Thanks to you!

Your donation made a real difference in 2014.

► Your DONATION helped…

… the CHS provide valuable SUPPORT and EDUCATION
… maintain proper CARE and TREATMENT across the country
… provide much needed funds for vital RESEARCH
… ensure a SAFE, SECURE BLOOD SUPPLY for all Canadians
… educate YOUTH to become future leaders

Thank you for joining hands with us!
Your donation made a real difference in **SUPPORT** and **EDUCATION**

- To keep the bleeding disorder community informed, we distributed three issues of our highly informative newsmagazine *Hemophilia Today*.

- 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, *Parents Empowering Parents* (PEP) workshops and mini-workshops were delivered, in collaboration with trained PEP leaders, in Nova Scotia, Saskatchewan and British Columbia.

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**CHS JAMES KREPPNER MEMORIAL SCHOLARSHIP AND BURSARY PROGRAM**

- To increase the number of people affected by bleeding disorders pursuing post-secondary education and vocational training, the *CHS James Kreppner Memorial Scholarship and Bursary Program* granted four $5,000 awards: two scholarships based on academic merit, one bursary based on financial need, and one mature student bursary.

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**The James Kreppner bursary will allow me to pursue my studies in the medical field that I love, help people understand and deal with their medical issues but also help me to be more comfortable and confident in taking care of my son’s hemophilia.**

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*– Amy Bullock*

recipient of a CHS James Kreppner Memorial Mature Student Bursary

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**Jae Won Hur**

Regina, Saskatchewan

**Pawanpreet Nijjer**

Surrey, British Columbia

**John Carriere**

Moose Jaw, Saskatchewan

**Amy Bullock**

Kirkland Lake, Ontario

**ACADEMIC SCHOLARSHIP RECIPIENT**

**ACADEMIC SCHOLARSHIP RECIPIENT**

**BURSARY RECIPIENT**

**MATURE STUDENT BURSARY RECIPIENT**
Your donation made a real difference in **CARE** and **TREATMENT**

- To increase awareness about the need to provide proper diagnosis to women with bleeding disorders, the CHS participated in exhibits at four major medical conferences: the *National Emergency Nurses’ Conference*, the *Annual Conference of the Canadian Association of Emergency Physicians*, the *70th Annual Clinical and Scientific Conference of the SOGC* and the *Family Medicine Forum* of the College of Family Physicians of Canada. Overall, the Guidelines for the diagnosis of von Willebrand disease was offered to more than 5,000 health care providers.

- To optimize care for patients treated in the 26 Canadian bleeding disorder treatment centres, the CHS, supported by the Association of Hemophilia Clinic Directors of Canada, completed thorough centre assessments across the country. As part of the process, a patient satisfaction survey was mailed to a random cross-section of patients. Interviews were also conducted with comprehensive care team staff. Individual reports and a national report will be published in 2015.

- To gain valuable training in the care and treatment of people with bleeding disorders, physicians, nurses, physiotherapists and social workers with three years or less experience attended the fourth *CHS New Team Workshop*.

- To increase knowledge on bleeding disorders in women, the CHS launched *A Negative* – a first-of-its-kind awareness initiative targeted at young women ages 16-24. Using the online story sharing platform *Wattpad*, we launched this e-novella about a woman with an undiagnosed bleeding disorder.

  **After only one month, A Negative had reached an audience of 100,000 readers!**

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Thank you so much for all the opportunities for professional development within hemophilia care. It’s incredibly generous and unique and I have loved being a part of it. The weekend was excellent, from the people to the multidisciplinary aspect and the case studies. I’ll take home all I’ve learned and apply it to my physio practice as well as my interactions with patients and other health care providers.

– Erin  
* a physiotherapist attending the New Team Workshop.
Breaking ground with RESEARCH

Thanks to the funding I received from the Canadian Hemophilia Society, Canada’s leading charity funding bleeding disorder research, my study will look at why platelets don’t work normally in some families with bleeding problems. Our goal is to find the causes of very common platelet problems.

- Dr. Catherine Hayward

The improvements in health, quality of life and life span of people with inherited bleeding disorders are directly related to the progress achieved in research. The fact is, 60 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 slightly lower than that for the average Canadian. The research, development and marketing of safer and more effective coagulation products have played a major role in this increase.

- How is quality of life impacted by vocational experiences and opportunities among males (≥16) with moderate and severe hemophilia throughout the lifecycle?

Claude Bartholomew, RSW
ST-Paul’s Hospital – Vancouver, British Columbia
This research seeks to answer the above question using questionnaires and focus groups with people with hemophilia in centres in four provinces: British Columbia, Manitoba, Ontario and Saskatchewan.

- Characterization of common inherited platelet function disorders

Dr. Catherine Hayward
McMaster University – Hamilton, Ontario
This research will involve testing of samples from people in families with increased bleeding due to platelet disorders. The goals are to better understand what causes these disorders, develop better tests and improve patient care.

- Understanding angiodysplasia in von Willebrand disease: Studies using BOEC (Blood Outgrowth Endothelial Cells)

Dr. Paula James
Queen’s University – Kingston, Ontario
This study aims to better understand the causes of angiodysplasia, small vascular malformations like varicose veins on the inside of the bowel, a common cause of gastro-intestinal bleeding in von Willebrand disease. It will also study the available treatments including concentrates of von Willebrand factor, estrogen, thalidomide and atorvastatin.

- Incorporation of rFVIII into platelets as a potential therapy in patients with inhibitory antibodies to factor VIII

Dr. Walter Kahr
The Hospital for Sick Children – Toronto, Ontario
The goal of the project is to improve methods for making rFVIII-loaded platelets and to demonstrate their potential for use in hemophilia patients with inhibitors. The rFVIII in these platelets would be longer lasting and limit the effects of inhibitors.
Mechanisms associated with hyper-responsive platelet GPIbα cause alterations in platelet activation and function leading to a bleeding phenotype

Dr. Harmanpreet Kaur  
QUEEN’S UNIVERSITY – Kingston, Ontario
This research will look at various aspects of platelet activation and clot formation using a mouse model for platelet-type von Willebrand disease (PT-VWD). It will also study the effect on bleeding of inhibiting hyper response GPIbα, a protein present on the membrane of platelets. This study seeks to better understand this rare disease and to develop strategies to treat bleeding in PT-VWD patients.

HR-pQCT: a novel imaging technology detects microarchitectural skeletal pathology in hemophilia patients

Dr. Adrienne Lee  
UNIVERSITY OF CALGARY – Calgary, Alberta
Several studies have shown that people with hemophilia develop osteoporosis at an early age. The goal of this project is to utilize new imaging technology called HR-pQCT (high resolution peripheral quantitative computed tomography) to visualize the bone structure in 3D so as to identify individuals at higher risk of bone fracture.

Implementation, utilization and effectiveness of an electronic application developed specifically for young men with mild hemophilia

JoAnn Nilson, PT  
UNIVERSITY OF SASKATCHEWAN – Saskatoon, Saskatchewan
This study will spread the use of a SmartPhone App, called HIRT? throughout Canada and test its effectiveness over a period of 12 months in helping young men with mild hemophilia better assess musculoskeletal injuries. The goal is to contribute to earlier treatment decisions by these young men and better communication with the health care workers.

After 12 months of individualized treatment plans, what is the long-term impact on physical activity and quality of life in a single treatment centre?

Sandra Squire, BScPT  
ST-PAUL’S HOSPITAL – Vancouver, British Columbia
This research will look at the long term impact on patients of an individualized prophylaxis plan, developed based on motivational interviewing philosophy. Over the 12 months, the study will measure how physical activity, quality of life and bleeds/infusions are influenced by the individualized plan.

Living with and managing hemophilia from diagnosis and through key care transitions: The journey for families of children with hemophilia

Dr. Roberta Woodgate  
UNIVERSITY OF MANITOBA – Winnipeg, Manitoba
This study will improve understanding of the experiences and needs of families of children with hemophilia. Children and their parents play an active role in defining issues, considering solutions and identifying priorities. Results will inform and improve existing services and programs.
Advocating for a **SAFE, SECURE BLOOD SUPPLY** for all Canadians

To remember and pay tribute to those who suffered and lost their lives as a result of the tainted blood tragedy and to emphasize the importance of maintaining a safe and secure blood supply, commemorative ceremonies were held across the country. One such event was organized by Faye Katzman (who serves on the Canadian Hemophilia Society’s HIV-Hepatitis Committee) at the Saskatchewan branch of Canadian Blood Services. “I believe so many decisions that were made in the ‘80s had to do with cutting costs and, as a result, safety was compromised”, Katzman said. “As a mother of a child with hemophilia, I’m always encouraged when I hear that Canada now has one of the safest blood systems in the world.”

In Woodbridge, Ontario, stones were placed around a dedicated tree, and attendees were invited to write a name on the stones to remember, honour, and celebrate loved ones.

- To ensure all Canadians have access to safe blood products in adequate supply, we continue to provide the voice of recipients on Health Canada, Canadian Blood Services, Héma-Québec and provincial government blood advisory committees.
Your donation made a real difference for our YOUTH

- To provide youth with tips to improve their communication skills, make them aware of the reality of people living with a bleeding disorder in emerging countries, take ownership of their own bleeding disorder and make smart choices when choosing a sport, the 2014 CHS Youth Workshop was held bringing together youth from across the country.

Finding out who I was as a person, through the personality assessment, was one of the highlights of my weekend. It also made me realize that there are many other types of personalities and that I should take this into consideration when communicating with others.

– A 19-year-old who attended the 2014 CHS Youth Workshop
With your help, our **MISSION** continues…

In 2015, the CHS remains committed to furthering its mission to improve the health and quality of life of all people with inherited bleeding disorders and ultimately to find a cure.

Some of our plans for **2015**…

- Host a medical and scientific symposium, as part of the biennial CHS *Rendez-vous*.

- Intensify awareness among obstetricians and gynaecologists by participating as an exhibitor at the 71st *Annual Clinical and Scientific Conference of the Society of Obstetricians and Gynaecologists of Canada*.

- Deliver the *Parents Empowering Parents* (PEP) program in Ontario, Atlantic Canada and British Columbia.

- Organize a workshop that will help youth to better understand the governance, strategic directions and operations of the organization.

- Develop two applications for computer and mobile devices to help both physicians and patients evaluate bleeding assessment scores.

- Continue to hold positions on all important blood system committees, nationally and provincially, so as to advocate for the most stringent blood donor screening criteria.

Thanks to you!

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