



Canadian Hemophilia Society
Help Stop the Bleeding

Société canadienne de l'hémophilie
Arrêtons l'hémorragie

STRATEGIC PLAN



our mission

The Canadian Hemophilia Society is committed to improve the health and quality of life of all people with inherited bleeding disorders and ultimately to find a cure.

our vision

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

Adopted,
November 27, 2010

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INTRODUCTION

This strategic plan is intended to be a simple, measurable roadmap to guide the Canadian Hemophilia Society, both the national organization and the 10 chapters, in both their programming and governance, through the years 2011 to 2015.

It will be accompanied by more detailed 2-year work plans, produced annually, that lay out the precise actions needed to meet the goals of the strategic plan.

TARGET POPULATIONS

The Canadian Hemophilia Society provides information, programs and services to...

- people with hemophilia, von Willebrand disease, rare factor deficiencies and inherited platelet disorders
- their families and friends
- the health care providers in the Canadian network of inherited bleeding disorder comprehensive care clinics
- the patients' community (daycare workers, teachers, employers...)
- the health care providers (primary care practitioners, dentists, specialists...) who may provide care for people with inherited bleeding disorders or who may come into contact with those who remain undiagnosed.

OUR VALUES

The Canadian Hemophilia Society is committed to the following values:

Inclusiveness

By providing information, programs and services to all people with inherited bleeding disorders of all ages and their families in both English and French.

Connectedness

By being well connected to our grassroots community.

Advocacy

By actively representing people with inherited bleeding disorders to improve their quality of life while working towards a cure.

Excellence

By achieving quality, efficiency and innovation while remaining open to change.

Integrity

By acting honestly, responsibly, openly and accountably.

Respect

By treating the people with whom we interact with dignity, fairness and compassion.

Collaboration

By fostering meaningful and collegial relations, and strong partnerships among our diverse stakeholders.

OUR GLOBAL RESPONSIBILITY

While the primary mission of the Canadian Hemophilia Society is to work within our own borders on behalf of Canadians, this strategic plan recognizes our responsibility to the global bleeding disorder community.

Canadians with inherited bleeding disorders enjoy access to the most advanced therapies in optimal quantities. Our comprehensive care clinics provide a high standard of care. Such is not the case around the world where 75% of people with hemophilia do not have access to safe factor therapy and highly trained health care providers. Life expectancy remains less than 20 years on average and these short lives are filled with pain and suffering.

The CHS, as a well-developed patient association, acknowledges its responsibility to work with the World Federation of Hemophilia to further its mission of TREATMENT FOR ALL.

OUR VISION, MISSION AND GOALS

Our Vision

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

Our Mission

The Canadian Hemophilia Society is committed to improve the health and quality of life of all people with inherited bleeding disorders and ultimately to find a cure.

Goals Related to Our Vision and Mission

Care and Treatment	Achieve optimal comprehensive care for all people with inherited bleeding disorders.
Awareness	Raise awareness among people with inherited bleeding disorders, their immediate communities and health care providers.
Research	Promote and fund research to improve treatment and ultimately to find a cure.
Education and Support	Provide effective delivery of information and support to patients and their families across Canada in both English and French.
Safe and Secure Supply	Advocate for access to a secure supply of the safest and most efficacious therapies for the treatment of inherited bleeding disorders.

Care and Treatment

Goal

Achieve optimal comprehensive care for all people with inherited bleeding disorders.

Objectives

- Maintain standards of care in collaboration with health care providers.
- Promote adherence to standards of care across the country.
- Advocate for equitable access to optimal comprehensive care in all parts of the country.
- Advocate for comprehensive care for women with inherited bleeding disorders.
- Advocate for quality care for people with HIV and/or HCV including access to transplants for those who are co-infected.
- Advocate for provincial designation and funding for inherited bleeding disorder comprehensive care clinics.
- Promote a continued high level of competence among health care providers in comprehensive care clinics.
- Contribute to an environment that helps recruit and retain physicians, nurses, physiotherapists, social workers and other health care providers to careers in the field of inherited bleeding disorders.

Some Key Strategies

- Develop and implement in collaboration with healthcare providers an external audit process in comprehensive care clinics to ensure compliance with national standards of care.
- Facilitate the professional development and promote knowledge transfer among health care providers in comprehensive care clinics.
- Offer research grants to attract young physicians to the field of inherited bleeding disorders.
- Offer professional development opportunities to nurses, physiotherapists, social workers and other health care providers.
- Advocate with hospital administrators and provincial governments to ensure a full staff complement in comprehensive care clinics, notably in the areas of physiotherapy and psychosocial support.
- Advocate with provincial governments to obtain designation and provincial funding for comprehensive care clinics.
- Promote and collaborate in data collection to support optimal evidence-based care and treatment.
- Encourage patient adherence to evidence-based treatment protocols.

Desired Outcomes 2011-2015

- All people with inherited bleeding disorders will have access to comprehensive care, delivered according to national standards of care.
- All comprehensive care clinics will have achieved accreditation in accordance

with the national standards of care.

- A national report card will have been published reporting the results of accreditation.
- All comprehensive care clinics will have introduced services for women with inherited bleeding disorders.
- All provinces will have designated provincial funding for the comprehensive care clinics.
- All comprehensive care clinics will have adequate resources, based on standards of care, to provide physiotherapy and psychosocial support, and to conduct outreach care and services.
- Qualified physicians will have been attracted to the field of hemostasis to replace those who are retiring.
- Qualified nurses, physiotherapists, social workers and other health care providers will have been attracted to the field of inherited bleeding disorders.
- Those co-infected with HIV and HCV will have greater access to liver transplants.

NATIONAL ROLES	CHAPTER ROLES
<ul style="list-style-type: none"> ▪ Develop standards of care (in collaboration with health care providers). ▪ Develop accreditation process (in collaboration with health care providers). ▪ Support the professional development of health care providers (e.g. via Rendez-vous, annual meetings of various disciplines, New Team Workshop...). ▪ Support chapters in their advocacy efforts to maintain and enhance comprehensive care clinics. 	<ul style="list-style-type: none"> ▪ Communicate with members to better evaluate care provided in comprehensive care clinics. ▪ Maintain a close relationship with the staff in comprehensive care clinics. ▪ Develop and maintain a relationship with hospital administrations and Ministries of Health. ▪ Advocate to maintain or enhance resources in comprehensive care clinics. ▪ Advocate to obtain provincial designation and funding for comprehensive care clinics.

Awareness

Goal

Raise awareness among people with inherited bleeding disorders, their immediate communities and health care providers.

Objectives

- Make CHS programs and services better known to all people with inherited bleeding disorders.
- Build “pockets of awareness” among those close to people with inherited bleeding disorders (extended families, neighbours, daycare workers, teachers, coaches, employers...).
- Promote understanding of inherited bleeding disorders among health care providers who may come into contact with people with inherited bleeding disorders (for example, in ERs) to optimize diagnosis and access to comprehensive care.
- Provide information to health care professionals so they can better recognize symptoms and refer people to comprehensive care clinics for diagnosis and treatment.
- Provide information, through our outreach efforts, to those who have symptoms of inherited bleeding disorders and are undiagnosed.

Some Key Strategies

- Provide tools to educate extended families, neighbours, daycare workers, teachers, employers, coaches, etc. about inherited bleeding disorders.
- Establish a multidisciplinary working group and partner with our existing networks on a collaborative approach to women’s outreach.
- Develop efficient tools for hematologists and nurses in comprehensive care clinics to help them reach out to other health care providers.
- Launch a targeted outreach campaign aimed at symptoms/diagnosis in women and those with rare inherited bleeding disorders.
- Develop and implement a cause-related marketing strategy for inherited bleeding disorders.
- Create public and media events on World Hemophilia Day.

Desired Outcomes 2011-2015

- All people with inherited bleeding disorders will be informed annually of the programs and services offered by the CHS.
- All people with inherited bleeding disorders who are known to comprehensive care clinics will be counted in the Canadian Hemophilia Registry (CHR).
- The number of women registered in comprehensive care clinics and in the CHR will have increased by 50% from 3,000 to 4,500.
- The number of people with rare inherited bleeding disorders registered in comprehensive care clinics and in the CHR will have increased by 50% from 1,350 to 2,000.

NATIONAL ROLES

- Work with chapters and the network of comprehensive care clinics to develop a package of information that can be delivered annually to all people with inherited bleeding disorders.
- Maintain and develop tools for community education.
- Establish a multidisciplinary working group focused on women's outreach.
- Create a targeted outreach campaign aimed at identifying symptoms/diagnosis in women and those with rare inherited bleeding disorders.
- Develop and implement a social marketing strategy for women with inherited bleeding disorders.
- Create materials and provide support for public and media events on World Hemophilia Day.

CHAPTER ROLES

- Involve the hematologists and nurses working in comprehensive care clinics in reaching out to other health care providers.
- Organize local Red, White & You events.
- Participate in Healthpartners presentations.
- Participate in social club (e.g. Lions, Kiwanis, Chamber of Commerce...) events to raise awareness about inherited bleeding disorders and the CHS.
- Publish articles on inherited bleeding disorders in local newspapers.
- Organize public and media events on World Hemophilia Day.

Research

Goal

Promote and fund research to improve treatment and ultimately to find a cure.

Objectives

- Increase the funds available for research.
- Attract more researchers to the field of hemostasis.
- Maintain the competitiveness of our externally funded research programs.
- Explore partnerships with other research-oriented bodies (e.g. Canadian Institutes of Health Research, Association of Hemophilia Clinic Directors of Canada, universities, hospital foundations...).
- Better define our research agenda.
- Encourage data collection to support optimal evidence-based care and treatment.

Some Key Strategies

- Create a multidisciplinary CHS research advisory committee.
- Better communicate the importance of CHS research programs and the results of the work to current and potential researchers.
- Better communicate the importance of CHS research programs and the results of the work to our membership.
- Communicate to our membership the importance of providing clear and accurate patient record data.
- Better educate patients on ethical questions related to research.
- Communicate to our membership the importance of participating in clinical trials.
- Publicize clinical research opportunities so that patients are aware of them.

Desired Outcomes 2011-2015

- The Ken Poyser Hemophilia Research Endowment (KPHRE)¹ will grow by at least \$100,000 annually with a target of two and a half million dollars in 2015. (It is currently at \$1.9 million.)
- The funds available annually for the CHS *Dream of a Cure Research Program* from the KPHRE, and from individual, chapter and corporate donations will have grown from \$150,000 to \$225,000.
- The number of high quality applications received for each of the CHS research programs will have doubled.
- Canadian researchers will have been able to recruit sufficient numbers of subjects to conduct their research.

¹ Formerly the *Hemophilia Research Million Dollar Club* (HRMDC).

NATIONAL ROLES

- Communicate the importance of CHS research programs to current and potential researchers and to our membership through the Web site and *Hemophilia Today* articles.
- Communicate the importance of being part of clinical trials and publicize opportunities for patients to participate in clinical research.
- Manage our 3 national research programs, including the application and granting processes.
- Manage the Ken Poyser Hemophilia Research Endowment (KPHRE).
- Match chapter and individual contributions to the KPHRE (budget permitting).
- Support our research program through direct mail appeals.
- Explore partnerships with other research-oriented bodies (e.g. Canadian Institutes of Health Research, Association of Hemophilia Clinic Directors of Canada, universities, hospital foundations...).
- Create a multidisciplinary CHS research advisory committee to better define our research agenda.
- Support chapters in promoting the research agenda.
- Encourage data collection to support optimal evidence-based care and treatment.

CHAPTER ROLES

- Communicate the importance of CHS research programs to current and potential researchers and to our membership through chapter newsletter articles and chapter meetings.
- Communicate to our membership the importance of providing clear and accurate patient record data.
- Communicate the importance of being part of clinical trials and publicize opportunities for patients to participate in clinical research.
- Raise money for current research in the *Dream of a Cure Research Program*.
- Raise at least \$50,000 collectively each year to increase the KPHRE.

Education and Support

Goal

Provide effective delivery of information and support to patients and their families across Canada in both English and French.

Objectives

- Determine the educational and support needs of people with inherited bleeding disorders through collaboration among the chapters, the national organization and the comprehensive care clinics.
- Increase utilization of existing education and support programs.
- Increase the level of knowledge and understanding of inherited bleeding disorders among people of all ages.
- Deliver relevant educational materials in both paper and electronic forms.
- Make CHS programs and services better known to all people with inherited bleeding disorders.
- Maintain and update the CHS catalogue of educational materials.
- Develop new materials if and when needed.

Some Key Strategies

- Encourage the integration of educational programs into chapter social events.
- Encourage all patients to become members.
- Enlist the support of all comprehensive care clinics in recruiting members.
- Remain current in the use of the Internet and social media so as to better communicate information and allow members to be inter-connected.
- Enhance evaluation and encourage timely feedback from chapters post program and/or service delivery.
- Identify the core programs and services to be offered nationally and in all chapters.
- Improve collaboration and communication among chapters and the national organization. (See *A Cohesive Organization*.)
- Clarify the roles and responsibilities of the chapters and the national organization in the delivery of information, programs and support.

Desired Outcomes

- A defined set of core programs and services will be offered nationally and in all chapters.
- Every person with an inherited bleeding disorder registered in a comprehensive care clinic will be informed of the existence of the Canadian Hemophilia Society and its programs and services.

NATIONAL ROLES	CHAPTER ROLES
<ul style="list-style-type: none"> ▪ Maintain and update the CHS catalogue of educational materials. ▪ Collaborate with chapters and health care providers to determine the educational and support needs of people with inherited bleeding disorders. ▪ Develop new materials and pilot workshops if and when needed, and distribute to all chapters. ▪ Deliver paper documents to clinics and chapters. ▪ Act as a clearinghouse for educational documents for members. ▪ Develop and maintain the national Web site, and a presence on appropriate social networks. ▪ Support chapters in developing provincial areas of national Web site. ▪ Operate a 1-800 line. ▪ Publish a national newsmagazine. ▪ Hold biennial medical and scientific symposia. ▪ Evaluate program and service delivery. 	<ul style="list-style-type: none"> ▪ Increase utilization of existing education and support programs. ▪ Collaborate with the national organization to determine the educational and support needs of people with inherited bleeding disorders. ▪ Integrate educational programs and distribute educational materials at chapter events. ▪ Develop pilot workshops if and when needed, and share results. ▪ Publish provincial newsletters or communicate key information through <i>Hemophilia Today</i> and the national Web site. ▪ Develop content for provincial areas of national Web site. ▪ Provide peer support through social events, workshops, family weekends, education days. ▪ Provide parent-to-parent support. ▪ Organize summer camp. ▪ Provide direct aid to members when possible. ▪ Evaluate and provide feedback to the national organization post program and/or service delivery.

Safe and Secure Supply

Goal

Advocate for access to a secure supply of the safest and most efficacious therapies for the treatment of inherited bleeding disorders.

Objectives

- Advocate so that clotting factor concentrates remain within the blood system budget, free of direct charge to the patient.
- Advocate for continued access to prophylaxis for children and adults, when indicated.
- Advocate for the continued availability of immune tolerance protocols.
- Advocate for the continued availability of all therapies approved for use in Canada, based on patient-physician autonomy.
- Engage people in advocating for a secure supply of safe and efficacious therapies.
- Educate our members on the importance of clotting factor usage data to support optimal evidence-based outcomes.
- Advocate for the availability of a single electronic log system to report factor usage, linked to CHARMS, owned by the Association of Hemophilia Clinic Directors of Canada.
- Advocate for the recovery of the factor VIII in Canadian plasma sent for fractionation.
- Influence decision makers to invest in the blood system in the interest of safety for all.
- Contribute to a safe and secure blood supply for all Canadians.
- Remember the lessons of the tainted blood tragedy.

Some Key Strategies

- Provide up-to-date information on factor therapies to our members.
- Maintain and renew the expertise of our volunteers and staff.
- Foster knowledge and expertise in all chapters.
- Hold positions on all important blood system committees, nationally and provincially, so as to have a strong voice on behalf of people with inherited bleeding disorders.
- Conduct research into the optimal process for tenders in the awarding of contracts for blood, blood products and their alternatives in Canada.
- Continue to play an influential role in the tender process and selection of clotting factor therapies for the Canadian market.
- Collaborate with other inherited bleeding disorder organizations (i.e. World Federation of Hemophilia, European Haemophilia Consortium, National Hemophilia Foundation).
- Hold annual commemorations across the country to maintain focus on a safe and secure blood supply for all Canadians.

Desired Outcomes 2011-2015

- Canadians with inherited bleeding disorders will continue to have access in a timely way to a secure supply of the most advanced therapies with optimal quantities at no cost to the end-user.
- Factor therapy usage will be reported through a single electronic log system, linked to CHARMS, and owned by the Association of Hemophilia Clinic Directors of Canada.
- 80% of patients will report their factor therapy usage using the electronic log system.
- The CHS will continue to have a strong voice in the blood system in Canada.
- 100% of the factor VIII in Canadian plasma will be recovered for use in Canada or abroad, ideally in countries where factor VIII concentrates are unavailable.

NATIONAL ROLES	CHAPTER ROLES
<ul style="list-style-type: none"> ▪ Seek positions on all important national blood system committees so as to have a strong voice on behalf of people with inherited bleeding disorders. ▪ Conduct research into the optimal process for tenders in Canada. ▪ Be involved in the national tender process, both in Quebec and the rest of Canada, and selection of clotting factor therapies for the Canadian market. ▪ Provide members with up-to-date information on factor therapies through the Web site and <i>Hemophilia Today</i>. ▪ Maintain and renew the expertise of our national volunteers and staff. ▪ Educate our members on the importance of clotting factor usage data to support optimal evidence-based outcomes. ▪ Advocate for the availability of a single electronic log system to 	<ul style="list-style-type: none"> ▪ Provide members with up-to-date information on factor therapies through provincial newsletters and chapter meetings. ▪ Seek positions on provincial blood system committees so as to have a strong voice on behalf of people with inherited bleeding disorders. ▪ Foster knowledge and expertise on blood system issues in each chapter. ▪ Educate our members on the importance of clotting factor usage data to support optimal evidence-based outcomes. ▪ Hold annual commemoration events to maintain focus on a safe and secure blood supply for all Canadians.

NATIONAL ROLES

CHAPTER ROLES

report factor usage, linked to CHARMS, owned by the Association of Hemophilia Clinic Directors of Canada.

- Advocate for the recovery of the factor VIII in Canadian plasma.
- Influence decision makers to invest in the blood system in the interest of safety for all.
- Support the chapters in commemoration events.
- Collaborate with other inherited bleeding disorder organizations.

KEY GOVERNANCE PRIORITIES

A Cohesive Organization	Build a cohesive organization through a combination of strong, effective chapters and better collaboration between chapters and the national organization.
Increased Membership	Increase membership in both the chapters and the national organization.
A Culture of Philanthropy	Develop a culture of philanthropy among the expanded membership so as to be able to achieve the mission and goals of the organization.

A Cohesive Organization

Priority

Build a cohesive organization through a combination of strong, effective chapters and better collaboration between chapters and the national organization.

Objectives

- Engage the national organization and all 10 chapters to work cohesively to reach the 5 key goals of the organization.
- Recognize the importance of good governance and work together to achieve best practice.
- Improve communication at all levels of the organization in both English and French.
- Engage skilled, effective volunteers to work towards the vision and mission of the CHS.
- Develop the next generation of CHS leaders.

Some Key Strategies

- Define clearly the roles and responsibilities of the chapters, both those with staff and those without staff, and the national organization with regard to program development and delivery, and fundraising. (See *Education and Support*.)
- Define clearly the set of core programs to be delivered by both chapters and the national organization.
- Ensure the existence of effective mechanisms to facilitate the sharing of information among chapters and the national organization on how their respective activities are serving our clientele and strengthening the CHS.
- Develop the CHS Intranet to improve access to information and tools.
- Increase the effectiveness of designated directors to represent their chapters and to communicate national information back to their chapters.
- Define the roles and responsibilities of the chapters' designated directors.
- Ensure that a representative of the national organization is present at every chapter Annual General Meeting.
- Create and implement a development model for chapters, including both those with and without staff, which identifies required aspects of governance and program delivery.
- Develop a template for chapter by-laws that is in accordance with national by-laws.
- Continue to invest in the recruitment, training, retention and recognition of volunteers.
- Create and implement succession planning in all chapters.
- Continue to foster the involvement of young people in the work of the chapters and the national organization.

Desired Outcomes 2011-2015

- Duplication of effort will be minimized.
- Resources will be utilized optimally.
- Young people will be involved as leaders in all 10 chapters.
- All 10 chapters will have sufficient volunteer resources to function adequately.
- All 10 chapters will be delivering a set of core programs and services.
- All 10 chapters will be governed according to approved by-laws and best practices in the not-for-profit sector.

NATIONAL ROLES	CHAPTER ROLES
<ul style="list-style-type: none"> ▪ Work with chapters to clearly define the roles and responsibilities of the chapters, both those with staff and those without staff, and the national organization with regard to program development and delivery, and fundraising. ▪ Work with chapters to define clearly the set of core programs and services to be delivered by both chapters and the national organization. ▪ Work with chapters to develop a template for chapter by-laws that is in accordance with national by-laws. ▪ Create and implement a development model for chapters, including both those with and without staff, which identifies required aspects of governance and program delivery. ▪ Have national participation at every chapter Annual General Meeting. ▪ Create effective mechanisms to facilitate the sharing of information among chapters and the national organization on how their respective activities are serving our clientele and strengthening the CHS. 	<ul style="list-style-type: none"> ▪ Define and deliver a set of core programs and services. ▪ Adopt chapter by-laws that are in accordance with national by-laws. ▪ Adopt a development model. ▪ Share information about chapter activities with the national organization and other chapters. ▪ Invite a representative of the national organization to each chapter Annual General Meeting. ▪ Invest in the recruitment, training, retention and recognition of volunteers. ▪ Create and implement succession planning. ▪ Continue to foster the involvement of young people in the work of the chapters.

NATIONAL ROLES	CHAPTER ROLES
<ul style="list-style-type: none">▪ Develop the CHS Intranet to improve access to information and tools.▪ Support chapters in the recruitment, training, retention and recognition of volunteers.▪ Involve young people in all aspects of the national organization.	

Increased Membership

Priority

Increase membership in both the chapters and the national organization.

Objectives

- Build the chapter and national membership base. (National by-laws stipulate that members of chapters are members of the national organization.)
- Develop communication strategies so that all people with inherited bleeding disorders know about the programs and services of the CHS.
- Provide all people with inherited bleeding disorders the opportunity to have access to information, programs and services.
- Involve more people with von Willebrand disease and rare bleeding disorders as members.
- Operate in accordance with our by-laws.

Some Key Strategies

- Conduct an annual membership drive directed at all individuals in the Canadian Hemophilia Registry (8,000 people in 2010) with the active collaboration of the national organization, chapters and comprehensive care clinics.
- Share chapter and national membership lists.
- Explore a health care provider membership category.
- Explore branding strategies to reflect all inherited bleeding disorders.

Desired Outcomes 2011-2015

- The chapter and national membership lists will have grown to 50% of those patients registered in the Canadian Hemophilia Registry. (Currently 8,000 people with inherited bleeding disorders are registered in comprehensive care clinics.)
- The CHS will have a large database enabling us to communicate effectively with a large majority of people with inherited bleeding disorders, and to appeal for their support.
- The national organization and all chapters will have an accurate database of their respective members.
- The CHS will be able to act in accordance with the provisions of its by-laws.

NATIONAL ROLES

- Develop and conduct an annual membership drive to all individuals in the Canadian Hemophilia Registry with the active collaboration of the chapters and comprehensive care clinics. (N.B. Chapters with the capacity may choose to lead the membership drive themselves, and then share the lists with the national organization.)
- Share each province's membership list with the chapter.
- Seek advice from chapters and from marketing experts on branding strategies to reflect all inherited bleeding disorders.

CHAPTER ROLES

- Lead the membership drive, if capacity permits.
- Share the chapter membership list with the national organization.

A Culture of Philanthropy

Priority

Develop a culture of philanthropy among the expanded membership so as to be able to achieve the mission and goals of the organization.

Objectives

- Create a culture of philanthropy among the expanded membership.
- Build stronger collaboration with the pharmaceutical sector.
- Contribute actively to increasing the fundraising capacity of Healthpartners.
- Maintain the profitability of the national direct mail program as long as possible.
- Develop and implement a cause-related marketing strategy for inherited bleeding disorders.

Some Key Strategies

- Conduct an integrated (chapter/national) annual appeal to members, which is profitable.
- Build support for the CHS from among members' social networks (families, friends, social clubs, religious groups, schools, local businesses...)
- Develop and implement integrated (chapter/national) planned giving appeals to members.
- Collaborate with chapters to cultivate major giving opportunities among the members and their social networks.
- Create a national resource centre on the Intranet to support chapter fundraising initiatives (golf tournaments, bike-o-thons, special events, galas...).

Desired Outcomes 2011-2015

- The pharmaceutical sector will continue to be a strong supporter of the CHS.
- Healthpartners will become a significant source of funds for the chapters and the national organization.
- Annual giving from the expanded membership and their social networks will become a source of funds for the chapters and for the CHS research program.
- Planned giving appeals targeted at the membership will be implemented.
- The national organization, chapters and members will contribute \$100,000 annually to the Ken Poyser Hemophilia Research Endowment.
- The national organization and the 10 chapters will have the resources necessary to achieve the mission and the goals of the organization.
- The national organization and all 10 chapters will maintain balanced budgets.
- The national organization will sustain its \$1,000,000 contingency fund.

NATIONAL ROLES	CHAPTER ROLES
<ul style="list-style-type: none"> ▪ Maintain and build stronger collaboration with the pharmaceutical sector at the national level. ▪ Contribute actively to increasing the fundraising capacity of Healthpartners. ▪ Manage the national direct mail program. ▪ Develop and implement a social marketing strategy for inherited bleeding disorders. ▪ Develop and conduct an integrated (chapter/national) annual appeal to members, which is profitable. (N.B. Those chapters with the capacity may lead the annual appeal in their provinces.) ▪ Develop and implement integrated (chapter/national) planned giving appeals to members. ▪ Collaborate with chapters to cultivate major giving opportunities among the membership and their social networks. ▪ Create a national resource centre on the Intranet to support chapter fundraising initiatives. 	<ul style="list-style-type: none"> ▪ Continue to work with the pharmaceutical sector to secure annual support for chapter programs and services. ▪ Participate in provincial Healthpartners campaigns, where active. ▪ Participate in (or lead, where capacity permits) an integrated chapter/national appeal to members to support chapter programs and services and the national research program. ▪ Participate in integrated (chapter/national) planned giving appeals to members and their social networks. ▪ Raise awareness and funds through <i>Red, White and You</i> events. ▪ Organize fundraising initiatives (golf tournaments, bike-o-thons, special events, galas...). ▪ Seek support from provincial governments and local businesses.

THE STRATEGIC PLANNING PROCESS

2009	National needs analysis completed, strategic plans adopted by Ontario, Quebec, Manitoba chapters
April 2010	Online survey of members of national Board of Directors, chapter and national staff, chapter presidents, national committee members
April 2010	In-depth interviews between CHS facilitator and key external stakeholders (health care providers, pharmaceutical contacts, CEOs of CBS and Héma-Québec)
May 15, 2010	Presentation of research results and facilitated session with CHS Board of Directors
May 30, 2010	Report to Board, chapters, committees and staff
June-July 2010	Work by Steering Committee to produce first draft of strategic plan
August 28, 2010	Presentation of draft strategic plan to the CHS Program and Youth Committees
September 2010	Draft plan and key questions circulated to Board, chapters, committees, staff and external stakeholders (via meetings, teleconferences and online tools)
October 2010	Period for comments
November 2010	2 nd draft plan prepared and circulated to Board of Directors
November 27, 2010	2 nd draft plan discussed and proposed for adoption
December 1, 2010	Strategic plan circulated to chapters and committees
Winter 2010-2011	2-year work plans, based on strategic plan, developed

WHO WE ARE

About 300,000 Canadians carry an inherited bleeding disorder gene. One in ten of these people—at least 30,000 Canadians—have symptoms severe enough to require medical care. Many of them have not been properly diagnosed. Only 8,000 people with inherited bleeding disorders are registered in the Canadian network of inherited bleeding disorder comprehensive care clinics.

Inherited bleeding disorders are a family of diseases in which blood proteins or platelets that help the blood to clot are missing or do not function properly, resulting in prolonged bleeding. These conditions include hemophilia A and B, von Willebrand disease, rare factor deficiencies (factors I, II, V, VII, X, XI, XIII), and platelet function disorders. While surface cuts and abrasions can create minor problems, the main risk for children and adults with these disorders is internal bleeding, mainly into muscles and joints or vital organs, which can cause death. For women there are additional risks: heavy menstrual periods, which in the absence of proper diagnosis can lead to reduced quality of life, unnecessary hysterectomies, and the risk of hemorrhaging during childbirth.

For all people with inherited bleeding disorders, prolonged bleeding after injury or surgery can be life threatening.

The Canadian Hemophilia Society (CHS), whose national headquarters are in Montreal, is a national voluntary health charity. Its Board of Directors is made up of 18 individuals designated by the organization's 10 provincial chapters, up to 4 directors-at-large, a medical advisor and a youth representative. Each provincial chapter in turn is managed by its own Board of Directors. Many chapters are separately incorporated and have their own charitable registrations. Three provinces—Quebec, Ontario and Manitoba—currently have offices with permanent staff. All chapters work in accordance with CHS by-laws and conform to national policies. The national organization and its 10 chapters share a common vision and mission. The CHS has approximately 300 active volunteers 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 health care providers in Canada's 25 inherited bleeding disorder comprehensive care clinics, 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.

OUR HISTORY

In 1953, a small group of hemophiliacs, their families and physicians in Montreal founded the Canadian Hemophilia Society. Their dream at the time was to improve the quality of life and find a cure for hemophilia. The close collaboration among patients, health care providers and researchers was unique then... and remains so today.

Through their tireless efforts, the CHS quickly developed from a small, Montreal-based support group to a national volunteer organization. Ontario created the first provincial chapter in 1957, followed by Quebec in 1959. By 1969, chapters existed in each province.

From the beginning, Frank Schnabel, the founder of the CHS, and the other Society leaders devoted their efforts to ensuring that adequate supplies of blood products—plasma, cryoprecipitate and, by the 1970s, clotting factor concentrates—were available to treat hemophilia. By the early 1980s, they had helped to build a network of hemophilia treatment centres across Canada to provide comprehensive care and treatment.

Tragically, during the 1970s and 1980s, Canada's blood supply became contaminated by blood-borne pathogens. Seven hundred hemophiliacs and 400 other Canadians were infected with HIV, the virus responsible for AIDS, through blood products. Three-quarters have passed away. Similarly, before 1990, approximately 1,600 hemophiliacs and thousands of other transfusion recipients were infected by the hepatitis C virus. Subsequently, the CHS advocated successfully on behalf of all Canadians affected by tainted blood for compassionate financial assistance from both the federal and provincial governments. The CHS was instrumental in the reform of Canada's blood system. As the patient group most affected by this public health tragedy, the CHS continues to work vigilantly to ensure that Canadians enjoy the safest blood products in good supply.

As care and treatment for hemophilia improved through the 1990s, the CHS was able to devote more time and energy to other inherited bleeding disorders: von Willebrand disease, platelet function disorders and rare factor deficiencies, while continuing to address complications arising for those with hemophilia who develop *inhibitors* (a serious health complication in which the body's own immune system rejects the clotting factor treatment). We have been and continue to be a leader in raising awareness around issues for women with inherited bleeding disorders, a group that continues to be under-served and whose health care needs deserve greater attention.

Historically, research has been a priority for the CHS. In recent years, the Society has invested half a million dollars annually in peer-reviewed research projects to improve treatment and ultimately to find a cure.

Over the last decade, the CHS has recognized its responsibility to the global bleeding disorder community. In addition to hosting two successful World Congresses—Montreal in 2000 and Vancouver in 2006—the CHS, through both its national organization and its chapters, has participated in World Federation of Hemophilia twinning relationships all around the world.

Today, the Canadian Hemophilia Society is governed by a group of experienced and dedicated volunteers from across the country. They are actively involved in the development of programs and services to meet the needs of all people with inherited bleeding disorders.

DEFINITIONS

The Canadian Hemophilia Society

The national organization and its ten chapters.

The national organization

The national Board of Directors, national committees, the national office and members.

The chapters

The ten chapters, their governance bodies and chapter offices, committees and members.

Vision

A statement giving a broad, aspirational image of the future that the CHS is aiming to achieve.

Mission

A statement that guides the actions of the CHS, spells out its overall goals, provides a sense of direction, and guides decision-making.

Value

Statements that describe actions that are the living enactment of the fundamental values held by most individuals within the organization.

Goal

Our overall aim.

Objective

What we aspire to do.

Strategy

How we intend to reach our goal.

Desired outcome

The measurable results of our work.

Information

Data that has been verified to be accurate and timely, is specific and organized for a purpose, is presented within a context that gives it meaning and relevance, and which leads to increase in understanding and decrease in uncertainty. The value of information lies solely in its ability to affect a behavior, decision, or outcome. The CHS delivers information through its newsmagazines and newsletters, Web site, publications, events and meetings for members.

Program

A collection of organizational resources that is geared to accomplish a certain major goal or set of goals. The CHS has research programs such as *Dream of a Cure*, awareness programs such as *Red, White & You*, education programs such as *Passport to well-being*, and support programs such as summer camp.

Service

The act of giving assistance to others. The CHS operates a 1-800 line to provide service; many chapters provide direct assistance in the form of mobility aids, financial assistance and psychosocial support.