

HORIZON

RESEARCH • SERVICE • EDUCATION

No. 144

Fall 2014

Finding The Right Care, At The Right Time!

Focusing on a person-centred care approach

By Dr. Rebecca Ferrini, MD, CMD, MPH

Imagine Clara: she is becoming frailer, falling and losing control of her bladder. She is thin and in constant movement. She wants to stay home but her husband is worried that she can no longer be alone. She smokes and drops the butts on the floor, forgets what she can do and often is dirty, refusing to bathe or comb her hair and wearing skimpy clothing. She is withdrawn, but at times can get very angry and yell. What are her options?

Huntington disease (HD), a progressive genetic disease, impacts physical, cognitive and emotional health and is associated with gradual decline progressing over years. There is neither a cure nor a treatment to slow down Huntington disease.

When a person requires more supervision, becomes incontinent, starts to fall frequently, loses significant weight or when the behavioural issues become too challenging, families consider alternate care.

Care is available in the home, in community placements (assisted living or supportive housing), in nursing homes and possibly in other sites in between. When the individual's care needs can no longer be met appropriately at home or in a community setting, a long-term care facility will need to be considered. Finding the right care can be difficult and each option has its own eligibility requirements, paperwork, rules, exceptions, benefits, and drawbacks. Financial matters may also be a consideration. Almost everyone needs help to navigate the maze. You can find that help by connecting with the Huntington Society of Canada (HSC) as well as other local resources. Many resources can be found on the Huntington Society of Canada website (www.huntingtonsociety.ca).

What works best for you and your situation depends on what is available in your area; your eligibility for services; the abilities, needs and

preferences of the individual and to some extent your income and assets. For example, is safety more important or autonomy? When looking for placement, it is important to realize that long-term care doesn't mean your loved one is watched all day and night; a nursing home cannot work miracles like making an individual start listening to instructions or stop falling. However, a long-term care facility can provide structure, routine and the ability to get help seven days a week, 24 hours a day. There are many helpful resources available to help you compare and evaluate facilities, including some checklists. For more information, contact your HSC Resource Centre Director or Family Services Worker. A contact list is available on the Huntington Society of Canada website in the **Learn About HD** section.

For Huntington disease care, you are looking for a facility designed to meet the needs of "longer term" residents, as your loved one may be there for 5-10 years. A facility comfortable with younger residents, those with brain injuries or those with HD can be a plus. Listen to the staff talk about their experiences. Did they seem flexible, creative and attuned to the individual? Ask about feeding and weight loss. Feeding a patient with HD is time consuming and expensive and they often need to eat more than others. Is there plenty of food and is it available 24 hours a day? For individuals losing the ability to walk without falling, ask the facility whether they use physical restraints. Restraints for persons with chorea can present significant risk of injury, can promote inactivity and even agitation. An alternative to physical restraints is permitting the residents to ambulate and fall and understanding the risks, while reducing risk by learning their routines, providing a safe environment and gradually introducing acceptable assistive devices like a walker, merry walker (a PVC framed walker), Broda

continued on page 10

Creating a Critical Mass of HD Research

By Julie Stauffer

Talk to anyone in the field and they will tell you the same thing: this is an incredibly exciting time for HD research. Today, investigators are preparing to move beyond the mouse model and start testing potential treatments in humans.

The University of British Columbia's Dr. Lynn Raymond lists a host of promising lab-bench breakthroughs, from drugs that target specific neural pathways to genetic therapy that lowers the levels of mutant huntingtin protein. "Things are really heating up," she says.

At the same time, observational studies like Enroll-HD are revealing the early, subtle signs of HD that will be crucial when it comes to judging the success of potential treatments. "We can now measure objectively if someone's HD is getting better or worse when we give them drugs," says Dr. Ray Truant, Chair of HSC's Research Council.

Amidst all that buzz, however, Huntington's research faces some significant challenges. One is funding cutbacks. Like many governments around the world, Canada slashed federal funding for basic research and clinical trials after the 2008 economic crash.

continued on page 9

INSIDE

- Lean On Me..... page 3
- Seeing An Impact..... page 4
- 2014 HSC National Conference
Schedule At a Glance..... pages 6-7
- A Decade of Dedication..... page 9



Note from the CEO

As we gear up for the fall season, the HD community has a lot of reasons to feel optimistic about what lies ahead. We are now officially halfway through our strategic plan and on track to achieve the goals we have set.

One of those goals was increasing our revenue. Across the country, our Chapters have really stepped up to the plate. They have engaged new families and individuals in existing fundraisers and they have introduced brand new events. I cannot tell you how impressed and inspired I feel when I see that kind of commitment from our volunteers.

I was also deeply moved by the incredible response to our Spring Challenge. Not only did we reach our fundraising goal of \$100,000, two very generous individuals stepped forward to make significant donations to the Society. As a result, we have been able to invest more dollars than ever into our two key priorities: serving families and supporting research into treatments to slow or stop Huntington disease.

Exciting things are happening on the Family Services front as well, and I am thrilled to announce the creation of our Southwestern Ontario Resource Centre, based in London. Our longtime London Family Services Worker Corey Janke will head up the centre, giving local families more access to the services they need.

Our youth mentorship pilot program is well underway, with rave reviews from the first mentees and their parents. Our new website has also attracted a lot of positive feedback, and we will continue to make improvements to ensure the best and most up-to-date information and resources are just a click away.

Meanwhile, thanks to the support of donors that believe in our strategic vision, we have been able to fund four excellent research projects. In some cases, this is research that builds on breakthroughs we have funded in the past. In other cases, we are supporting research that will explore new thinking into the underlying mechanisms of HD.

Great strides are also being made toward genetic fairness in Canada. As both federal and provincial legislatures return to parliament this fall, we will be continuing very productive conversation and building on our momentum to end genetic discrimination in Canada.

Finally, there is a flurry of activity happening as we get ready for the National Conference in Winnipeg in October. Our Chapter Development Team has been hard at work lining up a variety of world class speakers, and I am confident it is going to be inspiring as well as informative. I hope to see you there!

Bev Heim-Myers
Chief Executive Officer

HORIZON

ISSN 0827-7605

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

Huntington disease is a hereditary brain disorder which has devastating effects on both body and mind. The symptoms, which may include uncontrollable jerking movements and relentless cognitive and emotional impairment, usually appear between the ages of 30 and 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.

Editors:

Cyndy Moffat Forsyth
Kaija Hutteri

Associate Editors:

Edward Bird and Laurie Williams
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
Toll Free: 800-998-7398

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

Charitable Registration Number:
11896 5516 RR0001

HSC 2014 National Conference

October 24 & 25
To register, visit
www.huntingtonsociety.ca

*Embracing our
Strength*



Lean on Me: The Benefits of Huntington Disease Support Groups

By Josh Martin

In a bright and airy room on the second floor of the St. John's Ambulance Training Centre in New Westminster, B.C., Resource Centre Director Susan Tolley arranges a small circle of chairs. Before long, the first members of her HD caregivers support group trickle in.

The group is an eclectic mix of spouses, children and friends of people with HD, all there to support each other. Participants ranging from their mid-20s to late 70s exchange hellos and hugs and help themselves to a waiting pot of coffee. After taking their seats, Susan kicks off the hour-and-a-half session. Her goal? "To put more tools in their toolkit," she says.

To give the meetings structure and focus, Susan works through a different theme for each of the six monthly sessions she leads. Whether it's providing strategies for dealing with personality changes in a loved one, trading advice on navigating the long-term care system or bouncing ideas off each other about how best to carve out "me time," the support group is all about empowering its members.

As a caregiver to his wife, George certainly appreciates the self-care techniques he has learned from the support group. While his wife's physical symptoms are still quite moderate, it's the psychiatric manifestations that take their toll on him. "It's a hellish disease and it is very hard on relationships and families," George says. "If we go under, then the patient goes under too."

For Melinda, the feelings of belonging and community are other powerful motivations to sign up. Sure, grabbing coffee with friends is nice, she says. But it is just not the same as being part of a group of other HD caregivers. "I have got some great personal support networks and that's wonderful," she says. "But nobody's lived with it, nobody understands it."

It is also a chance for her to learn from the other members whose loved ones are further along in the disease progression. Every situation with HD is unique, she acknowledges, but there are similarities as well. The group helps prepare her for what might be down the road for her husband who was officially diagnosed a year and a half ago. "It is a progressive disease, and you have got to find different things as you go through it to get you the support you need," says Melinda. "Because if you are not well and you are not taken care of, you cannot take care of the other person."

Karen, another regular, admits that hearing about other people's experiences can be unsettling at first. She joined the group when her husband was still in the early stages of HD and was not sure if a support group would be a good fit for her. "I found the first one; it was a little overwhelming to hear some of the stories. But I did keep going and I am definitely glad I did," she says.

Susan understands Karen's reservations. It is one of the main reasons she feels it is so important to have the sessions facilitated by a professional who can keep things on track. "It is kept on a positive note," she says, "to balance negativity."

Susan goes on to point out that you do not necessarily need a group specializing in Huntington's to benefit if you are a caregiver. If you cannot find an HD-specific group in your area, get in touch with your local organization for Alzheimer's, ALS or other neurodegenerative diseases to see if they offer caregiver groups that you could attend.

Whether it is advice, encouragement, getting something off your chest or simply connecting with people who have walked a mile in your shoes, support groups have a lot to offer caregivers. "It has been a godsend for me," says George.

To find a support group in your area, contact your local Resource Centre Director or email us at info@huntingtonsociety.ca or call 1-800-998-7398.

An Ariel View with Winkie Simpson



For this issue, I've invited Winkie Simpson, former Clinical Nurse Manager at the Runnymede Healthcare Centre, to share some of her memories from the Society's early days.

Caring for Huntington's patients for 17 years taught me a great deal. Mainly never lose sight of the individual, and often it is the little things that count.

I remember our first HD client. She was a middle aged client who was no longer able to communicate verbally. She was acting out and often hit us when we didn't understand her requests. It turned out she just wanted the TV remote! Once that was solved, she was a happy camper.

Shortly after her admission, one of our nurses visited her family. She saw photos of her when she was young and learned about her earlier life. I can still see the staff sitting around the table listening to what she had discovered. Our eyes and hearts were opened. It just totally changed the way we looked at her and subsequent clients with HD.

Another example comes from a colleague who was training a new staff member. This trainee didn't believe that one young lady in very late-stage Huntington's knew what was going on around her. So my colleague paged one of the maintenance men. Now, the young lady just loved this fellow, and when she heard his name she perked right up and put on a big smile. The new staffer just couldn't believe the difference in her.

We met Ralph Walker shortly after we admitted that first client. We learned a lot from him. His special talent was his ability to listen and to make things happen.

For example, our clients were having a lot of difficulty with swallowing and communicating. The next thing we knew, Ralph had convinced the hospital to hire Estelle Klasner, a Speech and Language Pathologist, with the Huntington Society of Canada covering half her salary costs. Estelle came on like gangbusters and started a whole revolution in what we did.

We created a multi-disciplinary HD interest group at Runnymede made up of anyone who wanted to join; doctors, nurses, patients, families, social workers, clinical therapists, physical therapists, etc. If someone had an idea, we discussed it, and would try it out if it had merit. Some of them worked really well, so we started sharing those. Ralph would have us running around the country sharing our techniques.

One of the most important changes we made was how we dealt with negative behaviour. We started looking at the antecedents to see what caused the behaviour and then tried to prevent the cause, rather than respond to the consequences. There was a direct positive result in behaviour when we identified the causes and eliminated them.

The biggest rewards from my time at Runnymede? Seeing the changes in attitudes and results over the years and getting to know a lot of the families and patients. And of course, working with Ralph Walker was a real bonus. Meeting him was the beginning of a wonderful journey.

Thank you Winkie for sharing your memories and your journey. HSC is collecting stories and historical notes from years gone by. If you have a story to share, email us at info@huntingtonsociety.ca or call 1-800-998-7398.

Seeing an Impact: Mentor program makes a difference

By Josh Martin

With the first several mentor-mentee matches made, it is full steam ahead for HSC's youth mentorship program. In addition to her role as Saskatchewan Resource Centre Director, Erin Stephen has been busy spreading the word about the program, training mentors from across the country and recruiting young people affected by HD who are looking for one-on-one peer support.

Anyone from the age of 12 and up into their twenties can apply. Once matches have been made, mentees are free to reach out to their mentor whenever they need a listening ear or some advice from someone who's been in their shoes. Early on, that could mean just sending emails. As mentors and mentees become more comfortable with each other, those communications could move to text, phone calls or Skype. "Like all relationship-building, it takes time to build up that trust and that connection," says Erin.

One of the best things about the program is its flexibility, says Erin. After all, a 12-year-old whose mom has just been diagnosed with HD will be looking for different kinds of support than a 25-year-old who is wrestling with issues like genetic testing, life insurance and starting a family. Having a pool of mentors with a diverse range of life experience allows Erin to find the

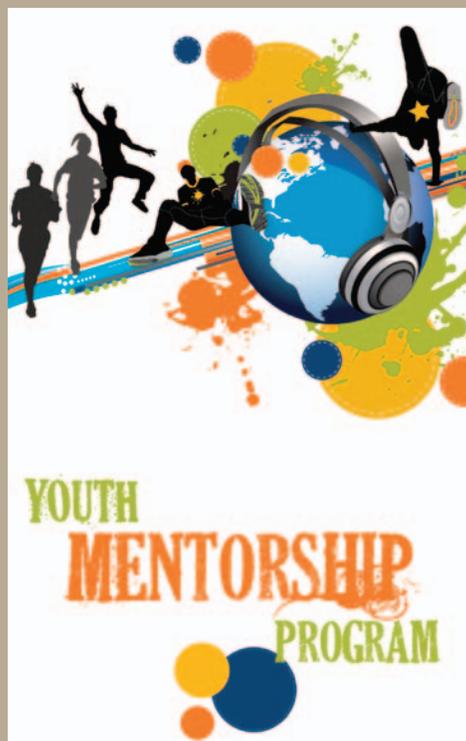
right match for each mentee.

So far the program has been getting enthusiastic thumbs up from participants. "Having someone available who you can share the good and the bad with helps me cope," says one of the mentees. "My family is always there for me, but it is nice to talk to someone who knows what I am going through." Erin is also hearing positive feedback from the parents of mentees such as, "I have a very open relationship with my child but I will never fully understand what my child is going through and their feelings. I am relieved my child can share their feelings with someone who truly understands. I know there are times when my children don't want to worry me and they might not want to share all of the feelings they are going through. I was always concerned that they would struggle keeping that all inside. I feel so much better knowing my child has someone comfortable to talk to. I highly recommend parents look into this program." To Erin, it is this kind of response to the program that motivates and inspires her. And, while she did not plan for it, Erin was thrilled to discover that the mentors have formed a tightly knit group and are leaning on each other for support.

In the longer term, Erin sees the program as a way of getting more youth involved with the HD community, whether it is through HSC's youth chapter, YPAHD, their local chapter or national events. Ultimately, what would be satisfying is to see the program come full circle, with today's mentees becoming tomorrow's mentors.

Like any new initiative, growing the mentorship program will take time. Still, having seen the good that can come from mentor-mentee relationships, Erin is fired up to get more youth connected with qualified mentors. "I am so excited to get everybody matched up," she says.

If you know someone who would like to be matched with a mentor, contact us at mentorship@huntingtonociety.ca or call 1-855-253-0215 for more information.



The Mark Mercier Foundation has supported the mentorship program since the inception of the program, and has recently invested further funding to advance the program.

Look How Far We've Come! Building Efficiencies in our Grassroots Machine

By Cyndy Moffat Forsyth

It has been over a decade since the Huntington Society of Canada's (HSC) Board of Directors, prompted by a recommendation from the auditors, identified a need to streamline a number of processes. Year after year, volunteers and staff have worked steadily to increase efficiencies within the Huntington Society. Together, we've come a long way!

Infrastructure

Thanks to the vision of Ralph and Ariel Walker, HSC operates as a unified model. This means that HSC's infrastructure is kept at a minimum. Other charities have offices and staffing structures in every province; HSC strategically places social workers across Canada to provide service in every province, but provides administrative support centrally to reduce costs. This allows HSC to be nimble and to direct the greatest amount of resources to the HSC mission. HSC's centralized model is a cost efficient structure and is only possible thanks to the dedication of our volunteer core, who represent the Society in communities across Canada.

National Community Advisory Group (NCAG)

The National Community Advisory Group was founded in 2011. Chapter Presidents from across Canada meet on a regular basis via teleconference to provide input on strategic direction and tactics pertaining to events, Chapters, and the Society as a whole.

The group's mandate is to provide proactive input on pressing issues facing the HD community, share best practices, and increase awareness. TeamHD originated through this group, and the success of the TeamHD brand has been immeasurable. This year, TeamHD runs and walks across Canada inspired more than 1800 participants. This is just one example of how this group shapes the evolution of HSC.

continued on page 8

Building Bridges with La Belle Province

By Julie Stauffer

Since the earliest days, the Huntington Society of Quebec (HSQ) has served the HD community in La belle province, while HSC has focused on the rest of Canada, a pragmatic decision based on language, culture and Quebec's fundraising regulations. However, the two organizations have a long tradition of collaboration.

"Huntington disease has no borders," say HSC CEO Bev Heim-Myers. "That is why we work closely with HSQ to share best practices."

According to HSQ President Marie-Claude Foisy, sharing strategies makes the most of limited resources. For instance, members of the HSQ Board are translating Young People Affected By HD (YPAHD) development materials into French, and they are keen to contribute to the national campaign for genetic fairness.

To facilitate that kind of sharing, Marie-Claude sits on the HSC Board and always leaves meetings impressed by the knowledge and experience of her fellow members. "They are all an inspiration for me," she says.

At the same time, Marie-Claude brings her own ideas and expertise to the table. HSQ's outreach to a large Innu community affected by HD is the perfect example. The organization has played a major role in training local healthcare professionals and providing respite for caregivers. Meanwhile, Nathalie Bolduc, a genetic counsellor and a former HSQ Board member, has developed a series of web-based videos about HD in French and Innu.

HSQ's biggest strength, says Marie-Claude, is its people-tailored approach. As well as running a very popular camp for people with HD, it offers an annual retreat for caregivers at a rural spa. It is a chance to relax, unwind and focus on their own needs, as well as to connect with others who understand their challenges.

In 2015, HSQ plans to add a camp for teens at-risk for HD. Further strategic priorities include partnering with other organizations to offer families legal and financial counselling.

As far as Marie-Claude is concerned, forging close links between HSC and HSQ benefits everyone. "I really see myself as being the bridge between the two organizations," she says.

The Huntington Society of Quebec (HSQ) serves the distinct needs of Quebec while maintaining strong links with the Huntington Society of Canada. An HSQ representative sits on our Board of Directors, and we partner to ensure all Canadians have access to the services they need. To learn more about HSQ visit www.huntingtonqc.org.



Manitoba on My Mind

By Devin Bonner

I recently had the pleasure of travelling to Manitoba, the heart of the continent, to meet with volunteers, take in some amazing events, and continue preparations for the HSC National Conference taking place October 24-25 in Winnipeg.

The trip began with a four hour drive from the Winnipeg airport to Pierson. Piersonites will have to forgive me, because I drove right past the town of 250 people at first. I thought to myself, "This can't be the town that raises \$20,000 at their event." Boy was I wrong! The entire population came out to the town hall to run 5 km, followed by food, music and fun! It was an amazing atmosphere, and it truly demonstrated the impact that a couple of families can make in their region when they commit to a cause and shout it from the rooftops.

From Pierson, I meandered across the prairie highways to meet Kyla, who was hosting the Regina, Saskatchewan Run & Walk for HD. The overcast conditions of the day did not stop thirty people from coming together to exercise, connect and share, raising \$7,500 along the way! There were many attendees taking in an HSC event for the first time, connecting with their local HD community. "That's the real achievement," Kyla told me. "The fundraising is great and will create a better future, but coming together and connecting with each other... that's creating a better now." I could not have said it better myself!

My trip then took me back to Winnipeg. Founding Chapter members Vern and Ellen were kind enough to show me the sights and sounds of the city. Together, we met with the Holiday Inn, host of our 2014 National Conference. The team seems eager to help us prepare to present some of the premier experts in HD care and research.

The Winnipeg Chapter hosted its Run 2 Finish Huntington Disease that sunny Saturday morning. It was an impressive crowd, consisting of the HD community and supported strongly by local businesses, sports teams, and the local firefighters. The event raised spirits, along with \$15,000!

From there, I continued my journey by joining Bert, a man who had started his odyssey from Winnipeg to Brandon (200 km!) earlier that morning. I met him on the Trans-Canada Highway, a quarter of the way to his destination. While transport trucks flew by us at lightning speed, Bert spoke to me about his motivation: friends affected by HD who he considers to be family. He wanted to inspire them, show his commitment, and raise funds for a better future. Twenty-six hours of straight running later, he had raised over \$16,000!

The next day, I was invited to the Brandon Chapter Golf Tournament, run by Chapter leaders Sandy and Cam. Reading the volunteer shirts: "We are going to beat Huntington disease... with a golf club", I knew I was in for a great day! Rarely have I seen a community so strongly behind a family and a cause. Golfers understood the struggle of an HD family and were truly committed. It was a sight to behold.

The trip was a fantastic opportunity to meet with our volunteers and families in Manitoba and Saskatchewan, and witness the energy building in that region of Canada. I am looking forward to our community coming to Winnipeg in October to see that energy for themselves!

National Conference Schedule: Friday, October 24, 2014

8:00 am	Welcome Breakfast			
	Opening Ceremonies			
	How Kinship and Friendship Can Help Build Resilience and Well-being Keynote Speaker: Dr. Greg Evans			
10:30 am	Refreshment Break			
Morning Sessions				
	HDYO: Improving Support for Young People Impacted by HD Matt Ellison Chandler Swope	Your Life Journey: Planning for the Future HSC Family Services Team	The Basics of Huntington Disease: Past, Present and Future Dr. Douglas Hobson	Studying Patient Cerebrospinal Fluid to Understand and Treat HD Dr. Ed Wild
12:30 pm	Lunch			
Early Afternoon Sessions				
	Out of Adversity Comes Opportunity Nathalie Bolduc	Predictive Testing and Prenatal Testing Options for Huntington Disease: A review of current practices Monique LaPointe Shannon Chin	Current Research in Huntington Disease Dr. Jeff Carroll	Clinical Research in Huntington Disease: Why You Should Become Involved Dr. Mark Guttman
3:00 pm	Refreshment Break			
	Getting Close: Increased understanding leading to new approaches to therapy Keynote Speaker: Dr. Michael Hayden			
	Closing Remarks			
5:00 pm	Break			
	Winnipeg Chapter Halloween Dinner			

Conference program subject to change

Proud sponsors of the
Huntington Society of Canada's
2014 National Conference



REIDER
INSURANCE



**The Winnipeg Community Foundation
Awards Society Special Funding**

Thanks to Vern Barrett, Winnipeg Chapter President, the Winnipeg Community Foundation has awarded HSC special funding to be used as financial support for youth and individuals in Winnipeg and remote areas of Manitoba to attend the 2014 HSC National Conference.

The generosity of the Winnipeg Foundation's Community Building Fund allows attendees to learn more about Huntington disease and the unique challenges individuals and family members face when managing the disease. Attendees will also make important connections with others in similar situations and learn about the latest research and the importance of clinical trials. The Society is most grateful to the Winnipeg Foundation's Community Building Fund.

National Conference Schedule: Saturday, October 25, 2014

8:00 am	Breakfast			
	Opening Remarks			
	Learn about HDBuzz and the Latest in HD Research Co-Keynote Speakers: Dr. Ed Wild and Dr. Jeff Carroll			
10:30 am	Break /Stay Strong Project		Annual General Meeting	
	Morning Sessions			
	Living the life of leisure Bev Farrell	YPAHD: The Youth Chapter of HSC	The Start of a New Era in Huntington's Disease Research: New Pathways and New Drugs on the Cusp of Clinical Trials Dr. Ray Truant	Hurry Up & Wait: Thinking About Thinking with HD Mr. Jim Pollard
1:00 pm	Lunch			
	Early Afternoon Sessions			
	Genetic Discrimination Bev Heim-Myers	HSC's Youth Mentorship Program Erin Stephen	Translational Medicine for Huntington Disease Dr. Katharine Sepp Dr. Joost Schulte	Caring for patients: The creation and benefits of Interdisciplinary Movement Disorders Clinic Dr. Douglas Hobson
3:15 pm	Refreshment Break			
	From Basketcase of Healthcare to Benchmark Keynote Speaker: Charles Sabine			
6:00 pm	Break			
	Dinner Banquet and Award Ceremony			

Conference program subject to change

Young People Affected By Huntington Disease Day: A day dedicated to youth

Back by popular demand, the HSC 2014 National Conference will include a day dedicated to youth.

Young People Affected by Huntington Disease (YPAHD) is delighted to announce the second national day dedicated to youth. Hosted at the Holiday Inn Airport West in Winnipeg, Manitoba the day before the National Conference, this day will focus on embracing our strength. The challenges faced by youth who are affected by Huntington disease are unique. By bringing young people together in a face-to-face forum, YPAHD's goal is to create a stronger network that addresses feelings of isolation and fear of the unknown. All youth are welcome.

To ensure your spot, please register by September 15, 2014. To learn more about this special day or to volunteer please check out www.huntingtonsociety.ca or call 1-800-998-7398.

Date: October 23, 2014

Where: Holiday Inn Airport West, Winnipeg, MB

Age Groups: 12–17 and 18–40

Register: www.huntingtonsociety.ca/ypahd-day or call 1-800-998-7398.

Genetic fairness: the momentum keeps building

By Julie Stauffer

Canada is the only G7 country without legislation to protect genetic information; however, thanks to your support, we are making significant progress.



Last fall's Speech from the Throne spelled out the federal government's commitment to ending genetic discrimination by employers and insurance companies. Over the summer, HSC's CEO Bev Heim-Myers has been working with the Federal Justice Ministry to turn that commitment into reality.

"We are very pleased with the willingness of the federal government to work with us," says Bev. "We are very close to making genetic fairness a reality in Canada."

Meanwhile, Senator James Cowan's genetic non-discrimination bill has passed second reading and was referred to the Standing Senate Committee on Human Rights.

According to Bev, the bill has been hugely successful in putting genetic discrimination on the public radar. This is an issue that affects all Canadians, including those within the Huntington's community.

As Bev points out, the lack of genetic fairness legislation may prevent people with HD from signing up for clinical trials, slowing down the pace of research. "We hope that the insurance companies will recognize that and stand behind the initiatives taken to end genetic discrimination in Canada," she says.

Raise your voice for genetic fairness! If you have not already contacted your MP, MLA/MPP and Senator, let them know how crucial it is to end genetic discrimination. You can find a sample letter at www.ccgf-cccg.ca/en/take-action.

Look How Far We've Come!

continued from page 4

Sharing Best Practices

Over the past decade, HSC's Town Hall meetings have evolved to a national level and now include all event organizers. This has resulted in a more cohesive, connected group that can learn from each other's experiences. Years ago each event was organized in isolation. Now, organizers have an opportunity to share best practices and learn from each event.

A great example of sharing best practices is the Vernon Run. Dan Middleton from British Columbia originally introduced the concept of a run. Based on his success, Dan mentored Tim Irwin from Toronto and the Toronto Run was created. Tim, now in his sixth year, has grown the Toronto Run significantly. The run model has continued to make its way across Canada; this year saw the first Saint John Run in New Brunswick, and the 3rd Annual Run in St. John's, Newfoundland. This collaboration and teamwork has expanded HSC's reach from coast to coast.

Streamlined Event Marketing

Volunteers and staff collectively streamlined HSC's approach to event promotion by creating brochure, poster, and flyer templates for our most common events. This created brand consistency and provided a quick and easy way to update information. This and the recent move to embrace online fundraising has led to exponential growth in event fundraising. Online tools help event organizers and participants broaden their reach. And best of all, the pledge process ensures that donors receive their thank you letter and tax receipt immediately.

Defining Roles

Creating volunteer job descriptions and defining roles within Chapters is another example of building capacity. In defining these roles, Chapters provide a clear path forward, which helps to build sustainability and eventually leads to succession planning. By engaging others and defining roles, opportunities are created to engage folks at a higher level, helping Presidents succeed over time and prepare for the future.

Efficient Financial Processes

Building upon present systems while providing volunteers with a high level of support is a top priority for HSC. Over the past two years, HSC has made a concerted effort to streamline financial policies for Chapters by using one financial institution instead of many. The goal: to make the lives of volunteers easier and our financial processes more efficient.

Looking Forward

As the Society evolves and reaches out to new volunteers it is important to remember HSC's history and learn from past experiences. With this in mind, the Chapter Development Team will debut a resource guideline handbook at the 2014 HSC National Conference. This initiative was spawned by a Town Hall meeting. It was their input and guidance that highlighted the importance of sharing best practices.

This past decade has seen a significant amount of change, capacity building and knowledge sharing. Our community is unique, and thanks to Ralph and Ariel Walker we are structured to ensure that we maximize our investment in mission by supporting those touched by Huntington disease. In building capacity and growing our collective knowledge, HSC is well positioned for the opportunities and challenges that lie ahead.

For more information on HSC events, HSC Chapters, or how to start a Chapter please email us at events@huntingtonsociety.ca or call 1-800-998-7398.



**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!**

Annual General Meeting of the Huntington Society of Canada

Date: Saturday, October 25, 2014

Time: 10:45 AM

Place: Holiday Inn Airport West
2520 Portage Avenue
Winnipeg, Manitoba R3J 3T6
The Chateau Riel Room

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

A Decade of Dedication:

How one research volunteer decided to make a difference

By Josh Martin

When Michelle signed up to be part of the PREDICT-HD study, her two kids were teenagers and Paul Martin was Prime Minister. A decade later, the kids are grown up, the study is wrapped up and Michelle is revved up by the progress researchers are making. "There is going to be a cure," she says. "I really, really believe that."

Michelle was 25 when her dad was diagnosed with Huntington disease. Recently married and in the process of renovating a new home and starting a family, Michelle's sunny future was suddenly clouded by fear and uncertainty. On her 40th birthday, Michelle had the blood work done that would confirm she was also gene-positive. A few months later, her dad passed away, but not before she made him a promise: that she would participate in every study she could to help put an end to this disease.

Shortly after, Michelle joined PREDICT-HD. As a 10-year participant in the long-term observational study, Michelle has contributed to a mountain of data for HD investigators around the world. Deepening our understanding of how Huntington disease progresses, the study has helped researchers pinpoint the little changes that occur before HD is officially diagnosed. Being able to identify subtle motor symptoms, small structural changes in the brain and, in some cases, mild cognitive changes has huge implications when it comes to measuring whether potential drugs can delay the onset of HD.

So what does a day in the life of a research participant look like? For Michelle, it meant annual trips to the University of British Columbia Centre for Huntington Disease. There, she'd spend the day with different members of the research team, taking psychological tests, motor tests, reflex tests... even tests for her sense of smell.

As much as she gave, Michelle also got a lot out of the experience. Participating gave her more access to medical experts and updates on the latest research developments. It gave her a chance to build relationships with the staff at the Centre, "they have such an amazing group of people," says

Michelle. She felt a sense of empowerment that came from taking action, rather than just waiting for symptoms to show up. Plus, she could be proud knowing that she was doing what she could to protect her children's future.

Michelle even noticed a drop in her blood pressure after a day at the clinic. "Every time I came out of there, I felt so positive, so full of hope," she says.

PREDICT-HD may be officially wrapped up, but the UBC Centre is currently looking for volunteers for Enroll-HD, another observational study. According to Clinical Research Manager Joji Decolongon, they are recruiting people who are gene-positive or have HD, and their close relatives.

Soon, they also expect to be testing potential treatments. The UBC Centre's Director of Medicine, Dr. Lynn Raymond, points to recent lab-bench breakthroughs that could alter the course of HD, from drugs that target specific neural pathways to genetic therapy designed to lower the levels of mutant huntingtin protein. "Things are really heating up," she says.

That means research centres like hers will need more volunteers than ever. Although progress is being made in animal models, at the end of the day it is human trials that determine what works and what does not. "We need volunteers so that we can get an approved drug for Huntington disease," says Dr. Raymond. "We cannot move forward with treatments without these studies."

She also points out that volunteers in these double-blind drug trials have a 50/50 chance of getting a potential new treatment. On top of that, if trial results look promising, all participants are often given the opportunity to continue taking the drug until it is approved.

The more people who sign up for trials and studies, the better, because HD is a relatively uncommon disease that progresses slowly and presents symptoms differently in different people. Researchers need participants to get enough data to produce meaningful results.

"No matter what you get involved in, it helps," says Michelle. "I am already signing up for the next one."

For more information on clinical studies in your area, contact your closest HSC Resource Centre or sign up for notifications at www.HDTrials.org.

Creating a Critical Mass of HD Research

continued from page 1

That makes HSC's donor supported research funding more vital than ever. Our program is designed to attract new talent to the Huntington's field and to help established investigators pursue new ideas. HSC's grants allow researchers to get better preliminary data or publish an initial paper, dramatically increasing their chances of attracting more funding.

Dr. Jeff Carroll is the perfect example. A New Pathways grant in 2013 allowed him to explore HD's intriguing effects on the liver. Based on the results of that work, he is now collaborating with a pharmaceutical company and has received grants to take the research further.

"Without the support of the HSC at this critical juncture, there is no question that this project would have died on the vine," says Dr. Carroll. "The HSC's grant programs fill a critical gap in the field."

Dalhousie University's Dr. Harold Robertson agrees. His 2012 assessment revealed that the research we fund is getting published in high-impact journals and helps investigators win bigger grants.

Meanwhile, volunteers are essential to clinical trials so research can move ahead. Take Michelle, for example. As a 10-year participant in the PREDICT-HD observational study, Michelle has contributed to a mountain of data for HD investigators. And although a lot of people like Michelle are stepping up to the plate, we need more. The faster researchers can recruit participants, the more quickly we can find out whether approaches that work in animals are equally successful in humans. "No matter what you get involved in, it helps," says Michelle.

To lay the foundation for clinical trials, HSC is connecting clinicians across Canada and fighting the genetic discrimination that prevents many people at-risk from taking the genetic test required for many trials.

According to Bev Heim-Myers, HSC CEO, that is all possible when we work together. "It's the community, it's the researchers, it's the Society," she says. "We want to continue to build that critical mass of research that leads to answers for slowing and stopping Huntington disease."

You can find more details on this research article and the rest of the story in the Latest News section at www.huntingtonsociety.ca.



Finding The Right Care, At The Right Time!

continued from page 1

type or Carefoam type chairs (www.brodaseating.com and www.carefoam.com).

Many persons with HD do best with unchanging routines, preferring the same staff day after day who know them and can anticipate their routine. Ask the facility about the staff turnover rate. Some facilities have high staff turnover each year; this could indicate a problem with working conditions. If a facility can maintain staff, this indicates better care. A best practice is the use of **consistent staff**, attempting to assign staff familiar with the resident for most of the shifts each week. Ask: What are the "hours per patient day" of nursing staff? Those seeking out long-term care need to understand the limitations of the care centre. Most facilities offer fewer than 4 hours a day of nursing care and supervision to each resident.

Align your expectations of what you want for your loved one with what long-term care options can offer. The best approach for those in the mid to later stages of the disease is to try to accommodate the preferences of the individual as much as possible while making the environment safer. The facility and you both need to understand that falls may happen even in the best placements, they may be serious and even cause death, and they cannot be 100% prevented if an individual has uncontrollable movements and doesn't ask for, or accept, help. For Huntington disease patients, **what is most important is their quality of life, developing a routine, and not being pushed to do what they don't want to or cannot do.** You and the nursing facility need to be comfortable with a person-centred care approach.

HD is associated with cognitive changes and dementia, and difficulties in concentrating, social interaction, maintaining attention and participating in activities. It is so common as to be almost normal for the individual with HD to want to be alone, to refuse to go to activities, to appear unmotivated at times, to wear little clothing, to have difficulty getting off a topic, to have unique quirks or preferences and to hate bathing. Trying to get the patient to change is difficult; changing the environment and approach of the caregivers not to "push too hard" is much more effective at improving everyone's quality of life and safety. Care planning helps the facility establish a routine and document exceptions or things the person with HD needs that are not standard for everyone. For example, if a person insists on going barefoot, then the care plan should state that this is more comfortable for them, and that applying shoes causes agitation.

Once a patient is in a facility, the **need for education** and advocacy does not end. Formal training materials are available through HSC, and its staff can provide educational sessions ("in-services") about caring for people with HD as well as ongoing consultation to the staff of long-term care facilities. However, it is important to recognize that the loved ones of those with HD can be a key resource. What is also helpful is to **focus not on the disease, but on the individual idiosyncrasies, habits, and preferences of the patient.** This is called "**person-centred care.**" Person-centred care is a practice and philosophy of listening to the person and what they want, their own goals, dreams, and needs and structuring the care environment to serve their unique situation. Educate with an understanding of the perspective of the staff. In a nursing home, most care is provided by nursing assistants, who have a long list of things to do to care for more than 6-10 people on an assignment. They are trained to turn, clean and feed older people on a schedule and they often know little or nothing about HD. As a loved one, you can help them with their tasks, support them, listen to them, and educate them about the reasons for the behaviours and what might work. If you can develop suggestions that help the resident and make the job of the staff easier, this is the most likely way to be effective. Sometimes you can help by writing down the care routines or preferences, and helping to make sure that the staff caring for your loved one understand that list of "the most important things."

The best way to influence people is to listen to their concerns, then use their own words and observations to reframe what they are saying to enhance understanding. For example, a nursing assistant states, "She hits and she knows what she is doing." You might educate her about the disease. You might reply, "I think sometimes she does know what she is doing, but the brain changes make it harder to inhibit impulses. She can't talk well so maybe she is trying to tell you to get away, or that she is fearful or doesn't like to be changed." The HSC Family Services Team can also assist in the ongoing process of working with and educating staff.

As a loved one of a person with Huntington disease, your observations can help professional caregivers improve care. Observe what works and what doesn't, gently help staff identify what they are doing that works (e.g. coming back later, offering a reward, explaining actions

kindly even if you think the resident knows, etc.) and what doesn't (for example, coming in large groups and holding the person's arms and legs down).

Staff need to learn to respect when the resident expresses "no" and to avoid doing things which may agitate them. One middle-aged man with HD was very rigid about meal times and refused to have his incontinence briefs changed in the two hours prior to lunch. Staff knew that to ignore a soiled brief would be neglect, but to try to fix it would often cause him to be agitated and strike out, risking staff injury. The team worked out a schedule where he is changed two hours before lunch, allowing him to be in the soiled brief through lunch with observation of his skin to make sure it doesn't get irritated. The staff and family agreed to do it this way and wrote it in the care plan with the benefits and concerns documented. It was a win-win with both staff and the resident happier and without injuries. What you are striving toward is a relationship with the staff that promotes pride in their own skills in dealing with the challenging resident.

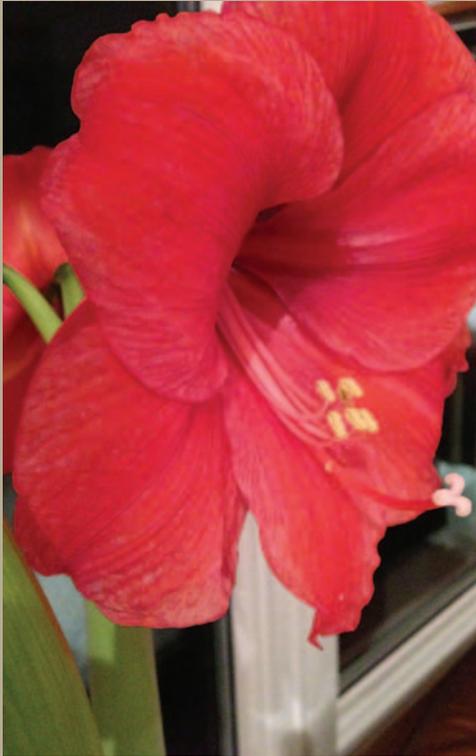
In our setting, we find the best strategy is to **maximize autonomy and choice** as much as possible within an **environment of structure and routine.** Assure that the focus is on the needs and preferences of the resident rather than family or staff preferences of how things should be. Remember that how easy you make it for your loved one will make a difference in whether the facility will take another HD patient in the future.

Dr. Rebecca Ferrini, MD, CMD, MPH is a full-time Medical Director in a long-term care facility in a suburb of San Diego, California which has developed an expertise in caring for those with mid to late stage Huntington disease, caring for more than 80 individuals in the last 14 years.

Dr. Ferrini is located in the United States and cannot help with placement options, but is willing to answer general questions about mid and late stage HD and provide resources and ideas for management. Her contact information is: Dr. Rebecca Ferrini, Medical Director, Edgemoor DP SNF 655 Park Center Drive, Santee, CA 92071 Mail stop 5-552 Office: 619-596-6350 Fax: 619-596-6367 Email: rebecca.ferrini@sdcounty.ca.gov

The Huntington Society of Canada would like to extend our sincere appreciation to Dr. Ferrini for her contribution to Horizon.

Inspiring Hope One Beautiful Amaryllis at a Time



By Josh Martin

It is the season for sweaters, pumpkin pies and, of course, HSC's Amaryllis Campaign! Each year, the brilliant orange-red blooms brighten homes and offices from coast to coast.

Last fall, for example, one of our volunteers dropped off an Amaryllis at his wife's care facility. Suddenly, all of the other residents wanted one too. "Something like this makes that time of year fun and cheery," says HSC Campaign Manager Jim Martin. "It energizes people."

This year, we are using social media to spread that cheer and inspiration even further. Pop over to [Pinterest.com/HuntingtonSC](https://www.pinterest.com/HuntingtonSC) and [Instagram.com/huntingtonsocietycanada](https://www.instagram.com/huntingtonsocietycanada) where you can add photos of your Amaryllis and see what others have posted.

Of course, the Amaryllis does far more than create a splash of colour. Last year, our volunteers raised more than \$120,000 in vital funds for our programs and services. "It's not just a flower," says Jim. "It represents hope."

Help us reach our goal of selling 25,000 kits. A perfect holiday gift, each \$15 kit contains an Orange Sovereign bulb, growing instructions, soil, pot and saucer. Order yours today by calling 1-800-998-7398 or go to www.inspirehope.ca.



Congratulations to Sarah Kallay from Orangeville, Ontario, winner of our early order contest and proud new owner of a Bosch Tassimo coffee maker!

HealthPartners Update

September marks the start of the annual Government of Canada Workplace Charitable Campaign (GCWCC), Canada's largest and most successful employee giving campaign. Federal government employees and retirees in hundreds of workplaces generously contribute to more than 4,000 charities of which HealthPartners and its 16 members (including HSC) are grateful recipients.

In 2013, employees and retirees donated more than \$36 million, of which \$10.5 million was directed to HealthPartners. The Huntington Society receives a portion of this funding and funnels it directly towards the Society's mission.

This past year an electronic pledge form and a new website www.healthpartners.ca were introduced in the campaign. The website includes testimonials from individuals who have been impacted by the support received by HealthPartners. The Huntington Society has included a testimonial.

Please take a look and learn more about HealthPartners and how the Society works in collaboration with 15 other health charities across Canada.

The Huntington Society and HealthPartners are incredibly thankful for the support of donors, and encourage supporters to contribute through the GCWCC if they are federal government employees or donors.

Recently HealthPartners expanded their workplace giving services and is pleased to announce that Leo Pharma, Pacific Blue Cross and New Brunswick Government employees, will participate in workplace giving. All of these companies will be offered the chance to support HealthPartners in their employee giving campaigns in 2014. These types of campaigns are opportunities for HealthPartners and the Huntington Society to expand our reach, increase awareness and engage Canadians in their place of employment to partner with employers and colleagues to build healthier companies.

If you are interested in starting a workplace giving campaign, email us at info@huntingtonsociety.ca or call 1-800-998-7398. Together we can achieve more.



Canada's New Anti-spam Legislation

On July 1, 2014 new legislation came into effect making it law for businesses to obtain permission before they send information. Many Canadians have received emails requesting permission to connect through email. This has been put into place to protect Canadians while ensuring that businesses can continue to compete. Charities have been exempt from certain aspects of the legislation; however, we still need to take measures to ensure, that as a charity, we are compliant with this new legislation and will over the next two years become fully compliant.

For more information on how the Huntington Society of Canada is ensuring compliance, please visit www.huntingtonsociety.ca or contact us at info@huntingtonsociety.ca or at 1-800-998-7398.



**Be Brave, Be Bold,
Be Ready: HD Clinical
Trial Preparation**

HD 101 Clinical Trials Workshop for Researchers, Scientists and Clinicians

**October 23, 2014
Winnipeg, Manitoba**

Calling all researchers, scientists, and clinicians in Canada! Join us in Winnipeg on Thursday October 23 for this innovative, cutting-edge workshop designed to create a national HD Clinical Trial strategy and build momentum for clinical trial readiness.

In partnership with Canada's Research-Based Pharmaceutical Companies (Rx&D), HSC is inviting Canadian researchers, scientists and clinicians to participate in the first HD 101 Clinical Trials Workshop. Learn what you need to know about setting up a clinical trial; who needs to be involved; how to engage the HD community to participate and how you can help advance clinical trials in Canada. By attending this workshop during the HSC National Conference, you will have the opportunity to learn from your peers and learn from those affected by HD.

To register for this unique opportunity contact info@huntingtonsociety.ca or call 1-800-998-7398.

Celebrating Our Heroes: The Sharpe Family



By Josh Martin

As an MBA student in 2003, Toby Sharpe had never heard of Huntington disease. In contrast, classmate Heath Sterling knew the disease all too well, seeing first-hand how it was affecting his mother. So when their assignment was to help a charitable organization improve its bottom line, Heath suggested HSC.

It was a welcome suggestion for Toronto stalwart Ellen Foster, who had been running the Huntington's Indy Go-Kart Challenge for many years and was ready for a break. She invited Toby and Heath to see what they could do to give the annual fundraiser a bit more horsepower. Priority one? Shaking things up with out-of-the-box thinking and fresh faces. "That brings new ideas and a whole new bunch of people that can help make it a bigger event," says Toby.

The pair got to work. They streamlined the registration process and found new sponsors. They arranged a henna painting booth, and added more prizes. Toby's wife, Michelle DeBattista, used her uncle's printing equipment to cut down the cost of t-shirts and hats. Between Heath's creativity, Toby's behind-the-scenes business savvy and the tireless work of volunteers, a new and re-energized Indy Go-Kart Challenge emerged.

Each year, the event draws more than 200 people to Mississauga's Playdium go-kart tracks. In 2013, it netted \$28,500. Still, Toby is always looking for ways to make a larger impact. Last year, he and Michelle donated a week at their new six-bedroom villa near Disney World as a prize, an incentive they offered this year at Calgary's "A Night to Flourish" gala in June.

From day one, the Indy has been a family affair for Toby and Michelle. In fact, their family has been at every event since, with daughter Sarah, 11, attending her first when she was just three weeks old. She and her little brother Christian, 8, have become familiar faces at the tracks, lending a hand at registration and using their charms to persuade auction participants to bump up their bids.

Passing on their passion for helping others means a lot for Toby and Michelle. "It gives our kids a chance to see how people are affected by something that they cannot control, and how they can contribute," says Toby. "It is all about helping those that you can." And they will be helping out again at this year's Indy.

Toby and Michelle are happy to offer a discount on their Florida vacation villa, MickeyGardenVilla.com, to members of the Huntington's community. Contact us at events@huntingtonsociety.ca or call 1-800-998-7398 for details.

Thank you

On behalf of families living with HD, thank you for your continued partnership and generous support. Our community makes the difference as we reach out to families who are not yet connected to HSC, continue to support and advocate for families from coast-to-coast, invest in world-class research, and play a leadership role in the international Huntington disease community.

With your help, we are continuing to improve the quality of life for people with HD, cultivating strength and resilience in the Huntington disease community and providing substantive reasons for hope. If you have questions, story ideas or comments about *Horizon* or the Huntington Society of Canada, please contact us at info@huntingtonsociety.ca or call us at 1-800-998-7398.