

Believe 
Transforming Tomorrow Together

**YPAHD
DAY**
#YPAHD2017

KELOWNA, BC
NOVEMBER 18, 2017
REGISTRATION PACKAGE



President's Message



I can hardly believe it is almost time for youth within the HD community to gather once more! On November 18th, young people between the ages of 14 and 35, who are 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, to topics that pertain to youth specifically!

Funding is available for young people to attend the location nearest you. Fill out an application by June 30 to be eligible. [Click here](#).

It is my hope that those attending YPAHD Day will have the same experience and feelings I had when I went to my first event, that this HD community we are in, it's a family and we are all here for each other. We have the ability to change the world and by each of you being part of this day, this community, this fight, makes you an HD warrior and something to be proud of.

Sincerely,

Jaclyn Skinner

Jaclyn Skinner
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 opportunity to meet other youth who understand their situation and benefit from much needed education and support. The fun antics are appreciated too! Regional YPAHD Days first took place in 2015 in Calgary, Toronto and Halifax.

How To Register

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

WHAT'S INCLUDED

Full registration includes: All workshops, breakfast, lunch and coffee breaks on November 18th.

Key Dates

MAY 25	Registration Opens
JUNE 30	Funding Application Deadline
AUGUST 31	Deadline to complete registration and book travel if funding received
SEPTEMBER 1	Registration fees increase to \$100 each
OCTOBER 2	Cancellation Deadline (with refund)
NOVEMBER 3	Registration Deadline
NOVEMBER 18	YPAHD Day

Schedule At A Glance*

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

FRIDAY NOVEMBER 17	
EVENING	Escape Room at Exit Kelowna <i>*at the attendees expense</i>
SATURDAY NOVEMBER 18	
9:00 AM	Introduction and YPAHD 101
9:45 AM	SocialSense: Thinking Through Social Media
10:45 AM	Clinical Trials in Huntington Disease: What's New and How Can You Help? with Dr. Lynn Raymond
12:30 PM	Mindfulness, Holistic Nutrition and Huntington Disease with Khalilah Alwani
1:30 PM	Grief and Guilt with Erin Stephen
3:15 PM	Event Round Tables
4:15 PM	Recap and Wrap-up

Session Descriptions

SOCIAL ACTIVITY

Join other YPAHD Day attendees, local YPAHD Executive members, and representatives from the Okanagan Chapter at Exit Kelowna, a local Escape Room. Get to know the group, have some fun and build relationships! We'll walk to Exit Kelowna together. The cost is \$25 per person – please note with your registration if you plan to attend, as we are required to book a reservation in advance. Payment will be made on the evening. The Social Activity is at the attendee's expense and is not part of funding support received from the Huntington Society of Canada for your attendance at YPAHD Day.

INTRODUCTION AND YPAHD 101

Our senior YPAHD volunteers help us get to know each other, and a little bit about the history and goals of YPAHD.

SOCIALSENSE

In the current environment, where genetic discrimination can still be a factor, thoughts around our social media presence are critical. Our YPAHD Executive members will guide a discussion on smart social media tips to avoid putting yourself at risk for discrimination. We'll also hear an update on current developments in the movement toward genetic fairness in Canada.

CLINICAL TRIALS IN HUNTINGTON DISEASE: WHAT'S NEW AND HOW CAN YOU HELP?

Join Dr. Lynn Raymond of the UBC Centre for Huntington disease as she explores the range of ongoing clinical trials, as well as those coming up in the near future at the Centre. Results of recently completed trials will be presented. Lynn will also talk about the role of HD families in making research progress happen with ample time for questions and discussion.

About Dr. Raymond:

Dr. Lynn Raymond is a Professor in the Department of Psychiatry, Djavad Mowafaghian Centre for Brain Health at the University of British Columbia. She is also Clinic Director of the Centre for Huntington Disease, and Director of the UBC MD/PhD Program. Dr. Raymond completed her MD and PhD degrees in New York and trained in Neurology at the Johns Hopkins Medical School in Baltimore. She combines a career in neuroscience research with clinical practice in Neurology. Her research focus for the past more than 15 years has been on understanding the specific roles of altered neuronal circuits and amino acid neurotransmitter receptors - like the NMDA-type glutamate receptor - in Huntington disease. In addition to managing patients with HD in the clinic, she has been the UBC site investigator for several multi-centre clinical trials in Huntington disease, including Predict-HD, and most recently, Amaryllis and LEGATO-HD.

MINDFULNESS, HOLISTIC NUTRITION AND HUNTINGTON DISEASE

Khalilah Alwani, local YPAHD Rep and holistic nutrition expert will explore how a holistic approach to nutritional health can support the wellbeing of people with HD and their families. We will discuss practical strategies for managing HD symptoms using whole foods nutrition, learn about recent research in this area, explore mindful eating, and blend up a tasty treat.

About Khalilah:

Khalilah has a background in community health, with a focus on nutrition, mental health and recreation. Teaching whole foods cooking classes to youth and adults of all ages, Khalilah seeks to inspire connection and mindfulness between people, the food we eat and the land it comes from.

For the past 12 years, Khalilah has taken care of her mother with HD - a journey that affirms food is medicine. Here, whole foods, herbs and natural medicines, have played important roles in helping to manage symptoms of HD and improving her mother's quality of life. They also play an important role in Khalilah's commitment to self-care and nourishment.

Khalilah believes that whole foods and a holistic perspective towards nutrition foster a strong sense of well-being, support the building of community, and can not only help to manage chronic disease but support us to thrive, be creative and have fun.

Khalilah is currently completing a diploma in holistic nutrition, and has an M.A. with a research focus on Indigenous food systems and community health.

GRIEF AND GUILT

Growing up in a family affected by Huntington disease means young people are forced to deal with grief and loss. Recognizing, managing and expressing the range of feelings associated with this grief, as well as understanding its stages may help with the process. Erin Stephen, a social worker with the Huntington Society of Canada will engage and facilitate a conversation around grief, loss and survivor's guilt.

About Erin:

Erin Stephen, BSW, RSW is the Saskatchewan Resource Centre Director for the Huntington Society of Canada as well as the Youth Mentorship Coordinator. Erin works with individuals, families and services providers affected by HD. She offers support, education, information and resources on HD and works closely with the Genetics Clinic and the HD Clinic in Saskatchewan. Throughout her career as a Social Worker, Erin has always been passionate about working with children and youth. In September of 2012, when the opportunity came along for Erin to become involved in the Mentorship Program, she jumped at it. As the Youth Mentorship Coordinator, Erin is responsible to recruit and train the mentors, as well as provide support and guidance to the mentees and the mentors.

EVENT ROUND TABLES

It's time to use today's inspiration to explore ways to give back and impact the future of HD research and support services! With help from senior YPAHD volunteers, we will work in small groups to brainstorm and develop fundraising and awareness events that we can implement in our local communities when we return home.

YPAHD Day Logistics

YPAHD DAY HOTEL AND VENUE

Best Western Plus Kelowna Hotel and Suites
2402 Highway 97 North Kelowna, B.C.

Additional details about the hotel can be found at www.bestwesternkelownahotel.com.

Contact events@huntingtonsociety.ca or call 1.800.998.7398 for more hotel and travel information.

Registration Information

HOW TO REGISTER

[CLICK HERE](#) or visit: www.ypahdkelowna.eventbrite.ca

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 18th.

Rates

	EARLY BIRD (on or before August 31st)	REGULAR RATE (September 1 - November 3)
Registration Only	\$80	\$100
Registration and hotel room (HSC will book your room and assign you a YPAHD roommate)	\$150	\$175

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

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

Youth Mentorship Program



The HSC Youth Mentorship Program is designed to support young people across Canada facing the everyday challenges of growing up in a family affected by Huntington disease. HSC is committed to offering a nationwide mentoring program that provides youth with one-on-one time and attention with a mentor who will receive ongoing support from a Social Worker within HSC.

The goal of the program is to offer young people the opportunity to connect with a mentor who will be able to provide them with valuable support at critical points in their lives. The adult volunteers involved in the mentoring program will also be from families affected by HD. Sharing this common experience may assist them in better understanding and connecting to the youth mentees. The mentors will be committed to supporting, guiding, and being a friend to the youth. The mentors will listen and provide the youth with accurate and age appropriate information.

The mentorship program strives to:

- Encourage and help prepare youth for the challenges they face
- Help break down the sense of isolation many youth affected by HD experience
- Assist youth in making informed decisions about their life
- Provide youth with positive role models and support
- Connect youth to YPAHD and the HD community

For more information, contact our Mentorship Coordinator at mentorship@huntingtonsociety.ca or call toll free at 1-855-253-0215.



151 FREDERICK ST SUITE 400 Fax: 519.749.8965
KITCHENER ON N2H 2M2 info@huntingtonsociety.ca
Phone: 519.749.7063 www.huntingtonsociety.ca
Toll Free: 800.998.7398 CRN: 11896 5516 RR0001