WFH USA is the awareness-building and fundraising affiliate of the World Federation of Hemophilia in the U.S.A.

WFH USA: The link to bringing Treatment for All

By Michael Rosenthal, National Director, WFH USA

Providing factor and the knowledge to use it, is our best tool for closing the gap in care for people with bleeding disorders. WFH USA is the conduit through which 23,203,469 IUs of the World Federation of Hemophilia’s donated factor flows. We call it the Humanitarian Aid Program, but in truth, it is much more than that.

Donated factor saves lives and limbs in developing countries. As our donor base grows, it also stands to enhance quality of life through preventative treatment and surgery. We help to establish comprehensive care in places where there is none, and build advocacy and community in places struggling with the basics of life.

How we do it

As a U.S. non-profit organization, manufacturers and home healthcare companies make tax deductible donations of treatment products to WFH USA. These products, collected by Hemophilia of Georgia, are then distributed internationally where they are needed. Shipping factor is complicated and expensive. WFH USA supports this expense from donations made by individuals and organizations who want to improve the lives of people with bleeding disorders worldwide.

The growth in donated factor has been nothing short of astounding. Many companies are beginning the practice of planned donations, setting aside a specific number of units each year for the Humanitarian Aid Program. Logistically speaking, we have the capacity to receive these products, but we do need to ramp up our ability to support the cost of shipping the increase in product.

How you can help

It is strategically important that WFH USA increase the number of people who support the Humanitarian Aid Program, specifically the cost of shipping factor, and there are two reasons for this. An increased number of people making monetary donations allows more revenue to support the shipment of factor. Second, it is important for us as a public charity to show that we are supported by the public. To accomplish this growth, we are asking for your help.

You receive this annual report because you are a supporter of our work. What you can do to help is to remain a supporter, and go get a friend or two to become supporters as well. We have made it easy to ask friends and colleagues. All you have to do is send them a link to a 30-second video that asks them to make a $10 donation that is billed directly to their cell phone. You can ask them to text the word “world” to 80888. Posting the link or the video to your Facebook page is also an effective method for recruiting friends to help. Watch the video at our website www.wfhusa.org, where you can also find more information on our programs, multi-lingual publications and information on the upcoming WFH 2016 World Congress to be held in Orlando Florida.

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On an unforgettable November evening in Phoenix, Arizona, hot air balloons rose to greet the setting sun, carrying attendees who support WFH USA’s Humanitarian Aid Program and FABC’s (The Foundation for America’s Blood Centers) blood collection and safety efforts. This joint Gala, themed “There’s Something in the Air,” brought together two dedicated organizations whose work directly benefits people with bleeding disorders.

The famed Arizona Biltmore Hotel, a Frank Lloyd Wright inspired property, served as a backdrop for food, music, touching speeches, and the raising of $100,000. The event included a silent auction and provided an opportunity for industry and patient advocate leaders to network, learn, and enjoy an evening together supporting important work.

We are grateful to all of the individual attendees and the following corporate sponsors:

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Each year the WFH USA receives in-kind humanitarian aid donations of clotting factor and other pharmaceutical products from various sources. The donated products are distributed to developing countries to treat thousands of people with hemophilia and other inherited bleeding disorders. In 2013 the WFH donated an impressive 24.8 million international units (IUs) to 64 countries, which is comparable to the total donated in 2012 of 26.8 million IUs. The dollar value of product donations in 2013 remained very high at $31,993,752 as compared to $34,324,945 in 2012.

We also had an excellent year in charitable monetary donations with a 2013 total of $119,450 compared to $64,440 in 2012, and the WFH USA was able to contribute $55,000 towards the cost of shipping and handling of the humanitarian aid donations. Although 2013 saw the WFH USA with a small annual deficit of $9,344, comparable to $9,578 from 2012, the organization remains in sound financial health with year-end unrestricted assets of $70,234.

The contributions to the WFH Research Program in 2013 totaled an impressive $150,000 compared to $75,000 in 2012, resulting in a total raised of $225,000 in the first two years. The donations to the Susan Skinner Memorial Fund totaled $43,155 in 2013 and $44,730 in 2012, bringing the endowment fund total to $244,540 from $201,385 at the end of 2012.

WFH USA continues to count on the generosity of those in our community who donate their time, energy and professional expertise to our product donation program and to the WFH USA Board and various committees. The estimated monetary value of the volunteer services has grown from $216,070 in 2012 to an impressive $269,154 in 2013.

We are humbled by the dedication and loyalty of our American community and know that without you, WFH USA could not continue its goal of improving access to care for people with bleeding disorders around the world. In short, without your contribution we could never dream of achieving Treatment for All.

Our complete financial statement can be found at www.wfhusa.org.
**2013 Humanitarian Aid**

The efforts of WFH USA, and those who generously support them, has allowed the WFH to fulfill commitments to develop long-term and sustainable care for those with a bleeding disorder, as well as assist in emergency situations overseas through the Humanitarian Aid Program.

The WFH receives donations from product manufacturers, treatment centers, and homecare companies and channels them to national member organizations (NMOs) and recognized hemophilia treatment centers (HTCs).

Donated products are used for WFH development projects and in emergency cases for patients with life-threatening bleeds or undergoing surgery who have limited access to treatment. These donations also help the WFH and national hemophilia organizations to demonstrate to governments the efficacy of clotting factor concentrates (CFCs) and the benefits of purchasing these products on an ongoing basis.

The WFH now channels the world’s largest supply of donated hemophilia treatment products.

The global distribution of treatment products is an immense task and involves the WFH’s extensive international network with the majority of donations secured and distributed in collaboration with WFH USA and Hemophilia of Georgia. The Humanitarian Aid Program also receives assistance from the Irish Haemophilia Society and the Angelo Bianchi Bonomi Hemophilia Treatment Centre in Milan, Italy.

The WFH now channels the world’s largest supply of donated hemophilia treatment products.

Each donated IU of CFC helps support the treatment of someone with a bleeding disorder and saves lives. In 2013, Bayer, Baxter, CSL Behring, Grifols, Kedrion, and Pfizer made donations to the Humanitarian Aid Program. Their ongoing commitment will continue to strengthen the program by providing life-saving medicine to those in need.

The Humanitarian Aid Program is a key component in the mission to bring treatment for all.

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**WFH announces new Associate Membership**

The World Federation of Hemophilia recently announced a new category of membership aimed at organizations rather than individuals. The Associate category is for an organization that wants to sign up to six individuals for personal memberships. Normally these six individual memberships would cost $360 while with the Associate membership category it costs just $300. This gives an organization the ability to give its staff the opportunity to take advantage of the range of enhanced benefits that a WFH membership brings such as access to over 300 WFH publications in six languages and special discounts on registrations fees to all WFH meetings, including the WFH 2016 World Congress in Orlando, Florida.

For more information on WFH membership and/or to sign up, visit www.wfh.org/membership.

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**Humanitarian Aid: Life-saving factor where need is greatest**

*Maria Carolina Arango, WFH Humanitarian Aid Program Officer*

When nine month old Hirwa Mpano Virgile sustained an intracranial bleed in May 2013, doctors knew he would not survive without immediate surgery. However, with just three vials of treatment in stock at the King Faysal Hospital in Kigali, Rwanda, he would require significantly more just to survive the surgery.

To receive the assistance they needed, the doctors requested a humanitarian aid donation from the World Federation of Hemophilia (WFH). The WFH, in turn, sent the treatment that the boy needed to get through his surgery and the subsequent recovery. The boy’s father, Sylvestre Mulindabyuma, later wrote thanking everyone that helped save his son’s life. Tragically however, as a result of the bleeding, the boy is now permanently blind.

Since 1996, the WFH Humanitarian Aid Program has channeled donations of life saving treatment products to people in urgent need, most often in countries where access is very limited. For 17 years, this program has directed over 245 million international units of life saving clotting factor concentrates to 86 countries, reaching people in need like Hirwa. In addition, one of the goals of this program is to encourage health authorities to provide this treatment by demonstrating the efficacy of using clotting factor concentrates. Therefore, this would in turn build a solid foundation for sustainable hemophilia care in the future.
The WFH 2013 Susan Skinner Memorial Scholarship was awarded to American Leslie Situ Ferber, who immigrated with her family to California from China when she was nine years old. Upon their arrival she immediately noticed a difference between her family and those around them.

“One of my earliest memories is of noticing how my father was different than others. He's rather immobile due to lack of treatment most of his life, but that never stops him. He was the reason I got involved in the bleeding disorder community."

Her involvement in the community started when she went to work with children who have bleeding disorders almost 15 years ago as a camp counsellor at Camp Hemoaction in Oakland, California and continued when she went to work with the National Hemophilia Foundation as a Young Adult Delegate, teaching teens about bleeding disorders and motivating them to join youth programs. During her time with NHF she also worked as a grassroots lobbyist in Washington D.C. and coordinated various national campaigns to promote advocacy.

“Our family was very fortunate to be able to migrate and receive proper healthcare. However this is an exception and not the norm, and we cannot rely on luck for our conditions to get better. Our community has to band together and pursue treatment for all.”

Ferber’s work with the community has informed her advocacy but so has her experience with doctors.

“It was easy to convince my doctor of my carrier status, but it was hard to get my bleeding disorder symptoms properly diagnosed. Many doctors don’t understand that a carrier can exhibit symptoms. The community should reach out to doctors, particularly OB/GYNs.”

Recipients of the scholarship have the opportunity to attend WFH educational and training events such as the WFH World Congress, and regional or global training workshops. Reflecting on how she has benefitted from winning, Ferber explains that it has given her access to people who have helped influence and inspire her, “I was able to learn from and network with the best people in the bleeding disorder community, while being able to brainstorm new advocacy ideas with like-minded individuals.”

Leslie is the fourth American to win since the establishment of the scholarship in 2007. Previous winners were Julia McDougal from Utah, Mallory O’Connor from Washington DC, and Alexandra Johnson from Michigan.

The Susan Skinner Memorial Fund endowment was established in 2007 by WFH USA to support the training, education and leadership development of young women with bleeding disorders. Scholarship recipients aged 18 to 30 years, from the United States and abroad, have demonstrated outstanding leadership to improve the care of women with bleeding disorders in their country and have the potential to become future leaders in the bleeding disorder community.

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

“Because bleeding disorders are rare and complex, it is very important for medical staff to work in collaboration with patients to come up with the best treatment plan.”
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 the people whose lives were saved or improved by your help in 2013, we thank you.

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Hemophilia Aid is a publication of the World Federation of Hemophilia USA (WFH USA).
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- $50
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The mission of WFH USA is to mobilize US support for the WFH’s global mission to improve and sustain care for individuals with inherited bleeding disorders around the world.
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You can also go to www.wfh.org and follow the membership link to a secure form.