BRITISH COLUMBIA COMMUNITY NEWSLETTER FALL 2020



CHAPTER INFORMATION

Vancouver Chapter

President: Lesley Nantel britishcolumbiahd@gmail.com

South Vancouver Island Chapter

President: Khalilah Alwani southislandHD@gmail.com

Okanagan Chapter

President: Dan Middleton hscokanagan@yahoo.ca

NEW! Yukon Area

Representative: Annette Sinclair

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HSC National Office

20 Erb St. W, Suite 801, Waterloo, ON N2L 1T2 1-800-998-7398 info@huntingtonsociety.ca

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

BC HSC Resource Centre

Rhonda Romolock, BSW, RSW • Resource Centre Director 604-822-7195 • rromolock@huntingtonsociety.ca

Natalie Cruz, BSW • Social Worker 604-818-5963

ncruz@huntingtonsociety.ca

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Natalie Cruz, BSW • Social Worker 604-818-5963 ncruz@huntingtonsociety.ca

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South Vancouver Island, Victoria

Jenni Aitken, MSW • Family Services Worker 250-704-2512 • jaitken@huntingtonsociety.ca

Okanagan, Kelowna and Area

Lara Kuchta, BSW, RSW • Family Services Worker 250-712-6225 • <u>lkuchta@huntingtonsociety.ca</u>

The British Columbia Huntington Disease Resource Centre (BC-HDRC) is located at the UBC Hospital, and offers the Huntington Society of Canada's Family Services Program. Rhonda Romolock is the Resource Centre Director and is available four days per week.

BRITISH COLUMBIA NEWS

Province-Wide Events

RaceHD is our national running group which at runs, walks or rolls in races across the country to raise money for Huntington disease (HD). 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 events@huntingtonsociety.ca.

Community Education Forums are taking place on November 14 and February 27 and will cover topics such as HD research and genetic testing. Go to www.huntingtonsociety.ca/cef to register.

Vancouver Chapter

COMMUNITY NEWS

We held our Annual BC Huntington Heroes Walk virtually this year and included the entire province! Families got together to walk in their own communities to raise funds and awareness for HD. Check out some photos from the event using the hashtag #BCWalk4HD.

UPCOMING EVENTS

BC VIRTUAL TRIVIA NIGHT – More information coming soon!

MEETINGS

CHAPTER MEETINGS - held on the second Wednesday of each month, via teleconferencing and google meet. For more information, contact the chapter at britishcolumbiahd@gmail.com.

HD SUPPORT GROUP - The HD Support group is postponed due to COVID-19. Please contact Natalie for updates and support at ncruz@huntingtonsociety.ca.

CAREGIVER GROUP - This groups offers carers an opportunity to build supports, share their experiences with others dealing with similar issues and learn strategies to provide care for themselves as well as the person with HD. We meet on the third Monday of every second month from 6:45 p.m. to 8:15 p.m. from September to June. Due to COVID-19 our meetings are online instead of in-person. If you are interested in joining us please contact Rhonda Romolock at rromolock@huntingtonsociety.ca.

South Vancouver Island Chapter

MEETINGS

The second Thursday of each month is the support group for **People Living** with **HD**

The third Tuesday of the month is the **Caregivers and Friends of People with HD Support Group**.

Please contact Jenni Aitken for more information on either group.

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HD RESOURCES

Clinical Trials

New clinical trials and observational studies are being offered regularly. Should you or a family member be interested in participating please visit:

www.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 involved in planning and participating in HSC events across the country.

Follow us on Facebook at www.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.

BRITISH COLUMBIA NEWS

Okanagan Chapter

COMMUNITY NEWS

Unfortunately, due to COVID-19 the Annual Vernon Run was canceled. However, participants across BC joined the Vancouver Chapter in their Virtual BC Walk. Thank you to all who participated. If anyone is interested in getting involved with the Chapter and planning events, please contact events@huntingtonsociety.ca.

Young People Affected by HD (YPAHD) Chapter

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

For upcoming events and more information on how to get involved with YPAHD, visit www.ypahd.ca.

ONLINE CARER SUPPORT GROUP FOR BC AND THE YUKON

This online group will look at the common stresses of being a carer, ideas on how to reduce carer stress and strategies to assist you as you care for someone with HD. It is a safe and confidential space to build supports, learn about resources and share your experiences.

It will run once a month from October 2020 to March 2021 on the 2nd Thursday of the month from 6:30 p.m. to 8:00 p.m. We will be using GoToMeeting (very similar to Zoom) but you can also join us by telephone via a toll free number if you do not have a computer or tablet that connects to the internet. If you are interested in joining us please contact Rhonda Romolock at rromolock@huntingtonsociety.ca.