



Canadian Hemophilia Society
Help Stop the Bleeding
Société canadienne de l'hémophilie
Arrêtons l'hémorragie



STRATEGIC PLAN | 2016-2020

Adopted by the Board of Directors
January 17, 2016

“A strategic plan is a document used to communicate with the organization the organization’s goals and the actions needed to achieve those goals.

Strategic planning is an organizational management activity that is used to set priorities, focus energy and resources, strengthen operations, ensure that employees and other stakeholders are working toward common goals, establish agreement around intended outcomes/results, and assess and adjust the organization's direction in response to a changing environment. It is a disciplined effort that produces fundamental decisions and actions that shape and guide what an organization is, who it serves, what it does, and why it does it, with a focus on the future. Effective strategic planning articulates not only where an organization is going and the actions needed to make progress, but also how it will know if it is successful.”

- Balanced Scorecard Institute

This strategic plan is intended to guide the Canadian Hemophilia Society’s national organization and ten provincial chapters in preparing their annual action plans over the next several years. In today’s rapidly changing world, planning accurately many years into the future is difficult. Long-term goals require periodic reviews and adjustments of the plan to take into account new developments and trends.

TABLE OF CONTENTS

What we learned about the changing environment

Care and Treatment	4
Research	4
Education and Support	5
A Cohesive Organization	
Governance	5
Member Engagement	5
Communications	6
Funding	6
Target Populations: Who We Serve	7
Our Values	7
Our Vision	8
Our Mission	8
Our Global Responsibility	8
Our Goals	9
Care and Treatment	10
Research	11
Education and Support	12
A Cohesive Organization	13
Our Respective Roles	14
Annex 1 – Key External Committees	16

What we learned about the changing environment

The strategic planning consultation process identified the following changes in the external environment that need to be considered in our plan.

CARE AND TREATMENT

Many innovative therapies for bleeding disorders are in development or entering the market; however access to these advances is not guaranteed as it was in the past. While the safety of blood, blood products and their alternatives has been a priority over the last three decades and will continue to be important, increasingly, the focus will need to switch to advocating for access to the most efficacious products.

High-quality comprehensive care for all people with inherited bleeding disorders remains critical to achieving optimal health outcomes. Difficult economic conditions and constrained provincial health budgets are putting pressures on the level of resources in the 25 inherited bleeding disorder programs. Patient community advocacy and formal accreditation processes will be key to respecting standards of care.

Factor concentrate utilization and health outcome data are increasingly important to maintain and advance the quality of care. The new Canadian Bleeding Disorders Registry (CBDR) and MyCBDR will be essential tools for patients and health care providers and will need to be widely implemented.

People with bleeding disorders are ageing with, for many, near normal life expectancy. This raises new challenges in treating the co-morbidities that are complicated by an underlying bleeding disorder. Programming needs to recognize the needs of this population.

Hepatitis C “wonder drugs” are now available. They present the real potential to eradicate HCV in just a few years. Those people with bleeding disorders affected by HCV must be informed about these new treatments and offered access.

Meanwhile, the traditional challenges remain: the complication of inhibitors, dealing with a new diagnosis, informed decision-making regarding education, career, sports and activities, diagnosis for women with bleeding disorders and people with very rare bleeding disorders, and the long-term joint damage caused by hemophilia, despite prophylaxis.

RESEARCH

Research continues to represent hope for a better tomorrow and is a priority for our members. It also represents a way to attract, retain and increase the knowledge of health care providers in our field. Consultation with members in 2010 and again in 2015 revealed that research and the quest for a cure are seen as high priorities for the CHS. The national organization and chapters have strongly supported research over the last 25 years and again during the 2011-2015 period. This will need to continue.

Patient-reported outcomes including measurement of quality-of-life are becoming increasingly important in the design of clinical trials as well as in the justification of new therapies. The CHS will need to play a greater role in generating such data.

A Research Advisory Committee and Peer Review Committee are in place to guide the organization in running its research programs and choosing the projects that will best advance knowledge.

EDUCATION AND SUPPORT

The ways people, especially younger people, access information are changing. The CHS will have to embrace these new technologies, while maintaining the traditional high quality of its educational tools and communications. Educational documents will need to be designed to be shared through a variety of media. The quality of the content remains critical, no matter what the medium.

We live in a world of information overload; there is an ongoing battle to attract people's attention. Our educational efforts will need to be creative, focused and carefully targeted.

Human and financial resources are increasingly scarce. Greater emphasis will need to be placed on evaluating needs and the results of our educational efforts so as to maximize impact.

A COHESIVE ORGANIZATION

Governance

A significant number of experienced volunteers and staff will be leaving their places to others over the next few years. This transition needs to be planned with succession and mentorship programs.

A new generation of talented young people has emerged over the last few years and is ready to take on greater roles at both the national and chapter levels. They need to be welcomed and encouraged.

Exerting influence over decision-makers in the health field is increasingly difficult. Bleeding disorders are seen as expensive, rare diseases. The provinces and territories, which deliver health care, are attempting to constrain expenses, especially for new drug therapies. The national organization and its chapters need to be closely aligned on issues of key importance to members if we are to advocate successfully.

Not-for-profit charities are being held to stricter account by the Canada Revenue Agency, donors, the public and their own members. The CHS and its chapters need to develop best-practice governance policies and train board members to use them. In addition, we need ways in which we can hold each other accountable.

The CHS exists as one national organization and ten autonomous chapters. Some chapters have staff; most rely entirely on volunteers. This strategic plan will need to be feasible for all parts of the country. The CHS governance structure will need to be examined to ensure it is appropriate for the changing environment.

The perception exists that communication between the national organization and chapters is far from ideal. Perception is reality. Communications must improve.

Member Engagement

Many individuals who responded to the online consultation of the community in May 2015 indicated they would be ready to volunteer if asked, but they had not been asked. The CHS and its chapters therefore have a great opportunity to attract more members and more volunteers by defining their volunteer needs and simply asking for help.

Communications

The CHS has always produced high-quality educational publications; however, the way people access information has changed radically in the past few years and will continue to change. The CHS needs to adapt to this changing reality by embracing new technologies and making information available to people in a multitude of ways while not leaving behind traditional ways of communicating nor sacrificing the high quality of its content.

Funding

Very competitive tender processes are resulting in lower prices for clotting factor therapies and a smaller total market value. While helpful in terms of reducing blood system pressures to restrict utilization, tenders may result in lower profit margins for companies and less funding for sponsorship and philanthropy.

Other traditional funding sources for the national organization and chapters (HealthPartners, appeals through direct mail, provincial government grants) are either stable or shrinking. As care has dramatically improved for many people with bleeding disorders and the tainted blood tragedy is increasingly a distant event, the external case for support has become less compelling. The collective budgets of the national organization and chapters have decreased by more than one million dollars in the last five years and that trend is expected to continue. A new, reliable source of funding needs to be found. Following the example of other health charities that are member supported, the 10,000 people diagnosed with bleeding disorders, their families and contacts constitute the most promising avenue. Increasing legacy gifts will need to be considered as part of the fundraising strategy. The CHS will have to do better, perhaps less, with fewer resources.

Target Populations: Who We Serve

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

- people with hemophilia, von Willebrand disease, rare factor deficiencies and inherited platelet disorders;
- carriers of these conditions;
- their families;
- the patients' communities (friends, co-workers, daycare workers, teachers, employers...);
- health care providers in the Canadian network of inherited bleeding disorder comprehensive care clinics;
- other health care providers (primary care practitioners, dentists, specialists...) who may provide care for people with inherited bleeding disorders.

Our 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 and, where possible, in other languages.

Integrity

By acting honestly, responsibly, transparently and accountably.

Respect

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

Engagement

By being well connected to our grassroots community.

Collaboration

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

Our Vision

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

Our Mission

The Canadian Hemophilia Society is committed to improving the health and quality of life of all people in Canada with inherited bleeding disorders and ultimately finding cures.

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 advanced therapies. 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 and efficacious treatments and highly trained health care providers. Life expectancy remains less than 20 years and these short lives are filled with pain and suffering.

The national organization and its chapters, as well-developed patient associations, acknowledge their responsibility to work with the World Federation of Hemophilia (WFH) to further its mission of TREATMENT FOR ALL.

Our Goals



Care and Treatment

Achieve standards and evidence-based comprehensive care for all people with inherited bleeding disorders throughout their lifespans.



Research

Promote, fund, facilitate and conduct fundamental, clinical and quality-of-life research to improve health and quality of life and ultimately find cures.



Education and Support

Deliver evidence-based information and support to patients, their families, health care providers and the general public across Canada in both official languages, English and French.



A Cohesive Organization

Build a cohesive organization through good governance, member engagement, effective communications and fundraising to support our strategic goals.

Care and Treatment

GOAL: Achieve standards and evidence-based comprehensive care for all people with inherited bleeding disorders throughout their lifespans.

Desired outcomes

- Canada's 25 inherited bleeding disorder comprehensive care centres will be well-resourced and provide high-quality evidence and standards-based care.
- The number of bleeding disorder programs with women and bleeding disorder clinics will increase by two each year from eight clinics in 2015 to 16 in 2019.
- The number of women diagnosed with inherited bleeding disorders will increase by 5 percent per year.
- Innovative therapies that have been shown to improve health outcomes and/or quality of life will be reimbursed in all provinces and territories and accessible at no cost to the end user no more than six months after approval by Health Canada.
- The CHS will maintain expertise in the blood system and continue to have influence.
- The number of people who use clotting factor therapies at home and use MyCBDR or iCHiP will increase from 25% at the end of 2015 to 95% by the end of 2018.
- All people registered in an inherited bleeding disorder program with HCV infection will be offered the opportunity to undergo therapy with direct-acting antiviral therapy by the end of 2017.
- The national organization and/or its chapters will be involved in two to three active twinning partnerships over the 2016-2020 period.

Privileged strategies

- All chapters will establish a plan to address recommendations contained in the 2014 "Centre Assessments" by the end of 2016.
- Workshops and other training formats will have been held by the end of 2017 in all chapters to increase the number of volunteers prepared to lead advocacy efforts in the areas of care and treatment, including access to innovative therapies.
- The CHS will maintain strong representation on all key national/provincial/territorial blood committees. (See ANNEX 1 for list.)
- The 2007 First Edition of the *Canadian Comprehensive Care Standards for Hemophilia and Other Inherited Bleeding Disorders* will be updated in collaboration with the four health care provider associations by the end of 2017.
- A formal bleeding disorder program accreditation process will be developed in collaboration with the four health care provider associations by the end of 2018.
- One-third of the bleeding disorder programs will be evaluated for accreditation each year, starting in 2019.
- The CHS will provide financial and logistical support for the annual meetings of the CANHC, CPHC and CSWHC to share best practices.

Research

GOAL: Promote, fund, facilitate and conduct fundamental, clinical and quality-of-life research to improve health and quality of life and ultimately find cures.

Desired outcomes

- The CHS will attract twice the number of high-quality research applications compared to grants available each year in each of its competitions.
- Two *Dream of a Cure* research projects will be funded each year from 2016 to 2020.
- The CHS will continue to offer *Care until Cure* research grant opportunities through 2020.
- To ensure research is conducted in a wide spectrum of areas that affect quality of life, the CHS will offer research programs for nurses, physiotherapists and social workers each year from 2016 to 2020.
- The CHS will collect patient-reported treatment and quality-of-life information to support evidence-based advocacy.

Privileged strategies

- Chapters will raise \$50,000 annually for the Hemophilia Research Million Dollar Club (HRMDC) endowment.
- The national organization will match this gift, supporting either the HRMDC endowment or current research.
- In the 2016-2020 period, the national organization and its chapters will publicize opportunities for patients to participate in research and clinical trials of innovative therapies.
- The CHS will facilitate knowledge transfer through organization of *Rendez-vous* Medical and Scientific Symposia in 2017 and 2019, support for health care provider participation in the AHDC Medical Symposia in 2016, 2018 and 2020, and communication of treatment advances via *Hemophilia Today*, the website and other communication tools.

Education and Support

GOAL: Deliver evidence-based information and support to patients, their families, health care providers and the general public across Canada in both official languages, English and French.

Desired outcomes

- Through collaboration with inherited bleeding disorder programs, 100% of people registered in these centres will be informed of CHS programs and services every two years, starting in 2016.
- People with inherited bleeding disorders and their families will have access in a variety of ways to evidence-based health and quality-of-life information.
- The CHS will provide support programs and activities to people with bleeding disorders and their families to help them cope with their chronic conditions and reach their full potential.
- The CHS will raise awareness about inherited bleeding disorders in members' immediate communities and the general public.
- The Multi-Provincial/Territorial Assistance Program (MPTAP) survivor benefits will be extended to post-1994 dependents by the end of 2016.
- The 1986-1990 HCV Settlement Trust Fund surplus will be allocated to enhance benefits to class members by the end of 2016.

Privileged strategies

- The CHS will hold high-quality knowledge transfer *Rendez-vous* events for the entire bleeding disorder community in 2017 and 2019.
- The CHS catalogue of educational tools will be updated as needed. New tools will be added based on needs assessments.
- Chapters will offer access to youth and/or family camps in every region of the country each year.

A Cohesive Organization

GOAL: Build a cohesive organization through good governance, member engagement, effective communications and fundraising to support our strategic goals.

Desired outcomes

- The national organization and eight of ten chapters will have their governance evaluated by participating in a recognized governance review process by the end of 2018.
- An Engagement Strategy will be developed that utilizes currently available technology and identifies engagement metrics. The National Organization and Chapters will have consistent communications that support the desired outcomes of the organization.
- Chapter membership will increase from 2,750 in 2015 to 3,500 by the end of 2020.
- A strategy will be developed and implemented by the end of 2017 to increase funding to chapters and the national organization from members, their families and their contacts. The goal for 2018 will be \$100,000.

Privileged strategies

- The CHS will maintain current fundraising activities in order to ensure stability of the organization.
- A Fundraising Strategy will be established to develop an internal case for support and increase fundraising capacity by mid-2017.

Our Respective Roles

Best managed by the national organization	Best managed by chapters
Development of evidence-based educational materials: publications, educational videos and podcasts, etc.	Delivery of patient and parent support programs, development of pilot programs
Development of a case for support from people affected by bleeding disorders and their close contacts	Membership drive
A national newsmagazine	Information on local programs and services
A national website focused on education and information	Provincial websites focused on chapter activities and services
Support for sharing of best practices by members of CANHC, CPHC and CSWHC	Chapter visibility at clinics
Collaboration with AHCDC, CANHC, CPHC and CSWHC on standards of care and accreditation of centres	Identification of care and treatment issues
Support of chapter advocacy re care & treatment	Advocacy work with hospitals and provincial governments re care and treatment
Evaluation of national programs/services	Identifying member needs, setting goals and evaluating results
Administration of research programs, applications and funding, research peer review	Raising funds for research
Government relations on a national level (Health Canada, CBS, Provincial/Territorial Blood Liaison Committee...)	Relations with provincial governments and Ministries of Health
Research involving patient-reported health and quality-of-life outcomes	Promotion of surveys related to patient-reported health and quality-of-life outcomes
Advocacy re safety and supply of coagulation therapies (Health Canada, Canadian Blood Services)	Advocacy re safety and supply of coagulation therapies (Québec MSSS, Héma-Québec)
Relations with Canadian Blood Services, Héma-Québec	Relations with Héma-Québec (CHSQ)
Involvement in product tenders (CBS and Héma-Québec)	Involvement in product tenders (CBS and Héma-Québec)

Best managed by the national organization	Best managed by chapters
WFH interactions re twinning with national organization	WFH interactions re twinning with chapters
National workshops (e.g. inhibitors)	Local educational workshops
Leadership on enhancements to compensation plans	Advocacy with provinces on enhancements to compensation plans
Corporate image and risk management (national)	Corporate image and risk management (chapter)
Organization of <i>Rendez-vous</i>	Chapter participation in <i>Rendez-vous</i>
National fundraising (pharmaceutical companies, HealthPartners, public individual giving ...)	Provincial fundraising (pharmaceutical companies, HealthPartners, local events, gaming, local sponsorship ...)
Media messaging	Identify local media opportunities (awareness)
Leadership in developing and evaluating national strategic plan	Provincial action plans
	Outreach/Access to new patients
	Engagement with members

ANNEX 1 – Key External Committees

Canadian Blood Services and Héma-Québec product selection and tender committees

Canadian Blood Services National Liaison Committee

Canadian Blood Services Regional Liaison Committees (BC & Yukon, Alberta, North/East Ontario, Central Ontario, Southern Ontario, Prairies, Atlantic)

Comité consultatif des représentants des receveurs d'Héma-Québec

Comité de la sécurité d'Héma-Québec

Comité de biovigilance du Québec

Ontario Blood Advisory Committee

World Federation of Hemophilia Therapeutic Products Safety, Supply and Availability Committee

Network of Rare Blood Disorder Organizations