



ANNUAL REPORT 2023

WFH.ORG



WFH

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



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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.

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.



When I look back at what we accomplished in 2023, it makes me proud. The WFH, national member organizations, healthcare practitioners, industry partners, and other stakeholders collaborated as a team to improve care for people with bleeding disorders. Together, we were able to deliver more support, more data, and more resources than ever before to those who needed it most."

—Cesar Garrido, President, WFH

LETTERS FROM THE PRESIDENT AND THE CEO OF THE WFH



Dear friends,
2023 was a busy year for the WFH! We accomplished much—and we made such a difference.

I must, of course, start by saying one highlight was celebrating the 60th anniversary of the federation this year. Sixty years of collaboration, training, education, advocacy, and support that have changed thousands of lives around the world. It seems like a long time—and yet it is just the beginning for us.

As important as this milestone was for the WFH, I had little time to dwell on it. I was busy visiting NMOs, hemophilia treatment centres (HTCs), specialists, people with bleeding disorders (PWBDs) and the other members of our community around the world to better understand their needs. What I learned will help us refine our programs and other endeavours to ensure we're supporting the community in the best way possible.

The WFH exists to provide the knowledge and tools that our stakeholders need to identify, support, and treat people living with bleeding disorders in their communities. We did so much in 2023 that it's hard to choose what to highlight here, but definitely, the WFH Global Policy and Access Summit (GPAS) and the WFH Global Summit on Women and Girls with Bleeding Disorders (WGBD) are top of mind because they're proof of our ability to deliver innovative, targeted offerings for our community.

We did much in 2023, and I'm proud of our accomplishments. But we need to do more. That is where we will be putting our energy. As our work and our profile grows on the world stage, so do the expectations of our community. I'm confident we will meet and surpass these expectations in 2024—and beyond. I'm confident that together, we can attain our shared vision of Treatment for All.

On behalf of everyone at the WFH, I would like to thank the global inherited bleeding disorders community, our pharmaceutical partners, governments, HCPs, NMOs, WFH USA, WFH staff and everyone else who put their confidence in us in 2023. Your trust energized us in 2023, and it will do so again in 2024.

A handwritten signature in black ink, appearing to read 'Cesar Garrido'.

Sincerely,
Cesar Garrido
President, WFH

MAKING PROGRESS AGAINST 2022-2025 STRATEGIC PRIORITY KPIs

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

Note: KPIs are based on the actual results of 2023, except for those based on our Annual Global Survey which, at the time of publication, is only available for 2022.



Dear friends,
In 2023, we continued the momentum that we have been building for several years now.

We have accelerated the delivery of support to the global inherited bleeding disorders community through multiple opportunities. We're now in the second year for the reporting of key performance indicators (KPIs) related to our 2022-2025 Strategic Priorities, and our progress has surpassed our expectations.

Last year, we delivered many important firsts for the community. The WFH 2023 Comprehensive Care Summit kicked off a major new thrust for our strategy: hosting a major event on off-Congress years. The Summit encompassed the biennial International WFH Musculoskeletal (MSK) Congress, and included MSK, medical and multi-disciplinary tracks—all centering around people with bleeding disorders.

Our other events were equally successful. The 13th WFH Global Forum—which included a comprehensive gene therapy component—was very well-received, as was the Global Policy and Access Summit (GPAS). And, once again, World Hemophilia Day was celebrated by thousands of people around the world.

Our innovative spirit was once again on show in 2023: we launched the Gene Therapy Registry (GTR) and expanded the World Bleeding Disorders Registry (WBDR)

to include people with von Willebrand disease (VWD). We also launched the Shared Decision Making (SDM) Tool for Hemophilia Treatment. This latter accomplishment is a significant one, as it makes it possible for clinicians and patients to work together to make treatment decisions based on clinical evidence that balances risks and expected outcomes with patient preferences and values.

The many programs the WFH offers continue to make a difference. The WFH Path to Access to Care and Treatment (PACT) academy graduated its second cohort of leaders. The WFH Humanitarian Aid Program continued to deliver donated factor and educational support to where it's needed most. Also, our many publications—such as the Annual Global Survey (AGS) and the WBDR 2022 Data Report—continue to provide the information that is so critical to researchers and advocates around the world.

This is an exciting time for our community. Never have there been so many treatment choices for PWBDs in the developed world. This in turn translates into great potential for the emerging countries of the world—a potential we are committed to realizing. We will continue to work to make sure the gap with emerging countries does not widen further, but gets smaller.

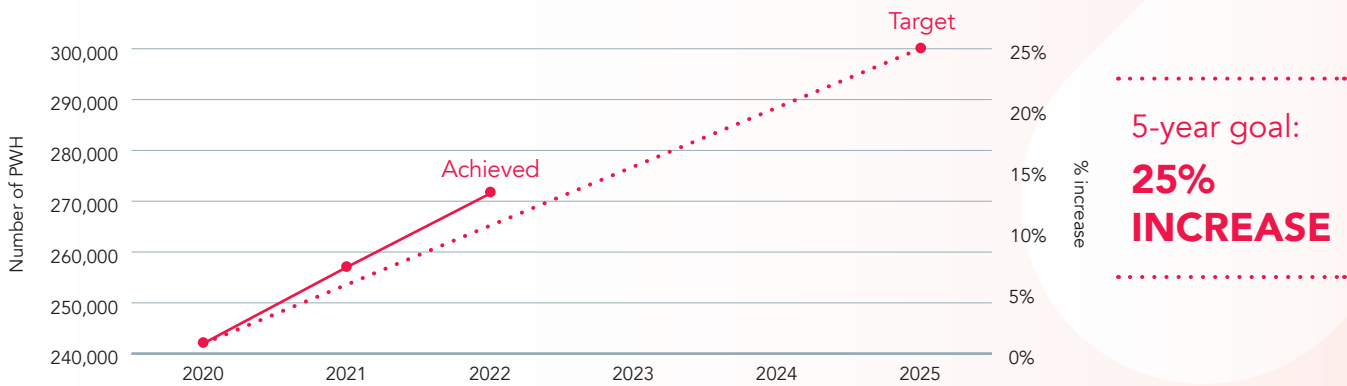
Sincerely,
Alain Baumann
Chief Executive Officer (CEO), WFH

- 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

Making progress:

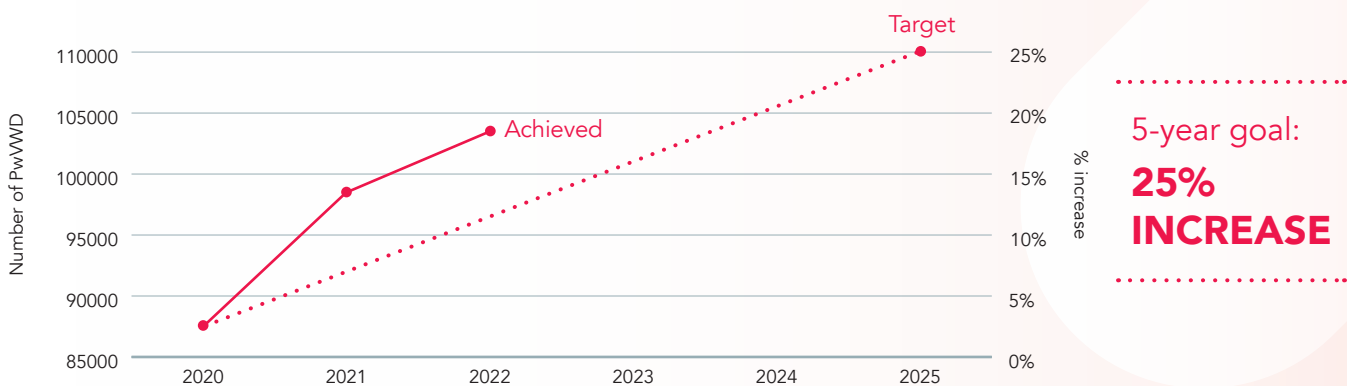
IDENTIFY AND DIAGNOSE PEOPLE LIVING WITH BLEEDING DISORDERS

Diagnosis of people with hemophilia (PWH)



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)



VWD is the most common bleeding disorder with an estimated 1 in 1,000 individuals 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 110,000 (25%).

Results for 2023...

Highlights

Enhanced diagnosis capacity and laboratory performance through the WFH International External Quality Assessment Scheme (IEQAS)

Increased the diagnosis of WGBDs

Fostered outreach and diagnosis capacity through the WFH PACT Program and other in-country initiatives

Conducted a survey on NMOs on barriers and strategies in outreach and identification of PWBDs and published two publications in *Haemophilia*, the official journal of the WFH.

Developed tailored training curricula to be piloted in two countries as part of the Outreach and Diagnosis Initiative

Supported national outreach and diagnosis initiatives to identify new PWBDs

Photo: WFH visit to Dominican Republic – 2023

CASE STUDY

57-year-old Sri Lankan man diagnosed with VWD

In 2023, a 57-year-old man was admitted to a hospital with a bleed in Anuradhapura, Sri Lanka. Because of the training and educational work the WFH has done in the country, doctors knew to test him for a bleeding disorder, and he was diagnosed with VWD. With this information, physicians were able to determine the best course of action for treatment, and his condition improved after a few days.

This kind of comprehensive care is only possible when a country's specialists are trained on looking for—and treating—a bleeding disorder. In Sri Lanka, the level of care for the bleeding disorders community has increased dramatically thanks to the support of the WFH.



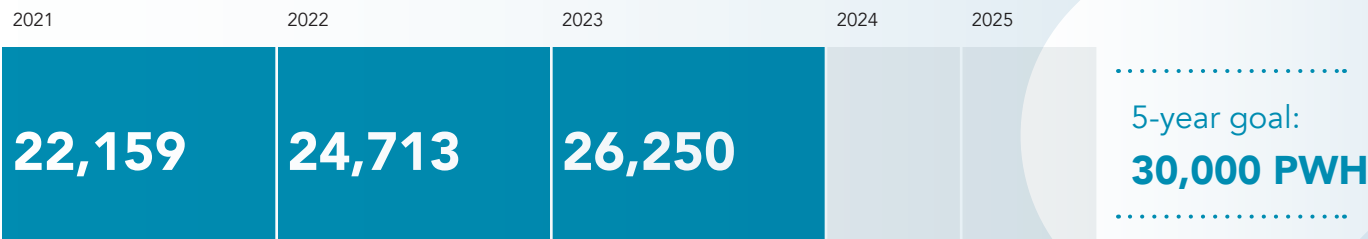
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Making progress:

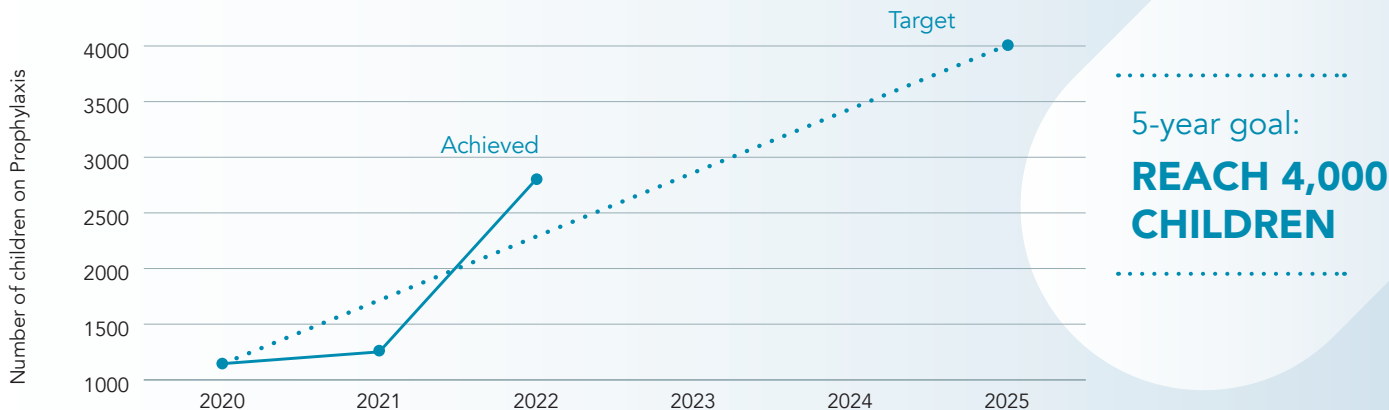
PROVIDE ADEQUATE CARE AND TREATMENT

Cumulative number of PWH receiving 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 Program donations by 7,000 people (35%).

Prophylaxis use among children benefiting from humanitarian aid



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) is to reach 4,000 children with hemophilia receiving prophylaxis through the WFH Humanitarian Aid Program

Results for 2023...

Highlights

Donated factor and non-factor replacement therapy to those who need it most through the WFH Humanitarian Aid Program

Built the capacity of HCPs around the world on the management of different bleeding disorders through International Hemophilia Training Centre (IHTC) fellowships

Facilitated peer-to-peer learning through the WFH Twinning Program

Held the third edition of the WFH Global Summit on WGBD, providing extensive educational content to HCPs and other stakeholders

Conducted an NMO survey on WGBD to collect comprehensive data on the diagnosis and treatment of this segment of the bleeding disorders population

Developed the WFH Gene Therapy Registry (GTR) to ensure that patient safety is always at the forefront of the mission of the WFH

Expanded the breadth of the 13th WFH Global Forum by incorporating dedicated talks related to Gene Therapy progress

Introduced basic care in resource constrained countries through the WFH Cornerstone Initiative

Improved the diagnosis capacity of healthcare professionals through virtual and in person workshops

Photo: WFH visit to Dominican Republic – 2023

CASE STUDY

Prophylaxis helps boy in Indonesia

Azreal is a five-year-old boy with severe hemophilia A whose life has greatly improved thanks to WFH Humanitarian Aid Program donations which have allowed him to go on prophylactic treatment. This means that he can go to school, play with friends, and do normal activities like any boy his age.

Prophylaxis means bleeds are a rarity for Azreal. This contrasts strongly to his earlier childhood when spontaneous acute bleeds would drastically impact the whole family, demanding constant, exhausting attention for days at a time. In short, prophylaxis means Azreal—and his parents—can enjoy a more normal life.

In parallel to support provided through the Humanitarian Aid Program, Indonesia participates in the PACT and HTC Twinning programs. A notable achievement in the country has been the development of new treatment guidelines that emphasize that prophylaxis is the standard of care. This led to successful advocacy resulting in an annual increase in the national procurement of treatment products



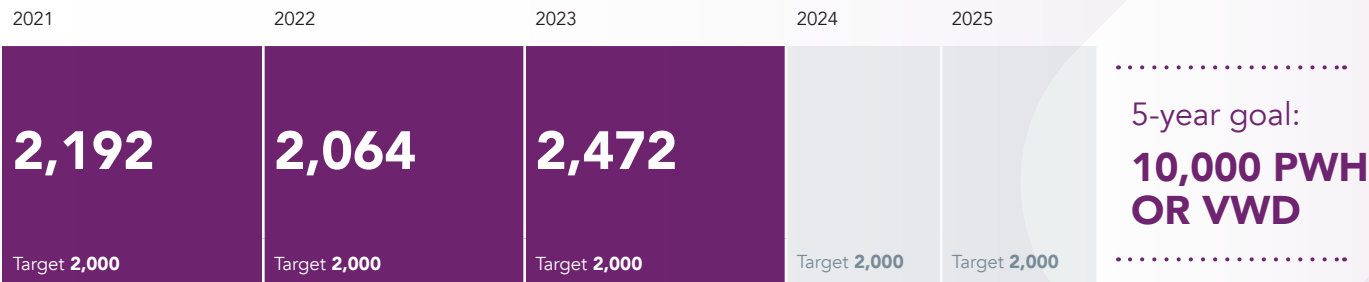
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Making progress:

COLLECT, INTERPRET, AND DISSEMINATE DATA

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



The WBDR provides a web-based data entry platform to a large network of participating HTC's 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 or VWD in the WBDR.

Expanded reach of the Annual Global Survey (AGS)



Many countries lack the data they need to fully support their communities. The 5-year goal of the WFH (2021 to 2025) is for 20 new or returning NMOs to report country data to the AGS.

Results for 2023...

Highlights

Expanded the AGS to further support medical care and advocacy efforts

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

Expanded the breadth of the WBDR to include data collection on people with VWD

Provided data analysis support at the country and HTC levels for research studies

Established new data partnership with the Norway national registry

Published peer reviewed article entitled “The World Federation of Hemophilia World Bleeding Disorders Registry: Insights from the first 10,000 patients” in the *Research and Practice in Thrombosis and Haemostasis* journal

Photo: WFH visit to Senegal – 2023

CASE STUDY

WFH improves the identification of WGBDs

Last year, the WFH helped to improve the identification of WGBDs through several endeavours. A collaboration with the Women’s Committee of the Argentinean Foundation of Hemophilia helped triple the number of WGBDs in the Argentinean Bleeding Disorders Registry to over 300 people in just two years. This achievement was made possible thanks to various awareness campaigns, workshops, and the inaugural national meeting of women with bleeding disorders. The WFH Development Grant Program and the WFH PACT Program also played a significant part in supporting WGBDs—as well as the general bleeding disorders community—in Argentina in 2023.

Another key WFH-led endeavour for supporting the identification of WGBDs was the addition of a module to the WBDR for collecting data on people with VWD (PwVWD). In 2023, over 1,000 PwVWD—including over 500 women and girls—from 46 HTC in 22 countries were included in the WBDR. These data will be valuable not only for clinical care management, but also for helping to identify gaps in care around diagnosis and treatment availability. The data will also act as an essential building block for advocacy initiatives for WGBDs.



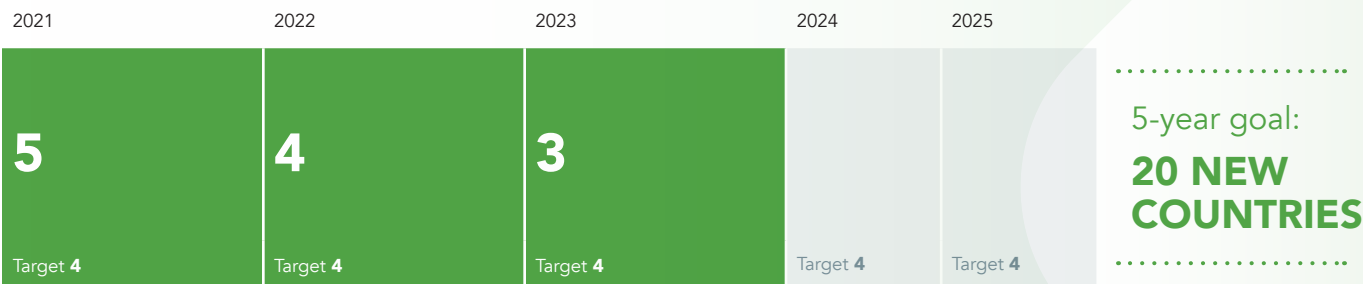
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Making progress:

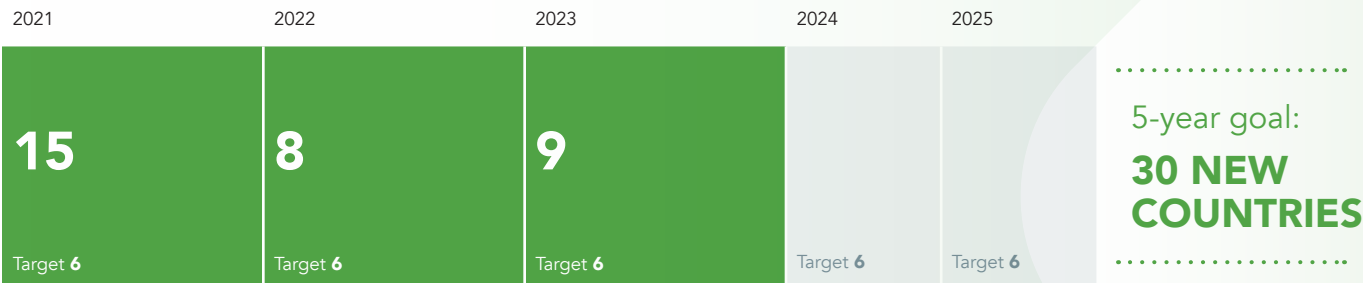
ADVOCATE FOR SAFE AND SUSTAINABLE TREATMENT AND CARE

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 2023...

Highlights

Expanded the reach of the WFH PACT Program to more countries

Graduated the second cohort of the WFH PACT Advocacy Academy

Implemented tailored national access plans to increase outreach, diagnosis, and access to sustainable care

Worked with NMOs to demonstrate to governments the value of treating PWBDs

Trained a new generation of leaders at the 2023 Global Youth Leadership Training

Held the third edition of the GPAS to bring stakeholders together to share strategies and learnings

Successfully supported policy changes with several governments to recognize hemophilia and other bleeding disorders as a health priority

Signed WFH PACT Program agreements and memoranda of understanding (MOU) with two governments to strengthen treatment and care for PWBDs

Photo: Comprehensive Care Summit, Argentina – 2023

CASE STUDY

Long-term support pushes sustainable care forward in Egypt

In October 2023, a trilateral memorandum of understanding (MOU) was signed for a WFH PACT Program partnership between the WFH, the Egyptian Ministry of Health (MOH) and the Egyptian Society of Hemophilia (ESH). The MOU is the result of the long-standing and ongoing collaboration between the WFH and the Egyptian bleeding disorders community.

Over nearly 24 years, the WFH has helped nearly double the number of identified PWBDs in the country. This collaboration has seen several programs play active roles in Egypt, including the WFH PACT Program, the WFH Twinning Program, and the WFH Humanitarian Aid Program. Another highlight in 2023 was the development of national treatment guidelines, and a consensus paper on immune tolerance induction (ITI)—two endeavours that the WFH contributed to.



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



SUCCESSFUL WORLD HEMOPHILIA DAY 2023 TOUCHES THOUSANDS

April 17, 2023 was World Hemophilia Day, and all around the world, thousands of people came together around the theme of **“Access for All: Prevention of bleeds as the global standard of care”**.

Events were held in dozens of countries—many of them in-person for the first time since the COVID-19 pandemic. Buildings and monuments were lit up in red, people celebrated in groups small and large, and the internet was buzzing with excitement as this important day for the global bleeding disorders community was celebrated once again.

HUNDREDS OF STORIES

were posted on the World Hemophilia Day website

OVER 24,000 PEOPLE

visited the World Hemophilia Day website

OVER 150 BUILDINGS AND MONUMENTS

participated in the Light it Up Red campaign—a **new record**



“

Growing up was challenging, as I had to constantly worry about when my next bleed was going to occur... Thanks to the advancement of treatment and care in Malaysia, I benefited from prophylaxis treatment from age 22 onwards which significantly reduced my bleeding episodes, and now I am able to lead a healthy and an active lifestyle.”

—Hazri Aris, Malaysia

“

...I live each day positively and with the courage to face the uncertainties and complications caused by hemophilia and my co-infection. I have seen life as not as simple as others have; the challenges I faced have given me the resolve to not only help myself but also others.”

—Masood Fareed Malik, Pakistan



“

I am the third generation with [VWD], I always thought it was normal to have anemia and heavy bleeding during my period... [but now I realize] that there are [medical] options for people with my condition. I thank everyone who has helped me on this path... and who taught me that it is possible to have a good quality of life despite the bleeding.”

—Génesis Cedeño, Venezuela



WFH 2023 COMPREHENSIVE CARE SUMMIT A SUCCESS

The WFH 2023 Comprehensive Care Summit: New Developments in Bleeding Disorders and MSK took place in Buenos Aires, Argentina from May 10 to 12, 2023, and was co-hosted with the Fundación de la hemofilia. The event encompassed the biennial International WFH Musculoskeletal (MSK) Congress, and included MSK, medical and multi-disciplinary tracks—all centering around people with bleeding disorders. The Summit provided a platform for healthcare professionals, industry experts, patients, and their families to discuss the latest advancements and challenges in the field of comprehensive care.

2

awards presented

the Pietrogrande Prize and the Christine Lee Young Researcher Award

91%

participant
satisfaction rate

115

abstracts, **101** eposters
and **14** free papers accepted

40

sessions

95

speakers

53%

of attendees were
healthcare professionals

725

attendees from
70 countries



THANK YOU

**TO OUR COMMUNITY AND CORPORATE
PARTNERS AND TO OUR DONORS**

OUR CORPORATE PARTNERS

The WFH gratefully acknowledges the generous support of our dedicated partners in 2023. Our Corporate Sponsors all play a significant role in helping us improve and sustain care for people with bleeding disorders around the world.

Global Partnership Recognition Program

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 2023 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
GC Pharma
Kedrion
LFB
Novo Nordisk
Octapharma

WFH programs and activity support in 2023

Corporate partner program

Visionary Partners

CSL Behring
Pfizer
Sanofi

Leadership Partners

BioMarin
Pharmaceutical Inc
F. Hoffmann-La Roche Ltd

Collaborating Partners

Bayer
Grifols
Novo Nordisk
Octapharma
Spark Therapeutics
Takeda

Contributing Partners

Biotest
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
Sanofi

Leadership Partners

CSL Behring
Pfizer

Collaborating Partners

Bayer
Grifols

World Bleeding Disorders Registry (WBDR)

Visionary Partners

Sobi
Takeda

Collaborating Partners

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

Gene Therapy Registry (GTR)

Visionary Partners

BioMarin Pharmaceutical Inc.
CSL Behring
Pfizer
Spark Therapeutics

Sponsored programs

Outreach and Diagnosis Initiative
Sanofi

Japanese localized website
Sanofi Japan

WFH International External Quality Assessment Scheme Program (IEQAS)

Novo Nordisk Haemophilia Foundation

WFH International Hemophilia Training Centre (IHTC) Fellowship Program

BioMarin Pharmaceutical Inc.
F. Hoffmann-La Roche Ltd

WFH Twinning Program
Pfizer

WFH Shared Decision Making Tool

BioMarin Pharmaceutical Inc.
CSL Behring
Novo Nordisk
Pfizer
Spark Therapeutics

Women and Girls with Bleeding Disorders Initiative
Novo Nordisk

WFH Global Forum
BioMarin Pharmaceutical Inc.
CSL Behring
Pfizer
Sobi
Spark Therapeutics

WFH 2023 Comprehensive Care Summit

Platinum sponsors

BioMarin Pharmaceutical Inc.
Pfizer
Sanofi/Sobi
Takeda

Supporting sponsor

Novo Nordisk



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 2023, 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.A. are conducted through WFH USA, a 501(c)3 affiliated entity.

Solidarity Fund

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

Susan Skinner Memorial Fund

Daniel Button
John Button
Arleigh Clemens
Amy Dunn
Hemophilia of Georgia
Charles Moore
National Bleeding Disorders Foundation (NBDF)
Oasis Foundation
Glenn Pierce
Amy Renz
Mark Skinner and James Matheson
Susan Peterson Thomas
Leonard Valentino
Vishal Venkatesh
Kyle Wilder

Tributes

The WFH is thankful for the work the Alliance franco-africaine pour le traitement de l'hémophilie (Afath) has done to support French-speaking African countries.

In honour of Dr. Kibet Shikuku and his wonderful work

In honour of the important work WFH has done through the decades and the many hemophilia patients who volunteered to participate in clinical trials

In memory of Virginia Barabino

In memory of Thomas W. Skinner

Photo: WFH visit to Sri Lanka – 2023



Donors

\$500,000+

Hemophilia of Georgia

\$100,000 to \$249,999

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

\$50,000 to \$99,999

Glenn Pierce
Beatrice Pierce

\$25,000 to \$49,999

Mark Skinner and James Matheson

\$10,000 to \$24,999

Donna Coffin
Phillips 66

\$5,000 to \$9,999

Canadian Hemophilia Society (CHS)
Barbara Goldman
Oasis Foundation

\$1,000 to \$4,999

Bahnhof Apotheke Thun AG
Paula Bell and Rob Christie
Bleeding Disorders Foundation of North Carolina
Coalition for Hemophilia B (The)
Eastern PA Bleeding Disorder Foundation
Cesar Garrido
Gateway Hemophilia Association
Great Lakes Hemophilia Foundation
Hemophilia Association of the Capital Area
Horowitz Family Foundation
Barbara Konkle and Peter Kollros
Lone Star Bleeding Disorders Foundation
Mary M. Gooley Hemophilia Center
John Murphy
New England Hemophilia Association
Northern Ohio Hemophilia Foundation
Pacific Northwest Bleeding Disorders
Edith Rosato
Rocky Mountain Hemophilia & Bleeding Disorders Association
Carlos Safadi Márquez
Kenneth Trader
Tri-State Bleeding Disorder Foundation
uniQure Inc.
Leonard Valentino

\$500 to \$999

Jennifer Brennan
Daniel Button
Jacie Cunningham
Daniel Doran
Amy Dunn
Haemophilia Association of Mauritius (HAM)
Dean M. Hindenlang
Kim Isenberg
Carol Kasper
Craig Kessler
Kate Khair
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Patrick and Clare Robert
Dawn Rotellini
Gina Schnabel
Sundar Selvaraj
Southwestern Ohio Hemophilia Foundation
Eric and Marion Stolte
Tremcar
Virginia Hemophilia Foundation

\$250 to \$499

John Button
Arleigh Clemens
Randall Curtis
Stephanie Devine
Rosa Maria Duenas-Rios
Kit Festa
Dietje Fransen van de Putte
Teruhisa Fujii
Ai Sim Goh
Hemophilia Foundation of Northern California
Christine Herr
Alfred Hiermann
Peter Hultgren
IQM Consulting
Phillip Kucab
Roshni Kulkarni
Jennifer Laliberte
James Luck
Prasad Mathew
Charles Moore
Anna Nixon
Wendy Quinn

Amy Renz
Debbie de la Riva
Electra Rozakis
Jill Sallade-Packard
Pedro Rodriguez Sanchez
Maria Santaella
Rebecca Schaffer
Sean Singh
Ekawat Suwantaroj
Susan Peterson Thomas
Andreina Tovar
Vishal Venkatesh
Kyle Wilder

\$150 to \$249

Antonio J. Almeida
Geneviève Beauregard
Hemophilia Philippines (HAPLOS Community) Foundation Inc.
Cedric Hermans
James Hunt
Yu Koga
David Page
Sundaresan Sivagnanamoorthy
Martha Soria
Marlene Spencer
Wing Yen Wong
Two anonymous donations





FINANCIAL REPORT

2023

(All amounts are in thousands of CAD dollars,
unless stated otherwise)

In 2023, the staff and volunteers of the WFH once again delivered world-class programs for the global inherited bleeding disorders community. We were able to do this despite persistent challenges related to the COVID-19 pandemic, such as higher travel costs and accommodation barriers.

The year ended with a net deficit of \$640 compared to a budgeted net deficit of \$2,863. This represents an improvement of \$2,223 over budget. A key contributor to this result was the improved performance of our investments as financial markets developed favourably, especially in the fourth quarter of the year. The strong U.S.A. currency (which averaged \$1.35 CAD throughout the year) further contributed to the positive result.

Continued stability of revenue

Our corporate sponsors continued their committed support with 2023 contributions of \$5,317, a decrease of \$280 (5%) over 2022. A major reason for this was the decreased funding for the WFH Humanitarian Aid General Program and the discontinuation of the WFH Development Grant Program. This was partially offset by the generous increased funding for the WFH PACT Program and the WFH Shared Decision Making tool.

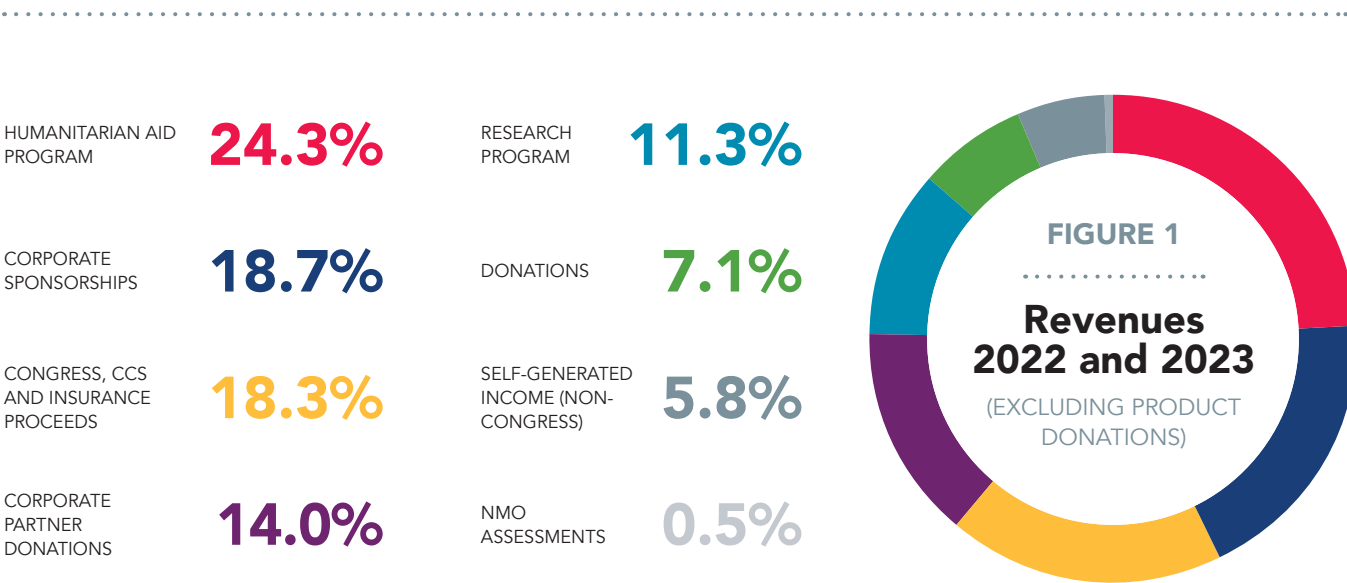
In 2023, the WFH Humanitarian Aid Program spent \$4,037 (\$4,066 in 2022) against funding received from our key corporate partners. Despite the now permanent higher costs and logistical challenges caused by the COVID-19 pandemic, we were able to treat over 26,000 people (cumulative) with hemophilia in 78 emerging countries.

For WFH Research Programs, \$1,911 was recognized (\$1,865 in 2022). These funds were put towards the WFH Gene Therapy Registry (GTR) to expand our data collection efforts for patients who receive this new therapy. They were also used to ensure the continued success of the World Bleeding Disorder Registry (WBDR)—which now includes more than 13,000 people with hemophilia enrolled from 119 hemophilia treatment centres (HTCs) in 44 countries globally.

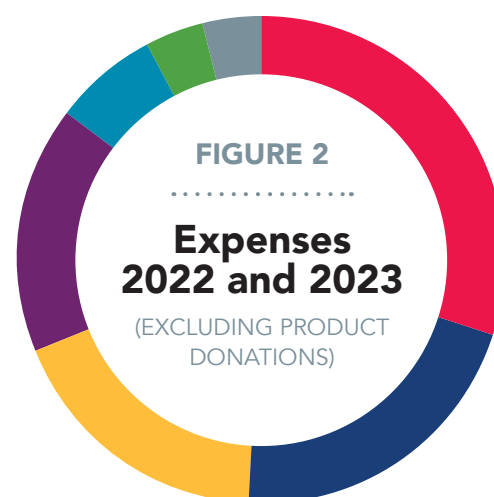
Fundraising revenues were at \$1,069 (\$1,302 in 2022). We received a larger amount of funding during the initial months of the invasion of Ukraine in 2022 when the Solidarity Fund was created. Funding has since decreased as the war enters its third year, but the WFH remains committed to supporting the bleeding disorders community, including Ukraine, through humanitarian aid.

Total WFH revenue, before Congresses, Insurance Proceeds, and Product Donations reached \$14,011—\$757 (6%) above 2023.

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, 33% of revenues over the two-year cycle are from sponsorships from WFH corporate partners; 36% are from restricted programs (Humanitarian Aid and the Research Program); 18% are from revenues from Congress, the WFH 2023 Comprehensive Care Summit (CCS) and insurance proceeds; and the remaining 13% are generated from financial donations, self-generating income activities, and national member organization (NMO) assessments.



HUMANITARIAN AID PROGRAM	30.3%	ADMINISTRATION	6.9%
HEALTHCARE DEVELOPMENT PROGRAMS	20.9%	FUNDRAISING AND CORPORATE RELATIONS	3.9%
RESEARCH AND EDUCATION	18.1%	GOVERNANCE AND COMMUNICATIONS	3.8%
CONGRESS AND CCS	16.6%	FLUCTUATION OF FOREIGN EXCHANGE	-0.5%



Expenditures aligning with strategic objectives

In aggregate, the healthcare development programs, the research and education 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 WFH 2022 World Congress and the CCS represented an investment of 17% 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 4%.

Humanitarian aid

The WFH distributes life-saving and sustaining humanitarian aid product donations from many of our corporate sponsors to WFH NMOs and HTCs around the world. Despite living in a post-pandemic world that has kept airfreight rates high, and created in-country barriers to movement, the WFH Humanitarian Aid Program team found alternative ways to deliver product cost effectively. The majority of these donations are included in the audited financial statements of WFH USA. The total value of all products shipped from both WFH USA and the WFH were approximately \$1.1 billion USD.

Year-over-year comparison

The 2023 and 2022 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 WFH Global Forum (GF) is held in odd years, and where the receipt of product donations vary in terms of frequency and amount. On the revenue side, before Congresses, Insurance Proceeds, and Product Donations, there was a growth of \$757, as already mentioned above. This was largely due to the growth in investment revenues of \$1,159 as a result of the significant market gains in the financial markets, as well as invaluable increases in contributions from our corporate partners to fund the new Shared Decision Making Tool (\$202) and the WFH PACT Program (\$232). This was offset by the decreased funding of the HA General Program (\$372); as well as a decrease in fundraising revenues of \$233 mostly due to reduced funding for the Solidarity Fund.

The overall spend of \$13,888 before Congresses and Product Donations (\$14,398 in 2022) reflects the continued efforts of the WFH to support the needs of the global bleeding disorders community. This was highlighted by the increases of \$334 for the WFH PACT Program and other country programs and \$360 for the biennial WFH GF that took place in 2023. This was offset by a \$903 decrease in the WFH Humanitarian Aid Program expenses, mostly due to reduced shipping costs through efforts made to lower the cost per vial to ship, and partly as a result of setting up operations in the India Free Trade Zone Hub.

Looking ahead

Our financial base is currently strong, with net assets of \$14.7 million. However, Congresses can no longer be relied upon to bring in the surpluses that they have in the past. This was evidenced by the results of our WFH 2022 World Congress and preliminary results of the WFH 2024 World Congress which had fewer participants than expected. Overall, the organization experienced a net deficit of \$515 for the years 2022 and 2023 combined, when we normally expect a surplus over a two-year period.

The WFH will 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.

Our continued prudence has allowed us to build a robust base of reserves that we are using to mitigate the impact of financial deficiencies. Our senior management team has also been proactive in alleviating some of these downward trends by implementing expense control measures.

We have prepared forecasts for a variety of realistically conceivable downside scenarios, and we are comfortable that our reserves are adequate to see us through the foreseeable future.

Our focus and dedication remain strong in terms of leveraging our resources for the benefit of our community so we can get closer to our vision of Treatment for All.

FIGURE 3

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Revenues and expenses

(Expressed in Canadian Dollars)

	2023	2022
REVENUES		
Donations	1,069,488	1,301,912
Corporate Partner Donations	2,315,712	2,371,857
Corporate Sponsorships	3,001,027	3,225,280
Research Program	1,910,669	1,865,449
NMO Assessments	63,374	93,807
Humanitarian Aid Program	4,037,174	4,065,513
Self-generated Income (Non-Congress)	1,613,138	330,000
Total Revenues before Congresses, Insurance Proceeds and Product Donations	14,010,582	13,253,818
Congress, Comprehensive Care Summit and Insurance Proceeds	1,127,650	5,002,191
Product Donations	311,534,109	273,574,144
TOTAL REVENUES	326,672,341	291,830,153
EXPENSES		
Healthcare Development Programs	3,579,163	3,514,518
Research and Education	3,134,737	3,011,548
Humanitarian Aid Program	4,681,476	5,584,572
Governance and Communications	608,068	681,498
Fundraising and Corporate Relations	616,952	701,648
Administration	1,294,262	1,043,380
Fluctuation of Foreign Exchange	(26,900)	(138,846)
Total Expenses before Congresses and Product Donations	13,887,758	14,398,318
Congress and Comprehensive Care Summit	1,890,812	3,732,164
Product Donations	311,534,109	273,574,144
TOTAL EXPENSES	327,312,679	291,704,626
EXCESS (DEFICIENCY)	(640,338)	125,527

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.



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WFH 2023 HIGHLIGHTS

26,000+
PEOPLE

with a bleeding disorder treated
since 1996

144
TREATMENT CENTRES
benefitting from the WBDR

130+
COUNTRIES REACHED
through global programs and events

WORLD FEDERATION OF HEMOPHILIA

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