

HORIZON

RESEARCH • SERVICE • EDUCATION

No. 150

Fall 2016

The Believe Campaign: *Transforming Tomorrow Together*

By Josh Martin

At the Huntington Society of Canada (HSC), we believe. We believe in a future where Huntington disease (HD) no longer ravages the mind and body. We believe that what we do today can transform tomorrow, and that together, we can do anything. Those sentiments lie at the heart of our new Believe initiative: a two-year campaign aimed at bringing new donors to the Huntington's cause to raise \$3 million for research and services to families, individuals and youth.

The Honourary Chair of the passionate and enthusiastic advisory cabinet for the Believe campaign is Julie Lawson Timmer, a Michigan-based author. Julie is a Canadian who grew up in Stratford, Ontario and graduated from McMaster University. While doing research for her first novel, *Five Days Left*, she became very aware of the many issues surrounding Huntington disease.

Based on her learnings and experience, Lawson Timmer believes that if we can help more people understand what this disease is all about, that collectively we can transform this disease and provide the support that is so desperately needed. Support comes in a variety of ways, reaching out to a neighbour to provide friendship, learning more about the disease to ensure we aren't isolating those who are impacted, supporting the Society through volunteering and supporting the Believe campaign.

"We are fortunate to have Julie heading up the Believe advisory cabinet" says the society's Senior Manager of Donor Relations, Danielle Havelka. "In addition to offering her support to our campaign, Julie is spreading awareness

Believe

Transforming Tomorrow Together

through her book and speaking about Huntington disease. Education is a powerful tool in our efforts to support people who are impacted by HD. Julie is putting words into action. We are so very pleased and honoured to have her participate."

The Believe: transforming, tomorrow together campaign focuses on the many activities that the Society is leading. On the research front, HSC has a proud history of providing strategic funding to investigators like Dr. Ray Truant, Dr. Blair Leavitt, Dr. Lynn Raymond, Dr. Simonetta Sipione, Dr. Francesca Cichetti, Dr. Michael Hayden, Dr. Jeff Carroll and other leaders in the field. Today, promising treatments have reached the stage of clinical testing. "For the first time, we have compounds that are addressing the root causes of neurodegeneration by mutant huntingtin," says Dr. Ray Truant. "The more promising projects we can support, the sooner we'll find answers that reverse, slow or prevent the progression of HD."

"Science is making great strides, but each year HSC has to leave a number of excellent research proposals on the table simply because we don't have enough money to invest in them all," say Truant, citing the suspension of the Canadian Institutes of Health Research (CIHR) fall competition following petitions from Canadian scientists about poor quality peer review at CIHR. "We are in the worst funding crisis for biomedical research in Canadian history."

While research is paving the way to treatments, HSC's Family Services team provides vital support and advocacy for people living with the impact of HD right now. "We are working hard to increase the number of multidisciplinary clinics across Canada, expand our youth programs, and continue to work closely with the federal, territorial and provincial governments to end genetic discrimination" says Angèle Bénéard, Director of Family Services and Community Development.

continued on page 2

The goal: \$3 million over 2 years

We envision a future where HD no longer ravages the mind and body. To make that happen, HSC's Believe campaign focuses on two key areas.

- **\$1.5 million for discovery research**

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

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

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

Our goals are simple, but the impact will be profound. Together, we are transforming tomorrow.

INSIDE

Introducing the Campaign Cabinet page 3

In Research News page 5

An Ariel View page 8

Love, Learning and Lobster page 9

Celebrating Our Heroes page 12

HORIZON

ISSN 0827-7605

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 50, 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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11896 5516 RR0001



Note from the CEO

The last few months have been a very busy time for all of us at the Huntington Society.

Congratulations to our amazing HD Community for a successful Event Season. We are incredibly appreciative of the HD Community and Chapters that continue to work hard increasing awareness through successful events. Working together, we are all making a big difference.

I would also like to extend a special thank you to Erin Wade and her Mom Cindy. Erin was the face and voice of our direct mail campaign this year. Erin's story is compelling, and where it is one that too many families from the HD Community are familiar with, it helped others outside of families dealing with HD daily, to better understand the challenges and the need to end HD.

I hope you all followed Martin Denonville and James Stewart's cross Canada bicycle ride to raise awareness and funds for HD. This "2-4-1" duo demonstrated amazing strength, endurance, commitment and media savvy. My husband and I had the pleasure of meeting Marty and Jim with their wives, Carrie and Ann, in Huntsville for lunch in June. When they were taking a short two day rest with Carrie and Ann before starting the next leg of their journey. In total, this amazing team raised over \$30,000. As I said in the CEO Blog after meeting with them, they are 2 "great" guys, with 4 wheels and 1 cause.

Conference planning is well underway. This year promises to be wonderful with the Chapter Development team and the Halifax Chapter working hard to help make this a very memorable conference. Our speaker line-up is motivating, fun and informative. Remember to put November 4 / 5 on your calendar and join us in Halifax.

Thank you for all that you do. See you at conference.

Bev Heim-Myers
Chief Executive Officer

The Believe Campaign: *Transforming Tomorrow Together*

continued from page 1

"By broadening and strengthening our foundation of support, we can do more. With increased capacity and tools, we can increase our reach and help as many individuals and families affected by HD as possible, including those in rural and isolated communities."

A world free from the devastation of Huntington disease cannot come soon enough. However, we believe a brighter future is not only possible but palpable. "We are at a unique and exciting time in the history of Huntington disease," says HSC CEO Bev Heim-Myers. "The Believe campaign will ensure we will have the funds to make a sustainable difference and together with our HD community change the reality of Huntington disease."

Believe: Transforming Tomorrow Together. "We are moving quickly to viable treatments. Now is the time to ensure we have the resources to fund the research that leads to those treatments and to prepare for clinical trials." Bev Heim-Myers, CEO Huntington Society of Canada

To learn more about our transformational campaign, our campaign cabinet and our honorary chair visit
www.huntingtonsociety.ca



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Introducing the Campaign Cabinet

Believe: *Transforming Tomorrow Together*

Julie Lawson Timmer – Honourary Chair

Julie is a lawyer and author whose first novel, *FIVE DAYS LEFT*, involved a character with Huntington disease. Julie's research for the book led her to become involved in fundraising for the Huntington Disease Society of America. After learning about the Huntington Society of Canada's Believe Campaign, she happily redirected her HD-related efforts to this side of the border. Julie was born in Saskatoon, Saskatchewan, and raised in Stratford, Ontario. She now lives in Ann Arbor, Michigan.

Heather Heike

Heather is a Program Director with 32 years of experience in the financial sector. She works primarily on large and highly complicated initiatives which in recent years have been focused in Asia. Additionally she is a CPA-CMA in good standing. Heather's affiliation with the Huntington Society of Canada started in 2001 when her father was diagnosed with Huntington disease. She continues to provide volunteer time to HSC although caregiving has been increasingly taking up her spare time. In the past, Heather has been on the board of directors for a Cuban Relief charity. Heather lives in Waterloo, Ontario and also supports animal rescue.

Vern Barrett

Vern is currently an Education Professor at the University of Winnipeg and enjoys working with young, aspiring teachers very much. Two of his more interesting projects include a program that places education students in Germany where they teach English to marginalized Turkish students, and a program where beginning teachers do extensive service learning activities with disadvantaged students in Winnipeg. Vern has worked hard for the Huntington Society of Canada for more than 40 years, both locally and nationally. Vern's wife Ellen was a member of the first Board of HSC and started the first Resource Centre and Chapter in Winnipeg. Vern has also served on the Board for many years and as Board chair for four years. Vern is currently Winnipeg Chapter president.

Jane Manning

Jane lives in White Rock, B.C. with her husband Paul, who was diagnosed with HD in 2013. As a committed volunteer, Jane has helped raise millions of dollars over the years for local organizations such as the Arts Umbrella, Southridge School, the YMCA and Peace Arch Hospital. Today, the former special-needs teacher is excited to leverage her considerable talent and experience for HSC's Believe campaign, making a difference for a cause very close to her heart.

Brenda Wasylow

Brenda is a CPA and is Vice President of Finance for JNE Welding in Saskatoon, Saskatchewan. Brenda has lost several of her family members to HD and spearheaded the inaugural HD Walk for a Cure in Saskatchewan a number of years ago. She has been involved with HD at both the community and the National level for many years. She currently sits as Vice Chair of the Board of Directors of Huntington Society of Canada. She is also Chair of the NSBA (a preeminent business association in Saskatchewan) and Treasurer on the Board of Directors of the Safety Association of Saskatchewan Manufacturers.

Dan Devlin

Dan has been a significant supporter of the Huntington Society of Canada for more than 10 years. Dan's entrepreneurial background as a successful co-founder of a bakery production company in Toronto brought business acumen to the HSC Board. Dan has served as an HSC Board Member for several years and more recently led the HSC Board as Chair. Currently Dan serves as past chair. Dan, his wife Jill and his two children have been generous with their time in supporting HSC events.

PROFILE

Julie Lawson Timmer: A powerful addition to the campaign team

By Josh Martin

As a novelist and chair of the Believe campaign's advisory cabinet, Julie Lawson Timmer is raising awareness about the gut-wrenching challenges that come with HD.

Until recently, Huntington disease was uncharted territory for the Michigan-based author. Julie has no connection to the disease and knew almost nothing about it until she did a little "Googling" for her first novel, *Five Days Left*. The more she learned about it, the more determined she was to portray the disease as accurately as possible, which led to countless hours of research and meetings with doctors and other experts in the field.

"I didn't want to parachute into the Huntington's community and steal a few symptoms that were sexy for a novel and then leave," says Julie. "I decided I had to get it right."

The hard work paid off. *Five Days Left* is a compelling page-turner – the story of a successful lawyer named Mara wrestling with saying goodbye to loved ones as her Huntington disease progresses. Heartfelt and real, it paints a very personal picture of what living with HD can be like.

Critics agree. As a review from the *Library Journal* put it, "Timmer's debut novel packs a powerful punch. Absorbing, deeply affecting, and ultimately uplifting, it heralds the arrival of an author to watch."



As buzz for the critically acclaimed novel grows, it's also proving to be a great opportunity to introduce the uninitiated to the world of HD. "I went to a book club in Michigan," Julie recounts. "And so

continued on page 6



Music to our ears

By Josh Martin

When Eli & the Straw Man hit the road earlier this year for their "Let's Boogie Tour for HD", they weren't travelling in luxury. Guitars, drum kit, and six band members filled the crowded vehicle, which sported a plastic-covered window after suffering a break-in in Vancouver.

But inside, spirits were high. "It makes it easier to cram into a van for ten hours at a time knowing that you're promoting not only your music, but something that may help people," says front man Eli Maiuri.

The indie roots rock band kicked off their 16-date adventure in April in partnership with the Huntington Society of Canada. Judging by the cheers and foot stomping, the five-province, month-long tour was a roaring success. From the Dakota Tavern in Toronto to Moose Jaw's Common Cafe to The Roxy Cabaret in Vancouver, the band raised the roof while raising awareness about an issue close to their hearts.

Trumpeter Tam Maiuri knows all about HD. The disease killed her grandfather, and now her mother is showing symptoms. When the at-risk musician isn't on stage, she's hard at work as a researcher in Dr. Ray Truant's Huntington disease (HD) lab at McMaster University. "We're finally coming to a time in HD research when we've got drugs going into the clinic," she says. "My greatest hope is that we will find a treatment soon for HD."

Throughout the tour, folks from HSC Chapters showed up in full force, showing their love and appreciation for what the group was doing. For the band, playing in front of a crowd is always exciting. But knowing the HD community was there to support them made the shows even more special. "Even though we've never been to these places, we weren't playing to strangers," says Tam. "It was awesome."

Our heartfelt thanks go out to the members of Eli & The Straw Man. To us, these awareness-raising rock stars are hitting all the right notes. For more information about Eli & The Straw Man and to get your hands on their upcoming album, visit www.eliandthestrawman.com.



Canadian Coalition for Genetic Fairness

Progress is being made with Bill S201, An Act to prohibit and prevent genetic discrimination. On April 14, 2016 Senator Cowan's Bill S201 was unanimously passed through the Senate to the House of Commons. On May 3, MPP Rob Oliphant, as sponsor of Bill S201 in the House, tabled first reading in the House. The Canadian Coalition for Genetic Fairness was hoping that Bill S201 would see second reading and first hour of debate prior to the House rising for the summer, but that was not the case and the plan is for the bill to have second reading on September 20th, in the House.

This past summer members of the Canadian Coalition for Genetic Fairness contacted their Member of Parliament (MP) to talk about Bill S201 and the importance of protecting genetic test information, for all Canadians. The Huntington Society of Canada is urging you to do the same. Please call or visit your MP and let them know how important this issue is for all Canadians. The Canadian Coalition for Genetic Fairness has provided a sample letter on their website at <http://ccgf-cccg.ca/en/take-action>.

On June 24, 2016, the American Society of Human Genetics announced that Senator Cowan and Bev Heim-Myers (as Chair of the Canadian Coalition for Genetic Fairness) will be receiving the American Society of Human Genetics Advocacy award for moving Canada forward regarding the protection of genetic test information. This is a great honour and demonstrates that the world is watching Canada. As Canada is the only G7 country that does not specifically protect genetic test information, it is time our legislation caught up with science. Senator Cowan and Bev Heim-Myers receive the award in October. It is the hope of the members of the Coalition that by the time they are recognized for their efforts, genetic test information is being protected in Canada – for the health and wellbeing of all Canadians.

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.

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



Stopping the stutter

By Julie Stauffer

Anyone who has undergone genetic testing for Huntington disease (HD) knows all about CAG repeats: a DNA stutter that, repeated too many times, causes the disease. Similar stutters can also occur on other genes, leading to myotonic dystrophy, spinocerebellar ataxia and more than fifteen other neuromuscular disorders.

For two decades, Dr. Christopher Pearson and his team at Toronto's Hospital for Sick Children and the Department of Molecular Genetics at the University of Toronto, have been piecing together a picture of how, where and why those stutters occur. Now, they know enough to start examining ways to address the root cause of this whole class of diseases. The Huntington Society of Canada is helping to fund this very promising line of research with a two-year, \$150,000 Navigator grant.

The genetic test for Huntington disease (HD) is based on the number of CAG repeats found in your blood cells. That number stays the same throughout your life. But in the parts of the brain affected by HD, the number grows year after year – sometimes into the thousands of repeats. The more it expands, the more it creates toxic products that damage the brain cells.

Ironically, Dr. Pearson's research has revealed that what seems to cause that expansion in the brain are DNA repair proteins. These molecules act as proofreaders for DNA, correcting any errors that might creep into the genes. Normally, that's a good thing. In the particular case of the CAG repeats, however, DNA repair proteins cause problems. "It does sound a little backwards," Dr. Pearson admits. "But Mother Nature is what she is."

So what's going on? Picture DNA as a zipper. The first step in producing huntingtin protein is to separate the two sides of the zipper, giving the cell access to the protein-making instructions encoded in that DNA.

When the two sides come back together, sometimes a few zipper teeth aren't quite right, kind of like when your zipper gets stuck and over-runs itself with extra teeth slipped-out on each strand. In this example each zipper tooth is a CAG repeat. For some reason, when the DNA repair proteins encounter those oddities along the "zipper DNA" in the Huntington's gene, they respond by generating a few more CAG repeats – repeats that lead to more toxic molecules in the brain cell.

Dr. Pearson figures that if you could take away certain DNA repair proteins in the parts of the brain affected by HD, you would remove the source of the problem. In fact, his lab has done preliminary experiments that prove him right. When they took mice engineered not to produce those proteins and crossed them with HD mice, they discovered the number of CAG repeats in the brain stopped expanding and, in some cases, even shrank.

Now, he wants to see if there are drugs that will have the same effect – and he has some promising candidates in mind.

The Navigator grant will fund the first steps of those investigations. This isn't a small undertaking, Dr. Pearson cautions. If the initial results are successful, they could ultimately lead to drugs that could stop or even reverse HD, along with a host of other genetic neuromuscular diseases. "That's what the goal is," he says.

To learn more about the NAVIGATOR research grant provided by the Huntington Society of Canada, visit www.huntingtonsociety.ca

Figuring out the function of the huntingtin protein

By Julie Stauffer

The mutant form of the Huntington disease (HD) gene creates a protein that damages brain cells. But what does the regular version of the HD gene do, when it's not mutated? Despite decades of Huntington's research, that question still has scientists puzzled.

With a \$150,000 NEW PATHWAYS grant from the Huntington Society of Canada, Dr. Jeff Carroll aims to shed some light on that mystery. And in the process, he hopes to create more insights into treating the disease.

Based on several different strands of research, Dr. Carroll believes the huntingtin protein produced by the normal gene plays a role in DNA damage and repair. Now, he's conducting a couple of clever experiments to test that idea.

In one set of Petri-dish experiments in his Western Washington University lab, he'll take healthy brain cells and damage their DNA. Then he will look at whether the normal huntingtin protein moves to that damaged DNA and, if so, where it binds and what other proteins are involved.

Another set of experiments will look at CAG repeats. Huntington disease is caused by too many repetitions of CAG within the HD gene. In certain brain cells, that number keeps growing, leading to higher levels of mutant huntingtin, which in turn creates cell damage. "Surprisingly, we also see CAG expansion in the liver," says Carroll. "In both cases, that expansion seems to be tied to DNA repair."

Dr. Carroll will use gene-silencing drugs to stop the production of the mutant huntingtin protein in HD mice. If his hypothesis is correct, that will restore normal DNA repair processes and therefore reduce the number of CAG expansions in the brain and the liver. In fact, he has already had some positive results from preliminary experiments with liver cells.

In an elegant twist, he will also conduct the same experiments in mice that have the gene for spinocerebellar ataxia type one – another neuromuscular disease caused by CAG repeats. If the huntingtin-silencing drugs also reduce the CAG expansion in these mice, it will provide very compelling proof that huntingtin plays a role in DNA repair.

It will also offer several potential drug targets – and the more targets, the better our chances of developing effective treatments for HD.

Dr. Carroll can't wait for the data to start rolling in. "I have that feeling you have at the beginning of good experiments," he says. That said, these are blue-sky experiments. They may not lead to the results he's hoping for, but, as Dr. Carroll points out, important scientific discoveries often come from unexpected findings.

"You do your experiments right, you keep your eyes open, and you follow your observations where they take you," he says.

Finding dollars for this kind of early-stage research is increasingly difficult, as big funding agencies become more conservative. According to Dr. Carroll, New Pathways is probably the best program in the world for this kind of HD research.

"That's exactly why we created New Pathways, to foster innovative lines of inquiry that will eventually lead to the next generation of targets for the treatment of Huntington disease," says Bev Heim-Myers, CEO of the Huntington Society of Canada. "Like Dr. Carroll, we'll be eagerly waiting for the results."

For a complete summary of the research projects in which the Huntington Society of Canada has invested in go to www.huntingtonsociety.ca

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Proud sponsors of the Huntington Society of Canada's 2016 National Conference.

A sincere thank you to Kindred Home Care, Clearwater Seafoods and the Municipal Group of Companies for your generous support. We could not be more grateful to have you as our partners.

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PROFILE

Julie Lawson

continued from page 3

many people had said, 'wow, I didn't know anything about Huntington's, and now I feel like I know so much more.'"

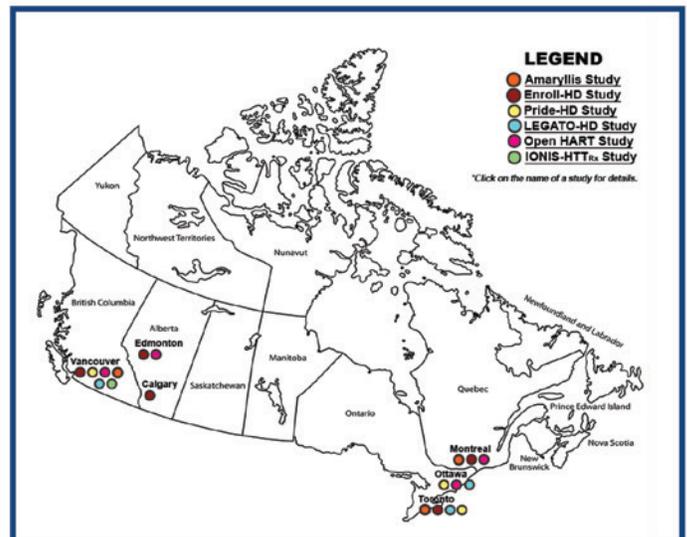
Although Five Days Left has done much to raise the profile of HD, Julie wanted to do more. She added links to her website, encouraging readers to donate to HSC and the Huntington Disease Society of America. And when we asked Julie if she wanted to get involved with our Believe campaign, we received an enthusiastic "yes" in response. "There are not enough people in the Huntington's community to raise all the money needed to fund the research," she says. "We have to get awareness out."

She believes that if we can help more people understand what this disease is all about, they'll reach into their pockets to support crucial research. We are so happy that, as head of the Believe advisory cabinet, Julie is helping us make that happen by creating awareness and increasing understanding of the disease.

To get your hands on a copy of Five Days Left and to learn more about Julie's second novel, *Untethered*, visit www.julielawsonstimmer.com. Want to meet the author in person? Julie will be at this year's National Conference in Halifax, facilitating a panel discussion on physician-assisted dying. To learn more about this year's conference and to register go to www.huntingtonsociety.ca

Find Clinical Trials in Canada

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



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

A new look and new Amaryllis campaign

By Josh Martin

The votes are in and the new look for our Amaryllis campaign has arrived! "A big thank you to everybody who took the time this past spring to let us know their favourite design," says Jeff Hoffman, who is spearheading the campaign this year. "With your input, we have given this signature fundraiser a fresh new face. The eye-catching kits are designed to grab attention, while the revamped promotional materials will help our volunteers spruce up their tables and selling areas."

The redesign is also an opportunity to showcase how much Huntington disease (HD) research and the Huntington Society of Canada have changed. A lot has happened in the world of HD in recent years, and our updated posters and educational materials that accompany each Amaryllis kit will provide supporters with the latest information. "With 20,000-plus kits in homes across the country, it's a great way for us to spread the word and raise awareness," says Hoffman.

While the packages have undergone a transformation, the heart of the campaign remains the same. Each \$15 Amaryllis kit contains a high-quality Orange Sovereign bulb,

along with a pot, soil and growing instructions. The bulbs can be planted immediately or given as holiday gifts. About 6–8 weeks after planting, stunning orange-red blooms appear, brightening homes and offices across Canada.

The decision to let the HD community decide on the final design was an obvious one. The Amaryllis campaign started as a volunteer initiative over 30 years ago, and it continues to be successful because of the dedicated volunteers who sell kits today, raising vital funds for research, family services and education. "Truly the heart of the Amaryllis program is the community," says Hoffman.

Each kit we sell brings us one step closer to finding a meaningful treatment for Huntington disease. We are already over 70 percent of the way to our goal. There's still time to order! Delivery starts the first week of October and continues until the first week of December. Amaryllis bulbs make great gifts, whether for your neighbour, a simple thank you gift for a teacher, friend or aunt or for yourself. Their blooms create a sense of festivity and hope. Please join us in spreading the hope and goodwill this holiday season.



Inspire hope today! Visit www.inspirehope.ca, call us at 1-800-998-7398 or email us at info@huntingtonsociety.ca to place your order today.

AGM Notice



Notice is hereby given of the 2016 Annual General Meeting of the Huntington Society of Canada.

Date: Saturday, November 5, 2016

Time: 11:30 am

Place: Holiday Inn Harbourview
101 Wyse Road, Dartmouth, NS B3A 1L9

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



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An Ariel View

An Ariel View is a column dedicated to Ariel Walker, one of the Society's co-founders. Ariel and her husband, Ralph Walker started the Society in 1973 from their home in Cambridge, Ontario. Since then the Society has grown, building on their legacy and hard work. Since Ralph's passing in 2002, Ariel has stayed involved with the Society, sharing her experience and wisdom. This column is Ariel's way of sharing the history of how two people decided to take action and create a movement - a powerful, strong organization that through our collective efforts makes a difference in the lives of those who are impacted by Juvenile Huntington disease and Huntington disease.

So much has changed over the years. It is so comforting to watch the transformation the Huntington Society of Canada (HSC) has made over these past four decades. I feel very privileged to be able to see incredible growth and impact around the world that we all have had.

It's so exciting to see all the international HD initiatives these days, like HD Buzz and HDYO. Of course, HSC has always played a big role on the global stage as one of the founding members of the International Huntington Association (IHA).

As I recall, it started with Mauveen Jones visiting us from the United Kingdom in 1974. We spent a great couple of days sitting on our deck and chatting before she and Ralph went to New York City to meet Marjorie Guthrie. The three of them had this vision of reaching out to other countries. A few years later, there was a bigger gathering of Huntington's associations in the Netherlands with Gerrit Dommerholt, and things just took off from there.

I was a little nervous when I went to my first IHA meeting. It felt very official, with tables set in a circle and simultaneous translation. But then I discovered everyone was just like us: trying to help families cope with HD. We built a real bond over the four or five days, and it was very emotional when we said goodbye.

Since then, I've been to many of the meetings, including one in Toronto that happened during the 2003 blackout. Until then, we held the IHA meetings at the same time as the International Neurological Association meetings, but they were separate events. Because of the blackout, however, all the scientists and lay people were forced to meet in the same room that year, and it's been that way ever since.

Today, it's hard to imagine just how much the IHA has grown. I thought I'd let Ann Jones, the current president, share her perspective.



Ann Jones - My involvement with the IHA began in 2005 when I was nominated by the Australian National Board to attend the IHA World Congress in Manchester. I was fortunate to be in the company of Robyn Kapp, a good friend of Ariel's who knew the background of the IHA. The Congress was quite an eye opener: I realized that Huntington's affected many more people than I'd thought. I knew very little about the IHA but I was willing to learn and took on the role of Secretary until 2011 when I became President.

HD is tough no matter where you live, but the more I see, the more I realize how fortunate my family is to have access to good health services. My heart goes out to the less developed countries. In many cases, services and basic care are almost non-existent, and it's important we recognize the challenges the HD community is facing wherever they live in the world.

There has been significant progress and scientific breakthroughs, and we applaud all those who work tirelessly in making a difference, but we need to remember we still have a long way to go in creating more awareness, education and a better understanding of the day-to-day care of families. The IHA role is to serve as a hub with connections in 58 countries currently. Some are formal organizations like HSC, and some are individuals.

It's a testament to Ralph, Ariel and Marjorie Guthrie, who helped establish the IHA without Skype, email or any of the other tools we have today. I take my hat off to them. It has been a pleasure to meet both Ariel and Bev (Bev Heim-Myers is an IHA Board Member). The HSC is very fortunate to have you on board. Warmest wishes, Ann. **To learn more about IHA visit them at www.huntington-assoc.com**

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.

PROFILE

Jane Manning – thrilled to be part of the Believe: Transforming Tomorrow Together Campaign team



When my husband Paul was diagnosed with Huntington disease on March 3, 2013, we had no idea it was in the family at all. It's hard. A little bit of him is disappearing every few months, but Paul isn't one to wallow in self-pity, and neither am I.

That's why I jumped at the chance to be part of HSC's Believe campaign. I've been involved in fundraising forever. I grew up involved with groups like Junior Auxiliary and Girl Guides. As an adult, I've had the opportunity to spearhead multi-million dollar fundraisers for a local arts organization, an independent school, YMCA and a hospital all located in the Vancouver lower mainland! I'm thrilled that I now get to put my experience to use for the HD community.

I hope we get beyond our \$3 million goal. If it can give more awareness to this very horrid disease, that would be the best thing that could happen. Ultimately, the more people who know about HD, the more likely donations will be forthcoming.

I very selfishly hope those donations will lead to treatments that could help Paul, because right now, there's nothing. I also worry about our son. Knowing that he could be on the wrong side of that 50/50 chance of inheriting the disease is a pretty hard pill to swallow.

I believe in a future without Huntington disease, and this campaign will help us get there. Every person who steps forward to support it gives us hope.

Love, Learning and Lobster National Conference 2016 is almost here

By Josh Martin

This November 4th and 5th, hundreds of members of the HD community will gather in Halifax to fill their minds with the latest research, their hearts with a sense of community and their bellies with some world-class seafood. National Conference 2016 is just around the corner, and judging by the program, it's a weekend you won't want to miss. "There has been a lot of progress on many levels, that we look forward to sharing with the HD community," says Huntington Society of Canada's CEO Bev Heim-Myers.

Kicking things off is Atlantic Canada native Terry Kelly, whose uplifting and comedic keynote address will set the tone for the two-day conference. Blind since the age of two, the singer, songwriter and Paralympian refuses to let anything slow him down, and we're thrilled to have him share his infectious message on the importance of celebrating life.

Meanwhile, the Halifax Chapter has been hard at work ensuring Atlantic Canada's famous hospitality will be on full display. On Friday evening the lobster pots will be bubbling and local fiddlers will be playing the best in Maritime music during a traditional Nova Scotia kitchen party.

As always, attendees will get the opportunity to connect directly with researchers pioneering the latest breakthroughs. Drs. Ray Truant and Tamara Maiuri will take centre stage on Friday to discuss new drugs on the cusp of clinical trials, while National Conference stalwarts Dr. Jeff Carroll and Dr. Ed Wild will talk about their work and what's coming down the scientific pipeline.

In addition to updates on all the latest research, HSC has a variety of other great sessions lined up. Learn more about family planning options, try some therapeutic yoga, take part in an open panel discussion on Medical-assisted in dying and much more. "We are also excited that Daily Planet's Jay Ingram will be joining us on the Saturday to explore how people like Nancy Wexler, who helped discover the HD gene, can shape the course of history," says Annie Vanexem, HSC's Chapter Development Manager. "It's an incredible opportunity to get in a room with like-minded individuals, share your experiences and share information that you otherwise might not be hearing".

HSC couldn't be more excited about this year's event. A huge thank you to the Halifax Chapter for helping it all come together! "There is always a wonderful, positive energy at the conference. We all connect and realize that it takes a community to make a difference in Huntington disease," says Heim-Myers.

There is still time to register for this year's National Conference! The \$200 fee for the full conference includes all your meals and access to the workshops and keynote addresses. Discounted rates are also available if you are not able to join us for the entire weekend. For more details, including program and registration information, visit www.huntingtonsociety.ca/conference or call 1-800-998-7398.

Kindred Spirits: Celebrating our National Conference sponsors

By Josh Martin

Pulling off the 2016 National Conference takes one heck of a team, from staff and volunteers to keynote speakers and members of the scientific community – and, of course, our incredibly generous sponsors.

A key member of this year's team is Kindred Home Care, whose generous financial support is making the event possible. "This is the largest sponsorship we have ever done, and I'm delighted that it's for the national Huntington Society of Canada's conference," says Kindred Home Care CEO Billy English.

kindred
home  care

As a leader in health services on the East Coast, Kindred Home Care works to keep people who need assistance in their homes independent for as long as possible. Billy's father Paul English founded the company in 1986. Today, hundreds of employees serve about 500 clients in communities throughout New Brunswick and Nova Scotia.

"Being a sponsor at this conference on the East Coast seemed like a great fit for us," says Billy. Kindred serves several clients with HD, he points out. The conference is taking place in Halifax, where Kindred will be opening a new office this fall.

But the strongest motivation for supporting the conference is deeply personal. Billy's father has Huntington disease (HD), making this a cause near and dear to Billy and the many employees who worked with Paul. "When I ran it by my business partner Will, there was no hesitation," says Billy. "He said, 'Absolutely! We have to.'"

Billy attributes a lot of his passion and entrepreneurial gumption to his dad. In his youth, Paul won a gold medal in running at the 1980 Paralympics. Now 60, the visually impaired athlete is still wearing out the soles of his sneakers, regularly tackling 20-kilometre runs despite his HD.

As active members of HSC's Halifax chapter, Paul and his wife are looking forward to attending the National Conference. Billy will be joining them, as will several keen Kindred staff. We promise them an enthusiastic welcome. After all, it's because of Kindred Home Care and our other sponsors that we're able to bring together researchers, experts and members of the HD community for this one-of-a-kind event.



From all of us at the Huntington Society of Canada, thank you, Kindred!

The Huntington Society of Canada extends its sincere appreciation to Kindred Home Care for their generosity in supporting this year's conference. If you are interested in supporting the 2016 National Conference, please contact the Huntington Society of Canada at info@huntingtonsociety.ca or 1-800-998-7398.

BE BRAVE · BE BOLD · BE READY



Be Brave, Be Bold, Be Ready: HD National Clinical Trials Readiness Initiative

By **Cyndy Moffat Forsyth**

“How wonderful that nobody need wait a single moment before starting to change the world” Anne Frank 1929 – 1945

Changing the world is in the DNA of the Huntington Society of Canada. From the first initiatives of HSC’s founders, Ralph and Ariel Walker, to our latest initiatives, protecting Canadians’ genetic information (see page 4) to carving a new path to ensure the HD community is prepared for HD clinical trials, HSC is at the forefront of change. One only needs to look at the website to see how HSC is changing the way the HD community, medical professionals and organizations are approaching clinical trials.

Meeting for the fourth time in four years, the HD Consortium, comprised of clinicians, researchers, HSC and family representatives, met on April 25, 2016 to continue their work on building a national HD clinical trials strategy.

This time the focus was on the recruitment strategy and how to increase the number of HD clinics and clinical trials sites in Canada as well as increasing the number of clinical trial participants. Key organizations were included to help streamline the work that needs to be accomplished, including the following:

- N2, the Network of Networks (a not-for-profit incorporated organization and an alliance of Canadian research networks and organizations working to enhance national clinical research capability and capacity)
- Clinical Trials Ontario (an independent not-for-profit organization established with support from the Government of Ontario to work collaboratively with the clinical trials community, the public and strategic

partners to improve Ontario’s clinical trials environment and attract clinical trial investment to the province, while supporting the highest ethical and quality standards)

- Innovative Medicine Canada (representing Canada’s innovative pharmaceutical industry)

Since the development of the 2012 HSC strategic plan, HSC and the HD Consortium have developed tools to encourage clinicians, family members and those impacted by HD to participate in Clinical Trials. Tools including an HD Clinical Trials Checklist for new clinicians, an inventory of HD clinics across Canada (www.huntingtonsociety.ca/huntington-disease-clinics-in-canada), an HD Clinical Trial map locator (www.huntingtonsociety.ca/clinical-trial-locations), and a sample list of questions for people who are thinking about becoming involved in clinical trials (www.huntingtonsociety.ca/questions-to-contemplate-before-considering-participating-in-a-clinical-trial).

This first-of-its-kind collaboration is taking HD clinical trials to a whole new level, based on a national all-inclusive approach which includes family representation at each meeting. What’s next for the HD Consortium? This next year will focus on implementing the recruitment strategy, preparing a clinical trials education module and collaborations including hosting a webinar with N2, on Saturday, October 1, 2016 for community members who are interested in learning more about clinical trials.

HSC has made tools available for families and medical professionals on the Society’s website for anyone interested in learning more about participating in HD clinical trials research. Learn more at www.huntingtonsociety.ca or contact info@huntingtonsociety.ca or call 1-800-998-7398.

Clinician-Scientist-to-Patient Virtual Network Launches This Fall

Two million dollars will go a long way to move HD research discovery forward. Thanks to the generosity of a donor and a partnership with Brain Canada, the Huntington Society launched the \$2 million Brain Canada-Huntington Society of Canada Clinician-Scientist-to-Patient Virtual Network research competition, at the beginning of 2016.

Top thought leaders in HD research were invited by HSC to help establish a research competition that would not only be innovative, but also expedite research discovery to the HD Community. The call for research proposals was answered by incredibly competent teams and globally recognized researchers from across Canada.

HD research has evolved and is now at a point where researchers and clinicians can connect more closely with the HD community. Knowledge transfer from the basic scientist to the clinician to the HD population is critical and exactly what this competition aimed to achieve. HSC also wanted to honour Canadian researchers, allowing for minimal international collaboration

with a focus on Canadian collaborations and strengthening the critical mass of Canadian research from the bench to the clinic to the client.

Of the several research proposals received, the one that meets all the criteria of the competition will be funded.

HSC’s partnership with Brain Canada is stronger and the door has been opened to launch this competition again, later this year.

Thank you to our generous donor, the thought leaders in HD research, the peer review committee that dedicated hours and expertise to ensure an appropriate outcome and to Brain Canada for their partnership and shared vision. The biggest thank you, however, must go to the HD Community. Your commitment to participating in studies and sharing your learned experience, is not only critical to the advancement of research, but also inspiring. Together, we will make a difference and ensure that HD’s days are numbered.¹

¹ Quote borrowed from our 2-4-1 Cross Canada Cyclists, Marty and Jim.

Lighting It Up 4 JHD and HD

By Katie Ridpath

May is Juvenile Huntington disease (JHD) and Huntington disease (HD) awareness month, a month where volunteers and staff make special efforts to reach out and showcase the impact of JHD and HD in Canada. Raising awareness and educating people about the nature of this disease is important for anyone who is touched by it.

Throughout the spring, events in support of JHD and HD are held all over the country bringing awareness and raising funds for research and services. This past May, inspired by Jamie, a volunteer who first lit up the CN Tower in 2015, HSC volunteers raised the bar by creating and implementing a social media campaign called #LightItUp4HD. Volunteers from across Canada chose specific monuments to light up in blue, for HD and purple, for JHD. The idea caught on and HD organizations from around the world took up the initiative and requested sites to #LightItUp4HD. All during the month of May, volunteers lit up buildings and posted them with the hashtag #LightItUp4HD. Buildings from coast-to-coast were lit up and countries including Ireland, Scotland and Spain got involved.

"This is an opportunity to spread our voices far and wide and make people stand up and take notice. To be able to share the knowledge and help people have a better understanding as to why it is so important to help us find a cure for this horrible disease", says Cindy Moore, a stalwart HSC volunteer and mother to Erin Wade who is impacted by JHD.

Building on this year's success, the Society has already started planning for 2017. If anyone is interested in volunteering to help #LightItUp4HD in 2017, Stephanie Rees recommends to get involved with the Huntington Society of Canada (HSC) early, connect with their local chapter and make it happen. "It's not hard to do. HSC has created letters that you can use to make it as easy as possible", says Rees.

Persistence is key in getting a monument lit up. "Once you have decided what you would like to be lit up, contact the site, ask who to contact to get email addresses and then connect with HSC; they have a letter stating why this is important and from there never let up", says Cindy Moore, proving that her volunteer efforts are lighting up hope and awareness all over.

A big thank you to every volunteer who took the time to light it up 4 HD this year! Your efforts, persistence and enthusiasm woke up the world in a fun, entertaining and meaningful way. More people know about JHD and HD! Your work was noticed.

"We need help advocating, educating and promoting the Huntington Society of Canada to help people with Huntington disease. Campaigns like #LightItUp4HD make a difference. There is a lot more work to be done but I can see that people are taking notice. That's very satisfying and makes the hard work worthwhile". Sharon Haig, Ottawa, Ontario Chapter Vice-President.

To get involved in the 2017 #LightItUp4HD campaign, email info@huntingtonsofcanada.ca or visit the HSC website at www.huntingtonsofcanada.ca to learn more.



The Kelpies, Scotland



Toronto, Ontario



Dublin, Ireland



BC Place in British Columbia

BE BRAVE · BE BOLD · BE READY CLINICAL TRIALS



YOU ARE INVITED

Join HSC and N2 (Networks of Networks) for a clinical trials webinar on Saturday, October 1, 2016.

This introductory webinar will focus on what clinical trials are and why they are important, what you can expect when you first meet a clinician to talk about considering participation in a clinical trial, what HD clinical trials are in progress now and how you may wish to get involved.

There will also be dedicated time for questions and answers.

FEATURED SPEAKER: DR. OKSANA SUCHOWERSKY

Professor of Medicine, Medical Genetics & Pediatrics, Toupin Research Chair in Neurology, Director of Clinical Genetics at the University of Alberta

&

A clinical trial participant who will speak about their experience.

This is a free event, however we do ask that you register in advance.

Visit www.clinicaltrialswebinar.ca to register.

Space is limited, so register early to secure your space.

Depending on registration numbers, registration may or may not remain open until September 25th.

Visit www.itstartswithme.ca to learn more about clinical trials.



Celebrating Our Heroes

Erin Wade

"My name is Erin. I am only 23. I have Juvenile Huntington (JHD) disease and I know that I'll probably die before I am 30."

Powerful words from a powerful woman. This past spring, thousands of Canadians found themselves captivated by these powerful words from a letter from Brockville, Ontario resident Erin Wade. Erin's deeply personal appeal letter struck a chord, inspiring donors from across the country to give over \$250,000. But the impact didn't stop there. Thanks to the matching pledge of an anonymous donor, Erin's message raised a total of \$500,000 for research and family services. "Thank you to each and every person who contributed, whether it was \$20, \$100, \$1,000 or \$5,000 or more, your donations made the difference", says Bev Heim-Myers, CEO of the Huntington Society of Canada.

Erin and her mother Cindy Moore, who helped pen the letter, are no strangers to supporting the Huntington Society of Canada. Since Erin's diagnosis seven years ago, the two have been powerful partners in raising awareness and to fund fortreatments for Juvenile Huntington disease (JHD) and Huntington disease (HD). "We'll do anything we can," says Cindy. "I'm thrilled to tell her story and get it out there, and hopefully it will make a difference."

A quick Google search returns many newspaper articles and blog posts of the dynamic mother-daughter duo spreading the word about JHD and HD. You'll also find a series of laugh-out-loud YouTube videos starring brave souls getting splattered with whipped cream in support of Erin and Cindy's Pie-in-the-Face fundraising challenge. And during May Awareness Month, they outdid themselves yet again, convincing the City of



Cindy Moore and Erin Wade

Niagara Falls to light up their beautiful iconic landmark, Niagara Falls in the blue and purple HD and JHD colours for Erin's 24th birthday.

In the face of such a devastating disease, it can be hard to get out of bed, let alone champion a cause. So what keeps Erin moving forward? Her letter offers a little insight. "It would be easy for me to give up and accept my fate but that's not who I want to be," she writes. "So I made a decision – to work as hard as I can to confront this disease head on."

In our books, that's the definition of a hero.

The Huntington Society of Canada would like to extend its gratitude to Erin and Cindy for everything that they do. They are a true inspiration. You can meet both Erin and Cindy at the Huntington Society of Canada's national conference this November. Be sure to register at www.huntingtonsociety.ca/conference

Thank you!

"We raised more than we ever imagined. It is moments like these that make me feel so grateful for our HD community. We can't do this alone. But together, there is nothing we can't do."

Cindy Moore

Thank you for being a part of the 2016 spring campaign, for your tremendous support and for inspiring a donor to match every dollar raised. Together you raised \$500,000 which will fund services for families and research to find a meaningful treatment.

Gratitude

By Joe, Marcene, Edi, Tony, Bruce, Les, Brian

What touched me today?

Who or what inspired me today?

What made me smile today?

What's the best thing that happened today?

Senses: Hear, Feel, Smell, See, Taste

Gratitude for the Air

Breathing, in and out

Moist, salt, tasting exotic food

Relaxation, deepened with massage

Feeling the breeze

Hearing music, ocean waves

I picture my grandkids playing

Among beautiful trees and cactus in bloom

Watching them discover wonder

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.