



HUMANITARIAN AID PROGRAM

IMPACT REPORT 2023



The WFH Humanitarian Aid Program:

A BEACON OF HOPE FOR PEOPLE WITH INHERITED BLEEDING DISORDERS



Hello friends,
The World Federation of Hemophilia supports the global inherited bleeding disorders community in many ways.

The Program is a key WFH endeavour for changing lives for the better. Through the Program, we support countries by providing them with predictable treatment product donations, education, training, and government lobbying assistance. All of this is done with one objective in mind: to help countries along their journey to sustainability in inherited bleeding disorders care.

In 2023, we once again delivered life-changing support:

- **4,260 patients** on prophylactic treatment
- **265 million IUs** distributed

- **15,500 people** with inherited bleeding disorders (PWBDs) treated
- **30,598 acute bleeding episodes** managed
- **1,768 surgeries** performed

2023 objectives

We are very happy to report that all our 2023 objectives were met—or exceeded. Together, we:



Significantly increased the number of children on prophylaxis:

- 22%** for children from 0 to 4 years old and
- 16%** for children from 4 to 10 years old



Continued to deliver care to where it's needed across **78 countries**



Trained specialists

on immune tolerance induction (ITI) and other aspects of hemophilia management care

2024 objectives

We are also very confident that we will meet our 2024 objectives, even though they are even more ambitious than last year's:

Increase by 5%

the number of children on prophylaxis

Increase by 10%

the number of PWBDs treated

Train specialists from seven countries on ultrasound diagnosis and synovectomy

Work towards securing donations of bypassing agents for treating acute bleeds in PWBDs with inhibitors

All of these successes were made possible by the dedication of our volunteers, staff and the commitment of our partners: WFH national member organizations (NMOs), hemophilia treatment centres (HTCs), healthcare professionals (HCPs), governments, donors, members of the WFH and WFH USA boards, and our global inherited bleeding disorders community.

On behalf of the WFH I would like to thank all our partners for their continued support.

Assad E. Haffar, MD, MSc

WFH Medical & Humanitarian Aid Director

WFH Humanitarian Aid Program support **SINCE 1996**

6,000+
patients on prophylactic treatment

1.9+ BILLION
IUs distributed since inception of Program in 1996

26,000+
people with inherited bleeding disorders (PWBDs) treated

400,000+
acute bleeding episodes managed

8,000+
surgeries performed



CASE STUDY

Cambodia

FACTOR DONATED IN 2023
3.31 million IUs

NON-FACTOR REPLACEMENT
THERAPY DONATED IN 2023
109,320 mg

PATIENTS TREATED IN 2023
136



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the full story
or scan the QR code

From bed to business: a story from Cambodia

Khan Sokhai was born to a farming family in a small village in Kampong Cham province, Cambodia. From the age of twelve, he began suffering from debilitating bleeds which would mainly affect his ankles. Despite the severity of his condition, and the best efforts of physicians, he wasn't diagnosed with a bleeding disorder until he was an adult.

Khan's daily life was full of challenges. Then, in 2020, his life took a dramatic change for the better. Thanks to the years-long work of the WFH Humanitarian Aid Program and the dedication of HTC staff, the level of care in Cambodia increased to a point where prophylaxis began to be more readily available. Sokhai was selected for a prophylactic treatment, and his condition improved dramatically. For the first time in his life, he was able to live bleed-free. Now, less than three years after he began the treatment, Sokhai runs his own barbershop, and provides for his wife and two sons.



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

Supporting the Nepalese NMO's advocacy efforts

The WFH Humanitarian Aid Program supports NMOs with their advocacy efforts to help them along the path to sustainable care. In Nepal, the WFH Humanitarian Aid Program has played a crucial role in helping the Nepal Hemophilia Society (NHS) effectively advocate with multiple levels of government. In 2017, a significant milestone was marked in Nepal when hemophilia was recognized as a disability under the Nepal Government Act.

In 2023, the effects of this milestone were already being clearly felt by the community: all three levels of government in Nepal—central, provincial, and local—provide minimal but crucial support for the procurement of factor concentrates. A 10-year strategic plan will provide PWBDs with free treatment. Other steps forward are in process, such as the establishment of better care centres for hemophilia patients, and commitments to provide day care facilities, coagulation labs, physiotherapy care, and psychosocial counseling to the community.

CASE STUDY

Nepal

FACTOR DONATED IN 2023
7.25 million IUs

NON-FACTOR REPLACEMENT THERAPY DONATED IN 2023
148,000 mg

PATIENTS TREATED IN 2023
200

IMPACT IN ACTION

The WFH Humanitarian Aid Program works to improve the lives of people with inherited bleeding disorders (PWBDs), giving them a quality of life that previous generations would not have thought possible.

The Program operates based on three key action pillars: supporting outreach and identification, improving quality of life, and enabling sustainable care. These pillars drive our main support activities: delivering donated factor and non-factor replacement therapy, conducting training events and providing logistics support.

1 Supporting outreach and identification by...

- Training general HCPs on how to recognize inherited bleeding disorders
- Supporting initiatives with local organizations to find new patients
- Encouraging our partners to increase laboratory diagnosis by providing both educational and logistics support

2 Improving quality of life by...

- Collaborating with physicians to provide critical factor and non-factor replacement therapy donations
- Making life-changing surgery possible through sustainable and predictable treatment donations
- Facilitating access to care for new and existing PWBDs by working with WFH NMOs and HTC

3 Enabling sustainable care by...

- Supporting the establishment of medical facilities so that NMOs and HTCs can provide patients with lasting care
- Demonstrating to governments the value of treating PWBDs to support advocacy initiatives
- Informing and training HCPs on new classes of treatment and new treatment methods in line with the WFH Guidelines for the Management of Hemophilia, 3rd edition



**DELIVERING
CARE**



**ADVOCATING
FOR CARE**



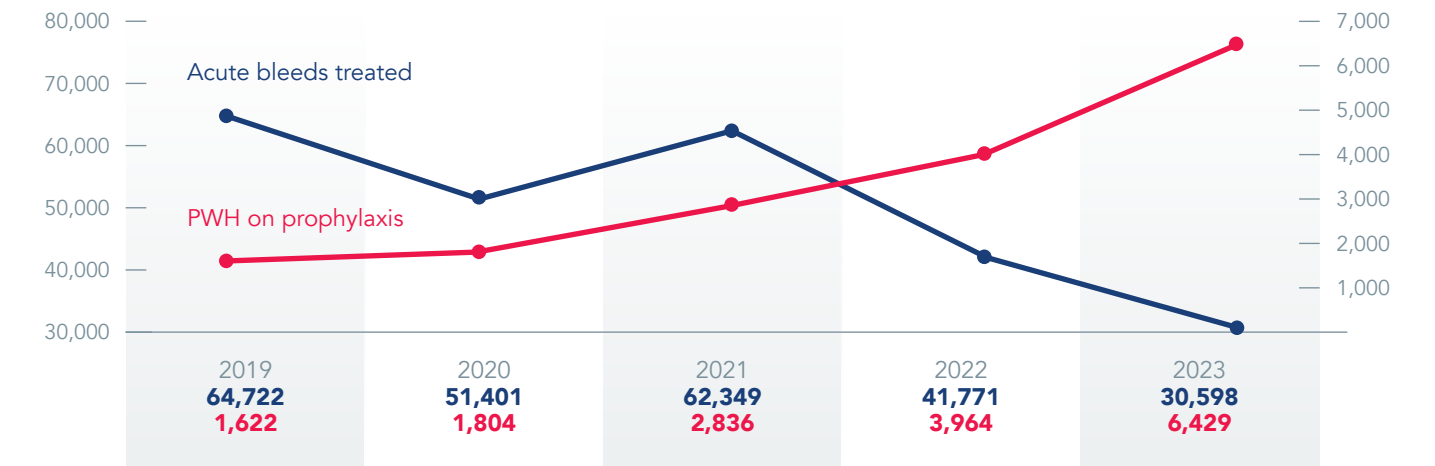
**MAKING SUSTAINABLE
CARE POSSIBLE**

DELIVERING CARE

Since the inception of the program in 1996, a total of **1.9 billion** of factor and **9.4 million mg of non-factor replacement therapy** have been donated worldwide.

Key Performance Indicators (KPIs)

Acute bleeds treated versus people with hemophilia (PWH) on prophylaxis since 2019

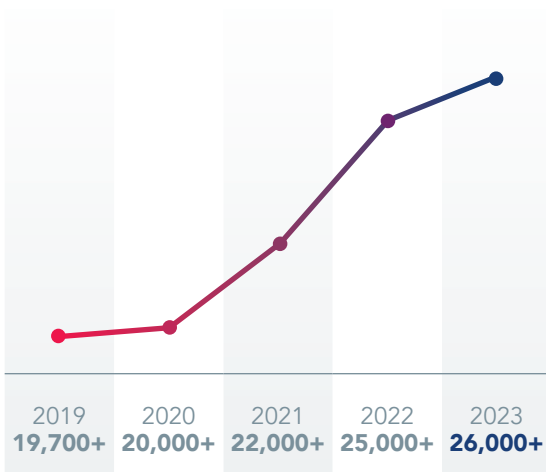


Because more patients are on prophylaxis, the number of acute bleeds dropped significantly in 2023.

Note: The WFH Quality Management System (QMS) and Standard Operating Procedures (SOPs) ensure that the WFH Humanitarian Aid Program respects all good distribution practices (GDP) requirements.

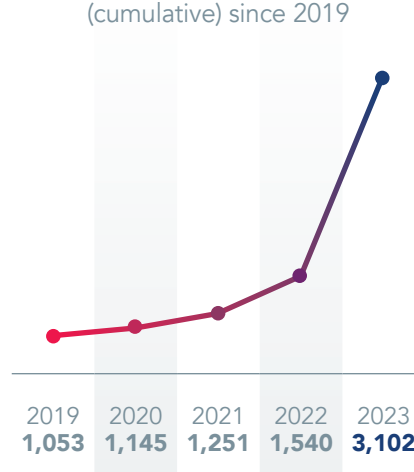
26,000+

Hemophilia A and B patients treated (cumulative) since 2019



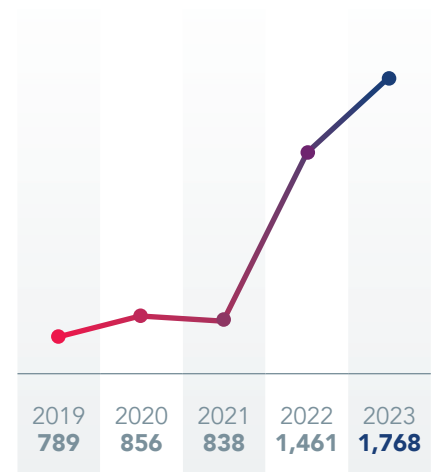
3,102

People with hemophilia (PWH) on prophylaxis under 10 years of age (cumulative) since 2019



1,768

Surgeries since 2019



ADVOCATING FOR CARE

The WFH Humanitarian Aid Program, along with other WFH global and local advocacy efforts, plays a leadership role in global advocacy by working with NMOs to advocate with governments to recognize and support their inherited bleeding disorders communities. Ultimately, government buy-in is required for a country to be able to provide fully sustainable care. Here are five videos which demonstrate the work the WFH Humanitarian Aid Program is doing around the world.



Senegal: giving children a chance at a normal life

The situation for PWBDs in the West African country of Senegal was very dire until 2015, when the WFH Humanitarian Aid Program's expansion meant that, for the first time, regular and predictable treatment product donations and training were made available to the country.

Donations have represented an important help forward for the Senegalese inherited bleeding disorders community because the government didn't provide any treatment products. PWBDs benefit, but so do physicians who can better manage their patients, because less patients in clinics means less time managing emergency situations, and more time working towards lasting care.



[Click here to watch the video](#)
or scan the QR code



Dominican Republic: creating opportunities

The WFH Humanitarian Aid Program has been active in the Dominican Republic for many years, providing the country with training and treatment product donations. Support greatly increased after the Program expanded in 2015, helping to dramatically improve the level of care in the country. PWBDs are now healthier and more involved in society. Treatment product that was once almost unattainable is now much more readily available. While the country is still facing challenges, it's on its way to one day being able to offer care self-sustainably.



[Click here to watch the video](#)
or scan the QR code

ADVOCATING FOR CARE



India: the power of training

The level of care in India has been steadily increasing over the years, thanks to WFH Humanitarian Aid Program donations and training efforts, as well as the dedication of HTC staff and WFH NMO volunteers.



Jamaica: change in just a few years

In just a few short years, care can be dramatically improved in a country—and Jamaica is an excellent example of this fact. Brandon Blake is a young man who was diagnosed with severe hemophilia A at birth. He has enjoyed a better quality of life than his older brother thanks to the WFH Humanitarian Aid Program.



Seeing impact first-hand: the Program in Indonesia

The WFH Humanitarian Aid Program donations have had a huge impact on the life of Azreal, a five-year-old boy with severe hemophilia A. He is on prophylactic treatment, which means that unlike children of previous generations, he is able to go to school, play with friends, and do normal activities like any boy his age.



Click here to watch the video or scan the QR code



Click here to watch the video or scan the QR code



Click here to watch the video or scan the QR code



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

Helping a male Sri Lankan patient with VWD

In 2023, a 57-year-old male patient was admitted to a Colombo hospital with a bleed in Sri Lanka. Because of the training the WFH Humanitarian Aid Program has done in the country, doctors knew to test him for a bleeding disorder, and he was diagnosed with von Willebrand disease (VWD).

With this information, physicians were able to determine the best course of action for treatment. The patient underwent several procedures, and received VWD concentrate during his treatment—donated by the Program, allowing him to fully recover.

CASE STUDY

Sri Lanka

FACTOR DONATED IN 2023
6.54 million IUs

NON-FACTOR REPLACEMENT THERAPY DONATED IN 2023
147,000 mg

PATIENTS TREATED IN 2023
310

CASE STUDY

United States of America



[Click here to read the full story](#) or scan the QR code

Supporting clinical trials in lower income countries

The WFH Humanitarian Aid team has worked with the St. Jude Children's Research Hospital in Memphis, Tennessee, U.S.A since 2019 to help them plan gene therapy clinical trials in lower/middle income countries.

The team met several times to help identify countries and HTCs that would be appropriate for the trials, and also to develop the clinical program. In 2023, this endeavour progressed to a point where it is now ready for a full roll-out.

The gene therapy clinical trials—which will be free for all participants—will consist of the Factor IX gene in an Adeno-associated virus (AAV) 8 vector. St. Jude filed the regulatory documents required to start the study in the U.S. in late 2023, and overseas site preparations for the trials will begin in 2024.

MAKING SUSTAINABLE CARE POSSIBLE

Training, logistics and compliance support are key endeavours for the WFH Humanitarian Aid Program. These activities provide the education and guidance that countries need to develop their infrastructure to provide lasting support.

Evolving training strategies and content

The expansion of the WFH Humanitarian Aid Program has drastically changed how PWBDs are supported. In the past, care was focused almost exclusively on acute bleeds—often in emergency situations. Now, care has moved in a much more sustainable direction, and the Program has adapted its training accordingly. This has been made possible by the following:

- Significantly higher volumes of treatment product donations
- More consistent and dependable shipping of treatment product
- Longer shelf life for treatment products
- Option to request special potencies of treatment product

As a result of this positive evolution, training has increasingly shifted from emergency care to procedures that aim to improve the long-term quality of life of PWBDs, such as:

- Prophylaxis, especially for children under five years of age
- Corrective surgeries
- Joint care
- Eradication of inhibitors with immune tolerance induction (ITI)

Hybrid education

In 2023, the Program leveraged learnings gained from online webinars delivered during the COVID-19 pandemic to bring more training to more people via a hybrid model.

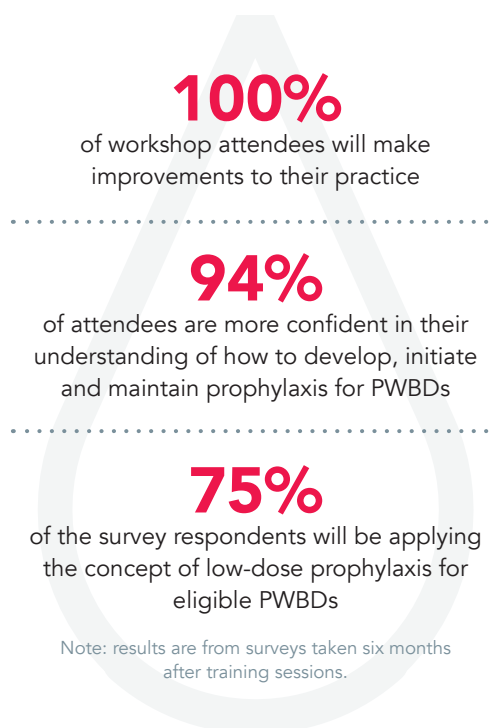
This approach adds online training to in-person training, allowing the Program to reach a larger population—including a significant number of specialists who are unable to attend in-person events. The hybrid model has also proved to be very effective at allowing the Program to increase the volume of training available to specialists—a necessity given the increased complexity of prophylaxis, surgery, and ITI training. It has also made it possible for the Program team to create training material for, and to hold, “train the trainer” sessions, allowing the WFH to significantly expand its training base beyond its internal resources.

The KAP model

The Knowledge Attitude Practice (KAP) model helps the WFH Humanitarian Aid Program team evaluate the lasting impact of training. The model looks at the sharing of Knowledge, the Attitude of participants after training has been completed, and the change in Practice of applying the knowledge learned. This allows us to answer important questions about what difference training is making, and whether levels of care are increasing. Surveys are done before, immediately after, and six months after training sessions are held.

Fundamentally, KAP is based on the belief that change is affected by knowledge and attitude. Thus, increasing the knowledge of HCPs will encourage them to adopt the current standards of treatment for hemophilia, which in turn will lead to better outcomes for the PWBDs they are treating.

2023 was the first full year of the implementation of the KAP model, and the results are already promising thanks to training sessions held by the WFH.



Logistics support

Getting donated factor to where it needs to be quickly and efficiently is a key activity for the WFH Humanitarian Aid Program team. In 2023, we continued to develop creative solutions to limit the risk of potentially catastrophic interruptions in factor donations to key areas.

KPIs	2020	2021	2022	2023	2022 to 2023 % increase
Shipments	257	318	269	347	29%
Vials	254,706	633,453	422,400	773,131	83%
Gross weight (tons)	46	113	82	139	70%
Compliance assessments	20	20	21	23	10%

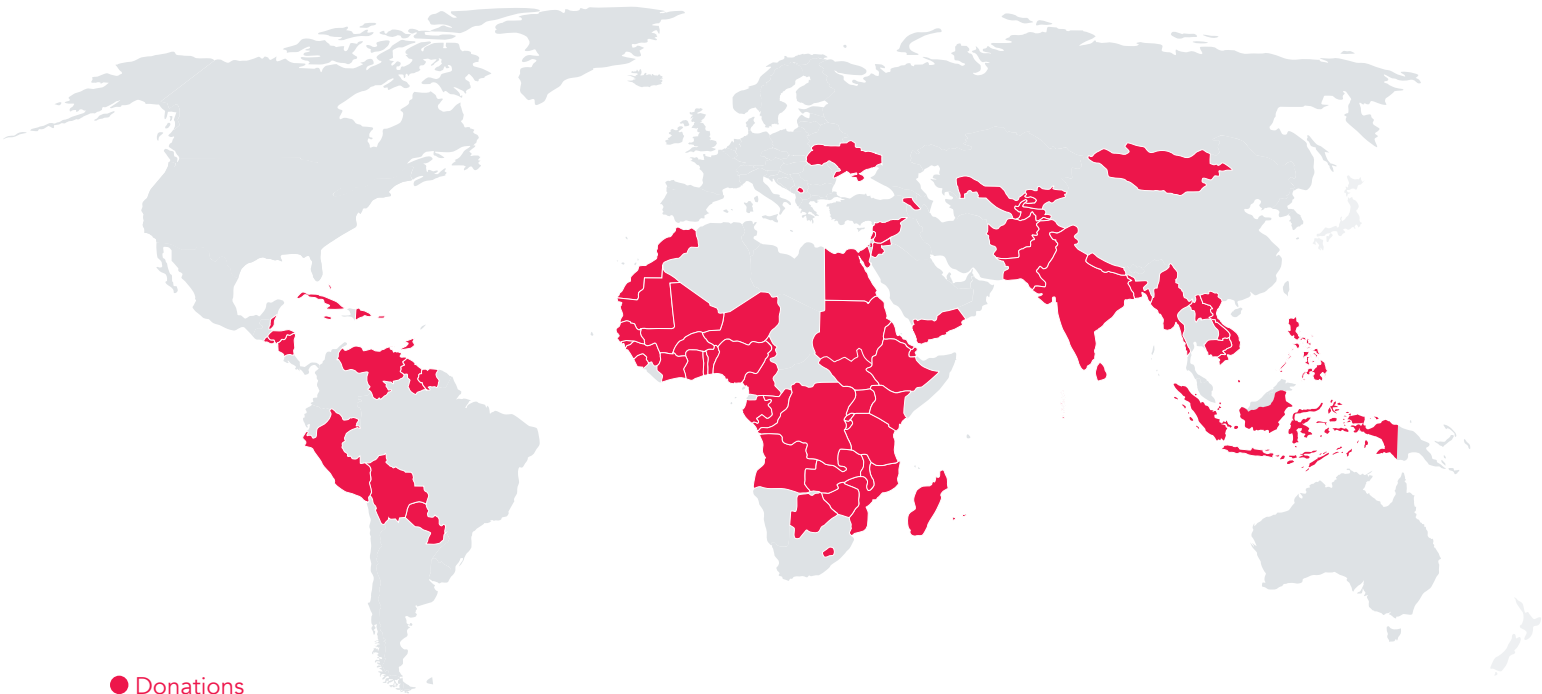
Countries that benefited from the WFH Humanitarian Aid Program in 2023

Received donations

(78 countries)

Afghanistan	Congo	Ghana	Madagascar	Pakistan	Togo
Angola	Côte d'Ivoire	Guinea	Malawi	State of Palestine	Trinidad and Tobago
Armenia	Cuba	Guyana	Maldives	Paraguay	Uganda
Bahamas	Democratic Republic of Congo (DRC)	Honduras	Mali	Peru	Ukraine
Bangladesh	Djibouti	India	Mauritania	Philippines	Uzbekistan
Barbados	Dominican Republic	Indonesia	Mauritius	Rwanda	Venezuela
Belize	Egypt	Jamaica	Mongolia	Senegal	Vietnam
Benin	El Salvador	Jordan	Morocco	Sierra Leone	Yemen
Bolivia	Eritrea	Kenya	Mozambique	Sri Lanka	Zambia
Botswana	Ethiopia	Kosovo	Myanmar	Sudan	Zimbabwe
Burkina Faso	Gabon	Kyrgyzstan	Nepal	Suriname	
Burundi	Gambia	Laos	Nicaragua	Syria	
Cambodia		Lebanon	Niger	Tajikistan	
Cameroon		Lesotho	Nigeria	Tanzania	

Note: most countries that received factor also received training.



● Donations

WORKING TOGETHER

to support Treatment for All

Founding Visionary Contributors



"At Sanofi, we believe that all people, regardless of where they live, should have access to the sustainable care they need to effectively manage their hemophilia and live a full life. As a founding partner of the WFH Humanitarian Program with Sobi, we are honoured to be a long-term supporter of a program that has resulted in more equitable access to treatments and improved standard of care for people living with hemophilia around the world."

—Alaa Hamed, Global Head of Medical Affairs, Rare Diseases, **Sanofi**



"We take great pride in the enduring impact of our commitment to the WFH Humanitarian Program. We are inspired by seeing that this important endeavour continues to make a difference in the lives of people with hemophilia around the globe. Sobi remains committed to the hemophilia community as we work to transform standards of care, improve access to sustainable and predictable treatment worldwide."

—Fabrizio Capetta, Vice President and Global Head of Haemophilia, **Sobi**

Visionary Contributors



"At Bayer, we are guided by our vision of 'Health for All, Hunger for None'. This is why we are very proud to work in close collaboration with the WFH Humanitarian

Aid Program to provide support and access to treatment for people with hemophilia where it is needed most. As part of our long-standing commitment to the global hemophilia community, the strong alliance between the WFH and Bayer is both a testament and a great opportunity to make a life changing difference in people's lives."

—Martin Renze-Westendorf, Global Therapeutic Area Head for Hemophilia, **Bayer**



"As a company committed to delivering on Our Promise and improving the lives of people around the world living with rare and serious diseases, CSL is proud of its value-driven partnerships with the WFH. With an innovative portfolio of therapies for the treatment of hemophilia, including the world's first ever gene therapy for hemophilia B, CSL is continuing its work to create life-saving therapies designed to meet the needs of the bleeding disorder community. With our donation of 500 million IUs of coagulation factor replacement therapy over 5 years to the WFH Humanitarian Aid Program, we are able to support people around the world with therapies which further improve quality of life."

—Paul McKenzie, CEO and Managing Director, **CSL**



Roche A member of the Roche group



A Member of the Roche Group



"Life-changing therapies can contribute to improving the quality of life of people with hemophilia A and their families. We are proud to support the WFH Humanitarian Aid Program in its mission to help address the need for greater access to therapies, particularly in developing countries. Listening to and collaborating with the hemophilia community in their efforts to improve the lives of people living with hemophilia A is a top priority for Roche. Improving the healthcare systems and working towards greater government engagement in all countries is important for creating sustainable access to therapies."

—Daud Chaudry, Global Head of Hemophilia, **Roche**

Leadership Contributor

GRIFOLS “It is an honor and privilege to support the WFH Humanitarian Aid Program. At Grifols, our support stems from our founder who was quoted as saying, ‘To live in society carries the moral duty to work to improve it.’ In this sense, our participation in the Humanitarian Aid Program is also considered an ethical imperative at Grifols. As a company active in the bleeding disorders community, we have both the desire and the obligation to help those in need.”

—Christopher Healey, Senior Vice President, Corporate Affairs, **Grifols**

Contributor



“Takeda congratulates the WFH on its admirable progress to achieve global health equity for PWBDs. With an

increasing number of children on prophylaxis in a growing number of countries where standards of care evolve, we can directly see the impact of the WFH Humanitarian Aid Program on the WFH vision of achieving Treatment for All.”

—Giles Platford, President, Plasma Derived Therapies Business Unit, **Takeda**



“We affirm the WFH’s vision of Treatment for All, and we are proud to contribute to the treatment

of hemophilia patients in countries with limited access to treatment by being part of the WFH Humanitarian Aid Program. In Japan, the export of blood products became partially possible through a legal amendment in 2018, and we were able to make our first donation last year. We will continue to cooperate with WFH for continuous donation.”

—Takahide Ishikawa, President, **Japan Blood Products Organization (JB)**

Other Partners



“Hemophilia of Georgia is proud to partner with the World Federation of Hemophilia to alleviate suffering,

support sustainable care, and reduce the impact of bleeding disorders in low and middle-income countries. We are committed to working with our WFH partners to build a future where all have access to treatment and are treated with dignity and respect.”

—Deniece Chevannes, Vice President of Public Policy, Health Equity, and Research, **Hemophilia of Georgia**



“We have seen first-hand the incredible level of commitment and passion the WFH has for making sure that all

donated medications reach those in need around the globe. WFH staff and volunteers inspire us to want to be better at what we do. The WFH and Kuehne+Nagel work together to save lives, and we thank you for the honour of allowing us to be your supply chain partner.”

—Anthony N. Catapano, Head, Humanitarian Aid & Relief NAM, **Kuehne+Nagel**



“At QProducts & Services, our commitment to a more secure and efficient cold chain has positioned us as a trusted supply chain partner. We are honored and proud to partner with the WFH in support of our shared vision of Treatment for All.”

—Kevin Lynch, Vice President, Global Sales, **QProducts & Services**

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. None of this would be possible without the generous support of our sponsors.

WFH Humanitarian Aid Program

KEY PERFORMANCE INDICATORS

KPIs	2019	2020	2021	2022	2023
Operational metrics					
Patients treated by donations (cumulative)	19,792	20,048	22,159	25,183	26,143
Total donations in MIUs	241	146	307	197	265
Total donations in mgs of non-factor replacement therapy	n/a	809,220	2,561,750	3,264,800	2,783,250
Number of countries receiving donations	73	69	74	72	78
Mean age of PWH* receiving treatment	22	22	21	21	20
Total number of infusions related to acute bleed treatment	119,658	68,889	159,458	63,492	116,067
Impact metrics					
Number of countries doing surgeries	25	25	26	22	32
New countries doing surgeries	0	0	2	2	8
Total number of surgeries	789	856	838	1,461	1,768
Life and limb-saving surgeries	112	121	83	72	83
Number of acute bleeds treated	64,722	51,401	62,349	41,771	30,598 [†]
Impact metrics (cumulative)					
Number of PWH on prophylaxis	1,622	1,804	2,836	3,964	6,429
PWH on prophylaxis under 10 years of age	1,053	1,145	1,251	1,540	3,102
Activity metrics					
Number of workshop attendees	250	691	1,468	470	385
Virtual	–	691	1,468	364	284
In-person	250	–	–	106	101

* PWH: person with hemophilia

† Because more patients are on prophylaxis, the number of acute bleeds dropped significantly in 2023.



CASE STUDY

Uganda

FACTOR DONATED IN 2023
3.46 million IUs

NON-FACTOR REPLACEMENT
THERAPY DONATED IN 2023
60,000 mg

PATIENTS TREATED IN 2023
160

Democratic Republic of Congo (DRC)

FACTOR DONATED IN 2023
1.28 million IUs

PATIENTS TREATED IN 2023
19



Cross border support between Uganda and DRC

Because the WFH Humanitarian Aid Program is active in so many countries, PWBDs who are refugees can often find care through NMOs and HCPs in their host countries. These organizations are often ready and able to help—despite their own continuing struggles. This year, a young refugee from the Democratic Republic of Congo (DRC) benefitted from this very kind of assistance. Here is his story.



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

Dear WFH Humanitarian Aid Program team,

My name is Christian Bahane, and I'm a 21-year-old man from the Democratic Republic of Congo (DRC). I'm a refugee residing in the Nakivale refugee settlement in Uganda.

My brothers and I started suffering from recurrent bleeds and joint pain and swelling at the age of one year old. Our parents took us to many hospitals and clinics back in DRC, but no one was able to diagnose us. It wasn't until 2016 when we came to Uganda... that we were all diagnosed with hemophilia after undergoing several tests.

Everything changed when a hemophilia treatment centre (HTC) opened in Nakivale about three years ago [Editor's note: the centre is indirectly supported by WFH Humanitarian Aid Program donations given to Uganda]. Because of this, our life has greatly improved.

I hereby wish to thank the WFH Humanitarian Aid Program team for all you have done. You have restored our happiness and hope and in a special way.

—Christian Bahane



Your continued support helps us

Increase quality of care

.....

Increase the number of patients treated

.....

Improve quality of life

.....

Enhance diagnosis

.....

Advocate for better care

.....

For more information, please contact us at:

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