



WFH
HUMANITARIAN
AID PROGRAM

Impact Report 2019

WFH HUMANITARIAN AID PROGRAM

GIVING HOPE TO PATIENTS AROUND THE WORLD

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. The WFH Humanitarian Aid Program was developed to address this issue by working with World Federation of Hemophilia national member organizations (NMOs) to provide continued access to treatment for emergency situations, acute bleeds, corrective surgeries, and prophylaxis for young children.

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

Facilitating sustainable care

Involving governments

Supporting outreach and identification

Ensuring the viability of corrective surgeries

Improving quality of life

The WFH Humanitarian Aid Program has drastically accelerated donations over the last five years. Now, 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 will continue to deliver care to those who need it most. In 2019, a record 241+ million IU^s of factor were provided to patients in developing countries. 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 Program respects all good distribution practices (GDP) requirements.



241M+
IU^s of factor distributed

19,800+
hemophilia A and B
patients treated

65,000+
bleeding episodes
managed

Donated treatments have significantly expanded since 2015 with the visionary contributions from Sobi and Sanofi Genzyme.

The number of people who have directly benefited from the WFH Humanitarian Aid Program has also drastically increased since 2015.

KEY PERFORMANCE INDICATORS (KPIs)	2016	2017	2018	2019
OPERATIONAL METRICS (UTILIZATION AND PROCESS)				
Patients treated by Humanitarian Aid donations (cumulative)	13,571	16,189	18,458	19,792
Total donation in millions of IU ^s	144	160	191	241
Number of countries receiving donations	58	60	62	73
Mean age of people with hemophilia (PWH) receiving treatment	25	20	20	20
Total number of infusions on demand (cumulative)	38,590	61,289	103,458	119,658
IMPACT METRICS (YEARLY)				
Number of countries doing surgeries	22	22	26	25
Total number of surgeries	795	781	685	789
Total number of life saving surgeries	56	78	62	112
Number of acute bleeds treated	36,881	45,161	58,458	64,722
IMPACT METRICS (CUMULATIVE)				
Number of PWH on prophylaxis	852	1,210	1,546	1,622
PWH on prophylaxis under 10 years of age	449	834	984	1053
ACTIVITY METRICS (TRAININGS AND REPORTING)				
Number of attendees of Humanitarian Aid training workshops	335	315	240	250

Overall, the key performance indicators (KPIs) used to measure the success of the WFH Humanitarian Aid Program show remarkable increases since 2016.

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 develops programs and 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.

KENYA

Salomon is a 10-year old Kenyan hemophilia A patient who lives in the second largest slum in the world. He used to walk a kilometre to school with a donated crutch — even when it rained or when he had a bleed. On several occasions his mother even carried him to school. If not for the WFH Humanitarian Aid Program, Salomon would not have the happy life he has — in fact, he might be severely disabled or worse. The donations have allowed him to go to school, where he enjoys science and playing soccer with his friends. His doctor says good-naturedly, “He loves football like you can’t believe. We fight every time he comes to visit me because he plays so much soccer.”



BANGLADESH

For far too long, the bleeding disorders community in Bangladesh struggled to get fair support from their government, with the result that patient care was significantly lower than it could be. The WFH Humanitarian Aid Program worked with the local NMO and government stakeholders over a sustained period to raise the issue of lack of funding with the government. This year, for the very first time, the Directorate of Health Service allocated funds to six medical college hospitals, allowing medical care to be brought to patients who need it around the country.



PHILIPPINES

Marco — a young boy living with severe hemophilia in the Philippines — is lucky. Unlike many other children in the Asian country with a bleeding disorder, he doesn't walk with crutches. To the contrary, he lives an active, normal life and goes to school with other children thanks to the prophylactic treatment he receives from the WFH Humanitarian Aid Program. The Program also provides Marco with donated product for the treatment of bleeds, which has saved his life on at least two occasions. He participates in school activities and has even won his school's oral presentation contest.



YEMEN

The conflict in Yemen is creating a dire situation in the country, making everyday life a challenge for its citizens. Those with a bleeding disorder are in a particularly dire situation. The WFH Humanitarian Aid Program is doing its very best to support the bleeding disorders community in Yemen, despite the fact that there isn't an NMO to coordinate with in the country. In 2019 the WFH was able to work with several specialists in order to establish a liaison with a physician at a hospital in the capital. By using a limited supply of factor strategically, the physician has been able to effectively treat many patients, including providing children with life-saving treatment.



TESTIMONIALS



LIZIA SAFINA ZONE
KAMPALA, UGANDA
13th DEC 2010

Dear WFH
Greetings to you all, I would like to express my heartfelt appreciation toward the life saving work you are doing. We are so grateful for your assistance of factor infusion. The World Hemophilia Federation has saved lives of many people living with hemophilia. Our children's lives have greatly improved. Our worries have reduced we truly are so grateful. Thank you so much for accepting to donate factor to our country Uganda due to your services our children, relatives and friends now have smiles on their faces, no more worries of disabilities due to joint bleeds or risks of excessive bleeding. Thank you indeed WFH.
We shall always pray for you, may the Almighty God bless you.
Yours
AIKO AGNES
(Parent)

"I feel really thankful [for WFH Humanitarian Aid Program] help and support... without it, my son's life would be at risk and he might even have lost his life."

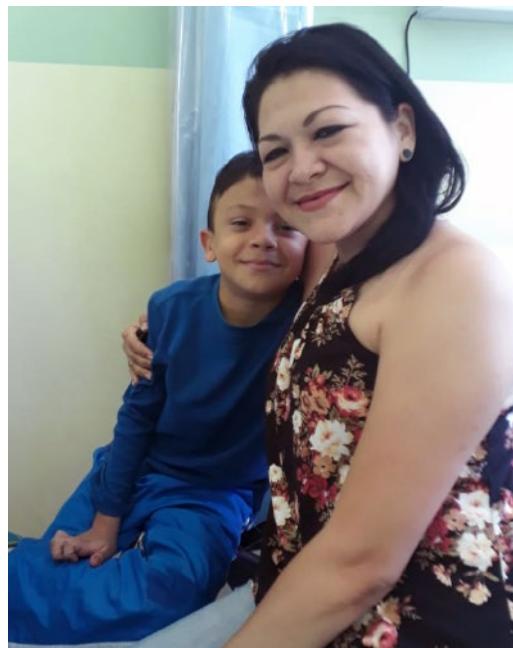
— Mafaal Saidy, father of Mutala Saidy, The Gambia

"Thanks to prophylactic treatment, I can join more activities in the school and I no longer feel excluded."

— Stefano Aldair Cruz Palacios, El Salvador

"I would like to express my heartfelt appreciation towards the life-saving work you are doing."

— Family of Mawejje Joel Rio, Uganda





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.

"At Sanofi Genzyme, patients are at the center of all that we do. We believe it is our responsibility to support patients with rare blood disorders, particularly those in the developing world who have limited or no access to treatment and care. Through our donation to the WFH Humanitarian Aid Program, with Sobi, we can see the life-changing impact a sustainable and predictable supply of factor therapy can have for people in the developing world. We are honored to be part of the solution to address this treatment gap for those most in need."

— Bill Sibold, Global Head of Sanofi Genzyme

"The WFH Humanitarian Aid Program embodies the CSL Behring core value of patient focus. We are proud to support this important pathway to bring essential resources to patients in developing countries where access to care can be challenging."

— Paul Perreault, CEO and Managing Director, CSL Limited

"At Grifols, we consider improving the lives of hemophilia patients around the world a moral obligation. We are committed to helping ensure sustained access to clotting factor treatments in developing countries through the WFH Humanitarian Aid Program."

— Christopher Healey, President, Corporate Affairs, Grifols

"Haemophilia treatment only makes a meaningful life changing difference to liberate the lives of people with haemophilia if access to therapy is predictable and sustained over the long-term. We continue to believe in and support the vision of the WFH, and our goal, along with Sanofi, 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 Haematology at Sobi

"At Bayer, we put patients first. Having partnered with the hemophilia community over a number of decades, we have a deep understanding of the evolving needs of people with hemophilia, and the importance of ensuring that FVIII treatments are available worldwide. The WFH is a leader in addressing the global unmet need of those living with hemophilia and therefore we are proud to be supporting the Humanitarian Aid Program, which we are sure will make a significant difference to those who need help most."

— Michael Devoy, Chief Medical Officer Bayer Pharmaceuticals

YOUR CONTINUED SUPPORT **HELPS US**

Increase product donations

Increase outreach

Increase training

Increase lab diagnosis

INCREASE SUSTAINABLE CARE

For more information please contact us.

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