



PRESS RELEASE

Majority of people with bleeding disorders globally do not have access to adequate treatment

(Montreal, April 13, 2011): While treatment for people with hemophilia and other inherited bleeding disorders has improved drastically over the past 40 years, approximately 75 per cent of people with these disorders, mostly in developing countries, still lack access to adequate treatment. Left untreated, bleeding disorders can lead to severe pain and disability and even death. The World Federation of Hemophilia (WFH) is organizing a global campaign to raise awareness of bleeding disorders and the struggle for adequate care on April 17, World Hemophilia Day.

“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, President of the WFH. “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.”

The World Hemophilia Day 2011 theme “Be Inspired, Get Involved in Treatment for All” celebrates supporting positive change for people with inherited bleeding disorders and encourages others to do the same. In honour of all of the dedicated people who make up the bleeding disorders community and to encourage Treatment for All, the WFH has been posting profiles of inspirational individuals in the bleeding disorders community, from a documentary filmmaker to a former Olympic athlete, on its website. Individuals are encouraged to become a fan of the WFH Facebook page and send their friends messages on April 17 to help spread awareness about the need for Treatment for All.

World Hemophilia Day is supported with funding from Baxter, Bayer, Biogen Idec Hemophilia, Inspiration Biopharmaceuticals and Novo Nordisk.

About hemophilia and other inherited bleeding disorders

Hemophilia, von Willebrand disease and other factor deficiencies are lifelong bleeding disorders that prevent blood from clotting properly. People with these bleeding disorders either do not have enough of a particular clotting factor, a protein in blood that controls bleeding, or it does not work properly. The severity of a person’s bleeding disorder usually depends on the amount of clotting factor that is missing or not working. People with hemophilia can experience uncontrolled internal bleeding. Bleeding into

joints and muscles causes severe pain and disability; bleeding into major organs, such as the brain, can cause death.

About the World Federation of Hemophilia (WFH)

The World Federation of Hemophilia (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. Visit WFH online at www.wfh.org.

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