



**WFH**

WORLD FEDERATION OF HEMOPHILIA  
FÉDÉRATION MONDIALE DE L'HÉMOPHILIE  
FEDERACIÓN MUNDIAL DE HEMOFILIA



# 2016

**WFH ANNUAL REPORT**

[WWW.WFH.ORG](http://WWW.WFH.ORG)

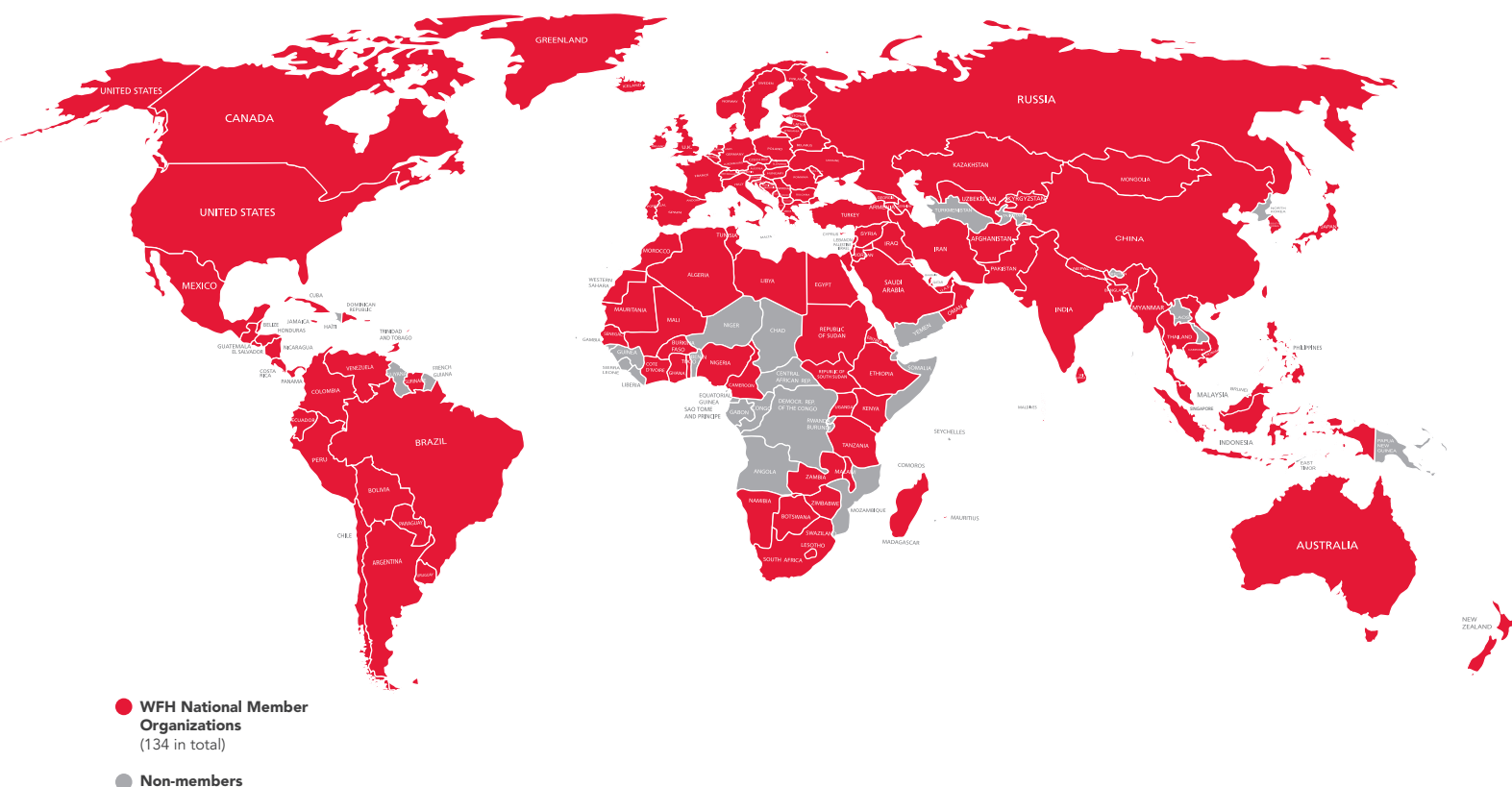
# WORLD FEDERATION OF HEMOPHILIA

We believe that every person with an inherited bleeding disorder deserves access to care and treatment. This includes people with hemophilia and von Willebrand disease (VWD), those with rare factor deficiencies, women with bleeding disorders, and other under-recognized populations. People with bleeding disorders, like hemophilia, can bleed longer than normal, with some experiencing spontaneous bleeding into joints, muscles, or other parts of their body. The reality is that globally, the majority of those affected still receive inadequate treatment, or in many instances no treatment at all.

For over 50 years, the World Federation of Hemophilia (WFH) has provided global leadership to improve and sustain care for all people, both men and women, and children with hemophilia and other inherited bleeding disorders, regardless of where they live.

The WFH has grown into a global network of patient organizations across 134 countries. National member organizations (NMO) represent the interests of people with hemophilia and other inherited bleeding disorders in their country. NMOs are key partners and make the WFH a truly international body.

Since 1969, the World Health Organization (WHO) has officially recognized and collaborated with the WFH on various projects related to the management and treatment of inherited bleeding disorders.







## OUR VISION AND MISSION

Those living without access to care and treatment face a life with severe disability, isolation, and chronic pain. Many young children will die in early childhood. For those who do survive, many are not able to attend school and future life opportunities are limited. Our vision of **Treatment for All** is that one day, all people with a bleeding disorder will have proper care, no matter where they live. The mission of the WFH is to improve and sustain care for people with inherited bleeding disorders around the world.

## OUR FOCUS

The lack of access to care and treatment in developing countries is an urgent and important public health challenge, as the cost of products to treat is prohibitively expensive for the majority of those affected with a bleeding disorder.

The WFH makes a difference by:

- + Supporting the training of healthcare professionals to properly diagnose and manage patients
- + Supporting our community so that it can effectively advocate for an adequate supply of safe treatment products
- + Supporting the education of people with bleeding disorders so that they are empowered by knowledge and tools to live healthier, longer, and more productive lives

# OUR PROGRAMS

There is no single solution for all of the challenges that people with bleeding disorders and their healthcare professionals face every day. In order to maximize our worldwide impact, we manage our resources across six major areas.



[www.wfh.org](http://www.wfh.org)

## **Patient and Healthcare Development Programs**

The WFH development programs, working in partnership with our NMOS, help foster patient and healthcare development.

## **Humanitarian Aid**

The WFH Humanitarian Aid Program leads the effort to improve lack of access in developing countries.

## **Treatment Product Safety and Supply**

The WFH Treatment Product Safety and Supply Program ensures patients are getting the products they need and learning how to use them safely.

## **Educational Resources**

The WFH educational resources empower the global bleeding disorders community with knowledge and advocacy tools to improve diagnosis rates, care delivery, and quality of life.

## **Research and Data Collection**

The WFH Research and Data Collection Programs create better evidence for the management of inherited bleeding disorders.

## **Congress and Meetings**

The WFH World Congress is the largest scientific international meeting dedicated to hemophilia and other inherited bleeding disorders. It plays an important overall support function in the community by bringing over 4,000 medical, government, industry, and patient representatives together every two years to meet and network. The WFH also organizes the WFH Global Forum on Research and Treatment Products for Bleeding Disorders and the WFH International Musculoskeletal Congress, both occurring every two years (in a non-Congress year).

# SUPPORTING OUR COMMUNITY

With help from our corporate partners and community supporters, we will bring certainty to those most in need.

- Donate: your gift will save lives; [www.wfh.org/donate](http://www.wfh.org/donate)
- Become a WFH Caregiver: Your monthly gift can help a child living with a bleeding disorder rise above uncertainty
- Join the WFH Global Community Program: Support our work, receive access to our online portal, and get connected globally; [www.wfh.org/en/globalcommunity](http://www.wfh.org/en/globalcommunity)

Charitable solicitations for the common purposes of WFH and WFH USA within the U.S. are conducted through WFH USA, a 501(c)3 affiliated entity.

# WFH PRESIDENT AND CEO MESSAGE



**Alain Weill**  
PRESIDENT



**Alain Baumann**  
CEO

At the end of 2016, we reflected on what our organization accomplished throughout the year. “Transform 2016” provided us with a blueprint to address the diverse and complex needs of the different regions around the world. It also gave the WFH and our Board direction on what we needed to best serve our vast and global community.

As part of “Transform 2016”, we are strengthening the WFH’s regional presence. Regional managers have been placed within each region, with a majority of the positions filled by the end of 2016. This will allow us to better meet our national member organizations’ (NMO) needs, determine the effectiveness of our programs, and generate revenue beyond our corporate sponsorships.

We experienced the highest participation ever during the WFH 2016 World Congress. This meant that the whole community was able to come together to help improve our knowledge on how to best treat and care for people with bleeding disorders. This was the first time in over 25 years that the WFH World Congress was held in the United States and this was the largest yet, with more than 5,400 attendees from 138 countries. The WFH World Congress provides the WFH and its NMOs with the financial stability to deliver our development programs, produce educational tools and resources, and provide training to our patients and healthcare professionals worldwide. The success of the WFH World Congress is imperative to further improve and sustain care for those most in need.

In addition, our programs delivered significant results in 2016. The pilot study for the World Bleeding Disorders Registry concluded in December 2016. It included 26 hemophilia treatment centres from 25 countries, with 356 people with hemophilia enrolled. The success of this pilot study demonstrated that the WFH could deliver a global database of high quality, real-world data which will be used to generate evidence and improve the quality of hemophilia care worldwide.

The WFH Humanitarian Aid Program completed its first full year post expansion. The number of patients treated rose to over 14,500 reported in 2016. Ensuring the sustainability of this program remains a priority for the WFH in the years to come.

These are only a few examples of how far we have come in 2016. We will continue to build upon our healthcare development program, support building capacity of our NMOs, and improve access for those who need it the most. The WFH will continue to service all our members, so that one day will together realize our vision of ensuring **Treatment for All**.



# WFH BOARD OF DIRECTORS

An extensive network of organizations and individuals share the WFH's vision of ensuring **Treatment for All** people with hemophilia and other inherited bleeding disorders worldwide.

We rely on the WFH Board of Directors, WFH staff, and volunteers to help bring our shared vision to life.



# WFH BOARD OF DIRECTORS, MEMBERS & PATRON 2016-2018

- |   |  |  |
|---|--|--|
| <b>1 Alain Weill</b><br>President<br>France                                 | <b>6 Barry Flynn</b><br>Lay Member<br>United Kingdom     | <b>11 Cesar Garrido</b><br>Lay Member<br>Venezuela   |
| <b>2 Marijke van den Berg, MD</b><br>Vice-President, Medical<br>Netherlands | <b>7 Flora Peyvandi, MD</b><br>Medical Member<br>Italy   | <b>12 Glenn Pierce, MD</b><br>Medical Member<br>U.S.A.   |
| <b>3 Eric Stolte</b><br>Vice-President, Finance<br>Canada                   | <b>8 Carlos Safadi</b><br>Lay Member<br>Argentina        | <b>13 Pamela Wilton</b><br>Lay Member<br>Canada  |
| <b>4 Jan Willem André<br/>de la Porte</b><br>WFH Patron                     | <b>9 Jerzy Windyga, MD</b><br>Medical Member<br>Poland   | <b>14 Deon York</b><br>Lay Member<br>New Zealand   |
| <b>5 Saliou Diop, MD</b><br>Medical Member<br>Senegal                       | <b>10 Magdy El Ekiaby, MD</b><br>Medical Member<br>Egypt | <b>15 Cedric Hermans, MD</b><br>Medical Member*<br>Brussels<br>*as of April 2017<br>(not pictured) |

## WFH STAFF







# WFH STRATEGIC PRIORITIES: 2015-2017

Our Strategic Plan for 2015–2017 takes into account the global opportunities and challenges facing the bleeding disorders community—and our organizational strengths—to continue to support our mission to improve and sustain care for all people with inherited bleeding disorders.

## STRATEGIC PRIORITIES

1

**IMPROVE DIAGNOSIS  
AND ACCESS TO TREATMENT**  
for all people with inherited  
bleeding disorders

2

**BUILD THE CAPACITY**  
of our NMOs to serve the inherited  
bleeding disorders community

3

**SHARE KNOWLEDGE  
AND BUILD AWARENESS**  
globally through information exchange,  
education, and training

4

**DEFINE AND PROMOTE  
PRACTICE STANDARDS,**  
collect data, and support clinical  
research to provide evidence to make  
the case for better care

5

**IMPROVE ACCESS**  
to safe and effective products through  
advocacy and product donations

6

**EXPAND OUR FINANCIAL BASE**  
and enhance operational excellence  
to advance our mission





# 1

## IMPROVING DIAGNOSIS AND ACCESS TO TREATMENT

### WFH PROGRAMS AND INITIATIVES

Global Alliance for Progress  
(GAP) Program

Country Programs

Cornerstone Initiative

Workshops for Healthcare Professionals

Hemophilia Treatment Centre Twinning

International Hemophilia Training Centre  
(IHTC) Fellowship Program

International External Quality  
Assessment Scheme (IEQAS)

## IMPROVING DIAGNOSIS AND ACCESS TO TREATMENT FOR ALL PEOPLE WITH INHERITED BLEEDING DISORDERS

In 2016, the WFH healthcare development programs and activities reached a total of 122 countries worldwide: 77 countries benefitted from global program activities, and 45 countries received support through the Global Alliance for Progress (GAP) Program, WFH Country Programs, and the Cornerstone Initiative.

### GLOBAL ALLIANCE FOR PROGRESS (GAP) PROGRAM

The second decade of the WFH GAP Program began in 2013 with the aim to identify, within 10 years, an additional 50,000 people with inherited bleeding disorders, of whom half live in the world's poorest regions. Our main objective in 2016 was to integrate four new GAP Second Decade countries into the program, as well as to maximize GAP results at a sustainable pace. This was achieved by continuing to target country development of national programs for bleeding disorders care, developing and publishing new educational material and tools, and providing general multidisciplinary training for healthcare professionals and NMO skills trainings to patient organizations.

We are making progress in reaching our Second Decade goals: 30,296 new people with bleeding disorders have been identified globally (60.8% of end target goal of 50,000), including 6,852 from the poorest countries (22.6% of end target goal of 25,000).



### OUTCOMES AND IMPACT

Through the implementation of targeted country programs in 12 GAP countries in 2016, the WFH actively continued to work on closing the gap in care for people with bleeding disorders.

- **Increased** level of diagnosis in GAP countries
- **Increased** number of newly identified people with bleeding disorders
- **Ensured** government commitment and support to national care programs for bleeding disorders
- **Improved** care delivery systems and developed national hemophilia treatment centre (HTC) networks
- **Developed** or expanded national patient registries in some countries
- **Enhanced** medical and paramedical knowledge and expertise of healthcare professionals on bleeding disorders; improving nursing, laboratory diagnosis, and psychosocial knowledge
- **Strengthened** the capacity of patient organizations by helping them improve their internal structures, strategy, and long-term planning, as well as developed skills of NMO leaders
- **Signed** two collaboration agreements with the governments of Jordan and Vietnam

***“Ultimately, the GAP Program...is not just about helping bleeding disorders patients with medical aid—it is also about encouraging and motivating them to take on greater leadership roles and be more active...”***

— Hemophilia World, December 2016

## COUNTRY PROGRAMS

WFH Country Programs are carried out within the framework of the comprehensive WFH Development Model. Country Programs strategically target two to three of the six areas outlined in this model: government support, care delivery, medical expertise and laboratory diagnosis, treatment products, patient organization, and data collection and outcomes research.

In 2016, there were a total of 21 active country programs.



## OUTCOMES AND IMPACT

- **Increased** level of diagnosis in countries within these programs
- **Increased** number of newly identified people with bleeding disorders
- **Improved** care delivery systems and developed national HTC networks
- **Developed** or expanded national patient registries in some countries
- **Enhanced** medical and paramedical knowledge and expertise of healthcare professionals about bleeding disorders
- **Improved** multidisciplinary, nursing, pediatric, physiotherapy, psychological, and dental knowledge
- **Strengthened** the capacity of patient organizations by helping them improve their internal structures, strategic planning, chapter development, outreach, as well as the development of advocacy skills for patients and NMO leaders
- **Increased** knowledge and education of patients about bleeding disorders





## CORNERSTONE INITIATIVE

The Cornerstone Initiative seeks to establish basic care in some of the world's most underserved countries and regions by providing support, expertise, and training to countries with minimal levels of care, which will help them improve and benefit from our full range of programs and activities. Through this initiative, the WFH will lay the foundation of basic care and build partnerships that lead to an integrated and sustainable structure of patient support and care delivery. Cornerstone Initiative activities were implemented in seven countries in 2016.



### OUTCOMES AND IMPACT

- **Increased** level of diagnosis in some countries with minimum care
- **Increased** number of newly identified people with bleeding disorders
- **Enhanced** basic medical and paramedical knowledge and expertise on bleeding disorders care for hematology nurses, physiotherapists, pediatricians, and laboratory specialists
- **Encouraged** some Cornerstone Initiative countries to recognize the role of the nurse as an essential member of the comprehensive care team
- **Strengthened** the capacity of patient organizations by helping them improve their internal structures
- **Raised** public awareness through media campaigns in Zambia and Nigeria
- **Advocated** activities in Zambia with the result that we engaged the government to invest more in hemophilia care, and in turn facilitated outreach efforts to help identify new patients
- **Joint** efforts between the Haemophilia Foundation of Nigeria and the WFH resulted in hemophilia being added to the non-communicable disease list and substantive dialogue was initiated with the Nigerian government to secure governmental support for hemophilia

***“We are confident that after conducting the training, the knowledge gained by lab technicians outside Lusaka will ensure that patients we identify through our outreach work can be verified through accurate diagnosis.”***

*— Charity Pikiti, Chairperson of the Hemophilia Foundation of Zambia*

## WORKSHOPS FOR HEALTHCARE PROFESSIONALS

Each year, the WFH organizes workshops, in individual countries and regions, which bring together various professionals from the multidisciplinary team to exchange ideas on the improvement of treatment and care. These workshops include both presentations and practical applications of new scientific developments.



### OUTCOMES AND IMPACT

In 2016, the WFH organized a total of 43 national and regional conferences and/or multidisciplinary workshops.

- **Enhanced** medical and paramedical knowledge and expertise of healthcare professionals on bleeding disorders; trained 4,109 healthcare professionals
- **Trained** laboratory technicians on techniques for conducting proper laboratory tests for hemophilia and inhibitors
- **Improved** recognition of the role of the nurse as an essential member of the comprehensive care team
- **Increased** knowledge of VWD
- **Increased** knowledge of psychosocial care as part of comprehensive care; psychosocial curriculum piloted at both regional and national workshops

## HEMOPHILIA TREATMENT CENTRE (HTC) TWINNING PROGRAM

The WFH HTC Twinning Program partners emerging and established HTCs to improve the diagnosis and medical care of people with hemophilia.



### OUTCOMES AND IMPACT

In 2016, the WFH implemented nine new HTC twins, including first-time partnerships with Trinidad and Tobago. This brings the total to 23 HTC twinning partnerships.

- **Expanded** the medical and comprehensive care expertise of twin treatment centres, which improved management of bleeding disorders
- **Enriched** the knowledge of healthcare professionals caring for patients with bleeding disorders
- **Improved** diagnosis and treatment by developing diagnostic capacity through various projects
- **Enhanced** care through the provision of medical equipment and supplies
- **Introduced** and reinforced the importance of comprehensive care through national multidisciplinary training

## 2016 HTC TWINS OF THE YEAR:

The partnership of Kampala (Uganda) and London (U.K.) won the 2016 HTC Twins of the Year Award.

# 1

## INTERNATIONAL HEMOPHILIA TRAINING CENTRE (IHTC) FELLOWSHIP PROGRAM

The IHTC Fellowship Program provides healthcare professionals, from developing countries, training in the diagnosis and management of hemophilia and other inherited bleeding disorders. The program is a great tool to improve the knowledge and engagement of healthcare professionals, and in turn, deliver better care, improve diagnosis accuracy, and improve patient outcomes. Since the program was launched in 1972, over 655 healthcare professionals from more than 93 countries have received training.

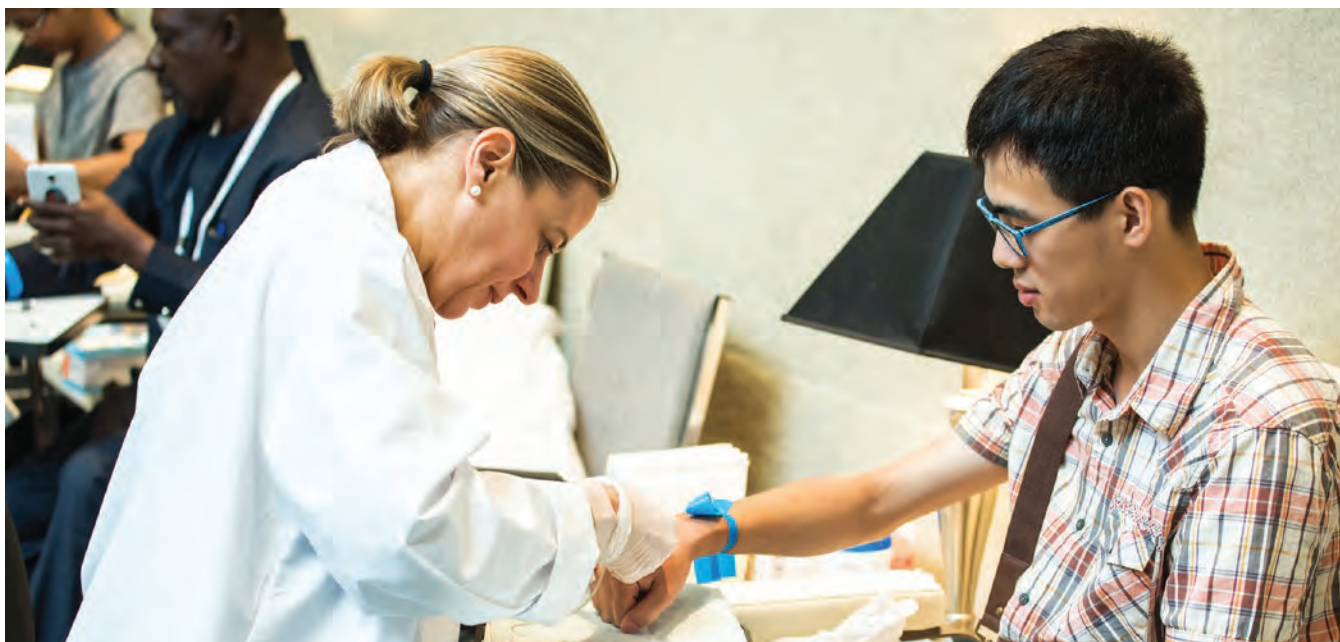


### OUTCOMES AND IMPACT

- **Trained** a global network of over 650 specialized healthcare professionals who improve the care of patients with bleeding disorders
- **Enhanced** and transferred medical and paramedical knowledge and expertise of healthcare professionals on bleeding disorders
- **Improved** diagnosis and management, leading to long-term and sustainable improvements in care for people with bleeding disorders by trained specialists upon returning to their countries
- **Provided** opportunities for IHTC Alumni to remain engaged with the WFH and bleeding disorders community by improving communications and offering more post-fellowship training and networking opportunities
- **Expanded** WFH training offerings in Africa in response to program training needs; recruited two new IHTCs

***“When I returned home, I began putting the skills that I gained into practice by improving the nursing care of patients with hemophilia. This role is no longer limited to administering care, but also promoting the role of education.”***

*– Jeanne Brigitte, Nurse, CHU de Yaoundé, Cameroon*





## INTERNATIONAL EXTERNAL QUALITY ASSESSMENT SCHEME (IEQAS)

IEQAS improves and standardizes laboratory diagnosis by auditing the effectiveness of the internal quality assurance systems in place and establishing a measure of a laboratory's competence. Laboratories can participate in this program to assess their quality assurance systems and the reliability of their test results.



### OUTCOMES AND IMPACT

- **Improved** laboratory performance in HTC's from around the world; 121 laboratories from 77 countries are enrolled in the program
- **Improved** effectiveness and competence of the quality assurance systems in participating laboratories
- **Improved** accurate diagnosis resulting in the identification of new people with bleeding disorders
- **Enhanced** the assistance provided to laboratories experiencing difficulties through on-site visits, assessments, troubleshooting, and training

## EDUCATIONAL RESOURCES FOR IMPROVING DIAGNOSIS AND ACCESS TO TREATMENT

In 2016, the WFH produced resources designed to help improve the rates of diagnosis and the availability of treatment for all people with inherited bleeding disorders.



- **Produced** master class videos of the three most fundamental manual techniques in the diagnosis of bleeding disorders; detailed step-by-step demonstrations and downloadable materials constitute an invaluable resource available to laboratory technicians the world over
- **Launched** a new *Guidelines for the Management of Hemophilia* eLearning Program featuring a Laboratory Diagnosis module available in English, French, and Spanish; enhanced features include detailed illustrations, interactive content, and supplementary resources
- **Developed** a Fact Sheet highlighting the therapeutic opportunities offered by the relatively affordable and available compound, DDAVP (desmopressin), in English, French, Spanish, Arabic, simplified Chinese, and Russian; designed to help NMOs capitalize on the return of DDAVP to the WHO List of Essential Medicines
- **Published** a Factor Replacement Therapy Schematic illustrating how factor replacement therapy improves blood clotting and how various products treat hemophilia A or B; in English, French, Spanish, Arabic, simplified Chinese, and Russian
- **Produced** panel discussions featuring international experts debating the impact of therapeutic developments on access to treatment for all and on the personalization of prophylaxis; hosted on the WFH eLearning Platform
- **Developed** monographs detailing the intricacies of genotypic and phenotypic diagnosis of VWD (to be released in 2017)
- **Developed** and piloted a 14-module Standardized Psychosocial Training Curriculum in two workshops for psychosocial professionals



# 2

## BUILDING CAPACITY

### WFH PROGRAMS AND INITIATIVES

Global NMO Training

National and Regional National Member  
Organization (NMO) Skills Training

Youth Leadership

Data Collection and Use of Data  
in Bleeding Disorders

Hemophilia Organization Twinning

## BUILDING CAPACITY FOR OUR NATIONAL MEMBER ORGANIZATIONS TO SERVE THE INHERITED BLEEDING DISORDERS COMMUNITY

Our role is to provide support, tools, and training to help WFH NMO leaders effectively serve their community. We focus on advocacy, youth leadership, best practices, and integrating digital resources and networking opportunities.

### GLOBAL NMO TRAINING

Every two years before its World Congress, the WFH holds a three-day Global NMO Training that includes a variety of information-sharing sessions and capacity-building workshops, which are simultaneously translated into Spanish, Russian, and French.

In July 2016, the WFH was pleased to welcome 113 participants from 92 countries to the 2016 Global NMO Training. A record number of 19 dynamic youth fellows participated in the event. Plenary sessions showcased a panel of NMO members with diverse experiences, an in-depth background on hemophilia treatment products, and news from the WFH. Interactive workshops walked participants through the development of hemophilia care, strategic planning, and the implementation of projects and outreach initiatives. The WFH collaborated with the National Hemophilia Foundation of the U.S.A. in the Opening Plenary Session, as well as in a joint workshop on volunteer development.



### OUTCOMES AND IMPACT

- **Developed**, enhanced, and provided patients and NMO leaders with new skills through tailored capacity-building training on hemophilia treatment products, development of care for bleeding disorders, strategic planning and implementation of projects, outreach initiatives, and volunteer development
- **Increased** knowledge and education of leading and emerging lay representatives through participation in key biennial WFH training
- **Provided** a space to facilitate in-person interconnection and communication as well as knowledge and experience sharing among lay representatives from around the world
- **Facilitated** the participation of 19 youth fellows and 47 NMO lay representatives through travel grants and an additional 13 key NMO leaders through country program grants





## NATIONAL AND REGIONAL NATIONAL MEMBER ORGANIZATION (NMO) SKILLS TRAINING

The WFH organizes regular training and capacity-building workshops, at national and regional levels, to strengthen the knowledge and skills of NMOs. In 2016, 30 such capacity-building workshops and conferences were organized across all regions. This training helps NMOs improve their internal structures as well as their external activities and relations, and equips them with management skills and thematic knowledge on relevant topics.



### OUTCOMES AND IMPACT

- **Trained** 2,377 patients and family members
- **Assisted** in further developing patient skills and sharing best practices through workshops
- **Developed** and provided NMOs with tailored skills training
- **Educated** and empowered patients and NMO leaders to live a healthier life and advocate for better care
- **Provided** patients, who participated in the trainings, with practical tools to share with their organizations and to apply, if possible, in their own countries

## YOUTH LEADERSHIP

The WFH holds inter-regional workshops to help NMO leaders improve advocacy efforts by sharing tools and techniques, and focusing on specific challenges. Youth from participating countries are included to promote leadership and succession planning.

The WFH organized a two-day Youth Leadership Workshop, which served as a follow-up to the WFH Global NMO Training and the WFH 2016 World Congress both held in Orlando, in July 2016. The workshop took place in Barcelona, Spain, from December 2–3, 2016, attracting 22 participants from 21 countries and linking a hundred more through a virtual Facebook Live event. The workshop was highly interactive, with minimal lectures and maximum time devoted to discussions and small group work.



### OUTCOMES AND IMPACT

- **Helped** youth leaders understand the importance of their contribution and commitment to their community and patient organization
- **Explored** practical tools for developing the innovative spirit of youth and enabling them to build support for their patient organization
- **Empowered** and enhanced the skills of future youth leaders to better advocate for the improvement of bleeding disorders care in their own countries
- **Provided** a space to facilitate (in-person and virtually) interconnection and communication as well as knowledge and experience sharing among future youth leaders from around the world

***“This session was an eye opener for me as I came to the realization that, despite whichever corner of the world we are from, we all shared a common denominator: there is a need for active youth leaders that will take the initiative in advocating for better care on behalf of WFH national member organizations.”***

— Hemophilia World Online: February 1, 2017

## DATA COLLECTION AND USE OF DATA IN BLEEDING DISORDERS

From October 28–29, 2016, the first WFH Data Collection Workshop was held in Johannesburg, South Africa. Entitled “Collection and Use of Data in Bleeding Disorders”, a total of 23 representatives, from 20 patient organizations across sub-Saharan Africa, participated in the two-day workshop.

The workshop program focused on four newly designed modules: Basics of Data Collection, Data Reporting, Using Data, and Economic Assessments. Three group exercises were integrated into the program to provide participants with a chance to interact and openly discuss the issues at hand. An expert facilitator in the field of health economics was invited, along with a representative from the South African national patient organization, provided a case study about establishing a national registry. Practical examples from the WFH World Bleeding Disorders Registry Pilot Project and the WFH Annual Global Survey were also presented.



### OUTCOMES AND IMPACT

- **Designed** the workshop to focus on the value and importance of data collection
- **Enhanced** global data collection, research, and analysis for the purpose of improving treatment and supporting health planning
- **Increased** practical guidance on how to collect and use data for advocacy
- **Empowered** the WFH NMOs to better advocate and support the improvement of care for people with inherited bleeding disorders

## HEMOPHILIA ORGANIZATION TWINNING

The WFH Hemophilia Organization Twinning (HOT) Program partners developing and developed hemophilia patient groups to share knowledge in areas; such as patient education, outreach, fundraising, and all other aspects of operating a successful hemophilia patient society.



### OUTCOMES AND IMPACT

The WFH implemented a total of 11 HOT twinning partnerships, including three new HOT twins.

- **Leveraged** outreach initiatives by patient organizations to increase number and strength of regional chapters; increase membership; develop and increase registries of people with rare bleeding disorders; and organize camps for children, adults, and families
- **Strengthened** patient organizations capacity through strategic planning, advocacy, volunteer development, fundraising, and database management training
- **Increased** knowledge and engagement of patients and family members through educational trainings and dissemination of educational materials
- **Increased** awareness through the organization of activities in support of World Hemophilia Day
- **Advocated** initiatives that led to improved care and increased government support for bleeding disorders

## 2016 HOT TWINS OF THE YEAR:

The partnership of Tanzania and Ontario (Canada) won the 2016 HOT Twins of the Year Award.

## EDUCATIONAL RESOURCES FOR BUILDING CAPACITY

The WFH produces resources designed to build the capacity of our NMOs to effectively serve the bleeding disorders community.



### OUTCOMES AND IMPACT

We developed educational content in several languages and across multiple media platforms.

- **Designed** and capitalized on an eLearning platform that showcases our innovative multimedia resources that meet diverse needs; the new WFH eLearning Platform provides easy access to all WFH resources; nine intuitively themed eLearning Centres connect basic information and related resources in a user-friendly interface; Featured Tools present the resources most relied upon by the WFH community (such as the treatment guidelines, the laboratory manual, and the Registry of Clotting Factor Concentrates)
- **Integrated** the WFH eLearning Platform “Browse by Topic” interactive search tool, which invites users to discover the WFH resources designed to support progress along each of the six pillars of the WFH Comprehensive Development Model
- **Launched** the *Guidelines for the Management of Hemophilia* eLearning Program; 18 modules present the entire guideline text in English, French and Spanish; enhanced features include detailed illustrations, interactive content, and supplementary resources
- **Presented** the state of the art of low-dose prophylaxis in the developing world as the first live interactive WFH webinar to an audience from over 30 countries; the recording is hosted on the WFH eLearning Platform and constitutes an invaluable enduring resource for healthcare professionals and advocates
- **Compiled** the online series of Young Voices articles into a single volume, in English, French, and Spanish; designed with a dynamic layout to engage and empower youth group leaders
- **Distributed** the Young Voices handbook to great acclaim at the WFH Global NMO Training, the National Hemophilia Foundation Annual Meeting, the WFH 2016 World Congress, and the 2016 Youth Workshop
- **Enhanced** the graphic capabilities of print and online educational resources through strategic collaborations







3

## SHARING KNOWLEDGE AND BUILDING AWARENESS

### WFH PROGRAMS AND INITIATIVES

Educational Resources  
World Hemophilia Day 2016  
WFH 2016 World Congress  
WFH Digital Platforms  
Hemophilia World

## SHARING KNOWLEDGE AND BUILDING AWARENESS GLOBALLY THROUGH INFORMATION EXCHANGE, EDUCATION, AND TRAINING

Information is powerful, and one of the important ways we empower our community is through increasing knowledge and awareness. For healthcare professionals we deliver effective training and develop relevant educational resources to improve clinical management and patient outcomes. We also develop and share information to help educate people with bleeding disorders and their families. In 2016 we began implementing our digital learning strategy, launching a custom-designed eLearning platform with innovative new multimedia resources that greatly expands our capacity to deliver to our diverse international community. The WFH 2016 World Congress provided opportunities to engage our community in person, to demonstrate the new WFH eLearning Platform, and to distribute physical resources into the hands of those who need them.

### EDUCATIONAL RESOURCES

In 2016, we custom designed an eLearning platform (eLearning.wfh.org) that provides one-stop easy access to all of our resources. The intuitively designed user-friendly interface showcases our educational content, while its flexibility provides the opportunity to create innovative multimedia resources that meet learning needs as diverse as our global community.



### OUTCOMES AND IMPACT

- **Launched** the new WFH eLearning Platform at the WFH 2016 World Congress, with nine eLearning Centres (Inherited Bleeding Disorders, Introduction to Hemophilia, Carriers and Women with Hemophilia, Inhibitors, Prophylaxis, VWD, Rare Clotting Factor Deficiencies, Inherited Platelet Disorders, and WFH World Congress); from its launch to the end of 2016, the Platform received over 6,000 unique visits to over 22,000 pages, with users spending an average of over five minutes per visit
- **Launched** the *Guidelines for the Management of Hemophilia* eLearning Program; 18 modules present the entire guidelines text in English, French, and Spanish
- **Produced** master class videos of the three manual techniques fundamental to the diagnosis of bleeding disorders (activated partial thromboplastin time, factor VIII assay, and factor VIII inhibitor assay)
- **Delivered** the first interactive WFH webinar, presenting the state of the art of low-dose prophylaxis as practised in the developing world, to a live audience from over 30 countries
- **Collaborated** with the McGill Patient Education Office to produce a Factor Replacement Therapy Schematic (in English, French, Spanish, Arabic, Russian, and simplified Chinese); specifically designed to support the first ever medical plenary at the Global NMO Training at Congress
- **Compiled** the Young Voices online article series into a single volume and distributed it during the WFH Global NMO Training, the National Hemophilia Foundation Annual Meeting, the WFH 2016 World Congress, and the 2016 WFH Youth Workshop
- **Developed** a Fact Sheet highlighting the therapeutic opportunities offered by the relatively affordable and available compound, DDAVP (desmopressin)
- **Developed** and piloted a 14-module Standardized Psychosocial Training Curriculum

- **Delivered** approximately 971,000 educational resources as downloads, online resources, and print distribution to individual users
- **Granted** permission to seven patient organizations to translate and reprint select WFH resources in six languages; WFH resources have been showcased on the Mayo Clinic internal information system and in the newsletter of the Québec Order of Dental Hygienists

## WORLD HEMOPHILIA DAY 2016

For World Hemophilia Day 2016, the global bleeding disorder community joined together to raise awareness about bleeding disorders and to recognize the shared goal of obtaining **Treatment for All**.



### OUTCOMES AND IMPACT

- **Designed** a new online area—the WFH Global Map—for people to share their thoughts and ideas about how we can obtain **Treatment for All**, as well as share photos
- **Produced** information packages for 1,157 HTC, 174 WFH NMOs, corporate partners, and many stakeholder groups (e.g., hospitals and medical professionals)
- **Instigated** the lighting up of more than 40 landmarks around the world to mark World Hemophilia Day (twice the number of landmarks lit up in 2015); there was more of a global effort in 2016, with participation in Europe and Asia
- **Focused** on online initiatives in order to reach the largest possible number of members of the bleeding disorder community and interact with them in the most engaging way possible; more than 80 participants from over 50 countries contributed to the online WFH Global Map; [www.worldhemophiliaday.org](http://www.worldhemophiliaday.org) promotions received 24,500 views and posts received 621 likes on Facebook

# TREATMENT FOR ALL THE VISION OF ALL



WORLD  
HEMOPHILIA DAY  
2016 | APRIL 17

GLOBALLY 1 IN 1,000 PEOPLE  
HAS A BLEEDING DISORDER  
MOST ARE NOT DIAGNOSED AND  
DO NOT RECEIVE TREATMENT



TOGETHER WE CAN CHANGE THAT





## WFH 2016 WORLD CONGRESS

The WFH World Congress provides a unique platform for the global bleeding disorders community to learn, network, and share knowledge. Throughout 2015 and 2016, every effort was made to ensure that the WFH 2016 World Congress in Orlando, Florida, would be a milestone in the history of the WFH. The global bleeding disorders community met for the first time in over 25 years in the United States and the XXXII International Congress of the WFH was the largest yet, with more than 5,400 attendees from 138 countries.

Collaboration between the National Hemophilia Foundation and the WFH, together with consistent and aligned marketing efforts, led to the participation of record numbers of U.S. healthcare professionals and patients (2,286 U.S. attendees).

The WFH 2016 World Congress had a strong multidisciplinary program, as well as professional development workshops. The Medical Program highlights included plenary and free paper sessions on VWD, genetic counselling, cutting-edge medical research, alternative therapies in the management of inhibitors, and clotting factor concentrates. Workshop topics ranged from data and demographics to the evolution of patient-centred care. Other subjects discussed were creative techniques in managing hemophilia, psychosocial issues arising from bleeding disorders, and challenges faced when ageing with hemophilia.

Congress continues to be a financial resource to help secure educational tools, developmental programs, and activities for the world bleeding disorder community, and to progress towards our mission to improve and sustain care for all people with inherited bleeding disorders.

**5,424**

participants

**Highest**

host country participation  
in Congress history



**138**

countries  
represented



**613**

poster abstracts  
displayed



**80**

sessions



**203**

speakers

**>20,000**

WFH educational  
resources distributed  
(75 unique titles)



**251**

visits to the  
treatment rooms



Patients  
from **55**  
different countries  
were treated



International units (IU) of  
**coagulation factor donated**  
by corporate partners to the treatment  
room:

**1,217,503 IUs**  
donated to the treatment room  
& **880,986 IUs**  
prescribed

## EDUCATIONAL RESOURCES AT CONGRESS

We capitalized upon the opportunity offered by the WFH 2016 World Congress to engage with our community in person, delivering record amounts of resources to the people who need them the most, and deriving content for the creation of enduring educational resources.



- **Distributed** more than 20,000 individual educational resources, comprising 75 titles in 6 languages; 6,500 of which were in Spanish alone
- **Created** and hosted the WFH Congress eLearning Centre on the new WFH eLearning Platform; featuring an interactive carousel of more than 500 ePosters, direct links to Congress abstracts and state-of-the-art papers published in *Haemophilia* Journal, and more than 70 webcasts of select talks covering a wide variety of topics from patient testimonials to the latest advances in gene therapy for hemophilia
- **Engaged** delegates at a demonstration computer pod at the WFH Resource Centre at Congress, on which we launched the new eLearning Platform, Treatment Guidelines eLearning modules, Lab Manual Demonstration Videos, and the Online Clotting Factor Concentrates Registry
- **Recorded** the first sponsored Congress symposium; which was accessible through the Congress eLearning Centre
- **Capitalized** on every opportunity at Congress to raise awareness of the WFH educational resources and the WFH eLearning Platform
- **Ensured** that six ePoster stations were accessible in the exhibit hall, allowing for 36 moderated poster sessions, in addition to 478 paper posters; 503 posters continue to be available online following Congress
- **Acquired** 70 webcasts (a record number, and nearly twice that from 2014); webcasts included workshops, plenary sessions, scientific presentations, and patient testimonials, all are easily accessible through the Congress eLearning Centre

## WFH DIGITAL PLATFORMS

Our community is small in numbers, but it is vast in terms of geography; therefore, some community members can find themselves isolated. To help address this, the WFH capitalizes on digital strategies to increase awareness and to provide networking and other learning opportunities.



### OUTCOMES AND IMPACT

- **Provided** online content on the English, French, Spanish, Arabic, simplified Chinese, Japanese, and Russian WFH websites
- **Published** news regularly on *Hemophilia World Online*
- **Provided** access to all WFH web platforms from one main website
- **Enhanced** website functionality so that educational resources can be accessed online by community members directly in their own language—resulting in a greater than four-fold increase in downloads

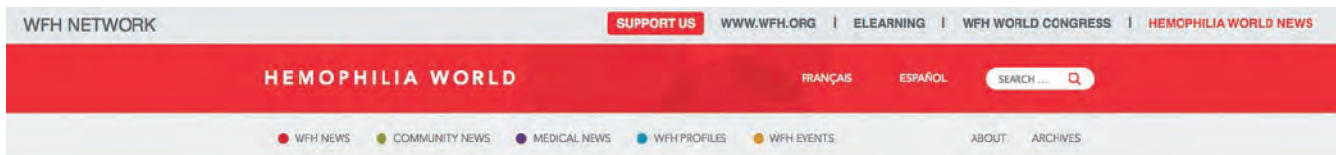
## HEMOPHILIA WORLD



The WFH announced in 2016 that beginning in January 2017 more *Hemophilia World* content would be available online. Prior to the end of 2016, *Hemophilia World* was published three times a year in print and online at [www.hemophiliaworld.org](http://www.hemophiliaworld.org). *Hemophilia World Online* will now be the primary news outlet for the WFH, featuring articles and information released weekly and monthly—as news happens. Then every September, we will publish a comprehensive print collection of the year's most important content in a magazine called *Hemophilia World Review*. This will replace the three print issues currently published.

**Visit [www.hemophiliaworld.org](http://www.hemophiliaworld.org)**

to read all news aimed at the global bleeding disorders community.







# 4

## DEFINING AND PROMOTING PRACTICE STANDARDS

### WFH PROGRAMS AND INITIATIVES

- World Bleeding Disorders Registry
- WFH Clinical Research Grant Program
- WFH Annual Global Survey



## DEFINING AND PROMOTING PRACTICE STANDARDS, COLLECTING DATA, AND SUPPORTING CLINICAL RESEARCH TO PROVIDE EVIDENCE TO MAKE THE CASE FOR BETTER CARE

Our aim is to continue to define and develop standards of care—such as the *WFH Guidelines for the Management of Hemophilia*—to document where the best evidence exists to support clinical practice. Similarly, through the WFH Research Program, we will help fund research to improve clinical management and standards of care. We will also continue to enhance and expand our data collection to support advocacy efforts and build evidence to make the case for better care.

## WORLD BLEEDING DISORDERS REGISTRY

The aim of the WFH World Bleeding Disorders Registry (WBDR) is to develop a database of high quality, real-world data on a large population of patients with hemophilia, which will be used to generate evidence and improve the quality of hemophilia care worldwide.



### OUTCOMES AND IMPACT

- **Conducted** a pilot study in 2016 to assess the feasibility of conducting a large-scale, patient registry in countries around the world. The full scale World Bleeding Disorders Registry is being implemented in 2017.



***“There is a human element to the WBDR that can’t be overstated. The patient registry is about bringing patients together from around the world in a cooperative fashion. It’s about all of us working as a team to further knowledge in the bleeding disorders community.”***

— Hemophilia World, December 2016

## WFH CLINICAL RESEARCH GRANT PROGRAM

The WFH Clinical Research Grant Program provides support for international clinical investigation relating to inherited bleeding disorders. The aim is to help create better evidence for the clinical management of hemophilia A and B, VWD, rare factor deficiencies, and inherited platelet disorders. The program is peer reviewed and open to researchers globally.



### OUTCOMES AND IMPACT

- **Distributed** US\$142,000 in clinical research grant funding
- **Awarded** grants to two researchers in 2016
- **Peer-reviewed** 13 manuscripts/oral presentations on funded projects since 2014

## EDUCATIONAL RESOURCES SUPPORTING THE WFH RESEARCH PROGRAM

In 2016, the WFH produced a number of resources designed to help define and promote practice standards.



- **Drafted** and peer-reviewed monographs on the genotypic and phenotypic diagnosis of VWD, and initiated the update of an inhibitor primer
- **Established** the *WFH Guidelines for the Management of Hemophilia* Update Working Group, including recruitment of a methodology co-chair, a systematic review consultant, working group members, and subject matter experts; detailed the procedure by which the Guidelines will be updated while upholding the highest standards of evidence-based medicine
- **Launched** the *Guidelines for the Management of Hemophilia* eLearning Program; 18 modules present the entire content in English, French, and Spanish
- **Realized** significant progress towards defining a measure of adequate care with the expectation of implementing a formula in 2016



## ANNUAL GLOBAL SURVEY

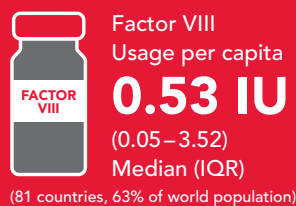
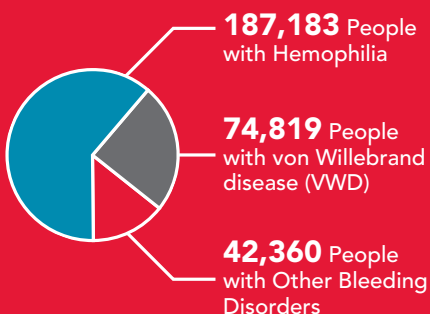
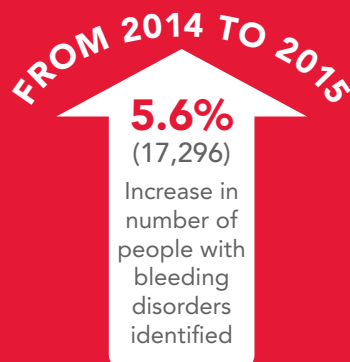
The Report on the Annual Global Survey (AGS) provides a cross-sectional view of selected demographic and treatment data on people with bleeding disorders around the world. The 2015 Report, published in 2016, includes data on more than 304,000 people with bleeding disorders in 111 countries. Ninety countries submitted data for 2015, which is a 10% increase over the previous year.



### OUTCOMES AND IMPACT

- **Increased** the total number of people identified with bleeding disorders and the number of countries submitting data; the AGS data are available to the bleeding disorder community for research and advocacy purposes
- **Redesigned** the report in 2016, making it easier to read, absorb, and understand
- **Developed** a four-module data collection curriculum, which was piloted by representatives from 23 African countries who met in South Africa in October 2016 for the two-day workshop entitled “Collection and Use of Data in Bleeding Disorders”

### KEY NUMBERS FROM THE 2015 REPORT ON THE ANNUAL GLOBAL SURVEY



WORLD FEDERATION OF HEMOPHILIA  
FÉDÉRATION MONDIALE DE L'HÉMOPHILIE  
FEDERACION MUNDIAL DE HEMOFILIA





# 5

## IMPROVING ACCESS

WFH PROGRAMS AND INITIATIVES

WFH Humanitarian Aid Program

Treatment Safety

## IMPROVING ACCESS TO SAFE AND EFFECTIVE PRODUCTS THROUGH ADVOCACY AND PRODUCT DONATIONS

Through the WFH Humanitarian Aid Program and the monitoring of safety and supply issues, we have been involved in product supply and safety for many years. The WFH will continue to explore new models of collaboration to increase the supply of predictable and sustainable product donations. With new treatments poised to enter the market, we also have an important global role in monitoring developments within our community and sharing pertinent information.

### WFH HUMANITARIAN AID PROGRAM

The expansion of the WFH Humanitarian Aid Program began in 2015. In 2016, a total of 58 countries received a landmark figure of over 140 million IUs of donations. The increase in clotting factor concentrates channelled through the WFH Humanitarian Aid Program meant there was a significant increase in the number of patients treated globally, from more than 3,500 in 2015 to more than 14,500 in 2016.

Donations were used for prophylaxis treatment for the first time in the program, with reports of 852 patients by the end of 2016. In addition, donations were used during surgery, with 795 surgical interventions. Of these surgical procedures, 7% were life-saving and the remainder were performed to improve quality of life.

An increasing number of contributors within the global bleeding disorders community have accepted the challenge of providing a sustainable and predictable supply of donated products. The visionary contribution from Bioverativ and Sobi to the WFH Humanitarian Aid Program translates into 500 million IUs over five years (2015-2020). In addition, the eight-year commitment (2014-2021) from Grifols totaling 200 million IUs, along with a ten-year commitment (2009-2018) from CSL Behring for a total of 22 million IUs, and the three-year agreement (2017-2019) 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 initiatives of Project WISH and Project Recovery allow for the manufacturing of clotting factor concentrates from previously discarded cryopaste which provide treatment products to countries most in need.

The WFH Humanitarian Aid Program also provides a range of integrated care development training programs to ensure the local infrastructure and medical expertise are available to optimize and appropriately use donated products.



### OUTCOMES AND IMPACT FROM ALL CONTRIBUTORS

**14,579**  
people treated  
**58**  
in countries

**42,195**  
treating acute  
**bleeds**

**1,112**  
of which  
were life **saving**

**458**  
Children under **10**  
receiving **treatment**

**795**  
surgeries

of which

**55** were limb-  
and life-saving **surgeries**





## TREATMENT SAFETY

The safety and supply of treatment products is a key concern for the bleeding disorders community. The WFH closely monitors product safety, efficacy, availability, and supply. We work in close cooperation with government agencies, industry, clinicians, and patient groups to achieve both the quality and desired quantity of treatment products. These critical issues remain a central theme of our work, and we continue to foster debate and dialogue on them. We also closely monitor and promote scientific and technological developments that can lead to safer, more efficacious treatment, or a cure.



## OUTCOMES AND IMPACT

- **Updated** and published the WFH Online Registry of Clotting Factor Concentrates
- **Issued** communiqués on plasma-derived clotting factor concentrates, Zika virus, the SIPPET study results, a case of variant Creutzfeldt-Jakob disease reported in a patient with a different genotype, and the European Medicines Agency investigation into rare adverse events associated with hepatitis C treatment
- **Updated** the WFH Product Selection statement
- **Produced** a Fact Sheet on DDAVP (desmopressin)
- **Initiated** the revision of the WFH Guide to the Assessment of Clotting Factor Concentrates; scheduled for release in 2017

## EDUCATIONAL RESOURCES FOR IMPROVING ACCESS



- **Produced** a number of resources specifically designed to support the success of the WFH Humanitarian Aid Program; seven Fact Sheets providing essential details of the transportation, storage, usage, and reporting of donated factor products; one Fact Sheet highlighting the therapeutic opportunities offered by the relatively affordable and available compound, DDAVP (desmopressin)
- **Produced** panel discussions on expanding access to hemophilia treatment products, current issues in inhibitor surveillance, and new developments in treatments for bleeding disorders
- **Updated** online information about inhibitors in English, French, and Spanish







6

**EXPANDING OUR  
FINANCIAL BASE**

# 2016 FINANCIAL REPORT

The resources to support our staff and thousands of volunteers around the globe as they strive to bring treatment for all are paramount. We are excited to announce that 2016 has been an exceptional year for the WFH, with a net surplus of \$5,077,195; compared to a budgeted surplus of \$2,115,628, this represents an improvement of \$2,961,567. These funds are reinforcing and energizing our mission.

The successful WFH 2016 World Congress in Orlando was the key contributor to this impressive result. The extremely strong U.S. currency (which ranged from \$1.25 to \$1.46 throughout the year) once again contributed to this robust result as the majority of revenues from both Congress and WFH corporate sponsors were received in US dollars against a budget that was set at US\$1 = CAN\$1.15.

The Congress contributed a net surplus of \$5,266,741 for the whole event (\$1.9 million of which is due to the US foreign exchange factor), and allows the WFH to support and fund programs and initiatives towards the achievement of its mission.

## CONTINUED DIVERSIFICATION OF REVENUE

Corporate sponsors of the WFH programs and initiatives continued their solid support with 2016 contributions of \$5,050,153, an increase of \$51,684 over 2015.

In 2016, the scope of the WFH Humanitarian Aid Program continued to expand, with 140.9 million IUs distributed. As per Canadian accounting rules, revenues received for restricted purposes can only be recognized in the year in which related expenses are incurred. In 2016, \$1,205,022 was used against the revenues we have received for the WFH Humanitarian Aid Program. Thus, only this amount is recognized in WFH revenues.

The WFH Research Program, which is also a restricted program, received \$420,798. With these funds, the WFH continued to award research grants in 2016.

The total WFH revenue, before Congress and Product donations, reached \$7,507,777, \$103,795 (1.4%) above 2015.

Generating income through the internal management of the biennial WFH World Congress and other WFH meetings, including the WFH International Musculoskeletal Congress and the WFH Global Forum, diversifies our income stream. As shown in Figure 1, excluding product donations, 34 per cent of revenues over the two-year cycle represent support from WFH corporate partners; 9 per cent are for restricted programs (Humanitarian Aid and Research Program); and the remaining 57 per cent are generated through the WFH 2016 World Congress, financial donations, and self-generating income activities.

## EXPENSES ALIGNING WITH STRATEGIC OBJECTIVES

The WFH World Congress not only represents the most important part of revenues, it also represents one of the largest investments with 40 per cent of the expenses incurred over the past two years, as seen in Figure 2. Health care development programs, education and public policy programs, and the WFH Humanitarian Aid Program together represent a total of 42 per cent of WFH spending, while communications expenses represent 4 per cent of this total. Additional expenses for the WFH include administration at 7 per cent, fundraising and corporate relations at 5 per cent, and governance at 2 per cent.

## HUMANITARIAN AID

The WFH distributes life-sustaining and life-saving humanitarian aid product donations from many of our corporate sponsors to WFH national member organizations (NMOs) and hemophilia treatment centres (HTCs) around the world. In 2016, 140.9 million IUs of clotting factor concentrates were strategically donated to 58 countries, improving and sustaining care for people in the developing world. This represents a 167% growth in volume (88 million more) of IUs distributed. The majority of these donations, worth US\$324,814,434, are reported in the audited financial statements of the WFH USA. The amount reported in the financial statements of WFH is CAN\$11,304,390.

## YEAR-OVER-YEAR COMPARISON

The 2016 and 2015 statement of revenues and expenses, illustrated in Figure 3, reflects the fluctuations within a typical two-year cycle where the WFH World Congress is held in even years, as well as the varying amounts of product donations received yearly. On the revenue side, there was excellent growth in contributions for humanitarian aid with \$1,205,022 recognized from revenues received compared with \$753,345 in 2015. Self-generated income includes publications and memberships that grew by \$42,223 and \$32,691 respectively. This was offset by WFH event registration and housing revenues of \$416,562 derived from the 14th International Musculoskeletal Conference and the WFH Global Forum events held in 2015.

The overall rise in expenses before Congress and Product donations reflects the continued efforts of the WFH to support the global bleeding disorders community. In 2016, WFH healthcare development program expenses grew primarily due to \$441,770 spent on the WFH Global NMO training held before the WFH World Congress. There were also increases in the GAP Program (\$218,049) and the Cornerstone Initiative (\$114,616), as we added three and four new countries respectively to these areas. In addition, \$206,309 was invested in a pilot study for the WFH World Bleeding Disorders Registry under the Education and Public Policy caption. There was a further upsurge in activities for the continued expansion of the WFH Humanitarian Aid Program. Expenses in this area rose to \$1,306,120 in 2016, compared with \$796,506 in 2015.

## LOOKING AHEAD

As we embark on a new two-year financial cycle, our financial base is solid and resources have been strategically placed both externally (local regional managers) and internally (towards fundraising efforts). This enables us to expand programs and activities, which will help us accomplish our mission together.

However, there will be challenges ahead that will not allow future congresses to be as profitable as they have been in the past. In addition, the U.S. dollar can experience a downturn as easily as it has achieved its current strength. Nevertheless, with so many people with inherited bleeding disorders suffering, we must continue to put our dollars to work for the benefit of our community; improving and sustaining care for people with inherited bleeding disorders around the world so that we are ever closer to our vision of **Treatment for All!**

FIGURE 1  
**REVENUES 2015 AND 2016**  
(EXCLUDING PRODUCT DONATIONS)

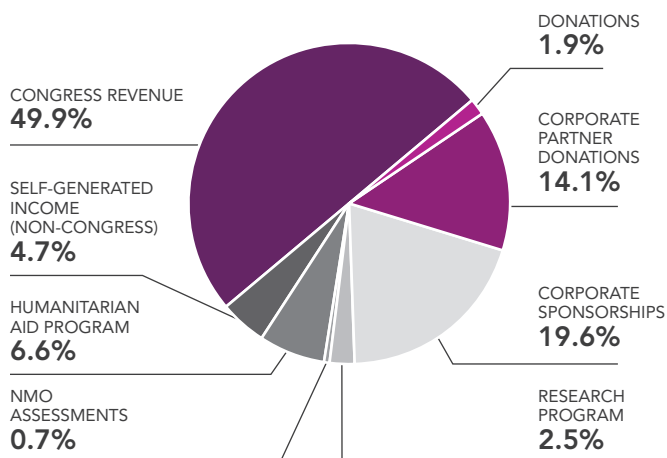


FIGURE 2  
**EXPENSES 2015 AND 2016**  
(EXCLUDING PRODUCT DONATIONS)

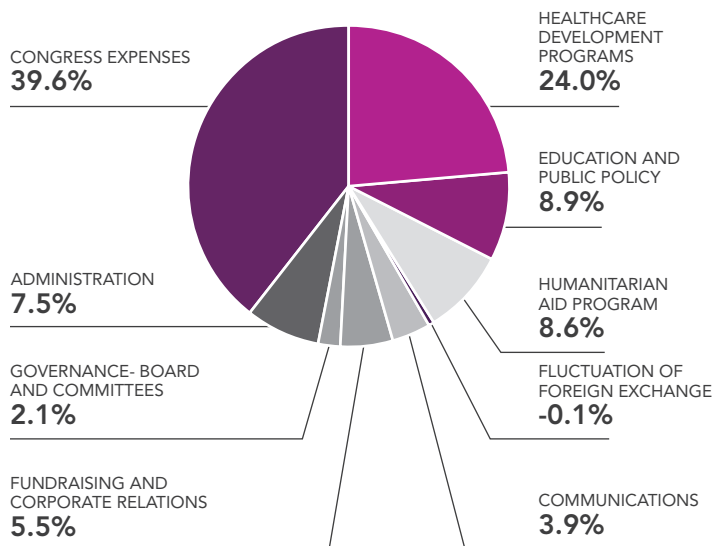


FIGURE 3  
**REVENUES AND EXPENSES**  
(EXPRESSED IN CANADIAN DOLLARS)

REVENUES	2016	2015
Donations	195,800	363,922
Corporate Partner Donations	2,272,701	1,933,393
Corporate Sponsorships	2,777,452	3,065,076
Research Program	420,798	335,696
NMO Assessments	105,276	98,878
Humanitarian Aid Program	1,205,022	753,345
Self-Generated Income (Non-Congress)	530,728	853,671

Total Revenues before Congress and Product Donations	7,507,777	7,403,981
Congress Revenue	14,847,683	0
Product Donations	11,304,390	9,258,352
<b>TOTAL REVENUES</b>	<b>33,659,850</b>	<b>16,662,333</b>

EXPENSES	2016	2015
Healthcare Development Programs	3,200,109	2,663,188
Education and Public Policy	1,159,392	1,002,745
Humanitarian Aid Program	1,306,120	796,506
Communications and Marketing	497,510	461,784
Fundraising & Corporate Relations	765,197	566,344
Governance- Board and Committees	263,360	241,841
Administration	956,665	867,485
Fluctuation of Foreign Exchange	140,081	-155,439

Total Expenses before Congress and Product Donations	8,288,434	6,444,454
Congress Expenses	8,989,831	674,404
Product Donations	11,304,390	9,258,352
<b>TOTAL EXPENSES</b>	<b>28,582,655</b>	<b>16,377,210</b>

<b>EXCESS (DEFICIENCY)</b>	<b>5,077,195</b>	<b>285,123</b>
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## EXPANDING OUR FINANCIAL BASE AND ENHANCING OPERATIONAL EXCELLENCE TO ADVANCE OUR MISSION

We continue to ensure that our financial and organizational foundation is sufficient to support the programs and activities we provide. The priority in 2016 was to maintain the financial health of the WFH and to develop sustainable and increasing sources of funding.

The newly renamed Philanthropy Department received WFH Board approval for a three-year philanthropy plan. This allowed the organization to properly resource the department and begin shifting organizational focus towards expanding our support base to provide a sustainable funding that will meet the needs of the growing global bleeding disorder community.

The plan's success rests on the three pillars of connection, community stewardship, and culture.

Over the past year, we connected through developing and renewing relationships with individuals, organizations, and foundations who can support our work. We acted as community stewards through engaging our donor and volunteer community by keeping them informed, consistently thanking them, and demonstrating the impact of their generosity. Through collaborations with stakeholders, we created an inclusive culture to develop strategic relationships that embrace the local, national, and international diversity of our community.



### OUTCOMES AND IMPACT

In 2016 the Philanthropy Department:

- **Laid** the groundwork, through extensive community consultations, for our new Global Community Program that is based on accessibility and inclusivity—the hallmarks of our community
- **Executed** a highly successful funding initiative supporting the WFH Humanitarian Aid Program
- **Recognized** the valuable contributions of our global community through the WFH Volunteer Awards Ceremony held at the WFH 2016 World Congress
- **Collaborated** with volunteers and senior leadership to identify priorities and philanthropic supporters to financially support our work





# THANK YOU TO OUR DONORS

The WFH gratefully acknowledges the many organizations and individuals whose generous financial contributions have helped bring certainty in care around the world.

In 2016, the following individuals, corporations, and organizations made financial contributions of CAN\$150 or more to the WFH or WFH USA.

## PATRON

Jan Willem André de la Porte

## CORPORATE PARTNER PROGRAM

Alnylam Pharmaceuticals  
Bayer  
BioMarin Pharmaceutical Inc.  
Biotest  
Bioverativ  
CSL Behring  
F. Hoffmann-La Roche Ltd.  
Gilead Science  
Green Cross  
Grifols  
Kedrion  
LFB  
Novo Nordisk  
Octapharma  
Pfizer  
Precision BioLogic  
Shire  
Sobi  
uniQure

## GLOBAL ALLIANCE FOR PROGRESS (GAP) SECOND DECADE

**Visionary Partner**  
Shire

**Leadership Partner**  
CSL Behring

## Collaborating Partner

Bayer  
Bioverativ  
Biotest  
Grifols  
Kedrion  
Novo Nordisk  
Pfizer  
Sobi

## SPONSORED PROGRAMS

**Twinning Program**  
Pfizer

**International External Quality Assessment Scheme Program**  
Novo Nordisk Haemophilia Foundation

**International Hemophilia Training Centre Fellowship Program**  
Bayer

**WFH Research Program**  
Bayer  
Grifols  
Haemophilia Center of Western Pennsylvania 340B Program  
Shire

**Website**  
WFH eLearning Centres:  
**Visionary Sponsor**  
Shire  
**Supporting Sponsor**  
Inhibitor: F. Hoffmann-La Roche Ltd., Shire

**Website localization projects**  
**Arabic:** Pfizer  
**Japanese:** Bioverativ  
**Russian:** Sobi  
**Simplified Chinese:** Bayer

## WFH HUMANITARIAN AID PROGRAM

**Visionary Contributor**  
Bioverativ/Sobi

**Contributors**  
CSL Behring  
Green Cross  
Grifols

## Project Recovery

Canadian Blood Services (CBS)  
Canadian Hemophilia Society  
Biotest  
Grifols

## Project WISH

Italian Blood Transfusion Services  
Kedrion

## Other sponsored programs

**Data Collection and Use of Data in Bleeding Disorders Training Workshop:** Shire  
**Inga Marie Nilsson Award:** Octapharma  
**Susan Skinner Memorial Fund:** Hemophilia Alliance Foundation  
**Von Willebrand Disease Workshop:** LFB  
**Youth Leadership Development Workshop:** F. Hoffmann-La Roche Ltd.  
**World Hemophilia Day:** Bayer, CSL Behring, F. Hoffmann-La Roche Ltd., Novo Nordisk, Precision BioLogic, Sobi

## SOLIDARITY FUND CONTRIBUTORS

The Solidarity Fund contributes towards the payment of assessment fees for national member organizations from developing countries.

Haemophilia Foundation Australia  
Österreichischen Hämophilie Gesellschaft (Austria)  
Hemophilia Society of Bangladesh  
Hemofilievereniging/ Association de l'Hémophilie (Belgium)

Belize Bleeding Disorders Foundation  
Haemophilia Society of Bosnia and Herzegovina  
Bulgarian Haemophilia Association  
Canadian Hemophilia Society  
Liga Colombiana de Hemofílicos  
Egyptian Society of Hemophilia  
Estonian Haemophilia Society  
Finnish Hemophilia Society  
Ghana Haemophilia Society  
Magyar Hemofilia Egyesület (Hungary)  
Indonesian Hemophilia Society  
Irish Haemophilia Society Ltd.  
Federazione delle Associazioni Emofiliaci – Onlus (Italy)  
Latvia Hemophilia Society  
Association Luxembourgeoise des Hémophiles  
Hemophilia Society of Maldives  
Haemophilia Association of Mauritius  
Montenegrin Society for Hemophilia  
National Center for Blood Diseases "Hippocrates" (Palestine)  
Fundación Panameña de Hemofilia  
Polish Hemophilia Society  
Associação Portuguesa de Hemofilia e de outras Coagulopatias  
Russian Hemophilia Society  
National Hemophilia Foundation of Saudi Arabia  
Serbian Hemophilia Society  
South African Haemophilia Foundation  
Korea Hemophilia Foundation  
Schweizerische Hämophilie-Gesellschaft (Switzerland)

Hemophilia Society of Turkey  
Haemophilia Foundation  
of Uganda  
Asociación de Hemofílicos  
del Uruguay

#### MEMORIAL FUNDS

Susan Skinner Memorial Fund

#### TRIBUTES

In Honor of Jan Willem André  
de la Porte  
In Honor of Susanne Gillespie  
In Honor of Frank L.  
Schnabel IV  
In Honor of Hemophilia  
of Georgia staff  
In Memory of Farid and Ange  
R. Cassis  
In Memory of Robert Mayer  
Goldman  
In Memory of Jeanne H.  
Lusher  
In Memory of G. Arlie Luxon  
In Memory of Kathleen  
McHugh  
In Memory of Frank Schnabel  
In Memory of Matt Stinger  
In Memory of Diane Varela

#### DONORS

##### \$100,000 and up

André de la Porte Family  
Foundation  
Hemophilia of Georgia, Inc.

##### \$50,000 – \$99,999

National Hemophilia  
Foundation

##### \$20,000 – \$49,999

Glenn and Beatrice Pierce

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340B Factor Program at Akron  
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Hemophilia Foundation  
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Hemophilia Foundation  
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Hemophilia Foundation  
of Oregon  
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Northern Ohio Hemophilia  
Foundation, Inc.  
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Association  
Tennessee Hemophilia  
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##### \$500 – \$999

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Hemophilia Foundation  
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Bruce A. Luxon  
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# WFH 2016 HIGHLIGHTS



GLOBAL REACH OF WFH  
HEALTHCARE PROGRAMS  
IN **122** COUNTRIES



DELIVERED OVER  
**970,000**  
EDUCATIONAL RESOURCES



OVER **4,109**  
**HEALTHCARE PROFESSIONALS**  
TRAINED WITH ENHANCED MEDICAL  
AND PARAMEDICAL KNOWLEDGE



HUMANITARIAN AID DONATED  
OVER **140** MILLION IUs  
TO **58** COUNTRIES,  
**14,579** PEOPLE TREATED



TRAINED OVER **2,377**  
**PATIENTS AND FAMILY MEMBERS**  
ON BLEEDING DISORDERS

## WORLD FEDERATION OF HEMOPHILIA

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