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# The Canadian Hemophilia Society

2007  
annual  
report

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determination  
perseverance



Canadian Hemophilia Society  
Help Stop the Bleeding

[www.hemophilia.ca](http://www.hemophilia.ca)

## OUR NATIONAL OFFICES

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To contact our 7 other provincial chapters,  
see our Web site at [www.hemophilia.ca](http://www.hemophilia.ca).

## OUR NATIONAL STAFF

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Executive Director

**Hélène Bourgaize**  
Director of Volunteer  
Development and Human  
Resources

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Annual Giving Coordinator

**Clare Cecchini**  
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**Pauline Major**  
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Development Manager

**Chantal Raymond**  
National Marketing and  
Communications  
Coordinator

# our vision

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



Photographe Marcel La Haye ©

# our mission

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



Photographe Marcel La Haye ©



Pam Wilton, RN  
President



David Page  
Executive Director

## Determination and perseverance pay off in 2007



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

Although results sometimes seem slow in coming, 2007 was a year when once again our determination and perseverance clearly paid off.

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

In 2007 four provinces—Saskatchewan, British Columbia, New Brunswick and Quebec—indexed the *Multi-Provincial/Territorial Assistance Program* to the cost of living. At the end of the year, only one province, Alberta, remained and it was only a matter of time before this province, too, would provide indexation to those infected with HIV through blood and blood products. All this was the result of determination and perseverance.

The criminal prosecution of certain individuals at the heart of the tainted blood tragedy of the 1980s also came to an end in 2007. While some may fault the judgment, the CHS has kept its promise to those affected that we would shine light on these terrible events to the utmost of our ability. And to remember the people who lost their lives, we launched the *Commemoration of the Tainted Blood Tragedy* with a memorial tree planting in Ottawa.

In 2007 the CHS was more involved than ever in today's questions of blood safety and supply. To mark the 10<sup>th</sup> anniversary of the *Final Report of the Commission of Inquiry on the Blood System in Canada*, we produced the Fourth Edition of the *CHS Report Card on Canada's Blood System*.

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

In 2007 we launched the *All About Carriers* program. This is a landmark in a long struggle to recognize the care and treatment needs of carriers of hemophilia and women with other inherited bleeding disorders. Again, determination and perseverance paid off.

And we saw renewed determination to push forward the research agenda to improve treatment and find a cure. The *CHS Research Summit* brought together clinicians and researchers, who re-affirmed CHS' key role in this area.

A major effort was made to invest in our current volunteers and in our youth. They will be the next generation of leaders to carry on our tradition of determination and perseverance.

# The Canadian Hemophilia Society

The Canadian Hemophilia Society (CHS) is a national voluntary health charity.

Our national headquarters are in Montreal and we have 10 provincial chapters. There are regional offices in three provinces: Quebec, Ontario and Manitoba. The CHS has approximately 300 active volunteers and 20 staff across the country.

The CHS is affiliated with the World Federation of Hemophilia, which is officially recognized by the World Health Organization.

We work in collaboration with specialists in Canada's 25 bleeding disorder treatment centres, the blood system operators (Canadian Blood Services and Héma-Québec), the Network of Rare Blood Disorder Organizations, the hepatitis C community, the AIDS community, and others who share our common interests.

## facts and figures

- More than one in 100 Canadians carry an inherited bleeding disorder gene, and more than 35,000 of them have symptoms severe enough to require medical care. Yet many have not been properly diagnosed!
- There are no cures for inherited bleeding disorders. They are lifelong conditions.
- Effective treatment is available for those diagnosed. Left untreated, however, bleeding disorders can be life-threatening.
- Blood products, their recombinant substitutes and other drugs are effective in treating people with bleeding disorders, but they are not a cure!
- The Canadian Hemophilia Society is active in ensuring the safety of the blood supply in Canada through constant vigilance and monitoring for all Canadians.

## bleeding disorders

### Hemophilia A and B

- Hemophilia A and B affect 3,000 Canadians. The most severe forms affect almost only males.
- Hemophilia is a genetic disorder; however, in about 1 in 3 cases, there is no history in the family. The cause is a new genetic mutation. Thus hemophilia can affect any family.
- The most common symptom is bleeding into muscles and joints. Untreated, this leads to severe crippling.
- When bleeding occurs in a vital organ, especially the brain, it can be fatal.
- In about 30 percent of people with severe hemophilia, the immune system reacts to reject the clotting factor that is infused to stop or prevent a bleed. This complication, called an inhibitor, reduces the effectiveness of treatment and can be very serious.
- Women who are carriers often have symptoms of mild hemophilia and can have bleeding problems that affect their quality of life.



### Von Willebrand disease

- Von Willebrand disease is the most common inherited bleeding disorder, with one in 100 Canadians (300,000 people) carrying the gene.
- Symptoms affect an estimated 30,000 Canadians, both male and female, and can range from mild to severe. The most severe form can be life-threatening.
- Many of these people have yet to be properly diagnosed.
- A woman's quality of life can be more seriously affected. Heavy menstrual bleeding can lead to unnecessary hysterectomies. These can be avoided if women are properly diagnosed and treated. Severe hemorrhaging can occur during childbirth.
- Effective treatment exists for von Willebrand disease.

### Rare factor deficiencies

- A small number of Canadians, probably fewer than 1,000, suffer from rare factor deficiencies. These people have low levels of a specific blood protein. Symptoms vary from mild to severe.

### Platelet function disorders

- There are many different kinds of platelet disorders. In these disorders, blood platelets do not function normally, resulting in blood not clotting properly. In a few individuals, bleeding can be severe. Some people have no symptoms at all until they have a serious injury or surgery.

# our strategic priorities

- Safe, Secure Blood Supply
- Care and Treatment
- Research
- Support and Education
- Public Awareness
- Fundraising
- International Development
- Volunteer Development
- Youth
- Advocacy
- Collaboration



Commemoration  
of the Tainted Blood  
Tragedy



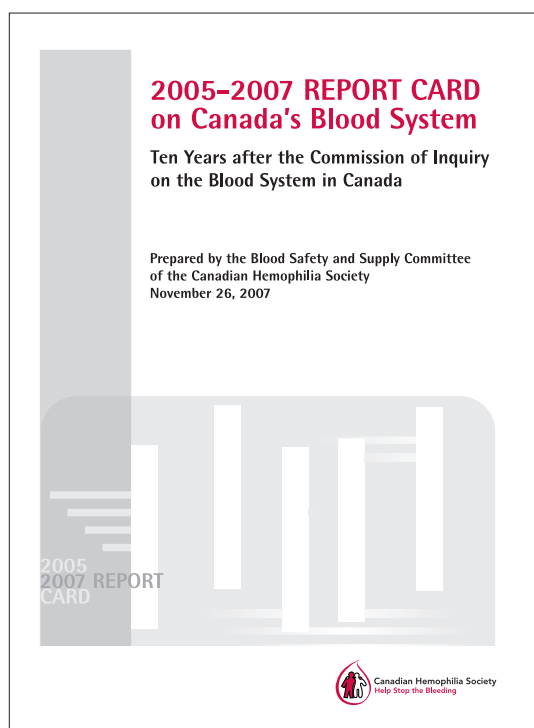
# safe, secure blood supply

## in 2007...

- We published the *2005-2007 Report Card on Canada's Blood System*. This evaluation, the fourth to be produced, was timed to coincide with the tenth anniversary of the publication of the *Final Report of the Commission of Inquiry on Canada's Blood System* (the Krever Commission).
- We participated in the Canadian Blood Services – Héma-Québec Selection Advisory Committee to provide recommendations to the blood services on the purchase of clotting factor concentrates for the 2008-2013 contract period.
- We played a key role with Canadian Blood Services in the review of current blood donor deferrals for men who have had sex with men. This led to a successful conclusion: no change in donor deferral criteria will be made at this time. Moreover, we have intervenor status in the case of Freeman vs. Canadian Blood Services and Health Canada, again to support the current blood donor deferral criteria in the interest of blood safety.

The CHS continues to be the leading patient organization in Canada to independently monitor the safety and supply of blood and blood products within the Canadian blood system.

To help ensure ALL Canadians have a safe and secure blood supply, CHS representatives participate actively in provincial, national and international blood advisory committees.



# care and treatment

Bleeding disorders are complex, lifelong conditions. Care and treatment for people with these disorders require the expertise of a team of healthcare professionals: physicians, nurses, physiotherapists, social workers and a range of other specialists. The CHS has been working since the 1970s to build a network of treatment centres for bleeding disorders serving people in every province. These centres offer *comprehensive care* services that have become a model for other disease conditions.

Comprehensive care for bleeding disorders has long promoted delivery of care in the home by the patient or a family member. This has included the infusion of intravenous clotting factor concentrates. Such treatment has proven both medically advantageous and economical for our healthcare system.

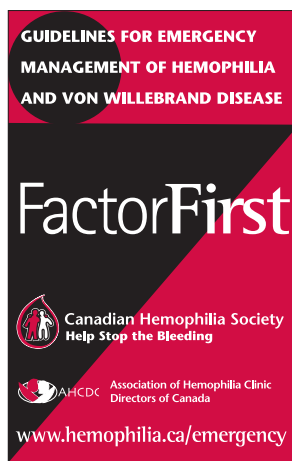
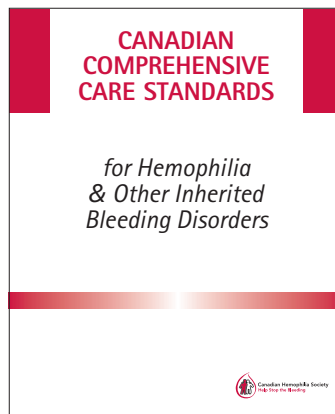


Photographie Marcel La Haye ©

Francis taking control of his treatment.

# in 2007...

- The CHS and the four professional associations representing physicians, nurses, physiotherapists and social workers endorsed the first edition of the *Canadian Comprehensive Care Standards for Hemophilia and Other Inherited Bleeding Disorders*. These standards will be critical in maintaining optimal care for people across the country.
- We organized the 2007 CHS - Association of Hemophilia Clinic Directors of Canada Medical and Scientific Symposium at *Rendez-vous Québec* in Quebec City. The 275 participants discussed standards of care and quality-of-life research.
- We supported 60 healthcare professionals with less than three years experience in bleeding disorder care to attend the *New Team Workshop* at *Rendez-vous Québec*.
- We provided administrative and logistical support so that the nurses, physiotherapists and social workers involved in bleeding disorder care could hold annual meetings and share expertise and best practices.
- We improved the *FactorFirst* card used by patients in Emergency Rooms (ER) and had bleeding disorders recognized in ER triage protocols.



# research

We provide clinical and research fellowships and we fund leading Canadian researchers working in the field of bleeding disorders in an effort to improve care and treatment, and ultimately find a cure.

Research is at the heart of CHS activities. Over the past 15 years, thanks to the Hemophilia Research Million Dollar Club endowment, generous individual donors, committed corporate sponsors and CHS chapters and regions across the country, the Society has invested more than four million dollars in both clinical and basic peer-reviewed research in Canada. The cure may not yet have been achieved, but it is closer every year.

On February 2, 2007, we brought together the Canadian bleeding disorder research community in what was called the *Research Summit*. The *Research Summit* gave participants the opportunity to provide advice to ensure that the CHS is getting the maximum benefit from its research programs. The summit was unique in that the bleeding disorder research community had never before come together in such a way.

## in 2007...

The CHS operated three research programs and provided funds to the:

### ■ CHS Dream of a Cure Research Program

**Dr. Wenda L. Greer**

Professor, Department of Pathology

Dalhousie University - Halifax, Nova Scotia

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

**Dr. Gonzalo Hortelano**

Assistant Professor, Department of Pathology

McMaster University - Hamilton, Ontario

*Gene therapy of hemophilia A*

**Dr. Maha Othman**

Adjunct Assistant Professor, Department of Pathology and Molecular Medicine

Queen's University - Kingston, Ontario

*Platelet type von Willebrand disease: An underdiagnosed cause of excessive mucocutaneous bleeding?*

**Dr. William P. Sheffield**

Associate Professor, Department of Pathology and Molecular Medicine

McMaster University - Hamilton, Ontario

*Factor VII(a) clearance behaviour*



Detailed descriptions of the projects at [www.hemophilia.ca/en/dream\\_of\\_a\\_cure2007](http://www.hemophilia.ca/en/dream_of_a_cure2007)



Participants at the *Research Summit*.

## ■ **Care until Cure Research Program in collaboration with Wyeth Canada**

The Care Until Cure Research Program was established in the year 2000 in collaboration with Wyeth Canada. This program allows Canadian investigators to conduct research on various medical and psychosocial aspects of bleeding disorders. Grants are given for clinical research, including outcome evaluation, in fields relevant to improving the quality of life of persons with hemophilia, persons with von Willebrand disease or other inherited bleeding disorders, persons with related conditions such as HIV or hepatitis C, as well as carriers of an inherited bleeding disorder.



### **Dr. Paula James**

Assistant Professor

Queen's University - Kingston, Ontario

*The prevalence of symptomatic pediatric VWD*



### **JoAnn K. Nilson, PT**

Saskatchewan Bleeding Disorders Program - Saskatoon, Saskatchewan

*Creating meaningful messages for individuals with mild hemophilia*



### **Dr. Rochelle Winikoff**

Staff hematologist

CHU Sainte-Justine - Montreal, Quebec

*Non-steroidal anti-inflammatory drugs and menorrhagia revisited*

Detailed descriptions of the projects at [www.hemophilia.ca/en/care\\_until\\_cure2007](http://www.hemophilia.ca/en/care_until_cure2007)

## ■ **Novo Nordisk Canada Inc. – CHS – Association of Hemophilia Clinic Directors of Canada Fellowship in Congenital and Acquired Bleeding Disorders**

This fellowship program was established in 2001. The goal of this program is to provide fellows in hematology or other relevant fields the opportunity to acquire clinical or research skills necessary to improve the care and quality of lives of patients with hemophilia and other congenital or acquired bleeding disorders.

### **Dr. Elianna Saidenberg**

Chief Resident in Hematology

McMaster University - Hamilton, Ontario

*Quality assurance of special coagulation laboratory practices*

Detailed description of the project at [www.hemophilia.ca/en/novo\\_nordisk2007](http://www.hemophilia.ca/en/novo_nordisk2007)

# support and education

We are the primary source of educational materials designed for people with bleeding disorders, their families, healthcare professionals and the general public. Our goal is to ensure access to up-to-date information that meets the needs of those we serve.

## in 2007...



- We hosted *Rendez-vous Québec* in conjunction with the CHS Annual General Meeting and sponsored people with bleeding disorders from across Canada to participate in educational workshops on the topics of *Navigating the ER*, *All About Carriers* and hepatitis C.

- We published two issues of our newsmagazine *Hemophilia Today*. Available at [www.hemophilia.ca/en/hemophilia\\_today](http://www.hemophilia.ca/en/hemophilia_today).



- In October 2007 we hosted a national training workshop, *Von Willebrand Disease in Women: Raising Awareness, Changing Lives*. The workshop provided women affected by VWD from across Canada with the opportunity to gain new knowledge and skills to enable them to raise awareness in their communities about this common but underdiagnosed bleeding disorder.



- We regularly updated our Web site to ensure we continue to be one of the top sites for reliable bilingual information about bleeding disorders. [www.hemophilia.ca](http://www.hemophilia.ca).



- In recognition that a sound education is of utmost importance for people with bleeding disorders, and in an effort to bring young volunteers into the CHS, we awarded three scholarships/bursaries in the amount of \$4000 each to applicants who met specific criteria.

- We offered *Passport to Well-Being* workshops in six provinces and regions increasing awareness of the many benefits of fitness, home infusion, medical record keeping and options to manage pain. A news bulletin, *Voyage*, featuring articles and activities relating to the four Passport themes was published.

# publications in 2007

[www.hemophilia.ca/en/printed\\_documents](http://www.hemophilia.ca/en/printed_documents)

- **All About Carriers: A Guide for Carriers of Hemophilia A and B**

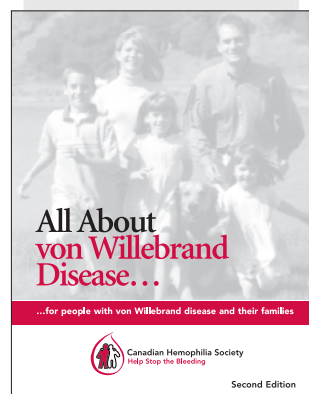
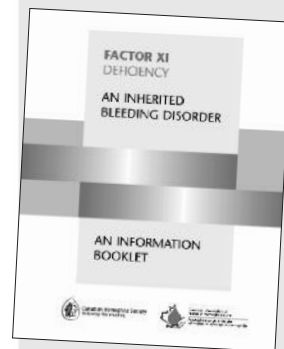
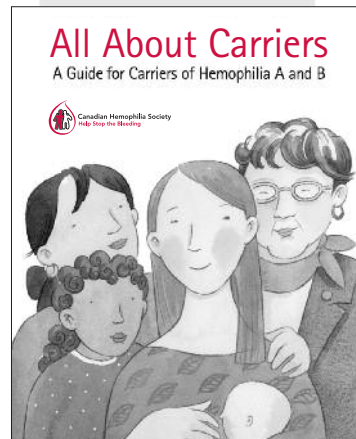
A comprehensive resource that provides the information and support needed to deal with the impact this disorder can have on the quality of life and health of carriers.

- **Factor XI Deficiency: An Inherited Bleeding Disorder**

The latest in our series on rare factor deficiencies, this document is a general information booklet about Factor XI Deficiency for patients, families and healthcare providers.

- **All About von Willebrand Disease – Second Edition**

A revised comprehensive guide for people with von Willebrand disease and their families.



# public awareness

## in 2007...

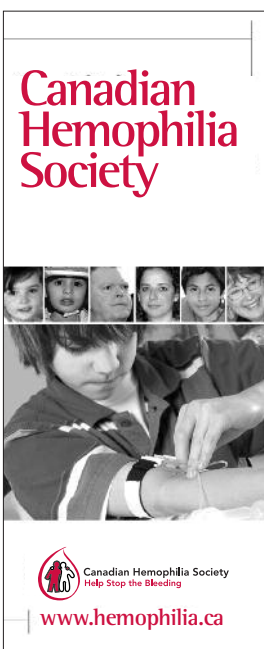
Even though hemophilia is not a common condition, we must raise public awareness of the various types of bleeding disorders given the large number of cases that remain undiagnosed right here in Canada. The public must also be made aware of the work carried out by the CHS in order to provide ALL Canadians with a safe and secure blood supply. Finally, the general public must come to understand the importance of supporting research as a means to eventually find a cure and build a brighter future for young people suffering from bleeding disorders.

Considerable efforts have been expanded to deliver our message beyond the members of the bleeding disorder community and help us forge closer ties with the public at large.

- We produced a compelling awareness video that provides insight into the lives of people coping with bleeding disorders.



Mathis, Nicolas, Jeff, Marc, Éric, Colleen, and Heather are only a few of those seeking the support of each and every Canadian in order to help the CHS achieve its dream of finding a cure.



- We produced, published and distributed a public awareness pamphlet on inherited bleeding disorders throughout Canada.
- We ran a bleeding disorder awareness campaign in the *National Post* on December 1, 8, 15 and 22, 2007.
- Following their participation in the von Willebrand disease workshop, many women organized awareness raising activities within their communities.

Shelley Mountain from PEI and her daughter Valerie, 4. Both have von Willebrand disease.



# fundraising

Helping us do more

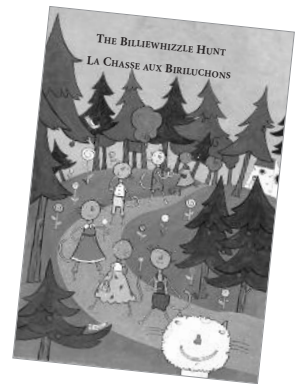
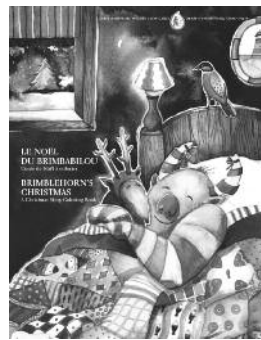
Every year many Canadian children and adults face the challenges of learning to manage their disease. Thousands more continue to need care and treatment, assistance and information to help them cope. CHS staff and volunteers across the country work diligently to raise much needed funds to help us offer programs and services that directly improve the lives of people suffering from inherited bleeding disorders.

The Canadian Hemophilia Society benefits from the generosity of many individuals, corporations and foundations. For this they have our heartfelt thanks, and the thanks of the many Canadians who benefit from their financial support.

## in 2007...

We reached out to individuals, corporations, foundations and friends asking them to support two new fundraising initiatives:

- We created two unique children's bilingual story colouring books, written and illustrated by award-winning Canadians, in an effort to raise awareness about bleeding disorders and to promote the love of reading, thereby enriching the lives of children across Canada. The colouring books were sold by our chapters across Canada.
- We launched our national signature event *Dare to Dream for Hemophilia*, an exciting pledge-based fundraising event that gives donors the opportunity to learn to safely drive a Formula racing car. Many demonstrated their commitment to the CHS by supporting this unique event. For more information visit [www.idaretodream.ca](http://www.idaretodream.ca).



# international development

As an active participant in the World Federation of Hemophilia's (WFH) international *Twinning Program*, the CHS and its dedicated teams of volunteers and healthcare professionals undertake leadership roles in supporting developing countries to improve care and treatment.

## Canadian organizational twins:

- South African Hemophilia Foundation & Canadian Hemophilia Society
- Tunisian Hemophilia Association & Canadian Hemophilia Society - Quebec Chapter
- Jordanian Hemophilia and Thalassemia Society & Toronto and Central Ontario Region - Hemophilia Ontario
- Belorussian Association of Hemophilia Patients & South Western Ontario Region - Hemophilia Ontario
- Iranian Hemophilia Society & Hemophilia Ontario
- Mongolian Hemophilia Association & Hemophilia Saskatchewan
- Serbian Hemophilia Society & Central Western Ontario Region - Hemophilia Ontario

## Hemophilia Treatment Centre (HTC) twins:

- Amman, Jordan HTC & St. Michael's Hospital Comprehensive Hemophilia Care Centre, Toronto
- Belgrade, Serbia HTC & Hamilton Health Sciences Corporation Hemophilia Program
- Minsk, Belarus HTC & South Western Ontario Regional Hemophilia Program, London Health Science Centre
- The China Network of HTCs & Southern Alberta Hemophilia Program in Calgary & the Hemophilia Centre at the Children's Hospital of Eastern Ontario

Our twinning projects with South Africa and Tunisia were among the 3 finalists for the WFH *2007 Twins of the Year Award!* This recognition has served as a new source of motivation for the international partnership work we accomplish in Canada and abroad!



Visiting our twin in South Africa.

# in 2007...

With the collaboration of the CHS twinning participants, many positive outcomes were accomplished by our twinning partners:

- Increased outreach activities with a focus on rural areas and youth, such as the Reach Out Centre for Kids (ROCK) in South Africa.
- Increased number of patients registered, upgraded diagnostic services and improved treatments. For example, a pilot project in Serbia resulted in 17 new people being diagnosed with hemophilia and 360 others being more precisely diagnosed as to the severity of their condition.
- Better informed and educated people with hemophilia, empowered to assist other families in their communities.
- More unified patient-medical communities capable of working with government. This resulted, for example, in the opening of a hemophilia treatment centre in Tunis, Tunisia.
- Better trained volunteers in the areas of fundraising, recruitment and program development.
- Better trained physiotherapists, hematologists, nurses and increased bi-lateral consultations. For example, in China, physiotherapy and nursing workshops were held to improve regional capabilities.
- Enhanced organizational capacity resulting in better services to a growing membership.
- Development and implementation of comprehensive action plans based on new strategic plans.

You can learn more about our international projects at [www.hemophilia.ca/en/international](http://www.hemophilia.ca/en/international)

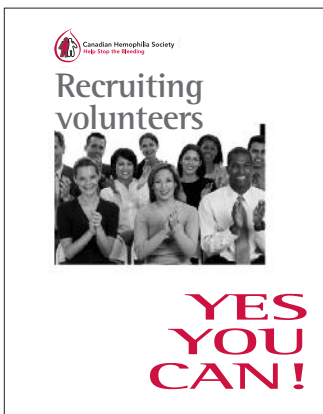


Canadian physiotherapists, Kathy Mulder and Nichan Zourikian, treating boys with hemophilia in North Africa.

# volunteer development

Our accomplishments are the result of the commitment of an outstanding group of dedicated CHS families and volunteers, composed of both veteran and newly recruited volunteers who each year help us to move closer to our ultimate dream of *A world free from the pain and suffering of inherited bleeding disorders*. Last year a new committee was created to help chapters recruit, train, retain and, most importantly, recognize our volunteers. We believe that recruiting new volunteers is crucial to securing the long-term stability of the organization. We will continue to work with our chapters in reaching this goal.

## in 2007...



- We produced *Recruiting Volunteers, YES YOU CAN!* a binder containing tools to support CHS chapters with their recruitment process.
- We developed a pamphlet for volunteers to increase awareness about our organization.
- We hosted a volunteer development workshop in May 2007, providing chapter leaders with strategies for getting the **right** volunteer with the **right** skills in the **right** job at the **right** time.
- We hosted a Board Orientation Session in May 2007 to increase the effectiveness of our Board of Directors meetings.
- We created a scholarship fund to promote the participation of volunteers in development training activities.
- In November 2007, we paid tribute to a group of dedicated volunteers and healthcare providers who had made a significant contribution to the bleeding disorder community during the past year.



Recipients of the CHS National Awards.

# youth

The organization is currently blessed with skilled, experienced volunteers who allow the organization to deliver high-quality programs to its members nationally, provincially and regionally. In its efforts to develop a plan for the future, the organization has established a National Youth Committee composed of representatives from each region of Canada who have the responsibility of reaching out and engaging their peers in the work of the organization.

## in 2007...

- We hosted a workshop where young people with bleeding disorders met to discuss strategies on how to engage youth in the planning and delivery of our programs and services.
- We developed a youth Web page on the CHS Web site to allow young people with bleeding disorders to stay connected with one another and to keep abreast of initiatives undertaken by youth across the country.
- We developed a pamphlet which, by outlining the benefits of volunteering at the provincial and national levels, encourages young people with bleeding disorders to get involved.
- We created a youth column that is published in each issue of our newsmagazine *Hemophilia Today*.



### Youth File



Emil Wijnker



Sarah Bradshaw

National Youth Committee Co-Chairs



# advocacy

- The CHS saw a successful conclusion to its 10-year effort to obtain compensation for all those infected with hepatitis C through the use of blood and blood products.
- The CHS and its chapters obtained cost-of-living indexation of the Multi-Provincial/Territorial Assistance Program for those infected with HIV through the blood system in Saskatchewan, British Columbia, New Brunswick and Quebec. Only one province remained to be indexed as of the end of the year.
- We were granted intervenor status in a Canadian Human Rights Tribunal case in which a person with hemophilia was hired, and then unjustly refused employment for health reasons. This was settled satisfactorily and created an important precedent.

# collaboration

- We continued our leadership of the Network of Rare Blood Disorder Organizations. This coalition brings together groups representing people with thalassemia, sickle cell disease, primary immune deficiency, aplastic anemia, hereditary angioedema and other rare blood conditions. Its goals are to promote comprehensive care, access to the best drug therapies and blood safety.

## Commemoration of the Tainted Blood Tragedy

On November 26, 2007, ten years to the day after the publication of the *Final Report of the Commission of Inquiry on the Blood System in Canada*, the CHS launched the *Commemoration of the Tainted Blood Tragedy* with a tree planting in front of the headquarters of Canadian Blood Services in Ottawa. The commemoration aims to remember those who have passed away as a result of the tainted blood tragedy, and offer families and friends tangible ways, both public and private, to honour their lives; highlight the sacrifice of those infected/affected by tainted blood in Canada's worst public health disaster so that those who came later could benefit from a safer blood system; and honour those who are living with the consequences of HIV and hepatitis C infection and send a message of hope.



# our team

The CHS is fortunate to have an amazing group of dedicated volunteers who work day after day to assist in the planning, delivery, and evaluation of programs. Without these very special individuals, many events and programs could not take place.

## our committees

Many of our volunteers are involved in our national committees and task forces, assisting in the development of policies and programs to meet the needs of people with bleeding disorders in Canada.

Those committees include the Blood Safety and Supply Committee, the Youth Committee, the Program Committee, the Medical and Scientific Advisory Committee, the International Projects Committee, the Volunteer Development Committee and the Finance and Administration Committee.

## our executive committee

**Pam Wilton, RN**  
President  
Ontario

**Eric Stolte**  
Past-President  
Ontario

**Tom Alloway, PhD**  
Vice-President  
Ontario

**Mike Beck**  
Vice-President  
Ontario

**Maureen Brownlow**  
Vice-President  
Nova Scotia

**Craig Upshaw**  
Vice-President  
Alberta

**James Kreppner, LLB**  
Secretary  
Ontario

**Norman Locke**  
Treasurer  
Newfoundland  
and Labrador

## our board of directors

### DIRECTORS

**Colleen Barrett**  
Newfoundland  
and Labrador

**JoAnn Craig**  
Prince Edward  
Island

**Sandy Watson**  
Nova Scotia

**Aline Landry**  
New Brunswick

**Mylène D'Fana**  
**Martin Kulczyk**  
**David Pouliot**  
Quebec

**Jeff Beck**  
**Venanz d'Addario**  
Ontario

**Bill Featherstone**  
Manitoba

**Anne Lukian**  
Saskatchewan

**Bea Bohm-Meyer**  
**Tony Niksic**  
Alberta

**Gabriel Ramos**  
**Bruce Rempel**  
British Columbia

**Dr. Bruce Ritchie**  
Medical and Scientific  
Advisory Committee  
Representative

**Emil Wijnker**  
Youth Representative



# our chapters

## our chapter presidents

**Colleen Barrett**  
Newfoundland  
and Labrador

**JoAnn Craig**  
Prince Edward Island

**Sandy Watson**  
Nova Scotia

**Aline Landry**  
New Brunswick

**François Laroche**  
Quebec

**Jeff Beck**  
Ontario

**Bill Featherstone**  
Manitoba

**Ann Wood**  
Saskatchewan

**Susan Anderson and  
Craig Upshaw**  
Alberta

**Haydn Hendricks**  
British Columbia

Our chapters do tremendous work reaching out to the bleeding disorder community. They organize local activities, provide direct support to their members, keep them informed through newsletters and raise money to keep it all going. The following are a few examples of their dedication.

## in 2007...

- Chapters worked with local health authorities to ensure that optimal care and treatment are available to all those with bleeding disorders.
- Chapters organized summer camps for children during which, along with games, sports and other activities, they mastered the art of self-infusing their clotting factor concentrates under the supervision of specialized nurses.
- Chapters organized workshops and events (for example, family picnics, father-and-son getaways) for members facing the challenges of bleeding disorders such as struggling with an inhibitor or raising a child with hemophilia.
- Chapters set up booths in public places to provide information and to reach out to people potentially suffering from a bleeding disorder.
- Chapters published local informative newsmagazines.
- Chapters organized fundraising events such as bowl-a-thons, golf tournaments, gala dinners and draws.



CHS chapters organize many events bringing together families and friends.



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**.

**PLATINUM**



**Bayer HealthCare**

**GOLD**

**Baxter**



**Wyeth**

**SILVER**

CSL Behring  
 Edwards Charitable Foundation  
 F.K. Morrow Foundation  
 J.P. Bickell Foundation  
 Dewdney Family Charitable Foundation

**BRONZE**

- |   |   |
|---|---|
| 3M - Canada                                 | Lillian and Don Wright Foundation (The) |
| Canadian Blood Services                     | Manitoba Liquor Control Commission      |
| Delta Hotel Winnipeg                        | Octapharma                              |
| De Luca's Specialty Foods                   | Power Corporation of Canada             |
| Fondation de Bienfaisance T.A. Germain (La) | Puma Canada                             |
| Great-West Life Assurance Company           | Schering Canada                         |
| Harold E. Ballard Foundation                | ScotiaBank                              |
| Héma-Québec                                 | Standard Limestone Quarries             |
| Jean Coutu Group (PJC) Inc. (The)           | Toronto Star <i>Fresh Air Fund</i>      |
| John Brouwer Foundation (The)               | Winnipeg Free Press (The)               |

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


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

# thank you

## *The* BeneFACTORS *Club*

Corporations that make annual unrestricted gifts of \$10,000 or more to our organization are recognized as members of the BeneFACTORS Club.

The Canadian Hemophilia Society recognizes their tremendous investment in 2007.

 Grand benefactor – multi-year commitment

**Visionary**  
Bayer

**Innovator**  
Baxter 

**Builders**  
Novo Nordisk  
Wyeth Canada

**Believer**  
CSL Behring

## our partners

The CHS is fortunate to be surrounded by exceptional partners helping us to fulfill our mission.

- Association of Hemophilia Clinic Directors of Canada (AHCDC)
- Canadian Association of Nurses in Hemophilia Care (CANHC)
- Canadian Physiotherapists in Hemophilia Care (CPHC)
- Canadian Social Workers in Hemophilia Care (CSWHC)
- World Federation of Hemophilia (WFH)



The Canadian Hemophilia Society is proud to be a member of HEALTHPARTNERS.

HEALTHPARTNERS is a partnership of national health charities raising funds exclusively through workplace charitable giving programs. Each HEALTHPARTNERS member organization is a national health charity, providing services to Canadians in all regions of our country.

*Member organizations share goals in two primary areas:*

- RESEARCH – Supporting medical research toward improved treatment and ultimately a cure for debilitating diseases.
- PROGRAMS – Sponsoring education as well as prevention efforts and services that assist Canadians living with disease.

# Canadian Hemophilia Society

## Balance Sheet

As at December 31, 2007

						2007	2006
	General Fund	Property and Equipment Fund	Contingencies Fund	Research Fund – Million Dollar Club	Endowment Fund – Million Dollar Club	Total	Total
	\$	\$	\$	\$	\$	\$	\$
<b>Assets</b>							
<b>Current assets</b>							
Cash	210,182	-	-	-	-	210,182	247,620
Term deposits	455,547	-	1,000,000	-	-	1,455,547	1,604,496
Accounts receivable							
Grants	-	-	-	-	-	-	27,685
Provincial chapters	9,654	-	-	-	-	9,654	31,702
Other	268,312	-	-	33,302	-	301,614	222,904
Prepaid expenses	12,163	-	-	-	-	12,163	7,463
	955,858	-	1,000,000	33,302	-	1,989,160	2,141,870
<b>Investments – Million Dollar Club</b>	-	-	-	134,056	1,733,176	1,867,232	1,810,074
<b>Property and equipment</b>	-	40,953	-	-	-	40,953	38,306
	955,858	40,953	1,000,000	167,358	1,733,176	3,897,345	3,990,250
<b>Liabilities</b>							
<b>Current liabilities</b>							
Accounts payable and accrued liabilities	238,084	-	-	22,675	-	260,759	371,503
Deferred contributions	468,652	-	-	-	-	468,652	616,603
	706,736	-	-	22,675	-	729,411	988,106
<b>Fund balances</b>							
Unrestricted	249,122	-	-	-	-	249,122	122,384
Invested in property and equipment	-	40,953	-	-	-	40,953	38,306
Internally restricted							
Contingencies Fund	-	-	1,000,000	-	-	1,000,000	1,000,000
Research Fund – Million Dollar Club	-	-	-	144,683	-	144,683	109,479
Endowment Fund – Million Dollar Club	-	-	-	-	175,277	175,277	175,277
Externally restricted	-	-	-	-	1,557,899	1,557,899	1,556,698
	249,122	40,953	1,000,000	144,683	1,733,176	3,167,934	3,002,144
	955,858	40,953	1,000,000	167,358	1,733,176	3,897,345	3,990,250

Extract from the audited financial statements prepared by PriceWaterhouseCoopers. The complete audited financial statements are available upon request either by mail or on our Web site.

Canadian Hemophilia Society  
Statement of Revenue and Expenses  
For the year ended December 31, 2007

	2007			2006	
	General Fund	Property and Equipment Fund	Research Fund – Million Dollar Club	Total	Total
	\$	\$	\$	\$	\$
<b>Revenue</b>					
Public support	598,818	-	-	598,818	692,783
Corporate support	1,923,880	-	-	1,923,880	2,026,362
Government grants	-	-	-	-	58,974
Investment income	70,208	-	71,391	141,599	151,398
Other	-	-	23,270	23,270	29,500
	2,592,906	-	94,661	2,687,567	2,959,017
<b>Expenses</b>					
Resource development	553,408	4,076	-	557,484	437,214
Programs	1,075,215	5,355	-	1,080,570	1,470,445
Prevention and education	170,230	1,007	-	171,237	195,370
Research	234,740	-	90,698	325,438	304,563
Committees	222,070	-	-	222,070	241,252
Administration	188,197	9,223	9,959	207,379	240,807
	2,443,860	19,661	100,657	2,564,178	2,889,651
<b>Excess of revenue over expenses (expenses over revenue) for the year</b>	149,046	(19,661)	(5,996)	123,389	69,366

Canadian Hemophilia Society  
Statement of Changes in Fund Balances  
For the year ended December 31, 2007

	2007					2006	
	General Fund	Property and Equipment Fund	Contingencies Fund	Research Fund – Million Dollar Club	Endowment Fund – Million Dollar Club	Total	Total
	\$	\$	\$	\$	\$	\$	\$
<b>Balance – Beginning of year</b>	122,384	38,306	1,000,000	109,478	1,731,976	3,002,144	2,828,003
<b>Change in accounting policies – financial instruments</b>	-	-	-	41,201	-	41,201	-
<b>Balance – Beginning of year restated</b>	122,384	38,306	1,000,000	150,679	1,731,976	3,043,345	2,828,003
<b>Excess of revenue over expenses (expenses over revenue) for the year</b>	149,046	(19,661)	-	(5,996)	-	123,389	69,366
<b>Endowment contributions</b>	-	-	-	-	1,200	1,200	104,775
<b>Investment in property and equipment</b>	(22,308)	22,308	-	-	-	-	-
<b>Balance – End of year</b>	249,122	40,953	1,000,000	144,683	1,733,176	3,167,934	3,002,144

Extract from the audited financial statements prepared by PriceWaterhouseCoopers. The complete audited financial statements are available upon request either by mail or on our Web site.