2006 World Hemophilia Congress a resounding success

Congress President Dr. Georges-Étienne Rivard in beat at Opening Ceremonies (see more on p.12)
We would like to thank the following companies, corporate foundations and employee fund programs for their generous support. Our way of recognizing them for their generosity is through our National Corporate Giving Program.

BAXTER
BAYER
JOHN DEERE FOUNDATION OF CANADA
NOVO NORDISK
SCOTIABANK
WYETH
ZLB BEHRING

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

Working together with the corporate sector in Canada helps the Canadian Hemophilia Society (CHS) accomplish its mission and vision by extending our reach and reinforcing our messages. This enables us to:

- Offer national programs of training, education and awareness.
- Support research into hemophilia and other bleeding disorders.
- Produce educational publications, periodicals (such as Hemophilia Today) and keep our Web site www.hemophilia.ca up to date.
- Interact with stakeholders in the health care field to promote the well being of all our families.
In this issue there will be a lot of discussion of the World Federation of Hemophilia’s XXVII\textsuperscript{th} World Congress. Because the event was held right here in Canada—in Vancouver, BC, to be precise—many members of the CHS were able to attend.

This kind of bi-annual event is an ideal opportunity to catch up on developments in bleeding disorders: medical, musculo-skeletal or multidisciplinary issues, complications, like inhibitors or synovitis, not to mention ethical matters. You will also find a number of articles in which participants talk about their experiences, as well as an interview, on page 13, that I did with the Congress President, Dr. Georges-Étienne Rivard, in which he gives us his impressions of this truly memorable event.

I was one of those who had the opportunity to go to Vancouver to take part in what turned out to be a very lively, interesting WFH Congress. A number of things caught my attention, but what I would like to share with you is a comment Dr. Rivard made in one of his talks: “The patient must be the focus of the healthcare team’s intervention.” Whereas in the traditional approach adopted by health professionals, the physician is the focus of the intervention, he felt that it would be preferable for the intervention to focus on the patient so that the treatment could be adapted to local resources and the patient’s needs. This certainly requires a certain amount of flexibility from the healthcare team, but has the advantage that it leads to an optimal intervention, including a diagnosis, treatment plan, treatment, reintegration, and correction of complications, all handled quickly and efficiently. This approach is right in line with the notion of having people suffering from bleeding disorders take responsibility for their own care. In fact in most cases, patients have gotten into the habit of doing this as a matter of survival.

On another subject, I would like to mention developments in the fight for compensation for people suffering from post-transfusion hepatitis C following the federal government’s recent announcement of the creation of a program to compensate people infected before January 1, 1986 or after July 1, 1990 (See Long-awaited pre-1986/post-1990 hepatitis C compensation finally on its way on page 5).

The CHS and its chapters and regions have long demanded publicly that the first recommendation of the Krever Report be implemented and that all victims of serious harm as a result of the administration of blood products be compensated, regardless of who was at fault.

Congratulations to everyone who worked so hard for the past eight years to correct this injustice. The road was long and sown with pitfalls, but the final victory is all the more deserved.\H
**PRESIDENT’S MESSAGE**

Eric Stolte

**CHARACTER**

*Character.* How would you define this? “A description of a person’s attributes, traits, or abilities” or “The inherent complex of attributes that determine a person’s moral and ethical actions and reactions.” These are certainly accurate to a point. But recently I read this definition of character: “Character: the ability to meet the demands of reality.”

What is our reality and what does this reality demand of us? Although we could each answer this from a very personal point of view, I would like to consider this question from a bleeding disorders community standpoint at it relates to the CHS and its mission. You’ll note that we now have a new mission statement.

*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.*

Our reality is characterized by both very positive and very challenging elements:

😊 We have what is considered by many to be the highest standard of care in the world.
😊 This care is not equally accessible to all.
😊 These standards are not maintained equally across our country.
😊 This care is costly to our health system and therefore vulnerable to funding cutbacks.
😊 We have a very safe blood system that we monitor with vigilance.
😊 There are potential threats from unknown pathogens.
😊 Justice Krever submitted his Final Report on the blood system almost 10 years ago and many politicians have a short memory.
😊 We have excellent strategic planning for both our programs and our fundraising initiatives.
😊 Our volunteer base across Canada is small.
😊 20% of our volunteers accomplish 80% of the work.
😊 We are overly dependent on a very narrow band of funders.
😊 We have one of the strongest hemophilia societies in the world.
😊 Our achievements have led to widespread complacency among affected families.
😊 There are leadership gaps at all levels of the organization.
😊 We have more twinning partnerships than any other hemophilia society in the world.
😊 75% of people with hemophilia around the world still have no access to factor replacement treatment.
😊 Although efforts are underway to change this, Canada still discards surplus factor VIII-rich cryoprecipitate that is no longer used for fractionation.

There is more that could be said but we must ask ourselves: Do we have the courage to face and meet the demands with which these realities present us? Many of our bleeding disorder brothers and sisters around the world are facing and meeting much greater demands than those that face us. Anyone who attended the WFH World Congress in May met hundreds of courageous people who are willing to take on the challenges of their onerous realities. They are giving themselves heart and soul to overcoming the obstacles they face in bringing an increased quality of life to people in their own countries affected by bleeding disorders. The stories of these people bring us much needed inspiration as we face our challenges.

Not only do individuals have character, organizations do, too. How would you describe the character of the CHS? Better yet, how would you describe your contribution to that character? In the past, we faced very grim realities and have continued to face the ones that have lingered. This tenacity has resulted in the federal government granting hepatitis C compensation to those who had been left out of the previous plan.

Our strength of character as a community of people affected by bleeding disorders has accomplished all the positive aspects of our reality. But will that strength fade or renew itself as we face the negatives of our reality? I believe that within our community there exists the courage and determination to struggle for a day when Canada and the world is free from the pain and suffering of inherited bleeding disorders.

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**FROM THE EXECUTIVE DIRECTOR**

Stéphane Bordeleau

**VANCOUVER 2006**

In May of this year, the Canadian Hemophilia Society played host to the XXVII Hemophilia World Congress in Vancouver and, once again, Canadians did themselves proud. The event was a great success, with close to 4,000 participants from a hundred different countries gathering to help advance our cause on all fronts—scientific, medical, clinical, and social. The Congress, which is held every two years, brings major improvements to the condition of the thousands of people coping with inherited bleeding disorders around the world. All those who participated—physicians, patients, researchers, nurses, social workers, physiotherapists, family members and representatives of other groups—returned home full of positive energy and new knowledge, and confident of a better future.

I would like to salute the contributions of the dozens of Canadian volunteers who donated hundreds of hours of their time to provide a warm welcome and excellent care to the thousands of visitors. During the closing ceremonies, World Federation of Hemophilia President Mark Skinner had nothing but good things to say about all the Canadians who helped organize the event. Thank you, and congratulations to all of you!
PUBLIC AWARENESS IN CANADA

As a result of our recent meetings and the 12 strategic directions we recently established (see mission and vision statement on page 6), we are now putting the different pieces of the puzzle in place to achieve our goals. One of the critical objectives at the CHS is raising public awareness. Our organization must become better known and help people understand what bleeding disorders really are.

The Board of Directors recently added another piece of the puzzle when it approved the creation of the Communication Committee. The task force, which already existed, is now recognized as an official committee. Even if only symbolic, this gesture underscores the importance of the role to be played in the coming years by the people who make up this committee.

In addition, the CHS has recruited a new employee, Chantal Raymond, whose exclusive job it is to raise public awareness of our cause. Chantal brings a number of talents, including a sound knowledge of the complexities of marketing and communication. Her intelligence, sensitivity, and her genuine desire to make a difference for our members make her a valuable ally.

We are also producing a public service announcement for television and a corporate video for our partners, donors, and supporters. These two communication tools will be available in the coming months to publicize our organization’s contribution and help people better understand what it is like to live with a bleeding disorder.

These are just some of the initiatives the CHS has undertaken to improve our communication efforts and help us find a solution to the puzzle. Once again, we have a group of very dedicated people to thank for all this. Hats off to all of you!

CONDOLENCES

We have learned of the accidental deaths of a few young people coping with hemophilia in just the past few weeks. We would like to express our very deep sadness and offer our condolences to family members and those close to them. Hemophilia weakens the slender thread by which we cling to life. One day, together, we will find a cure.

Chantal Raymond,
CHS National Marketing and Communications Coordinator

Prime Minister Stephen Harper announced last July 25 that the federal government and class action lawyers have reached an agreement on the elements of a settlement for those Canadians who contracted hepatitis C through transfusion of blood and blood products before January 1, 1986 and after July 1, 1990.

“All should be compensated equally, because all of the victims have endured pain and suffering,” said the Prime Minister.

Under the terms of the agreement announced that day, the federal government will set aside nearly $1 billion in a special settlement fund, the sole purpose of which will be to provide compensation to those who were infected prior to January 1, 1986 and after July 1, 1990. The level of compensation will be based on the principle of parity with compensation already provided by the federal government for those who were infected between 1986 and 1990.

Benefits will be paid on a present-value basis, meaning that class members will receive the entire sum of their compensation up front, based on such factors as current disease level and probability of disease progression. This will also serve to minimize administrative costs.

The Prime Minister added that the agreement provides the foundation for a detailed final agreement. Once this is completed and approved by the courts in four provinces, an application and review process will be established to ensure that compensation is provided as quickly and effectively as possible. He estimated that the first cheques would be issued in the first months of 2007.

This compensation plan is entirely distinct from those set up by the Red Cross and the provinces of Ontario, Quebec, British Columbia and Manitoba for those infected during the same time period.

John Plater, Chair of the CHS Task Force on Hepatitis C and HIV said, “The CHS has always advocated for equal compensation for all who contracted hepatitis C through the blood supply, regardless of when they became infected. We know that this plan is not exactly the same as that which already exists for people who became infected between 1986 and 1990. However, the total amount of money to be set aside in the pre-86, post-90 compensation fund and the number of people involved are similar. As with that previous settlement, it will be up to each individual, once the plan has been approved by the Courts, to determine if it is in his/her best interests.”

Mr. Plater added, “It is unfortunate that the process has taken so long. This highlights the need for a comprehensive no-fault Blood Injury Compensation Scheme (BICS) as proposed by the CHS several years ago.”

David Page, CHS Director of Programs and Public Affairs points out, "More than 95% of our members are already covered under the 86-90 settlement. We continued this fight for the last eight years in the name of justice for those few of our members not included and for the many thousands of other Canadians who received a tainted blood transfusion and who were not compensated. Without the work of CHS, and people like John Plater and Mike McCarthy, it is unlikely either plan would ever have seen the light of day."

Without the work of CHS, and people like John Plater and Mike McCarthy, it is unlikely either plan would ever have seen the light of day.

— David Page

COMMUNITY NEWS

Long-awaited pre-1986/post-1990 hepatitis C compensation finally on its way
**CANADIAN HEMOPHILIA SOCIETY**

**MISSION, VISION AND STRATEGIC DIRECTIONS**

On May 27, 2006 the Canadian Hemophilia Society Board of Directors formally adopted its new Mission, Vision and Strategic Directions. This followed a strategic planning process that received input from over 200 members, donors and health care providers from all parts of the country. This document will provide the orientation for the CHS in its work over the next three to five years.

**MISSION, VISION**

**MISSION**
The Canadian Hemophilia Society strives to improve the health and quality of life for all people with inherited bleeding disorders and to find a cure.

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

**THE PEOPLE WE SERVE**
The Canadian Hemophilia Society serves people with inherited bleeding disorders. These bleeding disorders include hemophilia, von Willebrand Disease, rare factor deficiencies and platelet disorders.

**THE CANADIAN HEMOPHILIA SOCIETY – WHO WE ARE**
The Canadian Hemophilia Society is an organization that works at three levels: nationally, provincially and locally. We have ten provincial chapters across the country. Some of our chapters have additional local structures that we refer to as regions. Together we are the Canadian Hemophilia Society.

**STRATEGIC DIRECTIONS**

**CARE AND TREATMENT**
We will work to ensure equitable access to optimal, publicly-funded, standards-based comprehensive care for all people with inherited bleeding disorders.

**RESEARCH**
We will fund research to improve treatment and ultimately find a cure.

**SUPPORT AND EDUCATION**
We will provide support and work to increase knowledge, awareness and understanding among members of the inherited bleeding disorders community including health care professionals.

**SAFE, SECURE BLOOD SUPPLY**
We will work to ensure a secure, publicly-funded supply of safe blood, blood products and their substitutes for all Canadians.

**INTERNATIONAL DEVELOPMENT**
We will be supportive of the global inherited bleeding disorders community.

**PUBLIC AWARENESS**
We will create greater public awareness of inherited bleeding disorders and of our organization.

**ADVOCACY**
We will seek to influence people and promote public policies to fulfill our mission.

**COLLABORATION**
We will develop and enhance partnerships to gain access to and share knowledge, resources and expertise.

**VOLUNTEER DEVELOPMENT**
We will create and implement a volunteer development program that helps the organization in meeting the needs of those it serves.

**YOUTH ENGAGEMENT**
We will engage youth in the planning and delivery of our programs and services.

**FUNDING**
We will create a future in which all are provided with the opportunity and motivation to partner in our mission through their financial generosity.

**ONE ORGANIZATION**
We will work as one organization at all levels – national, provincial and local – to achieve our common goals.

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**CHS BOARD OF DIRECTORS FOR 2006 – 2007**

The CHS Annual General Meeting and first Board of Directors Meeting for 2006 – 2007 were held on May 26 and 27 in Vancouver, B.C.

Following elections in the ten Chapters and at the Annual General Meeting, the members of the Board of Directors for the coming year are:

**President**
Eric Stolte

**Past President**
Tom Alloway, Ph.D.

**Vice Presidents**
Mike Beck
Heather Moller
Pam Wilton

**Vice President/Treasurer**
Norman Locke

**Secretary**
James Kreppner, LL.B

**Directors**
Steven Bardini
Colleen Barrett
Bea Bohm-Meyer
Mylène D’Fana
Marius Foltea
Christine Keilback
Martin Kulczyk
Aline Landry
Daryl McCarvill
Tony Niksic
Dane Pedersen
Bob Steffens
Craig Upshaw
Sandy Watson
Ann Wood

**MSAC Representative**
Bruce Ritchie, MD
The applications received this year were once again of an exceptionally high standard and indicate that the next generation of leaders in the Society will bring strong and varied talents to the organization. For the first time, due to the fact that two candidates were tied for the highest ranking, two scholarships based on academic merit were awarded.

**SCHOLARSHIP RECIPIENTS**

**Adam Del Gobbo,**
*Richmond Hill, Ontario*

Later this year, I will start my undergraduate degree in the Faculty of Engineering at the University of Ontario, located in London. I plan to enjoy my education as an engineer for four years (even though it is a lot of hard work) and once I achieve my degree, I plan to vie for a position in Western’s School of Dentistry. This may sound odd for a person entering engineering, but since I was a child, it has been my dream career to become an orthodontist. With much hard work and dedication, I plan to succeed in all of the goals that I set for myself.

**David Pouliot,**
*Varennes, Quebec*

I am now a graduate student in pure and fundamental mathematics at the Université de Montréal. This summer I began a research studentship at the university in which I am engaged in making parallel computing algorithms in order to increase their speed. This is what I prefer: subjects on the border between mathematics and computing. This fall I will be registered in a Master’s course in mathematics, still at the same university, with the hope of working on a project which is just as stimulating.

**BURSARY**

**Carrie Fleet,**
*Grand Manan Island, New Brunswick*

Growing up on a small island like Grand Manan always put pressure on academics as there is not much for teenagers to do. I worked hard in school and managed to maintain high marks all through school. Working hard on academics paid off in June when I graduated from high school as Valedictorian. All along I have known that I wanted to work in the health profession and, unlike most students, my future plans did not change as I grew older. I applied and was accepted into the University of New Brunswick’s Nursing Program, where I will be attending in the fall. Through the many times I’ve visited the hospital for numerous broken bones and bleeding disorder treatment, I have realized how important nurses are to patients. I am excited about starting my career as a nurse, and I cannot wait until I help someone as nurses in the past have helped me. It is a great honour for me to receive this scholarship as it will help in paying for my education, and I am very thankful!

**MATURE STUDENT BURSARY**

**Elizabeth Racz,**
*Toronto, Ontario*

Elizabeth graduated from Queen’s University with a BA in 2002. She is currently enrolled in the Bachelor of Health Sciences program (Medical Laboratory Sciences) at the University of Ontario Institute of Technology. Upon completion of her degree in 2008, she wishes to pursue graduate studies in Genetic Counseling and HIV research. In addition to her studies, Elizabeth volunteers at Toronto General Hospital in the Multi-Organ Transplant Clinical Trials department. This spring, she volunteered as a board member with the Toronto and Central Ontario Region (TCOR) of Hemophilia Ontario. As the spouse of a person with hemophilia, Elizabeth brings an empathetic perspective to both her studies and volunteering.
National Youth Committee

Last May, the CHS Board of Directors endorsed a strategic direction aimed at engaging youth. “We will engage youth in the planning and delivery of our programs and services.”

To respond to this strategic direction it was decided to strike a National Youth Committee composed of 18 youth from across the country. One of its main mandates will be to create a network of peer support to increase youth participation in each chapter. A nomination process will take place in early fall in each of the 10 provinces. Each chapter will be responsible for nominating its representatives. The number of representatives for each chapter will be the same as that for the CHS Board of Directors. If you are between 15 and 30 and would like to obtain more information on the nomination process, please contact your local chapter.

National Volunteer Development Committee

The CHS has recently created a National Volunteer Development Committee to recruit, train, retain and recognize its most valuable resource: its volunteers.

The Novo Nordisk Red, White and You Hemophilia Day was a success!

Employees viewed an informative video on hemophilia, played in a Red, White and You Hemophilia Day tournament that included volleyball, soccer, lawn bowling and horseshoes (the Red Team won!), and enjoyed an indoor barbecue style lunch. Employees not only raised awareness on inherited bleeding disorders but also benefited from coming together for this great cause!
New Resources Available!

We are pleased to announce the availability of three new resources about rare factor deficiencies. These booklets were developed by the Quebec hemophilia clinic nurses in collaboration with CHS.

- **Factor II Deficiency – An Inherited Bleeding Disorder**
  Factor II (FII) deficiency (also called hypoprothrombinaemia or prothrombin deficiency) is a rare coagulation disorder. People affected by this deficiency and those close to them have very little written information about it. This booklet explains the causes of FII deficiency, its symptoms and available treatments. We hope that this information will help answer your questions.

- **Factor V Deficiency – An Inherited Bleeding Disorder**
  Factor V deficiency, also called parahemophilia or Owren’s disease, is a very rare coagulation disorder. About one person in a million may be affected by this deficiency. Only 150 cases have been identified worldwide to date.

- **Factor X Deficiency – An Inherited Bleeding Disorder**
  Factor X (pronounced 10) deficiency is a very rare blood coagulation disorder with complications that vary with the severity of the disorder. This deficiency is not well known, even among health professionals. People affected by this deficiency and those close to them have very little written information about it. This booklet therefore seeks to provide information for people trying to cope with this health problem. It explains the causes of the deficiency, symptoms, possible complications and available treatments.

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.php.

Funding obtained for National Hemophilia Mutation Laboratory

At its Annual Meeting held in Vancouver in May, the Association of Hemophilia Clinic Directors of Canada (AHCDC) announced the continuation of funding for the National Hemophilia Mutation Laboratory at Queen’s University in Kingston, Ontario. For the 2006–2008 period, Baxter will provide a $375,000 grant. Some additional funding is provided through various research grants. Prior to 2006, the funding of the Laboratory was ensured by several agencies, including Health Canada.

The Laboratory is responsible for investigating the range of genetic mutations responsible for hemophilia A and B in Canada. This information is critical to the understanding of the disease. In addition, testing is done for Type III von Willebrand Disease (VWD) and confirmation of Types 2N, 2B and 2M VWD.

“The ability to provide direct genetic testing for patients with hemophilia enables them to make informed decisions about future family planning and also provides clinicians with new information to optimize the clinical care of these patients,” said Dr. David Lillicrap, the scientific director of the laboratory and an internationally renowned researcher in the field of genetics and hemostasis at the Department of Pathology and Molecular Medicine, Richardson Laboratory, Queen’s University.

Identification of the specific genetic mutation helps clinicians in the management of their hemophilia patients. They are better able to determine effective therapy regimens and predict the development of inhibitors to therapy.

So far the Laboratory has discovered 474 different mutations and issued 816 separate reports for hemophilia A; and 121 different mutations and 180 separate reports for hemophilia B. It is estimated that approximately 50 percent of Canadians with hemophilia A and B have been tested.

Each year the researchers at the Laboratory communicate in an anonymous manner all of the genotypes that are identified to the various international organizations that maintain databases for hemophilia A and B. In addition, testing results have aided several research studies on novel therapeutic approaches for hemophilia.

**ADVATE® APPROVED FOR USE IN CANADA**

August 2, 2006, MONTREAL - Baxter announced today that its recombinant factor VIII therapy, Advate®, has been approved for use by Health Canada for the treatment of hemophilia A.

“The Canadian Hemophilia Society is pleased to see the launch of Advate,” said CHS President, Eric Stolte. “A component of quality factor replacement therapy requires that a patient and his/her physician have the option to choose products which meet a patient’s individual needs. We therefore welcome the addition of Advate to the range of quality recombinant factor VIII products currently approved by Health Canada and other international regulators, and available to Canadians with factor VIII deficiency hemophilia.”

It is expected that Canadian Blood Services and Héma-Québec, which distribute clotting factor concentrates to hemophilia treatment centres in Canada, will gradually phase out the current Baxter therapy, Recombinate®, and replace it with Advate over a period which will last several months.

For more information on Advate, see the Spring 2004 issue of *Hemophilia Today* (Vol 39, No 1), available on-line at www.hemophilia.ca/en/1.0.php.
2-year-old Hamilton boy with severe bleeding disorder evacuated safely from Lebanon

David Page
CHS Director of Programs and Public Affairs

On July 23, 2-year-old Kareem Khalife and his family arrived safe and sound in Hamilton, Ontario after ten days in war-torn southern Lebanon and almost 72 hours of travel. The story of their evacuation is truly remarkable.

Kareem suffers from Type 3 von Willebrand Disease and a factor VIII inhibitor. This rare combination—there is only one other reported case—makes him susceptible to spontaneous intracranial bleeds.

Kareem and his parents, Hassan and Lina, his brother Ali, 9, and sister Lanise, 4, had left Canada in June to spend part of the summer with relatives in Ghazieh, south of Beirut. But on July 12, Israeli bombs began falling nearby.

The physician treating Kareem, Dr. Mohan K.R. Pai from McMaster University in Hamilton, confirms that the Khalife family was well prepared for their trip to Lebanon. “Kareem left for Lebanon with a sufficient quantity of factor concentrate for the duration of the trip. But when they were caught in Ghazieh, unable to move, the supply of his medication became critical.”

“At first, we thought the conflict wouldn’t last,” said Lina Khalife, “but when two bridges were destroyed and the bombs kept falling, we realized it was a war.”

“There was no power at all for four days, then only for a few hours a day,” she said. “It was hard to get food; we had to get by with what was in the house.”

Communications were difficult. “My brother-in-law in Canada registered us for evacuation but we were unable to get in contact with the Canadian Embassy in Beirut.”

The family became more and more concerned for their safety, and that of Kareem. So did Dr. Pai, who was in regular contact with the family. On July 18, he contacted the World Federation of Hemophilia (WFH) and the Canadian Hemophilia Society (CHS) to ask for help in getting the Khalifes evacuated. Both organizations used their contacts within the Canadian government to alert the Department of External Affairs of Kareem’s critical medical situation. Dr. Pai’s support as a physician proved invaluable. By early on July 19, External Affairs had designated Kareem as their top priority for evacuation and a massive effort began to find a way to get him home.

On July 20, through the combined efforts of the Hamilton and Kingston hemophilia treatment centres, CHS staff and the Canadian military, an emergency shipment of factor VIII-VWF concentrate and factor VIIa concentrate was rushed to Trenton Airbase and on to Cyprus.

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“I thank Dr. Pai every minute of the day,” Lina Khalife said. “And I want to express my gratitude to everybody who helped us get home safely.”

On July 21 began the Khalife family’s harrowing flight to safety. “It was the longest journey of my life,” said Lina. “We started out in my dad’s car and then switched to a taxi. A trip that normally takes 45 minutes took five hours. We had to go up into the mountains to find passable roads. Israeli planes were constantly overhead. Every second you imagined you would be bombed.”

On instructions from the Canadian Embassy, the Khalifes made their way to a Beirut stadium and from there to the British evacuation centre. They boarded a Royal Air Force helicopter and, along with 20 other medical evacuees, flew to a military hospital in Cyprus.

“Kareem had to sit on my lap on the helicopter,” Lina said. “It was boiling hot and he was restless. By the time we arrived, he was covered in bruises.”

The family was met in Cyprus by a Canadian military physician who, under Dr. Pai’s guidance, examined Kareem. The family’s remaining supply of concentrates, exposed to extreme heat, was discarded, and Kareem was infused with the emergency shipment of concentrates sent from Canada. The Khalifes were installed in a hotel in Larnaca, Cyprus, and twenty hours later evacuated by military aircraft to Montreal where they arrived on July 23. Later that day they flew to Hamilton, the first evacuees from Lebanon to arrive in that city.

“We were so relieved,” Lina said. “I dreamed about this moment. I wondered if I would ever see my family in Canada again. And I thought about my family back in Lebanon. Are they safe?”

Kay Decker, nurse coordinator at the Hamilton Health Sciences Corporation Hemophilia Program, met the family at the airport.

“This was a team effort,” she said later. “Everybody played their parts: the family, Dr. Pai, the CHS, the WFH, External Affairs, the military, the Hamilton and Kingston clinics. It took everybody to make this happen.”

“I thank Dr. Pai every minute of the day,” Lina Khalife said. “And I want to express my gratitude to everybody who helped us get home safely.”

Lina has told Hemophilia Today that her children have recovered from their ordeal and that she is in touch with her family in Lebanon and they are safe and well.
WHAT'S NEW ON THE CHS WEB SITE?

Rights Managed

C H S e N e w s
What's new on the Canadian Hemophilia Society Web site
Tel: 1 888 266 2667 • e-mail: info@hemophilia.ca
www.hemophilia.ca

▶ Regular updates to the home page highlighting “Upcoming events” in the bleeding disorders community.

▶ Expanded information on deficiencies in factors II, V and X in both .html at
www.hemophilia.ca/en/2.3.php and as a downloadable .pdf file at

▶ Summaries of the research projects funded by CHS in 2006:
CHS research grants at
www.hemophilia.ca/en/3.1.php
Care until Cure Research Program at
www.hemophilia.ca/en/3.2.php
The Novo Nordisk Canada Inc. - CHS -
AHCDC Fellowship in Congenital and
Acquired Bleeding Disorders at

▶ A registration button in the blue bar at
www.hemophilia.ca/en/index.html so that visitors can get regular updates
on what's new.

▶ A new discussion Forum at

UPCOMING EVENTS

CENTRAL WEST AND SOUTH WEST REGIONS OF HEMOPHILIA ONTARIO — JUST THE GUYS WEEKEND SEPTEMBER 15-17
The Central West and South West Regions of Hemophilia Ontario will be offering the fifth annual Just the Guys weekend on September 15-17 at Camp Ki-Wa-Y near Kitchener. This camping weekend for boys, 5-15 years old with a bleeding disorder, and their fathers or male role models provides an opportunity to learn more about bleeding disorders and make connections with others that share similar challenges and victories.

For more information contact:
Julie Serrador at 519 432-2365 or jserrador@hemophilia.on.ca
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TORONTO CENTRAL ONTARIO REGION (TCOR) SEPTEMBER 15-17
TCOR is hosting a Community Retreat Weekend September 15-17 at Camp Wanakita. The TCOR community retreat is an opportunity for community members of all ages to enjoy a weekend of fun and information sharing. Participants will have an opportunity to enjoy the many activities and benefits of Camp Wanakita in a supervised setting and have a chance to share concerns, ask questions, develop connections, expand their knowledge base and, most importantly, see what camp is all about! Space is limited and we're trying to arrange for transportation, so please RSVP to reserve your spot.

QUEBEC CHAPTER JUST THE GUYS WEEKEND SEPTEMBER 29 – OCTOBER 1
Just the Guys weekend will be held from September 29 - October 1 at L’Avenir, near Drummondville.
Contact: Geneviève Beauregard 514 848-0666 or 1 877 870-0666
gbeauregard@schq.org

NOVEMBER 4 – FIESTA SALSERA
On November 4, the Quebec Chapter is holding the first edition of the Fiesta Salsa, a fundraising event which will be held at the Just for Laughs Museum in Montreal. For tickets and information, contact the SCHQ office at 514 848-0666 or 1 877 870-0666.

HEMOPHILIA SASKATCHEWAN SEPTEMBER 10
Saskatoon Area BBQ and Volunteer Appreciation, 1 to 5 p.m. at Sergent’s Holiday Farm between Radisson and Borden. Hamburgers, hot dogs and refreshment supplied, pot luck salads and desserts.

OCTOBER
Fund Raiser Saskatoon, Steak Night and Silent Auction

DECEMBER 2
Kids’ Christmas Party

DECEMBER 16 AND 17
Old Elephant’s Christmas with Brenda Baker and Sheldon Corbett Children’s Concern Fund Raiser Refinery in Saskatoon
The record number of participants included people with bleeding disorders and their families, medical professionals, national hemophilia organizations, industry representatives and regulators.

The meeting was held in the spectacular waterfront setting of the Vancouver Exhibition and Convention Centre. The opening ceremony audience was treated to colourful performances by a 30-member pipe band and a First Nations drum group.

Sessions were well attended and topics ranged from the latest developments in inhibitors, prophylaxis, gene therapy, orthopedics, physiotherapy, pain management, quality of life research, family issues, psycho-social issues and nursing.

Other sessions focused on von Willebrand Disease and care for women with bleeding disorders, as well as the challenges for patients in countries with limited economic resources.

Congress exhibitors showcased the latest hemophilia treatment products, services and publications. Hemophilia associations from various countries, including the CHS, set up their own booths in the WFH area, while a poster display featured numerous contributions from individuals and organizations.

Significant media coverage of the World Congress raised awareness of hemophilia with television and radio reports on Canadian television and radio networks.

WFH volunteers were presented with awards at a ceremony honouring long-term volunteers who have significantly furthered the WFH’s mission to improve hemophilia treatment and care.

The WFH also organized an extensive training program for national member organizations before the Congress, as well as pre-Congress workshops in physiotherapy, laboratory sciences and nursing.

Canadians played an important role in the organization of the Congress. Nurses, physiotherapists and physicians from British Columbia, with the help of their Canadian colleagues, organized outstanding on-site treatment facilities for people with bleeding disorders. Many other Canadians were speakers, and still more volunteered their time to ensure that the Congress was as rewarding as possible for all who attended.

Please see the accompanying articles to get a taste of the resounding success that was Congress 2006.
Interview with Dr. Georges-Étienne Rivard,
President of the XXVII WFH Congress

François Laroche

Hemophilia 2006, the XXVII Congress of the World Federation of Hemophilia (WFH), held in Vancouver from May 21 to 25, has come and gone. It is already clear that it was one of the most successful congresses to date, and very much appreciated by medical participants, according to Congress President Dr. Georges-Étienne Rivard. Dr. Rivard is Medical Director of the hemophilia treatment centre at Hôpital Sainte-Justine in Montreal. Hemophilia Today talked to him recently and asked him for his impressions of the event.

Hemophilia Today (HT): Dr. Rivard, what are your first reactions now that the Vancouver Congress is over?

Dr. Rivard: First, even though there were no major revelations during the event, I believe that the doctors in particular felt this Congress was the best the WFH has held to date, mainly because of its scientific content and the active participation by health professionals.

HT: Specifically, if we look at the question of gene therapy, what did we learn from this Congress?

Dr. Rivard: In spite of the problems we’ve run up against in recent years, there is no reason to believe that this path should be abandoned. The animal models suggest some interesting possibilities. Targeting the gene insertion site still poses some problems, but once we solve that, a lot of things will be possible.

HT: There was a lot of talk about inhibitors during the week. What progress has been made recently in terms of this serious complication of hemophilia?

Dr. Rivard: In general, we can say that the environmental risk factors for inhibitor development are better defined. Based on preliminary results from the Canal’ multicentre study done by a research group in Utrecht (Netherlands) led by Dr. Marijke Van den Berg, the risk of developing an inhibitor is linked more to a serious inflammatory situation than to early exposure to replacement factor. Early exposure to replacement factor is thus not a risk factor in itself. With regard to the genetics of this inflammatory reaction, we know that intercellular communication molecules, proteins called cytokines, heighten the inflammatory reaction in some subjects, which creates a predisposition to inhibitor formation. The problem has to do with the polymorphism (wide variety in chemical composition) of these cytokines. In other individuals, mutations in the hemophilia gene promote the development of inhibitors. Unfortunately, these mutations do not appear to react well to immune tolerance treatment.

HT: What kinds of replacement products are available? In an interview you gave us lately, you mentioned the study by Dr. Jenny Goudemand2 which seemed to support the hypothesis that some plasma-derived products are less immunogenic due to their high von Willebrand factor content. Has this been confirmed by other studies?

Dr. Rivard: If we look at all the studies that have been done on this, we can say that there is no clear evidence that plasma derivatives are less likely to promote inhibitor development. Coming back to cytokines, the anti-inflammatory effect of some cytokines contained in plasma derivatives has a more protective effect than von Willebrand factor itself, but there is a grey area. Nor is there any evidence that plasma derivatives are more effective in immune tolerance treatment.

HT: Since you mention it, what progress has been made in inducing immune tolerance?

Dr. Rivard: An international randomized survey is currently underway, although because of problems recruiting candidates it is not advancing very fast. The main difficulty the researchers face, apart from the scarcity of cases, is resistance on the part of candidates and their physicians to having their treatment decided by chance (200 IU/kg once per day vs. 50 IU/kg three times per week). They hope to be able to answer the question: “Is it better to treat with larger doses for a shorter time, or smaller doses for a longer time?” The results appear promising, however, even though the “best” candidates are being selected from the outset.

HT: Any final thoughts?

Dr. Rivard: From my discussions with colleagues during the week I conclude that we are seeing favourable developments in the treatment of women with coagulation anomalies. This reality is gaining more recognition from physicians in their practices, and from community organizations through the services they provide to this clientele, and this can only benefit the women affected.

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1 The Concerted Action on Neutralizing Antibodies in Severe Haemophilia A (Canal Study), Journal of Thrombosis and Haemostasis, Volume 3, Supplement 1, August 2005.

2 Influence of the type of factor VIII concentrate on the incidence of factor VIII inhibitors in previously untreated patients with severe hemophilia A, Jenny Goudemand et al., Blood 2006 107: 46-51.
It was my privilege to co-chair the World Federation of Hemophilia Multidisciplinary Program Committee for Congress 2006. Planning for Congress XXVII began long before Congress XXVI took place and so I took advantage of my attendance in Bangkok in 2004 to observe the program from a different perspective. I watched carefully and asked participants, speakers, chairpersons and staff about their experiences, inviting informal feedback about the sessions and all the while thinking about how we could make the next Congress even better.

The Multidisciplinary Committee includes healthcare professionals from each of the disciplines, National Member Organization (NMO) staff and volunteers who have bleeding disorders, from around the world. The highly skilled and dedicated WFH Program Staff facilitate the work of the committee. During its one and only meeting, the committee spent a blustery weekend in Montreal brainstorming ideas and potential speakers for the program in Vancouver. The Medical Program committee was doing the same in a room down the hall. We got together to exchange ideas, to develop common themes and to argue politely about how to share the budget. By the end of the weekend, I knew there was still an almost overwhelming amount of work to be done, but that we were going to have an outstanding Multidisciplinary Program in Vancouver.

It is difficult for me to narrow down what were the highlights of the Multidisciplinary Program. It was amazing to see people, who to pull together a 90-minute session collaborated only by e-mail, finally meet in person for the first time, and literally step up to “make it happen”. Of course, I am proud of the program offered in Vancouver. The Committee worked extremely hard to deliver a program that would meet the varied learning needs and expectations of healthcare professionals, people with bleeding disorders and volunteers. Formal and informal feedback indicates that we achieved our goal.

I have reviewed all of the evaluations and, if we look at the numbers, the session with the highest attendance was ‘Venous Access: Current Management’, chaired by Vicky Vilder. This session included information about implantable venous access devices, use of arterio-venous fistulae, an educational program for children called ‘Poking School, ‘Cause Poking’s Cool and a family’s perspective. Until we sip factor milkshakes or inhale replacement products with our once-a-day vitamins, venous access will continue to be an important topic to a majority of our nurses, physicians, patients and families, which must be revisited at each conference.

The session which received the highest rating: 4.8 out of 5, and which was also one of my personal favourites, was ‘Musculoskeletal Issues Through the Generations’, chaired by an internationally famous Canadian, Kathy Mulder. One might argue that including a presentation entitled ‘Sex and the Psoas gave it an unfair advantage! While I will agree it may have had an impact on the attendance, I think it was popular because it is an issue that has not been previously discussed. I will shamelessly credit the Canadians for identifying “ageing in the hemophilia population” as an important and emerging issue, at least in the developed countries. This is an important achievement and can be credited to the dedication, knowledge, skill and passion of the entire WFH community. Ageing with hemophilia though will bring new challenges to patients, families, physiotherapists, nurses, social workers and physicians. Another session, ‘Wrinkles and Old Bones: Issues for Those Over 50, gave people a chance to think and learn about some of those new challenges. High scores for both of these sessions, including each of the individual presentations, indicate that speakers were well prepared, presented their information clearly and that the topic was relevant and important to those attending.

When asked what was the highlight of the Multidisciplinary Program at Congress for me personally, the answer is easy. Watching a speaker from a faraway NMO, who shyly accepted an invitation to present her thoughts, who left her family behind and traveled alone, who rarely speaks English, who has never spoken at an international conference, who e-mailed us a thousand times with questions, finally stand at the podium, whispering a “thank you” and beaming as 178 people applauded in appreciation.
For some at CHS, one of the highlights of Congress 2006 was the opportunity to meet our twins. This happened individually throughout the conference and it happened altogether on May 22 when the CHS hosted a dinner for all its twins. Representatives of the twinning partnerships from Canada and from Belarus, China, Jordan, Serbia, South Africa and Tunisia were present for an evening of discussion and celebration. Only our twins from Iran and Mongolia were unable to be present.

As host of Hemophilia World Congress 2006, the CHS receives a cheque from Wyeth. L to R: Eric Stolte, CHS President; Anne Myerson, Product Manager, Hemophilia Products, Wyeth; John Manthorp, Director, Global Hemophilia Strategy, Wyeth Pharmaceuticals; Claudia Black, WFH Director of Programs.

Some of the people from China who are twinned with the Hemophilia Treatment Centres in Calgary and Ottawa.

The WFH program staff who work so hard to make these partnerships work also attended. So did representatives of Wyeth, the principal sponsor of the twinning program.
Canadian healthcare providers organize world-class treatment centre at Congress

Led by the staff from the Vancouver clinics—Erica Purves, R.N., John Wu, M.D., Linda Vickars, M.D., Deb Gue, R.N., Kami McIntosh, R.N., and Sandra Squires, P.T.—healthcare providers from Canada’s hemophilia treatment centres organized and delivered world-class treatment facilities for the ten days of the Congress meetings.

For the first time at a WFH Congress, the treatment centre included physiotherapy evaluation and care.

Thanks to all those who volunteered their time at the centre. Without you, many of the participants would have been unable to attend the Congress. Many thanks also to Baxter, Bayer, Novo Nordisk and Wyeth who donated the clotting factor concentrates for the centre.

Erica Purves, R.N., administers an infusion to a participant at the Congress.

National Member Organization Training Experience

Cory Prestayko

I was lucky to see the entire landscape of western Canada on my drive to the WFH Congress that took place in Vancouver. Upon arrival on the west coast, I attended the National Member Organization (NMO) Training session that took place prior to the WFH Congress. Hearing the different perspectives of representatives from around the world really opened my eyes to how good hemophilia care is in Canada. It was also nice to see familiar faces from previous WFH Congresses.

The NMO training provided specialized sessions to countries based on how developed they were. Fundraising and volunteer recruitment were the sessions that the more developed countries attended. These two subjects are of the utmost importance both nationally and locally in Canada, and they provided a wealth of both knowledge and experience of people from all around the world. Hearing about the experiences of others opens your mind to new ways of thinking and taking into consideration many ideas that you would not have thought of on your own. In my own case I was able to come away with ideas for fundraising within my local chapter as well as nationally that have the potential to do very well. The whole experience of the NMO training really benefited all those who attended and gave a more worldwide perspective to hemophilia care. It allowed people the chance to converse and learn first-hand how we are doing throughout the world.

I would like to close by thanking everyone who made it possible for me to have the experience of attending the NMO training so that I can use what I learned to the benefit of the CHS both nationally and locally.

Lori Enns (right) from Winnipeg and Karen Christie (centre) from Hamilton examine a patient in the physiotherapy room of the Congress treatment centre.