U.S. donors and volunteers vital to advancing Treatment For All

By Michael Rosenthal, WFH USA national director

Three simple words, Treatment for All, elegantly describe our approach to bringing world-wide relief to people with bleeding disorders. Simple though it sounds, creating standards of care where often there are none, and working across 122 international borders, is not an easy task. That is why your support of World Federation of Hemophilia USA (WFH USA) remains vital. The mission of WFH USA is to mobilize U.S. support for the global mission of the World Federation of Hemophilia (WFH) to improve and sustain care for individuals with inherited bleeding disorders around the world. WFH USA is the best way for a U.S. donor and volunteer to make a meaningful difference.

Our primary goal is to support the WFH Humanitarian Aid Program, bringing treatment to international communities in need, along with the knowledge to treat and build organizations that will support comprehensive care. Because the reality for many people with bleeding disorders is that they do not have adequate care or any care at all, we support the wonderful efforts of the WFH in a variety of ways:

1. We collect and coordinate the distribution of donated unexpired factor from manufacturers, hospitals, pharmacies, and homecare companies, shipping it where it is needed.
2. We recruit U.S. organizations to participate in the WFH’s Twinning Program
3. We fundraise to support the programs and services of WFH (primarily humanitarian aid)
4. We educate and inform U.S.-based organizations, and summer camps on the plight of the underserved around the world.
5. We fund and administer the Susan Skinner Memorial Fund, providing scholarships to young women to attend WFH meetings around the world.

In addition,
1. We partner with like-minded organizations in the U.S. to cooperatively support and further our mutual missions.
2. We promote World Hemophilia Day and other awareness building activities
3. We communicate directly to donors and volunteers through email and newsletter publications
4. We operate a website (www.wfhusa.org) with links to valuable information
5. We will come to your community and make a presentation about people with bleeding disorders and how you can help.

CLOSING THE GAP TO SUPPORT THE CORNERSTONE INITIATIVE

The Close the Gap campaign, with the goal of raising $5 million in three-years, was launched at the WFH 2012 World Congress, to support the next phase of WFH healthcare development programs. To date, $4 million has been pledged for the WFH 50th anniversary campaign, with $1.4 million coming from WFH global leadership, the WFH USA Board, and many friends, all of whom are recognized at the end of this Report.

Now it is our turn, in the U.S., to help raise the last million dollars. This push will support the next decade of WFH development programs, including the new Cornerstone Initiative, to specifically aim at supporting care for those who live in countries which have previously been underserved and where the gap in care is greatest.

With a matching grant from the National Hemophilia Foundation for chapters and a matching grant from WFH patron Jan Willem André de la Porte already in place, every dollar given will be multiplied by three. Speaking of three, remember the three simple words, Treatment for All, and the impact it would have for people in developing countries? We will reach our $1 million goal if we all participate. Please read the articles in this report, see for yourself the advancements we have made, and the need still before us.

You receive this report because you are part of our family, the global family. Let’s continue to work together bringing Treatment For All.
In 2012, WFH USA continued to grow U.S. support for the global mission of the World Federation of Hemophilia (WFH), to improve and sustain care for individuals with inherited bleeding disorders around the world.

To mark the WFH’s 50th anniversary on our journey to achieve Treatment for All, WFH USA committed to accelerate our work to mobilize U.S. support to close the gap in care globally. As part of the campaign, we have been seeking U.S. support to enable WFH to amplify its work and increase programs to the most impoverished regions of the world.

In 2012, U.S. donations and pledges (excluding pharmaceutical support) to the 50th anniversary campaign exceeded $570,000. To kick-off the U.S. fundraising, the National Hemophilia Foundation (NHF) made an extraordinary pledge of support. The NHF pledged to match donations from U.S. chapters and hemophilia treatment centers (HTCs) over the three years of the WFH Close the Gap campaign, up to $50,000 per year.

Val Bias, NHF CEO wrote an inspirational message to launch our U.S. efforts: “In many ways we are privileged here in the U.S., while many around the world do not know they have a bleeding disorder and suffer in silence. We need to close the gap between those who have care and those who do not. We need to close the gap between hope and suffering...I am confident the entire American bleeding disorders community can rise to the occasion.”

Beyond direct fundraising, WFH USA is working in other areas to raise awareness of our programs and build U.S. support for our global family.

Other program highlights include:
- Continued growth of the Susan Skinner Memorial Fund, an endowment established in 2007 to support the training and education of young women with bleeding disorders who have the potential to be future leaders. Two remarkable young women Alexandra Johnson, from Michigan, and Aleksandra Ilijin, from Serbia, were awarded scholarships to attend the WFH 2012 World Congress. One past recipient recently characterized her Congress experience as “life-changing” and forever shaping her future commitment to addressing the unique needs faced by women within our community. For more information about the Susan Skinner Memorial Fund, go to page 6 in this report.
- WFH USA receives donations of factor concentrates for the WFH Humanitarian Aid Program, which are then channeled to developing countries to help build sustainable national care programs and address urgent needs. In 2012, 26.8 million international units (IUs) of factor were donated to 50 countries. We are grateful to the companies who have donated and also to Hemophilia of Georgia in Atlanta, Georgia, whose pharmacy and volunteers distributed the product donations on our behalf. To learn more about this program, go to page 3.
- WFH USA established a new restricted fund to support the recently launched WFH Research Program to create better evidence for the clinical management of bleeding disorders. In 2012, $200,000 was pledged from U.S. donors to launch the program, $75,000 has been granted to the WFH thus far. A special thanks goes to the 340B program of the Hemophilia Center of Western Pennsylvania for their leadership gift.

Elsewhere in this annual report you will find a story about our plans for 2013 and beyond. All of this could not have been achieved without the support of our volunteers, partners, members, and donors. Thank you for your inspiring collaboration throughout the year.

Mark W. Skinner
WFH USA president

WFH USA Adopts Strategic Plan 2013–15

By Phil Kucab, WFH USA board member

Since the World Federation of Hemophilia USA (WFH USA) was established in 1996, it has served as the U.S.-based awareness-building, friend-raising, and fundraising arm of the World of Hemophilia (WFH). The mission of WFH USA is “To mobilize U.S. support for the WFH’s global mission to improve and sustain care for individuals with inherited bleeding disorders around the world.” To achieve this, WFH USA and the WFH work in collaboration to carryout the strategic objectives of this plan.

Implementation is achieved through an integrated and unified approach to enhance the impact of both organizations. The following is a summary of the highlights of our plan to guide WFH USA in 2013 and beyond.

**STRATEGIC THEME #1 - Develop resources to support the WFH global mission to improve and sustain care**

**GOAL #1:** Raise funds to Close the Gap in care globally

**GOAL #2:** Support the WFH Humanitarian Aid Program

**STRATEGIC THEME #2 - Building U.S. awareness for the global vision of Treatment for All**

**GOAL #1:** Promote youth awareness and engagement to support global development

**GOAL #2:** Promote U.S. engagement in World Hemophilia Day by U.S. chapters and hemophilia treatment centers

**GOAL #3:** Support WFH in its strategic goal to increase the participation of National Hemophilia Foundation (NHF) chapters in the WFH Twinning Program

**GOAL #4:** Promote the WFH, WFH USA and U.S. involvement at NHF meetings and events

**STRATEGIC THEME #3 - Achieving operational excellence**

**GOAL #1:** Board development

**GOAL #2:** Adhere to best practices in fundraising and organizational governance and compliance

**GOAL #3:** Optimize WFH – WFH USA collaboration

We look forward to partnering with our community to achieve our goals and the collective vision of Treatment for All around the world.
WFH USA channels donations to the WFH Humanitarian Aid Program

By Maria Carolina Arango, WFH program officer, humanitarian aid & accreditation

In 2012, WFH USA contributed $36,142.31 to the WFH Humanitarian Aid Program. The funding of the program helped support an unprecedented donation of 40 million international units (IUs) of clotting factor concentrates (CFCs), from four pharmaceutical companies: Baxter, Bayer, CSL Behring, and Pfizer.

WFH USA funding to the WFH Humanitarian Aid Program helped cover the cost of distributing the CFCs to countries most in need. The WFH helped fulfill commitments, develop long-term sustainable care, and assist in emergency situations, due to the product donations from its humanitarian aid partners and the generous gifts from individual donors to WFH USA.

By the end of 2012, the WFH Humanitarian Aid Program had channeled more than 100 shipments, totaling almost 27 million IUs of CFCs, to 50 countries. People with inherited bleeding disorders, such as Adiele Ugochukwu (see adjacent story), benefited from these donations and are counting on us to help. The WFH Humanitarian Aid Program depends on donations from individual donors. Without this help, product donations would not reach the people with bleeds most urgently in need.

In October 2012, five-year-old Adiele Ugochukwu from Umuahia, Nigeria, was diagnosed with severe hemophilia A after he fell and cut his tongue while playing at school. The doctors who treated him immediately contacted the Haemophilia Foundation of Nigeria (HFN).

Since becoming a member of the WFH in 1972, the HFN has been working arduously to secure accurate diagnoses for those in their community, building a comprehensive care team, and building support for hemophilia care from health authorities.

Nigeria is a country of lower-middle income, where the average family has very little funds to access hemophilia treatment products. Thanks to the humanitarian aid donations from the WFH, the HFN was able to respond promptly and send the factor concentrates that would save Adiele’s life.

According to Megan Adediran, HFN president, 24 hours later, the treating doctor sent a photo of Adiele smiling, along with the following message: “thanks for saving a life.” To this day, government support for the purchase of CFCs has not yet been secured. As a result, in emergency cases, people with bleeding disorders in Nigeria continue to rely on donations from the WFH Humanitarian Aid Program.

WFH USA awards 2012 World Cups

Special recognition is given each year to U.S.-based bleeding disorders organizations that choose to support the mission of WFH USA. During the National Hemophilia Foundation 2012 Annual Meeting, the WFH USA World Cup Awards were co-presented by Mark Skinner, WFH USA president, and by Michael Rosenthal, WFH USA national director. At a luncheon for NHF chapter executives, donors to WFH USA were officially recognized for their commitment to advancing Treatment for All.

We applaud these leading organizations who serve individuals and families within their home states, and who choose to go an extra step to provide treatment to the underserved around the world. Donations to WFH USA are used primarily to support the WFH Humanitarian Aid Program, bringing vital medical supplies and knowledge to places where the need is great. Congratulations to our 2012 recipients.

Our list of World Cup winners grows every year. Organizations within the U.S. bleeding disorders community receive a letter from WFH USA annually, inviting them to support the vision of Treatment for All. Your organization can become a World Cup winner in 2013 by joining the roster of organizations that participate every year. Contact Michael Rosenthal (mike@wfhusa.org) for information.

The 2012 World Cup recipients were:

- Delaware Valley Chapter of the NHF
- Hemophilia Alliance
- Hemophilia of Georgia
- Hemophilia Foundation of Greater Florida
- Hemophilia Foundation of Michigan
- Hemophilia Foundation of Minnesota/Dakotas
- Hemophilia of North Carolina
- Hemophilia of Iowa
- Hope for Hemophilia
- Mary M. Gooley Hemophilia Center
- Western Pennsylvania Chapter, NHF
WFH USA and FABC to partner for Gala in the desert

November 14, 2012 — Phoenix, Arizona

There’s something in the air this fall. Join us for the 2012 FABC and WFH USA Joint Gala. Take a ride in a hot air balloon and enjoy a night of dinner and dancing at the historic Arizona Biltmore hotel in Phoenix, Arizona.

The Foundation for America’s Blood Centers (FABC) and WFH USA have joined together to create this special benefit. Blood Centers have long been a cornerstone of bleeding disorders care in the U.S., and this joint benefit is a natural extension of our history together. Proceeds from the event will be shared by the two organizations, and the goal is to raise $200,000 that evening. There will be opportunities to purchase individual tickets, tables, or become a sponsor of the event. Details may be found at: www.annualgala.com.

We welcome WFH USA supporters to attend the gala and support our mission to improve and sustain care for individuals with inherited bleeding disorders around the world. Mark your calendars for this event as it will truly be an evening to remember.

A special rate for attendees at the Frank Lloyd Wright inspired Arizona Biltmore has been established ($229 per night, includes resort fee, wireless access, and parking), and that rate can be extended to make it a truly memorable weekend.

Financial Report 2012

In keeping with its mission, WFH USA receives in-kind humanitarian aid donations of clotting factor and other pharmaceutical products, from various sources, to support the WFH Humanitarian Aid Program. Through this program, donated products are distributed each year in as many as 50 developing countries to treat thousands of people with hemophilia and related bleeding disorders.

For the fourth year in a row, humanitarian aid donations remain at a very high level. The value of product donations in 2012 was $34,324,945, as compared to $45,032,499 in 2011. As a result, in 2012, the WFH distributed 26.8 million international units (IUs) of factor concentrates (compared to 32.8 million IUs distributed in 2011).

Through charitable monetary donations, which reached $64,440 in 2012, compared to $42,377 in 2011, WFH USA was able to donate, for the first time, the $36,142 cost of handling and shipping the humanitarian aid. The WFH USA Board decided to assume this expense, which in the past was covered by WFH. Although the donation created a budget deficit for the fiscal year of $11,754, WFH USA remains in a sound financial situation with year-end unrestricted net assets of $79,578 (compared to $91,332 in 2011).

In 2012, WFH USA established a new restricted fund to support the recently announced WFH Research Program. Contributions of $75,000 from two U.S.-based donors were recorded in our financial statements as revenue and subsequently granted to the WFH.

The Susan Skinner Memorial Fund received $44,730 in 2012 (compared to $35,711 in 2011), bringing the endowment fund total to $201,385, from $156,489 at the end of 2011.

WFH USA continues to receive invaluable volunteer support from individuals who donate their time, energy, and professional expertise to help carry out the product donation program and, of course, to serve on the WFH USA Board and various committees. The estimated value of volunteer services grew from $195,410, in 2011, to $216,070 in 2012, representing a significant growth of 10.6 percent.

We are truly grateful for these loyal and inspiring donor and volunteer contributions from our American family. Without you, we could not continue our mission to improve and sustain care for people with bleeding disorders around the world.

Our complete financial statements can be found at www.wfhusa.org.
THANK YOU!

WFH USA depends on your gifts of time, medical supplies and products, and money. Without your support, there would be no way to help the thousands of people with bleeding disorders around the world. On behalf of those people whose lives were saved or improved by your help in 2012, we thank you.

HUMANITARIAN AID PARTNERS
Baxter
Bayer
CSL Behring
Pfizer

PARTNER ORGANIZATIONS
Hemophilia of Georgia, Inc.
National Hemophilia Foundation
U.S. Centers for Disease Control and Prevention

WFH RESEARCH PROGRAM
Baxter
Biogen Idec Hemophilia
Hemophilia Center of Western Pennsylvania 340B Program

Donors
Gifts of $100,000 or more
Hemophilia Center of Western Pennsylvania 340B Program

Gifts of $25,000 or more
National Hemophilia Foundation

Gifts of $20,000 or more
One anonymous gift

Gifts of $10,000 or more
ConocoPhillips Company
Hemophilia Alliance
Hemophilia of Georgia, Inc.
Scott and Kim Martin
The Skinner Family

Gifts of $5,000 and more
Delaware Valley Chapter
Patsy Carman
John R. Taylor
Lisa Sackovich

Gifts of $2,000 or more
Cheryl and Tony D’Ambrosio
Hemophilia of Iowa, Inc.
Adam Newsome

Gifts of $1,000 or more
340B Factor Program at Akron Children’s HTC
Mary M. Gooley Hemophilia Center
Carol K. Kasper
Glenn and Beatrice Pierce
William T. Sparrow

Gifts of $500
Lynne Capretto
Donald and Barbara Goldman
Hemophilia Foundation of Greater Florida, Inc.
Hemophilia Foundation of Michigan
Hemophilia Foundation of Minnesota/Dakotas
Hemophilia of North Carolina
Nigel and Melissa Key
Shannon W. Penberthy
Joseph Pugliese
Margaret V. Ragni
Claudia Schoening-Diesing

Gifts of $250 or more
Patricia A. Dominic
Jeanne Fellows
John and Penny Gisselbeck
Phil Kucab
John Murphy
Kirk and Robin Myers
Orthopaedic Hospital of Los Angeles
Craig Arthur Steinke
Mary Q. Wingate

Gifts of $100 or more
Two anonymous gifts
Ronald H. Cobb
Carol M. Dekernion
Barbara J. Gordon
Keith Hoots
Dana Kuhn
Patrice Bravo
David Brock
Donald Brophy
Paulette Bryant
Dustbun Burseth
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Fernando Rodriguez Chappell
Collen Clark
Arleigh R. Clemons
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John Curran
Randall Curtis
Jon Davis
Sandra Davy
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Bethanne Deuel
Amy Dunn
Chad Feay
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John G. Foster
Neil Frick
Marc C. Fullington
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Marc Gilgannon
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Nicolas Giraud
Suzi Greer
Kyme Groller
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Arthur and Janet Haines
Vicky Hannemann
Jennifer Harris
Ken Hatfield
Paul and Julie Heinrich
Joseph Hopcraft
Sean Hubbert
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Denise Armstrong
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Oldouz Dehghani Bonehkohal
Patrice Bravo
David Brock
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Fernando Rodriguez Chappell
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Chad Feay
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John G. Foster
Neil Frick
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Marc Gilgannon
Joan C. Gill
Nicolas Giraud
Suzi Greer
Kyme Groller
Glady’s Guberrez
Arthur and Janet Haines
Vicky Hannemann
Jennifer Harris
Ken Hatfield
Paul and Julie Heinrich
Joseph Hopcraft
Sean Hubbert
Anne Hurlet

*Every effort has been made to ensure the accuracy of this list. We invite you to contact us if you notice any errors.
The Susan Skinner Memorial Fund was established in 2007, as an endowment to support the training and education of young women with bleeding disorders. Scholarship recipients demonstrate outstanding leadership potential to improve the care of women with bleeding disorders in their country, and become future leaders of bleeding disorders organizations.

The fund commemorates the late Susan Skinner, an American woman determined to ensure the availability of safe and effective treatment for her two sons.

Initially endowed with $15,000, the fund has continued to grow thanks to the generosity of family, friends, and members of the bleeding disorder community. To date, the fund has awarded eight scholarships and has an end-of-year balance of $201,385. Donations to the fund increased by 28.7 percent from 2011 to 2012.

The 2012 scholarship was awarded to Aleksandra Ilijin, of Zrenjanin, Serbia, and the 2011 scholarship recipient was Alexandra Johnson of Michigan. Both young women attended the WFH 2012 Global National Member Organization Training, the WFH 2012 World Congress, and the WFH General Assembly in Paris, France.

The scholarships are awarded to women between the ages of 18 and 30 who have a bleeding disorder or are carriers. Recipients have the opportunity to attend WFH educational and training events, such as the WFH World Congress, and regional or global training workshops.

With the support of the scholarships, they learn about the care of bleeding disorders around the world, and develop skills that could be utilized to develop programs in their home country. Through this fund, WFH USA is building a global network of volunteers committed to women’s bleeding disorders, and cultivating a future generation of women leaders to support WFH’s mission to improve and sustain care for people with inherited bleeding disorders around the world.
TOTAL PLEDGE AMOUNT: $__________ US TO BE PAID AS:

☐ ONE SINGLE INSTALLMENT

☐ ANNUAL INSTALLMENTS OF $  __________ US commencing on_____________ over a period of 3 years.

☐ MONTHLY INSTALLMENTS OF $  __________ US commencing on_____________.

Signature ___________________________________________
Date: _______________________________________________

Your campaign contribution will be proudly acknowledged in the WFH USA Year-End Report as well as in Close the Gap campaign materials.

☐ List my name as follows:

_____________________________________________________

☐ I would like my gift to remain anonymous

PAYMENT INFORMATION

☐ Check or money order enclosed, payable to the World Federation of Hemophilia USA

☐ [Credit card logos]

Card number __________ - __________ - ___________ - ___________   Exp __________
Cardholder (please print)   _____________________________________________________

To make a secure donation online, please visit www.wfhusa.org
and click on the donate button.

☐ I would like more information about legacy giving
☐ I would like more information about making a gift of securities

TO MAKE YOUR GIFT

Please send in your completed gift form by:

Fax: +1-514-875-8916

Mail: World Federation of Hemophilia USA
PMB 142
911 Central Avenue
Albany NY  12206-12304

Tel.: 1-877-417-7944

E-mail: info@wfhusa.org

THANK YOU FOR YOUR GENEROSITY
WFH MEMBERSHIP FORM

YES!
I WANT TO SUPPORT THE WFH AND TREATMENT FOR ALL.

Please sign me up as a(n):
☐ Sustaining member: US$100
☐ Individual member: US$60
☐ Person with bleeding disorder/Family member: US$30

Please sign my HTC/organization/company up as an:
☐ Associate/Organizational member: US$300 (On a separate sheet, please provide contact information for the six individuals from your organization who will receive membership benefits.)

I would like to give a gift of membership
☐ Gift of WFH membership: US$50

ABOUT YOU

☐ Dr. ☐ Mr. ☐ Mrs. ☐ Ms. ☐ Miss ☐ Other
First name ____________________________________________
Last name ____________________________________________
Organization _________________________________________
Address _____________________________________________
City ______________________ State/Province ____________
Zip/Postal Code __________ Country ____________________
E-mail _______________________________________________
Telephone ______________ ___ Fax ______________________

GIFT MEMBERSHIP

☐ Dr. ☐ Mr. ☐ Mrs. ☐ Ms. ☐ Miss ☐ Other
First name ____________________________________________
Last name ____________________________________________
Organization _________________________________________
Address _____________________________________________
City ______________________ State/Province ____________
Zip/Postal Code __________ Country ____________________
E-mail _______________________________________________
Telephone ______________ ___ Fax ______________________

PROFILE

Please indicate all the categories that apply to you:
☐ Dental professional
☐ General practitioner
☐ Hematologist
☐ Laboratory personnel
☐ NMO staff/volunteer
☐ Nurse
☐ Occupational therapist
☐ Orthopedist
☐ Pediatrician
☐ Physiatrist
☐ Physiotherapist
☐ Researcher/scientist
☐ Rheumatologist
☐ Social worker/psychologist
☐ Student
☐ Other _____________________________________________

I work for:
☐ Treatment center or hospital
☐ Industry
☐ Government or regulatory agency
☐ Non-profit organization
☐ Other _____________________________________________

Preferred language:
☐ English ☐ Spanish ☐ French

WFH publication preference:
☐ Print ☐ Electronic

PAYMENT INFORMATION

Total memberships fees _______________________________________

☐ My check or money order is enclosed, payable to the World Federation of Hemophilia in US dollars drawn from a US bank or the US correspondent of my local bank.

I wish to pay by: ☐ ☐

Credit card number __________ - _________ - _________ - __________
Expiration __________________________________________________
Name on card (please print) _________________________________
Signature ________________________________________________

You can also go to www.wfh.org and follow the membership link to a secure form.