

# Hemophilia Aid

YEAR-END REPORT  
2007

## Twinning partnership promotes growth and learning

"Life is too short not to help people in need," declares Jocelyn Bessette Gorlin, a nurse at the University of Minnesota and Children's Hospitals and Clinics of Minnesota Hemophilia Center. Jocelyn is one of many volunteers involved in the treatment center's twinning partnership with a treatment center in Armenia. "Rather than being a hand that feeds, it's much more beneficial to help find a solution. A unique feature of twinning is that you are given the tools to help yourself. This lays a solid foundation for success."

In 2004, the Minnesota and Armenia treatment centers were partnered through the World Federation of Hemophilia Twinning Program, which matches emerging and established hemophilia organizations and treatment centers to facilitate two-way learning. This is the Minnesota center's second twinning partnership. They were paired with a treatment center in the republic of Georgia in Eastern Europe from 2000 – 2003.

So far, the latest twinning partnership is proving to be successful. Visits between centers and exchange of informational materials have helped educate healthcare providers and patients in both countries. The Minnesota center has also helped send donated medical supplies and works closely with Armenia's patient organization.

Volunteers at the Minnesota center have witnessed first-hand the contrast in care received in the US and around the world. "It's hard to see patients who have less access to treatment than we do in the US," says Joni Osip, a nurse volunteer. "In Armenia, bleeding disorders are disabling. The difference in quality of life is startling." Often, visits to Armenia remind Joni of her experiences treating patients with inhibitors in the US almost two decades ago. "With few treatment



Jocelyn Gorlin, CPNP, right, teaches a mother about home infusion.

options, we have to use creative techniques to control bleeding. Sometimes, we arrive with donated factor and patients line up for it because there is no other source."

Despite this, Margaret Heisel Kurth, who acts as the twin's main contact in Minnesota, says that twinning is an absolutely positive experience, and encourages other centers to take part. "Treatment centers have access to incredible resources that can be shared easily with other centers to improve care for their patients." However, she stresses the need for open lines of communication. "To improve care, there must be cooperation and trust between the hemophilia center, patients, and government. The willingness to share information can only help improve the care of bleeding disorders everywhere."

Jocelyn agrees that "twinning is an educational, life-changing experience." ■

## PRESIDENT'S MESSAGE

### Improving the global treatment crisis

One of the greatest challenges for people with bleeding disorders in developing countries is access to safe and affordable treatment. The WFH estimates that the target minimum treatment product per capita for survival is one international unit (IU) per capita. The average global per capita consumption now exceeds 1.25 IUs, but for two-thirds of the world treatment is still inadequate or non-existent.

The global supply of safe, affordable clotting factor concentrates is inadequate to meet this demand. In 1997, the WFH Global Survey identified 80,000 people with hemophilia A and B; in 2007, there were 135,000. While we have been successful in increasing the percentage of patients diagnosed with hemophilia, access to treatment products has not kept pace.

The WFH USA Humanitarian Aid Program is designed to provide both emergency aid, as well as serve as a catalyst for the development of sustainable care. Donated product is used for emergency, life-threatening cases in countries with limited treatment. Donations also help hemophilia organizations and treatment centers develop long-term sustainable care programs. Since 2003, over 60 million IUs of factor has been channelled through WFH USA to 56 countries around the world.

I encourage you to donate your excess or short-dated treatment products to WFH USA. Please contact Dr. Assad Haffar at [ahaffar@wfh.org](mailto:ahaffar@wfh.org) for more information about eligible factor donations. You can make a difference to the lives of people with bleeding disorders everywhere.

**Mark W. Skinner**  
WFH USA President

# Two young leaders trek to Istanbul for World Congress

The Susan Skinner Memorial Fund scholarship program recognizes young women with bleeding disorders who demonstrate outstanding leadership potential to improve the care of bleeding disorders in their country. The award honors the dedication of the late Susan Skinner, an American mother of children with bleeding disorders who was determined to ensure the availability of safe and effective treatment.

In 2008, two scholarships were granted for two young women – one from USA and one from Macedonia in Eastern Europe – to attend the Hemophilia World Congress in Istanbul, Turkey. The recipients took time to share their memories of the experience with us.

## Julia McDougal, 19, Orem, Utah

At the Congress, I had the privilege of meeting leaders from the international bleeding disorders community. There was a strong sense of belonging and community as we put aside political and cultural differences and searched for ways to learn from one another. I was touched to hear personal stories from my new friends.

This experience has renewed my desire to take action internationally and locally. Everyone should have access to the level of care that I am lucky to receive every day. We are truly a global family and can only grow stronger by growing together. I will never forget this incredible experience.

## Marija Nakeska, 26, Kicevo, Macedonia

Tolstoy wrote: "happy families are all alike; every unhappy family is unhappy in its own way." At the Congress, I was connected with families who could relate to my experiences with bleeding disorders. Sharing our stories, good and bad, helped erase the borders often formed by race, religion, and nationality. My goal to ensure that people with bleeding disorders can one day live a normal life was strengthened.

**Sharing our stories,  
good and bad, helped  
erase the borders often  
formed by race, religion,  
and nationality.**

All this would not be possible without the Susan Skinner Memorial Fund. I would like to thank the Skinner family and the WFH for this opportunity.

*WFH USA thanks the National Hemophilia Foundation for their great assistance to the Susan Skinner Memorial Fund scholarship program. For more information about the program, please contact Rosalind Franklin at [rfranklin@wfh.org](mailto:rfranklin@wfh.org).*



Julia McDougal, left, and Marija Nakeska, right, at the Hemophilia World Congress in Istanbul, Turkey.

## Financial Report

WFH USA ended 2007 with a deficit of \$7,000, although corporate and individual donations almost doubled from the previous year. This deficit is a reflection of WFH USA's growing awareness-building activities. In addition, we have hired one part-time staff.

The Susan Skinner Memorial Fund collected \$18,000 in donations in 2007, and donations to the Fund continue to increase each year. The growth of the Fund allowed us to grant the first two educational training scholarships in 2008.

There was a substantial decrease in humanitarian aid donations compared to last year. In 2007, we sourced over \$16,000 in product donations, which were used for emergency and life-threatening situations in Palestine. A monetary donation from our international partner, the World Federation of Hemophilia, helped ship the product donations.

WFH USA continues to receive invaluable support from its volunteers. The value of volunteer services in 2007 was estimated to be approximately \$51,000. We are truly

grateful for the continued support of both our volunteers and donors, without whom we could not continue our work to improve the lives of children and adults with bleeding disorders around the world.

Our complete financial statements can be found on our website at [www.wfhusa.org](http://www.wfhusa.org).

## How you can help

Your commitment to WFH USA is invaluable. You can make a difference in so many ways.

### Donate!

Your donation will help WFH USA deliver life-saving treatment free of charge to children and adults with bleeding disorders in the poorest regions of the world. Make a donation today at [www.wfhusa.org](http://www.wfhusa.org).

### Join Global Feast

Visit [www.globalfeast.org](http://www.globalfeast.org) for all the information you need to organize a fun food event this fall. Raise funds to help people with bleeding disorders around the world! Eat, drink and be caring!

### Share stories

We'd like to interview volunteers who are helping with our international efforts. If you are involved in our fellowship, twinning and/or overseas country programs, please email us at [info@wfhusa.org](mailto:info@wfhusa.org).

### Inform your members

Help us spread the word about bleeding disorders abroad to your members or clients. If you are interested in WFH USA making a presentation at your upcoming event, please email us at [info@wfhusa.org](mailto:info@wfhusa.org).

### Other ways to get involved

Please contact us with your ideas. We are happy to hear from you.

For more information, please visit our website at [www.wfhusa.org](http://www.wfhusa.org) or email us at [info@wfhusa.org](mailto:info@wfhusa.org).

## Hats off to hemophilia organizations!

WFH USA salutes Delaware Valley Chapter of NHF, Great Lakes Hemophilia Foundation, Hemophilia Association of the Capital Area, Hemophilia of Georgia and the National Hemophilia Foundation for their leadership gifts to support global hemophilia care. We hope that others will follow their footsteps

to improve the care of bleeding disorders everywhere.

If your organization would like to make a financial contribution to WFH USA, please contact Mike Rosenthal at [mike@wfhusa.org](mailto:mike@wfhusa.org).

Delaware Valley Chapter of the National Hemophilia Foundation



GREAT LAKES HEMOPHILIA FOUNDATION



Hemophilia of Georgia

NATIONAL HEMOPHILIA FOUNDATION for all bleeding and clotting disorders



## Your help is urgently needed

Training a boy to prevent bleeds in a country where factor is scarce can save his life. The WFH trains parents on how to motivate and instruct their children in proper hemophilia care. Let us spread your caring worldwide. Make a donation today to WFH USA.

### Yes, I will give children a chance to walk and play.

Here is my donation for:  \$ 50  \$ 100  \$ 250  \$500  Other \$ \_\_\_\_\_

Name: \_\_\_\_\_

Organization: \_\_\_\_\_

Address: \_\_\_\_\_

City: \_\_\_\_\_ State: \_\_\_\_\_ Zip Code: \_\_\_\_\_

Telephone: \_\_\_\_\_ E-mail: \_\_\_\_\_

The World Federation of Hemophilia USA is a 501(c)(3) non-profit organization recognized by the IRS, and all donations to the World Federation of Hemophilia USA are tax-deductible in accordance with IRS regulations. We will not sell or rent any personally identifying information obtained through your donation to any other organization, and will never willfully disclose any personally identifying information about you to any third party without first receiving your permission.

Send this coupon with your check, payable to WFH USA, to:

World Federation of Hemophilia USA  
PMB 142, 911 Central Avenue  
Albany, NY 12206-1304

You can also donate securely online at [www.wfhusa.org](http://www.wfhusa.org).

## Thank you for caring!



# Thank you!

WFH USA depends on your donations of time, in-kind medical supplies and products, and money. Without your support, there would be no way to help thousands of children and adults with bleeding disorders in the developing world each year. On behalf of the people whose lives were saved or improved by your help in 2007, we thank you.

## Humanitarian Aid Partners

Grifols USA

## Organizational Partners

Hemophilia of Georgia, Inc.  
National Hemophilia Foundation

## Corporate Supporters

Braden Financial Services, Inc.  
CSL Behring  
Hamilton Communications  
Hemophilia Innovation, LLC  
Interactive Forums, Inc.  
Novartis Vaccines and Diagnostics, Inc.

## Non-profit Supporters

Baxter International Foundation  
CSL Behring Foundation  
JustGive  
The Child Reach Foundation

## Hemophilia Organizations and Medical Centers

Cardeza Foundation Hemophilia Center  
Delaware Valley Chapter of NHF  
East Tennessee Comprehensive Hemophilia Center  
Fairview University  
Fort Worth Bleeding Disorder Program  
Great Lakes Hemophilia Foundation, Inc.  
Gulf States Hemophilia and Thrombophilia Center  
Hemophilia Association of the Capital Area  
Henry Ford Hemophilia Treatment Center  
Mayo (Rochester) Comprehensive Hemophilia Center and IHTC  
New England Hemophilia Center  
Orthopaedic Hospital Hemophilia Treatment Center  
Penn Comprehensive Hemophilia and Thrombosis Program  
Presbyterian Weill Cornell Center  
Regional Comprehensive Hemophilia Diagnostic and Treatment Center, New York Mount Sinai Regional Comprehensive Hemophilia Treatment Center  
University of North Carolina Comprehensive Hemophilia Diagnostic and Treatment Center

**Individual Donors**  
Dana L. Appling  
Ginger Barr  
Shari and Stephen Bender  
Kathleen Gay Bissell  
David Blanchard  
Don and Marian Button  
Richard Carleton  
Ronald Cobb  
Emily E. Czapek  
Cheryl N. D'Ambrosio  
William and Donna Dible  
Joann Deutsche  
J. Ollie Edmunds  
Nancy L. Erwin  
Bruce and Mary Evatt  
Nadia P. Ewing  
Larry and Jeanne Fellows  
Nancy Flemming  
LaNita Fortenberry  
Olivia Gable  
Monica Gaupp  
Catherine Glass  
Edward Gomperts  
David Green  
Robina Ingram-Rich  
Carol K. Kasper  
Nigel S. Key  
Anne King  
Daniel A. Kraus  
Roshni Kulkarni  
Martin Lee  
Josephine Li-McLeod  
Richard A. Lipton  
Jeanne Lusher  
Andrew B. Matthews  
Ariel Messeca  
Jim Munn  
Sally Owens  
Nolan and Rachel Patterson  
Shannon Penberthy  
Marie Renz  
Nidra Rodriguez  
Kathleen Rose  
Jack and Mardelle Shagool  
Stacy and Gary Shapiro  
Thomas W. Skinner  
Mark W. Skinner  
Susan P. Soleil  
Thomas E. Stolper  
Vickie Strange  
Marion and Chuck Stuart  
Terry D. Tenbrunsel  
Susanna von Oettingen  
Allen and Lynne Webber  
Mary Q. Wingate  
Margo B. Wray

## Hemophilia Aid

*Hemophilia Aid* is a publication of the World Federation of Hemophilia USA (WFH USA)

## Board of Directors

### PRESIDENT

**Mark W. Skinner**  
WFH President

### VICE PRESIDENT

**Craig Kessler, MD**  
Chief of the Division of Hematology,  
Georgetown University Medical Center

### SECRETARY/TREASURER

**Claudia Black**  
WFH CEO/Executive Director

### MEMBERS

**Trish Dominic**  
Executive Director, Hemophilia of Georgia

### Phil Kucab

Board Member, National Hemophilia Foundation

### Shelly Mattson

Co-Chair, National Youth Leadership Institute, National Hemophilia Foundation

### Sally Owens, RN

Acting Team Leader, Prevention Research Team, Division of Blood Disorders, Centers for Disease Control and Prevention

## Staff

### NATIONAL DIRECTOR

#### Mike Rosenthal

Email: [mike@wfhusa.org](mailto:mike@wfhusa.org)

For more information, please contact us:

WFH USA, PMB 142  
911 Central Avenue  
Albany, NY 12206-1304

Tel: 1-877-417-7944

E-mail: [info@wfhusa.org](mailto:info@wfhusa.org)

