



2023 ANNUAL REPORT

wfhusa.org

ADVANCING THE GLOBAL MISSION OF THE WORLD FEDERATION OF HEMOPHILIA IN THE UNITED STATES



“From that moment forward, my family and I had more hope for my life and future.”

— Jeremiah Ogenrwot, Uganda

Jeremiah Ogenrwot, a 15-year-old boy from Uganda was born with severe hemophilia A, Jeremiah’s early years were marked by life-threatening bleeds, including a spinal bleed at birth that nearly claimed his life. For years, his condition remained undiagnosed. Hope arrived when Dr. Humes at Mulago Hospital confirmed his condition, improving his access to necessary treatments. His story underscores the importance of early diagnosis and reliable treatment access.

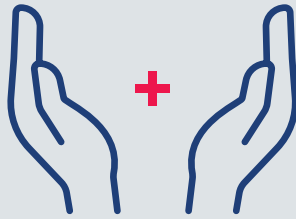
The World Federation of Hemophilia transforms communities by equipping and empowering its national member organizations (NMOs) and healthcare providers with the knowledge and tools they need to identify, support and treat people living with bleeding disorders around the world.

WFH USA furthers the mission of the WFH in the U.S. by deepening engagement of American citizens with our global vision of Treatment for All and raising funds to bring that vision to life.

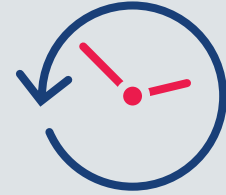
THE CHALLENGE



Globally,
68%
of people with
hemophilia remain
undiagnosed



62%
of the world's bleeding
disorders community
lives in developing
countries where access
to care is limited.
(Global Survey 2022)

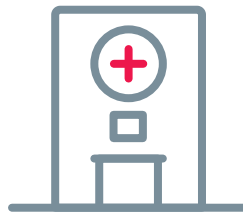


Care provided
in developing
countries lags up to
50 YEARS
BEHIND,
as compared
to care in the US

OUR IMPACT



26,000+
people with a
bleeding disorder
treated since
1996



144
TREATMENT CENTRES
benefitting from
the World Bleeding
Disorders Registry



130+
COUNTRIES REACHED
through global
programs and events

PRESIDENT'S REPORT

Greetings,

Reflecting on the past year, sustaining global partnerships and expanding our reach, even amid the challenges posed by global events and economic uncertainties has been challenging! But thanks to your generous support from across the US, invaluable support, guidance, and resources were offered to the global bleeding disorders community, particularly in under-resourced regions.

2023 marks the second year of reporting on the KPIs outlined in our strategic plans for both WFH and WFH USA: the [WFH's Roadmap to 2025](#) and WFH USA's [Together Towards Treatment for All](#). Progress has surpassed our expectations! Life-changing support continued through the WFH Humanitarian Aid Program, treating 15,500 people with bleeding disorders in 2023 alone and over 26,000 since 1996. Additionally, over 130 countries were reached through several global programs and events such as the Women & Girls with Bleeding Disorders Initiative, which amplifies the voices of women who have gone unheard for far too long, and the Global Policy and Access Summit, which connects the global bleeding disorders community to address the essential goal of improving access to care and treatment worldwide and many others.

None of this would be possible without the strong partnerships of donors and funders across the US. My heartfelt thanks go out to my fellow board members, volunteers, community leaders, healthcare providers, staff, and other stakeholders across the U.S. and around the world who help address the deep inequities that persist between those who have access to care and those who do not. Together, lives are being transformed, not just for today but for generations to come.

As we look ahead, we remain committed to our strategic goals under the WFH's Roadmap to 2025 and WFH USA's Together Towards Treatment for All. In the coming year diversifying our funding base and enhancing board development to ensure continued, robust and sustainable support for WFH's mission will be prioritized. By expanding financial resources and strengthening leadership, people with inherited bleeding disorders globally will be better served. This strategic focus will enable adapting to future challenges, maximizing impact, and continue advancing our vision of improving access to care

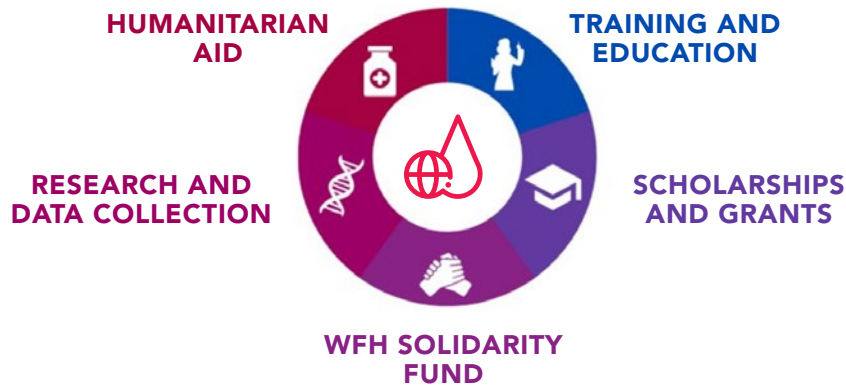
I would like to extend a special thank you to Ken Trader and Edith Rosato, who stepped down from the board last year. Ken and Edith's dedication and contributions have been instrumental in our efforts, and their leadership will be greatly missed. We are profoundly grateful for their service and commitment to our mission.

Together, we will strive for excellence, making a lasting difference in the lives of our global bleeding disorders community. Thank you for your continued support.



Eric Stolte
WFH USA President

The World Federation of Hemophilia USA (WFH USA) supports the global mission of the World Federation of Hemophilia (WFH) through its strategic priorities for 2021–2025. These priorities focus on key areas to improve the lives of individuals with bleeding disorders globally.



WFH USA STRATEGIC PRIORITIES FOR 2021–2025

- 1 FOSTER CONNECTION** Between the U.S. and Global Communities
- 2 EXPAND RESOURCES** to Support WFH Global Programs
- 3 DEEPEN COMMITMENT** to Principles of Diversity, Equity and Inclusion

BOARD OF DIRECTORS

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Sean Singh

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(NBDF) Liaison

NBDF Chief Operating Officer

Alain Baumann

Executive Director/Secretary
WFH Chief Executive Officer

Marlene Spencer

Acting National Director

TRANSFORMING LIVES

Through the WFH Humanitarian Aid Program

The WFH Humanitarian Aid Program addresses the lack of access to care and treatment by providing essential support to people with inherited bleeding disorders in developing countries. By ensuring a predictable and sustainable flow of donations, the program allows patients to receive consistent and reliable access to treatment and care.

In 2023, we:

- Treated more than 15 thousand patients and managed thousands of bleeding episodes
- Donated nearly 340 million IUs of clotting factor concentrates, bringing the total to over 1.7 billion IUs since the program's inception.
- Provided treatment products in 78 countries.

None of this would be possible without the generous support of our contributors, including Sanofi and Sobi, our Founding Visionary Contributors; Bayer, CSL Behring, and Roche, our Visionary Contributors; Grifols, our Leadership Contributor; and Takeda and Japan Blood Products Organization, our Contributors. The WFH and WFH USA collaborate to manage and control the WFH Humanitarian Aid Program.

MUHAMMAD AHMED'S STORY

Muhammad Ahmed, a young boy from Karachi, Pakistan, faced significant health challenges from birth. Diagnosed with Tetralogy of Fallot congenital heart disease five days after birth, he underwent surgery that revealed he also had moderate hemophilia B. Plasma infusions failed to stabilize his condition until the Hemophilia Patient Welfare Society-Karachi (HWSK) intervened with donated factor from the WFH Humanitarian Aid Program.



With his condition stabilized, Muhammad's family sought help for his heart surgery in India. Through the collaborative efforts of the Hemophilia Foundation-Pakistan (HFP), the Hemophilia Foundation-India (HFI), and additional WFH support, Muhammad successfully underwent heart surgery. Now on regular prophylaxis, Muhammad can look forward to a normal life, free from the debilitating effects of his condition.

TRANSFORMING LIVES

Through Research and Data Collection

The World Federation of Hemophilia (WFH) emphasizes the importance of research and data collection to advance the understanding and treatment of bleeding disorders. In 2023, significant strides were made through various initiatives, including the World Bleeding Disorders Registry (WBDR), the Annual Global Survey, the Living Guidelines Model and the launch of the WFH Gene Therapy Registry (GTR).

In 2023:

- **World Bleeding Disorders Registry (WBDR):** WFH launched the WBDR VWD module, making it the first global registry to collect data on VWD diagnosis, management, and health outcomes. Over 1,000 people with von Willebrand disease have enrolled in the WBDR during the first year.
- **WFH Gene Therapy Registry (GTR):** Launched in 2023, the GTR aims to gather data on gene therapy treatments for hemophilia, providing critical insights into long-term safety and efficacy.
- **Annual Global Survey (AGS):** 2023 survey continues to provide invaluable data to support clinical care, research, and advocacy efforts worldwide.
- **Living Guidelines:** *The WFH Guidelines on the Management of Hemophilia*, 3rd edition, has moved into a Living Guidelines Model, whereby each chapter will be updated on a regular and priority basis. The first update is underway and focuses on gene therapy for hemophilia.

IMPACT ON RESEARCH AND CLINICAL PRACTICE

The data collection efforts foster international collaboration among HTC, researchers, and healthcare providers, promoting the exchange of knowledge and best practices to improve treatment outcomes.



Data collected through these programs are used to highlight discrepancies in care, support evidence-based advocacy, and drive policy changes to improve patient outcomes globally.

The standardized data from the WBDR helps hemophilia treatment centers (HTCs) to enhance clinical practices and patient management, ensuring that patients receive the best possible care based on the latest research findings.

DR. NDOUMBA ANNICK'S STORY

Access to treatment and care for people with hemophilia in Cameroon has historically been very difficult. There are two hemophilia treatment centers (HTCs) in the country, but due to limited transportation infrastructure and financial challenges, people with hemophilia often struggle to visit these facilities regularly. Consequently, the community suffers from sub-optimal bleed treatment, leading to chronic joint disease and other long-term complications.

To address this, the HTC in Yaoundé University Teaching Hospital used a WFH WBDR Research Support Program (RSP) grant to collect prospective data and analyze the extent of joint disease in the Cameroonian bleeding disorders population. This data is critical for advocacy, as it provides evidence of the significant burden of disease, which is crucial for communicating with healthcare decision-makers.

“Using the WBDR to capture and analyze the data will be instrumental in helping us advocate for people with bleeding disorders (PWBDs) in Cameroon,” said Dr. Ndoumba Annick, Yaoundé HTC.

The research, conducted from December 2020 to November 2022, aimed to study the epidemiological, clinical, and radiological profile of joint disease in PWH in Cameroon. The team recruited 38 PWHs, examining 228 joints using the Hemophilia Joint Health Score (HJHS) method, radiographic assessments, and ultrasounds. The study found that 84% of PWH had damaged joints, with knees, elbows, and ankles being the most affected. The results highlighted the severe impact of sub-optimal treatment on joint health in Cameroon.



TRANSFORMING LIVES

Through Training and Education

Training and education are critical to creating long-lasting, transformative change. The WFH equips and empowers both patient leaders and healthcare providers and ensures they work together effectively in the best interests of people living with inherited bleeding disorders. We achieve this through:

- Healthcare Development Programs
- Meetings and Events
- Educational Tools and Resources

In 2023, we:

- Hosted the third annual **WFH Global Policy and Access Summit**, bringing stakeholders together to share strategies and learnings.
- Introduced a **shared decision-making tool** to facilitate better patient-provider communication and treatment planning.
- Hosted a 3rd edition of the **WFH Global Summit on Women and Girls with Bleeding Disorders (WGBD)**

Key Achievements

- Conducted numerous training sessions across various regions, focusing on the latest diagnostic techniques and treatment protocols.
- Launched new educational modules tailored to the needs of healthcare providers in low-resource settings.
- Partnered with leading medical institutions to provide comprehensive training programs.



“The level of care in Zambia has increased significantly over the last few years, thanks to the hard work of many committed stakeholders. The signing of this MoU signifies an exciting new chapter in this journey.”

— Cesar Garrido, President, WFH



ZAMBIA MINISTRY OF HEALTH

The WFH Path to Access to Care and Treatment (PACT) Program in Zambia, initiated through a new MoU in 2023, highlights our commitment to training healthcare professionals to improve diagnosis and care for people with bleeding disorders. This agreement ensures the government will procure essential hemophilia treatment products, significantly enhancing care standards.





TRANSFORMING LIVES

Through Scholarships and Grants

SUSAN SKINNER MEMORIAL FUND SCHOLARSHIP (SSMF)

The Susan Skinner Memorial Fund (SSMF) commemorates the late Susan Skinner, who was dedicated to ensuring safe and effective treatment for her two sons. The WFH USA is deeply grateful to the late Thomas Skinner, family members, friends, and organizations in the bleeding disorder community who continue to support the fund.

This fund provides a unique opportunity for recipients to network and develop skills to empower themselves and others to advocate for improved care of women with bleeding disorders in their communities and worldwide. The mission of the SSMF scholarship program is to cultivate leadership and promote the engagement of women of all ages in the global bleeding disorders community through education, training, and networking. SSMF scholarship program recipients are offered the opportunity to attend major WFH events.

THE HEMOPHILIA ALLIANCE TRAVEL FUND

The Hemophilia Alliance Travel Fund supports U.S.A.-based WFH multidisciplinary committee member's attendance of WFH international meetings and conferences. With the continued commitment and generosity of the Hemophilia Alliance for advancing the knowledge of healthcare professionals in the bleeding disorders community, travel grant recipients have opportunities for connection and exchange with their international peers.



In 2023, we:

- Awarded 8 scholarships to women from 7 countries who exemplify the values of the **SSMF Scholarship**, and who have the potential to have a positive impact on the bleeding disorder community.
- Three **Hemophilia Alliance Travel Grant** recipients participated in the **WFH Comprehensive Care Summit (CCS)** in Buenos Aires, Argentina.

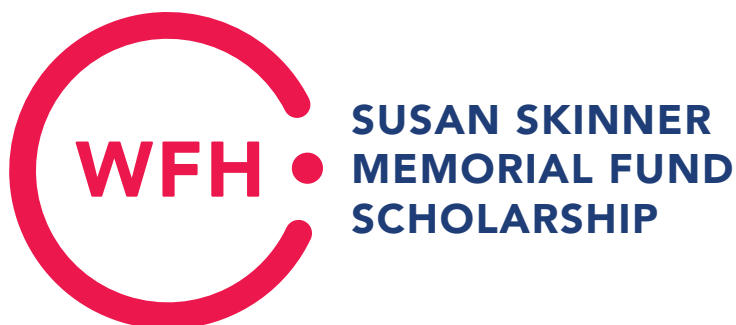
TATIANA BATHFIELD'S STORY

Tatiana Bathfield, a founding member of the Hemophilia Association of Mauritius, shares her experience: "I am thrilled to be on this journey and at the same time relieved to have Yannick [my mentor] guide me through this process. I am keen to learn from her past experiences and am looking forward to her advice in all aspects of this mentorship initiative."

Tatiana's tireless advocacy for people with bleeding disorders (PWBDs) in Mauritius, driven by her personal experience as a parent of a daughter with severe factor VII deficiency, exemplifies the transformative impact of the SSMF scholarship. Following her participation in the WFH 2024 World Congress, Tatiana was co-opted to the WFH Board of Directors as a Lay Member.



Change the narrative around women living with bleeding disorders by supporting the [**Susan Skinner Memorial Fund Scholarship**](#).





FINANCIAL REPORT

2023

The 2023 Financial Statements have been prepared under the US Generally Accepted Accounting Principles (GAAP) as required by US tax authorities.

According to US GAAP rules, donated pharmaceutical products that have not yet been shipped to beneficiaries through the Humanitarian Aid program are recognized as inventory in the Statement of Financial Position. These donated pharmaceutical products are recorded at fair value on the date of receipt in the Statement of Activities. Product donations that have been shipped to beneficiaries are presented in both the Statement of Activities and the Statement of Functional Expenses in the Audited Financial Statements.

In 2023, we received \$1,131,381,417 in contributions (including pharmaceutical product donations) from dedicated donors and partners towards the joint and coordinated

activities of the WFH and WFH USA. These include the WFH Humanitarian Aid Program (including pharmaceutical product donations), the WFH Research Program, the WFH Training and Education Program, and Other Programs.

From these contributions we spent \$1,070,865,393 which included the costs to distribute pharmaceutical products to beneficiaries around the world, as well as the costs to deliver the joint programs.

In 2023, we attained an increase in net assets of \$60,516,024, which is mostly due to the difference between the cost of the pharmaceutical products received vs those shipped. This helped us reach total net assets of \$436,649,597.

The donations to the Susan Skinner Memorial Fund (SSMF) totaled \$53,114. This brought the endowment fund balance to \$896,906. We thank all those who support this important initiative. The continued growth of this fund allows us to invest in our women leaders to the benefit of our entire community.

You can find our complete financial statements at www.wfhusa.org





**THANK
YOU
TO OUR
DONORS**



The support we receive from across the US ensures more people have reliable access to safe treatment and care, regardless of their type of bleeding disorder, their gender, or where they live.

\$250,000.00 +

Hemophilia of Georgia

\$100,000.00 +

Indiana Hemophilia & Thrombosis Center (IHTC)
National Bleeding Disorders Foundation (NBDF)
The Hemophilia Alliance

\$50,000.00 +

Glenn Pierce
Beatrice Pierce

\$10,000.00 +

Mark Skinner and James Matheson

\$7,500.00 +

Phillips 66

\$5,000.00 +

Barbara Goldman

\$2,500.00 +

Leonard Valentino
Lone Star Bleeding Disorders Foundation
Mary M Gooley Hemophilia Center

\$1,000.00 +

Edith A. Rosato
Paula Bell and Rob Christie
Bleeding Disorders Foundation of North Carolina
Coalition for the Hemophilia B (The)
Eastern PA Bleeding Disorder Foundation
Gateway Hemophilia Association
Great Lakes Hemophilia Foundation
Hemophilia Association of the Capital Area
Horowitz Family Foundation
Barbara Konkle and Peter Kollros
John Murphy
Northern Ohio Hemophilia Foundation
Pacific Northwest Bleeding Disorders
Rocky Mountain Hemophilia & Bleeding Disorders
Foundation
Kenneth Trader
Tri-State Bleeding Disorder Foundation

\$500.00 +

Alain Baumann
Daniel Button
Amy Dunn
Dean M. Hindenlang
Carol K. Kasper
Craig Kessler
LA Kelley Communications, Inc.
New England Hemophilia Association
Steven Pipe
Mr. Patrick Robert and Mrs. Clare Robert
Dawn S. Rotellini
Gina Schnabel
Sundar R. Selvaraj
Southwestern Ohio Hemophilia Foundation
Virginia Hemophilia Foundation

\$250.00 +

John Button
Arleigh R. Clemens
Randall G. Curtis
Hemophilia Foundation of Northern California
Rosa Maria Duenas-Rios
Christine Herr
Alfred Hiermann
Kim Isenberg
Phillip Kucab
Roshni Kulkarni
James V. Luck
Prasad Mathew
Charles Moore
Eric and Marion Stolte
Amy and Allen Renz
Jill Sallade-Packard
Maria E. Santaella
Sean Singh
Kyle Wilder

\$100.00 +

Jeannie Aschkenay
Patrick F. Barnes
Gary Bauer
Dennis Campbell
Kit Festa
Martha Jenkins
Khizra Khan
Deedra J. Miller
Kimberly Phelan
John C. Ramsey
Charles A. Rater
Debbie de la Riva
Debra Rook
Kahleen Rowe
Rebecca Schaffer
Sink, Gordon & Associates LLP
Marlene Spencer
Diane S. Standish
Susan Peterson Thomas
Teri Willey
Bruce H. Wingerd
Wing Yen Wong

Up to \$99

Avery Auto Parts
Brad Beems
Nancy Berggren
Jean Bergstrom
Karen Boyd
Stevem Brewer
Tamara Bullock
Maurice A. Catlin
Clay Center Rotary Club
Cathy Clemens
Heidi A. Cronn
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Arnold Knoettgen
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Vicky S. Mall
Tristan Martin
Barbara McClain
Henry Mead
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Derek Pfizenmaier
Pat Pfizenmaier
Jessica Richmond
Ken Ring
Nancy Ryan
Michael R. Schottelkotte
Robert Sidonio
Paul Spangler
Patrice Thomas
Gary Unruh
W.B Sweeney Elementary School



Continue Your Commitment

Join us in shaping a brighter future for individuals living with bleeding disorders worldwide. Your support helps us extend life-saving treatments and comprehensive care to those in need, fostering long-term impact.

PLEASE SUPPORT WFH USA AS GENEROUSLY AS YOU CAN

Online

Make your contribution quickly and securely at WFH Donation Page, usagive.wfh.org.



Mail

Send your tax-deductible gift to:

Federation of Hemophilia USA PMB 142, 911 Central Avenue Albany, NY 12206-1304

Phone

Connect with us at **877-417-7944** for assistance or inquiries.

Stock

For donations in the form of securities, please reach out to us directly at philanthropy@wfh.org for detailed instructions.

Legacy

Consider including WFH USA in your will, or as a beneficiary of your retirement or insurance plan, fostering a legacy of care. Please contact Marlene Spencer at m Spencer@wfh.org for more information.

Become a Global Champion

Join our circle of dedicated supporters who pledge regular contributions to ensure sustainable, transformative changes. Learn more about becoming a Global Champion and the exclusive benefits offered at WFH Global Champions Program, usagive.wfh.org.



26,000+

PEOPLE WITH A BLEEDING DISORDER

treated since 2015

144

TREATMENT CENTRES

benefitted from the WBDR

130+

COUNTRIES REACHED

through global programs and events



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