



**WFH**

**HUMANITARIAN  
AID PROGRAM**

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Impact Report 2020



# WFH

## HUMANITARIAN AID PROGRAM

# MAKING ACCESS TO CARE POSSIBLE EVEN DURING THE COVID-19 PANDEMIC

The lack of access to care, clotting factor concentrates and treatment for people affected by a bleeding disorder in developing countries is an urgent and important public health challenge. This daily challenge was magnified in 2020 due to the COVID-19 pandemic.

The WFH Humanitarian Aid Program was developed to address the issue of access to care by working with World Federation of Hemophilia (WFH) national member organizations (NMOs) to provide continued access to treatment for emergency situations, acute bleeds, corrective surgeries, and prophylaxis for young children. In 2020, the Program quickly responded to the COVID-19 pandemic by bringing education online and by collaborating with local organizations facing logistical restrictions in order to ensure that care would not be interrupted. 2020 also saw the WFH deliver the very first shipments of emicizumab to patients—a new prophylactic treatment to reduce the frequency of bleeding episodes in adults and children of all ages, newborn and older, with hemophilia A, with and without factor VIII inhibitors.

The WFH Humanitarian Aid Program makes impact  
in action possible by:

**Facilitating** sustainable care

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**Involving** governments

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**Supporting** outreach and identification

**Ensuring** the viability of corrective surgeries

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**Improving** quality of life

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Because of the work the WFH Humanitarian Aid Program is doing, more people than ever in the bleeding disorders community have hope that they can have a better quality of life. This success is a direct result of a collective effort between the WFH, pharmaceutical partners, governments, and the global bleeding disorders community.





# DELIVERING CARE TO THE COMMUNITY

The WFH Humanitarian Aid Program continues to deliver care to those who need it most. In 2020, over 146 million IUs of factor were provided to patients in developing countries, despite the major logistical challenges created by the COVID-19 pandemic, such as reduced shipment traffic and closed borders. The WFH also delivered the very first shipments of emicizumab in spring 2020, to two patients in Zambia.

Key performance indicators (KPIs) clearly show the impact the Program is having in the lives of patients and their families around the world. 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.

**146M+**  
IUs of factor  
distributed

**20,000+**  
hemophilia A and B  
patients treated

**51,400+**  
bleeding episodes  
managed

**27,000 x 30 mg**  
vials of emicizumab  
distributed \*

Key Performance Indicators (KPIs)	2016	2017	2018	2019	2020
<b>OPERATIONAL METRICS</b>					
Patients treated by donations (cumulative)	13,571	16,189	18,458	19,792	20,048
Total donations in MIUs	144	160	191	241	146
Number of countries receiving donations	58	60	62	73	69
Mean age of PWH receiving treatment	25	20	20	22	22
Total number of infusions related to acute bleed treatment	38,590	61,289	103,458	119,658	68,889
<b>IMPACT METRICS</b>					
Number of countries doing surgeries	23	23	26	25	25
New countries doing surgeries	18	5	3	0	0
Total number of surgeries	795	781	685	789	856
Life and limb-saving surgeries	56	78	62	112	121
Number of acute bleeds treated	36,881	45,161	58,458	64,722	51,401
<b>IMPACT METRICS (CUMULATIVE)</b>					
Number of PWH on prophylaxis (cumulative)	852	1,210	1,546	1,622	1,804
PWH on prophylaxis under 10 years of age (cumulative)	458	834	984	1,053	1,145
<b>ACTIVITY METRICS</b>					
Number of workshop attendees	335	315	240	250	691

\* Note: since emicizumab donations began in spring 2020, the first emicizumab KPI table will be developed for the 2021 WFH Impact Report, and will show the first full year of donation data.

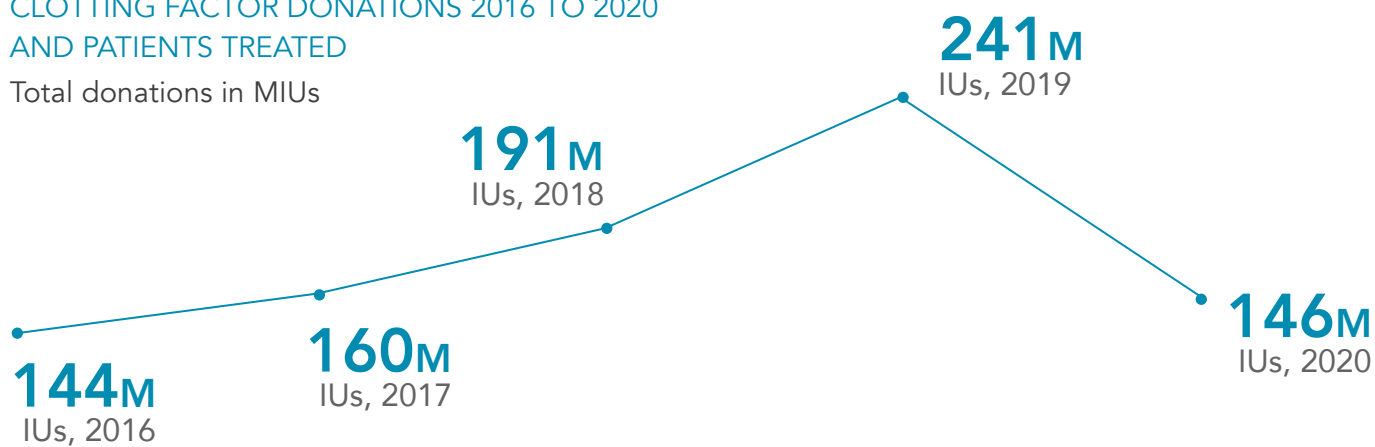




Border closures, lockdowns and reduced shipping capacity due to the COVID-19 pandemic greatly impacted the delivery of donated factor. Although the number of patients treated was relatively stable in 2020 versus 2019, the number of infusions those patients received was less.

#### CLOTTING FACTOR DONATIONS 2016 TO 2020 AND PATIENTS TREATED

Total donations in MIUs



# PROACTIVELY ADAPTING TO THE REALITY OF THE COVID-19 PANDEMIC

The WFH Humanitarian Aid Program adapted quickly to the COVID-19 pandemic in 2020 to limit impacts to education and donated factor delivery.

## WEBINARS AND ONLINE EDUCATION

Because many countries went on partial or total shutdown due to the COVID-19 pandemic, face-to-face educational and training sessions weren't possible for most of 2020. To ensure that education would not be interrupted, the WFH Humanitarian Aid Program team shifted learning delivery from in-person meetings to online webinars.

The following table shows the webinars that the WFH Humanitarian Aid Program delivered in 2020.

Webinar	Regions served	Countries	Attendees
Webinar on logistics, product handling, storage and use	South East Asia, Latin America, East (anglophone) Africa, West (francophone) Africa, Eastern Europe and Central Asia	46	182
Virtual case conference and bedside rounds	South Asia, South East Asia, East (anglophone) Africa, West (francophone) Africa, South America, Central America and the Caribbean	62	329
Workshop for front-line doctors and second-line treaters	East (anglophone) Africa, Afghanistan, Bangladesh, Nepal, Latin America and the Caribbean	31	207
Workshop on novel therapies on inhibitor management, including emicizumab	East (anglophone) Africa, Jamaica, Cambodia, Myanmar, Nepal, West (francophone) Africa, Rwanda, Madagascar, Latin America, Nigeria	23	114
Training the trainers	Global (selected treaters)	6	9
Virtual workshop on extended half-life products	South Asia	5	144
Home treatment and prophylaxis	South Asia	14	48
Webinar on utilization reports and training	India	1	172
<b>TOTAL</b>			<b>1,205</b>

## LOGISTICS SUPPORT

Country-wide partial or total shutdowns, and reduced transportation services meant that delivering factor to where it was needed was extremely challenging in 2020. To overcome these logistical obstacles, the WFH Humanitarian Aid Program team collaborated with organizations all over the world to develop creative solutions to limit the risk of potentially catastrophic stops in factor donations.

One example of WFH Humanitarian Aid Program logistics support took place in Nepal. The country was particularly hard hit by the COVID-19 pandemic when it went on a complete lockdown and lost access to donated factor for months. Fortunately, the WFH Humanitarian Aid department was able to collaborate with two NMOs and a logistics company to provide factor to the country before the situation got truly critical. The WFH mobilized with local resources to consider different options, eventually coordinating with the Hemophilia Federation of India (HFI) and Logenix International, a U.S.A.-based freight forwarder, to ship an emergency supply of factor by land. While this was taking place, the WFH worked with Logenix International to ship a larger donation from the U.S.A directly to Kathmandu via airfreight. In July 2020, the shipment arrived—the first full shipment of factor to make its way to Nepal since January when the COVID-19 pandemic first became serious in the region.

# GOAL OF THE HA PROGRAM

## THE WFH HUMANITARIAN AID PROGRAM: IMPACT IN ACTION

The WFH Humanitarian Aid Program improves diagnosis and treatment so that people with inherited bleeding disorders can enjoy a quality of life that previous generations would not have thought possible.

### FACILITATING SUSTAINABLE CARE

The WFH Humanitarian Aid Program supports the launch of medical facilities so that national member organizations (NMOs) and hemophilia treatment centres (HTCs) can provide patients with lasting care.

### INVOLVING GOVERNMENTS

The WFH Humanitarian Aid Program works with NMOs to support advocacy initiatives and urge governments to get involved and play an active role in the support of sustainable care in their countries.

### SUPPORTING OUTREACH AND IDENTIFICATION

The WFH Humanitarian Aid Program leads outreach and identification initiatives with local organizations to find new patients, and give them a better quality of life and a more productive place in society.

### IMPROVING QUALITY OF LIFE

The WFH Humanitarian Aid Program improves the long-term quality of life of very young patients by collaborating with physicians to give critical factor donations to children as young as five years old.

### ENSURING THE VIABILITY OF CORRECTIVE SURGERIES

The WFH Humanitarian Aid Program provides WFH NMOs with sustainable and predictable treatment donations so that caregivers can provide life-changing surgery.



# CASE STUDIES

The WFH Humanitarian Aid Program transforms lives by making it possible for parents to go back to work and for children to go to school.



## NICARAGUA

Accidents that cause physical trauma are particularly dangerous for people with a bleeding disorder—especially if they live in a country with limited access to factor. In Nicaragua, Isaías—a 27-year-old male patient with severe hemophilia A—suffered trauma to his face and right shoulder when he was injured by a tree branch. He was examined 24 hours after the trauma, and was found to have a large periorbital hematoma in the left eye which caused an inflammation of the underlying tissues and a partial loss of vision. This condition required immediate factor infusion in order to save his eye. Fortunately, the WFH Humanitarian Aid Program provides donated factor to Nicaragua—1.5 million IUs were delivered to the country in 2020 alone. Isaías—who did not have access to another other treatment alternatives—received some of this donated factor along with antibiotics and other treatments, and was able to make a full recovery from his injury.



## EGYPT

Hazem El Tahan is a man with severe hemophilia A in Egypt. He suffered several bleeds over a two-year period in his left knee which led to septic arthritis, permanent damage, and severely limited mobility. Doctors at Shabrawishi Hospital recommended that he undergo knee replacement surgery. Performing this difficult procedure on El Tahan was only possible because of donated factor provided by the WFH Humanitarian Aid Program. He later developed the same issue in his other knee, and the procedure was repeated—again using donated WFH Humanitarian Aid Program factor. El Tahan has since made a full recovery, has full mobility in both legs, and is able to once again work and support his family. Egypt received 13.4 million IUs of factor in 2020.



## NIGERIA

Nigeria is the most populous country in Africa, and yet the country's only source of factor is the WFH Humanitarian Aid Program. Because of this reality, the WFH works closely with the Haemophilia Foundation of Nigeria (HFN)—the country's NMO—in order to facilitate factor donations. Over 22.7 million IUs have been donated to Nigeria through the WFH Humanitarian Aid Program since 2015—with nearly 4.1 million IUs sent to the country in 2020. The Program helped save the life of Akintunde Richard, who was admitted to a hospital, complaining of a headache and neck stiffness. He was slated for brain surgery when one of the physicians discovered that he has hemophilia. They then cancelled the procedure, and Richard's father was put in contact with the HFN, who then worked with physicians to help the boy using factor donated by the WFH Humanitarian Aid Program.





## INDONESIA

Like many countries, Indonesia is still reeling from the effects of the COVID-19 pandemic. But the country has also gone through several other natural disasters at the same time. In one case, destructive landslides in the Majene region damaged property and injured three people with hemophilia (PWH). All three suffered bleeds because of the disaster, and were in 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, after exploring many options, the donated medicine was successfully delivered, along with the necessary injection equipment, so the three PWH would administer the factor themselves. The WFH Humanitarian Aid Program has provided factor to Indonesia for many years, and donated over 2.4 million IUs to the country in 2020.



## AFGHANISTAN

Muhammad Eisa is an 8-year-old boy who lives in the province of Herat, Afghanistan. After suffering a serious bleed, he was referred to the hemophilia treatment centre (HTC) in Kabul, a city over ten hours away from his home. Because Eisa's testing was inconclusive at the Kabul HTC, he was sent to India where he was diagnosed with factor XIII deficiency, and given his first factor treatment. The injected factor stopped his bleeding enough that he was able to return to Kabul. The boy's family then reached out to the WFH for support. The WFH Humanitarian Aid Program sent six vials of factor XIII to Afghanistan to treat Eisa, enough for six months of prophylactic treatment. This factor controlled the boy's bleeds, and allowed him to fully recover. In 2020, the WFH Humanitarian Aid Program provided Afghanistan with over 1.1 million IUs of factor.



## KENYA

In Kenya, circumcision is a deeply ingrained part of the country's cultural fabric. A boy who isn't able to get the procedure can often feel ostracised by his peers—and even by his own family. The WFH Humanitarian Aid Program is literally changing the lives of boys with bleeding disorders in Kenya by providing much needed factor to hospitals so that they can be safely circumcised. In 2020, the Program facilitated the donation of nearly 3.4 million IUs of factor. Since 2015, the WFH Humanitarian Aid Program has provided nearly 17 million IUs of factor to Kenya. This factor has allowed hospitals in the country to treat acute bleeds. Now, the Program is also making safe circumcision possible, including playing a major part in helping the Kenya Hemophilia Association implement a Safe Circumcision Program so that boys can be circumcised in a safe, welcoming environment.

# TESTIMONIALS



*"The WFH Humanitarian Aid Program has revolutionized the way we manage and care for patients with bleeding disorders."*

—Kibet Shikuku, MD, Chairman of the Kenya Hemophilia Association

*"Being part of the WFH Humanitarian Aid Program has been the difference between dying and continuing to live, living without pain or suffering from severe arthropathy for Dominican hemophiliacs."*

—Haydée Benoit, Fundación Apoyo al Hemofilico, Dominican Republic

*"I am very grateful to the WFH, whose valuable donation of clotting factor treated my bleeding, cured my eye and healed my pain... thank you very much."*

—Isaías, patient from Nicaragua



*"I can't imagine the life of a patient without WFH Humanitarian Aid Program support."*

—Bishesh Sharma Poudyal, MD, clinical hematologist and the head of the hemophilia treatment centre (HTC) at the Civil Service Hospital in Kathmandu, Nepal

# FROM OUR SPONSORS

## 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 Sanofi Genzyme and Sobi, our Founding Visionary Contributors; Bayer, our Visionary Contributor; Grifols and Roche, our Leadership Contributors; and our Contributor, CSL Behring.

*"Hemophilia treatment only makes a meaningful life changing difference to liberate the lives of people with hemophilia if access to therapy is predictable and sustained over the long-term. We continue to believe in and support the WFH's vision and our goal, along with Sanofi Genzyme, is to provide predictability and sustainability by contributing to this program at a scale that will make a true difference to lives. The results so far confirm that this is a truly transformational program for the people receiving treatment."*



**Philip Wood, Head of External Affairs & Alliance Management, Sobi**

*"Sanofi Genzyme has a longstanding belief that we have a responsibility to support patients who have limited or no access to treatment and care. Through our donation, we have seen the life-changing impact a sustainable and predictable supply of factor therapy can have for people with hemophilia in the developing world. Our commitment to the hemophilia community goes beyond R&D and together with Sobi, we are proud to have extended our support of the WFH Humanitarian Aid Program for up to another five years. Patients are the centre of all that we do and our mission is to offer hope to those most in need. We share the WFH's vision of 'treatment for all.'"*



**Bill Sibold, EVP & Head of Sanofi Genzyme, Sanofi**

*"Bayer is convinced that an inclusive approach through partnerships is critical in ensuring those in need have access to life-changing treatments and is proud to be one of the main contributors to the WFH Humanitarian Aid Program. The lack of access to care and treatment in developing countries is an urgent and important public health challenge and we are working closely with the WFH to ensure delivery and access to these treatments. This is even more important during these times where many countries are facing other health challenges as a result of COVID-19."*



**Klaus Marten, SVP Global TA Head, Hemophilia at Bayer**

*"We at Roche are humbled to see the continued incredible impact of the Program since joining in 2019. It is a privilege to partner with the WFH to support the critical need for improved access to care for people with hemophilia around the world and we gratefully applaud the WFH's tireless efforts, especially during these challenging times of a global pandemic."*



**Iqbal Mufti, Global Head of Haemophilia, Roche**

*"This year, more than ever, the WFH Humanitarian Aid Program is crucial to delivering resources to the patients who need them the most. As our long-standing partnership with the hemophilia community grows, supporting this initiative will always be central to our commitment because it embodies our core value of focusing on the needs of patients and enabling access globally."*



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

*"During an unprecedented year, Grifols expanded its donation of clotting factor medicines to help treat patients worldwide. These challenging times remind us of our commitment to society and to health equity. It is with these principles in mind that we pledge our continued partnership with the WFH Humanitarian Aid Program and to improving the lives of those with bleeding disorders."*



**Christopher Healey, President, Corporate Affairs, Grifols**