

**RESOURCES & CHAPTER INFORMATION**

**Vancouver Chapter**

Co-President: Manny Abecia  
Co-President: Graham Cook

Are you looking to make a difference in the local HD community? Consider joining our HSC BC Board (Vancouver Chapter). Contact us at [britishcolumbiahd@gmail.com](mailto:britishcolumbiahd@gmail.com).

**South Vancouver Island Chapter**

President: Shena Loganhume  
Tel: (250) 516-6664  
[shena.loganhume@shaw.ca](mailto:shena.loganhume@shaw.ca)

**Okanagan Chapter**

President: Dan Middleton  
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*Have YOU bookmarked OUR websites yet?* Everything you want to know about HD - local and national. What's new? What's happening? *Keep informed at* [www.britishcolumbiahd.ca](http://www.britishcolumbiahd.ca), [www.hike4huntington.ca](http://www.hike4huntington.ca), and [www.huntingtonsociety.ca](http://www.huntingtonsociety.ca).

**Check us out on Facebook at Huntington Society BC Chapter!**

**BC NEWS**

**BC-Huntington Disease Resource Centre (BC-HDRC) News**

**ANNOUNCEMENT: New Full Time Social Worker for BC**

We'd like to welcome Olivier Couture to the HSC BC-HDRC & the Centre for HD (CHD) team.

We are excited to have Olivier join the team. He has his Masters in Social Work and is a registered social worker in BC. He comes with clinical social work experience in a number of health settings and has a history of working in multidisciplinary teams. His work as a Social Worker has been very diverse, ranging from group work, supportive and grief counselling, resource allocation, education and advocacy.

Olivier & Susan are both working from the CHD site and will both be at the Clinics at the Centre for Brain Health location on Tuesdays.

Olivier's days of work are Monday to Friday with his main areas of focus being to provide services to:

- clients with HD and those at-risk
- facilitate the People with HD Support Group in Metro Vancouver
- offer in-service educational sessions to professionals
- coordinate the annual Therapeutic Retreat for people with HD
- take the lead to link & liaise with other professional groups in order to promote the needs of our families

Olivier can be contacted by phone at (604) 822-7195 and email [ocouture@huntingtonsociety.ca](mailto:ocouture@huntingtonsociety.ca)

Starting January 2015, Susan will work Tuesday, Wednesday and Thursday each week with her main areas being to:

- provide services to clients who are in a care giving capacity
- facilitate the Metro Vancouver Caregiver Support Group
- oversee the operations of the BC-HDRC
- support and supervise the BC staff and contract Social Workers

Susan can be contacted at [stolley@huntingtonsociety.ca](mailto:stolley@huntingtonsociety.ca) or a voice message can be left on her voice box at (604) 696-1399

**BC HSC Therapeutic Retreat 2014**

The first week in June, HSC held its 30<sup>th</sup> Retreat in BC! The 2014 HSC Therapeutic Retreat for People with HD was another wonderful success. Participants spent the week undertaking exercises in self-exploration, playing pool basketball and California Kickball, taking walks along the river, enjoying Casino night and making new connections in the community. The retreat took place from June 2<sup>nd</sup> to June 6<sup>th</sup> in Brackendale/Squamish, and the theme this year was *Preparing for your Journey*.

This year there were 12 participants, including four newcomers. We appreciate the efforts of our three staff and six volunteer staff members who made the week possible. Next year's dates are June 1<sup>st</sup> to June 5<sup>th</sup>, 2015. Applications will be mailed out in January to those who have expressed interest. Please contact (604) 822-7195 for more information.

## RESOURCES & CHAPTER INFORMATION

### **BC HD Resource Centre**

Susan Tolley, Director  
UBC Hospital, S179  
2211 Westbrook Mall  
Vancouver BC V6T 2B5  
Tel: (604) 696-1399  
[stolley@huntingtonsociety.ca](mailto:stolley@huntingtonsociety.ca)

**The British Columbia Huntington Disease Resource Centre (BC-HDRC)**, located at the UBC Hospital with the Centre for HD in Vancouver, offers the Huntington Society of Canada's Family Services Program. Susan Tolley is the Resource Centre Director and is available 5 days per week.

### **Family Services include:**

- Information on HD and related community services
- Short-term counseling
- Connecting families with community services through referral and advocacy
- Educational sessions to groups of professionals

The HSC Family Services Program is available to assist individuals and families living with HD. If you are in need of assistance, please contact your local Family Support Worker.

### **BC Family Support Workers**

Victoria: Lynne Reeve  
Tel: (250) 704-2512

Fraser River Valley: Randy Goossen  
Tel: (604) 851-0225

Okanagan Area: Tim Bayliss  
Tel: (250) 712-6225

**Metro Vancouver Caregiver Support Group** runs as a series, 6 sessions in a year.

The next series is scheduled for Oct 2015 to March 2016. To promote healthy communication and foster trust, the group discusses and agrees to individual and group guidelines as well as consensus established for confidentiality for the series of sessions.

Topics for each session are established from feedback provided by the previous series. Some focus topics have been: Good self care, Compassion fatigue (self love, no regrets, give love, live in the moment; Boundaries; Changing roles & Responsibilities, safety of self and others'; What, Where, How, Why, When- Questions around Change in Relationship & Intimacy; Gratitude; Positive Thinking; Humour; Forgiveness.

To get on the list to register for the next series please contact Susan Tolley at [stolley@huntingtonsociety.ca](mailto:stolley@huntingtonsociety.ca) or (604) 696-1399 (voice box message system).

A phone call interview is required for new members. Once accepted to group it is understood you will make your best effort to attend ALL sessions; however, if unable to attend ANY session please let Susan know 24 hours prior to the session.

### **Metro Vancouver Individuals with HD Support Group**

The group provides an opportunity for people with HD to get together and support one another in a caring and safe environment. This is a social-psycho-educational open group led by a social worker who assists people with HD explore coping strategies to gain acceptance of the disease process, to grieve losses and to offer support with educational information to become empowered with knowledge regarding HD. There are periodic guest speakers from the community to help educate the group about various resources. Past topics have included: stress management, planning for the future and nutrition.

The meeting dates for the first half of 2015 are: January 8<sup>th</sup>, February 12<sup>th</sup>, March 12<sup>th</sup>, April 9<sup>th</sup>, May 14<sup>th</sup>, June 11<sup>th</sup>.

The group runs the 2nd Thursday of every month from 1:00 pm - 3:00 pm in New Westminster.

For more information, please contact Olivier Couture at [ocouture@huntingtonsociety.ca](mailto:ocouture@huntingtonsociety.ca) or at 604-822-7195.

**Newcomers must phone or email prior to attending first session.**

**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!

**[www.HDtrials.org](http://www.HDtrials.org) - Enabling and Accelerating Clinical Trial Participation.** WHY take part in Clinical Studies and Trials?

- To find biomarkers that can be used to speed up other clinical trials testing drugs
- To find out if supplements of available drugs are safe and effective treatments
- To test new experimental drugs

**Register today! Right now more than 800 HD persons are needed for currently recruiting trials!**

### **Website on HD Predictive Testing**

Are you considering predictive testing for HD? First, be sure to visit [www.predictivetestingforhd.com](http://www.predictivetestingforhd.com)

This comprehensive website provides information and education on the testing process, deciding to be tested, interpreting results and coping with results. Plus, there are diagrams, expert videos and true stories of those who have considered and undergone predictive testing.

### **South Vancouver Island Chapter News**

#### **Events**

The Chapter sponsored potluck for the South Vancouver Island (SVI) Huntington community is held on the first Tuesday of each month, except July and August, at 7:00 pm at the Queen of Peace Church Hall at 849 Old Esquimalt Road. This social event is an opportunity to gather with family and friends and share a meal. Please contact Chapter President Shena Loganhume at (250) 516-6664 or e-mail [shena.loganhume@shaw.ca](mailto:shena.loganhume@shaw.ca) for more information.

**Dance/Show Fundraiser with the Timebenders** on March 28, 2015 at 8:00 pm at the Da Vinci Centre, 195 Bay Street. Former SVI Chapter President Geri Stewart and two friends are celebrating a milestone birthday and they are donating all profits from the celebration to the Huntington Society of Canada. The Timebenders Experience is a musical romp through the ages featuring the best dance music and outrageous impersonations of the greatest stars over the last 60 years. Costumes are encouraged and prizes will be awarded. \$25 per person. Call Geri Stewart at (250) 386-9891 for tickets.

The **Chris Clayton Memorial Indy Go-Kart Challenge** is on Sunday, September 13, 2015 at the All Fun Go-Kart Raceway at Western Speedway, 2207 Millstream Rd, Langford. More information coming soon!

#### **In Memoriam**

Our thoughts are with the family of Marty Knight who lost his battle with Huntington disease on December 6, 2014.

#### **South Vancouver Island Area Support Groups**

Lynne Reeve, the Family Services social worker, facilitates two monthly support groups. Registration is required if you would like to attend for the first time.

Please contact Lynne Reeve, Family Support Worker, at [lreeve@huntingtonsociety.ca](mailto:lreeve@huntingtonsociety.ca) or (250) 704-2512

##### 1. People with Huntington Disease

Once a month on a Thursday from 1:30 pm to 3:30 p.m. The meetings are held at Selkirk Place, 385 Waterfront Crescent and are for discussion and information sharing.

##### 2. Caregivers' Support Group (for individuals caring for someone with HD i.e., sibling, partner, friend or other family member)

Once a month on a Tuesday from 11:00 am to 1:00 pm. The meetings are at the Queen of Peace Hall, 851 Old Esquimalt Road and are for reinforcing healthy self care, discussion, information sharing, and education around Huntington disease.

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### TeamHD

Are you a fitness buff? Do you enjoy walking or running? We are looking for someone to take the lead on a new, exciting initiative.

*TeamHD* is a National team of runners who participate in local running events across Canada and fundraise for HSC. We are currently recruiting runners in the Victoria, Vancouver, and Okanagan regions.

If you are interested, contact Devin Bonner at  
1-800-998-7398 or  
[events@huntingtonsociety.ca](mailto:events@huntingtonsociety.ca).

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### Young People Affected by HD (YPAHD)

YPAHD is a Chapter of the Huntington Society of Canada with a mission of providing a community and support network for youth affected by HD. To get connected with others and stay informed visit  
[www.facebook.com/ypahd](http://www.facebook.com/ypahd) or  
[www.huntingtonsociety.ca](http://www.huntingtonsociety.ca).

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### Volunteers

We are always eager to hear from volunteers who would like to get involved. Opportunities exist with Events, Chapter Executive, and more. If you would like to volunteer please contact Devin Bonner at 1-800-998-7398 or  
[volunteer@huntingtonsociety.ca](mailto:volunteer@huntingtonsociety.ca).

### Okanagan Chapter News

The Okanagan Chapter is holding our annual dance & silent auction March 7, 2015 in Vernon. For tickets and info please call Ellie Smith @ (250) 546-9351. Our 8th annual Run to Finish HD will be on Saturday, May 23rd at Kin Beach Park in Vernon. This is a fun and inclusive family event and we provide the food. For more info please call Dan Middleton @ (250) 808-8072.

The HSC Family Services Social Worker, Tim Bayliss holds one or two information sessions in our area each year to maintain a connection with families in our area to the Huntington Society.

Our next information session will be sometime in May 2015 (date and place TBA). An electronic survey was sent out in December 2014 and one of the areas covered is asking people from the HD community some questions about our semi-annual meetings such as, have you attended any of our meetings, did you find them informative and helpful, do you have suggestions for future meetings, would you like the meetings held anywhere other than, in this case, Kelowna, any other suggestions for meeting such as potlucks, picnics, etc..

We are hoping that these survey questions will assist us to move forward by providing timely and helpful topics and convenient venues for future meetings and also to provide opportunities for connecting with others within the area including some enjoyable social get togethers.

To contact the Family Service worker in the Okanagan area please phone Tim Bayliss at (250) 712-6225 or email at  
[tbayliss@huntingtonsociety.ca](mailto:tbayliss@huntingtonsociety.ca)

### Fraser Valley Area

**Support Group for individuals with HD, those impacted by the disease and for caregivers** is held monthly with the exception of July, August and December when there are no meetings.

Meetings take place on the 4th Monday of each month in Central Abbotsford.

Meetings have an open, participant-focused approach and are operated on a continuous intake basis, meaning those wishing to participate can join at any time of the year. Support group meetings are a powerful means of both giving and receiving support, but our groups may not be suitable for everyone.

**Caregiver Only support groups** are also offered 3-4 times per year in addition to the regular monthly meetings.

Please call Randy at (604) 851-0225 to find out more specific information as well as to explore whether our support group might be a good option for you.