Thanks to the CHS and the comprehensive health care team who encouraged us to participate in a clinical research trial on preventive treatment when our son William was only one year old, we were able to play an active role in improving the quality of life, not only of our son, but also of other children and their families." – PAUL AND LUCY, WILLIAM’S PARENTS

As a preteen, it was overwhelming to see my mother suffering with her periods because I did not want to suffer like her. I was terrified. Since then, my mother taught me that we must share our experiences, give our opinions and help each other. It is high time to break the silence; menorrhagia should not prevent us from living our lives fully. I know that, with the support of a multidisciplinary team of medical experts and a network like that offered by the Canadian Hemophilia Society, solutions are possible. The creation of a national CHS program devoted exclusively to bleeding disorders in women is a big step in the right direction." – EMILY

"I was part of a focus group on ageing at Rendez-vous 2011 and it was such a positive experience to spend the day with a group of people who shared the same issues of chronic pain and illness as I. Some voiced: "We are the survivors of what is past! We are the pioneers of where we came from and where we’re going! We are strong in confidence earned from what we have overcome. We are committed to meeting the challenges of ageing that lie before us." The feeling within the group is that we have started a valuable process of discovery that will lead to the development of resources and programs of utmost importance to meet the needs of our ageing population." – MARK
Just like William, children with hemophilia rely on research to improve their quality of life. It is also true for women, like Emily, suffering from heavy menstrual bleeding due to an inherited bleeding disorder and for men with hemophilia, like Mark, facing new challenges brought on by ageing. They can all count on the relentless work of researchers to reach new heights in treatment as well as a better understanding of all inherited bleeding disorders.

I am very optimistic that the results of my research will show that new functional MRI techniques are able to diagnose early joint changes at a time when treatment is still able to avoid joint damage.

– Dr. Andrea Doria

I am confident that the knowledge gained through our project will be transferable across chronic conditions affecting adolescents. For youth with hemophilia, it will provide ongoing education and support through transition of care and beyond, using the Internet, a medium ideally suited for the delivery of health care to youth.

– Dr. Jennifer Stinson

By supporting RESEARCH, you have the power to help us reach new heights.
| Your donation made a real difference in SUPPORT and EDUCATION |

The PEP (Parents Empowering Parents) workshop I attended gave me great suggestions about home infusion. For example, using a glove on the holding hand to minimize slipping and taping the needle once it’s in the vein.

– Parent who attended one of the two regional PEP workshops held across Canada in 2011

One of the main things I took away from this weekend is to be proactive and totally responsible for my health at all times. I also understood that I have a very strong health care team to back me up at every turn.

– A participant at the Atlantic Rare Bleeding Disorder workshop

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

- To increase knowledge, networking and peer support among people who suffer from rare inherited bleeding disorders, two Rare Bleeding Disorders Through the Lifespan regional workshops were held.

- To increase the understanding about the impact of ageing on people affected by an inherited bleeding disorder, the topic of ageing was addressed at Rendez-vous 2011 during the CHS Medical and Scientific Symposium and through a focus group. Also, a new column on ageing, The Sage Page, now appears in Hemophilia Today and a Partners in Care card was developed for use with other specialists such as dentists and general practitioners.

- To increase awareness and knowledge among women and health care providers about symptoms, diagnosis and treatment of bleeding disorders such as von Willebrand disease, we developed a targeted outreach program entitled CODErouge: When women bleed too much.
Your donation made a real difference in CARE and TREATMENT

- To provide physicians, other health care providers and patients with the most recent knowledge on the care and treatment of inherited bleeding disorders, we hosted Rendez-vous 2011 – New Challenges, a medical and scientific symposium which included key sessions on rare inherited bleeding disorders, mild hemophilia and ageing.

- To increase awareness and knowledge among family physicians and gynaecologists about symptoms, diagnosis and treatment of von Willebrand disease (VWD), we participated as exhibitors at the Primary Care Conference in Toronto and the Family Medicine Forum in Montreal targeting 4,000 family physicians.

- To maintain standards of care across the country and to keep the medical community abreast of state-of-the-art developments in the care and treatment of people with bleeding disorders, we supported annual meetings of the physiotherapists, nurses and social workers associated with the 25 bleeding disorder treatment centres across Canada.

Your donation made a real difference for our YOUTH

- To provide young adults with a bleeding disorder stimulating opportunities to increase their knowledge about bleeding disorders and take greater control of their own bleeds, as well as learning to be the safest drivers possible, the second Drive Your Car/Drive Your Care workshop was held in Calgary during Rendez-vous 2011.

One of the highlights of Rendez-vous 2011 – New Challenges was the panel discussion where families and individuals related personal experiences and shared their stories. With all eyes on the panel, wiping away silent tears, we all realized why we work so hard at this job and walk away with more skills to confront the new challenges.

– A nurse in hemophilia care

This was the first time I attended a CHS conference and I am very thankful I had the opportunity to do so. The entire weekend was full of very informative sessions. My knowledge of the different types of bleeding disorders and their management has increased immensely from this experience. The Drive Your Car/Drive Your Care session centred on car/driving safety and pain management. This session was very helpful in identifying different types of pain and different approaches for treating it.

– CARRIE FLEET, New Brunswick
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 took place on October 15, when members of the Toronto and Central Ontario Region volunteered to plant trees at a public planting in Heathercrest. A private ceremony followed with a moving speech by Antonia “Smudge” Swann, widow of James Kreppner, a victim of this terrible tragedy. The trees planted at the park were a symbol of the strength and resilience of the inherited bleeding disorder community. The occasion allowed for reflection and a sense of inner peace while bringing together long-time members for a chance to reconnect.

To contribute to a safe blood system for all Canadians, we continued our vigilance as the “watchdog” of the blood system and published the 2008-2010 Report Card on Canada’s Blood System. This is the fifth report card to be released since the reform of the blood system in 1998 following the Krever Commission. For the complete report, please visit our Web site at www.hemophilia.ca/en/safe--secure-blood-supply.
With your help OUR MISSION continues

In 2012, 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.

Thanks to you, our work continues so that one day we will achieve our vision of a world free from the pain and suffering of inherited bleeding disorders.

Some of our plans for 2012...

▪ To increase the level of knowledge and understanding of women and health care professionals about symptoms, diagnosis and treatment of bleeding disorders such as von Willebrand disease, we will be hosting CODE rouge 2012 - the 1st Canadian Conference on Bleeding Disorders in Women.

▪ To increase skills and knowledge of parents raising a child with a bleeding disorder, we will deliver, in collaboration with trained PEP leaders, the Parents Empowering Parents (PEP) program in two more regions across Canada.

▪ To enhance our Passport to well-being program aimed at empowering people with bleeding disorders, a new module on patient rights and responsibilities will be developed.

▪ To provide support to people with bleeding disorders as they age, we will develop an online toolkit and pilot an interactive workshop.

▪ To support families whose children live with inhibitors, a serious complication of hemophilia, we will host the 5th National Family Inhibitor Weekend.

▪ To increase knowledge about bleeding disorders and develop the abilities of our youth to become advocates for their own care, we will host an advocacy workshop for youth.

▪ To ensure the safest blood products for all Canadians, we will continue to advocate for the most stringent blood donor screening criteria as well as serve on all important blood safety committees, provincially and nationally.