



MEDIA RELEASE

APRIL 17 IS WORLD HEMOPHILIA DAY BE INSPIRED, GET INVOLVED!

MONTREAL – April 15, 2011 – Over the next few days, the Canadian Hemophilia Society (CHS), its provincial chapters along with the World Federation of Hemophilia (WFH) and its 117 other national organizations will mark World Hemophilia Day in Canada and around the world.

What is World Hemophilia Day? It is a day to get out and let the population know about inherited bleeding disorders such as hemophilia and von Willebrand disease (the most common bleeding disorder in Canada and in the world); to talk about the symptoms of bleeding disorders so that undiagnosed people may take the first steps to access the care that will forever change their lives; to highlight the great work that is being accomplished by hundreds of volunteers; and to honour those who work so diligently to improve the quality of life of all people with inherited bleeding disorders.

It is also a day to share. To share stories of living with or treating a bleeding disorder and to show commitment to achieving the WFH vision of treatment for all. World Hemophilia Day is therefore a day to think about those who are not as fortunate to have access to the care and treatment they need to live a long, healthy life. It is a day to take action by supporting positive change for people with bleeding disorders and encouraging others to do the same... to inspire them.

“Fifty years ago, people with hemophilia in Canada suffered significant pain, endured significant joint damage and often died before the age of twenty,” said CHS President, Craig Upshaw. “Today, children who receive treatment are growing up to lead full, productive lives due to the advances in treatment and comprehensive care.”

One in 100 Canadians carry an inherited bleeding disorder gene, and more than 35,000 of them have symptoms severe enough to require medical care. There are not yet cures for inherited bleeding disorders but effective treatments are available for those diagnosed. Left undiagnosed and untreated, however, bleeding disorders are life-threatening.

“When I was born with hemophilia, treatment didn’t exist. My parents were told that it was doubtful that I would live into adulthood,” said Mark Skinner, WFH president. “Today, someone born with hemophilia can lead a relatively normal life if they have access to proper treatment. Access to treatment is perhaps the biggest challenge facing the majority of people with hemophilia throughout the world. Only 25 per cent of those living with hemophilia are receiving adequate care. The WFH’s vision is that one day treatment for all people with bleeding disorders will be available.”

Around April 17, a great number of awareness activities will take place in Canada. Events will be held in schools and in public places in every Canadian province.

To mark World Hemophilia Day, staff from the CHS along with volunteers from its Quebec Chapter and staff from the WFH, whose head offices are all located in Montreal, will unite forces once again. This year, on April 18, they will join Héma-Québec and Montreal's Collège de Maisonneuve in its annual blood drive to raise awareness about bleeding disorders and to personally thank the donors who will so generously make the gift of life.

World Hemophilia Day is a day when the entire bleeding disorder community around the world can inspire others by its courage, its tenacity and its commitment.

ABOUT THE CANADIAN HEMOPHILIA SOCIETY (CHS)

Founded in 1953, the Canadian Hemophilia Society (CHS) is a national voluntary health charity. It is committed to improve the health and quality of life of all people with inherited bleeding disorders and ultimately to find a cure. Its vision is a world free from the pain and suffering of inherited bleeding disorders.

ABOUT THE WORLD FEDERATION OF HEMOPHILIA (WFH)

The WFH is an international not-for-profit organization dedicated to improving the lives of people with hemophilia and other inherited bleeding disorders. Established in 1963, it is a global network of patient organizations in 118 countries and has official recognition from the World Health Organization.

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