

CHAPTER INFORMATION

Barrie/Muskoka Area

Representative: Steven Beatty stevenmbeatty@gmail.com

Belleville Area

Representative: Judy Harding <u>judyharding@cogeco.ca</u>

Durham Chapter

President: Bunny Clark durhamregionhd@gmail.com

Essex Chapter

President: Paul Bateman pjb8man@hotmail.com

Grand River Chapter

hdgrandriver@gmail.com

London Chapter

President: Paul McConomy hd.londonchapter@gmail.com

Niagara Chapter

President: John Stainsby stainsbyjohn@gmail.com

Ottawa Chapter

President: Sharon Haig sharon.haig@sympatico.ca

Peterborough Chapter

President: Heath Sterling ptbohd@gmail.com

Sarnia Area

Representative: Celine Payne celineangele@hotmail.ca

Sudbury Chapter

President: Lauri Miller hd.sudbury@live.ca

Thunder Bay Area

Representative: James Fletcher Ynkefn1@yahoo.com

Timmins Area

Representative: Lynn Walker lynn.walker@timmins.ca

Toronto Chapter

President: Natalie Marnica info@hdtoronto.org

HSC National Office:

20 Erb St. W, Suite 801 Waterloo, ON N2L 1T2

1-800-998-7398 info@huntingtonsociety.ca

ONTARIO NEWS

Province-Wide Events

Toronto Sports Getaway Raffle: The Toronto Sports Getaway Raffle is a great chance to win one of two amazing sports prize packages, including tickets to a game, a two-night stay in Toronto and much, much more! Check it out at www.hscevents.ca/SportsGetawayRaffle.

RaceHD: RaceHD is our national running group that runs, walks or rolls in races across the country to raise money for Huntington disease. If you would like more information about the races and how to register, visit <u>p2p.onecause.com/raceHD</u>. If you have found a race near you that is not listed, contact us at <u>events@huntingtonsociety.ca</u>.

Toronto Chapter

COMMUNITY NEWS

The Toronto Chapter had another successful Toronto Run in September and helped raise over \$37,000 for HD! Thank you to everyone who attended and supported the event! Our Community Education Forum in October was a great success. We also had some Chapter members participate in the Toronto Scotiabank Marathon in October, congratulations to our runners! Thank you to everyone for making this another successful year!

The Toronto Chapter is excited for the New Year, and is planning some great events and activities. Check out our Chapter Facebook at www.facebook.com/HSCTorontoChapter.

UPCOMING EVENTS

Toronto Comedy Night

March 26, 2020

For more information, call the HSC Events Team at 1-800-998-7398, ext. 138 or email events@huntingtonsociety.ca.

MEETINGS

Caregiver Support Group- Please contact Rozi if interested.

Join us for conference call **Chapter meetings**. The details are as follows: Pragmatic Toll Free: 855-392-2520 Toronto: 647-260-3077 Access Code: 7356960 For more information contact info@hdtoronto.org.

London Chapter and Area

COMMUNITY NEWS

Our Community Education Forum in October went great, thank you to our guest speaker Jimmy Pollard for a great presentation. We had a great Christmas Party in November. Thank you to everyone who attended! We are looking for volunteers to get more involved. If you are interested, please contact Paul McConomy.

MEETINGS

Meetings take place the third Wednesday of the month at Parkwood Hospital in the day use area. Parking is \$5.00 payable upon entry. If you have any ideas on speakers or topics you would like to see discussed, contact Paul McConomy.



HSC RESOURCE CENTRES

Family Services Program available at HSC Resource Centres includes:

- Information on HD and strategies for care
- Connecting families with community services/resources through referral and advocacy
- Educational sessions to community groups and healthcare professionals

East Central Ontario

Ms. Marilyn Mitchell, BSW, RSW Resource Centre Director Toll Free: 1-855-426-4333 905-426-4333

mmitchell@huntingtonsociety.ca

Monthly support groups are held in two locations in East Central Ontario

Huntington Support Group - Peterborough

Third Wednesday of each month, September to June (no meeting in December, July or August) from 6:30 p.m. - 8:30 p.m.

Huntington Support Group - Durham

Fourth Wednesday of each month, September to June (no meeting in December, July or August) from 7:00 p.m. - 9:00 p.m. Please contact Marilyn Mitchell for further information.

Eastern Ontario

This position is currently in transition. In the meantime, please contact the Director of Family Services at 1-800-998-7398.

Kingston/Belleville Area

Ms. Sherrie McKegney, MSW, RSW Family Services Worker 613-548-7153 smckegney@huntingtonsociety.ca

Northern Ontario

(inclusive of Barrie/Orillia Area)

Ms. Sarah Gauthier, RP Resource Centre Director Toll Free: 1-855-522-5319 705-522-5319

103-322-3319

sgauthier@huntingtonsociety.ca

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ONTARIO NEWS

Windsor/Essex Chapter

COMMUNITY NEWS

We had a great time at the annual Essex Indy this year! We were able to raise around \$14,000 for HD! Thank you to everyone who attended and supported the event. We also had the pleasure of having Jimmy Pollard come and speak to our group in October. Thank you Jimmy for the wonderful presentation! We are currently seeking individuals who are interested in organizing a concert, walk, paint night, or other fundraising events in the Windsor/Essex area. Contact Paul Bateman if you're interested.

Peterborough Chapter

COMMUNITY NEWS

We had a super Golf Tournament in September, raising close to \$4,000 for HD! Thank you to everyone who came out and supported us! We also enjoyed a wonderful Christmas party on December 10. We had a great time getting together and celebrating the holiday season!

Durham Region Chapter

COMMUNITY NEWS

The Durham Chapter hosted a very successful Community Education Forum on October 5 featuring Yvonne Heath as our keynote speaker. She delivered a very powerful message to an attentive audience. All who attended that day came away with new insights and tools but most of all, renewed hope for the future in the HD community. We had a nice Christmas social in November. Our core group has become an important part of our HD family. The President and Co-President position will be open in January. Contact durhamregionhd@gmail.com if you are interested.

CHAPTER MEETINGS

Chapter meetings are held on the third Wednesday of each month from 7:00 p.m. – 9:00 p.m. at the Real Canadian Superstore, 200 Taunton Rd. W, Whitby, ON. For more information, please call 905-410-0451 or email durhamregionhd@gmail.com.

Ottawa Chapter

COMMUNITY NEWS

After setting an Ottawa Chapter record in 2018, it was another milestone for Amaryllis sales in Ottawa and the surrounding region for 2019. Thanks to all the local volunteers who continue to amaze with their ability to up their efforts!

UPCOMING EVENTS

Registration is open **now** for the 2020 Ottawa Race Weekend May 23-24, 2020. If you will be participating in RaceHD, please head over to www.runottawa.ca and register. The race organizer employs tiered pricing; as each of the five tiers of registration per race fills up, prices rise by approximately \$20 per runner. So, register early for best rates! By popular demand fundraising will return to the RaceHD (p2p.onecause.com/RaceHD) site this year. Follow us on Facebook at facebook.com/HSCOttawa for more event information as the date approaches.



HSC RESOURCE CENTRES

Southwestern Ontario

Mr. Graeme Wood, BSW, MPH, RSW Resource Centre Director Toll free: 1-855-660-0670 519-660-0670

gwood@huntingtonsociety.ca

Toronto and Area

Ms Rozalia (Rozi) Andrejas, MSW, RSW Resource Centre Director Toll free: 1-877-573-7011 905-787-1645 randrejas@huntingtonsociety.ca

Halton/Peel Area

Ms. Ekta Hattangady, MSW, RSW Resource Centre Director Toll free: 1-833-584-3472 289-521-2090 ehattangady@huntingtonsociety.ca

West Central Ontario

Ms. Maike Zinabou, MSW, RSW Resource Centre Director Toll free: 1-866-796-8016 519-576-6102 mzinabou@huntingtonsociety.ca

Windsor Area

Ms. Gioia Levesque, MSW, RSW Family Services Worker 519-979-3211 glevesque@huntingtonsociety.ca

ONTARIO NEWS

Ottawa Chapter Continued

MEETINGS

Support Group Meetings: With Paul's pending departure, the Eastern Ontario Resource Centre Director role is currently in transition. Please contact the Director of Family Services at 1-800-998-7398 for up to date information on the schedule and location of the two groups available; a group for people in early to early-middle stage HD, and a Caregiver Support Group.

Simcoe/Muskoka Area

COMMUNITY NEWS

We had a great walk in October, doubling our fundraising efforts from last year. Thank you to everyone who participated and attended! After much discussion, we have decided to apply for Chapter Status. We will be having a meeting on January 26, 2020 at 1:00 p.m. to initiate. If you would like more information, please contact Steven Beatty.

Grand River Chapter

COMMUNITY NEWS

The group had an informative speaker come from Hospice Wellington to talk about Advanced Care Planning in November. We had a great time at our Christmas Party get together in December. Our Chapter is currently without a President and Treasurer. We have an Executive election coming up in February, so if you are interested, please contact us at https://docs.py.ndf. We are also looking for people with creative ideas for the group in general and for fundraising events.

UPCOMING EVENTS

We would like to start hosting more social evenings for the group in order to have fun and provide informal support. If you have any ideas, contact us by email.

MEETINGS

Chapter/Support Gatherings are held the second Wednesday of each month at the Hespeler Arena in Cambridge. A guest speaker from MAID (Medical Assistance in Dying) will be speaking at our support meeting on March 11, 2020. For more information, contact us at https://doi.org/10.1001/jdb.com/hdf-11.

Niagara Chapter

COMMUNITY NEWS

The Niagara Chapter has been very busy this fall. We had Jim Pollard come speak to us and had 36 people attend. Then we held our very last Niagara Chapter Book Sale at the Fairview Mall and made \$2,431 on top of the \$1,040 that we raised at our June and August barn book sales. Thank you to everyone who supported us over the past 28 years. Our Trivia Night netted \$2,090 with 64 people attending. The 3-on-3 Basketball tournament raised \$730 and we had Ron Culp, John Stainsby and his daughter, Brynne, run in the Marathon, raising \$5,100+. We hosted the HSC Community Education Forum in St. Catharines, ON with 44 people attending. Our Chapter sold 20 cases of Amaryllis plants. In December, we had our annual Christmas Get-Together with approximately 30 people enjoying a great evening.



HD RESOURCES

Clinical Trials

Participation in a clinical trial is a personal choice. Clinical trials can help advance medical research. HSC encourages those interested to connect with their Resource Centre Director to discuss possible impacts of participating. For locations and contact person, visit:

huntingtonsociety.ca/clinical-trial-locations

HDBuzz.net

HD research news. In plain language. Written by scientists for the global HD community. Stay up to date with the latest research news about HD from around the world! Visit:

www.en.hdbuzz.net for more information.

HD Fact Sheets

Fact sheets on a variety of topics relating to HD including communication, clinical trials and behaviour are available on our website at www.hdfactsheets.ca.

GET INVOLVED

TeamHD

Join the team of people that are involved in planning and participating in HSC events across the country.

Follow us on Facebook at facebook.com/hschappenings.

For more information on how to get involved in events, go to www.teamHD.ca or contact the HSC Events Team at 1-800-998-7398, ext. 138 or events@huntingtonsociety.ca.

Volunteer

Our strongest asset is our dedicated volunteers. To learn more about how you can get involved and to fill out an application, visit: www.huntingtonsociety.ca/volunteer.

ONTARIO NEWS

Niagara Chapter Continued

UPCOMING EVENTS

4th ANNUAL NIAGARA BENEFIT CONCERT

February 29, 2020

Contact Rob Martin at robmartin000@sympatico.ca for more details!

VOLLEYBALLL TOURNAMENT

April 4-5, 2020

Contact Lynn Miner at rminer2@cogeco.ca for more information!

If you are interested in learning more about our fundraising efforts or the Niagara Chapter, please contact Gail DeKoning at gaildekoning@gmail.com or John Stainsby at stainsbyjohn@gmail.com.

Kingston/Belleville Area

COMMUNITY NEWS

Belleville had its first ever function this season! Belleville hosted their 2019 Community Education Forum on October 25 with just under 25 people in attendance. There was a live panel including Sherrie McKegney, HSC Social Worker; Elvina Chu, Neuropsychiatrist with a specialty in HD; Danna Hull, genetic counsellor; and Judy Harding, local area representative. We are working on improving the support available in the Belleville area.

MFFTINGS

A support group is offered the fourth Wednesday of the month. There is a Carepartner Support Group and a Drop-In offered. Please contact Sherrie McKegney, Family Services Worker, for more information.

Northern Ontario Chapter (Timmins, Sudbury, Thunder Bay)

COMMUNITY NEWS

In September, one of the Sudbury Chapter's youngest members Vella Miller (age 11), with the help of her friends, organized a lemonade/bracelet making stand fundraiser, and raised \$134 for Huntington disease! Timmins hosted a Community Education Forum that reached over 13 people and provided updates on the latest HD research. Timmins also increased its Amaryllis sales from three to four cases this year and hopes to keep selling more cases in the future! In combination with the Amaryllis campaign, Lynn Walker did a news segment with CTV Northern Ontario, to help the Amaryllis campaign and raise awareness in Timmins. Lynn's brothers (both gene positive) participated in the story as well as her mother. You can find the link to this story on the CTV website at https://northernontario.ctvnews.ca/video?clipId=1835480. There is a newly formed group in Thunder Bay. We are starting to make plans for social get-togethers. Please contact events@huntingtonsociety.ca if you are interested in helping, or for more information.

MEETINGS

If you would like to be involved and attend Sudbury Chapter meetings, email, call or text Lauri for more details at 705-618-1082. All are welcome!



CALLING ALL YOUTH

Young People Affected by HD

YPAHD helps youth think about and discuss things like genetic testing, family life, and dating with HD, and supports them in their struggles of being affected by the disease.

Visit www.ypahd.ca for more information or follow

them on social media... Facebook: /YPAHD Instagram: @YPAHDFeed Twitter: @YPAby_HD

Youth Mentorship Program

The HSC Mentorship Program is designed to support young people across Canada facing the everyday challenges of growing up in a family affected by Huntington disease.

Visit

www.huntingtonsociety.ca/learn-about-hd/youth/ youth-mentorship-program/ for more information.

STAY CONNECTED

Sign up for our Newsletters

Are you interested in finding out about the latest research news from around the world, or what is happening in your local HD community, or tips for caring for a person with HD?

The Huntington Society of Canada is committed to providing you with the most up-to-date information on your topics of interest.

For more information on our three newsletters and to sign up to receive them directly to your inbox on release date, visit www.huntingtonsociety.ca/newsletters.

Social Media

You can find us on...

Facebook: /HuntingtonSC

Twitter: @HuntingtonSC

Instagram: @HuntingtonSocietyCanada

Youtube: /HuntSocCanada

ONTARIO NEWS

Sarnia Chapter

COMMUNITY NEWS

We are looking for anyone who is interested to join our Chapter and/or be a volunteer at our upcoming events. If you have questions, please contact Celine.

UPCOMING EVENTS

BOWLING NIGHT

March 2020

More details to come soon!

Young People Affected by HD (YPAHD) Chapter

This group gives young people someone with whom they can relate, talk to, and lean on. This support system can be incredibly important during this stage in life and beyond.

MEETINGS

YPAHD is a virtual chapter that meets monthly via telephone. YPAHD conference calls are typically scheduled during the evening of the second Sunday of each month but this schedule is subject to change. Check social media or contact ypahd@huntingtonsociety.ca for more information.