

Reaching out to ALL people with an inherited bleeding disorder...  
Even the one in a million.



The Canadian Hemophilia Society  
2008 annual report



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## NATIONAL STAFF

**David Page**  
Executive Director

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

**Deborah Franz Currie**  
Director of Resource Development

**Joyce Argall**  
Individual Giving Coordinator

**Clare Cecchini**  
Program Development Coordinator

**Stéphane Lemieux**  
Chief Accountant

**Michel Long**  
Program Development Coordinator

**Pauline Major**  
Corporate Philanthropy Manager

**Chantal Raymond**  
National Communications Coordinator

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

## our mission

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

## our vision

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





**Pam Wilton, RN**  
President  
Canadian Hemophilia Society

## One in a million

What does it mean if someone says, "You're one in a million."? Often it means that you did something extraordinary. Maybe you went out of your way to perform a service. Possibly you completed an extreme physical challenge. Rarer still, you committed a hideous crime, only an extreme few could be capable of.

What does it mean if a doctor says, "You're one in a million. You have factor VII deficiency."? The good news is that you finally have an answer and a diagnosis. The bad news is the doctor is right; the incidence of factor VII deficiency is one in a million. It probably means that for years, you (or your parents) have suffered through symptoms, repeated your history too many times to too many physicians, searched the Web for information, and worried through sleepless nights. It means that little is known about your condition and how to treat it. It means that you and your family will have difficulty finding information and evidence-based data to guide your management decisions.

Statistically, it also means that there are at least 31 other individuals in Canada with factor VII deficiency!

That is where the Canadian Hemophilia Society comes in. Our mission states: *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.* We have chosen to reach out to those 32 people in Canada who have factor VII deficiency (and those with other rare inherited bleeding disorders), their families and their healthcare providers to share our knowledge, experience and resources. We have made it our mission.

I attended the CHS *Living with a rare bleeding disorder* workshop in November 2008. I realized that I had never met most of the others in the room. I seemed to be among strangers. I had a feeling of apprehension. Would the workshop meet their expectations? Would they feel welcome? Would they see something in the CHS that would make them want to be a part of our community? Would I get to know them? I looked again. A guy in a golf shirt was telling a story that was making his group laugh; three women were sharing pictures of their kids; someone was complaining about Air Canada; and a fellow on crutches was skillfully navigating his way through the obstacles. I looked more closely. I saw men and women of all ages. I saw spouses and I saw parents. I saw volunteers. I saw smiles. I saw pain. I saw curiosity. I saw determination. I saw leaders. I knew these people. I knew them all.



# The Canadian Hemophilia Society

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

The CHS has 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.

- hemophilia A and B
- von Willebrand disease
- rare factor deficiencies
- platelet function disorders

## facts and figures

- 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. Bleeding disorders are hemophilia A and B, von Willebrand disease, rare factor deficiencies and platelet function disorders.
- 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.

To learn more about inherited bleeding disorders, please go to  
[www.hemophilia.ca/en/bleeding-disorders](http://www.hemophilia.ca/en/bleeding-disorders).



Some of our strategic priorities:

| Safe, Secure Blood Supply

| Care and Treatment

| Research

| Support and Education

| Youth

## safe, secure blood supply

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.



In 2008, the CHS took a moment to reflect on its past by:

- Remembering those who passed away as a result of the tainted blood tragedy and honouring those who are living with the consequences of HIV and hepatitis C through tainted blood with a tree-planting ceremony on October 9, 2008 at Héma-Québec's Montreal headquarters.

*This tree is a living memorial to the thousands of people who lost their lives in Canada's tainted blood tragedy. May their pain and suffering not be in vain.*

## care and treatment

care

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.

In 2008, to maintain standards of care across the country and to make constant progress in **CARE** and **TREATMENT**, some of our actions included:

- Supporting annual meetings of the physiotherapists, nurses and social workers associated with the 25 hemophilia treatment centres across Canada.
- Producing and distributing the revised *Factor First* cards to all hemophilia treatment centres.
- Assessing the needs for the establishment of provincial and/or regional rare blood disorder organizations.



## support and education

One of the fields for which the Canadian Hemophilia Society is most renowned is its high-quality, up-to-date, easy-to-understand educational materials designed for people with bleeding disorders, their families, healthcare professionals and the general public.

The Canadian Hemophilia Society made a difference **in 2008** by:

- Reaching out to people affected by a rare factor deficiency or a platelet disorder and hosting the very first Canadian workshop on *Living with a rare bleeding disorder*. This workshop was a life-changing experience for many of the participants who met with others and shared their respective experience, breaking their isolation.
- Keeping the bleeding disorder community informed on the most relevant news, with the distribution of three issues of our newsletter *Hemophilia Today*.
- Launching our revised Web site with expanded content, improved navigation and a revamped design. **Hemophilia.ca** is one of the CHS's best tools to continue providing the most reliable information on bleeding disorders in the world.

*I spent the first 30 years of my life living alone with my disorder. I went through some hard times: the tainted blood scandal, bleeding episodes, acceptance of my disorder. The workshop Living with a rare bleeding disorder opened my eyes to the world. In one of those rare moments in my life, I opened the gates of my secret garden to others, to "people like me"... I also had the opportunity to talk to people who had lived through situations similar to mine.*

- Sébastien Bédard, a man living with severe factor XIII deficiency  
Boucherville, Quebec



To support us



To volunteer



To contact us

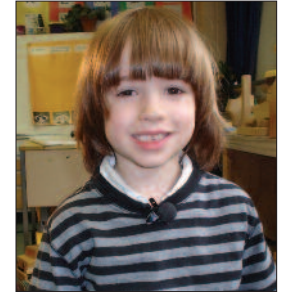
## CHALLENGES CHOICES DECISIONS

A Guide on Orthopedic Surgery for  
People with Hemophilia and Inhibitors



## support and education

- Providing information about elective orthopedic surgery to patients who have severe joint damage as a result of repeated bleeds with the publication of a new publication, *Challenges, Choices, Decisions: A Guide to Orthopedic Surgery for People with Hemophilia and Inhibitors*.
- Helping parents of children with hemophilia and school personnel prepare for the new school year with the production of our new video entitled *Hemophilia: What School Personnel Should Know*. Over 1,000 copies were distributed **in 2008!**
- Continuing to be active in twinning partnerships with South Africa, China, Tunisia, and Jordan, helping to improve hemophilia care and organizational capacity in developing countries. **In 2008**, the CHS-South Africa organizational twinning won the World Federation of Hemophilia *Twins of the Year* Award.



The Quebec Chapter in Tunisia



education

## research

Research is at the top of our priorities – 50 years ago a boy with hemophilia lived less than 20 heartbreakingly short, pain-filled years. Today, thanks to research, children with hemophilia can look forward to much healthier and more active lives... thanks to the “miracle” of preventive treatment.

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.

Over the past 20 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 CHS has invested more than four million dollars in research in Canada.

**In 2008**, the CHS funded eleven research projects in three research programs:

- The CHS Dream of a Cure Research Program
- The Care until Cure Research Program in collaboration with Wyeth Canada
- The Novo Nordisk Canada Inc. – CHS – Association of Hemophilia Clinic Directors of Canada Fellowship in Congenital and Acquired Bleeding Disorders.

Detailed descriptions of the funded research projects are available at [www.hemophilia.ca/en/research](http://www.hemophilia.ca/en/research).

### 1960



**RESEARCH** means **HOPE** for those affected by an inherited bleeding disorder.

### 2008



## youth



The CHS National Youth Committee

## 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 a National Youth Committee composed of representatives from each region of Canada who have the responsibility to reach out and engage their peers in the work of the organization.

**In 2008**, the CHS nurtured this new generation of leaders by:

- Hosting the first National Youth Leadership Workshop. Twenty-six young adults from across the country and a South African youth gathered together to participate in educational sessions focusing on leadership skills. This workshop was the first phase of engaging young adults to become future leaders and to help the CHS achieve its long-term vision.

## the CHS: a grassroots organization

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.

In addition, our chapters do tremendous work reaching out to the bleeding disorder community. They organize local activities, operate camps for children, keep members informed through newsletters and raise money to keep it all going.

## our chapter presidents

**Cindy Casey**  
Newfoundland  
and Labrador

**JoAnn Craig**  
Prince Edward Island

**Dianna Cuning**  
Nova Scotia

**Aline Landry**  
New Brunswick

**François Laroche**  
Quebec

**Jeff Beck**  
Ontario

**Bill Featherstone**  
Manitoba

**Ann Wood**  
Saskatchewan

**Susan Anderson**  
**Craig Upshaw**  
Alberta

**Haydn Hendricks**  
British Columbia

## our executive committee

**Pam Wilton**  
President  
Ontario

**Eric Stolte**  
Past-President  
Ontario

**Mike Beck**  
Vice-President  
Ontario

**Maureen Brownlow**  
Vice-President  
Nova Scotia

**David Pouliot**  
Vice-President  
Quebec

**Craig Upshaw**  
Vice-President  
Alberta

**James Kreppner, LLB**  
Secretary  
Ontario

**Norman Locke**  
Treasurer  
Newfoundland  
and Labrador

## our board of directors

### DIRECTORS

**Cindy Casey**  
Newfoundland and  
Labrador

**JoAnn Craig**  
Prince Edward Island

**Dianna Cuning**  
Nova Scotia

**Aline Landry**  
New Brunswick

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

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

**Bill Featherstone**  
Manitoba

**Ann Wood**  
Saskatchewan

**Clara Penner**  
Alberta

**Curtis Brandell**  
**Bruce Rempel**  
British Columbia

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

**Emil Wijnker**  
Youth Representative





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



GOLD



BRONZE

- Canadian Blood Services
- CIBC
- Club Colombo Welland
- Concord Projects
- Delta Hotel Winnipeg
- De Luca's Specialty Foods
- Fondation de Bienfaisance T.A. Germain (La)
- Fondation François-Bourgeois
- Fondation ING Direct
- Fondation Paul A. Fournier
- Héma-Québec
- Hidden Valley Colony
- Industrial Alliance

- John Brouwer Foundation (The)
- John Deere Foundation of Canada
- London Community Foundation
- Manitoba Liquor Control Commission
- Notre Dame College School
- Novartis
- Power Corporation of Canada
- Puma Canada
- Royal Bank
- Scotiabank
- Underworld Scuba & Sport
- Vintage Veruca Antiques

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 2008**.

### Innovators

- Baxter ◊
- Bayer

### Builders

- CSL Behring ◊
- Novo Nordisk
- Wyeth

◊ **Grand benefactor** – multi-year commitment

## 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, 2008

						2008	2007
	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	414,225	-	-	-	-	414,225	210,182
Term deposits	255,610	-	1,000,000	-	-	1,255,610	1,455,547
Accounts receivable							
Provincial chapters	4,101	-	-	-	-	4,101	9,654
Other	241,039	-	-	40,090	-	281,129	301,614
Prepaid expenses	3,899	-	-	-	-	3,899	12,163
	918,874	-	1,000,000	40,090	-	1,958,964	1,989,160
<b>Investments – Million Dollar Club</b>	-	-	-	171,945	1,768,276	1,940,221	1,867,232
<b>Property and equipment</b>	-	33,842	-	-	-	33,842	40,953
	918,874	33,842	1,000,000	212,035	1,768,276	3,933,027	3,897,345
<b>Liabilities</b>							
<b>Current liabilities</b>							
Accounts payable and accrued liabilities	168,936	-	-	27,634	-	196,570	260,759
Deferred contributions	699,227	-	-	-	-	699,227	468,652
	868,163	-	-	27,634	-	895,797	729,411
<b>Fund Balances</b>							
<b>Unrestricted</b>	50,711	-	-	-	-	50,711	249,122
<b>Invested in property and equipment</b>	-	33,842	-	-	-	33,842	40,953
<b>Internally restricted</b>							
<b>Contingencies Fund</b>	-	-	1,000,000	-	-	1,000,000	1,000,000
<b>Research Fund – Million Dollar Club</b>	-	-	-	184,401	-	184,401	144,683
<b>Endowment Fund – Million Dollar Club</b>	-	-	-	-	175,277	175,277	175,277
<b>Externally restricted</b>							
	-	-	-	-	1,592,999	1,592,999	1,557,899
	50,711	33,842	1,000,000	184,401	1,768,276	3,037,230	3,167,934
	918,874	33,842	1,000,000	212,035	1,768,276	3,933,027	3,897,345

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.

Statement of  
Revenue and  
Expenses  
For the year  
ended  
December 31,  
2008

				2008	2007
	GENERAL FUND \$	PROPERTY AND EQUIPMENT FUND \$	RESEARCH FUND MILLION DOLLAR CLUB \$	TOTAL \$	TOTAL \$
<b>Revenue</b>					
Public support	463,426	-	3,140	466,566	598,818
Corporate support	1,686,205	-	26,176	1,712,381	1,923,880
Investment income	47,165	-	131,075	178,240	141,599
Other	-	-	-	-	23,270
	<u>2,196,796</u>	<u>-</u>	<u>160,391</u>	<u>2,357,187</u>	<u>2,687,567</u>
<b>Expenses</b>					
Resource development	505,456	3,247	-	508,703	557,484
Programs	1,041,154	3,470	-	1,044,624	1,080,570
Prevention and education	124,475	652	-	125,127	171,237
Research	292,705	-	110,535	403,240	325,438
Committees	216,960	-	-	216,960	222,070
Administration	213,107	1,092	10,138	224,337	207,379
	<u>2,393,857</u>	<u>8,461</u>	<u>120,673</u>	<u>2,522,991</u>	<u>2,564,178</u>
<b>Excess of revenue over expenses (expenses over revenue) for the year</b>	<u>(197,061)</u>	<u>(8,461)</u>	<u>39,718</u>	<u>(165,804)</u>	<u>123,389</u>

Statement of  
Changes in  
Fund Balances  
For the year  
ended  
December 31,  
2008

						2008	2007
	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>	249,122	40,953	1,000,000	144,683	1,733,176	3,167,934	3,002,144
Change in accounting policies – Financial instruments	-	-	-	-	-	-	41,201
Balance – Beginning of year restated	249,122	40,953	1,000,000	144,683	1,733,176	3,167,934	3,043,345
Excess of revenue over expenses (expenses over revenue) for the year	(197,061)	(8,461)	-	39,718	-	(165,804)	123,389
Endowment contributions	-	-	-	-	35,100	35,100	1,200
Investment in property and equipment	(1,350)	1,350	-	-	-	-	-
<b>Balance – End of year</b>	<u>50,711</u>	<u>33,842</u>	<u>1,000,000</u>	<u>184,401</u>	<u>1,768,276</u>	<u>3,037,230</u>	<u>3,167,934</u>