

ANNUAL REPORT 2022

wfh.org

CONTINUING TO SUPPORT THE BLEEDING DISORDERS COMMUNITY

The World Federation of Hemophilia (WFH) is a non-profit organization dedicated to improving and sustaining care for people with inherited bleeding disorders around the world. We work in partnership with healthcare providers (HCPs), governments, and our global network of national member organizations (NMOs) in 147 countries. We provide our NMOs and HCPs with the knowledge and tools they need to identify, support, and treat people living with bleeding disorders in their communities, while promoting global advocacy and collaboration to achieve our common goals.

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OUR VISION AND MISSION

Our vision of Treatment for All is for a world where all people with inherited bleeding disorders have access to care, regardless of their type of bleeding disorder, gender, or where they live. Our mission is to improve and sustain care for people with inherited bleeding disorders around the world.

“2022 was a great year for the WFH family—a family of people with bleeding disorders, national member organizations, healthcare practitioners, industry partners, and other stakeholders. By working together and sharing our learnings for the greater good, we got closer to our shared vision of Treatment for All.”

—Cesar Garrido, President, WFH



Photo: WFH trip to Kenya – 2022



Q&A with the PRESIDENT AND THE CEO OF THE WFH

Cesar Garrido, WFH President, and Alain Baumann, WFH CEO, discuss what the organization accomplished in 2022.

Alain Cesar, when I reflect on what the global bleeding disorder community accomplished last year, it fills me with pride, but also humility, because we must accept that there is still so much to do.

Cesar I agree, Alain. We have much to be proud of. The WFH staff and volunteers have done much, but so have our partners, our patients, our NMOs... and everyone else who's a part of our community. We've all worked together to help people with bleeding disorders (PWBDs) live a better life.

Alain After two years of the COVID-19 pandemic, it's only this year that you truly started to visit many NMOs as our new WFH President. How important was that to you?

Cesar I had the chance to visit 22 NMOs. It was wonderful being able to meet leaders, healthcare providers and government representatives face-to-face for the first time in years, and really hear their feedback and concerns, and answer their questions. I learned so much by talking with them: their needs, and the needs of the PWBDs who live in their countries.

Alain I find it very encouraging that our local partners were so enthusiastic during your visits. This really shows that people believe in our ability to have a real impact on the lives of PWBDs. NMOs, patients, families, healthcare professionals, researchers, policy makers, advocates, and industry members... we are all working together for the same thing.

Cesar Absolutely. Of course, one highlight for our community was our successful WFH World Congress in Montreal, Canada. So many of us came together for a few precious days of face-to-face interaction. After years of COVID-19 pandemic closures, it was truly wonderful to see people together, talking and networking. Say what you will about the power of technology—nothing is better than getting together in-person.

Alain Absolutely. The Congress was also special because it was a hybrid event—so we really maximized the number of people who could participate. That made it possible for people from all around the world to take part, including PWBDs.

Cesar On the topic of getting together, World Hemophilia Day was also very successful despite ongoing difficulties in many countries. This event has a special place in my heart because it's almost like a family day for me. Our World Hemophilia Day theme of "Access for All: Partnership. Policy. Progress." really resonated with the community. Alain, what would you say is one thing we have to be grateful for in 2022?

Alain I would say that everyone who has benefitted from the WFH Humanitarian Aid Program can be happy that we significantly increased our donation capacity last year thanks to our partners' continuing generosity. Not only will we be able to continue providing donated factor and non-factor replacement therapies, and other training support, but we can now do more than ever for the people of our community.

Cesar I can think of another group of people who must be feeling very proud: the first cohort of 23 students from 18 countries who graduated from the PACT Advocacy Academy in 2022! It seems like just yesterday that the PACT Program was launched... and then the Academy was launched. Now, just a short time later, the first graduates are going to go out in the world to make a difference.

Alain As you know one of our priorities is to collect, interpret and disseminate data. We are particularly proud that more than 10,000 people with hemophilia (PWH) are now part of the World Bleeding Disorders Registry (WBDR), which is one of the largest registries in the world. These people—and the data they are sharing with us—are helping our NMOs and healthcare providers advocate with governments everywhere.

Cesar Another important thing to highlight is the way the global community came together to support the Ukrainian bleeding disorders community. This tragic war has been difficult for many people—in Ukraine, and in neighbouring countries. It's inspiring to see so many people from the global bleeding disorders come together to support their peers.

Alain It truly is inspiring, Cesar. PWBDs everywhere can always count on the global community for support. It's one of the things which makes us so unique. Working together, in the name of Treatment for All.

Making progress against 2022-2025 STRATEGIC PRIORITIES

The WFH actively monitors key metrics related to our four areas of capacity building

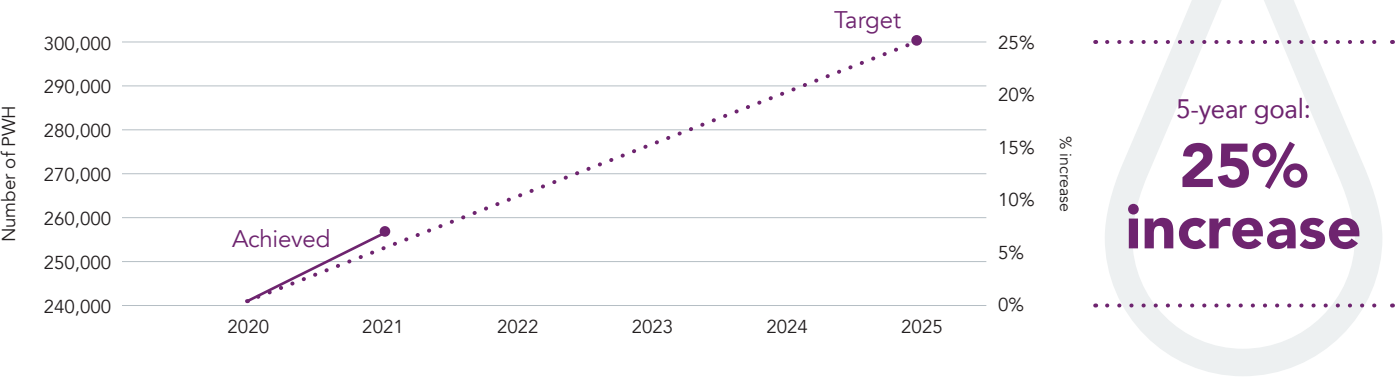
- 1 IDENTIFY and diagnose people living with bleeding disorders
- 2 PROVIDE adequate care and treatment
- 3 COLLECT, interpret, and disseminate data
- 4 ADVOCATE for safe and sustainable treatment and care

Note: All metrics are based on the actual 2022 results, except for those based on our Annual Global Survey which, at the time of publication, is only available for 2021.

Making progress:

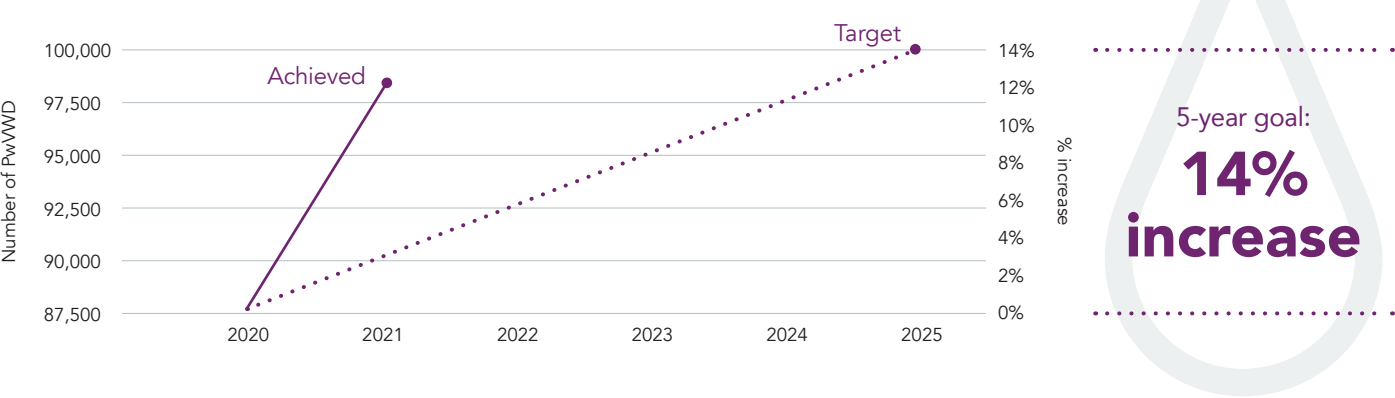
IDENTIFY AND DIAGNOSE PEOPLE LIVING WITH BLEEDING DISORDERS

Diagnosis of people with hemophilia



Globally, two thirds of people with hemophilia remain undiagnosed. The 5-year goal (2020 to 2025) of the WFH is to increase the number of people diagnosed with hemophilia by 60,000 (25%).

Diagnosis of people with von Willebrand Disease



VWD is the most common bleeding disorder with an estimated 1 in 1,000 impacted—but it remains vastly underdiagnosed. The 5-year goal (2020 to 2025) of the WFH is to increase the number of people diagnosed with VWD by 12,500 (14%).

Results for 2022...

Highlights

- Training stakeholders to improve diagnostic capacity through virtual and in-person workshops
- Enhancing laboratory diagnosis capacity through endeavours like the WFH International External Quality Assessment Scheme (IEQAS)
- Increasing the diagnosis of women and girls with bleeding disorders (WGBDs)
- Completing a Global VWD Call to Action campaign to raise awareness and advocate for improved access for people with VWD
- Supporting national outreach projects through the WFH PACT Program, the WFH Development Grant Program (DGP), the VWD Initiative Program, the Outreach and Diagnosis Multistakeholder Task Force, and other in-country initiatives.

CASE STUDY

Diagnosis of people with hemophilia (PWH)

The WFH Humanitarian Aid Program has been active in Cambodia for many years. The Program’s support has drastically transformed care in the country. Where once PWBDs were almost never diagnosed, now, they are properly treated and put on prophylaxis. Ourng Somali’s son has hemophilia—but his parents weren’t aware of this for years because despite countless appointments with different doctors, he was consistently misdiagnosed, and given treatment regimens that were ineffective. Fortunately, the situation completely changed when he went to the National Pediatric Hospital in Phnom Penh, which has a strong relationship with the WFH. He was finally correctly diagnosed, and his health immediately improved. Thanks to regular treatments he can now attend school consistently and play with other boys.

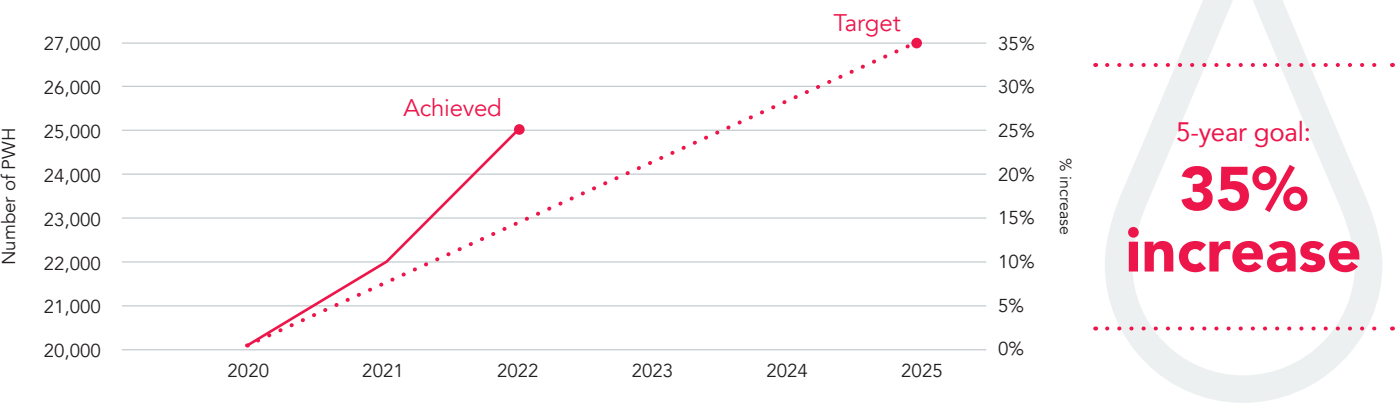


Click here to watch the video or scan the QR code

Making progress:

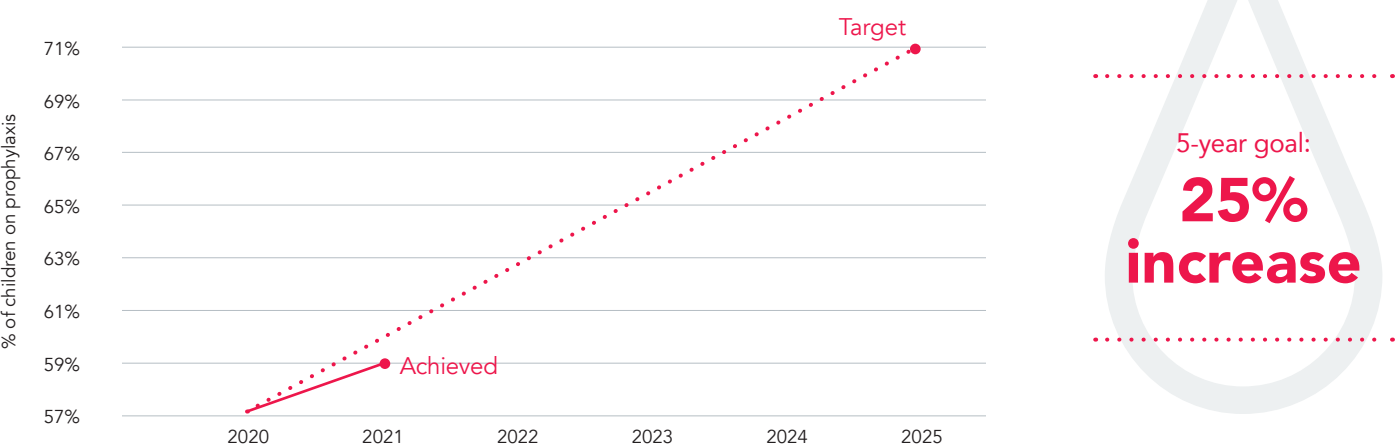
PROVIDE ADEQUATE CARE AND TREATMENT

New PWH receiving WFH Humanitarian Aid



The overwhelming majority of people living with inherited bleeding disorders around the world still do not have access to treatment and care. The 5-year goal (2020 to 2025) of the WFH is to increase the number of new PWH receiving WFH Humanitarian Aid donations by 7,000 people (35%).

Prophylaxis use among children with severe hemophilia



The WFH Hemophilia Treatment Guidelines have established that prophylaxis is the global standard of care for people with severe hemophilia. The 5-year goal (2020 to 2025) of the WFH is to increase the number of children with severe hemophilia on prophylaxis by 25%.

Results for 2022...

Highlights

Donating factor and non-factor replacement therapy to those who need it most

Educating and training stakeholders around the world

Building the capacity of healthcare professionals around the world on the management of different bleeding disorders

Expanding support for women and girls with bleeding disorders

Investing to grow the Gene Therapy Registry (GTR) to further support research

Convening the Gene Therapy Round Table to expand the global knowledge of this emerging treatment

Photo: WFH trip to Sri Lanka – 2023



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.



Click here to read the full story or scan the QR code

Making progress:

COLLECT, INTERPRET, AND DISSEMINATE DATA

New patients registered in the WFH World Bleeding Disorders Registry (WBDR)

2021	2022	2023	2024	2025
2,206	1,960			
Target 2,000	Target 2,000	Target 2,000	Target 2,000	Target 2,000

The WBDR provides a web-based data entry platform to a large network of participating hemophilia treatment centres (HTCs) to collect and manage their data. Over the next 5 years (2021 to 2025), the WFH aims to register 10,000 new patients with hemophilia and VWD in the WBDR.

Additional countries contributing high-quality data in the AGS

2021	2022	2023	2024	2025
4	4			
Target 4	Target 4	Target 4	Target 4	Target 4

Many countries lack the data they need to fully support their communities. The 5-year goal of the WFH (2021 to 2025) is to improve the quality of data and reporting of 20 NMOs participating in the Annual Global Survey (AGS).



Results for 2022...

Highlights

Expanding the AGS to further support medical care and advocacy efforts

Growing the WBDR to increase the breadth of data available for research

Enhancing the functionality and user-friendliness of the WBDR interface

Offering grants to HTCs through the WBDR Research Support Program (RSP)

Photo: WFH trip to Armenia – 2017

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.

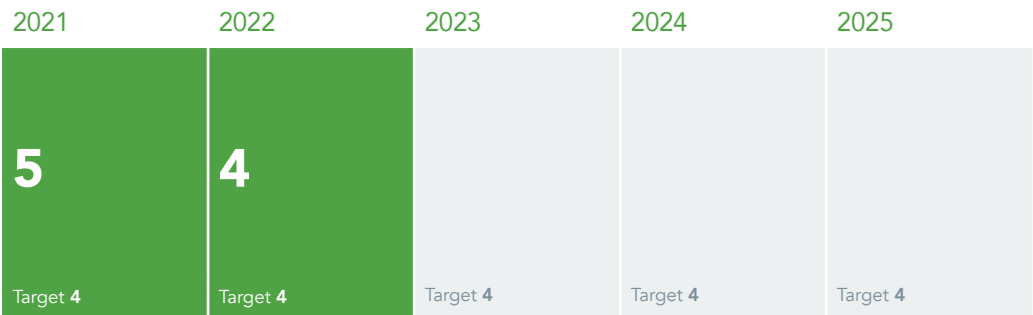
- The myWBDR mobile app has made it easy for PWH to collect patient reported outcome data, empowering them to participate in monitoring their own health outcomes
- The International Data Integration Program has made it possible to combine resources from existing hemophilia registries, allowing 300 Thai 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



Making progress:

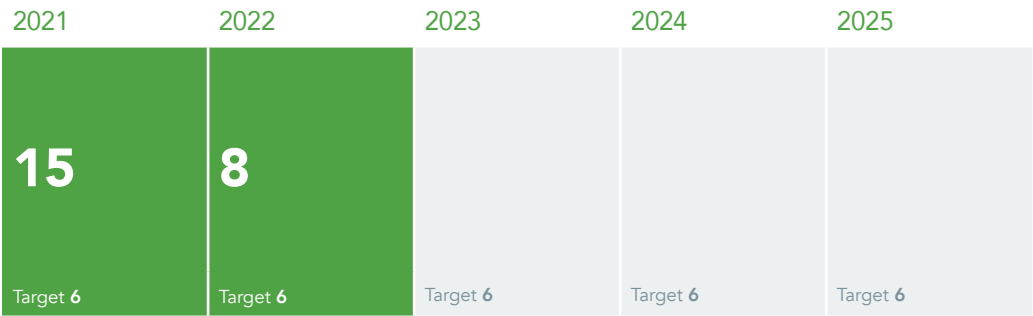
ADVOCATE FOR SAFE AND SUSTAINABLE TREATMENT AND CARE

Using the WFH Treatment Guidelines



WFH Treatment Guidelines serve as a powerful tool to guide best practices for bleeding disorders treatment and care and support advocacy efforts. The 5-year goal (2021 to 2025) of the WFH is for 20 new countries to produce new or updated national guidelines or policies based on the WFH Treatment Guidelines.

Increasing government support



One of the main goals of the WFH is to build capacity of NMOs and HCPs to advocate for safe and sustainable treatment and care. The 5-year goal (2021 to 2025) of the WFH is to have 30 countries increase government support for bleeding disorder treatment and care.



Results for 2022...

Highlights

- Expanding the reach of the Path to Access to Care and Treatment (PACT) Program to more countries
- Working with NMOs to demonstrate to governments the value of treating PWBDs
- Graduating the first cohort of the PACT Advocacy Academy
- Holding the second Global Policy and Access Summit (GPAS) to bring stakeholders together to share strategies and learnings
- Implementing tailored national access plans to increase outreach, diagnosis, and access to sustainable care

CASE STUDY

Increasing government support

In Morocco, WFH support has strengthened collaboration with the government and key stakeholders over a period of many years. Thanks to these efforts, the Ministry of Health has drawn up a national plan for the management of hemophilia and other bleeding disorders. The ministry has also increased the purchases of treatment products by hospitals, acquiring more than 9 million IUs of factor in 2022. This large purchase meant that WFH Humanitarian Aid Program donations became a supplement to government purchases, rather than the primary source—a huge step forward for the Moroccan bleeding disorders community.



Click here to read the full story or scan the QR code



Celebrating WORLD HEMOPHILIA DAY

The theme of World Hemophilia Day 2022 was:

ACCESS FOR ALL

Partnership. Policy. Progress.

Engaging your government,
integrating inherited bleeding disorders
into national policy.



World Hemophilia Day is about bringing the global bleeding disorders community together. The theme in 2022 was based on raising awareness and bringing hemophilia and other inherited bleeding disorders to the attention of policymakers to increase sustainable and equitable access to care and treatment. The world continued to be affected by the COVID-19 pandemic and the war in Ukraine in 2022, but the community still came together as always to celebrate World Hemophilia Day.

Over
15,800
people

visited the World Hemophilia Day page on our website

Over
63,000
people

viewed our World Hemophilia Day posts on Facebook

125
buildings and monuments

participated in the Light it Up Red campaign—a record despite the ongoing challenges of the COVID-19 pandemic

Photo: WFH trip to Sri Lanka – 2023



FIRST WFH HYBRID CONGRESS

a great success

The WFH 2022 World Congress was scheduled to be held during a difficult time: COVID-19 pandemic restrictions were just beginning to be eased, and the war in Ukraine had begun just months before. The WFH addressed these challenges by hosting another first for the global bleeding disorders community: a hybrid Congress.



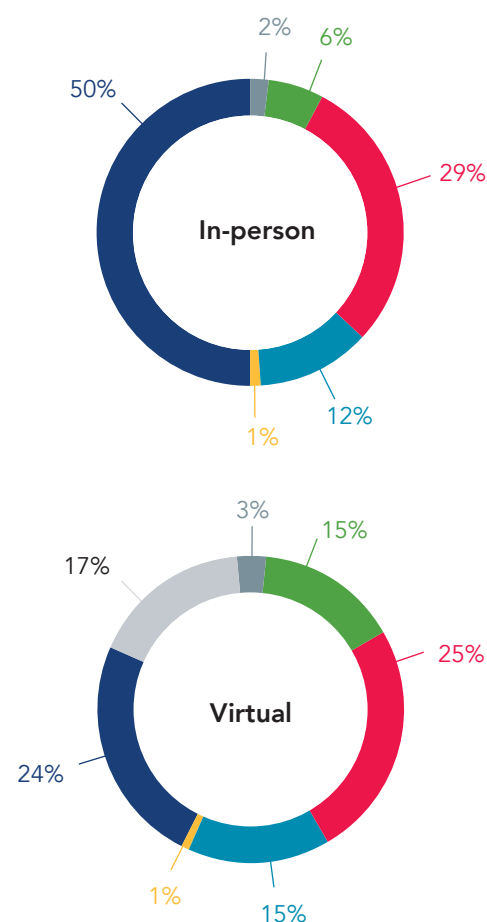
The hybrid Congress combined in-person and virtual attendance, and provided a forum for members to share knowledge, learn about the latest treatments and care, and contribute to a strong sense of global community. Here are some highlights from the event:

3,479 attendees from **147** countries

1,320 attended in person, **1,770** attended virtually and **389** watched on-demand content

213 speakers including virtual and in-person speakers

118 sessions including virtual and in-person sessions



■ Africa ■ Asia Pacific ■ Europe ■ North America
■ Latin America ■ Middle East ■ Unknown

Continuing to help the community OVERCOME CHALLENGES

2022 was a challenging year for many members of our community because of ongoing health and geopolitical challenges. The COVID-19 pandemic is showing encouraging signs of abating—but it is still very much present for millions of people around the world.

The war in Ukraine is also forcing unprecedented hardships on the people of that country, and others in Europe who are feeling the secondary effects of the conflict. Once again, the WFH has worked hard to surmount these challenges to support affected communities, and ensure care is maintained for those who have been impacted.

- Provided support to Ukrainian PWBD refugees and Ukrainian PWBDs in the country by working closely with HTCs and NMOs inside and outside Ukraine to offer WFH Humanitarian Aid Program donated factor, diagnostic reagents, medical supplies, and financial assistance
- Launched a project to provide coordinated assistance and an informational platform for Ukrainian PWBD refugees and PWBD who are in Ukraine
- Continued to work with donors and logistics companies via our WFH Humanitarian Aid Program to ensure the uninterrupted supply of donated factor to countries still affected by COVID-19 restrictions
- Maintained programs, services, safe access treatment and care, and practical recommendations related to COVID-19 treatment, vaccination, and relief for WFH NMOs

Photo: WFH trip to Jordan – 2017



THANK
YOU

to our **corporate partners**
and to our **donors**

Photo: WFH trip to Indonesia – 2022

Our corporate partners

The WFH gratefully acknowledges the generous support of our dedicated partners in 2022. Our Corporate Sponsors all play a major role in helping us improve and sustain care for people with bleeding disorders around the world.

Global Partnership Recognition

Global Partnership Recognition is based on our Corporate Partners' overall annual support and recognizes multiyear commitments and alignment with our strategic priorities. We are pleased to acknowledge our 2022 Visionary, Leadership and Collaborating Partners.

Visionary Partners

CSL Behring
F. Hoffmann-La Roche Ltd
Pfizer
Sanofi

Leadership Partners

Bayer
BioMarin
Pharmaceutical Inc.
Grifols
Sobi
Spark Therapeutics
Takeda

Collaborating Partners

Biotest
Freeline Therapeutic
GC Pharma
Kedrion
LFB
Novo Nordisk
Octapharma

WFH programs and activity support in 2022

Corporate partner program

Visionary Partners

CSL Behring
Novo Nordisk
Pfizer
Takeda

Leadership Partners

Bayer
F. Hoffmann-La Roche Ltd
Sanofi

Collaborating Partners

BioMarin
Pharmaceutical Inc
Grifols
Octapharma
Spark Therapeutics

Contributing Partners

Biotest
Freeline Therapeutics
GC Pharma
Kedrion
LFB
Sobi

WFH Humanitarian Aid Program

Founding Visionary
Sanofi
Sobi

Visionary Contributors

Bayer
CSL Behring
F. Hoffmann-La Roche Ltd /
Genentech / Chugai

Leadership Contributor

Grifols

Contributors

Takeda
Japan Blood Products
Organization

WFH Path to Access to Care and Treatment (PACT) Program

Visionary Partners
F. Hoffmann-La Roche Ltd

Leadership Partners

CSL Behring
Pfizer
Sanofi

Collaborating Partners

Biotest
Grifols

World Bleeding Disorders Registry (WBDR)

Visionary Partners

Sobi
Takeda

Collaborating Partners

Bayer
F. Hoffmann-La Roche Ltd
Grifols
Novo Nordisk
Pfizer
Sanofi

Gene Therapy Registry (GTR)

Visionary Partners

BioMarin Pharmaceutical Inc.
CSL Behring
Pfizer
Spark Therapeutics

Collaborating Partner

Takeda

Sponsored programs

Development Grant Program
Sanofi

International External Quality
Assessment Scheme Program (IEQAS)
Novo Nordisk Haemophilia Foundation

International Hemophilia Training
Centre (IHTC) Fellowship Program
Bayer

F. Hoffmann-La Roche Ltd

Shared Decision-Making Tool
BioMarin Pharmaceutical Inc.

CSL Behring
Pfizer
Spark Therapeutics

Gene Therapy Round Table (GTRT)

Bayer
BioMarin Pharmaceutical Inc.
CSL Behring
Pfizer
Spark Therapeutics

Twinning Program
Pfizer

Other Product Donation

Héma-Québec
KVR Pharmaceuticals Inc.
Novo Nordisk
Octapharma
Pfizer Canada ULC

WFH 2022 World Congress

Platinum sponsors

Sanofi
Takeda

Gold sponsors

BioMarin
CSL Behring
Novo Nordisk
Octapharma
Pfizer
Roche

Supporting sponsors

Spark Therapeutics
Tremeau Pharmaceuticals

Our donors

The WFH gratefully acknowledges the many donors whose generous contributions have ensured more people have access to care, regardless of their type of bleeding disorder, their gender, or where they live. In 2022, the following individuals, corporations, and organizations made financial contributions of CAN\$150 or more to the WFH or WFH USA.

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

Solidarity fund

Australia	Haemophilia Foundation Australia
Austria	Österreichische Hämophilie Gesellschaft
Bangladesh	Hemophilia Society of Bangladesh
Belgium	The Belgian Haemophilia Society
Bosnia	Haemophilia Society of Bosnia and Herzegovina
Bulgaria	Bulgarian Haemophilia Association
Costa Rica	Asociación Costarricense de Hemofilia (ASOHEMO)
Croatia	Croatian Hemophilia Society
Hungary	Magyar Hemofília Egyesület (Hungarian Haemophilia Society)
Iceland	The Icelandic Hemophilia Society
Iraq	Iraqi Hemophilia Society
Ireland	Irish Haemophilia Society, Ltd.
Kosovo	Kosovo Hemophilia Foundation
Latvia	Latvijas Hemofilijas biedriba
Lithuania	Lithuania Haemophilia Association
Madagascar	Association pour le Bien-Etre des Hémophiles à Madagascar
Maldives	Hemophilia Society of Maldives
Malta	The Malta Bleeding Disorders Society
Mauritius	Haemophilia Association of Mauritius (HAM)
Montenegro	Montenegrin Society for Hemophilia
Netherlands	The Netherlands Haemophilia Society (NVHP)
New Zealand	Haemophilia Foundation of New Zealand (HFNZ)
Senegal	Association Sénégalaise des Hémophiles
Singapore	Haemophilia Society of Singapore
South Korea	Korea Hemophilia Foundation
Suriname	Surinamese Society for Hemophilia Patients
Switzerland	Swiss Hemophilia Society
Thailand	National Hemophilia Foundation of Thailand
United Kingdom (U.K.)	The Haemophilia Society
Uruguay	Asociación de Hemofílicos del Uruguay
Venezuela	Asociación Venezolana para la Hemofilia

Susan Skinner Memorial Fund

John Button
Irene Chami
Nathan Connell
Hemophilia of Georgia
Glenn Pierce
Amy Renz
Mark Skinner and James Matheson
Eric Stolte
The Coalition for Hemophilia B
Vishal Venkatesh

Tributes

In honour of Glenn Pierce
In honour of Gina Schnabel
In honour of Frank Schnabel IV
In honour of Susan Skinner
In honour of Eric Stolte
In honour of the volunteers and staff who work for those with bleeding disorders throughout the world
In memory of Vicki Spangler

Donors

\$500,000+

Hemophilia of Georgia

\$250,000 - \$499,999

The Hemophilia Alliance

\$100,000 - \$249,999

National Hemophilia Foundation

\$50,000 - \$99,999

Glenn and Beatrice Pierce

\$25,000 – \$49,999

The Alliance Pharmacy
The Farly Foundation

\$10,000 - \$24,999

Mark Skinner and James Matheson
The Marketing Research Bureau
One anonymous donation

\$5,000 - \$9,999

Bank of America
BioMarin Pharmaceutical Inc.
Canadian Hemophilia Society
Donald and Barbara Goldman
LFB
Oasis Foundation
Frank IV and Lillian Schnabel
Phillips 66
One anonymous donation

\$1,000 - \$4,999

Alaska Hemophilia Association
Amwell Cares
Bahnhof Apotheke Thun AG
Alain Baumann
Bleeding Disorders Alliance Illinois
Ute Braun
Bright Funds Foundation
Canada Helps
Paula Bell and Rob Christie
Coalition for Hemophilia B
Donna Coffin
Andrea Cristaudi
FAMOHIO
Florida Hemophilia Association
Gateway Hemophilia Association
Great Lakes Hemophilia Foundation

Hemophilia Association of the Capital Area
Hemophilia Foundation of Southern California
Hemophilia of Indiana
Hemophilia of North Carolina
Miguel Izquierdo Zarco
Kate Khair
Barbara Konkle
Lone Star Bleeding Disorders Foundation
Mary M. Gooley Hemophilia Center
John Murphy
New England Hemophilia Association
Northern Ohio Hemophilia Foundation
Pacific Northwest Bleeding Disorders
Joseph Pugliese
Patrick Robert
Rocky Mountain Hemophilia and Bleeding Disorders Association
Edith Rosato
Dawn Rotellini
Texas Central Hemophilia Association
Andreina Tovar
Kenneth Trader
Tri-State Bleeding Disorder Foundation
uniQure
Leonard Valentino

\$500 - \$999

Bleeding Disorders Association of South Carolina
David Clark
Colorado Chapter of the National Hemophilia Foundation
Robert Cooper
Daniel Doran
Amy Dunn
Eastern Pennsylvania Bleeding Disorder Foundation
Cesar Garrido
Hemalytic
Hemophilia Foundation of Greater Florida
Hemophilia Foundation of Minnesota/Dakotas
Hemophilia Foundation of Northern California
Christine Herr
Kentucky Hemophilia Foundation
Jennifer Laliberté
Arvind Manjrekar

Yasuharu Nishida
Steven Pipe
Steve Prince
Sundar Rajan Selvaraj
Gina Schnabel
Southwestern Ohio Hemophilia Foundation
Eric and Marion Stolte
UNC Health Care System
Virginia Hemophilia Foundation
Simon Widmer
Pamela Wilton

\$250 - \$499

Laura Chalfin
Communications Fiona Robinson
Jacie Cunningham
Rosa Maria Duenas-Rios
Hawaii Chapter of the National Hemophilia Foundation
Hemophilia Alliance of Maine
Hemophilia Foundation of Michigan
Hemophilia Philippines Foundation
Peter Hultgren
IQM Consulting
Kim Isenberg
Carol Kasper
Craig Kessler
Mary Lesh
Louisiana Hemophilia Foundation
Prasad Mathew
Nebraska Chapter of the National Hemophilia Foundation
JoAnn Nilson
Carol Parker
Ulrike Reiss
Pedro Rodriguez Sanchez
Western Pennsylvania Bleeding Disorders Foundation

\$150 - \$249

Antonio Almeida
Geneviève Beauregard
Randall Curtis
James Hunt
Yu Koga
Wendy Quinn
Anna Rennie
Jerome Teitel
Elvin Thye Seong Yup



FINANCIAL REPORT

2022

As the world continued adjusting to a “new normal” environment in 2022, one thing remained consistent: the resilience of WFH staff and volunteers. These inspirational individuals resumed travel to deliver our events and activities—including the first hybrid WFH World Congress—and continued to grow our programs for the global inherited bleeding disorders community.

Photo: HA trip to Sri-Lanka – 2023

The year ended with a net surplus of \$126 compared to a budgeted net deficit of \$961. This represents an improvement of \$1,087 over budget. All amounts are in thousands of CAD dollars, unless stated otherwise.

Increased support from our community (non-corporate) partners was a key contributor to this result. We also received the final installment of \$286 of insurance proceeds for the cancellation of the WFH 2020 World Congress, which had not been budgeted for. The strong U.S.A. currency (which averaged \$1.30 CAD throughout the year) further contributed to the positive result.

Important revenue growth

The corporate sponsors of WFH programs and initiatives continued their committed support with 2022 contributions of \$5,597, a decrease of \$32 (0.6%) over 2021. A major reason for this relatively small decrease was related to contributions of \$262 towards the biennial WFH Global Forum (GF) and the WFH International Musculoskeletal Congress (MSK), both of which took place in 2021. Conversely, there were increases in the amount of funding for the WFH Twinning Program and the Humanitarian Aid General Program.

In 2022, the WFH Humanitarian Aid Program spent \$4,066 (\$3,115 in 2021) against funding received from our key corporate partners. Despite the continued rising costs and logistical challenges generated by the COVID-19 pandemic, we managed to treat over 25,000 people with hemophilia in 71 emerging countries.

For WFH Research Programs, \$1,865 was recognized (\$696 in 2021). This increase was geared towards an investment in growing the WFH Gene Therapy Registry (GTR) to expand our data collection efforts for patients who receive this new therapy.

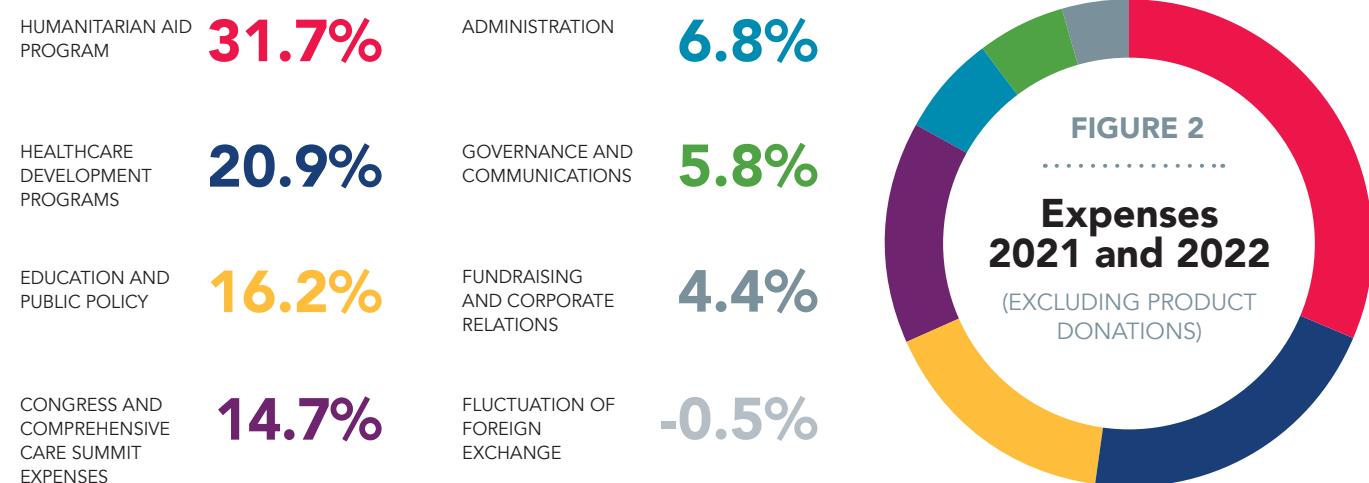
Fundraising revenues also increased markedly in 2022, at \$1,302 (\$826 in 2021). This was mostly due to the generous donations from our community partners to a Solidarity Fund to support people with bleeding disorders who have been impacted by the war in Ukraine, as well as increased contributions from Hemophilia of Georgia (HOG) towards the Humanitarian Aid General Program.

Total WFH revenue, before Congresses, Insurance Proceeds, and Product Donations reached \$13,254—\$1,733 (15%) above 2021.

As the WFH delivers the biennial WFH World Congress as well as other WFH meetings over a two-year period, it is typical for us to review our results over a two-year cycle. As shown in Figure 1, excluding product donations, 36% of revenues over the two-year cycle are from contributions from corporate partners; 31% are from restricted programs (Humanitarian Aid and the Research Program); 17% are from Congress revenues and insurance proceeds; and the remaining 16% are generated from financial donations, self-generating income activities, Canadian government relief for COVID-19, and national member organization (NMO) assessments.

HUMANITARIAN AID PROGRAM	22.8%	RESEARCH PROGRAM	8.1%
CORPORATE SPONSORSHIPS	20.9%	DONATIONS	6.8%
CONGRESS REVENUES AND INSURANCE PROCEEDS	16.8%	SELF-GENERATED INCOME (NON-CONGRESS)	4.7%
CORPORATE PARTNER DONATIONS	14.8%	CANADA EMERGENCY SUBSIDIES (CEWS & CERS)	4.5%
		NMO ASSESSMENTS	0.6%





Expenditures aligning with strategic objectives

In aggregate, the healthcare development programs, education and public policy programs, and the WFH Humanitarian Aid Program continued to represent the overwhelming proportion of expenditures at 69% of total costs incurred over the past two years, as seen in Figure 2. The The WFH 2022 World Congress and the Comprehensive Care Summit represented an investment of 15% of WFH expenditures, while fundraising and corporate relations costs represented 4% of the total. Expenses attributed to running the WFH organization included administration at 7%, and governance and communications at 6%.

WFH Humanitarian Aid

The WFH distributes life-sustaining and life-saving humanitarian aid product donations from many of our corporate sponsors to WFH national member organizations (NMOs) and hemophilia treatment centres (HTCs) around the world. Despite the pandemic continuing to keep airfreight rates high, and create in-country barriers to movement, the WFH Humanitarian Aid Program team found alternative ways to deliver care to those who needed it most. Most of these donations, worth \$680 million USD, are included in the audited financial statements of WFH USA. The amount included in the financial statements of the WFH is \$274 million. Combined, that represents a value of over \$1.1 billion CAD.

Year-over-year comparison

The 2022 and 2021 statement of revenues and expenses, illustrated in Figure 3, reflects the fluctuations within a typical two-year cycle where the WFH World Congress is held in even years, where the MSK and GF events are held in odd years, and where varying amounts of yearly product donations are received. On the revenue side, before Congresses, Insurance Proceeds, and Product Donations, there was an excellent growth of \$1,733, as already mentioned above. This was largely due to the invaluable increases in contributions from our corporate partners to fund the new GTR of \$1,198; as well as \$951 for the continued growth of the WFH Humanitarian Aid Program. Furthermore, the generous donations from our community partners brought in an additional \$476 versus 2021. This was offset by the decrease in investment revenues of \$587 as a result of the volatility in the financial markets that caused major unrealized losses; as well as the revenues derived from the MSK and GF events held in 2021 of \$418, which included WFH event registration and housing fees.

The overall spend of \$14,398 before Congresses and Product Donations—\$2,091 above 2021—reflects the increasing efforts of the WFH to support the needs of the global bleeding disorders community, while still adjusting to a post-pandemic world. This was highlighted by the increases of \$1,259 for the WFH Humanitarian Aid Program and \$1,119 for the GTR. Healthcare Development Programs grew by \$487, which included \$251 dedicated to a Global Relief Fund for Ukraine, as well as \$208 for the Global NMO Training at Congress. This was offset by a \$484 decrease in Communications expenses, mostly due to the high development cost of our new website in 2021 that did not occur again in 2022.

WFH 2022 World Congress

After the pandemic forced us to cancel the WFH 2020 World Congress, we were finally able to host the 2022 World Congress in Montreal. It was held in hybrid mode—a first—with combined in-person and virtual audiences. The event was a success from the standpoint of education and networking with the global community. Financially, it was less so, due mainly to much lower-than-usual in-person attendance, lower exhibit and sponsorship revenues, and increased costs to accommodate the virtual environment.

In total, the event, after taking expenses incurred in 2021 into consideration, brought us a very small surplus of \$362—a significant difference from the surpluses of prior Congresses, which are critical in funding our programs and activities over a two-year period.

Looking ahead

Our financial base is currently strong, with net assets of \$15.4 million. However, Congresses are not expected to bring the surpluses that they have in the past. This was evidenced by the results of our WFH 2022 World Congress. The success of the 2024 and future World Congress events will be vital in terms of keeping our operational capacity unimpaired. In the meantime, our senior management team is working hard to develop strategies to diversify and grow our revenue streams while identifying and implementing expense control measures.

The WFH will also need to rely on the continued support and flexibility of our corporate and community partners to be able to carry out our important work and broaden our revenue generation efforts.

As we progress on the path of our ambitious strategic plan, our focus remains the same: leveraging our resources for the benefit of our community, so we can get closer to our vision of Treatment for All.

FIGURE 3

Revenues and expenses

(Expressed in Canadian Dollars)

	2021	2020
REVENUES		
Donations	1,301,912	825,540
Corporate Partner Donations	2,371,857	2,281,626
Corporate Sponsorships	3,225,280	3,446,344
Research Program	1,865,449	695,484
NMO Assessments	93,807	105,593
Humanitarian Aid Program	4,065,513	3,114,509
Self-generated Income (non-Congress)	330,000	1,149,693
Total Revenues before Congress, CEWS, CERS and PDs*	13,253,818	11,618,789
Congress Revenues and Insurance Proceeds	5,002,191	306,233
Canada Emergency Subsidies (CEWS and CERS)	–	1,432,413
Product Donations	273,574,144	200,486,376
TOTAL REVENUES	291,830,153	213,843,811
EXPENSES		
Healthcare Development Programs	3,514,518	3,027,882
Education and Public Policy	3,011,548	2,056,671
Humanitarian Aid Program	5,584,572	4,325,180
Governance and Communications	681,498	1,147,787
Fundraising and Corporate Relations	701,648	665,568
Administration	1,043,380	1,095,308
Fluctuation of Foreign Exchange	(138,846)	(11,561)
Total Expenses before Congress and PDs*	14,398,318	12,306,835
Congress and Comprehensive Care Summit Expenses	3,732,164	853,375
Product Donations	273,574,144	200,486,376
TOTAL EXPENSES	291,704,626	213,646,586
EXCESS (DEFICIENCY)	125,527	197,225

*Product Donations

WFH Board of Directors

We rely on the WFH Board of Directors, WFH staff, and volunteers to support our shared vision of **Treatment for All**.



WFH board of directors and members

- | | | | |
|--|--|---|--|
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WFH 2022 HIGHLIGHTS

25,000+
PEOPLE WITH A BLEEDING DISORDER

treated since 2015

115
TREATMENT CENTRES

benefitted from the WBDR

156
COUNTRIES REACHED

through global programs and events

WORLD FEDERATION OF HEMOPHILIA

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