



~Bloodline~

~ Nova Scotia Chapter Newsletter ~

World Hemophilia Day April 17th

IWK Bleeding Disorder Program

– Sue Ann Hawes, IWK Bleeding Disorder Nurse Coordinator

On World Hemophilia Day an awareness session open house was held for IWK staff and visitors. We had a huge cake and door prizes. Many of the staff dropped by to view the CHS awareness video and some of educational material which has been published by our Atlantic nurses. The session was well received and I think many staff had a new awareness for individuals with bleeding disorders and their families and how it impacts their lives. I was very pleased to have hosted this and hope to continue this in the future.



SueAnn, CJ, Lynne



RBC – New Minas Staff

Royal Bank – New Minas Location

- Diane Cunning

On April 17th, to bring awareness to World Hemophilia Day, Royal Bank set up a display table in the mall. There was various educational material made available. In branch, the staff sold coloring books and raised \$120.00. It was an excellent opportunity to bring public awareness to our clients. I look forward to expanding the event next year hopefully to more Royal Bank Branches.

THIS ISSUE FEATURES :

- World Hemophilia Day
- Camp Naccho update
- Children's Wish Foundation
- Family weekend
- Word Find

To receive this newsletter please call :

Nova Scotia Hemophilia Society

(902) 403-2208

Nova Scotia Chapter receives award for Communications and Chapter Development

Sandy Watson (R), NS Chapter President, receives a national award from Pam Wilton on behalf of his chapter.

The Nova Scotia Chapter introduced Bloodline, the first newsletter in the chapter's 41 years of existence. It goes out to members and clinic staff several times per year. They also created a poster and pamphlet that was distributed to hospitals during 2007. The chapter maintains a Web site about Maritime Adventures Camp, their summer camp for children with bleeding disorders. The chapter has been successful in involving new volunteers to assist with the organization of the annual family weekend and fundraising activities including a fundraiser with the Royal Bank, the annual Pumpkin Regatta and the Curl for Hemophilia.

Canadian Hemophilia Society - Nova Scotia Chapter

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Past President - Sandy Watson
Vice President – Katie Hines
Treasurer – Sonia Watson
Secretary – Dean Hines

Communications & Newsletter
Diane Cuning

Fundraising Representative
Diane Cuning

Youth Representative
Katie Hines

Children’s Summer Camp
Katie Hines

Letter from the President...

Welcome to our fourth edition of Bloodline. I realize that it has been awhile since our last edition of Bloodline. My intention was to publish again in March. Things were delayed due to our Chapter’s AGM, elections, Camp, & CHS AGM. Now that things have calmed down with all the changes, it is time for our fourth edition.

There has been a lot of activity since our last edition. Three out of our four executive have changed. Sandy is now past president, and I am now president. Katie is now Vice-President, Sonia Watson is treasurer and Dean Hines is secretary. I would like to welcome and congratulate everyone on their new positions. I have large shoes to fill after Betty Ann and Sandy!

Sandy will continue working closely with Canadian Blood Services and will continue to nurture and develop our relationship. There is a tree planting event that is in the planning stages, we will keep you posted.

Camp planning is now in full swing. Unfortunately Peter is relocating to beautiful British Columbia, so he will not be involved with Camp this year. Peter, we will miss you, our loss is British Columbia’s gain. Thank you on behalf of our entire society. Your work was extraordinary, and the children loved you.

It has been decided that creating a camp committee would be an asset this year and for coming years. A committee was created, and has already held our first meeting. We were able to iron out a few wrinkles, and have action plans in place. Katie is holding our very first counselor retreat. It is a training weekend for potential camp counselors and counselors in training (CIT’S) this will take place in June. If you know anyone who may be interested for next year please let us know by contacting myself or Katie.

I would also like to Welcome Ryan Brownell. He will be replacing Peter with maintaining MAC website. We will have camp forms etc. updated on the website. If you have any suggestions for the website please contact us.

The CHS AGM was held in beautiful St. Johns Newfoundland on the weekend of May 16th. All flights for almost 2 days were cancelled due to the fog; most of us were able to get a flight in at the last minute, and were able to attend the meetings. The Newfoundland chapter welcomed us to celebrate their chapter’s 40th anniversary. It was an extremely busy couple of days but we were able to take a city tour and went to the most easterly point in North America as well as to see Newfoundland’s infamous Icebergs. It was amazing.

See you next time....
Diane

Friendly reminder

If you have access to email, you can also obtain an electronic version of “Bloodline”, on the Canadian Hemophilia Society website located at www.hemophilia.ca under “Provincial Chapters – Nova Scotia”.

Family weekend 2008 !
August 15th – August 17th

This year’s Annual Family weekend will be held at the NSAC in Truro, N.S. commencing at 6pm Friday August 15th, until Sunday, August 17th. Don’t miss out we have a fantastic weekend planned. For more information please email nshemophiliasociety@hotmail.com or call 902-403-2208.

EDITORIAL

Since this will be my last editorial I wanted to say Thank you. I am so grateful to be a part of such a fantastic organization. About 6 months after my son was diagnosed, I knew I just had to become involved.

Honestly, if someone had told me 5 years ago that I would be volunteering so many hours to any organization I would have thought they were out of their mind. I suppose it goes back to "when various things impact and touch your life". The NS Chapter has become my passion. I want to see us succeed, I want to challenge us as a chapter



to reach our goals, and to become a chapter that is a role model for other provinces of comparable size. I know that this road isn't easy, I know we have obstacles ahead of us, but we have a such a fantastic chapter, executive and

group of volunteers, that put countless hours into the chapter, and together, I know, we can make this happen. Just look at the progress in the past 5 years. Camp, Bloodline Newsletter, MAC Website, camp committee and the

Pumpkin Regatta, and this is just naming a few. We are moving in a positive direction, and as long as we remain focused, and remember that teamwork and cohesiveness is at the core of what makes a chapter successful.

As most of you know, I have taken on an entirely different role and am passing on the newsletter to Sonia Watson who will continue, with fresh ideas. It is always good to have fresh blood in a role.

Good luck Sonia – I know you will do excellent!!

~Diane

Farewell

For more than 19 years, I have made my living by writing reports, memos and letters. As a result, you might think that article writing comes to me easily. Wrong. Looking back on my two years as serving as your president for the Nova Scotia Chapter of the Canadian Hemophilia Society and as a National Director, I think about this quote I heard a long time ago, "The problem of being a leader is to tell if the people are following you or chasing you". I am sure, any of you that have served as leader of an organization or even with your job responsibilities, have felt when there are times when you are leading those to a common good and times when your leadership decisions have not been the best with the group and you feel like you are running around. One of the strengths of the CHSNS leadership and its members is that we work as a team to accomplish shared goals and to strengthen our society. I am happy to say that I never felt that I was being chased, challenged (maybe) to be a good leader, encouraged to lead the group for a better tomorrow and supported by the membership to make the best possible decisions for our society. I would like to thank everyone for the support during my presidency and look forward to serving the organization in another capacity as past president. Unfortunately, our members unselfish volunteering quite often is not appreciated. For me, I say thank you from the bottom of my heart. I would like to encourage all of our members to support our next President, Diane Cuning and help her lead CHSNS towards a stronger tomorrow. Thank you! ~Sandy

CHS Programs

Step by Step Program – The Step by Step program provides parents with support through the "steps" of their child's life and development. Various aids are available to facilitate help throughout the development stages. Initially info kits are provided to educate new parents about bleeding disorders. A new parent can go online and visit *Parent to Parent* to share experiences and coping strategies with other parents. A *forum* is available to share and read about topics related to raising a child with a bleeding disorder.

Passport to well-being – Passport to well-being is available to all people with bleeding disorders. The program is designed around 4 modules. Those modules are *Homecare: The Road to Independence*, *Charting Your Course*, *Destination Fitness*, and *Roadmap for Managing Pain*. If one wishes to participate in the program then he or she will receive a personal passport that will be stamped when he or she takes part in a workshop. To find out more, visit www.hemophilia.ca and refer to the online documents. You can even enter to win wonderful prizes, so don't miss out! The programs offered by CHS are designed by medical professionals and people who have personal experiences with bleeding disorders. These programs not only provide a wealth of information but they are also fun to participate in. There are programs in addition to the two mentioned above, so you are encouraged to visit the website.

Wish Child: Christopher Xiros
 D.O.B. 05/29/1999
 Wish: Camper

Eight year old Christopher Xiros is a smart boy, smart enough to know that with severe hemophilia, he had to pick and choose his activities carefully to avoid bleeds. Biking, swimming and other sports were fun, but were too hard on his joints. Playing games on his PS2 and Wii occupied his time, but left him feeling more like a spectator on life's sidelines when what he really wanted was to be a participant and do things with friends.

One activity he could and did enjoy was camping with his extended family and his dog Cosmo. But the family's camper was old, moldy and leaking, and far too small for his family to camp in. What he wished for, more than anything, was a camper big enough to hold his family on summer camp-outs, and his friends on cold, rainy nights for sleepovers at other times of the year. The problem was – how to make his wish come true?

Christopher wasn't sure about that until one day last year, while



in the hospital getting a third portacath in his chest and getting over a persistent staph infection, someone there suggested he might qualify for a wish from The Children's Wish Foundation of Canada. This worried Christopher a bit at first, as he thought getting a wish meant he might not have long to live! But when he discovered that kids just like him might also qualify to get a wish, he was so happy he almost cried. Here was the way to make his camper wish come true. Taking inspiration in hand, he carefully wrote his entire story out, as best he could, and sent it to the Nova Scotia Chapter of The Children's Wish Foundation, ending his plea with just one request

"If you could make my dream come true, I would be the happiest and luckiest little boy in the world."

Two months and a lot of anticipation later, Christopher took possession of a Mallard 35-foot trailer from Stones RV and Home Centre, courtesy of donor Atlantic Poly Liners Inc. and The Children's Wish Foundation. Friends, family and media were there to watch as he inspected his camper for the first time. His eyes shone with happiness and you could almost see him planning that slumber party with his friends.

We're not sure if there will be much sleeping done at his first sleepover, but we are sure that Christopher and his pals will make good use of the camper's full kitchen (to make enough popcorn to scatter all over the camper's living room) triple bunk beds for the boys, queen size bed (Cosmo has to have a place to sleep too!) and full bath to clean up in after all the fun. There are enough facilities and room for a small herd of little boys to play, to laugh, to make lifelong friendship bonds, and to sit up half the night telling stories of dreams and wishes realized...and those still in the planning stages!

Semi AGM and Christmas Party! – Katie Hines

On Sunday December 2nd, 2008 at the Enfield Volunteer Fire Department, we held our Semi AGM and Christmas party. Sandy Watson gave a presentation on chapter updates and upcoming events, I spoke about camp, and we met Melissa Hodgson, Atlantic Rep for the Children's Wish Foundation. To end the meeting we made a farewell presentation to long time Social worker Maureen Brownlow who is loved and missed deeply. We had a feed of KFC and the kids were surprised with gifts from Santa as he stopped in for a visit (Brayden-right). Overall it was a success, thanks to all who attended!



THE CHILDREN'S WISH FOUNDATION OF CANADA
Providing hope through the hurt

GRANTING WISHES TO CHILDREN AGES 3-18 DIAGNOSED
 WITH HIGH RISK, LIFE-THREATENING ILLNESSES



WWW.CHILDRENSWISH.CA
 1-800-267-WISH

I will get through this.



Naccho – 2008

“NACCHO” stands for “North American Camping Conference of Hemophilia Organizations”. This year was the 6th Annual NACCHO Conference and was held in Tempe, Arizona from January, 24th – January, 27th. I had the privilege of attending again this year and I was accompanied by Dean Hines, Senior Councilor of Maritime Adventures Camp, and Nicole Lake, Programming Coordinator of Maritime Adventures Camp. Funded by Wyeth Pharmaceuticals, the purpose for this conference is to further educate and aid in planning hemophilia camps for children with bleeding disorders all over the world. The sessions are truly phenomenal and very educational as well as highly recommended for any person helping run a Hemophilia Camp. Not only were there camps leaders present from all over North America, but this year we had camp leadership representatives from 10 other countries! The sessions were very informative and consisted of everything from fun themed programming to Skillful Discipline and Conflict Management. There's something to be said about sitting in the



middle of a room having a huge camp scrabble match with 100 other adults running around acting like children... No matter how different we all are as individuals, we all share a common goal, and that is your love for kids, and improving their Quality of Life through a Hemophilia Camp. I know I speak on behalf of all of my staff at Maritime Adventures Camp when saying that the kids are what it's all about. Improving their quality of life, making sure they have one great week of fun and adventure and realize that they are not alone in life. As the director of the camp, I can truly say its not just a wish, it's an every year occurrence I get to witness while seeing a child's life enriched by the wonders of camp, and the friendships made. Plans for Maritime Adventures Camp 2008 are underway and the deadline is near so to all my campers out there, it's our 5th Anniversary, be prepared to have another great adventure!!! Can't wait to see you! Sunday, August 24th! ~Katie Hines

In Honour Clinic in Sydney a success !!

On 19 December CHSNS and CBS worked on a joint venture for an "In Honour" clinic for people with bleeding disorders in Sydney NS. The President (Sandy Watson), Secretary (Katie Hines) and two members attended. This event included television, radio, and press coverage of CHS on Eastlink, a Sydney radio station and the local periodicals. The event was a success and the donations were higher than they have been in years. One of our youngest members, Rhys (right) was interviewed about his condition that was aired throughout the month of December. If anything will come back to haunt him from this interview was his admission that "Math" is his favorite subject! There are more events being planned between CHS and CBS. Please keep posted



Canadian Hemophilia Society
Help Stop the Bleeding



Dare to Dream for Hemophilia
www.idaretodream.ca

WORD FIND

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CABINS
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AMBITION

SUMMERTIME
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Welcome Anne !

I am treading in the footsteps of a wonderful social worker, Maureen Brownlow, a colleague who welcomed me into the IWK almost 6 years ago and who remains a committed leader and volunteer with CHS. I am very happy to join the bleeding disorders clinical team. I come from the excellent pediatric medicine team on the 7th floor and worked in various clinics including infectious diseases, immunology gastroenterology, and the pediatric multidisciplinary team, so I am familiar with seeing children and their families during hospital stays and in clinics. As a result of that deeply, life enriching experience, my respect for children and their families who routinely come to the IWK is very high. I have a special interest in working with youth. Happily, we are all different and I am endlessly impressed with the creative ways in which people meet both daily and life changing challenges. In my new team, I look forward to learning from you about your experience with bleeding disorders, whether you are a patient, family member or staff member.

IMPORTANT CAMP REGISTRATION INFORMATION !!!!

Registration for Camp is taking place this year on August 24th from 1pm - 3pm at Mt. Traber Camp. Also all campers **MUST** depart between 2pm - 3pm on August 29th. The camp address is: 14015 Hwy 224 Shubenacadie B0N 2H0 (902) 384-2238(camp number) or you may contact nshemophiliasociety@hotmail.com
See you at camp !!!

CDS Commendation

On 22nd November 2007, Captain G.A. (Sandy) Watson, CD, received the Chief of Defense Staff Commendation from General R.J. Hillier for: "FOR DEDICATION AND CONTRIBUTION TO FOSTERING RELATIONS BETWEEN MILITARY AND LOCAL COMMUNITY", in the award's citation, the Canadian Hemophilia Society was recognized along with other groups that he regularly contributes.



General Hillier acknowledged the Canadian Hemophilia Society during the presentation of the award as well as the ties between the Department of National Defense and the Canadian Blood Services. This acknowledgement may be a foreshadow the future relationship between CHSNS and CBS. The Chief of the Defense Staff (CDS) Commendation is awarded by the Chief of the Defense Staff to recognize deeds or activities beyond the demand of normal duty. The Chief of the Defense Staff (CDS) Commendation may be awarded to: members of the Canadian Forces (CF) who perform a deed or activity beyond the demands of normal duty; civilian members of the Defense Team who perform a deed or activity beyond the demands of normal duty and under exceptional circumstances; and members of the armed forces of a country other than Canada for an achievement or for meritorious service that is of benefit to Canada or the CF.

World Congress 2008 – Istanbul, Turkey

Update –Diane Cunning

Another successful record attendance of over 4200 delegates from all over the world attended the World Congress held in Istanbul at the beginning of June. Although CHS presented a fantastic presentation in hopes to secure, Toronto as the location of the 2012 World Congress, Paris in the end, won. The 2010 World Congress will be held in Buenos Aires, Argentina and the 2012 will be in Paris, France. More to come on 2008 congress held in Istanbul Turkey in our next edition.



Curl for Hemophilia ~ 2007

- Katie Hines

Curl for Hemophilia was another great success this year! Held again at CFB Windsor in Halifax, we had approximately 50 people attend, 8 teams playing. It was held Saturday, November 17th, and we raised just over \$2000.00 We had lunch catered by the Curling Club consisting of soups and chowder and rolls, the perfect thing to warm us all up! All who attended had a really great time and we look forward to see you all back next year!

CBS/DND event attended by NSCCHS

President

-Sandy Watson

On October 24th, 2007, Major General Herbert Petras, Chief of Reserves and Cadets, announced that Canadian Forces members and their families were inviting Canadians to donate blood to the Canadian Blood Services or Héma-Québec in November as a way of honouring the past and ongoing contributions of Canadian Forces personnel at home and abroad, especially Afghanistan. Being close to the Canadian public in their everyday life, reservists can easily relate to blood donors. "Members of the Canadian Forces are volunteers who give their time to something they believe in." said Major-General Petras. " They are in the business of saving lives and keeping Canadian's safe". As President of the Nova Scotia Chapter of CHS and a Captain in the Primary Reserves where I have served for 19 years and having served in Afghanistan I was invited to attend this event. I was able to relate to the media that having a 7-year-old boy who has hemophilia, how important it is to help the Canadian Blood Services ensure the stability of the blood supply". It really hit home when Corporal Shaun Fevens, a reservist from Yarmouth, Nova Scotia, injured in Afghanistan,said, "You don't realize how important blood donation is until you are the person who needs blood." I know that I didn't until my son Rhys came into my life. Since this event, we have fostered a relationship between CBS and ourselves, have directly supported a successful "In Honour" donation in Sydney for people with bleeding disorders and are planning another few events over 2008.

CHS Monthly Giving Program



More and more of our supporters are finding monthly giving to be a convenient, easy way to lend their support on a regular basis. Your ongoing contributions will help provide a steady stream of income for breakthrough research and the valuable programs and services that individuals and families with bleeding disorders count on.



Here are some good reasons to become a Monthly Donor:

- ✓ It's simple and efficient.
- ✓ You are able to spread your annual gift over several months.
- ✓ It reduces the SOCIETY's administration costs so it can support more projects and organize more activities.
- ✓ It ensures a regular intake of funds for better financial planning and budgeting.
- ✓ You don't have to worry about stamps and envelopes every time you want to donate to the SOCIETY.
- ✓ You receive a single receipt in January or February for tax purposes showing total contributions for the tax year.

TO JOIN THE **Monthly Giving Program**, PLEASE CONTACT:



Canadian Hemophilia Society
Nova Scotia Chapter • Telephone: 1-902-482-4054

www.hemophilia.ca

MOVING ???

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