



WFH USA

WORLD FEDERATION OF HEMOPHILIA USA

WFH USA HEMOPHILIA AID YEAR-END REPORT

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

2017

www.wfhusa.org



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** for 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 with 140 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.

SUPPORT OUR WORK

Your contribution will bring our vision of Treatment for All closer to reality.

- Donate today at wfhusa.org/donate
- Join today our Global Community Membership Program (GCMP). GCMP members support WFH programs and receive regular updates from the global bleeding disorders community. wfh.org/gcmp

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.

OUR FOCUS



Humanitarian Aid

The WFH Humanitarian Aid Program is leading the effort to improve lack of access in developing countries.



Research and Data Collection

The WFH Research and Data Collection programs create better evidence for the management of inherited bleeding disorders.



Training and Education

The WFH provides the community with free access to education resources and has organized hundreds of workshops for medical professionals and patient leaders.



Scholarships

The Susan Skinner Memorial Fund endowment supports the training and education of young women with bleeding disorders.

To learn more about the WFH USA:
www.wfhusa.org



Mark W. Skinner
WFH USA PRESIDENT

PRESIDENT'S REPORT

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Following the success of the WFH 2016 World Congress in Orlando, Florida, support has increased within the U.S. for the global mission of WFH USA.

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I would like to thank all the volunteers, supporters, and funding partners that have helped WFH USA advance the vision of Treatment for All people with bleeding disorders around the world. In addition, the WFH USA Board welcomed three new Directors; Dawn Rotellini, Frank Schnabel IV, and Joe Pugliese, all bringing invaluable expertise that will serve us well in the future.

The U.S. bleeding disorders community continues to take a leadership role within the international arena. We not only provide significant financial support, but also volunteer our expertise to help improve and sustain care for those who do not experience the same level of treatment as we do within the United States.

We continue to build our relationships with the National Hemophilia Foundation and its chapters. We are truly grateful for their ongoing support of our mission and look forward to many years of partnership.

To our corporate partners and individual supporters from coast to coast, I thank you for your continuing generosity. The following pages highlight some of our many achievements and I encourage you to visit news.wfh.org to keep up to date with the latest developments.

On behalf of the WFH USA Board, I thank you for your support.

2017 FINANCIAL REPORT

Charitable monetary donations, excluding the WFH Humanitarian Aid Program, were solid in 2017 with a total of \$260,611, compared to \$293,021 in 2016. Offsetting this was \$190,241 paid to the WFH for services they provided to WFH USA based on Canadian tax laws. These services were previously provided in kind. As the expanded scope of the WFH Humanitarian Aid Program continued, revenues and expenses toward this program remained high at \$1,041,287 in 2017, compared to \$1,257,937 in 2016. In 2017, there was a small deficit of \$6,408 versus a net surplus of \$145,156 in 2016. WFH USA remains in sound financial health with year-end unrestricted assets of \$232,619 (\$239,027 in 2016).

Each year, WFH USA receives in-kind humanitarian aid donations of clotting factor concentrates 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 2017, the WFH Humanitarian Aid Program continued to expand, with an impressive 160.1 million international units (IU) donated to 60 developing countries. This represents a 14% growth in the volume of IUs distributed, versus 2016 with a total donated of 140.9 million IUs. The dollar value of product donations in WFH USA financial statements for 2017 reached \$353,263,571, as compared to \$324,814,434 in 2016.

WFH USA is grateful to our 2017 Chapter Challenge Champions that support the mission of WFH USA. In particular we thank our Founding Champions, the National Hemophilia Foundation and Hemophilia of Georgia. Their participation has inspired chapters from around the country to participate, bringing the total of Chapter Challenge contributions raised to \$172,600 (\$211,912 in 2016).

The donations to the Susan Skinner Memorial Fund (SSMF) totaled \$70,361 in 2017 (\$18,619 in 2016). This brought the endowment fund balance to \$392,815 from \$322,454 at the end of 2016. It also allowed us to send 6 scholarship recipients to the WFH 2018 World Congress in Glasgow, Scotland.

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 \$394,882 in 2017, comparable to the value of \$398,125 contributed in 2016.

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 wfhusa.org

GLOBAL IMPACT



WFH HUMANITARIAN AID PROGRAM: INVESTING TO CHANGE PATIENTS' FUTURES

The lack of access to care and treatment in developing countries is an urgent and important public health challenge, as the cost of products to treat is prohibitively expensive for the majority of those affected with a bleeding disorder.

WFH USA strongly believes that where you live should not determine your access to care and treatment for an inherited bleeding disorder. In 2017, thanks to our contributors, we were able to distribute more than 160 million IUs to patients in 60 countries across the globe. Children in these countries can now have corrective surgeries and access to prophylaxis treatment that enable them to enjoy a vastly improved quality of life.

VISIONARY CONTRIBUTORS

Bioverativ, a Sanofi Company
Sobi



CONTRIBUTORS

CSL Behring
Green Cross
Grifols

The visionary contribution from Bioverativ, a Sanofi company, and Sobi to the WFH Humanitarian Aid Program translates into 500 million IUs over five years (2015-2020). Bioverativ and Sobi also make ongoing substantial financial contributions to support the logistics of product delivery and training of providers and patients in humanitarian aid recipient countries. Furthermore, 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, allows for a more predictable and sustainable flow of humanitarian aid donations to the global community.

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.

The factor has changed lives. The humanitarian aid has hugely made a difference to us.

— Dr. Reshma Roshan, Hematologist, India

IN 2017



160

MILLION IUs
TO PATIENTS

IN



60

COUNTRIES
ACROSS
THE GLOBE



WFH RESEARCH PROGRAM: INVESTING IN OUR KNOWLEDGE

The WFH World Bleeding Disorders Registry (WBDR) aims to provide a global platform for hemophilia treatment centers (HTC) to collect standardized patient data. The WBDR will complement the country level aggregate data collected through the Annual Global Survey, by providing patient level data from individual treatment centres. The WBDR houses real-world data on the patient clinical experience around the globe, allowing researchers to generate evidence, build evidence-based advocacy initiatives, and improve the quality of care worldwide.

The WBDR has already surpassed its 5-year goal of functioning in over 50 countries and is on track to enroll 200 HTCs and register 10,000 patients.

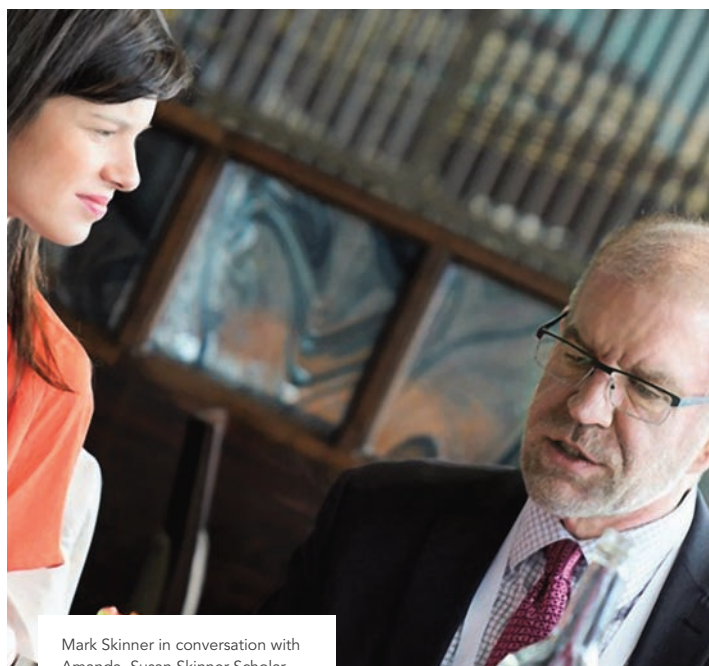
— Donna Coffin, WFH Director of Research & Public Policy

SUSAN SKINNER MEMORIAL FUND: INVESTING IN WOMEN LIVING WITH BLEEDING DISORDERS

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. The award invests in the future leaders of our community, as only women between the ages of 18 and 30 who have a bleeding disorder or are carriers are eligible to apply. This forward-looking initiative is building a global network of future leaders. Working together, they will become standard bearers for the WFH mission to improve and sustain care for people with inherited bleeding disorders around the world.

I feel so grateful to my country association and the Susan Skinner Memorial Fund supporters that I will work more than ever to accomplish the objectives we have in Uruguay and across the world.

— Amanda Brito Del Pino, mother to young boy with bleeding disorder and SSMF 2017 Scholar



Mark Skinner in conversation with Amanda, Susan Skinner Scholar

HEMOPHILIA ALLIANCE – INVESTING IN OUR MEDICAL PROFESSIONALS

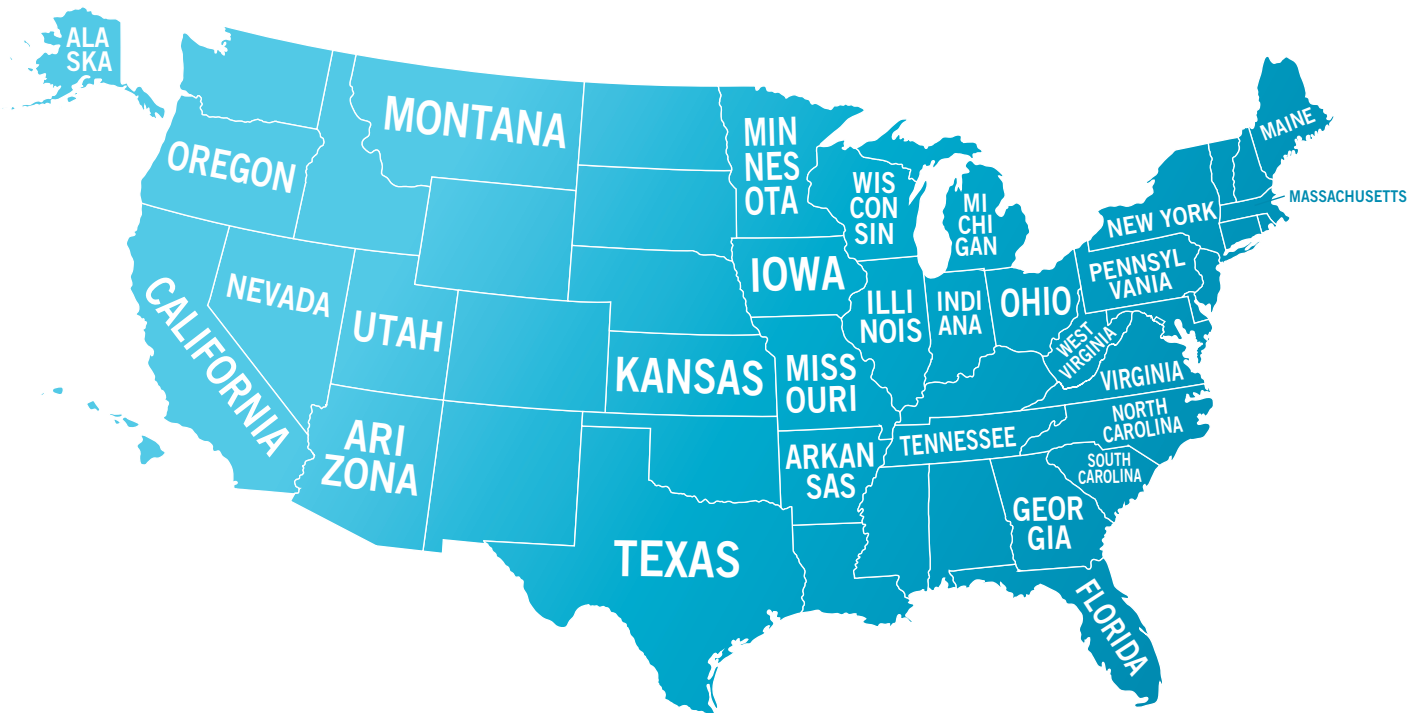
The Hemophilia Alliance is a non-profit that promotes the common interest of federally funded hemophilia treatment centers (HTC). Their funding established the Travel Grant Program, enabling U.S. based WFH committee members to attend WFH World Congresses, where they make valuable contacts and build capacity that will benefit the entire community.

The travel grants are an extension of our mission to educate leaders and advocates and we are proud to do so.

— Joe Pugliese, President and CEO of the Hemophilia Alliance

SUPPORT FROM COAST TO COAST

The WFH USA proudly salutes and thanks our 2017 Chapter Challenge Champions that support the mission of WFH USA. We would particularly like to thank our Founding Champions, the National Hemophilia Foundation and Hemophilia of Georgia.



CHAPTER DONORS

Alaska Hemophilia Association
 Arizona Hemophilia Association
 Bleeding Disorders Alliance
 Illinois
 Bleeding Disorders Association
 of Northeastern New York
 Eastern Pennsylvania Chapter
 of the NHF
 Florida Hemophilia Association
 Gateway Hemophilia Association
 Hemophilia Alliance of Maine, Inc.
 Hemophilia Association of the
 Capital Area
 Hemophilia Foundation of
 Arkansas, Inc.

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 Hemophilia of Georgia, Inc.
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Hemophilia of South
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 Lone Star Chapter of
 the NHF
 Midwest Hemophilia
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 Nevada Chapter of
 the National Hemophilia
 Foundation
 New England Hemophilia
 Association
 Rocky Mountain Hemophilia
 & Bleeding Disorders
 Association
 Virginia Hemophilia
 Foundation

OUR STORIES

WFH USA enjoys support from across America and what binds us together on our shared journey is the belief that where you live should not determine your standard of care. We are happy to introduce you to two members of our community whose individual journeys inspire all of us.

Dad to a thriving son living with hemophilia

Eric Stolte
WFH USA Board Member and past WFH Vice-President Finance



A dual citizen of both the United States and Canada, Eric understands how local experience informs action on a global scale. His first exposure to the bleeding disorder community was through his father-in-law who lived with hemophilia. He was fully aware of the likelihood bleeding disorders would become a part of his life as he set about building a family with his wife Marion.

Eric's son was born with hemophilia A and he started volunteering with his local chapter, doing what he could to help and learn from other families living through the same experience. Attending the WFH 2000 World Congress, in Montreal, was a watershed moment for him as he confronted in person the incredible disparity in access to treatment. At that moment, he decided to get involved on a larger scale, eventually serving as WFH Vice-President Finance. For Eric, supporting the WFH gives personal satisfaction at having a global impact and continually being surprised at what we can achieve together.

Mom to a thriving son living with hemophilia

Dawn Rotellini
National Hemophilia Foundation Senior Vice-President, WFH USA Board member, and WFH Board member.



When asked what message she wished to share with the entire bleeding disorder community and allies, Dawn immediately responded: "This is not ok, I will help today". Dawn came by her "can-do" attitude by way of her father, who managed his hemophilia without access to a treatment center (HTC) nor awareness of the work the National Hemophilia Foundation (NHF) was doing to advance the cause of those living with a bleeding disorder in the United States. When doctors diagnosed her son at nine-months old, Dawn began making the 10-hour commute to the nearest HTC in Colorado. It was there she learned about the NHF Chapter network and on the drive home a plan about how she could help other families facing the same challenges began to form. That initial desire to help led her to found Montana's first NHF Chapter, the Rocky Mountain Hemophilia and Bleeding Disorders Association.

Her professional trajectory continued upwards and there were two constants; she ensures those with little access to power are heard and a steadfast dedication to showing peoples how they can make a difference if they work together. Dawn now brings her expertise and passion for change to the global stage. She is going to use her new platforms to represent those who most need it. Her goal, in her own words: "I want to do my part to ensure WFH's vision of Treatment for All one day becomes a reality". WFH USA shares Dawn's enthusiasm and belief that change is possible when we all work together.

FREE GCMP MEMBER

Become a Global Community Membership Program (GCMP) member and receive regular updates about the global bleeding disorders community and WFH programs.

WFH.ORG/GCMP



THANK YOU!

Without the financial support we receive from our valued supporters, we would be unable to help those members of our community who are most in need. To all of you, we are eternally grateful.

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\$100,000 +

Hemophilia of Georgia, Inc.

\$50,000 – \$99,999

Hemophilia Alliance Foundation
National Hemophilia Foundation

\$25,000 – \$49,999

Glenn and Beatrice Pierce

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Northeastern New York
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Lone Star Chapter of the NHF

\$1,000 – \$2,499

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Dawn Rotellini
NHF Liaison
WFH Board Member

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