Canada's largest and most successful employee giving campaign. At HSC, Jeff Hoffman, Senior Manager of Development, has taken the HealthPartners' torch and will represent the Society on the national board of directors.

The GCWCC is where federal government employees and retirees in hundreds of workplaces

generously contribute to more than 4,000 charities of which HealthPartners and its 16 members (including HSC) are grateful recipients.

Jeff will not only sit on the national board of directors but also manage the volunteers who help to represent HSC during the campaign. Jeff takes over from Cyndy Moffat Forsyth, who sat on the board since 2008. "This is a great opportunity for Jeff and for HealthPartners," says Cyndy Moffat Forsyth, Vice-President of Development and Marketing for the Huntington Society of Canada. "Jeff brings a lot of corporate knowledge to the table from his previous experience with the Tim Horton Children's Foundation. This is a good partnership for both HSC and HealthPartners. I am looking forward to watching the partnership grow."

In 2015, employees and retirees donated more than \$33,346,179, of which \$9,479,094 was

iii HealthPartners

Charities At Work

directed to HealthPartners. The Huntington Society of Canada receives a portion of this funding and funnels it directly towards the Society's mission.

Thanks to the incredible work of our volunteers from across Canada who continue to volunteer to speak at GCWCC events to raise awareness for HealthPartners and for the Huntington Society of Canada. "It is our volunteer contribution which is critical in raising the funds required to help all 16 charities deliver on their missions," Moffat Forsyth concludes.

If you are interested in starting a workplace giving campaign at your workplace or volunteering to give educational talks at a workplace event, email info@huntingtonsociety.ca or call 1-800-998-7398. Together we are achieving more. For a complete list of the 16 charities that make up HealthPartners, go to <http://healthpartners.ca>

Keynote Presentations

Celebrate Life with Terry Kelly

Life offers everyone gifts, disguised as challenges. This was the message Dr. Terry Kelly wanted to convey in his inspiring presentation at the 2016 national conference. Conference delegates were encouraged to embrace their talents and abilities with gratitude. Having been blind since age two, Terry shared his commitment to celebrating life as a person and how we can choose to embrace our lives and that we have the choice to “bid the beast goodbye”. Terry’s inspirational message reminded us that everyone has a purpose for being on earth and how important it is to be open-minded and use hope to cope with what life throws our way. Using personal anecdotes from his own experiences, Terry peppered his presentation with humour, songs, and audience participation, encouraging us all to develop our own strategies for living and working happily and healthily, relative to where Huntington disease (HD) is in our lives. Terry cautioned us to look for our blind spots and those blind spots that others have in regards to our lives. He challenged us to develop new ways to achieve our dreams. “It is not what happens to you, it’s what you do with it” said Terry, and if necessary, even make a “dream adjustment”. Concluding his presentation, Terry reminded us that every dream must be honoured with an action.

The Start of a New Era in HD Research with Dr. Tamara Maiuri and Dr. Ray Truant

Dr. Ray Truant and Dr. Tamara Maiuri led conference delegates through an explanation of why the number 36 has such significance in HD research. In their talk, The Start of a New Era in HD Research, Truant and Maiuri explained that for years HD researchers have known that if someone has 36 or more CAG repeats, they will develop HD. They didn’t, however, know why. In their presentation, Truant and Maiuri explained that they now know the why. It came as a significant breakthrough in HD research leading to no fewer than four seemingly unrelated projects that are now correlated. This has opened up the possibilities; not only verifying that this breakthrough will dramatically speed up the hunt for treatments but resulting in a new era in HD research.



The Real Scientific Influencer: Powerful Personage with Jay Ingram

Using the influence of Nancy Wexler, who is well-known in the HD community for her involvement with a study group in Venezuela that discovered the location of the gene that causes HD, Jay Ingram spoke about the significance one person can hold, through their ‘powerful personage,’ which can influence the course of science. Taking the conference delegates through examples of how celebrities like Robin Williams, Rita Hayward and Ann Landers can influence and increase public awareness for certain diseases in positive ways, the reverse is also true as some celebrities can promote falsehoods based on misinformation. These falsehoods made by celebrities can be received as true by the public and this creates an imbalance. Jay explained to delegates that we tend to believe celebrities over science partly because people base their opinion on social culture and not necessarily on data simply to maintain their social position. Ending his presentation by circling back to Nancy Wexler, Ingram explained how Wexler used her powerful personage to generate awareness for Huntington disease.

The Best Time to Plant a Tree with Dr. Ed Wild and Dr. Jeff Carroll

Using humour and the analogy of planting a tree, Dr. Jeff Carroll and Dr. Ed Wild used their interactive session to share what is new in the HD research world. Describing the root of a tree as the HD gene discovery, the trunk of a tree as connecting research to people, the branches as the trials and the fruit as the treatments, Carroll and Wild walked delegates through the current HD clinical trials and new HD lab discoveries. They explained the most promising research in HD today and how to interpret the latest science news stories. They explained that there are currently 15 trials in progress around the globe and how researchers are working with real human data to speed up the discovery phase. They explained that there are drugs that are now specifically designed for HD – unheard of until recently. And they reminded delegates that the best time to plant a tree was, of course, yesterday but the second best time to plant a tree is today, which is exactly what the HD research community is doing in collaboration with the HD community. Carroll and Wild ended their presentation by thanking delegates for their support and explaining that their goal is to promote understanding that would lead to empowerment, hope and positive action.



Workshop Summaries

Living the Life of Leisure: Therapeutic Benefits of Recreation and Play with Bev Farrell

Research indicates that engaging in leisure pursuits, from exercise and socializing to games, can improve the brain's neuroplasticity. In her presentation, Bev Farrell provided an overview of the benefits of leisure from the cognitive ("grey matter"), psychosocial and physical perspectives. Caregivers can benefit by learning how to take care of themselves through their own leisure pursuits. She explained brain research findings on leisure and specific leisure activities, coupled with equipment modifications and website recommendations, for us to implement into our lives. She used a famous George Bernard Shaw quote ("We don't stop playing because we grow old; we grow old because we stop playing") to explain the importance of continuing to better ourselves with physical exercise and leisure and to adapt new and different devices to make an activity work for us the way we want, to achieve the results we want.

HD 101 with Dr. Kerrie Schoffer

Local neurologist Dr. Kerrie Schoffer provided us with an overview of what we know about Huntington disease: the basic science and genetics, symptoms, and inheritance. She then explained classic symptoms of HD, physical changes, and strategies to cope with cognitive and emotional changes and went over identification of HD genes, CAG repeats, genetic testing and current ongoing clinical trials. She explained that chorea is not the "first sign" of HD, a common misconception. Many doctors do not treat chorea with medicine as the side effects of medicine are often more troublesome to patients; medicine is something to consider down the road. A patient with HD experiencing loss of expression, or reduced talking, doesn't mean they can no longer comprehend – quite the opposite in fact. Difficulty in waiting is also a huge issue for someone with HD. For example, it's best to avoid using exact times. She finished her talk with saying that community participation in clinical trials is vital to keep research moving forward. Fun fact: Dr. George Huntington first described HD when he was 22.



HSC Youth Mentorship Program with Corey Janke

This workshop was led by a mentorship coach, Corey Janke, the National Director of Family Services, Angèle Bénard, and some youth mentors. Together, they provided an overview of the program itself, how to access it and how it has grown over the last three years. Mentors also shared their experiences of being part of the program and how it has had an impact on them. The workshop explained how mentors and mentees are selected and how the program has connected people who had no previous link with HSC. They also explained that each mentee has his or her own rhythm in connecting with mentors but once it's established, the relationship blossoms.

HDClarity: A New International Study of Spinal Fluid in HD with Dr. Ed Wild

In this workshop, Dr. Wild explained what cerebrospinal fluid (CSF) is and why it's so important for HD research. He discussed how we look at the brain and the importance of cellular investigation in the context of HD. With the introduction of HDClarity, his brand new study, Dr. Wild aims to produce the biggest collection of CSF ever, from volunteers around the world. With 150 ml of spinal fluid floating around our nervous systems, Dr. Wild emphasized that it's one of the best resources in reading information for future studies. HDClarity would include a lumbar puncture (or 'spinal tap') in which a 20 ml sample is collected. The sample's fluid is then used to look for biomarkers and changes to predict disease progression. It will hopefully measure and detect the mutant huntingtin protein in CSF. Currently in Canada, it has passed the first round through the ethics committee, and there are three sites open in Canada: Toronto (Dr. Mark Guttman), Edmonton (Dr. Oksana Suchowersky), and Vancouver (Dr. Blair Leavitt). Enrolment will be geographically and policy-dependent.

Yoga As Therapy: Essential Tools for Living Well with Natalie Marnica

Natalie Marnica explored the experience and benefits of conscious breathing, mindful movement, and meditation that promote health, longevity and peace. She emphasized the importance of being social, exercising and being active overall. Yoga, a practice recognized by most in Western medicine as an assistive modality, was developed as a way to reduce suffering and promote a state of enlightenment. Natalie also explored the biology of stress, dealing with uncertainty, and the holistic approach to healing. She indicated that yoga enables one to manage challenges such as stress, anxiety, depression – all of which could be related to HD. It allows us to determine what we can control, such as our breath, our diet and what we choose to do. It is a motivation to be healthy and cultivate joy.



HSC 2016 National Conference Summaries

No Right or Wrong Answers: Considerations in Genetic Testing and Family Planning with Jill Beis and Michelle Lane

In this workshop, Jill Beis and Michelle Lane discussed predictive and diagnostic genetic testing for Huntington disease, from the basic science of the procedure to making the decision to be tested. Michelle explained genetic counselling, the CAG repeats and the different reasons that individuals would seek assistance from genetic counsellors: if one is at-risk and wants predictive testing, or if he/she is showing potential symptoms and seeks diagnostic testing or if he/she wants general genetic testing. There are many factors to consider before seeking genetic testing. The importance of checking one's insurance coverage before being referred to the genetics clinic was mentioned. The process of genetic testing varies between regions and can take six months to one year. Jill reviewed options and considerations for family planning including natural conception, deciding to remain childless, prenatal testing (e.g. chorionic villi sampling or CVS, amniocentesis) egg, sperm and embryo donation, preimplantation genetic diagnosis or PGD, and adoption. It was noted that some of these procedures are expensive, and funding is non-existent or limited – depending on where one lives. Both presenters emphasized that their role is to provide information and remain unbiased throughout the process, and they recognize that decisions around genetic testing and family planning are very personal for the individual or couple.

Genetic Discrimination with Bev Heim-Myers and Richard Sturk

Genetic discrimination and its impact on individuals with genetic diseases is prevalent in Canada. In this workshop, CEO Bev Heim-Myers (also Chair of the Canadian Coalition for Genetic Fairness) and Richard Sturk explored the history of CCGF and what we have yet to do to protect genetic test information in Canada. Genetic tests are now more common than ever – with about 36,000 genetic tests currently available. Both Bill S201, An Act to Prohibit and Prevent Genetic Discrimination, and Bill 30 (in Ontario), have passed their respective 2nd readings. We are very optimistic that Canadian laws will change in favour of genetic fairness but timelines are yet to be determined. Sturk provided key information in obtaining insurance when genetic test information is not protected. For life, disability, critical illness and long term care insurance, he advised to only look at first degree relatives when it comes to family history. If you've already completed genetic testing, it must be disclosed. If an insurance policy is in place before testing and results are positive, your contract is still valid. If results are negative, the rate can be lowered. It's also important to note that all insurance companies are not the same. For instance, Desjardins does not cater to HD, as opposed to Sun Life which does.



New Pathways in HD Research with Dr. Jeff Carroll

Dr. Jeff Carroll and his team at Western Washington University, supported through funding from the Huntington Society of Canada, discussed their current research. Dr. Carroll discussed recent studies (within the last 20 years) including his own work, gene silencing and targeting HD cells outside the brain (specifically in the liver). All animals, from fish to humans, possess the huntingtin protein and some level of CAG repeats. For HD, the CAG repeat count generally starts at 36 – the higher the count, the sooner symptoms show. After being discovered 18 months ago, an accurate picture of the HD protein was also shown. This leads many researchers to believe that a drug for HD will be difficult to design but not impossible. Dr. Carroll's current research focuses on a potential solution to this difficulty – gene silencing. He's been working on making somatic instability better through mouse models.

Hypnosis and the Power of Positive Thinking with Margot Schelew

Margot Schelew walked us through the difference between one's conscious and unconscious mind, what hypnosis is, how it works and how it can help reduce stress by shifting one's brain to focus on positive outcomes. Schelew noted that it's important to determine one's desired state before a session begins since the unconscious mind can't differentiate between reality and thought. Hypnosis then, is the process of bringing the unconscious (which is always listening) to the forefront and being 'lost in your thoughts' is actually a mild form of hypnosis. She also cleared up some common myths about hypnosis. For instance, you won't reveal any deep dark secrets while hypnotized, or never reawake from hypnosis. Working with both the conscious and unconscious minds, you need to rewire your brain, or thought shift, and create a new habit to keep thinking positive thoughts as a way to alleviate stress and anxiety. She explained using a trigger word, like 'cancel' or 'delete' repeatedly when negative thoughts you don't want to accept, keep, empower or absorb cross your mind.



HSC 2016 National Conference Summaries

CHDI Foundation and Enroll-HD Clinical Research Towards Drug Development with Simon Noble

CHDI Foundation's Simon Noble addressed the translational gap between researchers and pharmaceutical companies in his presentation to conference delegates. He explained that HD is a good disease for research as it is a single gene mutation, is well characterized and has a predictable onset. He explained that despite being unable to see the immediate research outcomes of being involved in a clinical trial, the research is critical. Noble explained how CHDI identifies the gaps in research and works to fill them. Noble discussed the IONIS HTRx trial, the Enroll-HD clinical trial platform and how important it is in the strategy to find a meaningful treatment. Noble ended his presentation with 3 key principles: Better – making sure we get the answers; Smarter – knowing the participants and Faster – easier to recruit, getting people into the right trials and completing them in a shorter period of time.

Responsive Behaviours and Strategies for Caregivers with Angèle Bénard and the Family Services Team

In this session, Angèle Bénard, Director of Family Services, and the national Family Services team, explained how responsive behaviours are not under a person's control and are simply a "response" to their environment and to the changes occurring within the brain due to cell death. The team explained how responsive behaviours may appear as HD progresses, and as losses are experienced in the person's abilities and relationships. The team discussed common responsive behaviours and possible strategies for caregivers such as trying to determine the meaning behind each responsive behaviour; using the technique 'accept, avoid, allow and acknowledge' and incorporating a consistent care team with ongoing communication that accounts for various personalities and preferences. The team used case scenarios to help illustrate a variety of strategies.

Cannabinoids in the Context of HD with Dr. Eileen Denovan-Wright

Dr. Eileen Denovan-Wright discussed with delegates the use of cannabinoids and how they are actively being investigated as drugs for many conditions including HD. Dr. Denovan-Wright spoke about cannabinoids, including THC, and how effective and safe they are for HD patients. Denovan-Wright cited the current research on the positive and negative effects of different cannabinoid-based drugs in relation to models of HD and that people will respond differently depending on their personal medical circumstances. She indicated that researchers are exploring how cannabinoids can be made to be effective for HD patients, but we aren't where we want to be at this stage in research.

Medical Assistance in Dying Panel with Julie Lawson-Timmer, Senator James Cowan, Rob Laycock, Marlene Teske and Colleen Cash

Highlighting different viewpoints and considerations in Medical Assistance in Dying, this panel discussed various aspects of the highly-charged topic. The panel included Senator James Cowan (who spoke to the considerations in putting forth Bill C-14), Julie Lawson-Timmer (author of *Five Days Left*), Rob Laycock and Marlene Teske, community members who spoke about their personal stance on the choice and voiced their concerns about the limitations in the current legislation on medical assistance in dying. Delegates learned about Bill C-14 and how it might be too restrictive for neurological diseases; heard from a family member who stood by a loved one in making her personal choice to end her life, and learned that assisted dying has been available in other countries for decades. Information on the hospice and palliative care approach and proposed bill were also shared. One of the important takeaways from this session was to ensure that individuals, who choose it or not, are making a conscious decision; they are aware of all the services and resources available to them and make a fully informed decision.



HSC 2016 National Conference Summaries

Huntington's Disguise with Jim Pollard

As HD progresses, it often places a mask on the person that you love. Jim Pollard described the physical features that may or may not be associated with HD and how they manifest in different people with HD. Pollard explained that it is often difficult to see what is going on because of the disguise, but if we take the time to understand some of the more subtle physical and cognitive aspects of HD, it can help us see through this "Huntington's Disguise." Using humour and anecdotes, Pollard explained that a person with HD may not actually be bored, disinterested, angry or unwilling, despite that it may appear that way to some. He encouraged us to learn the characteristics of what the mask looks like in various forms on various people, ask for clarification and look beyond – keeping in mind that underneath the mask is the very same person you may have known, loved and cared for through the years.

Youth Opportunities with HDYO and YPAHD

Members of YPAHD (Young People Affected by Huntington Disease) shared information and experiences about services available through YPAHD and the Huntington's Disease Youth Organization (HDYO) with delegates, including explaining the history of each organization, their roles in Canada (YPAHD) and abroad (HDYO), and how they intersect to support youth. Delegates were encouraged to visit the YPAHD website (www.ypahd.ca) to learn more about resources available for youth including information on the HSC Mentorship Program and to visit the HDYO website (www.HDYO.org), which includes information on HDYO camps which are available to youth impacted by HD.

MISSED CONFERENCE?

Be sure to visit
[huntingtonsociety.ca/
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to see videos of the
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An Ariel View

Well, I'm back home from Halifax and I've unpacked my bags, but I'm still buzzing from the 2016 National Conference. What a weekend!

The Halifax chapter outdid themselves, getting us singing and clapping during the lively, down home Nova Scotia kitchen party that kicked it all off. The national team did a superb job of organizing everything, and the hotel staff went out of their way to make sure we all felt comfortable. And the food! Holy jumping, how much better could that lobster be?

Terry Kelly's opening address set the mood for everything that followed, energizing us with his message about tackling life head-on and not letting anything hold us back.

As always, the Conference gave me a chance to reconnect with all kinds of old friends from across the country. If I tried to list each one, I would run out of room in a hurry (and risk forgetting someone), so I'm not even going to start! I'll just say how good it was to see everyone. It was also lovely to see Paul Klodniski receive an award for his 25 years of service. Doesn't that say so much about the Society?

There were lots of new people to get to know as well. I loved seeing the YPAHD group so organized and working together – they're just full of energy. It was also wonderful to meet so many families who were there for the first time and discovering the vibe of this wonderful community.

And that community just keeps growing stronger. I had a chance to chat with Bunny Clark, whose group from the Durham Region in Ontario was announced as an official chapter at Conference for the first time, and to Steven and Michelle Beatty, who are starting a chapter in Muskoka.

Meanwhile, we had folks come from le Centre Uauitshitun, which supports people affected by HD in a small Innu community on the north shore of the St. Lawrence. It really reminded me how we're reaching more and more families in underserved parts of the country.

Of course, some of the biggest inspiration came from the new generation of scientists who are focusing on this disease. Dr. Ed Wild and Dr. Ray Truant updated us on all the promising medications, while Dr. Jeff Carroll discussed the history of HD research and how we've come such a long way.

It's true: we have come a long way. When Ralph and I started the Society, we had no money, just a conviction that we needed to do something. More than 40 years later, the Society's budget has grown to more than \$4 million, allowing us to provide hope and support for anyone who needs it. I'm overwhelmed!

I met one woman who was attending the Conference for the first time. She was just blown away. She told me she couldn't get over how warm and friendly everybody was. "It's like a family," she said.

It really is. Thanks to everyone who made our latest family reunion such a success. I'm already looking forward to 2018!

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



All-party support for genetic fairness

By Josh Martin

On October 25th, HSC CEO Bev Heim-Myers watched history unfold. MP after MP stood and voiced their support for Bill S-201, Canada's proposed anti-genetic discrimination legislation. In the end, it passed unanimously through Second Reading. "There was not one opposing vote," says Bev. "It was incredible."

To hear parliamentarians speak fluently and accurately about the issue and to see all-party support for Bill S-201 means a lot. Bev recalls the first time she met with MPs, the Prime Minister's Office and the Federal Human Rights Commission in 2010. "There really was no awareness about genetic discrimination in Canada and the impact that it was having," she says.

Ultimately, she found a champion in Senator James Cowan. Adaptations of Bill S-201 have been tabled three times. In 2013, Senator Cowan tabled Bill S-201 but it was gutted in the Senate committee and subsequently failed.

But we did not give up. And neither did Senator Cowan. He re-tabled the bill in December 2015, and this time a robust, effective version made it to the House of Commons. It contains three

components: a Genetic Non-discrimination Act that makes it illegal for anyone in Canada to use genetic test information or ask someone to get a genetic test without the written consent of that individual, an amendment to add genetic characteristics to the federal Human Rights Act and amendments to the Canadian Labour Code.

At Second Reading, Liberal MP Rob Oliphant gave a shout-out to HSC, acknowledging all the work the Society has done to promote genetic fairness. He isn't alone. This past October, Bev and Senator Cowan were presented with an Advocacy Award from the American Society of Human Genetics. The prestigious honour also came with a \$10,000 cheque to support our efforts.

Earlier that year, the American Society of Human Genetics issued a statement in support of Bill S-201 that read: "At a time when genetic testing is increasingly being incorporated into clinical care and researchers are performing analyses of human genomes on an unprecedented scale, it is critical that the genetic information of patients and research participants alike is not misused. There need to be laws in place to ensure not only that an individual's genetic information remains private, but also that their genetic information cannot be

used in a way that harms them."

According to Bev, that support and recognition provided proof that the world is watching.

However, while the American Society of Human Genetics award is hugely gratifying, the biggest award will be legislation.

Bill S-201 was referred to the federal Standing Committee on Justice and Human Rights. The Committee will review and debate the Bill and bring it back to the House. Once we have genetic fairness enshrined at the federal level, we'll be better equipped to advocate for strong protection at the provincial level as well.

"We are not at the finish line yet," Bev reminds us. "But we have come a long way, and we need to continue this move forward."

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



Pillars of the HD Care Community

continued from page 1

Those same patients and family members have also played a key role in world-leading HD research, participating in dozens of observational studies, biomarker studies and clinical trials run by the Centre.

Director of Research Dr. Blair Leavitt points to the synergy that creates. "What we do in the lab informs the clinic, and what we do in the clinic also helps inform the lab," he says.

Today, families have never had more reason to be excited about research. "We are moving into a new era," says Dr. Leavitt. In the early days of the B.C. Centre, clinical trials focused on drugs that had been developed to treat other illnesses. Now, thanks to breakthroughs in our understanding of HD, we're honing in on potential treatments – like gene-silencing drugs – specifically developed to target Huntington disease.

The Centre for Movement Disorders

Meanwhile, Ontario's Dr. Mark Guttman has been making a difference outside hospital and university environments. Keen to explore different models of treatment and research, he set up an independent centre in 1990 to treat movement disorders.

An early – and unexpected – visitor was HSC's founder Ralph Walker. "I thought that this was pretty impressive, that the head of the national organization would show up at my office one day," Dr. Guttman recalls.

Ralph had caught wind of the new specialist. Back then, neurologists were encouraged to focus their energy on the patients they could help. Ralph made the case that although there were no treatments for HD, neurologists still had an important role to play in giving patients with HD hope and expertise. "That really hit home for me," says Dr. Guttman.

For more than 25 years, he and his team have been doing just that. He has also brought his expertise to the north, collaborating with genetics nurse Francine Robert to create a traveling clinic to serve clients in North Bay, Sturgeon Falls, Sudbury and other remote northern Ontario communities. Meanwhile, the Centre for Movement Disorders has been a leader in clinical trials, providing a model for how other independent neurologists can participate in accelerating the discovery of treatments.

In 2016, Dr. Guttman joined the Society's Board of Directors, forging even closer links between HSC, clinicians and researchers. Like the teams at North York General Hospital and B.C.'s HD Medical Clinic, he believes that real care and progress happens when people work together. "I think the days are gone that a physician can work in isolation to try and help a complex condition like Huntington disease," he says. "We need to have an integrated approach with input from the patients and the families."



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“They grow best with hope and love”

by Josh Martin

If you stepped inside Karen Koester’s garage in Calgary this past October, you would have found it packed to the rafters with 58 cases of amaryllis kits. However, thanks to Karen’s 15 years of experience selling the orange flowers, those boxes did not stay there long. From getting the ball rolling in early September to emailing personal networks to arranging deliveries with a local bus company, Karen’s operation is a well-oiled machine. “I have a very good, dedicated team,” she says. “The key is organization.”

All told, Karen and hundreds of volunteers like her stepped up to help us once again sell out of amaryllis kits, raising \$115,000 for the Society. “The strength of the campaign is the people across the country who are so committed and so passionate,” says Jeff Hoffman, HSC’s Senior Development Manager.

Yvette d’Entremont points to the flower’s beauty as another major contributor to the fundraiser’s success. Yvette bought her first amaryllis the year her husband was diagnosed with HD in 2008. The following year she was buying them as early Christmas gifts, and in 2016 she sold more than 200 bulbs. “To me, it is a very easy sell,” the Halifax resident says. “You get a beautiful, brilliant orange amaryllis to enjoy for two or three months.”

Garry Kinzie from North Dumfries, Ontario can relate. For years, he has been selling 100+ flowers to friends, family and customers from all corners of the province – buyers who regularly send messages raving about their blooms. “You would not believe the phone calls I get or the emails or the people sending pictures,” he says.

This year’s campaign featured a fresh new design for our amaryllis kits. Meanwhile, an information sheet in each kit provided fun and helpful advice from our seasoned amaryllis experts, like Bev from Pincher Creek, Alberta who suggested “they grow best with hope and love.”



It is that same hope and love from the HD community that makes this campaign a success year after year. “We are just so grateful for all their hard work,” says Jeff. A huge thank you to all our amazing 2016 volunteers who collectively sold more than 20,000 amaryllis kits. Now that is inspiring!

We would love to hear your story of how you sell your amaryllis kits, email us at amaryllis@huntingtonsociety.ca, share your story and help inspire others to join our annual campaign. Don’t forget – we’re still accepting photos for the annual Amaryllis Photo Festival. Tag your photos on Facebook, Twitter or Instagram with #HSCAmaryllis to be entered.



Champion of Hope: Lara Hall

By Julie Stauffer

When your parents are the founders of the Huntington Society of Canada, contributing to the cause comes naturally.

Lara Hall grew up collating newsletters on the dining room table, stuffing the Raggedy Anne dolls the Society sold to raise funds, helping out at garage sales, and more. Summer holidays included visits to families with HD in whatever part of the country they were touring. Later, she volunteered at the Society’s annual camp in Paris, Ontario.

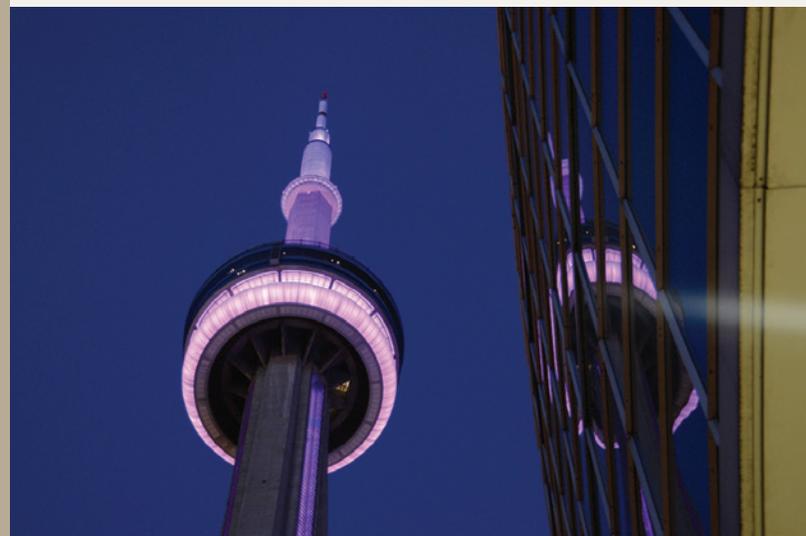
As a result, she has strong connections to members of the Huntington community across Canada and internationally. “They are like family,” she says. “Our extended Huntington disease family.”

And, of course, you help family. These days, having two kids, a farm, a career in marketing and a collectibles business on the side doesn’t leave a lot of time for volunteering, so Lara’s contributions are largely financial.

In 2010, she signed up as a monthly donor. She knows her dollars are funding crucial services and bringing us ever closer to realizing her father’s dream of a cure for HD. “I used to do it in lump sums every year,” she says. “But it would be ‘oh my gosh, it’s Christmas’ and I have realized I have not given.”

Automated monthly giving makes it simple: no cheques, envelopes or stamps required. “It is easy and convenient, and it makes me feel good that I’m doing something,” Lara says.

A big thank you to Lara and all our Champions of Hope – the monthly donors who give us regular income we can count on. If you’d like to join them, call us at 1-800-998-7398 or visit www.huntingtonsociety.ca/monthly-giving.



Get ready to #LightItUp4HD in May 2017 as we illuminate monuments across Canada (and internationally!) for HD awareness month.

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

Celebrating Our Heroes

Jenna

With a new baby at home, taking on a big HD awareness event or fundraiser was not in the cards for Jenna. Still, she was eager to give back to an organization that has helped her family immeasurably. So when we approached her to be the voice of our appeal in October for the Believe: Transforming Tomorrow Together campaign, she seized the opportunity.

For years, Jenna thought her mom was “difficult.” She had mood swings and outbursts. She stopped organizing family dinners and bothering with Christmas decorations. Medication did not help, nor did cognitive therapy. “We had sort of hit rock bottom,” Jenna recalls.

It was not until she watched an episode of Breaking Bad that mentioned the symptoms of HD that Jenna realized the truth – her mother had Huntington disease. After Googling reinforced her suspicions, she called the Huntington Society of Canada and spent hours talking with a social worker.

In the months that followed, the social worker helped walk Jenna and her family through the process of diagnosis, connected them to resources and was there to listen.

As Jenna wrote in our fundraising letter, “I do not know what I would do without the support of the Society’s social workers... This disease is complex and horrible and there is nothing more reassuring than talking to someone who has seen it all.”

Her personal message struck a chord and was extremely successful, raising vital funds to support families with HD across Canada and fund vital research.

Today, Jenna’s mom is doing well, thanks to her healthcare team and the support of an HSC social worker. She is sleeping better, participating in a day program and her outlook is more positive. Meanwhile, Jenna has become a youth mentor – yet another way she is giving back.

Our heartfelt gratitude goes out to Jenna for sharing her story and to everyone who responded to her appeal. Together, we are transforming tomorrow. If you would like to contribute to the Believe: Transforming Tomorrow Together campaign visit www.huntingtonsociety.ca



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Donate2Celebrate!

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

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

For more information, see our **Donate2Celebrate** page at www.huntingtonsociety.ca/Donate2Celebrate.

Thank you

On behalf of families living with HD, thank you for your continued partnership and generous support. Our community makes the difference as we reach out to families who are not yet connected to HSC, continue to support and advocate for families from coast to coast, invest in world-class research, and play a leadership role in the international Huntington disease community. With your help, we are continuing to improve the quality of life for people with HD, cultivating strength and resilience in the Huntington disease community and providing substantive reasons for hope. If you have questions, story ideas or comments about *Horizon* or the Huntington Society of Canada, please contact us at info@huntingtonsociety.ca or call us at 1-800-998-7398.

The Huntington Society of Canada is committed to reaching out to as many Canadians as possible. Should you wish to explore the French side of our website, select the français option at the top right hand corner of our website www.huntingtonsociety.ca. We partner with the Huntington Society of Quebec. Their resources can be found at www.huntingtonqc.org.

La Société Huntington du Canada a pour mission d’éduquer et d’aider autant de Canadiens que possible. Si vous souhaitez explorer la partie française de notre site Web, veuillez cliquer sur l’option française en haut à droite de la page suivante : www.huntingtonsociety.ca. Nous travaillons également en étroite collaboration avec la Société Huntington du Québec, vous pouvez visiter leur site Web à : www.huntingtonqc.org.