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Global Perspectives

World Federation of Hemophilia – Working with bleeding disorders communities around the world

Maria del Carmen de Agurcia discovered her mission about 20 years ago when she first took her baby son, Carlos Humberto, who has hemophilia A, to an insensitive doctor in Honduras.

“He told me it was not worth caring for people with hemophilia because they would all die like chickens,” she says.

“I then decided that fighting for people with hemophilia was going to be my life’s work.”

Maria’s son is now a young man and he is very much alive largely through his mother’s public efforts to improve government supplies of factor concentrate, patient care and knowledge of hemophilia treatment.

Maria del Carmen attributes much of her success to advocacy training and other support provided by the World Federation of Hemophilia (WFH) to 113 of its member organizations.

While people with bleeding disorders in developed countries are living longer, fuller lives, only about 25 percent of patients in the developing world receive adequate treatment.

The others die young or face a life of pain and disability.

For almost half a century, the WFH has saved or bettered the lives of thousands of these people worldwide.

The World Federation of Hemophilia is a global not-for-profit organization working to improve and sustain treatment of people with hemophilia and other inherited bleeding disorders.

With *Treatment for All* as its vision, the Montreal-based organization builds sustainable hemophilia care in cooperation with governments, medical practitioners, industry, and associations such as Maria del Carmen's Honduras Hemophilia Society.

For example, the Honduran association has been partnered with Hemophilia of Georgia as part of the WFH Twinning Program, which links hemophilia organizations and treatment centers in developing and developed countries.

Twinning partners share their experience in hemophilia treatment, patient education, outreach, organization, lobbying, fundraising, and the optimal use of resources.

"Exchange visits, training programs, and other activities forge friendships around the world and strengthen the global hemophilia community," says WFH president Mark Skinner.

"Feedback shows that twinning is a positive two-way experience that motivates staff and volunteers, attracts youth involvement, and enables both sides to learn from each other."

"It's a win-win situation; therefore we always welcome new twins."

Thousands of people are also helped each year by the WFH's Humanitarian Aid program, which distributes donated treatment products to hemophilia patients in developing countries.

More than 80 million units of factor have been channeled through the WFH to 65 countries for emergency cases of life-threatening bleeds or patients undergoing surgery.

In addition, the donations also support efforts by the WFH and national hemophilia organizations to lobby governments for ongoing purchases of these products and sustainable hemophilia care.

"Donated factor saved my leg," says Parimal Chandra Debnath from the Hemophilia Society of Bangladesh.

Debnath was hit by a car on his way home from work and suffered a broken knee. Complications from severe hemophilia A threatened his future ability to walk and earn a living. However, a WFH emergency supply of factor enabled him to recover and devote his life to helping other people with hemophilia.

"We need to reach out to them," he says.

To promote such outreach, the WFH annually organizes World Hemophilia Day on April 17. Participants increase awareness of hemophilia and other bleeding disorders with activities ranging from concerts, workshops, family outings and swimming races to media campaigns, body building competitions and even storytelling.

Based on the theme *Together, We Care*, World Hemophilia Day 2009, focused on the importance of comprehensive care for treatment of the physical, emotional, psychological, social, and educational needs of people with hemophilia and other bleeding disorders.

“The involvement and dedication of volunteers from so many different countries united in a global celebration was very moving and inspirational,” says Skinner.

“It showed that we can work together around the world to ensure that all people with bleeding disorders, no matter where they live, receive proper treatment and care.”

**For more information about WFH activities, visit www.wfh.org.
If you would like to request a photo to use with this article, contact WFH communications manager Sarah Ford at sford@wfh.org.**

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