

#YPAHD2019

YPAHD
DAY

NOVEMBER 16, 2019
REGISTRATION PACKAGE

TORONTO



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 - Paint Nite at Denny's
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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 with Clare Gibbons	Family Planning Group Discussion with Kristen Miller, Lindsay Groot & Erin Paterson
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1:00 p.m.	Research Updates with Dr. Mark Guttman
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2:00 p.m.	Why Do I Feel So Much Guilt? with HSC Social Worker	Introduction to Mindfulness with Ekta Hattangady
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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	Practical Event Planning with Lindsay Groot, Exeter Hike Organizer
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5:00 p.m.	Wrap-up
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Social Activity



Join other YPAHD Day attendees at Denny's for a Paint Nite at 7:00 p.m.! The artist will guide you, step-by-step, through the dragonfly painting so you have your own work of art to take home with you. Food and beverages are available at your own cost during the event. Get to know the group before your day together, have some fun and build relationships! No painting experience, creativity, or artistry required!

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.

Family Planning

Join the family planning circle, where youth will discuss the options available for starting your own family, including IVF and PGD, and adoption, alongside a genetic counselor.

About Kristen: Kristen Miller graduated from the Joan H. Marks Graduate Program in Human Genetics at Sarah Lawrence College in 2010. She currently works as a clinical genetic counsellor at North York General Hospital. Kristen is the coordinator of the Multidisciplinary Huntington Disease Clinic at NYGH, and has been providing predictive genetic counselling for HD and other genetic conditions since 2011.

Genetic Testing

Join the conversation on genetic testing with Clare Gibbons, genetic counselor. 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.

About Clare: 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.

Research Updates

Dr. Mark Guttman, neurologist at the Centre for Movement Disorders in Toronto, will talk about the exciting clinical trials in Huntington disease, including Enroll HD, HD-Clarity, Generation HD1 and WAVE, as well as how you can get involved.

About Mark: Mark Guttman is a movement disorders neurologist and practices in Toronto. His focus is on HD research and clinical care. He is a member of the HSC board and is active in HD research over the last 30 years. Dr. Guttman is actively involved in the Ontario Telemedicine Network and is a member of their board. He provides patient care to individuals throughout Ontario with telemedicine and is in charge of a program offering services to Africa as part of a Movement Disorders Society program.

Why Do I Feel So Much Guilt? / Introduction to Mindfulness

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.

Introduction to Mindfulness

An interactive session on the "What, why and how" of Mindfulness. This session will connect the usefulness of Mindfulness for everyone on the HD journey. Mindfulness empowers us to manage stress, anxiety and depression and live with hope. You will take away fun techniques to practice with friends and family!

About Ekta:

Ekta is a Registered Social Worker and is the RCD for HSC's Halton Peel Resource Centre. She has over 14 years of experience in the non-profit sector across India, USA and Canada. She has a special interest in people living with or at-risk for neuro-degenerative illnesses. She was a teen carer to her mother who had Young Onset Alzheimer's in her 40s and herself lives at risk for the same condition. Ekta says that she has found hope for her future since she began practicing different mindfulness techniques consistently. In February 2019, Ekta completed her goal of meditating daily for 365 days and has continued her daily practice. She has found meaning in living life based on values rather than goals and tasks. A certified yoga teacher, Ekta aspires to be a globe-trotting mindfulness catalyst.



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, Lindsay Groot, organizer of the Exeter Hike of Heroes will help you take your event to the next level through goal setting, revenue generators, sponsors and more!

About Lindsay: Lindsay plays the roles of nurse, farmer, mother and HD advocate. Lindsay has had a long history of involvement with HSC including Chapter involvement and speaking engagements. In 2015, she began working with her local HD hike which she eventually took charge of and in 2017, achieved the highest revenue generating hike across Canada. In 2018, at the HSC National Conference, Lindsay was presented with the National Board Chair's Award. Lindsay also works as an RN at a rural hospital ER located just 15 minutes from their family farm. The farm consists of acreage, sheep, hobby chickens, cows and calves, which she farms alongside her husband whenever available!

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.

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Connecting youth with an adult mentor from a family with HD for valuable support.

For more information visit:
HUNTINGTONSOCIETY.CA

YPAHD Day Logistics



YPAHD Day Hotel and Venue:

Sandman Signature Mississauga Hotel
5400 Dixie Rd. Mississauga, ON



Check in: 3:00 p.m.

Check out: 12:00 p.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 return 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 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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