

#YPAHD2019



YPAHD  
DAY

NOVEMBER 16, 2019  
REGISTRATION PACKAGE

HALIFAX

# 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,

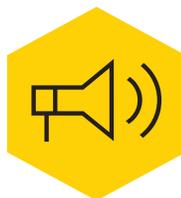
*Doug Mallock*

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
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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 Michelle Lane	Family Planning Group Discussion with Megan Dufton
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1:00 p.m.	Research Updates with Susannah Piercey and Nicole Blanchard
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2:00 p.m.	Why Do I Feel So Much Guilt? with HSC Social Worker	Yin Yoga with Margot Schelew
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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 Group Discussion with HSC Chapter Development Team
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5:00 p.m.	Wrap-up
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## Social Activity

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Join other YPAHD Day attendees in the Sambro Room for a Paint Nite at 7:00 p.m. (feel free to bring your own food and beverages from the on-site restaurant)! 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

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

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## Genetic Testing

Join the conversation on genetic testing with Michelle Lane, 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 Michelle:** Michelle Lane, MSc, CCGC, has a bachelor of science in Biology from St. FX University in Antigonish, NS. She completed her masters in genetic counselling from McGill University in 2013. Michelle has been working with Maritime Medical Genetics at the IWK Health Centre since October 2013 seeing a wide variety of cases in pediatric and general genetics as well as the expanded newborn screening program. She has been involved in genetic counselling and testing for Huntington disease and other neurologic conditions since 2014.

## Family Planning

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

**About Megan:** Dr. Megan Dufton joined the Atlantic Assisted Reproductive Therapies (AART) team in 2015 upon the completion of her post-doctoral fellowship with Dalhousie University and the IWK Department of Obstetrics and Gynecology. The focus of this fellowship was to establish a Preimplantation Genetic Testing Program (PGT) for AART, which has been in successful operation since 2015.

In addition to PGT coordinator for AART, Megan is also an embryologist in the clinic providing the hands-on care. Megan has recently returned to AART from a Faculty position at Yale University in the Yale Fertility Centre. Upon her return she was appointed as Laboratory Director for AART and will utilize knowledge gained in her guidance and oversight of the AART's laboratory.

# Research Updates

Nicole Blanchard and Susannah Piercey will talk about the exciting clinical trials in Huntington disease, including Enroll HD, and Generation HD1, as well as how you can get involved. Enroll-HD is an observational, multi-national study open to participants 18 years or older with the HD gene. Generation HD1 is a drug trial testing the safety and efficacy of RG6042 treatment.

**About Nicole:** Nicole Blanchard is the Director of Quality Assurance and Regulatory Compliance with True North Clinical Research, a local, private research clinic. Nicole has been with the company for over three years and is now working closely with the Principal Investigator of the Generation HD1 study, Dr. Kerrie Schoffer, to complete all of the regulatory and ethics applications, and is the main research coordinator working alongside Dr. Schoffer to carry out this trial in the Halifax location. Nicole is passionate about providing access to clinical research to Nova Scotian's and is always happy to share information and knowledge about the research happening at True North Clinical Research.

**About Susannah:** Susannah Piercey is a Research RN. She grew up in Corner Brook Newfoundland and completed her Bachelor of Nursing in Memorial University of Newfoundland. After completing her degree she moved to Halifax where she is now working as a research coordinator for Dr. Schoffer and the Huntington's Clinic working on Enroll-HD. Her experience working with neurosurgery and Neurology patients has been a great asset in building her foundations as a Research Coordinator and she greatly enjoys being a part of this study and being able to assist those with Huntington's and their families in navigating the Enroll-HD process.

## Why Do I Feel So Much Guilt? / Yin Yoga

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 cause 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 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.



## Yin Yoga

Yin yoga targets the connective tissue and is wonderful for both active and inactive people. The Chi, or energy in your body, flows through all tissues and bones moistening your joints. The smooth flow of chi brings physical and emotional health. While in the poses, Margot will encourage you to relax deeply, to slow down your breathing, and to release any stress or anxiety you be experiencing. All Yin yoga postures are done on the ground. Please bring a towel to this session.

**About Margot:** Margot has been doing yoga for over 45 years and has been teaching at Halifax Yoga for 10 years. She is passionate about her work because life can be challenging and fast-paced and her yogis find they can better manage stress by doing yoga regularly. Margot is also a certified hypnotherapist and neuro-linguistic programmer, and has spoken at previous YPAHD Days and HSC National Conferences.

## 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 a member of the Huntington Society's Chapter Development team as we

brainstorm fundraising and awareness initiatives you can try when you get home as well as ways to improve on your existing event successes through sponsorship, peer-to-peer fundraising, and new revenue streams such as raffles and auctions.

**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.

**youth**  
MENTORSHIP  
program

**Supporting young people**  
across Canada facing  
everyday challenges of HD.

**Become a Mentor.**      **Become a Mentee.**

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

For more information visit:  
**HUNTINGSOCIETY.CA**

# YPAHD Day Logistics



## YPAHD Day Hotel and Venue:

Best Western Plus Chocolate Lake Hotel  
250 Saint Margaret's Bay Rd. Halifax, NS



**Check in: 3:00 p.m.**

**Check out: 12:00 p.m.**

Contact [events@huntingtonsociety.ca](mailto: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](http://www.huntingtonsociety.ca/ypahd-day)

Alternatively, you can email [events@huntingtonsociety.ca](mailto: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

	<b>Early Bird</b> (on or before August 31)	<b>Regular Rate</b> (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](mailto:events@huntingtonsociety.ca)



## Questions?

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



#YPAHD2019



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