

HORIZON

RESEARCH • SERVICE • EDUCATION

No. 164

Fall 2021

Dr. Mark Guttman: A Career of Positive Impact

Dr. Mark Guttman retired at the end of August 2021 after a career as one of the leading neurologists in the country specializing in Huntington disease (HD), in both research and clinical fields. A hugely significant part of the Huntington disease (HD) community and a valued partner to Huntington Society of Canada (HSC), it is with great honour that we congratulate him on his retirement and share his career milestones.

Dr. Guttman started his education in the pharmacy field at the University of Toronto and then attended medical school at McMaster University, graduating in 1980. "I was interested in drug development and this background was good preparation for what lay ahead for me in my career," he says. Dr. Guttman gained experience during residencies in internal medicine at McGill University/Montreal General Hospital and neurology at University of Toronto, as well as research training, mostly focused on Parkinson's disease, at University of British Columbia, finishing in 1988. Here he met Dr. Michael Hayden and the two have been friends ever since.

He then took a faculty position at McGill University at the Montreal Neurological Institute and was there from 1988-1990. During this time, Dr. Guttman also became involved with the Huntington Society of Quebec, sitting on the Scientific Advisory Board. In 1990, Dr. Guttman decided to open his own practice in Markham, just east of Toronto. His reach extended beyond the Toronto area, however. From 1995 to the start of Covid, Dr. Guttman also participated in the Northern Huntington disease program in Sudbury and North Bay. For three days twice a year, he travelled to Northern Ontario to provide coverage for families who would otherwise not have access to a neurologist. He was also a pioneer of telemedicine and used this technology starting in 2001 to provide clinical consults for patients with HD.



A Passion Sparked for Huntington Disease

In 1983, during Dr. Guttman's neurology residency, he was able to obtain compassionate release from Health Canada to try an experimental therapy tetrabenazine for a patient with Huntington disease who was in the Veteran's Wing at Sunnybrook Hospital in Toronto. Stimulated by that, Dr. Guttman chose HD as the subject of his "fireside chat", monthly talks presented by residents. That very week, Dr. Jim Gusella's linkage analysis in HD was published in a high profile scientific article. It was a breakthrough – the first neurological genetic disorder to isolate where the gene leading to the disease was located on the chromosome. It provided the mechanism to start considering a genetic test. After Dr. Guttman's talk and that exciting news, the Chair of the Neurology Department noted that people should be aware of Huntington disease and this breakthrough, and then played an audio tape of Marjorie Guthrie speaking to Congress to obtain support for Huntington disease. She was successful in securing disease-focused support from the National Institutes of Health (NIH) for HD, the first medical condition to secure such

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New Clinical Fellowship Program

The Huntington Society of Canada (HSC) is pleased to announce the creation of a stable, long-term program to train a new generation of neurologists with expertise in treating patients with Huntington disease (HD) in Canada.

The new Clinical Fellowship award was made possible via a donation by Dr. Mark Guttman and his wife, Lesley Simpson. There is a shortage of neurologists in Canada trained to manage the care of HD patients and their families. Dr. Guttman wants to help fill the gap by creating this program.

"There are few neurologists who focus on HD in Canada, and of those that do, several will be retiring soon," comments Dr. Guttman. "We hope that the news of this stable, five-year Clinical Fellowship program will create an opportunity so that neurology residents trying to decide on a specialty will consider dedicating their careers to HD." The program will provide support for post-residency training for one year and is designed to add five new HD neurologists in Canada over the next five years.

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HORIZON

ISSN 0827-7605

Horizon is the newsletter of the Huntington Society of Canada. Issued two 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.

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Layout: Real World Graphic Design

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

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11896 5516 RR0001

Message from the CEO



Welcome to this issue of *Horizon*, our community newsletter. As you read the articles, you may notice a common thread; many of the subjects of these articles share a message to the community – their own words to live by. In this issue my theme, or message, is around giving.

People give in a variety of ways. In this newsletter, you will read profiles about Dr. Mark Guttman and Dr. Michael Hayden, each of whom have devoted their careers to improving the quality of life for individuals and families facing Huntington disease (HD). Brynne Dalmao, our new Board Chair, and Mack Erno, our outgoing Board Chair, give in a variety of ways, volunteering time, expertise and leadership. Our Halifax Amaryllis Coordinator Gillian Shay gives back with her hard work, creativity and passion to make a difference and inspire others to do the same. Over the next year, you will see a renewed focus on how we can support volunteers – the ultimate role models in giving. A new Volunteer Coordinator position has been created at the National Office of the Huntington Society of Canada (HSC), and we hope that this resource will enhance support for those community members who graciously devote their time and energy to helping.

Giving can also mean financial donations, in different forms, and we are so grateful for those as well. Legacy giving (leaving a gift in your will) provides future support for the Huntington community. You can learn more here www.huntingtonsociety.ca/legacy-giving/. Another option is to become a monthly donor, providing consistent support (www.huntingtonsociety.ca/monthly-giving/). This is such a help, because our Family Services programs and cutting-edge research are ongoing. Being able to fund these makes it possible for them to continue to help support individuals and families affected by HD.

In a few days, GivingTuesday will be upon us. This year, GivingTuesday is on November 30. It is a time when charities like us ask donors to consider making a gift to help us achieve our mission to improve the quality of life for those affected by HD. In 2020, our first year participating in GivingTuesday, we raised \$6,372, and this year our goal is to double that amount. Please consider making an early holiday gift to the community on GivingTuesday. To do so, call 1-800-998-7398, email rstjules@huntingtonsociety.ca, or visit <https://www.huntingtonsociety.ca/givingtuesday/>.

Giving is a beautiful thing. Thank you so much to everyone who gives in extraordinary ways. We are so grateful. 🌟

Shelly Redman
CEO

Huntington Society of Canada

Board Announcements

On Saturday, September 18 2021, the Huntington Society of Canada held its Annual General Meeting. The following appointments were approved:

- Brynne Dalmao, Board Chair
- Cam Barrett, Board Vice-Chair

Mack Erno has served his two years as Board Chair and will remain on the Board of Directors as Past Chair. Thank you so much, Mack, for all of your hard work and dedication. Welcome to Brynne Dalmao, our new Board Chair. Brynne has shared her vision and expertise as Vice-Chair and we are thrilled to have her stepping into this role.

We are also pleased to announce the newly elected Board Directors:

- Genevieve Giroday
- Marg Romanow

Two of our long-standing Board Directors, Dr. Mark Guttman and Dr. Ray Truant, are leaving the Board. We are so fortunate to have benefitted from their knowledge and guidance during their time on the Board and look forward to working with them on other projects and via different channels. 🌟



Huntington disease research news. In plain language.
Written by scientists. For the global HD community.

Visit hdbuzz.net to see what the buzz is all about!

A Message from New Board Chair Brynne Dalmao



It is a great honour to have been elected as new Chair of the Board. I am grateful for the opportunity to continue my work with the Huntington Society of Canada (HSC) and to help provide some direction to the incredible staff team. An important focus for me is supporting families and people who are affected by Huntington

disease (HD) through the clinical services we offer as well as research. These are such important priorities and I am very proud that, historically, HSC has truly valued both.

HSC is such a person-centred organization with a list of excellent achievements. I am very excited to continue to support that work, as well as to provide leadership and direction from the Board to continue to make lives better for people who are affected by HD. As the founding president of Young People Affected by Huntington Disease (YPAHD), I first joined the Board as the YPAHD representative in 2014. I became a Board Director in 2018 and then moved into the Vice Chair role in 2019. I have always been passionate about this Board, community and organization.

If you hear me referred to as Doctor, it is because in my day job, I am a chiropractor practising in Orangeville, Ontario. Being a health care

professional gives me a unique perspective into the clinical services HSC both offers and works to prioritize. At the same time, I have deep knowledge of the importance of research and the process of moving an idea from the laboratory through clinical trials and into use in the clinics. I also teach at the Canadian Memorial Chiropractic College and George Brown College in Toronto; I am extremely interested in education.

My message to the community is hope. One of the things that brings me the most hope is the hardworking, dedicated and supportive community. HSC is such a grassroots organization. That comes through in everything from the advocacy work that volunteers do to the fundraising taking place at the community level. This is a very challenging disease and I am extremely grateful to and inspired by all the members of our community who work tirelessly to improve the quality of life for so many people. 🌱

A Message from Outgoing Board Chair Mack Erno



It's been an eventful two years as Chair of the Board for Huntington Society of Canada (HSC). Like with any adventure story, the actual journey looked different from what I anticipated when signing on, pre-pandemic. But looking back, there are so many positives to take away from the adaptations we had to make and where HSC is today.

I'm big on connecting in person – especially when it comes to the HSC community - so it has been quite the change for me to shift to a largely virtual world. Having looked forward to in-person conferences, Board meetings and interactions with

our HSC community and staff, it was disappointing that none of that was possible and I had to adapt to a new laptop with a better camera and a headset that looks like I could be landing planes at an airport. However, going virtual is definitely better than grinding to a halt, and I think HSC managed quite effectively through this time.

I truly believe HSC is on a great path. I am so pleased with the HSC leadership team and think we are well positioned for them to lead HSC into a new chapter. I have no doubt that as things like Chapter meetings and events start to open up again, we will move forward with what we have learned and find even better ways to do things. I feel that HSC adapted to a largely virtual world really well and we have learned a great deal in the process. Our Virtual National Conference in March was a prime example of this. It saw more than double the attendance of a typical in-person National Conference – that's just a huge impact! Offering both virtual and in-person opportunities can be a great way to reach all members of the community across our big country, especially for those where travel is a limitation. For that, I am thankful for the unique situation of the past 18 months, because the pandemic encouraged us to try these new approaches to staying connected. I'm sure as we move forward we will find hybrid

solutions that allow a combination of virtual and in-person connections to have even greater impact for those affected by Huntington disease.

My message to the community is to keep doing what you're doing and don't be closed to new ideas. We have discovered solutions that have worked really well during these challenging times. Even without our in-person offerings, keep talking, keep communicating. There have been amazing success stories of volunteers who took the plunge and tried new ways of holding meetings, organizing events, or selling Amaryllis. I hope we can keep connecting and learning about what has worked and what hasn't from others in the community. Volunteers truly are the backbone of this organization and they work hard every day, even when it has been challenging to do so in the face of change.

A big thank you to our staff, volunteers and families who make up our amazing Huntington disease community. It has been a great eight years on the Board with the last two as Chair. I am pleased to demonstrate my ongoing commitment to the organization and the cause by staying on a Past Chair of the Board. As always, I am excited to see what comes next for HSC and the HD community. I look forward to our next connection – whether it be virtual or in-person! 🌱

Dr. Mark Guttman

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support. "It was a very powerful combination of being extremely interested in my patient with HD, that first presentation as a neurology resident, Marjorie Guthrie lobbying for support, and the research by fellow Canadians Jim Gusella and Marcy MacDonald," Dr. Guttman says. "It all came together to be the first step for me to really become passionate about Huntington disease."

Connection with HSC

Shortly after Dr. Guttman opened his clinic in Markham, Ralph and Ariel Walker contacted him and then drove from Cambridge to visit. Ralph and Dr. Guttman had a chat that was transformational, in Dr. Guttman's words. Dr. Guttman recalls Ralph saying that he understood that Dr. Guttman was setting up his practice, and that Ralph wanted him to focus on Huntington disease. Ralph wanted people to be there for patients and families, and that even if Dr. Guttman felt he could not do anything for HD, the HD community hoped research would change that. Ralph told Dr. Guttman that they needed him to be involved – he had an expertise and he could support patients and families. Dr. Guttman thought that visit and commitment was extraordinary.

"Ralph was a fantastic force to be reckoned with and we had a great relationship," Dr. Guttman recalls. "He was one of the reasons I started to do the Northern program, where I would eventually treat up to four generations of families with HD, as well as becoming the Toronto representative for the Huntington Study Group. He was truly a wonderful advocate for patients and families."



Dr. Guttman had many positive interactions with HSC's former CEO, Bev Heim-Myers. When government funding for multidisciplinary teams to work with neurology patients was taken away 10 years ago, Dr. Guttman and Bev worked together to lobby to overturn the decision. Unfortunately, they were unsuccessful, in spite of the fact that the model was, in Dr. Guttman's words, "absolutely effective and shown to be helpful."

Dr. Guttman has also worked closely with HSC's current CEO, Shelly Redman, and has been a member of the HSC Board of Directors for the last six years. Sept. 18, 2021 marked his last board meeting, but not the end of the partnership.

"Philanthropy and charitable giving is extremely significant to me," Dr. Guttman says. "I have volunteered on many boards and I've had so many positive experiences on them, including the HSC Board. I truly believe in giving back to things that are important."

Rewarding Interactions

One of the most rewarding aspects of Dr. Guttman's career has been working with families up north in the Sudbury, Sturgeon Falls and North Bay regions for 30 years. "There was no neurologist there at all," says Dr. Guttman. "These very detailed family interactions with so many people up there really meant a lot to me, as did the exceptional service provided by the HSC social workers." Dr. Guttman highlights that the genetics nurse from North Bay, Francine Robert, was the key motivating factor for these innovative clinics; she truly wanted to make a difference, making house calls and providing an exceptionally high level of care.

Dr. Guttman also encouraged these patients and families to get involved, especially with HSC, by volunteering and generally participating in a variety of ways.

"Working with these families was a pleasure and an honour and truly one of the best experiences of my career," Dr. Guttman says.

Vision for Clinical and Research Fields

When asked about his reflections on the clinical and research fields, Dr. Guttman hopes there will be more neurologists, expanded clinics and for multidisciplinary teams to receive funding. For research, he wishes that a successful disease-modifying therapy had been discovered before he retired. Sadly, this is not yet the case. "We're not there yet, but there are still many different strategies to look into." He also notes that Canada has set a high bar for research and that participation in clinical trials needs to continue. In fact, Dr. Guttman's clinic was one of the sites with the highest recruiting rate for clinical trials.

Message to the Community

Dr. Guttman's message to the HD community reflects his life's work. He tells the story of sharing office space with an oncologist, also a long-time friend, who asked Dr. Guttman, "How do you do what you do?" He was referring to the fact that there is no cure for HD, and wondered how Dr. Guttman coped in the face of those odds and outcomes. Dr. Guttman acknowledged to his friend that HD is a terrible disease affecting the lives of individuals and families, but he said he was hopeful about the research. He also believes having the right clinical and Family Services supports in place can make all the difference.

"There's still a lot of hope. It's all about quality of life, trying to help people cope with difficult situations and their condition with the best that we have in a supportive way," Dr. Guttman says in a message especially meant for the community. "Focusing on this quality of life – making the journey as easy as possible for people – was and still is the highlight of my career." 🧡

We know that all of Dr. Guttman's patients would agree – he truly made a difference to individuals, families and generations. For more on how you can keep his legacy going, please see the article about the Clinical Fellowship he has helped to establish.

New Clinical Fellowship Program

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Without a dedicated initiative to stimulate interest in the field of HD, a shortage of neurologists with expertise in HD care will only continue or worsen.

"We are so grateful to Dr. Mark Guttman and Lesley Simpson for this gift supporting the training of future HD neurologists," says Shelly Redman, CEO of HSC. "We hope anyone wishing to make a donation in recognition of Dr. Guttman's contributions throughout his career and honouring his retirement will do so; the funds will be directed towards our clinical Family Services programs directly helping families facing HD. We think this is a wonderful connection as Dr. Guttman was such a strong supporter of clinical Family Services programs and the positive impact they have."

People interested in donating can visit the HSC website and check off tribute gift while indicating the pledge is in honour of Dr. Guttman's retirement (<https://www.huntingtonsociety.ca/yes-i-want-to-donate/>). 🧡

An Ariel View

By Ariel Walker,
HSC Co-Founder

I turned 80 on August 20, and was so touched by how friends and family took the time to wish me well and help me celebrate this occasion.

I don't feel 80. Actually, that's not quite true! I definitely feel 80 when I wake up and experience all of my daily aches and pains, accompanied by a groan or two. These go away in no time, however, and then I'm ready to face the day. Still, my body can't do all of the things I did when I was 50, or 60 – and most definitely not 30. My mind feels like it did when I was younger, though, and for that I'm grateful.

My birthday was marked by many well-wishers dropping by with cards or gifts – totally unexpected! There were many Facebook comments as well, so thank you to my Facebook friends. In total, I received 45 physical birthday cards, prompting my mail carrier to exclaim, "Ariel, you must be celebrating a special birthday! I've been delivering cards for two weeks."

I enjoyed a lovely dinner with friends the night of my birthday, and then with family and friends for lunch on Sunday. I do love charcuterie and fancy sandwiches, especially when someone else makes them! The wine was flowing, my guests sang Happy Birthday to me, and all in it was about a six-hour celebration. I also had the opportunity to celebrate with more family at our Wasaga Beach cottage for three days. Much to my surprise, my four close workmate friends also took me out to a lovely spot for dinner – the celebrations continued, which was so caring and generous of everyone.

Then, in mid-September, it was time for my annual get-together with three of my Nursing School classmates. With the pandemic keeping us close to home, we opted to visit one friend's cottage north of Bobcaygeon in the Kawarthas in Ontario, and, luckily, another friend could join us this year. There we were, five 80-year-olds reminiscing and chatting about nursing and politics. It was so nice being together for three-and-half days, and even though we couldn't travel, we enjoyed seeing more of our own province. I did a lot of travelling in Europe and across Canada with Ralph, so I'm happy to stay close to home. It's important to change your boundaries a little bit from time to time and see nearby places in a new light, with more attention.

With my birthday celebrations behind me, it is time to focus on Amaryllis season. I received my 24 cases and made my way through a long list of people to call (my "regulars") to come and take a case or two off my hands. They always say, "I was just thinking about you! It's amaryllis time, isn't it?" I'm sure we'll have another wonderful year thanks to everyone's hard work and generosity.

Well, whether it is a special time of year because of a birthday, Amaryllis or the holidays, I wish you the very best and hope you are finding ways to see the beauty of your surroundings. 🍂



HealthPartners

This fall, the Government of Canada launched its Workplace Charitable Campaign (GCWCC); recipients include the United Way and HealthPartners. Since 1988, donors (federal employees and retirees) have contributed over \$204 million via the HealthPartners portion to research, support services, education, and advocacy – benefiting millions of Canadians from coast to coast to coast, regardless of age, gender, race, or orientation.

HealthPartners works in partnership with 16 national health charity members and Huntington Society of Canada is one of those trusted partners.

Here's how the charitable campaign works.

One donation supports the work of all 16 of HealthPartners' Member Charities and ensures more equitable shares to the smaller charities. Since 1997, HP campaigns have raised \$2,520,563 for HD - not including 2020 numbers.

In 2020 alone, HealthPartners and its 16 charities touched the lives of over **16 million Canadians** living with chronic disease and their caregivers. Last year, GCWCC donors invested over **\$7 million** towards a healthier Canada. HealthPartners and its 16 charities funded over **684 research** projects focused on treatments for over 400 chronic diseases

HealthPartners and its member charities invest donations in the four pillars of health:

RESEARCH: Keeping researchers on the cutting edge of fighting disease, discovering treatments for over 400 chronic diseases that exist now and exploring those we might face in the future.

SUPPORT SERVICES: Providing services to enhance the quality of life for persons living with chronic disease, like support programs for caregivers.

EDUCATION: Developing educational tools for disease management and prevention, treatment and caregiving information, and educating healthcare professionals on all aspects of chronic disease. Creating awareness campaigns about chronic disease to break the stigma, support treatments, and deliver trusted information.

ADVOCACY: Reducing barriers by improving accessibility and partnering with the government for a healthier Canada.

We at HSC are so grateful to HealthPartners and donors through this campaign for supporting Huntington Society of Canada. If you are a current or retired federal employee, please donate here: <https://bit.ly/gcwcc-donate> or send this link to someone you know who works for the Government of Canada. Thank you! 🙏

Behind every
face is a story.
Behind every story is you.



iii HealthPartners
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Become a 2021 GCWCC #HealthChampion!

YPAHD Day 2021

Huntington Society of Canada (HSC) and YPAHD (Young People Affected by Huntington disease) were excited to bring YPAHD Day to youth aged 14-35 in a safe, virtual setting this year. The conference took place on Saturday, November 13 and involved presentations, panel discussions, and social tables.

YPAHD Day is all about connection, and this year that connection was virtual. Previous offerings this year, from the Virtual National Conference to Continuing Education Forums, have shown that online events provide a much-needed lifeline to the youth community.

"YPAHD Day has always been about support, learning and interaction," says Kelsey Laidlaw, Events Coordinator for HSC. "It has been a favourite event with YPAHD since the first year offered. Participants talk about how much it means to have a network of caring individuals who are always there for someone in need."

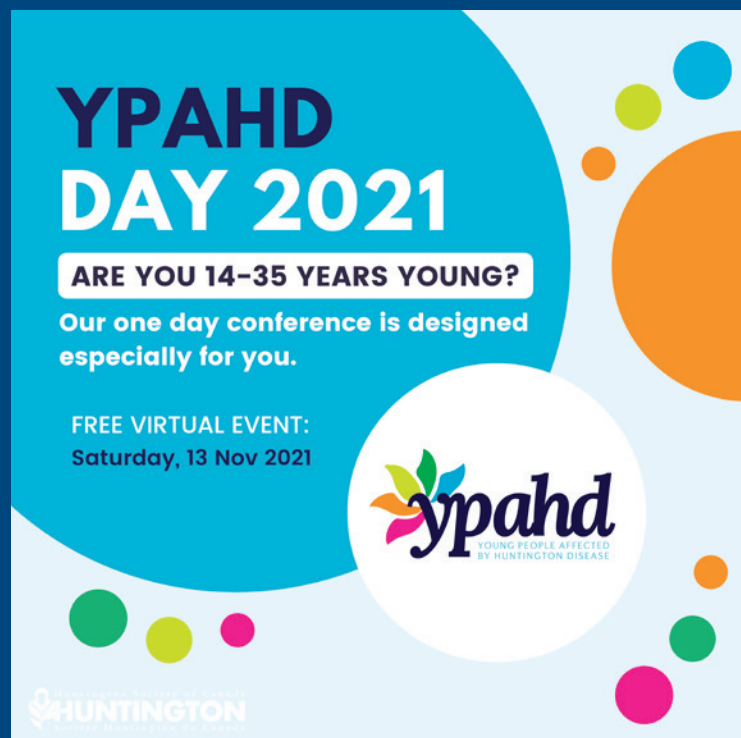
The event for 2021 looked a bit different from past YPAHD days, in true Covid fashion. Going virtual may have been a change, but it was also an opportunity to reach more youth than ever before. Not only was the event free, but there were no travel costs. And as many of the YPAHD membership have busy, active lives, a virtual offering made it easier to schedule.

The sessions themselves were full of relevant information. Topics ranged from family planning to navigating relationships, including romantic, friend-based and family. Genetic testing, an often-requested education session, was also on the agenda, as was an update on HD research.

"With YPAHD Day, there's always something for everyone," Kelsey adds. "We've found that YPAHD Day is a day of sharing and supporting. Everyone has a voice. There is always someone to listen and a virtual shoulder to lean on."

For more information, please visit:

<https://www.huntingtonsociety.ca/ypahd-day/> 





YPAHD DAY 2021

ARE YOU 14-35 YEARS YOUNG?

Our one day conference is designed especially for you.

FREE VIRTUAL EVENT:
Saturday, 13 Nov 2021


YOUNG PEOPLE AFFECTED
BY HUNTINGTON DISEASE






Q Dear HSC, can you tell me what a Speech Language Pathologist does and why they are important members of the health care team in Huntington disease (HD)?

A A speech language pathologist (SLP) is a health professional who can identify, diagnose, and treat communication and swallowing issues. An SLP provides valuable insight throughout the progression of HD. With an early assessment of communication abilities, the SLP can evaluate baseline and the need for any tools or resources.

Due to the progressive nature of HD, communication becomes a challenge, but it is possible to introduce and learn new skills. Based on the assessment, individuals with HD may consider using communication aids such as computerized speech devices, tablets, letter boards, word boards, picture boards, flash cards and talking mats. The earlier the idea for the communication tool and techniques is introduced, the better it can be used. For example, simple and clear communication tricks, such as giving a thumbs up or thumbs down (as a yes/no), can be introduced early on so they are easier to use in the later stages of HD.

It is important to visit your SLP for regular reassessments and to stay up to date on new strategies as HD progresses. Carers often educate others on how to best communicate with someone with HD. Remember, the ability to communicate may change, but the need to do so remains constant.

For more tricks and tips to help with communication in HD, please see HSC's Improving Communication in HD Fact Sheet. For more information on the role of the SLP in swallowing assessments, please visit the HSC fact sheet on Eating and Swallowing. Both are available at <https://www.huntingtonsociety.ca/hd-fact-sheets/> 



Profile:

Dr. Michael Hayden

Disease (CHD), as well as its dedicated HD medical clinic in 1996. The CHD houses the first Huntington Disease Biobank, established in the mid 1980's, now among the largest in the world.

The Biobank exists thanks to two types of donations: blood/DNA and tissue, including the brain. Being able to study DNA and tissue samples is critical in supporting further research into more effective diagnosis and treatment of HD. Tissue samples help researchers learn more about how the HD-associated DNA changes affect the physical characteristics and proteins of the brain and tissues. The Biobank donations have resulted in tens of publications by researchers at UBC and around the world.

"Having access to DNA and tissue helps us learn more about HD and varying approaches to thinking about therapies," says Dr. Hayden. "We are also so grateful to the donation of 'normal' tissue from family members without an HD diagnosis to help us contrast the changes with HD."

Stephanie Bortnick is the new Biobank coordinator. With this role, the Biobank can now facilitate the removal and transport process of the tissue for the first time across Canada. "We could never offer this before, and we are so pleased that we can support patients who make the ultimate gift and share tissue with us," says Dr. Hayden. Stephanie's role is to facilitate tissue donation Canada-wide, with the support of an HSC network that reaches across the country. A review committee supports the Biobank and ensures that rigorous ethical practices are followed for these precious samples.

HD Research

Dr. Hayden also has close ties to the Huntington Society of Canada, and was first invited to a meeting by Ralph Walker in 1983. "I became very close with Ralph," says Dr. Hayden. "It was a joyful collaboration and a long-time commitment." This positive attitude is reflected in Dr. Hayden's ongoing passion for research and what he calls "realistic hope", acknowledging that no study or drug is a sure thing. One of his aspirations is to find therapies that will offer neuroprotection. This

would help individuals affected by Huntington disease, and people at risk, retain their functional capacity, supporting activities like work, taking control of their finances, going for walks with their kids and grandkids, and being participating members of the community.

Currently, Dr. Hayden is working on PROOF-HD, a Phase III clinical trial studying the drug pridopidine developed by Prilenia Therapeutics, a clinical stage biotech company that he leads. The study is being conducted in Canada and the U.S and nine countries in Europe. Dr. Hayden hopes that the therapy will show a positive impact in maintaining the functional capacity of individuals affected by HD. Dr. Hayden is excited about the progress of the trial, including enrollment, which was completed ahead of schedule. "We are learning a lot with every research study," says Dr. Hayden. "Yes, we have failed in the past, but we need to focus on failing well. That means learning from the past about how to best conduct clinical trials and support family members." The team hopes to have some insights in about 65 weeks, by early 2023.

Message to the HD Community

Dr. Hayden has seen many individuals and families impacted by Huntington disease, and he knows how hard it has been for them to continue in the absence of light. He wants HD to be destigmatized, no different from other diseases like diabetes or cancer. Dr. Hayden's message to the HD community is that there are many collaborators around the world taking a constructive and collaborative approach to finding new treatments for HD.

"No one is giving up," he concludes. 🌱

For more information, please visit:

<https://chd.med.ubc.ca/>

www.hdbiobank.med.ubc.ca

<https://www.prilenia.com/what-is-huntingtons-disease>

<https://www.huntingtonsociety.ca/proof-hd/>

Dr. Michael Hayden first observed patients with Huntington disease (HD) in the late 1970s as a young physician in South Africa. Invited into the homes of families impacted by HD, he was moved by their dignity, resilience and courage, even during dark times. Marjorie Guthrie and Senator Ted Kennedy ensured that Dr. Hayden received a green card to come to the U.S., where he attended Harvard Medical School for a postdoctoral fellowship in Genetics.

"My commitment to work on Huntington disease was sealed," Dr. Hayden says. "Seeing the generosity of spirit of the Huntington disease community even while facing hopelessness was so moving. It motivated me to make sure I lived a life that meant something, that gave back."

A Lifetime of Research

So began a major focus of Dr. Hayden's medical and research career. In 1977, his first research article was published in *The Lancet*. He was further inspired and intrigued by the 1983 publication molecularly mapping the huntingtin (HTT) gene to a specific human chromosome. A passion has always been translating research into information, services, and products that could be used in the clinic. He has now authored approximately 900 peer-reviewed articles and invited submissions, and has trained over a hundred graduate students and postdoctoral fellows, many of whom continue their commitment and focus on HD.

Huntington Disease Biobank

Dr. Hayden joined the medical faculty at the University of British Columbia (UBC) in 1983 where he founded the Centre for Huntington

New Family Services Staff

We have been fortunate to welcome four new staff members to our Family Services team. Read on to learn more about their roles, background and messages to the community.

Meet Megan Blomfield, Southern Albertan Resource Centre Director (RCD)



What is your job role and area of focus?

Since February 16, 2021, I have been working as the Resource Centre Director (RCD) for Southern Alberta. In this role, I support, educate and advocate for families impacted by Huntington disease (HD) and liaise with health care professionals.

Lately more long-term care centres are taking me up on my offer of education sessions, likely because they have some patients with HD there whose disease is progressing. I'm trying to help long-term care centre staff better cope with and support the changes that come with progression.

I'm located in Calgary and I service the area south of Red Deer.

What is your background?

I have a Bachelor of Social Work (BSW) from the University of Calgary. My first job developed from my social work practicum at the ALS Society of Alberta. I went on to stay there for nine years as Client Services Coordinator. I had my daughter in 2016 and took a step back from direct service. I taught yoga – it's a great part-time job for a parent. In 2019, I started at the Calgary Fetal Alcohol Network in the

role of Assessment and Diagnosis Coordinator. I stayed there until Feb. 2021, when I joined HSC.

What drew you to the opportunity with HSC?

I was starting to feel called back to work directly with individuals and families, but I wasn't actively looking for a new job. I was renewing my social worker credentials online when I saw the job. It reminded me of my experience with the ALS Society, and how much I wanted to get back into that type of work. I sent in my resume, and here I am!

What message do you have for the HD community?

I've learned a lot from everyone I work with, but I know there's still so much more to learn. I'm so happy to be here and to be part of the community. I've met many wonderful families and I am honoured to be a part of their experience. I look forward to meeting the families I haven't had an opportunity to connect with yet.

I really want to say that I am here. I know it's tricky to build a relationship over the phone, or virtually, but I am here. Please reach out with any questions or needs and we'll work on them together.

What is a fun fact about yourself?

I am very interested in investments. Ever since my daughter was born, I've paid more attention to the stock market, because there was more to plan for. I find it fascinating and would love to manage portfolios, but for now I just have time to manage one of my investments, and it's definitely the best performing. A few years ago, I bought one share of Netflix – that certainly went well. I'd love to learn more about what does well, and why.

You've got great instincts, Megan – we're so happy to have you.

Meet Tanya Greaser, Family Services Educator



What is your job role and area of focus?

I started at Huntington Society of Canada on July 15 in a new role, Family Services Educator.

This role has a few different aspects, including supporting the HSC Family Services team as we offer more online programs and communications. For example, this would include better use of Penelope (our client management software), Microsoft Teams and Outlook. Another sizable chunk concerns educational materials, helping to edit the fact sheets, booklets and other literature that goes out to the public.

I'm located in Kelowna and work with the Family Services Team as well as other members of the National Office virtually.

What is your background?

I have a Bachelor of Arts with a major in psychology and a Bachelor of Social Work. I was hired right from my social work practicum at St. Paul's Hospital in Saskatoon. I worked there as a Medical Social Worker from 1997 to 2008. After I had my daughter in 2008, I was looking for a change and wanted to work part-time. I found the right opportunity with the Huntington Society of Canada as the Resource Centre Director (RCD) for Saskatchewan and worked there until 2011, when

I sadly had to leave HSC because my husband got a job in the United States. We lived in the States for five years, and I worked as a social worker for private companies. I was excited to move back to Canada in 2016. I had missed so much about it, including the health care and educational system. Earlier this year I was researching how to reinstate my Social Worker license and registration on the Canadian Association of Social Workers website and when I saw the HSC role, I thought it was the perfect fit – I was excited to return to an organization I had loved.

What drew you to the opportunity with HSC?

I am truly an educator at heart, and the primary function of this role is educating. I can't wait to reach more of the community through my work on the health education pieces.

What message do you have for the HD community?

From an educator point of view, I would say never stop inquiring and learning. It can be frustrating to receive answers you don't want to hear, but keep asking.

What is something personal that you are willing to share with the community?

I like to laugh and am very well known for that! I am also chronically late – my friends and families know to tell me to be somewhere 15 minutes before the actual time. One day I plan to have a tattoo of "Little Miss Late" with the words "I'm coming..."

Finally, my favourite inspirational quote is the following: "To the world you may be one person. But to one person you may be the world" *anonymous*

I really believe for all of us that one small person can make a difference.

Thank you Tanya, for the inspiration!

New Family Services Staff

We have been fortunate to welcome four new staff members to our Family Services team. Read on to learn more about their roles, background and messages to the community.

Meet Corrina Masson, Family Services Worker for Vancouver and Fraser Valley



What is your job role and area of focus?

I joined HSC on June 14, 2021, working with people impacted by Huntington disease (HD); this could be the individual with the diagnosis or family and caregivers. I follow-up one-on-one via phone or video calls to ask about any health changes or if the individual or family have any questions for me. In addition, I provide short-term counselling for the family and I offer support groups for caregivers.

I help families access different resources and I collaborate with many healthcare professionals, including neurologists, psychiatrists, nurse practitioners, case managers, and home health care providers. Because it's a rare disease, sometimes other health care professionals don't have as much familiarity with HD so I bridge the gap. I advocate for the clients and their needs and wants, serving as that extra support.

I focus on Vancouver and cover parts of the lower mainland, including Fraser Valley and upper B.C. (e.g., Prince George).

What is your background?

I have a Bachelor and Masters of Social Work from McGill. Originally from Montreal, I moved to B.C. three years ago. My job experience before

HSC mostly focused on children and family domestic violence. I also worked with the elderly in home health and long-term care.

What drew you to the opportunity with HSC?

I was really interested in the dynamic nature of the role. I liked the idea of being able to connect with clients and work individually with them, as well as in group and community settings. I enjoy the flexibility of identifying gaps between services offered and what clients want, and then being able to work through a solution.

For example, I really enjoyed organizing the virtual education session that took place November 2 with Dr. Heyland, a critical care doctor. He discussed advance care planning to help make sure that an individual's preferences are heard when medical decisions are being made in hospital. I find it rewarding to provide specific information and resources for the HD community in this way.

What message do you have for the HD community?

My message is this: ask for support from your family, community and health care professionals. This is truly a great, close-knit community and so I would keep encouraging connection — everyone is so willing to support one another.

You may feel alone at certain times, but by reaching out you will quickly see that others are experiencing similar things as you. We see that in support groups and it is really wonderful to connect others in a time of difficulty.

What is an accomplishment that makes you proud?

My greatest accomplishment is my almost-two-year-old toddler. She is spunky, energetic and wants to do everything by herself. All my free time and energy go to her — she's my biggest passion and excitement in life.

A warm welcome to Corrina!

Meet Sheri Mayhew: Eastern Ontario Resource Centre Director (RCD)



What is your job role and area of focus?

I joined HSC on December 16, 2020 as the new Eastern Ontario Resource centre Director (RCD). I help support individuals, caregivers, friends, and other professionals who have questions about Huntington disease (HD) or need resources. I speak with them, listen to their story, and learn what they need. Given the pandemic, my connections are virtual or via phone call. I am available for information sessions at medical or care facilities. My hope is to facilitate connections with caregivers virtually. I have built relationships with stakeholders, including genetic counsellors at CHEO, the Movement Disorder Clinic in Ottawa, and the HD supports within Kingston. I am active within the Ottawa Disability Coalition and disseminate valuable information via monthly newsletters to our HD clients and families.

I service the Eastern Ontario region from Hawkesbury down to Belleville and Kingston. I was born and raised in the Ottawa Valley and so I'm thrilled to be able to give back to my community via this position.

What is your background?

I enjoy connecting with people. I focus on a person's choice, during

times of stress and uncertainty. I have a wealth of information and connections, gathered from my career in education and mental health, and simply wish to share it.

I have over 20 years of mental health experience in Ottawa. I have worked at the Canadian Mental Health Association in both front line and leadership positions. I worked as a Behavioural Rehabilitation Therapist at the Acquired Brain Injury Program at The Ottawa Rehabilitation Centre. I was a college instructor at Canadore and Trillium Colleges. Currently, I am an Associate Faculty and Associate Program Director at City University in Canada in their Masters of Counselling Program. I hold a Doctor of Education degree and a Master of Education in Educational Counselling. I love learning!

What drew you to the opportunity with HSC?

I want to help people recognize their strengths and support building a team around each person who needs it. I want to help support people to understand Huntington disease by perhaps offering a different perspective, answering a question, navigating the system, or providing a resource.

What message do you have for the HD community?

Hopefulness is my key message. I'm a strengths-based person. We may not be able to cure HD presently, but we can work to take some of its power away.

What is a personal tidbit you can share with the community?

I am absolutely a dog lover. I adore my family, friends and great food. Plus, I'm a chocolate connoisseur, the sweeter the better!

A belated welcome to the team and the community, Sheri — please pass the chocolate! 🍫

HD Awareness Month and National Virtual Walk

May was a bright light in 2021 thanks to a wonderful Awareness Month and National Virtual Walk. We hope you felt the strong ties of community uniting us all across Canada – we know we definitely did. We reached new heights in raising awareness for Huntington disease (HD) and surpassed our fundraising goals.

Light It Up 4 HD Reaches Around the World

Light It Up 4 HD is a global phenomenon with buildings and structures lighting up in blue for HD and purple for Juvenile HD. These stunning visual displays offer the chance to have a conversation about HD – its impact, symptoms, and what it is like for an individual affected by HD and their families – as well as what can be done. We had a record-breaking year for Light It Up 4 HD with 173 sites participating, 39 in Canada and 134 internationally! Check out all the sites here: www.lightitup4hd.com

Thank you to all of the volunteers who worked with sites to arrange the lighting and for taking photos to share with our community.

HD Awareness Month = Spirit Month

This year also saw the first spirit month for HD Awareness Month. Our social media channels and email communications featured different themes each week, from “Fill Your Feeds with Blue and Purple” to “HD Spirit @ Home” to help us raise awareness for HD. We saw wonderful levels of engagement as our community grew in numbers and reach. This helped increase education about HD. It also lifted our fundraising efforts, with the goal to support those facing HD with Family Services and to fund research into better controlling the disease. We hope you participated in some of these offerings and enjoyed this show of spirit.

Huntington Heroes National Virtual Walk: Goals Exceeded!

We are so proud to have SURPASSED our fundraising goal for the Huntington Heroes National Virtual Walk, which took place May 29-30. We also had more participants than ever before. Thank you so much to everyone who walked and raised funds, volunteered, and organized online fundraisers to add to the initiative. Our heartfelt gratitude to donors everywhere – your support means so much to us.

The total amount was over \$250,000 – definitely more than our \$213,000 goal. An anonymous donor also matched the donations, meaning we raised over half a million dollars to support families facing HD as well as research!

We have said it a few times this year – together we can do amazing things. Let's celebrate those successes and continue to work for the community, the cause, and for families facing HD. 🌟



Fall Chapter Events

This fall finally saw the return of some in-person events, and we were so pleased with the gradual return to some of our favourite fundraising activities. Here are some of the happenings that started up again:

- The **12th Annual HD RIDE 4A Cure** took place Saturday, August 28, 2021 at the TeePee Creek Stampede Grounds in Alberta. This is our outgoing Board Chair Mack Erno's signature event – a hike, ride or run complete with food stops and live music. Thanks to everyone who supported!
- The **6th Annual Golfapalooza HD Classic in Welland, ON** took place on Sunday, September 12, 2021 and was a great day! The rain held off and there were many smiling faces. Thanks to volunteer Barb Eade for taking a lead in organizing as well as all the helpers.
- The **26th Annual Winnipeg HD Indy** took place Sunday, September 12. Twenty-eight teams had hours of go-kart fun and raised about \$30K. Thank you Vern Barrett and everyone else for this wonderful success.
- On Saturday, September 25, The Peterborough Chapter presented the **4th Annual Peterborough Golf Tournament** – what a great event! Many thanks to Leah Ridpath and her team of volunteers for making this happen.
- On Monday, October 4, Bobby Jinkinson and Liz Hobbs completed a **100 km Ultramarathon Run for Huntington Disease** in the Ottawa region. That's more than 130,000 steps in support of Huntington disease! WOW. Thank you so much Liz and Bobby.
- The Niagara Chapter of HSC was pleased to bring back the **Lake-to-Lake HD Fall Challenge** following the success of last year's inaugural event. On Saturday, October 16 and Sunday, October 17, participants travelled (collectively) the distance from Port Weller to Port Colborne and back, a total of approximately 72 km, as many times as possible, while raising funds for HSC. Thank you Ron Culp and other organizers, participants and donors for dealing with the rain, rain date, and still having a great time!
- The **24th Annual Trap Shoot for Huntington disease** took place Saturday, October 23 at the Rondeau Rod and Gun Club near Chatham, ON. Many thanks to organizer Dave Ulch.

All proceeds from these events go towards funding research and family services for those affected by Huntington disease. We appreciate all the efforts of our hardworking volunteers and fundraisers who always go the extra mile! 🙌



Amaryllis Spotlight:

Gillian Shay, Halifax Amaryllis Coordinator

Gillian Shay is somewhat of an Amaryllis whisperer. Not necessarily in helping them bloom – the Orange Sovereign bulbs sold by the Huntington Society of Canada (HSC) in the annual fundraiser will reveal their showy beauty for anybody, not just master gardeners. Rather, Gillian has found the sweet spot of connecting the flower kits with their forever homes.

Gillian Shay took on the role of Amaryllis Coordinator for the Halifax Chapter three years ago. "I had wanted to get more involved but I was looking for the right opportunity," she says. "When I heard that the Chapter was looking for someone to fill this role, I thought it would be a good fit with my schedule and skill set." Over the past three years, Gillian has been able to grow the success of the Chapter in selling the Amaryllis bulbs with a few key strategies.

The Solution Maker

One of the approaches Gillian uses is to offer the Amaryllis kit as a solution to holiday gift needs. "I might suggest the Amaryllis kit is a wonderful present for a relative in a care home, a child's teacher, or for a manager to give their employees in recognition of their hard work," Gillian says. "I had one contact purchase 30 flowers for their entire work team!"

Expand Your Network

Gillian notes that she doesn't always want to have to go back to the same people asking for support over and over, namely family and friends. She is excited to start participating in new activities such as curling and pickleball, which will open up a new customer base for the Amaryllis. "It's a pretty compelling sales pitch," Gillian comments. "When you consider that a big box store might sell an Amaryllis for \$15 or even more, I can let people know that they could buy the Amaryllis for \$15 from the Huntington Society of Canada and the funds go towards research and Family Services to support individuals and families facing Huntington disease. It's very impactful."

Gillian also notes that other Chapter members and HSC contacts provide tremendous support. "One of the Halifax Chapter members always orders about 40 kits and checks in with me early on. Barb Horner, the Resource Centre Director for Nova Scotia and PEI, is a tremendous supporter. Our Children's Hospital (IWK) staff are also amazing, ordering about 30 flowers. When HSC sold out last year and they couldn't get any, they asked to be alerted first thing for this year's campaign." Gillian also credits her family and friends with supporting the campaign in a variety of ways. "They know I have a

hard time saying no, so if they can help with a pick-up or delivery they'll do anything they can to take that off my plate. I really appreciate all they do."

Social Media and Conversations

Another one of Gillian's tactics is to use social media to let connections know that she is selling Amaryllis again. She creates a post, shares it to her Facebook page, and supplies other Chapter members with the draft as well so they can follow suit. "Social media is a great way to get the word out," she says. "It must be working, because in September, even before I had a chance to post, I had people reaching out asking about the Amaryllis. People love them."

Gillian has shared what she writes for social media:

As the weather becomes chillier, and the days become shorter, that could only mean one thing – it's Amaryllis Season, all in support of the Huntington's Society of Canada 💙

If you have \$15 ✅

Access to water ✅

A sunny warm window ✅

And a desire to make the world a better and more beautiful place 🌸

Then you're in luck!

I will be selling Amaryllis bulbs as a fundraiser for the Huntington's Society from now until December 24.

What is Huntington's Disease you ask? It's like having Alzheimer's, Parkinson's and ALS. At the same time.

For an easy \$15, you'll get:

👉 1 amaryllis bulb

👉 1 puck of fertile soil

👉 1 pot

Just add water and watch your Amaryllis grow 🌱

A perfect floral addition for the holiday season 🌸

These make great gifts for those hard to buy for folks or a nice addition to a windowed office or cubicle.

Interested? Let me know and I can deliver or coordinate contactless pick up 😊

(Editor note: Gillian welcomes the use of her social media "script" by other Amaryllis volunteers, if they wish.)



Gillian notes that she mentions the same points in a conversation. "I'll work it into whatever we're talking about, and ask if they have a sunny window. Then I'll let them know that I have an Amaryllis in my basement looking for a home – that usually does the trick!"

Meaning of Amaryllis Campaign

Gillian has noticed a lot of connection between the Amaryllis and the Huntington disease community. "With the Amaryllis bulb, you plant it and watch it bloom. It's so beautiful. It's like watching the impact of your donation of time or money grow," she says. "It also provides comfort during a season when many people need it." Gillian shares that when she gave her mother-in-law an Amaryllis, she was delighted with the growth, sending Gillian messages and photos daily about the gorgeous progress. "It was a lovely connection. She was just amazed at the beauty of the plant and flower."

HD Connection

Gillian decided to become involved in the community because HD runs in her family; several of her uncles have the disease and three of them have passed away. "After a lot of soul searching and weighing the impacts on his children, my dad finally decided to get tested for HD, and he's negative for the gene mutation," Gillian reflects soberly. "I know how extremely fortunate I am that this is how the genetic side of things turned out for me. I wanted to do something that will support those that are living with HD." Gillian didn't know how to help at first, but has now found her role with the Amaryllis campaign. She finds that having an open heart and sharing a personal story, or an Amaryllis flower, resonates with people. "They're usually happy to support."

Message to the Community

Gillian's message to the community reflects her experience finding her place in the volunteer community. "If you are interested and able, try to get involved in some way. Having a role provides meaning," she says. "If everyone did just a little bit, we could spread hope and positivity. That's how we can all move forward together." 🌱

There's still time to order your Amaryllis! Visit <https://www.huntingtonsociety.ca/product/case-of-amaryllis-2021/> or email Rachel Thompson at rthompson@huntingtonsociety.ca. Cases are shipped in packs of 12 and cost \$180 + \$10 shipping