



Canadian Hemophilia Society  
Help Stop the Bleeding



# STRATEGIC FRAMEWORK 2021-2025



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# INTRODUCTION

The Canadian Hemophilia Society (CHS) embarked on a strategic planning exercise early in 2020. Initial steps included the selection of an external consultant through a competitive process and the chartering of an internal steering committee comprised of volunteers and chapter staff leaders, reflecting different geographies, experiences, professions and ages.

Following a review of key background documents, an extensive interview process involving all categories of stakeholders was undertaken leading to the development of a set of key issues and a theory of change<sup>1</sup>. Board discussions over a two-day virtual meeting resulted in a set of strategic propositions. These were tested with national committees, chapter boards, provincial executive directors and the leaders of the national health care provider associations, some 81 individuals in total. The resulting emerging strategy was taken to the national board for consideration and comment. Lively engagement led to the development of the strategy outlined below.

# CURRENT SITUATION ASSESSMENT

The strategy addresses the following issues and opportunities, identified through the process of data gathering and consultation:

1. There is a need to move on: celebrating the past and now looking to the future. The success enjoyed by the CHS brings the organization to this point of having new choices to make.
  - a. While quality of life improvements over the past 30 or more years are to be celebrated, there is recognition of the fragility of these gains and the need for constant vigilance with respect to accessibility of both product and comprehensive care.
2. The CHS is primarily a patient advocacy organization, addressing issues of access, care models and product safety for people in Canada living with inherited bleeding disorders.
  - a. Opportunity to update approaches.
  - b. Data and stories will be required increasingly for success.
  - c. Gaps in internal alignment limit the pan-Canadian effectiveness of the organized inherited bleeding disorder movement to serve its community.
3. Funding will continue to be constrained across the system: for the operations of the CHS as well as for the reimbursement of innovative product and the implementation of the preferred multidisciplinary comprehensive care model as currently outlined in the 2020 Standards of care.
4. There is interest across the chapters to work more effectively and efficiently with each other and with the CHS.
5. Community engagement is challenging – contributing to this is generational differences and increasing recognition of different needs across the lifespan.

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<sup>1</sup> See Appendix.

6. The nature of volunteerism will continue to evolve, requiring the CHS to rethink expectations, ways of recruiting and engaging and how it recognizes volunteers. Succession planning remains a concern.
7. Patient education materials provided by the CHS are well regarded. Moving forward, resources are likely to be limited with respect to development and updating such documentation.
8. Research should continue to be managed nationally.
9. Value is seen in global engagement and the opportunity provided for chapters to engage in twinning projects.
10. The organizational culture is described as being in a state of evolution. Specific aspects requiring change include adoption of a culture of philanthropy, modernization of a number of core approaches and processes, becoming more collaborative, inclusive, and transparent, as well as growing the ability to have tough conversations respectfully, value differences, celebrate successes and require accountability.

## STRATEGY OVERVIEW

The strategy is expressed through the vision, mission and values, global responsibility statement and the strategic areas of focus. To avoid confusion, any use of the term “member” is reserved for the corporate members of the CHS i.e., the chapters; and the term “community” is used when referencing people in Canada living with inherited bleeding disorders.

### Vision <sup>2</sup>

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

### Mission <sup>3</sup>

Advocating to improve the health and quality of life for all people in Canada living with an inherited bleeding disorder until cures are universally available.

### Values <sup>4</sup>

Comprehensive care is founded on the belief that the patient is an equal partner. The success of the CHS is based on the same belief and set of values, namely:

**Collaboration** - Working with our provincial chapters and health care professionals to foster relationships, form partnerships with stakeholders, network and integrate across the system.

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<sup>2</sup> **Visions** are long-term statements of a preferred world, requiring multiple inputs from a range of players.

<sup>3</sup> **Mission**: defines more specifically the role and contribution that the CHS will make to the attainment of the overall vision.

<sup>4</sup> **Values** provide guidance as to the type of behaviour that is expected and rewarded in pursuit of delivering on the mission and overall strategy.

**Use of evidence** - Supporting the generation and adoption of new knowledge, using data to support decision making, and being committed to measurement and continuous improvement.

**Inclusion** - Engaging and reflecting the diversity of all people with inherited bleeding disorders and their families in everything we do.

**Open-mindedness** - Being curious about what is new and different and being respectful of diverse opinions and cultures.

**Results-focused** - Being responsible, transparent, action oriented and accountable.

## Our Global Responsibility

While the primary mission of the CHS is to work within Canada on behalf of people living in Canada, there is also a responsibility to the global inherited bleeding disorder community. In this regard, the CHS partners with the World Federation of Hemophilia in support of its vision of “TREATMENT FOR ALL.”

## Five-year Strategic Focus Areas

In fulfilling its mission, the CHS will channel its energies and resources in three directions, the first and primary focus relates directly to the ongoing well-being of the community; the second, to its important national collaboration and knowledge building role; with the third being the foundational enabling work of gaining access to resources. Each area of strategic focus is made up of interconnected threads which provide the framework for the work of the CHS.

### 1. Achieving optimal care for all

Success will be found through unified, persistent and consistent efforts that reflect community concerns and are supported by data and personal stories.

- **National planning** | Working together with chapters to develop and implement a multi-level comprehensive care plan inclusive of both product supply and care models.
- **Leadership** | A development plan to grow future advocates and leaders from different communities reflective of the spectrum of people living with inherited bleeding disorders.
- **Stakeholder relationships** | Strong bidirectional relationships with health care professionals and aligned stakeholders reflecting the national, provincial and territorial health systems, including health technology assessment organizations.
- **Communication and awareness building** | Consistent evidence-based messaging made available through a robust infrastructure that includes data gathering, story telling, education materials as well as national coordination.
- **Approach and toolkit** | Context specific and results-driven, mixing collaboration and collective action with knowing when to take a stand. Includes a toolkit and educational resources.

## 2. Fulfilling national responsibilities

The CHS has specific contributions to make in enabling support to be provided to all people in Canada living with inherited bleeding disorders, regardless of their geographic location.

- **Research** | Coordinating the research program which includes raising funds, adjudicating a credible peer review process, monitoring performance and reporting results.
- **Health care professionals' liaison** | Managing the special partnership between the community and its dedicated health care providers - physicians, nurses, physiotherapists and social workers – who value the opportunity for pan-Canadian conversations and connections.
- **Collaboration** | In all these responsibilities, chapters play important roles: raising research funds, engaging in twinning projects internationally and, interfacing with the treatment centres and individual health care professionals to engage their expertise for program and camp support. Moving forward, how best to coordinate, communicate and share in providing support across the country will need to be defined, building on such promising beginnings as the monthly President's meeting. The expectations of the chapters with respect to possible national level support such as the maintenance of a dynamic website, communication coordination and the provision of education and awareness materials remains to be determined together with a business model that is sustainable for all.
- **International liaison** | Acting as Canada's liaison to the World Federation of Hemophilia.

## 3. Building a mission-enabling culture and resource base

Enable the CHS to deliver on its mission requires sourcing and applying financial and human resources effectively and efficiently.

- **Funding** | Crafting a multi-dimensional resourcing/development plan, inclusive of strengthening current and emerging pharmaceutical relationships and reaching out to the inherited bleeding disorder community to fund the core work of the CHS. Developing creative mechanisms to fund national responsibilities that might include soliciting program-specific funding from government and foundations, as well as the identification and stewardship of potential major donors.
- **Strengthening leadership** | A different governance model for the CHS that is not based on chapter representation but rather comprises engaged individuals with specific strategic skills and expertise recruited from across the country. By not drawing on current chapter leaders and diverting time and effort from their provincial responsibilities, this change could also strengthen governance at the chapter level. Attracting and retaining strong volunteer leaders to the national board as well as into other leadership roles across the organization.
- **Restructuring** | Realignment of organizational resources and structures, mapping available resources with the strategic direction to create an affordable and streamlined structure.

– APPENDIX –

# THEORY OF CHANGE

**The data gathered to-date and the analysis conducted would suggest the following:**

**By leveraging current strengths, building relationships and demonstrating understanding of health system dynamics ...**

**By having patient leaders speak consistently and in an informed and balanced way using data, and ...**

**with their messages being amplified by key stakeholders, including physicians and other members of the health care community ...**

**The CHS will be a sought out and influential champion [advocate] for people living with inherited bleeding disorders, and ...**

**The community will have access, on an ongoing basis, to the highest possible standard of care.**