

Cramming it all in:

Dr. Jeff Carroll discusses family, research, being gene positive and HDBuzz

By Julie Stauffer

On the kind of cool, grey, drizzly day that marks fall on the West Coast, Jeff Carroll is putting together his new research lab at Western Washington University.

In a lot of ways, the 34 year old has it made: an impressive list of scientific publications, a job offer that has brought him back home to friends and family and a reputation as an up-and-coming researcher with a knack for communicating complex topics.

Ironically, he owes it all to a small DNA stutter, a few extra CAG repeats passed on from his grandmother to his mother, and now on to him.

As a 20-something, Jeff was bright but lacked direction. After dropping out of high school, he spent a few years in the army and was dabbling in a few community-college philosophy courses when his mother was diagnosed with Huntington disease (HD). With little information then available about the disease, Jeff signed up for a biology class to get a better grasp on what was happening to his mom.

One thing led to another. He completed a PhD with world-renown HD researcher Dr. Michael Hayden and recently wrapped up a post doc at Harvard Medical School. He is a co-founder of HDBuzz, a website covering Huntington's

research that attracts more than 70,000 visits a month, and he is a highly sought-after speaker who regularly earns standing ovations at Huntington's conferences.

"HD has given me a lot of clarity and direction," he says.

Don't misunderstand him. He would far prefer not to have a fatal neurodegenerative illness looming over his future. But given that there is a gene creating changes in his brain that will eventually manifest as HD, Jeff is determined to make the most of the time he has. That means prioritizing and focusing on what is most important in his life.

"As grad school got really busy, I decided 'look, I'm going to do two things,'" he recounts.

"One is have a family and the other is work."

So when Jeff isn't busy with his wife and five-year-old twins, you'll find him at the lab bench, in the classroom or wrestling with the clearest way to explain Huntington's discoveries to families around the world via HDBuzz.

Just as soon as his lab is set up, he will continue the work on HD metabolism that he began with Dr. Marcy MacDonald while at Harvard. According to Jeff, metabolism in Huntington's is "manifestly screwed up."

"You get HD patients that are eating 6,000 calories a day in some specialized nursing

home and they're losing weight dramatically and we don't know why," he says. By investigating brain cell metabolism in HD mice, he hopes to come up with some answers.

In his new role as a university lecturer, Jeff is looking forward to turning his students on to neuroscience. Meanwhile, HDBuzz has taken off in a big way. Less than a year after its launch, the site offers updates in ten languages, including Danish, Polish and Portuguese, and praise is flooding in from around the globe.

Yes, it makes for an unforgiving workload, but Jeff is driven as much by his love of science as his passion for helping families like his, who are grappling with HD.

"Figuring out how the human brain works is the most exciting thing humans have ever done, and I get to be a tiny little speck of that," he says. "That's pretty cool."

If his life would have been better without the HD gene, well, so be it. "The bottom line for me is that you don't choose your situation, but you do choose how to react to it," he says.

For Jeff Carroll, that means trying to push back the boundaries of science, give the Huntington's community the information it's hungering for and take care of his family for as long as he possibly can.

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Huntington's disease research news. In plain language. Written by scientists. For the global HD community. Go to www.HDBuzz.net to see what the Buzz is all about!

Horizon is the newsletter of the Huntington Society of Canada. Published three times per year (Spring, Fall and Winter), its purpose is to convey information to individuals with Huntington disease and their families, health care professionals, friends and supporters.

Huntington disease is a hereditary brain disorder which has devastating effects on both body and mind. The symptoms, which may include uncontrollable jerking movements and relentless cognitive and emotional impairment, usually appear between the ages of 30 and 45, and gradually worsen over the 10-25 year course of the disease. As yet, there is no meaningful treatment.

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

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Note from the CEO

I knew that when I accepted this position in 2009, that serving as CEO and Executive Director of the Huntington Society of Canada would be a privilege in so many ways. Recently, three events have continued to drive this point home for me.

First there was the World Congress on Huntington disease in Melbourne, Australia this past September. It was an incredible experience to join hundreds of families, researchers, healthcare professionals and staff from other international organizations, like ours, in this biennial event.

The Congress reinforced for me how there are no borders within the Huntington's community. People around the globe are truly working together and sharing information in order to find the answers to HD.

Today, those answers lie just around the corner. Researcher after researcher spoke about how close we are to human clinical trials, not just for drugs that may treat symptoms, but for drugs that may significantly alter the course of this disease. I came away feeling tremendously upbeat about what we have achieved to date and what we are going to achieve in the near future.

Secondly, while attending the Congress I was honoured to be invited to serve on the Board of Directors for the International Huntington Association, an organization that HSC helped found. This is a huge privilege and an opportunity: a privilege to work with such a committed group of people and an opportunity to share best practices with our global partnering organizations.

Finally, at the end of September, as the 41st Parliament got underway, I had the opportunity to speak to Canada's decision makers in Ottawa as a representative member of Neurological Health Charities Canada.

As a group, we made our case to 30 MPs and Senators: driving home the need for income security for individuals and families living with neurological conditions, for an end to genetic discrimination, for better access to care across the country and for increased caregiver support.

It was a highly successful day of advocacy. Thanks to our past work, Canada's politicians already understand the issues. Now they want to know how they can be a part of creating solutions. Although legislative change is never fast, we are making big strides.

I'm tremendously proud of how HSC continues to advocate for Canadian families with Huntington's through organizations like Neurological Health Charities Canada and the Canadian Coalition for Genetic Fairness.

One of the opening speeches at the Melbourne Congress was entitled "Yes We Can!" As we welcome in the New Year I am proud to say that our team at HSC embodies that spirit of optimism and achievement and I am confident that as a group, globally, nationally and locally we will approach the challenges that 2012 may bring with that same enthusiasm.

Bev Heim-Myers
CEO & Executive Director

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When IVF/PGD Doesn't Deliver

By Julie Stauffer

Amanda and Mack Erno finished university. They got married. They launched their careers. And, like many young couples, they talked about having children. There was just one catch: Amanda's mother was suffering from Huntington disease (HD), which meant Amanda was at risk as well.

When genetic testing confirmed their worst fears, that Amanda had inherited the HD gene, they went ahead with their plan to have children. To avoid passing along the gene, however, the Ernors turned to in vitro fertilization (IVF) with preimplantation genetic diagnosis (PGD).

This high-tech procedure involves screening embryos before they're implanted to ensure they do not carry the HD gene. "It is an amazing technology that offers the ability to do something that's remarkable," Mack says. "There's no other way to put it."

In their case, unfortunately, it didn't work.

In many ways, IVF/PGD comes down to numbers. The number of eggs harvested, the number that are successfully fertilized in the Petri dish and the number that successfully develop into eight-cell embryos that can be tested for the HD gene.

Next comes the number that test negative for the HD gene, the number that doctors choose to implant and, finally, the number that embed themselves in the lining of the womb, creating a successful pregnancy. At each stage in the process, the numbers and chances of success get smaller and smaller.

Going into the procedure Mack and Amanda were aware of the risks involved, as well as the limiting parameters of success. Even so, they arrived at the Vancouver fertility clinic in January 2009 with a high degree of optimism. "We had visions of being able to do it once and even if it didn't work that time, still have two or three HD-free embryos on ice so we could try again," Mack recalls.

After a series of hormone injections designed to put Amanda's ovaries into overdrive, the fertility clinic doctors harvested twenty eggs. Of those, eleven were successfully fertilized and five matured into healthy embryos for testing. So far, so good.

When the PGD lab results came back, however, they revealed four of the embryos carried the HD gene, leaving just one for implantation, an implantation that did not prove successful.

With these first results The Ernors were not discouraged. They were both under 30 and in



their reproductive prime. They had produced five embryos in the first round. Next time, they figured, the results could well be reversed: one embryo that carried the HD gene and four that did not.

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Introducing Our New Manager of Fundraising



Andrea Cliche spent the first six years of her working life in the financial sector. After a while, she began to feel she wasn't making the kind of

difference she wanted to make in the world.

"I realized that I wasn't really helping anybody," she explains. "And that's not the way I was raised, and it's not the way I wanted my future to look."

So when she received a headhunting call in 2005 from a fundraising executive at the CNIB, a charitable organization providing support to Canadians who are blind or partially sighted,

she didn't need much persuading to make the jump. "I was sold, and I've never really looked back," she laughs.

There was a lot to learn, but Andrea brought two key assets to her new role within the public sector. She had people skills in spades, plus the knowledge and experience of how money works, a distinct advantage when it comes to helping donors choose the best tools to achieve their vision.

Since then, she's had plenty of opportunity to hone the tools of her new trade, first handling major gifts and planned giving at CNIB and, later, as a development officer at Wilfrid Laurier University.

Today, her fundraising philosophy is all about developing trust relationships. "It's being able to talk to people and figure out what kind of investment they're looking for within the organization and what I can do to ensure that their personal passions and philanthropic goals are met," she says.

The role of Manager of Fundraising at the Huntington Society really piqued Andrea's interest, partially because of the size of our organization and partially because of how close the research community is to human clinical trials for promising HD treatments.

Since joining HSC in July, Andrea has been busy immersing herself in the Society's culture, getting up to speed on the latest Huntington's research and working with Janice Waud Loper, Director of Major Gifts, Western Canada to develop a pan-Canadian major gifts strategy.

"It's been wonderful," Andrea says of her experience to date. "What's impressed me the most, I think, is how small our infrastructure is, but how mighty we are. We accomplish great things with the resources that we have."

We at HSC would like to welcome Andrea. We are proud to have her as a leader within our Fundraising Team.

Posting, Tweeting, Digging

Social Media: Being a part of the next wave of how we can get the HD Message out there!



Why all the activity? Social media offers a fresh new way for HSC to engage in conversations with the Huntington's community. "For us, it is the next level of development," explains HSC Development Coordinator Jim Martin.

While HSC has had a Facebook page for several years, we've recently expanded our social media presence, thanks to the efforts of Jim Martin, Jane Dawkins, our new communications coordinator and our summer 2011 co-op student Dnyanada Palkar from Wilfrid Laurier University.

With so many members of the Huntington's community already spending time in places like Facebook and Twitter, providing more information via social media makes good communication sense.

One of the advantages is being able to share news in near-real time and get feedback just as quickly. "It's a two-way tweet now," says Jim, "It allows those affected by HD to communicate with us immediately on what information is important and of value in their lives."

Lauri-Jane Shattuck Lewis, one of our Facebook followers, states: "My husband has Huntington disease. Facebook has helped me keep up to date on the latest findings in research, etc. I always share any postings on my Facebook to let others know about HD.

It also lets me know that we are not alone out there. There are many others facing what we face on a daily basis. Getting out the word about HD is very important because not too many people know what it is. Thank you for all your information, and keep up the good work. :o)"

FB fan Karen Kovacs likes to use Facebook to help educate people on HD. "Huntington disease has been all around me for many, many years," she writes. "Facebook makes it easier for me to tell everyone I know about this disease. Thanks!!!"

Madoka Gray, HD caregiver, says, "I find it much easier to follow breaking news in Facebook rather than e-mail or RSS. My inbox is already quite full and messages unrelated to work or friends piles up fast. I feel stressed just talking about unread messages in my inbox... Somehow, Facebook doesn't give me that dreadful feeling. I am always happy to read any news and updates on Facebook. This could be just me. And yes, sharing news is much easier."

Another big plus is the ability to reach out to less central communities. "For families and individuals in rural areas or isolated situations, social media is a way to reach out to others who understand," says Maribeth Meijer, HSC's Director of Family Services and Community Development.

Our goal is to grow our Facebook page to 3,000 likes by April 30th. You can find us by searching "Huntington Society of Canada" on Facebook. So join the conversation, start topics, raise issues, ask questions, share stories and talk to your peers or follow news and research updates, fundraising events and media coverage on HD.

Other HSC Social Media sites:

- Search "Casino Royale – Huntington Society of Canada" on Facebook to follow the building of excitement about Casino Royale, HSC's upcoming premier fundraising event on Saturday, February 25, 2012 in Toronto.
- Visit "Amaryllis Inspire Hope for Huntington Disease" to post pics of your Amaryllis and share you fundraising stories.
- Join the "Fighting Genetic Discrimination" page to support the fight to prohibit discrimination on the basis of genetic characteristics.
- Follow us on Twitter @HuntingtonSC for late-breaking HD news in 140 characters or less!

Healthpartners: The Power of Workplace Giving

For decades, United Way has been tapping into the power of workplace giving to raise funds for communities. By reaching people where they work and making it easier to donate through payroll deductions, this organization has been able to raise hundreds of millions of dollars across the country each and every year.

Healthpartners has taken this highly successful model and applied it to health causes. The concept was born 20 years ago, when the Canadian Cancer Society brought together other national health charities and convinced the Treasury Board of Canada to allow us to conduct campaigns in federal government offices.

Last year's campaign raised more than \$12 million dollars for medical research, health

services and educational programs. Through this program, donors can choose to support all 16 Healthpartners members, including HSC, or they can direct their dollars to the causes most meaningful to them.

In linking up with Healthpartners "We see this as an excellent vehicle to raise the profile of HD and attract more funds for research and services," says Cyndy Moffat Forsyth, HSC's Director of Development and Marketing. "Being a part of this national campaign lets us reach hundreds of thousands of federal employees and retirees from coast-to-coast."

Healthpartners needs your help! Each year, volunteers are needed to staff HEALTH CHECK displays during the *Government of Canada Workplace Charitable Campaign* running throughout the fall of each year.



Alternatively, by becoming a member of Healthpartners' Speakers Bureau, a group of recipients of service, volunteers and/or staff members can talk about the difference Healthpartners' funded organizations have made in their lives and in the lives of the people they care about. You can help raise awareness of the difference Healthpartners can make.

If you'd like to learn more, call us at 1-800-998-7398, email us at info@huntingtonsociety.ca or visit the Healthpartners website at www.healthpartners.ca.

The Art of Getting up in the Morning

*I need to get up in the morning.
I need the transition of dark to light.
I need the blue light from the sun.
The light distorted as it travels through the horizon.
If I don't after two weeks my body will want to sleep all day and stay up all night.
That is our nature.*

*I need to get up in the morning.
God is not going to get me up.
A nagging spouse is not going to get me up.
Fear of consequences is not going to get me up.
It will keep me in bed.
I have to get my DNA to want to get up and face the day.
That means I have to convince my own DNA, that as a collaborative monkey, I am contributing.
I must prove to it I have meaning and purpose. It has to be real. That is our nature.*

*I need to get up in the morning, to eat well,
to go for a 2 hour walk for the BDNF so I can produce new brain neurons.
That is our nature.*

*I need to get up in the morning to ask of others and learn, discuss, ask questions, be terribly wrong, listen, think, project, assume, verify, articulate and write.
All that leads to production of new brain neurons.
That is our nature.*

*I need to get up in the morning knowing that over the last week someone said something with that incredible tone of voice that means I have made other's lives better.
That means it is very likely to happen again in the next week.
That is our nature.*

*I need to get up in the morning to go to bed at night at 10 p.m. for a full night sleep with the short and long term memory shuffling that comes with dreams and restorative cell work that comes during sleep.
That is our nature.*

*I get up in the morning because I know each day will be exceptionally wonderful and that takes my mind way beyond my physical limitations, including that broken part of my brain.
As the poem I once read to my kids revealed to me; "Good morning, good morning, its time to face the day, first we'll have breakfast and then we will play."*

Don McLeod

Courage to Lead Your Best Life: The October HSC Symposium

On October 1st, approximately 350 participants across the country joined together for HSC's latest National Video Conference, an event focused on advice, guidance and support from globally recognized scientists and local Huntington's experts on how those affected by HD can find the courage to live their best lives.

The star of the show was Dr. Ed Wild. Sporting a maple leaf T-shirt, the British neurologist teleconferenced in from London, England to deliver his popular 2010 National Conference presentation "Optimising Life with HD" to Canadians in key centres from coast to coast.

In his presentation, he reminds us that although there is currently no cure for HD, there are still plenty of practical ways people living with the disease can improve their quality of life.

Dr. Wild speaks of mountains, and although we have not yet conquered this Everest there are plenty of celebrations along the way. How do we do that? Dr. Wild suggests some of the following tactics to help make improvements in everyday life. Assembling a supportive team is key. Deal with hard planning issues early so that you can focus on living your best life. Be sure to celebrate smaller achievements each day. Recognize your needs, and don't be afraid to work with your healthcare providers to make informed decisions with regards to your care. Finally, be sure to know when to make smart concessions that can



lead to big life benefits, such as using a wheelchair to gain more mobility.

Dr. Wild encouraged his audience to take hope from the significant research advances we've made. "Hope is a byproduct of science," he said. Above all, he concluded, enjoy the journey. "We all have mountains to climb, and while HD may be a more difficult mountain than most, it's important to look back and admire the view."

The eight sites across the country complemented Dr. Wild's talk with their own programs, including community panels and talks from local Huntington's experts. In Edmonton, the local chapter used the occasion to hold the chapter's first-ever fundraising walk for HD.

Overall the national symposium was a success that attracted many new families and earned high scores from participants. We are looking forward to an even stronger attendance at our spring symposium in June 2012. The spring event will connect Dr. Wild to more communities across the country.

For full details, see the symposium website at www.hscsymposium.ca, via email at info@huntingtonsociety.ca or by calling 1-800-998-7398.

Courage
to lead
your best
Life



Oshawa HSC Symposium October 1, 2011



Inspiring Hope: Amaryllis Campaign 2011

After our sell-out Amaryllis success in 2009 and 2010, we set our targets even higher for the 2011 season. Between October 5th and December 2nd we shipped a record breaking number of Amaryllis bulbs to sellers across the country, from Vancouver Island to St. John's.

In his first year spearheading this national flagship campaign, Development Coordinator Jim Martin has learned a lot from veteran sellers, as well as his predecessors Kelly Macnab and Mandy Dennison. "There's a great connectedness to HSC founders Ariel and Ralph Walker around the Amaryllis," he says. "It really is something that reaches back to the roots of the organization."

While supporting HSC's tried-and-true marketing approaches, Jim injected a few fresh touches. Based on suggestions from volunteers, he added a promotional postcard to our marketing package, perfect for putting on coffee shop counters or pinning up on supermarket bulletin boards.

At the same time, the entire marketing package received a boost. "We produced some new and beautiful materials, starting with the box that the individual Amaryllis Kit arrives in," Jim explains. "It's quite a stunning new look."

Ads on Craigslist and Kijiji successfully helped connect would-be buyers with sellers in their communities, while the new Amaryllis page on Facebook helped generate momentum for the campaign in general, providing a great forum for sellers to exchange thoughts on selling tips and events ideas.



At National Office, Jim tested new markets, promoting the flowers to local realtors and financial planners as client thank-you gifts. "Having a plant in someone's home or office over the holiday time is a striking gift," he says. "They see it as an alternative to, or an addition to, a bottle of wine or a food basket for their clients." The Amaryllis offers more than traditional gifts: it is a keepsake that continues to give for months to follow.

Meanwhile, local chapters were just as enterprising. The Peterborough chapter, for example, organized a sale weekend at their local Costco — "a wonderful opportunity and wonderful exposure, not just for Amaryllis but also for HD and HSC," says Jim.

A huge thank you to the hundreds of HSC volunteers, old and new, who made this year a success. If you purchased a bulb, please be sure to share your photos on our Facebook page. And if you missed out on your opportunity to buy a live Amaryllis, why not stop by www.inspirehope.ca and plant a virtual bulb in our Hope Garden? HSC's virtual Amaryllis Garden is open for donations all year long!

Congratulations from HSC



Dr. Michael Hayden, Professor of Medical Genetics at the University of British Columbia, was awarded the 2011 Canada Gairdner Wightman Award for his research on Huntington's disease and other rare disorders. Dr. Hayden's work opens the door to new treatments, the Gairdner Foundation said. The awards, which include a \$100,000

prize, was handed out at a gala dinner at the Royal Ontario Museum to seven researchers from North America and around the world on Wednesday, October 26th.

In 2011 Dr. Hayden was also awarded the prestigious Killam Prize, an award that goes to outstanding Canadian scholars working in the humanities, social sciences, natural sciences, health sciences and engineering.

Thank you DIRTT for your great hospitality!



DIRTT Environmental Solutions Ltd. of Calgary hosted HSC at Lounge Thursday on October 13. DIRTT generously supports the Youth for HD and HD Kidz programs, and staff heard about how HD affects families from Southern Alberta Chapter and YPAHD reps Tara Johnson-Ouellette and Melissa Lingard.

Stephen Gould: A Decade of Service



When Stephen Gould stepped down as the Society's

chair in October, it marked a decade of service on our Board of Directors. Looking back, Stephen highlights three key achievements the Huntington's community can celebrate since then-chair Elaine Taylor first lured him onto the board in 2001.

First and foremost are the scientific and medical advances that HSC has helped to fund. Although Stephen is quick to acknowledge that progress can't come fast enough for families affected by HD, researchers have made tremendous progress in understanding the disease and readying potential treatments for clinical trials.

At the same time, the Society has graduated from revenues of \$1.5 million to \$3.5 million, a big leap within the Canadian non-profit sector that more than doubles the money we can invest in research and services. As well as overseeing that growth, HSC's board has worked hard to make sure the sophistication of our management and governance systems have kept pace.

Finally, Stephen says, HSC has channelled more energy and resources into advocacy. In recent years, we've focussed public attention on the issue of genetic discrimination, rallied politicians to the cause and attracted significant media attention.

The bottom line? "We've done some good work," Stephen

concludes. "Whether it's good enough is not for me to judge, but I've been privileged to be involved."

One of those privileges was attending the 2009 World Congress in Vancouver, packed with up-and-coming researchers passionate about their work and committed to finding a meaningful treatment for HD. "That created a lot of energy and a lot of hope," he says. "People really got the sense that we were getting somewhere."

Looking to the future, Stephen predicts the biggest challenge for the Society will be preparing for the day when long-awaited treatments arrive. HSC's Board of Directors has already begun preparing for the logistics of helping thousands of families access those drugs, but more remains to be done by Stephen's successor.

As for Stephen, he's handing over the reins satisfied that he has helped to make a difference. As the executive vice-president at Alberta Health Services, Stephen has served on many boards over the years, from the Toronto Children's Breakfast Club to community hockey, basketball and soccer organizations. This one, however, resonates in a special way.

"Another hockey game is just another hockey game," he explains. "HSC has been more meaningful because it has a dramatic impact on people's lives."

Although we know that he will stay closely connected with us, we will miss Stephen and thank him for his solid 10 years of dedication and service to HSC.

An Ariel View

It feels good to be home after so much travelling, but it was wonderful to connect with so many people at the 2011 World Congress in Melbourne, as well as with dear friends in Vancouver on my way back.

What stood out for me the most in Melbourne is just how international the Huntington's movement has become. I remember the first Congress I attended. It was in Belgium, in 1984, where we were trying to put together a mission statement and constitution for the International Huntington Association.

Back then, there were only six or seven countries represented around the table. Now, there are almost 40 members of the IHA. What a difference! On top of that, things like Twitter and Facebook are making the Huntington's community more connected than ever. When families are looking for information, the answers are often just a tweet away.

I think the other big change I've seen is much more communication between researchers and the lay community. In those early conferences, the scientists and medical experts would meet in one room and we would meet in another. We felt honoured when one of the scientists would come over to our room for an hour to tell us about new research.

Today there is so much collaboration. HDBuzz is giving families the latest information in language that we can all understand. Scientists and doctors are talking to families and paying attention to their experiences, while families are helping to advance research by signing up for clinical trials.

I'm also thrilled to see the Huntington's youth movement expanding. Now we have the new Huntington's Disease Youth Organization to support kids, teens and young adults who are impacted by HD all around the world.

We really have come so far. It's hard to believe, but HSC's 40th anniversary is just around the corner. I don't know where the time has gone, but I do know that the Society keeps growing and doing more and more for families living with HD.

To mark the 40th anniversary, HSC is getting ready to launch a new capital campaign. The goal is to raise \$5 million by 2013 to provide even more services, resources and money for research. It's a big goal, but when I think about how much we've achieved as an organization since those early days, I'm confident we can do it. Together, we can make this campaign a success.

Hoping you and your family had a wonderful holiday season.

With warm wishes,

Ariel



Enroll-HD

A Prospective Registry Study in a GlobalHD Cohort



Young People Affected By HD – My Story

by Catherine Price

As part of the October HSC Symposium, YPAHD member, Catherine Price, gave a presentation about YPAHD. Her presentation complemented the Newfoundland Symposium location in St. John's. In her own words, Catherine describes her own experience with HD.

"I became familiar with Huntington's disease when I was just a little girl. My grandmother was diagnosed with the disease just shortly before I was born and she passed away when I was 10 years old. After learning more about the disease as a child, I realized that Huntington's disease did not end with my grandmother, but could possibly affect my parent, aunts, uncles, cousins, and even me. Therefore, I became interested in getting involved with fundraising and awareness for the disease, but I didn't know where to start.

In 2010, I heard about YPAHD, which stands for Young People Affected by Huntington Disease, and I immediately became a member of the group. As a child, I could only deal with the issues and feelings that came along with HD with my older sibling. So, it was great to finally meet others who were also affected by this disease. Becoming a member of YPAHD has motivated me to fundraise and raise awareness whenever possible. It has also been great for

copied with issues and feelings relating to the disease because there's always someone who can relate to you.

"Young People Affected by Huntington Disease", also known as "YPAHD," was created in 2008 at the national convention with the initiative to connect youth within the HD community. As a chapter of the Huntington Society of Canada, YPAHD strives to:

- Provide a support network for young people affected by Huntington disease.
- Increase public awareness
- Raise funds to deliver services for those living with HD and to further research.

Since 2008, YPAHD has grown to well over 200 members from all across Canada.

In January of 2014, I felt the desire to connect with other youth in Newfoundland who are also affected by Huntington disease. Therefore, I created "YPAHD-NL," which is now a recognized group at Memorial University. YPAHD-NL focuses on connecting youth that are affected by Huntington disease in Newfoundland, working together in our province to meet the goals that were outlined by YPAHD.



Recently, we were involved in the volunteer fair at Memorial University where we focused on raising awareness about Huntington disease. Currently, we are working on creating and organizing various fundraising events.

In June, I was given the opportunity to represent Canada, along with four other members of YPAHD at the 2014 Huntington's Disease Society of America National Convention in Minnesota.

I also attended the first International Youth Meeting which took place in conjunction with the convention. This meeting brought together 22 young people from 11 different countries all around the world. The main purpose was to discuss the current state of support for young people in our countries and to introduce how the newly formed Huntington Disease Youth Organization (HDYO) could assist with providing support and consistent, accurate information to young people affected by HD.

HDYO is currently constructing an interactive website which will provide educational information about HD to kids, teens and adults. The information provided, along with its presentation, is all dependent upon age, so it's suitable for everyone.

Overall, I have had a wonderful experience with YPAHD. It has allowed me to connect with others from Newfoundland, across Canada and internationally that are also affected by HD."

If you are a young person whose life is affected by Huntington disease I encourage you to join!

Catherine spoke to a group of 25 people, including five youth who expressed interest in joining HSC and YPAHD in the fight against HD.



YPAHD Young people affected by
huntington disease

reaching out ...
giving hope ...

When IVF/PGD Doesn't Deliver

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In May 2009, they returned to the clinic for round two. This time the doctors harvested fourteen eggs and, of those, eight were inseminated, but only two survived to the eight-cell stage.

The Ernos now faced a difficult decision. Freeze the embryos, as the clinic suggested, undergo another round to produce more, and then send them all for testing? Or go ahead as originally planned and pin all their hopes on just two tiny bundles of cells?

Mack describes IVF/PGD as no small undertaking. "It basically turns your life upside down," he says.

There were many challenges, starting with the limited number of clinics. Since there are no clinics near their home outside Grande Prairie, Alberta, the Ernos had to travel for treatment. That meant spending two weeks in Vancouver for each attempt, far away from home, family and the grounding effect of daily routine.

The process was also physically demanding. The first time doctors harvested Amanda's eggs, she was completely exhausted and went back to the hotel and slept right through the day, for eleven hours straight. On top of that, there was the financial cost of IVF/PGD: more than \$17,000 a shot, drawn straight from their personal savings.

With limited time to make a decision, Mack and Amanda chose to go ahead with the two embryos they had and cross their fingers that at least one would be HD-free.

They were completely unprepared for the results that came back. According to the diagnostic lab, one embryo carried the HD gene, while the other was... inconclusive.

"Inconclusive?" they asked. "What does that mean?"

Ontario's GenetiKit research team reports that approximately ten per cent of embryos tested using PGD do not yield clear results. If there are enough gene-negative embryos, any inconclusive ones can simply be ignored. However, this was not in the case for the Ernos.

"So we had another difficult decision," Mack recounts. "Our whole goal was to try to not pass this on, and here it was no different than doing it the old-fashioned fun way."

After a lot of soul searching and discussions with friends and family, they went ahead with implantation of the inconclusive embryo. And, once again, the procedure was not successful.

After two rounds of IVF, seven months on an emotional rollercoaster and more than \$35,000 out of pocket, the Ernos decided not to try IVF with PGD again. One of the biggest factors in this decision was when the Ernos asked the doctors at the clinic what they would change to improve their chances if they went forward with another attempt, the response was nothing. There was no explanation for their poor results, the doctors said, so they could only do the same things again and hope for a better outcome.

While Amanda and Mack decided against another round, they also decided not to let HD hold them back from living life fully, and that included having a family. "The bottom line was that we weren't willing to not have children," Mack explains. Ultimately, they did what thousands of couples faced with Huntington's have done: they went ahead, took their chances and got pregnant without the intervention of medical technology.

Today, three-month old Claire is a happy, healthy baby whose parents adore her. Do the Ernos worry about whether she has inherited her mother's HD gene? Of course. As Mack sees it, however, Claire has a 50/50 chance of inheriting the HD gene from Amanda, and even if she does carry the gene, the likelihood of a meaningful treatment or cure for HD by the time Claire nears the typical age of onset is very good.

"I'm quite confident we're going to have something that's going to either stop the disease or cure it," he says. "Look how far we've come in 15 years of research, and just imagine what will be possible 30 years from now."

The Ernos have no regrets about trying IVF/PGD. They simply want to caution other HD families that the final outcome may be disappointing. As Mack says, "Biology is not always as simple as we would like it to be. You need to be prepared for that when it comes to IVF/PGD."

The truth is, IVF/PGD comes with no guarantees and there are risks. Sometimes test results can be positive, but they have an equal chance of being negative or inconclusive. With each attempt, the likelihood of a successful pregnancy is only 30 to 45 per cent. And that means some couples, like the Ernos, face hard choices.

"How do you figure out when to stop, when to say 'OK, it didn't work for us?'" Mack asks. "Is it after two rounds, is it after three, is it after six? When you top \$100,000? Or when you feel that you can't do it emotionally anymore?" The choice is personal and each case is different.

"I don't want to come across as being negative," he concludes. "It's amazing what it has done for some people. I guess our message is just to go in with realistic expectations. Optimistic, but realistic."

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Celebrating Our Heroes

Living Her Best Life: Angie Bond

By Julie Stauffer

The day Angie Bond's dad was diagnosed with HD was one of the worst in her life. Finding out that her father was fatally ill and that she herself had a 50 per cent chance of developing the same disease devastated the 19 year old. "I was bawling," she says. "I took it very hard."

Even tougher was her own diagnosis at the age of 33. Six years later, however, the petite woman from Duncan, B.C., is bubbling over with enthusiasm for life. Today, barely a sentence goes by that doesn't include the words "amazing," "awesome" or "wonderful".

Sure, Angie has involuntary movements. Sure, she has trouble swallowing and her brain doesn't work quite the way it used to. But she's not letting that stop her from squeezing the most out of every moment.

"You have to stay happy and try to laugh," she says, explaining her approach to coping with Huntington's.

After her diagnosis, Angie drew up a "bucket list" of things she wants to accomplish in life and has been steadily ticking off items ever since. Boat trip? Check. Helicopter ride? Check. Cirque du Soleil show? Check.

Top of the list was *The Price Is Right*. "I love Bob Barker," she says. And if she couldn't see him, now that he's retired, replacement host Drew Carey would just have to do. Fifteen friends and relatives from across the continent headed to Hollywood with her for a taping of the show, where they were given star



Angie Bond's family are travelling to Hollywood with her to attend a taping of the *Price Is Right*. Angie, who has Huntington's disease, said it's been a lifelong dream to kiss Bob Barker, but "now I guess I'll have to kiss (new host) Drew Carey". From left to right; Roz Wilson, Ashley Bond, Vicky Carter, Angie, Judi Doucette, Marie Doucette and Ashley Weirsma. (Photo by Mike D'Amour at the North Island Gazette.)

treatment. And when Angie's daughter, Ashley, got called as a contestant — well, that was icing on the cake.

"We were all screaming and jumping up and down," she laughs. "It was amazing."

Many of the highlights over the past few years weren't even on Angie's bucket list. Going to HD camp, for instance, proved to be a wonderful experience: an opportunity to get

away, have fun and meet other people who were just like her.

There was the thrill of having family members in Ontario participate in the 2011 Ontario Run for Huntington Disease in her honour, all decked out in "Team Angie" T-shirts. "I've got a wonderful family," she says. "I couldn't believe they did that for me."

Recently, Angie's daughter tested negative for the HD gene — "the best news ever," according to Angie. "I didn't want her to get tested because I didn't know if I could handle a positive result. But she went ahead and did it anyway because she wanted to know, it was bothering her. And then it came back negative," Angie recounts. "I couldn't believe it."

Finally, there's the diamond ring that's sparkling on Angie's left hand. On Valentine's Day, she got engaged to someone who writes poetry about her, treats her like a princess and isn't bothered in the slightest by the fact that she has HD. "He's wonderful to me," she says. "He's a wonderful guy."

These days, there's no question that Angie is living her best life. And with a wedding planned for next summer, the future promises to be even better.

What Are HD Retreats/Camps?

The HSC Therapeutic Retreat/Camps are annual events, occurring at different locations through the spring and summer months. "The retreat is a wonderful experience allowing each individual with HD to re-discover abilities which they think they have lost," says Susan Tolley, Resource Centre Director for British Columbia. "Activities at the retreat in British Columbia include therapeutic workshops each morning along with other activities such as swimming, singing, California kickball, card playing, sharing and offering help to other, all within a safe environment."

A goal of the retreat program is to help break isolation, as many individual have only met other family members with this disease, and the retreat allows people to learn more about themselves and meet others with HD. The retreat/camp is a positive way to connect with the HD community, support each other, share stories and get physically involved.

HSC offers retreat experiences in Alberta, Ontario and British Columbia.

To learn more about the retreats and other HD support services available, please contact your local HSC Resource Centre.

Please join us for our 2012 National Conference.

The Courage to Lead Your Best Life!



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at the InterContinental Hotel, Toronto, Ontario

Join us for two inspiration-filled days focused on "The Courage to Lead Your Best Life." We welcome all those who are interested in making a difference in the lives of those living with Huntington disease. Join us for clear, informative

sessions on research and care, along with the opportunity to connect with other families, healthcare professionals and researchers from across the country.

The conference is hosted by the Toronto Chapter and offers an opportunity for families, healthcare professionals and students from across Canada to learn more about the disease and how to manage the day-to-day challenges of those living with HD.

This year, we are including a bonus! Prior to the conference start we are proud to offer a full day of programs organized for youth by youth on November 8th, thanks to Young People Affected by Huntington Disease (YPAHD).

Look for details on the Huntington Society of Canada's website www.huntingtonsociety.ca. Check in regularly to find out what's in store. See you in T.O.!



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Thank you

Dear HSC,

For the last few years, I've been participating in the COHORT study through my local HD clinic. Now I hear that they're stopping COHORT and starting something called EnrollHD instead. Why are they doing this, and what will it mean for me?

Bob, Coquitlam

Dear Bob,

Thank you so much for taking part in COHORT! By participating in this long-term observational study, you've been helping researchers learn more about the first signs of HD and how the disease progresses, information that will be vital when it comes time to test potential treatments.

EnrollHD is a similar study, only bigger and on a wider international scale. Since HD is not a common disease, one of the challenges for scientists is getting enough participants in order to draw meaningful conclusions from the data they collect. That's why the

international HD research community is now launching EnrollHD.

While COHORT involved families in North America and Australia, this new study will also include Europe (where it will replace the current REGISTRY study), Latin America and parts of Asia. It's a great example of how Huntington's researchers around the world are working together to advance our knowledge of the disease, improve clinical care and accelerate the development of treatments.

So what does all of this mean for you?

Most clinics involved in COHORT will be switching to EnrollHD. To readers who have not already received information about this program, please contact your local clinical trials coordinator or contact our Family Services Department for information on how to find a coordinator in your area.

Like COHORT, the goal of EnrollHD is to learn more about how HD progresses. The study is open to people diagnosed with HD, people at risk, people who are gene positive and anyone else who is a member of a family affected by Huntington disease.

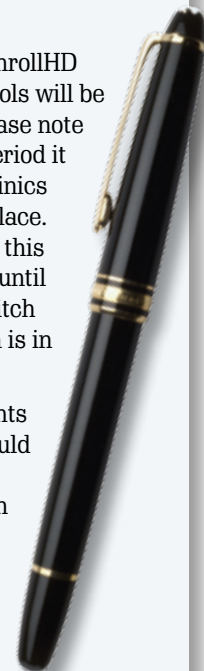
The main difference is since the study is bigger, it will provide the opportunity to gather even more valuable information for researchers. If you want to help speed up the race to find meaningful treatments, please consider signing up for EnrollHD and encouraging your family and friends to get involved as well.

When you go for your first EnrollHD visit, you will find the protocols will be very similar to COHORT. Please note that during this transition period it will take a few months for clinics to get the new protocols in place. If you have a visit scheduled this winter, it may be postponed until your clinic has made the switch as the studies official launch is in Spring 2012.

With support from participants like you, this major study could be the most comprehensive medical study for Huntington disease in history!

Thank you for your question Bob!

- HSC.



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