

NATIONAL VIRTUAL CONFERENCE

November 12-13, 2022



It is my great pleasure to welcome you on behalf of the Huntington Society of Canada (HSC) to the Fall 2022 National Virtual Conference. Of note, many people were anxiously awaiting registration to open on September 1 – we had a number of early confirmations and that certainly increased our anticipation for the event.

Conference is always an exciting time. It has the thrill of back to school, knowing that there are so many memorable teachings and stories to be shared. At the same time, reconnecting with old friends and making new ones is the sweetest part of the experience.

We are so fortunate that our Huntington disease (HD) community continually shows up to the call to participate, whether in the form of virtual conferences, fundraising, events, volunteering, or chapter involvement. Not even the many twists and turns of the past two years could dampen our spirit. I'm sure that's because to our core, HD community members are resilient, a theme you will see explored in conference sessions.

I invite you to make the most of our virtual conference and this accompanying program, full of tips on how to participate fully in the offerings. With this, our third online conference, we have demonstrated that we can live, learn and connect effectively in the virtual world, even as our in-person activities resume.

We are proud to present an incredible line-up of keynote presentations and workshops including topics such as research, caregiving and effective engagement at the Fall 2022 National Virtual Conference. Thank you for keeping the community strong and connected with your time, energy and attention. Enjoy the experience.



Shelly Redman
Chief Executive Officer
Huntington Society of Canada

Who Are We?



Family is at the heart of our community. Our families and volunteers tell a powerful story of caring people who pull together to improve the quality of life for Canadians impacted by Huntington disease (HD). HD is a fatal hereditary brain disorder with devastating effects on both the mind and body. It is like having the symptoms of Alzheimer's, Parkinson's and ALS all in one disease.

At the Huntington Society of Canada (HSC), our mission is to improve the quality of life for those affected by Huntington disease. We focus on this through the oversight and facilitation of excellent support services, providing access to the best and most up-to-date educational resources, increasing national and global awareness, advocacy and investing in promising research.

Find us on Social Media

Help us promote the National Virtual Conference, share your photos, and follow along with us on social media:

- Facebook: @HuntingtonSC
 - Twitter: @HuntingtonSC
 - Instagram: @HuntingtonSocietyCanada
- Don't forget to use our hashtag #HDCon22!

A Guide to Virtual Conference

We are so excited that you are joining our 3rd National Virtual Conference. Here are some tips to help you have the best experience.

Be on time

Consider joining sessions five minutes early. This gives you time to troubleshoot any technical difficulties with tech support, or independently. By being on time, we also reduce distractions for those already in session.

No screenshots, please

We want to respect everyone's privacy during the National Virtual Conference so we ask that you please refrain from taking screenshots or self-recording during sessions. If you want to share an image of you participating in the conference, please take these photos from our main conference lobby screen, rather than in a session. We will be recording the sessions and will make the links available to you, as well as any handouts.

Take breaks

We know it can be hard to sit in front of a screen for the full length of the conference. Rest assured that sessions will be recorded, so you can always come back to review information you missed. Be sure to stretch as you are able, grab refreshments, and step away as needed. Need a break from the presentations, but not ready to walk away? Bring a beverage and drop in on the virtual chill zone or virtual resource fair for a change of pace as you connect with fellow attendees or resource providers.

Use the chat

The more you use the chat feature throughout the platform, the more opportunities you will have to meet and connect with HSC staff, HD care professionals, and HD community members. Find the chat feature in each session, or in the lobby, introduce yourself, ask questions, and join the conversation.

Have fun!

Above all else, we want you to enjoy your time. We're here to connect, share, learn and grow the community. Make some new friends and have fun!

Tips if you're joining with audio or video

In sessions where you are encouraged to join using your own audio and/or video, consider the following:

Mute when not talking

There will be times in these sessions when you are encouraged to share with one another. When you're not sharing, please make sure your microphone is muted to reduce other sounds and noises for our speakers, volunteers and other attendees.

Share the mic

Joining conversations in a virtual space can be extra tricky so we need to take care to be respectful of our peers and make sure that all voices are heard. Use the 'Raise Hand' or chat box function if you want to share. This will help the Room Host and Speaker know you have a thought or question.

Use gallery view

Look in the top right corner of your screen and use Gallery View instead of Speaker View. This will let you see up to 16 other attendees of the National Virtual Conference on your screen. Are there more than 16 people in your session? You can also scroll between screens.

Lighting is key

When using your camera to participate in a session, think about your lighting. Avoid having any light (such as a window) behind you as that will make it difficult to see your face. Consider moving a small lamp or light over to the area you will be using during National Virtual Conference sessions (behind or to the side of your computer or device is best). This is especially important for those attendees with hearing challenges who may be trying to read lips.

Think about your background

Remember that everyone will be looking into your space when your camera is on. Check what (and perhaps who) you have on display behind you. Try to keep distractions to a minimum and even consider using a blur, or other virtual background.

Guest appearances

Part of virtual events includes potential guest appearances (specifically of the child/pet variety). Do what you can to stay focused, but otherwise, we will just go with the flow.

We have lots of great ways for you to get involved and have some fun during the conference!

Networking

Stay connected with all your conference friends via our networking tool. Click on the "Networking" tab and you'll be able to see other attendees, start a private chat with them and more. There is also the option to informally chat with a group of attendees. If you need a break from the conference programming to decompress, you can do so in the "Chill Zone". Simply click on the "group" tab at the top and select which group you'd like to join. You can join with your camera and microphone, or simply type in the chat.

Stay connected

Post in the PheedLoop social feed on the home page of the conference platform to let others know what you're up to during the conference. You can use our photo booth feature to snap pictures and share throughout the conference. There might even be some special perks for sharing your thoughts and photos throughout.

Earning points

Get involved for the chance to win prizes during the conference. You can earn points in tons of different ways including:

- Attending sessions
- Asking questions
- Downloading slides
- Visiting sponsor booths
- Posting in the PheedLoop social feed

The more you get involved, the more points you earn. Be sure to keep your ears and eyes open for secret codes throughout conference that can also be redeemed for points. These codes could be mentioned during a conference session, found on social media, or even somewhere in this booklet. To redeem the codes, click on the gamification tab, type in the code and click enter.

Enter code "FUNSTUFF" to earn your first points and get the ball rolling.

Winning prizes

You can also redeem the points you earn for a variety of prizes. In the gamification tab, click on "all prizes" to see the prizes available to redeem. There are small prizes like pens, big prizes like t-shirts and opportunities to enter draws for even bigger prizes! You can redeem your points in the virtual conference platform and all prizes redeemed will be shipped to you after the event.

Games & activities

You'll find a number of games and activities scattered throughout this book to complete at your leisure. To find the colouring page go to page 9. To find the connect the dots go to page 12. To find the word search go to page 16. And to find the word scramble go to page 17.



Inspire hope this holiday season...

Amaryllis bulbs for sale! Bulbs ship directly to you, Canada-wide in kits of 12 for \$204. Each kit is \$17 and includes a premium AAA Orange Sovereign bulb with a planting pot, soil and a saucer, all in a gift box. Inspire hope today by visiting, www.inspirehope.ca.

Virtual Resource Fair

Make sure to stop by the virtual exhibitor booths that will be sharing information and resources with the community. Join us throughout the conference to access information and download materials or drop in during the live Q&A time:

Saturday, November 12 from 3:45 p.m. – 4:15 p.m.
Sunday, November 13 from 3:15 p.m. – 3:45 p.m.

For every booth you visit (first visit only), you will receive points that you can redeem for prizes following the conference.

Confirmed booths include:

- HDYO
- HSC's 50th Anniversary
- HSC Youth Programs
- Volunteering at HSC
- Amaryllis
- National Virtual Walk
- Family Services

Please check the Virtual Resource Fair during conference for other booths still to be confirmed.



community

Nov 26

learn

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register now

2022

YPAHID DAY

HUNTINGTON SOCIÉTÉ HUNTINGTONNE DU CANADA ypahd

Keynote[🎤] Presentations

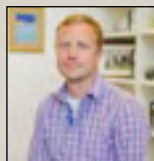
Saturday, November 12



HDBuzz

Dr. Jeff Carroll, Dr. Leora Fox, Dr. Rachel Harding, Dr. Sarah Hernandez and Prof. Ed Wild

The editorial board of the HD news website HDBuzz (www.hdbuzz.net), Drs. Jeff Carroll, Leora Fox, Rachel Harding, Sarah Hernandez and Prof. Ed Wild, will present an update on the current state of HD research. They will be covering cool new science, the latest from clinical trials, as well as all the exciting things coming down the pipeline.



Dr. Jeff Carroll

Jeff Carroll is a scientist studying HD as an associate professor at Western Washington University. He trained as a post-doctoral fellow in the lab of Marcy MacDonald at Massachusetts General Hospital/Harvard Medical School after completing his PhD under the supervision of Michael Hayden at UBC in Vancouver. He has worked for many years on Huntingtin-lowering experiments in mouse models – his recent work involves understanding what the Huntingtin protein's normal roles are in cells, particularly with respect to DNA damage and repair. As well as conducting research, Jeff is a member of an HD family and himself carries the mutation which causes the disease. Jeff also co-founded and serves as co-editor-in-chief of HDBuzz.net with Dr. Ed Wild.



Dr. Leora Fox

Leora Fox is the Assistant Director of Research and Patient Engagement at HDSA and has been working there since August 2017. She obtained her PhD in 2016 in Neurobiology and Behavior at Columbia University, where she studied Huntington's disease mouse models. Dr. Fox supports HDSA's efforts towards funding Huntington's disease research, communicating HD research news, and amplifying family voices in the process of HD drug development. She also serves as a contributing author and editor at HDBuzz.



Dr. Rachel Harding

Dr. Rachel Harding is the Principal Investigator of the Huntington's disease team at the Structural Genomics Consortium, University of Toronto. Rachel and her team research the 3D structure and shape of the huntingtin protein to try and understand how this molecule works and how the Huntington's disease mutation might affect this big and complex molecule.



Dr. Sarah Hernandez

Dr. Sarah Hernandez is the Director of Research Programs at the Hereditary Disease Foundation where she oversees the Foundation's scientific research portfolio and works closely with its Scientific Advisory Board to identify the most promising research. Sarah is also a Project Scientist in the lab of Dr. Leslie Thompson at the University of California, Irvine. Her research uses stem cells and fruit flies to understand the molecular consequences of extracellular matrix changes in HD to leverage for therapeutic intervention. Sarah also serves as an author and editor for HDBuzz.



Prof. Ed Wild, FRCP, PhD

Ed is Professor of Neurology at UCL Queen Square Institute of Neurology, Associate Director of UCL Huntington's Disease Centre, and a Consultant Neurologist at the National Hospital for Neurology and Neurosurgery. Ed 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. He has authored seven book chapters and over 90 peer-reviewed scientific publications, and is Chief Investigator of HDClarity, the first and largest multinational CSF collection study in HD. He received the Huntington's Disease Society of America Researcher of the Year Award, and Huntington Society of Canada Community Leadership Award. He co-founded HDBuzz, the leading source of accessible, impartial research news for the HD community.

Sunday, November 13



Chronic Resilience

Danea Horn, Author and Post-Doctoral Scholar

Danea demonstrates what it means to have resilience when there is no normal to get back to. In this intimate presentation, she shares the challenges, humour, and insights that led her to a unique brand of self-care which helps her manage multiple chronic conditions and remain engaged with life. Attendees will leave with a new understanding of self-compassion and a toolkit to manage the weight of being resilient.

Danea Horn is the author of *Chronic Resilience*, which is a personal and honest look at the intersection of life and chronic disease. She is currently a postdoctoral scholar researching policies to increase value and accessibility in health care.

Sponsors are a critical part of the 2022 Virtual Conference. To learn more about our exciting sponsor line up check out the sponsor tab on the conference platform.

Thank you sponsors!



HUNTINGTON SOCIETY OF CANADA
50TH ANNIVERSARY

Schedule at a Glance

This schedule is subject to change. All times shown are reflected in Eastern time.

Friday, November 11

8:00 - 9:00 p.m. Virtual Magic Show
Open to the first 300 participants!

Saturday, November 12

12:30 - 1:15 p.m. Conference Kick-Off and 50th Anniversary Announcement
Resource Booths and Chill Zone Open

1:15 - 2:15 p.m. Opening Keynote: HDBuzz Research Update
with Drs. Jeff Carroll, Leora Fox, Rachel Harding, Sarah Hernandez and Prof. Ed Wild

2:15 - 2:30 p.m. Icebreakers

2:30 - 3:30 p.m. Concurrent Sessions
1A: HD 101 with Marthe Gautreau, Corrina Masson and Rhonda Romolock
1B: Estate Planning and Power of Attorney with Vern Barrett, Zach Bronstein and Rebecca Little
1C: Juvenile HD – How is it Different, How is it the Same? with Dr. Oksana Suchowersky

3:30 - 3:45 p.m. Break

3:45 - 4:15 p.m. Resource Fair Q&A Time

4:15 - 5:15 p.m. Concurrent Sessions
2A: How HSC Supports Research in Canada with Alexander Maxan and Angèle Bénard
2B: Music: A Powerful Therapeutic Tool with Dr. Heidi Ahonen
2C: Talking to Kids about HD with Dr. Bonnie Hennig-Trestman

5:15 - 6:00 p.m. Chair Yoga & Mobility with Natalie Marnica

Sunday, November 13

12:30 - 1:00 p.m. Community Celebration

1:00 - 2:00 p.m. Concurrent Sessions
3A: Hurry Up and Wait with Jimmy Pollard
3B: An Update on HD Clinical Trials in Canada with Dr. Blair Leavitt
3C: Predictive Testing Process with Michelle Lane

2:00 - 3:00 p.m. Concurrent Sessions
4A: Social Media 101 with DeAnna Butt
4B: Current Knowledge and Unanswered Questions about Cannabis and Cannabinoids in HD with Dr. Robert Laprairie
4C: Speech, Language and Swallowing in Huntington Disease with Olivia Mann

3:00 - 3:15 p.m. Break

3:15 - 3:45 p.m. Resource Fair Q&A Time

3:45 - 4:45 p.m. Concurrent Sessions
5A: This is Me: Capturing and Sharing Memories with Ana Paret and Barb Horner
5B: Ask the Scientists Anything with HSC's Research Council
5C: Family Planning with Erin Stephen and Janet Lucas

4:45 - 6:00 p.m. Closing Ceremony and Keynote: Chronic Resilience with Danae Horn

Colouring page



Session Descriptions

Session descriptions are listed in the order of appearance on the schedule. For official presentation times, please refer to the schedule on page 8. For information on the keynote presentations, please refer to page 6.

Friday, November 11

Virtual Magic Show

Join us for an hour of fun before conference gets underway. The first 300 individuals to sign on to the link will be able to participate in this live and interactive virtual magic show, presented by WIJ the Magician. Have some laughs while connecting with other conference attendees. No magic wand required!

Saturday, November 12

Conference Kick-Off and 50th Anniversary Announcement

You don't want to miss this! Join us as we celebrate the start of the virtual conference and set the tone for the weekend ahead. The energy will be high as we get underway, but even moreso after a major announcement regarding the Huntington Society of Canada's 50th anniversary campaign. We can't spoil the surprise, but between us, we are about to share something that is the first of its kind in North America!

Icebreakers

Get to know your fellow conference attendees in this ice-breaker session. You will be split into small groups to discuss questions and get to know each other in this short session. This is a great opportunity to get to know new people in the HD community and connect on a personal level.

HD101

Join the Huntington Society of Canada Family Services Team for an overview of Huntington disease including genetics and predictive testing, symptoms and stages, and research. This session will provide you with an introduction to Huntington disease.

Estate Planning and Power of Attorney Panel

This session will feature a panel including an estate lawyer, a tax accountant and a member of the HD community as they explore the different facets of transferring power of attorney and preparing your estate. Attendees will learn about how to set up their estate goals and ensure the family's wishes are upheld. Furthering the conversation, a CPA will lead the discussion on maximizing tax benefits through charitable donations and taking advantage of different tax incentives. Finally, a member of the HD community will lend input on how to come to the personal decision of transferring power of attorney, what the process is like, and how to prepare your loved one for these changes. This multi-disciplinary panel is sure to inform the community on how to make estate planning and power of attorney decisions stress-free and informed.

Juvenile HD - How is it Different, How is it the Same?

The objectives of the session on Juvenile Huntington disease (JHD) are to review the various symptoms of JHD. The presentation will also compare and contrast the clinical features of JHD with adult onset HD. Participants will learn key features of JHD and its similarities and differences to the more prevalent adult form.

How HSC Supports Research in Canada

We would like to use this occasion to formally introduce Alexander Maxan, PhD as Research Lead at the Huntington Society of Canada. This session will provide Alexander an opportunity to discuss HSC's involvement in clinical trials as well as non-drug trial, HD-related studies. Furthermore, he will shed light on ongoing efforts behind the scenes aimed at supporting researchers and clinicians across the country in an effort to ameliorate our network of academics studying mechanisms of disease and those providing clinical support.

Music - A Powerful Therapeutic Tool

This presentation introduces the key neurological and psychological findings that impact music psychotherapy practice. The following premises will be explored: 1) Music is multisensory and may stimulate various sensory areas, 2) Music may retrieve memories and evoke emotions, 3) Music may elicit changes in hormones and neurotransmitters, and 4) Music provides a safe environment for trauma processing.

Talking to Kids About HD

This presentation covers a challenging but necessary aspect of facing Huntington disease as a family: talking to kids about Huntington disease (HD). It will go over the reasons for talking to kids about HD. Attendees will learn the who, when, and how to talk to kids about emotions. The session will discuss kids' emotions. Finally, participants will learn about the approaches of sharing information. We hope you will join us for this important topic that considers the different generations affected by Huntington disease.

Chair Yoga & Mobility

Join Natalie from Sacred Mountain Yoga as she guides you through a simple sit and stand Chair Yoga class to help reduce neck aches, back tension and improve mood. Our philosophy is simple: if you can breathe, you can do yoga. We teach a non-dogmatic, no-fluff approach to yoga. It's accessible for people in chairs and wheelchairs and no previous experience is necessary to attend.

Sunday, November 13

Community Celebration

Join us for a celebration of what the HD community has accomplished in Canada in the past year. This relaxed celebration will help ease you into the conference programming for the day and start us off on a high point as we recognize the hard work that has gone into where we are today and celebrate the amazing volunteers and participants that made it happen.

Hurry Up and Wait: Understanding Cognitive Challenges

Thinking with HD is a primary challenge to those living with it. Accommodating these cognitive features is just as challenging to caregivers. Understanding how it feels to think with HD often helps to see problems in a new light, that is, from the point of view of the person with HD. This is a series of virtual pen and paper exercises that shows how thinking with HD colours our interactions and challenges how we communicate with one another.

An Update on HD Clinical Trials in Canada

The session will cover current and upcoming clinical trials of relevance to patients and families affected by Huntington's disease in Canada. The focus of the talk will be on huntingtin-lowering therapies for HD and I will introduce the scientific basis for these approaches. The global Roche Tominersin program will be reviewed in significant detail in this talk, I will describe the current Wave ASO program, and will also discuss the upcoming PTC trial (which will be called PIVOT-HD). The PROOF-HD study, a non-huntingtin lowering study of pridopidine in HD that is being sponsored by Prilenia, will be the final clinical trial covered in this session.

Predictive Testing Process

Undergoing predictive testing is a very personal choice. Together we will explore what the science and process looks like to undergo predictive testing for the Huntington's gene mutation. Come to learn who to contact and how to get started if you choose to pursue this process. We will discuss the layers of making your choice, and the supports involved along the way.

Social Media 101

In today's society, the use of social media has become integrated into everyday life. It has developed into a necessity and a driving tool for event planning, raising awareness and spreading information. This 50-minute crash course with HSC's Marketing Administrator will teach you the basics of social media from tips and tricks to what to post and how to post it. Get ready to hit that "like" button because you're going to love this!

Current Knowledge and Unanswered Questions about Cannabis and Cannabinoids in HD

During our time together, attendees will hear about (1) how cannabinoids work in our bodies, (2) how our body's cannabinoid system changes in HD, and (3) the limited evidence for and against cannabinoid use for people living with HD. There will also be time for questions at the end of the session.

Speech, Language and Swallowing in Huntington Disease

This instructive session will educate individuals affected by HD and caregivers alike on speech, language and swallowing experiences and best practices. Led by a Speech Language Pathologist, attendees will learn about and view normal and impaired swallowing and what this means for mealtime; how medication can affect swallowing; speech and language changes in HD; and general safe swallowing guidelines for mealtime. Attendees should feel confident in managing expectations, adapting to speech and swallowing changes and ensuring mealtime is safe but enjoyable and appetizing.

This is Me: Capturing and Sharing Memories

In this presentation, Ana Paret and Barb Horner, both HSC Resource Centre Directors, will present how life/memory books can help capture who we are as people and how the life/memory book can help us see the individual beyond HD.

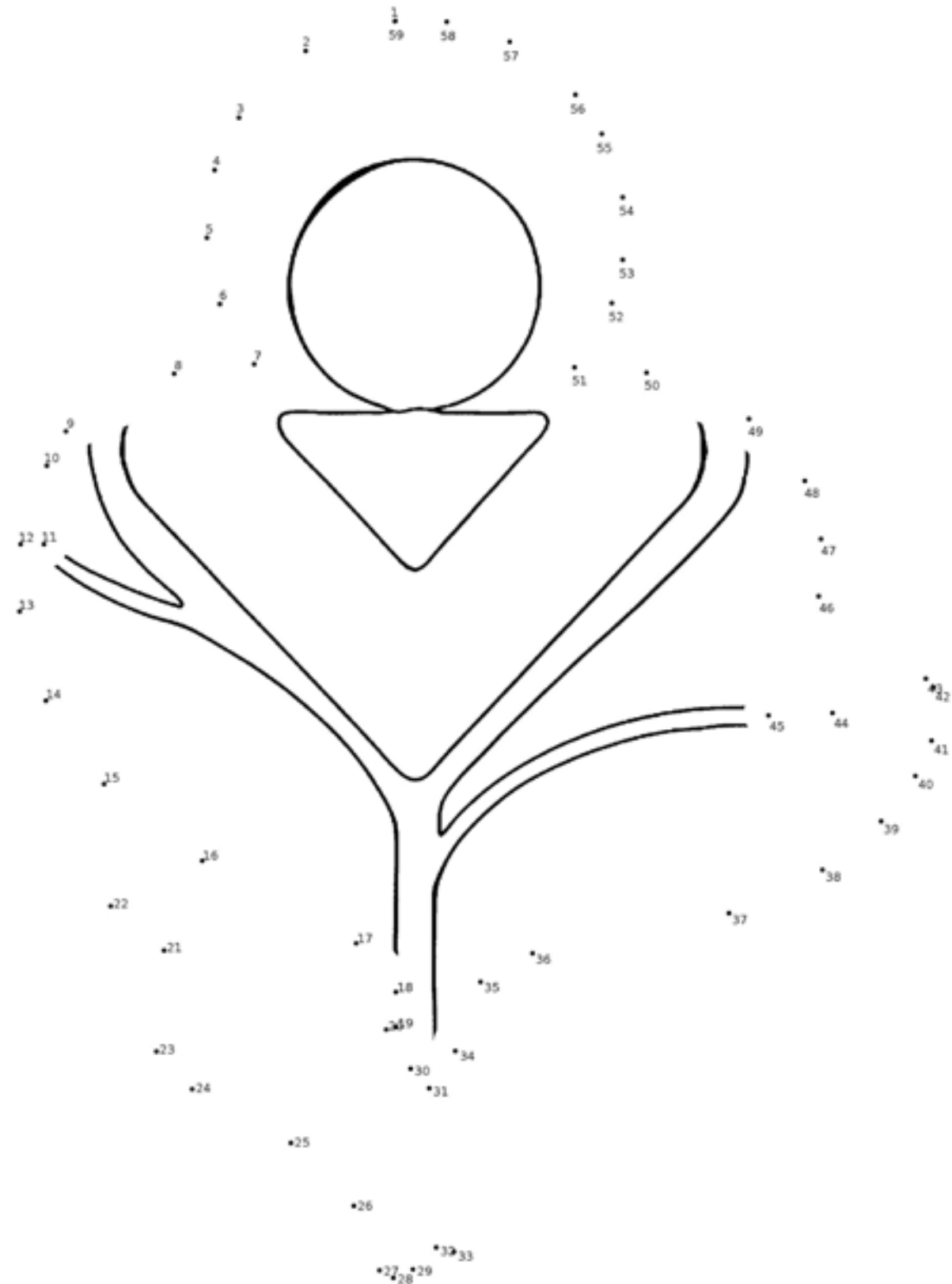
Ask the Scientists Anything

The dedicated HD research scientists that make up HSC's Research Council will be answering all of your burning questions about HD research including clinical and observational research and studies. No question is too simple or too complicated – come and ask whatever you've been waiting to understand!

Family Planning

The family planning session will focus on ways for you to consider starting a family or adding to your existing family. There are many options available including natural pregnancy with no prenatal testing, natural pregnancy with prenatal testing, adoption or assisted reproductive technologies.

Connect the *dots*



Speaker Bios

Presenter bios are listed in alphabetical order by last name. For information on the keynote presentations, please refer to page 6.



Heidi Ahonen

Heidi Ahonen, PhD, RP (Registered Psychotherapist), MTA (Accredited Music Therapist), FAMI (Fellow of Music and Guided Imagery). Professor of Music Therapy, Wilfrid Laurier University, Faculty of Music; Co-ordinator of Graduate Studies; Director of the Manfred and Penny Conrad Institute for Music Therapy Research (CIMTR).



Vern Barrett

Vern and his wife, Ellen have been involved with HSC since its inception over 49 years ago, and Vern continues to serve as President of the Manitoba Chapter. He also served 10 years on the HSC National Board and 4 years as its Chair. In his other life, Vern had a lengthy career as an educator at the public school, government and university levels.



Angèle Bénard

Angèle Bénard has been a social worker for over 20 years and is currently completing her master's degree in social work. Since 2008 she has been a part of the team at HSC, providing support and education to individuals and families affected by HD across northern Ontario. Angèle was also part of the team that developed the Youth and Young Adult Mentorship Program. In 2015, Angèle took on the role of National Director of Family Services, leading HSC's Family Services team and representing HSC on research collaborations with industry partners. Angèle is passionate about education and creating safer spaces so we can all have our voices heard.



Zach Bronstein

Zach is a Senior Tax Manager in the Enterprise Tax Practice at KPMG LLP out of the Waterloo office where he advises clients with respect to all matters of domestic income tax planning, with a focus on estate tax planning and acquisition and divestiture tax planning to optimize his clients' tax result. He was admitted to membership as a Chartered Accountant, Chartered Professional Accountant since 2014 and has been practicing Tax since 2011. During his career he has worked at various mid-size and Big Four accounting firms, as well as in industry.



DeAnna Butt

DeAnna Butt is the Marketing Administrator at the Huntington Society of Canada, creating and sharing all content on the society's social media platforms. She brings experience working with social media from her previous role as a Social Media Lead at Wilfrid Laurier University as well as taking valuable knowledge learnt from her Honours degree in Communications Studies concentrating in Digital Media. DeAnna has been raising awareness for HD since 2015 by walking alongside the Durham Chapter at their annual Huntington Heroes walk. She now uses her passion for HD and knowledge of digital media as a way to better spread awareness, educate and reach even wider audiences through social media.



Marthe Gautreau

Marthe Gautreau is the Huntington Society of Canada's Resource Centre Director (RCD) for New Brunswick. She is a Registered Social Worker (RSW) based in Moncton, N.B. Marthe has worked for the Huntington Society of Canada since October 2001. A self-described outdoors lover, Marthe adores her early morning walks, as well as baking and spending time with family and friends. Other favourite leisure activities see her out in the community going to restaurants and movies.

Speaker Bios continued



Dr. Bonnie Hennig-Trestman

Dr. Bonnie Hennig-Trestman has over 30 years of expertise providing and guiding clinical services to patients and family members suffering from neurodegenerative, physical, and psychiatric illnesses. She is the Director of the Carilion Clinic Huntington's Disease Program in Roanoke, Virginia, USA; Assistant Professor at Virginia Tech Carilion School of Medicine in the Department of Basic Science Education; and the Special Programs Director at HD Reach in Raleigh, NC. She is on the Board of Directors as the Research Co-Chair for the Huntington's Disease Youth Organization and Co-Chair of the Huntington's Study Group Credential Committee.



Barb Horner

Barb Horner is a Registered Social Worker and has been a member of the HSC Family Services team since 2004. As a Resource Centre Director (RCD), Barb supports individuals and families affected by HD who live in Nova Scotia and PEI. Barb, along with the rest of the Family Services team, provides support, education, resources and advocacy to those facing HD.



Huntington Society of Canada Research Council

The Research Council of the Huntington Society of Canada is comprised of leading HD research scientists with expertise in various areas of investigation. Council members are volunteers that analyze and prepare recommendations about applications received for HSC's research funding programs such as Navigator and New Pathways. The Research Council also provides advice with respect to matters related to the Society's role in funding HD research, including scientific advice about specific research projects and proposals that may be funded in concert with other national and international funding bodies. The current Research Council is comprised of Drs. Rachel Harding, Tamara Maiuri, Tiago Mestre, and Mahmoud Pouladi.



Rebecca Little

Rebecca is an associate lawyer who works with the Corporate-Commercial, Real Estate, and Wills and Estates Group. Before joining as an associate after her call to the bar in 2020, Rebecca completed her articles at Madorin, Snyder LLP where she was able to gain experience in a wide range of practice areas. Rebecca earned a Bachelor of Knowledge Integration at the University of Waterloo before earning her Juris Doctorate at Western University. She was actively involved in student politics at both institutions and her involvement included acting as Chair of the Board of Directors for the University Students' Council at Western and as Elections Chair for the Student Legal Society. Rebecca was born and raised in Bruce County and currently lives in Kitchener. In her spare time, she enjoys reading books, visiting the cottage and textile arts.



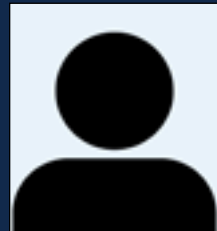
Janet Lucas

Janet Lucas is a graduate of the Sarah Lawrence College Master of Science Program in Genetic Counselling. She has been employed as a full-time genetic counsellor at the Medical Genetics Clinic in Saskatoon since graduating in 2001. Her areas of practice include prenatal genetic counselling as well as general genetics including genetic counselling for families at risk for Huntington Disease.



Olivia Mann

Olivia Mann, a Speech and Language Pathologist with 10 years' experience working with all ages including premature infants learning to feed, kids with articulation and language impairments, patients with voice difficulties, transgendered voice, adults with brain injury and neurological disorders, and swallowing and communication deficits in the hospital. Currently, she is working as the professional practice leader at GRH caring for patients in the ICU and rehabilitation after stroke, covid, and neurological disorders who require treatment of swallowing and language. In her spare time she enjoys acting and singing in theatre productions.



Michelle Lane

Michelle Lane graduated with a Bachelor of Science from St. Francis Xavier University in Antigonish, NS in 2008. She obtained a Master of Science in Genetic Counselling from McGill University in 2013 and has been working as Genetic counsellor at the IWK Health Centre in Halifax, NS since October 2013. Michelle currently works as a member of the Neurogenetics team in Maritime Medical Genetics at the IWK Health Centre.



Dr. Robert Laprarie

Dr. Robert Laprarie is an Associate Professor and Research chair in Drug Discovery and Development at the University of Saskatchewan's College of Pharmacy and Nutrition. Robert has been studying cannabinoids for about 10 years, including studies of cannabinoid use in people with HD. Robert is currently the President and Director of Education for the Canadian Consortium for the Investigation of Cannabinoids (CCIC) and is very excited to talk with you today.



Dr. Blair Leavitt

Dr. Leavitt is a full Professor in the Department of Medical Genetics & the Department of Medicine, Division of Neurology (Associate) at the University of British Columbia. Dr. Leavitt completed his medical degree at McGill, medical internship at Columbia-Presbyterian, and neurology residency at Cornell and Harvard. While in Boston, he completed a basic neuroscience research fellowship at Harvard Medical School and Children's Hospital of Boston. Blair is a consulting neurologist and Director of Research at the UBC Centre for Huntington's Disease. A scientist and physician, Dr. Leavitt's time (both clinical and research) is dedicated to developing new treatments for genetic brain disorders such as Huntington's disease.



Natalie Marnica

Natalie is a Certified Yoga Therapist with over 1000+ hours of training and 10 years of experience teaching. Natalie was also born into a family with Huntington disease (HD), a rare genetic neurological disorder, and has spent many years caregiving for her mom and others' growing needs. She's been a passionate advocate in the HD community for the past several years, teaching people facing neurological decline the benefits of maintaining what they still have and preventing or slowing down whatever they can.



Corrina Masson

Corrina joined the HSC BC Resource Centre as a family service worker in June 2020. She is a graduate from McGill University with a master's degree in Social Work and has been practicing in the field since 2016. Corrina helps families impacted by Huntington disease navigate resources, provides individual short-term counselling and facilitates support groups.



Alexander Maxan

Alexander Maxan is the Research Lead at the Huntington Society of Canada. He obtained his PhD in Neurobiology at Université Laval in Québec City, where he studied mutant protein propagation in Huntington's disease and completed a postdoctoral fellowship in Neurosurgery at the University of Michigan. He is excited to help the HD community remain well-informed of scientific progress in the field.

Speaker Bios continued



Ana Paret

Ana Paret is a Registered Social Worker and the Resource Centre Director (RCD) for Southwestern ON. HSC happily welcomed her to the Family Services Team in April of this year. Like the rest of the Family Services team, Ana provides support, education, resources and advocacy to individuals and families affected by HD living in Canada.



Jimmy Pollard

Jimmy Pollard is trained as a special education teacher and formerly licensed as a nursing home administrator in the US. For 35 years, his career has been caring for people living with Huntington's Disease in their homes, care homes, hospitals and other residential settings. His focus continues to be a better understanding and more effective accommodation of HD's cognitive challenges by family and professional carers.



Rhonda Romolock

Rhonda became the Director of the BC Resource Centre shortly after joining the HSC team in May 2017. She has worked with the HD community throughout BC and is one of the social workers at the Centre for HD clinic at UBC. Rhonda's social work practice includes short-term individual counselling, group facilitation and community development. She draws from her experience working with patients and interdisciplinary teams in acute care as well as rehabilitation hospitals. Rhonda values the relationships she has built within the HD community and with her team members.



Erin Stephen

Erin Stephen, BSW, RSW is the Saskatchewan Resource Centre Director for the Huntington Society of Canada. Erin works with individuals, families and services providers affected by HD. She offers support, education and resources on HD, works closely with the Genetics Clinic, and acts as the Coordinator for the HD Clinic in Saskatchewan.



WJ the Magician

More than just a magician, Toronto-based Wj (rhymes with 'fridge') combines clever magic with witty banter that leaves audiences both mesmerized and howling with laughter. Wj's unique blending of magic and humour has made him an award-winning performer. Wj Siva has performed on numerous television shows, for celebrities and many of the world's top corporate clients. Everywhere, audiences are saying that the unique comedy magic of Wj is the funniest they have ever seen. He's equally adept in "sleight of hand" strolling magic & mentalism for small groups, as well as sophisticated stage magic for larger audiences. Wj has been a full time professional magician for over 20 years. His performances have taken him as far away as Brazil, Cuba and Germany. There's no better magic and no magician as entertaining as Wj.

Word search



Find the following words in the puzzle.

Words are hidden → ↓ and ↘ .

AMARYLLIS

AWARENESS

BELIEVE

CAREGIVER

CHAPTER

CONFERENCE

CONNECT

DRAGONFLY

EVENT

FAMILY

FUNDRAISE

HERO

HOPE

HORIZON

HUNTINGTON

LIGHTITUP

MAY

SUPPORT

VOLUNTEER

WALK

YOUTH

YPAHD

Word *scramble*

Notes

Unscramble the #HDCon22 words:

(HINT: You can find all the words in the session titles)

entgice

ylmfai

iumcs

sraerceh

omtcuymn

liacciln

rntiuinto

tsecinist

vtgieinoc

This word scramble contains a **secret code**... can you guess which word?
(HINT: different colour)

