WFH USA HEMOPHILIA AID
YEAR-END REPORT

WFH USA advances the global mission of the World Federation of Hemophilia in the United States.
WFH USA
WORLD FEDERATION OF HEMOPHILIA USA

WFH USA advances the global mission of the World Federation of Hemophilia (WFH) in the United States. We provide American citizens, foundations, and corporations the opportunity to ensure Treatment for All people with bleeding disorders worldwide. WFH USA is a 501(c)3 charity recognized by the IRS. Donations are tax deductible.

WFH is an international not-for-profit organization based in Montreal, Canada, working in 134 national member organizations to close the gap in care and to achieve treatment for all men and women with hemophilia and other inherited bleeding disorders.

WFH USA 2016-2018
STRATEGIC PLAN

WFH USA and WFH work in collaboration to carry out the strategic objectives of this plan. Implementation is achieved through an integrated and unified approach to enhance the impact of both organizations.

STRATEGIC PRIORITIES

1. Develop resources to support the WFH global mission to improve and sustain care
2. Build U.S. awareness for the global vision of Treatment for All
3. Achieve organizational excellence

To learn more about WFH USA, visit www.wfhusa.org

SUPPORTING OUR COMMUNITY

With help from our corporate partners and community supporters, we will bring certainty to those most in need.

• Donate: Your gift will save lives. www.wfhusa.org/donate

• Become a WFH USA donor through the WFH Caregiver Program: Your monthly gift can help children living with a bleeding disorder rise above uncertainty.

• Join today, the WFH Global Community Program (GCP): Get engage and connected with our ‘give-back’ global community, and stay current with the latest news. www.wfh.org/cgp

Charitable solicitations for the common purposes of WFH and WFH USA within the U.S. are conducted through WFH USA, a 501(c)3 affiliated entity.
WFH USA
PRESIDENT’S REPORT

In July 2016, the global bleeding disorders community came together in the United States for the first time in over 25 years making the XXXII International Congress of the World Federation of Hemophilia (WFH) the largest yet, with more than 5,400 attendees from 138 countries. This was invaluable for the U.S. community as many healthcare professionals and people with bleeding disorders were able to meet and learn from others around the world.

The expansion of the WFH Humanitarian Aid Program resulted in a banner year – with donations rising to over 140 million IUs from all contributors. This meant a significant increase from just over 3,700 patients treated in 2015, to over 14,500 patients treated in 2016, including over 1,000 surgeries reported by early 2017.

Engagement and support from NHF and its chapters, responding to a call to action to strengthen the WFH Humanitarian Aid Program, meant that a record number of chapters were inspired to participate in the matching grant program championed by Hemophilia of Georgia and NHF. We set an ambitious objective of raising $200,000 to contribute to the shipment of humanitarian aid and provide operational support. With the help of NHF and its chapters, we met and surpassed this goal.

The donations to the Susan Skinner Memorial Fund (SSMF) totaled $18,619 in 2016 and $35,510 in 2015. After a disbursement of $20,000 for SSMF scholarships in 2016, it brought the endowment fund balance to $322,454 from $323,835 at the end of 2015.

WFH USA 2016 FINANCIAL REPORT

We had an excellent year for charitable monetary donations with a 2016 total of $293,021, compared to $195,992 in 2015. As there was an upsurge in distribution activities for the WFH Humanitarian Aid Program, expenses toward this program rose to $1,257,937 in 2016, compared to $671,362 in 2015. WFH USA was able to contribute $65,000 towards the cost of shipping and handling of the humanitarian aid product donations. In 2016, there was a net surplus of $145,156 versus $25,502 in 2015. WFH USA remains in sound financial health with year-end unrestricted assets of $239,027.

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 2016, the WFH Humanitarian Aid Program continued to expand, with an impressive 140.9 million international units (IU) donated to 58 developing countries. This represents a 167% growth in the volume of IUs distributed, versus 2015 with a total donated of 52.8 million IUs. The dollar value of product donations in WFH USA financial statements for 2016 reached $324,814,434, as compared to $97,098,511 in 2015.

The U.S. bleeding disorders community provides integral financial and volunteer support to help our brothers and sisters around the world. The pain and suffering that many experience, due to limited access to care and treatment, is not a reality that we experience in the United States. It is through your continued generosity that we are bringing certainty of treatment to an often uncertain world. Together we are moving closer to our vision of Treatment for All.

THANK YOU FOR YOUR SUPPORT.
The expansion of the WFH Humanitarian Aid Program began in 2015 and over 2016, the number of recipient countries totaled 58. The delivery of donations reached a landmark of over 140 million international units (IU) by the end of 2016. The increase of clotting factor concentrates (CFC) channeled through the WFH Humanitarian Aid Program meant that there was a significant increase in the number of patients treated globally, totaling over 14,500 in 2016.

For the first time in the program, there was utilization reported for prophylaxis treatment, with 852 patients reported by the end of 2016. In addition, donations were used for surgeries, with 795 surgeries reported in 2016. Of these surgeries, 7% were life- and limb-saving and the rest were conducted to improve the quality of life for those in need.

An increasing number of contributors within the global bleeding disorders community have accepted the challenge of providing a sustainable and predictable supply of donated products. The visionary contribution from Bioverativ and Sobi to the WFH Humanitarian Aid Program translates into over 500 million IUs over five years (2015-2020). In addition, the eight-year commitment (2014-2021) from Grifols totaling 200 million IUs, along with a ten-year commitment (2009-2018) from CSL Behring for a total of 22 million IUs, and the three-year agreement (2017-2019) with Green Cross for 6 million IUs, there will now be a more predictable and sustainable flow of humanitarian aid donations to the global community. In addition, the initiatives of Project WISH and Project Recovery allow for the manufacturing of clotting factor concentrates from previously discarded cryopaste which provide treatment products to countries most in need.

Through engagement and support, NHF and Hemophilia of Georgia (HoG), as founders for the NHF Chapter Challenge, inspired a record number of NHF Chapters to participate in the matching grant program to help support the WFH Humanitarian Aid Program. WFH USA would like to thank NHF, HoG, and its chapters for their continued support, which is needed to help strengthen the operational success of the WFH Humanitarian Aid Program. We also thank The Alliance Pharmacy who joined HoG as a contract pharmacy to support the shipping of humanitarian aid donations.

**VISIONARY CONTRIBUTORS**
- Bioverativ
- Sobi

**CONTRIBUTORS**
- CSL Behring
- Green Cross
- Grifols

*Companies who have committed to multi-year donations allowing for a predictable and sustainable supply for the WFH Humanitarian Aid Program.

**OTHER DONATIONS**
- Bayer
- Biotest
- Bioverativ
- CSL Behring
- Grifols
- Octapharma
- Shire

**CONGRESS DONATIONS**
- Bayer
- Bioverativ
- CSL Behring
- Grifols
- Novo Nordisk
- Octapharma
- Pfizer
- Shire

**2016 CHAPTER CHALLENGE CHAMPIONS**

**THE WFH PROUDLY SALUTES OUR 2016 NHF CHAPTER CHAMPIONS FOR HUMANITARIAN AID**

**FOUNDING CHAMPION**
- National Hemophilia Foundation

**FOUNDING CHAPTER CHAMPION**
- Hemophilia of Georgia

**CHAPTER CHAMPIONS**
- Bleeding Disorders Alliance Illinois
- Bleeding Disorders Association of Northeastern New York
- Central Ohio Chapter of the NHF
- Colorado Chapter of the National Hemophilia Foundation
- Eastern Pennsylvania Chapter of the NHF
- Florida Hemophilia Association
- Great Lakes Hemophilia Foundation
- Hemophilia Association of the Capital Area
- Hemophilia Foundation of Greater Florida, Inc.
- Hemophilia Foundation of Michigan
- Hemophilia Foundation of Minnesota/Dakotas
- Hemophilia Foundation of Nevada
- Hemophilia Foundation of Northern California
- Hemophilia Foundation of Oregon
- Hemophilia Foundation of Southern California
- Hemophilia of Indiana Inc.
- Hemophilia of Iowa, Inc.
- Hemophilia of North Carolina
- Hemophilia of South Carolina
- Lone Star Chapter of the NHF
- Mary M. Gooley Hemophilia Center
- Midwest Hemophilia Association
- Northern Ohio Hemophilia Foundation, Inc.
- Rocky Mountain Hemophilia & Bleeding Disorders Association
- Sangre de Oro, Inc. Hemophilia Foundation of New Mexico
- Tennessee Hemophilia & Bleeding Disorders Foundation
- Utah Hemophilia Foundation
- Virginia Hemophilia Foundation

**NHF Chapter Reception during the WFH Global NMO Training**
The aim of the WFH World Bleeding Disorders Registry is to develop a database of high quality, real world data on a large population of people with hemophilia, which will be used to generate evidence and improve the quality of hemophilia care worldwide.

Seed funding was generously provided through the 340B program and the Hemophilia Center of Western Pennsylvania (HCWP), allowing us to conduct a pilot study in a limited number of hemophilia treatment centers (HTCs). A total of 26 HTCs, representing 25 countries, participated in the pilot study, including the Boston Hemophilia Center, representing the U.S.A. This important project allowed us to confirm the feasibility of conducting a patient registry in countries around the world, in HTCs of varying levels of care. WFH USA extends its gratitude to the HCWP, the 26 HTCs, and the 356 patients who participated in the pilot study. Moving forward, participation of U.S. HTCs will continue to be an important component of the WBDR, as we seek to leverage the power of global data to benefit patients in the U.S. and around the world.

The full scale WFH World Bleeding Disorders Registry will be implemented in the latter half of 2017. WFH USA will continue to support this important initiative for the global bleeding disorders community.

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WFH WORLD BLEEDING DISORDERS REGISTRY

“There is a human element to the World Bleeding Disorders Registry that can’t be overstated. The patient registry is about bringing patients together from around the world in a cooperative fashion. It’s about all of us working as a team to further knowledge in the bleeding disorders community.”

— Glenn Pierce, WFH USA Vice-President
Hemophilia World, December 2016

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WORLD BLEEDING DISORDERS REGISTRY
Pilot Study, April–December 2016

26 Hemophilia Treatment Centres participated representing 25 countries

356 people with hemophilia enrolled
Throughout 2015 and 2016, every effort was made to ensure that the WFH 2016 World Congress in Orlando, Florida, would be a milestone in the history of the World Federation of Hemophilia (WFH). The global bleeding disorders community met for the first time in over 25 years in the United States and the XXXII International Congress of the WFH was the largest yet, with more than 5,400 attendees, from 138 countries.

The collaboration of NHF and WFH resulted in the consistent and aligned marketing efforts, leading to a participation of overall 2,286 attendees from the United States, record numbers both for U.S. healthcare professionals and patients.

The WFH World Congress is a unique platform for the global bleeding disorders community to learn, network, and share knowledge.

Hemophilia Alliance provided the first installment of travel grants for U.S. multidisciplinary healthcare professionals to attend 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, to attend an international meeting of the WFH.
WFH GLOBAL COMMUNITY PROGRAM

Our community asked and we listened. You told us you wanted an inclusive experience where community connection and engagement were the primary focus. We launched the WFH Global Community Program (GCP) on February 1, 2017, and the response to date has been overwhelmingly positive. The new GCP Citizen Affiliate category is free of charge and serves as an entry point into our global network.

Join today and you will receive news, access to our online GCP portal, and a way to give back.

• The GCP Friend Affiliate is an excellent way to financially support the work the WFH does for the global bleeding disorder community.

• The GCP Professional Affiliate will provide you with access to Haemophilia Journal, while supporting WFH initiatives around the world.

• The GCP Organization Affiliate can be shared with up to 10 of your team members and will support the work WFH does to achieve its vision of Treatment for All.

To learn more about this exciting new program and join today, please visit: www.wfh.org/cgp.

SUSAN SKINNER MEMORIAL FUND

The Susan Skinner Memorial Fund (SSMF) was established 10 years ago in 2007 by WFH USA to support the training, education and leadership development of young women with bleeding disorders. In 2016, we were proud to award a record four scholarships; two to international recipients and two from the U.S.A. Leading up to the celebration of the 10th Anniversary of the SSMF in 2017, we are reaching out to past recipients asking them to help commemorate this important milestone by sharing their stories of how your past support of this fund has helped make a positive impact in their lives. We will also be engaging the community in a special commemorative appeal in the fall to bolster the endowment fund for future life changing initiatives.

As we mark the 10th anniversary, WFH USA would like to express its gratitude to Mr. Thomas Skinner who initially endowed the fund, along with family members, friends, and organizations from the bleeding disorders community who continue their support.
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 from January 1 to December 31, 2016, we thank you.

DONOR ROLL

$100,000 +
Hemophilia of Georgia, Inc.

$50,000 – $99,999
National Hemophilia Foundation

$25,000 – $49,999
Kenneth Trader
Tennessee Hemophilia
Frank Schnabel III
Rocky Mountain Hemophilia
Joe Pugliese
Midwest Hemophilia
Sally K. McAlister
Mary M. Gooley Hemophilia
Hemophilia of North Carolina
Hemophilia of Indiana Inc.

$10,000 – $24,999
Lone Star Chapter of the NHF
Bleeding Disorders Association

$5,000 – $9,999
ARU Infusion Services
Eastern Pennsylvania Chapter of the NHF
Donald and Barbara Goldman
LA Kelley Communications, Inc. Phillips 66

$2,500 – $4,999
Bleeding Disorders Association

$1,000 – $2,499
Paula Bell
Central Ohio Chapter of the NHF
Colorado Chapter of the National Hemophilia Foundation
Hemophilia Foundation of Greater Florida, Inc.
Hemophilia Foundation of Michigan
Hemophilia Foundation of Oregon
Hemophilia Foundation of Southern California
Hemophilia of Indiana Inc.
Hemophilia of North Carolina
Mary M. Gooley Hemophilia Center

$500 – $749
Alain Baumann
Bleeding Disorders Alliance Illinois
The Capretto Family
Florida Hemophilia Association
Paul F. Haas
Hemophilia Association of the Capital Area
Hemophilia Foundation of Minnesota/Dakotas
Bruce A. Luxon
Maria Manahan
John Murphy
Kathleen Pratt
Maria M. Salas-Pilla
Utah Hemophilia Foundation
Leonard A. Valentino
Virginia Hemophilia Foundation
Mary Q. Wingate

$250 – $499
Akin Akin
Randall Curtis
Bruce L. Evatt
Great Lakes Hemophilia Foundation
Keith Hoots
Craig Kessler
Phil Kucab
Heidi Scanlan

$100 – $249
David Blanchard
Jim and Margie Braden
John and Heather Button
Leigh Carpenter
Amy Dunn
Joan C. Gill
John and Penny Gisselbeck
Jocelyn B. Gorlin
Sally Griffths
Hemophilia of South Carolina
Rodshi Kulkarni
Martin Loria
Harvey J. McCarter
Alan Reaigus
Mary Pham
Douglas W. Pierce
Shelly A. Reed
Amy and Allen Renz
Sangre de Oro, Inc.
Hemophilia Foundation of New Mexico
Gina Schnabel
Frank L. Schnabel IV
Brian Skinner
Michelle Witkop

UP TO $99
Neva L. Anderson
Charles Chiasson
Carlos Diaz
Joel Estes
Stephen Feig
John G. Foster
Marc Gilgann
Sandra Goldstein
Fabio Gratton
David Green
Jeremy Griffin
Teresa Hall
Gina Haynes
Robina E. Ingram-Rich
Susan Karp
Laurie Kay
Martin L. Lee
Emigh Litch
Antoinette Marcian
Christina Matamoros-Lapp
Prasad Mathew
Andrew Mattews
Jonathan Maybaum
Stephen Maybaum
Tony Maynard
Joseph Luis Mejia
Richard J. Metz
Ann-Marie Nazzaro
Jennifer O’Donnell
Joel R. Queen
Patrick Robert
Russell and Carol Rose
Dawn Rotellini
Sarah Roth
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