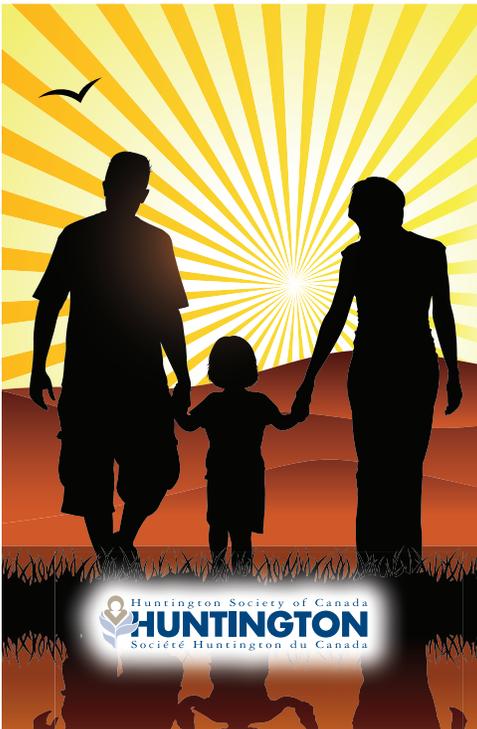


Climbing Higher: The 2010 HSC National Conference



Take 220 participants, one enthusiastic local chapter and a stellar lineup of speakers. Add the staff at the Sutton Place Hotel, who bent over backwards to accommodate all our needs and the generosity of the Rotary Club of Edmonton Strathcona, who organized a team of volunteers to shuttle delegates to and from the hotel and the Edmonton International Airport. Sprinkle with a dash of unseasonably beautiful November weather, and you've got all the ingredients for HSC's 2010 National Conference.

From the big banner and home-made cookies that welcomed conference-goers at the Edmonton airport to the powerfully moving "Amaryllis Garden" ceremony that wrapped up the banquet on Saturday night, the event proved to be a resounding success.

"We have never received so much positive feedback," says HSC's Wayne Greenway, reviewing the conference evaluations back at National Office.

It was particularly exciting to see a host of new faces, many of them teens and twenty-somethings attracted by our afternoon of workshops on meeting the needs of children and youth. For nearly a third of participants, this was their first HSC national conference.

There was laughter, tears, inspiration and plenty of jargon-free, no-PhD-required information on tap over the weekend. Our first-ever "Youth Morning Madness" for 14- to 17-years-olds earned a thumbs-up from participants, while our info hub continued to be a popular conference feature.

One of the themes that emerged over the course of 20-odd workshops and plenary sessions was the importance of a strong team. In our quest for a cure, each of us has a role to play, whether it's advocating for legislative change, raising funds, conducting research, helping people with HD to live their lives as fully as possible, or simply telling our story so that more Canadians understand the reality of HD.

However, perhaps the most powerful message from the weekend was Dr. Ed Wild's statement that while hope is good, substantive hope—hope based on good, solid reasons—is even better. And, he went on to say, the Huntington's community has plenty of good, solid reasons to justify our hope for a cure.

We're not there yet, but we're climbing higher every day.

Learning to Laugh When Life Stinks

Once upon a time, in the town of Three Hills, Alberta, there was an unsuspecting Sunday school teacher, a Ford Fairlane that was his pride and joy, and a small skunk, coaxed into

the trunk of the car with a trail of lettuce leaves laid by two boys with a little too much time on their hands.

You can imagine how the rest of the story unfolds. Yes, sometimes life stinks, whether the cause is a young Phil Callaway—the keynote speaker who confessed to this prank in his Friday morning address—or the game of genetic roulette called Huntington disease.

The key is how you react. During his 45-minute presentation, the Edmonton-based humorist, author and speaker revealed his secrets for handling what life throws at you, drawing on his own experiences dealing with his wife's seizures, the Huntington's that runs in her family and the Alzheimer's that killed his father.

If you weren't there, you missed the anecdotes, jokes and one-liners that had conference-goers laughing and giggling throughout the presentation, but you can still benefit from Callaway's five secrets of "skunk busting":

1. Laughter sure beats Prozac

Never lose your sense of humour, Callaway urged. The ability to see the funny side of life's hairy situations is what spells the difference between resignation and rejoicing. Not only that, he noted, laughter has no calories, MSG or trans fats and it's completely free.

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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 cure.

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

Editor: Kelly Macnab

Associate Editor: Edward Bird

Layout: Real World Graphic Design

Horizon welcomes your comments, ideas and suggestions for future articles. Please contact:

Huntington Society of Canada
151 Frederick St., Suite 400
Kitchener, ON N2H 2M2

Tel: (519) 749-7063
Fax: (519) 749-8965

Western Canada
4438 West 10th Ave., Suite 801
Vancouver, BC V6R 4R8

Email: info@huntingtonsociety.ca
Web site: www.huntingtonsociety.ca

Charitable Registration #: 11896 5516 RR0001

Introducing Our Newest Board Members

Our recent Board elections held at the Annual General Meeting, saw four new members join our board. Many thanks to our outgoing directors June Nichol, Tara Johnson-Ouellette and Karen Koester for their valuable contribution to the Society, and a warm welcome to our incoming directors, who bring a wealth of experience and insight to their new role.

Ray Bailey, Ottawa

Ray's involvement with HD began in the late 1990s, when his wife was diagnosed with the disease. He has been a driving force behind the newly invigorated Ottawa chapter, helping to re-establish it in 2005 and serving as president since then. Ray is a Certified General Accountant who worked for many years for Revenue Canada and, more recently, the Union of Veterans' Affairs Employees. He also serves on the Family and Friends Council of the Perly and Rideau Veterans' Health Centre, where his wife is a resident.

Mieke Wales, Edmonton

A familiar name to many HSC members, Mieke has been involved in the Society since the mid-1980s, when her brother-in-law was diagnosed with HD. Mieke served on the board from 1995 until 2008, including several years as Chair. As well as an in-depth knowledge of Board governance and Huntington's issues, Mieke brings more than three decades of managerial experience at TELUS, where she worked in technical engineering, sales and strategic planning.

Jacob Hendricks, Calgary

Jacob was introduced to Huntington's shortly after he met his partner in 1989. Since then he has been involved in the Society, most recently as president of the Southern Alberta Chapter. As well as being a strong advocate for families affected by HD, Jacob is a trained floral designer. Over the years he has put his skills to work as a store owner, freelance designer and instructor. Currently, he works in the wholesale distribution of floral products and plants for supermarket chains in Alberta.

Susan Wright, Toronto

The latest member of the Wright family to serve on the Board, Susan brings extensive experience in non-profit organizations. For the past ten years, she has served as Director of Operations for the Toronto Arts Council and the Toronto Arts Foundation, where she oversees financial management, human resources, facility management and general operations, as well as sitting on many external committees. Susan has also been very active in her children's school councils for nearly a decade.

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Janice Waud Loper: HSC's Fundraising Face in the West

When the Huntington Society welcomed Janice Waud Loper to our fundraising team on September 1st, we gained a seasoned professional.

Janice's career in the non-profit sector spans more than two decades, including stints as a Coordinator with the Olympic News Service team at the Vancouver 2010 Olympics—"a very proud moment for me," she says—heading up the major gifts team at Ontario's Oakville Trafalgar Memorial Hospital and at Tapestry Foundation for Health Care in Vancouver, and serving as executive director of the B.C. Hospice Palliative Care Association.

The Certified Fund Raising Executive professional, who recently completed a Master of Arts degree in Leadership at Royal Roads University, sees the heart of her work as developing partnerships with the Society's supporters. "Like building a strong friendship," she explains, "it's a process that takes time and patience but yields tremendous rewards."

"I love that I can bring people to understand the work of HSC, to begin to see the value of what goes on, to be excited and passionate by our work," she says. "I know I'm there when people say 'what can I do for you?'"

In the newly created position of HSC's Director of Major Gifts, Western Canada, Janice will build on the relationships already

established with donors in the region and foster new ones, freeing up fundraising colleague Paul Evered to concentrate on points east.

One of her key challenges is reaching out beyond the Huntington's community to broaden the base of support for our advocacy work, individual and family services and research funding. Janice isn't fazed by the task.

She speaks fluently about the ripple effects of HD that spreads far beyond the families affected by it, the Google alerts that arrive in her inbox daily with the latest news about the disease, and the momentum of research that is bringing us ever-closer to a cure—all points that she believes can help to engage a broader public.

What attracted her to HSC? "This organization is a powerhouse," she says. "As I got better acquainted with the people involved and the reality of HD, I knew I would be inspired in my work. And I was right."

Her first few months have been a whirlwind of activity, including setting up a Vancouver office; flying east for a three-day orientation and recent strategy meetings in Kitchener; meeting with Board members, Resource Centre Directors and families; and maintaining communication with National Office. "Email is a wonderful thing," she laughs. "It's like there's no distance between us."

Janice clearly doesn't lack for energy. She talks about the 30-, 60- and 90-day plans she's developed, her fondness for checklists, for the conversations with new friends at Vancouver's "Hike 4 Huntington's", and how much she enjoyed connecting with everyone at the National Conference in November.

"It feels like I've been here forever," she says. "And I'm enjoying every minute of it."

Janice can be reached by calling (604) 842-8053 or e-mail jwaudloper@huntingtonsociety.ca



Do One Thing a Day That Scares You

By Deepti Babu, MS, CGC

I recently did something I've rarely done before in my career as a genetic counsellor. I went to a conference put on by a support group, which are typically geared for families and those who care for them in the healthcare community. It's not that I've intentionally avoided these conferences, but I think my focus has been on attending those that gain me the most Continuing Education Units (CEUs), which these meetings do not usually offer, in order to avoid taking another Board certification exam. But when I learned that the Huntington Society of Canada (HSC) was having their annual national conference in Edmonton, where I live, I saw a unique opportunity. Although I'm a generalist, I do see quite a few families for Huntington disease (HD) counseling. The HSC has a Chapter in Edmonton that I always mention

to families, but I've never attended a support group meeting to check them out for myself.

I will admit, I wasn't sure what to expect. Would the meeting be scientific enough? Would I learn something? Would it be hard to see a bunch of people clearly affected by HD and their families all in one room? And would it be worth it not to get CEUs?

Going into the conference, I now suspect I was feeling early signs of compassion fatigue... or, at the very least, *fatigue*. I'd had a few trying sessions, then would come home to my young family needs with their own needs. I felt torn, like I wasn't able to offer my usual amount of understanding and patience to either group. As the conference approached, I wondered whether I'd be able to have the energy or attention span to get through 2½ days of topics all about HD.

As you all know, this year's HSC conference theme was "The Early Years," so many talks pointed the lens at a group often overlooked in the HD community: young people. Younger members of the group, some at risk to develop HD, spoke eloquently about the experiences of witnessing their loved ones "wear the mask of HD" as their symptoms progressed over time. Underneath it all, their parent with HD was still their parent. They talked about caring for their family members and growing up too quickly because of their circumstances. There were few dry eyes after listening to these brave young people openly talk about their lives. But what surprised me was that some of their relatives with HD were actually in the audience, and got up to hug them after they were done speaking. I wasn't expecting to be a witness to that kind of openness, tenderness, and love.

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2. You're better to live rich than die rich

What makes life rich isn't your bank account balance but your relationships with other people. Just don't expect perfection from others, Callaway warned, or your life will be filled with disappointment.

3. If you think you're too small to be effective, you haven't been in bed with a mosquito

Every person can make a difference. And when you add up all those individual efforts, the cumulative impact can be huge. For a prime example, you don't have to look any further than HSC.

4. Even if you win the rat race, you're still a rat

HD puts a lot of stress on families, on top of all the regular stresses of life. Find a way to get off the treadmill now and then, Callaway suggested.

5. Live so the preacher won't have to lie at your funeral

Be remembered for your good deeds, your good qualities—and, of course, your sense of humour!

Phil Callaway's Survival Guide for Caregivers

1. Laugh a little each day.
2. Find a confidante. Talking through your troubles puts things in perspective, even if you're just talking to your dog.
3. Exercise three times a week.
4. Carve hurry from your life. "There's nothing noble about a nervous breakdown," Callaway said. Learn to say "no," take breaks and take care of your own needs.
5. Enjoy the right food and take longer to eat it. According to scientific research, Callaway noted, the right food includes chocolate.
6. Worry less. "Worry steals everything worthwhile from today and adds nothing worthwhile to tomorrow," Callaway said.
7. Run away from home sometimes. Everybody needs a break.
8. Take care of the home front. Your strength comes from the people close to you, so nurture those relationships.
9. Remember you're more amazing than you think.
10. Go looking for blessings—they're everywhere.

Do you have more questions?

Contact us at 1-800-998-7398 and we will connect you with one of our Resource Centres or Individual and Family Services Workers across Canada

Pre-symptomatic HD

You won't find any researcher better able to speak about pre-symptomatic HD than Dr. Jeffrey Carroll. That's because the newly minted PhD, who recently began a post doc at Harvard Medical School, has the HD gene himself.

In his keynote address on Friday, Carroll told the audience that knowledge is power, and in the world of Huntington's, knowledge comes from genetic testing.

Knowing he inherited the Huntington's gene spurred him to pursue a career in HD research. He also used that knowledge to conceive his children through pre-implantation genetic diagnosis, ensuring they aren't at risk of HD.

For others like him, who know they carry the gene but haven't yet begun showing symptoms, Carroll explained what we're learning about this stage of HD and offered advice on what you can do to delay the onset of symptoms.

What do we know?

Everyone's brain grows as their body grows during childhood and adolescence. For people who carry the HD gene, the picture is no different. As adults, however, a part of the brain called the striatum will begin to change long before the symptoms of HD become apparent.

The striatum is responsible for organizing and planning your body's movements. New research shows that it is roughly 15 per cent smaller in people with HD, even in the pre-symptomatic stage.

Interestingly, however, the earliest symptoms of Huntington's are not the movements currently used to diagnose the disease but subtle emotional and cognitive changes such as depression, mood swings and anxiety. If you're gene positive, be alert to these symptoms, and make sure your doctor realizes they could be the first signs of HD.

If you have a partner, Carroll recommends involving him or her in the process of diagnosis. Sometimes it's hard to notice small, gradual changes in your own behaviour, while someone close to you may be able to see things more clearly.

Finally, he noted that although the number of CAG repeats in the HD gene influences the age of onset, it's not genetics alone that determine when you will begin showing symptoms.

What should we do?

If you're gene positive, there are steps you can take that may delay the onset of symptoms, Carroll says:

1. Exercise your body. Although there's no specific scientific proof that exercise will slow HD, it has a huge number of positive effects on the body that you can't afford to ignore.
2. Exercise your mind. Engaging in things that interest you will keep your neurons firing.
3. Build strong social networks. Interacting with other people regularly is another way to stimulate your brain and improve your mental health.
4. Get involved in the Huntington's cause. By making other people aware of HD, you can generate more support for the Huntington Society—and that, in turn, translates into more services and more research dollars.
5. Don't lose hope. In research labs around the world, we're seeing breakthrough after breakthrough in our understanding of HD. At the same, Carroll said, pharmaceutical companies are investing more and more money in clinical trials to test potential Huntington's drugs.

Optimizing Life with HD

Maybe it was his knack for seeing things from a patient's point of view. It could have been his mix of humour and practical, jargon-free advice. Or perhaps it was his ability to focus on the positive. Whatever the reason, Dr. Ed Wild's keynote address on getting the most out of life with HD was the hit of the conference, earning the British neurologist a standing ovation.

Wild began by describing the two mountains of HD: one that represents each individual's struggle with the disease and one that represents the collective struggle to find a cure. "Both HD peaks are surmountable," he said. "I stake my career on the collective one; you stake your life on the individual one."

And while there are no magic solutions—"a large mountain is a large mountain," Wild emphasized—the highly practical mountaineering tips he proceed to share left audience members upbeat and inspired.

1. Assemble the right team

Sir Edmund Hillary didn't climb Everest alone. Similarly, you shouldn't try to tackle your own peak single-handed. Surround yourself by a team who can give you the support you need.

Start with friends, family and the Huntington's community, Wild suggested. Your family doctor also has a key role to play, so make sure he or she is up to the job, and get an HD specialist onside as well. Round out the lineup with other healthcare professionals like occupational therapists, physiotherapists, speech pathologists and psychiatrists.

Assemble your team members early, Wild advised—before you think you need them, in fact—and check in with them regularly.

2. Plan your route carefully

Planning ahead can avoid disasters, so think about how you will deal with all the issues that Huntington's creates, from the financial implications to details of end-of-life care. Create backup plans as well, because life doesn't always unfold the way we expect it to. Be sure to set thresholds that will trigger the next phase of your plan: when you can no longer drive safely, for example, or when people are having difficulty understanding our speech.

As HD progresses it can affect your insight, so plan for that as well. Write a letter or record a video for your future self, Wild suggested, reminding yourself about the kind of relationships you have with your loved ones and how the disease will affect you and your relationships.

And then, said Wild, once you've got that planning out of the way, plan a vacation and get on with enjoying your life.

3. Know the terrain

A cure may still seem far away, but there are plenty of reasons to believe we'll conquer that peak, Wild said.

He mentioned the strength of the global HD community, along with the research infrastructure and collaborations we've put in place. He also pointed out that HD is the most curable of "incurable" brain disorders: the fact that it's caused by a single gene mutation that we've already identified puts us way ahead on the path to treatments.

Once treatments are available, we have even more cards stacked in our favour. Because a genetic test for HD is available, people with the gene should be able to take advantage of what Wild called the "golden window of opportunity" to begin treatments *before* they show any signs of the disease. And for those already showing symptoms, some very encouraging studies in mice suggest that switching off the gene can actually reduce their severity.

4. Pack the right equipment

Mountaineers have crampons, ice axes and climbing rope. People living with HD have medications. While they may not cure HD, he says, the right drugs can alleviate many of the symptoms.

Wild listed off his favourites: SSRIs for anxiety, irritability and depression; neuroleptics such as olanzapine and risperidone for chorea, aggression, mood swings and psychosis; and tetrabenazine for chorea. These aren't right for everyone but if your symptoms aren't under control, it's worth asking your doctor if one or more of them might help you.



He also mentioned Huntexil. While it's not on the market yet, clinical trials have shown this promising drug may reduce involuntary movements and, in some cases, improve voluntary movements.

Everybody is different, Wild cautioned, so it can take a lot of trial and error to find the right drugs and the right doses. And, of course, drugs have side effects that must be weighed against the benefits.

"While avoiding drugs is generally a good thing," he said, "try to stay open to the possibility that they may help."

5. Enjoy the journey

HD shouldn't stop you from getting enjoyment out of life. And if you're not enjoying it, draw on your team, make use of your equipment or activate your backup plan. "Life is not a dress rehearsal," Wild pointed out. "Do what you need to do to make sure that you can enjoy the life you have as much as possible."

He concluded his talk with a quote from a recent article in Britain's *Guardian* newspaper: "There is never a good time to have HD, but this is the best time so far in history."

Reaching Out to Youth Around the World

Take the challenges of launching a career, finding a life partner and establishing a family. Now add all the complications of Huntington's: dealing with the deterioration or death of a parent, facing genetic discrimination when you apply for insurance, wondering how and when to tell the person you're dating about the disease that runs in your family, and making decisions about if and how to have children.

No surprise, then, that most young people at risk for HD feel isolated—and not just from the broader community, but also from the Huntington's community that, until recently, has done little to address their specific set of needs.

Now that's starting to change, thanks to people like Dr. Brynne Stainsby.

In her keynote presentation on Saturday afternoon, the co-founder of Young People Affected by Huntington Disease (YPAHD) talked about the pivotal role youth that can play in building awareness, raising funds and participating in research—but only if they feel supported in their personal HD journey.

With a world map projected on the screen behind her, Stainsby highlighted efforts around the globe to foster that support and engagement.

In the U.S., the Huntington's Disease Society of America (HDSA) dedicates a full day of their annual convention to young people, helping them connect with each other and learn about HD.

Across the Atlantic, England will be holding its third conference specifically for young people this coming February, while camps for youth in Sweden and Ireland were fully booked.

In the southern hemisphere, Australia has developed a website dedicated to youth. And here at home there's also plenty happening, Stainsby pointed out, including last summer's highly successful "Unite the Fight" effort that passed a torch across Canada from one youth-led fundraising event to another.

What's particularly exciting is the emergence of international collaborations. YPAHD, a national virtual chapter of the Huntington Society, is currently teaming up with HDSA's National Youth Alliance. In Europe, a similar collaboration provided the inspiration.

Most ambitious of all is the Huntington's Disease Youth Organization. The global coalition is working to create a multilingual website, share resources between HD youth organizations, support collaborations and connect young people around the world.

By providing this kind of support, Stainsby said, we can move youth from isolation to engagement. One of the keys will be making the message upbeat. In an international online survey of youth affected by Huntington's, respondents made it clear that they are tired of the "gloom and doom" surrounding HD. What they want instead is a message of hope and inspiration.

Stainsby's presentation provided an example of how inspiring that message can be. While she laid out the many challenges facing young people, she also gave the audience a sense of what how much could be accomplished with a little vision, energy and investment.

"I hope this will be a call to action," she said as she wrapped up her presentation. Judging by the enthusiastic response of her audience, it certainly was.

A Very Special Thank You

The Huntington Society of Canada would like to extend its sincere appreciation to those people who volunteered their time, energy and writing talents to assist with the 2010 HSC Conference summary articles.

Mohammad Al-Refaei

Ameer Farooq

Janet-Rose Hurst

Scott McLeod

Your valuable contributions help to raise awareness and educate our HD Community and beyond.

An Ariel View

That night in our Nation's Capital, October 5th 2010 is as clear in my mind as if it were yesterday and I have lived and re-lived those marvelous moments over and over, again and again. There I was a former Mount Hope farm girl, along with my daughter Lara standing in the midst of senators, the Speaker of the House of Commons, a former Prime Minister, a room full of the who's who of Parliament Hill. It was a night of accolades and advocacy as together we celebrated the achievements of The Honourable James Jerome a man who, very much like my Ralph, had a heart of compassion and a desire to be a voice for those who needed to be heard. What a great honour it was for me as a co-founder of the Huntington Society of Canada to present the inaugural Great Canadians Award to Mr. Jerome's

widow, Barry Jerome. Upon meeting Barry you quickly realize that she is a lady in every sense of the word, gracious, kind and with a sense of humour much like my own. She and I have been on parallel paths for so many years that it was a privilege and thrill to finally have them cross. She has in a very short period of time become a very dear and close friend of mine.

Looking back, that evening in October was just one of those times I truly wished that my Ralph had been there to experience the evening because he would have been so proud to see the HD families moving amongst, and influencing, Canada's decision makers. What a privilege it was for me to be able to represent the hopes, dreams and aspirations of the Huntington Society of Canada past, present and future. Representing those, like Ralph, who passed away believing that one day the dream of a world free of HD would become a reality. Standing in place of those

who are presently running this race with our Summit of Success well in view. And finally representing those who one day in the not too distant future, will live in a world free of HD.

As we begin this brand new year I want to take this opportunity to challenge everyone to become an active member in the climb to our summit of success by considering either launching a Family Fund, or individually becoming a monthly Champion of Hope or joining all those who have become members of the Ralph and Ariel Walker Summit Society. Every gift counts and possibly now more than ever before! We have Ottawa's attention, so let's show them just how much we mean business.

May this coming year be filled with health, happiness and a harvest of hope for you and your family.

Ariel

Great Canadians launch a smashing success

By Julie Stauffer

When it comes to Huntington disease, it's all too easy to focus on the losses. But HSC's new Great Canadians series is putting the emphasis on the accomplishments of people touched by HD.

On October 5th 2010, the series kicked off with a tribute to the late James Jerome, past Speaker of the House of Commons as well as a respected lawyer, MP and judge. And what a kick off it was!

Nearly 300 people gathered in Ottawa's Government Conference Centre to salute The Honourable James Jerome, including several former prime ministers, party leaders, ministers and senators, as well as business executives and three generations of the Jerome family. For many in the room, it was the first time they had heard of HD.

The evening was co-hosted by the Honourable Peter Milliken, current Speaker of the House of Commons, while Senator Mike Duffy and Deputy Clerk Marc Bosc praised The Honourable James Jerome's many accomplishments. They include becoming the first member of an opposition party to serve as Speaker, as well as playing a pivotal role in allowing parliamentary proceedings to be broadcast and launching the modern-day page system.

In a historic moment, HSC co-founder

Ariel Walker presented the inaugural Great Canadians award to The Honourable James Jerome's widow, Barry, to great applause. There was also lots of laughter when she commented on the role of the great women behind the men who achieve so much.

Given the Ottawa setting, it was fitting that evening included a call to action for parliamentarians. Katie Lingard spoke about the impact Huntington's has had on her family—the "Bermuda Triangle" of physical, cognitive and emotional symptoms that transformed a loving father and astute businessman into an irrational man with mood swings who is no longer able to care for himself.

She then described her battle with the insurance industry to get the coverage she needed to open her chiropractic clinic. She wrapped up by urging the politicians in the room to create legislation to protect all Canadians from gene-based discrimination, telling them that coping with HD is already hard enough.

Although Katie has been speaking up on the issue for several years, she always figured that action on genetic discrimination would take a long time. The James Jerome event changed her mind.

"It was inspiring," she said, the excitement clear in her voice. "You put a lot of influential



Barry Jerome & Ariel Walker 2010.

people under one roof, you get these people together and something is going to happen."

Meanwhile, Dr. Michael Hayden's summary of research progress left everyone impressed with how far we've come.

"The evening exceeded our expectations. This was an opportunity to honour a respected parliamentarian who implemented sustainable, positive change as well as increase the awareness of Huntington disease and the issues that surround it, such as genetic discrimination," says Huntington Society of Canada CEO and Executive Director Bev Heim-Myers. "This was an evening the entire Huntington community can be proud of."



2010 Volunteer Awards

Kevin Glenney

The Dean Crain Memorial Award

Co-Op Atlantic

Michael Wright Award

Elisha Chen

Regional Award of Merit

DIRTT Environmental Solutions

Regional Award of Merit

Owens Construction

Regional Award of Merit

Katie Lingard

Chairmans Award

Bev O'Connor

Chairmans Award

June Nichol

Chairmans Award

HSC Toronto Chapter

Milestone Award for Fundraising

HSC Peterborough Chapter

Milestone Award for Communication

Tara Johnson-Ouellette

*Stan Edwards and
Dorothea Smith Award*

Brynne Stainsby

*National Award of Merit
(Volunteer)*

Maxim Power

*National Award of Merit
(Corporate)*

The Mark Mercier Foundation

*National Award of Merit
(Organizational)*

Do One Thing a Day That Scares You

continued from page 3

Many talks were scientific, from a workshop on clinical trials/studies to one mapping out the intricate start-to-finish process of pre-implantation genetic diagnosis, to another on CAG repeat sizes in the intermediate range and their clinical implications. The topics didn't surprise me, but the questions did. This audience knew their stuff. This information mattered to them. Their questions were complex, and they weren't afraid to ask them. I underestimated their knowledge base, and came away with several scientific learning points of my own. In fact, I may have learned more than I have in some academic meetings held by scientific groups.

My favorite part of the conferences was the humor and fun that was present throughout. Let's face it, I was prepared to be brought down. But quite the opposite happened, which was a wonderful surprise. I learned that many families with HD cultivate a wicked ability to laugh, perhaps in part to cope with the genetics they are handed. And with this, judgment falls away. I have rarely been around people so willing to be vulnerable and open, and that was a good lesson for me. The conversations I had with many families and the laughter I heard throughout the conference illustrated this vividly for me.

I think I saw this statement on a lululemon athletica™ shopping bag the other day, and I now know that it's more than a marketing ploy: "Do one thing a day that scares you." When I registered for the HSC conference, I'll admit that a part of me was trepidatious. I've been practicing genetic counselling for a while, so this was embarrassing to acknowledge—even to myself. But attending kept me engaged in life. It was recommended at the conference that those living with HD do things to keep themselves "engaged," but I think this is good advice for anyone. What I gained from attending the HSC conference is far more than can be encapsulated in a CEU. I now feel mentally refreshed, and I return to my "normal life" with a new perspective that I hope to cultivate and maintain.



New resource for HD families coming in 2011!

HDBuzz is a new internet portal that will bring the latest news about Huntington's disease research to the global HD community, written in plain language, by HD scientists. Being launched early in 2011, HDBuzz will provide easy-to-understand digests of scientific papers and conference reports that will be free to read and share. All information provided by HDBuzz will have an option to read material in various languages.

HDBuzz has the support of the HD lay organizations such as the Huntington Society of Canada, European Huntington's Disease Network, Huntington's Disease Association UK, and Huntington's Disease Society of America. To be contacted when HDBuzz launches, go to www.hdbuzz.net and enter your email address. You can also watch a video of Charles Sabine introducing the key members of the HDBuzz team when it was launched at the recent European Huntington's Disease Network plenary meeting in Prague, Czech Republic

Celebrating Our Heroes:

Don McLeod

How do you motivate yourself to get out of bed in the morning when you have a fatal disease?

That's one of the questions Don McLeod asked himself after his Huntington's diagnosis several years ago. The answers he has come up with are helping not just him and the Huntington's community but the business sector as well.

For many years, the high-tech marketing and sales executive believed motivation was all about rewards and punishments. But his "a-ha!" moment came when he read author Alfie Kohn's theory that real motivation comes from the act of doing something you can do.

"We need to collaborate on a daily basis. We need to feel that we're part of team," Don explains. "If you can understand that, you're not so worried about the things that you can't do. Instead, you can focus on the things that you can do."

Seeing the big picture has always been one of Don's strengths, along with a willingness to risk making mistakes.

He offers the example of Tai Chi. "It doesn't matter so much that you get it absolutely right," he explains. "If you go up on your feet a little bit and you lose your balance, well you don't go up

quite so high as everybody else. But those big movements you can do with Huntington's disease."

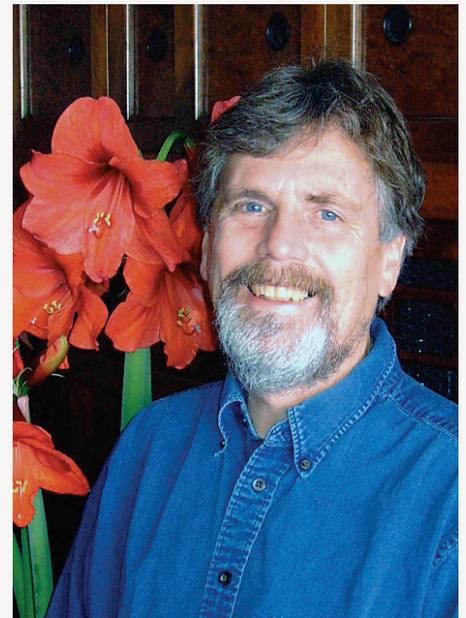
Now he's using the insights that Huntington's has brought him—along with his decades of business experience—to help companies succeed, with the hope that they, in return, would help raise money for Huntington's.

Take the example of his connection with Mike Morin. The senior coach at KWA Partners (Ottawa)—part of the cross-country career management services firm—was researching a book on leadership when he met Don two years ago.

"We found out instantly that we had this mutual interest in leadership and collaboration and making things better for people," Mike recalls. Since then, they've met up regularly to trade ideas.

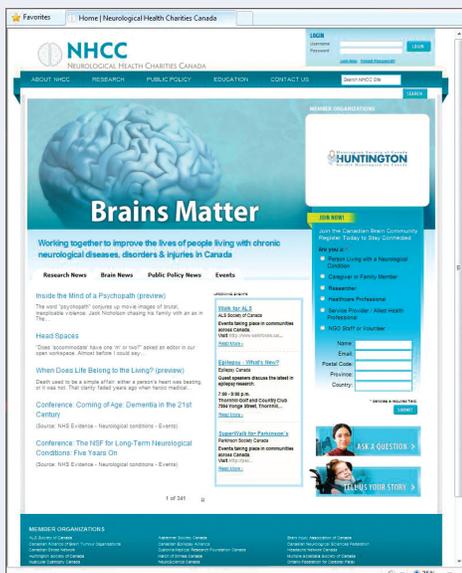
Today, Mike is working with a small company to help develop a collaborative software tool, while KWA became a corporate sponsor of HSC's recent James Jerome tribute—all thanks to Don. "He has that ability to influence you," Mike says. "Here I am doing all kinds of things I never thought I'd do, and all because of him."

Don also believes in passing his wisdom on to the next generation, serving as a mentor for up-and-coming designer and web developer Trevor Alexander.



"Trevor's 25 or 26 years old, he's starting a business, and the ideas that I gave him through living with Huntington's disease are going to help him for the rest of his life," says Don. "That makes it worthwhile for me. When I'm gone, he'll still be benefiting from the ideas that we talked about over coffee or a walk."

Today, that gives Don plenty of reasons to get up in the morning—along with a sense of accomplishment that helps him sleep soundly at night.



My Brain Matters

The NEUROLOGICAL HEALTH CHARITIES CANADA (NHCC) is a collective of organizations that represent people with chronic, often progressive, neurological and/or neuromuscular diseases, disorders, conditions and injuries (brain disorders) in Canada. The NHCC's role is to provide leadership, evaluating and advancing new opportunities for collaboration specific to advocacy, education and research projects, related to brain health. HSC is an active partner in this organization along with 17 additional sister charities all working together.

The NHCC has recently launched a new website called *My Brain Matters* www.mybrainmatters.ca. Please take a moment to visit the site and register to receive the e-newsletter Brain Matters. Learn more about Canada's Brain Strategy and the latest research development. Sign Up Today!

Dear HSC,

Dear HSC,

I know that having a parent with HD isn't easy for my kids. How can I help them cope?

- Angela, Abbotsford, BC

Dear Angela,

You're right. Having a parent with a terminal illness is tough on kids. First of all, there's the emotional distress of watching Mom or Dad become more and more ill, as well as dealing with the irritability, impatience and outbursts that can go along with Huntington's.

There's the financial stress created when one parent can't work, and the sense of neglect when the other parent is caught up in caregiving duties or working extra hours to make ends meet.

Kids also grapple with the embarrassment created when Mom or Dad isn't "normal" and the extra responsibilities they take on to help the household keep running. On top of all that, there's the knowledge that they might develop the same disease themselves when they grow up.

It's a lot to handle, and different kids react in different ways. For some the response is anger or frustration. Others feel guilty, sad or anxious.

The good news is that we can help kids build resilience and thrive, even when HD runs in the family. That was one of the key messages at our National Conference in Edmonton in November, where we dedicated an entire afternoon to the issue.

Over the course of the different workshops, a few themes emerged. For healthy development, children need:

- *Truthful, age-appropriate information.* While many parents feel they're protecting their children by keeping HD a secret, kids sense when something is wrong. It's better to give them the facts than to let them worry—or discover misinformation on the Internet.
- *Peers or adults they can talk to.* Having an emotional outlet outside the family helps kids cope better with the pressures at home. This could be a trusted adult, an HSC social worker, a close friend or other kids dealing with similar situations.

- *Normalcy.* Kids in families affected by Huntington's still need all the things that every child needs: attention, support, clear limits, consistent discipline and the opportunity to simply have fun and enjoy themselves.

For parents who weren't at the conference, HSC has some resources that can help. In the "Resources" section of www.huntingtonsociety.ca, you'll find two factsheets that you can download: *Talking to Children about HD* and *Suggestions to Help Children Cope*.

Looking for more information? There are also a couple of international books that you can order online: *HD and Me: A Guide for Young People* (<http://endoflifecare.tripod.com/livingwithhd/id47.html>) and *Talking to Kids About Huntington's Disease* (<http://www.talkingtokidsabouthd.com/book.html>).

And, of course, your local Individual and Family Services worker or Resource Centre Director is a wonderful source of information and support.

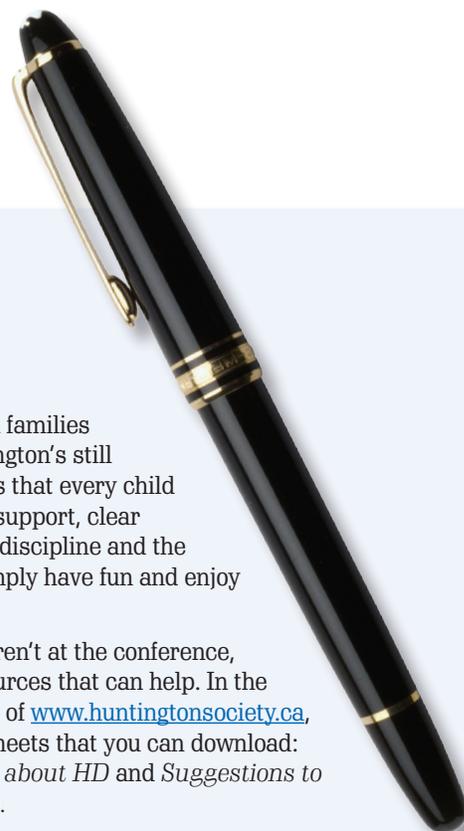
We believe there's more that the Huntington Society could be doing to support children and their parents. That's why we're in the process of developing a national program called Youth for HD to help foster resilience in children so that they can adjust to living with HD as constructively as possible.

Already, we've laid a lot of the groundwork. We've reviewed the scientific research on how HD affects children and youth, and we've conducted a survey of parents and adult children who were raised in families living with HD.

We're also getting valuable input from members of YPAHD—a virtual national chapter of the Huntington Society of Canada established for youth over 18—to get their insights on the challenges they faced growing up.

Now, we'd also like to hear from families like yours. What services would benefit your children? How can we better support you as a parent? Email us at info@huntingtonsociety.ca, or call 1-800-998-7398 for more information.

Together, we want to give next generation best possible opportunity for healthy development.



MEMBERSHIP DRIVE: Add Your Voice Today!

The Huntington Society of Canada is having a membership drive to encourage members of the Huntington's community to stand up and be counted.

Our members are partners in caring—there is strength in our numbers. Canadians living with HD, and their families, endure discrimination and stigma associated with this rare, complex and misunderstood disease. Our members add their voice to our chorus – and bravely step forward to be counted as a caring member of our community.

Our members represent a promise to the HD community: you are not alone. Our members stand in solidarity with HD families each and every day. Government, foundations, potential donors and the broader public recognize

us as a movement based on our number of members.

Your Membership

As a member of the Huntington Society of Canada, you receive the following:

- Invitation to every HSC event in your community
- Your copy of *Horizon*, our newsletter, delivered in print or electronically based on your preference
- Invitation to every Annual General Meeting
- Voting right at Annual General Meeting

Please, stand up and be counted as a member. Buy your annual or lifetime membership

today. Make a promise to families confronting HD and show them they are not alone.

We are calling on all members of our community to stand up and be counted. Today. Thank you for making a difference!

You can use the form below to mail in your membership today.

You can also visit www.huntingtonsociety.ca/membership

for more information and to make your payment online, or you can call us right now at 1-800-998-7398.

RETURN FORM

2200

- Enclosed is my **Annual Membership** donation (\$25 per person)
- Enclosed is my **Lifetime Membership** donation (\$250 per person)
- Enclosed is my donation of \$ _____ to further the fight against Huntington disease.
- I would like to remain anonymous

Method of Payment:

- Cheque Visa Mastercard

Credit Card # : _____

Expiry Date : _____ Signature : _____

Please send me more information on the following programs:

- Our Champions of Hope* monthly giving plan
- Ralph and Ariel Walker Summit Society*
- Please contact me on how I can volunteer for the Huntington Society of Canada.
- Please send me more information about getting involved in the Society's fundraising programs.
- Our Family Funds*
- Please add my name to the *Horizon* mailing list.
- Please remove my name from the *Horizon* mailing list.

Name: _____

Address: _____

City : _____ Province: _____

Postal Code: _____ Phone #: _____

Email: _____

Please print the name(s) as you want it to appear for recognition purposes (eg. The Smith Family or Mr. & Mrs. John Smith or Mary & John Smith)

Please note my change of address:

Effective : _____

The Huntington Society of Canada is committed to protecting the privacy of all of our members and stakeholders. We recognize the importance of privacy and are dedicated to maintaining the trust of our members.

Thank you

PREDICT-HD:

A Huntington disease study for presymptomatic volunteers

PREDICT-HD is attempting to pinpoint the earliest signs of HD. This may allow researchers to develop clinical trials to find treatments that will slow the progression of HD so people can continue to lead full, active lives for as long as possible.

We are recruiting volunteers for yearly study visits! Volunteers must:

- Be at least 18 years old
- Have genetically tested positive **OR** negative for HD
- Be able to undergo an MRI scan

We have study sites in **Edmonton, Vancouver, and Toronto.**

Reimbursement is available for travel costs.

For a full explanation of inclusion criteria and to find out more about participating, please contact us:

www.predict-hd.net predict-hd@uiowa.edu

Phone: (U.S. #) 319-353-4307



Saturday, February 26, 2011

7:00 p.m. at the Liberty Grand

25 British Columbia Road,
Toronto

Tickets \$135

www.hscasinoroyale.ca
casinoroyale@huntingtonsociety.ca

Return undeliverable Canadian addresses to:



151 Frederick St., Suite 400
Kitchener, Ontario
N2H 2M2

