



WFHUSA

WORLD FEDERATION OF HEMOPHILIA USA

A young boy with dark hair and glasses is smiling and giving a thumbs up. He is wearing a brown quilted jacket over a black turtleneck. The background is a soft-focus indoor setting with blue and yellow tones.

YEAR-END REPORT 2019

wfhusa.org

OUR MISSION

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

The two organizations work together to support a number of activities that are central to their shared vision of Treatment for All: that one day, all people with bleeding disorders will have access to care, no matter where they live. These activities include the WFH Humanitarian Aid Program, the WFH Research Program, and WFH Training and Education Programs.

WFH USA also offers a scholarship program to support the training and education of young women who have the potential to become future leaders of our community, as well as grants for US-based multidisciplinary healthcare professionals to connect with the global community and further develop their leadership and expertise.

TOGETHER WE ARE MAKING A DIFFERENCE

Support our work

Donate today at give.wfh.org/give-usa

Sign up to receive regular updates from the global bleeding disorders community at wfh.org/connect

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



PRESIDENT'S REPORT



Greetings,

As the world grapples with the unprecedented changes wrought by Covid-19 and a long-overdue, widespread anti-racism movement, I stand humbled by the level of engagement we are displaying as a community. I am not however, surprised. Over my two-decades plus involvement, the one thread pulling together our global tapestry is solidarity. We all recognize that together, we are stronger.

The WFH is leading the effort to help our community through the pandemic: offering free webinars featuring international experts covering all aspects of care and actively

listening to the emerging needs national member organizations as they grapple with their current reality. We at WFH USA are finding new and innovative ways to support those efforts. Compassion to Action: Together We Can is a fundraising initiative aimed at ensuring the WFH can continue to meet the needs of our global family, both in times of crisis and for long-term sustainability. We are also very proud to have renewed our historic agreement with Sanofi Genzyme and Sobi to donate up to 500 million IUs of clotting factor over the next five years. A special thank you to former WFH USA President Mark Skinner for his work securing this remarkable gift.

Responsiveness and inclusivity in coming together to improve the lives of people living with bleeding disorders is a hallmark of our community. We recognize however that we can do even better at reflecting these principles at the leadership level. We are working to incorporate a broad range of voices to represent all members of our community.

To this end, the WFH USA Board will be including diversity as a fundamental pillar in all our plans. To do this well, we'd value your voice. If you have ideas on how we can achieve this goal or simply want to relate your experiences to us, please reach out to me personally at estolte@wfh.org.

I look forward to moving forward, together.



Eric Stolte
WFH USA President

Board of Directors

PRESIDENT

Eric Stolte

VICE-PRESIDENT

Amy Dunn, MD

TREASURER

Ken Trader

MEMBERS

Paula Bell
Craig Kessler, MD
Phil Kucab, MD
Glenn Pierce, MD, PhD
Joseph Pugliese
Edith A. Rosato
Frank L. Schnabel IV
Mark W. Skinner

EX OFFICIO

Dawn Rotellini, National Hemophilia
Foundation Liaison
WFH Board Member

EXECUTIVE DIRECTOR/SECRETARY

Alain Baumann, WFH Chief Executive Officer

NATIONAL DIRECTOR

Jennifer Laliberté, WFH Director of Strategic
& Community Partnerships



TOGETHER, WE ARE CHANGING LIVES

In 2019, 241 million IUs of donated factor were delivered via the WFH Humanitarian Aid Program, treating 19,782 patients and allowing 1,622 to receive prophylaxis.

One of these patients is Salomon, a 10-year old boy with hemophilia A who lives in Kenya.

Rain or shine and often after a bleed, he makes the daily journey to school using a donated crutch, although on several occasions his mother Alice has carried him. The family faces many challenges living in the second-largest slum in the world, but access to factor is no longer one of them.

Prior to the WFH's arrival, he could not pursue his number one passion: playing soccer. Today, when his doctor Kibet Shikuku seeks him out amongst the makeshift homes and winding earthen streets holding over 1 million inhabitants, he often finds him laughing in a dusty corner, practicing.

“He loves football like you can't believe... We fight every time he comes to visit me because he plays so much soccer!”

- Dr. Kibet Shikuku, chairman of the Kenya Hemophilia Association

The WFH Humanitarian Aid Program improves the lack of access to care and treatment by providing much-needed support for people with inherited bleeding disorders in developing countries. By providing patients with a more predictable and sustainable flow of humanitarian aid donations, the WFH Humanitarian Aid Program makes it possible for patients to receive consistent and reliable access to treatment and care. WFH and WFH USA collaborate to manage and control the WFH Humanitarian Aid Program.

None of this would be possible without the generous support of Sanofi Genzyme and Sobi, our Founding Visionary Contributors; Bayer, our Visionary Contributor; Grifols and Roche, our Leadership Contributors; and our Contributor, CSL Behring. To learn more about the WFH Humanitarian Aid Program, visit www.treatmentforall.org



TOGETHER, WE ARE ARMING COMMUNITIES WITH DATA

The WFH's global registries provide treaters and patient organizations with an incredibly valuable tool: the power to understand and advocate for their communities. As of the end of 2019, the World Bleeding Disorders Registry (WBDR) included data on 4,166 people with hemophilia from 53 treatment centres in 29 countries.

Many treaters do not have the capacity or the infrastructure to collect clinical patient information. The WBDR levels the playing field by giving them access to a web-based system to easily collect uniform and standardized data on their patient population.

In Nigeria, the adoption of the WBDR is having a positive impact on patient advocacy. While healthcare professionals and community leaders have long been aware of the enormous burden patients carry, they can now demonstrate it in a way that makes decision-makers take notice. This advance will pay dividends today and tomorrow in the form of better treatment options and one day in sustainable, funded care for all Nigerians living with a bleeding disorder.

“The importance of the WBDR cannot be overemphasized. It has provided us with an important advocacy tool to draw attention to people with bleeding disorders in my community, and in Nigeria as a whole.”

- Theresa Nwagha, MD
Coordinator, Southeast University
of Nigeria Teaching Hospital.



TOGETHER, WE ARE PROVIDING VITAL EDUCATION AND TRAINING

WFH Training and Education programs are at the center of our efforts to improve and sustain care for all people with bleeding disorders.

Workshops extend across all aspects of patient care and skills development. In 2019, these ranged from data collection and advocacy to diagnosis and outreach.

Our Youth Leadership Program is an investment in the future of our community. In 2019, we held three workshops, helping 46 future community leaders acquire skills in project management, effective communications and conflict resolution. These young adults quickly begin contributing on the local and global stage.

One of these participants is Chavez Edgecombe from Nassau, Bahamas. When he was called upon to present at the 2020 WFH Virtual Congress on physical activity for joint health and wellness he readily accepted, crediting his willingness to participate and confidence to present to a global audience, to the exposure and training he received.

“The message I would like to send to the bleeding disorder community is to stay strong. I know it may feel like the world is against you but know that there is hope, and people around the world are working hard to give you the support you deserve.”

- Chavez Edgecombe
Youth Leader and Marketing
and Advertising student

TOGETHER WE ARE SUPPORTING WOMEN IN LEADERSHIP

The Susan Skinner Memorial Fund invests in women in our community, recognizing their voice and perspective are crucial to our future growth. The fund draws its name from a mother who strove to ensure her sons – and all patients – have equal access to care. Now over a decade old, this initiative has created a network of strong female leaders in communities spanning the globe. Their work individually and collectively embodies our mission to improve and sustain care for all patients, regardless of gender, type of bleeding disorder or geographic location.



“ *If we can increase the representation of women in the community and fight false notions working against us, we can improve care for all women living with bleeding disorders.* ”

- Allison Albright, 2019 SSMF scholar

TOGETHER WE ARE ENHANCING MULTIDISCIPLINARY CARE



The Hemophilia Alliance Travel Fund allows U.S.-based multidisciplinary healthcare professionals to attend WFH international meetings and conferences. Dong Chen and Rebecca Schaffer could only express a deep resolve to continue working with the bleeding disorders community after attending the WFH 2019 Africa Summit in Johannesburg, South Africa.

Both noted the summit provided a once-in-a-lifetime opportunity to witness physicians, patients, government officials, and patient organization leaders coming together to find ways to improve access to care.

UNITED IN SOLIDARITY: OUR COMMUNITY PARTNERS

The support of our 2019 Community Partners extends beyond the financial, as they freely give their knowledge, time, and experience to serve the global bleeding disorders community



NATIONAL HEMOPHILIA FOUNDATION

The National Hemophilia Foundation helps advance our mission on several fronts. They inspire others to follow their lead as a founding champion of the NHF Chapter Challenge. Their commitment to equality of access is demonstrated in their support of the Cornerstone Initiative, which lays the foundation for care in the world's most underserved regions, as well as programs that aim to raise awareness and improve care of women with bleeding disorders and those with von Willebrand disease. We also benefit from their steadfast engagement with various programs including the WFH Twinning Program and their individual leaders' contribution to our leadership and committees.



Hemophilia of Georgia has stood with us for over three decades, playing an early role in distributing donated factor via the WFH Humanitarian Aid program. Our relationship has deepened over the years as they continued to support this program and came on board as a founding Chapter Challenge champion in 2016. Their belief in educating future leaders is clear in their investment in the Youth Leadership Workshops, which has led to the training of over 50 young adults. They also support workshops devoted to educating providers and patient leaders on how to collect and use data to advocate for better patient care. Their staff generously volunteer their time as trainers and as well as serving on various committees.



Recognizing that training women leaders ensures the diversity our community need to thrive, the Hemophilia Alliance has been a longtime supporter of the Susan Skinner Memorial Fund. They deepened their engagement with the global community through the establishment of the Travel Grant Program, which allows US-based multidisciplinary healthcare professionals the opportunity to attend WFH global training workshops. The wealth of experience and perspective attendees bring back home to their communities helps patients across the country. Their patience and support as we grappled with changing norms in these challenging times gave us the flexibility to meet our community's needs with revamped programming.

2019 FINANCIAL REPORT



In 2019, \$2,333,930 was received in contributions from dedicated donors towards the joint and coordinated activities of the WFH and WFH USA (\$1,567,348 in 2018). These include the WFH Humanitarian Aid Program, the WFH Research Program and the WFH Training and Education Program. Of these contributions, \$2,228,851 was granted to the WFH as needed to carry out its responsibilities with respect to the joint programs (\$1,455,600 in 2018).

We also had a good year for charitable monetary donations with a 2020 total of \$220,417, compared to \$213,246 in 2018. In 2019, we obtained a small surplus of \$10,640 versus a surplus of \$9,131 in 2018. WFH USA remains in sound financial health with year-end unrestricted assets of \$252,390 (\$241,750 in 2018).

The WFH Humanitarian Aid Program continued to expand with the addition of two new partners in 2019: Bayer and F. Hoffmann-La Roche Ltd. This contributed to an impressive 241 million international units (IU) donated to 72 developing countries, which represents a 26% growth in the volume of IUs distributed, versus 2018 (191.5 million IUs). The dollar value of product donations in WFH USA financial statements for 2019 reached \$437,273,143, as compared to \$378,794,777 in 2018.

The donations to the Susan Skinner Memorial Fund (SSMF) totaled \$49,724 in 2019 (\$62,779 in 2018). This brought the endowment fund balance to \$497,885 from \$448,161 at the end of 2018.

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 \$349,545 in 2019, comparable to a value of \$314,950 in 2018.

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. Without your contribution we could never dream of achieving Treatment for All.

Our complete financial statements can be found at wfhusa.org and clicking on 'Our Mission.'

2019 CHAPTER CHALLENGE CHAMPIONS

Since 2016, the chapters of the National Hemophilia Foundation have come together to support the global community in an incredible show of solidarity. Together, we have worked to reduce the inequality in diagnosis and access to care that leaves most people living with a bleeding disorder around the world without treatment. The past year has not been easy, but with allies like these, we know we are never alone.

Thank you!



Founding Champions

National Hemophilia Foundation
Hemophilia of Georgia

Four-time Champions

Bleeding Disorders Alliance Illinois
Hemophilia Association of the Capital Area
Hemophilia Foundation of Greater Florida
Hemophilia Foundation of Oregon
Hemophilia Foundation of Southern California
Hemophilia of Indiana
Hemophilia of North Carolina
Hemophilia of South Carolina
Lone Star Chapter of NHF
Midwest Hemophilia Association
Nevada Chapter, National Hemophilia Foundation
Rocky Mountain Hemophilia and Bleeding Disorders Association
Virginia Hemophilia Foundation

Three-time Champions

Alaska Hemophilia Association
Bleeding Disorders Association of
Northeastern New York
Colorado Chapter, National Hemophilia
Foundation
Florida Hemophilia Association
Gateway Hemophilia Association
Hemophilia Alliance of Maine, Inc.
Hemophilia Foundation of Michigan
Hemophilia Foundation of Minnesota and the
Dakotas
New England Hemophilia Association

Two-time Champion

Great Lakes Hemophilia Foundation

First-time Champions (Welcome!)

Connecticut Hemophilia Society, Inc.
Hawaii Chapter, National Hemophilia Foundation
Idaho Chapter, National Hemophilia Foundation
Kentucky Hemophilia Foundation
Northern Ohio Hemophilia Foundation
Southwestern Ohio Hemophilia Foundation

THANK YOU TO OUR DONORS

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.

\$250,000.00 +

Hemophilia of Georgia, Inc.

\$75,000.00 +

The Hemophilia Alliance

\$50,000.00 +

National Hemophilia Foundation
Glenn and Beatrice Pierce

\$10,000.00 +

Anonymous
Mark Skinner and James Matheson

\$7,500.00 +

The Marketing Research Bureau, Inc.

\$5,000.00 +

Donald and Barbara Goldman
Matthew Ottmer and Megan McLean
Phillips 66

\$2,500.00 +

Lone Star Bleeding Disorders Foundation

\$1,000.00 +

Akron Children's Hospital
Anonymous
Paula Bell and Rob Christie
Bleeding Disorders Association of Northeastern New York
Coalition for Hemophilia B (The)
Colorado Chapter of the National Hemophilia Foundation
Florida Hemophilia Association
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.
Craig Kessler
Barbara Konkle and Peter Kollros
Midwest Hemophilia Association
John Murphy
New England Hemophilia Association
Joseph Pugliese
Rocky Mountain Hemophilia & Bleeding Disorders Association
Edith A. Rosato
Maria M. Salas-Pilla
Kenneth Trader

\$750.00 +

Phillip Kucab
Sundar Rajan Selvaraj

\$500.00 +

Anonymous
Bleeding Disorders Alliance Illinois
Amy Dunn
Gateway Hemophilia Association
Great Lakes Hemophilia Foundation
Hemophilia Foundation of Minnesota/Dakotas
Hemophilia of North Carolina
Kentucky Hemophilia Foundation, Inc.
Nevada Chapter of the National Hemophilia Foundation
Dawn Rotellini
Frank Schnabel IV and Lillian Schnabel
Gina Schnabel
Virginia Hemophilia Foundation
Mary Q. Wingate

\$250.00 +

Alaska Hemophilia Association
Alain Baumann
Connecticut Hemophilia Society
Jacqueline Curtis
Matt Gross
Hawaii Chapter of the National Hemophilia Foundation
Hemophilia Alliance of Maine, Inc.
Hemophilia of South Carolina
Christine Herr
Idaho Regional Hemophilia Center
Garrett Kennedy
Jennifer Laliberté
Northern Ohio Hemophilia Foundation, Inc.
Southwestern Ohio Hemophilia Foundation

\$100.00 +

Julia M. Alvarez and Alfred Hiermann
Jeffrey Barlekamp
David Blanchard
Miranda Geringer
Susan Karp
Carol K. Kasper
Roshni Kulkarni
Dan Levin
Pfizer Foundation, Inc.
Douglas W. Pierce
Kathleen Pratt
Amy and Allen Renz
Eric and Marion Stolte
Brian M. Wicklund

Up to \$99

Anonymous
Richard Atwood
Brad Benne
Oldouz Dehghan Bonehkoal
Martin L. Lee
Paul Spangler
Susanna von Oettingen



Contact us:

WFH USA
PMB 142
911 Central Avenue
Albany, New York
United States 12206-1304

Tel.: 1-877-417-7944

info@wfhusa.org