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CANADIAN AND GLOBAL BLEEDING DISORDERS COMMUNITIES MARK HISTORICAL ANNIVERSARIES ON WORLD HEMOPHILIA DAY

(Montreal, April 11, 2013): The Canadian and global bleeding disorders communities will come together on April 17 to mark World Hemophilia Day. Making the event even more special this year is that the Canadian Hemophilia Society (CHS) is marking its 60th anniversary and the World Federation of Hemophilia (WFH) its 50th.

Both organizations were founded in Montreal by Frank Schnabel, a Canadian businessman with hemophilia. With the establishment of these organizations, Schnabel's vision was to provide support to those with hemophilia in Canada and then around the world.

Leading up to World Hemophilia Day, the WFH will host its 2nd Global Research Forum to take place in Montreal, on April 15-16, 2013. This meeting provides a unique opportunity for discussion and debate of critical issues arising at a time when new treatment products and gene therapy provide great hope for improved care and even a cure. Many of the world's top experts in bleeding disorders will come together in Montreal.

While tremendous progress in care and treatment has been made over the past 50 years, in Canada and many other parts of the world, the stark reality remains that 75 per cent of people with hemophilia, von Willebrand disease, and other inherited bleeding disorders still receive very inadequate treatment or no treatment at all.

"Our hope is that the kinds of breakthroughs in research that will be discussed at the Forum will lead not only to better care, but also to more accessible care, for people around the world," said Craig Upshaw, CHS president.

World Hemophilia Day provides an opportunity for the global bleeding disorders community to raise awareness about where we have been, where we want to go, and how together, we can close the gap in care.

"One of the greatest benefits of participating in World Hemophilia Day is the recognition that our community is more powerful when we work together," said Alain Weill, WFH president. "People from around the world will mark this day and raise awareness about the need to achieve *Treatment for All*."

In Toronto, the CN Tower, Canada's tallest freestanding structure, will light up in red to mark World Hemophilia Day on April 17. A standard light show will run for eight minutes at the top of every hour, after which the CN Tower will glow in red. Other communities throughout Canada and the world will participate in World Hemophilia Day activities to help raise awareness about inherited bleeding disorders.

The WFH has also launched a social media campaign for World Hemophilia Day, featuring what members of the global bleeding disorders community hope to see occur over the next 50 years. These messages can be seen or read on the WFH Facebook page at www.facebook.com/wfhemophilia.

About hemophilia and other bleeding disorders

Hemophilia, von Willebrand disease, inherited platelet disorders, and other rare factor deficiencies are lifelong conditions that prevent blood from clotting properly. People with bleeding disorders do not have enough of particular clotting factors, proteins in blood that control bleeding, or platelets, or these substances do not work properly. For example, people with hemophilia can experience uncontrolled internal bleeding that can result from a seemingly minor injury. Bleeding into joints and muscles causes severe pain and disability, while bleeding into major organs, such as the brain, can cause death.

About the World Federation of Hemophilia

For 50 years, the World Federation of Hemophilia (WFH), an international not-for-profit organization, has worked to improve the lives of people with hemophilia and other inherited bleeding disorders. Established in 1963, it is a global network of patient organizations in 122 countries and has official recognition from the World Health Organization. Visit WFH online at www.wfh.org.

About the Canadian Hemophilia Society

The Canadian Hemophilia Society (CHS) is a national voluntary health charity. Since 1953 it has been 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. Visit the CHS online at www.hemophilia.ca.

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