

# Hemophilia Today

March 2011  
Vol 46 No 1

Canadian  
Hemophilia  
Society

Serving the  
Bleeding Disorders  
Community

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CALGARY



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in Calgary!



Canadian Hemophilia Society  
Help Stop the Bleeding

RENDEZ-VOUS  
CALGARY 2011  
MAY 26-29



NEW CHALLENGES

## THE BENEFACTORS CLUB

The Canadian Hemophilia Society (CHS) relies on the generosity of our donors to fulfill our mission and vision. We are fortunate to count on a group of exceptional donors who have committed to making an annual investment to support the CHS and its core programming needs.

To recognize this special group of donors we have created the BeneFACTORs Club, the CHS' highest philanthropic recognition, which symbolizes the critical bond between our organization, the donor and every person we serve with an inherited bleeding disorder. Corporations that make annual gifts of \$10,000 or more to support our organization and its core programming needs are recognized as members of the BeneFACTORs Club.

The Canadian Hemophilia Society acknowledges their tremendous effort.

### VISIONARIES



### INNOVATOR



### BUILDERS



### BELIEVERS



MARCH 2011

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*Hemophilia Today* is the official publication of the Canadian Hemophilia Society (CHS) and appears three times yearly.

The Canadian Hemophilia Society strives to improve the health and quality of life for all people with inherited bleeding disorders and to find a cure. Its vision is a world free from the pain and suffering of inherited bleeding disorders.

The purpose of *Hemophilia Today* is to inform the hemophilia and bleeding disorders community about current news and relevant issues. Publications and speakers may freely use the information contained herein, provided a credit line including the volume number of the issue is given. Opinions expressed are those of the writers and do not necessarily reflect the views of the CHS.

The CHS consults medical professionals before distributing any medical information. However, the CHS does not practice medicine and in no circumstances recommends particular treatments for specific individuals. In all cases, it is recommended that individuals consult a physician before pursuing any course of treatment.

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CHS is now on facebook

Go to the CHS Web site to be directed to our facebook page.

## Word from the Editor

François Laroche



As mentioned in the Word from the Editor of our July 2010 issue, the Quebec Chapter undertook a study of the situation and needs of Quebec hemophilia treatment centres (HTC), in close collaboration with medical personnel. This process consisted of a standardized questionnaire lasting from 20 to 30 minutes, conducted by two CHSQ volunteers with 37 members from the HTC multidisciplinary teams. From the invaluable data collected, a report of over 25 pages was drafted, and the professionals who participated in the survey were asked to comment on the report, provide clarifications or suggest additions. This feedback was integrated into the final report, which will be presented to Quebec's Minister of Health and Social Services, the Honourable Yves Bolduc. Incidentally, the Quebec Chapter's report will be translated into English and made available to other chapters and regions that would like to conduct similar evaluations.

Without going into detail, I would like to highlight certain findings, most already known prior to the study and in fact the reason for it. First, none of the four centres (if we exclude the *Quebec Centre for Inhibitors* which shares its resources with the *Centre d'hémostase* at Sainte-Justine Hospital) currently meet all of the *Canadian Comprehensive Care Standards for Hemophilia and Other Inherited Bleeding Disorders* adopted at *Rendez-vous Québec* in May 2007. The main shortcomings, which varied appreciably from one centre to the next, were insufficient time devoted to physiotherapy, lack of psychosocial support specialists in some centres, lack of staff for CHARMS and HeliTrax® data entry and management and, above all, a generalized lack of time for research, training and education—which I find, to say the least, very disturbing...

Generally speaking, our professionals seem to be

overburdened with work and without time for patient education. At best, education is provided outside the centres, at events organized by the Quebec Chapter and attended by the professionals (summer camps, family weekends, weekends for families affected by inhibitors, etc.). However, education is crucial. There is just so much to learn: self-infusion techniques, prophylactic measures, how to select suitable activities given one's condition, how to calculate one's factor level "x" amount of time after infusion... to only mention a few. All these things can help reduce bleeding episodes, save on factor concentrates and improve quality of life. And what are we to say about the lack of time for research and professional development...

Our professionals, once again, are managing to keep the hemophilia health care system going, thanks to their competence and experience, and above all, a dedication that goes far beyond the call of duty. Once a model not only for the rest of Canada but for the entire world, Quebec's hemophilia treatment centres are now slowly declining. We must put a stop to this. What is worse, the deterioration is not limited to Quebec. The care standards evaluation published in 2010 by the Association of Hemophilia Clinic Directors of Canada showed that only 14 of Canada's 25 HTCs have a full complement of professionals and that team members do not have enough time to fully carry out their duties. The first independent evaluations of Canada's HTCs will be performed in 2011.

We will make every effort to help ensure that our devoted health care professionals have the resources they need to provide complete and optimal care to those with bleeding disorders.

For the moment, the problems observed have had little impact on the quality of patient care, but it is only a question of time before we start seeing tangible consequences in the medium and the long term. Guaranteeing access to complete, optimal care for all suffering from an inherited bleeding disorder has been the number one priority of our organization's mission since the very beginning. The strategic plan adopted in November 2010 focuses insistently on the whole question of care standards, the capacities of the HTCs and the role of the CHS in fighting on behalf of the centres. We will make every effort to help ensure that our devoted health care professionals have the resources they need to provide complete and optimal care to those with bleeding disorders.◊

## Message from the President

Craig Upshaw



### The CHS adopts comprehensive strategic plan for 2011-2015!

Since my last message the strategic planning Steering Committee received final comments from the Board and committee members, chapters, health care professionals and key external stakeholders regarding the 2011-2015 strategic plan for the organization. The suggestions were incorporated into the plan and presented to the Board of Directors for discussion during the semi-annual board meeting on November 27. The Board wholeheartedly endorsed the five-year plan. (See pages 6 and 7 for a quick overview. The strategic plan in its entirety can be consulted at [www.hemophilia.ca/en/about-the-chs](http://www.hemophilia.ca/en/about-the-chs).)

With the five-year plan approved, the CHS and its chapters now have a comprehensive roadmap to guide national committees and chapters in the development of annual work plans. This common vision will allow us to strive to achieve the mission and goals of the organization.

Those of you who read the plan and are active in your chapters will recognize that many of the objectives, key strategies and desired outcomes in the strategic plan are consistent with current chapter directions; this is no coincidence. The planning process involved significant chapter and community involvement. The plan was developed for the entire Canadian Hemophilia Society – national organization and provincial chapters – in order to ensure that we are working collaboratively and cohesively to move our mission and vision forward.

Some chapter leaders may look at this plan and determine that they are already achieving a large proportion of these objectives. Others may

find the plan extremely ambitious. It was clear to the Board that some goals may prove to be a challenge for chapters with more limited volunteer resources, and that a collective effort with support from the national organization will be needed. However, based on all the feedback, it was recognized by the designated directors, who represent all the chapters, and the directors-at-large, who collectively make up the CHS Board of Directors, that this plan clearly targets critical issues for our community. These include:

- optimal comprehensive care for all people with inherited bleeding disorders;
- access to a secure supply of the safest and most efficacious therapies;
- increased funding for research to improve treatment and ultimately to find a cure;
- effective delivery of information and support to patients and their families across Canada in both English and French;
- greater awareness among people with inherited bleeding disorders, their immediate communities and health care providers.

In order for this strategic plan to be a success, all chapters need to strive to deliver on the goals that are most important to our membership.

The CHS biennial *Rendez-vous* will be held in Calgary from May 26 to 29. Events include the Medical and Scientific Symposium, CHS Annual General Meeting and Board meeting, meetings of the four health care provider teams, and community workshops. At the Board meeting, the CHS directors will come together to review the work plans created by the committees as well as provide an update on chapters' plans to deliver on the strategic plan.

At that time we will have a clear picture of the successes that are already occurring, the challenges we need to overcome and the kinds of tools, training and planning that need to be put in place to move the organization forward.

I am excited about the adoption of the 2011-2015 plan. I am committed to working with all of you to collectively ensure that we further our mission to improve the health and quality of life of all people with inherited bleeding disorders and ultimately to find a cure. ◊



#### Our Vision

A world free from the pain and suffering of inherited bleeding disorders.

#### Our Mission

The Canadian Hemophilia Society is committed to improve the health and quality of life of all people with inherited bleeding disorders and ultimately to find a cure.

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## Our Values

The Canadian Hemophilia Society is committed to the following values:

Inclusiveness | Connectedness  
 Advocacy | Excellence | Integrity  
 Respect | Collaboration

## Our Goals

### Care and Treatment

Achieve optimal comprehensive care for all people with inherited bleeding disorders.

### Awareness

Raise awareness among people with inherited bleeding disorders, their immediate communities and health care providers.

### Research

Promote and fund research to improve treatment and ultimately to find a cure.

### Education and Support

Provide effective delivery of information and support to patients and their families across Canada in both English and French.

### Safe and Secure Supply

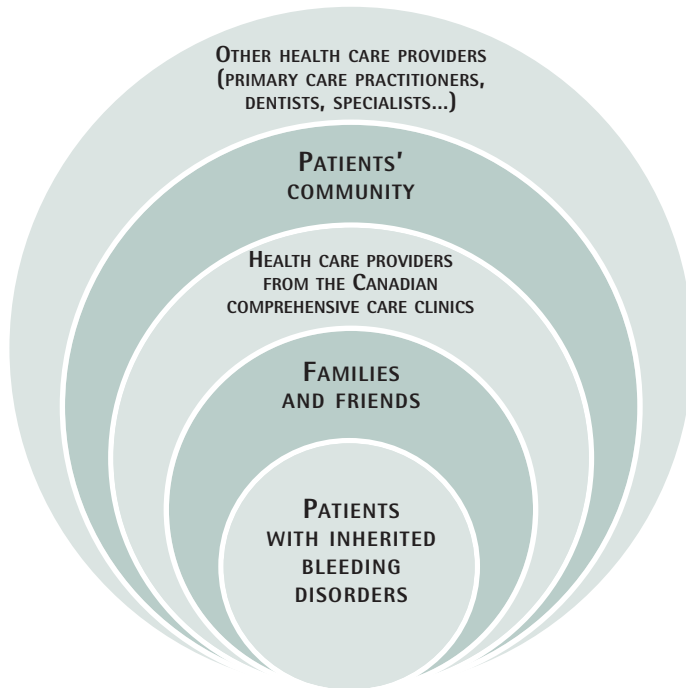
Advocate for access to a secure supply of the safest and most efficacious therapies for treatment of inherited bleeding disorders.



# 2011-2015 Strategic Plan

## Target Populations

The Canadian Hemophilia Society provides information, programs and services to...



## Our Global Responsibility

While the primary mission of the Canadian Hemophilia Society is to work within our own borders on behalf of Canadians, we recognize our responsibility to work with the World Federation of Hemophilia to further its mission of TREATMENT FOR ALL.



## Our Governance Priorities

### A Cohesive Organization

Build a cohesive organization through a combination of strong, effective chapters and better collaboration between chapters and the national organization.

### Increased Membership

Increase membership in both the chapters and the national organization.

### A Culture of Philanthropy

Develop a culture of philanthropy among the expanded membership so as to be able to achieve the mission and goals of the organization.



## Chapter Spotlight

### Manitoba Chapter

The Manitoba Chapter identified the development of its volunteer base as a priority in the chapter's strategic planning process in 2008. The chapter had reduced staff from four positions to one part-time position as a result of the economic situation at that time. If the chapter was to continue to offer services and programming at the level we were used to, it was imperative that it would have to rely on volunteers to do the work.

In 2008, Ashley Tolton became the chair of the newly created Manitoba Volunteer Committee. Finding volunteers to replace committee chairs and project leaders has been problematic in the past. The Volunteer Committee has tackled this problem in two ways: awareness and training. Current volunteers have written job descriptions for their positions. New volunteer recruits know what jobs are available, what the work will be and the time commitment required.

2010 marks the first year that the Manitoba Volunteer Committee has documented all of our volunteers and their hours of work. The results were astounding! The Manitoba Chapter has 12 Board members, 5 committees with 21 members, 31 episodic volunteers, and 9 special project volunteers. Eleven of our volunteers are not Chapter members. Together, this amazing group of dedicated people logged 1,227 working hours. It is the equivalent of having a paid staff, 23 hours a week.

Thank you to all the amazing volunteers, past and present, who have gifted their time and talents to the Manitoba Chapter.



Garage sale's volunteers.

### Hemophilia Saskatchewan

On December 5, 2010, Hemophilia Saskatchewan had its Family Christmas Party at the Radisson Hotel in Saskatoon. It was a fun afternoon with water sliding, gifts for the children, and dinner.

The first two weekends in December, Hemophilia Saskatchewan held The Old Elephant's Christmas fundraiser in conjunction with Brenda Baker, one weekend in Saskatoon and the other in Regina. These were very successful concerts and a wonderful event for all who attended.

### South Western Ontario Region (SWOR)

#### Wreaths, swags and pots fundraiser

We have had another successful year with our Holiday Wreaths fundraiser – response was amazing! This fourth year, our sales surpassed previous years with net profits of

approximately \$1,800. Thank you to the Bow Elves who made it easy for Kathleen Hazelwood, Sam Davis and Terri-Lee Higgins to pull together the orders for pick up on a beautiful but cold winter morning. Thank you to Michelle and John Lepera and Karen and Chuck Catton for coordinating sales in both Windsor and Chatham. You were outstanding. And finally thank you to those who sold, and those who purchased, the wreaths, door swags and holiday pots this past holiday season. We will be doing it again November 2011.



Unloading the truck for wreaths delivery.

#### Winter Celebration 2010

On November 20, the bright sunshine helped ensure that SWOR's Winter Celebration was well attended. The CHS Passport session, *Bon Voyage! Travelling with a Bleeding Disorder* – which was designed to help reduce

the risks related to travelling for individuals and families with an inherited bleeding disorder – was the first activity. Several youths helped with the handouts and the adults shared important hints and tips to help us learn methods of ensuring safer travel. Upon completion and prior to the amazing potluck lunch, families spread out amongst the various activities: cookie decorating, games, scrapbooking, face painting, cookies in a jar and snowman cutout decorating. Too soon it was time to hand out the grab bags and pack up the tables, another year of fun and frolic in the books.

Special thanks to Janice and Bill for their work at the hall, volunteers Supreet, Morgan and Hannah for the gift of their time to keep the activities moving, and to everyone who made the drive to Strathroy for the Winter Celebration.



Wijnker family decorating cookies.

## Central West Ontario Region (CWOR)

### Parents Education Day

The *Parents Education Day* was created to meet the needs of parents who expressed an interest to learn about what it's like for a child growing up with an inherited bleeding disorder.

The parents met at Pillitteri Winery located in the heart of Niagara-on-the-Lake's beautiful wine country. The program consisted of a facilitated discussion with questions designed by Linda Waterhouse, social worker at the Hamilton-Niagara Regional Hemophilia Clinic, and Alex McGillivray, CWOR regional service coordinator, as well as a tour of the winery. Parents had the opportunity to share stories about their children and also ask one of our youth representatives, Nicole Finstad, about her experiences growing up with VWD.

Many thanks are extended to all of the parents who openly shared their stories, and to Nicole for her willingness to share her experiences growing up.



From left to right: Filomena Calabrese, Alfonso Calabrese, Sherry Meszaros, Rachel MacPherson-Meszaros, Marvin Bauman, Leslie Bauman, Lesia Finstad, Caroline Mulder-Sutton, Nicole Finstad, Alan Sutton and Alex McGillivray.

### A trip to Christmas Town

On Sunday November 14, a total of 80 participants in the Central West Region came out to enjoy a fun-filled day at Mountsberg Conservation Area's Christmas Town.

Families experienced a close community feel and took part in the CHS' new *Passport to well-being* module, *Travelling with a Bleeding Disorder*. The presentation was conducted by Kay Decker, hemophilia nurse coordinator, Shannon MacKay, nursing student, Karen Strike, physiotherapist, and Theresa Almonte, hemophilia program secretary.

Kay and the clinic team had the families take part in an interactive quiz based on the module's slide show presentation. The families also had a chance to enjoy a horse-drawn buggy ride, pancake lunch, snowflake craft and song time with Santa.

Thank you to all of the Mountsberg staff for all of your hard work and for making our group feel welcomed. Also, many thanks are extended to the clinic team for taking time out of their weekend to educate and socialize with the families at this great event. Thank you!



All the families enjoying their pancake lunch in Christmas Town.

## Ottawa and Eastern Ontario Region (OEOR)

### Camp Wanakita Registration Party

On November 27, 2010, the Ottawa and Eastern Ontario Region in conjunction with the Children's Hospital of Eastern Ontario held a very successful Camp Wanakita Registration Pizza Party. Eight families attended to share information and fill in registration forms for camp. Diane Bissonnette, our clinic nurse, did a presentation on camp and two of our more experienced campers, Jordon Cabral and Cameron MacNeil, answered questions and did commentary on the virtual tour slide show on Camp Wanakita. The day resulted in three new one-week campers, five two-week campers and three counsellors-in-training signed up to attend camp this August.

### 'Twas the season!

A great time was had by all at the OEOR Holiday Party on December 5, 2010. Children of all ages joined Board members of the OEOR at the Ottawa Police Association to play games, sing carols, do crafts, eat, drink and be merry! This year's party was the best ever as guests were treated to a terrific puppet show by *Kids on the Block*. Also, each family decorated their very own gingerbread house to take home as a special souvenir. There were plenty of laughs and lots of good cheer as we shared the afternoon with several wonderful families in our community. A memorable visit from St. Nick completed the afternoon!



## Nova Scotia Chapter

### Curl for Hemophilia

What an exciting event was held in Nova Scotia! We had record turn outs, wonderful prizes for the teams, and after 3+ hours of curling on the ice, we were able to all settle in for a delicious chili and seafood chowder meal. There was teamwork and cohesiveness among the members. At events like this, it is always nice to sit back and watch the members interact and build stronger relationships. We also combined the Curl for Hemophilia with Volunteer Recognition. We had over 70 volunteer recognition certificates to hand out. Everyone seemed to have had a wonderful day and it ended on a note of appreciation from the NS Chapter – what a fantastic day!



### Nova Scotia Hemophilia Youth Group – Building new leaders everyday

We are thrilled to announce that the Nova Scotia Chapter of the CHS is introducing a youth group for young adults with bleeding disorders! This youth group is aimed at directing these young adults onto a path to

become future volunteers in the Hemophilia Society. As well as having fun, of course! We are so excited to get our youth group up and running. We hope to see a lot of new faces there along with lots of familiar faces! We will always be accepting to everyone in the bleeding disorder community.

## Quebec Chapter (CHSQ)

### Weekend for families living with inhibitors

The weekend for families living with an inhibitor took place last November in Orford. This year, five families were able to meet and share their experiences throughout the weekend. Smiles and praise were on the menu and, right from the first meal, the tables were separated. The children sat together and told the parents... "You have to sit over there!"

On Saturday morning, with the participation of a specialist from a research firm, a workshop was held to evaluate needs. The objective of this session was to learn about the concerns of families living with a child with an inhibitor. This session helped us to better understand their daily realities in order to better meet their needs.

For the very first time, on both mornings, the youngsters had a lesson in self-infusion with their nurse, Claude Meilleur, who took advantage of this opportunity to teach them a bit more about their health condition. It's incredible how much they know!

During the weekend, two

monitors gave the eight youngsters a wonderful time filled with activities specially designed for them. The theme of the weekend was: Super Heroes. Crafts, a movie evening, swimming, creating musical instruments were only a few of the activities organized. On Sunday, before leaving, we got to see a wonderful show and a mural made by the youngsters. What a great gift!

We would like to thank Claude Meilleur, who ensured the safety of the children, and Étienne and Vanessa for having entertained the kids during their stay. And finally, a special thank you to Dr. Georges-Étienne Rivard, who travelled to the Eastern Townships to meet with the families on Friday evening.

We're already looking forward to seeing everyone again next year! ☺

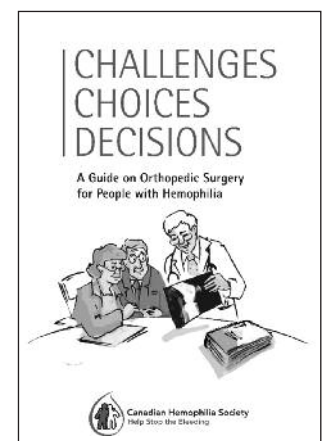


## NEW RESOURCE AVAILABLE

### *Challenges, Choices, Decisions: A Guide on Orthopedic Surgery for People with Hemophilia*

Almost all adults with severe hemophilia in Canada suffer from joint damage in the knees, ankles and/or elbows because they grew up in a time when treatment was less advanced. Chronic joint damage causes pain and limits range of motion. When the pain is severe and interferes with the activities of daily living, orthopedic surgery is an option.

This educational resource, has been developed as a guide to help hemophilia patients, not affected by an inhibitor, and their families understand what is involved in orthopedic surgery. It has been adapted from the original booklet published in 2008 for people with hemophilia and inhibitors. Available only as a pdf on the CHS Web site at [www.hemophilia.ca/en/educational-material](http://www.hemophilia.ca/en/educational-material). - C.C. ☺



## CHS western regional workshop: *Rare Bleeding Disorders Through the Lifespan*

Judy DesBrisay, *British Columbia*

Last November 5 to 7, my sister Sharon and I were among 32 participants at the CHS western regional workshop, *Rare Bleeding Disorders Through the Lifespan*. This event, sponsored by Novo Nordisk, was held at the Delta Airport Hotel, in Vancouver, British Columbia. People with rare bleeding disorders – including rare factor deficiencies (FI, FII, FV, FVII, FX, FXI, FXIII) and platelet function disorders (Glanzmann Thrombasthenia, Bernard-Soulier Syndrome) – gathered from across Manitoba, Saskatchewan, Alberta, and British Columbia. Participants also included some of their partners and the parents of children with rare bleeding disorders. Clare Cecchini, CHS national program coordinator, eight health care providers and a Novo Nordisk representative joined us for the proceedings.

The 2010 workshop gave participants the chance to renew old acquaintances and forge new relationships within the broad CHS community. Personal stories and information were exchanged in a multitude of directions.

On Friday evening, following Clare's welcoming comments, Manitoba's Susan Gray, winner of the introductory "ice breaker," was presented with one of my small paintings. Nora Schwetz, RN, then moderated a lively panel presentation wherein Robert Burfoot-Lobo, John Rogasky, Ryanne Radford and I shared our unique experiences of living with a rare bleeding disorder across our varied life spans.

The 2010 workshop gave participants the chance to renew old acquaintances and forge new relationships within the broad CHS community. Personal stories and information were exchanged in a multitude of directions.

Saturday's busy agenda began with Dr. John Wu's down-to-earth, well-illustrated talk about coagulation and rare bleeding disorders. Dr. Wu was joined by Dr. Shannon Jackson and Dr. Linda Vickars in presentations about best management for bleeds and medical procedures. Following these informative talks we benefited from interactive roundtable discussions with these three

very knowledgeable and approachable experts.

Sandra Squire, physiotherapist, presented us with her wide-ranging perspective and expertise about the benefits of a healthy lifestyle which includes physical activity throughout our lives. Sandra also led us through a stress-relieving and giggle-promoting tai chi session. The

last afternoon session saw Daniel Sirivar, RSW, Nora Schwetz, RN, and Claude Bartholomew, RSW, hosting small group discussions on topics which focused on specific life-stage concerns. Our exchange of ideas continued throughout the delicious dinner we savoured at an adjacent restaurant with a sparkling marina vista.

Following our



From left to right: Judy DesBrisay, Nora Schwetz, RN, John Rogasky, Dr. John Wu, Robert Burfoot-Lobo and Clare Cecchini.



The Factor V Ladies: Sharon and Judy DesBrisay and RYanne Radford

Sunday morning breakfast, Deb Gue, RN, and Nora Schwetz, RN, led us through two highly appreciated interactive sessions with "must know" insight and information for *Travelling with a Bleeding Disorder* and *Navigating the ER*. Dr. Wu and Clare Cecchini then prompted us to **Get Involved** with the Rare Bleeding Disorders Registry and research, and with the CHS at the national or provincial levels. Volunteer opportunities abound and are widely acclaimed by those involved. Clare, whose work is well recognized and appreciated, stands as

proof that the Canadian Hemophilia Society CARES.

CARES is the acronym for the Canadian Hemophilia Society's strategic directions and stands for: Care and Treatment, Awareness, Research, Education and Support, Safe and Effective Therapies.

At midday, reluctant farewells were made. Clare acknowledged the work of the CHS planning committee and expressed our thanks to Novo Nordisk whose representative, Daniel Brinza, joined us at the workshop with much good will, printed resources and T-shirts. Our interactive community continues its dialogue and activities.

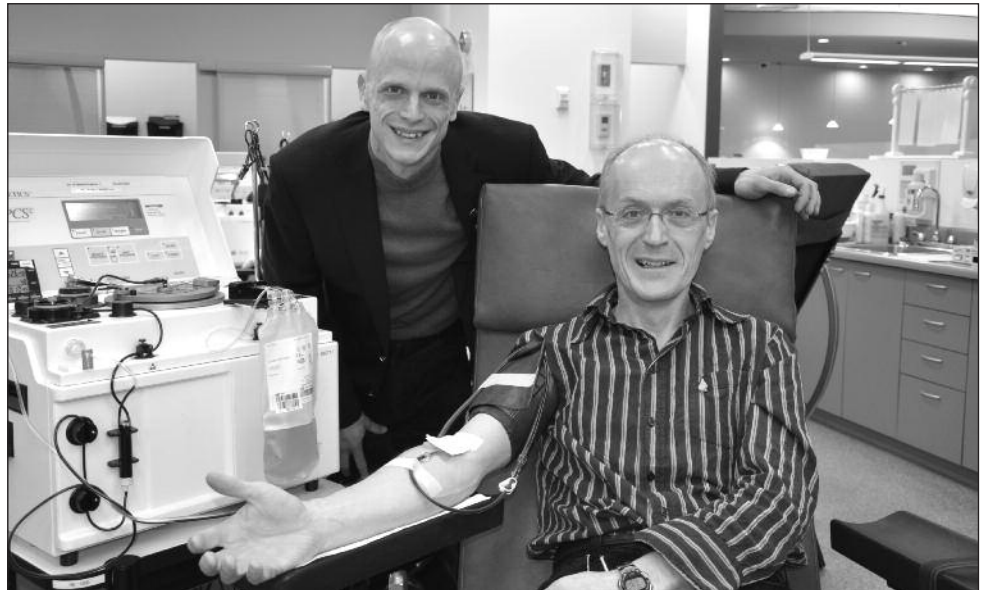
The education and support provided at this workshop were beneficial for my sister and me. We were delighted to share our diverse "mature years" and experiences of factor V deficiency with the ebullient young RYanne Radford, who lives quite differently with her factor V deficiency.

This winter seems warmer when we reflect upon our participation in the western regional workshop on rare bleeding disorders and its outcomes. The Canadian Hemophilia Society deserves a rousing round of applause for their planning and presentation of yet another collaborative and successful venture. ◊

## The gift of life... 1,000 times!

Jacques Paquin is an ordinary man who achieved an extraordinary thing. He gave blood and blood products 1,000 times! Inspired by his nephew, our very own *Hemophilia Today* editor François Laroche, the 55-year-old man started giving blood when he was 18 years old. He has never stopped since then. *"I was what inspired him at first, the triggering factor of this outstanding feat, stated François, but he deserves our full admiration for his availability, his altruism and abnegation. Through his gesture — repeated 1,000 times! — he contributed in helping, and possibly saving the lives of hundreds or perhaps even thousands of people. I am very proud of my uncle."*

About 18 years ago, when plasma donations became possible, he chose this option, allowing him to give this



On February 14, 2011, François Laroche accompanied his uncle, Jacques Paquin, for his 1001<sup>st</sup> gift of life.

amazing gift of life on a weekly basis.

Mr. Paquin is only the second person in Canada to have donated blood 1,000 times. In fact, such dedication is rare worldwide. Jacques Paquin is no ordinary man after all... - C.R. ◊

## 2008-2010 REPORT CARD ON CANADA'S BLOOD SYSTEM

# Blood system very safe but accountability takes giant step backwards

The 2008-2010 report on Canada's blood system, prepared by the Canadian Hemophilia Society (CHS), was released on January 27, 2010. It has found that blood, blood products and their alternatives are very safe and in sufficient supply; however, the system's accountability to recipients has taken a giant step backwards.

According to Canadian Blood Services (CBS) by-laws, and following recommendations of the 1997 Krever Report on Canada's Blood System, two of the 12 CBS Board positions are reserved for persons with "relevant knowledge or experience with organizations representing persons consuming blood and blood products." Over the last decade, almost all of these positions have been held by individuals with very close links to recipient organizations and extensive knowledge of safety and supply issues. However, during the 2009 and 2010 Board renewal process, the Members of CBS, the provincial/territorial Ministers of Health (except Quebec), named both "public directors" with no apparent links to recipient organizations and little knowledge of key issues from a recipient perspective. A number of recipient organizations have denounced the selection process as lacking transparency and resulting in the exclusion of an effective recipient voice at the top level of decision-making at CBS... to no avail. Members of recipient organizations see their exclusion as a clear contravention of CBS' own by-laws, and a giant step backwards in accountability.

Meanwhile, Héma-Québec has maintained Board positions for individuals with a recipient organization perspective.

On a more positive note, the report finds that CBS, Héma-Québec and Health Canada (the regulator of the blood system) have maintained a clear focus on safety. Blood and blood products are safer today than at any time in the past.

The provinces and territories continue to fund the suppliers of blood, blood products and their alternatives in such a way that they can provide life-saving products to Canadians in sufficient supply... with one exception. Solvent-detergent treated plasma (SD-plasma) is still

unavailable, despite licensure by Health Canada in 2006, a lower risk of blood-borne pathogens and adverse reactions compared to fresh frozen plasma, and the fact that SD-plasma is the standard of care in many European countries.

The September 2010 decision by Justice Aitken of the Ontario Superior Court in the case of CBS vs. Freeman was welcomed by recipient organizations. The judgment found that current donor deferral criteria for men who have had sex with men are not discriminatory. As a result, decisions on screening procedures will continue to be made on the basis of the latest science and epidemiology.

The period covered by this report also saw the adoption of legislation in Quebec to provide no-fault compensation in the event that persons are injured following a transfusion or transplant of products distributed by Héma-Québec. Such a measure was the first recommendation of the Krever Commission. The other provinces and territories are relying on CBS' self-insurance scheme to provide compensation in the event of another tainted blood tragedy.

Unfortunately, the last three years have seen little progress in the development of a national Orphan Drug Policy that would facilitate the licensure and availability of therapies for rare diseases. Canada is the only highly developed nation without such a policy.

In addition, the Public Health Agency of Canada has, without notice or explanation, stopped funding the Blood-Borne Pathogen Surveillance Project at the University of Alberta. This bank of blood samples from frequently transfused individuals is critical to effective monitoring of emerging pathogens in the blood supply.

The 2008-2010 Report on Canada's Blood System is the fifth to be released since the reform of the blood system in 1998 following the Krever Commission. In its preparation, the Canadian Hemophilia Society sought input from recipient organizations, Health Canada, manufacturers of fresh blood components, Canadian Blood Services and Héma-Québec. The 2008-2010 report card and the four previous report cards can be found on the CHS Web site at [www.hemophilia.ca/en](http://www.hemophilia.ca/en) in the **Safe, Secure Blood Supply** section. ◊

The 2008-2010 Report on Canada's Blood System is the fifth to be released since the reform of the blood system in 1998 following the Krever Commission.

## 2008-2010 REPORT CARD ON CANADA'S BLOOD SYSTEM

<b>Grades</b>	<b>A</b>	<b>Excellent performance, no criticism</b>
	<b>B</b>	<b>Very good performance, room for improvement</b>
	<b>C</b>	<b>Room for considerable improvement</b>
	<b>D</b>	<b>Not very good performance</b>
	<b>F</b>	<b>Serious problems</b>

		2003-2004	2005-2007	2008-2010
<b>Canadian Blood Services</b>	Safety	A	A	A
	Supply	A	A	A-
	Plasma self-sufficiency	C	C	B
	Project recovery	—	—	A
	Board appointments	—	—	F
	Accountability and transparency	A	A	B
	CBS' blood donors	A	A+	A+
<b>Héma-Québec</b>	Safety	A	A	A
	Supply	A	A	A
	Plasma self-sufficiency	D	C	C
	Project recovery	—	—	A
	Board appointments	—	—	A
	Accountability and transparency	A	A	A
	No-fault compensation	—	—	A
	Héma-Québec's blood donors	A	A+	A+
<b>Federal Government</b>	Commitment to safety	—	—	A
	Approval of biological therapies	C	B	B
	Orphan drug policy	—	D	D
	Standards for blood and blood components	B	B	B
	Surveillance	C	B-	F
<b>Canada's Justice System</b>		—	F	A
<b>Provincial and Territorial Governments</b>	Accountability and transparency	—	—	Quebec: A
				Other provinces and territories: F
	Funding of the blood system	A	Quebec: A Other provinces and territories: B	B
				C
	Comprehensive care for rare disorders	—	D	C
No-fault compensation	—	D	Quebec: A	
			Other provinces and territories: D	
Hemovigilance	Quebec: A	Quebec: A	Quebec: A	
			Other provinces and territories: C	

## NOTICE

### The Annual General Meeting of the Canadian Hemophilia Society will convene as follows:

**Saturday, May 28, 2011**  
**8:30 a.m.**  
**Delta Bow Valley Hotel,**  
**Calgary, Alberta**

- To receive the report of the Nominating Committee.
- To acknowledge the designated directors of each chapter.
- To nominate candidates for the director-at-large positions on the CHS Board for 2011-2012.
- To receive the audited financial statements of the Canadian Hemophilia Society for the year ended December 31, 2010.
- To appoint an auditor for the ensuing year.
- To receive the report of the Hemophilia Research Million Dollar Club.
- To transact such other business as may properly come before this Annual General Meeting of the members of the Canadian Hemophilia Society.

**Aline Landry**, secretary

## Upcoming Events



### CANADIAN HEMOPHILIA SOCIETY

- **April 30, 2011** – Deadline to submit an application for the *CHS James Kreppner Memorial Scholarship and Bursary Program*.
- **May 26–29, 2011** – *Rendez-vous 2011*. Medical and Scientific Symposium, community development workshops, and CHS Annual General Meeting.

### ALBERTA CHAPTER

- **June, 2011** – The Alberta Chapter will host its most popular event: Family Day and the Calgary Zoo. This event includes a BBQ and a chance to get up close and personal with a zoo animal!

### HEMOPHILIA SASKATCHEWAN

- **March 26, 2011** – AGM, Mayfair United Church, Saskatoon.

### MANITOBA CHAPTER

- **April 4, 2011** – Family Camp Registration, 9:15 a.m. until full.
- **April 16, 2011** – Annual General Meeting (details to come).

### HEMOPHILIA ONTARIO

- **April 16, 2011** – Hemophilia Ontario Annual General Meeting.

### SOUTH WESTERN ONTARIO REGION (SWOR)

- **June 10–12, 2011** – *New youth / Family program Prelude to Pinecrest* has been developed to help potential campers and their families learn more about camp by experiencing a day in the life of Pinecrest Camp. Youth aged 4 to 16 not currently participating in camp are invited to attend and participate with their families.
- **July 30, 2011** – *Guinness Book of World Records Ride in SWOR!* Become part of history! SWOR invites you to participate in our attempt to set a Guinness Book of World Record for the

Longest Parade of Motorcycles. Single riders can register for \$35, with a passenger \$45 (register online at [www.ridefortherecord.com](http://www.ridefortherecord.com)). This event is our opportunity to raise awareness of inherited bleeding disorders and much needed funds to achieve our mission.

- **August 24–28, 2011** – **Pinecrest Camp** – The only camp in Ontario specifically designed to meet the special medical needs of children with a bleeding disorder which includes their siblings, offers knowledgeable and specially-trained volunteer staff (medical, co-directors and counsellors) on site 24 hours per day. Watch future newsletters and mailings for details.

### QUEBEC CHAPTER (CHSQ)

- **April 16, 2011** – Bowl-a-thon in Sorel-Tracy.
- **May 1, 2011** – Bowl-a-thon in Montreal.

## World Hemophilia Day EVENTS



### ALBERTA CHAPTER

- **April 17, 2011** – The Alberta Chapter will have a display set up at the Alberta Children's Hospital.

### SOUTH WESTERN ONTARIO REGION (SWOR)

- **April 17, 2011** – *Are you brave enough to take the plunge?* Celebrate World Hemophilia Day with us by jumping in a lake! Again this year, SWOR is recognizing April 17 with a Polar Bear Dip. Your help raises funds to support programs for the more than 300 people living with hemophilia, von Willebrand disease and other bleeding disorders and their families living in South Western Ontario. Pledge Forms are available online at [www.lhsc.on.ca/About\\_Us/Bleeding\\_Disorders/SWOR](http://www.lhsc.on.ca/About_Us/Bleeding_Disorders/SWOR). For more information or directions, contact Terri-Lee at 519-432-2365 or [thiggins@hemophilia.on.ca](mailto:thiggins@hemophilia.on.ca).

### PRINCE EDWARD ISLAND CHAPTER

- Run for It event. Contact your chapter for more information at [cjcraig1@pei.sympatico.ca](mailto:cjcraig1@pei.sympatico.ca).



Canadian Hemophilia Society  
Help Stop the Bleeding

# RENDEZ-VOUS CALGARY 2011

MAY 26-29

## NEW CHALLENGES



The Canadian Hemophilia Society is pleased to invite you to attend *Rendez-vous 2011* which will be held May 26-29, 2011 in Calgary.

This important event will feature the Medical and Scientific Symposium: *New Challenges in the Care of People with Bleeding Disorders*, the CHS Annual General Meeting, informative community development workshops and annual meetings of the four health care professional groups.

*Rendez-vous* is jointly organized by the Canadian Hemophilia Society (CHS) and the members of the Association of Hemophilia Clinic Directors of Canada (AHCDC), the Canadian Association of Nurses in Hemophilia Care (CANHC), the Canadian Physiotherapists in Hemophilia Care (CPHC), and the Canadian Social Workers in Hemophilia Care (CSWHC). *Rendez-vous 2011* is presented by Bayer HealthCare and Pfizer and sponsored by Baxter, CSL Behring, Novo Nordisk, Biogen Idec Hemophilia and Octapharma.

This year the Medical and Scientific Symposium will be presenting sessions on aging with a bleeding disorder, mild hemophilia and rare bleeding disorders. Three community development workshops will be offered: *Drive Your Car/Drive Your Care* youth workshop, *Implementation of the CHS Strategic Plan* workshop and *Aging with a Bleeding Disorder* focus group.

This biennial conference will explore state-of-the-art advances in treatment and research benefiting people with inherited bleeding disorders. Attending this invaluable meeting gives you the rare opportunity, in only one weekend, of gaining new knowledge at the medical and scientific sessions and community development workshops, networking with peers and friends, visiting the pharmaceutical industry exhibits and participating in your organization's Annual General Meeting.

We hope to bring together as many people as possible from the bleeding disorder community. The CHS will be sponsoring twenty participants to attend and chapters are strongly encouraged to sponsor as many members as possible.

For more details, please consult the CHS Web site at [www.hemophilia.ca](http://www.hemophilia.ca) or contact your local chapter. We hope you can join us! - C.R. ◊

## SCHEDULE OF EVENTS

### THURSDAY, MAY 26, 2011

- |              |  |
|--------------|--|
| 9:00 – 17:00 | CANHC annual meeting                                 |
| 9:00 – 17:00 | Canadian Pediatric Thrombosis and Hemostasis Network |

### FRIDAY, MAY 27, 2011

- |               |   |
|---------------|---|
| 9:00 – 17:30  | Medical and Scientific Symposium<br><i>New Challenges in the Care of People with Bleeding Disorders</i> |
| 17:30 – 18:30 | Reception in exhibit area   |
| 18:30 – 22:00 | AHCDC dinner meeting  |

### SATURDAY, MAY 28, 2011

- |               |  |
|---------------|--|
| 8:30 – 9:30   | CHS Annual General Meeting                                   |
| 8:30 – 17:00  | CPHC and CSWHC annual meetings                               |
| 9:00 – 17:00  | Joint CANHC and AHCDC Scientific & Educational Meeting       |
| 9:45 – 12:00  | Workshop: <i>Implementation of the CHS Strategic Plan</i>    |
| 9:45 – 17:00  | Youth Committee event: <i>Drive Your Car/Drive Your Care</i> |
| 13:00 – 17:00 | CHS Board of Directors meeting                               |
| 13:00 – 17:00 | <i>Aging with a Bleeding Disorder</i> focus group            |
| 19:00         | Banquet and CHS Awards                                       |

### SUNDAY, MAY 29, 2011

- |              |                                |
|--------------|--------------------------------|
| 9:00 – 12:00 | CHS Board of Directors meeting |
|--------------|--------------------------------|



## Medical News

# Hepatitis & HIV Press Review

**Michel Long**

*CHS National Program Coordinator*

and **Dr. Elena Vlassikhina**

*Volunteer collaborator*

### ■ **Kidney transplants found safe in HIV patients**

People infected with HIV can safely receive a kidney transplant, researchers reported in the *New England Journal of Medicine*. The finding is good news for people with the virus, who are more prone to kidney disease in part because of the drugs they must take to stay healthy. [www.reuters.com/article/idUSTRE6AH3RQ20101118](http://www.reuters.com/article/idUSTRE6AH3RQ20101118)

### ■ **Advances made in developing hepatitis C vaccine**

Preliminary clinical trials are showing that a so-called therapeutic vaccine can boost the immune response in those infected with the hepatitis C virus (HCV). Still, a viable vaccine is a decade away. [www.montrealgazette.com/health/Advances+made+developing+hepatitis+vaccine/3866477/story.html](http://www.montrealgazette.com/health/Advances+made+developing+hepatitis+vaccine/3866477/story.html)

### ■ **Drinking more coffee linked to improved response to hepatitis C treatment**

Higher coffee consumption was associated with greater likelihood of response to hepatitis C treatment in a HALT-C trial, which looked at prior non-responders with advanced liver disease. People who drank more coffee were more likely to achieve early and sustained virological response to pegylated interferon plus ribavirin. Effects were strongest for consumption of three or more cups of coffee per day.

[www.hivandhepatitis.com/2010\\_conference/aasld/docs/1203\\_2010\\_a.html](http://www.hivandhepatitis.com/2010_conference/aasld/docs/1203_2010_a.html)

### ■ **Pre-treatment with ribavirin improves response to interferon-based therapy for hepatitis C**

Ribavirin "priming" – starting ribavirin monotherapy before adding pegylated interferon – was associated with a small but significant improvement in sustained virological response in patients with chronic hepatitis C

virus infection, according to a German study.

[www.hivandhepatitis.com/2010\\_conference/aasld/docs/1214\\_2010\\_a.html](http://www.hivandhepatitis.com/2010_conference/aasld/docs/1214_2010_a.html)

### ■ **Artificial liver device improves survival for hepatitis B and C patients with decompensated disease**

An artificial liver device known as ELAD – which runs a patient's blood through cartridges containing human liver cells – conferred a significant survival advantage for people with acute decompensated liver disease related to chronic hepatitis B or C, according to a Chinese study. After three years, 44 per cent of ELAD users were still alive without liver transplants, compared with 18 per cent in the standard therapy group.

[www.hivandhepatitis.com/2010\\_conference/aasld/docs/1214\\_2010\\_c.html](http://www.hivandhepatitis.com/2010_conference/aasld/docs/1214_2010_c.html)

### ■ **HIV-positive people may need triple dose of hepatitis A vaccine**

People with HIV require three doses of hepatitis A virus (HAV) vaccine to achieve the same level of antibody protection that HIV-negative people can get with two doses, according to a study presented at the 50th ICAAC conference in Boston. HAV antibody response was particularly weak among HIV-positive men with a CD4 count below 200, all of whom needed the third vaccine booster dose.

[www.hivandhepatitis.com/2010\\_conference/icaac/docs/1026\\_a.html](http://www.hivandhepatitis.com/2010_conference/icaac/docs/1026_a.html)

### ■ **HIV co-infection does not worsen liver transplant outcomes in people with hepatitis B or C**

HIV-positive liver transplant recipients with HBV or HCV co-infection did not fare worse overall than HIV-negative transplant recipients, according to a Spanish study. Co-infected patients were less likely to experience organ rejection, but HCV recurrence was a leading cause of adverse outcomes.

[www.hivandhepatitis.com/2010\\_conference/icaac/docs/1008\\_b.html](http://www.hivandhepatitis.com/2010_conference/icaac/docs/1008_b.html)

### ■ **Hepatitis C breakthrough could lead to cure**

University of Alberta researchers, led by neurologist Dr. Chris Power, discovered how the hepatitis C virus damages brain cells. Their discovery opens the door for developing better treatments, possibly even a cure. Power said it could even open the door to a hepatitis C vaccine. It's long been known that some hepatitis C sufferers have memory loss and poor concentration. The researchers discovered why: the virus attacks the brain cells responsible for motor functions, memory and concentration. It also causes inflammation, which

damages more brain cells, or neurons. "Now we have some understanding about the cause of these neurological symptoms, which can lead to the development of future treatments," Power says.

[www.edmontonsun.com/news/columnists/andrew\\_hanon/2010/10/05/15594016.html](http://www.edmontonsun.com/news/columnists/andrew_hanon/2010/10/05/15594016.html)

#### ■ New drugs carry hope for hepatitis C cure

Today's two-drug treatment for HCV cures only about 40 per cent of people with the most common variety of the virus, and causes some grueling side effects. Now major studies show adding a new drug – either Vertex Pharmaceuticals' telaprevir or Merck's boceprevir – can boost those cure rates as high as 75 per cent. And they allow some people to cut treatment time in half, to six months, thus lessening how long they must deal with the

side effects. If the U.S. Food and Drug Administration approves the drugs – a decision widely expected this summer – they would be the first that work by directly targeting the hepatitis C virus. "The future looks very bright beyond telaprevir and boceprevir," notes Dr. Fred Poordad, pointing to additional drugs in earlier-stage testing that promise to target more types of hepatitis C and perhaps eventually allow for pill-only, interferon-free treatment. Given that two-thirds of hepatitis C sufferers are thought to be baby boomers, what could be a treatment revolution is spurring the U.S. government to consider if it's time to start screening aging baby boomers for hepatitis C, just like various cancer checks.

[www.floridatoday.com/article/20110118/LIFE01/101180306/1086/New+drugs+carry+hope+for+hepatitis+C+cure](http://www.floridatoday.com/article/20110118/LIFE01/101180306/1086/New+drugs+carry+hope+for+hepatitis+C+cure) ◊



Canadian Association of  
Nurses in Hemophilia Care

## The Nurses' Station

**Sue Ann Hawes, RN, BN**

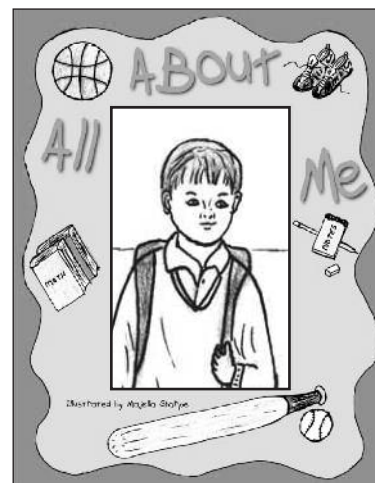
*Pediatric Bleeding Disorder Nurse Coordinator  
IWK Health Centre, Halifax, Nova Scotia*

*Submitted on behalf of the Atlantic Region, Canadian  
Association of Nurses in Hemophilia Care (CANHC)*

## All About Me – A storybook for children with bleeding disorders

Using a collaborative approach, the Atlantic Hemophilia Nurses group, a family and a very talented artist created a storybook for children with bleeding disorders. The idea for this book stems from an individual family's experience with hemophilia and acknowledgment goes to this family – Suzanne, Jacob and Austin Shaw. Suzanne, a school teacher and busy mom of two boys with hemophilia, put together some information to help her sons share their bleeding disorder experiences with their classmates. This idea was catchy and as a result the Hemophilia Nurses of Atlantic Canada, with Suzanne's permission, took on a regional project and developed a children's storybook.

The storybook is designed to provide young school-age children with bleeding disorders the opportunity to share information about his or her medical condition with his/her classmates. The title of the book, *All About Me*,



highlights the theme that a child can tell his or her own bleeding disorder story to his/her classmates. The book can be personalized as the cover has an opening for the child's picture and, on the front page, a spot to write the child's name and type of bleeding disorder. The theme throughout the book "Please don't worry" is

designed to help alleviate fears that classmates may have towards the child's bleeding disorder. The book describes scenarios of bleeding episodes from a child's perspective and is accompanied by illustrations to provide visualization. *All About Me* is written in children's language to ensure that a child with a bleeding disorder feels comfortable sharing information with classmates in an interactive way.

The majority of this project was done through WebEx, a very useful tool enabling nurses from different provinces the ability to work together. The illustrations for this book were designed by Majella Sharpe, an artist in Newfoundland. She was wonderful to work with and had great ideas for the book. Thank you to Bayer HealthCare for funding this project.

If you would like a copy of the storybook *All About Me*, please contact your local hemophilia clinic nurse or the CHS national office. ◊



Canadian Social Workers in  
Hemophilia Care

## Social Workers Face-to-Face

**Hulda Niv, MSW, RSW, Southern Alberta Pediatric  
Oncology and Bleeding Disorder Program  
Alberta Children's Hospital**

## Parents Empowering Parents Program



**D**uring the May 2008 annual meeting of the Canadian Social Workers in Hemophilia Care (CSWHC) that took place in Saskatoon, the social work group was introduced to the *Parents Empowering Parents* (PEP) program. The PEP Program was developed in 1996 and is designed specifically for parents of children with bleeding disorders. It is sponsored by Bayer and facilitated by a group of health care providers in the United States. The PEP model allows parents of children with bleeding disorders to share their expertise, promote the concept of self-empowerment, and provide support to meet the psychosocial needs of other parents. With trained parents and HTC social workers and nurses as integral members, the PEP training team models the collaboration between parents and professionals in the comprehensive care setting.

Knowing that the PEP program has been implemented in several countries around the world, the Canadian Social Workers in Hemophilia Care team invited facilitators from

the U.S. to introduce the program to our members with the goal of determining if it would meet the needs of the Canadian bleeding disorders community. As the day went by, the social workers were extremely impressed as it appeared that the PEP Program could be a valuable tool for empowering parents of children with bleeding disorders.



Parents recommended that the PEP program be continued in Canada to open this learning opportunity to all parents of children with bleeding disorders.

The PEP Train-the-Trainer workshop, held in Montreal in October 2009, included parents from across Canada who volunteered to take part in this exciting process. The first PEP workshop was launched in Alberta in March 2010 and was very well received by the parent participants. To date, feedback from participants from Manitoba, Ontario and the Maritimes describe the PEP activities as very successful.

Overall, although most parents were already well educated about bleeding disorders, they expanded their knowledge and benefited from the interactions, learning

and bonding with other parents who have similar experiences. Parents expressed gratitude to be part of this valuable program and encouraged other parents to attend a PEP workshop. "I believe in this program, and feel that there are so many more families out there that could benefit from it. I have over the last year spent many weeks reaching out to find people that are going through the same thing as us. I have made so many close friends and connections and this was probably the most effective," said Jennifer, on March 31, 2010.

Parents recommended that the PEP program be continued in Canada to open this learning opportunity to all parents of children with bleeding disorders.

Plans are underway to host PEP workshops in 2011. Parents who are interested in learning about the program and interested in attending the workshops should contact their HTC social worker, or the CHS national program coordinator, Clare Cecchini, at 1-800-668-2686. ◊

# The Blood Factor



**David Page**

*CHS National Executive Director*



## ▪ Use of tranexamic acid could save 70,000 lives a year

London – January 19, 2011 – A review of research by the Cochrane Collaboration has found that 70,000 lives could be saved annually if tranexamic acid were used around the world to treat injured patients with severe bleeding.

"Tranexamic acid reduces the risk of a patient bleeding to death following an injury and appears to have few side effects," said lead researcher Ian Roberts, of the London School of Hygiene and Tropical Medicine. "It could save lives in both civilian and military settings."

Injuries are a major cause of death around the world. Every year, more than a million people die from road injuries, making traffic accidents the ninth leading cause of death worldwide.

Hemorrhage is responsible for about a third of trauma deaths in hospitals. Experts estimate that about 600,000 injured patients bleed to death worldwide every year. Over 10 percent of these could be saved by the universal use of tranexamic acid.

Tranexamic acid is an off-patent generic medicine made by several companies and is relatively inexpensive. The Cochrane Collaboration concluded that it should be listed as an "essential medicine" by the World Health Organization (WHO).

Tranexamic acid is frequently prescribed to people with bleeding disorders to reduce mucosal bleeding, including nose bleeds and after dental work, and to reduce bleeding in menorrhagia.

## ▪ First patient dosed in phase 2/3 trial of long-lasting recombinant factor VIII

Weston, Massachusetts & Stockholm – December 6, 2010 – Biogen Idec and Swedish Orphan Biovitrum have announced that the first patient has been dosed with the companies' long-lasting recombinant factor VIII Fc fusion protein (rFVIII-Fc). The study, called A-LONG, is an open-label, multicentre, Phase 2/3 study designed to evaluate the safety, pharmacokinetics and efficacy of rFVIII-Fc in previously treated hemophilia A patients.

"There is a significant unmet need for a factor VIII product, like rFVIII-Fc, with the potential to prolong protection from bleeding and yet reduce the frequency of

infusions and improve quality of life," said John Pasi, M.D., co-principal investigator of the A-LONG trial and professor of Haemostasis and Thrombosis at the London School of Medicine and Dentistry.

rFVIII-Fc is a fully-recombinant clotting factor developed using Biogen Idec's proprietary monomeric Fc fusion technology. The A-LONG trial is designed to evaluate different prophylaxis dosing regimens of rFVIII-Fc. The study will also evaluate the efficacy of rFVIII-Fc in on-demand and surgical settings, and compare the pharmacokinetics of a single dose of rFVIII-Fc with a single dose of a commercially available recombinant factor VIII product (Advate®).

In September, the European Commission granted orphan drug designation to rFVIII-Fc. Such designation allows European Medicine Agency to reduce the licensing fee, provide protocol scientific advice, and give market exclusivity once the product is approved. Canada is the only highly developed country in the world without orphan drug legislation.

"Dosing the first patient in the A-LONG study is an important milestone," said Glenn Pierce, M.D., Ph.D., vice president and chief medical officer of Biogen Idec's hemophilia therapeutic area. "This trial, along with the ongoing Phase 2/3 study of our fully-recombinant, long-lasting Factor IX Fc fusion protein for the treatment of hemophilia B, further demonstrates our strong commitment to developing better treatments for the worldwide hemophilia community."

For more information on the trial, see

**[www.clinicaltrials.gov/ct2/show/NCT01181128?term=factor+VIII+fusion&rank=2](http://www.clinicaltrials.gov/ct2/show/NCT01181128?term=factor+VIII+fusion&rank=2)**

## ▪ Room-temperature NiaStase® now available

Ottawa and Montreal – October 2010 – Canadian Blood Services and Héma-Québec have begun distribution of a room-temperature formulation of NiaStase®. NiaStase RT®, manufactured by Novo Nordisk, can be stored between 2 and 30 degrees Celsius until product expiry. It is prescribed for the treatment of hemophilia and rare factor deficiencies in the presence of inhibitors.

The new formulation is accompanied by a number of enhancements:

- round-number vial sizes (1 mg, 2 mg and 5 mg) to simplify dosage calculations;
- 40% less infusion volume;
- solvent included in each package of NiaStase RT.

Novo Nordisk has also announced it will make available travel cases for easier home storage and travel. These are available through hemophilia clinics. ◊

## Volunteer File

"Volunteers do not necessarily have the time; they just have the heart."

-Elizabeth Andrew



**Marion A. Stolte**  
Chair, National Chapter Relations Committee

### National Chapter Relations Committee

**W**ho is a volunteer? It is someone who gives of their time and energy for a cause they believe is worthwhile – they care to see its mission and the people it serves advanced. For the Canadian Hemophilia Society and all its chapters, **volunteers are the lifblood of our organization.** Volunteers care deeply about seeing the care and quality of life improved for all with inherited bleeding disorders and volunteers care deeply about seeing a cure for these disorders.

The National Volunteer Development Committee has accomplished many things over the past few years – providing resources and giving strength to the various chapters across the country. Realizing that our focus is, indeed, our chapters' success at the grassroots, we've changed our name to **National Chapter Relations Committee (NCRC)**. We believe that this new name change will also better reflect the new directions of the

organization which were approved by CHS Board of Directors last November.

There are a number of initiatives in the works in order to provide further assistance to chapters. One is the revision of the Chapter Reference Manual which we are working at revising to ensure it is current and relevant for 2011 and beyond. As well, the intranet site is up and running for chapters to be able to access templates. (This is where the Chapter Reference Manual will be housed as well.)

One of our desires is to see a greater linkage of communication among chapters; as well, our NCRC members are taking back information to their respective chapters and seeking to serve well locally. For example, committee member Ashley Tolton presented the Intranet site to the Manitoba board so they would have an understanding of what is available. The "webinar" (web seminar) that was hosted on January 17, 2011, for chapter volunteers and staff is one of the ways that the NCRC is seeking to support chapters. Initiatives such as these will continue to be offered as they are elements that will contribute to the overall development of volunteers and greater service in the bleeding disorders community.

It is a pleasure to serve with the excellent volunteers who are on this committee. Thank you to each of you and thank you to each of you in our larger hemophilia community who give of your time and energy – together, we are the lifblood of *our* bleeding disorder community. ◊

## Youth File



**Rynne Radford**  
Co-chair  
National Youth Committee

**2011** promises to be a great year for the National Youth Committee of the Canadian Hemophilia Society!

A new project we are taking on this year is blogging! Our blog spot will be called *Generation Clot* and will focus on issues that are affecting youth with bleeding disorders. Some of the topics we will be touching on are: careers, travels, relationships, sexuality, etc. The blog will be launched very soon so check out the youth section of CHS Web site to learn more about it and see how you can become a contributor!

Our next exciting event will take place during *Rendez-vous 2011* in Calgary next May. We will focus on one of our newest programs, called *Drive Your Car/Drive Your Care*. This program provides young people with

opportunities to increase their knowledge about bleeding disorders, take greater control of their own care, and learn to drive more safely. The CHS and its chapters will be funding 20 youths from across the country to participate at this event. This is a great opportunity for all young people with bleeding disorders to hear from the experts at the medical symposium and learn all about the latest developments regarding bleeding disorders. For more information and to download an application form, please go to the CHS Web site.

Each member of the youth committee will also organize a youth event in their area such as a movie night, bowling, coffee dates or swimming. If you are interested in participating or organizing a youth activity, contact your local youth member. You can find the contact information on the youth section of the CHS Web site at [www.hemophilia.ca/en/youth-web](http://www.hemophilia.ca/en/youth-web).

The committee is for youth, but also for parents. We are currently working on a presentation for parents of "almost youths" which will be presented at local AGMs or during family weekend. Stay tuned for more information. ◊



## A Global Perspective

### Storm warning: High winds, poor visibility

**Pamela Wilton, RN, chair, CHS International Development Committee**

The night before my flight, I rechecked the weather forecast for Cairo and then dumped the contents of my suitcase onto the bed. Folding warmer clothing, I heard the familiar sound of our snow blower fire up again, as my husband began yet another circuit of our driveway. With more than 100 centimetres of snow on the city already and more falling, I knew I would get out of my driveway, but I was doubtful that I would get out of London, Ont.

I was bound for Egypt where I would meet up with Kathy Mulder, PT, and Michel Long to complete our "assessment visit" with the members of the Egyptian Hemophilia Society (EHS).

The three of us had been working hard for several weeks to increase our knowledge and to prepare ourselves in order to make the best use of our short time together with the key Egyptians. None of us is new to twinning, therefore, we were able to draw on our past experiences to guide us in setting goals, avoiding common mistakes and overcoming potential barriers to success. Fortunately, we had arranged the visit to take advantage of the fact that Assad Haffar, regional program director for the Middle East & Africa at the World Federation of Hemophilia (WFH), would be "in the neighbourhood" and he provided invaluable expertise.

Egypt is one of the oldest civilizations in the world. It is located in northeast Africa, bordering on the Mediterranean Sea. It covers one million square kilometres, with the majority of 80 million people living along the Nile valley. Life expectancy is 72 years. Arabic is the official language, but French and English are widely

understood. The literacy rate is about 83 per cent for men and 59 per cent for women. Egypt is subject to droughts, frequent earthquakes, flash floods, landslides and driving windstorms. The government continues to struggle to overcome economic problems. They have made huge investments in communications and physical

infrastructure.

Unfortunately, these efforts have failed to increase the standard of living of most Egyptians. Limited arable land and dependence on the Nile River continue to stress society and perpetuate high unemployment.

There are ten hemophilia treatment centres in Egypt. Approximately 5,000 people have been identified to have hemophilia and there

are about 1,500 additional known cases of other bleeding disorders, including VWD (according to WFH estimates in 2008). The EHS is currently led by a handful of extremely dedicated physicians who are supported by even fewer volunteers who have bleeding disorders. They have no staff, although the physicians' secretaries sometimes lend a hand with communications. They have an office, located right in the heart of Cairo, which they share with a branch >>

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Dr. Magdy El Ekiaby, EHS general secretary, explains his novel solvent-detergent process for the preparation of virally inactivated blood plasma.



Dr. Nadia Moharram, head of the Egyptian Hemophilia Society (EHS).

of the blood bank.

Part of the purpose of an "assessment visit" is to learn about the realities of the "emerging" twin. It is essential to understand their issues, their capacity for change and the level of commitment

required by each of the key leaders and from both countries who will take the plan, and make it successful. We used a SWOT (strength, weaknesses, opportunities and threats) analysis to help us work through what we needed to do. After two long days of meetings and hard work we had a draft action plan. The plan includes: clear goals and objectives, roles and responsibilities, a budget, expected outcomes, and ways to monitor and evaluate our progress.

The EHS participated in a successful WFH GAP (Global Alliance for Progress) program in 2002, so our focus will remain on further development of the EHS. The CHS will work with the EHS to develop a strategic plan and to put in place the policies, procedures and people to move it forward. This will not be easy, as although the physicians are extremely devoted, they are very busy. Volunteers are extremely limited and face many of the same issues that volunteers in most WFH national member organizations (NMOs) face. But it can be done and the CHS will draw on our own volunteers, staff and experience to see it through. We committed to this through our own strategic plan.

Yes, I made it out of my driveway, out of London, out of Toronto (this is where my suitcase and I parted), and even out of blizzard-blown Frankfurt to Cairo. I left behind one storm and flew directly into another that was oddly familiar (high winds and poor visibility) and yet excitingly different. Sand! Same problems. Different causes. New experiences. ◊

## ATH - CHSQ twinning December 2010 visit to Tunisia

**François Laroche, CHSQ President**

From December 10 to 15, 2010, three delegates from the Canadian Hemophilia Society - Quebec Chapter (CHSQ) travelled to Tunisia as part of a twinning program with the Association tunisienne des hémophiles (ATH). During this visit, the accent was on the structure and long term operation of the ATH.

Saturday was dedicated to a strategic planning exercise, led by David Page, during which the ATH revised its vision, its mission and its sphere of activity. The objective of this exercise is for the ATH to be more efficient in its initiatives at all levels: for its members, for the general public, for medical, paramedical and government personnel, etc. The ATH also identified a number of important problems that, once solved, would allow them to create a solid basis for the organization while assuring its continuity.

At the end of the day, a draft of the organizational structure was proposed, allowing more participation for hemophiliacs and their parents at the heart of the organization, especially on the Board of Directors and on committees.

The ATH Annual General Meeting was held on Sunday

The new members (...) must now be motivated to become involved, take on the role previously held by the health care professionals, and ensure this transition runs smoothly.

morning with almost 100 people in attendance. The ATH highlighted the official closure of our twinning project, or at least the financial support offered by the World Federation of Hemophilia (WFH), by presenting me with a symbolic plaque as the best twinning for the 2006 to 2010 period.

Sunday afternoon was reserved for a parents' workshop.

Facilitated by Mylene D'Fana, this workshop was attended by 17 parents who actively participated in discussions, without the presence of medical personnel. This gave them the freedom to openly discuss their problems, their experiences and their accomplishments. A number of possible solutions and suggestions were proposed and a few new members were identified to eventually join the ranks of the ATH.

Monday afternoon was devoted to an interactive

presentation on governance that I had the pleasure to lead. During this exercise, the accent was on organizational structure. We discussed the composition of various committees, making the distinction between Board committees, which have the power of recommendation, and working committees, who execute the work. We also dealt with the importance of developing a preliminary budget and periodically presenting the members of the board with up-to-date financial statements.

I ended the presentation by proposing an organizational chart that took into consideration suggestions that arose during the strategic planning exercise. Within this chart, a medical and scientific advisory committee would be created, composed of health care professionals working at the hemophilia treatment centres in Tunisia - five of whom presently sit on the Board of Directors - and a member from outside the medical profession. This committee would have the power of making recommendations to the ATH Board of Directors, while one of its members would be designated to sit on the Board of Directors. Furthermore, a certain number of other committees would be struck (programs, fundraising, advocacy, governance), as well as working committees (communications/information, social activities, parents, youth, etc.), and finally, task forces for each of the fundraising activities organized by the association.

The dominant impression, following our visit, was that the ATH is at a turning point in its existence. In order to

become a strong organization, in tune with its members, it needs to allow hemophiliacs and their parents a greater participation on the Board of Directors and working committees, to clarify the roles and responsibilities of each member and truly become a patient organization (along with their families). The consequence of this statement would mean that the members of the medical profession who are presently on the Board of Directors would progressively concede their positions in order to be involved on the Medical and Scientific Advisory Committee (MSAC), without this being seen as a step backward. On the contrary, these health care professionals as part of MSAC will still be present and ready to help move the organization forward.

The new members, already identified during the general meeting and the parents' workshop, must now be motivated to become involved, take on the role previously held by the health care professionals, and ensure this transition runs smoothly.

And finally, I'd like to thank all our Tunisian friends for their incredible welcome, once again, throughout our stay. Thank you for your generosity, your hospitality, your involvement in this twinning program and your dedication to all hemophiliacs. May this partnership be only a pale reflection of the great accomplishments to come for the Association tunisienne des hémophiles.

Inch Allah... ◊



Facilitated by Mylene D'Fana, a workshop brought together 17 parents who took an active part in discussions.

## Update on the TCOR - Jordan Hemophilia and Thalassemia Society (JHTS) twinning

Michel Long and Candace Terpstra

Even though the WFH twinning partnership between the Toronto and Central Ontario Region (TCOR) and Jordan Hemophilia and Thalassemia Society (JHTS) officially ended in December 2009, the relationship is still alive and strong.

At the World Federation of Hemophilia (WFH) Congress in July 2010, TCOR representatives Candace Terpstra and Mike Beck met with Jordanian partner Arafat Awajan to discuss how to sustain the twinning accomplishments. They agreed that an additional visit would be useful to advance the action plan.

In December 2010, with funding from the CHS International Fund, which is available for the very purpose of ensuring that our twinning efforts and successes are sustained, Candace Terpstra flew to Jordan to meet with JHTS Board members, volunteers and youths. The focus was on strengthening the Society in the areas of program planning, fundraising, and restructuring to include a number of working committees.

Three planning workshops were held with volunteers, young people and Board members.

**Program Planning:** The Mothers' Group established a preliminary action plan with their objectives and program outline for meetings this year, one of which will address use of the emergency room services. Members of the group meet with families "as needed" to address specific issues such as accepting the diagnosis, the need for prompt treatment, and other psychosocial and health-related issues. Family activities are held with extended family members to foster support. Two young people contributed to the process.

**Fundraising:** The Board developed a preliminary fundraising plan based on using existing sources and expanding to include special events – in this case a musical event. A Fundraising Committee will be established at the next Board meeting and tasked with advancing the plan. The Jordanian Society has increased its fundraising goal to 25,000JD per year.

**Organizational Structure:** The Board, volunteers and youth participants reviewed the current structure with a view to expanding it to include five committees (Fundraising, Volunteer Recruitment, Medical Care, Programs, Administration/Finance). This broader framework will involve more members in the organization's work, develop and enhance leadership, and

support the expansion of the Society's work to address the needs of Jordan's bleeding disorders population.

Volunteers were actively involved in the planning process and some will take on leadership roles. This bodes well for the future strength of the organization. Youth will require support to plan their future activities and this topic should be addressed at the next regional youth camp and a newly formed Program Committee. ◊

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## News update from South Africa

Michel Long, CHS national program coordinator

The formal twinning partnership between the Canadian Hemophilia Society (CHS) and the South African Hemophilia Foundation (SAHF) came officially to an end in December 2009 after four years of collaboration. The solid friendships and good communications that resulted from our collaboration in the World Federation of Hemophilia (WFH) Twinning Program continue to thrive between volunteers and staff of both organizations.

We are happy to inform our readers that the SAHF has been accepted into the WFH Global Alliance for Progress (GAP) program. Preparation will commence in 2011 and partnership with government is an integral part of the plan. It is hoped to improve hemophilia care for all and to identify 200 new patients.

During the 2010 WFH World Congress in Buenos Aires, South African delegates briefed WFH on the recent developments in the South Africa hemophilia care strategy. Due to the current economic crisis, some provinces, particularly Gauteng, started to reduce factor for home therapy with the result that persons with hemophilia must now go to the HTC's in order to get treated. They are then each allocated sufficient factor for two bleeds but there are occasional shortages. Participants felt that it is the right time for establishing a GAP program in South Africa as this could help in repairing the current situation and stimulate South Africa's Department of Health to invest more in hemophilia care at provincial and national levels.

The CHS wishes them good luck with their GAP program and has offered to help in any way it can. We hope the home therapy program can be restored in the near future. This goes to show that we must never take for granted progress we have made, and always remain vigilant to protect and build upon our successes no matter in what part of the world we may be. ◊



## Our Stories

# The story of "J"

This is a story I dedicate to my son Jason Leigh Stewart ("J"), who cannot write it himself – so who better than his mom!

**Corinda Smallman-Gallant**  
*Prince Edward Island*

July 7, 1981, was one of the most exciting days in my life – I gave birth to a healthy baby boy and handsome to boot, I thought. My son, Jason Leigh Stewart.

In the first year and a half, Jason suffered some febrile convulsions, throat, ear and other childhood infections but otherwise appeared healthy and active. But one day his dad and I brought him to Chaleur Regional Hospital, only to be wrongly accused of child abuse. Of course, we denied that. Then, a new word entered our vocabulary: *hemophilia*. We had never heard this word and were afraid knowing nothing about the disease.

The doctor explained the inheritance of hemophilia. You see, I was adopted and no mention or memory of hemophilia ever came up in my family. We were whisked off to Dalhousie University Medical Centre and also Moncton City Hospital for tests. The response: "Jason is a moderately mild hemophiliac." Our hearts sank but we set about to learn, comfort and go on with life.

All seemed to go well or at least not too bad until 1983, when within five months, Jason had an upper lip laceration, swelling in both knees and pain in his right leg. By this time, we had started regular visits to Dr. Sheldon Rubin (one of the greatest doctors in our lives). He didn't seem overly concerned at this time – just explained that these were common types of bleeds with hemophilia.

Then it all changed in May 1984. J was hospitalized at Chaleur Regional Hospital when he had to be transferred to Moncton City Hospital with a possible subdural hematoma (bleed in the brain). He had emergency surgery and remained in critical condition (comatose and on ventilator) for almost a week; then he opened his eyes and began to respond to verbal stimuli. It was unclear whether he would suffer brain damage at this point.

Dr. Rubin recommended that J start factor VIII



replacement therapy to secure hemostasis. The New Brunswick Extra Mural Nursing Staff of the Chaleur Region were so helpful, making home visits to give him factor injections directly into his veins.

We brought our boy home towards the end of June. J seemed on the road to recovery but he had to learn to walk, talk and potty train again.

July 12, 1984, his dad and I were at work, we received a call from his caregiver saying J did not seem well and was very drowsy and unresponsive. Off we went to the hospital only to be transferred to Moncton City Hospital; once again, he had an intracranial hemorrhage. Another operation... more blood transfusions, more factor treatment and a higher risk of brain damage. Jason made it through this surgery but with consequences.

And so began a new stage in our journey with our son... now re-diagnosed as having severe hemophilia, with mental delays placing him at various age levels on his psychological assessment and noticeably so in physical day-to-day activities. Our hearts were broken and we were scared! J once again began a regime of infusions every other day with the help of the great Extra Mural staff.

At one point, Jason had a plastic plate placed in his head where the skull did not fuse together properly. His body rejected it as foreign and yet another surgery was necessary. For a few years following, his dad and I were asked if we would like to have another plate placed but something told us not to; thus Jason has a soft spot in his skull like that of a newborn baby. When he goes to his favorite spot "Camp Gencheff" and plays with the other challenged individuals there, he wears a helmet for protection.

In 1986, J had his first port-a-cath inserted. His dad and I were trained to give infusions. At first I felt so bad, like I was hurting my son, but I just kept in mind that I was actually keeping him healthy and that the convenience was very helpful in planning our daily lives. Since then, >>

Jason has had three more – most recently in 1999. Unfortunately infections and other complications set in with others.

At one point, we received a letter stating some factor VIII product during the time J received therapy had been infected with Creutzfeld-Jacob disease. We thought, what more could happen, but luckily he wasn't affected. Thank God for another miracle!

We weren't so lucky with the hepatitis C virus – which my poor little angel now has. I often think what more does this wonderful, genuine, loving and caring little guy have to go through. Yes, the first few years of Jason's life were frantic – in and out of the hospital more than we liked and complications that changed all our lives forever. His dad and I ended our marriage; Jason and I moved back to P.E.I. in 1996 and now live in O'Leary. He has had some knee bleeds but otherwise the "Dude" as I call him is doing quite well. Just before he graduated from Three Oaks Senior

High School, Summerside, P.E.I., in 2000, J and his hero "Gampie Foster" were out golfing (a sport I might say J excels in) when a bleed started in one of his knees thus putting him in a wheelchair for his graduation. But he was still happy – nothing much bothers my Dude. After graduating, he was enrolled for a while in a day program on a part-time basis with the Community Inclusions program in our area. He enjoys his days listening to music, watching game shows (*Deal or No Deal* and *Wheel of Fortune* being two of his faves), playing video games, and visiting his Nana Orell. J also attends Camp Gencheff one weekend a month from October to May and then five days in the summer. Obtaining the services of medical staff to infuse him during the summer camp has proven tough and up 'til last year, I had to be available to do the



Nana Orell, "J" and Corinda.

infusions. With the cooperation of hemophilia nurse Dorine Belliveau, Queen Elizabeth Hospital and Nana Orell, we were able to have him infused at the hospital and I am able to take some much needed time.

As if it's not enough that J has severe hemophilia, hepatitis C and is mentally challenged – he is also epileptic. Some of the drugs he must take to prevent seizures do further damage to his liver. It seems like a "no win" situation, doesn't it?!

J's challenges make it quite difficult to obtain respite services, but the main reason people hesitate is because of the hepatitis and hemophilia and their lack of

knowledge. I can give all the information I can possibly provide but still hesitation prevails. Jason also experiences many spells of vomiting and fatigue, which in itself seem to scare away prospective caregivers.

In 2009, I made a "bucket list" for myself. One of the things on my bucket list was to take my son to Disney World in Orlando, Florida.

With much preparation – the packaging of his treatments to get through Customs, letters from physicians and Dorine Belliveau – and the blessings of Dr. Sheldon Rubin, Dr. Peter Gorman and Dr. Gil Grimes, we were able to make the flight and were on our way. The look of excitement in his eyes as we approached The Magic Kingdom brought tears to my eyes.

There is so much more I could tell you about J but I must end this story thanking all those who are so patient, understanding, loving and caring toward both of us as we try to live one day at a time. Since hemophilia is also known as the "Royal Disease", I must also say I believe I have a royal soldier who has won many battles and continues to do so. I pray for continued victories for Jason and all others with hemophilia across the world every day! ☺

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