



WFH

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

WFH ANNUAL REPORT **2017**

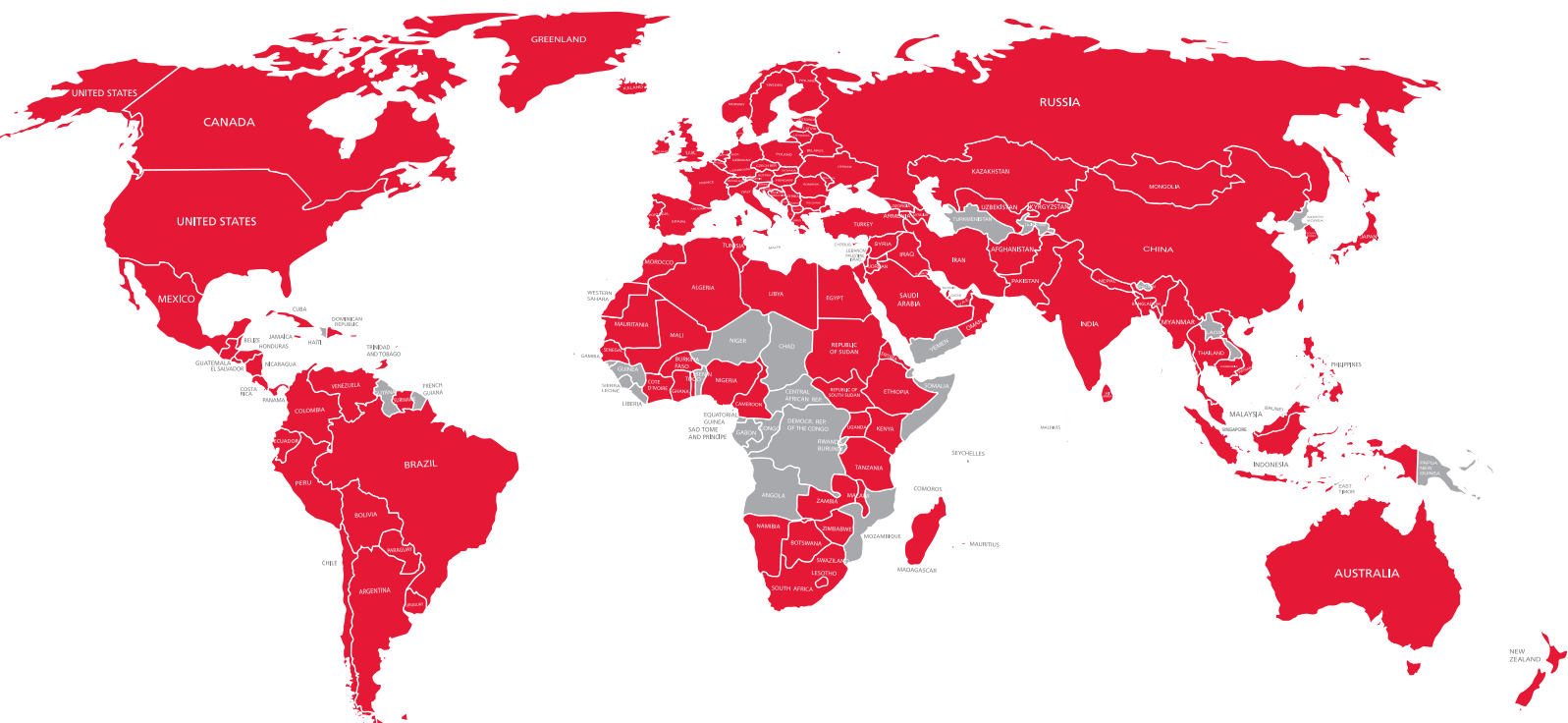
wfh.org

WORLD FEDERATION OF HEMOPHILIA

The World Federation of Hemophilia (WFH) believes that where you live should not determine your access to care and treatment for an inherited bleeding disorder.

We work to ensure every person, including those living with hemophilia and von Willebrand disease (VWD), those with rare factor deficiencies, and women with bleeding disorders have access to diagnosis, treatment, and care. Our corporate partners, donors, and volunteers all share this belief and we thank them for their past and ongoing contributions.

The reality is that the majority of those affected with a bleeding disorder receive inadequate levels of care and in many cases no treatment at all. The WFH and our global network of national member organizations (NMO) represent the interests of people with hemophilia and other inherited bleeding disorders in 134 countries. Our NMOs are the backbone of our organization; they keep us abreast of challenges they face on the ground, help us organize workshops to train healthcare professionals, and act as effective and dedicated advocates for patient concerns within their community.



● WFH National Member Organizations
(134 in total)

● Non-members

OUR VISION & MISSION

Our vision of Treatment for All is that one day, all people with a bleeding disorder will enjoy a more certain future filled with promise, 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.

WFH STRATEGIC PRIORITIES: 2015-2017

To continue to support our mission to improve and sustain care for all people with inherited bleeding disorders. Our Strategic Plan for 2015-2017 considers the global opportunities and challenges facing the bleeding disorders community, together with our organizational strengths.

- 1 IMPROVE DIAGNOSIS AND ACCESS TO TREATMENT**
for all people with inherited bleeding disorders
- 2 BUILD THE CAPACITY**
of our national member organizations 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

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WFH PRESIDENT AND CEO MESSAGE



Alain Weill
PRESIDENT



Alain Baumann
CEO

Thanks to the remarkable dedication of our board of directors, partners, team members and volunteers, the World Federation of Hemophilia helped tens of thousands of patients and families better manage their lives in 2017. Treatment for All is the shared vision that bonds us and this was a year of impressive progress on many fronts.

In 2017 we brought to a close the WFH 2015-2017 Strategic Plan. The WFH reached our strategic goal indicators in the number of planned activities in more than 100 countries, the development and use of electronic media and publications to reach our community more efficiently, and a record number of humanitarian aid donations.

We also accomplished our goal of developing a permanent regional presence around the world. We currently have seven Regional Development Managers fully operational and working closely with healthcare professionals, governments, and the patient community to improve access to care and quality of life. It has allowed for our activities to be better tailored to the community's needs.

Our Humanitarian Aid program has continued to grow and 2017 saw donations of more than 160 million IUs to 60 countries. We also expanded our network of partners and supporters. It is an exciting time as we continue to strengthen and develop the program to be the driving force for bringing treatment to those who need it most. We will continue to strengthen our medical training and outreach programs around the world to make sure all donations make a difference in the life of our patients.

The past year also saw the launch of the World Bleeding Disorders Registry (WBDR) which started with a global roll out at the end of 2017. The web-based data system will provide a platform for a network of hemophilia treatment centres around the world to collect uniform and standardized patient data and guide clinical practice.

The Global Alliance for Progress (GAP) program and, for the least developed countries, the Cornerstone Initiative, continue to be the foundation of many of our global activities. Adapted to each specific country, these programs have grown and developed and we are well on our way of identifying an additional 50,000 people with inherited bleeding disorders: an important goal of our second decade of the GAP program.

These accomplishments are a part of the numerous efforts being made by our teams of volunteers and staff to improve diagnosis, access to care and quality of life for our community. In 2017, via its electronic platform, workshops, training and exchanges (Twinning, and the International Hemophilia Training Centre (IHTC) Fellowship Program for instance), the WFH has provided tools to many member countries to ultimately make a difference.

We also began developing our next triennial Strategic Plan in 2017. More than ever, we will need to demonstrate the value of our programs to all our stakeholders. We are well aware that our success relies on the strength of our National Member Organizations and we will continue in our role of helping each country progress towards delivering better care to our patients.

THESE ACCOMPLISHMENTS
ARE A PART OF THE
NUMEROUS EFFORTS BEING
MADE BY OUR TEAMS OF
VOLUNTEERS AND STAFF
TO **IMPROVE DIAGNOSIS,
ACCESS TO CARE AND
QUALITY OF LIFE FOR OUR
COMMUNITY.**



1 WFH HUMANITARIAN AID PROGRAM

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.

1996-2016

MILLION IUs
DISTRIBUTED **462+**

COUNTRIES
REACHED **90**

PEOPLE
TREATED **15,000+**

The World Federation of Hemophilia (WFH) is leading the effort to change this lack of access in developing countries by providing consistent and predictable access to Treatment for All.

With increased multi-year donations and a steady flow of treatment products to the WFH network, it will be possible for people with bleeding disorders in the developing world to have continued access to treatment for emergency situations, acute bleeds, corrective surgeries, and also prophylaxis for young children.

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.

IN 2017

MILLION IUs
DISTRIBUTED **160+**

COUNTRIES
REACHED **60**

PEOPLE
TREATED **16,189**

Before the surgery, there were so many problems, I didn't even want to live. Couldn't do labor work, couldn't move quickly, didn't feel like meeting anyone... After the surgery, pain and bleeding is much reduced, now I want to live and happy to live.

— Govinda Malakar

2 WORLD BLEEDING DISORDERS REGISTRY

The WFH World Bleeding Disorders Registry (WBDR) is launched.

The WBDR is a web-based data entry system that will provide a platform for a network of hemophilia treatment centres (HTC) around the world to collect uniform and standardized patient data and guide clinical practice. As a global organization with access to a network of 134 national member organizations (NMO), more than 1,000 HTCs, and numerous patients in countries with varying levels of access to care, the WFH is uniquely positioned to develop such a registry.

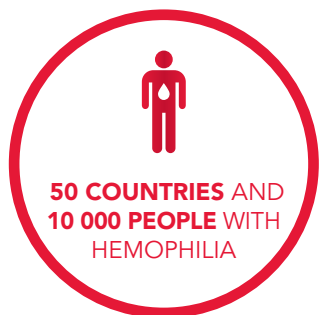
The strong collaborative relationships built over the past five decades between the WFH, NMOs, and HTCs, are essential to the success of unifying data collection methods around the world.

The WFH has been successfully collecting and publishing aggregate demographic data on people with inherited bleeding disorders for almost two decades through its Annual Global Survey. The WBDR will complement the country level aggregate data collected through the Annual Global Survey, by providing patient level data from individual treatment centres. The WBDR will house real-world data on the patient clinical experience around the globe, allowing researchers to generate evidence, build evidence-based advocacy initiatives, and improve the quality of care worldwide.

The WBDR represents a new era in the worldwide care of people with hemophilia. Having an easily accessible patient registry strengthens our capacity to diagnose, treat, and live with hemophilia.

IMPLEMENTATION OF THE **WBDR** BEGAN WITH A GLOBAL ROLL OUT IN COUNTRIES AROUND THE WORLD IN Q4 OF 2017, WITH A FIVE-YEAR GOAL OF

**ENROLLING
200 HTCs,
REPRESENTING**



Collecting data is an essential first step leading to improved care for people with hemophilia around the world. Data will provide us with a picture of the current state of care worldwide, which will in turn support our efforts to achieve Treatment for All.

— Glenn Pierce, MD, PhD

3 GLOBAL ALLIANCE FOR PROGRESS PROGRAM

The Global Alliance for Progress (GAP) Program's primary goal is to greatly increase the diagnosis and treatment of people with hemophilia, and other bleeding disorders, in 20 targeted developing countries.

Objectives of the second decade of GAP (2013-2022)

IDENTIFYING AN ADDITIONAL
50,000 PEOPLE
with inherited bleeding disorders
by 2022

WITH 50%
of them living in the world's
poorest regions

41,228
identified globally (2013-2016) –
82.5% of the goal
INCLUDING
13,919
from the poorest countries
(2013-2016) – **55.7%** of the goal

* As per WFH 2016 Annual Global Survey

In 2017, 13 countries enrolled in the GAP Program; 1,260 people with hemophilia, 258 with von Willebrand disease (VWD) and 257 with rare clotting factor deficiencies have been diagnosed/registered. Three new countries were enrolled in the WFH GAP Program in 2017: Tunisia, Uruguay, and Malaysia.

The program aims at closing the gap in treatment between developed and developing countries in three key areas: the number of people born with hemophilia and those who reach adulthood; the estimated and actual number of people known with bleeding disorders; and the need versus the availability of treatment products.

GAP PROGRAM STATISTICS TO DATE (January 2013 to December 2017)

Patients, family members, and national member organization (NMO) board members received training	6,285
Hemophilia team members and regulators received specialized training on bleeding disorders	4,470
Healthcare professionals acquired a general education on bleeding disorders	4,264
Memorandum of understanding (MoUs)	7 GAP MoUs SIGNED
International units (IU) cumulative increase in purchased product supply	5.698B

4 GLOBAL TRAINING PROGRAMS

The World Federation of Hemophilia (WFH) serves and supports the needs of all of its national member organizations through its global programs and activities, with a focus on:

IMPROVING

laboratory performance and expanding capacity to achieve accurate laboratory diagnosis

ENHANCING

and transferring medical and paramedical knowledge, and expertise of healthcare professionals and train treatment centres on bleeding disorders

INCREASING

knowledge and education of youth and patient organization representatives to better advocate for care through participation in key global skills trainings and twinning activities



IHTC FELLOWSHIP PROGRAM

The International Hemophilia Training Centre (IHTC) Fellowship Program provides training in all aspects of hemophilia and other bleeding disorders management to healthcare professionals from developing countries.

Since the IHTC Fellowship Program was launched in 1972, over 685 healthcare professionals from 96 countries have received training, with 36 trained in 2017.

The IHTC Fellowship Program aims to improve the knowledge and engagement of healthcare professionals, and in turn, deliver better care, improve diagnosis accuracy, and improve patient outcomes.

IEQAS PROGRAM

The International External Quality Assessment Scheme (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.

One hundred thirty hemophilia treatment centres from 79 countries were registered with the IEQAS Scheme in 2017. Seventeen new laboratories were enrolled.

Laboratories participating in this program are able to better assess their quality assurance systems and the reliability of their test results.



WFH TWINNING PROGRAM

The Twinning Program creates short-term collaborative partnerships between medical professionals, as well as between patient leaders, in developing and developed countries for a period of four years.

For more than 20 years, the WFH Twinning Program has established 215 partnerships, across 113 countries; a total of 76 hemophilia organization twins and 135 hemophilia treatment centre twins.

Hemophilia Treatment Centre Twinning

The Hemophilia Treatment Centre (HTC) Twinning Program partners emerging HTCs with established HTCs to help improve diagnosis and medical attention for people with hemophilia.

New HTC Twins in 2017

Harare – Zimbabwe / Chapel Hill – U.S.A.
Mansoura – Egypt / Knoxville – U.S.A.
Tehran – Iran / Milan – Italy

Hemophilia Organization Twinning

The Hemophilia Organization Twinning (HOT) Program partners emerging and established 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.

New HOT Twins in 2017

Mali – Algeria

TOGETHER, TWINS SHARE
INFORMATION AND **WORK**
SIDE-BY-SIDE

**TO BUILD
CAPABILITIES**



**TO ENHANCE KNOWLEDGE,
POLICIES, CARE, AND
SUPPORT FOR THOSE LIVING
WITH OR MANAGING A
BLEEDING DISORDER.**

TOTAL ACTIVE
HTC TWINS AS OF
DECEMBER 2017

24

TOTAL ACTIVE
HOT TWINS AS OF
DECEMBER 2017

8

GLOBAL TRAINING PROGRAMS



VWD INITIATIVE PROGRAM

von Willebrand disease (VWD) is by far the most common type of bleeding disorder. It is estimated that up to 1% of the world's population suffers from VWD, but because many people have very mild symptoms, only a small number of them know they have it.

Identifying VWD patients is a key challenge and laboratory testing is also difficult as no single test will suffice for diagnosis. With proper treatment, people with VWD can have much better health outcomes. However, there is a large gap worldwide in education, recognition, and diagnosis of VWD.

The WFH VWD Initiative Program seeks to respond to the unmet need for improved diagnosis and clinical management of VWD, as well as to create greater awareness around VWD for patients and health care professionals.



RESEARCH HAS SHOWN
THAT AS MANY AS

9/10 PEOPLE WITH
VWD ARE
UNDIAGNOSED

1st WFH International VWD Symposium: Prague – Czech Republic

In 2017, the WFH held its first international VWD symposium in Prague, bringing together patients, caregivers, and healthcare professionals. Participants from 14 different countries shared their experiences of what it is like living with VWD and discussed strategies on how to conduct outreach programs.



YOUTH LEADERSHIP PROGRAM

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.

3rd WFH Youth Leadership Workshop: Panama City – Panama

The event was organized through the WFH Youth Leadership Program, and was held to enhance the skills of future youth leaders so they can advocate for better bleeding disorders care in their own countries. Seventeen youths attended the event, from 15 countries, and received a wide range of training tailored to the realities of today's world.

5 REGIONAL AND NATIONAL PROGRAMS

The healthcare development work of the WFH is carried out in collaboration with its national member organizations (NMO) and a dedicated group of medical and lay volunteers.

It is based on a comprehensive development model that aims to achieve sustainable care and Treatment for All. The WFH carries out its work through country-specific as well as regional programs and activities.

It focuses on:

- National healthcare development programs to achieve sustainable comprehensive care
- Targeted country development action plans
- Capacity to achieve accurate laboratory diagnosis
- Training for health professionals
- NMO leadership skills training nationally, regionally, and globally
- NMO development



COUNTRIES CAN BE INVOLVED IN ONE OR MORE OF THESE

PROGRAMS AND ACTIVITIES

over extended periods of time.

- 1** “Underserved” countries may be considered for a Cornerstone Initiative when they, or their regions, demonstrate initiative, motivation, and potential to develop basic standards of care.
.....
- 2** Where there is the initiative, motivation, and potential to work more in-depth on improving hemophilia care, countries may be considered for Country Programs.
.....
- 3** When a Country Program demonstrates the potential for establishing a national hemophilia care program that is integrated within the health system and covers all or most areas of hemophilia care development, it may be considered for the Global Alliance for Progress (GAP) Program.



CORNERSTONE INITIATIVE

An estimated 1 in 1,000 people worldwide live with a bleeding disorder.

HOWEVER, APPROXIMATELY

 **75%** OF THEM STILL RECEIVE

VERY INADEQUATE CARE OR NO TREATMENT AT ALL, AND OFTEN THEIR DISORDERS **REMAIN UNDIAGNOSED.**

.....

IN 2017, WFH HEALTHCARE DEVELOPMENT PROGRAMS AND ACTIVITIES REACHED A TOTAL OF 121 COUNTRIES WORLDWIDE:

56 COUNTRIES FELL UNDER THE GLOBAL PROGRAM ACTIVITIES CATEGORY, AND 65 COUNTRIES FELL UNDER THE GLOBAL ALLIANCE PROGRAM (GAP), COUNTRY PROGRAMS, AND CORNERSTONE INITIATIVE COUNTRY CATEGORY.

The World Federation of Hemophilia (WFH)'s Cornerstone Initiative continues the work in closing the gap in care for people with bleeding disorders, with a particular focus on improving diagnosis and treatment in the world's most underserved countries and regions.

In 2017, Myanmar and Zimbabwe were enrolled in the Cornerstone Initiative, with a total of eight countries benefitting from the program. The programs focused on enhancing medical expertise through medical and multidisciplinary workshops for healthcare professionals and building NMO capacity through board and governance training.

The objective of the Cornerstone Initiative is to provide support, expertise, and training to countries with minimal levels of care, which will help them improve and benefit later from the WFH's full range of programs and activities.



COUNTRY PROGRAMS

The World Federation of Hemophilia (WFH) Country Programs follows its comprehensive development model and provides in-depth support in these areas:

- Government Support
- Care Delivery
- Medical Expertise and Laboratory Diagnosis
- Treatment Products
- Patient Organization
- Data Collection and Outcomes Research

.....

IN 2017, **45 COUNTRIES**
PARTICIPATED IN CAPACITY-BUILDING
AND ADVOCACY INITIATIVES THROUGH
WFH COUNTRY PROGRAMS.

.....



REGIONAL AND NATIONAL PROGRAMS

NATIONAL AND REGIONAL NMO TRAININGS

The World Federation of Hemophilia (WFH) organizes regular training and capacity building workshops at national and regional levels to strengthen the knowledge and skills of national member organizations (NMO), and to help them improve their internal structures as well as their external activities and relations.

.....

IN 2017, THE WFH ORGANIZED 51 CAPACITY BUILDING WORKSHOPS AND CONFERENCES ACROSS ALL REGIONS, WITH 2,317 PATIENTS AND THEIR FAMILY MEMBERS BENEFITTING.

.....

These workshops are designed around the needs of NMOs and address a range of areas such as leadership development and governance, strategic planning, data collection, youth engagement, fundraising and other topics.

2017 WFH Africa Summit on Hemophilia and Other Inherited Bleeding Disorders

Dakar – Senegal

The principal objective of the Africa Summit was to create a platform for all the key regional stakeholders; over 100 participants from 34 countries came together to discuss their own regional priorities. The Summit resulted in the adoption of an official set of recommendations urging governments, the WFH, and WFH national member organizations to join in collaborative working partnerships to undertake action in key priority areas.

L'Alliance franco-africaine pour le traitement de l'hémophilie (AFATH)

L'Alliance franco-africaine pour le traitement de l'hémophilie (AFATH) came to life from the commitment of The Association française des hémophiles and the WFH following the 2012 World Congress to support French-speaking African hemophilia patient organizations to take the necessary steps to join the WFH as National Member Organizations. Eight countries have benefitted from the AFATH program to date, including four countries where patient organizations have become WFH members.



WORKSHOPS FOR HEALTHCARE PROFESSIONALS

Each year, the World Federation of Hemophilia (WFH) organizes workshops in individual countries and regions that bring together professionals from the multidisciplinary team and members of the global bleeding disorders community to exchange ideas on the improvement of treatment and care.

In 2017, the WFH organized a total of 60 national and regional conferences and/or multidisciplinary workshops. These workshops/conferences allowed us to enhance medical and paramedical expertise and train 3,410 healthcare professionals around the world.

As part of the multidisciplinary trainings in regions, the WFH piloted its new standardized Musculoskeletal (MSK) training curriculum during a Regional MSK Workshop held in Lima, Peru. Musculoskeletal specialists from all the countries in the South American region benefitted from this workshop that included both theoretical sessions and practical ones with patient examinations.

Another highlight of the WFH efforts in improving MSK care for people with hemophilia and other inherited bleeding disorders was the WFH MSK Regional Workshop for the Middle East held in Cairo, Egypt. The workshop's key objective was to provide a platform to share the latest international expertise and knowledge, to evaluate the current situation of MSK care in the region, and to successfully mobilize participants to relaunch and expand the Arab Physiotherapy Network set up as part of the WFH Global Physiotherapy Initiative in 2009 into the Middle East MSK Network.



WORKSHOPS, CONFERENCES, AND GENERAL SYMPOSIA

INCLUDE BOTH SCIENTIFIC
PRESENTATIONS AND
PRACTICAL APPLICATION.

WFH 15TH INTERNATIONAL MUSCULOSKELETAL CONGRESS

May 5–7, 2017 / Seoul – Korea

Every two years, the WFH organizes an International Musculoskeletal Congress that brings together leading orthopedic surgeons, hematologists, and physiotherapists specialized in the treatment and care of patients with bleeding disorders, in addition to other professionals interested in the musculoskeletal aspects of hemophilia. The 15th WFH International Musculoskeletal Congress was held in Asia for the first time ever. A high-profile international event, the Congress saw over 250 delegates from 61 countries attend.



REGIONAL AND NATIONAL PROGRAMS

LABORATORY WORKSHOPS

National and Regional Workshops

National and regional laboratory workshops provide theoretical and practical training that is adapted to the needs of different countries. These workshops can provide a range of training, beginning with an introduction to basic testing for hemophilia to providing more advanced skills, such as extending diagnosis to von Willebrand disease (VWD) and other factor deficiencies. Participants include laboratory scientists and technicians selected from hemophilia treatment centres. The workshops are typically two to three days.

Out of the overall number of workshops held for healthcare professionals in 2017, the WFH organized three regional laboratory diagnosis workshops in Eastern Europe & Central Asia, Africa, and South Asia regions.

In total in 2017, 148 laboratory scientists and technicians, from 38 countries, were trained in the diagnosis of hemophilia, VWD, and inhibitors, through national and regional laboratory diagnostic workshops.

For the first time,
I have been trained
by senior lab
experts. I am now
confident to lead
lab diagnosis at
my hospital.

— Gomik Siddhi

“Training of Trainers” Workshop

Organized at the Royal Free Hospital in London, U.K., in cooperation with the WFH Laboratory Sciences Committee chair, the Training the Trainers Program provides participants with hands-on experience in laboratory practice, using both manual and semi-automated techniques. Emphasis is placed on the importance of internal quality control.

In 2017, 15 laboratory scientists, were trained at the Training of Trainers workshop, from 14 countries.

IN 2017



160

LABORATORY
AND
SCIENTIFIC

FROM



46

COUNTRIES

6 EDUCATIONAL RESOURCES

In 2017, we capitalized upon the custom WFH eLearning Platform (eLearning.wfh.org) to provide innovative resources tailored to identified unmet educational needs. From interactive eLearning modules to technical monographs to panel discussion videos, the World Federation of Hemophilia (WFH) transforms the knowledge of its expert volunteers into tools that advance education and advocacy in the global bleeding disorders community.

- **Launched** the first eLearning module of the Treatment Products Program — Introduction to Bleeding Disorders which explains how blood clots and the coagulation cascade, what goes wrong in factor deficiency, and how factor replacement therapy works by correcting this
- **Produced** an updated edition of the Guide for the Assessment of Clotting Factor Concentrates (in English and Spanish)
- **Developed** two peer-reviewed monographs on the diagnosis of von Willebrand Disease: Phenotypic Characterization and Molecular Diagnosis (in English and Spanish)
- **Developed** and piloted a 12-module Standardized Musculoskeletal Professional Training Curriculum
- **Delivered** approximately 1,072,155 educational resources as downloads, online resources, and print distribution to individual learners
- **Granted** permission to eleven patient organizations to translate and reprint select WFH resources in six languages
- **Produced** three videos of expert panelists discussing five successful VWD outreach programs

The new Introduction to Bleeding Disorders eLearning module is great for learning the essential science on your own or with a small group. The pop-ups and quizzes make it fun, and the beautiful colour illustrations really help to understand the ideas behind the text.

— Radoslaw Kaczmarek, PhD
Co-Chair, Education Advisory Committee



WORLD HEMOPHILIA DAY 2017

HEAR THEIR VOICES

The World Federation of Hemophilia (WFH) would like to thank our community that made World Hemophilia Day a truly global event, helping raise awareness for women and girls affected by bleeding disorders.

A big thank you to all who participated in the Light it Up Red campaign by having a landmark lit red on World Hemophilia Day. We are so pleased 69 landmarks participated in 2017. To see the photos, go to our Facebook page and visit www.worldhemophiliaday.org to read the amazing stories that were shared in 2017.

WFH DIGITAL PLATFORMS

The WFH capitalizes on digital strategies to increase awareness and to provide networking and other learning opportunities.

PROVIDED

online content on the English, French, Spanish, Arabic, simplified Chinese, Japanese, and Russian WFH websites

PUBLISHED

news regularly on *Hemophilia World Online* news.wfh.org

GLOBAL COMMUNITY MEMBERSHIP PROGRAM

Global Community Membership Program

As of January 1, 2017, the World Federation of Hemophilia (WFH) Membership Program became the WFH Global Community Membership Program.

Be Part of Our WFH Global Community Membership Program

When you join the Global Community Membership Program, your global support has local results.

SUPPORT OUR WORK

Living with a bleeding disorder often sidelines children and young adults, especially in the developing world, where patients often lack access to treatment. A child experiencing a bleed often cannot go to school, play with friends, or sometimes even sleep at night because of the pain. Parents miss work to care for their child or to take them for hospital visits.

YOU CAN CHANGE THAT.

You can support our work through making a regular monthly gift or a single one-time gift today.

7 RESEARCH AND DATA COLLECTION

A background image of a laboratory. A person's hands are visible, wearing a white lab coat and a gold watch. They are using a blue and white pipette to transfer liquid into a small vial. In the foreground, there is a white piece of laboratory equipment with a black multi-well plate on it. The background shows shelves with various lab supplies and a computer monitor.

The World Federation of Hemophilia (WFH)'s Research and Public Policy team works to enhance both data collection and research activities globally with the aim of creating better evidence to improve the clinical management of patients with bleeding disorders around the world.

WFH data collection programs include the WFH Annual Global Survey, the WFH World Bleeding Disorders Registry (WBDR), and the WFH Clinical Research Grant Program.



DATA COLLECTION

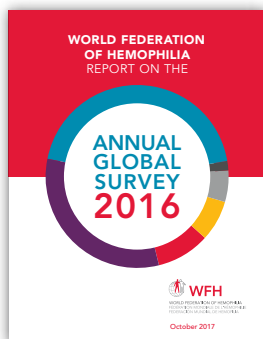
- The **Annual Global Survey** is a cross-sectional survey of WFH national member organizations providing country level data on the number of identified patients and access to care, around the world. Data are reported annually through the WFH Report on the Annual Global Survey.
- The **WBDR** is a longitudinal, prospective patient registry, which will provide patient-level clinical and outcome data. The WBDR will start enrolling patients in 2018 and aggregate data will be reported annually in the WFH Annual Report on the WBDR.

Combined, these data collection platforms allow the WFH to provide a comprehensive overview of the state of care around the world. These data are available to the entire bleeding disorders community for research and advocacy purposes.



ANNUAL GLOBAL SURVEY

The Report on the World Federation of Hemophilia (WFH)'s Annual Global Survey includes selected demographic and treatment-related data on people with hemophilia, von Willebrand disease (VWD), rare factor deficiencies, and inherited platelet disorders throughout the world.



The 2016 Annual Global Survey report includes data on more than 295,000 people with bleeding disorders in 113 countries. As in past years, the Global Survey Report provides analysis and results for a limited number of the survey questions asked each year. The full survey questionnaire is contained at the end of the report. The WFH thanks our national member organizations for their help in gathering this important data.

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 is open to researchers globally.



RESEARCH AND DATA COLLECTION

2017 GRANT RECIPIENTS

RUCHIKA GOEL

*New York Presbyterian Hospital, Weill Cornell
Medicine, New York, U.S.A.*

Identification of Age Varying Co-Morbidities
and Predictors of Mortality in Persons with
Hemophilia A and B and Derivation of a Mortality
Risk Prediction Score

MARIA EULALIA LANDRO

*Hospital General de Agudos Dr. Juan A.
Fernández, Buenos Aires, Argentina*

Platelet Rich Plasma for synovitis treatment
in Patients with Haemophilia (PWH)

SILVIA SPENA

*Angelo Bianchi Bonomi Hemophilia and
Thrombosis Center, Milan, Italy*

Non Invasive Prenatal Diagnosis of hemophilia in
male fetal cells circulating in the maternal blood

KARIN P.M. VAN GALEN

*University Medical Center Utrecht, Utrecht,
the Netherlands*

Pregnancy and inherited bleeding disorders,
the PRIDE study

10TH WFH GLOBAL FORUM ON RESEARCH AND TREATMENT PRODUCTS FOR BLEEDING DISORDERS

More than 190 people, from over 40 countries, participated in the 10th WFH Global Forum from November 9-10, 2017, in Montreal. For the second time, the WFH combined our Global Forum on Treatment Products for Bleeding Disorders with our Global Research Forum in a two-day meeting covering the latest developments in both areas.

Experts from around the world discussed the challenges of inhibitor development, the roll-out of extended half-life products, affording new treatments, gene therapy, new and novel therapies, and an update on plasma-derived product risks.

Data is the cornerstone
of everything.

— Murtaha Hasan, MD, Iraq

2017 FINANCIAL REPORT





In financial terms, 2017 has been a solid year for the World Federation of Hemophilia (WFH), with a net deficit of \$1,646,854 compared to a budgeted net deficit of \$2,568,149, an improvement of \$921,295. The strong U.S. currency (which averaged \$1.30 CAD for the year) once again contributed to this result, as the majority of revenues for sponsorship of programs was received in US dollars against a budget that was set at \$1 US = \$1.20 CAD.

CONTINUED STABILITY OF REVENUE

Corporate sponsors of the WFH programs and initiatives continued their committed support with 2017 contributions of \$5,447,650, an increase of \$397,497 (7.9%) over 2016. A portion of this increase was due to sponsorship contributions of \$161,884 towards the WFH Global Forum on Research and Treatment Products for Bleeding Disorders that takes place every two years.

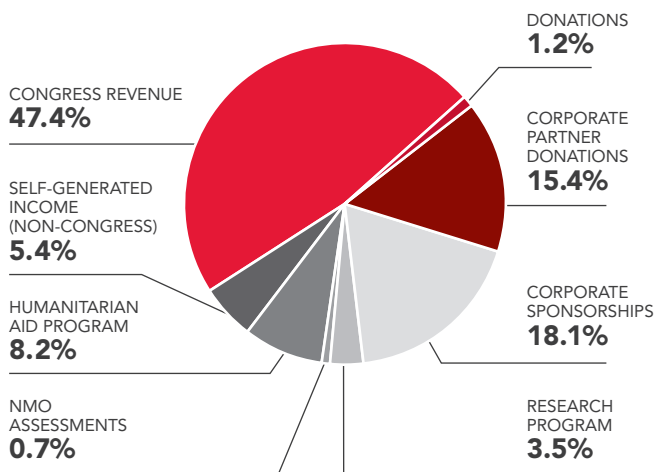
In 2017, the expanded scope of the WFH Humanitarian Aid Program continued with a total of 160.1 million IUs being distributed. As per Canadian accounting rules, revenues received for restricted purposes can only be recognized in the year in which related expenses are incurred. In 2017, \$1,377,619 was spent against the revenues we received for the Humanitarian Aid Program. Thus, only this amount is recognized in WFH revenues.

The WFH Research Program, which is also a restricted program, received \$683,273. With these funds, the WFH was able to continue to develop the World Bleeding Disorder Registry (WBDR), as well as award research grants in 2017.

The total WFH revenue, before Congress and Product Donations, reached \$8,974,045, \$1,466,268 (19.5%) above 2016.

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, adds to a diversified income stream. As shown in Figure 1, excluding product donations, 33% of revenues over the two-year cycle are for sponsorships from WFH corporate partners; 12% are for restricted programs (Humanitarian Aid and Research Program); and the remaining 55% are generated through the WFH 2016 World Congress, financial donations, and self-generating income activities.

FIGURE 1
REVENUES 2016 AND 2017
(Excluding product donations)



EXPENSES ALIGNING WITH STRATEGIC OBJECTIVES

Healthcare development programs, education and public policy programs, and the WFH Humanitarian Aid Program combined represent the largest proportion of expenses with 45% of the expenses incurred over the past two years, as seen in Figure 2. The WFH World Congress not only represents the most important part of revenues, it also represents one of the largest investments at 35% of the WFH expenses, while fundraising and corporate relations expenses represent 6% of this total. Additional expenses for the WFH include administration at 7%, communications at 4%, governance at 2% and fluctuation of foreign exchange at 1%.

HUMANITARIAN AID

The WFH distributes valuable humanitarian aid product donations from many of our corporate sponsors to WFH national member organizations (NMOs) and hemophilia treatment centres HTC around the world. In 2017, 160.1 million IU's of clotting factor concentrates were strategically donated to 60 countries, improving and sustaining care for people in the developing world. This represents a 14% growth in volume of IU's distributed (19 million more than 2016). The majority of these donations, worth \$353,263,571 US, are reported in the audited financial statements of the WFH USA. The amount reported in the financial statements of WFH is \$54,574,321.

FIGURE 2
EXPENSES 2016 AND 2017
(Excluding product donations)

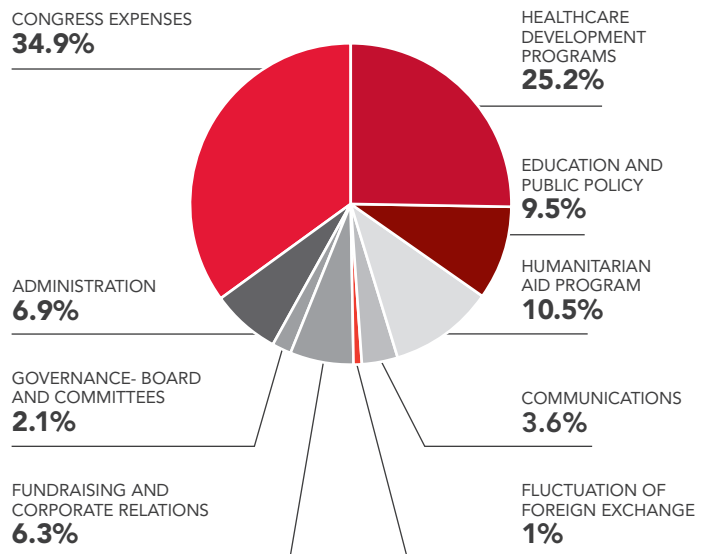


FIGURE 3
REVENUES AND EXPENSES
 (Expressed in Canadian Dollars)

REVENUES	2017	2016
Donations	184,380	195,800
Corporate Partner Donations	2,549,994	2,272,701
Corporate Sponsorships	2,897,655	2,777,452
Research Program	683,273	420,798
NMO Assessments	111,603	105,276
Humanitarian Aid Program	1,377,619	1,205,022
Self-Generated Income (Non-Congress)	1,169,521	530,728
Total Revenues before Congress and Product Donations	8,974,045	7,507,777
Congress Revenue	0	14,847,683
Product Donations	54,574,321	11,304,390
TOTAL REVENUES	63,548,366	33,659,850
EXPENSES	2017	2016
Healthcare Development Programs	3,835,655	3,200,109
Education and Public Policy	1,482,680	1,159,392
Humanitarian Aid Program	1,623,595	1,306,120
Communications and Marketing	517,634	497,510
Fundraising & Corporate Relations	983,155	765,197
Governance- Board and Committees	311,772	263,360
Administration	965,128	956,665
Fluctuation of Foreign Exchange	139,974	140,081
Total Expenses before Congress and Product Donations	9,859,593	8,288,434
Congress Expenses	761,306	8,989,831
Product Donations	54,574,321	11,304,390
TOTAL EXPENSES	65,195,220	28,582,655
EXCESS (DEFICIENCY)	-1,646,854	5,077,195

YEAR-OVER-YEAR COMPARISON

The 2017 and 2016 statement of revenues and expenses, illustrated in Figure 3, reflects the fluctuations within a typical two-year cycle where the World Congress is held in even years as well as the varying amounts of product donations received yearly. On the revenue side, there was solid growth of \$397,497 from our corporate partner contributions. Self-generated income stood at \$1,169,521 and includes \$479,771 derived from registration and housing revenues from the 15th International Musculoskeletal Conference and the Global Forum held in 2017. There was also excellent growth of \$262,475 in contributions for the Research Program that allowed us to develop the infrastructure and prepare for the launch of the World Bleeding Disorders Registry.

The overall rise of \$1,571,159 in expenses before Congress and Product Donations reflects the continued efforts of the WFH to support the needs of the global bleeding disorders community. WFH healthcare development program expenses grew by \$635,546 in 2017 primarily due to a significant increase in regional level meetings and training workshops organized by the seven regional managers, six of whom are based in different regions throughout the world. This increase was offset by costs incurred in 2016 for the Global NMO Training held before the WFH World Congress. There was also an increase of \$323,288 in Education and Public Policy partially due to the development of the WBDR; the issuing of research grants; as well as costs incurred for the Global Forum. Further, as activities for the WFH Humanitarian Aid Program remained robust, expenses in this area rose to \$1,623,595 in 2017, compared with \$1,306,120 in 2016.

LOOKING AHEAD

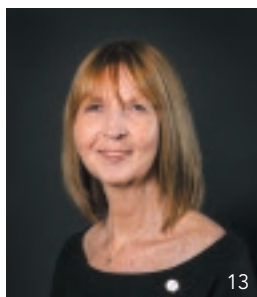
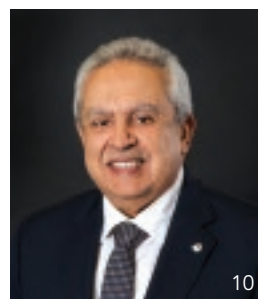
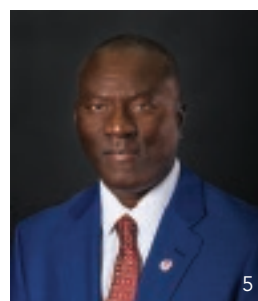
As we embark on a new two-year cycle, our financial base is solid and resources continue to be strategically placed both externally (local regional managers) and internally (towards Humanitarian Aid efforts) to enable us to deliver our programs and activities with the aim of accomplishing our mission.

However our overall financial strength must be balanced against the challenges ahead. The entrance of competition, and an increase in regulatory constraints, will not allow future congresses to be as financially successful as they have been in the past. We must also be prepared should the U.S. dollar experience a downward turn. Nevertheless, with so many of our people suffering, we will continually think of strategic ways 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!

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

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.

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WFH BOARD OF DIRECTORS, MEMBERS & PATRON 2016–2018

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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 2017, the following individuals, corporations, and organizations made financial contributions of CAN\$150 or more to the WFH or WFH USA.

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Jan Willem André de la Porte

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Grifols
Novo Nordisk
Shire

Leadership Partners

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WFH HUMANITARIAN AID PROGRAM

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WFH 2017 Africa Summit

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Other sponsored programs

Biotest
F. Hoffmann-La Roche Ltd.
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Other product donation

Bayer
Biotest
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Haemophilia Society of Bosnia and Herzegovina (Bosnia)
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Susan Skinner Memorial Fund

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In Honour of Canadian Physiotherapists in Hemophilia Care

In Honour of Cole and Miranda Schnabel Geringer
 In Honour of Hemophilia of Georgia Staff
 In Honour of Jason Isenberg
 In Honour of Frank Schnabel IV and Lillian Schnabel
 In Memory of Greg Doster
 In Memory of Shirley Gilbert
 In Memory of Jeanne Lusher
 In Memory of Frank Schnabel II

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\$100,000 +

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\$50,000 – \$99,999

Hemophilia Alliance Foundation
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\$25,000 – \$49,999

Glenn and Beatrice Pierce

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WFH 2017 HIGHLIGHTS



GLOBAL REACH OF WFH
HEALTHCARE PROGRAMS IN

121 COUNTRIES



OVER

3,410

HEALTHCARE PROFESSIONALS
TRAINED WITH ENHANCED MEDICAL
AND PARAMEDICAL KNOWLEDGE



TRAINED OVER

2,317

PATIENTS AND FAMILY MEMBERS
ON BLEEDING DISORDERS



DELIVERED OVER

1,072,155

EDUCATIONAL RESOURCES



HUMANITARIAN AID
DONATED OVER

160+

MILLION IUs TO 60 COUNTRIES
16,189+ PEOPLE TREATED

WORLD FEDERATION OF HEMOPHILIA

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