



HEMOPHILIA ONTARIO

SUPPORTING THE INHERITED
BLEEDING DISORDER COMMUNITY

2022 - 2025

STRATEGIC PLAN

HEMOPHILIA ONTARIO

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**ADOPTED BY THE BOARD OF
DIRECTORS**

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Table of Contents

Introduction	2
Current Situation Assessment	4
Guiding Principles	7
Strategic Priorities	9
Advocacy & Clinic Relations	10
Building our Community	11
Camps	12
Communication	13
Fund Development	14
Governance	15
Honouring our Legacy	16
Womens Health	17
Acknowledgments	18

Introduction

For over 65 years, Hemophilia Ontario has been the foremost patient advocacy and support organization for individuals with inherited bleeding disorders in Ontario. Founded in 1956, Hemophilia Ontario is an independently incorporated not-for-profit charitable organization, and member of the Canadian Hemophilia Society. Hemophilia Ontario has a rich history of educational in-person programming, community building and support, and political advocacy.

Throughout the years, Hemophilia Ontario has helped members navigate the many changes in the treatment of inherited bleeding disorders, supported our community through the events and fallout from the tainted blood tragedy, and continues to work to meet the needs of the inherited bleeding disorders community in Ontario today through the efforts of its five full-time staff members, board of directors, and an extensive network of committed volunteers.

CONSULTATION

Starting in the fall of 2020, Hemophilia Ontario undertook a series of comprehensive surveys in order to assess how our organization was meeting the needs of our members. Having recently experienced a period of internal instability, and changes in leadership, we wanted to ensure that the organization understood and was actively working to meet the expressed needs of our community. With much of our in-person program having been temporarily suspended due to the COVID-19 pandemic, we seized the opportunity for reflection and self-assessment. We hired a consultant, Tracy Lindsay, to undertake surveys and analyze the results, directed towards the following areas: members, camps, clinics and a women's website. The consultation process was extensive, and included an intentional effort to better understand the interests of our stakeholders.

In the spring of 2021, the results of the surveys were presented to the Board of Directors and shared with our stakeholders. While the goal of this exercise was to better inform board members and staff of our organizational priorities, we were pleased to learn that our current work was well-aligned with the needs of our members. The surveys also revealed a number of themes that this strategic plan seeks to address.



SURVEY RESULTS

Throughout our consultations, we consistently received feedback indicating a desire for in-person, interactive programming. At the beginning of the pandemic, Hemophilia Ontario was quick to pivot programming and meetings to virtual platforms, including our children's summer-time Pinecrest Adventures Camp, which ran online during the summer of 2020. As restrictions eased, we moved back to in-person events in the fall of 2020, and in-person children's and family camps in 2021.

Within the camp survey, there was a tendency by respondents to favor in-person camps and an expansion of programming and camp locations. There was also strong positive feedback on current camp programs and participants felt that camps were offering the right activities.

Within the member survey, a number of respondents suggested that more work needs to be done to help transition patient members from one stage of life to another. For example, from pediatric to adult care. Other aspects were also highlighted, such as supporting the needs of parents and caregivers. This survey also highlighted the importance of branding to ensure inclusion beyond hemophilia, for example inherited bleeding disorders such as Von Willebrand's Disease. Lastly, the survey revealed a desire to better capture the value of Hemophilia Ontario's website and fund development opportunities.

The clinic survey revealed a strong desire for education and communication programs. A need for advocacy to obtain clinic resources was revealed as part of the study. COVID-19 has been a strong component when thinking about what patient care and virtual care may look like in the future. Additionally, patient support and clinic supports were also highlighted as areas of opportunity.

Lastly, the women's website survey recommended further promotion of the site as it develops. The content appeared to be the most important aspect. Demand for content on research, management, treatment, information on different life stages, and lived experiences was noted to be significant.

DEVELOPING A PLAN

The Hemophilia Ontario Board of Directors struck a Strategic Planning Committee in the summer of 2021 with the goal of developing a three-year (2022-2025) strategic plan based on the data we have collected, and in renewed and ongoing consultation with our staff and key stakeholders. The committee was guided in its work by Peter Zhang, an MBA fellow who was working with the Hemophilia Ontario Board of Directors through the Rotman School of Business OnBoard Fellowship Program. This plan is the result of the work of this committee.

Current Situation Assessment

OUR COMMUNITY AND ORGANIZATIONAL CULTURE

Hemophilia Ontario's relationship with our community functions is like a big family. We reach out regularly, we listen, we share ideas, we meet, and we work together to find solutions to our problems. When someone needs help, we pick them up. If we need help, we ask and our community responds.

Hemophilia Ontario's organizational culture is based on a team approach between staff, board members, and volunteers. Hemophilia Ontario works on a consensus-based decision making process, whenever possible and legally permissible. We work together to identify issues and concerns for our community and our organization. We meet regularly to discuss our work and observations, and decide on solutions together with a high level of buy-in for all involved parties. We realize that whatever successes we achieve as an organization are the result of many people working together.

MANAGING IN THE PANDEMIC

COVID-19 has been a major disruption for not-for-profit organizations since March 2020. Yet, we are proud to report that Hemophilia Ontario never stopped fighting back against the limitations presented to us, continuously shifted priorities and resources, and we delivered the high quality programming, educational events and support that our community relies on us to provide. We moved early in the pandemic in 2020 to reset our priorities and manage our resources effectively to deliver for our members. Our staff already worked remotely, and there has been no disruption to staffing and organizational function. We moved to online programming immediately, including high quality webinars which had record-breaking attendances. We delivered in-person community programs in Ottawa and London in 2020. We delivered a week-long virtual camp for kids in the summer of 2020 when no in-person camping was possible, which also allowed attendance by children from eastern Canada. In 2021, we ran in-person camps for children at Pinecrest, and a family camp for a week at Wanakita attended by over 150 people. All of our events have been conducted with no reported cases of COVID-19. We achieved this not by luck, but by continually readjusting to changing public health requirements, carefully scrutinizing our finances and managing expenses, finding new opportunities for support, forward thinking, and a lot of time and energy spent planning for things that none of us have experienced before. Over the past two years we succeeded in our mission by meeting our community's needs.

Our view is that there exists in Ontario a wealth of untapped financial, human, and other resources for our organization to discover, both from within, and outside of our current community, stakeholders and supporters. Our present obligation is to identify opportunities to grow these resources in the most efficient and effective way possible for years to come. In addition, we will continuously monitor and update our by-laws, policies, and other internal documents to ensure they are relevant, contain adequate safeguards and oversight mechanisms, especially around our funds, and are in compliance with the law.

SUPPORTING OUR COMMUNITY

We recognize that there continues to be many members of our community whose needs are not met by the social welfare and health care systems that currently exist in our province. We strive to identify members whose needs are not met, and we take seriously our obligation to help our most vulnerable members in every way that we can.

Mentorship of families with young children and newly diagnosed members is the way that our community has supported our members for generations. Our community has benefited from this spirit of generosity and sharing of knowledge and life experience. We understand that there is a pressing need for Hemophilia Ontario to engage new members of our community and our youth, as well as to ensure the vitality of our community and our organization. Over the next several years, this work will include reaching out in new and effective ways to people who are not currently members of Hemophilia Ontario, newcomers to Canada, newly diagnosed families, and youth. One way we did this is by starting the John Plater Scholarship and Bursary Program in 2021 to support members attending post-secondary education in a time when funds for education were scarce.

PARTNERSHIP WITH HEMOPHILIA TREATMENT CENTRES

The ability of Hemophilia Ontario to deliver meaningful results in the day-to-day lives of members of our community is based on our ability to engage and support Hemophilia Treatment Centres and their staff. For the last three years, we have fostered relationships with staff, and we are presently working together on a regular basis on programming, clinic resources, member support, and education. Hemophilia Treatment Centre staff help us understand the present needs of our members, and they connect us with members who are most in need of our help. They also help us by providing opportunities to work together from within and outside medical institutions to improve funding for clinics and other resources that benefit our members. We will continue to engage in comprehensive dialogue with clinic staff, ensure appropriate support for current initiatives and undertake new ventures and opportunities to support all Hemophilia Treatment Centres in Ontario.

WOMEN WITH BLEEDING DISORDERS

Improving the lives of women with bleeding disorders has been a call for several years in the bleeding disorders community. While important work has been done in this area,

Hemophilia Ontario is of the view that we still have a long way to go to make a meaningful difference in the lives of many women in Ontario. Over the past four years, a tremendous amount of work and resources have been poured into programming and education, as well as community building and awareness raising. We are committed to delivering meaningful changes for this community that result in improvements in public awareness, education, support for women's health, and mentorship.

CAMP IS OUR TOP PRIORITY

Since the launch of our camp programs in the early 1990's, these unique opportunities have proven to be invaluable tools in the education and empowerment of our youth. Hemophilia Ontario is proud to be one of the leading providers of camps across all provincial and state hemophilia organizations in North America. Our goal is to provide the highest quality and best attended camps in the world. In 2020, we created the position of Camps Director, a full-time staff position devoted solely to the planning and delivery of our camp portfolio. This position is the only full-time camp director position in a Hemophilia charity in North America. Our goal over the next several years is to expand our camp portfolio by increasing capacity at our current camp locations, and to open new camps across the province.

COMMUNICATION MATTERS

Hemophilia Ontario recognizes the need to adapt when it comes to how people communicate and get information in the 2020s. We developed a robust website that launched in 2020 that has been consistently upgraded with informative, compelling, and relevant content. Over the past two years we have delivered high quality webinars on topics that are of great interest to our community, such as: COVID treatment considerations, gene therapy, Hemlibra, and sexual health. Our email communications are sent weekly, and contain high quality content packaged in a concise format. Our social media has been improved. We implemented Raiser's Edge, the leading membership and donor management platform. We are launching a website devoted solely to women with bleeding disorders in 2022. We will not lose sight of the need to maintain and improve our communication strategy over the next several years.

OUR GLOBAL RESPONSIBILITY

Hemophilia Ontario recognizes that we have a responsibility to recognize the history of the bleeding disorders community, and to support people with bleeding disorders throughout Canada and around the world. We are blessed to have the financial and human resources necessary to do this important work. It is our responsibility to help the bleeding disorders community outside of our provincial borders, and we are committed to doing so whenever possible. At present, we look for ways to scale our programs and build in mechanisms for others to participate, such as webinars. This work continues to evolve at present, and it affects the planning and delivery in all aspects of our work.

Guiding Principles

As we began our strategic planning process, the Strategic Planning Committee examined our organization's guiding principles, starting with our Mission and Vision.

The Committee decided that our existing Mission and Vision remain valid for the organization. The Committee made a substantive addition to our guiding principles by defining our organization's charitable purpose as concisely as possible. This definition has become the main criteria by which we assess the priorities for our organization.

The Committee, in consultation with our staff, also outlined eight values that guide the work of the organization. Those are outlined below, along with brief descriptions explaining how they each apply to the work of Hemophilia Ontario.

MISSION

To strive to improve the health and quality of life for all people with inherited bleeding disorders, and to find a cure.

VISION

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

CHARITABLE PURPOSE

Inform, Educate, Support



VALUES

INCLUSIVENESS

By providing information, programs and services to all people affected by inherited bleeding disorders.

CONNECTEDNESS

By keeping in touch with our grassroots community.

REPRESENTATION

By actively representing and advocating for all people affected by inherited bleeding disorders.

EXCELLENCE

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

INTEGRITY

By acting honestly, responsibly, openly, and with accountability.

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.

SUPPORT

By helping those in our community meet their wellness, educational, and financial needs related to inherited bleeding disorders.

Strategic Priorities

As part of the strategic planning process, the Committee identified eight strategic priorities. These were further expanded to shape the goals for the organization that are at the heart of this Strategic Plan. The goals were further decomposed into specific objectives with distinct and measurable outcomes that allow the organization to assess its efficacy and alignment with the plan throughout its implementation.

ADVOCACY & CLINIC RELATIONS.....	10
BUILDING OUR COMMUNITY.....	11
CAMPS	12
COMMUNICATION	13
FUND DEVELOPMENT	14
GOVERNANCE	15
HONOURING OUR LEGACY	16
WOMENS HEALTH	17

Advocacy & Clinic Relations

GOAL

Advocating for the best care for patients with inherited bleeding disorders

RATIONALE

The nine Hemophilia Treatment Centres in Ontario (“HTCs”) are the key point of contact for our members in meeting their medical needs on a daily basis. HTCs are also an important source of support for the physiological, physical, educational and financial well-being of many of our members. The HTCs provide Hemophilia Ontario with information, a connection to our members (especially those who are vulnerable), and education. Maintaining effective lines of communication, and information sharing, with the HTCs is crucial for Hemophilia Ontario to continue to support our community.

Hemophilia Ontario can assist HTCs by identifying shortcomings in resources and support for our members. Areas where Hemophilia Ontario can offer assistance include increasing staffing levels, creating educational resources, and helping members transition from pediatric to adult clinics. Through this work, Hemophilia Ontario can provide meaningful support for members of our community, especially those who require extra support, such as aging members. Hemophilia Ontario will continue to expand financial support for members and their families and continue to provide assistance in navigating the medical and social welfare systems, in areas such as translation and advocacy.

OBJECTIVES

- Enhance member support program
- Translate documents, including for newly diagnosed patients
- Support professional development for clinic staff
- Improve resources, education, services and support for aging members
- Monitor clinic staffing, medicinal issues and other clinical resource requirements and advocate for required changes
- Maintain effective and regular communications with clinics
- Ensure seamless transitions from child to adult clinics
- Provide education and resources for clinics

Building our Community

GOAL

Building our community partnerships, locally, nationally, and internationally.

RATIONALE

Through the years, our community has leaned on each other in difficult times, looked to others for mentorship, sought support for our needs, and shared knowledge and experience. As we embrace a broader definition of the population we serve, Hemophilia Ontario must also strive to focus on programs that educate, inform, and support all members of our bleeding disorders community.

Hemophilia Ontario needs to place its focus squarely on our community, maintain our traditional grassroots approach, by bringing the community together, and delivering our programs and services in the places that our members live. The vitality of our community and organization is enhanced by engaging with groups such as parents, youth and non-traditional bleeding disorder groups. We have learned that our members most often derive meaningful information and knowledge when they are speaking to people who shared the same lived experience. We also seek to build a larger community of people with bleeding disorders and their families by supporting our community outside of Ontario through programs such as the World Federation of Hemophilia's twinning program.

OBJECTIVES

- Develop a family mentorship program
- Engage youth locally
- Improve engagement with Von Willebrand Disease members
- Locate annual general meetings and community camps throughout the province
- Engage with international bleeding disorders community
- Build annual regional marquee events to support local engagement

Camps

GOAL

Grow a robust and varied slate of camp programs

RATIONALE

Hemophilia Ontario has a long tradition of offering camp programs for children and families that serve the educational and leadership goals of our community. Our Camps provide unique opportunities for our young people with bleeding disorders to explore appropriate physical activity, while also fostering independence in managing their treatment and learning to self-infuse.

With respect to our current camp portfolio, we will continue to deliver high quality camp programming, to increase attendance at our camp programs and ensure we have the appropriate medical professionals in attendance to meet the stated medical goals of our camps and ensure a safe camp experience for everyone. At the same time, we will seek new camping opportunities across the province. Our plans to expand our camp programs are aimed at children and youth who are too young or too old to attend our current camps. By fostering a robust and varied camp program agenda, and ensuring that women and girls are part of that initiative, we are helping to develop future leaders within our community.

OBJECTIVES

- Maintain high quality camp programs
- Develop an adventure camp for youth
- Partner with Manitoba Chapter for Family Camp in Thunder Bay region
- Develop a Youth Leadership Program
- Increase the number of medical personnel who attend our camps
- Ensure community-based events deliver programming that dovetails with camp programs
- Camp leadership opportunities for women

Communication

GOAL

Maintain an effective communication strategy

RATIONALE

Over the past three years, Hemophilia Ontario has spent a tremendous amount of time and resources to improve communication channels such as our website and email. We need to build on this work by creating and maintaining mechanisms that analyze the effectiveness of our communications and ensure the delivery of high quality, timely, and engaging content for our digital channels. It is imperative that we continue to think outside of the box by engaging professionals and youth when it comes to how we interact with members, stakeholders, and donors.

OBJECTIVES

- Continue to maintain high quality and consistent digital communication
- Train staff in utilization of online analytics tools
- Development of a paid marketing strategy
- Pilot student social media coordinator positions
- Continuously update Hemophilia Ontario's websites

Fund Development

GOAL

Diversify and expand our current sources of funding

RATIONALE

Hemophilia Ontario has several substantial sources of funding, which is unique among hemophilia charities, and we need to build on our strengths in this area. Fund development and diversification needs to be a continuous and shared responsibility among board members and staff. Opportunities for fund development exist outside of traditional fundraisers. Fundraising campaigns that we launch have to be thoroughly conceived, issue-focused, and compelling. Grant writing geared towards government and foundations needs to be vigorously pursued. We need to do more to demonstrate to our funders the value of our work and how it relates to their support.

OBJECTIVES

- Continuously seek out new opportunities for fund development and diversification
- Prospect grant opportunities in light of COVID-19
- Develop social media fundraising opportunities beyond Facebook
- Create and execute compelling fundraising campaigns
- Develop a major fundraising program geared at corporate funders
- Launch estate giving program
- Develop further opportunities for support with our pharmaceutical partners
- Create digital and online opportunities for fundraising
- Create and execute fundraising strategy for Von Willebrand Disease and women with bleeding disorders
- Create a process for thanking donors and demonstrating how their dollars are being spent

Governance

GOAL

Implementation and revision of governance & operations policy

RATIONALE

Hemophilia Ontario strives to develop and implement governance policies and procedures that are transparent, ensure appropriate oversight, provide appropriate guidance for staff, and comply with applicable legislation. Hemophilia Ontario is committed to implementing policies and procedures that address issues of equity, diversity, and inclusion.

OBJECTIVES

- Develop an equity, diversity, and inclusion framework
- Review By-laws for compliance with new not-for-profit legislation
- Regular review of governance & operations policy manuals
- Revision of accounting frameworks

Honouring our Legacy

GOAL

Honouring the history and legacy of the bleeding disorders community

RATIONALE

One of our ongoing duties is to recognize the impact of the tainted blood scandal on our community, so that those who died, their loved ones, and those who survived, are recognized and supported. This work serves as a permanent commemoration of those who are no longer with us, fosters a high level of awareness regarding what happened to our community, and ensures that the tragic and difficult circumstances we have faced will never happen again.

We will also highlight the significant developments in the management and treatment of bleeding disorders, and improvements to the quality of life for those with bleeding disorders over the decades.

OBJECTIVES

- Maintain funding for our HIV/AIDS programming and services
- Create a digital memorial to honour those affected by the tainted blood scandal
- Launch an event to draw attention to the findings of the Krever Inquiry
- Demonstrate the history of advancements made in therapeutics and quality of life

Women's Health

GOAL

Meeting the needs of women with bleeding disorders

RATIONALE

The needs of women in the bleeding disorders community have been overlooked for many years. Over the past three years, Hemophilia Ontario has engaged women in our community to make women's services and programming an intentional priority. We need to expand on this foundation by increasing resources directed at this strategic priority, including awareness, educational and outreach campaigns. As part of this expansion, we are also committed to diversity and gender inclusivity, more closely examining gender-based programming where it is needed. By creating additional leadership opportunities for women and programming for adolescents, we will continue towards our goal of fostering the leaders of our community today and in the future.

It is imperative that we continue to connect with women throughout the entire province, raising awareness and offering support, particularly in isolated communities such as the Sudbury and Thunder Bay regions. We will strive to extend out across all of Canada to further support our partners in other Chapters servicing women throughout the country. The launch and continuous updating of our women's website will help us to meet the needs of women everywhere.

OBJECTIVES

- Launch women's website
- Outreach to non-diagnosed
- Enhance resource development
- Leadership opportunities for women
- Create adolescent programming
- Knowledge dissemination to medical professionals

**HEMOPHILIA ONTARIO**SUPPORTING THE INHERITED
BLEEDING DISORDER COMMUNITY

Acknowledgments

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