# ATLANTIC COMMUNITY NEWSLETTER SPRING 2020



## **CHAPTER INFORMATION**

#### **Prince Edward Island Chapter**

President: Steve Clement <a href="mailto:steveclement@pei.sympatico.ca">steveclement@pei.sympatico.ca</a>

#### **Nova Scotia Chapter**

President: Shirley Smith halifaxhsc@gmail.com

#### Newfoundland: St. John's Area

Representative: Catherine Price <u>catherine.price@mun.ca</u>

#### **Newfoundland: West Coast**

Representative: Susan Fitzgerald <a href="mailto:susanwalsh36@hotmail.com">susanwalsh36@hotmail.com</a>

#### **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

#### **Nova Scotia and Prince Edward Island**

Barbara Horner, BSW, RSW Resource Centre Director 902-446-4803 bhorner@huntingtonsociety.ca

#### **New Brunswick**

Marthe Gautreau, BSW, RSW Resource Centre Director Toll-Free: 1-844-384-2345 506-384-2345

mgautreau@huntingtonsociety.ca

#### Newfoundland

Elaine Smith, BSW, RSW Resource Centre Director Toll-Free: 1-877-745-1155 709-745-1155

esmith@huntingtonsociety.ca

## **ATLANTIC NEWS**

#### **Province-Wide Events**

RaceHD is our national running group which 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 <u>events@huntingtonsociety.ca</u>.

### **Prince Edward Island Chapter**

#### **UPCOMING EVENTS**

#### **PEI INDY GO-KART CHALLENGE**

Check out <u>www.huntingtonsociety.ca/events</u> for up-to-date information about the PEI Indy.

#### **MEETINGS**

We will be holding monthly social activities, and all are welcome. If you are interested or would like to be involved in the PEI Chapter in a leadership or volunteer capacity, please contact <a href="mailto:events@huntingtonsociety.ca">events@huntingtonsociety.ca</a>.

## **Nova Scotia Chapter**

#### **COMMUNITY NEWS**

Contact <u>halifaxhsc@gmail.com</u> if you are interested in helping with upcoming activities or events in our area.

#### **MEETINGS**

Please visit our website at <u>www.hdhalifax.ca</u> or visit our Facebook page for upcoming chapter meeting information. All are welcome to attend.

#### **Newfoundland Area**

#### **COMMUNITY NEWS**

We are seeking volunteers interested in planning a provincial fundraising hike in Gros Morne, or other events across Newfoundland. If you are interested, please contact events@huntingtonsociety.ca.

#### **UPCOMING EVENTS**

#### **BARKER'S BATTLE RUN**

Check out <u>www.huntingtonsociety.ca/events</u> for up-to-date information on the run.

#### **MEETINGS**

The Support Group will run every second month from September to June. Please contact the Resource Centre Director, Elaine Smith at 709-745-1155 for more information as well as dates and location.

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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: <a href="https://www.huntingtonsociety.ca/clinical-trial-locations">www.huntingtonsociety.ca/clinical-trial-locations</a>

#### 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 <a href="https://www.en.hdbuzz.net">www.en.hdbuzz.net</a> 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 <a href="https://www.hdfactsheets.ca">www.hdfactsheets.ca</a>.

## **GET INVOLVED**

#### **TeamHD**

Join the team of people involved in planning and participating in HSC events across the country.

Follow us on Facebook at <a href="https://www.facebook.com/hschappenings">www.facebook.com/hschappenings</a>

For more information on how to get involved in events, go to <a href="https://www.teamHD.ca">www.teamHD.ca</a> or contact the HSC Events Team at 1-800-998-7398, ext. 138 or <a href="https://www.teamHD.ca">events@huntingtonsociety.ca</a>.

#### Volunteer

Our strongest asset is our dedicated volunteers. To learn more about how you can get involved and to fill out an application, visit <a href="https://www.huntingtonsociety.ca/volunteer">www.huntingtonsociety.ca/volunteer</a>.

## **ATLANTIC NEWS**

#### **New Brunswick Area**

#### **COMMUNITY NEWS**

Annie Vanexem, Senior Manager, National Events and Chapter Development attended our Chapter meeting on Jan. 14, 2020. Annie shared the benefits of an active Chapter. We made a calendar for the year. We agreed to focus on four key areas; fundraising, awareness, social, and education. Together we came up with different ideas for each area. We need volunteers to help us with organizing these activities. If you would like to get more involved, please email <a href="mailto:events@huntingtonsociety.ca">events@huntingtonsociety.ca</a> for more information.

#### **UPCOMING EVENTS**

May Awareness: #LightltUp4HD, blue and purple lights and flag raising at different locations in NB (as COVID-19 precautions allow) during the month of May to help create awareness for Huntington disease.

Check out www.huntingtonsociety.ca/events for the latest events listings.

#### **MEETINGS**

There is a growing interest within our community for support groups. Marthe will be contacting people individually to discuss the process and get interested people registered. Marthe will share the details for the date, time, and location of the support group meetings as soon as confirmed.

## 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 <a href="mailto:ypahd@huntingtonsociety.ca">ypahd@huntingtonsociety.ca</a> for more information.