



*"Optimum health and well-being for those living with
HAE and other related angioedema in Canada."*

HAE Canada Inc.

Strategic Plan

2019-2024

STRENGTHENING OUR FOUNDATION

December 2019

Table of Contents

<u>Introduction</u>	1
<u>Our Target Audience</u>	2
<u>Our Values</u>	3
<u>Our Global Responsibility</u>	4
<u>Our Vision, Mission & Goals</u>	5
Strategies:	
Association Effectiveness	6
Equipping Patients & Health Care Providers	8
Building the Community	10
Advocacy	11
Increased Membership	13
Sponsorship and Fund Development	14
<u>About HAE Canada Our Pioneers</u>	16
<u>Definitions and Acronyms</u>	17
<u>Appendix A - Action Plan</u>	18

Introduction

Our strategic plan is intended to be easy to understand, measurable and used as a roadmap to provide direction to HAE Canada in its delivery of programs and services, through the years 2019-2024.

This plan will be supplemented by more detailed work plans that will be produced annually, which set out the specific actions required, to meet the goals of our plan.

The plan will be reviewed annually by the Board and work plans will be amended as required, in response to changing circumstances.



Our Target Audience

HAE Canada exists to provide information, programs and services to:

- those with angioedema symptoms due to disorders of the bradykinin pathway, which include Hereditary Angioedema (HAE) Types I, II, Acquired Angioedema and Angioedema with normal C1 inhibitor (Sometimes referred to as Type III)
- their families and caregivers
- the health care providers treating HAE patients;
- the patient's community (employers, coworkers, educators, friends...);
- the health care providers (family physicians, dentists, specialists, community clinic staff, hospital staff...); who may provide care for people with HAE or may come in contact with those who remain undiagnosed;
- Government and regulatory bodies (Federal, Provincial & Territorial, local health authorities); and
- strategic partners (AOHQ, CBS, , CORD, CHAEN, HAEi, researchers ,scientific community, pharmaceutical companies, etc....).

Our Values

HAE Canada embraces the following values:

Advocacy – Actively representing all who have HAE¹ and other related angioedema² to improve their quality of life by actively engaging our members and representing their needs.

Respect – Treating people with whom HAE Canada interacts with dignity, fairness and compassion.

Collaboration – Fostering strong and meaningful relationships with our stakeholders and partners, where collaboration, discussion and exchange of ideas is encouraged and supported by members, directors and staff.

Stewardship – HAE Canada’s resources belong to its members and the Canadian HAE community at-large. Members, directors and staff will act responsibly by effectively planning and managing of all available resources.

Learning – HAE Canada’s programs and services promote awareness and convey information to and from targeted audiences. Members, directors and staff value learning opportunities to help improve its services to HAE patients throughout Canada.



¹ **Hereditary angioedema or HAE**, is a rare, debilitating and potentially life-threatening genetic blood disorder resulting from a problem with the protein C1 esterase inhibitor (C1-INH). C1-INH normally keeps swelling at a level that is appropriate to any trauma, hormonal change or other triggers. If this protein is absent or not functioning properly, disproportionate swelling occurs. There are two types of HAE, **Type I**, which is characterized by decreased or nonexistent C1-INH and **Type II**, in which normal levels of C1-INH exist but the protein does not function properly. HAE affects about 1 in 10,000 to 1 in 50,000 Canadians.

² **Other related angioedema** includes **Type III**. It is also referred to as Angioedema with normal C1-INH. Diagnosis and treatment of this group are poorly understood.

Our Global Responsibility

Although our primary mission is to work on behalf of Canadians living with HAE and other related angioedema, our plan recognizes our responsibility to the world-wide HAE community.

Canadians living with HAE and other related angioedema have worked diligently to gain access to the most advanced treatments. Work continues with our partners both in Canada and world-wide to further improve the standard of care available.

HAE Canada is a patient advocate group that acknowledges our responsibility to work with the International Patient Organization for C1 Inhibitor Deficiencies (HAEi) to further their mission of promoting cooperation, coordination and information sharing between HAE specialists and national patient associations in order to promote and facilitate the availability of effective diagnosis and management of HAE and other related angioedema throughout the world.



Our Vision

Optimum health and well-being for those living with HAE and other related angioedema in Canada.

Our Mission

HAE Canada is committed to creating awareness about HAE and other related angioedema, to speed diagnosis of patients to enable them to become champions for their own quality of life.

Goals Related to Our Vision and Mission

Association Effectiveness

Improve our ability to achieve our mission and goals by engaging and empowering our members; developing our Board; training our volunteers; and by collaborating with our stakeholders and partners.

Equipping Patients & Health Care Providers

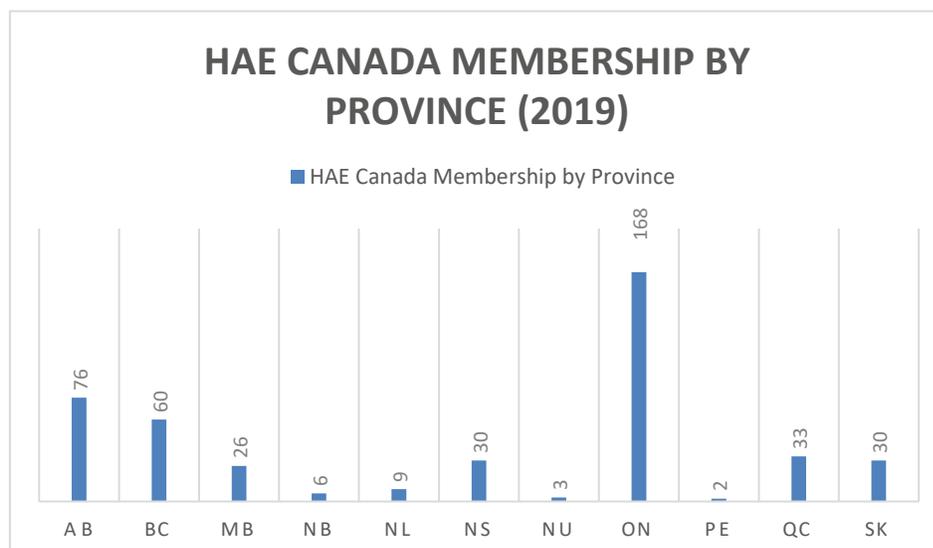
Equip patients, caregivers, family members and health care providers with the information, tools and resources needed to ensure that those with HAE and other related angioedema live healthy and productive lives.

Building the Community

Convey relevant information, about HAE and other related angioedema, to those in the community.

Advocacy

Enhance our ability to advocate for our members by communicating our mission; lobbying and influencing governments; by educating people; and by promoting awareness of the issues faced daily by those with HAE and other related angioedema.



Association Effectiveness

Goal

Improve our ability to achieve our mission and goals by engaging and empowering our members; developing our Board; training our volunteers; and by collaborating with our stakeholders and partners.

Objectives

- Determine the tools and resources required, through collaboration with our target audience to achieve our mission and goals.
- Garner support from our stakeholders and partners to support mutually beneficial goals and objectives.
- Increase our volunteer numbers to build effective committees.

Key Strategies

- Maintain the website to enable HAE Canada to
 - better inform our target audiences about our current and future activities and to create greater awareness of HAE and other related angioedema;
 - better inform our target audiences about new developments;
 - to better facilitate member interaction; and
 - to provide a secure channel for our Board to receive and discuss confidential information.
- Develop, implement and maintain a comprehensive marketing & communications plan to improve our reach with our target audiences that defines the value propositions for each and ensures all messaging is consistent.
- Continue sending delegations to local, national and international meetings that facilitate information sharing and promotes and helps to facilitate the availability of effective diagnosis and management of HAE and other related angioedema.
- Maximizing the ever-expanding reach of social media (ie Facebook, Instagram, Twitter and LinkedIn) to maintain effective and reliable channels of communication to the target audience.
 - The act of accessing information via social media can be broken down into 4 steps:
 1. Acquisition: The act of accessing information using the Internet
 2. Dissemination: The act of distributing information found through acquisition.
 3. Participation: The act of engaging with the information found through acquisition or dissemination.
 4. Verification: The act of quality-checking the information gathered through acquisition, dissemination, or participation.

Desired Outcomes 2019-2024

- An enhanced online presence (i.e. website and social media) that enables members' access to tools, resources and information they require from HAE Canada and our stakeholders and partners;
- Marketing and communications plans and strategies to:
 - a) increase awareness of HAE and other related angioedema and our mission;
 - b) assist in attracting new strategic partners;
 - c) assist in retaining existing stakeholders and partners; and
 - d) better enable HAE Canada to effectively engage governments at all levels.
 - e) serve the members in both official languages.
 - f) increase membership via promotion of active participation, conversation, and sharing of knowledge.
 - g) track and share successes, recruitment of support and grow for the future
- The identification of new alliances that enhance our ability to realize our mission and goals.

Identified Projects 2019-2024

1. Implement and maintain the Board only secured section
 - Ability to access member lists by sort criteria to ensure access to target groups
 - Connect with the target audience via new platforms. The current Social Media landscape can be broken into three distinct categories: Social Media Sites, Blogs, & Social Media Applications
 - Bilingual content
2. Develop and implement a social media strategy.
3. Create a marketing and communications plan and accompanying implementation strategy.
 - Post success stories to the website with links shared on social media platforms. The concept is to offer the user something that they can engage in, and a need to return.
 - Use forums to create conversation. HAEC could create a list of questions, have a well-known HAE advocate with national appeal answer the question and engage others in a discussion to share knowledge.
 - Recruit and support – Increase traffic on the HAE Canada website to generate interest in potential industry support and funding.
4. Identify local, national and international meetings that HAE Canada should attend.
5. Increase membership on already established volunteer committees (Program Development Committee and other committees as required).

Equipping Patients & Health Care Providers

Goal

Equip patients, caregivers, family members and health care providers with the information, tools and resources needed to ensure that those with HAE and other related angioedema live healthy and productive lives.

Objectives

- Identify, develop and disseminate the tools and resources required to achieve our mission and goals.

Key Strategies

- Organize regional patient updates across Canada.
- Develop and disseminate with our strategic partners, patient focused tools and resources that enable patients to become champions for their own health and well-being.
- Develop and disseminate materials for caregivers that enable them to provide support to those living with HAE and other related angioedema.
- Identify, develop (where possible) and disseminate tools and resources for use by health care providers (i.e. CHAEN --- Canadian Hereditary Angioedema Guidelines) that enable them to provide optimal care for those with HAE and other related angioedema.
- Identify and implement new methods to disseminate information to our target audiences.

Desired Outcomes 2019-2024

- Hold patient updates, either in person or via webcast, and identify the ideal times and locations in each region, enabling those with HAE and other related angioedema and their families to share experiences, exchange information and ask questions of physician and health care experts.
- Tools and resources for patients living with HAE or other angioedema and caregivers that enables them to become champions for their own health and well-being Dissemination of tools and resources for use by health and dental care providers who manage patients with HAE and other related angioedema to assist them to provide core therapeutic services, guided by clear standards driven by best practice (i.e. Canadian Hereditary Angioedema Guidelines).
- Hold an online Patient Summit which will include participation by specialists from various regions.

Identified Projects 2019-2024

1. Advance schedule of “Patient Update” across Canada
 - To include youth specific/focused events. (ie Teddy bear picnics)
2. Develop and disseminate resources designed for caregivers and family members.
3. Ensure that our website contains links to existing resources and ensure our members are made aware of resources that are available,
4. Distribute Canadian Hereditary Angioedema Guidelines developed by CHAEN to identified health care providers who are managing patients with HAE and other angioedema (i.e. Allergists & Immunologists, Internists, Hematologists, Emergency Physicians, Gastroenterologists, Otolaryngologists, Family Physicians and Dentists).
5. Develop and implement a peer mentorship program.
6. Collaborate with HAEi regarding the Child & Youth program activities.
7. Increase social media presence and educate patients on how to engage website and social media.

Building the Community

Goal

Convey relevant information, about HAE and other related angioedema, to those in the community.

Objectives

- Identify, develop and disseminate information required to achieve our mission and goals.

Key Strategies

- Develop and disseminate information needed to ensure that individuals included in the patients' community (e.g. employers, educators, co-workers, etc.) can better understand HAE and other related angioedema and how it affects a patients' health and well-being and ability to participate in activities of daily living.

Desired Outcomes 2019-2024

- Resources to better understand HAE and other related angioedema and how the disorder affects all aspects of the patients' life.

Identified Projects 2019-2024

1. Build a strategic partnership to strengthen community awareness
 - Canadian Association of Emergency Physicians (CAEP)
 - Council of Emergency Medicine Residency Directors
 - Canadian Dental Association.
2. Develop a list of recommendations for patients as it relates to HAE from both the physician and the patient perspective.
3. Include a "Do's" information page on the website
4. Identify, develop and disseminate information, tools and resources to community members that will help to increase awareness about HAE and other related angioedema.
5. Building a document sharing page on the HAE Canada website.

Advocacy

Goal

Enhance our ability to advocate for our members by communicating our mission; lobbying and influencing governments; by educating people; and by promoting awareness of the issues faced daily by those with HAE and other related angioedema.

Objectives

- That patients in Canada have timely access to the most effective treatments of their choice that are consistent with clinical practice guidelines and ensures their health is not negatively affected while waiting for care.
- That government policies, at all levels, support equitable and most effective treatments and enable timely access to new treatments as they become available.
- That Canadian teaching institutions and scientific community to focus their efforts on the development of promising new treatment options for those who have HAE and other related angioedema.
- Produce an effective mechanism to develop strategies and solutions to ensure equitable access to the most effective available treatments and products.
- Create an advocacy planning model that assists in the proactive development of strategies to resolve identified issues.

Key Strategies

- Provide feedback to all levels of government in Canada, on policy and initiatives that may affect the treatment, affordability and access to treatment for those with HAE and other related angioedema.
- Liaise with Canadian teaching institutions and the scientific community, to promote awareness of our mission, create awareness and educate about the disorder and encourage research into HAE and other related angioedema and their treatment, with the hope of someday leading to potential cures.
- Creation of an Advocacy Committee whose mandate is to develop effective strategies and solutions that can be implemented Canada-wide to solve issues associated with equitable and affordable access to available treatments and products.
- Develop and implement a media strategy to publicize our position statements, achievements, and fundraising efforts and helps educate people about HAE and other angioedema.

Desired Outcomes 2019-2024

- Collaborate with other organizations to further develop and then disseminate the Canadian Comprehensive Care Standards for HAE to hospital administrators and nurse educators and government officials at all levels.
- In partnership with other rare diseases groups via CORD (see <http://www.raredisorders.ca/cord-membership/our-members/>), provide timely information to governments about the effect policies can have on the costs and availability of treatments for those who have HAE and other related angioedema.
- Develop a working relationship with Canadian research institutions and their researchers who are doing or may be considering research on HAE and other angioedema.
- An effective Advocacy Committee that develops and helps implement lasting solutions for issues faced by those with HAE and other angioedema.
- An effective media strategy that enables the public to make informed decisions about how they can help those with HAE and other related angioedema.
- An effective well-trained group of volunteers composed of both members and health care professionals, who are able to lead information sessions on HAE Canada and our mission and effectively deliver information on HAE and other related angioedema, at conferences, patient updates, workshops, hospital-in-services and at other public events and meetings.
- Well-developed materials and resources on HAE and other related angioedema, for use by those volunteers who are part of our HAE Canada Speakers Bureau.

Identified Projects 2019-2024

1. Further develop the Advocacy Committee.
2. Develop and implement a media strategy.
3. Create and operationalize a Speakers Bureau. This includes developing materials for use at events (i.e. CAEP, Hospital in services, Conferences, Patient Updates, Workshops, etc.).
4. Identify a celebrity ambassador for HAE Canada

Increased Membership and Associates

Goal

Increase member base.

Objectives

- Develop a membership program that engages members in the activities of the organization.
- Create new opportunities and partnerships with individuals, who may not have HAE or other related angioedema, who have no previous affiliation with HAE Canada.
- Create new opportunities and partnerships with organizations who have no previous affiliation with HAE Canada but wish to help HAE Canada achieve our mission and goals.
- Further develop the Child and Youth Associate program that engages young members in the activities of the organization.

Key Strategies

- Expand the benefits of membership.
- Identify a new Associate category that will include Medical Advisors.
- [Provide Canadian Hereditary Angioedema Network \(CHAEN\) with potential new members for their organization,](#)
- Work with stakeholders and partners to identify those with or who are awaiting a diagnosis of HAE and other related angioedema, who are not currently members.

Desired Outcomes 2019-2024

- In each year of our plan, increase in our overall membership

Identified Projects 2019-2024

1. Redefine member and associate categories,
2. Identify patients who are awaiting diagnosis or who have been diagnosed and are not currently members,
3. Identify individuals who have an interest in our mission and goals who are not currently members,
4. Introduce members to their HAE Canada Regional Directors
5. Develop Child and Youth Program,
6. Encourage HAEC Child and Youth Associates to participate in HAEi's Youth Programs.

Sponsorship and Fund Development

Goal

Maintain current levels of sponsorship and identify and secure new sources of funding to enable HAE Canada to achieve its mission and goals.

Objectives

- Develop relationships with like-minded organizations that help HAE Canada identify and secure new sources of funding.
- Introduce and foster a culture of philanthropy among our membership, board, stakeholders and partners to better enable HAE Canada to achieve our mission and goals.

Key Strategies

- Develop and implement a cause marketing strategy with businesses that have a solid history and strong brand image, who would like to make a financial contribution that is significant to Canadians with HAE and other related angioedema.
- Identify potential funders (governments, agencies, and foundations) who offer grants to non-profit organizations and apply for available funds.
- Develop a fundraising strategy that connects donors to our mission and to the difference HAE Canada can make for those with HAE and other related angioedema.

Desired Outcomes 2019-2024

- Diversification of our funding and increased independence from our valued pharmaceutical sponsors.

Identified Projects 2019-2024

1. Develop and implement a fundraising strategy.
 - Add a “Donate Now” button to the website. Donations will be directed to the appropriate fund location.
2. Determine the feasibility of creating a separate foundation to provide a source of funding for HAE education and research to HAE Canada Inc. or other appropriate organizations.
3. Obtain Charitable Status under Corporation Canada,
4. Identify potential funders that offer grants and apply.
5. Identify potential funds that will offer support for HAE patients.
6. Develop and implement a specific project marketing strategy.
7. Identify a high-profile spokesperson for HAE Canada.

About HAE Canada

HAE Canada is a patient group that was formed in 2010 to work with physicians, nurses and other health care professionals to create a better life for those patients living with HAE and other related angioedema in Canada.

Hereditary angioedema or HAE is a rare, debilitating and potentially life threatening genetic blood disorder resulting from a problem with the protein C1 esterase inhibitor (C1-INH).

Our goal is to assist those with HAE and other related angioedema achieve optimum health and well-being.

The HAE community is small and spread out. Many patients live in towns where access to medical facilities is limited and support for hereditary angioedema is nonexistent.

In fact, since its inception, HAE Canada has identified patients who were unaware that treatment is available.

HAE Canada works to support and to advocate on behalf of all those with HAE and other related angioedema.

“HAE Canada, will represent new hope and vision for Canadian HAE patients.”

“Our approach will be positive, focusing on overcoming adversity, breaking out of confines, and working for and with the next generation, striving for achieving a better quality of life for everyone.”

--- HAE Canada Founder, Della Cogar

Our Pioneers

HAE Canada was officially formed in September 2010. Its roots, however, can be traced back a number of years.

2002 – CHAES (Canadian Hereditary Angioedema Society) the predecessor to HAE Canada was formed through the hard work of Dr. Tom Bowen and Jeanne Burnham, the mother of two children with hereditary angioedema.

2003 – CHAES, with funding from CSL Behring, hosted a conference in Toronto which resulted in two key outcomes for HAE patients:

- An international consensus algorithm for the diagnosis, therapy and management of hereditary angioedema; and
- The formation of the Network of Rare Blood Disorder Organization (NRBDO).

2006 – The NRBDO, led by the Canadian Hemophilia Society (CHS) and with funding from the Public Health Agency of Canada, sponsored a Conference on Comprehensive Care for Rare Blood Disorders. Consensus was reached on the components of comprehensive care for rare blood disorders and that the NRBDO, collectively and its member groups, individually, would work towards the establishment of comprehensive care clinics and the development of national data base registries for rare blood disorders.

2007 – After the dissolution of CHAES, a group of physicians formed the Canadian Hereditary Angioedema Network (CHAEN) in the fall of 2007 with the first meeting held in conjunction with the Canadian Society of Allergy and Clinical Immunology (CSACI) annual meeting.

2010 – In May, CHAEN hosted a meeting in Toronto, where an international consensus was formed on the diagnosis and treatment of hereditary angioedema. Dr. Tom Bowen approached a small group of HAE patients and told them that they needed to form a patient organization. Henrik Boysen, Executive Director for HAE International, offered to assist them to get started and in September a small patient group, led by Della Cogar, was formed under the name HAE Canada.

2011 – Driven from the vision of Dr. Tom Bowen and inspired by the success of Dr. Bruce Ritchie, HAE Canada worked on “Building a Strong Foundation”, the first stage in its five-year strategic plan. With the “Poised for Success” conference held in Winnipeg in November and the launch of the HAE Canada website, the second stage of the strategic plan, “Building HAE Canada’s Community” began.

Definitions and Acronyms

Advocacy	Public support for or recommendation of a particular cause or policy.
Alliances	A union or association formed for mutual benefit, especially between organizations.
Angioedema	The rapid swelling of the deep layers of skin --- the dermis, subcutaneous tissue, mucosa and submucosal tissues.
APIQ	Association des patients immunodéficients du Québec.
Board Development Program	A program designed to help equip Directors with the tools and resources needed to effectively direct HAE Canada.
Canadian Comprehensive Care Standards	The focus of these standards is on the structural and resource requirements necessary for a treatment center to effectively provide care and on its functions and responsibilities.
CBS	Canadian Blood Services
CHAEN	Canadian Hereditary Angioedema Network
CHAES	Canadian Hereditary Angioedema Society
Champion	An individual who fights for a cause that benefits themselves or someone else.
Disseminate	Spread or disperse information widely
Equitable	Dealing fairly and equally with all concerned.
Governance model	The structure and operations used to achieve an organization's goals.
HAE	Hereditary Angioedema
HAEi	Hereditary Angioedema International
Marketing Plan	A marketing plan is a comprehensive blueprint that outlines an organization's overall marketing efforts.
Membership Class	A distinct designation for a group of members with similar characteristics. Each class can have different rights within the organization.
NRBDO	Network of Rare Blood Disorder Organizations
Optimum Health	Best possible or most favorable health possible for each individual.
Philanthropy	The desire to promote the welfare of others, expressed especially by the generous donation of money to good causes.
Policy	A course or principle of action adopted or proposed by a government, party, business, or individual.

Social Media	Websites and applications (e.g. Facebook, Twitter) that enable users to create and share content or to participate in social networking.
Stakeholder	A person with an interest or concern in something, especially a business or organization.
Strategic Plan	A strategic plan is a document used to communicate with the organization the organizations goals, the actions needed to achieve those goals and all of the other critical elements developed during the planning exercise.
Volunteer Development	The process of identifying, recruiting, training and evaluating potential volunteers.

Many thanks to our sponsors:

