BRITISH COLUMBIA COMMUNITY NEWSLETTER SPRING 2020



CHAPTER INFORMATION

Vancouver Chapter

Co-Presidents: Manny Abecia and Yasmin Hamzah britishcolumbiahd@qmail.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

867-634-2888

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HSC National Office

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

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

Fraser Valley

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

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. 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.

Vancouver Chapter

COMMUNITY NEWS

The Chapter (thank you, Corinne!) took part in the Amaryllis Campaign and raised more than \$10,000. Our Huntington Heroes Walk, originally scheduled for May 31, 2020, has been postponed. We are hoping to have the event the second Sunday in September, but will update everyone on the date once we have that confirmed. As with last year, dress up as your favourite hero and join us for a beautiful walk around False Creek in Vancouver! Check www.huntingtonsociety.ca/events for updates!

UPCOMING EVENTS

BC WALK - POSTPONED, STAY TUNED FOR NEW DATE.

For updates, check out <u>p2p.onecause.com/bcwalk</u> or <u>www.huntingtonsociety.ca/events</u>.

MEETINGS

CHAPTER MEETINGS - held on the second Wednesday of each month, alternating between the Centre for Molecular Medicine and Therapeutics - 950 W 28th Ave., Vancouver, BC, at 7:10 p.m., and teleconference meetings. For more information, contact the Chapter at britishcolumbiahd@gmail.com.

HD SUPPORT GROUP - This group is for people diagnosed with HD and meets on the second Wednesday of each month from 6:30 p.m. to 8:30 p.m., from September to June. It's a safe place to discuss various topics related to HD, get support and have some time at the end of the group to socialize. Please contact Natalie for more information at ncruz@huntingtonsociety.ca.

CAREGIVER GROUP - This groups offers caregivers an opportunity to connect with others experiencing similar concerns. We meet on the third Monday of every second month from 6:45 p.m. to 8:15 p.m. from September to June. 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, at Selkirk Place, 385 Waterfront Crescent in Victoria, BC.

The third Tuesday of the month is the **Caregivers and Friends of People with HD Support Group** at Queen of Peace Church Hall, 849 Old Esquimalt Road, Victoria, BC.

Please contact Jenni Aitken at <u>jaitken@huntingtonsociety.ca</u> for more information on either group.

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HD RESOURCES

Clinical Trials

Participating 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: 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

Thanks to our generous supporters, we raised over \$8,000 at our recent 9th Annual dance and silent auction held in Vernon!

UPCOMING EVENTS

VERNON RUN – CANCELLED. POSSIBLE POSTPONEMENT UNTIL FALL. Check out www.facebook.com/HSCOkanagan/ or www.huntingtonsociety.ca/events for updates.

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. Check social media or contact ypahd@huntingtonsociety.ca for more information.