

# HORIZON

RESEARCH • SERVICE • EDUCATION

No. 152 Spring 2017

## How to manage stress – and why it is so important

By Julie Stauffer

It is no secret: looking after a loved one with Huntington disease is tough. According to Southwestern Ontario Resource Centre Director Corey Janke, dealing with the physical and emotional demands year-after-year can create chronic stress.

For some people, that shows up as anxiety or panic attacks. For others, it is depression, headaches, abdominal pain, insomnia, hypertension or cardiovascular disease.

Those symptoms can linger long after a loved one has passed away. In other cases, a caregiver who has stayed strong throughout the course of the disease can fall apart once their job is done. "All of a sudden, they crash and burn because they haven't focused on themselves, haven't taken

care of themselves," says Bev Farrell, a therapeutic recreation specialist in London, Ontario.

That is why it is so important for caregivers to look after their own health, both physical and emotional, at every stage along this journey. Look for support from family and friends, Corey suggests. Some people find it helpful to turn to their faith community. Others do yoga or meditation. And, of course, HSC's Family Services team is also here to help.

Don't forget the basics: get regular exercise, make smart food choices, and don't skimp on sleep. Meanwhile, make time for meaningful leisure activities (see sidebar), even if it means you don't vacuum the house or mow the lawn quite so regularly.

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## A recreational recipe for resilience

By Josh Martin

Spending time on an adult colouring book or deep breathing may seem frivolous. But according to Bev Farrell, a therapeutic recreation specialist in London, Ontario, enjoyable leisure activities help you de-stress and recharge your batteries so you can tackle the rest of your day more effectively.

The key, she says, is choosing a meaningful activity that you find absorbing and rewarding. For her, it's playing guitar. "An hour later my fingers are killing me and I haven't even paid attention to the time," she says.

For you it might be yoga, swimming, painting or getting together for coffee with a friend. Everybody is different, so find an activity that's right for you and then make time for it, even if it's just 15 minutes each day.

And switch off the guilt: leisure time isn't wasted time. "A lot of research shows if we're engaged in meaningful activity, we have more resilience," Bev explains. "To take care of yourself, you need to do some things that are good for you."

## HDClarity: How a new study will help researchers assess HD drugs faster

By Julie Stauffer

For everyone within the Huntington community, a treatment for Huntington disease (HD) cannot come soon enough. The good news is that several very promising drugs are undergoing clinical trials right now, and even more are coming down the pipeline.

However, because Huntington disease progresses quite slowly, it takes years for physical brain changes to show up on an MRI scan or for clinical symptoms to get measurably worse. That means it currently takes years to judge whether a potential treatment is working.

Speeding up that assessment would get effective drugs to market sooner and rule out ineffective ones faster. To do that, researchers need a more sensitive measure of HD progression, some kind

of biomarker that reflects the changes happening inside brain cells.

Of course, taking a sample of someone's brain tissue is very invasive. Instead, British neurologist Dr. Ed Wild suggests researchers look in the cerebrospinal fluid (CSF): the liquid that surrounds the brain and spinal cord. He is willing to bet that as HD starts to change the levels of certain proteins within brain cells, there will also be changes in the level of those proteins in the CSF.



Dr. Ed Wild

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# HORIZON

ISSN 0827-7605

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

Huntington disease is a hereditary brain disorder which has devastating effects on both body and mind. The symptoms, which may include uncontrollable jerking movements and relentless cognitive and emotional impairment, usually appear between the ages of 35 and 55, and gradually worsen over the 10-20 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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Charitable Registration Number:  
11896 5516 RR0001



## Note from the CEO

By now, many of you will have heard that Bill S-201, the Genetic Non-discrimination Act (GNA), passed 3rd reading in the House by a very supportive vote of 222 to 60. The normal process will be to get Senate approval and then Royal Assent to make Bill S201 law. With aggressive push back from the insurance industry, the Prime Minister and Minister Wilson-Raybould have indicated in the media that they want the opinion of the Supreme Court of Canada, to appease their constitutional concerns. It is a matter of public record that the most cited constitutional experts in Canada during testimony for Bill S201, did not raise concerns and stated that the bill is indeed constitutional. After four years of tireless efforts by many, this move by our government is, at the very least, disappointing and may hold up the process.

On March 8, we witnessed democracy at its best when the Liberal backbenchers, Conservatives and NDP stood together to pass Bill S201. It appeared that Canada finally caught up to science and other countries to have laws in place to protect our private, complicated genetic information. We will overcome this hurdle as protecting genetic test information is far too important for the health and wellbeing of all Canadians. With the strength and resilience demonstrated by our HD community, we continue this journey – the end is near.

I would like to thank everyone who worked so hard to achieve this milestone. Ralph and Ariel Walker founded this Society because they believed that by coming together, we could make a difference. Once again, we have proved them right.

Stay tuned, we will keep you posted as our progress moving forward.

On another note, I am delighted to announce that thanks to the extraordinary generosity of Wayne Atkinson and Marg Steed, families in New Brunswick now have a much needed HD Resource Centre. I am also delighted that our long-time Family Services Worker in New Brunswick, Marthe Gautreau, has stepped forward as our newly appointed Resource Centre Director. Marthe will apply her expertise and continue to make a tremendous difference for everyone she serves. Marthe has already made significant strides to get the centre up and running.

Meanwhile, our network of chapters just got stronger. This past November, our Board of Directors granted official chapter status to a passionate group of volunteers in Durham, Ontario, headed up by Bunny Clark. I knew from the moment I attended their first walk, that this group would achieve big things. Congratulations!

Like other chapters across the country, they will be working hard to make May Awareness 2017 a success. Each year, I am impressed by how our community rallies to share their stories, organize events and raise hundreds of thousands of dollars. I want to thank every one of you who steps forward, to organize, to participate, to speak about your experience or to make a donation. Every single action has impact.

As all of that unfolds, our staff is already putting together plans for our 2017 fall Symposium and regional YPAHD Days. Stay tuned for details!

On the research front, our team of Research experts is busy reviewing applications for HSC's NAVIGATOR grants. We are also working closely with Brain Canada to have the HSC/Brain Canada proposals reviewed. We will be announcing our funding decisions for both initiatives before the end of June.

Finally, as two stalwarts of the Society take a well-deserved retirement, I would like to thank them for all their contributions. Collectively, B.C. Resource Centre Director Susan Tolley and our National Office Administrator Shirley Barnes served the Huntington community for nearly 50 years. We are going to miss them in a big way.

Bev Heim-Myers  
Chief Executive Officer



**Huntington disease research news.**

**In plain language.  
Written by scientists.**

**For the global HD community.**

**Go to [www.HDBuzz.net](http://www.HDBuzz.net) to see  
what the Buzz is all about!**



# On the road again – travelling with Huntington disease

By Cyndy Moffat Forsyth

Having Huntington disease (HD) means plans, routines and pre-set expectations. While applying strategies in day-to-day activities is vital to ensuring a high quality of life, we all enjoy a change of scenery once in a while, a break from the everyday routine. This is why the Huntington Society of Canada (HSC) has created, in collaboration with the Alzheimer Society of Canada, some HD specific tips for those who wish to travel with Huntington disease.

Careful planning can help manage new surroundings and make traveling easier for everyone involved. Consider trying a shorter trip. This allows everyone to adjust to travelling and become comfortable, enabling you to build up to a longer trip.

As you start to plan your trip, include the person with HD in your planning and in the decision-making process. Once the planning stage is completed, provide a copy of the trip itinerary so it can be reviewed ahead of time.

If you are planning to visit friends and family during your trip, let them know about any symptomatic changes since your last visit so they are prepared. Consider sharing the Society's *Understanding Behaviour in Huntington Disease: A Guide for Professionals* publication so they can read about the stages of HD and



When Jim Wiswell retired, it marked the end of a big chapter in his life. However, it also signalled the beginning of a new one for him and his wife Ellen Foster – one that has taken them to the deserts of New Mexico, along the shores of Prince Edward Island and through the rolling

countryside of southern Ontario. "We figured, if we're not going to work anymore, we might as well do a lot of travelling," says Jim.

For Jim and Ellen, a 25-foot Airstream trailer was just the ticket. The mobility it offered caters to Jim's love of seeing new things. At the same time, it creates consistency that has become increasingly important as Jim's HD progresses. While his motor symptoms are mild, getting a good night's sleep and controlling his anxiety can be a challenge. Having the same bed, the same kitchen and all their clothes makes travel much easier.

Because Jim also has more difficulty making decisions these days, they opt for prearranged tours with other Airstream owners. Not only does that mean they know exactly where they are going, they also enjoy having other couples to swap stories with at the end of the day.

Over the years, Jim and Ellen have developed a number of strategies to ensure their journeys run smoothly. Their trailer is well stocked with snacks and water, and a good GPS system gives them the confidence to navigate from point A to point B. They drive a maximum of 400 kilometres a day with frequent breaks along the way. Meanwhile, taking time each evening to review the next day's route and plotting out detours to avoid potential traffic jams helps keep Jim's anxiety at bay. The trailer provides stability and continuity for Jim and a safe place to get away (if required) for some quiet moments.

Now in their tenth season, Jim and Ellen just wrapped up a tour in Texas. And from there, who knows? Although HD has made travelling more complicated, this couple is proof that with the right approach, it's possible to keep the adventures going. "Just do it," says Jim.

the symptoms that the individual with HD is experiencing. This will assist family and friends to better cope with any behaviour with which they are not familiar.

Some families consider a holiday package, where everything is organized for them. This alleviates some of the planning pressure as meals and activities are pre-planned. Try to learn as much as you can about the place you will be visiting, as this will help you anticipate what might be required. For example, if you are travelling to a resort call ahead to ask about booking a tour of the facility. This will introduce you to the staff at the resort, give you a chance to explain HD (including any special requirements needed such as meals, stairs) and provide you with the layout of the resort. This will also help you anticipate possible activities that may need to be adjusted to accommodate HD. Ask for a point person at the resort. This is someone who can provide that extra level of service you will require.

It is also important to have all medications organized and ordered ahead of time. Let your pharmacist know you are travelling and ask for any recommendations i.e. an anti-nausea medication might be required if going on a flight or on a cruise. You can also request a print out of the current medication list with names and doses to have with you in case of an emergency. In case of lost luggage or any other unforeseen circumstances, research the location of the nearest pharmacy and record the address and phone number, in advance.

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**NATIONAL VOLUNTEER WEEK**  
APRIL 23 - 29, 2017

CANADA 150

Crossword No.150 - **Volunteering, Eh?**  
How do you recognize volunteering in 2017?

ACROSS  
1. Volunteering improves this  
2. A leadership role that can be found in a dining room

DOWN  
3. Something you gain when you volunteer  
4. Expression of appreciation

volunteer.ca/nvw2017  
#NVW2017

Investors Group  
VOLONTÉRIE BÉNÉVOLES CANADA

# Amaryllis impact: 20,000+ reasons to smile

By Josh Martin

Say cheese! The Huntington Society of Canada's Amaryllis Photo Festival may have wrapped up, but there is still plenty to smile about. Throughout 2016, the Amaryllis team extended an invitation to share photos of the Society's official flower. As usual, the HD community stepped up in a big way, sending awesome snapshots of their bulbs and blooms in homes and offices, in front of Christmas trees and menorahs and with loved ones, furry friends and more.

Thank you to everyone who submitted photos or voted for your favourites. Congratulations to our shared first-place finishers Marilyn Lightfoot, Judy Stevenson and Kayly Erno for their winning entries!

The entire Amaryllis Campaign has HSC's Senior Manager of Development, Jeff Hoffman, grinning from ear-to-ear. Jeff notes, "In 2016, we completely sold out of kits, with more people than ever buying bulbs". According to Jeff, you can thank the hundreds of dedicated volunteers for his cheery mood, whether they are 30-year veterans or the slew of first-time sellers who participated last year.

"It's really inspiring," he says. "There's a real passion with this group to make a significant difference for individuals that are impacted by Huntington disease."

That effort translated to more than 20,000 bulbs sold and over \$115,000 raised for Huntington disease research and family services. The campaign also helped raise awareness about the disease and gave families across the



Kayly Erno



Judy Stevenson



Marilyn Lightfoot

country reasons to smile. "It helps inspire a sense of hope around a real positive future for everybody impacted by HD," says Jeff.

As always, the rave reviews about the flowers poured in. In fact, many veteran green thumbs tell us that HSC bulbs produce the best amaryllis blooms by far. That is due in part to the special, hardier variety that HSC uses. This variety is only grown in a few spots in Holland. It's also because HSC volunteers and growers put so much love into their plants.

Whatever the reason, the campaign sells out year-after-year, so get your 2017 orders in early!

HSC will launch the 2017 campaign on May 1, 2017. To reserve your amaryllis kits visit [www.inspirehope.ca](http://www.inspirehope.ca), call 1-800-998-7398 or email [amaryllis@huntingtonsociety.ca](mailto:amaryllis@huntingtonsociety.ca).

## How to manage stress – and why it is so important

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For some caregivers, troubling symptoms can show up months or even years after their loved one has died. If you find yourself grappling with intrusive thoughts and memories that won't go away, you may be experiencing a form of post-traumatic stress disorder. Symptoms to watch for include emotional numbness, anxiety, guilt, dread, depression and apathy.

In this situation, reach out for help. There are treatments available, including medication, so see your doctor. HSC's Family Services team can also offer short-term counselling.

Every person manages stress differently. No matter what symptoms you are dealing with, and whichever stage you are at in the caregiving journey, Corey offers a simple message. "Remember," he says, "you matter. You have the right to put yourself first sometimes."

To learn more about caregiver stress, speak to your HD Resource Centre Director or visit [www.huntingtonsociety.ca](http://www.huntingtonsociety.ca).

## HDClarity: How a new study will help researchers assess HD drugs faster

*continued from page 1*

That is why he put together HDClarity. This new international study, sponsored by CHDI, aims to collect samples of CSF from several types of volunteers: gene-positive people without any symptoms of HD, gene-positive people who have symptoms and people who are either gene-negative or have no family history of HD.

Participating in HDClarity doesn't involve a big time commitment. After an initial screening visit, volunteers will have a needle inserted into their lower spine to collect a small sample of CSF, a process called a lumbar puncture. "It is far less intimidating than you might think," Dr. Wild says.

"I've had it done to me three times, and I'm not a brave person. I shy away from avoidable pain," he says. "Having a lumbar puncture, for me, on all three occasions, was easier than having a dental anaesthetic."

Volunteers who are particularly keen to move research forward can opt for a second lumbar puncture six to eight weeks later. This second CSF sample will help researchers see how the levels of different proteins naturally vary.

Dr. Mark Guttman at the Movement Disorder Clinic in Toronto is currently looking for HDClarity participants. At the University of Alberta, Dr. Oksana Suchowersky is overseeing site setup, and Dr. Blair Leavitt in Vancouver will be starting to recruit soon.

By the end of 2017, Dr. Wild hopes to see a total of 30 sites up and running around the world. As the CSF samples flow in, the HDClarity team will use some of the precious fluid to measure levels of huntingtin protein and see whether they could be an accurate biomarker for Huntington disease. The team will also set some aside for other investigators who are conducting intriguing HD research.

Of course, the success of HDClarity depends on volunteers stepping forward. Dr. Wild calls these research participants "superstars." "They are all my personal heroes," he says. "They are the frontline in the fight against Huntington disease."

For more details on HDClarity, including a list of Canadian sites, visit the map of HD clinical trial site locations at [www.huntingtonsociety.ca](http://www.huntingtonsociety.ca).

# New Brunswick's big boost: The HD Resource Centre

By Josh Martin

For the past 16 years, Marthe Gautreau has faithfully supported individuals and families affected by Huntington disease as HSC's Family Services Worker in New Brunswick. But with budget constraints, her hours were limited and she was only able to do so much. That all changed in January, thanks to an incredibly generous four year funding commitment from Wayne Atkinson and his partner Marg Steed.

It all started when Wayne's son Mark received an unexpected Huntington disease diagnosis in 2015. Suddenly, the future looked very different for the Fredericton based freelance journalist, his wife and their 7-year-old daughter.

Wayne and Marg knew they could only offer so much hands-on support from their home in Toronto, but they were determined to do everything they could to ensure that Mark, and others in the same situation, received the care they needed. So they sat down with the Society to discuss possibilities.

The result is the Huntington Society of Canada's New Brunswick Resource Centre.

"I'm really, really excited," says Marthe, who retired from her full-time government job to take up directorship of the new centre. Thanks to Wayne and Marg's generosity, she now has dramatically more capacity to provide her clients with the services they deserve. "It is going to open up more doors for them," she says.

For starters, Marthe now has a direct toll-free number and a consistent schedule, making it easier to get in touch with her. Meanwhile, more hours means Marthe will be able to visit clients in underserved areas more often. She can deliver educational workshops to care facilities and other service providers more frequently. In addition, she is working hard to get support groups up and running in Moncton, Saint John and Fredericton.

And when National Office started putting together plans for this year's chapter-led Fall Symposium, Marthe said, "Put us on the list." New Brunswick doesn't currently have a chapter, but she is determined to get one up and running soon.

One of the biggest items on her list of priorities is resurrecting a Huntington disease clinic. Although

New Brunswick briefly had such a clinic several years ago, it closed down when the neurologist moved away. This forced New Brunswick clients with Huntington disease needing multidisciplinary care, to travel out-of-province. Already, Marthe has begun conversations with neurologists and other team members to get the ball rolling.

None of this would be possible without the amazing support of Wayne and Marg. "It's just wonderful that they have come forward to help us out in our mission," says Angèle Bénéard, HSC's Director of Family Services and Community Development. "These dollars are really going to make a difference for the families in New Brunswick."

For Wayne, it was a simple choice. "We saw the need and the lack of resources that were in New Brunswick and we said, 'here's how we can help,'" he explains. "We want anyone or any families that are touched by this disease to be supported."

To access services in New Brunswick and to connect with the New Brunswick Resource Centre, call Marthe Gautreau at 1-844-384-2345 or email her at [mgautreau@huntingtonsociety.ca](mailto:mgautreau@huntingtonsociety.ca).

## Announcing the 2017 HSC National Symposium

In communities across Canada, many individuals and families are affected by Huntington disease (HD). Countless social service professionals and health care professionals work with someone affected by HD on a daily basis. Even though each day offers a different challenge, these communities

wake up each morning to face HD with strength and perseverance.

Every other year, these communities of champions come together for a one-day conference. Together the HD community can learn and be inspired by one another, and they can offer support to each other.

In 2017, the Symposium takes place on October 14th. This Symposium will focus on facing the reality of HD, that no one can do it alone, and that collectively the HD community can transform, tomorrow, together. By working closely with volunteers, HSC is building a list of community hosts. This year, HSC is hoping to offer 20 viewing locations, making this Symposium the largest to date!

Participants will meet at a predetermined Symposium hosting site where two presentations will be live-streamed, allowing them to ask questions to presenters in real time. The focus of the presentations will be learnings and new developments in HD research. In some communities, local programming will also be added. This will provide further learnings on care strategies, services, or regional research information options, to facilitate networking

opportunities with other HD families, healthcare professionals and local HSC staff. Individuals are also welcome to join the streamed presentations from their home computer, providing a level of accessibility to information that otherwise may not be available for those unable to travel to a Symposium location.

For more information about this year's Symposium, visit

[www.huntingtonsociety.ca/symposium](http://www.huntingtonsociety.ca/symposium). If you'd like to host a Symposium viewing location in your community, or would like information about sponsoring Symposium, please contact [events@huntingtonsociety.ca](mailto:events@huntingtonsociety.ca).

### HSC 2017 National Symposium



For more information: [huntingtonsociety.ca/symposium](http://huntingtonsociety.ca/symposium)  
To host a symposium location: [events@huntingtonsociety.ca](mailto:events@huntingtonsociety.ca)



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HUNTINGTON'S DISEASE  
YOUTH ORGANIZATION

To learn more  
please visit [www.hydo.org](http://www.hydo.org)

# On the road again

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For individuals with HD, carry the HSC emergency card and ensure that it has the most up to date emergency contact information. Don't forget to keep a copy of the name and number of your hotel in a familiar spot as well. HSC recommends families register with MedicAlert. MedicAlert will provide an engraved identification bracelet which allows police and emergency responders, internationally, to quickly identify a person who gets separated. For information on MedicAlert, please visit [www.medicalert.ca](http://www.medicalert.ca)

Once you are on your way, try to make as few changes in the routine as you reasonably can. This will help the person with HD understand what is happening and anticipate next steps. Involve the person with HD in as many decisions as possible. Keep the decisions to a minimum, and depending on the stage of progression, frame the questions accordingly. See *Understanding Behaviour in Huntington Disease: A Guide for Professionals* (Third Edition) pages 19 - 22 for more information.

When it comes to method of transportation, try to get a direct flight, or if you are travelling by car for a long distance, consider extending the time to get there and driving shorter distances each day with frequent breaks.

If possible, have an additional person travel with you to help. Take the time to reflect on who would be the best person to assist you. If you are using a travel agent, make sure they are aware of any special needs and ask about additional support that could be prearranged.

Make sure you inform the airline that you are travelling with a person with HD. You may want to request early boarding, a wheelchair, transportation upon arrival, help getting on and off the plane or with stowing carry-on baggage. Check in early or prearrange seating near washrooms and with extra leg room.

If you are staying at a hotel, let the staff know about your needs, explain some of the possible difficulties you think you might encounter and ask for a point person, reducing the number of times you have to explain HD.

The Huntington Society of Canada wishes to thank the Alzheimer Society of Canada for sharing their tips for traveling. Modified with permission from the Alzheimer Society of Canada, [www.alzheimer.ca](http://www.alzheimer.ca). For a copy of *Understanding Behaviour in Huntington Disease: A Guide for Professionals* please visit [www.huntingtonsociety.ca](http://www.huntingtonsociety.ca)

## Find Clinical Trials in Canada

The Huntington Society has created a NEW interactive map, listing clinical trial sites across Canada.



To learn more about the trials and find locations near you, visit [www.huntingtonsociety.ca](http://www.huntingtonsociety.ca).



YOUTH  
MENTORSHIP  
PROGRAM

For more information, visit:  
[www.huntingtonsociety.ca](http://www.huntingtonsociety.ca)

# The Final Countdown: #LightItUp4HD 2017

By Sobia Khan

With less than 10 days away from the start of Huntington Disease Awareness Month, HSC is gearing up for another fantastic year of night skies illuminated in blue and purple across the country and across the globe.

Throughout the month of May, events in support of Huntington disease (HD) and Juvenile Huntington disease (JHD) are held all over the country bringing awareness and raising funds for research and services. After the creation of last year's social media campaign called #LightItUp4HD, volunteers and organizations from other countries reached out as well – they too wanted to be a part of the movement. This year, HSC has added Germany, Australia and several other nations to the roster. Each site will light up on a certain date in May (to find the full calendar visit [www.lightitup4hd.com](http://www.lightitup4hd.com)).

A big thank you goes out to each and every volunteer who took the time to get involved and illuminate sites. Your efforts, persistence and enthusiasm brought a visibility to Huntington disease and Juvenile Huntington disease that woke the world up in a fun and meaningful way. Because of #LightItUp4HD, more people know about HD and JHD.

Now, in the last few days leading up to the events, the entire global community is looking forward to flooding the Internet in blue and purple. Head out to a site near you, take photos and let the world know what #LightItUp4HD is all about.

Help us make this a global success. Share the buzz on social media. Check [www.lightitup4hd.com](http://www.lightitup4hd.com) to see what's happening near you.

## 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; Lembit and Karen Janes 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



# 2017 Spring Calendar of Events



## Indy's

**Sunday, June 25**

### St. John's Indy & Family Fun Day

St. John's, NL  
[events@huntingtonsociety.ca](mailto:events@huntingtonsociety.ca)

**Saturday, June 17**

### PEI Go Kart Indy Challenge

Kensington, PEI  
[www.hscevents.ca/peiindy](http://www.hscevents.ca/peiindy)



## Walks

**Sunday, April 30**

### 19th Annual Wiswell Family Architectural Gems Walk

Toronto, ON  
[www.hscevents.ca/GemsWalk](http://www.hscevents.ca/GemsWalk)

**Saturday, May 27**

### Vernon Walk/Run to End Huntington Disease

Vernon, BC  
[www.hscevents.ca/vernonrun](http://www.hscevents.ca/vernonrun)

**Saturday, May 27**

### Edmonton Walk to Cure HD

Edmonton, AB  
[www.hscevents.ca/edmontonwalk](http://www.hscevents.ca/edmontonwalk)

**Sunday, May 28**

### Durham Walk to Cure HD

Bowmanville, ON  
[www.hscevents.ca/durhamwalk](http://www.hscevents.ca/durhamwalk)

**Saturday, June 3**

### Exeter Hike of Heroes for Huntington Disease

Exeter, ON  
[www.hscevents.ca/exeterhike](http://www.hscevents.ca/exeterhike)

**Saturday, June 3**

### Winnipeg Walk/Run to Cure HD

Winnipeg, MB  
[www.hscevents.ca/winnipegrun](http://www.hscevents.ca/winnipegrun)

**Saturday, June 3**

### Saskatoon Walk to Cure HD

Saskatoon, SK  
[www.hscevents.ca/SaskatoonHDWalk](http://www.hscevents.ca/SaskatoonHDWalk)

**Saturday, June 10**

### Lafleche Walk to Cure HD

Lafleche, SK  
[www.hscevents.ca/LaflecheWalk](http://www.hscevents.ca/LaflecheWalk)

**Saturday, June 24**

### Windsor Walk to Cure HD

Windsor, ON  
[events@huntingtonsociety.ca](mailto:events@huntingtonsociety.ca)



## Runs

**Sunday, May 7**

### Toronto Goodlife Marathon

Toronto, ON  
[www.hscevents.ca/teamhd](http://www.hscevents.ca/teamhd)

**Sunday, May 7**

### Victoria Run/Walk for Huntington Disease

Victoria, BC  
[www.hscevents.ca/victoriarun](http://www.hscevents.ca/victoriarun)

**May 19 to 21**

### Scotiabank Bluenose Marathon

Halifax, NS  
[www.hscevents.ca/teamhd](http://www.hscevents.ca/teamhd)

**Friday, May 26**

### Sprint into Summer

Pierson, MB  
<https://secure.hscevents.ca/registrant/startup.aspx?eventid=212352>

**Saturday, May 27 & Sunday, May 28**

### Tamarack Ottawa Race Weekend

Ottawa, ON  
[www.hscevents.ca/teamhd](http://www.hscevents.ca/teamhd)

**Sunday, May 28**

### Scotiabank Calgary Marathon

Calgary, AB  
[www.hscevents.ca/teamhd](http://www.hscevents.ca/teamhd)

**Saturday, June 10**

### Calgary Hope Run for HD

Calgary, AB  
[www.hscevents.ca/calgaryhoperun](http://www.hscevents.ca/calgaryhoperun)

**Saturday, June 24**

### "Barker's Battle" Huntington Heroes Run

Coachman's Cove, NL  
[www.hscevents.ca/barkersbattle](http://www.hscevents.ca/barkersbattle)



## Golf

**Sunday, June 4**

### Golfapalooza HD Classic Golf Tournament

Niagara Falls, ON  
[beadestainsby@gmail.com](mailto:beadestainsby@gmail.com)

**Saturday, June 10**

### Brandon Golf Tournament

Brandon, MB  
[sandson10@hotmail.com](mailto:sandson10@hotmail.com)

**Saturday, June 17**

### 10th Annual Camrose Chapter Golf Tournament

New Norway, AB  
[RCampbell@leduc-county.com](mailto:RCampbell@leduc-county.com)

## Other

**Saturday, May 6**

### Benefit Concert featuring Eli and the Straw Man

Kitchener, ON  
<http://bit.do/GrandRiverConcert>



**Friday, May 12**

### Zumbathon

Newmarket, ON  
<https://secure.hscevents.ca/registrant/startup.aspx?eventid=212367>

**Saturday, May 13**

### Tats for a Cure 3.0

Victoria, BC  
<https://www.facebook.com/events/1738290639750708/>

**Thursday, May 18**

### Race for a Cure

Ottawa, ON  
<https://secure.hscevents.ca/registrant/startup.aspx?eventid=212345>

**Saturday, June 24**

### Edmonton Veterans Motorcycle Club Charity Ride

Edmonton, AB  
[secretary@vcmwest.org](mailto:secretary@vcmwest.org)

**Saturday, June 24 & Sunday, June 25**

### 100 Mile House Campout

100 Mile House, BC  
[dlbongers@yahoo.ca](mailto:dlbongers@yahoo.ca)

**Sunday, July 16**

### BBQ & Street Fair

Fredericton, NB  
[kecr2550@gmail.com](mailto:kecr2550@gmail.com)

**Friday, August 25 to Sunday, August 27**

### Ride 4 a Cure

Grand Prairie, AB  
<http://www.peacecountryhd.ca/>

Looking to get involved? To volunteer, participate, or for event ideas, please contact us at 1-800-998-7398 or email us at [events@huntingtonsociety.ca](mailto:events@huntingtonsociety.ca).

# Dan Devlin: Stepping up to the plate

By Josh Martin

Having a conversation with Dan Devlin about his contributions to the Huntington Society of Canada can be tricky. Not because there is a shortage of things to talk about. Quite the opposite. His support as a long-time board member, donor and tireless champion would give us enough fodder for a dozen articles. No, it is Dan's tendency to deflect praise to other people that makes it a challenge.

So when he was asked about receiving the Ralph and Ariel Walker Founders Award at the 2016 National Conference, it came as no surprise that he shied away from the spotlight. "For every person who gets one, there are ten other people in the room who absolutely deserve it," he says. "There should be an award for everyone in the trenches fighting these battles."

Dan is quick to point to the progress CEO Bev Heim-Myers has achieved on genetic fairness. He points to the enthusiastic young HD researchers he meets at scientific conferences. And then there's the "quiet grandmothers" of the HD community: the ones who don't know the meaning of burnout and run bake sales for the Society twice a year, every year.

For Dan, these people do more than raise money, spread awareness or provide support. They give those affected by Huntington disease the strength to keep going, knowing there are folks out there working

toward a brighter future. "People don't need much to get out of bed in the morning," he says. "All they are looking for is some hope."

Like many in the HD community, Dan first got involved with the Society because of his family. Although Dan is gene-negative, his father and two sisters were diagnosed with HD, inspiring him and his wife, Jill, to get involved.

In the early 90s, that meant making donations to support Dr. Michael Hayden's HD research, contributions that B.C.'s Children's Hospital Foundation recognized in 2010 with the naming of the Hayden-Devlin Lab. Meanwhile, the Devlin Fund for Families that Dan and Jill set up with the Huntington Society of Canada has provided vital support to many members of the HD community.

In 2007, Dan joined the Huntington Society of Canada's Board of Directors. Over the years, he has helped shape and guide the organization, including serving as Chair and, most recently, past Chair. However, for Dan, the real reward was seeing the HD community in action. "That is a privilege to be sitting in a board room and reviewing the results of what chapters across the country have done," he says. "It's heart-warming to see."

Throughout his long tenure, he has watched the Society grow by leaps and bounds and seen

incredible progress in HD research. He is encouraged by the new generation of people joining the cause, whether it is recently graduated scientists in the lab or young families coming out to a walkathon for the first time.

And of course, he is inspired by the stalwarts of the organization who continue to make a difference, decade after decade. "These are the people who are the absolute heart and soul of HSC," he says. "They just keep stepping up to the plate and doing their thing. It's amazing. It really is."

*The Society would like to extend its heartfelt gratitude to Dan, Jill and their family for their past and ongoing support. To read more profiles of the outstanding volunteers in the HD community, visit [www.huntingtonsociety.ca](http://www.huntingtonsociety.ca).*

## WE'RE SOCIAL

follow us on your favourite social media sites



## Youth Connections

By Jackie Skinner

Welcome to HSC's new youth column! As President of YPAHD (Young People Affected by HD), HSC's virtual youth chapter, I'm always on the lookout for new ways to get the word out about all the great things we are doing.

I have been part of this group since the early days, and it's heart-warming to see how much it's grown in just a few short years. We had a flood of applicants for last year's YPAHD Day in Halifax, with participants from every province. And it wasn't just those who are gene-positive or at-risk, we also had many partners there to support loved ones.

The event itself was amazing, with sessions on family planning, grief and more that really resonated with us. But I think the biggest benefits were for youth to see that they are not alone, that they are supported by others who are going through the same thing. Everyone I have spoken to has said it has changed their lives, and I'm sure the regional YPAHD days we're hosting this November in Moncton, Toronto and Kelowna will be just as powerful.

We are also planning another round of mentorship training, which will open up more spots for young people looking for peer support. (If you want to get involved, either as a mentor or a mentee, email [mentorship@huntingtonsociety.ca](mailto:mentorship@huntingtonsociety.ca) or call 1-855-253-0215). And thanks to Corey Janke, our new Mentorship Coach, we have more support for mentees and mentors than ever!

Meanwhile, there is funding available for the HDYO Camp in Maryland this August. If you want to attend this awesome event, contact the Huntington Society of Canada for an application at [info@huntingtonsociety.ca](mailto:info@huntingtonsociety.ca).

Finally, we are kicking off our YPAHD Champion Challenge in May, where we are encouraging youth

to come up with creative ways to raise \$25,000 for HSC. Whether it's flash mobs, bottle drives or knitting mittens, I'm excited to see what our passionate members think up!

To get involved in YPAHD, visit [www.ypahd.ca](http://www.ypahd.ca).

ARE YOU READY FOR  
**YPAHD DAY?**  
NOVEMBER 18 2017

MONCTON  
NEW  
BRUNSWICK

TORONTO  
ONTARIO

KELOWNA  
BRITISH  
COLUMBIA

YPAMD  
HUNTINGTON SOCIETY OF CANADA

YPAHD is a virtual Chapter of the Huntington Society of Canada led by youth, for youth.  
[WWW.YPAHD.CA](http://WWW.YPAHD.CA)



# An Ariel View

It is incredibly tough to lose someone you love. That is why Ralph always kept a copy of *Water Bugs & Dragonflies* to hand out to anyone who was grieving. It is the story of a colony of water bugs living at the bottom of a pond.

From time-to-time, one of them would climb up the stem of a pond lily and never return. The rest of the colony never understood why they left or where they went, so one day the bugs made a pact. They agreed that the next one of them to disappear up the lily stem would come back to explain the mystery.



When the next one climbed up the stem, he broke through the surface of the water and collapsed on the lily pad. When he woke up, he discovered he had transformed into a dragonfly. And because dragonflies can't swim, he couldn't go back to the other bugs to explain what had happened.

When Ralph died so unexpectedly in 2002, we read that story at his funeral to honour him and help our grandkids understand his death. Ever since then, I have worn a dragonfly pin in his memory.

But the story doesn't end there. For the past 14 years, once a year without fail, a dragonfly lands on my front door and stays there for the entire day. I'm convinced that it's Ralph, coming back to make sure everything is okay.

Based on this story, the Society engaged a designer from British Columbia, Chloe Angus, and an artist, Clarence Mills, to create a beautiful button wrap for the Society. I was presented with a dragonfly button wrap as a gift at the Huntington Society's 2016 National Conference. Together with the memories of Ralph, it is keeping me beautifully warm this spring.

To purchase a dragonfly button wrap, please visit [www.chloeangus.com](http://www.chloeangus.com).

Have a story to tell about your involvement with HSC? We are collecting memories of the impact the Society has made over the years. To share your story with Ariel, please contact us at [info@huntingtonsociety.ca](mailto:info@huntingtonsociety.ca) or call us at 1-800-998-7398.

# A Roller Coaster Ride to Genetic Fairness

By Julie Stauffer

For too many years, Canada has failed to protect genetic test information, unlike most western countries. Now, it finally appears Canadians will get the legislation we need. Parliament has officially passed Bill S-201, Genetic Non-discrimination Act (GNA), through 3rd reading. There are still steps to go, but we are further along than we have ever been.

The bill protects Canadians three ways. For starters, it provides pan-Canada protection making it illegal to use your genetic test information without your written consent. A breach of the GNA could lead to a significant fine and a prison term. It also amends the Canadian Labour Code, prohibiting employers from forcing an employee to take a genetic test, reveal the results of a genetic test or use genetic test information against the employee. Finally, it amends the federal Human Rights Act, which applies to federal government workplaces, making it illegal to discriminate against employees based on their genetic characteristics.

For all Canadians, and especially Canadians at-risk for Huntington disease, this is huge.

Getting to this point has been a roller coaster. In December, the Coalition was feeling very optimistic. At the hearings conducted by the Standing Committee on Justice and Human Rights, expert after expert testified on the need for robust protection of genetic information. And while insurance industry representatives opposed the Bill, the Committee unanimously supported it and sent it back to the House of Commons with only a single minor technical amendment.

After considerable push back and last minute tactics, fortunately, MPs listened to their conscience, and their constituents, and chose to do the right thing. On March 8, they passed Bill S201 as it was presented by the Senate Committee on Justice and Human Rights.



Cabinet may choose to send Bill S201 to the Supreme Court due to constitutional concerns even though Peter Hogg Q.C. and the foremost constitutional lawyer in the country testified that the Bill was constitutional. According to the Minister of Justice they will let the Parliamentary process take its course before they consider referring the Bill. Once the final hurdle is cleared Canadians will be able to have a genetic test based on their medical needs and personal circumstances, without fear of discrimination.

"Although disappointed by this last turn of events by the Liberal Cabinet, we are thrilled to have moved this far forward. The support from the majority of MPs in Parliament has been breathtaking. Led by Senator Cowan through the Senate and Rob Oliphant through the House, our government now fully understands that genetic discrimination is a reality in Canada. We have many champions that will help us end that reality," says HSC's CEO Bev Heim-Myers, who has spearheaded the Canadian Coalition for Genetic Fairness since 2010. "Our job isn't over. We still need legislation passed and we hope to work with each province to strengthen their human rights acts. But when strong pan-Canadian legislation is in place, we have a solid foundation to build on. We won't stop until it is".

To everyone who has worked so hard for this result, thank you. Today is a day to celebrate. To learn more about the Canadian Coalition for Genetic Fairness visit <http://ccgf-cceg.ca/en>.



## Happy trails to Susan...

By Julie Stauffer

For 28 years, Susan Tolley has helmed our B.C. Huntington Disease Resource Centre, supporting families across the province with her signature blend of energy, enthusiasm and positivity.

At UBC's Centre for Huntington Disease, she helped pioneer a multidisciplinary approach to serving people with HD. However, her greatest source of pride comes from transforming B.C.'s annual summer retreat into far more than a simple getaway for people with mid-stage symptoms. Today, the therapeutic retreat gives participants the opportunity to rediscover their strengths and equip themselves for the journey ahead.

Although Susan's job hasn't always been easy, it's been hugely rewarding. "The courage and resilience that families with HD have really inspires me," she says. Working with families affected by HD has taught her to do her best and to get the most out of each day. Meanwhile, the broader HD community has proved just how much is possible when people unite to make a difference. "That's powerful," she says. "I feel so grateful to have had that."

Those who know Susan won't be surprised by the long list of things she has planned for retirement, including yoga, art, furniture restoration and travel, starting with a trip to Peru. She heads off knowing that the B.C. HD Resource Centre is in capable hands under the direction of Antoine Coulombe. "He's taken the torch and he's going to move forward," she says.

And as the French say, this isn't adieu, but au revoir. Susan may be hanging up her hat, but she's not turning her back on a cause that means so much.

*Bon voyage, Susan! We'll see you at the Hike 4 Huntington disease this fall.*



## ... and to Shirley

By Julie Stauffer

For thousands of people who have called the Huntington Society of Canada over the past two decades, Shirley Barnes has been a warm, friendly voice on the other end of the line. Meanwhile, for her colleagues across the country, she has been a calm, organized teammate who has kept everything running smoothly.

Now, after almost 18 years of service, Shirley is retiring. And she will be missed.

It was fate that brought her here in 1999, she says. She started looking for work, initially without success. "Then I saw the advertisement for this position," she says. "I thought, that's me. That's exactly it."

The Society thought so too. Shirley brought the compassion and understanding that was needed, as well as a slew of administrative skills.

In the years since then, she has provided behind-the-scenes support to almost every aspect of the Society and relished the opportunity to grow both personally and professionally. "I learned from my coworkers, I learned from our Family Services ... but I especially learned a lot about life from the families," she says.

For her, the best part of the job has been seeing the Society grow and knowing how much difference that makes for our families. "I'm proud to be part of an organization that has been able to reach out to such a large community and to help others understand that community," she says.

*Thanks, Shirley, for all your contributions. We wish you a very happy retirement!*

**Believe**  
*Transforming Tomorrow Together*

## Campaign Update

The Believe: Transforming Tomorrow Together campaign is a three million dollar, three year fundraising campaign focusing on the many activities that the Society is leading. On the research front, HSC has a proud history of providing strategic funding to investigators through the NAVIGATOR and NEW PATHWAYS research grants leading to promising treatments that have reached the stage of clinical testing.

While research is paving the way to treatments, HSC's Family Services team provides vital support and advocacy for people living with the impact of HD right now. By broadening and strengthening our foundation of support, we can do more. With increased capacity and tools, the team can increase our reach and help as many individuals and families affected by HD as possible, including those in rural and isolated communities, work to increase the number of multidisciplinary clinics across Canada, expand HSC's youth programs, and continue to work closely with the federal, territorial and provincial governments to end genetic discrimination.

To date, the campaign cabinet has raised \$1.92 million and continues to open doors and introduce HSC to new and valuable relationships. These funds are already making a substantial difference and, together with the HD community, changing the reality of Huntington disease. A good example of how the campaign has already made a significant difference is the establishment of the new HD Resource Centre in New Brunswick, supported by the Mark Atkinson Family Fund.

The campaign cabinet is interested in developing more opportunities and invites the HD community to share the names of companies, foundations, organizations or individuals who may be interested in contributing to the Believe campaign.

*To learn more about our transformational campaign, our campaign cabinet and our honourary chair, visit [www.huntingtonsociety.ca](http://www.huntingtonsociety.ca) and to recommend a lead, please contact us at [info@huntingtonsociety.ca](mailto:info@huntingtonsociety.ca).*

## Making A Difference

# Tara Johnson-Ouellette: Leaving a lasting impact

By Josh Martin

Tara Johnson-Ouellette first discovered the Huntington Society of Canada 23 years ago, when her mother was diagnosed with Huntington disease. The Society offered crucial support as Tara looked after her mother and later, when she decided to undergo genetic testing.

Tara has returned that support, as a committed volunteer, Board member and donor. Now, she is ensuring her commitment continues long after she is gone by including HSC as a beneficiary in her estate planning.

For Tara, leaving a gift to the Society in her will offers a powerful way to keep her mother's memory alive. It also provides a way to help others affected by HD: members of her own family, as well as the hundreds of families she has gotten to know in Calgary and across the country.

She knows her gift will be put to good use. During her six-year tenure on the HSC's Board of Directors, Tara learned firsthand how every dollar makes a difference. She has seen how donations have benefited families in their day-to-day lives – by hiring more social workers, funding HSC's youth chapter programs, supporting advocacy efforts around genetic fairness and more. "It's pretty outstanding," she says, "but there's still a lot of need."

She has also seen how donations are supporting game-changing HD research and how a shortfall in funding can leave potential breakthroughs on the table. For Tara, a legacy gift is a wonderful

way to help address those needs beyond her own lifetime.

Although she doesn't carry the mutant HD gene, being part of the HD community has taught her the importance of making the most out of life. For her, that includes having a positive impact on the world after she dies. "Leaving something in your will creates your legacy," she says.

Many people shy away from the topic of estate planning. They don't feel comfortable thinking about death, or they worry about complicated paperwork and steep fees. However, "it's not as intimidating as you might think," says Tara. "Your lawyer, financial advisor and insurance agent can all help you develop a giving strategy tailored to the specific needs of you and your family."

Today, Tara continues to support the Society as a monthly donor and an active member of the Southern Alberta Chapter. As a legacy donor, she is also helping to transform the face of HD tomorrow, and she invites others to contribute to that transformation.

"Whether you have the disease, carry the gene or look after someone who is affected, HD shapes you," she says. "Everybody has the decision to make that either a positive or a negative," she explains. "For us, we've made it a positive."

You can too.

*Thinking of making a planned gift to the Huntington Society of Canada? For more information, contact the Society at 1-800-998-7398 ext. 125 or via email at [info@huntingtonsociety.ca](mailto:info@huntingtonsociety.ca).*

## Are You a Supporter of the Huntington Society of Canada?

### Interested in getting more involved?

HSC is now accepting nominations to its Board of Directors for vacancies beginning in 2017 and 2018. This national board includes 15 directors from across the country who combine enthusiasm for the work of the Society with expertise in one or more areas of business including law, fundraising, communications, strategic planning, media and human resources. If you, or someone you know, is interested, please let us know. There is a process that we follow, and expertise that we are looking

for, but it starts with your interest. Forward your CV and Letter of Interest outlining your skills and experience to:

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

All nominations received by May 7, 2017 will be considered.

## Serving up support, well done

By Josh Martin

If you find yourself at a Keg Steakhouse with a server named Bri Vojnovich, don't be shy about leaving a big tip. Last year, The Keg Spirit Foundation recognized Bri with a \$1,000 honourable mention award to be donated to the charity of her choice. Her pick? The Huntington Society of Canada.

The award, which is given to Keg employees who demonstrate outstanding contribution to their communities, was well deserved. Among other volunteer initiatives, Bri helped spearhead a massive fundraiser two years ago in the parking lot of Kelowna's then still-to-open location. The outdoor extravaganza was a huge success, raising over \$41,000 for Big Brothers Big Sisters of the Okanagan and WE Charity.

According to Bri, the chance to contribute to these kinds of events is one of the big benefits of working for The Keg. "My family instilled in me that it was important to give back in whatever shape or form you could," she says. And she's done just that: running laps at an Easter Seals relay, getting her hands dirty with the local parks and recreation department and representing her community in the Miss Nanaimo Ambassador program.

Given Bri's compassionate nature, it's not surprising her manager passed her name along to Carolyn Torhjem, the Executive Director of The Keg Spirit Foundation. Equally unsurprising was Carolyn's enthusiastic response to Bri's nomination. "The people that volunteered alongside her and attended the event just couldn't say enough great things about her," she says. "She is such an inspiring person... very organized, tons of spirit."

Although Bri's family is not directly affected by Huntington disease, her best friend discovered she was gene-positive last year. As such, directing her prize money to the HSC's youth programs felt like the right thing to do. But she's not stopping there. Bri and her friend are now hard at work organizing a run in Victoria this May to support the Society.

Judging by her impressive track record, this next event is definitely another one to get excited about. "She is extraordinary," says Carolyn.

*The Society extends its sincere appreciation to The Keg Spirit Foundation and to Bri for her efforts to raise awareness and funds. If you are interested in hosting an event or raising awareness for the Society, our Chapter Development Team is here to help. Contact them at [events@huntingtonsociety.ca](mailto:events@huntingtonsociety.ca).*

# Celebrating Our Heroes

## Amy Nichol: Translating personal skills into meaningful action

**By Josh Martin**

Ever since Amy Nichol was a young child, Huntington disease has been a part of her life. Her grandfather and dad passed away from HD, and many in her extended family continue to grapple with the disease. That's why, from an early age, Amy has been giving back.

As a kid in Saskatchewan, that meant zipping around the track at the local HSC go-kart fundraiser. She kept up those efforts as an adult in Toronto, hitting the trails in local walkathons, participating in an awareness event at a Raptors game and becoming a monthly donor, giving HSC funds to count on.

Although she's always on the lookout for opportunities to help, Amy admits it can be a challenge. Today, the 30-year-old criss-crosses the continent as a flight attendant: a profession with the kind of ever-changing schedule that doesn't always jibe with volunteer commitments.

But one day last year, Amy needed to call the HSC office to update information for her monthly donation. She went to the website to get the phone number. Since she had just recently finished a translation degree, she clicked on the French version of the site to see what was there. What she found wasn't as robust as the English version. "I thought, well maybe that's a golden opportunity," she says. "Translation just kind of fit nicely into a way I could help."

So when she called us with her updated information, she also offered up her translation services. "We were thrilled," says Sobia Khan, HSC's Communications Coordinator. Since then, Amy has translated information about the science of HD and HSC's research grants, as well as loads of social media content. "Thanks to Amy, we are able to expand our reach and offer more to Francophones across the country."

And, for Amy, educating more Canadians about HD is hugely rewarding. "The more people that know, the better," she says.

To visit the French side of the Huntington Society of Canada's website, visit [www.huntingtonsociety.ca](http://www.huntingtonsociety.ca) and click on Français at the top right hand corner. If you are interested in volunteering for the Society in a non-conventional way, let us know at [info@huntingtonsociety.ca](mailto:info@huntingtonsociety.ca).

# Volunteer week: Caring and connecting

**By Josh Martin**

Mary Lou Nicolson Klimek clearly remembers the day she met Ralph Walker at an HSC chapter meeting in Calgary. "He turned to me and he said, 'Ha! They sucked you in, eh?'" she recalls. "They did indeed, and 30 years later I'm still working with our families."



**Mary Lou Nicolson Klimek**

It all began when Mary Lou took a job as a nurse at Calgary's genetic clinic in 1984. To get to know her patients with HD better, she sat in on a local support group meeting. When she saw how many participants were starving for medical information and resources, Mary Lou knew she had to help.

Mary Lou became an invaluable resource. "They didn't feel they had any medical or community support," she says. "So I connected them."

For a short time, Mary Lou was a volunteer with the HDSA National Office in New York City. For ten years prior to retirement, Mary Lou was the HD Genetic Research Coordinator for all the HD Research Trials at the University Of Calgary. Volunteering is another matter. You'll still find her at most support group and chapter meetings. She also uses her formidable powers of persuasion to sell amaryllyis and recruit volunteers for Calgary's annual HD run.

Mary Lou is part of a network of volunteers that choose to give their time, skills and talents in making a difference locally, provincially and nationally. From April 23 – 29, the Huntington Society of Canada is celebrating all HSC volunteers, including Mary Lou, during National Volunteer Week. Visit [www.huntingtonsociety.ca/nvw2017](http://www.huntingtonsociety.ca/nvw2017) to see some of the fantastic work of HSC volunteers.

2017 also marks Canada's 150th anniversary, and, along with Volunteer Canada's annual National Volunteer Week initiative, this year the Society wants to challenge the HD community to contribute 150 hours of volunteer time. The challenge encourages Canadians to give back in celebration of Canada's 150th anniversary. Create a profile and start tracking your hours because those who contribute the most hours in each province and territory will be invited to Ottawa to be recognized in a ceremony!

To learn more about National Volunteer Week, the 150 for 150 Challenge, and to create your profile, please visit [www.huntingtonsociety.ca/nvw2017](http://www.huntingtonsociety.ca/nvw2017).

## Thank you

On behalf of families living with HD, thank you for your continued partnership and generous support. Our community makes the difference as we reach out to families who are not yet connected to HSC, continue to support and advocate for families from coast to coast, invest in world-class research, and play a leadership role in the international Huntington disease community. With your help, we are continuing to improve the quality of life for people with HD, cultivating strength and resilience in the Huntington disease community and providing substantive reasons for hope. If you have questions, story ideas or comments about *Horizon* or the Huntington Society of Canada, please contact us at [info@huntingtonsociety.ca](mailto:info@huntingtonsociety.ca) or call us at 1-800-998-7398.

The Huntington Society of Canada is committed to reaching out to as many Canadians as possible. Should you wish to explore the French side of our website, select the Français option at the top right hand corner of our website [www.huntingtonsociety.ca](http://www.huntingtonsociety.ca). We partner with the Huntington Society of Quebec. Their resources can be found at [www.huntingtonqc.org](http://www.huntingtonqc.org).

La Société Huntington du Canada a pour mission d'éduquer et d'aider autant de Canadiens que possible. Si vous souhaitez explorer la partie française de notre site Web, veuillez cliquer sur l'option française en haut à droite de la page suivante : [www.huntingtonsociety.ca](http://www.huntingtonsociety.ca). Nous travaillons également en étroite collaboration avec la Société Huntington du Québec, vous pouvez visiter leur site Web à : [www.huntingtonqc.org](http://www.huntingtonqc.org).