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

Hemophilia Aid
YEAR-END REPORT
2014

WFH USA well positioned for growth based on 2014 achievements

By Michael Rosenthal,
National Director, WFH USA

It was a milestone year for WFH USA, thanks in large part to the support of individuals and companies who share the goal to bring “Treatment for All.” This support has helped to position WFH USA for growth in 2015. As you will read in this report, the WFH Humanitarian Aid Program will begin distributing over 100,000,000 IUs of factor, a 500 percent increase as a result of decisions and contributions announced in 2014. Many organizations struggle to measure their achievements toward their mission. We are fortunate in this regard because more factor means more opportunities for needed surgeries, prophylactic treatment, fewer bleeds, and a higher quality of life.

Nothing like this happens overnight. It is the result of hardworking volunteers, professionals, advocates, and donors building relationships with each other, and awareness of the plight of 75 percent of the global bleeding disorder population who don’t have adequate access to treatment. Though this report covers the activity of 2014, truly each fiscal year is the culmination of each and every year that came before.

The WFH humanitarian aid effort, providing factor to developing countries along with the knowledge to use it, totaled 21.1 million IUs to 58 different countries. Individuals and companies donated funds to support the shipment of this vital treatment product, and the year was capped by the stunning announcement at the WFH 2014 World Congress in Melbourne, Australia, of a donation of 500 million IUs of factor over the next five years by Biogen and Sobi. Read WFH USA President Mark Skinner’s article in this report detailing how we will meet this exciting opportunity.

The year also saw the rollout of our Powerful Thumbs Campaign, a video and Text 2 Give program that enables U.S. smart phone users to donate $10 to WFH USA via their phone (text the word WORLD to 80888). The video has had nearly 2,000 views and raised close to $20,000. We are grateful to Baxter, our gold sponsor, and to Biogen for helping to make this new program possible.

Development of Journey Around the World (JAW) 2.0, WFH USA’s awareness program for summer camp age children began in 2014 for roll out in 2015. With sponsorship from Pfizer, JAW 2.0 will introduce campers to the challenges that developing countries struggle with of having limited resources to treat people with active bleeds. Through an interactive game, camper’s role play difficult treatment scenarios, and through discussion, learn the impact on people who don’t have access to care, and why “Treatment for All is an important goal.

Other highlights of the year include the expansion of the Susan Skinner Memorial Fund program, growing financial support from U.S. hemophilia organizations donating to WFH USA, and the generosity of individual and corporate donors in 2014, all of which are detailed in this report.

For the first time in close to 30 years, the World Congress of the World Federation of Hemophilia will be held in the U.S. in 2016. This is a meeting to attend! This will be a gathering of around 6,000 medical professionals, scientists, patients, and advocates from all over the world working together to educate each other, advancing treatment and solving the challenges of access to care. Take this opportunity to participate in the worldwide effort, mark these dates, July 24–28, 2016 in your calendar, and join us for this life-changing experience.
PRESIDENT’S MESSAGE

U.S. community helps make Treatment for All a reality

The year 2014 brought an important change for the World Federation of Hemophilia (WFH) Humanitarian Aid Program. During the WFH 2014 World Congress in Melbourne, Australia, WFH president Alain Weill announced that over 700 million units of donated factor concentrates would now be channelled through the Program over the next five years. This significant expansion of our capacity will in turn provide sustainable and predictable treatment to those most in need in developing countries.

WFH USA has placed high priority on this expansion of the WFH Humanitarian Aid Program within its strategic objectives. Within the U.S. community, there has been marked generosity towards supporting global healthcare development programs and other initiatives aimed at advancing the vision of Treatment for All. By supporting the WFH USA and the WFH Humanitarian Aid Program, the U.S. community will play an integral role in ensuring that this program will remain sustainable and provide predictable access to treatment products.

We are very fortunate to live in a country like ours where those in need will not routinely experience the pain and suffering that comes with living with a bleeding disorders without treatment. The reality is that a vast majority of people with hemophilia and other inherited bleeding disorders living in developing countries have little or no access to diagnosis, treatment or care. Many do not survive to adulthood, and if they do survive, they face a life with severe disability, isolation, and chronic pain.

We can change this and we will change this. With your help, Treatment for All will be a reality for those suffering without treatment and they will go onto experience an improved quality of life that we have been so lucky to have achieved for ourselves. Thank you for your support.

Mark W. Skinner, WFH USA president

Susan Skinner Memorial Fund to double U.S. awards

As a result of a successful 2014, the WFH USA Board of Directors made the milestone decision to double the number of fellowships granted to young women who will be given the opportunity of attending the WFH 2016 World Congress. Historically the award has been given to one American candidate and one international candidate but there will now be two recipients in each category.

The decision was made possible because of the generous donations from companies and individuals to the SSMF, and as a result of favorable returns on the invested funds.

The SSMF honors the memory of Susan Skinner, a mother dedicated to insuring that safe and effective treatment was available for her two sons. It is in this spirit that young women, ages 18–30, who have a bleeding disorder or are carriers, and have demonstrated leadership potential in their bleeding disorder communities, are invited to apply. The SSMF Award funds the travel, housing, and registration expenses of these young recipients to WFH world meetings. The next WFH World Congress will be held in Orlando, Florida, and promises to be the largest ever held. The WFH World Congress is often a life-changing event for attendees, and it is the intent of the SSMF to inspire its recipients to return to their communities and assume leadership roles, and to work internationally as well toward Treatment for All.

Past U.S. SSMF winners include: Julia McDougal, Shelley Matteson (now a WFH USA Board Member), Mallory O’Connor, Danielle Schwager, Alexandra Johnson, and Leslie Situ-Ferber.

In the U.S., the SSMF program is administered by the National Hemophilia Foundation (NHF). The NHF is the national member organization (NMO) of the WFH, and through NHF’s National Youth Leadership Institute (NYLI) program, grant applications are distributed to individuals and chapters. NYLI collects the applications which are then reviewed by a WFH USA selection committee and their candidate recommendations are forwarded to the WFH USA Board.

We are grateful to the NHF for their administration of the program, to the chapters who nominate candidates, to our donors and to the candidates who apply. Everyone working together creates the unique opportunity for global leadership training for three young women of the bleeding disorder community.

To learn more about the program or to make a donation that funds the scholarship, please visit: www.wfhusa.org/susanskinnerfund.

Left to Right: 2013 Susan Skinner Memorial Fund Scholarship winner Leslie Situ-Ferber, 2014 winner Salma Kiran with Mark Skinner.
Financial report 2014

Each year WFH USA receives in-kind humanitarian aid donations of clotting factor and other pharmaceutical treatment products from industry partners which are in turn channelled through the WFH Humanitarian Aid Program. These donated products are distributed to developing countries to treat thousands of people with hemophilia and other inherited bleeding disorders. In 2014, the WFH Humanitarian Aid Program donated an impressive 21.1 million international units (IUs) to 58 countries, which is comparable to the total donated in 2013 of 24.6 million IUs. The dollar value of product donations in WFH USA financial statements for 2014 remained high at $24,301,582, as compared to $31,993,752 in 2013.

We also had an excellent year for charitable monetary donations with a 2014 total of $113,519, compared to $119,475 in 2013, and WFH USA was able to contribute $40,000 towards the cost of shipping and handling of the humanitarian aid donations. Although in 2014 there was a small annual deficit of $1,865, versus a deficit of $9,344 in 2013, WFH USA remains in sound financial health with year-end unrestricted assets of $68,369.

The contributions to the WFH Research Program in 2014 totaled an impressive $150,000 similar to 2013, resulting in a total raised of $375,000 over the last three years. The donations to the Susan Skinner Memorial Fund totaled $43,785 in 2014 and $43,155 in 2013, bringing the endowment fund total to $288,325 from $244,540 at the end of 2013.

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 was a remarkable $262,929 in 2014, comparable to the value of $269,154 contributed 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 statements can be found at www.wfhusa.org.

WORLD CUP HONOREES

WFH USA honors and acknowledges hemophilia chapters and bleeding disorder organizations who donate vital funds to our WFH Humanitarian Aid Program. This non-profit to non-profit giving is vital to the success of the program and somewhat unique in the world of giving. Who better to understand the plight of people who go without treatment for bleeding disorders, than the people in organizations closest to patients? With sincere gratitude we list 2014’s World Cup winners:

- Colorado Chapter of the National Hemophilia Foundation
- Delaware Valley Chapter of the NHF
- Florida Hemophilia Association
- Hemophilia Alliance Foundation
- Hemophilia Association of the Capitol Area
- Hemophilia Foundation of Greater Florida
- Hemophilia Foundation of Michigan
- Hemophilia of Georgia, Inc
- Hemophilia of Iowa, Inc.
- Hemophilia of North Carolina
- Hemophilia of South Carolina
- Mary M. Gooley Hemophilia Center
- Rocky Mountain Hemophilia and Bleeding Disorders Association
- Virginia Hemophilia Foundation
- National Hemophilia Foundation

CLOSE THE GAP CAMPAIGN ENDS ON A HIGH NOTE

The Close the Gap Campaign officially ended on December 31, 2014. This was the WFH’s first multi-year campaign, raising $5 million to help improve care for those who need it most. The corporate portion of the campaign raised nearly $3.5 million from existing and new WFH corporate partners. The community portion of the campaign raised an outstanding $1.5 million.

The U.S. bleeding disorders community demonstrated an unprecedented level of support during the three-year fundraising drive. More than 320 donors gave a total of $988,648 in a meaningful show of solidarity with to global bleeding disorders community. To honor this solidarity, WFH patron Jan Willem Andre de la Porte pledged to donate an additional $2 for every $1 donated to the campaign. The National Hemophilia Foundation also took the additional initiative to match all contributions made by their chapters throughout the campaign. This resulted in nearly $120,000 of contributions made directly from NHF chapters, in addition to NHP’s contribution.
WFH USA’s first video production titled Powerful Thumbs, asks viewers to ‘Use those powerful thumbs’ and make a donation by texting the word WORLD to 80888. This first foray into video and fundraising by texting saw almost 2,000 views and raised close to $20,000 its first year. “We are hopeful to grow participation, and have more people actually donate $10 on their phone,” said WFH USA National Director, Michael Rosenthal. “It is such an easy way to support WFH USA, it only takes a few key strokes, a few seconds, and boom, you've helped to save the world.”

Anyone with a U.S. based smart phone can make a $10 donation that will appear on their monthly phone bill. The funds that are generated from this Text 2 Give program are used to support the shipment of factor to developing countries through WFH USA’s Humanitarian Aid Program.

“It’s an immediate way to respond to a crisis,” Rosenthal explained. “Whenever you see a disaster on TV like the earthquake in Nepal, don’t you wonder what happens to the people with hemophilia? The video is based on the annual World Hemophilia Day observance, which makes it also a good way to donate in times of celebration and remembrance.”

If you haven’t tried it yet, go ahead and use your powerful thumbs. You can see the video at our YouTube channel, World Federation of Hemophilia USA, or go directly to your phone and text WORLD to 80888. It will prompt you what to do. It’s easy and WFH USA doesn’t use your phone information, just your $10 to support Humanitarian Aid.

WFH RESEARCH PROGRAM UPDATE

The WFH Research Program was launched in 2013 with the goal of supporting and facilitating clinical research in inherited bleeding disorders. The program has two components:

- ENHANCED DATA COLLECTION, INCLUDING A NEW EPIDEMIOLOGICAL RESEARCH PROGRAM
- A CLINICAL RESEARCH GRANT COMPETITION

In 2014, the WFH made significant progress on both fronts. Thanks to the funding provided by its partners, which include the Hemophilia Center of Western Pennsylvania, Baxter, Bayer, and Grifols, we:

- IMPLEMENTED a new, web-based data collection system with integrated validation tools. Along with the training materials WFH developed, these improvements led to a seven percent increase in the quality of the data reported in the WFH 2013 Report on the Annual Global Survey.
- LAUNCHED a public webpage featuring online interactive graphs that allow our community to access, manipulate, and visualize WFH data. The graphs were accessed over 5,000 times from visitors in 90 countries (from May to December 2014).
- DELIVERED a workshop on the importance and value of data collection to over 100 participants from 80 countries at the 2014 WFH Global NMO Training in Melbourne.
- DEVELOPED the framework for a new WFH Epidemiological Research Program, which calls for the creation of an international registry of individual patient data. Once implemented, the registry will provide an unprecedented population for epidemiological and outcomes research.
- AWARDED just over $129,000 in funding to support four clinical research projects. For more information go to www.wfh.org/crgp.
Growing up in a rural area of Uganda, Segawa Wasswa knew very early on that he was different from the other kids in his community. Segawa was born with severe hemophilia A but he never knew it. In fact, his brother and two uncles had all died from complications related to hemophilia but none of them had even heard of the condition let alone received a diagnosis.

The situation in Uganda for people with a bleeding disorder has always been challenging, but in 2012, the Ugandan Haemophilia Foundation (UHF) joined the World Federation of Hemophilia (WFH) taking an important step to improving care in the country.

Since then the UHF has taken steps to improve care within the country by attending several workshops, as well as a productive Twinning partnership with the Great Ormond Street Hospital from London, United Kingdom. Since joining the WFH in 2012, the UHF has worked towards improving diagnosis and care for people with bleeding disorders but there are still many challenges ahead for this African nation.

These challenges are perfectly illustrated by the case of Segawa. It was not until the age of 12, after suffering a painful knee bleed in 2013 that Segawa was brought to a rehabilitation care unit for children with bone disabilities. Doctors at this center misdiagnosed him with a bone disease and proceeded to perform orthopedic surgery on his knee without any clotting factor concentrates. Luckily he survived the surgery but his condition only worsened.

Fearing the worst, the rehabilitation center transferred Segawa to Mulago Hospital in Kampala, where he was tested and finally received the proper diagnosis of severe hemophilia A.

Segawa’s condition was reported to the UHF, who was able, through the WFH Humanitarian Program, to provide him with the factor concentrates he needed to survive. The only problem that remains for him and his family is getting enough money to pay to travel from his rural village to the city where the treatment is available.

The situation on the ground for people with a bleeding disorder in Uganda is less than perfect, but it improves slightly with every day that passes. With assistance from the WFH, the UHF is providing proper training to people in the field and the WFH Humanitarian Aid Program ensures that in cases like Wasswa, that there is treatment available where there was none before.

The WFH Humanitarian Aid Program channels donations of life-saving treatment products to people with bleeding disorders who need them all around the world. This program is one of the many ways in which the organization supports its vision of Treatment for All.

We would like to thank the following for their donations to the WFH Humanitarian Aid Program for 2014–2015

Baxter · Bayer · Biogen · Biotest
CSL Behring · Grifols · LFB Biotechnologies

Maria Carolina Arango,
WFH Humanitarian Aid Officer

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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 2014, we thank you.

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Hemophilia Center of Western Pennsylvania
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Tulane University
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AND TREATMENT FOR ALL.

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