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## **Addressing the underserved populations in our global family XXIX International Congress of the WFH**

**(Buenos Aires, July 11, 2010):** The sessions of the XXIX International Congress of the World Federation of Hemophilia (WFH) opened with the WFH president's plenary, focusing on our global family. In particular, Mark Skinner, WFH president, addressed the needs of the underserved populations in the global bleeding disorders community.

"Women and men, young and old, and those in developing and developed countries are all important members of our global family, regardless of where they might live in the world," said Skinner. The WFH's mission to improve and sustain care "goes beyond hemophilia to incorporate advocacy and support for all people with inherited bleeding disorders."

Remarkable progress and success in diagnosis and care has been achieved in many areas to date, but much work remains to be carried out particularly for women with bleeding disorders, patients and families in sub-Saharan Africa, and children and youth.

Women with bleeding disorders, including von Willebrand disease (VWD), rare factor deficiencies, inherited platelet disorders, and carriers of hemophilia, often have no idea their symptoms are abnormal even though they have a significant impact on their quality of life. Lack of awareness among caregivers often delays proper diagnosis and treatment when they do seek help.

In 2003, the U.S. Centers for Disease Control and Prevention found that women with VWD wait an average of 16 years from onset of symptoms to diagnosis. Yet some estimates place the incidence of VWD as high as 1.3% of the population. “The number of women reported with bleeding disorders is growing rapidly in some developed countries,” said Skinner. “The next step is developing innovative tools and strategies that can be adapted globally to accelerate the identification and treatment of women with bleeding disorders.”

With only 15 of 53 African countries as WFH national member organizations, it is the most underrepresented geographic area within the WFH. This year, the WFH expects to welcome Ethiopia, Ghana, and Tanzania as accredited members (along with Bolivia and Suriname). However, there is more to be done to deliver diagnosis, training, and capacity-building through three regional centres in sub-Saharan Africa – Kenya in the east, Senegal in the west, and South Africa in the south.

“Integral to the approach to achieving Treatment for All is building a core centre of expertise within each African region to serve as a hub for further regional development, as well as regional role models,” said Skinner. Regional training workshops and the WFH’s twinning program, for example, maximize opportunities for practical learning and achieving sustainable care.

“An analysis of data collected since the introduction of the WFH Global Alliance for Progress (GAP) in 2002 demonstrates improvement in the mortality of patients with hemophilia,” said Skinner. “These improvements can be achieved even in countries with lower levels of economic development or limited access to clotting factor concentrates.”

WFH programs have played an important role in improving care delivery during this period. Education and psychosocial support of patients and families, better organization of care, and training of multidisciplinary health teams can reduce mortality, independent of the availability of clotting factor.

Securing youth involvement was also key focus during this plenary. Recent steps were described on how the WFH is integrating youth into the work of the organization, and to expand its youth programs to ensure that a future generation is ready to assume the mantle of leadership.

#### **About hemophilia and other bleeding disorders**

Hemophilia, von Willebrand disease, and other factor deficiencies are lifelong bleeding disorders that prevent blood from clotting properly. People with bleeding disorders 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 that can result from a seemingly minor injury. 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 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 113 countries and has official recognition from the World Health Organization. Visit WFH online at [www.wfh.org](http://www.wfh.org).