ALBERTA COMMUNITY NEWSLETTER FALL 2019



CHAPTER INFORMATION

Southern Alberta Chapter

President: Heather Dodds hdcalgary@gmail.com www.facebook.com/SouthernAlbertaHD

Edmonton Chapter

President: Greg Taylor taylorg1@telusplanet.net

Camrose Chapter

President: Arnold Foss fossman@telusplanet.net

Peace Country Chapter

President: Mack Erno mack@jadecash.com

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

Northern Alberta Resource Centre

Bernadette Modrovsky BSW RSW Resource Centre Director

Edmonton, AB

Tel: 780-434-3229 • Toll free: 1-855-554-9484

<u>bmodrovsky@huntingtonsociety.ca</u> *Available 3 1/2 days per week*

Southern Alberta Resource Centre

Shelley Thiele, BSW, RSW, Resource Centre Director Calgary, AB

Tel: 403-532-0609 • Toll free: 1-844-532-0609 sthiele@huntingtonsociety.ca

ALBERTA 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.

Southern Alberta Chapter

COMMUNITY NEWS

We are very excited about our vast community! We have had amazing turnout for our recent events. Our Hope for a Cure Run and Walk had close to 30 volunteers and over 200 participants. We came together for an amazing community event with a run/walk, BBQ, silent auction and much, much more! We were amazed to have raised nearly \$70,000 – that's a \$15,000 increase over last year and a \$45,000 increase over 2017! We would like to continue to encourage engagement in our community through our events and community gatherings and are currently seeking a treasurer and event planner for a fall event to replace the gala.

UPCOMING EVENTS

RED DEER TOOLS FOR RESILIENCE AND SOCIAL

September 14, 2019 - Red Deer Public Library, Red Deer, AB Panel discussion on services and future planning. Chapter updates and meetings. For more information, contact Shelley Thiele or Bernadette Modrovsky.

CALGARY COMMUNITY EDUCATION FORUM

October 26, 2019 - 10:00 a.m. to 2:30 p.m.

CNIB Meeting Room, 10-11A St. NE, Calgary, AB

Enjoy local presentations from Dr. Sarna (neurologist) and Linda Maclaren (genetic counsellor)!

For more information and to register, visit www.huntingtonsociety.ca/CEF.

MEETINGS

We are working on a plan for our fall community gatherings. We are looking for new ways to reach the community in a meaningful way and bring people together. Details to come.

Edmonton Chapter

COMMUNITY NEWS

We had a very successful Annual Walk at Rundle Park. This year's walk was cooler than usual as a result of snow two days earlier, but our participants were there with warm hearts. In May, we had our barbecue fundraiser at the Leduc Canadian Tire. For two days our members and volunteers flipped burgers and smokies to support HSC. We also had the city of Edmonton light up the High Level Bridge and Alberta Treasury Branch Tower in HD colours. This summer we had three of our HD families out on Dream Casters Wabanum Lake fishing expeditions. Our summer ended on a high note with our HD fundraising Casino on July 30-31, 2019!

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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.

HSC'S 2019 AMARYLLIS CAMPAIGN

It's that time of year again! We are very excited to kick off the 2019 Amaryllis Campaign. Our goal this year is to sell over 20,000 bulbs.

Amaryllis kits are priced at \$15.00. Each kit is packaged in a lovely gift box which contains one high-quality Orange Sovereign bulb, growing instructions, soil, a planting pot, a plant stake and a saucer. They come in cases of 12 kits and are shipped across Canada.

Orders can be made at any time, with delivery dates from October to December.

Thank you for your tremendous and continuing support and for helping us to Inspire Hope!

ALBERTA NEWS

Edmonton Chapter Continued

COMMUNITY NEWS

We are currently seeking individuals interested in joining a team for the Holiday Hustle, or organizing a Paint Nite.

UPCOMING EVENTS

RED DEER TOOLS FOR RESILIENCE AND SOCIAL

September 14, 2019 - Red Deer Public Library, Red Deer, AB.

Panel discussion on services and future planning. Chapter updates and meetings. For more information, contact Shelley Thiele or Bernadette Modrovsky.

FROCK BOX CLOTHING

Date and Location TBA

EDMONTON CHRISTMAS PARTY

Sunday December 1, 2019

Contact Greg Taylor for more details on any of these events. Social/game/craft events every other month restarting on October 16, 10:30 a.m. - 12:30 p.m. — if interested please contact Bernie.

MEETINGS

Edmonton Chapter meetings are the first Tuesday of the month from 7:00 p.m. - 9:00 p.m.

Camrose Chapter

COMMUNITY NEWS

Thanks to our sponsors, chapter members and other volunteers, after a hiatus, the Annual Golf Tournament returned this year and was hugely successful, raising over \$53,000 and exceeding everyone's goals and expectations. We also held a successful BBQ in May at the Camrose Co-op. Thank you to everyone who came out and supported us.

MEETINGS

Follow us on Facebook and Twitter (@hscamrosechapt) or visit our website (www.hdcamrose.ca) for meeting dates and Chapter information. We are always looking for new volunteers and ideas!

Peace County Chapter

COMMUNITY NEWS

We had a great turnout for our Community Education Forum in May, it was great to see lots of new faces! Our 10th Annual HD Ride 4 a Cure was held on the weekend of August 24. Thank you so much to all our supporters for coming out and taking part and everyone that pledged a rider! What an incredible 10 years this event has had! Visit out chapter website for photos and results at www.peacecountryhd.ca.

Our amaryllis campaign will start in October and run through November — we will be bringing in 20 cases of Amaryllis (240 kits) to sell this year! Kits are \$15 each and make a great gift. Contact Mack Erno to arrange to get yours.

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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. 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.

ALBERTA NEWS

Peace County Chapter Continued

MEETINGS

If you would like to get on the email list for the Peace Country Chapter, email Mack Erno. Once subscribed, you will get our notifications for chapter meetings and activities. We are always looking for new chapter members!

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.