

MAKING ACCESS TO CARE POSSIBLE

even during the COVID-19 pandemic

Hello friends,

The WFH Humanitarian Aid Program provides predictable and sustainable treatment for those who need it most, promotes diagnosis, and incentivizes governments to invest in bleeding disorders care.

It does this by supporting WFH national member organizations (NMOs), hemophilia treatment centres (HTCs), and healthcare practitioners (HCPs) in emerging countries.

In many ways, 2021 was a record year for the Program. We hit a major milestone: we have now donated over **1 billion IUs** of factor since the expansion of the Program in 2015. We also treated **22,000+** patients with hemophilia A and B and put **2,836** patients on prophylactic treatment—**2,011** through factor replacement therapy and **825** through non-factor replacement therapy. The statistics go on: **51,400+** bleeding episodes managed. **838** surgeries performed. **112** countries supported since the inception of the Program in 1996.

The Program continued to support our goals of increasing the number of people diagnosed and treated by working with national member organizations (NMOs) to hold outreach and identification campaigns. Significant progress is also being made advocating with governments to show them the impact investing in hemophilia care can have on the lives of people with a condition in their countries. All of this was achieved despite the challenges of the COVID-19 pandemic. These accomplishments make one fact clear: the WFH is making a difference in the lives of people with inherited bleeding disorders worldwide.

In 2022, we plan to do even more. Our goals for next year include securing more donations from donors and providing donations for people with von Willebrand disease (VWD) and other rare bleeding disorders.

The WFH Humanitarian Aid Program gives people with the bleeding disorders hope—the hope of leading a normal life. Our success is a direct result of a collective effort between the WFH, pharmaceutical partners, governments, and the global bleeding disorders community.



Assad E. Haffar, MD, MSc WFH Medical & Humanitarian Aid Director





Webinar session for doctors and treaters

LOCATION

Central and South America

donations of factor in 2021 42.5 million IUs

TOTAL DONATIONS OF FACTOR SINCE 2015

220.91 million IUs

DONATIONS OF NON-FACTOR REPLACEMENT THERAPY IN 2021

341,250 mg



The WFH estimates that over 75% of the approximately 815,000 people with hemophilia worldwide are undiagnosed. Rates of diagnosis are even lower for women and for those living with von Willebrand disease and other rare bleeding disorders. For this reason, supporting outreach and identification is an important endeavour for the WFH Humanitarian Aid Program.

In 2020 and 2021, the Program held a number of webinars designed to give healthcare practitioners (HCPs) the tools they need to sustainably improve outreach and identification. One such series—"Scientific Session on Front-Line Doctors and Second-Line Treaters" -was geared to HCPs in Central and South America. Participants were from two important sets of carers for PWBDs: front-line physicians working in the primary care setting, such as clinics, local health centres, and second-line treaters. This latter group is made up of treaters working in hospitals who may not necessarily be hemophilia specialists, such as registrars, residents, and fellows-in-training, pediatricians, internists, and emergency room physicians. By training these two groups the Program was able to both provide tools for early identification of PWBDs, and increase the level of care those individuals would receive upon diagnosis.

IMPACT IN ACTION

The WFH Humanitarian Aid Program works to improve the lives of 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 of factor and non-factor replacement therapy, conducting training events and providing logistics support.

- Supporting outreach and identification by...
- Training general HCPs on how to recognize 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 donations
- Making life-changing surgery possible through sustainable and predictable treatment donations
- Facilitating access to care for new and existing PWBDs by working with NMOs and HTCs
- Enabling sustainable care by...
- Supporting the launch of medical facilities so that NMOs and HTCs can provide patients with lasting care
- Demonstrating to governments the value of treating PWBDs with adequate treatment to support advocacy initiatives



DELIVERING CARE



MAKING SUSTAINABLE CARE POSSIBLE



ADVOCATING FOR CARE



Trinidad and Tobago

DONATIONS OF FACTOR IN 2021
1.35 million IUs

TOTAL DONATIONS OF FACTOR SINCE 2015

4.4 million IUs



WFH Humanitarian Aid Program donations are increasingly used to treat young PWBDs prophylactically. Treatment at an early age means less bleeds, less joint damage, and a more normal life. It allows children to go to school and adults to work—both of which benefit society. Increasingly, the benefit of prophylaxis is used to show governments how sustainable care can ultimately benefit their society as a whole.

O'Brian, Joel, and Nathan are brothers with severe hemophilia A with inhibitors who live in Trinidad and Tobago. Aged ten to thirteen, lack of access to sufficient care has left them with permanent disabilities. O'Brian and Joel developed arthropathy of the left and right knee joints respectively, and Nathan lost vision in his right eye from an accident and the subsequent unavailability of bypassing agent.

Fortunately, thanks to factor replacement therapy provided by the WFH Humanitarian Aid Program, they have seen their quality of life improve drastically. The brothers can now go to school, take part in activities with their peers, and even participate in sports like swimming. If prophylaxis had been available to the bothers earlier, they would have led almost normal lives.

DELIVERING CARE

In 2021, the WFH Humanitarian Aid Program provided a record 308 million IUs of clotting factor concentrates around the world. Since the expansion of the program in 2015, a staggering 1 billion IUs have been distributed around the world. Over 1.5 billion IUs have been distributed since the inception of the Program in 1996.



Key Performance Indicators (KPIs)











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.



Guyana

DONATIONS OF FACTOR IN 2021
1.18 million IUs

TOTAL DONATIONS OF FACTOR SINCE 2015 2.8 million IUs



An incorrect diagnosis or lack of adequate care can have a devastating effect on the life of a PWBD. By working with NMOs and HTCs to increase medical knowledge, the WFH Humanitarian Aid Program helps to increase the diagnosis of people with bleeding disorders in developing countries.

Sarju Persaud, a young man from Guyana, was often bedridden because of injuries which would sometimes bleed for

more. It was only after undergoing treatment for a benign tumour caused by his condition—which had been misdiagnosed as cancer—that he was finally diagnosed with hemophilia A. Now, he is receiving factor donated by the WFH Humanitarian Aid Program. His bleeds have stopped, and he is currently scheduled for potentially lifechanging surgery that he hopes will correct a previous operation done prior to his diagnosis. Persaud feels that if it were not for the donated factor, he would not be alive today. While he still suffers because of his pre-diagnosis surgery—a burst abscess means he must live with an ostomy pouch and low energy levels—he has hope that his next surgery will give him a more normal life.

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The Hemophilia Federation (India) is highly indebted and grateful to the WFH Humanitarian Aid Program, which has allowed us to support more than 8,000 patients. We can now manage bleeds, perform corrective surgeries, and save lives. This donation—along with training support provided by WFH—has immensely improved the day-to-day lives of our patients. We draw a lot of confidence from this initiative to advocate with the government and work towards our collective vision of 'Treatment for All'.

—Premroop Alva, President, Hemophilia Federation (India)



MAKING SUSTAINABLE CARE POSSIBLE

Training and logistics support are the other key pillars of the WFH Humanitarian Aid Program. These activities provide the education and guidance that countries need to develop their infrastructure to provide lasting support.

Webinars and online education

In 2020, the Program shifted learning from face-to-face educational and training sessions to online learning because of the COVID-19 pandemic. This continued in 2021, and was enhanced thanks to a year of experience and valuable feedback from participants. Last year, we held over 40 sessions on a variety of topics.

Webinar	Number	Regions served	Countries	Attendees 346	
Laboratory Diagnostics Workshop	2	India, Pakistan, Bangladesh, Sri Lanka, Afghanistan, Mongolia, China	21		
Scientific Session on Hemophilia for Front-line Doctors and Second- line Treaters	2	West (francophone) Africa, South East Asia and Western Pacific	14	256	
Scientific Session on Prophylaxis in Hemophilia Management	2	West (francophone) Africa, East (anglophone) Africa	24	144	
Training the trainers	1	Armenia, Mali, Morocco, Venezuela	4	5	
Virtual Case Conference and Bedside Rounds	4	West (francophone) Africa, India, South Asia, South East Asia and Western Pacific	23	178	
Virtual workshop on Experience with EHL (extended half-life products) *	1	Global (selected treaters)	10	40	
Webinar on utilization reports**	21	West (francophone) Africa, Latin America	21	130	
Workshop on Novel Therapies on Inhibitor Management, Including non-factor replacement therapy***	8	Global (countries receiving non-factor replacement therapy) West (francophone) Africa, Latin America, Armenia, Pakistan	39	369	
TOTAL	8			1,468	

^{*}Countries included: Bangladesh, Egypt, India, Mozambique, Myanmar, Nepal, Pakistan, Sri Lanka, Uganda, Vietnam

^{**}Countries included: Benin, Bolivia, Burkina Faso, Burundi, Cameroon, Cuba, DRC, El Salvador, Gabon, Guinea, Honduras, Ivory Coast, Madagascar, Mali, Mauritania, Nicaragua, Paraguay, Peru, Senegal, Togo, Venezuela

^{***}Countries included: Armenia, Bangladesh, Benin, Bolivia, Burkina Faso, Cambodia, Cameroon, Colombia, Congo, China, East (anglophone) Africa, Cuba, El Salvador, Gabon, Ghana, Honduras, Ivory Coast, Jamaica, Kenya, Madagascar, Malawi, Mali, Mauritania, Mozambique, Myanmar, Nepal, Nicaragua, Nigeria, Pakistan, Philippines, Rwanda, Senegal, Sri Lanka, Tanzania, Togo, Trinidad and Tobago, Uganda, Venezuela, Vietnam, Zambia

I would like to express my gratitude for the support provided by the staff of the WFH Humanitarian Aid Program who have given us tools and training we have used for diagnosis, follow-up, and treatment—including new therapy treatment. Using this knowledge, we have been able to train our HTC staff as well as colleagues from other centres in the country. All of this has allowed us to better manage and use the resources provided by the Program. This has ultimately resulted in a better quality of life for PWH in Venezuela.

—Apsara Boadas de Sanchez, MD, Centro Nacional de Hemofilia, Caracas, Venezuela

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Logistics support

Getting donated factor to where it needs to be quickly and efficiently is a difficult task—and the pandemic has made the process even more challenging. Fortunately, the Program continues to develop creative solutions to limit the risk of potentially catastrophic interruptions in factor donations.

Key Performance Indicator (KPI)	2019	2020	2021	Δ 2019-2021
Shipments	331	257	318	-4%
Vials	321,553	254,706	633,453	+97%
Gross weight (tons)	58	52	100	+72%

CASE STUDY

Nigeria

DONATIONS OF FACTOR IN 2021

8.82 million IUs

TOTAL DONATIONS OF FACTOR SINCE 2015

35.7 million IUs

DONATIONS OF NON-FACTOR REPLACEMENT THERAPY IN 2021

90,720 mg



Improving care in a country can only happen through the dedication of an NMO. By working with NMOs and providing them with organizational, training, logistics and advocacy support, the WFH Humanitarian Aid Program helps countries move along the road to self-sufficiency.

In 2005, the Nigerian bleeding disorders community future took a drastic turn for the better when the Hemophilia Foundation of Nigeria (HFN) was relaunched by Megan Adediran.

Working with the WFH, Adediran developed new programs, enhanced the country's hemophilia care infrastructure, and built a strong relationship with the WFH Humanitarian Aid Program. One beneficiary of this hard work is David Aremu, a 19 year-old with severe hemophilia A. His condition went undiagnosed for many years, and as a result, he suffered. He had internal bleeds, including bleeds in his legs that impacted their development. David felt alone and hopeless—until he was introduced to Adediran. Through the HFN, Aremu was able to access donated factor and proper care. This made it possible for him to get surgery on one of his legs to improve his mobility and allow him to go back to school. Prophylaxis—made possible by donated non-factor replacement therapy provided by the WFH Humanitarian Aid Program—kept him more consistently healthy and allowed him to attend school regularly and enrol in a computer science degree in university.

ADVOCATING FOR CARE

The WFH Humanitarian Aid Program plays a leadership role in global advocacy by working with NMOs to advocate with governments to recognize and support their bleeding disorders communities.

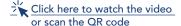
Ultimately, government buy-in is required for a country to be able to provide fully sustainable care to its bleeding disorders community. In 2021, the WFH released two videos to showcase the work the WFH Humanitarian Aid Program is doing around the world. Here are two videos we did in 2021.

Zambia





The WFH Humanitarian Aid Program has collaborated with the Haemophilia Foundation of Zambia to provide over 1.25 million IUs of factor to local hospitals. This factor has allowed children to go back to school and lead more normal lives.

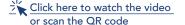


Vietnam





In Vietnam, the WFH Humanitarian Aid Program has worked with HTCs to teach specialists how to best manage patients in during emergency situations and surgeries, and how to offer patients optimal comprehensive care.





A key focus area of the WFH Humanitarian Aid Program is enabling sustainable care. While Program donations can have an impact in developing countries, the only way to secure a better quality of life for future generations is to secure the support of governments.

In Nepal, the clear benefits of WFH Humanitarian Aid Program donations helped convince the government to start providing hemophilia treatment products. In 2006, the Nepal Hemophilia Society (NHS) affiliated with the National Federation of Disabled Nepal (NFDN), and two years later, hemophilia was formally recognized as a disability. Since then, at least one representative from the NHS has been a board member of the NFDN. The NHS was soon able to secure funding from the Ministry of Women, Children, and Social Welfare of Nepal and the District Development Committee of Kathmandu. Later, the government agreed allocate funds to procure the necessary medicine for the treatment of hemophilia—marking the first major actionable policy for hemophilia at the provincial level. In 2017, the Nepalese government passed the Act Relating to Rights of Persons with Disabilities, and hemophilia was included. This major step allowed the NFDN to advocate for procurement of hemophilia medicines at the policy level.



Nepal

DONATIONS OF FACTOR IN 2021

6.50 million IUs

TOTAL DONATIONS OF FACTOR SINCE 2015

18.9 million IUs

DONATIONS OF NON-FACTOR REPLACEMENT THERAPY IN 2021

400,680 mg

Countries that collaborated with the WFH in 2021

Donations

(74 countries)

Afghanistan Angola Armenia Bahamas Bangladesh Barbados Belize Benin Bolivia Burkina Faso Burundi Cambodia Cameroon Cape Verde Congo Brazzaville Cuba

Dominica Dominican Republic Democratic Republic of the Congo (DRC) Egypt El Salvador Eritrea Ethiopia Gabon Gambia Ghana Guinea Guyana Honduras India

Indonesia Ivory Coast Jamaica Jordan Kenya Kosovo Kyrgyzstan Laos Lebanon Madagascar Malawi Maldives Mali Mauritania Mongolia Morocco

Myanmar
Nepal
Nicaragua
Niger
Nigeria
Pakistan
Palestine
Paraguay
Philippines
Rwanda
Senegal
Sri Lanka
St-Lucia
Suriname
Syria

Mozambique

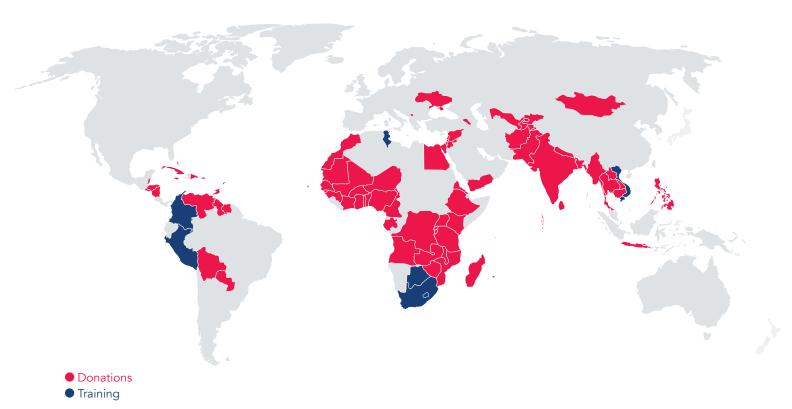
Tajikistan
Tanzania
Thailand
Togo
Trinidad
& Tobago
Uganda
Ukraine
Uzbekistan
Venezuela
Yemen
Zambia

Zimbabwe

Training (+8 countries)

Botswana
Colombia
Lesotho
Mauritius
Peru
South Africa
Tunisia
Vietnam

Note: most countries that received factor also received training.



WORKING TOGETHER

to support Treatment for All

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.

Founding Visionary Contributors



"At Sobi, we are committed to contributing to improved access to care for those who are overlooked. The WFH

Humanitarian Aid Program gives us an opportunity to make a meaningful difference for people with hemophilia, as only predictable and sustained care over the long term can truly liberate lives. Together with Sanofi, we continue to believe in and support the WFH vision. Our goal is to provide predictability and sustainable access to care by contributing to this program at a scale that can transform lives. We are proud to be able to support this program that means so much for the people receiving treatment."

—Guido Oelkers, CEO and President, Sobi

sanofi

"Our commitment to patients extends beyond the development of therapies. We believe it is our responsibility to support people

with rare blood disorders who have limited access to diagnosis and care, especially in the developing world. Through our support of the WFH Humanitarian Aid Program with Sobi, we have seen first-hand the far-reaching impact a predictable and sustainable supply of factor replacement therapy can have on patients and their families. We are honored to play our part in helping to address this global public health challenge."

—Bill Sibold, EVP and Head of Specialty Care, **Sanofi**

Visionary Contributors



"The work we do at Bayer is guided by our vision 'Health for All, Hunger for None'. We are very proud to be able 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 most needed. As part of our long-standing commitment to the global hemophilia community, joining forces with the WFH in a strong alliance is a great opportunity for us to make a tangible difference in people's lives."

—Joseph Lin, Global Therapeutic Area Head for Hemophilia, **Bayer AG**







"For Roche, it is a privilege to support the WFH Humanitarian Aid Program since the beginning of 2019 to address critical needs of people with hemophilia around the world. We applaud the WFH's and the local communities' tireless efforts to improve the lives of people with hemophilia through improved access to life changing therapies."

—Igbal Mufti, Global Head of Hemophilia, Roche



Leadership Contributor

GRIFOLS

"Despite the demands of working through a global pandemic, Grifols has redoubled its partnership with

the WFH Humanitarian Aid Program by extending until 2030 its commitment of providing a minimum of 30 million IU of clotting factor per year. Regardless of other challenges the world may face, we are mindful of our moral obligation to continue assistance and care for persons with bleeding disorders in geographies with limited access to treatment. Partnering with the WFH Humanitarian Aid Program is a foundational part of meeting this ethical imperative and advances our mission of improving the health and well-being of people around the world."

—Christopher Healey, President, Corporate Affairs, Grifols

Contributor



"Takeda's aspiration is to work toward a world without bleeds by enabling prophylaxis and achieving good joint

health. Our ability to achieve this is largely dependent on patients across the globe being able to access the necessary therapy. We commend the World Federation of Hemophilia's efforts in getting therapy to patients and advancing standards of care through the WFH Humanitarian Aid Program. We are pleased to continue our partnership with the WFH as we strive together to deliver equitable treatment for all."

—Giles Platford, president of the Plasma-Derived Therapies Business Unit, **Takeda**

CSL Behring Biotherapies for Life™

"Protecting the health and wellbeing of our patients, communities and people around the world sit at the centre of our

purpose. And it's through collaborative actions, including values-driven partnerships, that will enable us to further foster a healthier, more sustainable and equitable planet. The WFH Humanitarian Aid Program embodies our promise and we are grateful for the opportunity to partner with an organization that extends our purpose to improve patients' quality of life."

—Paul Perreault, CEO and Managing Director, CSL Limited, *CSL*

Community Partners



"We are all one bleeding disorder community regardless of geographic boundary. HoG patients, families,

Board of Directors, and staff are steadfast in our commitment to partner with the WFH Humanitarian Aid Program to bring hope, access to medicines and solidarity to the worldwide bleeding disorder community. Our longstanding support of the WFH Humanitarian Aid Program allows Hemophilia of Georgia to fulfill our mission of service to the community as we support WFH's vision of Treatment for All."

—Deniece Chevannes, Senior Director of Grants Management, **Hemophilia of Georgia**



"Logenix is grateful for the ability to assist the world's most vital programs such as the WFH Humanitarian Aid

Program. We are proud of our continued partnership with WFH to overcome logistical obstacles, develop solutions, and evolve the supply chain in order to deliver reliable access to treatment and care to all of those who need it most."

—Ron Cruse, President and Chief Executive Officer, *Logenix International*



Key Performance Indicators (KPIs)	2017	2018	2019	2020	2021
Operational Metrics					
Patients treated by donations (cumulative)	16,189	18,458	19,792	20,048	22,159
Total donations in MIUs	160	191	241	146	307
Number of countries receiving donations	60	62	73	69	74
Mean age of PWH receiving treatment	20	20	22	22	21
Total number of infusions related to acute bleed treatment	61,289	103,458	119,658	68,889	159,458
Impact Metrics					
Number of countries doing surgeries	23	26	25	25	26
New countries doing surgeries	5	3	0	0	2
Total number of surgeries	781	685	789	856	838
Life and limb-saving surgeries	78	62	112	121	83
Number of acute bleeds treated	45,161	58,458	64,722	51,401	62,349
Impact Metrics (Cumulative)					
Number of PWH on prophylaxis	1,210	1,546	1,622	1,804	2,836
PWH on prophylaxis under 10 years of age	834	984	1,053	1,145	1,251
Activity Metrics					
Number of workshop attendees	315	240	250	691	1,468



Indonesia

DONATIONS OF FACTOR IN 2021
4.25 million IUs

TOTAL DONATIONS OF FACTOR
SINCE 2015
16.6 million IUs



Providing NMOs with advanced logistics techniques allows them to get care and donated factor to where it needs to be—fast. In many developing countries, PWBDs live in remote areas, adding an extra level of complexity to the process. In many cases, having a strong logistics knowledge base can be the difference between life and death.

19 pandemic. But the country has also gone through several other natural disasters during the same period. In one case, destructive landslides in the Majene region injured three PWBDs. All three suffered bleeds because of the disaster and were in dire need of factor. This factor—available to the Indonesian Hemophilia Society (HIS) thanks to donations provided by the WFH Humanitarian Aid Program—was readily available, but transporting it to the patients was challenging because of infrastructure damage. Fortunately, through ongoing collaboration with the Program, the HIS was well-versed in the best logistics techniques. Consequently, they were able to coordinate the delivery of the donated medicine, along with the necessary injection equipment, and the three PWBDs were able to self-infuse.

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The WFH has invested in supporting us with diagnosis, the improvement of care, and the strengthening of the skills of healthcare practitioners. Factor donations—including non-factor replacement therapy—have greatly improved the quality of life of people with hemophilia in our community. Overall, our management of hemophilia is better structured and works around a dedicated, well-trained multidisciplinary team.

—Eleonore Kafando, MD, Department of Hematology, Université Ouagadougou, Burkina Faso

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Your continued support helps us

Increase patients treated

Increase quality of life

Increase quality of care

Improve diagnosis

Advocate for better care

For more information, please contact us at:

WORLD FEDERATION OF HEMOPHILIA

1425, boulevard René-Lévesque Ouest Bureau 1200 Montréal (Québec) H3G 1T7 Canada

T +1 514.875.7944 F +1 514.875.8916 humanitarianaid@wfh.org

wfh.org treatmentforall.org





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