

Grassroots Making An Impact – The National Community Advisory Group connects National Office with Chapter Leaders

By Julie Stauffer

When Bev Heim-Myers needs feedback on the impact of strategic direction, fundraising initiatives, or communication strategies, she knows where to go; right to the Society's grassroots.

Since June 2014, the National Community Advisory Group (NCAG) has been linking HSC's CEO with chapter leaders, creating an invaluable dialogue.

According to Bev, the results have been fabulous. "This past year has seen a stronger connection right across Canada due to the National Community Advisory Group," she says. "The presidents of our chapters have met regularly to share best practices and provide guidance on strategic initiatives and help us to truly be the best that we can be."

Four times a year, Bev and Chapter Development Manager Devin Bonner engage with Chapter Presidents on teleconference calls to discuss topics ranging from symposium planning to the latest Board

decisions. "It's an opportunity for chapter presidents to have a say in the direction of our organization," says Devin. "It keeps a healthy conversation going."

Edmonton chapter president Debbie Taylor agrees. "Just to know that they're there and listening to what you're saying, that's the part I've found more beneficial than I probably would have realized," she says. Having everyone together on a call also lets chapter presidents draw from the collective wisdom and experience of the group. It's a great opportunity for everybody to give advice, share what they've learned in their own chapters and provide encouragement.

"If you need help with something or you're doing something for the first time, there are other people who have done that," Debbie explains. "You don't always have to reinvent the wheel."

Finally, NCAG calls keep chapter leaders in the loop. "I've found it really beneficial to hear what's going on nationally," says Debbie.

NCAG calls have helped her stay up to date on research developments and HSC initiatives and then pass that information along to her chapter members.

Call it a win/win/win. Bev gets input to help shape the Society's initiatives, presidents get a direct line to the Society's CEO, and chapters across Canada stay better connected and informed.

HSC has always been a tight knit organization, back from the days when Ralph Walker knew every member by name. Now this new forum for dialogue keeps the tradition alive and well.

NCAG is a national advisory group consisting of Chapter Presidents, the CEO and the Manager of Chapter Development, they meet on a quarterly basis to discuss relevant issues pertaining to the Society.

To learn how you can make a difference in your area contact us at 1-800-998-7398 or at info@huntingtonsociety.ca, and we can direct you to the Chapter located closest to you.

HSC Family Services Gets Bigger and Better

By Julie Stauffer

Maribeth Meijer has a vision. As HSC's Director of Family Services and Community Development, she wants to make sure that if you're affected by HD, you have a link to a Family Services team member to provide support and services, no matter where you live in Canada.

With the addition of two new positions last fall, the Society is getting closer to that goal.

Last October, Renee Aeyelts joined the B.C. HD Resource Centre in Vancouver as our newest Social Worker. With experience in community outreach and mental health and a master's degree in social work, Renee is an excellent fit for the Society. She will focus on supporting individuals with HD from across the province, running the metro

Vancouver support group for individuals with HD, and planning the annual B.C. therapeutic retreat. That frees up Resource Centre Director Susan Tolley to focus her time on supporting persons at-risk, caregivers across the province and individuals with HD who are not able to get to the Centre for HD, as well as on community education and development."

Meanwhile, the opening of our East Central Ontario Resource Centre last November marks the Society's first new resource centre in more than five years. Director Marilyn Mitchell currently works 20 hours a week, serving the fast-growing region of Durham, the areas of Peterborough and Kawartha Lakes, and rural Northumberland and Haliburton.

Marilyn is a highly experienced social worker with strong speaking and organizational skills. Most recently she has provided support services to families of children and youth with special needs, and served as Executive Director of Big Sisters Association of Ajax/Pickering.

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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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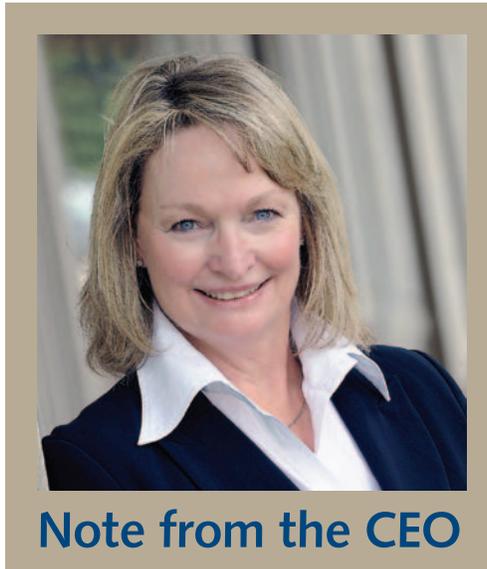
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One of the things that makes the Huntington Society of Canada so powerful is the passion and determination driving our staff, volunteers and donors. Now, with a new strategic plan to focus that passion and commitment, I truly believe we are unstoppable.

Here are the key goals we are aiming to achieve in the coming few years:

Invest in world-class research. According to an external review we commissioned last year, HSC has built a critical mass of HD research in Canada and fostered collaborations that move us closer towards meaningful treatments. To quote from the review "HSC is getting excellent value for its investments." As we look forward to applications for our latest round of research funding, I am confident we will continue to build on that excellence.

Advocate for Canadians living with HD and enhance the services we provide. As you can read in this issue of *Horizon*, we are reaching out to diverse communities and remote areas to ensure that all Canadians affected by HD have access to the services they need. As an expert in First Nations health issues, our new Board member Dr.

Tom Dignan will be very instrumental in helping us achieve that goal.

Meanwhile, we are thrilled that *The Globe and Mail* provided such extensive and balanced coverage of Canada's Personal Genome Project. We will build on that awareness in the coming year as we continue advocating for genetic fairness.

Increase awareness of HD and the Huntington Society of Canada. Many of you have seen *Do You Really Want to Know?*, an award-winning Canadian documentary about genetic testing. We're incredibly fortunate to be able to use footage from this film in a powerful new Public Service Announcement that we will launch for HD Awareness Month in May. As well, watch out for a fresh, updated HSC website later this year!

Demonstrate leadership locally, nationally and globally. Because Huntington disease has no boundaries, we have founded organizations such as the Canadian Coalition for Genetic Fairness, the International Huntington Association and the *Huntington's Disease Youth Organization* to share best practices and resources.

Strengthen the focus on young people. One participant at our amazing Youth Day last November told us "This is the first time that I have hope." We are going to give *Young People Affected by HD* (YPAHD) even more reasons for hope by launching a new mentorship program and updating the YPAHD website. The youth initiative is part of the fabric of the Society, evidenced by the newly created YPAHD director position, with voting rights, on our HSC Board of Directors.

Ensure financial and organizational stability, effectiveness and excellence. Our 40th Anniversary Campaign is building tremendous momentum. What an incredible way to celebrate our achievements, increase awareness and help us meet our \$5 million, over five years fundraising goal! Simultaneously, between January and June, our chapters will be running over 30 events from coast to coast. Chapters are the backbone of the Society, their collective strength and determination provides incredible annual support to the Society year after year and allow us to achieve amazing results.

On a related note, I would like to thank Janice Waud Loper for getting our 40th Anniversary Campaign off to such a strong start. While she has moved on to an exciting new opportunity in B.C., she remains a valuable friend of the Society.

Bev Heim-Myers
CEO and Executive Director

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

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



The Anonymous Donor: Helping us Climb Mountains

By Josh Martin

HSC's 40th Anniversary Campaign is off to an amazing start. Already we've raised more than 20 per cent of our \$5 million goal in just a few short months! The ambitious fundraising campaign, launched this past November at the 2012 National Conference, is resonating with supporters from coast to coast. "Old and new donors alike are very excited about the momentum that the Huntington Society has been building over the last 40 years," says Bev Heim-Myers, HSC's CEO and Executive Director. "They are really celebrating and embracing our grassroots history and the mountaintops that we want to reach."

In particular, Bev believes that our message of the "domino effect" is contributing to the campaign's success. By explaining that funding research for Huntington disease may lead to treatments for other diseases such as Alzheimer's, ALS and Parkinson's, we are

giving the broader community compelling reasons to support our cause. "It's helping people who are affected by other diseases realize the impact of researchers working together," she says.

As we thank all the donors who have contributed to this phenomenal kick off, we would like to put the spotlight on a special group of supporters: those who remain anonymous.

There are many different reasons why donors may choose not to be recognized for their generosity. Some simply don't want the recognition for their good deeds. For them, the act of giving is reward enough. Others avoid public recognition to protect themselves and their family from discrimination.

"Whatever their reasons, we are happy to respect their wishes," says Bev. "At the same time, we would like to take a special moment



to thank them for their support and pay tribute to the impact they create."

Each year, these unsung heroes give significant dollars to help us fund research, support families, reach out to youth, and end genetic discrimination. It is this kind of generosity that is helping the Grassroots to Mountaintops 40th Anniversary Campaign reach its goals.

HSC is proud to have the opportunity to work together with so many incredible supporters, anonymous or otherwise. How ever you choose to contribute, our heartfelt thanks go out to you for your generosity. Together, we are shaping the future and making history.

Let's keep the momentum going! Learn more about our Grassroots to Mountaintops campaign and help us reach our \$5 million goal by visiting www.huntingtonsociety.ca.

A New Generation of Leaders

Bob Scriven

By Josh Martin

When issues go to a vote at the Huntington Society of Canada's (HSC) next Board meeting, Bob Scriven will be one of the directors raising his hand. Since Young People Affected by Huntington Disease (YPAHD) was founded in 2008, Bob has played a key role in getting this virtual chapter off the ground.

As one of the most important developments within HSC in the past five years, YPAHD has not only raised a significant amount of money and awareness across Canada, it has also created a forum for young people to discuss and take ownership of issues associated with HD.

In 2010, Bob joined HSC's Board of Directors as a non-voting member, bringing the voice of youth to strategic decisions. This past

November, the Society turned that position into a full-fledged Board directorship with full voting rights.

Reserving a seat on the Board for a YPAHD member is a first for HSC, reflecting our commitment to involving youth. Bob's new status allows him to vote on and shape important budget and policy issues, as well as act more effectively as a liaison between the Board and YPAHD. "I like being the middle person," he says, "If there are issues that youth need to be addressed, I take it to the Board. The Board has been extremely receptive."

As a newly minted lawyer, Bob also brings legal skills to the Board's pool of diverse expertise. However, it's his personal connection with HD through someone close to him that he prefers to emphasize.

While he has much to offer HSC's governing body in terms of experience, expertise and energy, Bob is quick to acknowledge that the relationship cuts both ways. "There are a lot of exceptional and talented people on the Board that, as a younger person, I can learn a lot from," he says. "The Board is a very passionate organization. There's always great discussion, and it's always great hearing the other perspectives on any and all issues. I'm really looking forward to working with them."

So what's on the Board's radar over the next couple years? "I think genetic discrimination and preparing those affected by HD for clinical trials is huge," Bob says. "And revenue. Revenue is always important."

Young leaders like Bob are the future of HSC. We're thrilled to welcome him aboard and wish him all the best in his new role!

To learn more about Young People Affected by Huntington Disease check out www.huntingtonsociety.ca or call 1-800-998-7398 or join the conversation on Facebook.



Save the Date

A Night to Flourish benefitting Huntington Disease
Saturday April 20, 2013

Calgary Italian Club
Calgary, Alberta
Tickets are \$100

For more information contact: Tara Johnson Ouellette at
tarajo@shaw.ca or 403-861-5730

Is there a Doctor in the House?

Dr. Thomas Dignan

By Josh Martin

As someone who has worked as a licensed pilot and fly-in physician in northern Ontario, Dr. Thomas Dignan knows a thing or two about providing services to hard-to-reach areas. A member of the Six Nations of the Grand River, Dr. Thomas Dignan has devoted his life to helping First Nations people and bringing attention to health issues on reserves for more than 30 years.

Now he's bringing his decades of medical and remote community experience to the HSC boardroom, helping ensure that all Canadians, no matter where they live, have access to the services they need.

"Reaching out to diverse communities and remote areas is one of our top priorities,"



says Anne Brace, Chair of HSC's Board of Directors. "That's why we're so fortunate to have Tom join our Board."

Dr. Dignan's road to the HSC boardroom table has been a fascinating one. He always wanted to be a doctor, but as is often the case, life had other plans. At age 14, his father died. To help his mother and two sisters make ends meet, he dropped out of high school to work as an office boy and stockroom clerk.

The dream of becoming a doctor stuck with him, however. He eventually got his high school diploma and went on to become Canada's first Native male nurse. After a successful career that included stints in big-city psychiatric hospitals and remote outpost stations, he earned his MD from McMaster University in Hamilton, becoming the first-ever Native graduate from the Faculty of Medicine.

Dr. Dignan continued to be a man of firsts: the first emergency physician in Thunder Bay, the first president of the Native Nurses

Association of Canada, and a founding member of the Native Physicians Association.

He now works with Health Canada as a medical officer with the First Nations and Inuit Health branch. This is another asset for HSC as we continue to push for genetic fairness.

"Tom brings that insight into government decision-making and priorities," explains HSC's CEO Bev Heim-Myers.

Dr. Dignan's impact in Canada over the years has not gone unnoticed. In 2003, he was honoured with the Queen's Jubilee Medal. In 2005, he received the National Aboriginal Achievement in Medicine award. In 2006, he was inducted into the Order of Ontario.

And in 2012, we're thrilled to say that Dr. Thomas Dignan joined the Board of the Huntington Society of Canada!

To learn more about the Huntington Society's Board of Directors and the governance structure please go to www.huntingtonsociety.ca; the About Us section provides details.

Snapshots of Success

Each year, our chapters raise more than a million dollars for the Huntington's cause through walks, runs, volleyball tournaments, golf tournaments, horseback rides and more. Here we pay tribute to just a few of the powerhouse events from 2012.

Run for Lor

What: 1 and 5 km walk/run

When: September 23, 2012

Where: Masich Place Stadium, Prince George, B.C.

Why: To mark the first anniversary of Lorelei Dale's death



In the words of organizer Heather Chalmers: Twenty people registered for the event but over 60 people actually came out. I was blown away. I started off thinking it might just be a small

group since this was the first event for HD in Prince George, but I was very glad I was wrong!

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 Celebrating
People
in Action

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!

We achieve amazing things given our small infrastructure. Our blessing is the wonderful volunteers that support us at all levels of the Society and from all areas of Canada. We could never achieve what we do without the amazing commitment of the many volunteers that help us be the best that we can be. Daily we are grateful for the wonderful volunteers that choose to make a difference with us.

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

AWARENESS MONTH

May is Huntington disease Awareness Month

Make an Impact
Tell Someone about HD

1-800-998-7398

Snapshots of Success

continued from page 4

I did most of the organizing, but I have amazing friends and family who got everything set up on the day itself, and my good friend Kathleen helped me stay on track. The National Office held an information session the day before, and having Lor's family come from various places in B.C. to take part was very special.

I think what made the run successful is that it needed to happen. I lost a very good friend to Huntington's, and there is not enough awareness about the disease. That needed to change.

This event was just the beginning. Last fall I launched an Amaryllis campaign in Prince George, and I'm already starting to plan the next Run for Lor. Our goal for the 2012 run was to raise \$3,000. We surpassed that by almost 200 per cent. Next year we will aim higher, and even higher for every year from then on, because we have shown that we can do it.



5th Annual Camrose Golf Tournament

What: Annual golf tournament, dinner and silent auction

When: June 23, 2012

Where: Silver Creek Golf Course, New Norway, Alberta

Why: To bring the community together for a great cause, year after year

In the words of organizer Greg Staal:

We probably had about 160 people there. We just make it a fun tournament. It's pretty laid back and everyone gets prizes. We have a steak dinner afterwards and a silent auction. This year we also had Phil Calloway as a guest speaker, Phil is an award-winning Canadian author, humourist and speaker. He had the place laughing. Everybody was talking about him afterwards.

The tournament has grown and grown and grown since we started it five years ago. In the first year I think we made \$12,000. We were

like, "this is fantastic." Last year we raised approximately \$50,000, we were pretty much in tears by how big it's got.

My mom suffers from HD right now. To raise all this money that will hopefully go to finding a cure some day, it's blown me away.

The tournament is a lot of work to organize, but we have about half a dozen of us that run it, and our community support has just been outstanding. Every time we've asked, we've basically never been turned down, whether it's a prize or a contribution or some kind of support. People just come out of the woodwork now. They'll just walk up to us and say, "Hey, are you guys doing the golf tournament? I've got stuff for you at my house. Come get it."

Now we're already planning out 2013 event.



4th Annual Run for Huntington Disease

What: 5 and 10 km run/walk

When: June 24, 2012

Where: Wilket Creek Park, Toronto, Ontario

Why: To encourage runners across southern Ontario to support HSC

In the words of organizer Tim Irwin:

This time I really wanted to appeal to the non-HD running community. To do that, we had to invest in chip timers, technical t-shirts and other things to make the race "official," but it really paid off. We had over 600 participants and raised \$85,000. It was a tremendous way to reach out to the general public.

We're quite overwhelmed and humbled by how much support we received from partners like the Running Room. They handled all the registrations and played a key role in spreading the word to the non-HD community. Chapter volunteers went to Running Room stores across Ontario to hand out brochures and promote the event to their running groups.



Making it really family-friendly paid off too. We had 4K and 5K walks that were very popular with families with youngsters. We also had some great entertainment. Country music star Kristy Howes sang Woody Guthrie songs, we had performances by a Latin dance group, and students from Medix School gave massages.

It's amazing what you can accomplish when you put your mind to something. We had 60 fantastic volunteers, and everybody pitched in to make the event a success. Each year, we're setting bigger and bigger goals for ourselves. In 2013, we're planning to raise \$100,000.

"The Challenge" Cowboys versus City Slickers!

What started as a friendly wager between the two top fundraising groups is shaping up to be quite the showdown in 2013. This summer, Teepee Creek's HD Ride 4 a Cure is going head-to-head against Toronto's annual Run for Huntington Disease in a friendly competition to see which event can raise the most money.

"There's nothing I'd be more pleased to lose," says HD Ride 4 a Cure organizer Mack Erno. "But," he adds, "we plan to win."

Both teams have set their sights on netting \$100,000.

Who will come out on top? The rough, tough horseback riders of Teepee Creek, Alberta, population 25? Or the hard-running city slickers of Toronto, Ontario, population 2.6 million? Stay tuned to find out!

Check out the events page on the Society's website (www.huntingtonsociety.ca) for updates on this year's Challenge.

Planning for our 2013 events has been underway since early January. If you wish to plan an event or host a fundraiser let us know, we are happy to help. Contact us at info@huntingtonsociety.ca or call us at 1-800-998-7398.

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 www.huntingtonsociety.ca/events

April

April 6

score ONE for the TEAM

Peterborough, ON
Peterborough Sport and Wellness Centre

Join us for the 5th annual score ONE for the TEAM, 3 on 3 Basketball Tournament! For more information, email score.one3on3@gmail.com. Web: <http://score-one-for-the-team.com/>

April 20

A Night To Flourish

Calgary, AB
Calgary Italian Club

This year's event features a Mardi Gras theme. Cocktails at 6:00pm, Dinner at 7:00pm, Cash bar. Tickets \$125. For tickets or more information, call Tara at (403) 861-5730.

May

May 5

15th Annual Architectural Gems of Toronto Walk

Toronto, ON
Starting location: Parking lot of Howard Public School, 30 Marmaduke Street

Walking tours of Roncesvalles Village. Registration 1:00pm, walking tours 2:00pm, social gathering 3:30pm at Gate 403. For more information, call Jim at (416) 809-2469 or email gems@hdtoronto.org. Web: <http://huntington.akaraisin.com/2013GemsWalk>

May 5

TeamHD St. John's Run & Walk for HD

St. John's, NFLD

Join us for a fun run (or walk) around the Quidi Vidi Lake Trail (3.8km). Registration begins at 10:30am, the run/walk starts at 11:00am, and is followed by lunch and refreshments. For more information, contact Catherine Price at (709) 832-7870 or catherine.price@mun.ca. Web: <http://huntington.akaraisin.com/StJohnsHOPERunforHD>

May 5

GoodLife Fitness Toronto Marathon

Toronto, ON

Join TeamHD and the 2013 Running Challenge. Run for a reason! Options include a marathon, ½ marathon, 5k run, 5k walk, and a Relay event. Web: <http://huntington.akaraisin.com/TeamHDTorontoMarathon>

May 7-11

Niagara Book Sale

St. Catharines, ON
Fairview Mall

Semi-annual fundraiser, Monday to Friday 9am to 9pm, & Saturday 10am to 4pm. For more information, call Gail at (905) 892-6024 or email gaildekoning@gmail.com.

May 25

6th Annual Run to Finish Huntington Disease

Vernon, BC
Kin Beach Park

Options include 1 km walk, 5 km walk or run. Registration 8:00am, Run 10:00am. For more information, call Dan at (250) 808-8072 or email hscokanagan@yahoo.ca. Web: <http://huntington.akaraisin.com/VernonRuntoFinishHD>

May 25

Edmonton Walk to Cure HD

Edmonton, AB
Emily Murphy Park

The Walk is held at Edmonton's wonderful Emily Murphy Park (11904 Emily Murphy Park Road NW) on the south bank of the North Saskatchewan River. Registration begins at 1:00pm, Walk begins at 2:00pm. No dogs please. Please contact Joan at (780) 352-7937 or jcallum@hotmail.com for more information. Web: <http://huntington.akaraisin.com/EdmontonWalktoCureHD>

May 25

Walk to Cure Huntington Disease

Peterborough, ON
City Hall

Registration starts at 9:00am. The Walk starts at 10:00am and is followed by a Party in the Park at Del Crary Park. For more information, call Amanda Manley at (705) 932-3300 or email president@peterborough.org. Web: <http://huntington.akaraisin.com/PeterboroughWalktoCureHD>

May 25 & 26

Ottawa Race Weekend

Ottawa, ON

Join TeamHD and the 2013 Running Challenge. Run for a reason! Options include marathon, ½ marathon, 10k, 5k, 2k, Y kids marathon & wheelchair marathon. For more information, contact Ray at (613) 741-0282 or raybailey209@gmail.com. Web: <http://huntington.akaraisin.com/OttawaTeamHD>

May 26

Scotiabank Calgary Marathon

Calgary, AB

Join TeamHD and the 2013 Running Challenge. Run for a reason! Options include marathon, ½ marathon, 10k, 5k, & kids marathon. HSC is a registered charity in this event. For more information, call Melissa at (403) 903-5259 or email lingard.mel@gmail.com. Web: www.teamHD.ca

May 31

Karaoke for a Cure

Fort St. John, BC
North Peace Cultural Centre

Join us for a night of karaoke and fundraising! For more information, contact Kristy at kristyhowes@hotmail.com.

June

June 1

6th Annual Saskatchewan Walk to a Cure

Saskatoon, SK
Meewasin Trail, University of Saskatchewan

Registration 9:30am, Walk 10:00am. For more information, call June at (306) 997-2052.

June 1

3rd Annual Hope for a Cure for HD

Waterloo, ON
Waterloo Park

Join the Grand River Chapter, TeamHD, and the 2013 Running Challenge. Run for a reason!

Registration 9:30am, Run 10:00am, 5k run/walk. For more info, email Murray at murray.mccullough@gmail.com or call Pamela at (519) 651-2330.

Web: <http://huntington.akaraisin.com/GrandRiverRun>

June 2

18th Annual Golf Tournament

Brandon, MB
Glen Lea Golf Course

Shotgun start at 12 noon, 3 divisions of 2 teams, mens/ladies/mixed. For more information, call Sandy at (204) 724-0534.

June 8

Run 2 Finish Huntington Disease

Winnipeg, MB
Assiniboine Park, Duck Pond Shelter

Options include 10k run, 5k run, or 5k walk. Registration 8:30 am, Start 9:30am. Pancake breakfast free to all participants. For more information, contact Jeff at (204) 668-8703 or huntingtonrun@gmail.com, or contact Vern at (204) 694-1779 or vbarrett@mts.net. Web: www.hdmanitoba.ca

Legend



TeamHD



Golf Tournament



Go-Kart Indy



HD Run/Walk

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 suggestions, please email events@huntingtonsociety.ca or call 1-800-998-7398

June 8

PEI Indy Go-Kart Challenge



Burlington, PEI
Burlington Amusement Park

Join us at the PEI Indy for a fun family day from 9:30am to 12:30pm. For more information, call Stephen or Janet-Rose Hurst (902) 888-3013.

June 8

1st Annual Game On for Huntington disease



Tweed, ON
Poplars Golf Club

Registration at 9:00am, Shotgun start at 10:00am, best ball format. For more information, contact Becky or George at (613) 902-0549 or georgerrussell34@yahoo.com.

June 10

3rd Annual HSC Golf Tournament



Calgary, AB

For more information, please contact Jacob Hendricks at jhendriks1962@gmail.com.

June 13

Race for a Cure

Ottawa, ON
Rideau Carleton Raceway

Join us at Canada's fastest 5/8 mile track for a fun night at the races! For more information, please contact Sharon Haig at sharon.haig@sympatico.ca or (613) 739-4446.

June 15

HOPE for a Cure Run & Walk



Calgary, AB
Glenmore Park, Snowy Owl Picnic Site

5th Annual 8k Run, 5k Run, or 5k Walk. For more information, contact Stephanie at strees@shaw.ca.
Web: <http://huntington.akaraisin.com/2013HOPERunCalgary>

June 22

Camrose Golf Tournament



Silver Creek Golf Course, New Norway, AB

For more information, please contact Greg Staal at greg.staal@goauto.ca.

June 23

Run for Huntington Disease



Toronto, ON
Wilket Creek Park

Options include a 10k run, 5k run, and a 5k hike. Registration 8:00am, 10k run 10:00 am, 5k hike 10:05am, 5k run 10:15am. For more information, call 1-800-746-0645 or email run@hdtoronto.ca.
Web: <http://huntington.akaraisin.com/TorontoRunforHD>

JULY

July 20

10th Annual Beach Volleyball Tournament for HD

Barry's Bay, ON

For more information or to register a team, contact Melissa at (613) 756-3060.

August

August 14

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 information, call Kim at (416) 529-4340 or email kim_cameron@rogers.com.

August 24

4th 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 information, call Mack at (780) 897-8048 or email merno@jadecash.com.
Web: www.peacecountryhd.ca

September

September 7

Bert Sauder Memorial Golf Tournament



Port Colborne, ON
Whisky Run Golf Club

Shotgun start at 10:00am. For more information, please contact Gail DeKoning at gaildekoning@gmail.com or (905) 892-6024.

September 8

Indy Go-Kart Challenge



Winnipeg, MB
Thunder Rapids Fun Park, Headingley

Join us for a great day full of fun and prizes! For more information, contact Vern at (204) 694-1779 or vbarrett@mts.net.
Web: www.hdmanitoba.ca

September 8

Indy Go-Kart Challenge



Windsor, ON
XS Family Fun Centre

Join us for a great day of family fun! Check in begins at 8:45am and racing goes from 9:30am to 11:30am. For more information, contact Paul at thebatemans@sympatico.ca or (519) 322-5924.

September 8

Indy Go-Kart Challenge



Halifax, NS
Atlantic Playland, Hammonds Plains

Join us for a great day full of fun for the entire family! For more information, contact Jim at (902) 445-3516 or email jimrussell@eastlink.ca.
Web: <http://huntington.akaraisin.com/HalifaxIndy2013>

September 22

Run for Lor



Prince George, BC
Masich Place Stadium

Join us for our annual Run for HD. Options include a 5k run or walk, and a 1k walk. Registration starts at 11:00am, Run/Walk starts at 11:30am. For more information, contact Heather at (250) 596-1705 or heather.3.reasons@gmail.com.
Web: <http://huntington.akaraisin.com/2013TeamHDRunforLor>

September 22

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: <http://huntington.akaraisin.com/H4H2013>

September 22

Indy Go-Kart Challenge



Mississauga, ON
Playdium, 99 Rathburn Road West

Join us for a great day of family fun! Check in begins at 8:30am and racing goes from 9:30am to 11:00am. For more information, contact Bob at (416) 520-6066 or at bobspizziri@hotmail.com.



TeamHD is an exciting national fundraising program aimed at educating the running community about Huntington disease. We invite you to join our *National Running Team* by signing up to participate in any of our TeamHD events across Canada. Whether you're looking for a corporate team building experience or simply an opportunity to run for a reason, TeamHD is for you! For more information visit www.teamhd.ca and get running!

HSC Family Services

continued from page 1

In keeping with our new Strategic Plan, these two positions help boost our level of service in rural and remote areas. They also expand our services by more than five per cent — a big achievement in an environment where costs are rising and fundraising is challenging.

"I'm thrilled," says Maribeth. "In my opinion, the amount of service that we are able to provide based on the amount of resources we have is just incredible, although there is still a strong need to keep growing we are making incredible strides".

Today, Canadians affected by HD can access a member of our family services team in every province from coast to coast except P.E.I., which is served from our resource centre in Halifax. We have a team of 24 dedicated professionals, working anywhere from 10 hours a month to full time.

"I take pride in the fact that that we're really stretching every single dollar to provide as much quality service as we possibly can," says Maribeth.

Her secret? Securing some new funding in British Columbia, combined with creative redeployment of funds within the existing budget.

"I don't want anybody to be left with the impression that there was fat in the budget, because there wasn't," she says. Rather, she scrutinized every line item to find ways to deliver services more effectively. For example, in Ontario and Saskatchewan, using telehealth technology has cut down on travel expenses. She credits the willingness of our Resource Centre Directors to do things differently and shift priorities so that we could create these new positions. "It's really a good indicator that the heart and soul of this organization is a really strong commitment to serving individuals and families," she says.

To learn more about Family Services, please visit our website at www.huntingtonsociety.ca and check out the Education/ Family Services Program. The Society publishes a caregivers e-bulletin called Strength and Knowledge every other month throughout the year. To receive copies, sign up at info@huntingtonsociety.ca.



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!

An Ariel View



Last week, I had a lovely visit with Christiane Lohkamp, who belongs to the German Huntington's Association. I first met her at a Huntington's meeting in Denmark years ago. She had just lost her husband to HD, and we talked about it as we walked around a pond near the conference centre. We've stayed in touch ever since.

It got me thinking about all the wonderful people I've met through the Huntington Society and all the long-lasting friendships I've developed.

At the beginning, there were the families who set up some of those first chapters: the Ellises, the Barretts, the Janeses, the Kuzycks, the Webers, the Stainsbys, Bob and Norma Stevens, Mary and Claude David, Gaetance Habla and many more. Then there were the volunteers and supporters who had no connection to HD but pitched in to make Raggedy Ann dolls, organize garage sales, stuff envelopes, and keep our little organization alive.

And, of course, there were the health care professionals like Elaine Hardy, Winky Simpson, Dr. Oleh Hornykiewicz, Dr. Andrea Barbeau along with many, many more professionals who contributed their expertise, far too many to mention.

Together, we created the foundation. If it hadn't been for them in those first years, the Huntington Society wouldn't be what it is today.

It doesn't stop there, of course. All kinds of people have contributed to the Huntington Society over the years — far, far too many to list. I can't tell you how many Christmas cards and emails I receive from my Huntington's connections. Mind you, I send out a lot as well!

I think of everyone who has come to stay at the house or the cottage over the years, and everyone I've visited on trips across Canada or abroad. I remember the camping trips we made out East and West as we were setting up chapters, the great fun Ralph and I had travelling with International Huntington Society president Gerrit Dommerholt across Europe, my trip to Tasmania with Robyn Kapp from Huntington's New South Wales after the Melbourne meeting ... I could go on and on!

So many folks have become part of my life because of Huntington's. I know all their children and they know mine. Some have passed away now, but they're still so alive in my memories. Others I haven't seen in decades, but then I'll run into one of them at some conference or other, and when we start talking it suddenly seems like no time has passed at all.

And then there are all the people I'm in touch with regularly, including many of the former staff. When I think of how former assistant executive director Nancy Johnson and her partner Sandy supported me in those first years after I lost Ralph, I get choked up.

What brought us together was our determination to make life better for people with HD and, ultimately, to eradicate the disease. It gives me such a warm feeling to have created those connections. There's no question that Huntington's is a terrible thing, but it also brings out the best in people. And to me, that's really what the Society is all about.

To celebrate our 40th anniversary, we're collecting memories of the Society's impact over the years. If you have a story that you'd like to share, email us at info@huntingtonsociety.ca.

Ariel

By Julie Stauffer

For 20 hours, 51 minutes and 21 seconds last November, Terri Biloski ran from St. Thomas to Tillsonburg to Port Burwell and then to Port Stanley. The 36-year-old covered 161 kilometres — an epic 100 miles — through Ontario's Elgin County to raise funds to cure a disease she may inherit.

"It was really, really tough," she says. "Coming into the last 30 kilometres, I so wanted to quit." But she pushed on, knowing that she was running for her grandmother, who passed away from Huntington's; for her mother, now in the early stages; and for everyone touched by HD.

Elgin County residents were firmly behind her. At every town along the way, no matter what time of day or night it was, people came out to cheer her on. School kids helped her kick off the event. Local police volunteered to guide her out of St. Thomas. Friends and strangers joined her on the route or applauded as

she ran past. As she neared the finish line along the Port Stanley waterfront, a hundred people lined the street to salute her achievement.

"It was so amazing," says Terri. "I never thought that that many people would come out and support me and some strange little disease they'd never heard of."

Her friends and family worked around the clock to ensure it all went smoothly, even when Terri fell behind schedule. "I remember sitting there in Port Stanley at four in the morning thinking about how I'm going

to make the town wait," says Eric Salin, Terri's run organizer. "We used Facebook and communication tools and got the word out there, and instead of everyone meeting at 8 o'clock, we welcomed her at 10 o'clock in the morning."

Local media coverage was fantastic, helping them reach thousands of people. And when the donations from the run, celebratory brunch and silent auction were all counted up, the event raised a whopping \$6,300 — \$5,300 more than Terri's original goal.

Her proudest moment? "After the run, my daughter says to me, 'Mommy, you're my hero,'" Terri recounts. "Not because you ran a hundred miles. I mean, you're cool that you ran a hundred miles. But the fact that you did this for people you don't even know."

A keen runner, Terri has never been afraid to take on big challenges. Earlier she tackled a 135-kilometre event, and she puts in dozens of kilometres each week leading running groups from the Run For Your Life store she owns in St. Thomas.

So perhaps it's no surprise that she's taking on yet another bold challenge. Terri and a team of 19 others from the global Huntington's community are attempting to collectively cover the circumference of the Earth throughout 2013. That's 40,000 kilometres! What a way to celebrate HSC's 40th Anniversary.

"I've always kind of had the theory that if I don't stop, I won't have to," she says. "This is my goal in life, as well as with HD."

To find out more about the Circumference Challenge, check the group's Facebook page at www.facebook.com/CircumferenceChallenge.



Healthpartners Gathers for a Strategic Retreat

The Huntington Society of Canada is a member of Healthpartners, an alliance of 16 national health charities that raises funds through workplace charitable giving programs. Using a model similar to United Way, Healthpartners gives Canadians an opportunity to support important health causes and help people in their community who face disabling and life-threatening diseases through workplace charitable giving.

Donors have the option of supporting Healthpartners through regular payroll deductions or cash donations. The dollars they contribute go to Healthpartners members, including HSC, to fund direct services, public education, health promotion and research into treatments.

In December 2012 the Healthpartners Board met for two days to discuss governance and organisational structure to ensure that we have the right skills and experience to assist in strategy growth.

Over the next year, Healthpartners will focus on: the Government of Canada Workplace Charitable Campaign; working with member charities to develop a partnership agreement; rolling out a refreshed brand and communications strategy; and finding new opportunities for workplace campaigns.



Healthpartners
Partenairesanté
CHOOSE HEALTH • CHOISISSEZ LA SANTÉ

Positioning for long-term growth to benefit all sixteen member charities, Healthpartners is working to raise more dollars, find more donors and more volunteers for our members, and to become the entry point for member delivery of programs and information in the workplace. Through the Healthpartners program, the HSC is able to reach large workplace audiences to provide information and awareness about HD and to receive significant revenue from workplace donations.

HSC can be part of this growth. 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.



Making a Difference 22 years of teeing off for a good cause

by Josh Martin

For the past 22 years, Andrew Wright and his team at CBRE have been organizing charity golf tournaments in support of HSC. Sure, the Toronto-area event has been rained out a couple times. And yes, one year a golfer's cart — containing his clubs, cell phone and car keys — rolled into a pond. Despite those inevitable hiccups, however, the company's annual Huntington Classic Charity Golf Tournament has raised over half a million dollars for HSC.

Andrew has been a long-time volunteer with the Society and served for several years on the National Board of Directors. His passion for the cause goes back to 1980, when his mother was diagnosed with HD. Andrew's family immediately got to work raising awareness and funds for the cause.

However, the golf tournament wouldn't have gotten off the ground if not for the generosity of CBRE, where Andrew works as Executive Vice-President and Executive Managing Director in Toronto. Back when charity tournaments were an innovative idea,

his boss suggested organizing one for Huntington disease. Naturally, Andrew jumped on the idea.

Since then, the real estate company has sponsored the popular tournament each year, tapping into its wide network of clients and partners to make the event a roaring success. Held just after Labour Day, the Huntington Classic Charity Golf Tournament draws more than 200 golfing enthusiasts and impressive corporate support. "I send out 50 letters and I get 50 positive responses," says Andrew. "The whole industry is aware of it."

According to Andrew, this is just one of the ways CBRE supports the 20-plus communities where it operates across Canada. However, the Huntington Classic Charity Golf Tournament is by far the longest running. Stefan Ciotlos, President of CBRE Canada, says: "We are proud of our legacy of support for HSC and look forward to being a part of HD's eradication in the not-so-distant future."

A big thank you to CBRE for their amazing support over the years. The partnership has been a real hole-in-one!

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Wedding gifts that make a difference

By Josh Martin

When Terry Bergnards, 59, heard that her best friends, Barb and Bernie, were getting married, she was thrilled. When she received their wedding invitation, she was over the moon.

"Thank you for celebrating with us," the invitation read, "In lieu of a gift we are asking you make a donation to the Huntington Society of Canada."

HD has played a big part of Terry's life, ever since her father started showing signs of the disease almost 20 years ago. She and her two brothers discovered that they had inherited the gene, as did her only son Matthew.

Bernie and Barb, however, have no personal connection to the disease. For Terry, their generous gesture came as a complete surprise.

"I was just blown away," she recalls. "Here's the most important day in their lives, starting together, and that's what

they decided to do." Barb and Bernie's 130 guests loved the idea too, appreciating the opportunity to give something that meant so much to the happy couple.

The wedding, held on a sunny September afternoon near Aurora, Ontario, raised more than \$10,000 for the Huntington Society. "For me the biggest impact is that my son is 36," Terry says, "and the fact that that kind of money and awareness-raising can make a big difference for his life." Terry believes that the reason it was so successful is that the card included the HD logo, the website and phone number, making it very easy to make donations.

She hopes her friends' creative alternative to conventional gift giving will inspire others to do the same, whether it's a wedding, birthday party, anniversary or Christmas.

After all, what better way to express love or friendship? "I'm still so touched about it," Terry says.


Thank you for
celebrating with us.

In lieu of guest favours a donation has
been made in your honour to the
Huntington Society of Canada.



If you wish to include a card similar to the one above, the Society has designs to suit any occasion. Contact us at 1-800-998-7398 or email us at info@huntingtonsociety.ca for more information. Cards also include the Society's logo, phone number and charitable registration number to ensure those thinking of donating can easily find out more or contact us.

CONNECTING • INSPIRING • INFORMING

RETURN FORM 2200

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.

- Enclosed is my donation of \$ _____ to further support the Huntington Society of Canada.
- I would like to remain anonymous

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 : _____

May is “Leave a Legacy” Month – What will yours be?

At HSC we are incredibly fortunate that so many people donate their time, money and energy to us. Many are now taking their contributions one step further, by including the Society in their wills and estate plans. “Some of the largest gifts we receive come from bequests,” says Jim Martin, HSC’s Development Coordinator. “It’s a way to make a tremendous impact and control what your legacy is.”

There are many reasons to consider a legacy gift. It is a great way to ensure your memory lives on. It’s also a way of acknowledging an organization that has had an impact on your life or the lives of those important to you while helping the charity to continue their important work. In addition, there are the financial benefits associated with charitable contributions. For some, including a charity in your will can actually increase the amount of money your spouse or children inherit because it offsets taxes.

Here are some tips to consider as you plan your legacy:

- Talk to your family about your wishes. End-of-life conversations can be tough, but discussing your wishes ahead of time makes decisions much easier for your loved ones after you pass away.
- Get professional advice. A financial advisor can help you explore various legacy options to find the best fit for you and your family. Once you’ve made your decisions, a lawyer can put together the nuts and bolts of a will.
- Talk to HSC’s development team. There are a myriad of options for leaving gifts and making a difference. Email us at info@huntingtonsociety.ca or call 1-800-998-7398 to discuss the kind of legacy you want to leave.

Many years ago, to recognize the very special nature of a legacy gift, Ariel Walker took the lead and helped HSC to establish the Ralph and Ariel Walker Summit Society. This support tells a powerful story, a story of a community of caring people who pull together and change the reality of families living with HD. We are honoured to thank those who have made a pledge of a bequest for their commitment and we invite you to join this very important group of donors who are helping transform the future for all Canadians affected by HD.

May is “Leave a Legacy” Month in Canada. What better time to start thinking about your lasting impact.

To discuss your legacy and join the Ralph and Ariel’s Summit Society contact us at 1-800-998-7398 or email us at info@huntingtonsociety.ca



Return undeliverable Canadian addresses to:



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

