

Hemophilia

TODAY

Canadian Hemophilia Society
Serving the Bleeding Disorders Community

SPRING 2008

www.hemophilia.ca

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1960



Eddy and Donald Burns

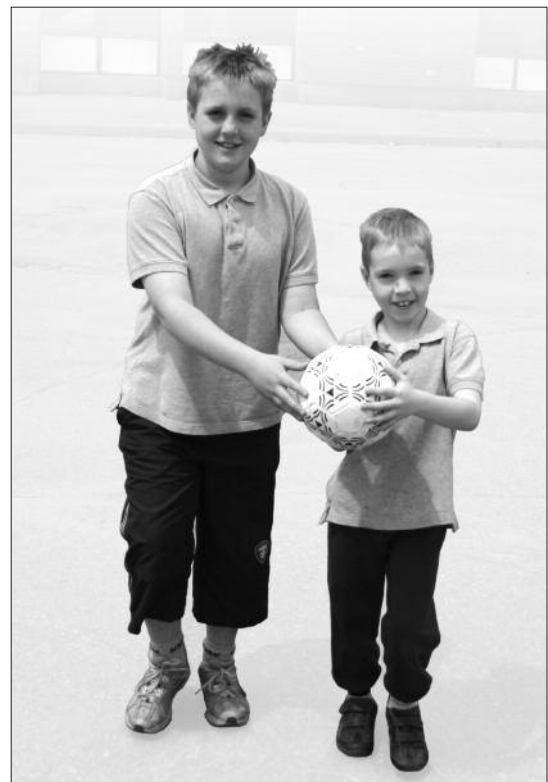
Our Mission

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.

Research

has made great strides in less than 50 years, but a cure has yet to be found.

2008



Nikolas and Patrick Muinonen

Hemophilia TODAY

Canadian Hemophilia Society
Serving the Bleeding Disorders Community

SPRING 2008 • VOL 43 • NO 2

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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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We would also like to thank our numerous additional donors – individuals, corporations and foundations – who each year express their confidence in us by making substantial supporting donations.

Working together with individuals and the corporate sector in Canada helps the CHS accomplish its mission and vision by extending our reach and reinforcing our messages.



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Word from the editor

François Laroche



A large part of this issue of *Hemophilia Today* is dedicated to research. Thanks to the research and advances over the past 50 years or so, the quality of life of people affected by inherited bleeding disorders has improved immensely. A greater variety of treatment options, more effective and safer treatments, as well as the introduction of home treatment, self-infusion and prophylaxis have all helped preserve joints and muscles, prolong the lives of those affected and contribute to better quality of life. Treatment, however, remains difficult and complicated for cases where inhibitors are involved, and much investigation remains to be done in this area. Apart from those who develop inhibitors, people coping with bleeding disorders today are active and productive individuals who have the same opportunities—or nearly so—as the rest of the population.

Supported by funds from the *Hemophilia Research Million Dollar Club*—whose endowment is nearing \$2 million—the CHS *Dream of a Cure* Program now provides research grants and scholarships in basic or clinical sciences related to advancing hemophilia treatment and finding a cure. The Peer Review Committee, which approves the projects for funding, actually received close to twice the number of applications in 2008 as in 2007, which is very encouraging.

In this issue, you can also learn more about the projects supported by two other CHS programs: *Care Until Cure*, in association with Wyeth, and the *Fellowship in Congenital & Acquired Bleeding Disorders*, in conjunction with the Association of Hemophilia Clinic Directors of Canada and Novo Nordisk. The issue also includes research by partners in the pharmaceutical industry, who assure us that several new, more effective products for various bleeding disorders will be on the market soon.

All this is part of the CHS's primary commitment and its vision—that is, to help bring about a world without the pain and suffering caused by inherited bleeding disorders, and eventually find a cure for these conditions. In the light of recent advances in research, we can definitely say that we are on the right track. ◊

LETTER TO THE EDITOR

Subject: Kogenate® FS and Helixate® FS – Two distinct products

Dear François,

In the winter issue of *Hemophilia Today*, both in the *Word From the Editor* and in the *Introduction of Helixate® FS* article on page 21, Kogenate® FS and Helixate® FS are referred to as "identical" products.

Bayer HealthCare Pharmaceuticals would like to clarify that Kogenate® FS supplied with BIOSET and Helixate® FS are in fact two distinct products on a number of fronts:

- 1) Bayer manufactures both of the recombinant factor eight (rFVIII) (lyophilized / freeze dried powder) preparations, fills and seals the product vial. However, all subsequent steps for Helixate® FS, including those described in Point 2, are not conducted in a Bayer facility.
- 2) Important components of Kogenate® FS supplied with BIO-SET, including the product label, package insert, infusion set and diluent are not the same as those provided with Helixate® FS.
- 3) Only Kogenate® FS is supplied with the Bio-Set reconstitution system which is integrated with the Kogenate rFVIII vial.
- 4) Our complete product offering extends beyond the actual product and package to include programs like the EZ-log patient diary system, Kogee/Kojo Club Newsletters, etc.

As the manufacturer and distributor of Kogenate® FS, Bayer firmly believes that Canadians living with hemophilia A should have a clear and accurate understanding of the differences which make Kogenate® FS and Helixate® FS distinct products.

Should your readers have any questions about Kogenate® FS, they may contact the Bayer Inc. Medical Information hotline at 1 800 265-7382.

Thank you,

Alan Birrell
VP, Hematology / Cardiology
Bayer HealthCare Pharmaceuticals
Bayer Inc.

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Message from the President and the Executive Director

Determination and perseverance pay off

The Canadian Hemophilia Society has long been known for its determination and perseverance. Perhaps this character trait originated in the chronic nature of bleeding disorders and the never-ending challenge of individuals and families to cope with them.

Although results sometimes seem slow in coming, our determination and perseverance has clearly paid off over the last four seasons.

After a decade-long effort to obtain financial compensation for those infected by hepatitis C from blood and blood products, this past summer saw the first payments in the pre-86/post-90 hepatitis C class action settlement. This meant help for all people infected through the blood system, regardless of the date of transfusion. The CHS can be proud that after the 86-90 class action settlement was announced in 1998, the organization continued to work on behalf of those who had been left out.

The five remaining provinces – Saskatchewan, British Columbia, New Brunswick, Quebec and Alberta – indexed the *Multi-Provincial/Territorial Assistance Program* to the cost of living for those infected with HIV through blood and blood products. All this was the result of determination and perseverance.

The criminal prosecution of certain individuals at the heart of the tainted blood tragedy of the 1980s came to an end this winter. While some may fault the judgment, the CHS has kept its promise to those affected that we would shine light on these terrible events to the utmost of our ability. And to remember the people who lost their lives, we launched the *Commemoration of the Tainted Blood Tragedy* with a memorial tree planting in Ottawa.

The CHS is more involved than ever in today's questions of blood safety and supply. To mark the 10th anniversary of the *Final Report of the Commission of Inquiry on the Blood System in Canada*, we produced the Fourth Edition of the *CHS Report Card on Canada's Blood System*.

This past year, the CHS and the four professional associations representing bleeding disorder healthcare providers endorsed the First Edition of the *Canadian Comprehensive Care Standards for Hemophilia and Other Inherited Bleeding Disorders*. This process began 29 years ago with the groundbreaking 1978 Winnipeg Conference on Comprehensive Care. Implementation of these Standards will help ensure high-quality care for all Canadians with bleeding disorders.

Over last summer and fall we launched the *All About Carriers* booklet and program, and trained a committed group of women to do von Willebrand disease outreach with the program called *Raising Awareness, Changing Lives*. These are landmarks in a long struggle to recognize the care and treatment needs of carriers of hemophilia and women with other inherited bleeding disorders. Again, determination and perseverance paid off.

And we saw renewed determination to push forward the research agenda to improve treatment and find a cure. The *CHS Research Summit* brought together clinicians and researchers, who re-affirmed CHS' key role in this area. Perhaps as a direct result, the CHS received double the number of research applications in 2007 compared to 2006 and is investing a record amount of funds in research in 2008.

A major effort is being made to invest in our current volunteers and in our youth, and to attract new volunteers. They will be the next generation of leaders to carry on our tradition of determination and perseverance. ◊



Pam Wilton, RN
President



David Page
Executive Director

LETTER TO THE PRESIDENT

April 14, 2008

Dear Ms. Wilton,

This April 2008, the Alberta MPTAP recipients received word from the Provincial Health Minister, Ron Liepert, that the Province of Alberta is granting cost of living indexing of these payments. Further to that, they have included retroactivity to 1994/1995. This was great news as it has been seven years since Ontario provided indexing, the first province to do so. Now, as of this April, all the provinces have indexed their MPTAP packages for all of their citizens who were infected with HIV through the use of blood or blood products. The province of Nova Scotia created its own separate program.

As representatives of the HIV-transfused community of Canada, (individuals who received HIV-infected blood or blood products for surgery, childbirth, trauma or other medical reasons unrelated to bleeding disorders) we would like to thank the Canadian Hemophilia Society. We know that it took a lot of effort and perseverance to convince the provinces, one by one, to provide us with indexing. Indexation was an important issue because many of us have lived with HIV and its debilitating effects for more than 20 years and the cost of living has risen considerably in that time. We are grateful to the Presidents, the HIV/HCV Task Force, staff and individual members of the CHS at the national level who kept up this effort over so many years.

Also, we would like to thank all those in the CHS provincial chapters who never gave up and kept on writing letters, meeting with Ministers, MLAs, candidates for parties, and government officials on our behalf.

We would like to thank the provincial governments for providing us with the indexing of the MPTAP payments and the Canadian Blood Agency for their efficient and sympathetic administration.

Although we are very pleased to receive indexation, we are also aware of the inequality among the provinces with regards to retroactivity and hope that the Canadian Hemophilia Society will continue to press those provincial governments to make the situation fair and equal across all the provinces of Canada and grant retroactivity to all dating back to 1994/1995.

In closing, we would like to express our sincere appreciation to the Canadian Hemophilia Society for including the HIV-transfused community in all of its advocacy efforts and for its continued support over the years.

Sincerely,

Members of the HIV-transfused community of Canada

CHS recognizes Bayer as platinum level donor for 2007

The Canadian Hemophilia Society provides special recognition to donors who contributed over \$450,000 to the work of the organization at the national and chapter levels in the previous year. For 2007, the CHS is pleased to recognize Bayer HealthCare as a Platinum level donor. A donor at this level contributes between \$450,000 and \$650,000 to the organization's efforts.

"Bayer has long been a major donor to the CHS," said Pam Wilton, CHS President. "Their support is truly valued; without it, we would not be able to provide the level of programs and services to the bleeding disorder community that we do today."

In 2007, Bayer contributed \$400,000 in unrestricted funding at the national and

chapter levels. These funds were critical in the ability of the CHS to fulfill its mission in the areas of care and treatment, education and support, a safe and secure blood supply, and advocacy.

In addition to the unrestricted funding, Bayer sponsored the following programs and activities in whole or in part: the *CHS Research Summit* held in February 2007 organized to solicit advice from the medical and scientific community on how the CHS could maximize its impact in the area of research; *Rendez-vous Québec*, a 4-day Congress that included the biennial CHS – Association of Hemophilia Clinic Directors of Canada Medical/Scientific Symposium, New Team Workshop, annual meetings and consumer workshops; and the *Step by Step* Program for Parents that provides critical tools of support and edu-

cation to families of newly diagnosed children with hemophilia.

"Our partnership with the CHS is very important to Bayer," said Alan Birrell, Vice President, Hematology/Cardiology. "Bayer has supported the CHS for over 15 years, and is proud to be recognized as a Platinum sponsor."

Editor's note: The philanthropic relationship between Bayer and the CHS is governed, for the CHS, by its *Policy on Relations with Companies in the Pharmaceutical Industry* and its *National Corporate Giving Program*; and, for Bayer, by the *Collaborative Partnership Guiding Principles* developed by *RX&D*, the national association representing Canada's research-based pharmaceutical companies.

Community News



Manitoba Chapter

The Manitoba Chapter celebrated World Hemophilia Day with an awareness table at the Health Sciences Centre (HSC) in Winnipeg. HSC is the home of the Manitoba Bleeding Disorders Program for both adults and children. We were fortunate to have

CBC Radio come by and conduct an interview with our



Executive Director, Christine Keilback, and with Manitoba Board Member, Ingrid Olson. The awareness table was an excellent way to educate the general public about inherited bleeding disorders.

Northern Alberta Region

■ Hemophilia Day at 742 Signals Squadron, Edmonton, Alberta

by Brent Buchanan

It was April 17. I came in early, because it was a special day for "the bleeder" or as my old Commanding Officer used to call me "the mutant." It was World Hemophilia Day and I was starting to set up my display I had just received the day before.

2008 World Hemophilia Day



On April 18, the World Federation of Hemophilia invited staff from the CHS national office and the CHSQ to join them for lunch to celebrate World Hemophilia Day together. Lunch was followed by inspiring presentations about outreach, the theme of the 2008 World Hemophilia Day.

Before I get too far in my article, let me give you a quick background on how I got here. I joined the Military in 1987 and was medically released in 2005, after totally falling apart due to some major bleeds and surgeries to stop bleeds, etc. I found out I had hemophilia in October 2000, hence earning the new nickname "the mutant." I know one thing is for sure, the military and being a bleeder don't mix and my body reminds me of it everyday.

So there I was, setting up my display, and I already had people asking me what was going on. I thought to myself... good start. After I finished the display I put a sign up that read, "If you have any questions about bleeding disorders ask Bucky" (my real nickname), and I was actually surprised by how many people talked to me throughout the day.

The majority of questions were caring and thoughtful mixed in with the usual military edgy banter. One of my comrades, who has known me for years, asked what it was all about and after I reminded him I was "the bleeder" and that "hemophilia" was the fancy term for it, he took every piece of material away for a read.

Overall, the display was only viewed by about 100 people, but I think it opened some eyes on how life is for those with bleeding disorders. I spoke about the society's hopes for the kids and how we need to keep our clinics open for them and for the future. I spoke of how sad it was for those families that have lost love ones from the tainted blood era. I spoke of how some of my friends are in chairs and scooters. But most importantly, I spoke about how inspired I am by

continued on page 6

continued from page 5

others in the society who possess so much dedication and pure guts to get through their daily lives and still make the time to do what they need to do to, ensuring that our society is here for a long, long time.

I came in early; it was a special day for hemophilia, and it didn't hurt as much today.

■ Donalda School participates in *Red, White & You Day* April 17, 2008

My name is Mary Mueller and my son Alden Mueller has severe hemophilia A. When I was asked by the Alberta Chapter to participate in spreading awareness of hemophilia in my community I jumped at the chance to give back to the society. We have never participated in a *Red, White & You Day* in our school before so the plans were under way. Alden's friend, Morgan Baker, has a nephew with severe hemophilia so we got her planning the day with us.

Alden and Morgan made posters and put them up around the school, asking the students and staff to wear red and white, and to please give a loonie or toonie to help find a cure for hemophilia. The school included the event on the April calendar and I put a display up in the hallway. I never dreamt that the day would have turned out so successful. At least 60 out of 75 people wore red, white or both and the students that forgot wore red pinnies to support the day. One student told me it was just like Halloween. With having such a small school, I thought that if we took in one dollar for every student we would be successful, but we surpassed that by four times!!!

Alden's classmate Jessica Nelson is a little girl we all should model our lives upon. She presented Alden with an envelope that morning and inside the envelope were two 50-dollar bills. A note was attached saying that she hoped this money will help find a cure for her best friend. It was so awesome the donation she gave. I talked with her mom later that day and she told me that Jessica has been saving for a laptop. She willingly gave her savings in hopes to help find a cure for her friend. She wants to help make the world a better place to live in when she grows up, her mom Laura told me – but she should realize that she already has been doing just that. May we all give as freely as Jessica, so a cure for hemophilia is closer to being found.



Jessica, Alden and Morgan



An enthusiastic group at Donalda School.

■ Breakfast Television Show

A couple of people in Edmonton also appeared on a local Breakfast Television Show on April 17 to raise public awareness on bleeding disorders. It wasn't a long interview but enough for us to provide the basics and the CHS contact information.

■ *Red, White & You* at Mother Teresa Catholic School

Anika and Korri Spruyt organized a *Red, White & You Day* at school for April 17. They go to Mother Teresa Catholic School in Sylvan Lake which is grades 3 to 9. The girls made an announcement about World Hemophilia Day and asked that everyone wear red and white. A lot of kids did wear red and white. We did not have a fundraiser with this day, but quite a few of the kids did ask about the blood disorders and most of the teachers also wore red. Sheri, their older sister, also had a *Red, White & You Day* at the Royal Bank where she works in Strathcona (Edmonton). All of the employees wore red and she had an info session with the employees.



Eager students at Mother Teresa Catholic School.

Southern Alberta Region



National office provided an excellent kit that included the Fact Sheet and brochures. We set up an information display in the University of Calgary Medical School, near one of the amphitheatres, and chatted with passersby, including students, staff and the general public.

As we only had a few seconds to get our message out, we had a big bowl of Kit Kats to draw the students over. The information about von Willebrand disease generated a lot of questions. We emphasized that the Web site is a wonderful resource.

We hope that some of these students will want to learn more about blood disorders or consider a hematology specialty.

Quebec Chapter

On World Hemophilia Day a number of public outreach tables were set up to promote the cause we work for. In conjunction with the CHS national office, and the World Hemophilia Federation (WFH), we are proud to have held our very first information day for the general public on April 17.



CHSQ, CHS and WFH at Montreal Central Train Station.

The CHSQ also had an outreach table at a hospital, and another at the Quebec National Assembly, where badges marking the event were handed out to all the MNAs. The Minister of Health and Social Services, Philippe Couillard, tabled an unannounced motion to recognize World Hemophilia Day.



CHSQ at the Quebec National Assembly.

Lastly, a radio program on hemophilia featuring resource persons from the CHSQ and the CHS and the medical community was broadcast on April 17 and will soon be available on the CHS Web site.

2008 CHS Board of Directors

Sitting, from left to right: Venanz D'Addario (Ontario), Craig Upshaw (Vice-President), Dr. Bruce Ritchie (MSAC Representative), David Pouliot (Vice-President). Standing, from left to right: Eric Stolte (Past-President), Jeff Beck (Ontario), James Kreppner, LLB (Secretary), Ann Wood (Saskatchewan), Martin Kulczyk (Quebec), Mylène D'Fana (Quebec), Aline Landry (New Brunswick), Bill Featherstone (Manitoba), Dianna Cuning (Nova Scotia), Mike Beck (Vice-President), Clare Penner (Alberta), Maureen Brownlow, RSW (Vice-President), Pam Wilton, RN (President), Colleen Barrett (Newfoundland and Labrador). Missing from the picture: Norman Locke (Treasurer), Elaine MacRae (Prince Edward Island), Gabriel Ramos (British Columbia), Bruce Rempel (British Columbia), Julia Sek (Ontario), Emil Wjinker (National Youth Committee Representative).

Prince Edward Island Chapter



The first ever "Run For It" event was held in Charlottetown on April 19, to raise awareness about inherited bleeding disorders and to fundraise for the PEI Chapter. It was a 13km run along the Confederation Trail, on a cool but sunny spring day, and about 75 people showed up to run or walk the 13km, or 5, 3 and 1km which were also marked. It was uplifting to see people unrelated to the cause show their support. Despite a few minor glitches, it was declared a success by all, so next year should be bigger and better!

On World Hemophilia Day, Chapter VP, Elaine MacRae, held a *Red, White & You Day* at the high school where she is a teacher. The package sent along by the CHS national office was used to raise awareness among her colleagues.



Nova Scotia Chapter



Dianna Cuning of the Nova Scotia Chapter set up a table in front of the Royal Bank branch where she works, with tons of info. Employees all wore red and/or white. And they asked each client to buy a colouring book for that day only.



World Hemophilia Day celebration at IWK Health Centre in Halifax.

Bayer marks Hemophilia Day

Bayer was a sea of red and white as employees at the Toronto head office celebrated *Red, White & You Day* on April 17 (World Hemophilia Day), raising over \$900 for the Canadian Hemophilia Society.





Chapter Spotlight

Prince Edward Island Chapter

A local group of sportsmen decided to show support to the PEI Chapter as their annual "charity of choice" and held a wildlife dinner open to the public. Donations were made at the door where we had a small display of CHS brochures and pamphlets. This unique event raised over \$1,000 and was a truly fun and heartfelt afternoon!



Quebec Chapter

4th edition of the Bowl-a-Thon

The Quebec Chapter has held another of its traditional Bowl-a-Thons, which have brought in over \$10,000 gross in Victoriaville, Montreal and Quebec City! A first Bowl-a-Thon was held in Victoriaville thanks to a volunteer who handled organization for the event. It is important to note that the work done by all our volunteers across Quebec in setting up these events has been amazing, and we can only encourage initiatives of this kind everywhere in Canada!



CHSQ pens

We now have a new promotional item: a pen with CHSQ logo! Easy to sell and very practical, the pen is already a big success with our members, many of whom have promised to promote it to their friends and acquaintances. This will help diversify our sources of funding and, at the same time, help raise awareness about hemophilia.

Newfoundland and Labrador



Norman Locke, from the NL Chapter, receiving a *Red White & You* donation from Chris Ryan, NL Account Manager for Genworth Financial Canada.

Hemophilia Ontario

Jeff Beck, President, is pleased to announce that Heather Heagle has accepted the position of Executive Director, Hemophilia Ontario, as of May 20, 2008.

Heather has had significant experience in senior management positions, providing leadership in developing a diverse array of fund development programs, sponsorship campaigns and events. Those opportunities have served a range of concerns, municipally for Vaughan, Ontario, provincially for the Ontario Association of Landscape Architects, and nationally for the Ontario Association of Chiefs of Police - York Region Police Services and for the Canadian Association for Community Living.

As a community member, Heather has been an active volunteer and board member in organizations such as TD Canada Trust - Friends of the Environment, Wings of Hope - Eating Disorders of York Region, Opera York, and the Ontario Special Olympics.

The Board and staff of Hemophilia Ontario invite you to join us in welcoming Heather to the bleeding disorders community.

South Western Ontario Region (SWOR)

On March 29, 2008, SWOR hosted a member conference, "Let's Talk About Me." This educational conference was designed to provide access to speakers and information sessions for carriers, youth with hemophilia, adults with hemophilia and individuals with von Willebrand disease. The conference was a huge success. Overwhelmingly participants have requested that as a region, SWOR continue to provide access to educational opportunities. As a result, we are in the process of devel-

oping a plan that will continue to bring education to our members. Without your support, this would not have happened. Thank you very much for your continued support of SWOR and our efforts to enhance supports and programming within the region.

Toronto and Central Ontario Region (TCOR)

This year TCOR held their annual AGM at the Playdium in Mississauga. The day was complete with presentations and reports, many awards, and entertainment for the children. It concluded with a buffet and play time at the Playdium.



Board member Luke Kilner and TCOR Board President Mike Beck presented the Karttik Shah Award to James Kreppner and Antonia Swann for long standing commitment and advocacy.

Central West Ontario Region (CWOR)

On April 6, 2008, members came out to enjoy the artistic scenery at the Art Gallery of Hamilton for CWOR's 2008 AGM. Guest speakers included Nigel Small, Provincial HIV/HCV Program Manager, and Pediatric Hematologist Dr. Anthony Chan of the Hamilton-Niagara Regional Hemophilia Clinic. The children who attended the event also enjoyed a private tour of the gallery with an artsy craft session to end the day. An enjoyable time was had by all! ○

Historical overview of Multi Provincial/Territorial Assistance Program (MPTAP) indexation

by Michel Long, CHS Program Development Coordinator

In May 1990, the Government of Canada established its Extraordinary Assistance Plan (EAP) to provide financial assistance to an estimated 1,250 individuals (or their estates) who were infected by HIV through the transfusion of tainted blood or blood products in Canada between 1978 and 1989. This assistance plan was funded solely by the federal government and consisted of compensation of \$120,000, tax free. Qualifying individuals had to apply before December 31, 1990, in order to receive an indemnity of \$30,000 for four years. Indemnities were paid out by Health and Welfare Canada in April in the years 1990, 1991, 1992 and 1993.

On the 15th of September, 1993, provincial and territorial Health Ministers announced the creation of the Multi Provincial/Territorial Assistance Program (MPTAP) to provide financial support to people who have contracted HIV through tainted blood transfusions or components received in Canada. Only Nova Scotia is not part of this program, having set up its own plan earlier that same year.

The MPTAP program took over from the EAP, with compensation administered by the provincial and territorial health ministries instead of federally. Improvements to this plan were made on the 1st of December, 1993. Individuals approved for financial assistance through the EAP were eligible for additional assistance through MPTAP, which provides \$30,000 per annum for life. In all jurisdictions, this amount has been linked to the cost of living and the actual annual payment is over \$30,000.


The CHS and its members have fought long and hard across Canada to ensure the payments are indexed to the cost of living. Below is a table which summarizes when the indexations were obtained in all provinces and results, except for Nova Scotia. All nine provinces base the increased payments on the difference in the cost of living between 1994 and the present.

Date indexation agreed upon	Province /Territory	Retroactivity
May 4, 2001	Ontario	YES. As of 1994, year of the beginning of the program
July 2005	Manitoba	No
October 2005	Newfoundland and Labrador	No
March 2006	Prince Edward Island	No
May 2007	Saskatchewan	No
July 2007	British Columbia	No
September 2007	New Brunswick	No
November 2007	Quebec	No*
March 2008	Alberta	YES. From 1994/95 to 2007/2008

* Retroactivity was offered as of April 1, 2007. Quebec chapter members are still negotiating to obtain better retroactivity.

The CHS HCV/HIV Task Force is currently verifying if there are any victims in the Yukon, Northwest Territories and Nunavut regions to determine if indexation requests should be made.

Assistance Program for HIV Secondarily Infected Individuals

In December 1998, the federal, provincial and territorial governments agreed on a joint program to provide *ex gratia* payments of \$240,000 per individual to Canadians who were secondarily infected with HIV by a primary recipient (spouse/partner or mother to child). This program supplements the financial assistance provided to Canadians directly infected with HIV from the blood supply ("primary infections") under the federal Extraordinary Assistance Program (EAP) and the Multi Provincial/Territorial Assistance Program (MPTAP). Estates of secondarily infected individuals can also apply for benefits. The program is administered by the federal government (Health Canada) on behalf of the federal/provincial/territorial governments. 

May 19: World Hepatitis Day

by Michel Long, CHS Program Development Coordinator

In 2008, the CHS along with other concerned Canadian organizations, healthcare professionals and patients joined the World Hepatitis Alliance (WHA) to launch the first ever global WORLD HEPATITIS DAY.

The WHA is a global coalition committed to changing the fate of more than 500 million people living with viral hepatitis B or C worldwide. The international campaign theme *Am I Number 12?* was designed to communicate the statistic that one in 12 people worldwide has viral hepatitis B or C. "12 asks for 2012" were presented to governments around the world, 6 internationally mandated and 6 nationally focused.



To reduce the health and social impact of hepatitis B and C on the liver health of Canadians, we ask federal, provincial and territorial governments of Canada to adopt, by 2012, a coordinated national strategy that:

- **Promotes prevention** of hepatitis B and C through expanded education, immunization and harm reduction programs all across Canada.
- **Improves access** to comprehensive care and treatment programs in all areas of the country.
- **Increases knowledge and innovation** through interdisciplinary research and surveillance to reduce the burden of hepatitis B and C on Canadians.
- **Creates awareness** about risk factors, stigma and the need for testing among the general population and at-risk groups.
- **Builds capacity** through training and recruitment of qualified health professionals.
- **Supports communities and community-based groups** in developing, delivering and evaluating peer-driven and focused initiatives.

For more information, please visit www.aminumber12.org 

What really was wrong with the Armour criminal trial decision?

by John Plater, *Chair of the CHS HIV/HCV Task Force*

As I stood in front of the Superior Court of Ontario building and expressed my outrage at the not guilty verdict that had just been pronounced by the Honourable Madame Justice Benotto, it was a struggle to articulate why there was such disappointment. The day had been long anticipated and though the verdict was not completely unexpected, the tears and anguished faces of many who spilled out of the room weighed heavily on everyone involved with the case. The media wanted answers and, given the few minutes we had to digest the 63-page decision, it was tough to articulate just what was so wrong with the verdict.

There were obvious errors. Madame Justice Benotto referred to the freezing of plasma as "lyophilizing [so that] factor VIII could be separated from other blood components." *Lyophilizing* is actually a freeze drying step used towards the end of the process of producing FVIII concentrate that allows it to be stored at higher temperatures than cryoprecipitate. The judgment may not have hung on this mistake but it does speak to a lack of detailed understanding.

The same can be said for the description of the situation that the defendants faced; Madame Justice Benotto suggested that "they were forced to choose between distributing a product that was not risk-free and leaving hemophiliacs without a life-saving treatment." During the time in question, the vast majority of blood products used by hemophiliacs were not for life-saving circumstances. There is no mention in the judgment as to whether the four identified victims received product for life-saving reasons. I spent a lot of time in front of the media explaining that this case was about a limited set of circumstances related to one product distributed for a short period of time in the mid-1980s. Is it possible that this point was not made clear in court during the one and a half years this trial was prosecuted?

Justice Benotto dismissed in three short paragraphs what I suspect many people

Justice Benotto dismissed in three short paragraphs what I suspect many people viewed as the least serious of all the charges in the case, but which was in my opinion the key to the whole case.

The pharmaceutical company Armour was charged with failing to immediately notify the Canadian Minister of Health of a deficiency or an alleged deficiency in its product.

viewed as the least serious of all the charges in the case, but which was in my opinion the key to the whole case. The pharmaceutical company Armour was charged with failing to immediately notify the Canadian Minister of Health of a deficiency or an alleged deficiency in its product. The allegation referred to studies done by Dr. Alfred Prince, retained by Armour to conduct studies on its heat treatment process. Justice Benotto found these facts. Dr. Prince did those studies and "concluded that the efficacy of dry heat by Armour was somewhat limited." He wanted to publish but Armour refused. Then Justice Benotto concluded that there were problems with the studies, finding they were unreliable, confusing and inconclusive. She decided that his findings "could not reasonably be construed to allege deficiencies in the viral inactivation process."

History of course proved Dr. Prince right but, in fairness, the benefit of hindsight cannot be relied on to prove criminal liability. But is that the issue? The judgment

implies that it is up to a company to decide whether research that appears to raise doubt about the safety of its product should or should not be reported to the government. I submit that this is not acceptable. This conclusion also meant that the defendants had not failed to discharge a legal duty, a finding necessary to prove criminal negligence or public nuisance related to the bodily harm that was caused to the victims. The case fell apart.

Would anything have changed if the information had been reported? Would the government officials (who were also found ultimately not guilty) have acted any faster to save the lives at issue? We will never know. But again that is not the point. Failing to report is a crime. I would argue that companies that make a profit from their products should not be in a position to decide what should be reported and what should not. It appears as though Justice Benotto, based on her understanding of the facts, felt the defendants worried about a global shortage of hemophilia products more than they worried about their company's share of the market of those products. I would prefer a system that requires a company to provide the results of internal research to regulators for evaluation. Rules of privilege and confidentiality can protect their interest in intellectual knowledge while our public servants protect our safety.

Would it have been satisfactory for only Armour to have been convicted of the limited charge of failing to notify the Minister? For many people I suspect not. Unfortunately, they viewed this case as an indictment of the whole system, which it was not. Clearly, the outcome of the Armour case led to the dropping of charges against Dr. Roger Perrault, in the trial that was to take place in Hamilton. That trial would have looked at a broader range of issues but still would not have been a complete review of everything that went wrong. The Krever Report (Commission of Inquiry on the Blood System in Canada) tells the story of the tragedy as a whole and speaks to how the system failed us.

I do believe such a conviction would have been a better outcome for Canadian healthcare. ◊

Calgary's Justin Shenher appointed as the new Teen Ambassador for the Alberta Children's Hospital

by Lisa Little, Calgary, Alberta

During a luncheon organized by the Alberta Children's Hospital (ACH) on Friday, February 29, Justin Shenher was "sworn in" as the 2008 Children's Miracle Network Champion Child by Justine Clay, Communications and Marketing Coordinator of the ACH Foundation. In this capacity, Justin will serve as the ACH Foundation's official teen ambassador to the Children's Miracle Network Champions Across Canada Program, which is sponsored by Wal-Mart Canada. The 14 Champion Children selected from across the nation gathered in Ottawa with their families to meet each other and exchange stories. They will then fly to Disneyland to meet their "Champion Child" counterparts from the US, the UK and Ireland.

Many of Justin's friends and family members attended the luncheon along with media representatives, Morna Brown and Andrea Pritchard (two hemophilia nurses) and other medical and hospital staff. There were several guest speakers, including Dr. Man-Chiu Poon, Hemophilia Clinic Director (Calgary), Brad Baker, District Manager, Wal-Mart Canada, and Paul Lethbridge, Director, Corporate Development, Children's Miracle Network.

On this occasion, Dr. Poon presented a moving speech and video about Justin, whom he has known since he was three days old. When Justin was born, he had a routine blood test on his heel that bled for 10 consecutive hours. At that time, Dr. Poon was called in and eventually diagnosed Justin with severe hemophilia A. After his first few factor treatments, he developed inhibitors. Unfortunately, Justin did not respond to the effective immune tolerance treatment that is generally administered to hemophiliacs with inhibitors. A variety of very expensive products with inconsistent efficacy were used on Justin. One of these products had to be injected every two hours. For nearly five years, Justin was in so much pain and discomfort from ankle bleeds that he was in and out of a wheelchair.



Dr. Poon presented a moving speech and video about Justin.

Dr. Poon (...) eventually diagnosed Justin with severe hemophilia A. After his first few factor treatments, he developed inhibitors. Unfortunately, Justin did not respond to the effective immune tolerance treatment that is generally administered to hemophiliacs with inhibitors.

About four years ago, there was an unexpected turn of events when Dr. Poon and several other Canadian specialists got together and decided to try an experimental drug called Rituximab®, which is used to treat lymphoid cancer. There were several reports indicating that this

chemotherapy drug could be used to treat some immune problems associated with unwanted antibodies. This team of physicians developed a protocol and tried it on Justin to see if it would crash his immune system and destroy his inhibitor. Justin was one of the first Canadian patients to receive this experimental treatment that must be repeated every six to eight months. Rituximab has not cured Justin of the inhibitors, but their level has become low enough that factor VIII can be administered to prevent bleeding. He has gone from having multiple bleeds every other week to only twice a year. And although he experiences some fear about the treatment losing its effectiveness, it has not stopped him from living a very active and fulfilling life. In essence, this miracle drug has given him his life back.

Without this treatment, Justin would not have been well enough to serve this year as the teen ambassador for the Alberta Children's Hospital. During Justin's speech, he thanked the staff in the hemophilia treatment centre and all other medical personnel that have helped him along the way. His desire to become the spokesperson for the seventy-six thousand children who visit the Alberta Children's Hospital every year was motivated in part by wanting to shine a light on the extraordinary care that the hospital staff has provided to him and all of the other children that pass through the hospital's doors. It is also a way of giving back to a community that has been by his side ever since he was three days old.

As Justin spoke during his acceptance speech, it became abundantly clear to everyone in the audience that he is a witty, smart and articulate young man who has wisdom beyond his years. His wisdom stems in part from his suffering and the medical struggles he has experienced in his short life. Whatever the source of his character, his positive attitude and caring disposition make him a perfect role model and spokesperson for the hemophilia community and the larger hospital community. There was not a dry eye in the house when Justin completed his speech. It is an honour to know this young man and to be part of the hemophilia community that we all share.

For more information about the Children's Miracle Network, please visit their Web site at www.childrensmiracletnetwork.ca

■ Quebec re-introduces no-fault compensation bill for blood injury

QUEBEC CITY, March 17, 2008 - The government of Quebec has re-introduced no-fault compensation legislation as recommended by the Commission of Inquiry on the Blood System in Canada (the Krever Commission) in 1997. An earlier bill died on the order table when an election was called.

Bill 67 would provide for compensation for injuries caused by a blood product distributed by Héma-Québec, regardless of fault. It would not, however, indemnify against negligence on the part of a healthcare professional.

In the absence of any claims against Héma-Québec, such a program would save the blood operator several million dollars a year in insurance costs. Quebec would be the first province in Canada to introduce such legislation.

■ Hemophilia, one of the 12 diseases that changed the world

In his book *Twelve Diseases That Changed Our World*, Irwin Sherman, a professor emeritus of biology at the University of California Riverside, describes how bacteria, parasites and viruses have swept through cities and devastated populations, felled great leaders and thinkers, and in their wake transformed politics, public health and economies.

He also describes how hemophilia had serious effects on the crowned heads of Europe. According to Sherman, the rise of Spanish dictator Francisco Franco in the 1930s can be traced to the lack of an heir to the throne because of hemophilia. Another example is the collapse of the Romanov dynasty in Russia, in part caused by the family's distraction of having to care for young Alexei, heir to the throne, who had severe hemophilia. This set the stage for the rise of the Bolsheviks and the Russian Revolution in 1917.

Irwin W. Sherman, *Twelve Diseases That Changed Our World*, American Society for Microbiology, ISBN-10:1555814662

■ Optimizing care for patients presenting with bleeding disorders to the emergency department: the impact of the new CTAS triage guidelines

Robert Klaassen, MD, FRCP(C)

Director, Hemophilia Program
Children's Hospital of Eastern Ontario,
Ottawa
Co-Chair CHS ER Advisory Group

An important update regarding emergency care for patients with bleeding disorders was published in the March edition of the *Canadian Journal of Emergency Medicine*. Dr. Michael Bullard, who had worked with the CHS Emergency Advisory Group, was the principal author of the article on the revisions to the Canadian Emergency Department Triage and Acuity Scale (CTAS) adult guidelines.

The revised guidelines include a new "first-order modifier" for the triage of adults with inherited or acquired bleeding disorders who present to the emergency department. Life- or limb-threatening bleeds are assigned a CTAS level 2 (2/5 - 2nd highest acuity), which indicates emergent care is needed. Mild or moderate bleeds are assigned a CTAS level 3, which indicates urgent care is recommended. Other first-order modifiers may apply that may affect triage level such as those relating to hemodynamic stability or level of consciousness. CTAS levels range from level 1 (resuscitation) to level 5 (non urgent). What this means is that only patients who need active resuscitation will be prioritized ahead of level 2 patients, such as bleeding disorder patients with life- or limb-threatening bleeds. This is the same level of acuity assigned to pregnant women in active labour, individuals presenting with significant chest pain, hemodynamically unstable trauma patients or head-injury patients with a Glasgow Coma Scale (GCS) score of 10-13.

Patients with bleeding disorders who have a major or moderate bleed require rapid factor replacement, and it has long been known that the key to avoiding long-term damage to joints is prompt treatment. Ideally, treatment should begin within an hour of the injury. These revised guidelines will improve emergency department triage and treatment of bleeding disorder patients.

The revisions focusing on bleeding disorder

came about through discussions between the CHS ER Advisory Group and Dr. Bullard, who is Co-Chair of the CTAS National Working Group. The Advisory Group was in the process of revising the *Factor First* card for patients with bleeding disorders, which outlines the individual's diagnosis and therapy and can be presented to triage nurses to facilitate appropriate

These revised guidelines will improve emergency department triage and treatment of bleeding disorder patients.

emergency care. Dr. Bruce Ritchie, the previous chair of the advisory group, invited Dr. Bullard to participate in the discussion, which in turn led to the inclusion of bleeding disorder patients in the new CTAS guidelines.

The new *Factor First* cards are ready and patients can expect to receive new cards when they come for their next clinic visit. It is also important that patients and their families advocate for adequate system capacity to help eliminate inpatient and emergency department overcrowding which is limiting the ability to deliver acceptable quality of care.

Now that we have the new *Factor First* cards and a new CTAS first-order modifier, patients should be prepared to show their cards when they go to the emergency department and help to introduce the changes to the ED staff. It may take up to a year to disseminate and educate the entire emergency community about these CTAS revisions across Canada and even longer for the broad introduction of CTAS electronic decision support tools. It is hoped and anticipated that the updated and standardized CTAS guidelines will result in better care for bleeding disorder patients. ○

Upcoming Events

Canadian Hemophilia Society

- **August 20, 2008** – The 2008 Ron Fellows/Mosport Hockey Challenge in support of the Canadian Hemophilia Society will be held at Campus Ice Centre in Oshawa, Ontario. For more details, please contact the CHS national office at 1 800 668-2686.
- **September 5-7, 2008** – National Youth Leadership Workshop at the YMCA Geneva Park, Orillia, Ontario.
- **November 2008** (Date to be confirmed) – The 1st CHS National Workshop for Patients with Rare Factor Deficiencies will take place in Montreal.

Manitoba Chapter

- **June 30, 2008** – Deadline for Scholarship/Bursary Applications.
- **July 13-22, 2008** – Family Camp at Luther Village, Ontario.
- **September 5-7, 2008** – Men's Retreat at Lake Manitoba Narrows Lodge.
- **October 9, 2008** – Member Meeting (Location to be confirmed).

Alberta Chapter

- **September 19-21, 2008** – The CHS Alberta Chapter Annual Family Retreat will be held at the Goldeye Centre near Nordegg.
- **October 2008** (Date to be confirmed) – Both Regions are in the early planning stages of an event to celebrate the 30th anniversary of the establishment of our clinics in Alberta.

Toronto and Central Ontario Region (TCOR)

- **June/July 2008** – Families In Touch Summer Picnic – A day where families and friends can connect, learn and picnic in a relaxed outdoor setting. Watch for more details.
- **June 29-July 12, 2008** – YMCA Camp Wanakita Summer Camp – A place for children with inherited bleeding disorders to enjoy regular camp activities while learning to manage their condition with the help of clinic staff.
- **August 23, 2008** – John Plater Lamb Roast – A great opportunity for members within the TCOR community to meet and join together for an afternoon of fun and fantastic food! This special event is generously provided and planned by Mr. and Mrs. John Plater. For more information please call 416 972-0641.
- **September 19-21, 2008** – Just the Guys weekend – A weekend for fathers and their sons to have an opportunity to learn and play together. This weekend is held in conjunction with two other regions (SWOR and CWOR). If you are interested in participating in this weekend please call 416 972-0641.
- **October 2008** (Date to be confirmed) – Transition Program Evening – The transition program evening is designed to help transitioning families familiarize themselves with the entire transition process from the Hospital for Sick Children to the St. Michael's Hospital adult clinic. The program is open to families or individuals 17 years of age who will be transitioning the following year.
- **October 2008** (Date to be confirmed) – Women In Touch Group – A day for women to learn, gather, share and express their thoughts, life lessons and ideas. Please call 416 972-0641 if you wish to attend.

Ottawa & Eastern Ontario Region (OEOR)

- **August 9, 2008** – The 14th Annual Shawn Duford Golf Tournament for Hemophilia will be held at the Meadows Golf Course in Ottawa. Early Bird Registration Fee is \$95 per person, which includes, golf, cart, box lunch, buffet roast beef dinner, prizes and FUN. Book early if you don't want to miss this event. For registration please contact Colin Patterson at cpatterson@hemophilia.on.ca or call 613 739-3845.

Central West Ontario Region (CWOR)

- **July 20, 2008** – This year, CWOR will be holding their annual Summer BBQ & Education Day at African Lion Safari. The day will be packed with family fun and a picnic-style barbeque lunch. Members are encouraged to bring their families to this event for a walk on the wild side!

Quebec Chapter (CHSQ)

- **August 10-15, 2008** – Children's summer camp in Saint-Raymond-de-Portneuf, Quebec.
- **Summer 2008** (Date to be confirmed) – A one-day activity for young adults.
- **Mid-October 2008** – Family weekend for families dealing with inhibitors.

Prince Edward Island Chapter

- A fall meeting is planned for the PEI Chapter in Charlottetown, with an invited guest speaker. Location and date to be confirmed.

What's new on the CHS Web site?



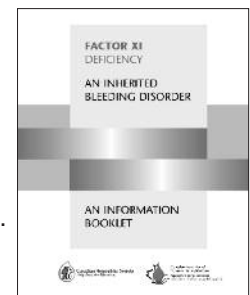
■ Bernard-Soulier Syndrome – An Inherited Bleeding Disorder

The latest in the series on Rare Factor Deficiencies, this document is a general information booklet about Bernard-Soulier Syndrome for patients, families and healthcare providers. This booklet was developed by the Quebec hemophilia clinic nurses of the Canadian Association of Nurses in Hemophilia Care (CANHC) and published by the CHS.

You can download it at

www.hemophilia.ca/en/printed_documents.

You can also order copies by contacting the CHS office at 1 800 668-2686 or chs@hemophilia.ca.




■ CHS 2007 Annual Report

The CHS 2007 Annual Report and the complete Financial Statements are available at www.hemophilia.ca/en/1.5.php.

The
Canadian
Hemophilia
Society

2007
annual
report



determination
perseverance

Canadian Hemophilia Society
Help Stop the Bleeding
www.hemophilia.ca

Youth File

Sarah Bradshaw



Emil Wijnker

National Youth Committee Co-Chairs

It's official! The National Youth Committee (NYC) will be holding its first Youth Leadership Retreat at Geneva Park in Ontario from September 5 to 7, 2008. This event is limited to 40 participants aged 15 to 25 from all corners of Canada, so be sure to apply through your local chapter ASAP!

The retreat will provide an opportunity to develop leadership skills, better understand what it means to be involved in the CHS, participate in great team-building activities and meet peers from across the country. Not to mention the presence of an amazing guest speaker.

In other news, the NYC is busy planning events for 2009. The upcoming year will prove to be a big step towards new youth programming and promises to be very exciting. If you have any ideas, be sure to share them with your local representatives before the committee meets in mid-November.

Keep checking the Web site for upcoming national youth events and stay in touch with your local chapter for all of their future events.

See you in September! ☺

A WEEKEND RETREAT FOR YOUNG PEOPLE

The Canadian Hemophilia Society

September 5 to 7, 2008.



Are you between 15-25 years old and would like to make a difference in your community while building your professional and social skills and having fun?

Mark your calendar for

September 5 to 7, 2008

The Canadian Hemophilia Society

will be holding a weekend leadership retreat for young people from around the country with the purpose of learning, personal growth and building relationships.

This workshop will take place at the YMCA Geneva Park in Orillia, Ontario, with the main focus being on leadership training and activities to help you build self-esteem, develop concrete thinking abilities, and make decisions that reflect true leadership qualities. Participation and travel for selected candidates will be covered by the CHS, but please apply early, as spaces are limited!

For more information or to obtain an application form please contact

Hélène Bourgaize at either 1 800 668-2686 or by e-mail at hbougaize@hemophilia.ca



Volunteer File

by Marion Stolte

Chair of the CHS Volunteer Development Committee



Welcome to the first article on volunteerism. Our story began in the spring of 2006 when ten wonderful volunteers desiring to help "grow" the ability of the CHS to successfully recruit, train and recognize volunteers got together and formed the Volunteer Development Committee. Hélène Bourgaize, the CHS Director of Volunteer Development and Human Resources has proven to be an invaluable asset and leader in helping the committee develop a variety of tools for use by chapters and regions.

Not only do the volunteers on this committee *have the heart*, so do all the volunteers across our country, in each of our chapters, on each committee. What a privilege to volunteer together – to see the mission and vision of the Canadian Hemophilia Society fulfilled – to see lives changed and quality of life improved for all with bleeding disorders.

Over the past two years we have successfully developed a number of tools for our chapters and regions. They range from templates of job descriptions, skills and interest surveys, planning calendars, how and where to recruit volunteers, crafting your recruitment message, evaluation forms, terms of reference templates, recognition ideas. In addition, a new volunteer brochure has been designed and can be used by Chapters. The

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

– Elizabeth Andrew

items listed above have all been compiled together into an "easy to use" binder that each chapter/region has been given. Members of the committee have given presentations at CHS AGMs, at chapter AGMs, as well as at the World Federation of Hemophilia's NMO (National Member Organization) training session in 2006. Hélène was also invited to present on volunteering at one of Ireland's Hemophilia meetings. Earlier this month, we presented a poster at the World Congress in Istanbul.

Moving forward we are creating a CHS volunteer Web page which will be usable by both chapters and national levels. Volunteer

opportunities can be posted on the Web and people can regularly go there to see what is available and where they might like to volunteer. We are in the process of researching some type of volunteer database, which could be used by both chapter and national levels. This would facilitate tracking volunteers and their hours, both of which are necessary to obtain certain types of funding.

We have a tremendous committee – and it's a privilege to work with each member. Often committee work is seen as drudgery and not a lot of fun. However, one of our committee members said, "This is my favourite committee!" It's great working together to see volunteers across our country empowered to continue succeeding. The abundant achievements we've made over the years were made possible due to the remarkable volunteers that have worked toward a common vision. We will continue to work diligently to strengthen our organization – so that quality of life for all with bleeding disorders will be improved.

Indeed, the volunteers on this committee, and those of you who participate in some way in the organization, *"have the heart"*.

To find out more about the committee's work or to obtain a copy of the tools mentioned above, please contact Hélène Bourgaize at hbougaize@hemophilia.ca ☺

FUNdraising

Be part of an amazing day when **YOU**

Dare to Dream for Hemophilia

and when **YOU** become a race car driver!

Keep raising pledges at www.idaretodream.ca and for every \$100 raised your name will be entered into the next draw to win your very own seat in the new Van Diemen Formula SCCA Race car at the Bridgestone Racing Academy.

PLUS!... **EXCITING NEWS**

All participants who were encouraged to register by another participant please rush to your event profile and answer the question – Who asked you to register for the *Dare to Dream for Hemophilia* event? The person who asked you to join will receive an extra ballot for the next draw if you successfully raised at least \$100.



Christine Ford of PriceWaterhouseCoopers and Dr. Georges-Étienne Rivard participating in the March 27 draw.

***FEEL** the speed...*

***HEAR** the engine...*

***DRIVE** the hairpin turn, and...*

***DARE** to Dream for Hemophilia*



Dare to Dream for Hemophilia

presented by

Wyeth

FINAL DRAW:
August 28, 2008

BIG EVENT:
September 19, 2008

Don't wait! Invite your friends now to register and raise pledges! YOU could be behind the wheel of a Race car faster than YOU think!



Winners so far...

Derek Gates, Matthew D'Addario, Sarah Bradshaw, John Mullan...**YOU?**

2008 Ron Fellows/Mosport Hockey Challenge in support of the Canadian Hemophilia Society

The CHS is proud to be selected as the benefiting charity for the 2008 Ron Fellows/Mosport Hockey Challenge. Hosted by Ron



Fellows, world-renowned road racer for the factory Corvette team, this exciting hockey challenge will feature current and retired professional hockey players (NHL & AHL), along with race car drivers and crew from the American Le Mans Series.

WHEN: Wednesday, August 20, 2008

WHERE: OUIT Campus Ice Centre in Oshawa, Ontario

TICKETS: \$25 General Admission
\$125 VIP Ticket
\$500 "Play with the Greats" Experience

For more information and to find out how you can participate please contact 1 800 668-2686.

Our thanks to Ron Fellows and Mosport for their support of the CHS!

1960



Research

For those affected by bleeding disorders, research means hope

2008



by David Page, CHS Executive Director

The mission of the Canadian Hemophilia Society is to strive to improve the health and quality of life for all people with inherited bleeding disorders, and to find a cure. Therefore, research is at the heart of our activities. Over the past 17 years, thanks to the Hemophilia Research Million Dollar Club endowment, generous individual donors, committed corporate sponsors, and CHS chapters and regions across the country, the Society has invested more than four and a half million dollars in both clinical and basic peer-reviewed research in Canada. The cure may not yet have been achieved but it is closer every year.

In 2007 and 2008, the CHS is operating three research programs:

- the CHS *Dream of a Cure* Research Program with funding from the Hemophilia Research Million Dollar Club, generous public donations and Bayer HealthCare;
- the *Care until Cure* Research Program in collaboration with Wyeth
- and the Novo Nordisk Canada Inc. – CHS – Association of Hemophilia Clinic Directors of Canada Fellowship in Congenital and Acquired Bleeding Disorders.

Descriptions of the programs and the research projects funded in 2007 and 2008 follow on pages 18 to 22.

The goal of this special feature on research is to inform the community of the tremendous work being accomplished and to acknowledge the commitment of the researchers who have worked to improve the quality of life of people with bleeding disorders over the last year. For those affected by bleeding disorders, research means hope.

We would also like to highlight the behind-the-scenes work of the scientists who have volunteered their time on the Peer Review Committees to evaluate the grant applications. Without them, the CHS would not be able to operate its research programs. They are:

- Dr. Patricia McCusker, *Chair, CancerCare Manitoba*
- Dr. Anthony Chan, *McMaster University Medical Centre*
- Dr. Michael Delorme, *Kelowna, BC*
- Dr. Christine Demers, *Hôpital de l'Enfant-Jésus, Quebec City*
- Dr. Lawrence Jardine, *Children's Hospital of Western Ontario*
- Dr. Michael Nesheim, *Queen's University*
- Dr. Fred Ofosu, *McMaster University*
- Dr. Bruce Ritchie, *University of Alberta*
- Dr. Mary-Frances Scully, *Memorial University of Newfoundland*
- Dr. Jean St-Louis, *CHUM – Hôpital Maisonneuve-Rosemont, Montreal*

We thank you for your dedication. ◊

Hemophilia Research Million Dollar Club



by Maurice Marette, *Chair*

The Hemophilia Research Grants Review Committee, under the chairmanship of Dr. Patricia McCusker, met earlier this year and announced the 2008 CHS Dream of a Cure Research Program grant recipients. Summaries of their projects can be seen on pages 18 to 20. These grants total \$222,000 and were made possible by funding provided by the Hemophilia Research Million Dollar Club, Bayer and the Canadian Hemophilia Society. The Million Dollar Club and the CHS have contributed close to \$3,000,000 in support of hemophilia research in Canada since 1991.

The Hemophilia Research Million Dollar Club endowment fund has now surpassed \$1,800,000 and our dream is that by the end of 2010 the endowment will reach the \$2 million mark. In partnership with the CHS, we hope we can generate even more money each year towards ongoing research.

The Million Dollar Club is the most effective way in which you can support bleeding disorders research in Canada. This is "our" fund – it is a tangible and visible evidence of our commitment to research. Every single dollar, whether you purchase a membership or make a donation, goes to research (there are no administration or fundraising costs) and is tax deductible.

To benefit new families and members of our community who don't know about the Million Dollar Club we have included in this issue of *Hemophilia Today*, a brochure describing the Club and how you can make a difference by investing in hemophilia and other bleeding disorder research.

We would like to acknowledge the Canadian Hemophilia Society and all its chapters and regions, and the individuals, families and groups who are members of the Million Dollar Club or have supported us through donations. Our supporters are also recognized in the Administrators' Annual Report to the members, and at the Annual General Meeting of the Canadian Hemophilia Society. Once again, we thank all of you who are dedicated to supporting bleeding disorder research. ◊

VOTING MEMBERSHIPS

Ken, Darlene and Tony Poyser
Terry Douglas
Lynne Kubin & Family
C. Kang Tan
Mr. and Mrs. Joe Laxdal
Audrey Irene Saigeon
Poyser, Schultz & Glass
Hemophilia Ontario
Manitoba Chapter
The Isaacs
Northern Alberta Region
Toronto & Central Ontario Region
Ray & Helen Poyser
Nova Scotia Chapter
Central West Ontario Region
British Columbia Chapter
Dr. and Mrs. Ron George
Desharnais-Pépin Family
Hemophilia Saskatchewan
Marcel & Aline LaFrance
Estate of Mary Ann Olson
Shaun Aaron Bernstein
Mrs. R.W. Rudd
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Dream of a Cure

CHS Research Program



Supporting research towards improving the quality of life for persons with hemophilia and finding a cure have been goals of the Canadian Hemophilia Society (CHS) since it was founded in 1953. Since 1990, through funds provided by the **Hemophilia Research Million Dollar Club** and the **CHS**, the Society provides basic scientific research grants and studentships aimed at developing treatments for hemophilia and finding a cure.

The following reports describe the projects funded in 2007 and 2008.

DREAM OF A CURE

The role of X-inactivation in the expression of hemophilia A in women

2007 - 2008

Dr. Wenda L. Greer, FCCMG

Professor, Department of Pathology
Dalhousie University - Halifax, Nova Scotia

Hemophilia A is an X-linked bleeding disorder resulting from mutations in the FVIII gene. One functional FVIII gene is sufficient for normal clotting. Thus, typically XY males who inherit one mutated FVIII gene are affected while heterozygous XX females are not. Rarely, heterozygous females with Hemophilia A have been described. These can arise due to unfavourably skewed X chromosome inactivation. This is a dosage compensation mechanism that causes one X in every female cell to be inactivated early in development. In most females, approximately half of their cells inactivate their maternal and half their paternal X. In rare cases, X chromosome inactivation is skewed. If it is skewed toward the activation of a mutated gene, a heterozygous female can be affected. A family has presented with several males and several females affected with Hemophilia A. In the females, most cells were expressing the mutated paternal X chromosome. It is unlikely that chance could account for the dramatic skewing of X chromosome inactivation leading to three affected females.

Our objective is to understand why these females are expressing Hemophilia A. Our hypothesis is that it is due to skewed X chromosome inactivation ratios resulting from an inherited predisposition for the mutated X-chromosome to remain active.



Our aims are to:

- determine X chromosome inactivation patterns and correlate these with disease expression
- determine whether X chromosome inactivation ratio skewing is more consistent with genetically influenced or random X chromosome inactivation.
- delineate, through microsatellite analysis, a region of the X-chromosome that is associated with varied susceptibility of X chromosome inactivation.
- consider potential candidate genes from this region.
- identify the clinical symptoms and standards of care of carrier females, and their experiences with medical treatment by interviewing carrier females and healthcare professionals.

We believe that this family provides a unique opportunity to study X chromosome inactivation and its role in the expression of Hemophilia A in heterozygous females. It also provides an opportunity to document the clinical phenotype of female carriers who differ in their factor VIII activities according to their respective X chromosome inactivation ratios.



DREAM OF A CURE

Gene therapy of hemophilia A

2007 - Second year funding

Dr. Gonzalo Hortelano

Assistant Professor, Department of Pathology

McMaster University - Hamilton, Ontario

We will evaluate the feasibility of cell transplantation therapy to reverse severe hemophilia A in mice. Although current factor VIII (FVIII) products are safe, patients must endure life-long regular FVIII infusions. Thus, a safe and more economic treatment is desirable.



Gene therapy is an alternative. Gene therapy strategies use virus as vehicles to introduce the FVIII gene, but they are associated with undesirable immune responses. Alternatively, transplanted cells producing FVIII are only temporarily functional. We propose the transplantation of non-autologous cells (not from the patient) genetically engineered to continuously produce FVIII. To avoid rejection of the transplanted cells, they are enclosed in tiny microcapsules (less than 1mm in diameter) before being transplanted. The microcapsules allow the free flow of FVIII, but are impermeable to immune cells, therefore protecting the enclosed cells.

We found that mice transplanted with microcapsules containing muscle cells engineered to secrete factor IX contained high amounts of factor IX in the blood for at least 120 days and did not mount an immune response to human FIX. More importantly, this treatment was able to reverse the disease in severe hemophilia B mice. If this were achieved in humans, it would eliminate severe and moderate hemophiliacs. Therefore, we will apply the same strategy to hemophilia A.

Initially, we will engineer muscle cells to produce FVIII, and determine the amount of FVIII they produced. Second, we will enclose FVIII-producing cells in microcapsules that will then be transplanted into mice to determine how much FVIII is found in blood, and for how long. Any immune responses to FVIII will be studied. Finally, the correction of the disease in hemophilia A mice will be investigated.

This transplantation therapy could reduce and ultimately eliminate the need for regular FVIII injections. Importantly, the microcapsules can be removed, increasing the safety of the treatment.

DREAM OF A CURE**Platelet type von Willebrand disease: An underdiagnosed cause of excessive mucocutaneous bleeding?***2008 - Second year funding***Dr. Maha Othman**Adjunct Assistant Professor, Department of Pathology and Molecular Medicine
Queen's University - Kingston, Ontario

Platelet type von Willebrand disease (PT-VWD) and type 2B von Willebrand disease have similar clinical as well as laboratory features while resulting from abnormalities in two different genes. Type 2B VWD results from a defective von Willebrand factor (VWF) and PT-VWD is caused by platelet GP1BA gene defect. The discrimination between the two disorders is often a challenge. The general tests necessary for the identification require particular technical experience and necessitate fresh blood samples. Definitive diagnoses can be made by revealing the gene defect in either the VWF or the GP1BA. The correct diagnosis and discrimination between the two disorders has important implication on treatment decision. The VWF/FVIII concentrate, the major treatment in type 2B-VWD, may worsen platelet count and bleeding conditions in PT-VWD. Platelet concentrate is the ideal treatment for PT-VWD. In this study, we propose that patients with PT-VWD are being under/misdiagnosed among type 2B VWD and we adopt the use of a genetic approach for a definitive diagnosis of PT-VWD. The DNA analysis will include the related area of the VWF gene responsible for type 2B VWD and also the platelet GP1BA gene responsible for PT-VWD in 100 patients initially diagnosed with type 2B VWD from Canada and worldwide. Under the auspices of the International Society for Thrombosis and Hemostasis: Scientific and Standardization Committee on von Willebrand Factor, we established an online database/disease registry now accessible at www.pt-vwd.org. The project/registry will address the question of how many PT-VWD cases are being misdiagnosed among the type 2B VWD cases, increase awareness among physicians, specialists and patients about this diagnostic problem and will indicate the significance of the genetic analysis in these patients with subsequent implication on treatment decision.

DREAM OF A CURE**Factor VII(a) clearance behaviour***2008 - Second year funding***Dr. William P. Sheffield**Associate Professor, Department of Pathology and Molecular Medicine
McMaster University - Hamilton, Ontario

The hemophilia community knows all too well that the replacement therapy that can restore hemophiliacs to an active life is not always problem-free. For individuals with hemophilia A, replacement therapy with purified recombinant factor VIII (FVIII) can sometimes be complicated by inhibitor formation. Inhibitors are antibodies directed against the injected FVIII. Fortunately, administration of recombinant factor VIIa (FVIIa) can bypass this potentially serious problem. However, FVII is one of the coagulation factors that leaves the circulation the most rapidly. This clearance behaviour is not completely understood. For this reason, Drs. Bill Sheffield and Bryan Clarke, of McMaster University and Canadian Blood Services have received a CHS research grant to study the clearance of FVII(a) in mice genetically altered to have hemophilia A. The investigators will use DNA and cell culture technology to make both human FVII identical to current clinical products, and new forms of FVII in their laboratories. Once purified, how long the FVII-related proteins last in the mouse circulation, and how well they control bleeding will be determined. The most unusual products to be tested are "fusions" - in which FVII and human serum albumin, ordinarily separate proteins, are combined into a single chain. The researchers propose that FVII will continue to work in this new format, and will remain in the circulation for much longer than the current product. The longer it remains, the more effective it should be in combating bleeding. Sheffield and Clarke hope that their research will lead to better understanding of the mechanism of action of rFVIIa, and to the design of improved rFVII(a) products to provide caregivers with novel tools to help hemophiliac patients with inhibitors.

DREAM OF A CURE**Structural and genetic analysis of the complexes between factor VIII and low density lipoprotein receptor-related protein: Toward a long-acting factor VIII***2008 - First year funding***Ann English, PhD**Department of Chemistry and Biochemistry
Concordia University - Montreal, Quebec

Scientific developments have provided a new generation of safer factor VIII (FVIII) biopharmaceuticals that are free of blood-borne pathogens. However, the high cost of FVIII still remains a big hurdle in hemophilia treatment. Only certain countries can afford prophylaxis or on-demand treatment while many others cannot even meet on-demand requirements. Clearly, FVIII has to be further developed to yield a product with a prolonged half-life.

Our project that is being supported by the CHS *Dream of a Cure* Research Program will provide the critical structural information to inform the development of longer acting FVIII. It is well known that low-density lipoprotein receptor-related protein (LRP), a receptor molecule, is responsible for eliminating FVIII from blood. FVIII clearance by LRP requires that the two proteins bind to each other. Thus, if the FVIII-LRP binding interaction is decreased, FVIII will remain in the blood stream longer. However, FVIII/LRP binding mechanisms have to be well understood to avoid possible side effects such as the induction of inhibitory antibodies. We will generate a 3D model of the FVIII/LRP binding interfaces using x-ray crystallography. Complexes between specific FVIII domains and LRP clusters will elucidate at the molecular level how LRP binds and eliminates FVIII. Such atomic-level structural details of the binding interfaces will indicate how the sequence of FVIII should be modified to decrease its interaction with LRP. Reduced affinity between FVIII and LRP will be evaluated using state-of-the-art biophysical techniques. The results will guide the development of the next generation of FVIII biopharmaceuticals with a prolonged biological half-life. Longer lasting FVIII will allow *treatment for all* and bring us one step closer to a cure.

DREAM OF A CURE

An evaluation of the prevalence and functional significance of non-neutralizing antibodies to factor VIII

2008 - First year funding

Funded through a research grant to the Canadian Hemophilia Society from Bayer HealthCare

Dr. David Lillicrap

Department of Pathology and Molecular Medicine Queen's University – Kingston, Ontario

The development of antibodies to factor VIII (FVIII) represents the main treatment-related complication of current therapies for hemophilia A. For the past 30 years, this complication has been evaluated by a laboratory test that detects only those antibodies that interfere with FVIII's clotting function. There is growing evidence to suggest that in addition to antibodies that inhibit the functional activity of FVIII, some "non-neutralizing" antibodies are also generated by FVIII exposure. The prevalence of these antibodies, their overlap with neutralizing inhibitors and their clinical significance are all factors that are very poorly characterized and form the basis for the studies proposed in this research project. In this project, we will establish a laboratory test to detect and quantify the levels of antibodies that bind to FVIII in plasma. The test plasma samples have already been characterized with a functional antibody test (the Bethesda assay) and thus overlapping patterns of reactivity will be apparent. Finally, when detected, we will attempt to correlate the presence of non-neutralizing antibodies with in vivo FVIII recovery and half-life.

**Care Until Cure**

The Care Until Cure Research Program was established in the year 2000 in collaboration with Wyeth Canada.

Wyeth Canada is engaged in the discovery, development, and commercialization of human pharmaceuticals through recombinant DNA and other technologies. This program allows Canadian investigators to conduct research on various medical and psychosocial aspects of bleeding disorders. Grants are given for clinical research, including outcome evaluation, in fields relevant to improving the quality of life of persons with hemophilia, persons with von Willebrand disease or other inherited bleeding disorders, persons with related conditions such as HIV or hepatitis C as well as carriers of an inherited bleeding disorder.



The following reports describe projects funded in 2007 and 2008.

CARE UNTIL CURE**Creating meaningful messages for individuals with mild hemophilia**

2007 - Second year funding

JoAnn K. Nilson, PT

Physiotherapist

Saskatchewan Bleeding Disorders Program
Saskatoon, Saskatchewan

This multi-phased project brings individuals with mild hemophilia and physiotherapists together to create more meaningful educational materials specifically for people with mild hemophilia. The Canadian Physiotherapists in Hemophilia Care (CPHC) have serious concerns about gaps in patients' understanding of mild hemophilia. Young adults with mild hemophilia are often seen in the emergency room days after a traumatic incident with an uncontrolled bleed which then takes weeks or months to totally resolve. These clinical experiences suggest that the educational materials and strategies currently in use, that target individuals with severe hemophilia, are not effective in providing information that facilitates those with mild hemophilia to seek care in a timely manner.



The purpose of this study is to consult young adults with mild hemophilia, parents of children or adolescents with mild hemophilia and PTs from across Canada in order to identify appropriate communication strategies to be used in educational mate-

rial about health and healthcare specifically for people with mild hemophilia. In Phase 1 we will focus on the lived experiences of young adults with mild hemophilia from four locations in Canada. Through semi-structured interviews, we will learn about participants' internal 'processes' and choices that they make in accessing medical care after injury, learn about messages, information and knowledge that participants feel would motivate them to seek care in a timely manner. During Phase 2, the knowledge gained in Phase 1 will be used to guide a group of PTs from across Canada. They will identify educational strategies that are grounded both in the experiences and attitudes of individuals with mild hemophilia and in the realities of the health care system. In Phase 3, these strategies will be further refined during focus groups of young adults and PTs and parents of children with mild hemophilia and PTs in both French and English. This phase will also include written or telephone consultation with young adults with mild hemophilia who live in rural settings. Participants from each phase will be invited to continue their involvement in the project through written or verbal feedback after each phase.

This research will help to develop a model that demonstrates a viable way of integrating the perspectives and knowledge of patients and health care professionals in order to create the most meaningful, client centered, realistic educational strategies specifically for persons with mild hemophilia.

CARE UNTIL CURE

The prevalence of symptomatic pediatric VWD

2008 - Second year funding

Dr. Paula James, FRCPC

Assistant Professor

Queen's University - Kingston, Ontario

Von Willebrand disease (VWD) is an inherited bleeding disorder that causes bleeding from mucous membranes (ie: nosebleeds, bleeding gums and heavy menstrual periods) and easy bruising. Diagnosing the condition can be very difficult, particularly in children. Although bruises and nosebleeds are common among children with VWD, very young children may not have had a chance to manifest other characteristic bleeding symptoms, such as heavy menstrual periods or bleeding after surgery. To compound this, it is often difficult for patients to recognize whether certain symptoms are normal or abnormal and most of the attempts to address this by creating standardized bleeding questionnaires have been focused on the adult population.



In the current study, we propose to address the issue of the **symptomatic** prevalence of VWD in children by investigating children who have symptoms of bleeding or bruising for VWD. Additionally, we propose to validate a commonly used (modified) adult bleeding questionnaire in children during the course of this study. We will accomplish this by screening between 10,000 and 15,000 children attending a pediatric outpatient centre for bleeding or bruising symptoms. Those that report a problem with bleeding or bruising symptoms will be further evaluated using a bleeding questionnaire. Children with positive bleeding scores will then be investigated with VWF laboratory studies. The bleeding questionnaire will also be administered to a group of ~300 normal children to allow for the validation of the questionnaire. This study will be carried out by investigators who have recently completed a complementary study, performed primarily on adults, evaluating the prevalence of VWD at the level of primary care.

CARE UNTIL CURE

Non-steroidal anti-inflammatory drugs and menorrhagia revisited

2008 - Second year funding

Dr. Rochelle Winikoff, FRCPC

Staff hematologist

CHU Sainte-Justine - Montreal, Quebec

Menorrhagia is a common clinical problem to which there is no standard medical treatment approach. It is estimated that about 30% of women complain of menorrhagia and it is the main presenting complaint in women referred to gynecologists. Non-steroidal anti-inflammatory drugs (NSAIDs), which non-specifically inhibit cyclooxygenase (COX), are effective in approximately 50 to 60% of women with menorrhagia, with reductions in menstrual blood loss (MBL) of the order of 30 to 40%. Clinical studies have shown that NSAIDs are more effective in women who have higher baseline MBL. A subset of women with menorrhagia have increased MBL related to overproduction of prostacyclin (PGI₂) and increased local uterine vasodilatation, which may be targeted by NSAID therapy.



Among women with menorrhagia, those who produce higher baseline levels of PGI₂ are more likely to have a better response to non-specific COX inhibition by NSAIDs than women who secrete lower levels. The variability and degree of response to NSAIDs observed in the literature may, at least in part, depend on the baseline levels of PGI₂ production in women with menorrhagia. Other clinical factors such as age, weight, parity and dysmenorrhea may also predict a favourable response to NSAID therapy. The main objective of this study is to identify clinical predictors of response to NSAID therapy in women with menorrhagia. We will also determine if higher baseline levels of PGI₂ in women with menorrhagia correlate with their clinical response to COX inhibition by NSAIDs.

Women between the ages of 18 and 40 with primary menorrhagia will be treated with an NSAID for two consecutive menstrual periods and the MBL will be recorded using the Pictorial Blood Assessment Chart (PBAC). Recruitment for this study will take place over 18 months. Potential clinical predictors of response to NSAIDs will be

collected. Baseline levels of PGI₂ urinary metabolites will be measured in all eligible women. Logistic regression will be used to assess various clinical variables and PGI₂ as a predictor of significant response to NSAID therapy. A significant response will be defined as a $\geq 30\%$ decrease in PBAC score. The average baseline PBAC score will be compared with an average of 2 post-treatment PBAC scores.

The results of this study should help clinicians identify women for whom NSAID therapy should be considered upfront to treat menorrhagia. Clinical indices including baseline PGI₂ measurements could be a part of the initial clinical evaluation for menorrhagia and could help distinguish between women with menorrhagia who are likely to respond to treatment with NSAIDs and those who are not, in whom alternative therapies may be more beneficial. A similar treatment strategy could eventually be applied to women with menorrhagia related to bleeding disorders

CARE UNTIL CURE

Bleeding disorders, menorrhagia and iron deficiency: An examination of quality of life

2008 - First year funding

Dr. Ronald Barr

Department of Clinical Epidemiology and Biostatistics

Health Sciences centre - McMaster University, Hamilton, Ontario

The Canadian Hemophilia Society has awarded Dr. Ronald Barr of McMaster University, and co-investigators at three other Canadian centres, a research grant to analyze data from a national survey of women and men with inherited bleeding disorders. The survey was undertaken because a pilot study had shown that women with the most common bleeding disorder, von Willebrand disease, had much poorer overall health than men with the same disease and about the same level of poor health as severe hemophiliacs who are infected with the AIDS virus. It was proposed that bleeding disorders in women, by causing heavy menstrual bleeding, lead to chronic iron deficiency, poor overall health and low educational achievement. All re-

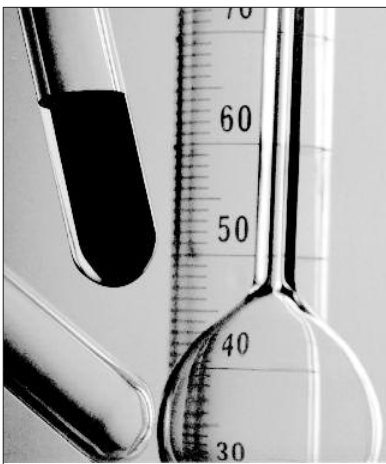


gional hemophilia centres in Canada supported the national survey that collected information and blood samples (to determine iron levels) from a total of 408 people. A questionnaire asked about 14 important aspects of overall health, highest level of education and use of iron supplements. Women in the survey answered a set of questions about their menstrual bleeding pattern. A state-of-the-art measurement system was used to measure the overall health of each person. Statistical tests will show whether women with bleeding disorders

have poorer health and lower educational achievement than comparison groups, such as men with similar bleeding disorders and whether these deficits are related to iron deficiency. Results from the study may justify a large randomized clinical trial of iron supplements to improve overall health and educational achievement in

women with excessive menstrual blood loss associated with inherited bleeding disorders. This study is important because iron supplements are inexpensive to make, easy to take, and could greatly improve the quality of life for millions of such women around the world.

This study is important because iron supplements are inexpensive to make, easy to take, and could greatly improve the quality of life for millions of such women around the world.



Novo Nordisk Fellowship

The Novo Nordisk Canada Inc. – Canadian Hemophilia Society – Association of Hemophilia Clinic Directors of Canada Fellowship in Congenital and Acquired Bleeding Disorders is a

fellowship program established in the fall of 2001. Novo Nordisk has a leading position within areas such as coagulation disorders, and manufactures and markets pharmaceutical products and services that make a significant difference to patients, the medical profession and society.

The goal of this fellowship program is to provide fellows in hematology or other relevant fields the opportunity to acquire clinical or research skills necessary to improve the care and quality of lives of patients with hemophilia and other congenital or acquired bleeding disorders.

The following report describes the project funded in 2007.



NOVO NORDISK FELLOWSHIP

Quality assurance of special coagulation laboratory practices

2007 funding

Dr. Elianna Saidenberg

Chief Resident in Hematology
McMaster University - Hamilton, Ontario

It is a pleasure for me to have this opportunity to introduce myself to the hemophilia community of Canada. I am presently in my sixth postgraduate year of medical training and am enrolled in a transfusion medicine fellowship at the University of Ottawa. Concurrent with this training I am working in the coagulation laboratory and with the clinical hemophilia and bleeding disorders service. Given the necessity of treating many haemostatic defects with human and recombinant blood products, the connection between transfusion medicine and hemostasis medicine feels very natural.

This year I am the very fortunate and grateful recipient of the Novo Nordisk – Canadian Hemophilia Society – Association of Hemophilia Clinic Directors of Canada Fellowship in Hemophilia. I aim to use the opportunities afforded to me by this fellowship to gain the skills needed to effectively manage a coagulation laboratory. Availability of prompt, precise and accurate measurements of hemostatic parameters is vitally important in the provision of medical care to patients with bleeding disorders. To further my knowledge

and understanding of procedures and process in the coagulation lab I am planning several quality assurance projects.

The first project I have undertaken relates to creation of normal ranges for platelet aggregation and secretion tests done at our site. These tests are very important in the diagnosis of congenital and acquired disorders of platelet function as well as other disorders of coagulation such as von Willebrand disease. The testing machines used are called aggregometers. They provide a visual representation of the test results as a graph and also provide measurements of the slope and amplitude of the curve. Interpretation of these tests relies heavily on the interpreting physician's reading of the curve. Thus, the results could vary based on the eye of the interpreter. To improve the accuracy of these test results it is recommended by the Clinical Laboratory Standards Institute that every laboratory calculate normal ranges for their own aggregometers. To comply with these recommendations, I have begun the task of compiling data on aggregation test results done on healthy volunteers at our centre. This information will then be evaluated by a statistician who will apply the necessary mathematical processes to determine the normal ranges.

Subsequent projects I have planned will evaluate the quality of other tests done in the coagulation lab to help ensure their quality. Through assessment of these procedures, I will gain vital skills in laboratory management which will hopefully help me ensure that I can provide the best possible care for my patients with bleeding disorders. ◊





Full Moon Wish

by Karen Dunn



I always looked up to my older brother Patrick. He was older, smarter, and better than me at just about everything. He had what people call "The Midas Touch" or better yet, "The Patrick Touch". Most brothers and sisters fight – and sometimes even dislike each other – not us.

For the first ten years of my life, everything was just right. It even seemed normal to watch Patrick giving himself needles at the kitchen table. Patrick had a bleeding disorder called hemophilia. This rare condition is passed down from parent to child at birth. Some parents may not even know they are carriers. My mom did not know she would give hemophilia to my brother.

The blood of people with hemophilia does not clot normally and they can bleed for long periods of time, usually into their muscles and joints. To make his blood clot, Patrick had to get a needle into his vein.

Despite having this serious condition, my big brother never wanted – nor did he settle for – a protected life inside our home. He faced every day head on, even if it meant enduring pain from internal bleeding. Patrick skied, skated, and even raced down the toboggan hill. I never gave much thought to his bleeding disorder until I was old enough to learn the truth and details about his condition.

Patrick lived with a secret. I learned that he needed large amounts of blood products to survive. With each needle he put into his body, Patrick was accepting someone else's

In the story *Full Moon Wish* Lyanne Fortin-Foster tells us in her own words about her experience with her older brother Patrick, a young hemophiliac who contracted HIV and AIDS.

Lyanne shares this story of love, courage, and compassion. With each full moon, Patrick made a wish: a wish that a way would be found to eliminate HIV and AIDS before he drew his last breath.

Patrick0AIDS, the dream, remains alive through the organization dedicated to his memory, **Patrick4Life**, and the annual Partici-Patrick project in schools. Through awareness raising, education, and dialogue we will make Patrick's wish come true one day. Visit www.patrick4life.org.

blood. Unfortunately – and tragically – it was a time when some people donated blood contaminated with HIV. At age 7, Patrick became HIV-positive, which meant he had a great chance to someday develop the full-blown, life-threatening disease called AIDS.

When I realized that Patrick's illness would lead to his death, my world came crashing down. I could not imagine my life without him. *Why would the blood that he needed to survive take his life away?* These life-and-death issues and unanswered questions were too much for a 10 year old who liked to play and have fun with her big brother.

Patrick sensed the shock I felt upon learning his secret and engulfed me in his arms with a "hug of love", welcoming me as one of his "secret keepers". My brother had not changed, but I had. I realized that each minute spent with him was very precious.

Full moons became our symbol of hope. Patrick taught me to wish upon every full moon in the hopes that a cure for AIDS would be found before he took his last breath.

Patrick entered high school and his accomplishments mounted: trophies, awards, and early university acceptance. To the outside world, Patrick had it all. But the secret of living with AIDS continued to cast a dark shadow over his many successes and he knew that this shadow had to be lifted. Patrick decided to make his journey with AIDS public, knowing that many people were afraid of this disease because they did not understand it. He revealed that he had contracted HIV through tainted blood, like many other Canadians. Patrick told his story so that people would realize that HIV and AIDS are preventable.

Although he was very sick, my dear brother, friend and teacher never stopped sharing his gift of love and laughter with everyone. As days turned into weeks, it was soon apparent that our full moon wish would never come true. His medical care intensified while his smile and grace brought us peace.

Patrick never complained about his pain or expressed anger about dying. He didn't question God about his imminent death; he accepted what was to be. Patrick's optimistic outlook taught me FAITH, LOVE and ACCEPTANCE.



The day Patrick died was like no other day in my life. My mom woke me up to say goodbye to my brother, forever. It was a cold, rainy, November morning. When I entered his hospital room, tears poured down my face. I said goodbye to his body that day but I will never say goodbye to his spirit.

I wear the precious rosary ring that Patrick left me with pride. It is a simple gold band with ten knots for prayer, one for each year I lived without knowing his secret.

Having a brother like Patrick and watching him die changed me. It has empowered me to dispel the myths about HIV and AIDS. Patrick taught me the importance of talking about HIV and AIDS as a means of prevention. He shared his journey and faced his death with bravery. He paved the way for us to continue his teachings and eradicate HIV and AIDS. Patrick left me with the hope that someday AIDS will no longer take the lives of brothers, sisters, mothers, fathers and friends.

With each full moon I still wish for a cure for AIDS. This was Patrick's wish. It is mine. And I hope that it is now also yours. ○



Medical News

Hepatitis C Press Review

by Michel Long, CHS Program
Development Coordinator

■ Study shows positive findings in treating patients with advanced hepatitis C

April 24, 2008 – The hepatitis C therapy peginterferon alfa-2b, when given as low-dose maintenance therapy, can prevent disease progression in certain patients who failed previous interferon-based hepatitis C therapies and have advanced liver disease, according to findings from a large, four-year study. The study, called COPILOT (Colchicine versus Peg-Intron Long-Term), showed that low-dose peginterferon alfa-2b was superior to colchicine in improving the disease-free survival of patients with cirrhosis and portal hypertension, especially in patients who stayed on treatment. "These findings make a strong case for considering low-dose peginterferon alfa-2b as a maintenance therapy in patients with cirrhosis and portal hypertension who have failed hepatitis C eradication therapy," said principal investigator Nezam Afdhal, MD. "While other interferon maintenance therapies have been studied in the past few years in previous interferon nonresponders, these findings show, for the first time, a clinical benefit in a specific population with advanced disease," he said.

For more information:
www.medicalnewstoday.com/articles/105346.php

■ Alcohol, Tobacco and Cannabis All May Promote Liver Disease Progression in People with Chronic Hepatitis C

In the April 2008 *Journal of Hepatology*, three hepatology experts reviewed environmental factors associated with accelerated liver fibrosis progression in chronic hepatitis C (HCV) patients. They noted that these factors have been

investigated in order to improve clinical outcomes, especially for "difficult-to-treat" patients who tend to respond poorly to interferon-based therapy. The authors wrote, "Several studies have shown that a combination of HCV infection and high levels of alcohol abuse results in synergistic acceleration of liver fibrogenesis." In addition, more recent data indicate that even light alcohol consumption may also worsen fibrosis progression. Some studies have suggested that tobacco smoking may enhance histological activity in chronic hepatitis C patients, thereby promoting fibrosis progression. This may be due to cytokine changes triggered by low oxygen levels. Cannabis use is increasingly emerging as a novel factor linked to liver disease progression in patients with chronic hepatitis C. Studies have shown that regular cannabis smoking is an independent predictor of both fibrosis and steatosis severity in HCV-infected patients. The authors concluded, "Patients should be informed of the deleterious impact of alcohol, tobacco and cannabis use, and should be offered appropriate support to achieve abstinence."

For more information:
www.hivandhepatitis.com/hep_c/news/2008/032808_a.html

■ Use of CT Scans to Monitor Liver Fibrosis in People with Hepatitis C

January 15, 2008 – Liver biopsy is regarded as the "gold standard" for diagnosing and staging liver fibrosis in people with hepatitis C, but the procedure is unpleasant, costly, and carries a small risk of complications. Thus, researchers have explored a variety of non-invasive methods, including blood tests and external imaging, to monitor liver disease progression without repeated biopsies.

Spanish researchers reported the results of study of one such method – computed tomography, or CT scans – in the December 20, 2007 advance online edition of the journal *Hepatology*. This study evaluated an image-processing method for assessing liver fibrosis using conventional CT scans in patients with chronic hepatitis C.

Based on their findings, the authors concluded, "Optical digital analysis of CT images of the liver is effective in

determining the stage and distribution of liver fibrosis in chronic hepatitis C." They added, "Fibro-CT is a simple to use, readily available and useful method for the diagnosis of fibrosis in patients with chronic hepatitis C."

For more information:
www.hivandhepatitis.com/hep_c/news/2008/011408_b.html

■ Liver Transplant Outcomes in HIV Positive Patients with Viral Hepatitis

April 29, 2008 – Until a few years ago, HIV-positive individuals were typically considered ineligible for organ transplants due to a high risk of poor outcomes. This changed, however, with the advent of combination antiretroviral therapy that enabled full HIV suppression, good immune recovery and longer life expectancy. At the 43rd Annual Meeting of the European Association for the Study of the Liver (EASL) held in Milan in April, researchers presented data on outcomes of liver transplantation among HIV-positive individuals in Italy, most of whom were coinfecting with the hepatitis C virus (HCV) or hepatitis B virus (HBV).

To evaluate possible extension of the indication for orthotopic liver transplantation to include HIV-infected individuals, the Italian National Centre for Transplantation nominated a committee of experts to design a protocol to be applied on a national basis. The program was voluntarily adopted by six Italian liver transplant centres. Between September 2002 and November 2007, 60 HIV-positive individuals with liver cirrhosis underwent transplantation using cadaver donors. The investigators concluded that, "The short-term results of orthotopic liver transplant in HIV-infected individuals are slightly inferior when compared with those observed in HCV or HBV mono-infected orthotopic liver transplant recipients."

For more information:
www.hivandhepatitis.com/2008icr/easl/docs/042908_g.html ○



Opportunities to participate in research

■ The differential identification of platelet type von Willebrand disease (VWD) from its non-identical twin type 2B VWD: A significant impact on treatment decision

Canadian PT-VWD molecular study and international database/registry

There is a growing concern about the appropriateness of the differential identification between type 2B von Willebrand disease (2B VWD) and platelet type-VWD (PT-VWD). The two similar bleeding disorders result from genetic defects at two different genes, the VWF and the platelet GP1BA genes.

The required platelet aggregation based phenotypic tests are poorly applied in the general hemostasis laboratory and requires fresh blood samples. The genetic analysis is a gold standard confirmatory test with feasibility of sample transport.

Evidence exists that PT-VWD is being misdiagnosed among cases of type 2B more often than not and even among cases of idiopathic thrombocytopenic purpura (ITP) and possibly unexplained platelet disorders. There is an obvious critical impact on treatment decisions. We discussed this diagnostic dilemma at the ISTH VWD subcommittee meeting in Geneva in July 2007 and an international online PT-VWD database/registry was proposed and approved at the meeting. The database is currently available at: www.pt-vwd.org.

This database represents a rich resource for PT-VWD and outlines the Canadian PT-VWD molecular study which is based mainly on genetic analysis of the related region of the VWF gene in phenotypically diagnosed type 2B VWD cases and, in mutation negative, the platelet GP1BA

gene where mutations responsible for the PT-VWD cases have been reported. The study will address two major questions:

1. Is PT-VWD truly rare or underdiagnosed?
2. How many cases are being misdiagnosed among type 2B VWD cases?

The Canadian molecular study is funded by the CHS, directed by Dr. Maha Othman and carried out at David Lillicrap's laboratory facilities at Queen's University. It aims to achieve a target of 100 cases before the end of 2008.

We need collaboration from general practitioners, clinical directors and all hematologists who may have identified cases with provisional diagnosis of type 2B VWD based on clinical and laboratory data to send in DNA samples together with phenotypic information. The genetic analysis will be performed to confirm the differential diagnosis and results from the study will be reported back to the participating laboratories and clinics.

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■ AHCDC-CHAVI: An international research collaboration on HIV proposed

by Drs. Irwin Walker and Bruce Ritchie

SASKATOON, Sask, May 3, 2008 – At the annual meeting of the Association of Hemophilia Clinic Directors of Canada (AHCDC), an international HIV research collaboration was proposed between AHDCDC and CHAVI. CHAVI is the Center for HIV/AIDS Vaccine Immunology and is currently one of two implementation projects under the Global HIV Vaccine Enterprise. In July 2005, the National Institute for Allergy and Infectious Diseases (NIAID) awarded the CHAVI grant to a consortium of investigators from Duke University, the Dana-Farber Cancer Institute, Beth Israel Deaconess Medical Center, Oxford University, and the University of Alabama-Birmingham, led by Dr. Barton Haynes.

The achievements of CHAVI can be viewed on their Web site (www.chavi.org). In a recent paper, they showed that both control of viral load and control of disease progression could be tracked to specific DNA polymorphisms.

The project would investigate whether resistance to HIV infection can be tracked to differences in genes (polymorphisms) among individuals. It is sometimes said that HIV-negative individuals with hemophilia were "lucky" to have escaped HIV infection, but maybe they have an in-born resistance that could be traced to their genes. If there were more knowledge about this resistance, there could be opportunities to develop vaccines and drugs to enhance this resistance for people around the world still faced with HIV exposure.

The specific project, *Investigations of Gene Variants Associated with Resistance and Susceptibility to HIV-1 infection in HIV-1 Exposed but Uninfected Individuals with Severe Hemophilia A*, has been funded and approved by the National Institutes of Health.

The hemophilia community that was so devastated by HIV now has an opportunity to contribute in an important way towards solving the world's continuing problem of HIV infection. Individuals with hemophilia A seem the most suited for this project as they were almost all infected within a period of five years and the infection rate was high. Eligible individuals include those with severe hemophilia A (<1% factor VIII), who are HIV negative and who were born in or before 1980.

Why select Canada?

Though other countries have been approached and will likely contribute, Dr. Lucy Dorrell, from Oxford University and coordinator of the CHAVI project, feels that Canada is best situated to kick-start the project because of its up-to-date Canadian Hemophilia Registry and sample collection system, the Blood Borne Pathogens Surveillance Project (BBPSP).

How can individuals take part in this research?

The project fits very well into the BBPSP project. For those individuals who have donated samples to BBPSP and have signed the latest consent form, nothing more needs to be done as the samples at BBPSP in Edmonton are entirely suitable. Those who signed an earlier version of the consent form can re-consent on this latest version, with or without an extra blood sample. This form states, "I consent to search for genetic features that affect the predisposition to disease caused by blood borne pathogens described above." ◊

AHDC and Baxter Canada announce multi-year research partnership

SASKATOON, Sask, May 3, 2008 – The Association of Hemophilia Clinic Directors of Canada (AHDC) and Baxter Corporation (Canada) have announced a research program called the Baxter-Canadian Hemophilia Epidemiological Research Program (B-CHERP).

Through the B-CHERP program, Baxter will provide \$875,000 in funding over three years. This support will fund the establishment of a data analyst position to oversee key research projects utilizing the CHARMS database, and the initiation of an open competition for research grants annually over the next three years. Three peer-reviewed grants will be awarded annually.

"The research grants and funding provided for the CHARMS database are important investments in necessary infrastructure and resources that allow researchers to ask meaningful questions about hemophilia care and treatment."
- Dr. Manuel Carcao

"We are very pleased to have this continued partnership with Baxter Canada," said Dr. Manuel Carcao, a physician with the Hospital for Sick Children, Division of Haematology/Oncology, in Toronto and outgoing president of the Association of Hemophilia Clinic Directors of Canada. "The research grants and funding provided for the CHARMS database are important investments in necessary infrastructure and resources that allow researchers to ask meaningful questions about hemophilia care and treatment."

"Through our ongoing partnership with the AHDC we continue to gain a deeper understanding of what the hemophilia community needs and how we can help," said Serge Messerlian, Business Unit Director, BioScience, Baxter Corporation. "The work the AHDC does is invaluable and Baxter is proud to be their partner."



CANADIAN PHYSIOTHERAPISTS IN
HEMOPHILIA CARE

PHYSIOTHÉRAPEUTES CANADIENS
EN HÉMOPHILIE

Rethinking the meaning of "spontaneous"

by Nicole Graham, PT

Vice-President, Canadian Physiotherapists in Hemophilia Care

The term "spontaneous bleed" is used extensively within the hemophilia community. Recently, the Canadian Physiotherapists in Hemophilia Care (CPHC) group has been discussing the meaning of this term and its implications.

"Spontaneous bleeding" is referred to in the medical literature; it is used by medical professionals and is found in various printed materials. There are numerous scientific articles quoting the term, especially when referring to central nervous system (CNS) bleeds. Medical professionals including physicians, nurses, social workers and physiotherapists also refer to the term "spontaneous bleed" when a bleed occurs for which the cause is unknown. In the resource binder *All About Hemophilia: A Guide for Families*, it states:

"There is often no obvious cause for the bleeding – it just happens. This is called *spontaneous bleeding*." In addition, some believe that spontaneous bleeding can occur in persons with severe hemophilia or in those with inhibitors.

The term "spontaneous" is defined as a process or event occurring without apparent external cause. This leads us to believe that a person with hemophilia can sustain a bleed for no good reason. Is this true? Is the problem in hemophilia not only a lack of factor which affects the coagulation cascade, but also a problem of bleeding with no apparent cause, without stimulus or trauma? Is there a problem with the integrity of the tissues? Is there any evidence to show that normal tissues can start bleeding without any disturbance in hemophilia?

In the absence of any evidence-based data on the topic, we do have long-term clinical follow-up. Take for example, a knee joint bleed. After an initial trauma followed by a bleed, the tissues are disrupted. Recurrent bleeding in the same joint may occur after minimal trauma that may go unnoticed, leading one to believe that the resulting bleed happened "spontaneously." Perhaps it is semantics. Rather than using the term "spontaneous bleed," would it add clarity to say "a bleed with an unrecognized cause?" Getting away from the term spontaneous may help the person with hemophilia and those who treat them to recognize that even minimal trauma can trigger a bleed and thus lead to prevention, better recognition and more timely response to treatment so that the health of the person with hemophilia can be improved.

Perhaps more questions are raised than answers exist at this point. However, the CPHC looks forward to your opinions and ongoing discussion on the topic. ◊

Rather than using the term "spontaneous bleed," would it add clarity to say "a bleed with an unrecognized cause?"

The Blood Factor

by David Page,
CHS Executive Director



■ Companies report on new developments at AHDCDC annual meeting

SASKATOON, Sask, May 4, 2008 – At the annual meeting of the Association of Hemophilia Clinic Directors of Canada, held May 2-4, companies in the Canadian marketplace reported on progress in the development of novel clotting factor concentrates.

■ Baxter to introduce 2000-IU vial size of Advate®

Baxter confirmed that the company will introduce the 2000-IU vial size for its recombinant factor VIII product, Advate®, in late summer or early fall 2008.

It also presented news of products in its pipeline. Baxter has applied for Investigational New Drug (IND) approval to proceed to clinical trials for its recombinant von Willebrand factor. In addition, the company is engaged in pre-clinical development of a longer half-life recombinant factor VIII product.

■ Bayer moving ahead with liposome factor VIII

Bayer reported that it is moving ahead with a Phase III clinical trial of its novel factor VIII concentrate, BAY 79-4980. This combination of Kogenate® FS and liposomes is intended to produce a longer-acting factor VIII which would reduce the frequency of infusions for both prophylactic and on-demand therapy.

The randomized, double-blind, crossover trial will recruit 250 patients from countries around the world, including Canada. It will last three years and be the largest trial of its kind ever conducted in the field of hemophilia.

■ CSL Behring refines Humate P®

CSL Behring reported that it had made several refinements to Humate P®, a plasma-derived product used to treat von Willebrand disease. Humate P is now available in a formulation that requires less volume of diluent. It comes shipped with the Mix2Vial® administration set and has

approval for room temperature storage.

Helixate® FS, a recombinant factor VIII product, will be introduced into Canada in summer 2008. (See *Hemophilia Today*, Vol 43, no 1.) The product will soon be made available in the 2000 IU vial size.

CSL Behring also described its albufuse™ technology, designed to extend the half-life of therapeutic proteins through genetic fusion to recombinant human albumin. Pre-clinical data suggest that fusion of recombinant factor VIIa (rFVIIa) to recombinant human albumin, using albufuse, extends the circulatory half-life of the recombinant protein six- to nine-fold.

■ Novo Nordisk develops factor VIIa analogues

Among the products in the pipeline at Novo Nordisk Canada is a long-acting analogue of factor VIIa, called NN1728. This GlycoPEGylated Factor VIIa, currently in pre-clinical development, is being developed by Novo Nordisk under a license from Neose.

Factor VIIa is used in the treatment of bleeding episodes and for the prevention of bleeding during surgery in hemophilia patients with inhibitors to coagulation factors VIII or IX.

Also in development at Novo Nordisk are a short-acting, high-potency analogue of factor VIIa, called NN1731, and a recombinant factor VIIa, called VII-25, that is stable at room temperature for 24 months.

■ Octapharma introduces two new products

Octapharma Canada Inc. announced that Wilate® and Octaplex® will be available in Canada as of May 2008.

Octaplex is a plasma-derived prothrombin complex concentrate (PCC), containing human coagulation factors II,

VII, IX and X in combination. It is currently licensed in 26 countries worldwide, including Canada, for the treatment and prophylaxis of bleeding in hereditary and/or acquired coagulation deficiencies of the prothrombin complex factors. PCCs are used in the treatment of factor II and X deficiency.

Wilate is Octapharma's plasma-derived von Willebrand factor/FVIII concentrate. It is licensed in 18 countries for the treatment and prophylaxis of hemophilia A and/or von Willebrand disease (VWD). In Canada, Wilate is currently approved for the treatment and prophylaxis of bleeding in patients with hemophilia A. Octapharma's submission to Health Canada for a VWD indication is currently under review.

■ Wyeth's Xyntha® approved by Health Canada

Wyeth reported that Health Canada's Biologics, Radiopharmaceuticals and Genetic Therapies Directorate has approved its new genetically engineered factor VIII concentrate, Xyntha®, for the treatment of hemophilia A. Xyntha is a third-generation recombinant factor VIII; the culture in which the cells are grown is free of any human or animal material. In addition, the purification process has been refined by utilizing a synthesized affinity ligand rather than a mouse monoclonal antibody.

Xyntha contains the identical B-domain deleted factor VIII molecule as Refacto®, Wyeth's other factor VIII concentrate. In clinical trials, Xyntha was shown to be effective at preventing or controlling bleeding, including preventing bleeding in surgery, for hemophilia A patients. It is licensed for routine and surgical prophylaxis. The marketing date for Xyntha in Canada is not known. ◊

Health Canada Endorsed Important Safety Information on PREZISTA™ (darunavir)

On May 12, 2008, Health Canada issued a Public Communication providing patients with important new safety information about serious liver side effects that have been reported with Prezista™ (darunavir).

Prezista, which is used in combination with another antiretroviral medication known as ritonavir, is used to treat adult patients in whom other HIV therapy has failed.

The warning says that in clinical trials, 0.5 per cent of people who took the drug developed hepatitis or inflammation of the liver.

The department says people on the drug should contact their doctor immediately if they have any of these symptoms: dark urine, yellowing of the skin, abdominal pain (especially on the right side below the ribs), general itchiness, decreased appetite, nausea or vomiting and tiredness.

Patients should NOT discontinue their medication without consulting a doctor or pharmacist first.



A Global Perspective

CHS continues to support valuable projects in 2008!

by Michel Long, CHS Program Development Coordinator

The CHS International Projects Committee, impressed with the quality of the work being accomplished by the national office, CHS Chapters and Canadian HTC's involved in World Federation of Hemophilia twinning initiatives, is proud to be able to continue to support the various Canadian and international partners who submitted funding proposals in 2008. Grants have so far been confirmed for the following projects in 2008. (The committee will continue to accept proposals until June 30.)

■ **South African Hemophilia Foundation (SAHF) & Canadian Hemophilia Society (CHS)**

\$3,034 has been granted to SAHF to allow a South African youth to take part in the CHS Youth Leadership Training Workshop to occur September 5-7, 2008.

■ **Tunisian Hemophilia Association (ATH) & Canadian Hemophilia Society – Quebec Chapter (CHSQ)**

\$7,000 has been granted to these partners to support them in making possible various activities from their 2008 action plan, including medical and psychosocial workshops, survey visits to 10 southern governorates, sponsorship of an ATH delegate to attend the WFH Congress and for CHSQ members to travel to Tunisia to provide training on strategic planning and the creation of an efficient organizational structure.

■ **Jordanian Hemophilia and Thalassemia Society (JHTS) & Toronto and Central Ontario Region (TCOR) – Hemophilia Ontario**

\$7,500 has been granted to these partners to sponsor one JHTS delegate to attend the

WFH Congress. Furthermore, two members of TCOR will travel to Jordan and two Jordanians will travel to Canada to obtain knowledge and skills in patient education, volunteer development, recruitment and management, strategic planning, leadership development and succession planning.

■ **Shanghai, China HTC & Southern Alberta Hemophilia Program, Calgary & Hemophilia Centre, Children's Hospital of Eastern Ontario**

\$15,000, for the next two years, has been granted to these partners to complete the second part of a program to develop an educational tool for teaching and self-learning for physiotherapists in China. The project will focus on training physiotherapists as trainers to facilitate dissemination of this important discipline in proper hemophilia care.

To learn about past and present accomplishments of our twinning partners, our 2008 action plan and more, please visit the international section of the CHS Web site: www.hemophilia.ca/en/international.



SAHF innovates with its outreach clinic on wheels!



Letter of commendation for our 2007 international partnership work!

We are proud to inform our readers that our twinning project with South Africa and the one between the CHSQ and Tunisia were among the three finalists for the **WFH 2007 Twins of the Year Award**. While we did not win first place, this is still very encouraging news and will serve as a new source of motivation for the work we accomplish through these projects.

Mr. Cesar Garrido, Chair of the WFH Hemophilia Organization Twinning Committee, wrote: "The committee had the difficult task of selecting a winner for the 2007 Twins of the Year Award. Though in the end your twinings were not selected for the award, I would like to let you know that the committee was very impressed with your activities in 2007, and that you were among the three finalists for the award. On behalf of the entire committee, I would like to thank you for your hard work and dedication to twinning, and wish you continued success in 2008." ◊