

Ground breaking Canadian Research: Motor symptoms reversed in mice

By Julie Stauffer

We may not have a treatment for Huntington disease yet, but new results by University of Alberta researcher Dr. Simonetta Sipione and McMaster University's Dr. Ray Truant brings us one giant step closer.

Sipione, who holds a Canada Research Chair in the Neurobiology of Huntington disease and Truant, HD Researcher at McMaster University have been able to completely reverse the movement symptoms of HD within a mouse model by injecting a substance called ganglioside GM1 into their brains. "The improvement was dramatic," she says. "We were jumping with excitement in the lab."

GM1 is a type of fat molecule found in cell membranes. It plays a crucial role in the brain, helping cells communicate with one another. Since people with HD have less GM1 than normal, Sipione suspected that boosting the levels of this ganglioside could bring benefits.

"We thought that if we restored the normal levels of these molecules, we would improve symptoms," she explains. "But to be honest, we didn't expect to see complete recovery."

However, a complete recovery is exactly what occurred. Sipione and her team started with five-month-old mice that clearly showed the motor symptoms of HD. After 14 days of treatment with GM1, all the mice recovered normal motor skills. If the researchers deprived the mice of GM1, the symptoms gradually returned.

The discovery still leaves plenty of questions. Because the experiments focused strictly on

motor symptoms, we don't yet know whether GM1 has a similar effect on cognitive skills. Sipione plans to test that in a new set of experiments. Nor do we know precisely why the injections work. Sipione's team, together with McMaster University's Dr. Ray Truant, has found that GM1 adds phosphate "tags" to the mutant huntingtin protein, but it's not clear how that reverses the course of the disease.

"We think GM1 has a number of beneficial effects that target not only mutant huntingtin, but also the way brain cells function and communicate," Sipione says.

Then there's the million-dollar question: can GM1 reverse Huntington's symptoms in people? It will take at least two to three years before clinical trials can be established and this question can be answered. "It takes time to translate the basic discovery to a therapy," Sipione says. On top of that, what works in mice doesn't always work in humans.

That said, GM1 has already been tested in humans as a potential treatment for Parkinson's disease. One small-scale study



showed promising results, and recent trials revealed that GM1 doesn't create any major side effects. This track record could speed up approval for clinical trials of GM1 for HD.

The bottom line? "While we need to be patient to see whether GM1 produces similar results in humans, Dr. Sipione's research creates real reason for optimism," says HSC's CEO and Executive Director Bev Heim-Myers. "We are proud to have supported her work, and we look forward to seeing the clinical trial results."

The full details of the study are published in the February 2012 issue of *The Proceedings of the National Academy of Sciences*. For a no-PhD-required summary, see www.HDBuzz.org.

Celebrating a Quarter Century of Service

By Julie Stauffer

In 1986, when Sandra Funk was seven months pregnant, she saw a job posting for director of the newly opened HSC Manitoba Resource Centre. The position intrigued her, but she figured she had little chance of getting it. Who would want to take on a new employee, only to have her disappear on maternity leave two months later?

The hiring committee, headed up by Ralph Walker, thought differently. They saw an experienced social worker with the talent and skill to lead the new centre. She got the job, and she has held it ever since.

Those early days had challenges, she recalls. She worked on her own, juggling her new job with new motherhood. There was little in the way of information resources back then that she could offer families, and HD specialists were few and far between. And, she laughs, snowdrifts often blocked the windows of her basement office, leaving her in the dark.

On the plus side, a new sense of energy animated the Huntington's community. HSC was establishing resource centres and chapters across the country, while



INSIDE

Welcome to our New Chair.....	3
HSC Launches National Running teamHD.....	3
HD Friendly Recipe from Celebrity Chef Michael Smith.....	5
National Events Schedule.....	6
An Ariel View	8

ISSN 0827-7605

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

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

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

Managing Editor: Cyndy Moffat Forsyth
Editor: Jane Dawkins

Associate Editor: Edward Bird

Layout: Real World Graphic Design

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

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

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

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

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

Charitable Registration #:
11896 5516 RR0001



Note from the CEO

If there's one word that sums up the Society these days, it's momentum. Politicians are working with us, the media is telling our stories, and National Office is a hive of staff and volunteer activity.

In January, the Ontario government reinstated the Special Diet Allowance for people with HD. They read your letters, they listened when we said that weight loss is a biological reality of HD, and they worked with us to better understand and resolve the issue.

Meanwhile, we held very productive meetings with Alberta government relations experts, Alberta government decision makers

and with Genome BC to move forward on genetic fairness in those provinces. Not only are legislators paying close attention to this issue, so is the media. The *Globe and Mail* did a feature article on genetic discrimination in January, turning to the Huntington Society for guidance and expertise. In February, Dr. Michael Hayden, YPAHD member Brynne Stainsby and I were featured on *CBC's The National*, again putting the issue of genetic discrimination on the national stage.

HSC couldn't succeed without our legions of dedicated volunteers. In this issue of *Horizon*, you'll read about how Mike and Vickie Micallef have transformed their home into an accessible space for anyone who strives to make living spaces easy. What the article doesn't tell you is how Vickie has also graciously donated her IT expertise to help with a major undertaking: the redesign of our website and the upgrading of our IT resources. (Stay tuned for more information about that in the months ahead!)

We're also in the process of planning the 2012 HSC National Conference. You'll be hearing plenty more about that soon. We have a few wonderful surprises in store for you, so plan to join us in Toronto on November 9 and 10 this year.

Finally, we're putting the finishing touches on our strategic plan. This truly collaborative vision created by staff, Board members and key stakeholders, will guide our organization over the next three to five years.

It all adds up to an atmosphere of positive energy and achievement. Together, we're making huge strides, together, we're making a difference.

The Huntington Society of Canada's NAVIGATOR research program is supported by the following funds:

Benefactor:
Sun Life Financial



Leadership Partners: AGF Group of Funds; George Weston Ltd.; The Joseph S. Stauffer Company; TELUS Community Connections

Family Fund Partners: Barrett Research Fund; Bloom Family Fund; Rick and Norma Brock Fund; The Kelly Bumstead Family Fund; Chaplin Family Fund; Cranston-Dorr Family Fund; Annie J. Cutler Memorial Fund; Barbara Dorr Research Fund; Goodman Family Fund; Irwin Family Fund; McArthur Family Fund in memory of Megan McArthur; Reklitis Family Fund; Garth Shuster Family Fund; Skene/Stevens Family Fund; Skeoch Family Fund; Sterling Family Fund; Wright Family Fund in memory of Helen-Mary Wright; Yeung Family Fund



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!

Anne Brace: Passion and Vision

The new chair of HSC's Board of Directors radiates energy and drive. It's what propelled her to executive ranks in the corporate world, where she served as chief financial officer of an IT distribution company, and what has made her such a valuable member of our Board for the past eight years. Now, she brings those same qualities to her new role as chair.

"I have a lot of passion for this," says Anne. No surprise, given that she watched her mother pass away from Huntington's. Rather than dwell on the devastation of HD, however, she prefers to focus on what can be achieved.

Talking with researchers at the HD World Congress in Australia last year has left her distinctly optimistic about the future. "They are some of the smartest people in the whole world," she says. "They are so committed to this. You can't help but believe there's hope for us when you're exposed to these people."

Indeed, Anne believes treatments are close enough that the Society needs concrete plans for how to deal with that day when it arrives. "It's not something that's going to happen overnight," she cautions. "Drugs may work in some people but not others" she says "or delay some aspects of Huntington's but not others. A treatment will happen, and HSC will need to be prepared."

In the coming years, Anne and the Board plan to stay focussed on key priorities for HSC. We need to continue to invest in research, of course: "If we're not involved in research, there is no cure," she says. At the same time, though, we have to meet the immediate needs of families. To do this, the Society plans to expand family services into underserved areas, create more multi-disciplinary clinics and examine new ways to deliver services.

Advocating for genetic fairness will continue to be important, along with engaging youth

through Young People Affected by Huntington Disease (YPAHD) and the new international Huntington's Disease Youth Organization (HDYO).

How will we fund all of this? One way, says Anne, is partnering with other health charities. Because relatively few Canadians are touched by HD, reaching out to other organizations helps us tap into a bigger donor base. The benefit isn't one-sided, however: scientists agree that finding treatments for Huntington's will create a domino effect of treatments for other diseases such as Parkinson's, ALS and Alzheimer's.

It's a jam-packed agenda, but Anne believes HSC has the capacity and the commitment to achieve our goals. "It's a great organization," she says. "I'm excited about what we can accomplish as a group and where we're going to go."

The Power of Volunteering



There are lots of reasons why people choose to volunteer their time, from wanting to make a contribution to the community, to meeting new people and making friends, to gaining experience and new skills for career

development, to giving back to an organization that supports a cause that personally affects one's life.

For Carla, who has been volunteering at The Huntington Society of Canada's National Office since 2007, volunteering has been an extremely empowering experience. This is one of the ways Carla chooses to **lead her best life!**

"It feels good to be able to help in any way I can" says Carla. She has been diligently volunteering once or twice a week for the past 4 years, helping out in HSC'S Administration department. "Carla's support is invaluable!" says Shirley Barnes, Office Administrator "We look forward to her coming into the office each week."

Prior to coming to HSC, Carla had to give up a career she loved because of Huntington disease. Volunteering helps her contribute, in a meaningful way and keeps her brain active. Perhaps most importantly, it gets her out of the house regularly. "Sometimes if you don't have anything to wake up for, you can get very down," she explains. Plus, she adds, she gets to work with a great team at National Office. "The people there are awesome," she says. "They're a cut above."

April 15th-21, 2012 is National Volunteer Week. The Huntington Society of Canada would like to thank each and every one of our volunteers across the country. We deeply appreciate your hard work & dedication. Thank you!

TeamHD – HSC Launches National Running Team!

If you're ready to lace up your runners, hit the pavement and support a great cause, we want you on teamHD.

Each year, running events across Canada help raise thousands of dollars for the Huntington Society of Canada. In some cases, it's money from events organized by HSC chapters. In other cases, Huntington's community members participate in third-party runs such as the Scotiabank Calgary Marathon or the Niagara Falls International Marathon.

"We were looking to unite our runners across the country," explains Pamela Blackmore, HSC's Coordinator of National Events and Chapter Development. "The idea is to create more visibility for the Huntington's cause and make fundraising as easy as possible while attracting new supporters from the running community. So far everyone is very excited about it."

Whether you're gearing up for a marathon, running in your very first three-kilometre fun run, or aiming to log 10 km on the treadmill every week, you're invited join the team.





The Gardening Prescription

By Julie Stauffer

Want to do your mind and body some good? Get a little dirt underneath your fingernails. According to Kitchener, ON horticultural therapist Cathy Desmond, gardening brings all kinds of benefits.

First of all, there's the mental lift. You don't need a PhD to recognize that inhaling the scent of a rose or picking a sun-warmed tomato fresh from the vine can make you feel happy, but researchers confirm it: contact with nature improves your mood.

Next, there's the exercise. Gardening gets you moving around as vigorously or as gently as you want, whether it's digging a bed for potatoes or simply putting bulbs in pots.

Gardening also brings cognitive benefits, according to Cathy, because it stimulates your brain in many different ways. "You use all of the senses," she says. "the smell of the flowers, the feeling of moisture in the air, the sounds of the water as you're watering the flowers, the feel of sunlight on your face."

Studies show that nature has healing powers. Hospital patients who see greenery outside their window recover faster from operations than patients who face a brick wall.

Finally, there's the fact that although Huntington's robs people of many things, gardening remains within reach long into the course of the disease. Even in relatively advanced stages of HD, people can still plant, water, weed and see the results of their labours.

"It builds confidence and self-esteem," says Cathy. "It helps people to feel better about themselves and about life in general." And if something goes wrong, well, that's OK. Many plants will come back of their own accord, nature is forgiving. Other plants can simply be replaced.

So how do you make gardening accessible in the face of HD? For outdoor gardening, Cathy recommends raised beds. These bring the soil to the gardener rather than forcing the gardener to bend and stoop. Be sure to plan pathways that are wide enough to accommodate a wheelchair and a wheelbarrow at the same time. Incorporate seating so that you can pause for a rest, and

make beds narrow enough that the centre lies within arm's reach.

You'll find helpful tips on accessible gardening on the Lee Valley website www.leevalley.com along with ergonomically designed, easy-grip tools and telescoping tools that help gardeners in wheelchairs or walkers reach where they need.

No access to garden space? Use containers to bring nature indoors, Cathy suggests. Pots or hanging baskets can fit on patios or balconies or in a sunny window. Just put hanging baskets on a pulley system so they can be lowered for tending and watering.

As for those long Canadian winters, bring greenery indoors. By forcing bulbs or even branches, you can be enjoying blooms like amaryllis, hyacinth, forsythia, magnolia and crab apple despite the blizzards outside.

Cathy's tips for gardening with HD

1. Keep sessions short enough that you don't get tired.
2. Choose tasks that suit your abilities. Trying to plant seeds may be frustrating if you have involuntary movements, for example, but planting bulbs is much more manageable. They are easier to work with and plants will still grow even if they are planted on their side.
3. Follow your interests. Some gardeners love the satisfaction of putting food on the table. Others revel in flowers or plants that attract birds to their garden. Similarly, figure out which tasks you enjoy. Yanking out weeds or smashing broken pots can be an excellent outlet for anger.
4. Create a garden space that appeals to all the senses. Incorporate plenty of colour, texture, scent and taste.
5. Remove any sense of pressure. "If it takes longer, that's all right," says Cathy. "There's no time limit on this."

A Ray of Hope

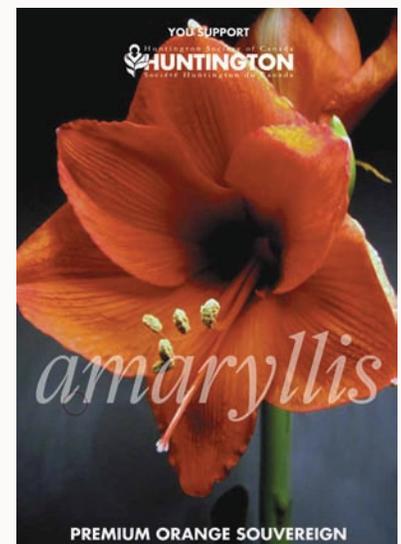
Carl Van Noort knows all about the joys of watching plants grow. After all, it's the family business. For more than 80 years, B.C.-based Van Noort Bulb Company has been importing, growing and distributing flower bulbs and perennials that brighten gardens across the country.

Among them are thousands of Amaryllis bulbs destined for the Huntington Society of Canada's signature fundraising campaign. Since 2004, Van Noort Bulb Company has been importing Orange Sovereign bulbs from Holland and packaging them up each fall, ready to be sold to HSC supporters across the country.

Although no one in the Van Noort family is affected by HD, Carl takes pride in helping to drive the hunt for treatments. "From a company point of view, it's nice to be able to support a cause like Huntington's," he says. "Hopefully we'll have a solution to the problem, and the only way that that is going to happen is if funds become available to do research."

He sees the Amaryllis as a perfect fundraising symbol, blooming during the darkest days of winter and offering a promise that spring lies just around the corner. "It's like a ray of sunshine," he says. "It's a ray of hope."

HSC's Annual Amaryllis Campaign improves the lives of Canadians across the country that are living with the affects of Huntington disease each and every day. Volunteers interested in selling Amaryllis in 2012 can sign up or submit pre-orders as early as May 1, 2012. For more information please contact us at amaryllis@huntingtonsociety.ca or visit www.inspirehope.ca.



Nutrition Does a Body Good: Eating well with HD

By Julie Stauffer

Health and diet go hand in hand. But when it comes to Huntington's, eating right has a few special challenges.

Because the disease affects the movements involved in chewing and swallowing, it makes eating more difficult. Not only that, for reasons scientists don't fully understand, HD causes people to burn more energy. People with Huntington's may need as much as 5,000 to 6,000 calories a day to maintain a healthy body weight.

Since consuming so much takes a concentrated effort, people with HD are often underweight. So how do you stay at a healthy weight and give your body the nutrition it needs?

Cramming in the calories

Look for foods that give you the most bang for your buck, advises Chrissie Ohlund, a registered dietitian who works with clients who have Huntington's at the Evergreen Hamlets adult care community in Surrey, B.C.

She recommends using energy-dense additives like butter, sour cream and whipped

cream, as well as high-protein options like beans, lentils, nuts, seeds and tofu.

Take a pass on the chips and pop, however. "You don't want to be consuming empty calories," Chrissie says. "You want to be getting your nutrients and vitamins and minerals as well." Finally, she suggests, round out your diet with whole grains and plenty of vegetables.

Producing appetizing purées

As the disease progresses and choking becomes a bigger risk, pay careful attention to texture. Add thickeners to liquids to make them easier to swallow, and purée solids.

The trick to producing appetizing purées is paying attention to flavour. "You need to make sure that your diet for the purée is just as palatable and has just as good a taste as a regular diet would," Chrissie says. Think about mimicking the flavour of favourite foods you are used to eating.

If you need to add a little liquid to purée certain foods, don't use water, Chrissie says. Instead, opt for things that enhance flavour and add extra calories such as milk, butter or broth. It takes a little practice to get things

right, but don't be afraid to experiment.

From plate to mouth

As involuntary movements and swallowing issues get worse, feeding techniques become just as important as good nutrition in maintaining a healthy weight. For people who need help to eat, patience is key. Create a quiet, calm atmosphere, Chrissie says, and take plenty of time to avoid any risk of choking.

Feeding the whole family

While people with HD need plenty of calories, foods laden with butter and cream aren't so healthy for the rest of the family. The good news is there are ways to ensure everyone gets the meals they need without spending every night preparing separate menus.

Add calorie-dense toppings after everyone else has been served, Chrissie suggests. You can cook the same oatmeal for everyone, for example, but stir in cream or full-fat yoghurt when you're dishing up a bowl for the person with HD. Nutritional supplements like Ensure or Carnation Instant Breakfast are another quick way to boost calorie intake.

It takes a little extra preparation and planning to meet everyone's needs, but caregivers shouldn't shortchange their own health needs. "You want to make sure that your caregiver is getting a good diet," says Chrissie. "being a caregiver is a lot of work and it is important to keep yourself energized".



Extra-Green Soup with Spinach, Broccoli, Peas, Parsley, and Green Onions

From "Chef Michael Smith's Kitchen" ©2011

Sometimes nutrition gets a bad rap in the flavour department, but this soup proves that healthful also means flavourful. It shows off the incredible nutritional density of dark green vegetables while revealing the aromatic flavours of these vital foods. It's as fun to eat as it is to look at!

Serves 4

- 2 tablespoons (30 mL) of olive oil
- 4 garlic cloves, thinly sliced
- 1 large onion, diced
- 4 green onions, green and white parts sliced separately
- 3 cups (750 mL) of chicken broth, vegetable broth, or water
- 1 cup (250 mL) of whipping cream
- 1 bunch of broccoli, cut into small florets, tough stem peeled and thinly sliced

- 1 cup (250 mL) of fresh or frozen peas
- 1 tablespoon (15 mL) of fresh thyme leaves, or 1 teaspoon (5 mL) dried
- 6 ounces (175 g) of baby spinach
- 1 bunch of parsley, tougher stems discarded
 - A sprinkle or two of salt and lots of freshly ground pepper

Splash the olive oil into your favourite soup pot and heat it over medium-high heat. Toss in the garlic, onions, and the white part of the green onions. Sauté until the onions are tender but not brown, about 5 minutes. Pour in the broth and cream and bring to a simmer. Add the broccoli, peas, and thyme and simmer just until the broccoli is tender but still bright green, another 4 or 5 minutes. This will give the hardier vegetables a chance to cook before you add the more delicate ones.

Stir in the baby spinach, parsley, and green onion tops. Cook for just another minute or so

until the spinach wilts and turns bright green. Season to your taste with salt and pepper.

At this point you may serve the soup as is, but if you have finicky eaters who don't like to see their green vegetables whole, purée the soup in a blender or food processor or with an immersion blender. For the smoothest results, strain the soup through your finest strainer. Serve and share!

Kitchen Tip

Green vegetables are some of the healthiest possible foods you can eat, and the darker the green, the better. They're low in calories and fat, high in fibre, and packed with a laundry list of nutrients such as folic acid, vitamin C, potassium, magnesium, and various antioxidants and phytochemicals. A diet rich in green veggies has been proven to reduce the risk of many different cancers, improve vision, and strengthen your bones. Bottom line? Extra-green soup for all!

Events Calendar: Coming to your Neighbourhood Soon!

Join us, to help raise funds and awareness for HD! For a complete list of all HSC events across Canada, visit the Events & Pledging section of our website at www.huntingtonsociety.ca

April

April 16 - 21

Niagara Book Sale

St. Catharines, ON
Fairview Mall

Semi-annual fundraiser, Mon-Fri, 9 am to 9 pm, Sat 10 am to 4 pm. For more info call Gail at (905) 892-6024 or email at ngdekon@sympatico.ca

April 21

A Night To Flourish

Calgary, AB
Calgary Italian Club

Cocktails 6 pm. Dinner 7 pm. Cash bar. Tickets \$125. For more info call Tara at (403) 861-5730 or email tarajo@shaw.ca

April 26

Saskatchewan Walk to Cure HD

Wawota, SK
11 Thatcher Avenue

Registration 4 pm, Walk 4:15 pm. For more info call (306) 739-2237 or email wwtchd@gmail.com

We invite all of Saskatchewan to unite in the fight against HD! Plan your own walk in your local area and help us raise much needed funding for social services and research. Last year we were up to 5 locations, this year lets make it more!

May

May 6

Celebrating our Canadian Families Day

All Across Canada

Name that Day – Huntington Awareness Month Contest!

On Sunday May 6th, HSC is launching a day to Celebrate Our Extraordinary Families – a day where we encourage families and loved ones to spend time together. The genetic nature of Huntington's puts families at the heart of HSC. As part of this national celebration, HSC will be asking families to share their stories with the community to educate and increase awareness.

We need YOUR help to name this very important day! The winner will receive Airfare, Accommodation, & Registration for the 2012 National

May 6

14th Annual Architectural Gems of Toronto Walk

Toronto, ON

Starting location: urban park opposite the Royal Alexandra Theatre at 260 King St. W

Walking tours of the *Downtown West* neighbourhood. Registration 4pm, walking tours 2 pm, social gathering 3:30 pm. For more info call Jim at (416) 809-2469 or email gems@hdtoronto.org

Web: www.huntingtonsociety.ca, Events & Pledging section

May 12

5th Annual Run to Finish Huntington Disease

Vernon, BC
Kin Beach Park

Options include 1 km walk, 5 km walk or run. Registration 8 am, Run 9 am. Early bird entry fees until March 15th: Run \$20, Walk \$10. For more info call Dan at (250) 766-5527 or email hscokanagan@yahoo.ca

Web: www.teamHD.ca

May 26

Walk to Cure Huntington Disease

Edmonton, AB
Emily Murphy Park

Registration 1 pm, Walk 2 pm, Social 3 pm. For more info call Joan at (780) 352-7937 or email littledinosaur4jc@hotmail.com

Web: www.huntingtonsociety.ca, Events & Pledging section

May 26

Walk to Cure Huntington Disease

Peterborough, ON
City Hall

Registration 9 am. For more info call Bev O'Connor at (705) 742-2294 or email walk@hdpeterborough.org

Web: www.teamHD.ca

May 26 & 27

Ottawa Race Weekend

Ottawa, ON

Join TeamHD and the 2012 Running Challenge. Run for a reason!

Options include marathon, ½ marathon, 10k, 5k, 2k, Y kids marathon & wheelchair marathon. For more info contact Ray at (613) 741-0282 or email raybailey209@gmail.com

Web: www.teamHD.ca

May 26 & 27

Scotiabank Calgary Marathon

Calgary, AB

Join TeamHD and the 2012 Running Challenge. Run for a reason!

Options include marathon, ½ marathon, 10k, 5k, & kids marathon. HSC is a registered charity. For more info call Melissa at (403) 903-5259 or email lingard.mel@gmail.com

Web: www.teamHD.ca

June

June 2

6th Annual Exeter Hike for Huntington's

Exeter (London region), ON
McNaughton Park

Sponsored by the Knights of Columbus. Registration 9:30 am, Walk 10 am. For more info call Herman Steffens at (519) 237-3719 or Don O'Rourke at (519) 235-1558.

Web: www.huntingtonsociety.ca, Events & Pledging section

The Huntington Society of Canada
is a proud supporter of



HUNTINGTON'S DISEASE
YOUTH ORGANIZATION

To learn more
please visit www.hydo.org

Looking to get involved? To volunteer, participate or if you have an event idea please contact us.

To volunteer please email volunteer@huntingtonsociety.ca, for event suggestion please email events@huntingtonsociety.ca or call 1-800-998-7398

June 2



2nd Annual Hope for a Cure for HD

Grand River Region – Cambridge, Guelph, Kitchener, Waterloo, ON
Waterloo Park

Join TeamHD and the 2012 Running Challenge. Run for a reason!

Registration 10 am, Run 11 am, 5k run/walk. For more info call Susan at (519) 267-8222 or email susanbridges@comfortkeepers.ca

Web: www.teamHD.ca

June 2



5th Annual Saskatchewan Walk to Cure HD

Saskatoon, SK
Meewasin Trail, University of Saskatchewan

Registration 9:30 am, Walk 10 am. For more info call June at (306) 997-2052.

We invite all of Saskatchewan to unite in the fight against HD! Plan your own walk in your local area and help us raise much needed funding for social services and research. Last year we were up to 5 locations, this year lets make it more!

Web: www.huntingtonsociety.ca, Events & Pledging section

June 3



17th Annual Golf Tournament

Brandon, MB
Glen Lea Golf Course

Two person best ball, men, ladies & mixed divisions. For more info call Cam or Sandy at (204) 724-0534.

June 9



Run 2 Finish Huntington Disease

Winnipeg, MB
Assiniboine Park, Duck Pond Shelter

Options include 10k run, 5k run, or 5k walk. Registration 8 am, Start 9 am. Pancake breakfast free to all participants. For more info call Jeff (204) 668-8703 or email huntingtonrun@gmail.com or Vern (204) 694-1779, email vbarrett@mts.net

June 9



Indy Go-Kart Challenge

Burlington, PEI
Burlington Amusement Park

Join us for a fun family day, 9:30 am to 12 noon. For more info call Stephen Hurst (902) 888-3013 or email s.hurst@pei.sympatico.ca

June 16



HSC NATIONAL SYMPOSIUM Courage to Lead Your Best Life

Join us for a national teleconference with Dr. Ed Wild, from London, England, as he presents on how to optimize life when living with HD.

At multiple locations across Canada including: Victoria, BC • Grande Prairie, AB • Winnipeg, MB • Sudbury, ON • London, ON • Halifax, NS • Moncton, NB

For more info call 1-800-998-7398.

Web: www.hscsymposium.ca

This event is sponsored by Assumption Life.

June 16



HOPE for a Cure Run & Walk

Calgary, AB
Glenmore Park, Snowy Owl Picnic Site

4th Annual 8k Run, 5k Run, or 5k Walk. For more information call Arlene at (403) 249-4258 or email darowan@shaw.ca Web: To find out more about this event or to pledge online, please visit the Events section of our website at www.huntingtonsociety.ca

June 24



Run for Huntington Disease

Toronto, ON
Sunnybrook Park, Wilket Creek

Options include 10 km Run, 5 km Run, or 5 km Walk. Registration 8 am, 10 km run 9:40 am, 5 km run & walk 10 am. For more info call Tim at (647) 238-6294 or email run@hdtoronto.ca

Web: www.teamHD.ca

August

August 22



Cameron Golf Tournament

Toronto, ON
Deer Creek Golf & Banquet Facility

In partnership with Cameron & Associates. Join us for a great day of golf, games, dinner, and a silent auction. For more info call Kim at (416) 529-4340 or email kim_cameron@rogers.com

August 25

3rd Annual HD Ride 4 a Cure Trail Ride

Grande Prairie, AB

Bring your horse, jump in a wagon, or just come down for a drink and dance the evening away! For more info call Mack at (780) 897-8048 or email mack@jadecash.com

Web: www.huntingtonsociety.ca, Events & Pledging section

September

September 9



Indy Go-Kart Challenge

Winnipeg, MB
Thunder Rapids Fun Park, Headingley

Join us for a great day full of fun and prizes! For more info contact Vern at (204) 694-1779 or email vbarrett@mts.net

Web: www.huntingtonsociety.ca, Events & Pledging section

September 9



Indy Go-Kart Challenge

Halifax, NS
Atlantic Playland, Hammonds Plains

Join us for a great day of full of fun for the entire family! For more info contact Jim at (902) 445-3516 or email jimrussell@eastlink.ca

Web: www.huntingtonsociety.ca, Events & Pledging section

September 30



Hike 4 Huntington's

North Vancouver, BC
Lower Seymour Conservation Reserve

Registration 8:30 am, Entertainment & warm-up 9:15 am, Hike 10 am, BBQ 11 am. For more information contact Diane at (604) 596-6615 or email dianetullson@hotmail.com

Web: www.huntingtonsociety.ca, Events & Pledging section

YPAHD Young people affected by huntington disease



New website launching in 2012
www.ypahd.ca

Education/
Information Days

Golf
Tournament



TeamHD



Go-Kart Indy



HD Run

An Ariel View By Ariel Walker

The arrival of spring always inspires me to clean house. There's something about the fresh breezes and new life that makes me want to clear away the clutter. Thanks to HSC, however, I started my annual cleaning early this year.

A couple of months ago, National Office called me, wondering if I might have some of the early issues of *Horizon*. Down to the basement I went and hauled out the boxes and binders where I keep the old Society documents. Let me tell you, looking through it all brought back a ton of memories!

I was especially delighted to discover a letter to Ralph from Stan Weber. For long-time HSC members, the name Weber will be very familiar. Stan's mother, Shirley, was an important force behind the Calgary chapter and supported many families in their struggles with HD.

Stan's father, Jerry, was a major supporter of the Society and a member of the Board for many years. Jerry was a great guy: kind, thoughtful and generous. Ralph stayed at his home many times when he visited Calgary, and

Jerry often organized wonderful dinners after Board meetings and AGMs. As the president of Cardinal Coach Lines, Jerry also had a lot of valuable business experience to share with our growing organization.

Stan's 1987 letter included a copy of a picture showing a ship's captain and a second sailor, both dressed in oilskins, holding the tiller as waves wash over the deck. On the back, he explained how the picture had hung in Jerry's office for many years and reflected Jerry's philosophy. It came with a message that Stan copied out.

"To the clipper captains of yesterday," it begins, "foul weather meant sharp sailing with decks awash, taunt rigging, prow deep in spray. They conquered storms with seamanship, bleak skies with iron hearts and brave spirits."

I don't have to tell you how many storms and how much foul weather Huntington's can create. But when I look at the Society today, I'm astounded at what we've accomplished through strength, determination and brave spirits. So

many people, like Jerry, have put their shoulder to the helm to help this Society grow and to support one another through rough times.

Today, I think the message is just as relevant as it was in the 1930s, when Jerry's father first hung it on the wall. It finishes off by saying, "Plant both feet squarely before the wheel and, with vision that looks beyond the turbulent waters of today, bring your ship safely to port."

Jerry passed away in 1996, but I see his philosophy in action every day within the Huntington's community. When times are tough, hang in there. When you see someone who is feeling discouraged, give them a hand. Together, we can stay the course.



Ariel

Celebrating a Quarter Century of Service

continued from page 1

scientists were honing in on the HD gene. Shortly after Sandra joined the Society, predictive testing was introduced. "It was an exciting time," she says. "It was all gearing up."

Since then, we've seen dramatic changes. Today, potential treatments are moving into clinical trials. Doctors have a much better understanding of the disease, and there are more drugs available to deal with symptoms. Couples who want to have children have many options available. And because HSC is now triple the size it was in 1986, we're able to do far more.

Of course, many things haven't changed. Despite the plethora of information now available online, Sandra still spends a lot of time helping families come to terms with what HD means for them. "You can get bombarded with information on the Internet," she says. "I think the personal connection makes it easier to start learning about the disease by asking questions that are pertinent to them in their particular place and time."

On top of one-on-one counselling, there are always support groups to run, crisis calls to deal with, presentations to make and healthcare professionals to educate. What keeps her going in a field where burnout is a real danger? Partly, she says, it's the people she serves.

"Because it's such an all-encompassing and devastating disease, people really open up to the Huntington social worker," she explains. She gets to know individuals and families on a very personal level and shares their ups and downs, decade after decade.

"It's given me a lot of strength to see what families have been able to endure and still live happy, productive, satisfying lives," she says.

Her colleagues across the country provide another source of strength. "HSC has a wonderful group of social workers," she says. "Everybody works together. We're all here for the same cause."

And there's no question that they're making an impact. Today, she's getting calls from people in their 20s looking for support who start the conversation by saying "I remember how much you helped Mom." "There really isn't another resource in the community that can do what we do," Sandra says.

Although she has clocked more than a quarter century of service, Sandra has no plans to retire in the near future. "I still find it very satisfying," she says. "There's always a bit of newness and challenge."

That's good news for Manitoba families living with HD, and for the Huntington's community across Canada.

"Huntington's is an extraordinarily complex disease, so having someone with Sandra's depth of knowledge and experience makes a big difference to the whole family services team," says Maribeth Meijer, HSC's Director of Family Services and Community Development. "Working with her is a real privilege."

Saturday, April 21, 2012

(formerly Achieve)

A Night to Flourish

Calgary Italian Club

For further information or to purchase tickets please call (403) 861-5730 or email tarajo@shaw.ca

Enroll-HD

A Prospective Registry Study
in a GlobalHD Cohort





Jane Dawkins: Creating Emotional Connections

"If you tap into what moves people," says HSC's new

Communications Coordinator, Jane Dawkins, "you will have their attention." Throughout her career, Jane has put this philosophy to good use.

In her previous role at Beardmore Leathers, she concentrated on marketing strategies that touched her customers emotionally, as well as developing an easy-to-navigate website and attention-getting e-blasts.

After 12 years at the family business, however, she was ready for a new challenge. "I wanted to move into something where you are sharing information rather than making a sale," she says. "It's a different conversation that you're having with people, and it's a lot more meaningful."

There's been plenty to learn. The non-profit sector speaks an entirely different marketing language from the manufacturing sector, but that's just fine by the newest member of our communications team. "I do best when I'm constantly learning," Jane says. "That's what I enjoy."

At the same time, Jane has plenty to offer the Huntington Society, including branding know-how. "By making our look and

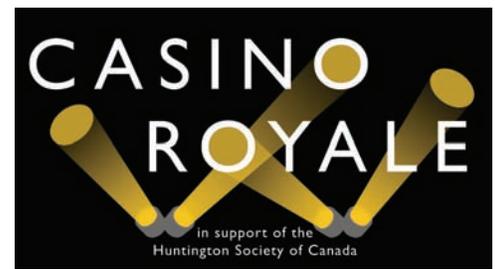
messaging as consistent as possible", she says, "we can build more recognition for HSC and create more momentum around our cause". That's why, in conjunction with the Director of Marketing, she's involved in developing branding toolkits and communication strategies to help ensure a consistent look and feel for the society.

She also brings social media savvy. "I've fallen back in love with Facebook," Jane laughs. She sees it as an important tool for the organization that goes far beyond racking up "likes" or "shares." Instead, it's about deepening connections with families and donors. "It's another way for us to be there every day for people," she explains.

She'll have plenty of opportunity to put her skills and experience to work in the months ahead. With the Spring Symposium, Fall National Conference and HSC's 40th anniversary coming up quickly, the communications department is a busy place these days.

"There's so many creative projects for those events that I'm working on that I'm excited about," says Jane. "So far it's been amazing."

To join the conversation, share your stories as well as daily updates on HD research news and HSC'S events find us on facebook by searching "Huntington Society of Canada"



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

High Roller

VALEANT
Valiant Canada limitée / Limited

Media Sponsor

NEWSTALK 1010

Gaming Tables

EVANS INVESTMENT COUNSEL

CAMERON ASSOCIATES
Insurance Consultants

BLACKSTONE SOLAR INC

JOSHUA GOLD
RESOURCES

AMAZINGLY GREEN

Casino Host

NORTHLAND POWER

CAD

Players

The MILLS
THE GOLF AND COUNTRY CLUB

HIGHLAND PISTONCRAFT
A FORD DEALER

TRC
Transatlantic
Reinsurance Company

B3

STRONE
Commercial Construction

NORTRAX
CORPORATION

SHININGTREE RESOURCES INC.

ToolBox

GORDMAN, GORDMAN & GAE
ATTORNEYS AT LAW

BORDEN LADNER GERRARD

AVG
division of quest



Individually, Canada's national health charities accomplish a lot. But bring them together, says new National Executive Director for Healthpartners, Eileen Dooley, and they can accomplish even more.

The alliance of 16 national organizations, including the Huntington Society of Canada, raises money and awareness for its members through campaigns in federal government workplaces. This collaborative approach has proved enormously powerful.

Because Healthpartners represents many different causes, chances are good that everyone has either personally benefitted from the work of a Healthpartners member or knows someone who has.

Accomplishing More Together

"Our members, through the dollars they've invested in research, in testing out different models of support, have had an incredibly positive impact on the lives of Canadians," says Eileen.

On top of that, Healthpartners makes giving easy. Instead of being forced to choose between many important health causes, donors can support 16 charities with a single donation. As a result, the organization has been able to raise millions of dollars for its members each year.

"Government employees have been incredibly generous in every province across the country," Eileen says.

Now, Healthpartners is planning to build on this success by reaching into other workplaces.

It's an ambitious undertaking, but Eileen is confident that the mission of Healthpartners – supporting excellence in health research, services and programs – will resonate with a broader range of donors.

The Huntington's community can help. Tell your friends and colleagues about Healthpartners, and if you know of a workplace that might be receptive to a Healthpartners campaign, please let us know. Contact us at 1-800-998-7398 or info@huntingtonsociety.ca.

PREDICT-HD:
A Huntington disease study for presymptomatic volunteers

www.predict-hd.net predict-hd@uiowa.edu
Phone: (U.S. #) 319-353-4307

Celebrating Our Heroes

Easy Living: How one Mississauga couple designed their condo for accessibility and independence

By Julie Stauffer

Mike and Vickie Micallef's Mississauga condo may be designed with Mike's HD in mind, but you won't find a plastic bath seat or pressboard wheelchair ramps anywhere within the stylish two-bedroom unit.

"Elegant," is how he sums up the marriage of functionality, beauty and accessibility they created over the course of three



months of renovations. "Everything here has a reason."

The wide doorways create a sense of space and openness, but can also accommodate a wheelchair or walker. (Or, as Vickie points out, a baby stroller or returning traveller loaded down with luggage.) Meanwhile, the levered door handles are easy to grasp.

In the bathroom, seamless, solid glass shower panels provide support in case of falls. Instead of a single showerhead, an overhead spray, six adjustable body sprays and an extendable hand shower make bathing easy, even for someone with limited mobility.

The second bedroom, which currently does double duty as an office and exercise room, can be easily transformed into a room for a live-in caregiver, complete with en-suite bathroom.

Meanwhile, the kitchen comes loaded with features to delight any cook. The oven is waist-high: no need for bending and leaning. The smooth cooktop is a cinch to clean. Below counter height, the Micallefs have replaced doors with drawers that slide out to display their contents. "You can see everything," says Vickie. "It makes life a lot easier."

Renovating the condo didn't come cheap. The Micallefs stripped the 1,080-square-foot apartment down to the studs, replacing everything from the flooring on up. However, Mike contends it was a smart financial move.

By incorporating energy efficiency into their redesign, they've slashed their heating and electricity costs. All their appliances have earned an Energy Star rating, while the Micallefs traded their old 50-watt halogen lighting for six-watt LEDs.

More importantly, the renovations allow Mike to continue living at home even as his symptoms get worse. "Consider that the average nursing home room in Toronto costs \$43,000 a year", he says, "our renovations cost less than twice that. If I am able to live at home for just two extra years, their investment has paid off in financial terms."

If Mike has his way, the Micallefs' barrier-free approach to design will be replicated in millions of households here and abroad. Accessible housing makes life better not just for people with HD but for everyone from couples with young children to older people contending with arthritis and other ailments.

Guiding the Future: You and the Ralph and Ariel Walker Summit Society

Throughout our lives, we give many gifts. We make a difference by supporting the causes and people that matter most to us. And that doesn't have to end when we pass away. With a little planning now, you can continue to make a difference long after you are gone.

Leaving a charitable gift to the Huntington Society in your Will is a powerful way to help the Huntington Society continue to support families, fund research, and educate future generations about the disease. By making a planned gift to the Society, you also become part of the Ralph and Ariel Walker Summit Society, honouring the legacy of our founders.

It's easier than you might think. The Huntington Society of Canada is ready to help you with these plans and ensure that your wishes for you and your family are

carried out. Or perhaps you've already set up a gift to HSC in your will. In that case, we'd love to know so that we have an opportunity to thank you.

Over the past 5 years HSC has received almost a half a million dollars from those who have created a charitable gift in their Will. These gifts help us provide quality programs and services to people affected by HD and preserve the memory of our generous supporters.

To receive more information about this special way to support HSC, please contact us at 1-800-998-7398 or email info@huntingtonsociety.ca. We will discuss the steps with you to make sure your estate wishes can be honoured and the example of your generosity preserved.



SAVE THE DATE:
HSC National Conference
November 9th-10th, 2012!

The HSC Conference committee is working hard to make the 2012 Conference a smash hit! Join us for a fantastic weekend of education, building our HD team and fun! The conference will be held at the Intercontinental Hotel, Toronto Centre, just steps away from Rogers Centre, Air Canada Centre, the CN Tower and all Toronto has to offer! For more information and to volunteer, please contact us at 1.800.998.7398 or email us at volunteer@huntingtonsociety.ca

Conference Keynote Speaker:
Dr. Marcy MacDonald, Harvard University.

Special YPAHD Day – November 8th:

For the first time ever "YPAHD Day" will be held on November 8th providing an opportunity for young people to connect even before the conference begins. A day for young people affected by HD, created by young people affected by HD (YPAHD). This day will be full of fun, networking, and information, with age appropriate streams for ages 14 to 29 (and the young at heart).



HSC Spring Symposium June 16th, 2012!

Please join Dr. Ed Wild, neurologist and co-founder of HDBuzz.net, for a riveting presentation that is full of wisdom. Optimizing life is the primary focus of Dr. Wild's message. He will explore the good news and how we can prepare for the journey; what we can do to make a difference now, and what we can do to make the most of the support available, maximizing our independence. "Optimizing life" with HD means staying active, informed and involved. Join Dr. Wild as he helps us to see what we can do and how we can do it. Contact us for city locations near you!

For more information www.hscsymposium.ca or call Toll free: 1-800-998-7398

R E T U R N F O R M

2200

- Enclosed is my donation of \$ _____ to further the fight against Huntington disease.
- I would like to remain anonymous

Please send me more information on the following programs:

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

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

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

Thank you

Method of Payment:

- Cheque Visa Mastercard

Credit Card # : _____

Expiry Date : _____ Signature : _____

Or to donate online please visit go to www.huntingtonsociety.ca

Name: _____

Address: _____

City : _____ Province: _____

Postal Code: _____ Phone #: _____

Email: _____

Please note my change of address:

 Effective : _____

Dear HSC,

I have heard that certain foods like blueberries, strawberries and fish oil contain natural compounds that may be beneficial to people with Huntington disease. I was wondering if this is true?

*Sincerely,
Hungry for a Cure in Kingston, ON*

Dear Hungry for a Cure,

Yes, there has been a lot of intriguing research into foods that might slow down the progress of HD.

One study showed that a diet rich in blueberries can reverse some of the declines that happen in ageing rat brains. Another suggested that omega 3 oils helps prevent the kind of protein misfolding that occurs in Huntington disease. Most recently, a team of researchers showed that a compound called fisetin found in strawberries could prevent cell death in a mouse model of Huntington disease.

According to Dr. Ed Wild, the co-editor of HDBuzz, the research is sound. But – and this is a big but – there's a huge difference

between mice and humans. Before we can conclude anything about the impact that a specific compound will have on people with Huntington's, we need to test it in humans using randomized, placebo-controlled trials.

"Dozens of molecules have been reported as slowing down disease in mouse models of HD, but so far they've all failed when tested in human patients," explains Dr. Wild. "That's not to say the next drug won't work, but all the evidence from human trials tell us to be cautious when it comes to interpreting results in mice."

Minocycline, for example, showed promise in slowing HD in mice, but it didn't work in humans. On top of that, it actually proved to be harmful for patients with ALS, another neurodegenerative disease.

So why aren't we running clinical trials on strawberry extracts or fish oils? These kinds of studies are very costly, so it makes sense to focus funds on testing only the most promising treatments in humans.

The upshot is that each person has to make a personal choice. Some people living with Huntington's want to seize every chance to slow down the disease, even if there's a risk

it might have the opposite effect. Others prefer to play it safe. There's also the question of cost: some of the supplements touted as "treatments" can cost a lot.

Based on the research evidence right now, the best advice scientists can offer is that people who have HD need to eat a balanced diet that includes enough extra calories to maintain their weight. (You'll find more information on diet in our nutrition story on page 5.)

Food such as blueberries, strawberries and fish can certainly be a healthy part of that diet, but at this point it's far too early to tell whether they will do anything to slow the progress of the disease.

As well as eating a good diet, Dr. Wild suggests staying active both mentally and physically and not drinking too much alcohol. "For all of us, whether we're at risk of HD or not, that's a pretty good recipe for making the most of whether time we have left," he says.



Return undeliverable Canadian addresses to:



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

