WFHUSA
WORLD FEDERATION OF HEMOPHILIA

ANNUAL REPORT
2021

wfhusa.org

Advancing the Global Mission of the World Federation of Hemophilia in the United States

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.

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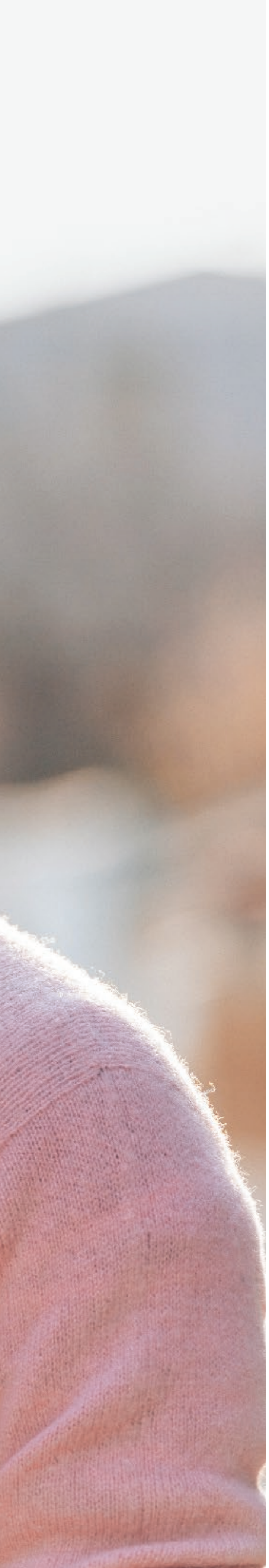

Over 75% of people

living with hemophilia remain 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.

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

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[*] WFH Report on the Annual Global Survey

[**] WFH World Bleeding Disorders Registry 2021 Data Report

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.

President's Report

Greetings,

As we all grappled with the ongoing effects of the pandemic, we learned how resilient and resourceful we can be. Our teams ensured vital humanitarian aid continued to get to those who rely on it for treatment: a record 22,000 people benefited from donated treatment products in 2021! We also found new ways to bring people together, with these technologies bringing us closer than ever before.

2021 was also a year of renewing our commitment to our mission, resulting in new strategic plans for both the WFH and WFH USA. The WFH's Roadmap to 2025 and WFH USA's Together Towards Treatment for All explain what we aim to achieve, both in the U.S. and around the world over the next five years, and how we will mark our progress. We are more determined than ever to make sure 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 U.S. 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

Eric Stolte

WFH USA President

Board of Directors

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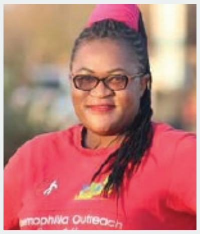
COMMUNITY VOICES

Charity Pikiti



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

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 four key areas:

- HUMANITARIAN AID
- TRAINING AND EDUCATION
- SCHOLARSHIPS AND GRANTS
- RESEARCH AND DATA COLLECTION

Our 2021-2025 Strategic Priorities

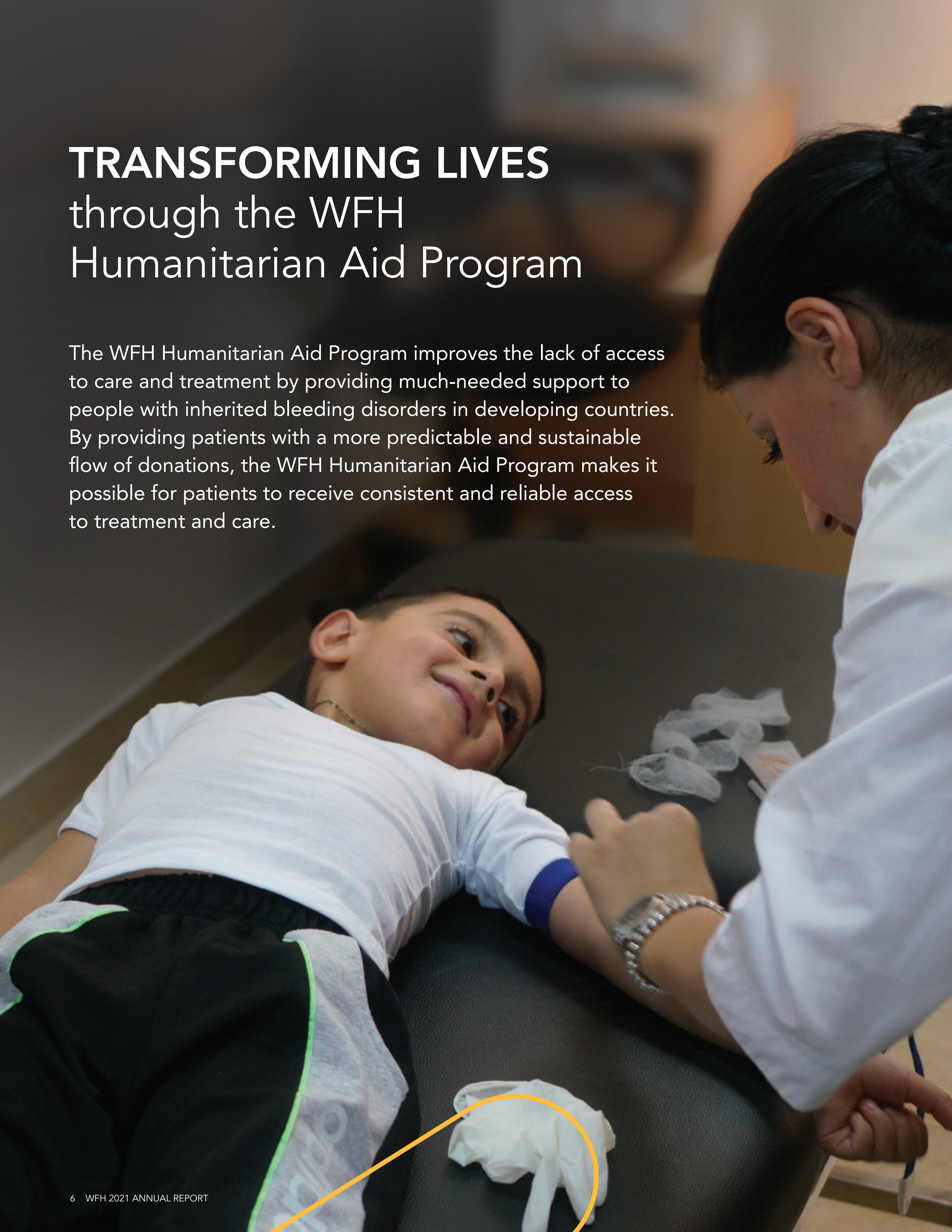
1 **Foster connection**
between the U.S. and global communities

2 **Expand resources**
to support WFH global programs

3 **Deepen our commitment**
to principles of diversity, equity and inclusion

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 2021, we:

treated over

22,000 patients and 51,000 bleeding episodes.

hit a major milestone:

The WFH has now donated over

1 billion IUs of factor

along with non-factor replacement therapy since the expansion of the program in 2015.

1 BILLION+ DISTRIBUTED

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.

COMMUNITY VOICES

O'Brian, Joel, and Nathan

O'Brian, Joel, and Nathan are brothers with severe hemophilia A and inhibitors who live in Trinidad and Tobago. Aged ten to thirteen, lack of access to care has left them with permanent disabilities. O'Brian and Joel developed arthropathy in their knees and Nathan lost vision in his right eye following an accident.

With factor replacement therapy provided by the WFH Humanitarian Aid Program, they have seen their quality of life improve drastically. The brothers can now go to school, take part in activities with their peers, and even participate in sports like swimming.

The WFH has shipped 4.4 million IUs of factor to Trinidad and Tobago since 2015.

LEARN MORE
www.treatmentforall.org

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 soon-to-launch 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 2021, we:

Enrolled
18 more treatment centers and over 2,000 new patients
in the World Bleeding Disorders Registry

Expanded the reach
of the Annual Global Survey
and provided more data to support research and advocacy efforts

COMMUNITY VOICES

Dr. Adeyemo and Dr. Poudyal

"We can now store our patient data in a systematic and timely manner. It is a great tool to use as a guide for my clinical decisions and as a discussion aid with my patients"

—Dr. Titilope Adeyemo, Lagos University Teaching Hospital HTC, Nigeria

"It has been very difficult to demonstrate the need for more support to decision makers. With these data, doctors in Nepal can now provide evidence of the sub-optimal level of care. Our patients have higher rates of bleeding and disability, compared to patients in countries with better government support."

—Dr. Bishesh Poudyal, Civil Service Hospital, Kathmandu, Nepal

LEARN MORE
https://wfh.org/usa/research-and-data-collection/

TRANSFORMING LIVES
through Training and Education

Training and education are critical to creating long-lasting, transformational 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

COMMUNITY VOICES

Cassie Osejo

"Having the opportunity to share experiences opens the space for us to be able to address national problems, with another perspective. It inspires us to take action."

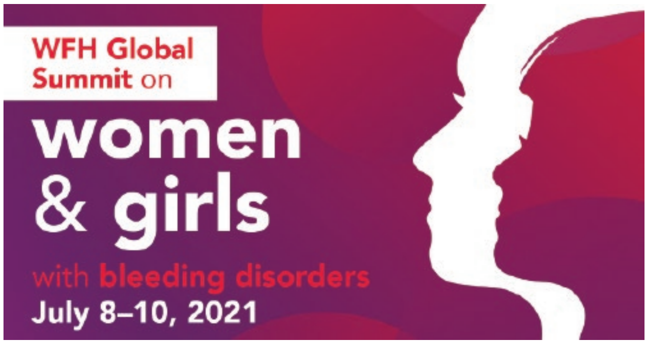
—Cassie Osejo, Fundación Panameña de Hemofilia, Event participant and speaker currently enrolled in the WFH PACT Advocacy Academy

LEARN MORE
https://wfh.org/usa/training-and-education/

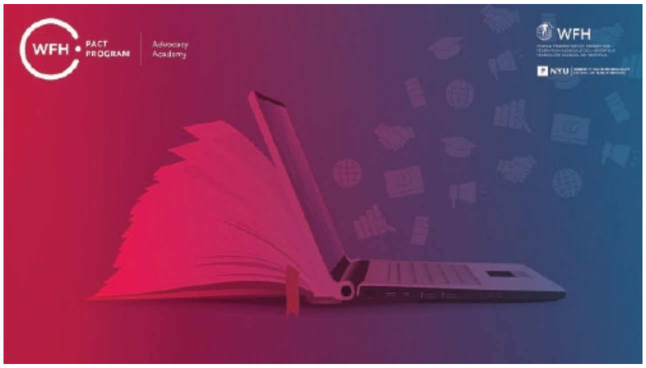
In 2021, we:

created
spaces for education and exchange
by hosting a Global Youth Leadership Training, the WFH Global Summit on Women and Girls with Inherited Bleeding Disorders, and the first-ever WFH Global Policy and Access Summit

launched the
PACT Advocacy Academy,
the WFH's first online course



produced
valuable educational tools
including the WFH Treatment Guidelines Resource Hub and a series of videos on Intimacy and Sexuality



TRANSFORMING LIVES through Scholarships and Grants

While ongoing travel bans made in-person meetings impossible, we continued to build momentum and investment in the Susan Skinner Memorial Fund, which provides scholarship opportunities for women and girls with inherited bleeding disorders.

COMMUNITY VOICES

Nikole Scappe and Maria Nacheska

"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

LEARN MORE
https://wfh.org/usa/training-and-education/

In 2021, we:

expanded the eligibility
to include women between the ages of 31-60

awarded 10 scholarships
to deserving women from 7 countries

raised over $11,000 dollars
through our first community campaign

FINANCIAL REPORT
2021

In 2021, we received $3,407,270 in contributions from dedicated donors and partners towards the joint and coordinated activities of the WFH and WFH USA ($3,774,681 in 2020). These include the WFH Humanitarian Aid Program, the WFH Research Program and the WFH Training and Education Program.

From these contributions

we granted $3,261,770 to the WFH

as needed to carry out its responsibilities with respect to the joint programs ($3,686,552 in 2020).

Charitable donations fell slightly, with $193,277 received

compared to $302,061 in 2020.

However cost reductions allowed us to finish the year with

healthy surplus of $102,340

versus a surplus of $59,060 in 2020.

WFH USA remains in

sound financial health

with year-end unrestricted assets of $413,790 ($311,450 in 2020).

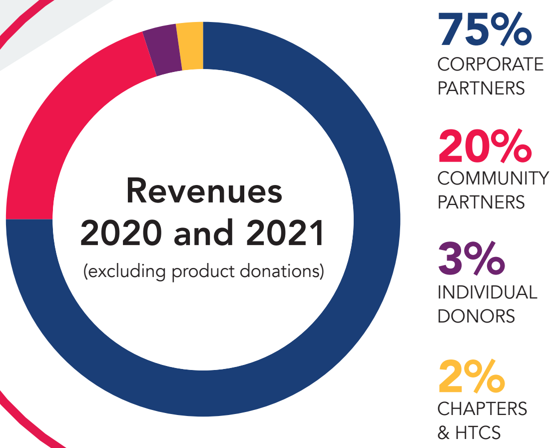
Despite the continued logistical challenges created by the COVID-19 pandemic (impacting shipping capacity and keeping airfreight rates high), the WFH Humanitarian Aid team found alternative ways to deliver care to those who needed it most. In 2021, treatment was provided to over 22,000 patients in 74 emerging countries. The majority of these donations, worth $819,254,269, are included in the audited financial statements of WFH USA ($394,273,901 in 2020).

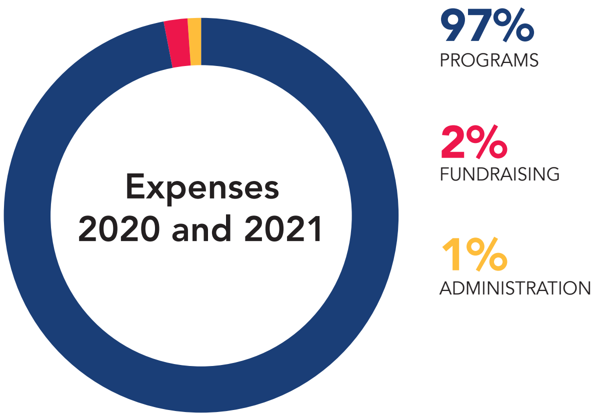
The donations to the Susan Skinner Memorial Fund (SSMF) totaled $51,431 in 2021 ($52,766 in 2020). This brought the endowment fund balance from $550,651 to $602,082 at the end of 2021. We thank all those who support this important initiative. The continued growth of this fund allows us to invest in our 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 $244,955 in 2021 ($271,820 in 2020).

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.

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





THANK YOU TO OUR DONORS

The support we receive from across the U.S. 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 +

National Hemophilia Foundation

The Hemophilia Alliance

$50,000.00 +

Logenix International

Glenn and Beatrice Pierce

$10,000.00 +

Mark Skinner and James Matheson

$7,500.00 +

Phillips 66

$5,000.00 +

Donald and Barbara Goldman

Frank IV and Lillian Schnabel

Mary M. Gooley Hemophilia Center

WuXi AppTec

$2,500.00 +

Employees of uniQure

Hemophilia Association of the Capital Area

Hemophilia Foundation of Michigan

Lone Star Bleeding Disorders Foundation

New England Hemophilia Association

uniQure

$1,000.00 +

Alain Baumann

Bleeding Disorders Alliance Illinois

Daniel Button

Paula Bell and Rob Christie

Coalition for Hemophilia B

Colorado Chapter of the National Hemophilia Foundation

Florida Hemophilia Association

Gateway Hemophilia Association

Great Lakes Hemophilia Foundation

Hemophilia Foundation of Southern California

Hemophilia of Indiana

Craig Kessler

Barbara Konkle and Peter Kollros

Phillip Kucab

Midwest Hemophilia Association

John Murphy

Nebraska Chapter of the National Hemophilia Foundation

Pacific Northwest Bleeding Disorders

Joseph Pugliese

Rocky Mountain Hemophilia & Bleeding Disorders Association

Edith A. Rosato

Dawn S. Rotellini

Texas Central Hemophilia Association

Kenneth Trader

Tri-State Bleeding Disorder Foundation

Leonard A. Valentino

1 Anonymous Donation

$750.00 +

Christine Herr

Mary Lesh

$500.00 +

Bleeding Disorders of South Carolina

Amy Dunn

Hemophilia Alliance of Maine

Hemophilia Foundation of Greater Florida

Hemophilia Foundation of Minnesota/Dakotas

Intouch Group

Kentucky Hemophilia Foundation

Jennifer Laliberté

Northern Ohio Hemophilia Foundation

Steven Pipe

Gina Schnabel

Sundar Rajan Selvaraj

William T. Sparrow

The Idaho Chapter of the National Hemophilia Foundation

Virginia Hemophilia Foundation

$250.00 +

Alaska Hemophilia Association

Kimberly Baumann

John and Heather Button

Connecticut Hemophilia Society

Randall G. Curtis

Hawaii Chapter of the National Hemophilia Foundation

Hemophilia Foundation of Northern California

Louisiana Hemophilia Foundation

Ulrike Reiss

Amy and Allen Renz

Sean Singh

Eric Stolte

Southwestern Ohio Hemophilia Foundation

West Virginia Chapter of the National Hemophilia Foundation

Western Pennsylvania Bleeding Disorders Foundation

$100.00 +

Chun Ahmed

BioMatrix Specialty Pharmacy

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Kimberly Phelan

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Joyce Sharon

Wing Yen Wong

Claire Zellner

Up to $99

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Maria M. Salas-Pilla

Rebecca Schaffer

Robert Sidonio

Leslie J. Situ-Ferber

Lena Volland

Christine Woltman

Hassan M. Yaish

WFHUSA 2021 HIGHLIGHTS

$3,4M	Raised to deliver **WFH programs and events,** reaching patients in **156 countries**
22,000+	Patients accessing treatment through the **WFH Humanitarian Aid Program**
100+	HTCs collecting clinical data using the **WFH World Bleeding Disorders Registry**

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WFHUSA
WORLD FEDERATION OF HEMOPHILIA