

VOYAGE

VOLUME 3 NO 1

NEWSLETTER OF THE PASSPORT TO WELL-BEING PROGRAM

SUMMER 2006



WHAT'S NEW?



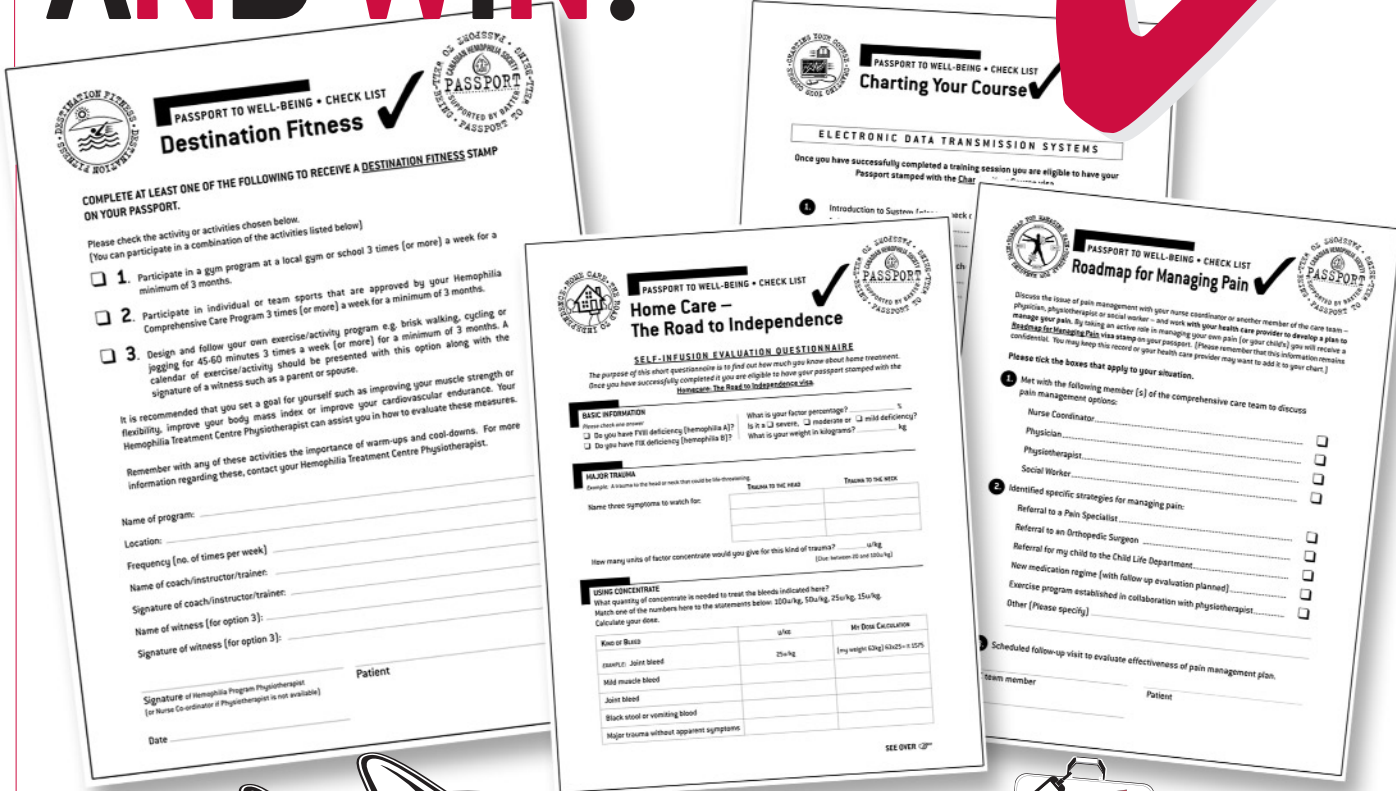
The *Destination Fitness Checklist* encourages individuals to participate in physical activities in order to promote overall fitness and physical wellbeing. In order to receive a "Destination Fitness" stamp on your CHS passport, you must participate in at least one of the following options:

1. Participate in a gym program at a local gym or school three times (or more) a week for a minimum of three months.
2. Participate in an individual or team sport, approved by the Bleeding Disorders Program, three times (or more) a week for a minimum of three months.
3. Design and follow your own exercise/activity program e.g. brisk walking, cycling, or jogging for 45-60 minutes three times a week (or more) for a minimum of three months.



It is recommended that you set a goal for yourself such as improving your muscle strength or flexibility, improving your body mass index, or improving your cardiovascular endurance. Your HTC physiotherapist can assist you with setting and monitoring your goals. Once you have completed one (or more) of the above options, please contact the physiotherapist at the Bleeding Disorders Program and they will arrange to have your passport stamped and to provide you with an entry form for the Passport to Prizes draw.

CHECK IT OUT AND WIN!



Speak to your HTC team member about how you can participate in a Passport to Well-Being Checklist and collect visas for your passport to win prizes. And, by participating in a Checklist, you will be helping your HTC treatment team to be eligible to win a Day at the Spa!! Good luck!



ASK THE EXPERTS

STEP UP YOUR ACTIVITY LEVEL WITH A PEDOMETER!

Kristy Wittmeier, PT, MSc, PHD Candidate, Innovations & Best Practice Coordinator, Winnipeg Health Sciences Centre

- How many steps do you take in a day?
- How many steps SHOULD you take in a day?
- How can counting steps lead to a healthier lifestyle?



Pedometers are being used now more than ever to promote physical activity and health for individuals of a wide range of age and ability. A pedometer is a small (~3cm x 4cm) unit that clips to a person's waistband. The pedometer records each step taken through the use of an internal motion-sensitive lever. A display screen on the pedometer shows how many steps have accumulated. By providing an objective measure of activity, pedometers are great tools to motivate children and adults to increase their physical activity participation. A well-structured physical activity program can improve fitness, strength, flexibility, coordination and body composition; important for people with and without hemophilia!

So, where to start?

According to the literature, adults should accumulate ≥10,000 steps each day to realize health benefits, and children should accumulate ≥12,000 (boys) to ≥15,000 (girls) steps per day.

To set goals to achieve (and surpass) the recommended targets, one must first determine his/her individual "normal" or baseline step count. Wearing the pedometer for one week, and recording steps daily, will provide this baseline number. One easy method of increasing activity is as follows: from the week of baseline measurement, pick the highest daily step count. For the next week, daily step counts cannot be below that value. Each week, the highest step count becomes the minimum target for next week and so it continues. This provides a realistic and achievable plan to continually increase activity.

Where the pedometer is placed along the waistband can affect the accuracy of the step count. If a pedometer is not accurate, people will be less likely to use it. The "step test" easily addresses this problem. Pedometers are usually most accurate when placed on the side of a person's dominant leg, (the leg they would use to kick a ball). Placing the pedometer on the waistband "in line with the knee" works for many. To determine the most accurate position, place the pedometer, take 60 steps (counting aloud) and check your count with the pedometer. The pedometer should be ±2 steps from 60 to be considered accurate. If it is more than ±2 steps, adjust the position until it is accurately recording steps. All pedometers are not created equal; a higher quality pedometer will usually be more accurate, and last longer.

There are some limitations to pedometers; they cannot be used for water activities, and they may be less accurate for individuals with a significant gait asymmetry. As well, they pick up stepping – so will not account for resistance training and certain other activities. Combining pedometer use with a logbook to record activity is one way to get the most out of your pedometer.

Pedometers are a great way to encourage physical activity for individuals, groups and families. Keeping track of pedometer steps counts as a "physio" approved physical activity – so get stepping!



DID YOU KNOW? 2ND DRAW 2006

Due to popular demand, a 2nd Passport to Prizes Draw will be held in 2006 with the same great prizes:

- 1st Prize Roundtrip airplane tickets for 2 people to any Canadian destination (1 winner)
- 2nd Prize 3 Piece set of luggage (2 winners)
- 3rd Prize Backpack (5 winners)

To participate in the 2nd Passport to Prizes Draw, complete the entry form below.

Name: _____
 Address: _____

 Tel: Res: _____
 Bus: _____
 Email: _____

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 1st contest are not eligible to re-enter unless they collect 3 new visas. **Please note that, for the 2nd 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.**

Homecare: 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) _____
 Signature: _____

Please return by November 15, 2006 to:
 Canadian Hemophilia Society 625 President Kennedy, Suite 505
 Montreal, Quebec H3A 1K2 Fax: (514) 848-9661

PROFILES

STORIES FROM THE BLEEDING DISORDERS COMMUNITY



KEVIN BLANCHETTE



Kevin Charts His Course

Kevin Blanchette, a ten year old boy from Beloeil, Quebec shares his experience with using a palm pilot to record his bleeding episodes.

I received my palm pilot EZ-Log® on the 6th of January last year. In my mom's country of birth, January 6th is the day of the three kings, Epiphany (Dia de Reyes). On this day all children receive presents. My mom has always tried to keep up this tradition but last year when she left for the hospital I had not received anything. She said she would come back with a surprise. You can imagine how excited I was when I saw that it was a palm pilot!

I knew about EZ-Log® from listening to other people that were in trials at the same hospital and from flyers my mom had brought back from a congress. I kept on asking my mom when I would receive my palm pilot. For me it was just the scanning feature that made me think I was at the grocery or department store that really appealed. I didn't really know what else could be done with it. But the agenda and fun games that come with all palm pilots would be included as well.

At the hospital my nurse had been telling me that we would get one soon but my mom told me that it would be only when I was old enough. I didn't really know what old enough meant. I was soon to be 9 years old and my older brother close to 12 years old was still not old enough to do lots of things. My mom explained to me that what she meant was that I would be able to prepare and infuse the recombinant factor for myself. Then I would be old enough to own a palm pilot. I had learned to reconstitute factor and get it ready for infusions while attending summer camp but always preferred my mom to do it herself and never had tried infusing myself.

The day after I received the EZ-Log® my mother taught me how to use it. I was so excited that I finally had something that I had always seen grown ups using. It didn't take me long to learn all the features of the palm pilot and the EZ-Log® and not long after I was preparing the factor and injecting myself. It took awhile for me to find the vein but the fact that I was trying to "poke" my arm was enough for my mom to tell me I was growing up.

I would always see my mom spending lots of time getting ready the calendars and infusion sheets (part of the prophylaxis study) especially right before a hospital visit. Now it only takes minutes to go online to the EZ-Log® website and print the calendars. We also know exactly how much factor I have in inventory and the nurse can easily find out how many times I received factor and the reasons why.

Last summer my sister and brother went to visit my grandparents in Florida for a month and my mom said that I would be able to go with them when I will be a pro at infusing myself. A week after their return we went to summer camp. For the first time, with the help of my nurse, I was able to find the vein. Once at home I showed my mom what I was able to do without her help and she realized that now I could do it all by myself. I have been infusing myself ever since. I even started infusing in my arm a place that I had always found very painful every time I went for blood test. I have to admit that sometimes I let my mom still do it – that way she doesn't feel left out!

Now I'm getting ready to return to camp and look forward to my trip next summer to visit my grandparents. One thing is for sure. The palm pilot, EZ-Log® will come along!

PASSPORT TO WELL-BEING

ON THE ROAD



• OTTAWA AND EASTERN ONTARIO REGION

On March 12, 2006 as part of the Annual General Meeting for The Ottawa and Eastern Ontario Region, Diane Bissonnette, Nurse Coordinator, presented the fourth and final session of the Passport to Well-Being Program: Road map for Managing Pain. The workshop was well attended and everyone found the presentation informative. The accompanying information (folders, slides, passports and stamps) made the presentation interesting and also easy to present. Many thanks to Diane for her support in presenting three of the Passport sessions.



• QUEBEC CHAPTER

The Quebec family weekend and AGA were held March 17-19, 2006 at Matawinie. 158 people took part and attended a variety of workshops. Claudine Amesse, nurse-coordinator from Saint-Justine's and Catherine Van Neste, physiotherapist from Enfant Jésus in Quebec City co-presented a Pain Management workshop. Parents, children and adult hemophiliacs learned about different ways to deal with the pain.

• MANITOBA CHAPTER

The Destination Fitness and Home Care components of the Passport to Well-being Program were presented at the West End YMCA-YWCA on January 28th. A wonderful day was planned including an opportunity for members to participate in sample introduction Y fitness programs. Thank you to Lori Enns, Physiotherapist and Nora Schwetz, R.N. for presenting the Passport components.



In addition to all the wonderful information and physical activity opportunities of the day, members in attendance were eligible to enter to win one of two door prizes:

1) a three-month individual membership to the YMCA, and; 2) a three-month family membership to the YMCA. Lori Enns presented the Fitness component again at the Chapters' Parent's Meeting on April 11th, 2006. This meeting coincides with the rural clinic and allows those families to participate.

• CENTRAL WEST ONTARIO REGION

On May 1, 2006 the Destination Fitness workshop was held during the long awaited clinic in Thunder Bay. The session attracted not only those affected by a bleeding disorder, but doctors, physiotherapists and other interested hospital personnel. 17 people were in attendance to learn how physical fitness is an essential part of the overall management of bleeding disorders. Participants affected by a bleeding disorder were encouraged to ask questions to the physiotherapist during their clinic visit that day.

• TORONTO AND CENTRAL ONTARIO REGION (TCOR)

On March 25, 2006 TCOR held its AGM at the North York Public Library. After the meeting was adjourned, the Passport to Well-Being session "Charting Your Course" was led by Paul Tascione, nurse with St. Michael's Hospital Hemophilia Clinic. Many great questions were asked and participants got an opportunity to learn more about the importance of keeping good bleed records.



PASSPORT TO WELL-BEING ON THE ROAD

• QUEBEC CHAPTER

Date: Sept. 29 - Oct. 1, 2006

Topic: Homecare: the Road to Independence

Location: Just the Guys Weekend, L'Avenir, (near Drummondville), QC

Contact: Genevieve Beauregard: 1-877-870-0666

• TCOR

Date: Sept. 15-17, 2006

Topic: Charting your Course

Location: Community Retreat Weekend, Camp Wanakita, Haliburton, On

Contact: Amanda Hechter 1-888-838-8846

RESERVE THE DATE
Join the CHS and the local chapter at the following workshops:



www.hemophilia.ca



Bleeding Disorders Initiative

In November, 2006 we will announce the winning HTC team for a "Day at the Spa".

THANK YOU TO BAXTER FOR SPONSORING THIS PRIZE!!

Checklists and the **Passport to the Spa** form are available in PDF format on the CHS website at: <http://www.hemophilia.ca/en/11.2.php>