

YPAHD DAY

2022

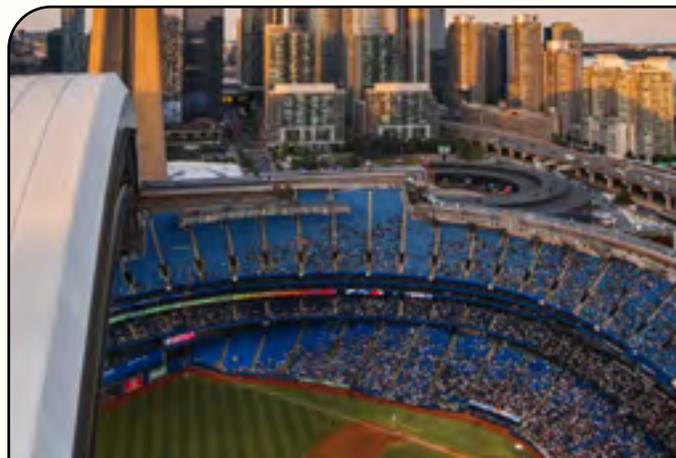
Toronto
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#YPAHDDAY2022



Nov
26



President's Message

We are beyond excited that YPAHD Days 2022 will be in person once again! Youth ages 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!

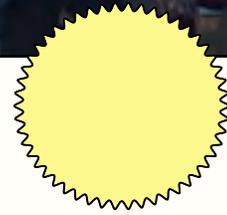


Caleb Harding
YPAHD Chapter President



What is YPAHD?

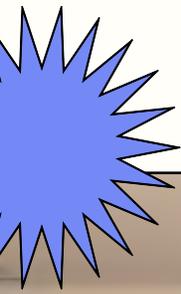
The Huntington Society of Canada operates through a national network of volunteers and professionals who, since 1973, have worked to improve the quality of life for those affected by HD. In 2008, a virtual Chapter connecting youth across the country was formed called Young People Affected by Huntington 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.

learn



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
1

Registration
Opens

Sept
30

Funding
Application
Deadline

Oct
15

Registration
fees increase
to \$160 per
person

Oct
28

Deadline to complete
registration and book
travel if funding
received

Nov
11

Registration
Deadline

Nov
18

Cancellation
Deadline
(with refund)

Nov
26

YPAHD
Day

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

1:00 PM Testing (To Test or Not to) with Clare Gibbons

After the Test with HSC Social Worker

1:45 PM Family Planning with Clare Gibbons

Survivors Guilt with HSC Social Worker

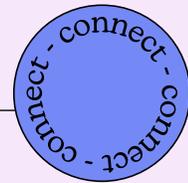
2:45 PM Emotions & Mood Changes with HD with Corrina Masson (virtual)

Grief and Loss with HSC Social Worker

3:30 PM Self-Care and Coping Strategies with TBD

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.

Nov
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 Clare Gibbons 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, Clare Gibbons, 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.

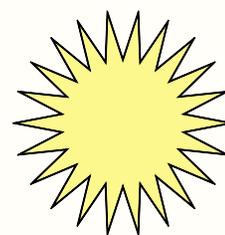
Sessions

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.



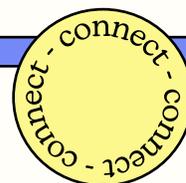
Self-Care and Coping Strategies

Join this presentation for a session on strategies around self-care and coping. Learn how to prioritize your own well-being and discover ways to relieve stress. These strategies will help youth through the stressful challenges that are present when coping with the effects of HD and provide them with resources to help manage their stress and take time for themselves.

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!

community



Presenters



Clare Gibbons
Genetic Counsellor

Clare Gibbons joined the Genetics Program at North York General Hospital in Toronto where she currently works as the manager of Clinical Genetics. Throughout her career, she has participated in the care of a wide variety of patients and has been a member of the North York General Hospital Huntington Disease Multidisciplinary team for 20 years. Clare is currently a research coordinator for Enroll HD and has previously been involved in clinical drug trials for the treatment of HD.

HSC Social Workers

The Family Services Team of the Huntington Society is composed of 21 highly skilled professionals from social work, psychotherapy, counselling and psychology backgrounds. As a team, they provide services to individuals and families affected by HD across Canada in-person and virtually. Through their work, these dedicated and caring individuals help support, educate, and advocate for folks within their communities.



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.

Youth and Young Adult Mentorship

HSC's Youth and Young Adult Mentorship Program (YMP) offers young people the opportunity to connect with a trained mentor who is able to provide valuable support at critical life points. Matches between mentors and mentees are virtual, making communication through phone, text, email, and social media easy and accessible.



Hotel and Venue



**Sandman Signature
Toronto Airport Hotel**
55 Reading Ct., Toronto, ON

Check in: 3:00 p.m.
Check out: 12:00 p.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
Alternatively, you can email events@huntingtonsociety.ca or call 1.800.998.7398 to request a registration form which you can scan and email to events@huntingtonsociety.ca or fax to 519.749.8965.

What's included

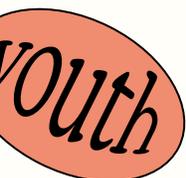


Full registration includes:
All workshops, breakfast, lunch and coffee breaks on November 26th and a social activity on November 25th.

Rates

	Early Bird <small>(on or before October 14)</small>	Regular Rate <small>(October 15th - November 11th)</small>
Registration only	\$140	\$160
Registration and hotel room <small>(HSC will book your room and assign you a YPAHD roommate)</small>	\$210	\$230

* Full funding for youth is available. Contact conference@huntingtonsociety.ca



Questions?

Contact conference@huntingtonsociety.ca
or 1-800-998-7398

