

Pushing Scientific Boundaries: How Huntington's research has transformed the biomedical world

By Julie Stauffer

When a former classmate offered Canadian Dr. Marcy MacDonald an opportunity to work on Huntington disease (HD) research, the young molecular geneticist jumped at the chance. She packed her bags and headed to Boston to join Dr. Jim Gusella in the hunt for the HD gene.

It was 1984, and the search had captured the imagination of scientists around the world. Jim had found the rough location of the HD gene, somewhere near the tip of chromosome 4. Researchers were fired up at the prospect of identifying the single gene mutation that lay behind the disease and then using that information to develop treatments.

The breakthrough came a decade later. Dr. MacDonald and Dr. Gusella and their team, working in an international collaboration, made headlines around the globe with the announcement they had finally found the elusive HD gene, thanks in part to the cutting-edge genetic manipulation techniques that Dr. MacDonald's laboratory brought to the project.

While the Huntington's community celebrated, the discovery also inspired a new wave of genetic research. Suddenly, there was proof that molecular genetic techniques could successfully be used to identify genes based solely on their chromosomal location. "It really inspired a paradigm," Dr. MacDonald explains.

Since then, Huntington's research has continued to break new scientific ground, pioneering the use of "knockin mice" that replicate the HD mutation as an animal model for genetic disease and providing the impetus for accurate genetic animal models to provide fundamental insights into other neurological diseases such as Alzheimer's and ALS.

Dr. MacDonald is quick to emphasize the crucial role that families have played in all aspects of this research. She cites the detailed family history records that guided the hunt for the gene, the blood samples from families around the world that made genetic research possible, and the hundreds of individuals who have participated in clinical trials to date.



What lies ahead? Most exciting, says Dr. MacDonald, are studies tracking the pre-clinical progress of Huntington disease. Thanks to genetic testing, researchers have a rare opportunity to observe the subtle changes that take place within cells and tissues of gene-positive individuals before clinical symptoms appear. "That's extremely powerful," she says.

Among other things, these pre-clinical studies will help to answer a puzzling question: If the disease is caused by a single gene mutation, why do different people have different symptoms? The better that we understand that variability, the more targeted we can make clinical trials. Not only that, but the fewer participants we'll need.

"I think that Huntington's disease is going to lead the way in changing how clinical trials are designed," she says.

She's also intrigued by the "amazing" tools now available that allow researchers to measure change in DNA, RNA and proteins, revealing exactly how the disease unfolds at the molecular level.

Last but not least, she highlights HDBuzz (<http://hdbuzz.net/>), a website that translates the latest HD research results into plain language and puts new discoveries in context. For Dr. MacDonald, HDBuzz offers a service not only for families but the entire biomedical community as well.

"Huntington disease is changing the way in how research is communicated," she predicts.

Dr. Marcy MacDonald is just one of the fabulous keynote speakers HSC has lined up for our National Conference in Toronto this November. Please join us. To find out more, visit www.huntingtonsociety.ca or to register contact us at 1-800-998-7398 or email info@huntingtonsociety.ca

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

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

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

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Note from the CEO

If I had to choose one word to describe the Huntington Society of Canada (HSC), it would be 'Powerhouse'. Time and again, we have overcome adversity to accomplish great things. The past year was no exception.

While all Canadian charities faced revenue challenges in 2011/12, HSC was up to the task. Thanks to many skilled volunteers, dedicated staff, and to participants from our local *Experience Matters* program, we were able to manage expenses across Canada.

At the same time, we broadened our fundraising efforts, reaching beyond the Huntington's community to make HSC the charity of choice for more and more Canadians. As part of that effort, I'm pleased to say we've forged relationships with several significant new donors.

We have strengthened our internal communications by launching regular conference calls with our chapter presidents to discuss strategies, share information and create a two way dialogue between key staff members and our grassroots leaders.

Our advocacy work continues to bring results. We influenced the Ontario government's decision to extend the Special Diet Allowance to people living with HD. Meanwhile, we are keeping genetic discrimination on the national radar, with regular coverage in the national, provincial, and local media.

Additionally, HD hit the big screen with *Do You Really Want to Know?*, a powerful, award-winning Canadian documentary about predictive testing. We were proud to host the world premiere at the DOXA Film Festival in Vancouver earlier this year. Now, we're looking forward to the Ontario premiere at the Ottawa film festival (OIFF) and again at our National Conference this coming Fall.

We look forward to our National Conference in November, and have lined up a wonderful selection of speakers, including Dr. Marcy MacDonald, a member of the team that discovered the HD gene mutation, and Dr. Simonetta Sipione, one of the researchers who was able to reverse HD symptoms in mice earlier this year. Noteworthy, for the first time, we're featuring an entire day of programming for youth, by youth.

We are expecting a record turnout, so be sure to sign up soon by going to our online registration site at www.conferenceHSC.ca.

Looking ahead, we are developing a strategy to reach families from all ethnic and national backgrounds, so that every Canadian dealing with HD has access to the resources and support that they need.

Lastly, with the Society's 40th anniversary just around the corner, we're busy planning celebrations and ways to focus more attention than ever on the Huntington's cause. Stay tuned!

Bev Heim-Myers,
CEO & Executive Director,
Huntington Society of Canada

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

2012 National Conference: Toronto

On November 9 and November 10, 2012, the Huntington Society of Canada is proud to present our 2012 **National Conference**. Please join us to learn from top notch International Huntington disease experts & presenting speakers, learn more about HSC Support Services and much more! This year's conference promises to **Connect, Inspire and Inform** families that are affected by Huntington disease and medical professionals and researchers that wish to specialize or learn more about HD. **Featured speakers include:**

Dr. Marcy MacDonald, PHD – Professor of Neurology, Harvard University.

**Topic: Huntington Disease
Research: Trailblazing and
Pioneering**

Huntington's disease is at the forefront of biomedical research, as a deeper understanding of the effects of the inherited mutation permit data-driven, rather than best-guess approaches, to the development of therapeutics.

Dr. MacDonald earned her PHD in Medical Biophysics at the University of Toronto in 1980 and is currently a Professor of Neurology (Genetics), at Harvard Medical School and the Massachusetts General Hospital and is a founding member of the Center for Human Genetic Research. Dr. MacDonald has worked on Huntington's disease since 1984 and is using genetic research to understand the rate-limiting biological events that predate and predict the onset of Huntington disease symptoms, as these offer novel routes to improved disease management and therapeutics.

Dr. Mark Holder, PHD – Associate Professor of Psychology, University of British Columbia

**Topic: Creating Happiness: The
Science of Personal Well-Being**

Traditionally, psychology and medicine have asked the question, "What is wrong with you and how do we fix it?" Positive psychology asks a very different question: "What is right with you and how do we promote it?" Positive psychology is the scientific study of what makes life worth living.

Dr. Holder earned his PHD at the University of California, Berkeley and completed his postdoctoral training at the Brain Research Institute of UCLA. As a professor at Memorial University of Newfoundland, he studied how natural chemicals, 200 times the strength of heroin, were released when people ate chocolate chip cookies. During this time he worked as a Biological Consultant with the NutraSweet Company to determine whether aspartame is safe for pregnant mothers and their offspring. Dr. Holder is an award winning teacher and researcher and is currently an Associate Professor at the University of British Columbia, Okanagan, where he studies the science of happiness.

Dr. Alex D. Goumeniouk MD, FRCP, FAPA

**Topic: Treating Symptom Groups
With Huntington Disease With A
View To Improve Quality of Life.**

Join Dr. Goumeniouk as he explores *Treating Symptom Groups with Huntington Disease with a View to Improving Quality of Life*. Dr. Goumeniouk's presentation will deal with strategies, both pharmacological and psychological, aimed at addressing specific symptom groups that constitute Huntington disease. These symptoms include the three main spheres of HD, motor, psychiatric and cognitive. In addition, other specific issues such as insomnia, pain and adverse drug side effects will be discussed.

Dr. Alex D. Goumeniouk, MD, is Clinical Professor of Anaesthesiology, Pharmacology and Therapeutics at the University of British Columbia (UBC) in Vancouver, British Columbia, Canada. Dr. Goumeniouk earned his medical degree at UBC in 1987. He completed a postgraduate program in Internal Medicine at the University of Western Ontario before returning to UBC to complete a fellowship in Psychiatry. In addition to his academic appointment, Dr. Goumeniouk serves as Consultant Psychiatrist and Psychopharmacologist to the Centre for Huntington Disease at UBC.

AGM Notice

Notice is hereby given of the 2012
Annual General Meeting of the
Huntington Society of Canada.

Date: Saturday, November 10, 2012

Time: 10:45 AM

**Place: Intercontinental Hotel
225 Front Street West
Toronto, ON M5V 2W6**

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



New Website Strengthens the Youth Voice



In 2008, the first Canadian youth group of its kind was founded in Prince Edward Island. That group called themselves YPAHD, Young People Affected by Huntington Disease. The group was established to provide a forum for young people to network with one another, to foster relationships, and to promote the fact that no one is alone in the face of Huntington disease (HD). It was a small group of 27 young people wanting to make a difference. There was no network, no structure dedicated to helping young people affected by HD connect with each other.

Fast forward five years and it's a different story, with YPAHD firmly established this group has reached out internationally to form connections, thanks to the efforts of Canada's Brynne Stainsby, Britain's Matt Ellison and the United States' BJ Viau. Together, the trio founded the international Huntington's Disease Youth Organization (HDYO) and, most recently, launched a new website: www.HDYO.org.

The lively, upbeat site offers a ton of resources for young people around the world: stories, videos, forums and more, covering everything from caregiving to genetic testing to dealing with the challenges of having a parent with HD.

You'll find sections for kids, teens, young adults, parents and professionals, as well as a section about juvenile HD. Ask a question. Connect with your peers. Share your poems, blogs or artwork.

According to BJ, the goal is to offer information, create a sense of community, and encourage youth to get involved in the Huntington's cause.

Since HDYO's web launch in February, praise has flooded in. "It's been awesome," says BJ. Many say it's the first time they've connected with anybody else growing up with HD. Others ask how they can get involved.

HDYO volunteers are now busy translating the site into a dozen different languages, as well as creating print publications that can be used around the world.

That leaves Canada's YPAHD free to focus on national events and initiatives, like the first-ever YPAHD day at HSC's conference this fall: an entire day dedicated to educating youth, developing support networks, reducing stress and just having fun.

YPAHD has also been busy setting up a major cross-Canada fundraising campaign and launching a new and improved version of www.ypahd.ca. With two major projects



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Canada's YPAHD is delighted to work in tandem with HDYO to ensure there is sharing of information and resources. This is truly a synergetic strategy that works for everyone.

For both Brynne and BJ, creating HDYO has been a life-changing experience: an opportunity to make an impact and gain a small sense of control over HD in the process.

"Being involved has been so powerful," says Brynne. "It's incredible how far we've come."

Check out HDYO and YPAHD and provide your feedback by connecting with us on facebook and twitter. We welcome your comments and hope you will share these resources with friends and family.

HSC 40 Years!: History in Motion

by Julie Stauffer

When Bob Stevens' first wife was diagnosed with Huntington disease (HD) in 1969, the neurologist could tell them very little about the disease. At medical school, he said, they had spent only an hour on the topic. "Go to the library," he suggested.

Four years later, Ralph and Ariel Walker founded the Huntington Society of Canada (HSC) to change that picture.

Part of that involved reaching out to families like the Stevens and building chapters across the country. Bob recalls the first meeting in Vancouver: 25 people who had never met one another, assembled in a church to hear Marjorie Guthrie, founding member the Committee to Combat Huntington's Disease (an American organization that has since developed into the Huntington Disease Society of America /HDSA), and Ralph Walker speak. "It really fired people up," he says. "It was a chance to get out and talk to people that had the same problem."

As the Society grew, HSC began setting up Resource Centres and hiring Social Workers

across the country to provide support and information to Canadian families. Currently the Huntington Society of Canada has at least one specialized Social Worker to provide support in each province.

While building support for families, Ralph was also busy recruiting young researchers and clinicians to the cause. Neurologist Dr. Mark Guttman describes how Ralph called on him not long after he set up his movement disorders practice in Ontario. "I thought that this was pretty impressive, that the head of the national organization would show up at my office," he says.

Ralph emphasized how patients living with Huntington disease needed the support of specialists, even though there were no treatments to offer for HD. He convinced Dr. Guttman to get involved in clinical research and to make regular outreach trips to more remote areas in Ontario, as well as serving the Toronto-area clientele.

By developing relationships with the scientific community and offering strong services to families, Canada became a

hotbed of Huntington's research and a global example of excellence in Huntington's care.

While Ralph was a major force behind the Society's success, many others have contributed over the years. "We've drawn in all kinds of good people," Bob says. Dr. Guttman agrees. "HSC is really a partnership with clinicians, researchers, patients and families all working together," he says.

Today, as potential treatments near the stage of clinical trials, it's a partnership worth celebrating.

In 2013 HSC will celebrate its 40th Year, an exciting accomplishment and something worth being proud of. We want to celebrate our history and the incredible success we have had and continue to experience.

Please help us continue Ralph and Ariel's legacy; we invite you to consider making a leadership gift. For more information, contact us at 1-800-998-7398 or info@huntingtonsociety.ca

An Ariel View

I can't believe that almost 40 years have gone by since Ralph and I first founded the Society. I won't say it feels like yesterday, but it certainly doesn't feel like four decades ago!

Back then, we saw a need and decided to do something about it. We were young and energetic, and we certainly worked hard, but I don't think we could have created the foundations for today's successful organization without the help of many, many people.

One of the doctors I worked with connected us with neurologists willing to share their expertise. The local chapter of Beta Sigma Phi adopted us as their cause and helped us organize the garage sales that kept us going through those early years. A group of ladies at our church helped me sew Raggedy Anne dolls to use for fundraising.

When we were overwhelmed with the amount of mail that poured in from families who heard about our new organization, a pair of sisters volunteered to come to our house each week to type our correspondence.

Whenever we reached out, people responded.

Thanks to them, we were able to do the same thing for people across the country affected by HD. Now when families reach out, there are chapters to support them. There are social workers with a wealth of information to share who can connect those affected by HD with resources in their communities. And there are national symposiums and conferences and even international congresses that bring people together from around the world.

I remember being at the World Congress in Vancouver in 2009 with Cheri Delargie, whose husband, Bob, had been diagnosed with HD a few years before. She turned to me at one point and said, "Ariel, this has been phenomenal."

I feel exactly the same way after every conference and every congress. It's wonderful to see so many people realizing that there are other families like theirs, healthcare professionals who want to find the best ways to care for them, and dedicated scientists working to find treatments.

My nursing career taught me how tough dealing with a serious illness can be. It's our networks of support that give us strength to keep going through the difficult times.

So don't be afraid to ask for help when you need it. Huntington disease isn't something you have to fight alone. If you can, come to the National Conference in Toronto this coming November. To me, seeing hundreds of people come together to support one another is what HSC is all about.

Please join us at the HSC National Conference November 9 & 10, 2012. To find out more, visit www.huntingtonsociety.ca or to register contact us at 1-800-998-7398 or email info@huntingtonsociety.ca



Ariel

It's All About Caring

By Julie Stauffer

Coping with Huntington disease (HD) is devastating enough, as thousands of Canadian families can testify. But what happens when the caregiver becomes seriously ill as well?

Back in the late 90s, Sarah Mulcahy felt depressed, anxious and out of control. She thought she was going crazy, and her doctors couldn't offer any explanation.

Then her husband, Jim, was diagnosed with cancer. Sarah ignored her own disturbing symptoms while he battled non-Hodgkin's lymphoma. It was only after his treatment proved successful that Sarah finally got her own diagnosis. She had Huntington disease, a disease she did not know was in her family.

A year after that bombshell, Jim's cancer returned—this time in an incurable form.

Jim found himself simultaneously a caregiver and a patient. He spent sleepless nights coming to terms with his fatal disease and worrying about what would happen to Sarah and their four children when he died. Meanwhile, Huntington's had blunted Sarah's emotions, leaving her unable to support her husband through that dark period.

Experimental stem cell treatment five years ago bought Jim some time, but today everyone recognizes that his grace period could end at any moment.

For daughter Caitlin, it has meant not thinking more than a few months down the line, always ready to drop everything and move home to help when that phone call comes. But, she adds, there have been blessings as well.

"You very quickly learn what's important in your life and what's really not important," she says. "You so appreciate the good times that you do have."

Today, Jim dedicates himself to looking after Sarah. It is because of Jim that she is living at home, going for walks, accompanying him during his volunteer activities and enjoying visits from their grandchildren. According to Caitlin, her Mom's the happiest woman in the world.

Jim will readily admit it isn't easy, but his frankness about the bad days and his sense of humour keep him going.

The Mulcahy's would be excused for feeling bitter about the hand that fate has dealt them. However, as Caitlin points out, in some ways their experience is typical: most Canadians will either need care or end up caring for someone at some point in their lives.

Her advice? "I think all you can do is take each day at a time and try to find the value in what you're doing and also be honest with yourself about those days when it really is awful," she says. "Be kind to yourself and to each other."

"We've been lucky to see both of our parents rise to the occasion really bravely," she concludes. "We have gotten to see this wonderful example of caring for one another, which is what you end up realizing life is all about."

Caitlin is currently completing her PhD dissertation on the role that mothers play in preserving family memories, and what happens when they begin to lose their own memory. Look for an article on her research in an upcoming issue of Horizon.



The Mulcahy Family

Caregivers and Technology:

By Jane Dawkins

Without a doubt technology has changed the way we do business and how we connect with our families. It has changed the speed in which we communicate information, how we manage our time and how we relate in general. Across Canada, the creation of Telehealth (a free, confidential telephone service where you can access a Registered Nurse for health advice or general health information) has dramatically transformed the way we have connected with our health care system over the last 10 years. With the growing popularity of smartphones and tablets we are now seeing new developments in **"accessibility technologies"**: applications and programs that are specifically designed to aid and assist people who have physical or cognitive difficulties or impairments often seen in those living with Huntington disease (HD). These programs can also serve as meaningful communications tools to home caregivers and a variety of professionals who work with HD patients.

Applications that can help:

MiHealth is a secure line of communication between a caregiver, patient and family doctor, this application works on iPhones, iPads, Androids or BlackBerry platforms. It offers the ability for people to access and organize critical

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Healthpartners Teams up with Benevity!

As one of the 16 Health Charities that belong to Healthpartners Canada, the Huntington Society (HSC) is poised to be well represented in the Canadian workplace from coast-to-coast. As part of Healthpartners efforts to find new donors and new dollars for its 16 members, they have partnered with Benevity as a featured "health" pillar and as a member of Healthpartners, HSC is proactively participating.

Benevity is a Calgary based company that has developed a workplace giving software called Spark to help more Canadian workplaces build engaging, strategic and choice-driven philanthropy and workplace giving programs.

Their latest on-line giving tool called Spark delivers a "one-stop" solution for giving and volunteering so employers can increase participation and impact from their employee giving programs. Today's workplaces are looking to engage their workforce, boost their culture and enhance their community investment impact.

Spark gives Healthpartners, a convenient on line tool that offers donors the opportunity

to contribute through payroll deductions, credit card or paypal donations; it also offers health charities the opportunity to recruit volunteers.

"Spark connects donors and volunteers to Healthpartners and its members, having the potential to greatly extend our reach into an evolving Canadian donor landscape. As part of a refreshed new marketing strategy, an alliance with Benevity is just one of our efforts to increase the awareness of Healthpartners amongst Canadians". says Eileen Dooley, Executive Director of Healthpartners.

Spark software is also making it easy for charities to reach donors who want to be reached. Through Benevity's secure site for causes, charities can identify specific projects that they want to promote which are displayed through any giving program supported by Benevity's platform. For the Huntington Society it means we can offer donors opportunities to engage with us on different levels such as participate in an event, provide travel for a YPHAD member to get to the conference or volunteer at one of our symposiums – as always with Benevity,

the choice is given to the user (the donor) and the client (the Charity).

"The Huntington Society is delighted with this partnership", says Cyndy Moffat Forsyth, Director of Development. "This is innovative, engaging and simple, a win-win-win for employees, companies and charities. We have already received donations and look forward to a long successful partnership with Benevity and continued long term success with our colleagues and partners at Healthpartners".

The Huntington Society encourages readers to check out Benevity at www.benevity.org to learn more about this unique tool and to check out Healthpartners at www.healthpartners.ca to learn more about workplace giving. Together our partnerships make us stronger!



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Growing a Brighter Future with Amaryllis

Our Amaryllis Campaign is bursting into bloom. We are already more than half way to our target of 25,000 kits for 2012. With your help we can exceed last year's target and raise even more dollars to help families in our communities and to fund research to find meaningful treatments for HD.

An Amaryllis bulb is a great way to introduce your friends, neighbours and local schools and businesses to HD. The bright vibrant flower is a welcome sight in the months of November and December. So why not order a case today?

There are more ways than ever to get involved. Find out more about our campaign by visiting www.inspirehope.ca. You can plant a flower in our virtual garden, order your own live Amaryllis from one of our volunteers, or order Amaryllis kits to give as gifts or sell in your community.

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





Caregivers and Technology:

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health information 24 hours a day, via an internet connection or smart phone. It is password protected and secure in order to protect your health information and allows you to share all or part of your medical information with family members or your selected support system. *MiHealth's* mission is to "empower patients with the information they require to take better control of their own health and wellness". This approach reduces dependence on the health care system and facilitates a proactive approach to health management. The objective is to dramatically improve overall health and wellness.

Proloquo2Go™ provides a full-featured communication solution for people who have difficulty speaking. It brings natural sounding text-to-speech voices, close to 8000 up-to-date symbols, a large default vocabulary, is fully expandable and is easy to use with the iPhone, iPod Touch and iPad. This very helpful tool can improve communication between patient and caregiver. And while the price is significant (an iPad is close to \$1000 and the program itself is approximately \$200) the total investment is still lower than for other computerized speech devices and it is portable!

"Clear communication between those living with Huntington disease and their caregivers is critical" says Maribeth Meijer, Huntington Society of Canada's Director of Family Services and Chapter Development, "Harnessing any and all tools can help make life easier and caregiving more effective. For many of us, of all ages, embracing technology can provide the extra support needed to help make our lives easier."

To learn more about these technologies go to <https://mihealth.com> or call 1-855-341-4040 or visit www.assistiveware.com.



Huntington Society of Canada would like to thank all of our sponsors for Casino Royale 2012!

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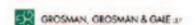
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Architecture for the Mind and Body:

Innovative ideas for long-term care facilities

Surroundings matter. Light, sound, colour and space all affect how we feel emotionally. Emotions, in turn, affect our physical well-being. That's the philosophy driving new designs for the special care unit of Cummer Lodge, a long-term care facility in north Toronto.

This idea of redesigning the special care unit had been under discussion for many years among the Cummer Lodge Administrative team and their Psychogeriatric Resource Consultants (PRCs). It was social worker Karin Adlhoch's connections at Ottawa's Carleton University and Carleton U's Azrieli School of Architecture and Urbanism that helped make this project a reality. The Cummer Lodge Team invited socialwork and architecture students to develop new designs for the special care unit: home to residents with Alzheimer's, Dementia and Huntington disease.

For many, it was their first exposure to this kind of environment. Over the course of three months, the masters-level students conducted research, toured the facility and incorporated input from Cummer Lodge staff.

The biggest challenge was thinking small. "These are future architects who really want to innovate and do big projects," explains Carleton architecture professor Frederica Goffi, who supervised the project.

Instead, the students had to focus on individual elements, such as the design of a window or door. But Goffi emphasized how much impact those elements could have. "You know, a small detail like that can change somebody's life," she says. "The notion of designing from the details, which inspired our work, is an approach theoretically argued by our school's Director Dr. Marco Frascari."

Built in 1990, the 32-bed special care unit is bright and spacious. Back then, it was considered quite innovative, incorporating ideas like an "endless corridor" that allowed residents to walk in a continuous loop. However, Adlhoch believed that new ideas could increase the independence of the residents while creating a safer, calmer, more pleasant and more home-like environment.



Image provided by Carleton University.
Drawing created by Emily Webster Mason.

The students delivered, presenting a dozen different plans aimed at reducing stress, increasing well-being and providing comfort and care. Their "mind-body architecture" approach took into account the specific needs created by degenerative neurological diseases, as well as the strict provincial regulations that govern long-term care facilities.

One student proposed walk-in baths that offer more dignity and comfort than the current setup, which relies on a mechanical lift to transfer residents in and out of the tub. Another student used wooden ceiling elements to dampen noise levels in the unit.

Some focused on improving air circulation by redesigning windows and doors. Finally, several offered innovative "wayfinding" systems, including textured handrails and visual cues to help residents navigate around the unit.

"They were very innovative but sensitive to the patient's needs," says Dr. Elizabeth Johnston, the facility's medical director. "There were a lot of really interesting ideas."

While Cummer Lodge doesn't have the budget for sweeping changes, the students'

concepts have sparked a dialogue around what could be implemented as money becomes available.

Meanwhile, the students hope their ideas will spread more broadly, inspiring new thinking about long-term care architecture far beyond Cummer Lodge. To that end, they went above and beyond the course requirements, producing a book that can be downloaded at <http://newsroom.carleton.ca/wp-content/files/aD2-now.pdf>.

"The aim is to challenge current standards and the implementation of ordinary details into unique places with specific needs," Goffi writes in the foreword.

She praises their imagination, their thoroughness and their dedication to the project. "It was a really amazing group to work with," Goffi says. "I really felt they had a sense of purpose."

Contact your closest Family Services Resource Centre to learn more about how making small changes to your environment can help. www.huntingtonsociety.ca or to register contact us at 1-800-998-7398 or email info@huntingtonsociety.ca

Celebrating Our Heroes

Larry and Suzanne Csordas

By Julie Stauffer

Larry and Suzanne Csordas have faced some tough times over the years. First, there were the battles with alcoholism, although both have now been sober for more than 25 years. Next came a 1990 aneurysm that left Larry relearning how to speak and walk. Then, in 1998, Larry was diagnosed with HD.

Suzanne was devastated when they got the news. Although one of Larry's sisters had died of the disease, the family didn't realize it was hereditary. "It was a total shock to me," she says. "I took it really, really, hard as I knew what the family had just been through with Larry's sister. She was in a nursing home at the age of 40 with Huntington disease and passed away at the age of 53 from the disease. I had a lot of fear because so much was unknown."

Early on, Larry suffered from temper outbursts. On one occasion, his difficulties writing a few thank-you cards sent him into a towering rage, only to tearfully apologize to Suzanne the next morning.

"From that point on, we both realized we have to work together on this," she recalls. "One person can't do it on their own."

Larry's family has rallied around, going to the Huntington Society of Canada's local chapter meetings, raising money and escorting him to activities. His sister Margie has dedicated over 50 volunteer hours with HSC in a single year, earning a \$500 donation from her employer.

The local HSC support group was a "godsend," helping them understand and cope with the disease. "We are so thankful to Maiké, our local HSC Resource Centre Director, who is so dedicated and rallies for our well being". Meanwhile, medication has helped Larry keep his emotions under control and calmed his involuntary movements.

Today, the Ontario couple fills their days with laughs, hugs, movie dates and a long list of activities to keep Larry busy.

Retired from his career as a postal carrier, Larry walks their dog two or three times a day to keep fit. He works part-time as a groundskeeper and serves breakfast to the needy every month. He enjoys cribbage and bowling in winter and a steady diet of crosswords and word searches year-round.



On top of that, he's active in their church and regularly goes to events at the local Alzheimer's Society. He and Suzanne are stalwart members of HSC's Niagara Chapter support group, helping newcomers face all the challenges they have overcome.

Best of all, says Larry, are the monthly potlucks with his brothers and sister, followed by poker nights.

Sure, sometimes car keys and can openers go missing. "My left hand doesn't know what the right hand is doing," he laughs. As the years go by, HD will take its toll.

But Larry just focuses on his mantra: stay active and be positive. "One day at a time," he says. "You have to beat it one day at a time."

Larry, Suzanne and their extended family are great examples of how we can all lead our best life. To share your stories of how you lead your best life connect with us on facebook www.facebook.com/huntington SC or twitter @huntingtonSC

Visit our website to view EHDN's new Standards of Care www.huntingtonsociety.ca

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Making a Difference: Kristy Howes

For Kristy Howes, it's a simple equation. Trey Gray is her friend. Trey has Huntington disease (HD). Therefore, she's going to raise money and awareness for the Huntington's cause. "To me, that's what friends do," says the up-and-coming country singer.

Kristy met Trey purely by chance in 2009. Back then, she had a one-song publishing deal and was shooting the music video in Prince George, BC. As it turned out, country superstars Brooks & Dunn were checking into the same hotel.

The duo's bus driver introduced her to Brooks & Dunn drummer Trey Gray, who also works as a music producer. A few minutes of discussion and a 30-second sample of her song, he was sold. "I knew she had it in her within the first few lines," Trey recalls.

In the whirlwind three years that followed, Kristy left her job as a social worker and went to Nashville to record a full-length album with Trey Gray/Littleton Music Group. She has toured North America, opened for Canadian Idol finalist Tara Oram, and her second album is due to be released in Fall 2012.

But the same impulse that led to her initial career in social work impelled Kristy to do something about the disease that was slowly killing her friend and mentor.

"He changed my life. I can't change his, but I can help, and support in whatever way I can," she says. "It's a no-brainer."

Despite her hectic schedule, Kristy has organized two successful walks to raise funds and awareness for HD in her hometown in Northern BC. She has spoken at schools and colleges, taken part in HSC's National Amaryllis Campaign by selling amaryllis kits, held a fundraising house concert in Victoria and performed a Woody Guthrie tribute to 500+ runners at the annual Run for Huntington disease in Toronto this past June.

Music may be her passion, but so is fighting HD — for the sake of Trey, his family and all the "amazing" people she has met within the Huntington's community. "A lot more people are affected by it than we realize," she says. "It breaks my heart."

What's next for the fundraising superstar? "I'm thinking of doing 'Karaoke for a Cure,'" Kristy muses. "Karaoke might be where it's at."



To learn more about how you can start an event, help raise funds or awareness for Huntington disease. Visit the events section of our website www.huntingtonsociety.ca or contact us at 1-800-998-7398 or email volunteer@huntingtonsociety.ca

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A Day Dedicated To Youth

YPAHD Day – November 8, 2012



Calling All Youth! Young People Affected by Huntington Disease (YPAHD) is delighted to announce the first national day dedicated to youth. Hosted at the Intercontinental Hotel (Toronto Centre) the day before the National Conference, this day will focus on connecting, inspiring, and informing youth.

The challenges faced by youth who are affected by Huntington disease (HD) 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. "No matter how supportive your environment and community are, nothing can replace the connection you have when you find someone who is close to your age facing the same questions and circumstances" says Maribeth Meijer, Director of Family Services and Community Development. "Connecting people who are going through similar circumstances and building strong networks

are important for every young person. With HD being a relatively rare disease these networks are particularly crucial." YPAHD is the Huntington Society of Canada's first "virtual" chapter connecting Canadian youth from all geographical areas that are faced with the same questions and life decisions.

"This day is about inspiration and working together to develop strength to find the courage to lead our best life," says Leah Skinner, Vice President YPAHD, "it is about inclusion and discussing the issues that we face as young people who have HD in our lives. We are different from our friends and peers in many ways. This day is dedicated to connecting with each other, learning from each other and allowing ourselves to get that emotional break we all need to move forward. The day is about creating a strong support network that is outside our immediate families".

Thanks to the support of Maxim Power Corp. and the efforts of YPAHD volunteers over this past year for helping to make this day possible. All youth are welcome; please visit www.huntingtonsociety.ca for more information on registration fees, accommodation and travel information. To ensure your spot, please register by September 30, 2012.

To learn more about this special day or to volunteer please check out www.huntingtonsociety.ca or call 1-800-998-7398.

Date: November 8, 2012

Where: Intercontinental Hotel, Toronto, ON

Age Groups: 12–17 and 18–40

Register: www.huntingtonsociety.ca

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