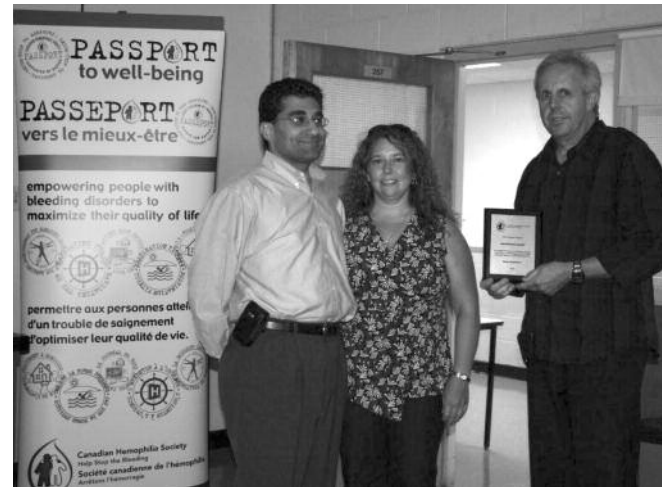


Navigating the ER launched!!!

In response to feedback from chapters, a new module of the CHS *Passport to Well-Being* program has been developed. The module was launched on August 16th at the Nova Scotia Chapter Family Weekend. The chapter was excited to be the first to introduce the new module, *Navigating the ER*. Sue Ann Hawes, RN, facilitated the hands on interactive workshop. Dr. Walid Shammass, Medical Scientific Liaison and David Auld, Biopharmaceutical Specialist, Atlantic, from Baxter BioScience were present at the launch. Volunteers acted out different scenarios that might actually happen when people with bleeding disorders go to the ER for a bleeding episode. Participants were taught how to effectively communicate with the ER staff and how to work in a positive, proactive way. They also had the opportunity to develop new skills to better handle situations when not taken seriously at the ER.

After the workshop, Dianna Cuning, Nova Scotia Chapter President remarked, "This workshop was a real "hands on" approach. I loved it. It showed us what we should do, shouldn't do and everything in-between. I can't recommend this new module enough – it was fun, interactive, and most of all educational."

As with all of the Passport modules, tools have been developed to help with the implementation of *Navigating the ER* including workshop guidelines, a PowerPoint, a booklet, a checklist for clinics and a visa stamp. A revised version of the *Passport to Well-Being* on the Road manual has been produced that includes all of the material to enable chapters and clinics to implement the program. A new promotional banner is also available for chapters to use at their regional events.



Dianna Cuning, Nova Scotia Chapter President with Baxter BioScience representatives, (L) Dr. Walid Shammass, Medical Scientific Liaison and (R) David Auld, Biopharmaceutical Specialist, Atlantic.

Sue Ann Hawes, RN, Pediatric Bleeding Disorder Program, IWK Health Centre, Halifax pictured with the new *Passport to Well-Being* Banner.

CHECKOUT THE CHECKLIST



Checklists are another way that people with bleeding disorders can get involved with the *Passport to Well-Being* program through their Hemophilia Treatment Centre and collect visa stamps. Starting with this issue, we will feature a story relating to one of the five Passport checklists. In this issue, 2 hemophilia nurse coordinators share how they have promoted homecare and self infusion with adults and children in a fun and informative way and enabled kids to obtain a visa stamp.

Pizza and a Poke



Colleen Buehler, RN

Saskatchewan Bleeding Disorders Program, Royal University Hospital, Saskatoon, SK

The Saskatchewan Bleeding Disorders Program had an educational in-service on March 14, 2008, with three of their youth to practice home infusion techniques. The guys did a pre and post test of their knowledge about hemophilia and their comfort levels in providing treatment. They were able to practice with a demo hand and participate in fitness testing and exercise education. A pizza eating contest to finish off the afternoon was enjoyed by all. Kids who participated were able to have their passports stamped with the *Homecare: the Road to Independence* visa stamp. The goal toward independent self- infusion will be followed up with each attendee by the clinic staff. Great job guys!

(L-R): Justin Hur, Randel Morris, and Dustin Souter practicing their infusion technique



PASSPORT TO WELL-BEING • CHECKLIST ✓

Home Care – The Road to Independence

Home treatment can empower you to take control over a bleeding disorder. It allows the bleed to be treated at the earliest possible moment by avoiding the delays in travelling to the hospital and waiting for treatment. This is the best way to stop bleeding, reduce damage to joints and speed recovery.

Complete at least one of the following to receive a **HOME CARE: THE ROAD TO INDEPENDENCE VISA stamp:**

- Parents of a child with a bleeding disorder have successfully learned to infuse their child at home.
- Young person with a bleeding disorder has successfully learned to self-infuse.
- Person with a bleeding disorder, who is on self infusion, has successfully completed the HOME CARE: THE ROAD TO INDEPENDENCE SELF-INFUSION QUESTIONNAIRE.

Nurse Coordinator _____

Patient _____ DATE _____



Tyler Neal practices his infusion technique

"Pokin School"



Morna Brown, RN

Bleeding Disorders Program, Calgary, AB

"Pokin School cause pokin's cool" is the theme of the activity and "it's my vein and I will poke if I want to" is the idea. The vision for the idea came from

Calgary not having a summer camp for several years. Usually at camp, children have the opportunity to learn self-infusion of their factor in a fun group environment. Our goal was to provide an opportunity for kids to share a meal (pizza) together and to network with others in the same situation thus helping to decrease the feeling of isolation that they may experience by having this chronic condition. The kids learn how to prepare their own factor, practice infusion on teaching aids and eventually are able to master giving their own needle.

The Calgary clinic has had a series of sessions dating back to 2003 that included summer camps, which started 4 years ago. It has been interesting tracking the kids' progress from the little guys first coming to pokin school and playing with the factor tools to them actually starting their own IV's. By incorporating this activity with the *Homecare: the Road to Independence* checklist, the participants were able to obtain a visa stamp for their passport.

PROFILES

STORIES FROM THE BLEEDING DISORDERS COMMUNITY



Nikolas Muinonen COMPETITIVE SWIMMER



My name is Nikolas Muinonen, I am 12 years old, and I live in Roxboro Quebec. I am a grade 7 student at John Rennie High School in the Sports-Études program. I have two sisters and one younger brother. My

brother and I are the only ones in my family that have hemophilia.

At school, I am in the sports-études program for competitive swimming. Sports-études is a type of program in which the school day is compressed so that you have enough time after school to do your homework, as well as your sport. I started competitive swimming at the Dollard Swim Club when I was nine years old. I had a lot of fun, and that winter I got an award for the most valuable swimmer in my group. My favorite strokes are butterfly and backstroke, but I take part in races for all the strokes. When I first started competing I was doing 50m races. Over the last couple of years I have progressed to swimming in 200m, 400m, and even 1500m races.

I also like playing other sports like curling, basketball, touch football, diving, and water polo (only after an infusion, and with certain restrictions). Sometimes I wish that I could play football on a team, but I know that I can't because I can get injured very easily. When I swim I have very few injuries, except for the occasional nosebleed.

Last year I got my P1's (provincial qualifying times). This winter I am working toward getting my P2's. Someday maybe I will be able to swim in the Olympics. Until then I will just keep having fun and trying to improve my times.

Andrew Whitehead ATHLETE OF THE YEAR



Andrew Whitehead (L) from Winsloe, PEI, after he won the Provincial title for the 100 metre sprint and friend Joel Doran

Andrew is having a great soccer season and wrapped up his grade six year by winning male-athlete of the year for his school. He's looking forward to grade 7. Andrew has severe Hemophilia A and is on prophylaxis three times per week.

PASSPORT TO WELL-BEING ON THE ROAD

Don't forget to have your passports stamped so that you can enter the 2008 PASSPORT TO PRIZES CONTEST!!



Workshops on the five modules of the Passport to Well-Being Program will be offered throughout the year at chapter and regional events. People with bleeding disorders are encouraged to take advantage of these opportunities to gain new knowledge, strategies and skills to empower them to maximize their quality of life.

Hemophilia Ontario – Northwest Ontario Region (NWOR)

The Northwest Region of Hemophilia Ontario hosted an evening of education and fun at the local Sports Dome on Tuesday, July 8, 2008.

Karen Roberts, Nurse Coordinator, presented the *Destination Fitness* module from the *Passport to Well-Being* program. Members received a pedometer and were encouraged to participate in safe physical activity, especially walking. Members also received passports which were stamped with their first "official" stamp.

After the presentation, the adults met to discuss their vision for programming and services in their community. At this time, the children took the wheel of their own virtual race cars then enjoyed a playful game of mini putt.

This interactive evening was a positive introduction to the *Passport to Well-Being* Program. It provided an opportunity for members to get to know one another and encouraged them to return for future programming.



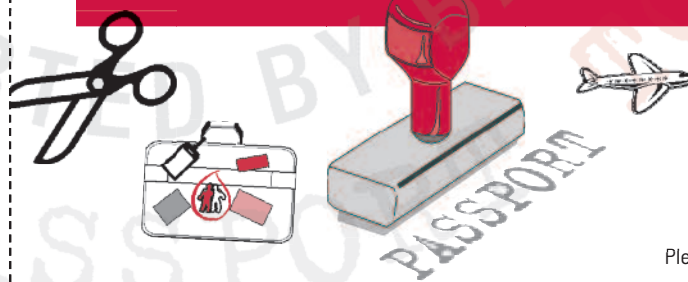
NWOR kids having fun at mini putt

Newfoundland and Labrador Chapter



On July, 2008, during the annual family weekend at Max Simms Camp in Bishop Falls, NL, CHS NL was pleased to present the *Destination Fitness* module of the *Passport to Well-Being* Program to our members. Colleen Barrett gave the presentation and 28 people participated in the workshop. Colleen stressed how important it was to add physical activity to everyone's daily routines. Exercise can be fun and people were encouraged to choose something that they liked such as walking or swimming. Everyone seemed to enjoy the program. Pedometers were given to the members after the session and everyone seemed anxious to use them!

4th PASSPORT TO PRIZES DRAW ENTRY FORM



4TH DRAW 2008

Name: _____

Address: _____

Tel: Res: _____

Bus: _____

Email: _____

Please return by November 15, 2008 to:

Canadian Hemophilia Society
625 President Kennedy Avenue, Suite 505
Montreal, Quebec H3A 1K2
Fax: 514 848-9661



Canadian Hemophilia Society
Help Stop the Bleeding

www.hemophilia.ca

Please indicate the *Passport to Well-Being* Activities you or a family member have participated in, along with the **date of the activity** and the **name of the chapter or HTC** where the activity took place. A minimum of 3 visas must be collected in order to enter the draw. Only 1 entry per family will be accepted. Individuals who received a prize in the previous contests are not eligible to re-enter unless they collect 3 new visas. **Please note that, for the 4th contest, it is not necessary to send in copies of the visa stamps. Winners will be asked to provide proof that their passport was stamped with 3 visas in order to qualify.**

Home Care: The Road to Independence Date: _____

Location (chapter or clinic) _____

Destination Fitness Date: _____

Location (chapter or clinic) _____

Roadmap for Managing Pain Date: _____

Location (chapter or clinic) _____

Charting Your Course Date: _____

Location (chapter or clinic) _____

Navigating the ER Date: _____

Location (chapter or clinic) _____

Signature: _____