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 VISION

A world free from the pain and suffering of inherited bleeding disorders.
MESSAGE FROM THE PRESIDENT AND CO-EXECUTIVE DIRECTORS

The year 2019 truly was a year that saw the CHS come together, from our 7th biennial Rendez-vous symposium to our first ever member engagement campaign. This ability for our entire community – from our health care workers, industry partners, families and friends – to all work together to improve the health and quality of life for people with inherited bleeding disorders is one that makes the CHS stand out from other organizations of our size.

We are often asked how the CHS, as a relatively small organization, has such a strong global and national footprint. And the answer lies not in gatherings or programs, but rather with the behind-the-scenes work of staff and volunteers, especially in advocacy.

What started 66 years ago around a kitchen table with Cecil, Frank, and other parents of children with hemophilia, continues to be our legacy today. From the days of cryoprecipitate to becoming the first country to make a complete transition to recombinant factor VIII, to the tireless work during the tainted blood crisis, we now are advocating for near cures in novel therapies.

While our work has not waned, we have become a smaller, mightier organization. This is a direct reflection of our success, as it is our hope that we, one day, may not be needed because a cure has been found. Despite the progress we have made, there are still people in our community who face significant challenges related to their bleeding disorder. We must continue our work towards cures while focusing on helping those in our community who are most in need. It has been an amazing journey so far, and one that we are honoured to continue.

PAUL WILTON  
HÉLÈNE BOURGAIZE  
DEBORAH FRANZ CURRIE

President  
National Co-Executive Director  
National Co-Executive Director
In 2019, the CHS was assisted by over 300 active volunteers and 20 staff across the country.

Founded in 1953, the Canadian Hemophilia Society (CHS) is a national voluntary health charity. The CHS is affiliated with the World Federation of Hemophilia (WFH), which is officially recognized by the World Health Organization. The CHS works in collaboration with health care specialists in Canada’s 26 bleeding disorder treatment centres, 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.
FOR OVER 65 YEARS, THE CHS HAS BEEN DEDICATED TO HELPING THE ONE IN 100 CANADIANS CARRYING THE GENE OF AN INHERITED BLEEDING DISORDER …

- More than 35,000 of them have symptoms severe enough to require medical care. Yet many have not been properly diagnosed.
- Effective treatment is available for those diagnosed. Left untreated, however, bleeding disorders can be life-threatening.
- Blood products, their recombinant substitutes and other drugs are effective in treating people with bleeding disorders, but they are not a cure … at least not yet!
- The Canadian Hemophilia Society is active in ensuring the safety of the blood supply in Canada through constant vigilance and monitoring for all Canadians.

THE INHERITED BLEEDING DISORDERS ARE:

- HEMOPHILIA A AND B
- VON WILLEBRAND DISEASE
- RARE FACTOR DEFICIENCIES
- PLATELET FUNCTION DISORDERS

To learn more about inherited bleeding disorders, please go to www.hemophilia.ca/bleeding-disorders.
THE CHS PROVIDES
EXCEPTIONAL SERVICES TO
PEOPLE WITH INHERITED
BLEEDING DISORDERS.

The quality of the numerous programs and services offered by the Canadian Hemophilia Society would not be possible without our major partnerships.

Indeed, the CHS joins forces with health care providers at the comprehensive care treatment centres, with generous corporate and individual donors and with volunteers to accomplish its goals in:

- RESEARCH
- CARE AND TREATMENT
- SUPPORT AND EDUCATION
- SAFE AND SECURE BLOOD SUPPLY
RESEARCH

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

There is hope for a cure because of research.

The improvements in health, quality of life and life span of people with inherited bleeding disorders is directly related to the progress achieved in research.

Sixty-six years ago when the Canadian Hemophilia Society was founded, the life expectancy for a person with severe hemophilia in Canada was around 20 years: today, life expectancy is only slightly lower than that for the average Canadian. The arrival of new innovative game-changing therapies means the world for many patients with hemophilia. This is proof that the research, development and marketing of safer and more effective coagulation products are playing a major role in the health and quality of life of people with bleeding disorders.

For nearly 30 years, thanks to the Hemophilia Research Million Dollar Club endowment, generous individual donors, committed corporate sponsors and CHS chapters and regions across the country, the CHS has invested over nine million dollars in research in Canada.

The development of inhibitors to factor VIII or IX products remains the most significant complication of hemophilia treatment. Inhibitors result in factor VIII and IX infusions being ineffective. Inhibitors can be eradicated with immune tolerance induction (ITI) which involves frequent and high doses of factor. In this Canadian cohort study, we aim to describe the burden of inhibitors in our adult patients. With a better understanding of the current state of our inhibitor patients, we will be able to identify both the clinical and research needs of this population. / / /

– Dr. Natalia Rydz, recipient of the CHS/Bayer/ADVANCE Canada research grant
CARE AND TREATMENT

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

The CHS is tireless in its efforts to maintain and improve a network of treatment centres for bleeding disorders serving people in all Canadian provinces. Proper care and treatment for people with inherited bleeding disorders is only possible with the expertise of a multidisciplinary team of health care providers: physicians, nurses, physiotherapists, social workers and other specialists, such as psychologists, dentists and gynaecologists.

It is so nice to be kept informed and abreast of current research taking place in Canada, as well as upcoming, recently funded studies. The clinical case discussions were really awesome!

— A participant at Rendez-vous 2019

IN 2019

- We organized Rendez-vous 2019, providing networking, training and development opportunities to more than 125 members of the health care teams from the 26 bleeding disorder treatment centres across the country. This year’s multidisciplinary Medical and Scientific Symposium, The dawn of a new era, featured a wide range of topics: novel therapies, communication between health care providers and patients, women and bleeding disorders, choosing sports and physical activities, and patient engagement in care decisions.

Eighty (80) other individuals including patients, researchers and staff from across the country also benefited from the Medical and Scientific Symposium presentations, an advocacy workshop, a community engagement workshop, as well as a presentation on amplifying the patient voice in the era of new data.
We provided funding and logistical support for annual and regional meetings of the nursing, physiotherapy and social work groups associated with the 26 bleeding disorder treatment centres across Canada and for health care provider projects. Sixty-one (61) of these health care providers attended meetings in Montreal, in conjunction with Rendez-vous 2019. This support is dedicated to help maintain standards of care and to keep the medical community abreast of state-of-the-art developments in the care and treatment of people with bleeding disorders.

There is so much value in learning about new treatments options and hearing personal stories of patients and their families! It is always helpful when doctors/medical personnel can speak in laymen’s terms.

– A participant at Rendez-vous 2019
SUPPORT AND EDUCATION

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.

One of the CHS’ strengths is its extensive educational catalogue of printed material and videos, which continue to be regularly consulted and commended inside and outside Canadian borders. Life-changing workshops and educational meetings organized by the CHS are also a trademark of the organization.

IN 2019

- A Parents Empowering Parents (PEP) workshop was held in Alberta, increasing the skills and knowledge of parents raising a child with a bleeding disorder, and encouraging peer support among families. In addition, the new PEP 2.0 launched by PEP International, tailored to parents of teenagers, was offered in Saskatoon as a facilitator training session.

- We distributed three issues of our newsmagazine Hemophilia Today to keep the bleeding disorder community well informed. These were the last three issues of the magazine; as of 2020, it will be replaced by an online news platform.

/// When I participated in the PEP workshop, I felt welcomed and comfortable right away with the facilitators and the other participants. Being a single mother, it has sometimes been difficult to manage my two young sons’ hemophilia. It was comforting to relate with other parents who were going through the same challenges as I was. The workshop offered me tools on how to treat and diagnose my sons’ bleeds more efficiently and also tips on how to better communicate with them and the medical staff. ///

– A participant at PEP
We tested a new social media campaign aimed at raising awareness of women and bleeding disorders (WBD). The pilot campaign featured a video and imagery created to reach women, ages 18-54, not currently familiar with the CHS or bleeding disorders. A landing page was created listing common bleeding disorder symptoms in women and showing the next steps for a woman to take if she recognizes the symptoms described in the campaign from her own experiences. Over 180,000 women were reached through Facebook and Instagram, in a three-month period.

The CHS James Kreppner Memorial Scholarship and Bursary Program granted three $5,000 awards: one scholarship based on academic merit and two bursaries based on financial need. The program’s objective is to increase the number of people affected by bleeding disorders pursuing postsecondary education and vocational training.

---

I am grateful for the Canadian Hemophilia Society, which perpetually invokes a fostered sense of community. It is precisely this collaborative and united approach that nurtures research, support, and a sense of unity that will bring us a step closer to finding a cure.

— Michel Khoury, recipient of the James Kreppner academic scholarship
SAFE AND SECURE BLOOD SUPPLY

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

The CHS is the leading patient organization in Canada to independently monitor the safety and supply of blood and blood products within the Canadian blood system.

IN 2019

- We continued to provide the voice of recipients on Canadian Blood Services (CBS), Héma-Québec, health technology assessment and provincial government blood advisory committees in order to ensure all Canadians have access to safe blood products in adequate supply.
- We conducted research into how people with bleeding disorders and their caregivers live with their conditions day to day, how their current treatments are working and what improvements they hope for in the future. This information allowed us to present the patient voice to governments in health technology assessments of new and promising therapies. Our goal is access to the most efficacious coagulation products.
YOUTH, TOMORROW’S LEADERS

Youth are the future of any organization and the CHS is highly conscious of this.

This is why we recognize the value of past experience while making tremendous efforts to bring on the leaders of tomorrow. This is also why we strive to engage young members to join in and participate in the vital growth and development of our community and ultimately ensure the sustainability of the organization.

Learning from a presentation made by the Association française des hémophiles about youth projects in progress on the international scene was really exceptional.

— A participant at the youth workshop

In 2019

- We invited young adults from across Canada to gather together during Rendez-vous 2019 to discuss the creation of a CHS leadership program tailored to the needs of the organization. The meeting included topics such as the budget, the structure of a future program and the division of labour by province.

— A participant at the youth workshop
INTERNATIONAL COMMITMENT

Canada’s role at the international level is essential.

For over 15 years, the CHS, its provincial chapters and Canadian bleeding disorder treatment centres have participated in 20 twinning partnerships, making them leaders in the Twinning Program of the World Federation of Hemophilia (WFH).

By linking emerging and established bleeding disorder organizations and treatment centres, the Twinning Program of the WFH has tremendously improved treatment and care for people with hemophilia around the world and the CHS can be genuinely proud to have contributed to this success.

IN 2019

- The following twinning partnerships continued: a special Youth Pilot twinning partnership between the youth committees of the CHS and Bangladesh (HSB); CHS-Philippines (HAPLOS); Quebec Chapter-Tunisia; and an HTC twinning between Barbados and SickKids and St. Michael’s hospitals in Toronto. The Manitoba Chapter-Mongolia partnership concluded and an assessment visit to Serbia took place from July 14-18; a new partnership was confirmed for 2020.

SOME OF OUR PLANS FOR 2020 ...

- We will embark on a vast reform of our strategic plan. The consultation process with key stakeholders will allow the development of a pan-Canadian strategy, with specific responsibilities and actions defined for all.
- We will continue to provide clinical and research grants to leading Canadian researchers working in the field of bleeding disorders.
- We will continue to keep our community well informed via our online news platform, CHS CONTACT.
- We will hold positions on all important blood system committees, nationally and provincially, so as to advocate for the most stringent blood donor screening criteria and to stay abreast of developments related to a safe supply of blood products for all Canadians.
VOLUNTEERS ... THE HEART AND SOUL OF THE CHS!

Our volunteers, these very special individuals, give an incredible amount of time to contribute to the success of our activities and programs.

Volunteers at our chapters do a great job of reaching out to the bleeding disorder community. They organize local activities, operate children’s summer camps, keep members informed through newsletters and coordinate a variety of fundraising events.

IN 2019

BOARD OF DIRECTORS
Paul Wilton, president
Dianna Cunning, vice-president
Jeff Jerrett, secretary
Doug Carr, treasurer
Bruno-Gil Breton
Brenda Godin
Kathy Lawday
Carmen Nishiyama
Milena Pirnat
Wendy Quinn
Erin Van Dusen (January to May) | Rachel Wright (June to December)
Rick Waines
Kristen Walsh
Emil Wijnker
Cathy Wright

CHAPTER PRESIDENTS
Curtis Brandell
British Columbia
Carmen Nishiyama
Hillary Wapple
Alberta
Wendy Quinn
Saskatchewan
Milena Pirnat
Manitoba
Cameron Peters
Ontario
François Laroche
Quebec
Victoria Ingalls
New Brunswick
Cathy Wright
Prince Edward Island
Erin Van Dusen
Rachel Wright
Nova Scotia
Gordon Stokes
Newfoundland and Labrador
CORPORATE PHILANTHROPY PROGRAM

We would like to thank the following companies for their generous support. Our way of recognizing them for their generosity is through our Corporate Philanthropy Program which acknowledges the cumulative support given to the CHS for core programming needs and program sponsorship.

We would also like to thank numerous additional donors – individuals, corporations, employee fund programs and foundations – who each year express their confidence in us by making substantial supporting donations.

Working together with individuals and the corporate sector in Canada helps the CHS accomplish its mission and vision by extending our reach and reinforcing our messages.
Corporations that make annual gifts of $10,000 or more to the core programs of our organization are recognized as members of the Benefactor’s Club according to their level of support.

THE CANADIAN HEMOPHILIA SOCIETY RECOGNIZES THEIR TREMENDOUS INVESTMENT.

**The Benefactors Club**

**PARTNERSHIPS**

The CHS is fortunate to be surrounded by remarkable partners helping us to fulfill our mission.
- Association of Hemophilia Clinic Directors of Canada (AHCDC)
- Canadian Association of Nurses in Hemophilia Care (CANHC)
- Canadian Physiotherapists in Hemophilia Care (CPHC)
- Canadian Social Workers in Hemophilia Care (CSWHC)
- World Federation of Hemophilia (WFH)

**HealthPartners**

The Canadian Hemophilia Society is proud to be a member of HealthPartners. HealthPartners is a unique collaboration of 16 of Canada’s most trusted national health charities, raising funds exclusively through workplace charitable giving programs. These charities provide services to Canadians in all regions of our country.

Member organizations share two primary goals:
- **RESEARCH** Supporting medical research toward improved treatment and ultimately a cure for debilitating diseases.
- **PROGRAMS** Sponsoring education as well as prevention efforts and services that assist Canadians living with disease.
## Balance Sheet / As at December 31, 2019

<table>
<thead>
<tr>
<th>Assets</th>
<th>2019</th>
<th>2018</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Current assets</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Cash</td>
<td>453,282</td>
<td>525,690</td>
</tr>
<tr>
<td>Term deposits</td>
<td>805,494</td>
<td>999,724</td>
</tr>
<tr>
<td>Investments – Million Dollar Club</td>
<td>136,895</td>
<td>132,594</td>
</tr>
<tr>
<td>Accounts receivable</td>
<td>14,115</td>
<td>10,562</td>
</tr>
<tr>
<td>Provincial chapters</td>
<td>679</td>
<td>7,679</td>
</tr>
<tr>
<td>Other</td>
<td>58,805</td>
<td>61,626</td>
</tr>
<tr>
<td>Prepaid expenses</td>
<td>163,770</td>
<td>212,802</td>
</tr>
<tr>
<td>Lease deposit</td>
<td>4,685</td>
<td>4,685</td>
</tr>
<tr>
<td>Term deposits</td>
<td>805,770</td>
<td>973,064</td>
</tr>
<tr>
<td>Investments – Million Dollar Club</td>
<td>187,563</td>
<td>2,425,402</td>
</tr>
<tr>
<td>Property and equipment</td>
<td>14,115</td>
<td>1,000,000</td>
</tr>
<tr>
<td><strong>Liabilities</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Current liabilities</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Accounts payable and accrued liabilities</td>
<td>124,962</td>
<td>124,962</td>
</tr>
<tr>
<td>Deferred contributions</td>
<td>1,165,284</td>
<td>1,165,284</td>
</tr>
<tr>
<td><strong>Fund Balances</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Unrestricted</strong></td>
<td>196,469</td>
<td>196,469</td>
</tr>
<tr>
<td>Invested in property and equipment</td>
<td>14,115</td>
<td>14,115</td>
</tr>
<tr>
<td>Internally restricted</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Contingencies Fund</td>
<td>1,000,000</td>
<td>1,000,000</td>
</tr>
<tr>
<td>Research Fund – Million Dollar Club</td>
<td>383,111</td>
<td>227,099</td>
</tr>
<tr>
<td>Endowment Fund – Million Dollar Club</td>
<td>175,277</td>
<td>175,277</td>
</tr>
<tr>
<td>Externally restricted</td>
<td>4,046,726</td>
<td>3,838,515</td>
</tr>
</tbody>
</table>

Extract from the audited financial statements prepared by Gosselin & Associés. The complete audited financial statements are available upon request by mail or on the CHS website.
### Statement of Revenue and Expenses / For the year ended December 31, 2019

<table>
<thead>
<tr>
<th>Fund</th>
<th>General Fund</th>
<th>Property and Equipment Fund</th>
<th>Research Fund – Million Dollar Club</th>
<th>TOTAL</th>
<th>TOTAL</th>
</tr>
</thead>
<tbody>
<tr>
<td>2019</td>
<td>$</td>
<td>$</td>
<td>$</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Public support</td>
<td>196,756</td>
<td>-</td>
<td>6,709</td>
<td>203,465</td>
<td>245,802</td>
</tr>
<tr>
<td>Corporate support</td>
<td>1,483,935</td>
<td>75,639</td>
<td>1,559,574</td>
<td>1,534,641</td>
<td>1,761,768</td>
</tr>
<tr>
<td>Investment income</td>
<td>40,975</td>
<td>-</td>
<td>220,587</td>
<td>261,562</td>
<td>(18,675)</td>
</tr>
<tr>
<td><strong>TOTAL</strong></td>
<td>1,721,666</td>
<td>-</td>
<td>302,935</td>
<td>2,024,601</td>
<td>1,761,768</td>
</tr>
</tbody>
</table>

**Revenue**

- Public support
- Corporate support
- Investment income

**Expenses**

- Programs
- Resource development
- Governance
- Administration

**Excess (Deficiency) of revenue over expenses for the year**

- 55,078
- (3,529)
- 156,012
- 207,561
- (122,158)

### Statement of Changes in Fund Balances / For the year ended December 31, 2019

<table>
<thead>
<tr>
<th>Fund</th>
<th>General Fund</th>
<th>Property and Equipment Fund</th>
<th>Contingencies Fund</th>
<th>Research Fund – Million Dollar Club</th>
<th>Endowment Fund – Million Dollar Club</th>
<th>TOTAL</th>
<th>TOTAL</th>
</tr>
</thead>
<tbody>
<tr>
<td>2019</td>
<td>$</td>
<td>$</td>
<td>$</td>
<td>$</td>
<td>$</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Balance – Beginning of year</td>
<td>148,473</td>
<td>10,562</td>
<td>1,000,000</td>
<td>227,099</td>
<td>2,452,381</td>
<td>3,838,515</td>
<td>3,937,453</td>
</tr>
<tr>
<td>Excess (Deficiency) of revenue over expenses</td>
<td>55,078</td>
<td>(3,529)</td>
<td>-</td>
<td>156,012</td>
<td>-</td>
<td>207,561</td>
<td>(122,158)</td>
</tr>
<tr>
<td>Endowment contributions</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>650</td>
<td>-</td>
<td>650</td>
<td>23,220</td>
</tr>
<tr>
<td>Investment in property and equipment</td>
<td>(7,082)</td>
<td>7,082</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td></td>
</tr>
<tr>
<td><strong>Balance – End of year</strong></td>
<td>196,469</td>
<td>14,115</td>
<td>1,000,000</td>
<td>383,111</td>
<td>2,453,031</td>
<td>4,046,726</td>
<td>3,838,515</td>
</tr>
</tbody>
</table>

Extract from the audited financial statements prepared by Gosselin & Associés. The complete audited financial statements are available upon request by mail or on the CHS website.
NATIONAL OFFICE
301-666 Sherbrooke Street West
Montreal, Quebec H3A 1E7
Tel.: 514-848-0503
Toll-free: 1-800-668-2686
chs@hemophilia.ca

PROVINCIAL OFFICES

Manitoba Chapter
Suite 324
120-1400 Ellice Ave.
Winnipeg, Manitoba R3G 0J1
Tel.: 204-775-8625
info@hemophilia.mb.ca

Hemophilia Ontario
300-10 Milner Business Court
Toronto, Ontario M1B 3C6
Tel.: 416-972-0641
Toll-free: 1-888-838-8846
info@hemophilia.on.ca

Quebec Chapter
514-2120 Sherbrooke Street East
Montreal, Quebec H2K 1C3
Tel.: 514-848-0666
Toll-free: 1-877-870-0666
info@schq.org

To contact our seven other provincial chapters, please consult our website at www.hemophilia.ca/provincial-chapters.

NATIONAL STAFF

Hélène Bourgaize
National Co-Executive Director

Deborah Franz Currie
National Co-Executive Director

David Page
National Director of Health Policy

Joyce Argall
National Individual Giving Manager

Stéphane Lemieux
Chief Accountant

Rachel Leslie
National Project Coordinator

Michel Long
National Program Manager

Chantal Raymond
National Communications Manager