



WORLD FEDERATION OF HEMOPHILIA  
FÉDÉRATION MONDIALE DE L'HÉMOFILIE  
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## Recipients Double As the WFH Humanitarian Aid Program Expands

MONTREAL, Canada – October 5, 2016 – One year following the expansion of the World Federation of Hemophilia (WFH) Humanitarian Aid Program, the number of recipient countries went from 58 to 63, while delivered donations reached a landmark of 100 million international units (IU), with over 6,000 people receiving much needed treatment to date. As part of their commitment to donate up to 500 million IUs over five years, shipments of clotting factor concentrates (CFC) from Biogen and Sobi have now been delivered to areas most in need in developing countries around the world.

“With the expansion of the WFH Humanitarian Aid Program, Senegal has improved accessibility to treatment by providing surgeries for people with hemophilia, establishing a new prophylaxis program for children, and finally helping improve government involvement to ensure the sustainability of the treatment for patients,” said Saliou Diop, Director of the Senegalese National Center of Blood.

With an increase of CFCs channelled through the WFH Humanitarian Aid Program, there has been a significant increase in the number of patients treated globally, from 1,425 in 2015 to more than 4,000 in 2016 to date. For the first time with the program, there was also remarkable product utilization reported for both prophylaxis treatment - 897 patients (10.2 million IUs utilized and reported to date) and for 559 surgeries (4.4 million IUs utilized and reported to date). Of these surgeries, 18% were lifesaving interventions and the rest were able to improve the physical functioning of the patients, with many finally able to walk after a lifetime confined to a wheelchair.

“The WFH is leading the effort to change this lack of access in developing countries by helping to provide more consistent and predictable access to treatment,” said Alain Weill, WFH President. “It is through collaborations, like with Biogen and Sobi, the WFH Humanitarian Aid Program is able to make this change a reality. Expanding this program has been part of advancing the WFH vision of Treatment for All, through many years of strategic planning and outreach to global partners.”

The lack of access to care and treatment in developing countries is an urgent and important public health challenge, as the cost of treatment is prohibitively expensive for the majority of those affected with a bleeding disorder. Hemophilia is a rare, chronic, and inherited disorder in which the ability of a person’s blood to clot is impaired. Due to the limited access to diagnosis and treatment in many developing countries, people with severe hemophilia in these areas often do not survive to adulthood.

“We are very fortunate to live in a country like ours where we will not routinely experience the pain and suffering that comes from living with a bleeding disorder without access to care and treatment,” said Mark Skinner, WFH USA President. “As a partner with the WFH in helping build the WFH Humanitarian Aid Program, WFH USA continues to raise support within the United States to further strengthen the work that the WFH does within these countries most in need.”

Since the WFH Humanitarian Aid Program was created in 1996 and before the expansion of the program, over 322 million IUs of CFCs have been distributed to over 90 countries, helping over 100,000 people with hemophilia. An increasing number of collaborators within the global bleeding disorders community have accepted the challenge of providing a sustainable and predictable supply of donated products. Through the donation by Biogen and Sobi, along with



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other collaborators, there will now be a more predictable and sustainable flow of humanitarian aid donations to the global community.

“Biogen has long been committed to improving the care of people worldwide, and our donation is intended to be a major step toward improving the quality of care and outcomes for people with hemophilia in developing countries. In just one year, our collective efforts are already making a meaningful impact in the lives of thousands of people,” said John Cox, Chief Executive Officer of Bioverativ, a spin-off of Biogen’s hemophilia business that is expected to launch in early 2017. “Bioverativ and Sobi look forward to continuing to work with the WFH and WFH USA to expand the WFH Humanitarian Aid Program and help close the treatment gap.”

“We are inspired to see the transformational impact that the donation program is having in developing countries,” said Geoffrey McDonough, CEO and President at Sobi. “We hope this will inspire other companies to join in to allow for the further expansion of the WFH Humanitarian Aid Program, to benefit more people who do not currently have access to treatment.”

Through the expansion of the WFH Humanitarian Aid Program there is now an increased possibility for people with bleeding disorders in the developing world to seek continued access to treatment for emergency situations, acute bleeds, corrective surgeries, and also prophylaxis for young children.

### **About the WFH Humanitarian Aid Program**

For many developing countries, product donations are often the only source of treatment product for patients with hemophilia and other bleeding disorders. The WFH receives requests, many urgent in nature, from our national member organizations (NMOs) and from recognized hemophilia treatment centres (HTCs) around the world. An increasing number of collaborators within the global bleeding disorders community have accepted the challenge of providing a sustainable and predictable supply of donated products. Through the donation by Biogen and Sobi to the WFH Humanitarian Aid Program of up to 500 million IUs within five years, the three year commitment from Grifols for 20 million IUs per year, the three year agreement with CSL Behring for a total of 10 million IUs, and the agreement with Green Cross for 6 million IUs, there will now be a more predictable and sustainable flow of humanitarian aid donations to the global community. In addition, the continued efforts of the Canadian Blood Services, Biotest, and Grifols with Project Recovery, and the work by the Italian National Blood Services through Project Wish, allow for the manufacturing of clotting factor concentrates from previously discarded cryopaste which provide treatment products to countries most in need. These commitments will contribute to the further expansion of the WFH Humanitarian Aid Program.

### **About the World Federation of Hemophilia**

For over 50 years, the World Federation of Hemophilia (WFH), an international not-for-profit organization, has worked to improve the lives of people with hemophilia and other inherited bleeding disorders. Established in 1963, it is a global network of patient organizations in 134 countries and has official recognition from the World Health Organization. Visit WFH online at [www.wfh.org](http://www.wfh.org).

WFH USA advances the global mission of the World Federation of Hemophilia in the United States.