A word from our President...

As I am typing this on my computer the rain is currently wreaking havoc on most of Eastern & Southern Newfoundland. Maybe now is a good time to remember many of the chapter activities that have gone on over the summer months and the amazing weather and fun enjoyed at our camp!

For those of you who may not know me, or my family, I would like to introduce myself. Nine years ago, this past August we had our first child, his name is Spencer. After many days in Neo Natal ICU we came to discover he was born with Severe Hemophilia B.

Over the next months, the Hemophilia community was a great support to us. To list the names here would require this whole newsletter and more. However, it was at camp this year, my first time, that we again experienced the support of this amazing group of individuals and families. It became quite evident that it was time for us to take more of an active role within our local Hemophilia Chapter.

I would like to take this opportunity to personally thank all those members that served on the board last year and the many other volunteers that invest their time and effort to support our community. I would also like to thank the new members of our board for volunteering their time and I look forward to working with you!

Volunteers are our “life blood”.

On behalf of my wife, Robyn, and my two boys, Spencer and Casey, I would like to extend a big thank you for all you have done!!

A Word from our Vice President...

Hello!

I hope that everyone had a great summer! Our Annual Family weekend took place from July 8-11, 2010 in Bishop’s Falls, NL. We had great weather and an excellent turn-out. It was great to see everyone and so nice to have new families attend. Thank-you to Bayer, Baxter and Novo Nordisk for their financial support for camp.

Our programming team did a great job! Thank-you Shirley Hart, Ruby Locke, April Hart and Mona Maye and to the Jerrett family for their talented music. Thank-you Helene Bourgaize, David Auld and Serge Simon LeClerc for your excellent presentations. Our AGM also took place at camp on July 10, 2010. Our new board was chosen at this time.

We would like to welcome our new board members. A big thank-you to those of you who stayed on the board. To Colleen, Ruby, Cyril, Theresa, Kirby thank-you for your hard work and dedication to the chapter. We will miss you!

I would also like to remind you to call the clinic before your scheduled appointments for surgery or any dental procedures. The clinic team is very busy and calling in advance saves everyone a lot of time. If you have any comments, questions or concerns, please get in touch with me or any of our board members. We would be happy to help you.

Stay well!

Cindy Casey
Vice President
Hi everyone!

This year camp was just as exciting as ever. The annual family weekend is what our children look forward to year after year...a time when we can get together with our extended families from all over our vast province. Adults look forward to our meetings, which are extremely informative, and of course our playtime with our children in an excellent facility. Not only do we get to have this awesome facility at our disposal, but we get valuable information and make friends that will last a lifetime. As usual our talent / no talent contest was a hit along with the campfires, boat rides and the numerous times we were able to use the swimming pool. Mark it on your calendars folks for next summer...July 7-10, 2011. We can't wait to see you again or meet you for the first time!

Susan and Marven Anstey
Communications

A few highlights from camp...Talent / No Talent night and Hawaiian Night

Every penny counts!

Our penny appeal has been very successful in the past. If every member of our chapter donated 100 pennies, it would make an incredible difference to our activities. Get your friends and family involved....remember, every penny counts!

This year's fundraising efforts have shown a definite improvement...

- At Camp the pennies collected raised $74 and through tickets sales we made $180.
- Our annual June walk raised $2440.
- Recyclables raised $1060.

Keep up the hard work everyone!

"Volunteer of the Year Award" went to Jordan Anstey for all his hard work collecting recyclables.

Scholarship News

We encourage everyone pursuing post secondary education to check out the national scholarship and bursary at www.hemophilia.ca and the Newfoundland and Labrador Chapter of the Canadian Hemophilia Society scholarship at http://www.hemophilia.ca/en/8.9.php#4. This year's $500.00 recipient was Jason Cutler. Congratulations Jason!

A Little FYI...

Some different research funding programs that are presently taking place. They are geared for researchers and medical students but thought you would like to know what's going on.

- Dream of a Cure, CHS Research Program
- Summer 2011 Dream of a Cure Studentships in Hemophilia Research
- Hemostasis Fellowship Program in collaboration with CSL Behring and AHCDC
- Care Until Cure Research Program in collaboration with Pfizer

Deadline: November 15, 2010
WFH: Acupuncture Eases Pain in Hemophilia Patients

* In a small pilot study of acupuncture in hemophiliacs with chronic pain, it was helpful in six of nine patients and no episodes of bleeding occurred.

* Note that this study was published as an abstract and presented at a conference. These data and conclusions should be considered to be preliminary until published in a peer-reviewed journal.

BUENOS AIRES -- Sticking needles into patients with a blood-clotting disease may seem counterintuitive, but researchers here said that acupuncture appears to alleviate some joint pain commonly experienced by people living with hemophilia.

In a pilot study, six of nine patients achieved substantial pain relief, including one patient whose visual analog pain scale score dropped from 10 to 5, said Angela Lambing, MSN, nurse practitioner coordinator at Henry Ford Health System, Detroit, at her poster presentation during the Hemophilia 2010 World Congress.

In the quality-of-life survey using the Short Form (SF-36) questionnaire, patients reported improvement in physical functioning, emotional problems, mental health, pain relief and positive changes in health.

"Importantly, we saw no bleeding in any person. We saw no bleeding after any treatment session. And we didn’t see any bleeding if the patient was taking blood factor to prevent bleeding episodes or was not on those treatments," said Lambing.

"The number of patients is really too small to do any meaningful statistical analyses," she told MedPage Today, "but I consider this a successful trial."

The trial was conducted in Detroit and in Karnataka, India, part of the "twinning" program that connects treatment centers around the world.

Lambing said she really didn’t expect any bleeding issues with the acupuncture needles because the instruments used are 36-gauge needles -- about the width of a human hair, and the needles do not penetrate all the way through the skin.

The acupuncture treatment program involved two sessions a week for four weeks, followed by weekly sessions for six weeks. Lambing said the long course of treatment probably reduced the enrolment in the trial. She said the small number of patients is a limitation of the study.

"This is an interesting study," commented Johan Eerens of the Belgian Haemophilia Society. "I think it could be part of the treatment plan for individuals who are having difficulty getting relief of pain. It would be worth a try."

Adults diagnosed with hemophilia were eligible for the study if they reported chronic pain and were diagnosed with severe hemarthrosis. They were treated with acupuncture at 20 sites, including specific points in the knee, ankle, lower back, and elbow for patients experiencing pain in those areas.

"Obviously we need larger randomized studies," Lambing said. "But as an alternative therapy, acupuncture may provide some benefit to chronic pain patients with hemophilia in a multimodal approach."

Neither Lambing nor Eerens had financial disclosures.
We remind everyone that the Canadian Hemophilia website, [www.hemophilia.ca](http://www.hemophilia.ca) holds a wealth of information on all types of bleeding disorders. The site also contains a forum where you can ask questions or view answers to questions. Thanks to the work of David Page, the site is continuously updated and expanded. We encourage you to visit it regularly. This Newsletter and Hemophilia Today are also available at [http://www.hemophilia.ca](http://www.hemophilia.ca). The Newfoundland and Labrador Chapter of the Canadian Hemophilia Society does not endorse
the use of any one medical product/device, nor does it have the medical expertise to do so. We encourage people to make an informed decision after consultation with their treating physician, based solely on the medical benefits and risks of the product/device itself. Brand names of treatment products are provided for information only. Their inclusion is not an endorsement of a particular product or company.