



# 2024 ANNUAL REPORT

[wfhusa.org](http://wfhusa.org)



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



**“I want to become an aeronautical engineer. Now, I can walk, write, and study without the threat of acute bleeds.”**

— Mohnish Patil, 12-year-old boy from India living with hemophilia A

Born with hemophilia A, Mohnish’s early years were fraught with pain and limited mobility. Access to care was scarce, and his condition remained largely unmanaged. Hope arrived when Sahyadri Hospital in Pune, India, supported by the WFH Humanitarian Aid Program, provided him with comprehensive care and donated treatment products. This support transformed his life, enabling him to pursue his education and dream of becoming an aeronautical engineer.

The World Federation of Hemophilia (WFH) transforms communities by equipping and empowering its national member organizations (NMOs) and healthcare providers with the knowledge, tools and treatment products 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.A by deepening the engagement of American residents with our global vision of Treatment for All and raising funds to bring that vision to life.

# THE CHALLENGE



**75%**

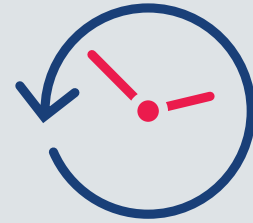
of people with bleeding disorders worldwide remain undiagnosed



**ONLY 8%**

of people with hemophilia have been diagnosed in low income countries compared to 73% in high income countries

*2023 Annual Global Survey*



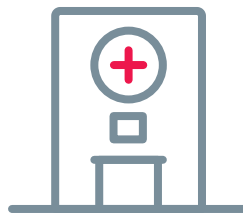
Care provided in developing countries lags up to **50 YEARS BEHIND** standards available in the U.S.A.

## OUR IMPACT



**OVER 29,000 PEOPLE**

with bleeding disorders treated since 1996 thanks to donations provided through Humanitarian Aid Program



**124 TREATMENT CENTERS**

worldwide benefiting from the World Bleeding Disorders Registry



**130+ COUNTRIES**

reached through WFH global programs and events

# MESSAGE FROM THE PRESIDENT



It is a privilege to serve as President of the World Federation of Hemophilia (WFH) USA and to continue our unwavering commitment to advancing the global mission of the WFH here in the United States. As a hematologist, I have witnessed firsthand the life-changing impact of equitable access to care, and I am honored to continue my contribution to transforming lives across borders.

Last year marked a time of renewal for our board. I stepped into the role of President, joined by Philip Kucab, MD, as Vice President. We also welcomed four new board members—Jeff Blake; Joanna Davis, MD; Robert J. Maloney, Jr.; and Dawn Rotellini—whose experience and passion strengthen our shared mission. I also want to extend our heartfelt thanks to Eric Stolte, whose thoughtful leadership as President helped guide WFH USA through a period of strategic growth.

In 2024, WFH USA continued to fulfill its role as a vital bridge between U.S. supporters and the global bleeding disorders community. Thanks to the continued generosity of individuals, chapters, and corporate partners across the United States, WFH programs reached over 130 countries—delivering treatment, training, advocacy, and hope. Resources mobilized through WFH USA supported a wide range of global initiatives across four key

areas: humanitarian aid, training and education, research and data collection, and scholarships and grants. From lifesaving treatment delivered through the WFH Humanitarian Aid Program to transformative initiatives like the Cornerstone Initiative, the Women and Girls with Bleeding Disorders Program, and the World Bleeding Disorders Registry (WBDR), this support is helping to close the global treatment gap and build sustainable care systems worldwide.

The value of this work also extends back to the U.S. community. The Living Guidelines initiative, for example, is advancing global standards of care based on the latest clinical evidence. U.S. experts are actively involved in this work, and we work closely with the National Bleeding Disorders Foundation's (NBDF) Medical and Scientific Advisory Council (MASAC) to ensure that treatment recommendations are aligned and mutually reinforcing. By supporting these efforts, our donors are helping to promote consistent, evidence-based care for people with bleeding disorders—both globally and here at home.

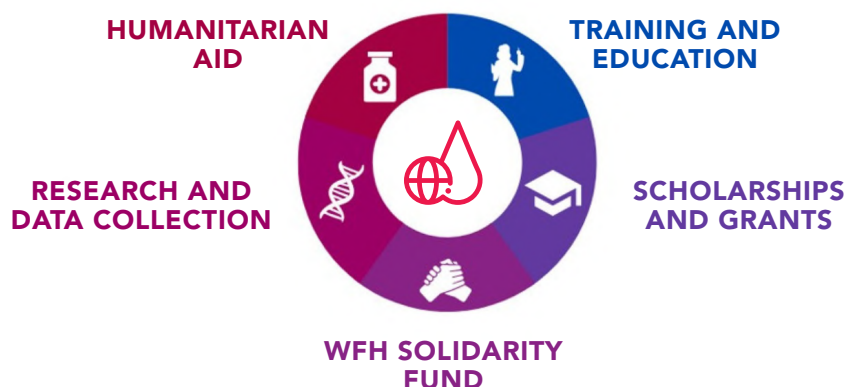
As we look to the future, the WFH is completing the final year of its Roadmap to 2025 and laying the groundwork for a new strategic plan that will guide our efforts from 2026 to 2030. In this time of growing economic pressures and shifting philanthropic trends, WFH USA remains focused on diversifying our funding base, deepening engagement with U.S. supporters, and strengthening our capacity to adapt and respond to global needs. Building strong partnerships, maintaining trust, and demonstrating the lasting impact of every dollar raised will be central to our efforts in the years ahead.

I am grateful to serve alongside a dedicated board and staff, and I am deeply appreciative of the support of our partners across the country. Together, we are helping to close the treatment gap and build a more just and healthier world for all people with bleeding disorders.

With gratitude,

**Leonard A. Valentino, MD**  
President, WFH 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 ensure access for all

## BOARD OF DIRECTORS

### PRESIDENT

Len Valentino

### VICE-PRESIDENT

Phil Kucab, MD

### TREASURER

Sean Singh

### BOARD MEMBERS

Paula Bell

Jeff Blake

Joanna Davis, MD

Amy Dunn, MD

Robert J. Maloney, Jr.

Glenn Pierce MD, PhD

Dawn Rotellini

Frank L. Schnabel IV

Mark W. Skinner

Eric Stolte

## EX-OFFICIO

Alain Baumann

**Executive Director/Secretary**

**WFH Chief Executive Officer**

Marlene Spencer

**National Director**

# TRANSFORMING LIVES

## Through the WFH Humanitarian Aid Program

Delivering hope and health worldwide through life-saving treatments

### 2024 highlights

- **291 million IUs** of clotting factor concentrates distributed
- **2.8 million mg** of non-factor replacement therapy distributed
- **17,533 individuals** with inherited bleeding disorders treated in 2024
- **2,958 surgeries** performed in 2024, including **167 life- or limb-saving procedures**

### Patient story and testimonials



## INCREASING CARE AND CHANGING LIVES IN SENEGAL

When the WFH Humanitarian Aid Program team visited Senegal in May 2024, they met families whose lives have been profoundly changed by access to donated treatment. One such story came from the parents of Ousmane, a young boy who had been suffering from acute bleeds since birth. His mother recalled instances where he would receive treatment, and then after getting back home, the boy's bleed would return, and they would have to go back to the hospital. This stopped once he started receiving donated treatment product provided by the WFH Humanitarian Aid Program.



*"We really saw the importance of this treatment," said Ousmane's mother. "We hope other children like him will receive it too. Here it is lacking, and we want everyone to be able to benefit from it."*

Read the full story here.



# TRANSFORMING LIVES

## Through Research and Data Collection

Building evidence-based pathways to equitable care

### 2024 Highlights

- **17,059** people with hemophilia (PWH) and von Willebrand disease (PwVWD) enrolled globally in the WBDR from **124 hemophilia treatment centers (HTCs)** across **47 countries**
- **28% increase** in participation since 2023
- Launch of a **new WBDR Data Visualization Dashboard** and expanded use of the **myWBDR mobile application** to enhance patient-reported outcomes
- The WFH Living Guidelines initiative completed its first update: a new chapter focused on treatment guidelines for individuals with hemophilia who have received gene therapy.

### Advancing global health through data

Data is the cornerstone of equitable care. Through sustained U.S. donor support, the World Bleeding Disorders Registry (WBDR) continues to equip healthcare providers and patient communities with the insights they need to improve outcomes, advocate effectively, and influence policy.

In 2024, the WBDR expanded both in scale and scope, strengthening the global evidence base for bleeding disorders. Its growing reach has been especially meaningful for women and girls, whose inclusion in data systems is critical to closing long-standing diagnostic and treatment gaps. This momentum has also helped catalyze improvements in real-time reporting, with the new Data Visualization Dashboard and enhanced myWBDR app placing actionable information directly into the hands of clinicians and patients.

### IMPACT STORY: EMPOWERING HEALTHCARE IN INDIA

Joseph John, MD, from Christian Medical College in Ludhiana, India, emphasized the transformative potential of robust data collection:

*"The WBDR's emphasis on efficient data entry and analysis has empowered us to refine patient care and significantly advance our research. This level of detail allows us to meet patient needs more precisely and advocate effectively for better resources."*



# TRANSFORMING LIVES

## Through Training and Education

Training and education empower healthcare providers and patient leaders, creating lasting, transformative change. WFH USA proudly supports global capacity-building programs, ensuring patient advocates and healthcare professionals collaborate effectively to provide equitable, sustainable care.

- **Over 600 healthcare professionals and patient leaders** participated in WFH-supported educational workshops and advocacy trainings, significantly expanding global expertise and local leadership capacity
- The **Cornerstone Initiative extended vital services to five under-resourced countries**—Togo, Rwanda, Madagascar, Tanzania, and Tajikistan. In Tanzania alone, **58 new people with hemophilia** were diagnosed, marking a **2.5x increase** in identified patients since 2019.
- The **WFH International Hemophilia Training Centre (IHTC) Fellowship Program** provided specialized clinical training to early-career hematologists and healthcare professionals from low- and middle-income countries. In 2024, 16 fellows received hands-on instruction at internationally recognized treatment centers and returned to their countries equipped to lead care improvements, strengthen diagnostic capacity, and contribute to national health strategies.



### SUCCESS STORY: EMPOWERING WOMEN THROUGH PEER-TO-PEER EXCHANGE

In 2024, a **women and girls peer-to-peer pilot project** brought together healthcare teams from Hemophilia of Georgia and Mexico City's Centro Integral de Hemostasis. This initiative established multidisciplinary clinics dedicated to women's care, providing comprehensive training for healthcare providers and creating patient educational resources on heavy menstrual bleeding and iron-deficiency anemia.

The success of this pilot highlights the profound impact of U.S.A.-supported training initiatives, setting a model for sustainable, equitable care for women and girls globally.



# TRANSFORMING LIVES

## Through Scholarships and Grants

Nurturing the next generation of bleeding disorders leaders and advocates

### 2024 highlights

- **Eight Susan Skinner Memorial Fund Scholarship** recipients attended the WFH 2024 World Congress in Madrid
- **Youth Fellowship program brought 14 young leaders** to Spain for training, mentorship, and global collaboration
- Fellows have since launched peer-led projects, strengthened NMO ties, and expanded access to care and advocacy

For women and youth living with bleeding disorders, access to education, mentorship, and international exposure can be life changing. In 2024, WFH USA donors helped make this possible by supporting the **Susan Skinner Memorial Fund (SSMF)** and global youth development initiatives.

Fourteen emerging leaders from 14 countries were selected through a competitive process to participate in the Global NMO Training and General Assembly in Spain. Since then, several fellows have launched peer-led advocacy projects, built new ties with healthcare systems, and led capacity-building efforts within their NMOs.

To deepen this investment, the WFH launched a **new two-year Youth Leadership Program** in 2024. This initiative empowers young advocates to stay engaged with their NMOs through structured activities, project implementation, and shared leadership development—helping ensure a strong and sustainable next generation of bleeding disorders leadership.



2024 Susan Skinner Memorial Fund recipients





# FINANCIAL REPORT

2024

The 2024 Financial Statements have been prepared under the US Generally Accepted Accounting Principles (GAAP) as required by US tax authorities.

According to U.S. GAAP rules, donated pharmaceutical products that have not yet been shipped to beneficiaries through the WFH 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 2024, we received \$1,095,539,762 in contributions from dedicated donors and partners in support of WFH USA operations as well as joint and coordinated activities between the WFH and WFH USA. This amount includes in-kind donations of blood clotting factor and other related pharmaceutical products valued at \$1,090,753,383.

The 2024 expenditures totaled \$1,154,889,784 which included the value of the pharmaceutical products distributed to beneficiaries of \$1,150,255,781.

In 2024, net assets decreased by \$59,350,022 compared to 2023, primarily due to the difference between the cost of the donated pharmaceutical products received and those distributed during the year. Activities related to these in-kind donations are presented as in-kind revenue and in-kind expenses in the statement of activities, leading to significant year-over-year fluctuations in the total change in net assets.

At the end of the year, total net assets amounted to \$377,299,575.

The donations to the Susan Skinner Memorial Fund (SSMF) totaled \$24,054, bringing the endowment fund balance to \$958,040. 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](http://www.wfhusa.org)







**THANK  
YOU  
TO OUR  
DONORS**

**\$500,000+**

Hemophilia of Georgia

**\$100,000 to \$249,999**

Indiana Hemophilia and Thrombosis Center  
The Hemophilia Alliance

**\$50,000 to \$99,999**

National Bleeding Disorders Foundation  
Beatrice Pierce  
Glenn Pierce

**\$25,000 to \$49,999**

Mark Skinner and James Matheson  
Jeannie and Leonard A. Valentino

**\$10,000 to \$24,999**

The Marketing Research Bureau

**\$5,000 to \$9,999**

Barbara Goldmann  
John Murphy  
Oasis Foundation  
Frank Schnabel IV and Lillian Schnabel

**\$2,500 to \$4,999**

Lone Star Bleeding Disorders Foundation  
Tides Foundation

**\$1,000 to \$2,499**

Paula Bell and Rob Christie  
Eastern Pennsylvania Bleeding Disorders Foundation  
Gateway Hemophilia Association  
Hemophilia Association of the Capital Area  
Dean M. Hindenlang  
Barbara Konkle and Peter Kollros  
Phillip Kucab  
Pacific Northwest Bleeding Disorders  
Rocky Mountain Hemophilia & Bleeding Disorders Association

**\$500 to \$999**

Alain Baumann  
Nathan Connell  
Joanna A. Davis  
Edward Johnston  
Jason Kappel  
Dawn S. Rotellini  
Gina Schnabel  
Southwestern Ohio Hemophilia Foundation  
Eric and Marion Stolte  
Virginia Hemophilia Foundation

**\$250 to \$499**

Daniel Doran  
Christine Herr  
Kim Isenberg  
Carol K. Kasper  
Amy and Allen Renz  
Evan Rimer  
Patrick and Clare Robert  
Maria M. Salas-Pilla  
Jill Sallade-Packard  
Sundar R. Selvaraj  
Sean Singh  
Marlene Spencer  
Howard Winet

**\$100 to \$249**

American Online Giving Foundation, Inc.  
John and Heather Button  
David B. Clark  
Randall G. Curtis  
Ryan Griffith  
Kimberly Herard  
James V. Luck  
Rohini Ravindranathan  
Joyce Sharon  
Wing Yen Wong

**Up to \$99**

Clarivate Analytics (Compumark) Inc  
Debbie de la Riva  
Boaz Greenwood  
Courtney Gustin  
Mary Lesh  
Kim Mauer  
James Mueller  
Paul Spangler  
Hiroyuki Suzuki  
Eliza VanZweden







# 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.

## SUPPORT WFH USA TODAY



### Online

Make your contribution securely at [usagive.wfh.org](https://usagive.wfh.org).

### Mail

Send your tax-deductible gift to:  
World 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

To make a gift of securities, contact [philanthropy@wfh.org](mailto:philanthropy@wfh.org) for detailed instructions.

### Legacy giving

Consider including WFH USA in your will or naming us as a beneficiary of your retirement or insurance plan. For more information, contact Marlene Spencer, National Director at [mspencer@wfh.org](mailto:mspencer@wfh.org).



### Become a Global Champion

Join our circle of monthly donors whose ongoing generosity ensures sustainable, transformative change. Learn more and sign up at [usagive.wfh.org](https://usagive.wfh.org).



# 29,000+

## PEOPLE WITH A BLEEDING DISORDER

treated since 1996 thanks to donations through Humanitarian Aid Program

.....

# 124

## TREATMENT CENTERS

benefitted from the WBDR

.....

# 130+

## COUNTRIES REACHED

through global programs and events



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