

An “energizing experience” for the new president of the World Federation of Hemophilia

January 15, 2005: “The first months as WFH president have been energizing,” says Mark Skinner. “The extent, reach and complexity of the organization’s activities are immense. Delivering treatment products to emergency patients, lobbying a health minister to spend more on hemophilia care, training doctors or advising concerned parents – it’s all in a day’s work for the WFH.”

The 44-year-old attorney from Washington, DC, was elected in October, to replace Brian O’Mahony who had served as WFH president since 1994.

In his new role, Skinner is pursuing a number of goals: “One of the most significant challenges is the need to diversify the WFH’s funding base and look outside the pharmaceutical industry for new sources of revenue. I am using my background to secure more and diverse resources for the organization.”

Skinner has an extensive and life-long involvement with the bleeding disorders community. A member of the WFH executive committee since 2002, Skinner was also president of the National Hemophilia Foundation (NHF) in the USA. He is the inaugural recipient of the NHF’s Distinguished Leaders Award and was selected in 2003 as Humanitarian of the Year.

The new WFH president has a strong background in public policy and advocacy for improved safety and supply of blood products. He belongs to the WFH Blood Products Safety, Supply, and Availability Committee, and serves on the NHF’s Medical and Scientific Advisory Council (MASAC). Skinner regularly consults on a range of public policy issues including the development of effective and sustainable public policy programs for non-profit organizations.

Skinner has been a regular presenter on important blood safety, supply and availability issues. He continues to serve as a member of the NHF blood safety and gene therapy working groups. Skinner has been an active fundraiser, including a research campaign that raised \$5 million dedicated to finding a cure for bleeding disorders. He chaired the NHF Advocacy Committee that guided the Ricky Ray Hemophilia Relief Fund, which provided compensation for people with hemophilia infected with HIV from tainted clotting factor.

Growing up in rural Kansas during the 1960s with severe hemophilia A has made Skinner acutely sensitive to the needs of those with limited access to treatment. His early life experiences have had a lasting impact. In 1984, he began his advocacy involvement by helping to enact a state program for those without affordable treatment.

He takes a global view on this issue: "I am looking for ways to make safer treatment products more affordable for emerging countries. This will require innovation and great collaboration with all stakeholders including governments, regulators and industry."

The new WFH president sees the position as an exciting opportunity and the culmination of a lifelong passion to help people with hemophilia around the world: "I am pleased to be at a point in my life where I can give something back to the community. My passion runs deep. I remember the pain and frustration of my early life. There is no need for any child to go through that."

Mark Skinner is available for media interviews.

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