



Navigating the ER: a success story!



Jennifer with son Carter.

Jennifer Ruklic, Calgary, Alberta

My son Carter has severe hemophilia A, and because he is only 11 months old, he can't tell me when he is bleeding or hurt. So, at any given time, we pack our things up and off to the hospital we go to check things out. I live in Calgary, and we have a great comprehensive care clinic at the Alberta Children's Hospital. However, my son likes to remind me of his disorder when the clinic is closed and we need to go to the ER.

In April of this year I attended a workshop for women with bleeding disorders put on by the Canadian Hemophilia Society. Deb Gue, nurse coordinator at the Vancouver adult Hemophilia Treatment Centre, presented a session on *Navigating the ER*, one of the modules of the *Passport to Well-Being Program* and I was able to learn some great tools to use when I find myself in the emergency room next.



It just so happened that the evening after the workshop my son fell into a hard wooden table and his nose and forehead were swelling up and bruising. I called the hematologist on call and he advised us to go to the ER. So, with my new knowledge in hand, I confidently went to the ER. When I arrived, I spoke clearly and calmly stating that my son has severe hemophilia, had hit his head and that we had been advised by the hematologist on call to go to the ER. I handed the nurse my *FactorFirst* card and waited to hear her response. After looking Carter over the nurse asked me to sit in the waiting room until I could be seen.

I then remembered what Deb Gue had said during our workshop. There was no need to be aggressive; however I needed to be assertive but calm. It is easy to lose your temper and yell and scream when things are scary. However, it is more effective to remain calm; the words come out a lot easier and clearer. I responded with, "Sure, however would it be a problem if after 15 minutes I check to see if there is any progress in finding a room?" The nurse didn't mind and there was no need to worry as we were given a bed within moments of sitting down. The nurse we had was great! She had the physician in the room within 15 minutes and Carter had his factor after 30 minutes.

I was very relieved that we had a nurse that was so responsive to our situation. It helps that I now know what my sons' needs are. I find it very easy to get help from people once you know what you are talking about. There was a time months ago that I was not sure the dosage to give Carter or what veins are the best. These are all things that the nurses will ask you. It is very important to educate yourself about the disorder in order to be heard.

Carter and I arrived, were treated, and left within 1.5 hours, and I do attribute this to Deb Gue and her guidance during the *Navigating the ER* session. As suggested at the workshop I did take it a step further. I took a thank you card and some chocolates to the staff at the ER a few days later. They were very appreciative!

Once again I want to thank Deb Gue for the tools she gave me for dealing with visits to the ER. We were in again roughly 2 weeks later with a similar situation as Carter is learning to walk. Two of the nurses recognized us and we were triaged as the factor was being ordered. I am aware that it isn't always going to be this easy; however I just need to keep a level head and remain calm. This is the key to success!

4th PASSPORT TO PRIZES CONTEST WINNERS !!!

Individuals or families who had collected 3 or more visas before November 25, 2008 by participating in *Passport to Well-Being* activities were eligible to enter the 4th *Passport to Prizes* contest. On November 29, at the CHS semi-annual Board of Directors meeting in Montreal, Pam Wilton, Deborah Franz Currie, and Jeff Bakker drew the winning entries.



Jeff Bakker, National Specialty Manager Biopharmaceuticals, Baxter BioScience, Deborah Franz Currie, CHS National Director of Resource Development and Pam Wilton, CHS President, participated in the draw.

Winners of the 4th *Passport to Prizes* contest

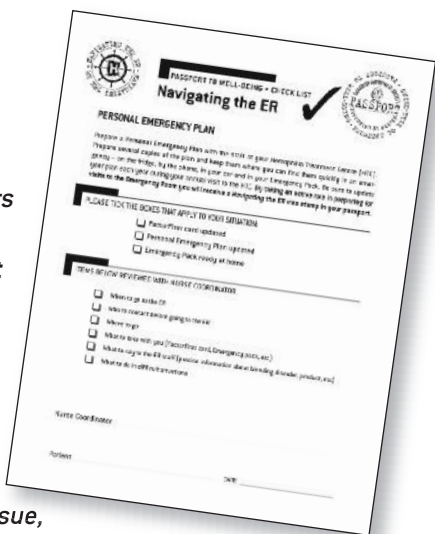
- 1ST PRIZE** Roundtrip Airline tickets for 2 people to any Canadian destination
Winner: **Keith Mercer**, Corner Brook, Newfoundland
- 2ND PRIZE** 2 piece set of luggage
Winners: **David Joy**, Fredericton, New Brunswick
Susan Anstey, Marystown, Newfoundland
- 3RD PRIZE** Backpack
Winners: **Debra Wilson**, Fredericton, New Brunswick
Tara Curwin, Fredericton, New Brunswick
Celena Moody, Perdue, Saskatchewan
Barbara Pepin, Harvey, New Brunswick
Ronald Pearman, Saint John, New Brunswick

Although 2008 was the final year of the *Passport to Prizes* contest, we encourage people to continue to get their passports stamped with visas when attending activities related to the *Passport to Well-Being Program*. And, we encourage chapters to consider offering a prize to the individual in their region who has collected the most visa stamps within the year!

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. In this issue, find out about how to complete the Navigating the ER checklist.



Has this ever happened to you?

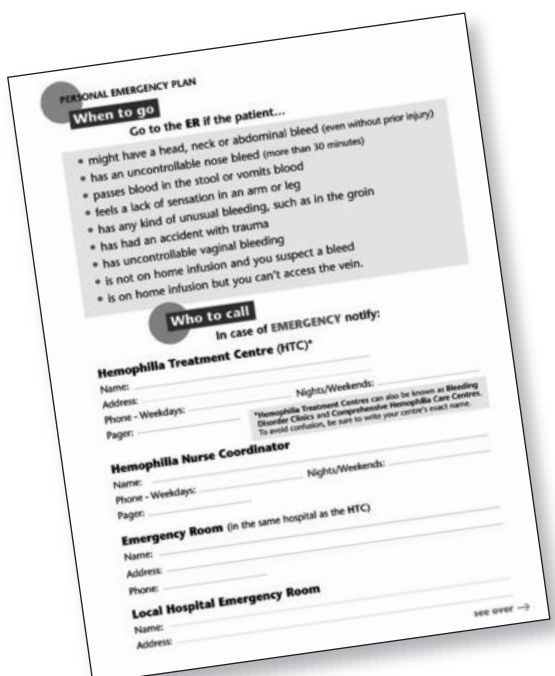
It's 10:00 pm. Your child with hemophilia fell earlier in the day and now he has awoken in tears and his ankle is swollen. You have no factor at home to infuse. You rush over to the nearest hospital emergency room and sit in the waiting room... and wait, and wait, and wait. When your child is finally examined, the ER doctor says, "I'm not sure your son's ankle is bleeding. I'll have to run some tests."

Or, does this scene sound familiar?

It's the middle of the night. You have Type I von Willebrand disease and you are having a bad nose bleed. You are unable to control it at home and so you go to the ER. The waiting room is full and the triage nurse does not seem to think your nose bleed is serious. So you wait. You know that you need an injection of desmopressin (DDAVP). When you finally see the ER doctor, he/she prescribes packing and refuses to call the hematologist on call. The nose bleed continues.

Unfortunately, stories like these have occurred all too often and many people with bleeding disorders have experienced first-hand the frustrations and anxiety of accessing timely and appropriate care for themselves or their child at the ER. ER visits will be necessary from time to time, despite your best efforts to prevent injury. However, before ever stepping into the ER, by being prepared and well informed about your bleeding disorder, you can pave the way to a successful visit.

Prepare a **Personal Emergency Plan** with the staff at your Hemophilia Treatment Centre (HTC). This will include the phone numbers of people to be contacted during an emergency, 24 hours a day/7 days a week. These emergency instructions vary from one HTC to another. Make several copies of the plan and keep one on the fridge or beside your phone, in your car, in your child's schoolbag and anywhere you can find it quickly in an emergency. Be sure to update your plan each year at your annual HTC assessment. To obtain a copy of the **Personal Emergency Plan** speak to your HTC nurse coordinator or contact the CHS. And, don't forget to get your passport stamped with the **Navigating the ER** visa stamp!



PASSPORT TO WELL-BEING ON THE ROAD



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.

New Brunswick Chapter

On Saturday, November 22, 2008, at the New Brunswick chapter family weekend, 30 participants had the opportunity to gain new knowledge and ask questions at a **Destination Fitness** workshop presented by Annette Vautour, the physiotherapist from the Moncton Hemophilia Treatment Centre. This was followed by a workshop on **Navigating the ER** presented by Dorine Belliveau, the nurse coordinator from Moncton. These two workshops, which are part of the **Passport to Well-Being Program**, were greatly appreciated by all. Several participants were eligible for the 4th **Passport to Prizes** draw that took place on November 29th since they had attended three or four workshops of the Passport program.



Annette Vautour, physiotherapist from Moncton, accepting a thank you gift from Tara Curwin.

Dorine Belliveau, nurse coordinator from Moncton, presenting the **Navigating the ER** workshop



Quebec Chapter

On March 28, a **Charting your Course** workshop was held as part of the CHSQ family weekend activities at Saint-Michel-des-Saints. Facilitated by Catherine Sabourin, nurse-coordinator at Montréal Children's Hospital, the activity drew a dozen interested participants, for the most part 25 years of age and over.

During the workshop, Ms. Sabourin addressed the key elements of a bleed diary. The goal was to raise awareness among adult hemophiliacs and parents of young hemophiliacs about the importance of providing this information to the hemophilia treatment team on a regular basis. Some of the elements covered were bleed sheets, perfusion schedules and electronic transmission of treatment diary data.

The participants felt that the workshop had provided a useful forum to exchange information and to learn more about the importance of daily record-keeping. Having an opportunity to share experiences with other participants was a major plus to the workshop's content. Those who took the time to complete the evaluation form indicated that they were generally "very satisfied" with the activity and suggested that it be held again in the future.



Catherine Sabourin, RN presenting at the **Charting Your Course** workshop

Hemophilia Ontario Northeastern Ontario Region (NEOR)

Teresa Genereux, Regional Service Coordinator, NEOR

The NEOR held a clinic on May 23, 2009 at the Laurentian Hospital in Sudbury, Ontario. This is one of the many clinics that Dr. Gill, hematologist and Betty Ann Paradis, hemophilia nurse coordinator, have held over the years. Although I have attended clinic with my children for six years, this was my first time as the NEOR Regional Service Co-coordinator. Two sessions relating to the **Passport to Well-Being Program** were offered during the day. The **Destination Fitness** session included a yoga and wellness program to show participants the importance of staying fit through exercise and clear spiritual minds. The young children enjoyed swimming in the pool while the more mature enjoyed the yoga. The clinic physiotherapist, Nicole Graham, participated as well in the spirituality and relaxation activities.

We also talked to patients about the importance of **Navigating the ER** in a safe and calm way. The clients really enjoyed this as well as it taught everyone how to be more effective in the ER. Participants were able to have their passports stamped with the **Navigating the ER** visa stamp. After a long day at the hospital, we all enjoyed a great supper while the children talked and played and parents had a chance to network with each other. It was a very good day for all that were involved in the event.



L-R: Wailyn, Sara and Katiya enjoying the **Passport to Well-Being** activities



PASSPORT TO WELL-BEING ON THE ROAD

■ Newfoundland and Labrador Chapter

Date: October 17, 2009
Topic: **Navigating the ER**
Location: Twillingate, NL
Contact: Cindy Casey: chsnlcc@nl.rogers.com

■ Hemophilia Ontario SWOR

Date: September, 2009
Topic: **Navigating the ER**
Location: Just the Guys workshop
Contact: Terri Lee Higgins: thiggins@hemophilia.on.ca

RESERVE THE DATE

Join the CHS and the local chapter for this workshop.



Canadian Hemophilia Society
Help Stop the Bleeding

www.hemophilia.ca