



2022 ANNUAL REPORT

wfhusa.org

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

All people with inherited bleeding disorders should have access to care, regardless of their type of bleeding disorder, their gender, or where they live.

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.

TABLE OF CONTENTS

President's Report.....	4
Our strategic priorities.....	5
Transforming Lives: Through Research and Data Collection.....	6
Transforming Lives: Through Training and Education	8
Transforming Lives: Through the WFH Humanitarian Aid Program	10
Transforming Lives: Through Solidarity	11
Transforming Lives: Through Scholarships and Grants.....	12
Financial Report.....	14
Thank You to our Donors.....	16
WFH Global Champions.....	19

70% of the estimated 819,000 people living with hemophilia worldwide, are undiagnosed.* This represents more than the populations of Atlanta or Milwaukee. Rates of diagnosis are even lower for women and those with other bleeding disorders.

Even when they are diagnosed, only 29% of adults and 30% of children with severe hemophilia received prophylaxis in 2021,** even though it is the established standard of care.

* WFH Report on the Annual Global Survey 2021

** WFH World Bleeding Disorders Registry 2021 Data Report

Together, we can address this inequity and give more people with inherited bleeding disorders a chance at a better life

“So many things are happening, and they all add up to a very bright future for our community. Thank you to all those who support the WFH.”

—Charity Pikiti, Haemophilia Foundation of Zambia

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.

HA visit to Sri-Lanka – 2022



PRESIDENT'S REPORT

Greetings,

WFH USA provides the foundation for the WFH's Humanitarian Aid (HA) program. I recently accompanied our HA team to Sri Lanka allowing me to see the people whose lives are directly affected. It was both heartwarming – listening to the stories of the vast improvement in the lives of those who are now receiving treatment; and heart-breaking – seeing the impact of the lack of treatment and the great need that still exists. This trip puts faces to the names of those represented by the statistics which demonstrate that over 25,000 people received treatment from our HA program, including almost 11,000 on prophylaxis. We continue to strive toward our vision of Treatment for All!

2022 was also a year of continuing commitment to our mission 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. These explain what we aim to achieve, both in the US and around the world and how we will mark our progress. We work to ensure more people with inherited bleeding disorders have access to care, regardless of their type of disorder, their gender, or where they live. The strong partnerships we develop with donors and funders across the U.S. are vital to helping our global community.

My heartfelt thanks go to my fellow board members, the volunteers, community leaders, healthcare providers, staff and other stakeholders across the US and around the world who help us address the deep inequities that persist between those who have access to care and those who do not. Together we are transforming lives, not just for today but for generations to come!



Eric Stolte

WFH USA President

BOARD OF DIRECTORS

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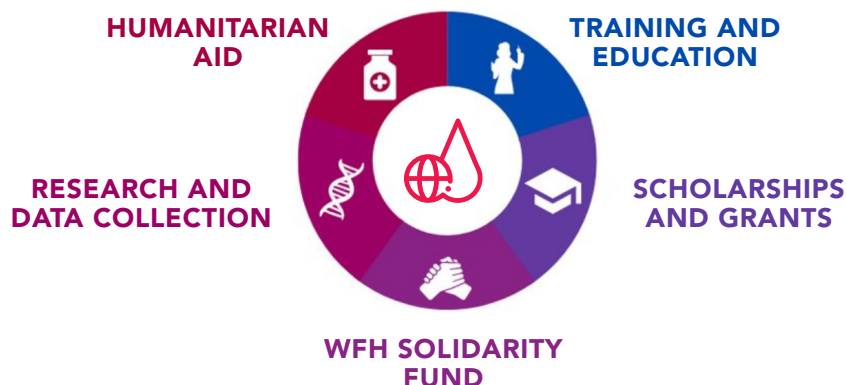
Edith A. Rosato

Frank L. Schnabel IV

Sean Singh

Mark W. Skinner

In support of WFH's mission to improve and sustain care for people with inherited bleeding disorders around the world, WFH USA raises vital funds and pursues partnerships in five key areas:



OUR STRATEGIC PRIORITIES

- 1 FOSTER CONNECTION** between the US and global communities
- 2 EXPAND RESOURCES** to support WFH global programs
- 3 DEEPEN OUR COMMITMENT** to principles of diversity, equity and inclusion

HA visit to Indonesia – 2022



TRANSFORMING LIVES

Through Research and Data Collection

The WFH supports the collection of data and evidence at local, national and global levels through the **ANNUAL GLOBAL SURVEY**, the **WORLD BLEEDING DISORDERS REGISTRY**, and the now launched **GENE THERAPY REGISTRY**.

These programs provide national member organizations and hemophilia treatment centres with the framework to collect data on people with bleeding disorders, and the education and training to use that data to improve clinical care, conduct vital research and support evidence-based advocacy.

In 2022, we:

- Enrolled 1,960 new patients in the **WORLD BLEEDING DISORDERS REGISTRY**.
- Began work on our **LIVING GUIDELINES** that serve to coordinate care for those affected by bleeding disorders around the world.

HA visit to Kenya – 2022





WFH 2022 World
Congress, Montreal

CASE STUDY

Enhancing data gathering around the world over the last year, the WFH has increased the number of patients registered in the WBDR through a number of innovative efforts. Thanks to these endeavours, there are now over 10,000 PWH— and counting—reporting data on the platform.

- The my WBDR mobile app has made it easy for PWH to collect patient reported outcome data, empowering them to participate in monitoring their own health outcomes
- The International Data Integration Program has made it possible to combine resources from existing hemophilia registries, allowing 300 Thai patients with hemophilia A and B to be integrated successfully in the WBDR
- In 2022, multilingual functionality was brought to the WBDR, allowing hemophilia treatment centres (HTCs) in Spanish-, French- and Russian-speaking countries to use the platform in their own language



TRANSFORMING LIVES

Through Training and Education

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

- Healthcare development programs
- Meetings and events
- Educational tools and resources

The **WFH eLEARNING PLATFORM** features educational content on topics relevant to bleeding disorders and over 800 educational resources, including educational videos, webinar recordings, interactive learning modules, and online tools for healthcare professionals, people with bleeding disorders (PWBDs), and their families. Official WFH translations of materials are available in Spanish, French, Arabic, Russian, Simplified Chinese, and Japanese. Many of the materials have been translated by other organizations and are available in 18 additional languages.



HA visit to Sri-Lanka - 2023



In 2022, we

- Were finally in person again for WFH's World Congress in Montreal, Canada.
- Hosted the second annual WFH Global Policy and Access Summit to bring stakeholders together to share strategies and learnings.
- Graduated the first cohort of 23 students from 18 countries from the PACT Advocacy Academy.



WFH GLOBAL POLICY
AND ACCESS SUMMIT



PACT
PROGRAM

WFH 2022 World
Congress, Montreal



[Learn more](#)

TRANSFORMING LIVES

Through the WFH Humanitarian Aid Program

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

In 2022, we:

- Treated over 25,000 patients and managed 41,700 bleeding episodes.
- Hit a major milestone: the WFH has now donated over 1.5 billion IUs of factor along with non-factor replacement therapy since 2015.
- Facilitated 1,400 surgeries.



CASE STUDY

New people with hemophilia receiving WFH Humanitarian Aid Program support

Sheldon Simson is a 40-year-old man who was diagnosed with severe hemophilia A when he was three months old. During his childhood, he developed permanent joint damage to his ankles, knees, and elbows. Things changed dramatically for Sheldon when the WFH Humanitarian Aid Program began providing donated factor to his country in 2021. He went from having rare access to factor to being able to begin a prophylactic treatment regimen. Simson's story is proof that change is almost immediate even at the initial stages of WFH Humanitarian Aid Program work in a country.

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



[Read more](#)

TRANSFORMING LIVES Through Solidarity

The WFH Solidarity Fund was established in 2022, with inaugural funding from partners like you who were eager to support the bleeding disorders community affected by the war in Ukraine. The Solidarity Fund is a natural evolution from the Covid-19 Relief Fund, established in 2020 to help our National Member Organizations (NMOs) cope with the far-reaching effects of the global pandemic. It aims to ensure we have the capacity to support all our 147 NMOs in their efforts to improve outreach and diagnosis, provide adequate treatment, collect and interpret data, and advocate for sustainable care.

In 2022, the Solidarity Fund made it possible for the WFH to provide over \$250,000 in support to people with inherited bleeding disorders affected by the ongoing war in Ukraine.

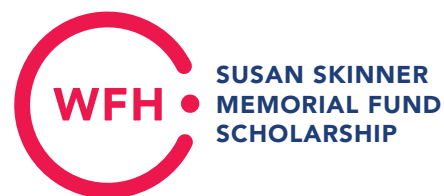
HA visit to Indonesia



TRANSFORMING LIVES

Through Scholarships and Grants

The fund commemorates the late Susan Skinner, an American woman determined to ensure the availability of safe and effective treatment for her two sons. The WFH USA is deeply grateful to the late Thomas Skinner who created the fund, family members and friends, as well as 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 that can be used to empower themselves and others to advocate for the 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.

HA visit to Senegal – 2023



In 2022, we

- In 2022, the SSMF scholarship program increased the application age limit from 30 to 60 years old.
- Awarded 10 scholarships ranging in ages from 21 to 58, from the United States, Ireland, France, Kyrgyzstan, Senegal, Lesotho and Jordan.

“The [SSMF scholarship] increased my confidence as a person as well as the confidence in my abilities to work internationally and be successful.”

—Nikole Scappe, USA; 2018 scholar and current staff member, National Hemophilia Foundation

“The experience I had through this scholarship gave me the motivation to go back to my country and deepen my engagement. I was president of my Society for 8 years and [now] I am a member of the Board of Directors.”

—Maria Nacheska, Republic of North Macedonia; 2008 scholar and board member of the Civil Haemophilia Association of Republic of Macedonia



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

WFH 2022 World Congress, Montreal



A photograph of two young girls with dark hair peering over a dark, possibly metal, ledge. The girl on the left is wearing a yellow shirt and a pink headband with a green bow. The girl on the right is wearing a pink shirt and a large red flower headband. They are both looking towards the camera with slight smiles. The background is a warm, orange-brown wall.

FINANCIAL REPORT

2022

In 2022, we received \$4,531,728 in contributions from dedicated donors and partners towards the joint and coordinated activities of the WFH and WFH USA (\$3,407,270 in 2021). These include the WFH Humanitarian Aid Program, the WFH Research Program, the WFH Training and Education Program and the newly created Solidarity Program to support Ukraine. From these contributions we granted \$4,370,031 to the WFH as needed to carry out its responsibilities with respect to the joint programs (\$3,261,770 in 2021). We also had a very good year for charitable donations with \$257,169, compared to \$193,277 in 2021. In 2022, we obtained a surplus of \$56,714 versus a surplus of \$102,340 in 2021. WFH USA remains in sound financial health with year-end unrestricted net assets of \$470,504 (\$413,790 in 2021).

Despite the continued logistical challenges created by the COVID-19 pandemic (keeping airfreight rates high and creating in-country barriers to movement), the WFH Humanitarian Aid team found alternative ways to deliver care to those who needed it most. In 2022, treatment was provided to over 25,000 patients in 71 emerging

countries. The majority of these donations, worth \$679,771,855, are included in the audited financial statements of WFH USA (\$819,254,269 in 2021).

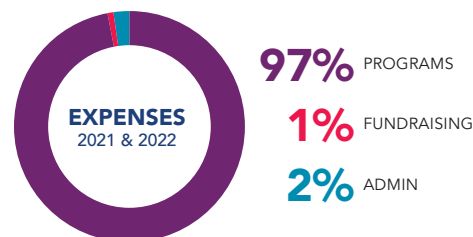
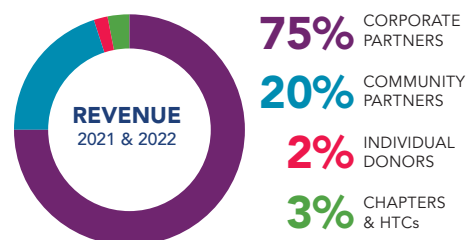
The donations to the Susan Skinner Memorial Fund (SSMF) totaled \$63,001 in 2022 (\$51,431 in 2021). This brought the endowment fund balance from \$602,082 to \$665,083 at the end of 2022. We thank all those who support this important initiative. The continued growth of this fund allows us to invest in our women leaders to the benefit of our entire community.

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. The estimated monetary value of the volunteer services was at \$276,241 in 2021 (\$244,955 in 2021).

The dedication and loyalty of our American community humbles and inspires us. Without you, WFH USA could not continue advancing the global mission of the WFH to improve access to care for people with bleeding disorders around the world.

REVENUE	2022	2021	TOTAL
Corporate Partners	3,473,631	2,702,270	6,175,901
Community Partners	968,000	665,000	1,633,000
Individual Donors	103,353	55,442	158,795
Chapters & HTC's	139,316	132,635	271,951
TOTAL REVENUE	4,684,300	3,555,347	8,239,647

EXPENSES	2022	2021	TOTAL
PROGRAMS	4,583,526	3,421,936	8,005,462
FUNDRAISING	61,078	47,665	108,743
ADMIN	87,579	28,606	116,185
TOTAL REVENUE	4,732,183	3,498,206	8,230,390



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.

\$500,000.00 +

Hemophilia of Georgia

\$250,000.00 +

The Hemophilia Alliance

\$100,000.00 +

National Hemophilia Foundation

\$50,000.00 +

Glenn and Beatrice Pierce

\$25,000.00 +

The Alliance Pharmacy

\$10,000.00 +

Mark Skinner and James Matheson

The Farfy Foundation

\$7,500.00 +

Phillips 66

The Marketing Research Bureau, Inc.

\$5,000.00 +

Bank of America

Donald and Barbara Goldman

Frank Schnabel IV and Lillian Schnabel

Mary M. Gooley Hemophilia Center

Employees of BioMarin Pharmaceutical Inc.

\$2,500.00 +

Bright Funds Foundation

Hemophilia of Indiana

Mary M. Gooley Hemophilia Center

Lone Star Bleeding Disorders Foundation

New England Hemophilia Association

Employees of uniQure

\$1,000.00 +

Alaska Hemophilia Association

Amwell Cares

Alain Baumann

Bleeding Disorders Alliance Illinois

Paula Bell and Rob Christie

Coalition for Hemophilia B

FAMOHIO Inc.

Florida Hemophilia Association

Gateway Hemophilia Association

Great Lakes Hemophilia Foundation

Hemophilia Foundation of Southern California

Hemophilia of North Carolina

Barbara Konkle & Peter Kollros

John Murphy

Pacific Northwest Bleeding Disorders

Joseph Pugliese

Rocky Mountain Hemophilia & Bleeding Disorders Association

Patrick Robert

Edith A. Rosato

Dawn S. Rotellini

Eric and Marion Stolte

Texas Central Hemophilia Association

Kenneth Trader

Tri-State Bleeding Disorder Foundation

Leonard A. Valentino

\$500.00 +

Bleeding Disorders Association of South Carolina (BDASC)

Colorado Chapter of the National Hemophilia Foundation

David B. Clark

Amy Dunn

Eastern PA Bleeding Disorder Foundation

Hemophilia Foundation of Greater Florida

Hemophilia Foundation of Minnesota/Dakotas

Hemophilia Foundation of Northern California

Kentucky Hemophilia Foundation

Jennifer Laliberté

Steven Pipe

Steve Prince

Gina Schnabel

Sundar Rajan Selvaraj

Southwestern Ohio Hemophilia Foundation

Virginia Hemophilia Foundation

\$250.00 +

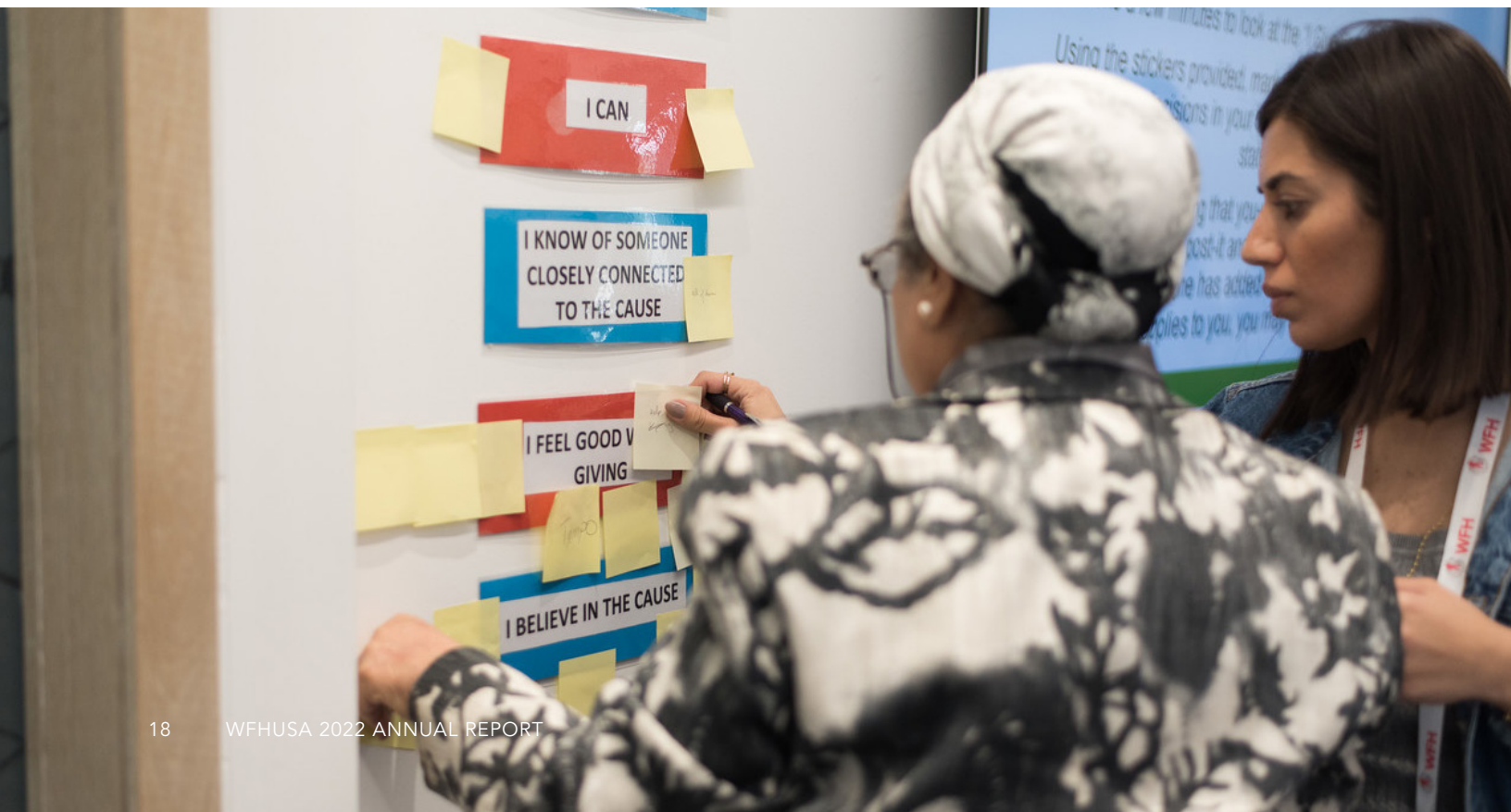
John Button
Nathan Connell
Rosa Maria Duenas-Rios
Hawaii Chapter of the National Hemophilia
Foundation
Hemophilia Alliance of Maine
Hemophilia Foundation of Michigan
Christine Herr
Kim Isenberg
Craig Kessler
Mary Lesh
Louisiana Hemophilia Foundation
Prasad Mathew
Nebraska Chapter of the National Hemophilia
Foundation
Carol Parker
Ulrike Reiss
Amy Renz
UNC Health Care System
Western Pennsylvania Bleeding Disorders
Foundation

\$100.00 +

Randall George Curtis
Donna DiMichele
Marion A. Koerper
Carol K. Kasper
Richard and Jane Metz
Susan Resnik
Diane S. Standish
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West Virginia Chapter of the NHF
Ellen White

Up to \$99

Arizona School of Dentistry & Oral Health
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Regina Butler
Dana Francis
Laura Gusba
Rebecca Schaffer
Marie Schnabel
Robert Sidonio
Sean Singh
Mike Skinner
Paul Spangler
William T. Sparrow
Paula Zeff





WFH Global Champions

Community solidarity that transcends borders

TRANSFORMING LIVES AROUND THE WORLD

The WFH Global Champion's program is the perfect opportunity to share your commitment to the global bleeding disorders community and be a part of the transformational change we are creating for the thousands who still live without access to diagnosis, treatment and care.

YOUR CONTRIBUTION → OUR IMPACT

“ Because of your donations, we can plan surgeries, treat life-threatening bleeds, and put kids on prophylaxis...this was not imaginable ten years ago. ”

DR. THERESA NWAGHA
SOUTH EAST HTC COORDINATOR, NIGERIA



[LEARN MORE](#)



WFH

WORLD FEDERATION OF HEMOPHILIA
FÉDÉRATION MONDIALE DE L'HÉMOPHILIE
FEDERACIÓN MUNDIAL DE HEMOFILIA



25,000+

PEOPLE WITH A BLEEDING DISORDER

treated since 2015

.....

115

TREATMENT CENTRES

benefitted from the WBDP

.....

156

COUNTRIES REACHED

through global programs and events



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