PRESS RELEASE

WFH president challenges current models of care to meet global disparities and improve quality of life for people with bleeding disorders

(Paris, France, July 9, 2012): Speaking at the opening session of the World Federation of Hemophilia’s 2012 World Congress today, president Mark W. Skinner called for a rethinking of current practices and models for treating hemophilia and related bleeding disorders, which affect one in 1000 people worldwide.

Treatment has come a long way since 1963, when the World Federation of Hemophilia (WFH) was founded, he said. “We are on the cusp of a new revolution in treatment,” with breakthroughs on all fronts over the next few years, ranging from biosimilars, longer lasting products, and the real prospect of a cure through gene therapy.

Skinner said that now is the time to rethink current definitions of optimal care and he challenged current thinking on minimum desirable clotting factor levels, which is currently 1 per cent, suggesting that we should incrementally increase levels to 3, 5, and perhaps ultimately 15 times higher to fully prevent bleeding and joint damage from occurring.

“Today, patients and clinicians have been conditioned to accept converting a patient from a severe to a moderate state as the desired end-point of regular replacement therapy.” This standard is based on what was achievable given product supply constraints, economics, and product half-life limitations. “Improving patient quality of life should drive treatment decisions, not economics or supply constraints,” he concluded.

Making optimal treatment affordable was the next hurdle Skinner addressed. He encouraged manufacturers to adopt a new 21st century business model based on high volume and lower margins. He also challenged government, payers, and manufacturers to “rise to the challenge by improving market accessibility and adopting market-based business solutions to achieve it.”

Skinner noted that challenges in economically less developed countries are even greater, due to the high cost of products. Using WFH data collected over the last 10 years, he showed that patients in poorer countries are far less likely to be diagnosed, treated, or survive into adulthood.

Through WFH healthcare development programs, improvements in care can and have been achieved in such countries. Skinner announced that the WFH has achieved its goal of identifying 50,000 new patients with hemophilia through the Global Alliance of Progress (GAP), a 10-year healthcare development program launched in 2003.

To mark the WFH’s 50th anniversary in 2013, Skinner announced that the WFH will launch a new decade of GAP, to identify 50,000 new patients with bleeding disorders by 2022, with 50 per cent of those in impoverished or underserved countries. The WFH will also launch a new program, the Cornerstone Initiative, to work in the poorest countries to improve basic aspects of care and lay the cornerstone for the development of care.
About hemophilia and other bleeding disorders
Hemophilia, von Willebrand disease, inherited platelet disorders, 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 else 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 functioning. 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 over 120 countries and has official recognition from the World Health Organization. Visit WFH online at www.wfh.org.

For more information please contact:

World Federation of Hemophilia
Sarah Ford
+1 514 726 2830
sford@wfh.org
www.wfh.org