

Believe 
Transforming Tomorrow Together

**YPAHD
DAY**

TORONTO, ON
NOVEMBER 18, 2017
REGISTRATION PACKAGE

#YPAHD2017



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

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 \$120 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	
7:00 PM	Bowling! <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	HDClarity: How You Can Participate with Dr. Mark Guttman
12:30 PM	Finding Meaningful Activity through Music for Health and Well-being with Bev Farrell
1:30 PM	Grief and Guilt with Corey Janke
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 Toronto Chapter at Planet Bowl, Etobicoke. Get to know the group, have some fun and build relationships! We will meet in the hotel lobby at 6:45pm or you can meet us at the alley! \$20 per person for 2 hours of bowling (at attendee's expense, paid on arrival). Or come to socialize and skip the bowling!

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.

HDCLARITY

Dr. Mark Guttman, neurologist at the Centre for Movement Disorders in Toronto, will talk about HDClarity. This is an exciting platform study that is part of ENROLL HD and will assess the concentration of mutant huntingtin protein in spinal fluid as a window of what is going on in the brain. This study will pave the way to using this measurement as an outcome measure in clinical trials and understanding the biology of HD. Come to hear how you can get involved.

About Dr. Guttman:

Dr. Guttman is the Director of the Centre for Movement Disorders in Markham, Ontario which is one of the largest Parkinson's practices in the country, with over 2000 Parkinson's patients. The Centre for Movement Disorders is a National Parkinson Foundation Centre of Excellence based on its support of clinical and research efforts in Parkinson's disease.

Dr. Guttman has extensive experience in clinical and research activities relating to Huntington disease. In addition to providing multi-disciplinary care to HD patients and families, he is involved with peer reviewed HD research and sits on the Steering Committee of ENROLL HD. He is a consultant to CHDI and is actively engaged in many HD research collaborations.

Dr. Guttman is considered an international expert in videoconferencing for patients with Parkinson's disease and other movement disorders. With 12 years of clinical experience delivering care through telemedicine, he is a frequent speaker at international conferences relating to this topic. Dr. Guttman has been a board member of the Ontario Telemedicine Network (OTN) from its inception until June 2013 and was the Vice-Chair of OTN for the last two years. He is currently serving on the Huntington Society of Canada's Board of Directors.

FINDING MEANINGFUL ACTIVITY THROUGH MUSIC FOR HEALTH AND WELL-BEING

Come and explore the benefits of music. Music is unique in each person's life. Various types of music can promote wellness, decrease stress, alleviate pain, and enhance mood. Listening to, and appreciating music is a complex process involving memory, learning and emotions. We will discuss and experience the impact of music and how it affects us. All brains are musical - you don't have to be a musician to benefit!

About Bev:

Bev Farrell is a Therapeutic Recreation Specialist at Third Age Outreach, part of Parkwood Institute of St. Joseph's Health Care London where she has worked for over 29 years. She also works part time, for over 25 years, for the London Chapter of the Huntington Society of Canada. In her spare time she teaches a therapeutic recreation course at Fanshawe College. She graduated with a diploma in Recreation and Leisure Services from Fanshawe College and is a registered member of Therapeutic Recreation Ontario. Her current work with seniors is to help them engage in meaningful activity throughout London. Bev is the Chair of the City of London's Recreation and Leisure Committee. She is the Co-Chair of the Age Friendly London Social Participation Network. She is a recipient of the Sisters of St. Joseph Award for Excellence and the Michael Wright Community Leadership Award.

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. Corey Janke, a social worker with the Huntington Society of Canada will engage and facilitate a conversation around grief, loss and survivor's guilt.

About Corey:

Corey Janke, M.Ed, RSW is the Southwestern Ontario Resource Centre Director for the Huntington Society of Canada as well as the Youth Mentorship Coach. Corey works with individuals, families and service providers affected by HD. He offers support, education, information and resources on HD and works closely with the HD Clinics in London, Ontario. Throughout his 26 year career as a social worker, he has worked primarily in the healthcare field, in the areas of chronic illness as well as rehabilitation. More recently, Corey has specialized in the field of trauma and in addition to his work with the HSC, he runs a private practice. In May, 2016, Corey became involved with the Youth Mentorship Program. As the Youth Mentorship Coach, Corey is responsible to work with the Youth Coordinator and to assist in the support of mentors and the continued roll-out of the Youth Mentorship Program.

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

Hampton Inn by Hilton Toronto Airport Corporate Centre
5515 Eglinton Avenue West, Toronto, 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 information.

Registration Information

HOW TO REGISTER

[CLICK HERE](#) or visit: www.ypahdtoronto.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	\$100	\$120
Registration and hotel room (HSC will book your room and assign you a YPAHD roommate)	\$175	\$200

*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.



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