The high quality of the many programs and services offered by the Canadian Hemophilia Society (CHS) would not be possible without your support. Indeed, the CHS joins forces with the health care providers at the comprehensive care treatment centres, with generous corporate and individual donors and volunteers to accomplish its goals in:

RESEARCH • CARE AND TREATMENT • SUPPORT AND EDUCATION • SAFE AND SECURE BLOOD SUPPLY
Accountability to our supporters is, and always will be, a priority for the CHS.

In our commitment to be accountable to you, the CHS continues to be accredited by the Imagine Canada Standards Program.

The main objective of the Imagine Canada Standards Program is to increase transparency of charitable organizations in five fundamental areas: board governance, financial accountability and transparency, fundraising, staff management, and volunteer involvement. Its goal is to strengthen public confidence in individual organizations and the sector as a whole.

To maintain its accreditation, the CHS demonstrates compliance with 73 standards. This process gives the CHS the opportunity to update and compare its policies against leading practices, and to provide direction to both the CHS Board of Directors and staff. In addition, the CHS feels it is important to provide its stakeholders with a level of confidence that the organization has a strong framework.

The use of the Standards Program Trustmark signals that an organization demonstrates compliance with each of the Imagine Canada Standards.

2019 CHS Board of Directors

Front row, from left to right: Milena Pirnat, Carmen Nishiyama, Rick Waines and Brenda Godin. Middle row: Wendy Quinn, Kathy Lawday, Kristen Walsh, Bruno-Gil Breton, Cathy Wright and Dianna Cunning. Back row: Emil Wjinker, Jeff Jerrett, Paul Wilton, Doug Carr and Rachel Wright (sitting in for Erin Van Dusen).
Your donation was crucial in providing SUPPORT and EDUCATION

- To increase skills and knowledge of parents raising a child with a bleeding disorder, and to encourage peer support among families with newly diagnosed children, a Parents Empowering Parents (PEP) workshop was held in Alberta. The new PEP 2.0 launched by PEP International, tailored to parents of teenagers, was offered in Saskatoon as a pilot workshop and facilitator training session.

When I participated in the PEP workshop, I felt welcomed and comfortable right away with the facilitators and the other participants. The weekend progressed smoothly in a very relaxed and sharing environment. 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. It is a wonderful workshop which I strongly recommend to all parents and caregivers of children with a bleeding disorder.

- A participant at PEP

- To keep the bleeding disorder community informed, we distributed three issues of our high-quality newsmagazine Hemophilia Today.

The James Kreppner Memorial Scholarship and Bursary Program

- To encourage the pursuit of post-secondary education and vocational training among people affected by bleeding disorders, the CHS James Kreppner Memorial Scholarship and Bursary Program granted three $5,000 awards: one scholarship based on academic merit, two bursaries based on financial need.

Academic scholarship recipient
Michel Khoury
Ottawa, Ontario

Bursary recipient
Alec Mather-Shapiro
Calgary, Alberta

Bursary recipient
Gordon Rhys Watson
Whitehorse, Yukon

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

- Michel Khoury, recipient of the James Kreppner academic scholarship
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.

Detailed descriptions of all the funded research projects are available at [www.hemophilia.ca/research](http://www.hemophilia.ca/research).

The following projects were funded in 2019:

- **Towards finger-prick factor testing to guide dosing**
  
  **Dr. Peter Gross**
  McMaster University – Hamilton, Ontario

- **The hemostatic stress response: Do differences explain phenotypic variability in VWD?**
  
  **Dr. Paula James**
  Queen’s University – Kingston, Ontario

- **The role of platelet procoagulant membrane dynamics in DDAVP mediated mechanisms of coagulation enhancement**
  
  **Dr. Adrienne Lee**
  University of Calgary – Calgary, Alberta
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

Canadian Hemophilia Management in the Perinatal Setting (CHiMPS)

**Dr. Paul Moorehead**
Janeway Children’s Health and Rehabilitation Centre – St-John’s, Newfoundland and Labrador

Assessment of hemostatic abnormalities in children with 22q11.2 deletion syndrome with or without congenital heart disease

**Dr. Margaret Rand**
Hospital for Sick Children – Toronto, Ontario

Adult Canadians with Hemophilia Living with Inhibitors Study (ACHILLES)

**Dr. Natalia Rydz**
University of Calgary – Calgary, Alberta

Bone health in symptomatic carriers of hemophilia A

**Dr. Michelle Sholzberg**
St. Michael’s Hospital – Toronto, Ontario

Indirect costs and consequences of frequent national tenders for coagulation factor concentrates in the era of extended half-life products: Health economics and patient perspectives

**Dr. Haowei (Linda) Sun**
University of Alberta – Edmonton, Alberta

When you support **RESEARCH**, you play a major role in improving the **HEALTH AND QUALITY OF LIFE** of so many
Your donation was crucial in maintaining CARE and TREATMENT.

To provide physicians, other health care providers and patients with the most recent knowledge on care and treatment of inherited bleeding disorders, we hosted *Rendez-vous 2019 – The dawn of a new era*, a multidisciplinary medical and scientific symposium, which included sessions on novel and emerging coagulation therapies, women and bleeding disorders, sports and physical activities and patient engagement in care decisions.

To train key chapter volunteers on how to influence policy decisions related to evidence- and standards-based comprehensive care and implementation of the recommendations made in the treatment centre assessments, as well as access to innovative coagulation products, a workshop on the past, present and future of CHS advocacy was offered during *Rendez-vous 2019*.

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*

- A participant at *Rendez-vous 2019*
Your donation was crucial in ensuring a **SAFE, SECURE BLOOD SUPPLY** for all Canadians

- To ensure all Canadians have access to safe blood products in adequate supply, we continue to provide the voice of recipients on Canadian Blood Services (CBS), Héma-Québec, health technology assessment and provincial government blood advisory committees.

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**Your donation was crucial in supporting our YOUTH**

It was very rewarding to be able to collaborate with others who have the same goal as me and examine different aspects of what type of youth activities we should make for youth at the national and provincial levels and to build a foundation for this CHS youth group.

- A participant at the youth workshop

It was interesting to learn from a presentation made by the Association française des hémophiles about youth projects in progress on the international scene.

- A participant at the youth workshop

- To discuss the creation of a CHS leadership program tailored to the needs of the organization, young adults from across Canada gathered together during *Rendez-vous 2019* to discuss budget issues, the structure of a future program and the division of labour by province.
In 2020, the CHS remains committed to further its mission to improving the health and quality of life of all people in Canada with inherited bleeding disorders and ultimately finding cures.

**Some of our plans for 2020 ...**

- Host the 7th National Inhibitor Weekend to support adults with inhibitors and families whose children live with inhibitors, a serious complication of hemophilia. Families will be offered the opportunity to discuss new treatment options and consult with specialists in the treatment of inhibitors.

- Host **CODErouge 2020** – *the 3rd Canadian conference on bleeding disorders in women* featuring sessions on iron administration, rare bleeding disorders, management of heavy bleeding in adolescents and access to care, among other topics.

- Continue to provide clinical and research grants to leading Canadian researchers working in the field of bleeding disorders.

- 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.

**Your donation made a real difference in the LIVES OF SO MANY PEOPLE**

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