

# YPAHD DAY

2022

Calgary  
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#YPAHDDAY2022



Nov  
**26**



# President's Message

We are beyond excited that YPAHD Days 2022 will be in person once again! Youth aged 14 to 35 affected by HD will gather at two locations across Canada, to learn from expert speakers and engage face-to-face on the issues that matter most.

Local social activities have been planned by your YPAHD representatives and local Chapter members!

Funding is available for young people to attend the closest location. To be eligible for funding, please fill out an application by September 30. [Click here](#) to register or access the funding application.

We are looking forward to seeing friends new and old join us in November!

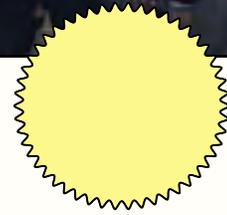


**Caleb Harding**  
YPAHD Chapter President



# What is YPAHD?

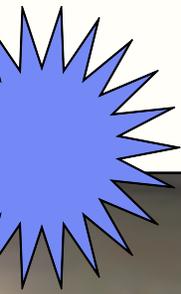
The Huntington Society of Canada operates through a national network of volunteers and professionals who, since 1973, have worked to improve the quality of life for those affected by HD. In 2008, a virtual Chapter connecting youth across the country was formed and called Young People Affected by Huntington Disease (YPAHD). YPAHD helps youth ages 14 to 35 process and discuss topics like genetic testing, family life, and dating with HD, and supports them in the struggles resulting from being affected by the disease. The group gives young people someone to relate to, talk to, and lean on – something incredibly important during this stage of life.



# What is YPAHD Day?

In 2012, YPAHD created a one-day youth conference (YPAHD Day) that sees youth gather in two locations in Western or Eastern Canada. YPAHD Day attendees have mentioned how appreciative they are of the fun activities offered and opportunity to meet other youth who understand their situation, as well as needed education and support provided.

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# How to Register

[CLICK HERE TO REGISTER](#)

This package includes all of the information needed to register for your Regional YPAHD Day.

# What's included

## Full registration includes:

All workshops, breakfast, lunch and coffee breaks on November 26th and a social activity on November 25th. See page 10 for pricing details.

## Key Dates

Aug <b>1</b> Registration Opens	Sept <b>30</b> Funding Application Deadline	Oct <b>15</b> Registration fees increase to \$160 per person	Oct <b>28</b> Deadline to complete registration and book travel if funding received	Nov <b>11</b> Registration Deadline	Nov <b>18</b> Cancellation Deadline (with refund)	Nov <b>26</b> YPAHD Day
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## Thank you to our Sponsors!



# Schedule at a glance\*

\*Subject to change; where not listed, presentations will be facilitated by local YPAHD representatives/executive members

7:00 PM Social Activity - Games Night

8:30 AM Icebreakers and YPAHD 101

9:00 AM HD 101

9:45 AM Round Tables

11:00 AM Research Updates with Dr. Rachel Harding and Dr. Tamara Maiuri (virtual)

1:00 PM Testing (To Test or Not to) with Linda MacLaren

After the Test with Corey Janke

1:45 PM Family Planning with Linda MacLaren

Survivors Guilt with Corey Janke

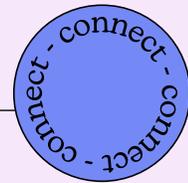
2:45 PM Emotions & Mood Changes with HD with Corrina Masson (virtual)

Grief and Loss with Corey Janke

3:30 PM Wellness, Wellplayed - the Power of Music with Jennifer Buchanan

4:30 PM Event Team Presentations

5:00 PM Wrap-up



# Sessions ☺

community

## Social Activity

Join other YPAHD Day attendees for a games night at 7:00 p.m. (feel free to bring your own food and beverages)! We have a fun night of games and activities planned to help facilitate connection and cause uproarious laughter in the process.

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25

## Icebreakers and YPAHD 101

Start the day with a little “getting-to-know-you” fun and the chance to hear about the history and goals of YPAHD such as fundraising and raising awareness. You will be challenged to break out into small groups to plan your own hypothetical fundraiser for HSC, work on it throughout the day and present your final proposal.

## Round Tables

With help from senior YPAHD volunteers, we will work in small groups to discuss those topics that matter to us. Examples of potential topics include relationships, mentorship, clinical trials, genetic testing, family planning, and fundraising/event planning.

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## HD101

Our senior YPAHD volunteers will discuss the basic science behind HD genetics. This primer session will ensure you have a good understanding of the basics as we dig into deeper topics throughout the day.

# Sessions

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## Research Updates

Join Dr. Rachel Harding and Dr. Tamara Maiuri, HD researchers, as they provide a fun and spirited update on the latest HD research and clinical trials, as well as how you can get involved!

## Survivor's Guilt

Survivor's guilt can often be hard to identify and difficult to admit. It creeps up in many aspects, but especially for those with a negative test result. Join our HSC social worker during an open discussion as we work to identify feelings of survivor's guilt as well as coping strategies. Come and share your experiences with survivor's guilt.

## Family Planning

Join genetic counsellor Linda MaLaren to discuss the options available for starting your own family, when you are at-risk or gene-positive for HD. This session will give youth the opportunity to share their own stories and listen to other's experiences with family planning.

## To Test or Not to Test

Join genetic counselor, Linda MaLaren, as we take a look at the science and process behind getting tested for Huntington disease and what it may mean for you. Listen and share with the group as we talk about experiences with testing and reasons for choosing to be tested or not tested for the gene mutation that leads to HD.

## After the Test

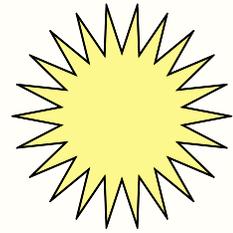
Whether you have received a positive genetic test result or are planning for the possible outcomes of the process, join our HSC social worker on site to discuss your next steps after a positive test, and ways to be prepared. Have you already navigated the process? Join our discussion to share your lived experiences with others considering what a positive test could mean for relationships, insurance, support systems, and more.

## Emotion & Mood Changes with HD

Based on information presented and learned during the first virtual support group for partners of someone affected by HD, HSC social worker, Corrina Masson will help those in a carer role to understand more about the emotional symptoms of HD, how these changes present and ways to support the person with HD.

## Grief and Loss

Growing up in a family affected by HD leads to young people facing grief and loss on many levels. Together we will discuss what grief is, the many forms it can take (including anticipatory grief), and moments when it may present. Recognizing, managing and expressing the range of feelings associated with grief as well as understanding the stages may help. There will be opportunity for group discussion and sharing experiences with grief.

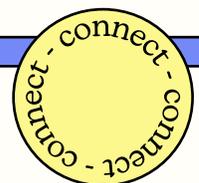


## Wellness, Wellplayed - the Power of Music

Through a collection of inspiring real-life examples, research, and implementation strategies this presentation will connect you with a resource that can be used immediately to enhance your well-being. Hear case studies demonstrating how the intentional use of music is an effective and proven tool that can reduce stress and anxiety. Learn the latest evidence of why music supports our mental health and overall wellness. Gain practical music-based strategies, including the power of a playlist, to strengthen your mood, memory and motivation. Music helps us process life's significant challenges and inevitable transitions. When words are not enough, let music start the conversation.

## Event Team Presentations

Groups will present their hypothetical fundraiser proposal that has taken shape throughout the day. Share your plans for what kind of event you would run and how you'd run it. Let inspiration strike as you hear all of the amazing plans your peers have come up with!



# Presenters



**Linda MacLaren**  
Genetic Counsellor

Linda MacLaren is a certified genetic counsellor working in the field of Clinical Genetics since 1986. Since 1997, she has been employed at the Genetics Clinic, Alberta Children's Hospital with her main area of interest being inherited neurological conditions. Linda has been involved in the predictive testing process since arriving in Calgary and works closely with the multidisciplinary team at the Movement disorders clinic, Foothills Medical Centre, as well as enjoying interacting with social workers at the Southern and Northern Alberta HD Resource Centres. Linda is honoured to be invited to participate in the upcoming YPAHD Day and is very much looking forward to meeting together with attendees.



**Corey Janke**  
HSC Social Worker

Corey has been a long time member of the HD community, serving in various roles over his 29 years of service. Currently, he is the National Social Worker, overseeing and implementing virtual programs on a national level as well as supporting the Youth Mentorship Program. Corey is passionate about working with the youth population and has worked closely along side YPAHD and HDYO over the past several years.



**Corrina Masson**  
HSC Social Worker

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.



**Dr. Tamara Maiuri**  
Research Associate

Dr. Tam Maiuri is a Research Associate in Dr. Ray Truant's group at McMaster University. The Truant lab studies the normal biological functions of the huntingtin protein in hopes of understanding how the expanded huntingtin gene that causes HD may disrupt these functions. Dr. Maiuri is investigating the role of the huntingtin protein in the DNA repair process in a project funded by the HDSA Human Biology Project.



**Dr. Rachel Harding**  
Principal Investigator

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 this might the Huntington's disease mutation might affect this big and complex molecule.



**Jennifer Buchanan**  
Executive Director of the Canadian Association of Music Therapists

Jennifer Buchanan is the Executive Director of the Canadian Association of Music Therapists, has been instrumental in the implementation of hundreds of music therapy programs throughout Canada since 1991 through JB Music Therapy, and is the author of several books including *Wellness, Wellplayed: The Power of A Playlist*. She is regularly invited guest to speak at industry conferences that aim to strengthen and inspire the people serving in healthcare, education, and the public sector including law enforcement. As a board member and service provider with the National Music Centre, Jennifer champions music for health and wellness throughout Canada and beyond.

## Hotel and Venue



### Hotel Clique

24 Aero Crescent Northeast,  
Calgary, AB

Check in: 3:00 p.m.

Check out: 11:00 a.m.

Contact

conference@huntingtonsociety.ca  
or call 1.800.998.7398 for more hotel  
and travel info.

## How to Register



Click [here](#) or visit: [www.huntingtonsociety.ca/ypahd-day](http://www.huntingtonsociety.ca/ypahd-day)  
Alternatively, you can email  
[conference@huntingtonsociety.ca](mailto:conference@huntingtonsociety.ca)  
or call 1.800.998.7398 to request a  
registration form that you  
can scan and email to  
[conference@huntingtonsociety.ca](mailto:conference@huntingtonsociety.ca)  
or fax to 519.749.8965.

## What's included



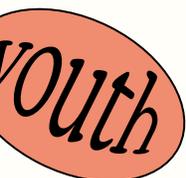
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a social activity on November 25th.

# Rates

	<b>Early Bird</b> <small>(on or before October 14)</small>	<b>Regular Rate</b> <small>(October 15th - November 11th)</small>
<b>Registration only</b>	\$140	\$160
<b>Registration and hotel room</b> <small>(HSC will book your room and assign you a YPAHD roommate)</small>	\$200	\$210

\* Full funding for youth is available. Contact [conference@huntingtonsociety.ca](mailto:conference@huntingtonsociety.ca)



### Questions?

Contact [conference@huntingtonsociety.ca](mailto:conference@huntingtonsociety.ca)  
or 1-800-998-7398

