WFH USA advances the global mission of the World Federation of Hemophilia in the United States.

Hemophilia Aid

YEAR-END REPORT
2015

Connecting the Global Community

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2015

The WFH 2016 World Congress, in Orlando on July 24 to 28, is expected to be the largest meeting of the global inherited bleeding disorders community in the history of the World Federation of Hemophilia (WFH). Hosted by the National Hemophilia Foundation (NHF), this is the first time in over 25 years that the Congress has been held in the United States.

WFH USA works continuously to advance the global mission of the WFH within the United States, to improve and sustain care for people with inherited bleeding disorders around the world.

The WFH 2016 World Congress may be the first opportunity for many within the American bleeding disorders community to meet with their global counterparts. For WFH USA, it is imperative to show the U.S. community that the lack of access to care and treatment in developing countries, for people with inherited bleeding disorders, is an urgent and important public health challenge. The reality for most of the world, in particular in developing countries, is that the cost of products to treat is prohibitively expensive for the majority of those affected with a bleeding disorder.

With increased multi-year donations and a steady flow of treatment products to the WFH network, it will be possible for people with bleeding disorders in the developing world to have continued access to treatment for emergency situations, acute bleeds, corrective surgeries, and also prophylaxis for young children. An increasing number of partners within the global bleeding disorders community have accepted the challenge of providing a sustainable and predictable supply of donated products. Read more about the WFH Humanitarian Aid Program on page five.
WFH USA President’s Report

It is with great excitement we welcome the global community, to the United States, for the WFH 2016 World Congress. It is due to the tireless work of the WFH and National Hemophilia Foundation (NHF) that this valuable experience will occur for the U.S. community to meet and learn from others around the world.

It was a record year for WFH USA in 2015, with an increase in financial donations, solid support provided by our organization to the WFH, the expansion of the WFH Humanitarian Aid Program, and the growth of the Susan Skinner Memorial Fund. The generosity of the U.S. community has truly been immeasurable. With your help, we will continue our work towards achieving our shared vision of Treatment for All. In 2015, an impressive 19 chapters contributed to WFH USA. Equally notable, 100% of the members of the WFH USA Board of Directors made a personal financial contribution. Thank you to all our donors and supporters.

The leadership of NHF towards advancing this vision has also been integral in raising support within the United States. The NHF Chapter Challenge: Be a Champion for Humanitarian Aid has been generously supported by NHF and Hemophilia of Georgia. It is a unique collaboration which will continue to bring our community together in support of the WFH Humanitarian Aid Program.

We are very fortunate to live in a country like ours where we will not routinely experience the pain and suffering that comes from living with a bleeding disorder without access to care and 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.

Your generosity has enabled children and adults in developing countries to receive the care that we in the U.S. have come to know and expect. The good news is that the WFH Humanitarian Aid Program has seen a growth in product donations; however, we do not have sufficient funds to cover distribution costs to countries currently receiving and needing aid. WFH USA is committed to raising the necessary funds to make the products available where needed. Our hope is that by collaborating with you, we can help defray these shipping costs and help move us closer to our vision of providing Treatment for All.

I firmly believe that we can change this and it is through your support that those most in need will no longer needlessly suffer.

Thank you for your support.

Mark W. Skinner, WFH USA President

WFH USA 2015 Financial Report

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 channeled 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 2015, the WFH Humanitarian Aid Program continued to expand, with an impressive 52.8 million international units (IUs) donated to 63 developing countries. This represents a 150% growth in the volume of IUs distributed, versus 2014 with a total donated of 21.1 million IUs. The dollar value of product donations in WFH USA financial statements for 2015 reached $97,098,511, as compared to $24,301,582 in 2014.

We also had an excellent year for charitable monetary donations with a 2015 total of $195,992, compared to $113,519 in 2014, and WFH USA was able to contribute $70,000 towards the cost of shipping and handling of the humanitarian aid donations. In 2015, there was a net surplus of $25,502 versus a deficit of $1,865 in 2014. WFH USA remains in sound financial health with year-end unrestricted assets of $93,871.

The contributions to the WFH Research Program totaled $80,000 in 2015, versus $150,000 in 2014, resulting in a notable total raised of $455,000 over the last four years. Furthermore, contributions toward the WFH Humanitarian Aid Program amounted to $626,745 in 2015, compared to $500,000 in 2014. The donations to the Susan Skinner Memorial Fund totaled $35,510 in 2015 and $43,785 in 2014, bringing the endowment fund total to $323,835 from $288,325 at the end of 2014.

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 of Directors and various committees. The estimated monetary value of the volunteer services was a remarkable $289,824 in 2015, comparable to the value of $262,929 contributed in 2014.

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.
WFH Humanitarian Aid Program: Transforming Lives

The lack of access to care and treatment in developing countries for people with inherited bleeding disorders is an urgent challenge for our community. Globally 1 in 1000 people has a bleeding disorder and a vast majority of these people still receive inadequate care or no treatment at all.

Most live in areas where there is limited access to diagnosis and treatment. Due to this tragic situation, people with severe hemophilia in these countries often do not survive to adulthood. If they do survive, they face a life with severe disability, isolation, chronic pain, and very often early death. The stark reality is that a majority of people with hemophilia in developing countries die before age 20.

So far, our efforts have been how to address this lack of access to diagnosis, care, and treatment for the most vulnerable in the global bleeding disorders family. It is almost inconceivable for those of us living here in the U.S. that both children and young adults are still facing this reality. However, in most parts of the developing world, governments do not have the financial resources to provide treatment products, at the current prices, for their bleeding disorders populations. The need for a sustainable and predictable humanitarian aid source is the only chance for these patients and their families to receive access to diagnosis and then treatment.

To address this challenge, WFH USA supports the WFH Humanitarian Aid Program which is leading the effort to change this by providing consistent and predictable access to Treatment for All. Since it was created in 1996, the WFH Humanitarian Aid Program has distributed over 322 million IUs to 90 countries, helping over 100,000 people directly who are in urgent need. In 2015, the WFH donated 52,829,144 IUs of clotting factor to 63 developing countries.

An increasing number of partners within the global bleeding disorders community have accepted the challenge of providing a sustainable and predictable supply of donated products. Through the donation by Biogen and Sobi of over 500 million IUs within five years, along with the continued efforts of the Canadian Blood Services, Biotest, and Grifols with Project Recovery, and the work by the Italian National Blood Services through Project WISH, there will now be a more predictable and sustainable flow of humanitarian aid donations to the global community. In addition, CSL Behring and Grifols have signed multi-year commitments of treatment products which will contribute to the further expansion of the WFH Humanitarian Aid Program.

The expansion of this program is significant and will indeed help achieve Treatment for All. However, we need to ensure community support for the shipping, education, and training that goes along with this new availability of treatment. With your help, we can transform the lives of those who are desperately searching for much needed care.

Visit www.treatmentforall.org to learn more.

Championing Humanitarian Aid

WFH USA continues pursuing our shared vision of Treatment for All. In 2015, we took considerable strides towards bringing treatment, healthcare professional training, and much-needed treatment products to all corners of the globe through the WFH Humanitarian Aid Program. Our support has a demonstrable impact upon the global bleeding disorder community, regularly confirmed through stories such as that of Bachir, a young Senegalese boy. Five years ago, his mother, after hearing about the WFH Humanitarian Aid Program via our growing network of volunteers and healthcare professionals who have participated in WFH training sessions, contacted Dr. Saliou Diop in Dakar, Senegal. We were able to provide her son with the required treatment and support. Recently, Bachir returned to visit with us while we were in Senegal and we are happy to report that this courageous young man continues to have improved health. We personally saw the impact of humanitarian aid.

We would not be able to tell this story without the support of our community. Thank you to everyone who gave of their time and financial resources over the past year. You made a significant difference in the lives of many just like Bachir!

WFH USA is committed to continuing making a difference and we are thrilled to announce our latest campaign in support of the WFH Humanitarian Aid Program—The NHF Chapter Challenge: Be a Champion for Humanitarian Aid. Our founding champions, National Hemophilia Foundation and Hemophilia of Georgia, have set the bar high through contributing $50,000 each towards a fund that will be used to match gifts from other Chapter Champions. The WFH USA Board of Directors sees the potential for this unique collaboration with NHF and they hold out great hope for this program and look forward to telling many more success stories, like that of Bachir’s, which can be made possible through the generosity of the Chapter Challenge.

We look forward to seeing all of you at the WFH 2016 World Congress from July 24-28, 2016, in Orlando, Florida.
World Hemophilia Day 2016: Treatment for All is the Vision of All

On April 17, 2016, the global bleeding disorders community joined together to raise awareness about the shared goal of obtaining Treatment for All. Globally 1 in 1,000 people has a bleeding disorder. Most are not diagnosed and do not receive treatment. Together we can change that.

Following the great success of last year’s online gathering, the WFH connected with the community online again, providing them with an opportunity to share their stories and photos. We designed www.worldhemophiliaday.org for people to share their thoughts about how we can obtain Treatment for All. The site was based on a world map and encouraged people to share where they are from; at the end of April there were 78 participants from 32 countries.

Another element of our World Hemophilia Day awareness campaign, that has grown impressively in recent years, is the lighting of landmarks in red around the world to mark World Hemophilia Day. This past April 17, more than 40 landmarks were lit around the world; more than doubling the number from last year. The U.S. led the way, with a majority of the landmarks coming from around the country. We are pleased to note that in 2016, there was increased global efforts to participate in this initiative, with landmarks in South America, Europe, and Asia lighting up in red. Highlights from the list are the U.S. and Canadian sides of Niagara Falls, Jesus Christ the Redeemer in Rio de Janeiro, Brazil, and Trafalgar Square in London, United Kingdom.

Photos can be viewed on the WFH Facebook page at www.facebook.com/wfhemophilia.

The WFH is also very pleased to announce that World Hemophilia Day 2016 marked the launch of our ten-part Treatment for All video series. This series gives an in-depth perspective about the WFH Humanitarian Aid Program and how we have expanded it significantly in recent years with the support of our partners. You can access all the videos at www.treatmentforall.org.

World Hemophilia Day joins us all around one important goal—to raise awareness about the common challenges that our community members face. It also demonstrates that we are all in this together—that each of us is intricately linked together on a global scale.

Susan Skinner Memorial Fund Recipients Represent Global Community

The Susan Skinner Memorial Fund honors the memory of a woman who worked tirelessly to ensure that her sons and many others received effective treatment for their bleeding disorder. This year marks the 10th anniversary of the establishment of the Fund to support the training, education, and leadership development of young women with bleeding disorders.

It is hard to say whether Mrs. Skinner envisioned her legacy stretching across borders to bring women living with a bleeding disorder together but thanks to the generosity of many supporters, her commitment to the bleeding disorder community lives on. The growth of the endowment fund has enabled us to double the number of scholarships awarded for the 2015-2016 award cycle.

Joelle Palmatier from Alaska, Michelle Cecil hailing from Michigan, Ashley Taylor-Fowlie of New Zealand, and Claudia Teresa Peña Villena from Peru will all be attending the WFH 2016 World Congress with all housing, transportation, and registration expenses covered thanks to this fund. Attending this event is a life-changing experience and we look forward to seeing the impact these four dynamic award-winners have on their community in the coming years.

To learn more about this program or to make a donation, visit www.wfh.org/en/about-us/wfh-usa/susan-skinner-memorial-fund-scholarship or contact us at info@wfhusa.org.
WFH USA acknowledges the contributions of the following National Hemophilia Foundation (NHF) Chapters and other bleeding disorder organizations that gave generously towards the WFH Humanitarian Aid Program in 2015. Their philanthropic leadership represents a tremendous vote of confidence in the work we do in pursuit of Treatment for All, as all of these organizations work closely with patients, their families, and healthcare professionals. It also sends a clear signal to other community members and potential supporters of their belief in the difference that we can all make when working together.

It is with deep gratitude that we salute our 2015 World Cup Winners:

- Arizona Hemophilia Association
- Bleeding Disorders Alliance Illinois
- Colorado Chapter of the National Hemophilia Foundation
- Eastern Pennsylvania Chapter
- Florida Hemophilia Association
- Hemophilia Association of the Capital Area
- Hemophilia Foundation of Greater Florida, Inc.
- Hemophilia Foundation of Minnesota/Dakotas
- Hemophilia Foundation of Northern California
- Hemophilia Foundation of Oregon
- Hemophilia of Georgia, Inc.
- Hemophilia of Iowa, Inc.
- Hemophilia of North Carolina
- Hemophilia of South Carolina
- Louisiana Hemophilia Foundation
- Mary M. Gooley Hemophilia Center
- National Hemophilia Foundation
- Rocky Mountain Hemophilia & Bleeding Disorders Association
- Virginia Hemophilia Foundation

Hemophilia Alliance Supports U.S. Healthcare Professional Continued Training

WFH USA is pleased to announce the first installment of Hemophilia Alliance Travel Grants which will begin this year in time for the WFH 2016 World Congress. This grant will advance the art and science of bleeding disorders nursing, psychosocial work, dentistry, physiotherapy, and laboratory sciences. Funded through the generous grant support from the Hemophilia Alliance, a $15,000 grant per year is committed to support scientific exchange and global learning through attendance of one American member, from selected WFH multidisciplinary committees, at international meetings of the WFH.

WFH Epidemiological Research Program Launches World Bleeding Disorders Registry

The WFH Research Program was launched in 2013 with the goal of supporting and facilitating clinical research in inherited bleeding disorders. This program is supported by grant support provided through WFH USA. The program has two components: the WFH Epidemiological Research Program and the WFH Clinical Research Grant Program.

The priority for the WFH Epidemiological Research Program is to collect individual patient data from an international network of treatment centers and create a World Bleeding Disorders Registry, which would serve as a platform for directed epidemiological and outcomes research. In 2016, we will be initiating a pilot project in a few centers around the world, with the intention of including U.S. hemophilia treatment centers in the pilot.
THANK YOU!
WFH USA depends on your gifts of time, medical supplies and products, and resources. 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 2015, we thank you.

$500,000 and more
Biogen

$150,000-$499,999
Hemophilia Center of Western Pennsylvania

$50,000-$149,000
Hemophilia of Georgia, Inc.

$50,000-$149,000
Packaging Coordinators, Inc. (PCI)
Pfizer

$25,000-$49,999
National Hemophilia Foundation

$10,000-$24,999
Anonymous Gift

$10,000-$24,999
Eastern Pennsylvania Chapter Hemophilia Alliance Foundation
Mark Skinner & Jim Matheson

$5,000-$9,999
Glubrizol Foundation
Phillips 66

$2,500-$4,999
Bayer HealthCare
LA Kelley Communications, Inc.
The Marketing Research Bureau, Inc.

$1,000-$2,499
Arizona Hemophilia Association

$1,000-$2,499
Center for Inherited Blood Disorders
Community West Foundation
Cheryl D’Ambrosio
Geoffrey Dietrich
Florida Hemophilia Association
Hemophilia Foundation of Greater Florida, Inc.
Hemophilia Foundation of Northern California
Hemophilia Foundation of Oregon
Mary M. Gooley Hemophilia Center
Sally McAllister
Declan Murphy
Ken Trader

$500-$749
Alain Baumann
Paula Bell
Colorado Chapter of the National Hemophilia Foundation
Donald Goldman

Hemophilia Foundation of Minnesota/Dakotas
Hemophilia of Iowa, Inc.
Hemophilia of North Carolina
Hemophilia of South Carolina
Hudson Montessori Middle School
Ali Karimi
Mary Pham
Margaret V. Ragni
Rocky Mountain Hemophilia & Bleeding Disorders Association
Claudia Schoening-Diesing
Karen Tubridy
Mary Wingate
Virginia Hemophilia Foundation

$250-$499
John Button
Bruce Evatt
Hemophilia Association of the Capital Area
Nancy Flemming
Peter Kouides
Phillip Kucab
Dana Kuhn
Roshni Kulkarni
Paul Monahan
Ken Nolan
Allen Renz
Dawn Rotellini
Arthur Thompson
Ellen White
Wing Yen Wong

$100-$249
Patsy Carman
Donald Cobb
Randall Curtis
Amy Dunn
Angela Forsyth
John Gisselbeck
Sally Griffiths
Kirby Hesler
Joan Jacques
Carol Kasper
Craig Kessler
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Pierce Douglas Living Trust
Mathew Prasad

Kathleen Pratt
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Patrick Robert
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Frank Schnabel
Barry Sudbeck
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Susanna von Oettingen
Wendy Wild
Hassan M. Yaish

$50-$99
Neva Anderson
Brad Benne
Leigh Carpenter
Charles Chiasson
Arleigh Clemens
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David Green
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Myers Plumbing & Heating Inc.
Alan Neaigus
Greg Price
Bob Sawyer
Virginia Starkweather
Stephanie Storey
Srilatha Tangada
Karen Wulf

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Anonymous Gift
Judy A. Bagato
Matt Chapman
Teresa Curran
Rebecca Grubman
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One Decision: A Lifetime of Service

DR. GLENN PIERCE

Like so many of our life paths, Dr. Glenn Pierce’s involvement with the global bleeding disorder community over the past four decades began with an unassuming step. In his case, it was the decision to volunteer on weekends with his local chapter in Northern Ohio. While volunteering there, he met an early mentor, former WFH President Charles Carman. The experience instilled within him a belief that working with the WFH was a worthy use of his time and talents. The lessons Glenn took to heart continue to inform his actions, including his decision to support the WFH Humanitarian Aid Program financially through his annual donation.

He views it all as an organic process; there was no master plan as he took on increasingly senior leadership roles within the community, culminating in joining WFH USA in 2014 as Vice-President of the Board, and the WFH Board of Directors in 2015. There is however, one current motivation coursing through his decisions; a sense of giving back to his community. For many of us, this means volunteering with a local charity, but in Glenn’s case his community stretches across the globe. His work in the developing world forms a second powerful influence upon his altruism; a deep devotion to ensuring that everyone, regardless of country, has access to the same level of care we enjoy in the United States.

In many of his trips, Glenn witnesses firsthand the disastrous impact bleeding disorders have upon those living with substandard levels of care. In keeping with his sense of community, Glenn vocally advocates in the U.S.A. and abroad for patient access to medication and trains healthcare professionals in proper diagnosis and treatment techniques within the developing world. To him, this is just a natural extension of his personal hands-on approach to giving of his time and resources. Yet to the many individuals who have benefited from his involvement over these many years, it means addressing the disparities in care, one life at a time. Glenn’s commitment to ‘give back’ transforms the lives of these individuals and yours can as well. We invite you to support the WFH Humanitarian Aid Program through visiting www.wfh.org/donateusa today.

Over forty years of giving back began with one young man’s decision to help; we encourage you to join Glenn so that one day we can raise our hands together in triumph as we reach our goal of Treatment for All.

Community*

*Membership Matters  wfh.org/membership

WFH
WORLD FEDERATION OF HEMOPHILIA
Friend*

*Humanitarian Aid Required  wfh.org/donateusa