

MAINLINE



Hemophilia Newfoundland and Labrador

Fall 2013

A word from our President...



Hello everyone! For those of you that may not know me, my name is Jeff Jerrett. I have severe Hemophilia A, and have been involved with the Hemophilia Society for the past several years. I have attended our annual family retreat at Max Simms Camp with my family for many years now. Camp has always been a highlight of my summer, and this past summer I was very happy and proud to take on the roll of President for our Provincial Chapter.

For a small group of people we have accomplished so much. With our annual Hemophilia walks in St. John's and Gander, Hemophilia Day presentations, and various fundraising efforts all over our little province, we have raised a great deal of awareness for inherited bleeding disorders. I encourage you to continue your hard work with fundraising and supporting our society.

This upcoming January we are hoping to send members of the board of directors to attend NACCHO (North American Camping Conference of Hemophilia Organization). This conference is a great opportunity to learn how to facilitate a camping program to help families, health care providers and the community on the unique needs of those with bleeding disorders. It is also a great chance to meet people with Hemophilia from all over the world and learn their stories. This conference will be an excellent asset when planning our annual family weekend this summer!

I want to encourage everybody to stay up to date with all activities involved with our Hemophilia society by following us on our Facebook page. Keep an eye out for a write up in "Hemophilia Today" about this past summer's camp at Max Simms Camp too! I would also like to remind everyone about the Canadian Hemophilia Society website, <http://www.hemophilia.ca/>, which holds a wealth of knowledge on all types of bleeding disorders.

I would like to personally thank our previous board members and all the many volunteers that have helped support our community. To the new board of directors and everybody involved in the society, I look forward to working with you in the future. It is through hard work and dedication from volunteers like you, that we are able to have an enthusiastic and successful Hemophilia Society.

Jeff Jerrett

And from our Vice Pres...

Just look at those beautiful Fall leaves!!

I would like to start by welcoming our new board members and thank those who have stayed on board for another year. It's wonderful to have such dedicated people volunteering their time. I look forward to working with each and every one of you.

This past year has been great for fundraising efforts and raising awareness of Hemophilia and other inherited bleeding disorders. As always, we are open to any and all new ideas with fundraising. You don't have to be a board member to make comments or give ideas. Please feel free to contact Robyn Pearce: robyn.pearce@gmail.com or myself: jennypenton@yahoo.com. We look forward to hearing from you.

One last point I would like to mention is that my family and I will be putting a float in the Gander Santa Clause Parade this year to raise some awareness. If anyone in Gander and surrounding area would like to be a part of this please contact me.

On behalf of myself, my husband, Brian, and our 2 son's, Jayden and Caleb, we wish you all a Merry Christmas and a Very Happy and Healthy New Year!



Jenny Jacobs
Vice President

Camp:

This summer past we had a great camp with fun for all ages. There were presentations by Baxter, Bayer, our Nurse Coordinator, Charlotte Sheppard, our Physiotherapist, Coleen Jones and Dan Doran from the National Hemophilia Society. We had a visit from Jigg's Farm, a Carnival Night and some hiding Gnome friends. For Summer 2014 we plan to have just as much fun or more! Our dates are scheduled for July 3rd- 6th. Applications will be sent out in the Spring 2014 Newsletter. Hope to see you there!

Melissa Jackson
Program Coordinator



Scholarship:

Congratulations are extended to Brent Anstey and Jenny Jacobs on being awarded the 2013 Memorial Scholarship of the NL Chapter of the Canadian Hemophilia Society. Each have received an award of \$500. Brent continues his Nursing education at the British Columbia Institute of Technology. Jenny is furthering her education in Orthopedic Nursing Through the Canadian Nurses Association. Way to go Brent and Jenny! Further information on scholarships are available on the CHS website at www.hemophilia.ca where you can download a copy of the national scholarship application. From all of us at the Newfoundland and Labrador Chapter, best wishes and good luck with future endeavors.

Sincerely
Angela Jerrett Legge

Fundraising:

A big thank you to everybody who continues to support the chapter by fundraising and supporting fundraising efforts. Almost \$100 was raised at camp through the sale of tickets on various generously donated items. Expanding on this idea, Irene Layden has donated the beautiful quilt displayed below. Robyn and Angela are selling tickets for \$1 apiece, and will be drawing a lucky winner on Sunday, December 7. If you have any thoughts or suggestions related to Irene's quilt or fundraising in general, please contact either of these fine ladies through the CHSNL email at the back of this newsletter.



Featured App: Baxter Beat Bleeds

Just wanted to let you know about a cool app called Baxter Beat Bleeds. Jenny has been using it for a while and finds it very useful for tracking bleeds to show healthcare professionals.

Clinic Corner

Hi to everyone. The clinic nurses have had a busy year. Dr. Scully holds adult clinics every 4th Wednesday of the month. Dr. Bowes holds pediatric clinics the 3rd Wednesday every three months. Clinics have been well attended. Patients are seen on an urgent basis between clinics.

We are pleased to announce that Dr. Paul Moorehead joined the Janeway hematology team in Feb as Pediatric Hematologist/Oncologist and is seeing bleeding disorder patients with Dr. Bowes and Dr. Goodyear. Paul is well known to the Janeway, having completed his residency there and returned as locum for pediatric hematology/oncology on several occasions. He completed his medical degree at University of Manitoba and his fellowship in Pediatric Hematology/ Oncology at University of Ottawa. Paul is currently involved in several hematology research projects with colleagues across Canada.

A travelling clinic is being planned for Twillingate for Nov 18 & 19. Dr. Ravalia will contact patients and Dr. Ravalia is planning an Education session for Twillingate doctors to familiarize them with bleeding disorders.

Dr. Bowes had travelling clinic in Grand Falls in October. Jill and I travelled to Clarendville, Grand Bank and Burin in June, to teach nurses about reconstitution of new Factor XIII product called Tretten (factor XIII in Danish). Novo Nordisk representative Adrian LaBelle accompanied us and presented on Tretten as well. It was great to talk to nurses who work with our patients outside of St. John's.

Colleen and I attended Rendezvous in June where the latest information on bleeding disorders was discussed among multidisciplinary health professionals.

Dr. Scully and other guest speakers have been doing monthly sessions at the Geo Centre that are targeted for consumers and health care professionals related to hematology including bleeding disorders. Anyone is welcome to attend.

Jill and I just did a poster presentation on bleeding disorders for the Janeway Kids Rock Conference on Oct 4th from 7-10 in the Medical School foyer. Health care professionals from across NL attended the Friday night session. The video will be on the Janeway site in November if you want to see it.

Dr. Bowes, Jill and I will attend the Atlantic Hemophilia Conference for Health Care Professionals on Nov 14-16. This is part of a larger conference by the Atlantic Provinces Pediatric Hematology/Oncology Network (APPHON). Dr. Bowes will present at the Hemophilia Conference.

Please keep those transfusion cards coming in a timely manner and do call the clinic if you are having a dental or surgical procedure where you need medication to prevent bleeding.

Charlotte & Jill

Discussion topics:

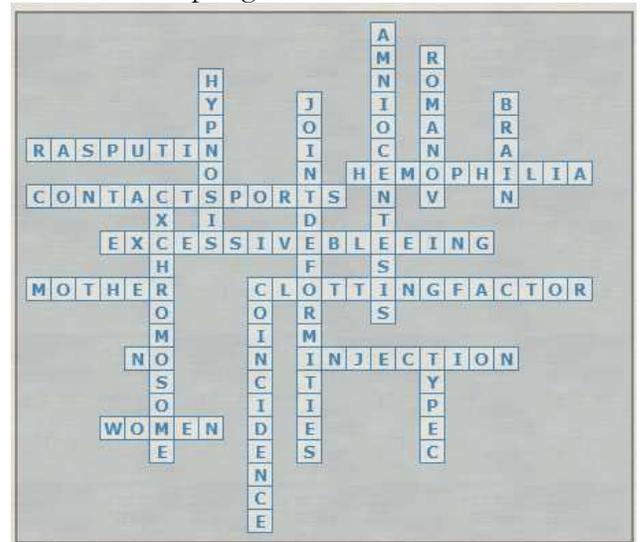
- New products are expected to have much longer half lives. Should this result in fewer injections or more stable factor levels?
- Wisdom of ice: Some researchers question the benefit of ice to treat swelling in people with bleeding disorders. What do you think?
- Many people around the world lack access to factor. Is there anything we can we do to help?

For further details on any of these topics, please contact me at <coopworld@gmail.com>

Feel free to share your thoughts on our Facebook page < Hemophilia Newfoundland & Labrador >

Just for Fun:

Solution to the Spring 2013 crossword:



OUCH! Help Hank find the Hospital. Quick!



Executive and Board

President: Jeff Jerrett

Vice President: Jenny Jacobs

Secretary: Tina Brace

Treasurer: Norman Locke

Director of Programming: Melissa Jackson

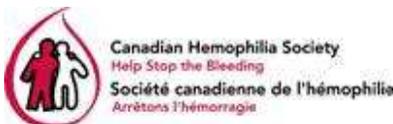
Director of Communication: Michael Barrett

Director of Fundraising: Robyn Pearce

Scholarship: Angela Jerrett Legge

Von Willebrand Chairperson: Elaine March

Youth Director: April Heart



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Clinic

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Newfoundland and Labrador

Medical Healthline

Confidential and Free
1 – 888 – 709 – 2929
TTY: 1 – 888 - 709 – 3555
E-mail: yourhealthline.ca

National Organization

Office: Montreal, QC
Phone: 1-800-668-2686
Web: <http://www.hemophilia.ca>
E-mail: chs@hemophilia.ca

We remind everyone that the Canadian Hemophilia website, www.hemophilia.ca holds a wealth of information on all types of bleeding disorders. The site also contains a forum where you can ask questions or view answers to questions. Thanks to the work of David Page, the site is continuously updated and expanded. We encourage you to visit it regularly. This Newsletter and Hemophilia Today are also available at <http://www.hemophilia.ca>. The Newfoundland and Labrador Chapter of the Canadian Hemophilia Society does not endorse the use of any one medical product/device, nor does it have the medical expertise to do so. We encourage people to make an informed decision after consultation with their treating physician, based solely on the medical benefits and risks of the product/device itself. Brand names of treatment products are provided for information only. Their inclusion is not an endorsement of a particular product or company.