

#YPAHD2019

YPAHD DAY

NOVEMBER 16, 2019
REGISTRATION PACKAGE

CALGARY



President's Message

I can hardly believe it is almost time for youth within the HD community to gather once more!

On November 16, young people between the ages of 14 and 35 affected by HD will gather at 3 locations across Canada to learn and inspire one another.

We are excited for the line-up of local social activities planned by your YPAHD representatives and local Chapter members, as well as for the outstanding topics and speakers we will learn from throughout the day - from research, to care, and topics that matter to youth specifically!

Funding is available for young people to attend the location nearest you. Fill out an application by June 28 to be eligible.

[Click here.](#)

As YPAHD-ers, we are **#inittoendit**, and I can't wait to have you join our movement. Looking forward to having you join us in November!

Sincerely,

Doug Mallock

Doug Mallock
Chapter President



What is YPAHD?

The Huntington Society of Canada operates through a national network of volunteers and professionals united in the fight against HD since 1973. In 2008, a virtual Chapter connecting youth across the country was formed and called Young People Affected by Huntington Disease (YPAHD). YPAHD helps youth think about and discuss topics like genetic testing, family life, and dating with HD, and supports them in the struggles of 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). Every other year, these conferences are held regionally in Western, Central and Eastern Ontario. YPAHD Day attendees appreciate the fun antics and opportunity to meet other youth who understand their situation, as well as needed education and support. Regional YPAHD Days first took place in 2015.



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How to Register

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

[Click here](#) to register!

What's Included

Full registration includes:

All workshops, breakfast, lunch and coffee breaks on November 16 and a social activity on November 15.

Key Dates

May 1 - Registration Opens

June 28 - Funding Application Deadline

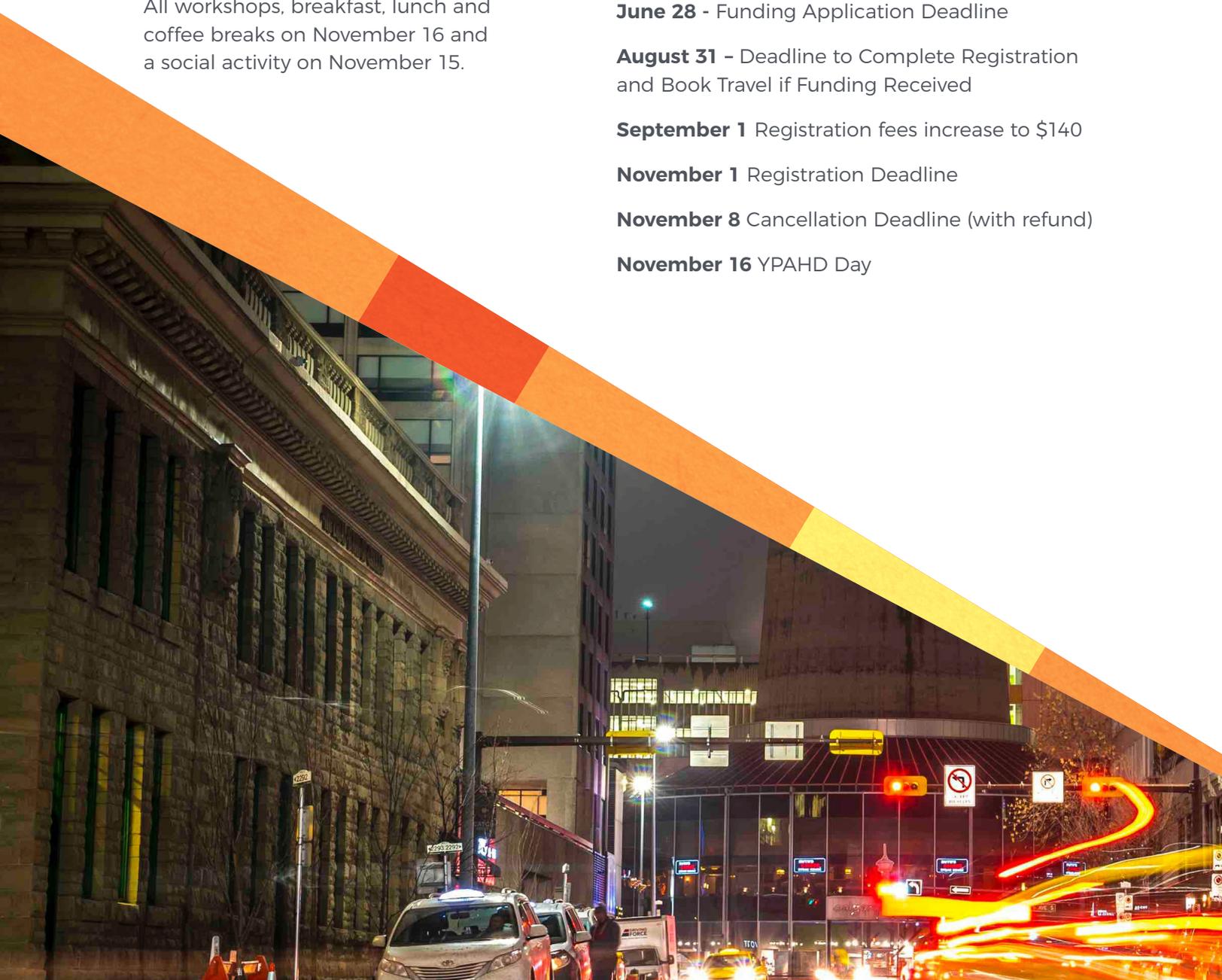
August 31 - Deadline to Complete Registration and Book Travel if Funding Received

September 1 Registration fees increase to \$140

November 1 Registration Deadline

November 8 Cancellation Deadline (with refund)

November 16 YPAHD Day



Schedule at a Glance*

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

FRIDAY NOVEMBER 15

7:00 p.m.	Social Activity - Flying Squirrel Trampoline Park
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SATURDAY NOVEMBER 16

8:30 a.m.	Icebreakers and YPAHD 101
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9:00 a.m.	HD 101
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9:45 a.m.	Round Tables
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11:00 a.m.	Testing Group Discussion	Family Planning Group Discussion with Stephanie and Derek Rees
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1:00 p.m.	Research Updates with Paul McCann
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2:00 p.m.	Why Do I Feel So Much Guilt? with HSC Social Worker	Drum for your LIFE: The Integrated Community Drum Circle with Jamie Gore, Circles of Rhythm
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3:00 p.m.	Speak Up and Be Heard with HSC Social Worker
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4:00 p.m.	Event Planning 101 with HSC Chapter Development Team	Event Planning 201 with Calgary Hope Run Planning Committee
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5:00 p.m.	Wrap-up
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Social Activity



Join other YPAHD Day attendees at Flying Squirrel Trampoline Park for an evening of socializing and fun. A table has been reserved so you don't need to jump! Meet our group in the lobby at 6:45 p.m. to walk over together. Participants are asked to sign a waiver before the event (link will be provided once registered for YPAHD Day). If you have trampoline socks, please bring along, or these can be purchased at Flying Squirrel for \$3. Get to know the group before your day together, have some fun and build relationships.

Icebreakers and YPAHD 101

Start the day with a little “getting-to-know-you” fun, and a chance to hear about the history and goals of YPAHD.

HD101

Our senior YPAHD volunteers 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.

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.



Genetic Testing/ Family Planning

Our group will break into two discussion circles. Choose to join the conversation on **genetic testing** or alternatively, join the **family planning** conversation.

Genetic Testing

This group will look at the science and process behind getting tested for Huntington disease, as well as having an opportunity for youth in the group to share their experiences, or reasons for choosing to be tested or not tested for the gene.

Family Planning

Alternatively, join the family planning circle, where youth will discuss the options available for starting your own family, when you are at-risk or gene-positive for HD.

Research Updates

Paul McCann, lead study coordinator at the University of Alberta, will talk about the exciting clinical trials in Huntington disease, including Enroll HD, SIGNAL, Generation HD1 and WAVE, as well as how you can get involved.

About Paul: Paul is a Registered Nurse who has worked in Mental Health, Emergency Response Teams, and most recently, as Clinical Research Study Coordinator with Dr. Suchowersky at the University of Alberta Movement Disorders Program. He has worked as the lead Study Coordinator for CREST-E, ENROLL-HD, Gangliosides in HD, LEGATO-HD, SIGNAL, WAVE (pending), and Generation HD1 (pending). He has served on the Huntington Society of Canada - HD Clinical Trial Consortium, The Huntington's Study Group Publication Committee, and The Huntington Study Group Care and Education Working Group. He enjoys travelling, cycling, and spending time with family. He has a tendency to talk a lot (having kissed the Blarney Stone) and speaks with an Irish brogue, so feel free to ask him "what did you say?".

Why Do I Feel So Much Guilt? / Drum for Your LIFE: The Integrated Community Drum Circle

Once again, we will break into two groups based on your interests.

Why Do I Feel So Much Guilt?

Join this open group discussion led by an HSC Social Worker on recognizing different causes of guilt. Feelings of guilt can creep up through the carer's role ("Am I doing enough for my loved one?") or through the predictive testing process, for both those told they are gene positive or gene negative, and those choosing not to be tested. Guilt can have a negative affect, and we will look at ways to address its various aspects.

About HSC Social Workers: The Family Services Team of the Huntington Society is comprised of 24 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. Through their work, these dedicated and caring individuals have helped support, educate, and advocate for folks within their communities.

Drum for your LIFE

The drum circle is an experiential workshop offering participants an opportunity to **re-vitalize, relax and re-connect**, using an ancient tool: the drum! Using a modern, evidence based rhythmic methodology: The Integrated Community Drum Circle (ICDC), your Circles of Rhythm Master ICDC facilitator will offer insights and core lessons on mindfulness, the power of meditation, and the importance of self-care.



About Circles of Rhythm: Circles of Rhythm is a community-based, social enterprise, supporting a team of facilitators who are passionate about life and the development of conscious communities across Western Canada. We offer hands-on workshops using drums and percussion from across the globe in community events, team-building settings, therapeutic programming, festival gatherings, and many other social and recreational events! Our goal is to inspire each participant to 'lean-in' throughout our experiential drum circle sessions. Our facilitators offer a collaborative approach to music making, co-creation, and rhythm - supported by an evidenced based methodology: The Integrated Community Drum Circle. The result: improvements in physical and mental health and wellness, increased joy and vitality, and a deepened sense of connection to self and others!

Speak Up and Be Heard

Learning how to communicate your needs is a very important skill. The ability to understand what the other person is trying to say is also a crucial part of communication. Once you can both express yourself and understand others, this can greatly improve relationships. It can also make it easier for friends and family to provide you with support. This session will focus on how to effectively communicate and advocate for yourself.

Event Planning

What can you do to impact the future of HD in Canada? Join our discussion circles based on your experience planning events. In the 101 circle, a member of the Huntington Society's Chapter Development team will walk you through the basics of planning and event, and brainstorming fundraising and awareness initiatives you can try

when you get home. In the 201 circle, the Calgary Hope Run Planning Committee will help you take your event to the next level, drawing on their experience growing an event from \$23,000 to over \$50,000! Learn about sponsorship, peer-to-peer fundraising, and new revenue streams such as raffles and auctions.

About the Calgary Hope Run Committee: The Calgary Hope for a Cure Run and Walk committee took on organizing this event in 2018. In 2017, they saw an opportunity, and reached out to see if they could help. The event was completely handed over to the team that is made up of 5 ladies Rachele, Jenna, Brittany, Ashley, and China. Every member of the committee is deeply impacted by Huntington Disease, and have had a deep desire to do something more to help raise awareness, and funds for a cause so close to them all.

About the Chapter Development Team: The Chapter Development team supports over 20 volunteer-led Chapters and 130 fundraising and awareness events every year. Combined, these events raise over \$1.4 million for research and support services. The team is also responsible for the planning, organizing and management of the bi-annual Community Education Forums, YPAHD Days, and the National Conference. Combined, the team has over 30 years of event planning experience, including weddings, Conferences, seminars, festivals and fundraising events that have welcomed over 700 people and raised upwards of \$250,000.

The poster features a colorful, multi-colored border at the top and bottom. The central text reads: 'youth MENTORSHIP program' with a small logo of a person with arms raised. Below this, it says 'Supporting young people across Canada facing everyday challenges of HD.' There are two call-to-action boxes: 'Become a Mentor.' and 'Become a Mentee.' At the bottom, it says 'Connecting youth with an adult mentor from a family with HD for valuable support.' and 'For more information visit: HUNTINGTONSOCIETY.CA'.

YPAHD Day Logistics



YPAHD Day Hotel and Venue:

Hotel Clique
24 Aero Cres. Northeast, Calgary, AB



Check in: 3:00 p.m.

Check out: 11:00 a.m.

Contact events@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 back or fax to 519-749-8965



What's Included

Full registration includes:

All workshops, breakfast, lunch and coffee breaks on November 16 and a social activity on November 15.



Rates

	Early Bird (on or before August 31)	Regular Rate (September 1 - November 1)
Registration only	\$120	\$140
Registration and hotel room (HSC will book your room and assign you a YPAHD roommate)	\$230	\$250

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



Questions?

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



#YPAHD2019



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