



WFH USA YEAR-END REPORT

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

2018

www.wfhusa.org

CHAMPIONS AMONG US

Supporters of WFH USA believe that where you live should not determine your access to care. These incredible champions draw the inspiration and courage to make a difference both in their own communities and far beyond.



The McGuire Smith Family

INSPIRED BY FAMILY: MEET MADONNA MCGUIRE SMITH

Madonna knew she would devote her life to helping others. After her son, both daughters and her husband received the news they had von Willebrand Disease, her path became clear: she would work within the bleeding disorder community. This path led to her current position of Executive Director of the Hemophilia Foundation of Oregon (HFO).

Her first exposure to the work of the WFH was a Twinning Program presentation at the 2016 WFH World Congress in Orlando. Impressed with the impact of the program, she applied soon after returning home. HFO was paired with the patient organization in Ethiopia. Upon arrival for their first site visit, they knew their decision would leave a legacy in both communities, as their organizations learn from each other and create bonds that will last a lifetime.

Madonna knows first-hand the difference having access to trained healthcare professionals and medication can make. In 2018, their family adopted a young boy from China who lives with a bleeding disorder. Before arriving in Oregon, he had limited access to medication and could not play with friends outside. Thanks to reliable access to medication, he now enjoys many of the activities the Pacific Northwest offers.



Reunion: Ed first met Roger in Peru in 2005 when Roger was just 8 years-old

INSPIRED BY YOUTH: MEET ED KUEBLER

Ed is a well-known presence within the US and the international bleeding disorder community today, but his involvement began three decades ago when he designed a Youth Leadership program for a summer camp in Texas. The experience lit a spark for Ed, and he devoted his career to helping young patients develop their personal capacity and reach their goals.

In 2005, his Hemophilia Treatment Center in Fort Worth participated in a WFH exchange program with the Hospital dos de Mayo in Lima, Peru. Inspired by the experience of helping those with minimal access to treatment, Ed joined the WFH Psychosocial Committee in 2008. Since then he has devoted countless hours to training healthcare professionals and meeting with patients across the globe. He is grateful for the experience and believes he has gained as much - if not more - from those he has helped. Providing opportunities for subject matter experts like Ed to share their knowledge and learn from our diverse community benefits all of us. Ed acknowledges that without first-hand exposure to the hardship patients face in the developing world, his career and life could have gone down a markedly different path.

PRESIDENT'S REPORT



Eric Stolte WFH USA PRESIDENT

It is with great humility and motivation that I took on the role of WFH USA President in September 2018. Meeting people from the global bleeding disorders community for the first time at the 2000 WFH World Congress opened my eyes to the disparity in care around the world and called me to action.

As a dual citizen of both Canada and the US, I can appreciate how lucky we are in North America, and I have a deep desire to make sure children with bleeding disorders don't suffer needlessly. With your help, we will continue engaging the US community with the global vision of Treatment for All.

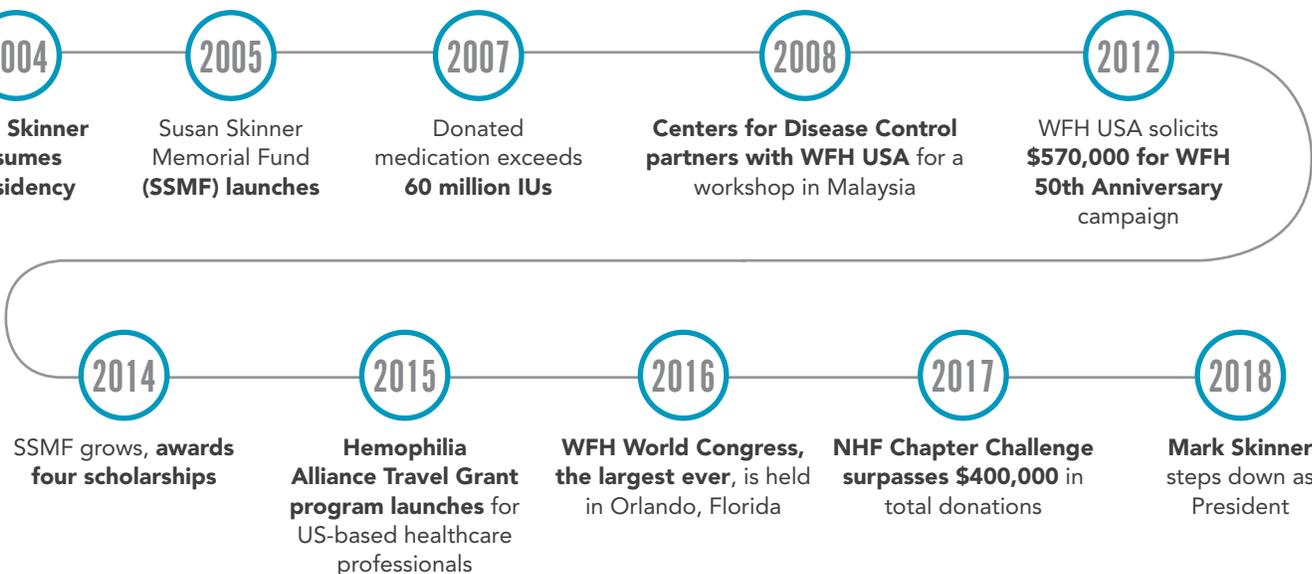
To our corporate and community partners as well as our growing number of individual supporters in the US community, I thank you for your support and look forward to what we will achieve together in the coming years.

THANK YOU, MARK.

Starting from the belief that no one should have to suffer the pain you endured as a child you have changed the future of thousands of people living with a bleeding disorder. Your work as President of WFH USA leaves a legacy of hope for our community members living in the developing world. Thank you for your inspirational leadership and steadfast commitment to ensuring no member of our community is left behind.



KEY MILESTONES OF YOUR PRESIDENCY





HUMANITARIAN AID

PROVIDING PREDICTABLE ACCESS TO CARE

In 2018 alone, the WFH Humanitarian Aid Program helped doctors treat more than 58,000 bleeding episodes, perform 685 major and minor surgeries, and made it possible for 1,546 patients to receive regular prophylaxis.

191M+

IUs of factor distributed

The visionary contribution from Sanofi Genzyme and Sobi to the WFH Humanitarian Aid Program translates into 500 million IUs over five years (2015-2020). Sanofi Genzyme and Sobi also make ongoing substantial financial contributions to support the logistics of product delivery and training of providers and patients in humanitarian aid 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.

VISIONARY CONTRIBUTORS

Bioverativ, a Sanofi Company
Sobi

CONTRIBUTORS

CSL Behring
GC Pharma
Grifols



“Because of [factor] donations I have been able to go to school and perform my daily activities just like an average kid. Your donations have literally taken the pain away from my life.”

— Julio Jose Ylanan, 15 years old, Philippines



RESEARCH AND DATA COLLECTION

PROVIDING EVIDENCE TO SUPPORT CARE

The WFH’s Report on the Annual Global Survey presents aggregate data on the number of people affected by bleeding disorders around the world and their level of access to care, while the World Bleeding Disorder Registry supports the collection of standardized, clinical patient data. The success of these initiatives depends on the valuable contributions and support from HTC’s, WFH national member organizations (NMO), and people with hemophilia from around the world.

Take Nepal, where treaters face many challenges: a lack of medication, few trained healthcare professionals, and inconsistent data are at the top of the list. Dr. Bishesh Sharma Poudyal has a new tool at his disposal thanks to the World Bleeding Disorder Registry: the ability to mount evidence-based advocacy campaigns for better patient care. He believes it will be easier to convince the government to help to buy clotting factor with accurate data to support his claims.

The WFH and WFH USA participate in joint and coordinated activities to support their common charitable goals. These activities include the WFH Humanitarian Aid Program, the WFH Research Program and the WFH Training and Education Program.



Bishesh Sharma Poudyal, MD:
Kathmandu, Nepal

“Having quality data has made all the difference in our advocacy efforts”



TRAINING AND EDUCATION

SHARING EXPERTISE ACROSS BORDERS

In 2018, we distributed over a million educational resources in six languages and offered dozens of training workshops to patient organization leaders and healthcare providers around the world.

A native of Tartu and a 2018 WFH Youth Leadership Workshop participant, Jo Kroll barely remembers a time when bleeding disorders were not part of her life. At just four years old – after doctors diagnosed her brother’s severe hemophilia A – she began a lifelong involvement with the Estonian Haemophilia Society. Jo herself is a carrier and wants to ensure her children have the same chance at a bright future that she does.

The WFH Youth Leadership program trains next generation leaders like Jo in goal setting, project management, personal development and other crucial leadership skills. This investment is critical to ensure the next generation has the tools to achieve success and the motivation to remain engaged in the pursuit of Treatment for All.



Jo Kroll: Tartu, Estonia

“The chance to learn and share experiences with my peers from countries all over the world has left me inspired to work harder on behalf of patients in my community”



SCHOLARSHIPS

SUSAN SKINNER MEMORIAL FUND PREPARING FUTURE LEADERS

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. Since its launch 10 years ago, this forward-thinking initiative has been leaving a legacy of future female leaders. Recipients continue to inspire us with their steadfast dedication. The global networks they create, thanks to the relationships forged at the WFH World Congress they attended, ensure that women will have a strong voice in our community today and tomorrow.

“I’ve always known that I would be involved in the bleeding disorders community for my whole life. And now, because of the Susan Skinner Memorial Scholarship, I can truly make a difference.”

– Marlee Whetten, 2018 Susan Skinner Scholar



Mark Skinner with Susan Skinner Memorial Fund Scholars at the 2018 WFH World Congress in Glasgow

2018 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 treat thousands of people with hemophilia and other inherited bleeding disorders around the world. In 2018, the WFH Humanitarian Aid Program continued to expand, with an impressive 191.5 million international units (IU) donated to 62 countries in the developing world. This represents a 20% growth in the volume of IUs distributed versus 2017, with a total of 160.1 million IUs donated. The dollar value of product donations in WFH USA financial statements for 2018 reached \$378,794,777, as compared to \$353,263,571 in 2017.

Effective September 9, 2018, a renewed Collaboration Agreement was signed between the WFH and WFH USA. The agreement defines joint and coordinated activities to support the common charitable goals of the two entities. These joint programs include the WFH Humanitarian Aid Program, the WFH Research Program and the WFH Training and Education Program. In 2018, \$1,567,348 was received in contributions from our corporate and community partners (\$1,041,287 in 2017) to support these programs. Of these contributions, \$1,455,600 was granted to the WFH to carry out its responsibilities with respect to the joint programs (\$1,005,500 in 2017). Other charitable donations fell slightly in 2018, totaling \$213,246, compared to \$260,611 in 2017.

In 2018, we obtained a surplus of \$9,131 versus a small deficit of \$6,408 in 2017. WFH USA remains in sound financial health with year-end unrestricted assets of \$241,750 (\$232,619 in 2017).

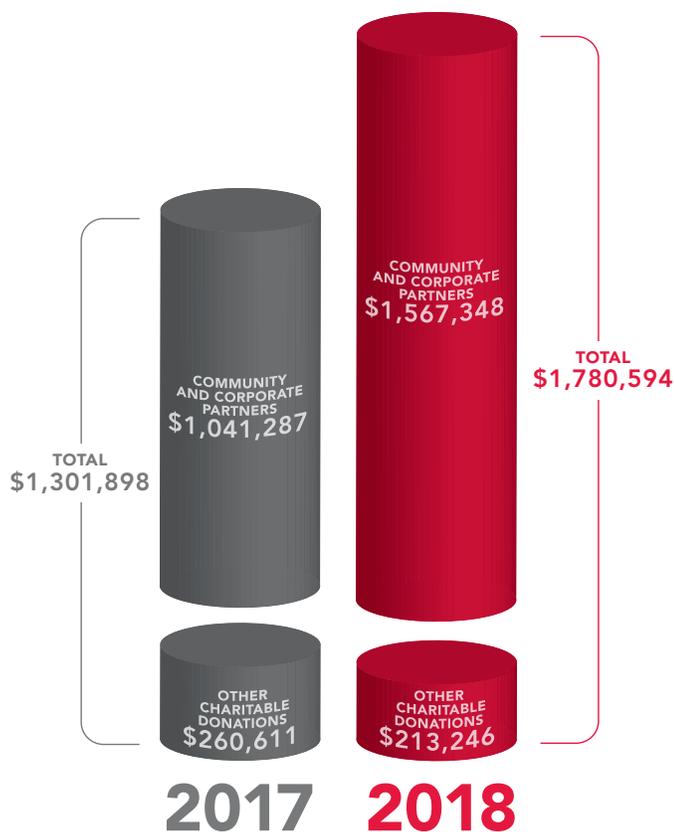
WFH USA is grateful to our devoted community partners for their continuing support. In particular, we thank the National Hemophilia Foundation, Hemophilia of Georgia and Hemophilia Alliance for their year after year contributions towards our mission.

The donations to the Susan Skinner Memorial Fund (SSMF) totaled \$62,779 in 2018 (\$70,361 in 2017). This brought the endowment fund balance to \$448,161 from \$392,815 at the end of 2017. It will also allow us to send 6 scholarship recipients to the WFH 2020 World Congress in Kuala Lumpur, Malaysia.

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 at \$314,950 in 2018, comparable to the value of \$394,882 contributed in 2017.

We are humbled by the dedication and loyalty of our community in the U.S and know that without you, we could not continue towards our goal of improving access to care for people with bleeding disorders around the world.

Our complete financial statements can be found at www.wfhusa.org



WFH USA provides U.S. citizens, foundations, and corporations the opportunity to ensure **TREATMENT FOR ALL** people with bleeding disorders worldwide.

SUPPORT OUR WORK

- Donate today at wfhusa.org/donate
- Sign-up to receive regular updates from the global bleeding disorders community at wfh.org/connect

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.

CHAPTER CHALLENGE CHAMPIONS

Since launching in 2016 the NHF Chapter Challenge has raised \$482,462 in support of the WFH USA mission. We would like to thank those who gave in 2018 as well as our two founding champions, the National Hemophilia Foundation and Hemophilia of Georgia



FOUNDING CHAMPIONS

Hemophilia of Georgia, Inc.

National Hemophilia Foundation

2018 CHAPTER CHAMPIONS

Alaska Hemophilia Association
 Bleeding Disorders Alliance Illinois
 Colorado Chapter of the National Hemophilia Foundation
 Gateway Hemophilia Association
 Hemophilia Alliance of Maine, Inc.
 Hemophilia Association of the Capital Area
 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
 Hemophilia of South Carolina
 Kentucky Hemophilia Foundation, Inc.
 Lone Star Chapter of the NHF
 Mary M. Gooley Hemophilia Center
 Midwest Hemophilia Association
 Nevada Chapter of the National Hemophilia Foundation
 New England Hemophilia Association
 Rocky Mountain Hemophilia & Bleeding Disorders Association
 Virginia Hemophilia Foundation

THANK YOU!

The support we receive from across the US allows us to ensure every child with a bleeding disorder receives the care they need, regardless of where they live. Your support signals to the world that we are united in our commitment to **TREATMENT FOR ALL.**

\$250,000 – \$499,999

Hemophilia of Georgia, Inc.

\$50,000 – \$74,999

National Hemophilia Foundation

\$25,000 – \$49,000

Glenn and Beatrice Pierce
The Hemophilia Alliance

\$10,000 – \$24,999

Anonymous
Mark Skinner and James Matheson
The Estate of John Primus
The Marketing Research Bureau, Inc.

\$7,500 – \$9,999

Phillips 66

\$5,000 – \$7,499

Donald and Barbara Goldman
Institute for Policy Advancement Ltd.
LA Kelley Communications, Inc.

\$2,500 – \$4,999

Lone Star Chapter of the NHF

\$1,000 – \$2,499

Paula Bell and Rob Christie
Colorado Chapter of the National Hemophilia Foundation
Hemophilia Association of the Capital Area
Hemophilia Foundation of Greater Florida, Inc.
Hemophilia Foundation of Oregon
Hemophilia of Indiana Inc.
Barbara Konkle and Peter Kollros
Mary M. Gooley Hemophilia Center
Midwest Hemophilia Association
Paul E. Monahan

Perla Pine

Joseph Pugliese
Kenneth Trader
Leonard A. Valentino

\$750 – \$999

Anonymous Donations
Nevada Chapter of the National Hemophilia Foundation
Sundar Rajan Selvaraj

\$500 – \$749

Amy Dunn
Gateway Hemophilia Association
Hemophilia Alliance of Maine, Inc.
Hemophilia Foundation of Michigan
Hemophilia Foundation of Southern California
Hemophilia of North Carolina
Hemophilia of South Carolina
Kentucky Hemophilia Foundation, Inc.
Craig Kessler
Prasad Mathew
New England Hemophilia Association
Kathleen Pratt
Rocky Mountain Hemophilia & Bleeding Disorders Association
Gina Schnabel
Virginia Hemophilia Foundation
Mary Q. Wingate

\$250 – \$499

Anonymous
Bleeding Disorders Alliance Illinois
Jacqueline Curtis
Phillip Kucab
Amy and Allen Renz
Dawn Rotellini

\$100 – \$249

Alaska Hemophilia Association
Neva L. Anderson
Anonymous
Anonymous
David Blanchard
Leigh Carpenter
Bruce L. Evatt
Matt Gross
Christine Herr
Roshni Kulkarni
Dan Levin
Alan Neaigus
Pfizer Foundation, Inc.
Shelly A. Reed
Frank Schnabel IV and Lillian Schnabel
Cynthia Secrest
Eric and Marion Stolte

Up to \$99

Anonymous
Jeffrey Barlekamp
Brad Benne
Barbara Byrne
Joseph Carmelo Poliafico
Kristen Chapman
Arleigh R. Clemens
Ronald H. Cobb
Rose Fombe
Robert Hanson
Penelope Kumpf
Martin L. Lee
Andrew B. Matthews
Russell and Carol Rose
Alan Skinner
Marion Stuart
Pauline Tang
Paula Zeff

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