BRITISH COLUMBIA COMMUNITY NEWSLETTER FALL 2019



CHAPTER INFORMATION

Vancouver Chapter

Co-Presidents: Manny Abecia and

Yasmin Hamzah

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

867-634-2888

annettepatriley@gmail.com

HSC National Office IS MOVING IN OCTOBER! New address: 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 • <u>rromolock@huntingtonsociety.ca</u>
Natalie Cruz, BSW • Family Services Worker 604-822-7195 • ncruz@huntingtonsociety.ca

Fraser Valley

Randy Goossen MSW RSW • Family Services Worker 604-851-0225 • <u>rgoossen@huntingtonsociety.ca</u>

South Vancouver Island, Victoria

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

Okanagan, Kelowna & Area

Lara Kuchta BSW RSW • Family Services Worker 250-712-6225 • <u>Ikuchta@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 4 days per week.

BRITISH COLUMBIA NEWS

Province-Wide Events

Holiday Hustle: The Holiday Hustle is a great way to stay active and involved during the Winter season! Check out our website for a race near you, and start fundraising for some amazing prizes: www.hscevents.ca/HolidayHustle. If you've found a race near you that is not listed, contact us at events@huntingtonsociety.ca.

Vancouver Chapter

COMMUNITY NEWS

On May 4, 2019, we held a Community Education Forum, with fantastic speakers, and an excellent lab tour from those working hard to cure HD. A big thank you to the CMMT Lab for showing us around! On June 3, we held our 4th Annual Trivia Night at the Junction Pub on Davie Street in Vancouver. It was a fantastic evening and we were able to raise over \$1500 for HD! On June 23, we held our annual picnic and barbecue at Queens Park in New Westminster. Thank you to Rhonda and everyone who came out to enjoy the sunshine and good company! We had a great turnout for our Walk to Cure on Sept. 15. Thank you to everyone who came out and participated!

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, 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 1:00 p.m. to 3:00 p.m. from September to June. Please contact Natalie for more information at ncruz@huntingtonsociety.ca.

CAREGIVER GROUP – This group 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

COMMUNITY NEWS

The chapter welcomes volunteers to help coordinate the Fall Community Education Forum on October 19. We are also looking for a communications and/or social media coordinator, as well as a volunteer coordinator. Volunteer support can be provided by distance. If you are interested in getting more involved in the local chapter, please contact SouthIslandHD@gmail.com.

AMARYLLIS FUNDRAISER

To purchase amaryllis plants, please contact Geri Stewart, at geristewart@telus.net. All funds raised go to HSC, and the recipient receives a beautiful and resilient annual.

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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 that are 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. 128 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

South Vancouver Island Chapter Continued

MAY HD AWARENESS MONTH UPDATE

The South Vancouver Island Chapter had a great May Awareness Month. The BC Legislative Assembly lit up again this year, and we were able to spread awareness to the public. The City of Victoria declared May HD Awareness Month and flew the HD flag. Members of our Chapter also attended the Crofton Eagles Mother's Day Tea, and were grateful to receive their donation for HSC. Check out the Chapter's Facebook page at www.facebook.com/groups/285790031618411/ to see photos from these events.

UPCOMING EVENTS

SOUTH VANCOUVER ISLAND COMMUNITY EDUCATION FORUM

October 19, 2019

1:00 p.m. - 4:00 p.m.

Greater Victoria Public Library - Central Branch, 735 Broughton St., Victoria For more information and to register, visit www.huntingtonsociety.ca/CEF

MEETINGS

We recently had a meeting on September 15. For information on upcoming meetings, email SouthIslandHD@gmail.com.

Okanagan Chapter

COMMUNITY NEWS

We had a great event season this spring! Thanks to our generous supporters the 12th Annual Vernon Run to End Huntington disease was able to raise over \$12,500! We wouldn't have been able to do it without you all! We are currently seeking chapter members, including (but not limited to), anyone interested in the secretary or treasurer positions. Email us at hscokanagan@yahoo.ca if you're interested.

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.

UPCOMING EVENTS

YPAHD day is coming up on November 16, 2019. YPAHD day is a one-day conference specifically designed for youth (14-35) affected by HD. Youth from across the country gather regionally to learn about genetic testing, family planning, caring for someone with HD, guilt, event planning, round table discussions and more! For more information, visit: www.huntingtonsociety.ca/ypahd-day.