

Hemophilia TODAY

Canadian Hemophilia Society
Serving the Bleeding Disorders Community

WINTER 2008

www.hemophilia.ca

VOL 43 NO 1



Commemoration of Canada's Tainted Blood Tragedy



see page 8

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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.

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Commemoration
of the Tainted Blood
Tragedy

Word from the editor

François Laroche



At the moment, recombinant treatment options for Canadians with hemophilia A are either Kogenate® FS (Bayer) or Advate® (Baxter). This situation will be changing in the late spring of 2008 when Helixate® FS (CSL Behring) is released in the Canadian market.

First of all, patients must understand that Kogenate and Helixate are identical products that share the same efficacy and safety profiles. While both of these antihemophilic factors are manufactured at the same plant in Berkeley, California, there are differences in their reconstitution device and packaging. In addition, patients switching to Helixate FS will have to familiarize themselves with a new system for logging and transmitting infusion data.

Representatives from both the Canadian Hemophilia Society (CHS) and the Association of Hemophilia Clinic Directors of Canada (AHCDC) participated in the tendering process, as sitting members of the Selection Advisory Committee.

Ultimately, Canadian Blood Services and Héma-Québec were responsible for deciding to include Helixate FS (alongside Baxter's Advate and Bayer's Kogenate FS) and for determining the ratio for Bayer and CSL Behring products. Their final decision was based on product quality, security of supply and economics. Under this new agreement, Canadian Blood Services and Héma-Québec hope to achieve combined savings in the tens of millions of dollars without compromising the quality of care, thereby alleviating the financial burden placed on our healthcare system.

The new contracts will take effect in April 2008. However, we do not expect Helixate FS to be distributed prior to June 2008 as blood product suppliers and hospitals will have to deplete any remaining stocks of Kogenate FS first. Until then, task forces have been created throughout Canada to ensure a smooth transition from one product to the other. Each task force is comprised of hemophilia nurses and physicians as well as one CHS representative. Patient information sessions will be held in the coming months. (Please read official statements on page 21.) ◊

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Call us now or send us an e-mail to receive your copy of *Hemophilia Today*.



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President's Message

Pam Wilton, RN



On November 26, 2007 at Canadian Blood Services head office in Ottawa, the Canadian Hemophilia Society launched the Commemoration of the Tainted Blood Tragedy.

The following is the transcript of Pam Wilton's speech the day of the event.



"This tree will not flourish and grow on its own. The Canadian Hemophilia Society and Canadian Blood Services will continue to work together to nourish and protect this tree, symbolizing our promise and commitment to be ever vigilant so that this tragedy can never, never happen again."

First, on behalf of the Canadian Hemophilia Society, I want to say "thank you" to CBS for hearing us and for supporting our idea to commemorate Canada's Tainted Blood Tragedy.

Today, we are planting the very first tree in what we hope will become a small memorial forest, stretching across the entire country.

This tree is a powerful symbol.

Those who see it in this public place will recognize it as a symbol of hope. Hope for those Canadians living with HIV and hepatitis C. And hope for those needing a blood transfusion.

Those who pass by it on their way into work at CBS will be reminded of the vital work they do each and every day, and of the trust Canadians place in them to keep our blood system safe and secure.

Those who pause long enough to take comfort in the shade of this tree will have new hope of a future free of the pain and suffering of a bleeding disorder.

Those who admire the strength and beauty of this tree will know that we now have a good blood system—perhaps the best in the whole world. This is evident in the release of our 2007 Report Card on Canada's Blood System, with excellent marks for a high priority on safety and supply.

This tree will not flourish and grow on its own. The Canadian Hemophilia Society and Canadian Blood Services will continue to work together to nourish and protect this tree, symbolizing our promise and commitment to be ever vigilant so that this tragedy can never, never happen again.


But remember—this is only the first tree of a whole forest. CHS is working with the federal government to designate October 27 as the annual day for the National Commemoration of Canada's Tainted Blood Tragedy.

Next fall, on October 27, the forest will begin to grow as the federal government will plant a tree and will be joined by Héma-Québec and all of the provincial governments.

Each one of these trees will remind Canadians of the thousands who died as a result of the tragedy. And each tree will give us new hope.

Hundreds of other trees will be planted in fields, on farms, in gardens, beside rivers and in backyards. Trees will be planted in very quiet, very private ways by individuals, families and friends who have lost loved ones.

I would like to acknowledge and thank the many members of the Canadian Hemophilia Society who have joined us today along with their very personal memories and a new hope.

Thank you. 

Community News



CHS honours VOLUNTEERS

At the CHS Awards Banquet, held November 24, 2007 in Ottawa, in conjunction with the CHS Semi-Annual Board of Directors Meeting, the CHS recognized a group of dedicated volunteers, health care providers, and staff members who had made a significant contribution to the bleeding disorders community in 2006 or during preceding years.



■ FRANK SCHNABEL AWARD

This award was initiated to honour the outstanding service of Frank Schnabel, founder of the Canadian Hemophilia Society, for his valued role in the growth and development of the CHS, the education and care of people with hemophilia, and education of the public regarding hemophilia needs. The award is presented in his memory to honour a volunteer who, over a number of years, has rendered distinguished service and noteworthy contributions to the mission and objectives of the Canadian Hemophilia Society.

2006 RECIPIENT | Eric Stolte

Eric Stolte has demonstrated exceptional devotion to the Canadian Hemophilia Society for over 20 years, both at the chapter and national levels. He first became involved in 1989 when he served as Vice President of Hemophilia Saskatchewan, where he went on to be Chapter President for the next seven years. Eric's contribution at the national level has been outstanding. He has been a member of the CHS



Eric Stolte receives his award from Pam Wilton, CHS President.

Board of Directors for over 15 years. He has participated on many committees during this time, including Fundraising, Administration and Finance, International Development, National Awards, and the Executive Committee.

Eric served as President of the CHS from 2004-2007, providing strong leadership and guidance, particularly in the development of the CHS fundraising culture. He has also been a steadfast advocate of supporting hemophilia care around the world, encouraging CHS participation in the World Federation of Hemophilia (WFH) International Twinning Program. His passion for engaging in international development has inspired many in the Canadian hemophilia community, and as a result the CHS is the most active national organization in WFH twinning activities for hemophilia organizations and treatment centres. Eric's dedication, leadership and contributions to the mission and vision of the Canadian Hemophilia Society make him a very worthy recipient of the Frank Schnabel Award.

■ INTERNATIONAL CONTRIBUTION AWARD

This award is presented in recognition of a volunteer who, through his/her continuing efforts over a number of years, has contributed to the development of care and services for people with bleeding disorders at the international level.

2006 RECIPIENT | Dr. Man-Chiu Poon

Dr. Man-Chiu Poon's contribution to the improvement of care and treatment for people with hemophilia in China is outstanding. In 1993, sponsored by the CHS, Dr. Poon traveled to Tianjin, China, to lead the first hemophilia workshop organized in the region by the WFH. Since then, Dr. Poon has devoted his time and skills to improving care for people with hemophilia in China, serving as a central WFH contact person whenever physicians or patients in China needed information on hemophilia care.

In 1997, a formal WFH twinning was

established between the Hematology Institute in Tianjin and the Southern Alberta Hemophilia Clinic in Calgary. The success of this project, thanks in large part to the dedicated efforts of Dr. Poon, led the WFH to focus

on developing and improving care in China. In 2000, the WFH launched a development project for China with the objective of increasing the rate of diagnosis of the country's hemophilia population as well as training medical personnel in hemophilia treatment. An additional twinning partnership was formed between Nanfang Hospital in Guangzhou and the Ottawa Hemophilia Centre (led by Dr. Brian Luke), and in 2002 Shanghai's Ruijin Hospital was twinned with Calgary and Ottawa jointly. Thanks to these initiatives, China now has a National Hemophilia Treatment Centre Collaborative Network to coordinate care across the country.

Dr. Man-Chiu Poon has shown tremendous commitment to advancing the care of people with hemophilia in China. In 2005, he devoted his year-long sabbatical to the twinning project, travelling to China to work with treatment centres and hold medical symposia and workshops on hemophilia. He has made an immense contribution to hemophilia care on the international level, bringing improvement to the lives of millions of people with hemophilia in China.



Dr. Man-Chiu Poon (L) receives his award from Dr. Brian Luke, Ottawa Hemophilia Centre Director.

■ EXCEPTIONAL SERVICE AWARD

This award is presented in recognition of an individual or organization who, through his/her exceptional service, has contributed to the growth and development of the mission of the CHS.

2006 RECIPIENT | Ian DeAbreu

For the last five years, Ian DeAbreu has diligently searched the Internet for news items related to hemophilia, VWD, other bleeding disorders, gene therapy, blood safety, hepatitis C treatment and HIV treatment. He has created a mailing list of people in the hemophilia community who are interested in receiving news stories



Ian DeAbreu (L) receives his award from David Page, CHS Executive Director.

from around the world, news releases from companies and community organizations, and research publications. Individuals who are on his mailing list have been able to choose items that are pertinent and forward them to those who need the information. Thanks to Ian's efforts, hundreds of items about blood products and blood safety have been forwarded to the CHS Blood Safety and Supply Committee and hundreds more about hemophilia around the globe to World Federation of Hemophilia volunteers and staff. The same has been done with HCV/HIV articles. Ian has helped the CHS build a reputation of being "tuned in". Ian's Internet service allowed the CHS to cancel its news clipping subscription and save thousands of dollars over the years. His reliability has allowed CHS staff to focus on other tasks and saved hundreds of hours of staff time. Ian is a fine example of volunteer dedication that makes a difference and is worthy of the Exceptional Service Award.

■ CHAPTER LEADERSHIP AWARD

This award is given to an individual who has merited special national recognition for outstanding efforts to further the growth and development of a particular chapter in an outstanding and significant way.

2006 RECIPIENT | Norman Locke

Norman Locke has worked to improve the quality of life and standards of care of people with hemophilia and inherited bleeding disorders in Newfoundland and Labrador since 1994. Norman has filled many roles within the Newfoundland and Labrador Chapter including chapter treasurer, chapter president and member of a variety of committees. He has also been a representative on the National CHS Board of Directors for the past five years and served as Treasurer for the past three years.

In 2004 Norman initiated community walkathons in the province to raise money specifically for research. This has become a yearly event and his enthusiasm and encouragement has resulted in thousands of dollars being donated to the *Hemophilia Research Million Dollar Club*. Each year Norman appeals to his employer, Scotiabank, for corporate donations. Under

the Scotia Employee Volunteer Program, the bank has been contributing \$1,000 per year for several years. Norman has also been a leader for the *Red, White & You* fundraising initiative by hosting events at his workplace.

Norman is a strong advocate for our members. Years of appealing to government through a succession of health ministers culminated in MPTAP indexation for Newfoundland and Labrador in 2005. Norman's tenacity and determination were key to achieving this important milestone.

Norman continues to contribute to the growth and development of our organization by volunteering his time and energy, assisting in fundraising and lending his support to our efforts. He is most deserving of the Chapter Leadership Award for his outstanding contributions to the Newfoundland and Labrador Chapter over many years.



Norman Locke receives his award from Colleen Barrett, NL Chapter President.

■ DR. CECIL HARRIS AWARD

This award honours distinguished contributions in the areas of hemophilia-related research or the advancement of the care of patients with hemophilia or related bleeding disorders.

2006 RECIPIENT | Dr. Bruce Ritchie

Dr. Bruce Ritchie's accomplishments as Assistant Director and most recently Clinic Director of the Edmonton Comprehensive Centre for Bleeding Disorders have been both local and national in scope. Dr. Ritchie is extremely dedicated to the care of his patients and goes far beyond the requirements of a physician and medical director in this regard. He advocates for services that his patients require and is willing to try new treatments.



Dr. Bruce Ritchie

He is dedicated to patient care but is also driven by his commitment to research and education. While President of the Association of Hemophilia Clinic Directors of Canada (AHCDC), Dr. Ritchie worked to improve the funding of the organization and roll out improved technology for the CHARMS database. Another significant contribution has been the organization and delivery of the Blood Borne Pathogens Program that is being maintained at the University of Alberta under his direction.

Dr. Ritchie has been a strong supporter of standards of comprehensive care and has lent his support to other regions of the country who were advocating for improved comprehensive care in their region. In addition to serving as Chair of the CHS Medical and Scientific Advisory Committee (MSAC), Dr. Ritchie is an active member of the CHS Blood Safety and Supply Committee and the Network of Rare Blood Disorders Organizations.

Dr. Ritchie is a most deserving recipient of the Dr. Cecil Harris Award for his unwavering dedication to the care of people with bleeding disorders over the years.

■ AWARD OF APPRECIATION

This award honours individuals who have demonstrated outstanding service to the care of persons with hemophilia or related bleeding disorders over and above their responsibilities as a member of the hemophilia healthcare team.

2006 RECIPIENTS |

Dorine Belliveau, RN

Dorine Belliveau has been the hemophilia nurse at the clinic in Moncton, New Brunswick, for over 12 years. During this time she has given outstanding service to the care of persons with hemophilia or related bleeding disorders in both New Brunswick and

Prince Edward Island. Dorine has shown leadership by playing an active role on the executive of the Canadian Association of Nurses in Hemophilia Care (CANHC), where she served as

Secretary for three years and then went on to become President from 2003-2005. She has been the CANHC representative on the CHS National Program Committee for two years. Over the years she has provided exceptional support to the New Brunswick Chapter through her participation in family weekends, summer camp and at strategic planning sessions. Her dedication to people



Dorine Belliveau (R) receives her award from Aline Landry, NB Chapter President.

■ PIERRE LATREILLE AWARD

This award for excellence is given to a current or former staff member of the CHS working at the national, chapter or regional level.

2006 RECIPIENT | Aline Ostrowski

Aline has worked for the Quebec Chapter for five years. Originally hired as the Quebec Regional Coordinator, she quickly demonstrated her capabilities and applied her management skills, good judgment and leadership to move the chapter forward after a difficult period. Since October 2004, she has served as Executive Director of the Quebec Chapter. Her ability to work with a team and the support



Aline Ostrowski (L) receives her award from Patricia Stewart, CHSQ volunteer.

with bleeding disorders in two Maritime provinces for over 12 years makes her a very worthy recipient of the Award of Appreciation.

Ruanna Jones, RSW

Ruanna has been the social worker at the Calgary Children's Hospital Hemophilia Treatment Centre for over 10 years. She has been an active member of the Canadian

Social Workers in Hemophilia Care (CSWHC) and has served as co-chair for the past seven years. She is an excellent advocate for the role of social workers in the care of patients and families living with bleeding disorders and has served as a mentor with her national colleagues.

Ruanna's commitment to the bleeding disorders community in Canada has been reflected in her willingness to become involved in CHS projects. She has worked on the planning committee and as a facilitator at several national inhibitor workshops. On the international stage, she has been the Canadian representative on the National Hemophilia Foundation Social Workers Committee and participated on the newly formed WFH Psychosocial Committee. Ruanna has recently moved to another program and her contribution to the southern Alberta bleeding disorders community, the CHS and CSWHC will be greatly missed.



Ruanna Jones (R) receives her award from Maureen Brownlow, Chair of the CHS Program Committee.

■ CHAPTER RECOGNITION AWARDS

These awards are designed to recognize chapters who have demonstrated an achievement over the preceding year in a specific area.

2006 RECIPIENTS | Nova Scotia Chapter Communications and Chapter Development

The Nova Scotia Chapter introduced *Bloodline*, the first newsletter in the chapter's 41 years of existence. It goes out to members and clinic staff several times per year. They also created a poster and pamphlet that was distributed to hospitals during 2007. The chapter maintains a Web site about Maritime Adventures Camp, their summer camp for children with bleeding disorders. The chapter has been successful in involving new volunteers to assist with the organization of the annual family weekend and fundraising activities including a fundraiser with the Royal Bank, the annual Pumpkin Regatta and the Curl for Hemophilia.



Sandy Watson (R), NS Chapter President, receives the award from Pam Wilton on behalf of his chapter.

Newfoundland and Labrador Chapter Public Awareness

Once again, the Newfoundland and Labrador Chapter made outstanding efforts to raise awareness about bleeding disorders in conjunction with World Hemophilia Day. An interview appeared in the *Lewisporte Pilot* and public service ads were published in Transcontinental newspapers and the *Telegram*. Additional public awareness activities to promote bleeding disorders on April 17 included displays at the Health Sciences Centre in St. John's and at Lewisporte Academy, a classroom party, a Hat Day fundraiser and a presentation at Lewisporte School. ○



Colleen Barrett (R), NL Chapter President, receives the award from Pam Wilton on behalf of her chapter.

The deadline to submit nominations for the year 2007 National Awards is June 30, 2008. For further details about the National Awards Program, please visit the CHS Web site at:

www.hemophilia.ca/en/11.5

FIRST "TREE OF LIFE" PLANTED TO COMMEMORATE CANADA'S TAINTED BLOOD TRAGEDY



by **Chantal Raymond**
CHS National Marketing and Communications Coordinator

It has been 25 years since one of Canada's worst public health disasters, the tainted blood tragedy, began to unfold. Thousands of Canadians died after receiving blood products contaminated with the human immunodeficiency virus (HIV). On November 26, 2007—the 10th anniversary of the release of the Final Report of the Commission of Inquiry on the Blood System in Canada—the first "tree of life" was planted to commemorate Canada's tainted blood tragedy and to ensure that the lives lost will not be forgotten nor in vain.

The ceremony, held at the headquarters of Canadian Blood Services (CBS) in Ottawa, included people with hemophilia and families of those affected by the tragedy, hemophilia treaters and advocates, and public health officials from across Canada. The poignant commemora-

"The Canadian Hemophilia Society hopes that the planting of 'trees of life' in all parts of Canada in the coming years will create a memorial forest extending across the country, as a permanent national commemoration to the tainted blood tragedy of the 1980s that has devastated so many lives."

tion allowed everyone present to reflect on the terrible losses of the catastrophe, and the efforts made since then to ensure a safe and secure blood system in Canada.

"Lessons learned from this tragedy will never be forgotten and today, Canada's national blood system is recognized by the World Health Organization as having developed the highest standards of blood safety and is a model for other countries," said Federal Health Minister Tony Clement about the commemoration.



Dr. Graham Sher,
CEO of Canadian
Blood Services

The landmark 1997 Krever Report led to extensive reforms towards a safer blood system and the creation of Canadian Blood Services and Héma-Québec to manage blood safety and supply for the population. Dr. Graham Sher, CEO of Canadian Blood Services, unveiled a memorial plaque with the sapling planted outside CBS headquarters.

"The Canadian Hemophilia Society hopes that the planting of 'trees of life' in all parts of Canada in the coming years will create a memorial forest extending across the country, as a permanent national commemoration to the tainted blood tragedy of the 1980s that has devastated so many lives," said Pam Wilton, President of the CHS.

The concept of the "tree of life" was chosen for the Commemoration because the tree is an important symbol in almost every culture. With its branches reaching into the sky, and roots deep into the earth, a tree symbolizes life. For families who have lost a loved one, it can be a daily reminder that the person is not forgotten, that his/her memory lives on.

Tainted blood crisis in the 1980s

More than 1,100 Canadians were infected with HIV through tainted blood products in the 1980s, including 700 people with hemophilia or other bleeding disorders. The tragedy affected not only the hemophilia community, but also other Canadians who had received blood transfusions for childbirth, trauma, cancer, or surgery. Three-quarters of these individuals have died. A much larger number—up to 20,000 people—were infected with the hepatitis C virus (HCV) through blood and blood products before testing was introduced in 1990. The number of Canadians



From left to right: Jeremy Beaty, John Plater, Mike McCarthy, Pam Wilton and James Kreppner

who have died from HCV-related liver disease caused by tainted blood is not known, but is estimated to be in the thousands and continues to rise.

Elaine Woloschuk, President of the Canadian Hemophilia Society from 1988 to 1990, has led the development of the CHS commemorative tree-planting initiative. "This is a bittersweet reunion. Bitter, because we know that too many have



Elaine Woloschuk, Chair of the Organizing Committee

needlessly lost their lives to the disease known as Acquired Immune Deficiency Syndrome (AIDS). But sweet, because for those of us who have been affected by the tainted blood

tragedy, this tree and many others like it across Canada will become a nationwide tribute by which we will remember those many individuals who have lost their courageous battle with this disease," she said.

It was 25 years ago that Canadians began hearing about the deaths of individuals from a disease called AIDS, which would soon have a devastating impact on the lives of people dependent on blood and blood products for their health. No one at that time could predict the monumental tragedy that lay ahead. Research began to point towards an infection that was blood borne and transmitted through blood transfusions—"as we later learned, through infusions of the very product that promised hope for those who had inherited hemophilia, a bleeding disorder affecting primarily the male population," she noted.

The treatment for people with hemophilia at the time was clotting factor concentrates that had been derived from blood. But the product that had provided so much hope for a life of normalcy would be the very one that shattered as many dreams. "We felt a deep sense of betrayal by those who had been appointed to man-



CHS representatives at the ceremony (from left to right): Norman Locke, Mike McCarthy, Aline Landry, James Kreppner, Bill Mindell, David Page, Elaine Woloschuk, Eric Stolte, Pam Wilton, John Plater, Patricia Stewart and Colin Patterson

age the blood system, having placed our trust in them to provide us with important, effective and life-saving products."

Due to unrelenting efforts by the Canadian Hemophilia Society, in 1993 the federal government announced an inquiry into the blood system: the Commission of Inquiry on the Blood System in Canada. The Krever Commission spent four painstaking years investigating the events that contributed to Canada's tainted blood tragedy. The commission brought the tragedy into the public eye, and made landmark recommendations to ensure the safety of blood and blood products through the Canadian blood system.

National commemoration: the healing process

"Today, 10 years after the final Krever Report was tabled, we gather to continue the healing process," Elaine Woloschuk said.

The CHS has requested that the federal government designate an annual commemorative day in memory of Canadians who have died due to the tainted blood tragedy in the 1980s. The CHS National Commemoration of the Tainted Blood Tragedy, to be presided over by the Honourable Horace Krever, will be inaugurated later this year at a ceremony on October 27 (the date of Justice Krever's appointment to head the public inquiry). A tree and memorial plaque will stand as a permanent reminder of the tragedy in the nation's capital. Trees of life will also be planted in provincial capitals.

Families that have been affected by the tainted blood tragedy are invited to plant trees in public parks or in their private spaces, to commemorate their loved ones in their own way. A national commemoration Web site will provide people with the opportunity to tell their stories of living with the consequences of tainted blood, or of loved ones who have passed away. ◊

The Canadian Hemophilia Society invites all chapters, individuals with hemophilia and their families, and any organizations interested in commemorating the tainted blood tragedy to contact us at chs@hemophilia.ca.

COMMEMORATION ORGANIZING COMMITTEE

Elaine Woloschuk
Chair of the Committee
President of the CHS from 1988 to 1990

Jeremy Beatty
Past President of the Hepatitis C Society of Canada

Gershon Growe, MD
Former Medical Director,
British Columbia Hemophilia Clinic
Medical Director,
Canadian Blood Services, BC/Yukon Division

James Kreppner, LLB
Secretary of the CHS Board of Directors

Mike McCarthy
Former Vice President of the CHS (1999-2001)
Former Chair of the CHS HIV/HCV Task Force (1997-2001)

John R. (Jack) McDonald, PhD
Professor Emeritus, Social Work,
University of Calgary

Eric Stolte
President of the CHS from 2004 to 2007
with a son infected by hepatitis C

Mary M. Thomson
Partner, Gowlings LLP

Pam Wilton
President of the CHS

CHS releases Report Card on Canada's Blood System

by David Page, CHS Executive Director

The Canadian Hemophilia Society presented its 2005-2007 *Report Card on Canada's Blood System* on November 26, 2007—the 10th anniversary of the release of the Final Report of the Commission of Inquiry on the Blood System in Canada. This was the fourth such evaluation by the CHS since the milestone 1997 commission report known as the Krever Report, which led to a new national blood system.

The CHS also chose this day to launch the Commemoration of the Tainted Blood Tragedy, with a tree-planting ceremony at the headquarters of Canadian Blood Services, in Ottawa.

"We promised our members we would do all in our power not to let such a tragedy happen again," said Pam Wilton, CHS President. "The commemoration to remember those who lost

their lives, and the Report Card to focus attention on a safe and secure blood system, are two parts of that commitment."

The Report Card was prepared by the members of the CHS Blood Safety and Supply Committee (see below) in consultation with stakeholders in the blood system, including representatives of other blood product recipient groups.

"Transfusion medicine has advanced greatly," Pam Wilton added. "Clotting factor concentrates to treat bleeding disorders are now considered one of the safest therapeutics available; transfusions of red cells, platelets and plasma are safer than ever before. Following the recommendations of the Krever Commission, major reforms were made to Canada's blood collection and distribution system. But we must remain vigilant." ☉

SUMMARY GRADES

Canadian Blood Services A-

A	CBS continues to put a high priority on safety in the blood system
A	CBS has maintained an excellent supply
C	CBS shows little measurable progress in its plan to move towards greater plasma self-sufficiency
A	CBS continues to be accountable and transparent in its decision-making
A+	Active Canadian blood donors get an "A+"

Héma-Québec A-

A	Héma-Québec deserves the highest marks for its commitment to safety
A	Héma-Québec has also maintained an excellent supply
C	Héma-Québec has developed a plan to move towards greater plasma self-sufficiency
A	Héma-Québec continues to be open and transparent
A+	Active Quebec blood donors get an "A+"

The Federal Government B-

B	Health Canada has reduced the backlog in approvals of biologic therapies
D	Canada still has no Orphan Drug Policy
D	The Health Canada drug approval process remains secretive
B	The Standard for Blood and Blood Components is kept up to date
B-	Surveillance systems are essential in a world where new pathogens are emerging yearly
A	The federal government extends hepatitis C compensation to all

Canada's Justice System F

F	The verdicts in the "Armour case" send the wrong message
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Provincial Governments

A (Quebec)	The provinces again deserve good marks for funding a safe, adequate supply of blood and blood products through CBS and Héma-Québec
B (Other provinces)	Provinces are slow to introduce comprehensive care for rare blood disorders
B (Capital Health in Edmonton and the Calgary Health Region)	
D (Other provinces)	
D	Recommendation # 1 of the Krever Report, no-fault compensation, has not been implemented
A	Quebec has an excellent hemovigilance system
A	Ontario provides full cost-of-living indexation for HIV compensation payments
B	7 more provinces have acted to index MPTAP over the last 3 years
F	Alberta stalls on MPTAP indexation

CHS BLOOD SAFETY AND SUPPLY COMMITTEE

Tom Alloway, PhD
(Ontario)

Bill Featherstone
(Manitoba)

Michael King, MD
(Alberta)

James Kreppner, LLB
(Ontario)

Martin Kulczyk
(Quebec)

Wilma McClure, RN
(Alberta)

Bill Mindell
Chairperson
(Ontario)

David Page
Staff support
(Quebec)

Mohammad Qadura
(Ontario)

Bruce Ritchie, MD
(Alberta)

Craig Upshaw
(Alberta)

Pam Wilton, RN
(Ontario)

The complete Report Card can be viewed at www.hemophilia.ca/en/10.1.

MPTAP Update: Good news! New Brunswick and Quebec indexation of payments leaves only Alberta stalling

by Michel Long, CHS Program
Development Coordinator

Diligent advocacy work by CHS members has produced the results that we have long been hoping and waiting for: the governments of New Brunswick and Quebec have finally confirmed that they will be adjusting the payments that the provinces' residents receive through the Multi-Provincial/Territorial Assistance Program (MPTAP) to the cost of living (COL) index. This leaves Alberta as the only province lagging behind in indexation.

In a September letter to the CHS, New Brunswick Health Minister Michael B. Murphy stated that the province had decided

to index the payments to recipients under the MPTAP effective April 1, 2007, to reflect increases in the annual Consumer Price Index (CPI) since the MPTAP program was established in 1993. Recipients would be notified of the change and issued a cheque reflecting the CPI adjustment for payments covered under the MPTAP since April 1, 2007. As of April 1, 2008, payments will be adjusted yearly to reflect increase rates of the CPI. "Our government is committed to improving the lives of all New Brunswickers and this decision will mean increased annual financial support to the individuals receiving benefits under the assistance program," Minister Murphy wrote.

On November 23, 2007, Quebec Health Minister Philippe Couillard announced that the province's MPTAP indexation plan would be retroactive to April 1, 2007. The indexation takes into account consumer price index variations since 1994-95 and will raise the annual payment from the current \$30,000 to

\$38,956 per year. Payments were scheduled to begin in December 2007: in order to receive the retroactive adjustment, beneficiaries must reply to the notification letter from the Canadian Blood Agency. Future payments will be adjusted according to the annual consumer price index.



As for Alberta, CHS members in the province continue their advocacy work and remain hopeful that the government of Alberta will follow the other provinces and index payments to the province's residents covered by the MPTAP program. ◊

Ken Poyser, Member of the Order of Canada

The Canadian Hemophilia Society (CHS) was very pleased to learn that Kenneth E. Poyser, CHS President (1980-1982), is among this year's inductees into the **Order of Canada**.

Ken, an Honorary Life Member of the CHS and a founding member of the *Hemophilia Research Million Dollar Club*, was cited for his "lifelong dedication to improving the lives of those living with hemophilia in Canada and abroad."



Ken's important work with the bleeding disorders community started decades ago as he was instrumental in obtaining home care for people with hemophilia. In the early 1980s, as CHS President, he recommended heat treating the blood components used to control hemophilia. Health Canada failed to heed the advice until it was too late and Ken became one of thousands of hemophiliac victims of what became known as the tainted blood tragedy.

Ken then went on to play an active role with the World Federation of Hemophilia (WFH) serving on the WFH Executive Committee for over 12 years.

At the December 2006 CHS Awards Banquet, Ken was presented with the *International Contribution Award* in recognition of his outstanding contribution to the development of care and services for people with bleeding disorders at the international level. On this occasion, Ken announced that he would make a \$500 donation to the *Hemophilia Research Million Dollar Club* to honour his angel, his wife Darlene, and issued a heartfelt challenge that, if five others would match his donation, he would double his gift and provide a \$1,000 donation. His challenge was quickly taken up by seven others and collectively they raised \$5,000 for the club.

It is with great pride that the CHS has created a special *Angel Club* for any individual wishing to join Ken in this challenge by making a \$500 to \$999 donation.

Over the years Ken has demonstrated exceptional leadership and outstanding efforts towards the development of care and services for people with hemophilia both in Canada and around the globe. We are very proud of him!

Canadian hemophilia nurse coordinator honoured

Elizabeth (Betty Ann) Paradis, has been selected by the Canadian Nursing Association (CNA) as one of 100 exceptional registered nurses in Canada, in conjunction with their centennial celebrations, *Celebrate a Century of Leadership*. Betty Ann has been the Hemophilia Nurse Coordinator for the Sudbury and Northeastern Ontario Hemophilia Program for twenty-seven years. She is Past President of the Canadian Association of Nurses in Hemophilia Care (CANHC) and currently serves as their representative on the World Federation of Hemophilia (WFH). Betty Ann has attended and presented at hemophilia nursing conferences at the provincial, national and international levels and has been instrumental in the development of hemophilia camps in Ontario for the past 16 years. She is a past recipient of the CHS Award of Appreciation. Congratulations, Betty Ann!





Chapter Spotlight

Nova Scotia Chapter

The First Annual Pumpkin Regatta was held in Windsor, Nova Scotia on October 14, 2007. This year was the largest race yet with 48 competitors in total and Wim, our Factor Man, came in 11th place – fantastic for his first time rowing this awkward round pumpkin across the lake. Not to mention that he beat the former Boston Bruins player, Bob Sweeney, and Cleon



Daskalakis, a local politician!

It all started with a parade that was a huge success. We had about 35 people from the chapter and their families. Our float looked fantastic, we had two children's wagons being hauled behind the float handing out apples, and grandmothers, aunts, friends and children seated on the haystacks on the float waving and tossing out Bayer's Dinosaurs. The dinosaurs were a HUGE success, people were talking, pointing, noticing CHS NS Chapter! We had about 15 people "running" behind the float handing out booklets on CHS and the NS Chapter, handing apples out to as many as we could, while the dinosaurs were flying everywhere.

Mark your calendars now, for the second Sunday in October in Windsor, Nova Scotia for our Second Annual Pumpkin Regatta for CHS Nova Scotia Chapter!

Prince Edward Island Chapter

Throughout the months of November and December, one of the PEI Chapter's newest members, Shelley Mountain, has been busy with the VWD Public Awareness Campaign. She has already done 2 presentations, both well received, and has plans for at least two more in early 2008. It seems there is a population we haven't tapped into yet, so we hope to round up some new members for our chapter!

In December, we had a blood drive, complete with posters and radio announcements and a local cable production, giving us lots of exposure. Thanks to Canadian Blood Services!

Quebec Chapter (CHSQ)

The importance of fundraising and teamwork
As demanding as the strategic planning exercise that the Quebec Chapter has embarked upon has turned out to be, it has the merit of creating a profound feeling of team-

work among members, partners, and employees, while also helping develop a sense of belonging to the organization.

Because they are now more aware of the guidelines of the organization that represents them, for which they work, or that they support, the people and organizations affiliated with the CHSQ are coming together to find ways to reach our goals, in terms of building relationships and finances.

"The only route that offers any hope of a better future for all humanity is that of cooperation and partnership."

– Kofi Annan

The emergence of a strong team spirit within the organization, motivated by the desire to "do better, together, for our community," has led to numerous benefits: a positive response to our requests for donations, self-financing activities, and our new way of looking at our membership (i.e., voluntary contributions instead of compulsory fees); registration by several of our members in the *Dare to Dream for Hemophilia* activity; the better understanding of the importance of cultivating and maximizing our collaborative ties with our organization's national body, which complements our activities and supports the well-being of persons suffering from bleeding disorders beyond the geographical boundaries of the provinces; the motivation to move ahead together, our arms linked, toward a world without the pain and suffering caused by inherited bleeding disorders.

Hemophilia Ontario

Though we had our share of challenges in 2007, Hemophilia Ontario was able to provide one of its more memorable programming years to date. With the help of committed staff and an equally committed community, Hemophilia Ontario was able to provide a full range of programming. At the chapter level we witnessed the successful delivery of familiar programs like Camp Wanakita, Hemophilia Ontario Youth summer and winter events, the Families in Motion Marathon and Just the Guys. At the regional level a whole host of programming took flight and found success.

For 2008, we look to continue this momentum and to provide those programs you have come to know and love as well as to explore new programming ideas and delivery methods. We invite the entire community to join in our initiatives and to help make 2008 the most memorable year ever!

South Western Ontario Region (SWOR)

It has been a very busy time in SWOR. We were represented in October's Toronto Marathon Relay by Team Burrows and Team Travaglini (who ran the 42-km relay race in 3 hours 44 minutes, – 5.2 minutes per km –, and

placed 40th out of 101 teams) and by Cathryn Arnold who ran the half-marathon. Their efforts raised \$3,800 for the region. Thank you all for your continued dedication to this event.



In November and December, SWOR hosted

"Winter Celebration" member events, one in the north and one in the south end of the region. Our visit to Colisanti's Tropical Gardens near Windsor included an exotic animal show, mini golf, kiddie rides, lunch and shopping in the sports shop, home decorating centre or greenhouses.



Goderich's Huron County

Museum shared the region's rich heritage for our north event. Touring the museum, learning from the interactive displays, watching two local history short movies, sharing pizza and potluck dessert passed too quickly and we said farewell once again. We thank everyone for sharing their time and fellowship.

As a fundraiser, SWOR sold holiday wreaths – beautiful pine and balsam wreaths with a large bow. We sold a total of 160 wreaths. Many thanks to our Board and members for supporting this initiative through their purchases and sales efforts. Next year we'll have bigger sales!

Toronto and Central Ontario Region (TCOR)

Toronto Marathon

Janis (centre), a volunteer for TCOR, ran 10 out of the 42-km relay race at the Toronto Marathon on October 14, 2007. Janis ran with Team



Travaglini from SWOR.

TCOR Winter Party

This year's TCOR Winter Party was held at the Science Centre. It was a great success and members of the TCOR community enjoyed every moment of it. ☺



Upcoming Events

Canadian Hemophilia Society

- **April 30, 2008** – Deadline for the 2008 CHS Scholarship and Bursary Program. Applications are now available on the CHS Web site at www.hemophilia.ca/en/11.4. The following awards are granted:
 - One \$4,000 academic scholarship
 - One \$4,000 bursary
 - One \$4,000 mature student bursary
- **May 17–19, 2008** – CHS Annual General Meeting and Board of Directors Meeting (St. John's, Newfoundland and Labrador).

Quebec Chapter (CHSQ)

- **March 28–30, 2008** – Annual Family Weekend / Annual General Meeting.
- **April, 2008** – *Red White & You* events organized by members across the province.
- **May, 2008** – Bowl-a-thon in Quebec City and Montreal.

Hemophilia Ontario

- **February 22–24, 2008** – Hemophilia Ontario Youth (HOY) Winter Event at Camp Wanakita. Please call Luke Kilner for more details at 416 924-3446.
- **April 18–20, 2008** – Hemophilia Ontario Volunteer Summit and Annual General Meeting at Toronto BMO Learning Centre. Please call Nigel Small for more details at 416 972-0641.

Toronto and Central Ontario Region (TCOR)

- **Early-mid June, 2008** – Stress and Anger Management Workshop, presented and hosted by Inalex Communications. (date and venue TBA)
- **June 19, 2008** – The TCOR Annual Golf Tournament will take place again at the Lionhead Golf & Country Club. We're asking anyone interested in donating prizes, making a donation or participating in this year's event, to contact Luke Kilner at the Toronto Hemophilia Office: 1 888 838-8846, ext 23.
- **Mid-late June, 2008** – Family and friends of the Hemophilia Society are invited to come and join in this year's Families in Touch Annual Summer Picnic. (Date and venue TBD)

South Western Ontario Region (SWOR)

- **March 29, 2008** – SWOR is very excited to provide an educational opportunity to its members in an upcoming conference. Topics to be covered include von Willebrand disease, carriers issues, pediatric issues and hemophilia and aging— truly a lifespan conference. Watch your mail for a brochure containing all details.

NOTICE

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

Saturday, May 17, 2008 – 8:30 a.m.
at the Fairmont Newfoundland,
St. John's, NL

1. To receive the report of the Nominating Committee.
2. To acknowledge the Designated Directors of each Chapter.
3. To nominate candidates for the Director-at-Large positions on the CHS Board for 2008-2009.
4. To receive the audited financial statements of the Canadian Hemophilia Society for the year ended December 31, 2007.
5. To appoint an auditor for the ensuing year.
6. To transact such other business as may properly come before this Annual General Meeting of the members of the Canadian Hemophilia Society.

James Kreppner
Secretary

What's new on the CHS Web site?

■ **CHS 2005–2007 Report Card on Canada's Blood System** – This report marks the fourth such analysis since the publication of the Final Report of the Commission of Inquiry on the Blood System in Canada (the Krevier Report) on November 26, 1997, exactly 10 years ago. You can download it from the home page www.hemophilia.ca

■ **Factor XI Deficiency – An Inherited Bleeding Disorder** – Download the latest of our series on factor deficiencies. www.hemophilia.ca/en/13.1

■ **Information booklet on Mild Hemophilia** – Developed by the Atlantic Hemophilia Nurses Group of the Canadian Association of Nurses in Hemophilia Care (CANHC) and published by Bayer HealthCare for people living with mild hemophilia and their families. www.hemophilia.ca/en/13.1

■ **Reminder – Self-Infusion: Confidence, Autonomy, Freedom** – Video starring young people with bleeding disorders describing their paths to self-infusion and the benefits they experience. Filmed at summer camps in Quebec, the Maritimes and Ontario, it can be ordered from the National Office and viewed online. www.hemophilia.ca/en/13.3

■ **All About Carriers: A Comprehensive Guide for Carriers of Hemophilia A and B** – Download the complete document published by the CHS in May 2007. www.hemophilia.ca/en/13.1

■ **All About von Willebrand Disease (Second Edition)** – Download the Second Edition of this comprehensive guide first published in 2000 and revised in 2007. www.hemophilia.ca/en/13.1

■ **The home page** – Follow the latest news in the Canadian bleeding disorders community by regularly consulting the CHS Web site home page. www.hemophilia.ca/en

New resources available!

French version of **All About Carriers: A Guide for Carriers of Hemophilia A and B** is now available.

We are also pleased to announce the availability of two new resources developed by the Canadian Association of Nurses in Hemophilia Care (CANHC):

Factor XI Deficiency – An Inherited Bleeding Disorder

The latest in the series on Rare Factor Deficiencies, this document is a general information booklet about Factor XI Deficiency for patients, families and healthcare providers. This booklet was developed by the Quebec hemophilia clinic nurses in collaboration with the CHS.

Information booklet on Mild Hemophilia

Mild hemophilia can be very serious and even life-threatening if injuries or bleeds are not treated promptly and adequately. This new information booklet for people living with mild hemophilia and their families was developed by the Atlantic Hemophilia Nurses Group and published by Bayer HealthCare.

To order copies please contact the CHS office at 1 800 668-2686 or chs@hemophilia.ca. The booklets are also available in PDF format at www.hemophilia.ca/en/13.1.

FUNdraising.....

by Joyce Argall, CHS Annual Giving Coordinator and Pauline Major, CHS National Resource Development Manager



Dare to Dream for Hemophilia

On Friday, October 5, 2007, the Canadian Hemophilia Society held one of the most exciting pledge-based fundraising events to hit Canada in years—*Dare to Dream for Hemophilia*, held at the Bridgestone Racing Academy just outside Toronto, Ontario. Participants spent the day at one of North America's most respected race car driving schools, learning how to safely drive a Formula 2000 racing car. These pictures and testimonial from one participant sum up the thrill and excitement that permeated this very special day.

Dare to Dream for Hemophilia



Curtis Spicer, Honorary Chair, *Dare to Dream for Hemophilia*

Ian DeAbreu, looking cool in both his pilot outfit and in his race car!



Mark DeAbreu, happy like a kid driving a race car!



The "Astronauts"...



.....FUNdraising

"It was a dream coming true for me. Trying and succeeding in something challenging, and at times fearful, was great. I can only imagine the challenges and fearful moments people with hemophilia experience—your Dare to Dream for Hemophilia event showed me and the people there that you can succeed... Seeing the happy boy with severe hemophilia smiling and laughing while watching his father proudly as he takes off in the fast sleek formula 2000 car—he dreams, dreams of that being him one day. He is allowed to dream, because one day he will be the person going out in the race car... Many challenges, many fearful moments for people living with hemophilia including their parents and friends... I wish that we continue to 'dare to dream' and focus on improving the current state, day by day, week by week, year by year—ultimately making life better for people with hemophilia."



Pam Wilton, contemplating her entry on the fast track.

David Page, our very own Speed Demon



Pam Wilton and David Page, the CHS happy campers

Wanted... Speed Demons with Hearts of Gold!

You could be behind the wheel of a Formula 2000 racing car at the Bridgestone Racing Academy on September 19, 2008 faster than you think.

To register: www.idaretodream.ca
Next draw: March 27, 2008

Colouring BOOK REMINDER

In the last issue of *Hemophilia Today*, we asked for your assistance in purchasing and promoting our unique Bilingual Story Colouring Book. If you have already done so, thank you!

If you have not yet had a chance to order your colouring book, there is still time! Help us promote the love of reading and enrich the lives of children across Canada while supporting the inherited bleeding disorders community.

To order your copy for \$10, or for more information please call 1 800 668-2686 or e-mail us at pmajor@hemophilia.ca.



Youth File

Sarah Bradshaw



National Youth Committee Co-Chairs



Emil Wijnker

A year has passed since the National Youth Committee was struck. Since then, several activities took place at both the national and provincial levels. Two of our major accomplishments were the implementation of our Web page and our participation in *Rendez-vous Québec*. In 2008, our biggest endeavour will be the CHS National Youth Leadership Retreat, which will be held from September 5 to 7 at the Geneva Park YMCA Conference Centre located in Orillia, Ontario. The curriculum will consist of specially designed educational sessions for young adults with leadership potential, focusing on leadership skills, team-building activities, goal setting, conflict management and creative problem solving. A planning committee consisting of Emil Wijnker, Sarah Bradshaw, David Pouliot, Katie Hines, Patrick Syriani, Julia Sek and H  l  ne Bourgaize has been struck. More information regarding the retreat including the selection criteria for participants will be announced and available on our Web page by the beginning of February. You can also contact your local chapter or youth representative to obtain more information.

In 2007, we were lucky to send representatives to Orlando, Florida, to participate in the American National Youth Leadership Institute Meeting as well as have four Canadians out of 15 participants attend the first International *Step Up Reach Out* Program. You will find below two overviews, one from Emil Wijnker and one from Alex Little, summarizing these two events. Once again, if you want to get involved or learn more about youth activities, please feel free to visit our Web page (www.hemophilia.ca/en/12.0) and contact your local representative, who will be more than happy to hear from you.

Some participants at the First Annual *Step Up Reach Out* Program

Building relationships

by Emil Wijnker, *National Youth Committee Co-Chair*

The American National Hemophilia Foundation (NHF) held its 59th Annual General Meeting from November 1–4 at the World Centre Marriott Resort and Convention Centre in Orlando, Florida. During this time, the National Youth Leadership Institute (NYLI—the NHF's young adults group) also met and ran a parallel mini-conference focused on youth leadership, advocacy, and organizational skills. CHS National Youth Committee (CHS-NYC) members Sarah Bradshaw, David Pouliot, H  l  ne Bourgaize, and I attended the NYLI session in the hopes of making connections with our American counterparts and learning from NYLI (established in 2004) as they prepare to host a National Teen Leadership Weekend in February. The NYLI group in Orlando was amazing! They were very welcoming and provided us with some great thinking points throughout the weekend. Sarah and I (CHS-

NYC Co-Chairs) also met with Shelly Mattson and Alex Nothorn (NHF-NYLI Co-Chairs) to discuss the similarities and differences between our two groups and talk about the possibility of working together on a future, internationally focused youth-oriented project. The weekend was not only a success for the NHF and their AGM, but for us as well, as we came away from the weekend having made new friendships, established new connections within the bleeding disorders community, and having learned a lot about leadership, advocacy, and organizational skills.



Participants at the National Youth Leadership Institute Meeting

Hemophiliacs unite at leadership conference

by Alex Little, *Calgary, Alberta*

Blood brothers from around the world came together at the First Annual *Step Up Reach Out* Program that took place in San Francisco, California, from September 14–17, 2007. The program brought together hemophiliacs from Britain, Germany, New Zealand, Spain, Canada, and the United States in order to encourage them to become more active in their respective communities. Participants shared stories about their individual experiences having hemophilia, learned a great deal about their condition in the valuable 'Hemophilia 101' session, and toured the abundant San Francisco attractions. Great accommodation was provided, delicious meals enjoyed, and friendships created. The participants were treated to a baseball game, a tour of the plant where Kogenate[®] FS is produced and distributed, and meals overlooking the gorgeous San Francisco wharf.

It was a very unique and rewarding opportunity to spend time with other young people born with the same life-altering condition.

Conversations and information sessions focused around the concept of living with a bleeding disorder, depending on different cultures, ages, and backgrounds. The men gathered at the conference were brought together with only one unifying thread, but other undeniable similarities came through and it proved to be a fascinating look into how such a condition can shape one's beliefs, and identity. Care for bleeding disorders in different countries was compared, and the participants got a firsthand look into how care differs around the world.

This trip to San Francisco was the first part of the two-part program that sees the participants heading to Houston for the second part in February of 2008. In the interim, participants are encouraged to become more active in their respective countries and take the first steps to becoming a leader in the bleeding disorders community. These participants are ideally stepping up to fill the shoes of the valued leaders that the community currently has. If the excitement and anticipation that was exhibited at the end of the first sessions was any indication, these men are more than willing to do what it takes to fill these shoes. ◊



Our Stories

Diane and Mackenzie: love at first sight

by Chantal Raymond, CHS National Marketing and Communications Coordinator

Diane is not an ordinary woman. She is an energetic fun-loving single mom of a five-year-old adopted son with hemophilia.

Diane had always wanted a child. Her perseverance led to numerous surgeries and artificial insemination until a ruptured appendix that nearly killed her put

a stop to the hope of her ever being pregnant. Three weeks after that terrible event, she registered to adopt.

Then, the good news came: a friend of a friend, a 15-year-old, chose adoption for her child and wished for Diane to adopt her baby. Both women spent four great months together preparing for the birth. One Thursday, the little miracle was born; the following Monday, the birth-mother had changed her mind.

Following this last-minute failed adoption, Diane was very depressed for a couple of months. When she got back into the "sane world" as she says, she registered again to adopt. Eleven months later, Diane was holding her dream baby in her arms. It was love at first sight. Everything was going to be all right now.

A year and a half later, Mackenzie fell off his bed. Diane took him into her own bed for the rest of that night. When Diane woke up the next morning, there was literally blood everywhere. Mackenzie's lip was bleeding non-stop. Then, the phone rang: Diane's mother had had a mini stroke. The drama just wouldn't stop.

Diane packed some bags to make the three-hour trip from her home to Halifax to see her mom while trying to stop Mackenzie's bleeding lip. Before leaving for Halifax, she decided to stop at the hospital to have Mackenzie checked. There, they tried many ways to stop the bleeding but nothing worked. She was then told to leave for Halifax, that the wound would heal by itself, that she was overreacting. Off she went. Blood was everywhere in the car.

When they arrived in Halifax, Diane left her son in the care of her sister and went to see her mom. When she came back, the bleeding had not stopped. Diane took him to Children's Hospital where doctors and nurses stripped him down and seemed to be looking for bruises. They were looking at Diane as if she had beaten her son. It's a look she will never forget.

She finally reached a hematologist who said they would do some more blood tests. In the meantime, they would give Mackenzie a transfusion to compensate for his blood loss. Diane, who had lost many friends to AIDS and knew about the tainted blood tragedy, put her hand on the bag and prayed that this blood was safe.

The next morning, the news broke: "We know what's wrong with your son." Diane's heart skipped a beat at the hemophilia diagnosis. In shock, she didn't hear much after that. Four days later, the nurse coordinator who would take care of Mackenzie explained what she needed to know and gave her reading material to take home. It was all overwhelming.

A different life was starting for Diane and Mackenzie. A life that included unusual care and treatment, with some pretty scary moments. Once, at two and a half years old, Mackenzie repeatedly fell on his bum.

Diane discovered his ankle was swollen to the size of an orange. It took four months to get over that series of bleeds! Diane was told that, although Mackenzie had been diagnosed with moderate hemophilia, he could still suffer from severe bleeds.

Starting the infusion process was also quite frightening. Like any parent infusing her child, Diane has to emotionally detach herself. She feels that if Mackenzie senses her anxiety, she has trouble finding a vein and as a result, the infusion cannot proceed. Mackenzie is now on prophylaxis three times a week. In August 2006, when infusing Mackenzie became very difficult, a child psychologist came to the rescue.

One day, the social worker from the treatment centre mentioned to Diane that she could probably register Mackenzie with the Children's Wish Foundation. And she did. To their great joy and surprise, Mackenzie was granted his wish. He will be going on a Disney cruise and then to Disney World for a week. He can take along his cousin, Blake, and Diane can also bring a friend to share in this great adventure.

In Diane's eyes, Mackenzie deserves that his wish be fulfilled. Not long ago, when Mackenzie's friend asked him why he was taking medicine, he replied, at the young age of five, "Without my medicine, I'm going to die." To Diane, that's just one example of what can go through the mind of a child with hemophilia and that, alone, deserves that a special wish be granted to all children with hemophilia.

Having benefited from the programs and activities offered by the CHS, Diane decided to become a volunteer at both the chapter and national levels. At the Nova Scotia Chapter, she is responsible for communications and the chapter newsletter and is also their fundraising representative. She has been a great advocate for the CHS. Among other things, she has shown the CHS public awareness video to social clubs and to many branches of the Royal Bank for whom she works.

Diane is not an ordinary woman. Yet she doesn't see herself as brave. She just does what she has to do for her son to stay healthy. It's her son



Blake and Mackenzie, at the NS Chapter Pumpkin Regatta fundraising event



Mackenzie and Diane, a perfect match

who is very brave, she says. She just makes sure her life with Mackenzie is all about having fun and appreciating every moment they have together. Nothing is ever taken for granted in the lives of Diane and Mackenzie. ○

Children's Wish Foundation of Canada

The Children's Wish Foundation of Canada works with the community to provide children living with high-risk, life-threatening illnesses or disorders the opportunity to realize their most heartfelt wish. Included in a wish can be airline tickets, accommodations, transportation, medical insurance (an exclusive agreement between the Children's Wish Foundation of Canada and Blue Cross provides each of the wish families with medical insurance, waiving the "pre-existing illness" clause for the wish child, and covers the rest of the family for medical emergencies as well), expense money, attraction passes, emergency assistance, etc.

For more information, please go to the Children's Wish Foundation of Canada at www.childrenswish.ca.



Hepatitis C Press Review

by Michel Long, CHS Program Development Coordinator

■ Drug boosts platelets in hepatitis C patients

www.HealthNewsDigest.com. Nov. 29, 2007 – It's not a cure, but this may be some of the best news patients infected with the hepatitis C virus (HCV) have heard in a long time: A new drug, eltrombopag, appears to be effective in boosting low platelet counts, one of the major reasons why patients can't endure antiviral treatments. Other drugs that can restore normal platelet functions are infusions or injections; eltrombopag is a pill taken just once a day.

Researchers at Duke University Medical Center and other centres worldwide studied eltrombopag (marketed as Promacta in the U.S. and Revolade in Europe by GlaxoSmithKline) in 74 patients with low platelet counts and cirrhosis of the liver due to HCV infection. They found that it boosted platelet counts in a majority of patients at each of three dosage levels, enabling most of them to continue or start conventional antiviral treatment. "We feel this is an important development for many people infected with the hepatitis C virus worldwide," says Dr. John McHutchison, Professor of Medicine and Associate Director of the Duke Clinical Research Institute. "A significant number of patients with HCV infection will at some point develop platelet problems that will compromise their getting the best treatments we have. Anything we can do to prevent that from happening would improve their care."

Platelets are cells made in the bone marrow that are important in clot formation, and serious bleeding can occur if platelet levels fall too low. Some diseases, like HCV infection, can cripple the body's ability to manufacture platelets, but so can some medical treatments. The Duke study found that eltrombopag worked in a dose-dependent manner, meaning that patients got a better response with increasing amounts of the drug. Seventy-four percent of those in

the trial who took the lowest dose saw their platelet counts go up significantly, while 79 percent and 95 percent of the participants saw increases with the higher doses.

"We are encouraged by these results and are already working on another multi-centre, international, phase III trial where we hope these results will be confirmed," says McHutchison. However, eltrombopag does cause side effects. Some of the patients complained of headaches, dry mouth, abdominal pain and nausea.

■ Treatment with Pegasys provides hepatitis C patients a second chance to achieve a cure after not responding to Peg-Intron

www.medilexicon.com. Nov. 5, 2007 – Roche announced final results from the REPEAT study which demonstrate that treatment with once-weekly Pegasys (peginterferon alfa-2a) and daily Copegus (ribavirin) can achieve viral clearance in a number of patients who did not respond to initial treatment with Peg-Intron (peginterferon alfa-2b), another drug commonly used to treat hepatitis C.

This outcome gives hepatitis C patients the opportunity to tackle their disease a second time after initial treatment failure. Furthermore, the results show that a patient's response to treatment at 12 weeks is a powerful predictor of the eventual outcome: the majority of patients with undetectable virus levels at 12 weeks went on to achieve a sustained virological response (SVR), indicating treatment success. Few patients with detectable virus at 12 weeks achieved SVR.

"One of the greatest areas of need in hepatitis C today is to find solutions for patients who have not had treatment success with an initial course of therapy. REPEAT is a landmark study that adds significantly to our knowledge about how to manage these patients, demonstrating that extending treatment with Pegasys is a promising option," said Donald Jensen, MD, Professor of Medicine and Director of the Center for Liver Diseases at the University of Chicago Hospital in Chicago, and lead investigator in REPEAT. "An important finding from REPEAT is confirmation of the reliability of using a patient's response at 12 weeks as a predictor of treatment success, even in patients with cirrhosis. This means that patients who achieve undetectable virus at 12 weeks can continue treatment with a good likelihood of success. It also means that

clinicians can confidently discontinue treatment in patients who do not achieve an early response."

Pegasys plus Copegus is the only pegylated interferon combination therapy to have demonstrated significantly superior benefits over conventional interferon combination therapy across all HCV genotypes, irrespective of viral load. The combination of Pegasys and Copegus consistently shows high cure rates, up to 66 percent overall sustained virological response across a number of large, randomized clinical studies including in patients with difficult-to-cure disease such as genotype 1 HCV, cirrhosis, and HIV-HCV co-infection. Pegasys is available in Canada. Given that the criteria for financial coverage may vary from province to province, interested individuals should verify the criteria in their own jurisdiction based on their own situation.

■ Interim data show Nitazoxanide (Alinia) improves anti-HCV activity when added to pegylated interferon plus ribavirin

www.hivandhepatitis.com. Nov. 13, 2007 – The addition of the experimental anti-HCV drug nitazoxanide (Alinia) may significantly increase sustained response rates when added to pegylated interferon plus ribavirin, according to data presented at the recent 58th Annual Meeting of the American Association for the Study of Liver Diseases (AASLD 2007) in Boston, November 2-6, 2007.

"Patients treated with nitazoxanide responded earlier and maintained their responses without relapse after receiving only 36 weeks of treatment with peginterferon and ribavirin," said Dr. Emmet B. Keeffe, Chief of Hepatology at Stanford University School of Medicine. "These data suggest the emergence of a new therapeutic approach for treating hepatitis C. While more study is needed to confirm these results in a broader population of patients, nitazoxanide appears to increase the potency of interferon without increasing toxicity or inducing resistance."

"Results from this trial validate a new approach to treating HCV that focuses on the interaction between the virus and the cell," said Dr. Jean-François Rossignol, Director of the Romark Institute for Medical Research.

Romark Laboratories is currently conducting a U.S. Phase II trial with nitazoxanide plus standard of care in patients with hepatitis C genotype 1 who were previously treated with interferon. The company also

plans to initiate a Phase II trial in treatment-naive patients early in 2008. Alinia is an investigational new drug in the United States for treating chronic hepatitis C.

■ **In largest U.S. hepatitis C trial, researchers determine weight-based dosing is key to optimal treatment**

www.medilexicon.com. Dec. 28, 2007 – As reported recently in the journal *Hepatology*, WIN-R, a multicentre study of over 5,000 patients with HCV, showed treatment with weight-based Rebetol® (ribavirin) (RBV) in combination with pegylated interferon (PEG-IFN) alfa-2b achieved significantly higher rates of sustained virologic response (SVR) and lower relapse rates compared to combination therapy using a flat dose of RBV 800 mg/day. Superior response was found particularly in patients with the most difficult-to-treat form of the disease, genotype 1 HCV. Efficacy was consistent across all weight groups.

For patients infected with genotype 2 or 3, a 24-week course of treatment with flat-dose RBV and PEG-IFN was as effective as the standard 48-week course, with better tolerability, and in the overall study population flat dosing of ribavirin was as effective as weight-based ribavirin. However, within the flat-dose cohort of patients with genotypes 2 and 3, sustained response rates showed a slight decline in the higher-weight patients given flat-dosed ribavirin.

"These findings help define optimal therapy for U.S. hepatitis C patients," says the study's principal investigator, Dr. Ira M. Jacobson. "Our findings underscore that weight-based dosed combination therapy is significantly more effective than the flat-dosed RBV regimen, especially in more difficult-to-treat patient groups, such as patients with genotype 1 and African-American patients. Patients being treated for hepatitis C should talk to their doctors to be sure they are receiving the most effective therapy."

"The study data strongly suggest adopting a 1400 mg/dose for patients who weigh more than 105 kg. In my opinion, the larger dose provides an opportunity for very heavy patients to have the same chance of cure as lighter patients without compromising safety," says Dr. Jacobson.

Overall safety with weight-based dosing was similar to that of the flat 800 mg dose. There was no difference in the occurrence of serious adverse events in the entire group, as well as in the African-American group. ○

OPPORTUNITIES TO PARTICIPATE IN RESEARCH

Study on coagulation in pregnant women by Dr. Christine Demers

Pregnant women who are carriers of a hereditary coagulopathy are at risk of bleeding, especially in the post-partum period. Treatment in these cases is complicated by the fact that there is little data on variation of coagulation factor levels during and after pregnancy. A study designed to measure coagulation parameters in pregnant women with and without coagulopathy is currently underway. The study is being carried out by the Subcommittee on Women with Bleeding Disorders of the Association of Hemophilia Clinic Directors of Canada and is supported by the Canadian Hemophilia Society. Recruitment of pregnant women without coagulopathy is now complete, but recruitment of pregnant women with coagulopathy (von Willebrand disease, Factor XI deficiency, and hemophilia A and B carriers) is ongoing. The *Centre d'hémophilie pour l'Est du Québec* is currently recruiting volunteers, and the Ste-Justine University Hospital Centre and the Montreal Children's Hospital plan to begin shortly.



CANADIAN PHYSIOTHERAPISTS IN
HEMOPHILIA CARE

PHYSIOTHÉRAPEUTES CANADIENS
EN HÉMOPHILIE

Clinical Mentoring Program

by Catherine Van Neste, PT, *Hôpital de l'Enfant-Jésus, Quebec City*

For several years now, Canadian Physiotherapists in Hemophilia Care have participated in twinning activities in order to lend a hand to hemophilia clinics elsewhere in the world. Subject to local restrictions that may apply, they provide assistance in the form of teaching and setting up basic physiotherapy care in the hope that the knowledge they contribute will make a small difference in the long run.

Physiotherapy care in Canada is something else entirely. Not only do all treatment centres in the country have qualified physiotherapists, but the treatments provided here are based on the most recent findings in the field. To improve and maintain this standard of care, an ongoing effort is required, and various measures have to be put in place, such as:

- Drafting of a constitution defining our group's role
- The recent adoption of precise standards based on convincing scientific data
- Plans to create of an interactive DVD as a teaching tool
- Creation of the Canadian Physiotherapists in Hemophilia Care Web site
- Regular participation by new physiotherapists in the New Team Workshop
- The brand new Clinical Mentoring Program

The Clinical Mentorship Program, which enjoys financial support from Bayer, is designed to help new physiotherapists in treatment centres quickly familiarize themselves with hemophilia and its consequences by pairing them with more experienced colleagues in the field. They have the opportunity to witness different clinical situations, so they grasp the important points, and can establish an appropriate treatment plan. The mentoring is done in Winnipeg, Toronto or Montreal, and we hope to be able to accommodate two physiotherapists a year. This approach should considerably improve the knowledge of young physiotherapists as they start working directly with hemophilia patients, enabling us to provide a high level of service nationwide. ○

The Blood Factor

by David Page,
CHS Executive Director



■ Inspiration Biopharmaceuticals set to begin clinical trials with new recombinant factor IX

LAGUNA NIGUEL, CA, November 13, 2007 - Inspiration Biopharmaceuticals has filed an Investigational New Drug (IND) application with the U.S. Food and Drug Administration (FDA) to begin clinical trials with IB1001, an intravenous recombinant Factor IX (rFIX) product for the on-demand and prophylactic treatment of hemophilia B.

Phase I/II clinical trials will evaluate the pharmacokinetics (PK) and safety profile of IB1001, compared with the commercially available factor IX products, BeneFIX[®], manufactured by Wyeth, and Mononine[®], manufactured by CSL Behring, both currently used in Canada.

Research will also include a six-month phase I/II trial to document safety and efficacy in on-demand treatment of spontaneous bleeding episodes, and a phase II/III prophylaxis trial to show safety and efficacy in the prevention of spontaneous bleeding. In addition, IB1001 will be evaluated in the control of bleeding during surgical procedures. The rate of inhibitor formation will be measured throughout all phases.

"We are excited to be filing an IND for IB1001," said Michael Griffith, PhD, President and CEO, Inspiration Biopharmaceuticals. "Preclinical studies have demonstrated the expected PK and safety profile for IB1001 when compared to the clinically proven commercial factor IX products. Our cost-effective manufacturing platform for factor IX positions Inspiration to expand the global supply of rFIX and to develop next-generation products to facilitate prophylactic care of hemophilia B patients worldwide."

"Our vision is that one day all patients with hemophilia, regardless of where they live, will have access to treatment. More affordable treatment is critical to achieving treatment for all," stated Mark Skinner, President, World Federation of Hemophilia. "The availability of lower-cost rFIX products to treat hemophilia B could facilitate more prophylactic use, as well as make treatment more accessible to people worldwide."

■ Study shows feasibility of developing a half-life extended recombinant FVIIa

ATLANTA, GA, December 10, 2007 - CSL Behring today announced the results of a pre-clinical study that show for the first time that it is feasible to genetically fuse recombinant factor VIIa (rFVIIa) to human albumin, prolonging the half-life of this therapeutic protein while retaining its biologic activity. The study was presented at the American Society of Hematology 49th Annual Meeting and Exposition.

The half-life of the rFVIIa-albumin protein was shown to be extended six- to ninefold compared to current formulations of rFVIIa. Additionally, rFVIIa-albumin demonstrated comparable biologic activity.

Recombinant factor VIIa is used to control bleeding episodes in hemophilia patients with inhibitors. However, rFVIIa has a short half-life of approximately 2.5 hours. This necessitates multiple injections, which are inconvenient for both physicians and patients, particularly during surgery.

"The pharmacological properties seen in our study could one day facilitate a single dosing regimen of one injection per bleeding event, as well as significantly reduce the number of injections hemophilia patients with inhibitors need during surgical interventions," said lead investigator Dr. Stefan Schulte, Head, Pre-clinical R&D, CSL Behring.

■ Novo Nordisk in partnership with French biotech company on inhibitor therapy

COPENHAGEN, Denmark, December 17, 2007 - Novo Nordisk of Denmark has announced it has licensed global rights to a potential new hemostasis therapy now in early preclinical development.

The agreement with the French biotechnology company C2X Pharma and the French national institute for health and medical research (Inserm) is related to thrombin-activable factor X. The protein is a bypassing agent capable of promoting blood clotting, a Novo Nordisk spokesperson said.

Other bypassing agents, notably Niastase[®] (recombinant FVIIa), also manufactured by Novo, and FEIBA[®] (made up of factors II, IX and X, plus activated FVII), manufactured by Baxter, are currently used in the treatment of bleeding episodes in people with hemophilia A and B and inhibitors. ◊

UPDATE TO CLOTTING FACTOR CONCENTRATE CHARTS

In the Spring and Summer 2007 issues of *Hemophilia Today*, the CHS presented charts summarizing characteristics of clotting factor concentrates distributed in Canada. Please see this additional information.

- Advate[®] is not currently available in the 2000 IU vial size in Canada.
- Recombinate[®] is approved by Health Canada but not currently distributed in Canada.
- Hemofil M[®] is approved by Health Canada but distributed only through the Special Access Programme.
- FEIBA VH[®] is stored at 2-8°C or at room temperature for up to 6 months.

Introduction of Helixate® FS

CHS supports introduction of Helixate® FS

by David Page, CHS Executive Director

The Canadian Hemophilia Society supports the introduction of Helixate® FS in Canada. Helixate FS is a recombinant factor VIII concentrate distributed by CSL Behring.

"Helixate FS in fact is identical to Kogenate® FS," said Bill Mindell, Chairperson of the CHS Blood Safety and Supply Committee, and member of the Selection Advisory Committee, which provided recommendations to Canadian Blood Services and Héma-Québec on behalf of the CHS. The Committee's mandate was to provide advice on the range of factor products to be purchased in Canada over the next five years.

Helixate FS is manufactured by Bayer at Bayer's Berkeley California facility and is exactly the same recombinant factor VIII product as Kogenate FS. Through a business arrangement between CSL Behring and Bayer, CSL Behring distributes a portion of the Berkeley production under the brand name Helixate FS. Only the packaging and reconstitution devices are different from Kogenate FS.

"In addition to the quality and safety of products, security of supply has always been a key CHS objective," Bill Mindell added. "Therefore the involvement of a third commercial supplier in the provision of recombinant factor VIII products is welcome news."

The other recombinant factor VIII product distributed in Canada is Advate®, manufactured by Baxter.

Helixate FS is not new to the Canadian market. Several million units were distributed during the factor VIII shortage in 2002.

Starting in the second quarter of 2008, Helixate FS will be distributed by both Canadian Blood Services and Héma-Québec. (See the accompanying statements from both Canadian Blood Services and Héma-Québec for details.)

Introduction of Helixate® FS by Canadian Blood Services

January 10, 2008 - Canadian Blood Services recently carried out a Request For Proposal (RFP) process for plasma products, recombinant factor VIII (rFVIII) and contract fractionation. Patient and physician stakeholder groups were included on a Selection Advisory Committee (SAC) that assessed the bids from the vendors and made recommendations to Canadian Blood Services. The Canadian Hemophilia Society (Bill Mindell) and the Association of Hemophilia Clinic Directors of Canada (Dr. Bruce Ritchie) were represented on the SAC.

Security of supply is the primary objective for Canadian Blood Services and its consumer partners. Diversifying the supplier base for plasma products and recombinant products supports that objective. Where feasible, achieving cost savings through competitive bids for products is also an important objective.

One of the outcomes of the RFP was the recommendation by the SAC to include CSL Behring's Helixate® FS in the group of rFVIII products distributed by Canadian Blood Services (in addition to Bayer's Kogenate® FS and Baxter's Advate®).

After negotiations between Canadian Blood Services and the vendors, the mix of Bayer's Kogenate FS and CSL Behring's Helixate FS was finalized at 90% Bayer's Kogenate FS and 10% CSL Behring's Helixate FS. The objective is to remain close to this 90/10 ratio from year to year over the next five years. Canadian Blood Services expects to distribute Helixate FS beginning in approximately mid-summer 2008. This target date may change depending on factors such as product availability from CSL. Canadian Blood Services is currently discussing the best approach to implementing Helixate FS with representatives of the Canadian Hemophilia Society, the Association of Nurses in Hemophilia Care, and the Association of Hemophilia Clinic Directors of Canada.

- Canadian Blood Services

CSL Behring will be Héma-Québec's sole supplier for Helixate® FS, the antihemophilic factor

January 15, 2008 - Last year, as part of its mission to supply adequate quantities of optimal quality blood components and substitutes to meet the needs of all Quebecers, Héma-Québec issued a public Request For Proposals for antihemophilic factor, as the contract with Bayer ends in 2008. Bayer and CSL Behring were the proponents chosen by the selection committee, which included representatives from the Association of Hemophilia Clinic Directors of Canada and the Canadian Hemophilia Society.

Subsequent to the financial analysis of the submissions received through the Request For Proposals, and in compliance with the *Secrétariat du Conseil du Trésor du Québec* regulations regarding procurement and contracts, Héma-Québec has decided to retain CSL Behring as its sole supplier for Helixate® FS, the antihemophilic factor which is, for all practical purposes, identical to Kogenate® FS.

A work group of representatives of Québec's hemophilia clinics, the Canadian Hemophilia Society - Quebec Chapter, and Héma-Québec are collaborating with CSL Behring to make sure that the needs of patients and nursing staff are met. To handle the transition smoothly, the company will provide work tools for patients and nursing staff at hemophilia clinics.

The contract was awarded to CSL Behring pursuant to *Secrétariat du Conseil du Trésor du Québec* regulations regarding procurement and contracts to which Héma-Québec is subject. The decision to procure Helixate FS exclusively was made in the best interests of Québec's health system and will generate major savings over the next five years, without affecting patient treatment. As of the spring of 2008, therefore, Québec hemophiliacs who are currently receiving Kogenate FS will begin to be treated with Helixate FS.

- Héma-Québec



A Global Perspective

This inspiring story, about the key role of Dr. Man-Chiu Poon, Director of the Southern Alberta Hemophilia Treatment Centre, in helping save a child's life in China was originally published in the fall 2007 issue of the CHS Alberta Chapter newsletter. The article has been reprinted with the permission of the chapter and the families mentioned in the article.

Dr. Poon first began to devote his time and skills to improving care and treatment for people with hemophilia in China in 1993, when he led a hemophilia workshop organized by the World Federation of Hemophilia (WFH). In 1997, a formal WFH centre twinning was established between the Hematology Institute in Tianjin, China, and the Southern Alberta Hemophilia Treatment Centre in Calgary. Dr. Poon was recently awarded the CHS International Contribution Award for his outstanding efforts to improve the care and treatment of people with hemophilia living in China. (Please see article on National Awards on page 5.)



Hosanna on May 29, 2007 at about twelve months old

CHS connections: witnessing a miracle

by Juanita Pickerl, Spruce Grove, Alberta

I have been volunteering with the CHS Alberta Chapter for several years now. I've had the privilege of meeting many members of the Alberta Bleeding Disorders Community and also been fortunate to get to know the staff at both of our Alberta Clinics through my involvement on the Chapter Executive over the past several years. I have to admit that I have faced times where I have questioned whether I should devote so much time to the CHS. That questioning was put to rest recently when all of my involvement in the CHS came together and enabled me to become a small part of an effort to save the life of a precious little girl in China.

When I heard the words 'blood disorder', I thought, "Well, we can help with that!"

Friends of mine have been in China for a couple of years doing humanitarian work. They had become familiar faces at an orphanage there and at the end of May were met with a request from the Director of the orphanage. A baby had been abandoned and been brought to the orphanage but she was very sick. The Director asked my friends if they would take this little girl home and care for her in what was believed to be her last days. My friends agreed. I learned of their life with this little child through regular communication that we share through our circle of friends. The picture at left is of Hosanna (Hebrew translation means "Save")

when she first came to them. She was about 12 months of age and weighed less than 4 kg. Seeing Hosanna's poor little frail body just made my heart ache. My friends sought medical attention for her in China to see if anything could be done. It took a few weeks to begin to get a sense of what was wrong (take note folks – appreciate your access to your local clinic!). Finally, the word came that they believed this child had a blood disorder called Beta Thalessemia Major. This meant that Hosanna had a complete lack of beta

What a difference TLC and good medical care make! Take a look at our little miracle now! Only four months have passed and the change in Hosanna is amazing!

protein in her hemoglobin which caused life-threatening anemia. When I heard the words 'blood disorder', I thought, "Well, we can help with that!" From my involvement in the CHS, I knew that through the World Federation of Hemophilia Dr. Man-Chiu Poon, Director of our Southern Alberta Hemophilia Clinic, had twinned his Calgary clinic with Hematology Clinics in China.



Dr. Man Chiu-Poon and Hosanna in September, 2007



Hosanna on September 30, 2007, after only 4 months of proper medical treatment

I emailed Dr. Poon and asked if he might be able to help. And help he did! Dr. Poon kindly reviewed test results, helped confirm the diagnosis and put my friends in touch with a Hematologist in China who could treat Hosanna. The treatment for Beta Thalessemia Major is frequent blood transfusions. The challenge is that these frequent transfusions eventually cause iron-overload which must be further treated with chelation therapy. Through Dr. Poon and his colleagues in China, my friends were able to purchase appropriate medical equipment and medicine and receive training to administer daily chelation therapy for Hosanna.

What a difference TLC and good medical care make! Take a look at our little miracle now! Only four months have passed and the change in Hosanna is amazing! I am truly inspired by the love and care my friends have shown this precious little one. Thanks doesn't fully express the gratitude I feel for the caring and compassion graciously given by Dr. Poon and Dr. Jing Sun in China in everything they have done to save Hosanna's life. I have deep admiration for them both! Lastly, I want to challenge each of you reading this article to become involved in your Chapter of the CHS. Our volunteer numbers are small and we need you! Value the care you have and be prepared to support and share it with others. You never know when you might become part of a life saving adventure! ☺

The Female Factor

by Patricia Stewart



VWD in Women: Raising Awareness, Changing Lives

Training weekend for women

An estimated 300,000 Canadians have the gene that causes von Willebrand disease (VWD), the most common bleeding disorder. The inherited disorder affects males and females equally, however females have the extra problems associated with gynecological and obstetrical bleeding (97% of girls and women with VWD consult for these specific problems compared to 10% of the general

female population). While approximately 10% (30,000 people) may experience medical problems related to bleeding, only 8% of this subgroup (2,500 people) are currently registered at hemophilia treatment centres in Canada.

The Canadian Hemophilia Society published its first comprehensive book for people with von Willebrand disease, *All About von Willebrand*, in 2000, and launched the VWD Public Awareness

"It was an exceptionally joyful and fun event."

Campaign in 2001 to help increase recognition of the symptoms of VWD and thus increase diagnosis of people living with this disorder. The *Community Education Kit*, a binder that includes a visual presentation and corresponding information, was developed as a tool for educating the public about VWD. The kit was sent out to all chapters, but follow-up evaluation in 2006 determined that it was seldom used.

continued on page 24



Enthusiastic participants at the VWD training workshop

In addition, despite the publication of *Treatment Guidelines for Women with Bleeding Disorders* by the Society of Obstetricians and Gynecologists of Canada (SOGC) in 2005, women continue to go undiagnosed.

The CHS consequently decided to organize a training workshop to familiarize individuals from CHS chapters on how to use the *Community Education Kit* to raise public awareness of VWD in their local communities, and to train others on using

"One of the highlights for me was meeting other women with VWD. I have only known my own sisters, and we often felt very alone. I personally seldom discussed VWD with anyone but that will change now."

the kit. A broader goal of the training workshop was to generate at least three awareness activities in every province in the coming year. On October 26-28, 2007, 20 women from across Canada attended the VWD training workshop held in Montreal by the CHS. The goal of the workshop, called *VWD in Women: Raising Awareness, Changing Lives*, was to give participants helpful public-speaking and presentation skills towards educating the general public and raising awareness about this common bleeding disorder.

Once someone has been properly diagnosed, preventive treatment can make the difference between having a simple medical procedure for a common surgery such as tonsillectomy, or experiencing a severe bleeding episode that can be life-threatening. The workshop began with personal accounts from three women who spoke about the medical problems they experienced due to lack of diagnosis. The next

day, Clare Cecchini, CHS Program Development Coordinator, described CHS advocacy efforts to meet the needs of women with bleeding disorders. Participants also heard from Dr. Rochelle Winikoff, hematologist at Ste. Justine Hospital in Montreal, on the history, symptoms and treatment options for von Willebrand disease.

Another session featured tips on public speaking, by Teri Kingston of Toastmasters International. It was followed by a screening of the visual presentation component of the *Community Education Kit*. Participants then engaged in a hands-on session, in which each person practiced giving the VWD presentation before a small group. The final day's sessions dealt with setting up an information kiosk. Groups were given time to set up an information table and practice their "sales pitch" to passers-by, including members of the CHS Executive Committee who were meeting at the same hotel.

Brainstorming sessions also took place on potential target audiences and locations where information kiosks could be set up, with individuals exchanging experiences and presentation tips. Participants also developed individual action plans for 2008.

The enthusiasm among participants was contagious. Everyone was eager to learn how to get the message across and help increase awareness and diagnosis to ensure that people with VWD get the information they need to control the bleeding disorder and change their lives.

The results were immediate. Shelley Mountain from PEI gave three community presentations and two newspaper interviews in the weeks following the training workshop. And, in December, information kiosks about VWD were set up by CHS volunteers at blood donor clinics held in PEI and Nova Scotia.

The community education kit on VWD isn't a medical presentation—it's a simple tool with basic information on the disorder for the general public. As someone living with a bleeding disorder, you're already an expert. You can give the presentation yourself, or simply offer to help someone else set up a kiosk for a day. If you would

like more information about the *VWD Community Education Kit* or know of any group that might be interested in an information session, don't hesitate to contact Clare Cecchini at the CHS and she can put you in touch with the person from your chapter who attended the training workshop. Your chapter may also be organizing a training day or a VWD information session in which you can take part.

"Practicing the presentation in our groups made me feel much more comfortable with the material."

Raising awareness about bleeding disorders can help change lives, improving the quality of life and health for those who are undiagnosed and untreated. Because they are inherited genetic disorders, having one family member diagnosed with a bleeding disorder can lead to other family members being diagnosed, thus changing many lives. ◊



Shelley Mountain and her daughter, Valerie, four, both have von Willebrand disease.