

# VOYAGE

VOLUME 3 NO 2

NEWSLETTER OF THE PASSPORT TO WELL-BEING PROGRAM

FALL 2006



## 2<sup>nd</sup> PASSPORT TO PRIZES Contest Winners!!!

**1<sup>ST</sup> PRIZE – ROUNDRIP AIRLINE TICKETS FOR 2 PEOPLE TO ANY CANADIAN DESTINATION**

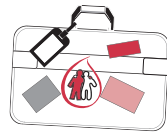
**WINNERS:** Emil Wijnker, London, Ontario

**2<sup>ND</sup> PRIZE – 2 PIECE SET OF LUGGAGE**

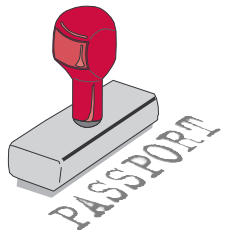
**WINNERS:** Gail Osmond, Mount Pearl, Newfoundland  
Cindy Casey, Mount Pearl, Newfoundland

**3<sup>RD</sup> PRIZE – BACKPACK**

**WINNERS:** Isabelle Blette, Sorel-Tracy, Quebec  
MJ O’Grady, Burlington, Ontario  
Eric Stuckless, Twillingate, Newfoundland  
Mathieu Boudreau, Calgary, Alberta  
Matthew Devereaux, Scarborough, Ontario



“The envelope... please”



Deren Svendsen, Technical Specialist BioPharmaceuticals and Jeff Bakker, National Speciality Manager Biopharmaceuticals from Baxter BioScience and Eric Stolte, CHS President, participated in the draw.

Individuals or families, who had collected 3 or more visas before November 30<sup>th</sup>, 2006 by participating in Passport to Well-Being activities, were eligible to enter the 2<sup>nd</sup> Passport to Prizes Contest. On December 1<sup>st</sup>, at the Joint Chapter Presidents’ and Staff meeting in Scarborough, Ontario, Eric Stolte, CHS President, drew the winning entries. Jeff Bakker, National Speciality Manager Biopharmaceuticals, and Deren Svendsen, Technical Specialist BioPharmaceuticals, from Baxter BioScience participated in the draw and announced that a

**3<sup>rd</sup> Passport to Prizes contest will be held in 2007.**

## WHAT’S NEW?

### Mindfulness-Based Chronic Pain Management

Dr. Jackie Gardner-Nix  
Chronic Pain Consultant, Department of Anaesthesia, Pain Clinic,  
St Michael’s Hospital, Toronto



Chronic pain, defined as pain, intermittent or continuous, lasting 6 months or beyond normal healing times, is not well managed anywhere in the world, with the exception perhaps of in multidisciplinary centres, which offer a variety of interventions. Usually patients require more than one approach to manage pain which is beyond acute stages. Pain medications often offer only partial relief, and procedures may be only useful, if at all, for localized pain sites. Yet pain, such as in an inflamed or bleeding joint, can be excruciating.

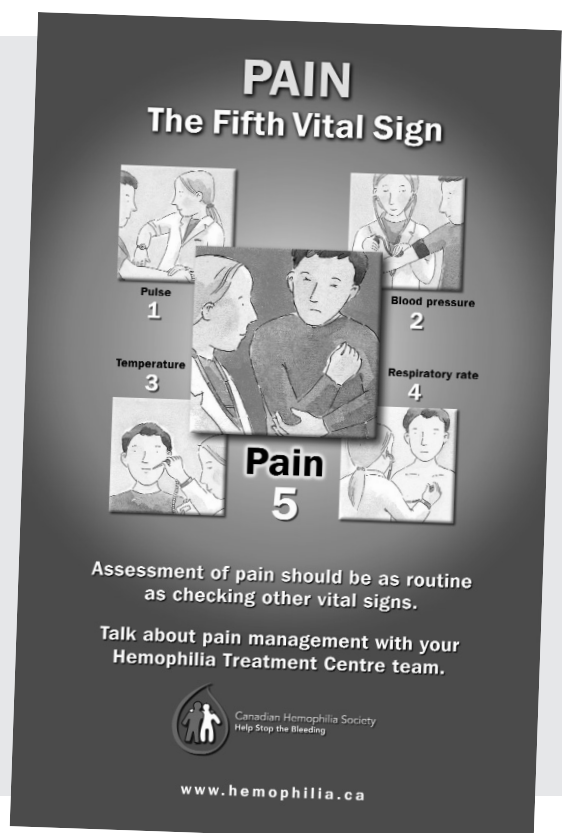
Into the “mix” of why pain can be so hard to control is the realization that beliefs, thoughts and emotions play a very important part in coping with pain, winding up its intensity, and even affecting the body’s ability to heal sites of inflammation. Behavioural therapies such as cognitive behavioural, or Mindfulness-based stress reduction, have proved important in adding what is missing in the conventional medical approach to pain management up to now.

Dr Jackie Gardner-Nix, a chronic pain consultant, offers courses in “Mindfulness-based Chronic Pain Management” at St Michael’s Hospital and at Sunnybrook Health Sciences Centre, two teaching hospitals in Toronto, linking these courses through Telehealth, to outpatients at other hospital sites in Ontario. The course involves a weekly class lasting 2 hours for 12 weeks, doing daily meditation at home, and also practicing how to live non-judgementally “in the moment”. This has an effect, over time, of increasing coping abilities with the challenge of pain, and improving the relationship the patients have with the experience of pain. Their data has shown that patients decrease catastrophizing over the pain, and experience improved mental health. Some patients report they respond to their medications better also, and some have dramatic improvements in their pain. Patients learn to notice when their thoughts start to sabotage them, and when fear and anticipation are increasing the pain experience.

Recognition of how the mind deals with pain is the way of the future in pain management. The “placebo effect” is

acknowledged as “real” and a powerful ally, with benefits from medications and procedures added in, if they prove helpful. Meditation and Mindfulness is no longer something practiced only in Eastern countries: it will soon be coming to a clinic near you!

A physician’s referral is needed to the pain courses which are available only in Ontario, and should be faxed to: (416) 480-4772, marked: attention Mindfulness programme. More information is on the website: [www.painspeaking.com](http://www.painspeaking.com), and a CD box set of the meditation tracks for the courses, and education about pain management, is obtainable from this website.



New CHS Poster, Pain the 5th Vital Sign, now on display in Hemophilia Treatment Centres

## 3<sup>rd</sup> DRAW 2007

### PASSPORT TO PRIZES

#### 3<sup>RD</sup> PASSPORT TO PRIZES CONTEST ENTRY FORM



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 1<sup>st</sup> contest are not eligible to re-enter unless they collect 3 new visas. **Please note that, for the 3<sup>rd</sup> 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, 2007 to:  
Canadian Hemophilia Society  
625 President Kennedy, Suite 505  
Montreal, Quebec  
H3A 1K2  
Fax: (514) 848-9661



## MY JOURNEY TO SELF INFUSION

Josh McCormack, Carlisle, Ontario

I was diagnosed with Hemophilia B, when I was about 1 week old and began prophylaxis treatment at 9 months when my first port-a-cath was inserted. When I was about 2 years old I developed an inhibitor to factor IX. In my first 10 years I had four port-a-caths that assisted with hundreds of infusions.

However, shortly after my tenth birthday I developed a very serious infection from my port and my fourth and final port was removed.

After many, many appointments with the Child Life Specialist at the hospital and several more with other professionals, I was willing to let my mom begin peripheral infusions. I had a real fear of needles from some very traumatic experiences that I had as a young boy. Letting someone access my veins in the back of my hand was frightening to me. But we kept at it and together with my nurse, Lori and the Child Life Specialist, Terry, we made it. In the summer of 2003 my Mom started to infuse me everyday. Everyday got easier and less frightening. Soon I could no longer remember what the fuss was all about. If I had known how easy this was, I probably would have let my Mom do this much sooner.

As time went on and I began looking forward to high school and increased independence in my life, I began to consider self infusion. The idea did not really appeal to me at first, but little by little it began to make sense. I might like to go to friends or to family for a night or two and then I could infuse myself. I also thought that maybe my mom might like to go away for a couple of days and then I could manage on my own.

I began to work with my nurse, Kay at the hospital, and by watching my Mom infuse me everyday I learned how to mix factor and how to access the veins on my hand to infuse my factor.

My younger cousin and I both have had a lot of needles for our different medical problems, and we agree that there are two types of nurses, "pokercs and sliders". We both prefer the sliders so I set out to perfect my technique by holding the needle above the vein on a 45 degree angle, then inserting, flattening out the needle and gently sliding the needle forward into the vein. The trick is in the sliding. This technique is perfect for me and I am happy to report that I am a certified, competent, proud self infuser. I might add that as a reward I bought myself a "sweet" Xbox 360. Life is sweet.



Adapted from the Passport to Well-Being Destination Fitness Booklet produced by the Canadian Hemophilia Society, 2004.

**Perspective written by Raymond O'Shaughnessy, who grew up in Montreal in the 1960s when something so natural as physical activity was discouraged for a boy with hemophilia.**

As far back as I can remember, being active was as natural as breathing; physical activity was the way to get around and to get ahead, and the guarantee of long life and independence.

I was born with hemophilia in 1960. At that time, it took a strong dose of determination to become involved in physical activities. They were prohibited by my physicians because of the associated risks—repeated bleeding and hospitalizations. Despite these risks, how could I have refused my body's call, the irresistible need to "be like everybody else", the profound feeling that I could reach my potential while respecting the limits set by my hemophilia? I learned very early in life that it was up to me to begin this long journey by mastering the tools I needed, listening to and getting to know the marvellous machine of my body so different from that of others.

It was thus with confidence and assurance that activity became as normal and essential for me as eating and drinking. Touring by bicycle, sailing, canoe-camping, mountain hiking, cross-country skiing... to name just a few... became synonymous with independence and freedom. In my mind, they were associated with travel, but also with well-being because of the very real benefits they brought me, including an important decrease in bleeding episodes.

Hemophilia has not ruled my life. Through physical activity I have achieved independence, and health of body and mind. I have experienced adventure and found my place in this world.



Raymond O'Shaughnessy at the helm

## PASSPORT TO WELL-BEING ON THE ROAD

Don't forget to have your passports stamped so that you can enter the 2007 PASSPORT TO PRIZES CONTEST!!



Workshops on the four 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.

## Toronto and Central Ontario Region (TCOR)

On September 15-17, 2006 an enthusiastic and excited group of families and community members of all ages gathered together at the TCOR Community Retreat Weekend at Camp Wanakita.

In total there were 120+ people in attendance for the weekend. This retreat was designed to further enhance, develop and extend friendships and supports within the bleeding disorders community. The weekend offered a variety of both educational sessions as well as the vast list of outdoor activities offered by Camp Wanakita. One might assume that this weekend was already jam-packed with excitement, great weather and learning, but we managed to also incorporate two of the Canadian

Hemophilia Society Passport to Well-being Sessions. We completed the "Charting your course" session, emphasizing the importance of keeping good bleed records. As well, we took part in the "Destination Fitness" session through a combination of a presentation and a "Families in Motion Hike for Hemophilia", a minor fundraising initiative of Hemophilia Ontario. The retreat received rave reviews and we look forward to hosting another event like this in years to come. Thanks to everyone for participating and for all of your energy!

At the annual Winter Party Palooza on November 26, 2006 TCOR completed a third Passport to Well-being session. This time "Roadmap for Managing Pain" was the topic of discussion. Given the extensive amount of useful knowledge and the welcoming, exuberant and warm personality of our own (retired) adult hemophilia nurse Ann Harrington, we felt it was a great opportunity to share her extensive level of knowledge with the bleeding disorder community.



M.J. O'Grady and Pam Hilliard, PT



## New Brunswick Chapter

On September 30 and Oct.1, 2006, the NB Chapter of CHS hosted their first AGM Symposium in Fredericton NB. It was a great weekend of networking and sharing which brought the NB hemophilia community together from all 4 corners of the province. The Passport to Well-Being Program was one of the highlights of the weekend. Attendees had the opportunity to attend two sessions; one on Roadmap for Managing Pain and the other on Home Care; The Road to Independence. These sessions were given by Dorine Belliveau and Carol Mayes, the hemophilia nurses from Moncton and Saint John and were given simultaneously in French and English. The discussion following these sessions was a learning experience for all. Thanks to the NB Chapter volunteers and the nurses for their hard work and innovative efforts to try and resurrect a sleeping CHS chapter.



## Quebec Chapter

It was on a sunny October weekend that eight fathers and their sons met to spend quality time together and to strengthen the bonds between them. It was also time to initiate some fathers to the important tasks of infusion of blood products to their child. That is why the Quebec Chapter presented the Passport to Well-Being workshop, Homecare: the Road to Independence during the Just for Guys weekend. Some were novices to the concept of infusing their child and some were veterans. Nevertheless, all had the occasion to listen to Catherine Sabourin, the attending hemophilia nurse during the weekend, about the importance of prompt infusion after a bleed occurs and the importance of prophylaxis.

Fathers newly initiated to home infusion sometimes find it hard to overcome the barrier which separates injecting their child, which produces some harm to the child (no parent wishes to cause pain to their child), and the benefits obtained after infusing the factor. And so, Catherine volunteered her own veins for the workshop! Instead of factor products, a saline solution was used in the injection. The procedure was a great success for the newly initiated fathers! It was wonderful to see the dedication of the hemophilia nurses towards building the confidence of loving parents to help their children live healthy and productive lives. The Quebec Chapter would like to thank Catherine and all the dedicated hemophilia nurses that have touched our lives.



Canadian Hemophilia Society  
Help Stop the Bleeding

[www.hemophilia.ca](http://www.hemophilia.ca)



empowering people with bleeding disorders  
to maximize their quality of life