



FOR IMMEDIATE RELEASE

**REACHING OUT TO THE UNDIAGNOSED ON
WORLD HEMOPHILIA DAY**

MONTREAL – April 16, 2009 – Tomorrow, April 17, the Canadian Hemophilia Society (CHS), its provincial chapters along with the World Federation of Hemophilia (WFH) and over 110 other national organizations will mark World Hemophilia Day in Canada and around the world.

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. Unfortunately, a great number of them have not yet been diagnosed, particularly those affected with the most common bleeding disorder in Canada and in the world, von Willebrand disease. This bleeding disorder affects men, women and children. A woman's quality of life, however, can be more seriously affected; heavy menstrual bleeding can even lead to unnecessary hysterectomies if the woman has not been properly diagnosed! "Stories of young Canadian girls who went through such an invasive, life-changing surgery as young as 12 or 13 years of age are not rare," says CHS President, Pam Wilton.

There are no cures for inherited bleeding disorders but effective treatments are available for those diagnosed. Left untreated, however, bleeding disorders can be life-threatening.

This year, the 20th anniversary of the celebration of World Hemophilia Day, the international theme is *Together, we care*, which emphasizes the importance of including a multidisciplinary team, otherwise known as comprehensive care, in the delivery of healthcare to people with bleeding disorders.

"Comprehensive care is fundamental to improving our health and our lives," noted Mark Skinner, WFH president. "However, it may not exist in developing countries and it may be threatened in developed countries by government budget cuts and other measures. Our challenge is to ensure that all people with bleeding disorders, no matter where they live, receive proper treatment and care."

On April 17, a record number of awareness activities will take place in Canada. Events will be held in schools in Alberta, Saskatchewan, Ontario, Quebec, Nova Scotia and Newfoundland and Labrador; and in public places in every Canadian province.

Moreover, a special focus in 2009 is the 30th anniversary of the opening of hemophilia treatment centres in Alberta and Quebec. This year also sees the Quebec Chapter (CHSQ) celebrate 50 years of commitment to serving its members. Continuing a 10-year tradition, representatives from this chapter will be present next Tuesday, April 21, at the National Assembly. A motion

without prior notice will be pronounced by the Minister of Health and Social Services to highlight World Hemophilia Day and an awareness table will be set up in the hall of the Parliament Building.

Finally, for the second consecutive year, the CHSQ, the CHS and the WFH, whose head offices are all located in Montreal, will join forces to host an awareness day at Montreal's renowned Place Ville-Marie.

It's one thing to suffer because nothing can be done. It's entirely another to suffer with an inherited bleeding disorder because of a lack of awareness. That's tragic. That's why the WFH and the CHS are so committed to increasing awareness and informing people about the symptoms and treatment of bleeding disorders.

The goal of World Hemophilia Day is to reach out to people potentially suffering from a bleeding disorder to educate them on the benefits of early diagnosis and how to better treat and manage these disorders.

About the Canadian Hemophilia Society (CHS)

Founded in 1953, the Canadian Hemophilia Society (CHS) is a national voluntary health charity. Its mission is to strive to improve the health and quality of life for all people with inherited bleeding disorders, and 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 related bleeding disorders. Established in 1963, it is a global network of patient organizations in more than 110 countries and has official recognition from the World Health Organization.

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