HORIZON

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Supreme Court Ruling a Win for all Canadians

Decision Upholds Genetic Non-Discrimination Act

By Julie Stauffer

When Bev Heim-Myers read the Supreme Court of Canada (SCC) ruling on the constitutionality of Canada's Genetic Non-Discrimination Act (GNDA), her hands shook. "It was a very emotional moment," says the chair of the Canadian Coalition for Genetic Fairness (CCGF), who led the fight for genetic privacy.

In a landmark 5-4 decision in July, Canada's top court upheld the GNDA. According to Bev, it is a massive win for all Canadians – and especially the Huntington disease (HD) community.

A Victory Decades in the Making

As a PhD student in genetics in the late 90s, Yvonne Bombard noticed stories of discrimination kept cropping up among patients visiting the University of British Columbia's HD clinic.

So she dug deeper, conducting interviews and launching a survey of people living in Canada who either carried the HD gene mutation or were at-risk. Her groundbreaking research revealed that more than one in three of them had experienced discrimination – despite the fact they had no symptoms.

Many were denied insurance, charged higher premiums, or forced to take a genetic test in order to qualify. Others were deprived of job promotions or had adoption applications turned down. And there were no laws to prevent it.

Nancy Barteaux, a lawyer based in Halifax, NS, knows that well. When her brother-in-law, Steve, was in his 20s, with a wife and young family to support, he wasn't able to get life insurance. Although he had no symptoms of HD, his mother had died of the disease.

Obtaining insurance is an important way for individuals to protect their families. "It's not fair that they take away a person's right to make choices," Nancy says.

Creating the Canadian Coalition for Genetic Fairness

Dr. Bombard's research attracted international attention, but she wanted to do more. So she worked with the Huntington Society of Canada (HSC) to found the CCGF. Launched in 2009, it brought together more than a dozen organizations to push for genetic privacy legislation. Ultimately, the coalition grew to 20 organizations, including Parkinson's Canada, Alzheimer's Canada, ALS Canada, the Foundation Fighting Blindness and the Centre for Israel and Jewish Affairs.

The fledgling coalition organized events, put out media releases and worked with supportive Members of Parliament (MPs) to introduce bills banning genetic discrimination. Unfortunately, each effort either died on the order paper or failed to pass.

The Bill S-201 Rollercoaster

In 2012, CCGF shifted their focus to Senate. There, they found a willing ally in Senator James Cowan, then leader of the Liberal Party of Canada (Liberal) opposition. Together, they crafted a bill barring insurance companies and employers from requesting genetic testing or asking for results. After several attempts, Bill S-201 was ultimately passed by the Senate in 2016 with unanimous support.

CCGF/CCEG

The Supreme Court of Canada in Ottawa, ON.

The next step was winning approval in the House of Commons, where Liberal MP, Rob Oliphant, championed the bill. The insurance industry strongly opposed it, however, and the Minister of Justice saw issues with its constitutionality.

Last-minute amendments to gut the bill failed to pass. When the final vote was called, the Liberal cabinet voted against Bill S-201. However, in an unheard-of split, all but four Liberal backbenchers supported it, as did the entire Conservative Party of Canada (CPC) and New Democratic Party (NDP) caucuses. On May 4, 2017, the GNDA became law.

Taking it to the Courts

The celebrations were short-lived, however. Just a few weeks later, the Government of Québec challenged the constitutionality of the new law, and the fight moved to the courts. The CCGF brought in Joe Arvay, one of Canada's top constitutional and civil liberties lawyers, to fight the case.

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INSIDE

HORIZON

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

Huntington disease (HD) is a hereditary, neurodegenerative illness with physical, cognitive and emotional symptoms. Symptoms vary from person to person and at different stages of the disease but may include involuntary movements and difficulty with focus and thought. Symptoms usually appear between the ages of 35 and 55, and gradually worsen over the 10-20 year course of the disease. But HD can also appear in youth (under 20 years – Juvenile HD) or older adults (Late Onset HD). As yet, there is no meaningful treatment.

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

Managing Editor:
Lianne (Lia) Appleby

Community Editors:
Luca Henriksen
Gillian Weatherall

Layout: Real World Graphic Design

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

Huntington Society of Canada
20 Erb St. W., Suite 801
Waterloo, ON N2L 1T2

Tel: 519-749-7063
Toll-Free: 800-998-7398

Email: info@huntingtonsociety.ca
Website: www.huntingtonsociety.ca

Charitable Registration Number:
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Message from the CEO

Thank you to everyone who has welcomed me with such warmth since I joined the Huntington Society of Canada (HSC) in July. COVID-19 has prevented me from meeting you face to face, but I have had the chance to connect by phone and videoconference with many volunteers, supporters and researchers – and, of course, our incredible staff.

I feel tremendously fortunate to work with a team that is so passionate about what they do and with a community that is so committed and engaged. HSC really feels like a big family. In tough times, families come together and that is certainly what I am seeing here. During this extraordinary pandemic, everyone has rallied in extraordinary ways.

Our volunteers found creative ways to mark Huntington disease (HD) Awareness Month in May and raise funds for valuable HD research and family support services. Our family services team embraced videoconferencing technology and moved their support groups online and Young People Affected by HD (YPAHD) has achieved great success with their new Facebook Live sessions.

However, what has struck me most is the determination that has enabled a small, grassroots organization to achieve so much. The Genetic Non-Discrimination Act (GNDA) is just one example. The Supreme Court of Canada's recent decision to uphold the GNDA is a win for all Canadians – and it was made possible thanks to many members of the HD community who spoke up for genetic fairness over the past decade.

In this issue of *Horizon*, you will also read about Triplet Therapeutics' new observational study that will pave the way for Phase I trials next year to test an entirely new way to treat HD. It is no coincidence that the first site to begin running the study is right here in Canada. We also profile HSC's latest clinical fellow, neurologist Dr. Dung Nguyen, who hopes to bring clinical trials to Winnipeg, MB.

Although COVID-19 has forced us to postpone the national conference originally scheduled for this fall, I hope you will join us virtually for our Community Education Forum (CEF) series. Our first virtual CEF in May was very successful, and we hope to build on that engagement in November. On Nov. 14, we will go live with an update on the latest research developments with the ever-popular duo of Prof. Ed Wild and Dr. Jeff Carroll. Meanwhile, our events team and volunteers have put together a host of online fundraisers and even some in person events. Be sure to check our events calendar!

Clearly, COVID-19 has affected HSC's operations and our revenues. However, our board and staff have risen to the challenges of our current reality and have embraced new ways of operating and new possibilities. Adversity brings with it the potential for opportunity and growth and I am really excited by what the future holds.

This is especially true when it comes to clinical treatments, and I feel that same energy from everyone I talk to. I am looking forward to working alongside HD researchers and helping bring these drugs to market.

I am also looking forward to travelling widely and connecting with many of you in person as soon as COVID restrictions are lifted. In the meantime, I invite you to reach out to me by phone or email.

In closing, I would like to extend a special thank you to Bev Heim-Myers, for returning to HSC to serve as interim CEO, as well as her tremendous work as chair of the Canadian Coalition for Genetic Fairness and her advocacy for the GNDA. It was a pleasure working with Bev closely for my first month, as I took over the reins of this wonderful organization.

Shelly Redman
CEO
Huntington Society of Canada

Huntington Society of Canada
HUNTINGTON
Société Huntington du Canada

Supreme Court Ruling

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After the Québec Court of Appeal ruled the GNDA fell outside Parliament's criminal law power, the CCGF appealed to the Supreme Court of Canada. Last October, the CCGF team presented their arguments at the highest court in the land, opposed by the Attorneys General of both Canada and Québec. And then they waited.

The Power of Collaboration

Nancy Barteaux breathed a big sigh of relief when the final decision was announced: the federal government has the constitutional right to protect the genetic privacy of Canadians. The ruling comes too late for her brother-in-law, who died of HD in 2014. But her niece and grand-nephew – and other individuals at-risk for HD – will not have to deal with the struggles and uncertainty that Steve did.

"I'm very thankful for the work of HSC and the work of all the other organizations that supported the case and moved it forward," she says.

"It was a wonderful team effort," adds Senator Cowan. "And the significance and the importance of this is increasing with each passing day."

When he proposed Bill S-201 in 2013, fewer than 2,000 genetic tests were available. Today, that number has ballooned to more than 76,000. The results can inform everything from risk of heart attack to the best cancer treatment.

Fear of discrimination prevented many people from taking tests that could help them make informed choices or participate in research that could lead to new treatments. Now, those barriers have been removed. "Finally, after all these years, the law has caught up to the science," says Bev.

And the benefits extend even further. "This was a case with profound implications," explains CCGF lawyer Joe Arvay. "The decision upholds the right of Parliament to prohibit and punish actions that threaten public health, autonomy, privacy or equality."

This achievement would not have been possible without the HD community, who stepped forward time and time again to share their stories in Parliament and in public, making it clear just how much was at stake.

All parties involved in the quest to protect genetic test information for all Canadians – including the Canadian Human Rights Commission and the Office of the Privacy Commissioner of Canada – agree that against all odds, mountains can be moved when using the power of a collaborative effort.

Cultivating Hope with HSC's Amaryllis Campaign!

It's that time of year again! The Huntington Society of Canada (HSC) is very excited to kick off the 2020 Amaryllis campaign. The goal this year is to sell over 25,000 bulbs and inspire hope in as many lives as possible!

The Amaryllis is the signature flower of HSC. Amaryllis volunteers across the country sell bulb kits to help raise vital funds for HSC's programs in research, services and education. Every year, around 20,000 Amaryllis bulbs bloom from coast to coast, inspiring hope for a world free of Huntington disease (HD). Since 1985, HSC's dedicated volunteers have raised well over $5 million in support of HD.

"I think this year's campaign will really showcase the strength of our community," says Rachel Thompson, HSC's manager of development (and coordinator of the Amaryllis campaign). "Throughout these unprecedented times the HD community has really banded together; it's been so inspiring!"

Amaryllis kits are priced at $15.00. Each kit is packaged in a lovely gift box, which contains one high-quality Orange Souvereign bulb, growing instructions, soil, a planting pot, a plant stake and a saucer. They come in cases of 12 kits and are shipped across Canada.

Orders can be made at any time, with delivery dates from October to December.

Bulbs can be planted immediately after receipt or can be stored in a cool, dry place for later. Many people like to give them out as holiday gifts. Gorgeous orange-red blooms will appear approximately 6-8 weeks after planting.

Each kit HSC sells means being a step closer to finding a treatment for HD or supporting another family with HD. Every Amaryllis bulb blooming in someone's home or business holds the promise of a world free from this disease.

"I'm excited to see the support through sales and our volunteer sellers" adds Thompson. "I think this year's campaign will be our best yet."

Government of Canada Charitable Campaign Set to Launch

By Eileen Dooley, CEO, HealthPartners Canada

Donations to HealthPartners directly help 16 of Canada's most trusted health charities – including the Huntington Society of Canada (HSC) – which all work to prevent chronic disease and to care for those affected by it. The arrival of COVID-19 poses a serious threat to all of us, especially those Canadians who live with a chronic disease. At HealthPartners, we witness the impact of COVID-19 every day. In every workplace. In every family. In every community.

Chronic disease does not stop during a pandemic, but donations do. HealthPartners' member charities are on the front line, working tirelessly on behalf of Canadians who are among the most vulnerable to COVID-19. These member charities are now reporting a significant and immediate financial challenge as they adjust to the pandemic.

It is a critical time for Canadian scientists who are conducting leading-edge research as the pursuit for effective treatments for Huntington disease (HD) continues. For those in the HD community, treatment cannot come soon enough. Several very promising drugs are undergoing clinical trials right now, and even more are in the pipeline. HealthPartners is proud to have contributed to the success of this research through 30+ years of partnership with HSC. Donations to HealthPartners will help ensure that this research continues.

The Government of Canada Workplace Charitable Campaign (GCWCC) launches this fall. To date, HealthPartners has raised over $179 million for our member charities. If you know federal government employees, please take a moment to thank them for their generosity and remind them that they can support HSC and HealthPartners through the GCWCC, which raises money for the important work our member charities do.

Every donation to HealthPartners helps improve the lives of people in Canada living with diseases like HD.

HealthPartners

Charities At Work

A New Virtual Reality

By Josh Martin

For families affected by Huntington disease (HD), connecting with others who are living with or facing the same issues offers comfort, counsel and strength. That is more important than ever as COVID-19 adds new layers of stress, but the pandemic has forced the Huntington Society of Canada (HSC) to put in-person support groups on hold.

To fill that gap, the family services team has gone online.

Consider the Closed Facebook Group, managed and moderated by Corey Janke, HSC's national social worker. Launched last fall, this online platform provides a safe space to share stories, ask questions and find practical coping strategies. "It's a place for people to drop in around the clock, seven days a week, to post whatever's on their mind," says Janke.

Today, the group has nearly 300 members, and Janke has added new features like facilitating live discussions. Looking ahead, he hopes to organize presentations from guest speakers. But the biggest benefit of the group is the lived experience of its members. "I have been really impressed with the amount of support that people are receiving from others within the HD community by being part of this group," he says.

There is also HSC's new virtual support group for people who are at-risk or gene-positive – a pilot project that was in the works before COVID-19 hit. While most of HSC's groups focus on carers or people with HD symptoms, this new initiative offers a forum to discuss issues like relationships, family planning and whether or not to get tested. It is a group for those living at-risk or gene positive.

"I think that it is a great opportunity for sharing and learning from one another," says Janke, who launched the six-week pilot project in July. If feedback is positive, he plans to run the group regularly.

In Western Canada, resource centre director Rhonda Romolock is launching a new online group to reach carers across the province, in addition to shifting her regular Vancouver, BC, carer support group online.

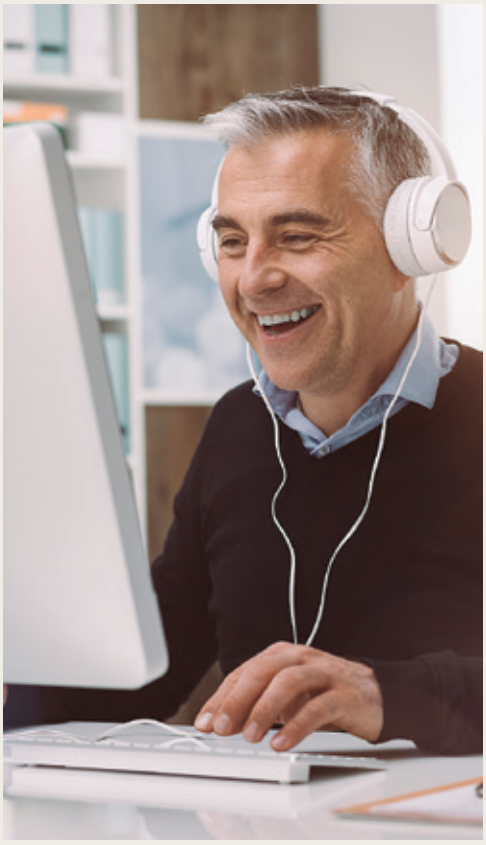
Romolock points to several advantages of virtual meetings. For starters, it gives carers living in remote areas a chance to participate and those in larger centres, an HD specific group. "It's a large province and we wanted to expand beyond our Vancouver and Victoria carer groups," she explains. "So this is an exciting way to reach more people."

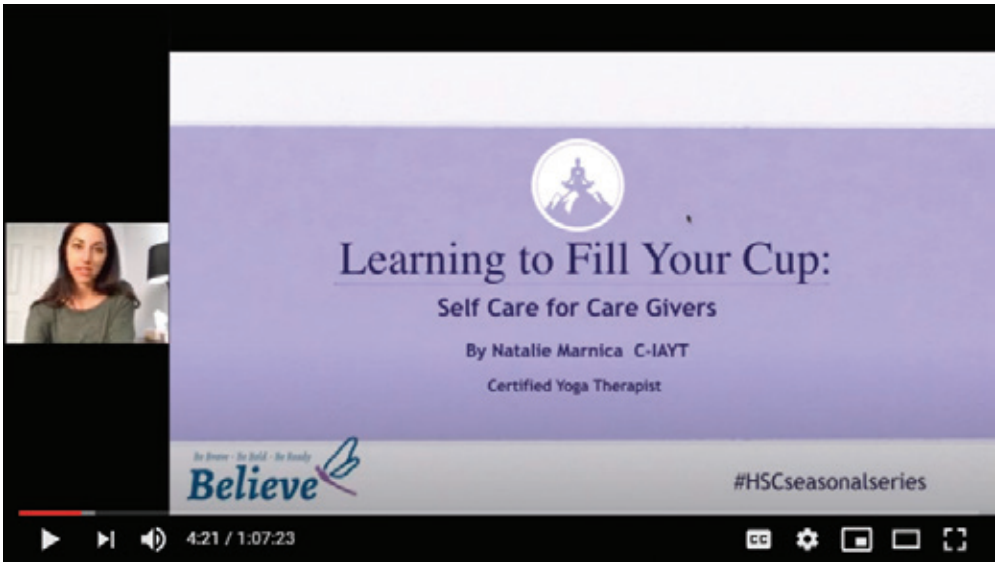
For someone caring for a loved one whose health is deteriorating, it becomes increasingly difficult to leave the house to attend a meeting. Virtual groups like Romolock's give them the freedom to connect online (or by teleconference if they don't have access to the Internet).

Videoconferencing comes with challenges, of course, from technology glitches to learning how to connect with each other virtually rather than in person. But due to the pandemic, people are getting more comfortable with how it works.

According to Romolock, online meetings can open up new opportunities for people to connect with others in the HD community and get crucial support – thanks to technology, wherever you live you can still access face to face support. "I see it as being a really great extension of the services that we have," she says.

To learn more about virtual support groups, contact your local family services worker. Interested in HSC's closed Facebook group? Visit www.huntingtonsociety.ca/closed-facebook-support-group.





2020-2021 Community Education Forum Seasonal Series

The Huntington Society of Canada (HSC) is pleased to be offering three live broadcasts as part of a 'Seasonal Series' of Community Education Forums (CEFs) which runs until February 2021.

The seasonal series offered by HSC kicked off in May with a presentation on self-care for the caregiver by Natalie Marnica. With 58 participants on the webinar, HSC achieved its highest ever attendance for a virtual meeting. A recording of the presentation can be found on HSC's YouTube channel.

The second CEF will go live Saturday, Nov. 14 at 1:30 p.m. EST and focuses on the latest updates in Huntington disease (HD) research. The 1-hour broadcast will be led by Prof. Ed Wild and Dr. Jeff Carroll. Prof. Wild and Dr. Carroll are co-founders and editors of HDBuzz, an online resource providing HD research updates in layman's terms. In recognition of their efforts, HSC awarded the duo the Michael Wright Community Leadership Award in 2012. Prof. Wild is Professor of Neurology at University College London (UCL), and Associate Director of UCL's Huntington's Disease Centre in the United Kingdom. He has worked on HD since 2005 and leads a team focusing on clinical trials of new HD treatments and studying cerebrospinal fluid to understand HD. Dr. Carroll studies HD as an associate professor at Western Washington University and has worked for many years on huntingtin-lowering experiments in mouse models. Dr. Carroll is a member of an HD family and himself carries the gene mutation which causes HD.

"It's a time of great progress and excitement in research to develop and test new drugs to fight HD, but lots of new therapies means more research and terminology that could confuse and overwhelm, and more hype that could lead to disappointment," notes Wild. As such, Dr. Carroll and Prof. Wild will walk participants through what's going on, what's coming soon, what it all means and where to direct excitement and energy in order to help in the fight.

The series concludes with a presentation led by Clare Gibbons, genetic counsellor at Toronto's North York General Hospital on Saturday, Feb. 27, 2021. The presentation will focus on genetic testing and the variety of considerations when being tested for a gene mutation like the one carried by individuals with HD.

Pre-registration is required in order to receive login information for the webinars. Those interested can learn more at www.huntingtonsociety.ca/cef. As with the first webinars, the remaining two will also be posted to YouTube after the event.

HSC sincerely thanks Series Sponsors Roche and Novartis for making the CEF Seasonal Series possible.

Roche

NOVARTIS

An Ariel View

By Ariel Walker, HSC Co-Founder

These are difficult times, aren't they? I hope you and your family have been managing through this pandemic!

I can't say I've enjoyed social isolation, but at least it's given me an opportunity to clear out my crawl spaces and go through my cupboards. You wouldn't believe how much I got rid of! I've also been busy sewing face masks. With the help of some nursing buddies and neighbours, as well as my daughter Lara, we've made 1,600 or 1,700 masks for local nursing homes and retirement homes. They've just been thrilled!

Keeping occupied has definitely helped. I've also adopted two delightful cats to replace 16-year-old Dougal, who died last Thanksgiving. And, of course, I've been speaking with lots of family and friends – and visiting at a safe distance.

This pandemic is a pain in the rear end, but I'm adapting. I had never heard of Zoom before, but now everybody's Zooming, and I just learned how to FaceTime with my grandchildren. It's so great that we live in a time where technology can keep us connected!

I know the Huntington Society of Canada (HSC) is adapting as well. As an organization, we've certainly faced tough times in the past. There were many weeks early on when we wondered whether we could make the payroll. But we always managed, and we'll manage now. This is a resilient community, and together, we'll get through this.

I'm sure we'll find ways to make sure the scientists can keep working on treatments and HSC can keep supporting families. I know staff are offering virtual support, and we'll have virtual Community Education Forums (CEFs) instead of the conference this year. And the volunteers are doing incredible online fundraisers, like Sophie Pollock's lovely dragonfly keychains.

For Ralph, dragonflies were a symbol of hope and transformation. I've been seeing lots of little dragonflies in my garden this year, so I take that as a sign of good things to come!

Stay well and stay safe.

Message from the Board Chair

By Mack Erno, HSC Chair

Leading an organization like the Huntington Society of Canada (HSC) is a big job, there's no two ways about it. To find the right fit for our next CEO, the board's hiring committee conducted a thorough search. We attracted lots of qualified candidates, but as the process went on, one name rose to the top for us: Shelly Redman.

Shelly is a strategic executive who brings a proven track record at a critical time for HSC. As you will see in the following article, her focus on building strong teams and commitment to bringing people together will be invaluable to our community. Meanwhile, her leadership experience and extensive clinical background as a nurse practitioner will ensure our organization continues to advocate for the needs of people living in Canada who are affected by Huntington disease (HD).

Those skills will be critical as the organization moves into this next phase of its evolution. These are exciting times, with multiple drugs being tested in clinical trials and many more in the pipeline. Supporting families will always remain our focus, but as the HD landscape changes, so will our place within it. For example, as treatments become available, HSC may need to take on more of an advocacy role to ensure families have access to them.

The coming years hold many unknowns, from how this current pandemic plays out to what outcomes we see from clinical trials. It is a new frontier filled with new challenges, and I know that Shelly is absolutely up for the task.

She is also backed by a strong team. I have been floored by the dedication of our staff across Canada and in our national office, especially over the past few months. Meanwhile, a month of overlap with Bev Heim-Myers helped make the transition as smooth as possible, despite COVID-19 disruptions.

On that note, I can't thank Bev enough for agreeing to come out of retirement and serve as interim CEO while we searched for our next leader. My name is probably mud with her grandkids for pulling Bev away, but having her back at the helm was truly the best-case scenario.

Now, I feel a lump in my throat as we say a second farewell. We are deeply indebted to Bev for the enormous contributions she has made to the HD community, and we wish her the best as she heads (back) into retirement.

HSC's board chair, Mack Erno (left), looks forward to the leadership of Shelly Redman and sincerely thanks Bev Heim-Myers (right) for her dedication and guidance as interim CEO over the past 10 months.

Introducing Shelly Redman

HSC's New CEO Will Hit the Ground Running

By Julie Stauffer

When Shelly Redman saw the job posting for CEO of the Huntington Society of Canada (HSC), it felt like the stars had aligned. Shelly was already familiar with Huntington disease (HD), thanks to her work in hospitals and social service agencies. Along with 25 years of experience in the health-care system, Shelly knew she had the expertise required to lead the organization into a new era of clinical treatments.

It was the focus on supporting families that really resonated with her. "It's always been something that I've been very passionate about," Shelly says.

Growing up there was never any question what Shelly wanted to be. "I think nursing is one of those things that you're just born into," Shelly says. After completing her diploma in nursing, Shelly launched her career as a registered nurse.

Shelly enjoyed the fast-paced environment of the Intensive Care Unit and the Emergency Room, caring for patients and their families during times of crisis. Over time, Shelly also grew to appreciate helping patients and their loved ones who required ongoing care for chronic health issues, meeting them where they were and making a lasting difference in their lives.

Shelly went back to school to complete a bachelor's degree in nursing and nurse practitioner (NP) certification and worked in both the community and the emergency department environments as an NP. Shelly submitted a winning proposal to the Ontario Ministry of Health to create one of the province's NP-led clinics, which focused on providing care to marginalized populations.

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Along with a host of other duties in her inaugural summer, HSC's new CEO Shelly Redman recorded an inspirational video for participants of the Huntington Heroes National Virtual Walk.

Introducing Shelly Redman

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As the clinic director, Shelly fell in love with leadership and returned to school again to complete a Master of Business Administration in healthcare leadership, realizing the contribution she could make at a systems level in healthcare.

Shelly got to do exactly that while managing and directing complex care programs at Grand River Hospital in Kitchener, ON. During this time, Shelly directed support for individuals with neurodegenerative diseases such as Alzheimer's, Parkinson's, ALS and HD. Shelly also worked with patients and their families in palliative care, helping them through incredibly difficult times. "To be able to share in that experience and support them through their struggles is really a blessing and a gift," Shelly says.

Most recently, Shelly served as CEO and Chief Nursing Officer at St. Leonard's Place Peel, a transitional housing facility that supports the successful reintegration of men exiting the prison system as well as those facing homelessness due to mental health and/or addictions. Over the course of three years, Shelly guided the organization through a period of growth and change that included new partnerships, new telemedicine services and the launch of new programs to better serve clients.

Since joining HSC, Shelly has been impressed by the collaborative spirit of the HD community and the passion of staff and volunteers. "The level of engagement is like nothing I've ever encountered before," Shelly says.

During the month-long handover process from interim CEO Bev Heim-Myers, the two women focused on making connections and transferring the great partnerships that Bev spent so much time nurturing. That includes HSC's incredible donors, funders, researchers, clinicians and drug companies, as well as all the staff at national office, the family services team and volunteers across the country.

Looking down the road, Shelly is excited about drawing on her strong healthcare background to help translate successful clinical trials into accessible treatments for families. For now, however, her main priority will be supporting HSC through the pandemic, ensuring that the organization's programs remain strong and that research can continue. Innovative thinking will play an important role as HSC navigates this new terrain. COVID-19 creates many unknowns, especially when it comes to fundraising. Shelly believes the key is to stay flexible.

Although taking over the helm of organization in the midst of a public health crisis is a tall order, Shelly isn't daunted. "With every hardship, I always believe that there are new opportunities that present themselves," Shelly says. "I love the challenge, and I'm really excited to be looking at what the future holds."

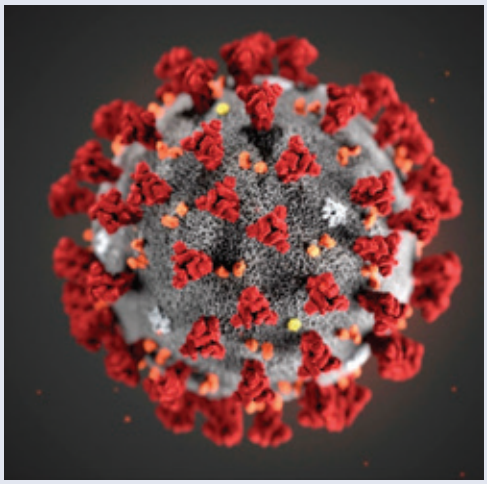
Shelly lives in Southwestern Ontario with two of her three sons (her eldest having flown the coop) her dog and her cat. She loves cooking, gardening and hiking.

(Not) Business as Usual: Operations in the Time of COVID-19

By Julie Stauffer

Like every organization across Canada, the Huntington Society of Canada (HSC) has been obliged to adjust to the new realities created by COVID-19. What is remarkable, according to outgoing interim CEO, Bev Heim-Myers, is how quickly and smoothly HSC was able to make that transition. In the face of uncertainty, the organization's staff have proved just how flexible and adaptable they can be. "We honestly have not missed a beat," says Bev.

HSC resource centre directors and family service workers shifted to virtual-only mode, moving support groups online and serving clients via phone and videoconferencing. HSC's communications team quickly ramped up to issue weekly COVID-19 updates during the first few weeks of lockdown, so that the Huntington disease (HD) community could be kept abreast of how HSC was adapting.



The HSC events team pivoted swiftly as well, postponing the national conference and organizing a series of Community Education Forums to fill the gap. They have also worked closely with chapters to postpone as many fundraising events as possible or take them online, rather than cancel them.

Of course, this has affected HSC's revenues. In response, the finance team have been revising budgets and cash flow projections – sometimes daily – as the picture continues to change. They have overhauled financial operations to handle everything remotely, and they have also navigated HSC through its very first virtual audit – no small feat!

In the midst of this turbulence, good communication is key. Each team within the organization has instituted daily or weekly check-ins, and the CEO is in regular contact with the board of directors, which has been monitoring the situation closely. Meanwhile, weekly virtual coffee breaks bring the entire staff together, offering an opportunity to chat more informally.

Unfortunately, this public health crisis continues to create uncertainty, and it is difficult to predict how operations might need to shift this fall. Provincial governments have been relaxing restrictions, but HSC remains cautious.

Once the pandemic has ended, HSC plans to continue to make use of the virtual capabilities it has built. Blending face-to-face services with online services will allow HSC to serve more people, especially in remote areas, and offer clients everywhere more flexibility.

Meanwhile, HSC has seen how working from home offices has maintained the productivity and efficiency of national office staff. For the time being, staff will continue to operate virtually for their own safety and the safety of the families we serve. A return-to-workplace plan has been completed, with the goal of staff beginning to work from the Waterloo, ON office, in a blended on-site/remote-work model as soon as it is safe to do so.

HSC is doing things a little differently these days, but rest assured its core mission has not changed. "We've been supporting families affected by HD since 1973, and we're not stopping now," says HSC's CEO, Shelly Redman. "I'm confident that we're going to emerge from these challenges stronger than ever."

Event Planners Rolling with the Pandemic Punches

By Josh Martin

Each year, volunteers from coast to coast organize a slew of events to support the Huntington Society of Canada (HSC). From raucous concerts to wildflower walks, those events raise about a third of the revenue HSC relies on to support families and Huntington disease (HD) research. Then, 2020 arrived and threw a pandemic-sized wrench into the works.

Since the beginning of March, the HSC events team has been monitoring the pandemic measures in each province and adapting accordingly. "There's a lot to keep on top of right now and it's always changing," says Annie Vanexem, HSC's senior manager of national events and chapter development.

But true to form, volunteers have shown how resilient and flexible they can be. "Our community has been stellar about changing their plans and working with us to come up with new ideas," Vanexem says.

Although COVID-19 forced the cancellation or postponement of some in-person events, others were able to move ahead with additional safety precautions in place. As this issue of *Horizon* comes together, loosened restrictions in Newfoundland meant HSC could go ahead with the Barker's Battle Run in Coachman's Cove in mid-August.

Similarly, expanded limits for outdoor gatherings in Western Canada allowed HSC to go ahead with the annual Ride 4A Cure in Teepee Creek, AB at the end of August. And organizers of the Winnipeg, MB Indy Go-Kart Challenge still waved the checkered flag at an in-person event in September.

In other cases, volunteers transformed their events into virtual ones. The Lafleche Walk to Cure HD in Saskatchewan, the Winnipeg Huntington Heroes Walk and the Calgary Hope Run and Walk were the first to test the new format. "Those all went really, really well," says Vanexem. "We're seeing the online fundraising performing better than we anticipated."

Inspired by these early successes, HSC has organized its first ever Huntington Heroes National Virtual Walk. The event encourages supporters

from across the country to stand together by walking alone. Throughout September and October, participants can join virtual and in-person activities happening in their community – or choose a date or time to walk or run on their own.

HSC will be hosting virtual post-walk celebrations and giving out prizes to the top fundraisers in each province, as well as the participants who walk the farthest distance. And thanks to an anonymous donor, every dollar raised will be matched until Sept. 30.

Virtual alternatives like these aren't just a safer option during a pandemic. They also allow more people to participate, regardless of their schedules or where they live. To get in on the action, visit www.hscnationalwalk.ca and help HSC reach its goal of raising $270,000 for HD research and family services.

Looking for other pandemic-friendly fundraiser ideas? Vanexem and her team have been building a growing collection of "event-in-a-box" resources (see article on page 9).

"We're constantly dreaming up new resources and new ways to support," says Vanexem. Meanwhile, the events team offers weekly drop-in coffee chats every Thursday at 8 p.m. Eastern time, where organizers can connect, ask questions and share ideas (to learn more, contact events@huntingtonsociety.ca).

There is no question that COVID-19 will affect HSC event revenues this year, and budgets have been adjusted to reflect that. But when Vanexem looks at how the community has rallied, she sees lots of reasons for optimism. She points to the benefits of thinking outside the box and to the amazing volunteers who are doing everything they can to continue supporting the organization. "I think we're going to find that when this is over, there will be some really positive changes for our chapters and our events," she says.

Clinical Trials in Canada

Online Map Makes Locating the Trial Nearest You Simple and Quick

The clinical trial landscape can prove to be overwhelming and confusing for members of the Huntington disease (HD) community. Because of this, the Huntington Society of Canada (HSC) maintains an online clinical trials map which outlines the locations of the major studies currently underway in Canada. Using icons and a legend to define types of studies, the map includes markers which can be clicked on to reveal more detail about the location of the trial, recruitment status and the drugs/treatments involved. The map is updated regularly and all information checked for accuracy on an ongoing basis.

The map can be accessed at www.huntingtonsociety.ca/clinical-trial-locations/. Should you have any questions about the map or the locations, please contact HSC's national director of family services, Angèle Bénard at 1-800-998-7398, ext. 132 or abenard@huntingtonsociety.ca.

2020 Fall Calendar of Events: Coming to Your Neighbourhood Soon!

Note: In light of COVID-19, events and event dates are subject to change. For the most current information, and to find event websites to show your support, visit www.huntingtonsociety.ca/events.

NATIONAL EVENTS

Ongoing

RaceHD
Canada-Wide
p2p.onecause.com/racehd

Weds., Sept. 1 – Sat., Oct. 31

Huntington Heroes National Virtual Walk
In your own neighbourhood!
www.hscnationalwalk.ca

ALBERTA

Sun., Oct. 4

Edmonton (Virtual) Walk
In your own neighbourhood!
https://p2p.onecause.com/edmontonwalk

ONTARIO

Sat., Oct. 17

Barrie (Virtual) Walk
In your own neighbourhood!
https://p2p.onecause.com/barriewalk

Event Season 2020 – A Fresh Take

While the COVID-19 pandemic created some challenges for the Huntington Society of Canada (HSC) events team and volunteer organizers this spring, there is still much to celebrate! HSC volunteers got creative, exploring new ways of doing things and bringing in much needed donations. Volunteers and donors have remained steadfastly supportive throughout the spring.

Throughout this edition, you can read about many of the events and fundraisers, including Sophie's keychains, and Manny's century ride. A number of individuals have also hosted Facebook fundraisers, which to date have raised over $14,000 combined!

Before virtual runs were cool (thanks to COVID-19), long-time volunteer Terri Biloski set out on the Great Virtual Road Race Across Tennessee through RaceHD, HSC's national running team. Terri has already run over 2,000 km and raised almost $1,500.

Speaking of RaceHD, the Ottawa Chapter saw an opportunity this spring after the Tamarack Ottawa Race Weekend went virtual. Typically chapter members raise funds with RaceHD to participate in the event, but instead, this year, the chapter set up a virtual fundraising page, raising over $2,500 to date.

Several of HSC's usual community-led events also went virtual including the Lafleche Walk to Cure, Winnipeg Walk to Cure (which encouraged participants to take part in the physical activity of their choosing, including water skiing!), and the Calgary Hope Run. The latter was the final event of the spring season, taking place on June 27. Organizers got creative, adding curbside pick-up for fundraising incentives, early-bird registration prizes, and sharing apps for participants to track their distance as well as connect with one another while walking! All told, 65 people registered online and over $30,000 was raised.

Combined, these events have raised roughly $80,000, with that amount to be matched by an anonymous donor. COVID-19 won't stop HSC's generous community and creative volunteers! Thank you to everyone who has supported an HSC event so far in 2020!

To find an event near you to support, visit www.huntingtonsociety.ca/events or contact events@huntingtonsociety.ca to discuss hosting your own fundraiser for HSC!

HSC Events Team Packages Events in a Box

Do you want to plan an event but you're not sure where to begin? Now there is help!

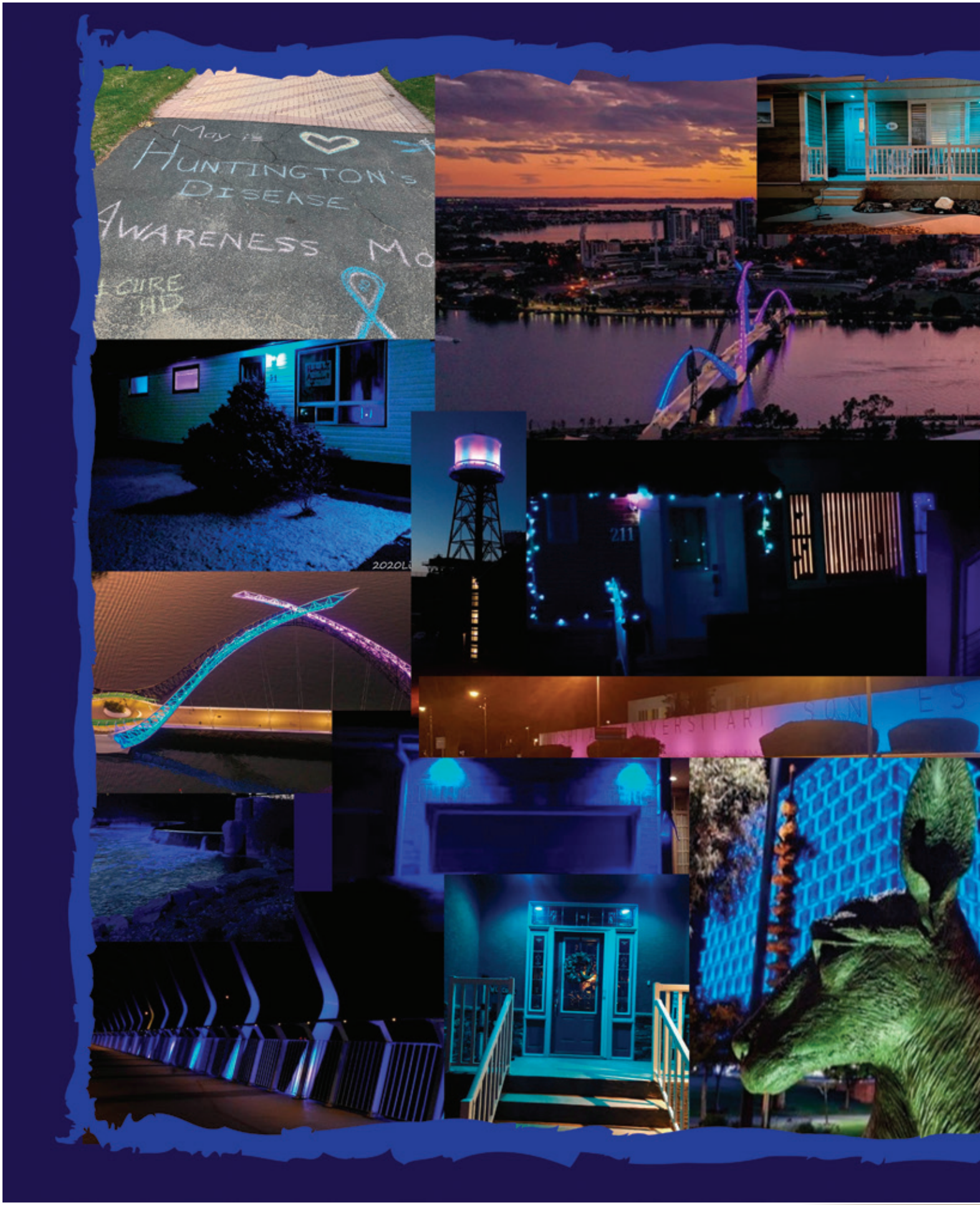
In the winter of 2020, the Huntington Society of Canada (HSC) was pleased to launch "Event in a Box." This is a resource for anyone interested in planning a fundraising event in support of HSC. It outlines the steps to planning an event and the different ways to get involved with events in the organization.

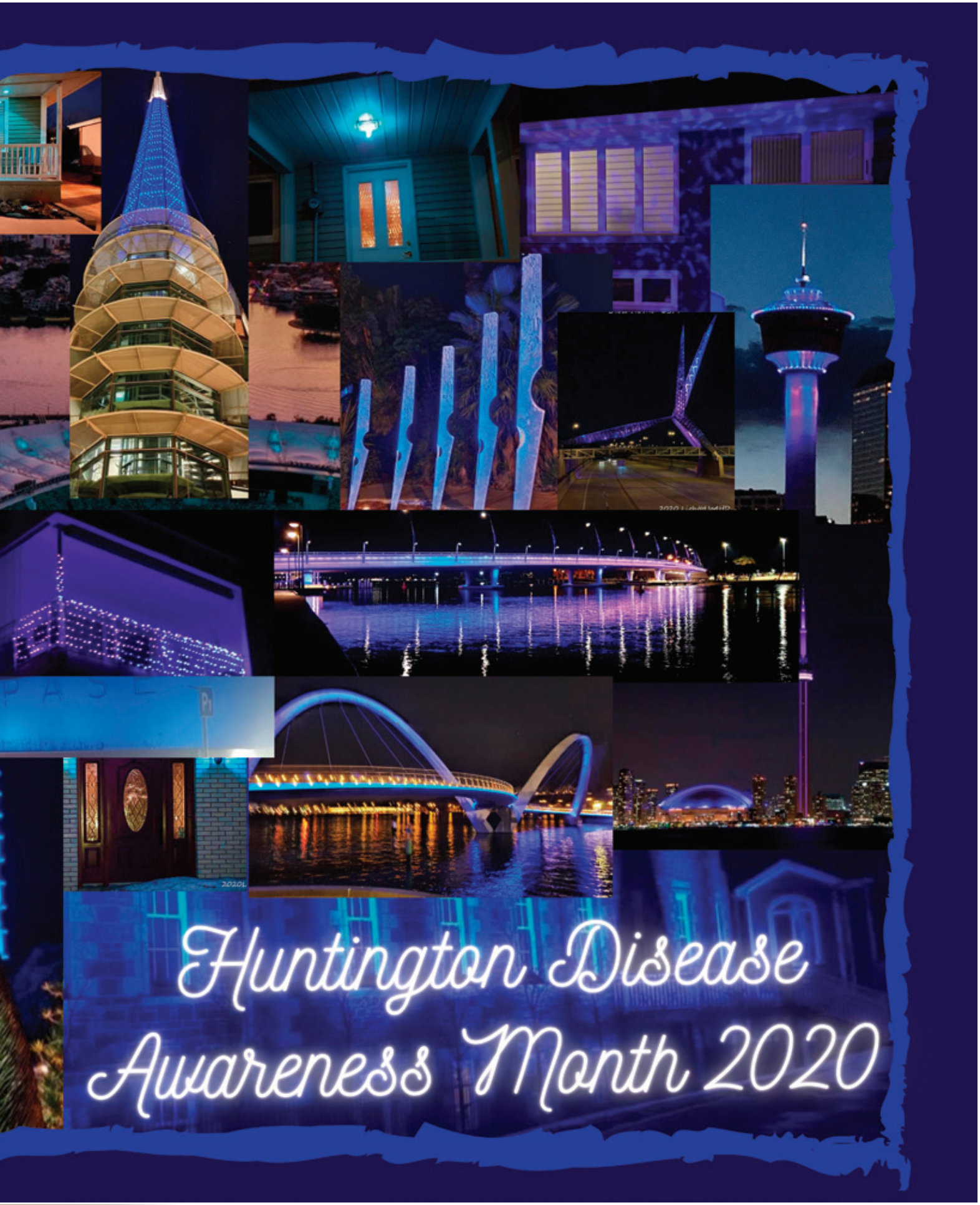
With the Event in a Box resources, planning an event has never been easier. It's like you are opening a box, and receiving everything you need to plan a particular type of fundraiser. The tool includes step-by-step instructions on how to manage the event as well as all of the resources needed to help you get there. The Event in a Box page makes it incredibly easy to get started with event planning, even if it is your first time!

"Every month we are releasing a new event type on the page," says Kelsey Laidlaw, HSC's community events assistant. "Each release has a step by step guide on how to plan that type of event, tips and tricks, as well as templates for posters and different documents to help you along the way!"

So far, the event ideas posted include Facebook fundraisers, paint nights, trivia nights, silent auctions, comedy nights and more!

To learn more, visit www.huntingtonsociety.ca/event-in-a-box/


May is
HUNTINGTON's
DISEASE
AWARENESS
CURE
HD
211


Huntington Disease
Awareness Month 2020

YPAHD Column

By Doug Mallock, YPAHD President

Under normal circumstances, I'd be telling you about our plans for Young People Affected by Huntington Disease (YPAHD) Day at HSC's national conference. Since that won't be happening, thanks to COVID-19, the executive team has been finding other ways for YPAHD members to connect.

One thing we've done is replace our monthly teleconference calls with Facebook Live sessions. And yes, it's about time.

Even eight years ago, when I joined YPAHD, the conference calls felt a bit dated, so we've been in talks for a while about trying something new. Well, there's nothing like a global pandemic to shove you in the right direction.

One of our first Facebook Live broadcasts looked at having a loved one in long-term care during lockdown. It received nearly a thousand views. Our next session – on being quarantined with somebody affected by Huntington disease – attracted an even bigger audience. So we've kept going.

The sessions are a chance to see familiar faces from YPAHD Days. We usually have a discussion with a few guest speakers. There's no pressure to participate, but you can ask questions or make comments if you want to. You can watch it live or on your own time, and it becomes a resource for people to share.

Moving forward, we're aiming to offer Facebook Live events every month at www.facebook.com/YPAHD. We're also looking at doing some virtual board game nights, so watch out for those.

Meanwhile, because we couldn't hold elections at YPAHD Day, our current executive team have agreed to stay on for another year. We'll also be adding a youth engagement coordinator position to help more young people get involved in local Huntington Society of Canada chapters.

COVID-19 may be making life more challenging these days, but technology allows us to stay connected like never before. I'm seeing so much energy and so many people stepping up to the plate. It all leaves me feeling pretty optimistic.

More Than a Job

Losing their Dads to HD Becomes a Powerful Career Motivator for Two Young Women

By Josh Martin

You only need to look around the room at a Young People Affected by Huntington Disease (YPAHD) Day to feel optimistic about the future. Time and again, Huntington Society of Canada (HSC) staff are inspired by what young people in the Huntington disease (HD) community are doing – from raising awareness to organizing fundraisers to participating in clinical trials. Some are even turning this cause into their career.

Kaitie Neuman is a great example. In September, she started a new adventure working in Dr. Ray Truant's HD lab at McMaster University in Hamilton, ON. "It's a dream that I've had since I found out that HD was in my family," she says.

Kaitie was seven years old when her father was diagnosed with the disease, and his condition steadily deteriorated. In high school, when other kids were going home to their families after classes, she was going to visit her dad in a long-term care facility. He passed away two years ago. Meanwhile, Kaitie has also tested positive for the HD gene mutation.

After completing an undergrad in biochemistry and molecular biology, Kaitie wasn't sure about applying to grad school. Although she excelled academically, she worried she might not be good enough to work with one of Canada's leading HD researchers. But with a little encouragement from

Continued on page 13...

Kaitie Neuman has started a new adventure working in Dr. Ray Truant's HD lab at McMaster University in Hamilton, ON.

More Than a Job

...continued from page 12.

her thesis advisor, Dr. Robert Huber – and Dr. Mark Guttman at the Centre for Movement Disorders in Toronto, ON, where she participates in Enroll-HD – Kaitie submitted her application one week before the deadline.

Not only did she get accepted into McMaster, she also received two scholarships. Meanwhile, Dr. Truant is thrilled that she will be working in his lab. "The themes we have been uncovering, and will continue to uncover with her efforts, will have profound implications towards drug development," he says.

And how does Kaitie think her dad would feel about her work to find treatments for HD? "Ridiculously proud," she says. "I think he'd just be beaming."

In November 2019, Nicole Patterson also lost her father to HD. And, like Kaitie, her personal connection to the disease is shaping her career choices. As a health sciences student at the University of Waterloo, Nicole is spending her latest co-op term as a clinical research assistant with Dr. Guttman, the same man who cared for her dad. "It's really awesome," she says. "I get to work with the best of the best."

From May to August, she is performing a number of duties – from preparing patient documents to fetching ice packs during lumbar punctures, where clinical trial participants are receiving drugs that could alter the course of HD.

Her stint at Dr. Guttman's lab isn't her first experience supporting the HD community. Nicole has participated in multiple HD runs in Toronto, ON and regularly volunteers at HSC's national office, which is now in Waterloo, ON.

Although she herself does not carry the HD gene, Nicole is deeply committed to the cause. "If the people affected by HD aren't the ones pushing for the change, pushing for the cure, pushing for advocacy for things like genetic testing, then who else is going to?" she argues.

After her pending graduation in 2022, Nicole is considering a Master's degree in genetic counselling, so she can continue working in the field of genetic diseases. Wherever the road takes her, she is determined to make meaningful contributions to the world. "That's one of the things that helps me get through: knowing that I'm making a difference," says Nicole.

For Dr. Guttman, it's inspiring to see the next generation of young people playing an active role in the hunt for treatments. "There's a whole cohort of these young women that are just amazing. They're scientists, they're doing groundbreaking work and they come from HD families." he says. "I'm very motivated by them."

As a health sciences student at the University of Waterloo, Nicole Patterson is spending her latest co-op term as a clinical research assistant with Dr. Mark Guttman, the same man who cared for her late father (pictured above with Nicole).

Keychain Campaign Fills Hearts with Hope

By Josh Martin

In the Spring 2020 issue of Horizon*, we featured Lisa Pollock, an award-winning fundraiser for the Huntington Society of Canada (HSC). Now, it looks like she is getting some stiff competition from her talented nine-year-old daughter.*

The arrival of COVID-19 meant that Sophie Pollock couldn't go to school or play with her friends. That was a bummer. But it did give her more free time to spend on her latest fundraiser for HSC.

In May, Sophie started designing, making and selling beaded keychains, many featuring a dragonfly: a symbol of hope within the Huntington disease (HD) community. "Sometimes you can feel sad and you just need a little hope to cheer you up," Sophie explains from her home in Weyburn, SK.

Popping out to the store isn't easy during a pandemic, so Sophie's mom, Lisa, ordered an assortment of glass and plastic beads and metal keychain rings online. When Sophie's first batch was ready to go, they set up a Facebook page to sell them – $10 for an adult version, which includes the dragonfly wings, and $5 for a kid's version made with plastic beads. Their page also includes a "donate" button for individuals who want to support the cause without purchasing a keychain.

Initially, they figured they could probably sell 15 or 20 and raise a few hundred dollars for HSC. Today, Sophie has blown her goals out of the water, selling more than 500 keychains and raising more than $5,700. You will find her dragonfly doodads clear across Canada, from British Columbia to Newfoundland. Sales have even gone international, with stateside customers in California and Wisconsin.

Closer to home, the project has attracted media attention, plus some important fans. Sophie mailed a letter and keychain to Weyburn mayor, Marcel Roy, who insisted on meeting her and donating to her campaign. She also sent one of her creations to Saskatchewan Premier, The Honourable Scott Moe, who wrote back asking if he could buy four more.

The popularity of her products kept Sophie pretty busy through the summer. But for her, it was worth it. "It does take work and effort," she says. "But if you want to do it and it's for a good cause, you should."

Fundraising definitely runs in the family. After Lisa's grandmother died of HD in 2012, Lisa started getting involved with HSC in a variety of ways, including participating in the Saskatchewan chapter's annual Walk to Cure HD in Sasktatoon, SK, becoming a youth mentor and organizing online fundraising auctions.

In recent years, Sophie has been right there alongside her mom – painting pictures for the auctions, running lemonade stands and now making keychains. Lisa could not be more proud. "She has such a big heart, and she's always wanting to help other people," she says.

As Sophie settles into a new school year as a grade five student, she has pressed pause on her keychain campaign. However, she is keen to keep the momentum going, so anyone who missed out on getting one this year should look for more of her beaded handiwork next summer.

Sophie with some of her beautiful keychains.

Sophie and Mayor Marcel Roy of Weyburn, SK.

Saskatchewan Premier, The Honourable Scott Moe, with the keychain Sophie sent to him (designed in the province's official colours).

2020 "#LightItUp4HD" Shines Brightly in May

May was Huntington disease (HD) Awareness Month and despite challenges brought about by the COVID-19 pandemic, sites around Canada and the world again lit up in support. Since 2015, volunteers from across Canada have been working to illuminate various buildings, monuments and statues during the month of May to raise the visibility of HD and Juvenile Huntington disease (JHD).

Thanks to the enthusiasm of the HD community and many HD volunteers, "LightItUp4HD 2020" saw 42 sites participate, worldwide. In Canada, 19 sites participated in #LightItUp4HD, while another 23 international buildings, monuments and other structures lit up in blue for HD and/or purple for JHD. The impact of COVID-19 on the initiative (in 2019, an international total of 169 sites participated) may have meant less sites were able to come on board, but hope continues to flourish in the HD community.

"When lockdown started, we began to hear back from sites that they weren't in a position to participate this year – for various reasons" says James Walters, founder of the Global Huntington Association and the LightItUp4HD initiative. "So, we counted each site in 2020 as a small victory in strange times."

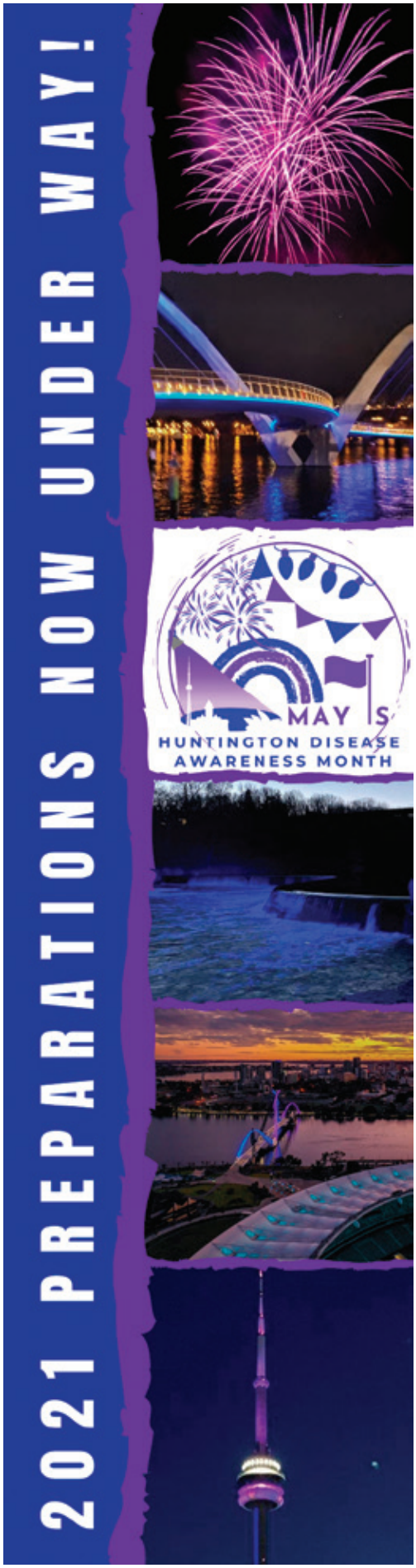
Walters and other HD volunteers across Canada – such as National #LightItUp4HD Volunteer, Carolyn McKinney – reached out to HD organizations from around the world and invited them to "LightItUp4HD." Along with the 19 sites in Canada, the following countries also participated: Australia, Cyprus, Germany, Ireland, Spain and the USA. Through the determined efforts of local volunteers, Calgary, AB Mayor, Naheed Nenshi, also made a proclamation to declare May as HD Awareness Month in that city. In most cases, flag raisings (public gatherings) were cancelled in order to comply with COVID-19 measures, although Guelph, ON, Sudbury, ON and Chatham, ON raised flags in a safe manner or residentially. Members from the HD community also lit up their own homes in blue or purple, strung lights or drew sidewalk art with chalk.

"Each year, in addition to the sites we ask to participate, I continue to hear from new HD ambassadors around the world who want to be part of #LightItUp4HD," adds Walters. "It's not just creating awareness, it's also fostering more relationships within the HD community – and that's a powerful thing."

Thanks to Walters, McKinney, chapter volunteers across Canada and international partners, #LightItUp4HD continues to increase awareness and in 2021, hopefully the bar will be set at levels higher than the records set in 2019.

For a comprehensive list of participating sites and to view a video montage of 2020 pictures, please visit www.huntingtonsociety.ca/lightitup4hd-2020/.

Although not as many sites participated in 2020 as in 2019 (pictured above), plans are already under way to make 2021 another record-breaking year for HD Awareness Month.



Q …My spouse has Huntington disease (HD) and is no longer able to work or drive. He is at home every day and does nothing but watch TV. I come home from work and still have to cook supper, do laundry, groceries and keep our house tidy. Our children are older and can fend for themselves. How can I motivate my spouse who doesn't seem to care about these things anymore?

Signed, Stressed Out Spouse

A Dear Stressed Out Spouse:
HD will cause cognitive changes and people who are affected will often lose sight of their day-to-day role and may seem less motivated. Thanks to HD, they are losing the ability to initiate and follow through with tasks and household responsibilities. With a greater understanding of these changes, you can become better equipped to approach some of these challenges.

Potential changes in cognition due to HD include slower thinking; reduced ability to initiate tasks and recall becomes more challenging. There is also an increased difficulty in switching tasks, organizing thoughts, maintaining focus and waiting.

Some strategies that have worked for other families include:

- A routine with clear, simple instructions outlining a daily "to-do" list
- Reminders throughout the day of what is expected/needed
- Slowing down when talking and waiting for questions
- Deciding what's important and what isn't: "don't sweat the small stuff"
- Taking things one day at a time
- Celebrating ALL successes no matter how big or small

Depression could also play a role in the changes. Reaching out to your local HD or Movement Disorder Clinic can be extremely helpful. You can also contact your local Huntington Society of Canada (HSC) family services team member; we are here to provide on-going support to guide you through these changes and challenges as a family.

There are HSC factsheets on various topics with several strategies that may prove helpful and don't be afraid to reach out to HSC's family services team members to discuss your current needs: https://www.huntingtonsociety.ca/family-services-team-list/.

Sean Dewart: From the Courtroom to the HSC Boardroom

By Josh Martin

When Sean Dewart isn't fighting for justice in the courtroom, he's standing up for the Huntington disease (HD) community as a member of the HSC board of directors. Even though the disease doesn't run in his family, the Toronto lawyer has lent his expertise to the Huntington Society of Canada (HSC) for more than two decades.

Sean first connected with HSC through his long-time friend Susan Wright, whose family is affected by HD. More than 20 years later, his dedication to the cause has only grown.

That commitment is doubly impressive considering Sean's profession doesn't leave him with a lot of spare time. His career as a high-powered lawyer has included many high-profile cases. In the 90s, he helped stop attempts to privatize Hydro One in Ontario. He also served as lead counsel on Jane Doe v. Toronto Police, successfully defending the Charter rights of a sexual assault survivor.

More recently, his passion for police accountability has taken him all the way to the Supreme Court of Canada, where his efforts helped win *Hill v. Hamilton-Wentworth Police*. Thanks to this landmark 2007 case, Canada is the only jurisdiction in the world where people who are wrongly charged can sue the police for negligent investigations.

"It's definitely fun to do a big case where all eyes are on you and you're really trying to change something radical," Sean says. "But more and more, I find that I'm rewarded by the cases where I'm helping ordinary people."

Despite a demanding schedule, Sean has always made time for HSC. "It's a remarkable organization," he says. "It is simultaneously very grassroots and yet very, very sophisticated in terms of the science that it promotes and the educational function that it serves."

Sean also admires the reach HSC has across the country, the strength of local chapters and the resilience of the HD community when faced with an obstacle – whether it's fighting for genetic fairness in the Supreme Court of Canada or adapting to COVID-19. "We've had challenges over the years, and yet somehow we appear to come out of them stronger every time," he says.

Today, he couldn't be more excited about the organization's achievements. When it comes to helping advance research, HSC has always punched above its weight. "That's paid off," he says, pointing to the multiple clinical trials currently underway, testing potential treatments for HD.

Sean hopes all that progress will soon make his involvement with HSC unnecessary. "I look forward to the day – and I hope it's in the very near future – where we can shut our doors because the disease has been defeated," he says. "That may not be this year or next, but let's hope it's on the close horizon."

Sean Dewart is excited by HSC's achievements to date and hopes that a treatment for HD is found in the very near future.

Until that happens – or until it's time for new blood on the board – Sean has no plans to step back. "I'm sure that people will come to their senses sooner or later and kick me out," he jokes. "But they're going to have to do that before I turn over my keys."

A Passion for Pedaling Raises Big Bucks

By Josh Martin

As the COVID-19 lockdown dragged on, Manuel (Manny) Ferreira started developing a serious case of cabin fever. The keen athlete missed pickleball and group rides with his cycling buddies around his home near Ayton, ON, a rural community two hours northwest of Toronto. Itching for a challenge, Manny decided to get out of the house by working towards an Imperial Century – cycling lingo for a one-day ride that is 100 miles (160 kilometres) long.

To up the challenge even further, he turned the ride into a fundraiser for the Huntington Society of Canada (HSC). He is certainly no stranger to the cause: his partner, Lia, works as HSC's communications and marketing manager, and some of the patients at his various chiropody clinics have Huntington disease (HD). As well as those two connections, volunteering at HSC events for the Barrie chapter has left Manny inspired. "I'm so amazed by what the HD community handles on a daily basis and how strong everyone I've met is," he says.

HSC helped him set up an online donation page, while Manny reached out to friends, family and his pickleball pals for contributions.

While Manny has completed century rides in the past, it is always important to train as much as possible. Consistently bad spring weather, however, meant his longest training ride this time was only 52 kilometres. Nonetheless, Manny got up at 6 a.m. on June 6, hopped on his bike, known affectionately as "Precious" – now sporting blue handlebar tape in honour of HD – and started his ambitious cycling adventure.

With an ambitious goal of eight hours, Manny made his way through rolling countryside, winding west towards Lake Huron. After an ice cream pit stop in Southampton, ON Manny began the second half of the loop, returning inland. Luckily, Manny's favourite routes are those with lots of elevation change. This part of Canada might not be the Rockies, but it is awfully hilly. "I enjoy hills," he recalls wryly. "Which is good because there weren't too many flat stretches!" And the biggest hill was one kilometre from home on the return route.

When those climbs set his legs on fire, Manny drew strength from the HD community. "I would think, 'this is nothing compared to the challenges of living with HD,'" he says. "The inspiration really came from them." He also knew that his progress was live online via the tracking app Strava – at least 30 donors and supporters had said they would follow his progress, so that was a huge motivator.

Lia and her dad followed in a support vehicle, carrying tools and spare parts in case Precious had a run-in with a nail or pothole. They also served as paparazzi and caterers, snapping photos and handing off electrolyte gels as needed. Meanwhile, Manny's twin boys showed up along the route with their girlfriends to show their love and support – since no one else on the road could have known what Manny was doing.

Seven hours and 43 minutes (177.29 kilometres) later, Manny returned home to a hero's welcome. His sons held up the HSC flag, while the rest of the family clapped and cheered as he crossed the finish line. They even had an ice cream cake waiting, adorned with the words "Allez, Allez, Allez" – a phrase commonly shouted by spectators at the Tour de France to motivate the competitors. "It was quite an emotional thing," says Manny.

Although COVID-19 forced Manny to embark on a solo ride this time, he has heard from many people keen to join him next year. But for now, he and Precious can enjoy a hard-earned rest, having raised more than $7,000 for HSC. "It was a fun day," he says. "But even more importantly, it raised funds for such a great organization."

If Manny has one regret, it is that he didn't have an HSC cycling jersey to promote the cause, as a conversation starter on his pit stops. This year, everything happened so fast that it was about a month from deciding to do it to the actual ride date. "We didn't have much time to plan ahead. But, I have an in at HSC," he says with a wink. "Lia promises they'll have a jersey made if I do this again in 2021 – but only if I raise more money than this year. She drives a hard bargain!"

Triplet Therapeutics Pursues a Radical New Approach to HD Treatment

By Julie Stauffer

With each passing year, more promising treatments for Huntington disease (HD) are entering clinical trials. Roche and Wave Life Sciences are both evaluating huntingtin-lowering therapies, while Vaccinex is testing a drug that targets the inflammation pathway. Now, yet another exciting approach is in the works.

A recently launched biotechnology company in Cambridge, MA – Triplet Therapeutics – believes it can create a silver bullet that can potentially treat more than 50 diseases associated with expanded DNA nucleotide repeats. And the first disease they will test it on is HD.

"What excites me most is the science behind it," says Dr. Irina Antonijevic, the company's chief medical officer. Triplet Therapeutics is taking aim at one of the fundamental upstream drivers of HD: a stage in the process that contributes to the production of the continuously-increasing toxicity of the mutant huntingtin protein.

That's possible because of some very recent discoveries.

CAG Counts can Increase Over Time

HD is caused by too many CAG repeats in the huntingtin gene. For many years, the scientific community believed that the number of CAGs you are born with never changes. Today, we know that is true for many parts of the body. However, researchers have discovered that CAG counts actually increase in the parts of the brain most affected by the disease.

So when you look at a sample of blood, genetic testing might reveal a CAG count of 42. But in the brain cortex and striatum, the number might grow to several hundred over the course of someone's life.

Because that DNA serves as a recipe for creating huntingtin protein, cells with more repeats produce longer stretches of mutant huntingtin. And that's bad news. "The longer it is, the more toxic it is," Dr. Antonijevic explains.

"Accelerator" Genes Speed up the Age of Onset

Meanwhile, we have known for a long time that two people with the same CAG count can develop HD symptoms at different ages. Now, thanks to data from observational studies like COHORT, TRACK-HD, EnrollHD and PREDICT-HD, scientists are starting to understand why.

It turns out there are a number of genes that influence the age of onset. Some accelerate the development of symptoms, while others slow it down. Many of the "accelerator" genes code for DNA repair proteins – and that's where Triplet Therapeutics is focusing their attention.

Easing Up on the Accelerator

DNA repair proteins serve as proofreaders, fixing errors that creep into genes over time. Unfortunately, when they encounter a disease-causing stretch of short DNA repeats, they respond by adding more – making the problem worse instead of better. "The longer it is, the faster they add additional repeats. So there is this accelerated increase in the CAG repeats," explains Dr. Antonijevic.

As the CAG repeats increase, the affected brain cells produce longer and longer mutant huntingtin that does more and more damage. That's why Triplet Therapeutics wants to develop a drug that lowers expression of one of the key DNA repair genes.

If it proves successful, the same approach could also be used to treat other repeat expansion diseases like muscular dystrophy and spinocerebellar ataxias. "There's a whole range of other brain and neuromuscular diseases we could also target," says Dr. Antonijevic.

SHIELD HD Study Launches

The company plans to launch a phase 1 clinical trial in the second half of next year, but first, they need a few key pieces of information to prepare for the clinical trial. That's where SHIELD HD comes in. Launched in May, this "natural history" study will gather data on new biomarkers and clinical outcomes. The company is looking for volunteers who carry the HD gene but are not yet clinically diagnosed with the disease and also volunteers at an early stage of HD.

As of mid-September, the study is more than two thirds enrolled with a number of patients undergoing screening – a response that thrills Dr. Antonijevic.

Dr. Irina Antonijevic, Triplet Therapeutics' chief medical officer.

Dr. Mark Guttman's clinic in Toronto, ON was the first to start running the study. Dr. Blair Leavitt at the University of British Columbia also prepared to begin recruitment as soon as COVID-19 restrictions were lifted in that province. Unfortunately, the study quickly filled before those regulations allowed enrollment to begin.

When screening is complete, Triplet Therapeutics hopes to have enrolled approximately 60 patients in sites across Canada, the United States and Europe. The two-year follow-up period includes lumbar punctures, brain MRIs, blood tests, and a variety of assessments.

Dr. Antonijevic hopes many SHIELD HD participants will also go on to take part in the Phase I clinical trial in the second half of 2021.

Multiple Shots on Goal

"I'm very excited about the fact that we have multiple shots on goal here," says Dr. Leavitt. More drugs in development – each with a different mode of action – means more hope of finding one that is effective, he explains. Or we may end up with a combination of treatments, much like the drug cocktails used to treat certain cancers.

"We need to keep trying to develop more and better therapies," he says, in conclusion. "We're not going to stop until we have what we would feel is a cure."

TRIPLET THERAPEUTICS

Training an HD Specialist in Winnipeg – Dung Nguyen

By Julie Stauffer

In 2019, the Huntington Society of Canada (HSC) launched a clinical fellowship program to attract promising young neurologists to the field of Huntington disease (HD). It proved highly successful, offering in-depth training in how to diagnose and manage HD and how to run clinical trials.

This year, we are pleased to announce HSC's latest clinical fellow: newly-minted Winnipeg neurologist, Dr. Dung Nguyen.

In July, he started his fellowship at the city's Movement Disorders Clinic at Deer Lodge, a facility that serves the province of Manitoba, as well as patients from northwestern Ontario, eastern Saskatchewan and Nunavut.

Dr. Nguyen has been intrigued by the brain for a long time. Before starting medical school, he did a Master's degree in neuroscience. So when it came time to pick his medical speciality, neurology was a natural choice. It's a field where researchers are making rapid advances, he explains, but there is still much to discover.

But it was the passion of his mentors at the Movement Disorder Centre, where he spent several months as a resident that convinced him to focus on movement disorders. Now, he is excited to be returning there and taking on additional responsibilities. "The training wheels are off," he says. "You're making more decisions."

Over the course of the one-year fellowship, Dr. Nguyen looks forward to benefiting from the expertise of the centre's three neurologists: Drs. Sean Udow, Andrew Borys and Doug Hobson. "I'm just hoping to learn as much as possible," he says.

There is plenty to master. According to Dr. Nguyen, being a good neurologist starts with making good diagnoses. Empathy and the ability to build strong patient relationships are also key. He points to the importance of managing quality of life, when caring for conditions where there are no definitive cures. Maximizing optimal symptom treatment for these conditions is challenging and rewarding.

Fortunately, Dr. Nguyen can draw on the multidisciplinary team at the Movement Disorder Centre, including doctors, specialty nursing, physiotherapy, occupational therapy, speech pathology, dietitians and HSC's Manitoba resource centre director, Marla Buchholz. "It's a really good one-stop shop," he says.

Dr. Dung Nguyen began his clinical fellowship in Winnipeg, MB, in July.

As part of the fellowship, Dr. Nguyen will also be doing a four-month stint with Dr. Mark Guttman in Toronto, ON, at the Centre for Movement Disorders, where he will learn how to conduct clinical trials like GENERATION HD and PRECISION HD.

According to Dr. Udow, the training Dr. Nguyen receives will give him unique knowledge and perspectives on managing HD that he can share with other clinicians in Manitoba. Hopefully, it will enable him to bring clinical trials to Winnipeg, MB.

Dr. Nguyen knows just how much that would mean to the local HD community. Recently, he was reunited with his favourite teacher from the "English as a Second Language" school he attended as a young newcomer to Canada two decades ago. She came into the movement disorders clinic with her brother, who has HD. It was an emotional reunion, Dr. Nguyen recalls. And it was made even sweeter by the fact he is training to become the go-to person in Winnipeg, MB for people – like her brother – affected by HD.

HSC gratefully acknowledges the support of Roche Canada, whose generous grant made this fellowship possible.

Flower Power: Victory Garden Adds Pops of Colour and Positivity to Community

By Josh Martin

During the first and second World Wars, families would plant so-called "Victory Gardens" to provide fresh vegetables and a boost to morale. Inspired by the tradition, Joanne Kaattari decided to create her own Victory Garden this spring to lift the spirits of families, like hers, impacted by Huntington disease (HD) – and everybody facing COVID-19. Instead of planting vegetables, however, she chose to plant hope in the form of heartwarming blooms.

This isn't her first floral foray. In 2018 and 2019, Joanne organized Wildflower Walk fundraisers each spring for the new Huntington Society of Canada (HSC) chapter in Barrie, ON. Unfortunately, the pandemic nixed plans for this year's event, so she directed her energies to her front garden instead.

Joanne picked out flowers that not only looked beautiful but also carried a special meaning. For example, she planted cheerful merry-bells to encourage people to focus on positive things in their lives. "We have to remember to be joyful," she says. "Despite hard times, there's still goodness and joy in the world."

That was just the beginning. Forget-me-nots served as reminders of those who are alone and vulnerable. Pink and purple flowers called "Soldiers and Sailors" represented service. Tea roses signified gallantry and kindness. Chives highlighted the importance of practical, everyday actions. Lantern columbines

On Sept. 14, 2020, Kaattari hosted Barrie-Innisfil Member of Parliament, John Brassard, who toured her Victory Garden while learning about Huntington disease and the Huntington Society of Canada.

symbolized beacons of hope for better days ahead for the HD community and the world more broadly with COVID-19.

From love and sorrow to duty and togetherness, the collection of flowers captured a wide range of sentiments – and the imagination of the neighbourhood. The garden became a popular attraction for kids and adults out for a stroll who would stop and chat with Joanne. Meanwhile, photos on Facebook generated plenty of smiles.

"I just did it for myself because it was something to do to keep me busy in a difficult time," she says. "But it really turned out to be a blessing to others."

The garden included a teacup with an HD bracelet on it, as well as flowers that paid tribute to the strength of the HD community. "Some of the plants are for endurance and courage," she says. "You think of the people with HD and how they have that in absolute spades."

Although the Victory Garden's blooms have now shed their petals, Joanne knows her flowers will come back in the spring. And that might be the most powerful message of all – for individuals facing HD, COVID-19 or any of life's hardships. "We'll prevail," says Joanne. "Like the perennials."

Thank You!

On behalf of families living with Huntington disease (HD), thank you for your continued partnership and generous support. The HD community makes the difference as the Huntington Society of Canada (HSC) reaches out to families not yet connected to the organization. HSC is committed to supporting and advocating for families from coast to coast, investing in world-class research and playing a leadership role in the international HD community. With your help, HSC is continuing to improve the quality of life for people with HD, cultivating strength and resilience in the HD community and providing substantive reasons for hope. If you have questions, story ideas or comments about *Horizon* or HSC, please contact HSC at communications@huntingtonsociety.ca or call 1-800-998-7398.

HSC is committed to reaching out to as many Canadians as possible. Should you wish to explore the French side of the HSC website, select the Français option at the top right hand corner of the website www.huntingtonsociety.ca.

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.