



WFH ANNUAL REPORT

2019

wfh.org



WFH

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



The WFH continues to have an impact

Where you live should not determine your access to care and treatment.

Most people with an inherited bleeding disorder do not receive an adequate level of care—in many cases, they don't receive any treatment at all. The WFH and our global network of national member organizations (NMOs) represent the interests of people

with hemophilia and other inherited bleeding disorders in 140 countries. Together, we work to ensure every person with a bleeding disorder—including those living with hemophilia and von Willebrand disease (VWD), those with rare factor deficiencies, and women with bleeding disorders—have access to world-class care. Our corporate partners, donors, and volunteers all share this conviction, and we thank them for their dedication.

Table of contents

Our vision & mission	1	World Hemophilia Day	15
Letter from the leadership of the WFH	2	United in solidarity	16
Global programs making a difference	4	Thank you to our donors	17
WFH Humanitarian Aid Program	8	Thank you to our corporate partners	19
Research and data collection	9	2019 Financial Report	20
Congress and meetings	10	WFH Board of Directors	24
Regional highlights	11		

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.

Strategic plan

The WFH 2018 to 2020 Strategic Plan is designed to align the organization around the priorities and objectives that will allow us to realize our vision of Treatment for All. Key performance indicators (KPIs) and measurement approaches are set for each strategic objective and will be used to monitor the progress of these priorities.

The strategic priorities of the WFH for 2018 to 2020 are to:

1 **Improve outreach and diagnosis**
of people with bleeding disorders

2 **Increase access**
to adequate and affordable care

3 **Increase sustainable access**
to safe therapies

Letter from the leadership of the WFH



Alain Weill
President

Alain Baumann
CEO

2019 was another year of great achievements and challenges for the World Federation of Hemophilia. We are proud to report that we achieved many of the very ambitious targets we had taken on. However, it was also a year of “normality” before everyone’s life was changed by the COVID-19 pandemic. Fortunately, the robust base we built in 2019—and in previous years—gave us the strength to face this challenging new reality. There is, however, no doubt that the COVID-19 pandemic will be disruptive to all of us, creating new risks and uncertainties worldwide.

The WFH was very active in 2019 and we realized a number of major accomplishments through our many new and established programs. We are pleased to report that two companies decided to join the WFH Humanitarian Aid Program—making it the biggest donation program in the world of rare diseases. Also, the World Bleeding Disorders Registry (WBDR) is now a well-established endeavour that will help us gather critical real-world data in a way that has never been done before. Led by local national member organizations (NMOs) and WFH Regional Managers, our regional initiatives have blossomed all around the world and have helped address key regional and local needs. Also, WFH von Willebrand Disease (VWD) and women with bleeding disorders initiatives have driven real results for two traditionally underserved communities.

Technology continues to evolve in our field, with new product launches, and new studies—a multitude of possibilities, each promising to provide our community with dramatically better care. It’s an exciting time, but we are also very cognizant of the fact that the WFH needs to play a part in making sure that these new technologies will be safe and accessible to everyone, no matter where they live. This important point was covered during the second WFH Gene Therapy Round Table (GTRT).

Of course, there are many challenges in 2020 and beyond. We have done much to support the bleeding disorders community—but much still needs to be done. A scientific study spearheaded by the WFH updated the prevalence of hemophilia to higher numbers than previously estimated—clearly indicating that there are many more patients that have not been identified than we thought. The data show that a large amount of diagnosis work still remains to be done, particularly in low- and medium-income countries.

Will people in the future consider 2019 to be a turning point in the history of the WFH? How will the 2020 COVID-19 pandemic impact our work as a global organization? We do not know the answers to these questions yet, but what is clear is that we need to find new ways to be effective—virtually and digitally instead of on the road and face-to-face. In the short term, healthcare systems will be challenged, so understanding how the WFH can continue to be relevant to our patient community—knowing that that the community will have to work harder than ever before to make its voice heard—will be critical. Fortunately, our community has proved in the past that we can overcome crises and come out stronger, so we should continue to look into the future with confidence. Technology, innovation, creativity and the dedication of our community will bring us closer to Treatment for All than we have ever been.



Alain Baumann
WFH CEO



Alain Weill
WFH President

Global programs making a difference



The WFH supports the needs of its national member organizations (NMOs) and the development of hemophilia treatment centres, and makes it possible for them to achieve sustainable comprehensive care and treatment for people with inherited bleeding disorders, including hemophilia, von Willebrand disease, rare factor deficiencies and inherited platelet disorders.

Global Alliance for Progress
(GAP) Program

International Hemophilia Training
Centre (IHTC) Fellowship Program

WFH Twinning Program

International External
Quality Assessment Scheme
(IEQAS) Program

VWD Initiative Program

Youth Leadership Program

Global Alliance for Progress (GAP) Program

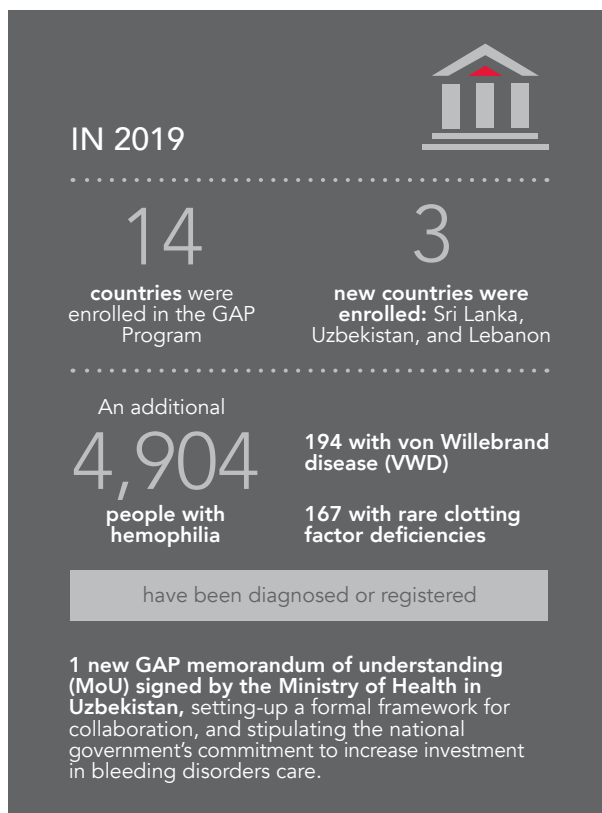
The main goal of the Global Alliance for Progress (GAP) Program is to greatly increase the diagnosis and treatment of people with hemophilia and other bleeding disorders.

The program aims to close the gap in treatment between developed and developing countries in three key areas:

- The number of people born with hemophilia and the number that reach adulthood
- The estimated and actual number of known people with bleeding disorders
- The need versus the availability of treatment products

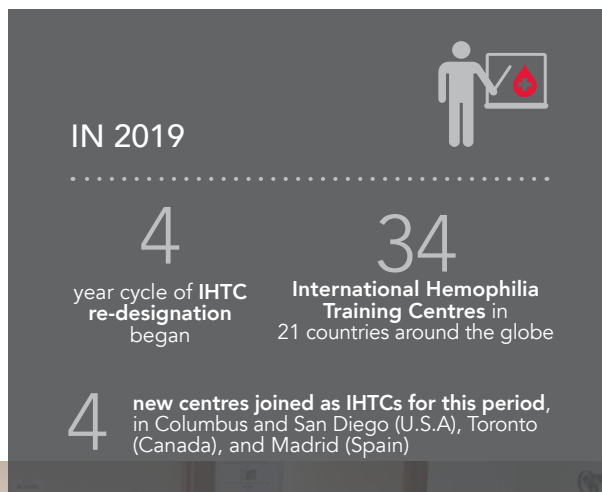
In 2013, the WFH initiated the second decade of the GAP Program to actively continue to work on closing the gap in care for people with bleeding disorders in 20 new target countries. The overarching goals for the second decade (2013 to 2022) of GAP are to:

- Increase by 50,000 the worldwide number of people identified or diagnosed with a bleeding disorder
- Ensure that 50 per cent of those newly diagnosed are from the world's most impoverished countries



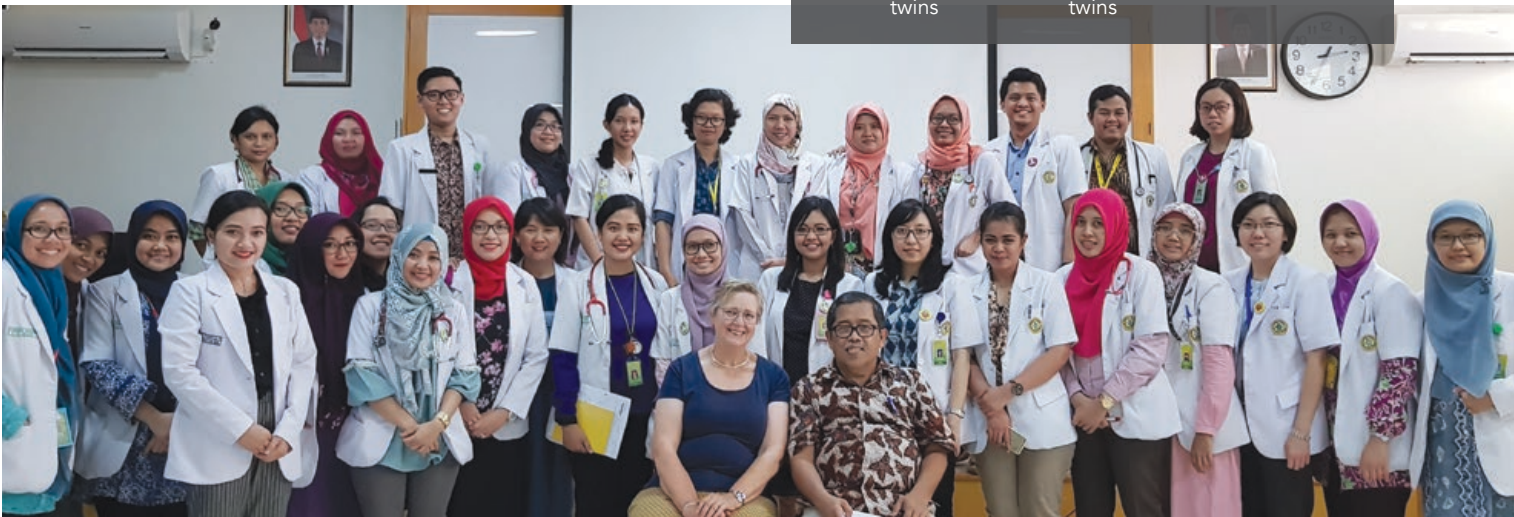
International Hemophilia Training Centre (IHTC) Fellowship Program

IHTC Fellowship Program provides clinical or medical training in all aspects of hemophilia and other bleeding disorders management to healthcare professionals from developing countries in order to enhance knowledge and engagement, and, in turn, deliver better care, improve diagnosis accuracy, and improve patient outcomes. For the 2019 fellowships cycle, a total of 131 applications were received from 67 countries—the most ever received in a single application cycle. In 2019, 37 fellowships were awarded and 22 fellows completed their training during the year.



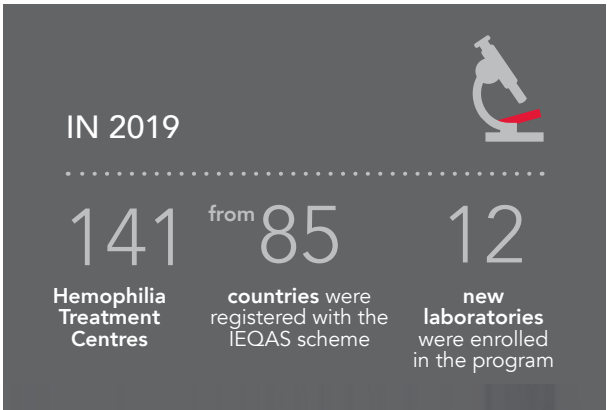
WFH Twinning Program

The WFH Twinning Program creates short-term collaborative partnerships between medical professionals, and between patient and youth leaders in developing and developed countries. The youth twins have completed a full two-year cycle since the new component of the program was piloted. A complete evaluation of the program was initiated in 2019 involving a series of stakeholders.



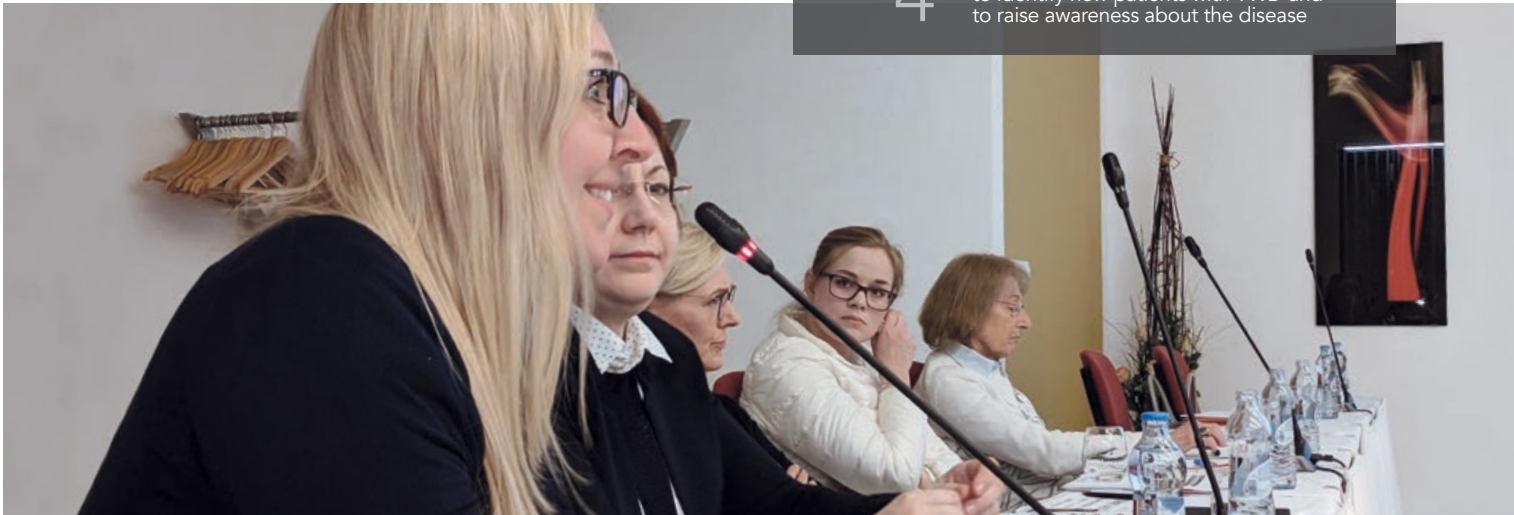
International External Quality Assessment Scheme (IEQAS) Program

IEQAS improves and standardizes laboratory diagnosis by auditing the effectiveness of laboratory internal quality assurance systems and establishing a measure of a laboratory's competence. Hemophilia treatment centres participating in this program are able to better assess their quality assurance systems and the reliability of their test results.



VWD Initiative Program

The WFH VWD Initiative Program seeks to respond to the unmet need for improved diagnosis and clinical management of von Willebrand disease (VWD), as well as to create greater awareness around VWD for patients and healthcare professionals.



IN 2019

39

NMOs had signed on to our Call-to-Action to raise awareness about VWD

4

NMOs initiated outreach projects to identify new patients with VWD and to raise awareness about the disease

Youth Leadership Program

The WFH Youth Leadership Program helps foster the next generation of leaders in the bleeding disorders community and ensures that they are well prepared to take on a leadership role. These workshops focused on providing opportunities for youth to develop their skills in areas such as leadership, project planning, communications and media relations, building alliances and fostering advocacy.



IN 2019

3

Youth Leadership Workshops

46

youths attended workshops from 37 countries

WFH Humanitarian Aid Program

Continuing to have an impact

The lack of access to care, clotting factor concentrates and treatment for people affected by a bleeding disorder in developing countries is an urgent and important public health challenge. The WFH Humanitarian Aid Program was developed to address this issue by working with recipient hemophilia treatment facilities and WFH national member organizations (NMOs) to provide continued access to treatment for emergency situations, acute bleeds, corrective surgeries, and prophylaxis for young children.

The WFH Humanitarian Aid Program makes impact in action possible by facilitating sustainable care, involving governments, supporting outreach and identification, ensuring the viability of corrective surgeries, and improving quality of life.

The WFH Humanitarian Aid Program has drastically increased donations over the last five years. Now, more people than ever in the bleeding disorders community have hope that they can have a better quality of life. This success is a direct result of a collective effort between the WFH, pharmaceutical partners, governments, and the global bleeding disorders community.

IN 2019



241+
Million IUs donated

72
Countries reached

19,700+
People reached



Research and data collection

Helping to improve care

The WFH Research and Public Policy department works to create better evidence to improve the clinical management of patients with bleeding disorders around the world.

Annual Global Survey

The report on the WFH Annual Global Survey (AGS) includes selected demographic and treatment-related data on people with hemophilia (PWH), von Willebrand disease (VWD), and other rare bleeding disorders throughout the world. In 2019, the WFH celebrated the 20th anniversary of the AGS. The most recent report included data on more than 337,000 people with bleeding disorders from a record breaking 125 countries.

World Bleeding Disorders Registry

The World Bleeding Disorders Registry (WBDR) provides a unique platform for hemophilia treatment centres (HTCs) around the world to collect standardized data on PWH. Over 4,100 patients were enrolled in the WBDR by the end of 2019. Last year, the WBDR proof of concept study for linking hemophilia registries was successful, and data from 771 patients with hemophilia were transferred directly from the Czech National Hemophilia Programme Registry into the WBDR.

WBDR Research Support Program

The WFH WBDR Research Support Program is designed to provide research funding to participating HTCs to encourage the use of their data for research and advocacy purposes in order to increase knowledge of the epidemiology of hemophilia A and B globally. In 2019, funding was provided to eight new HTCs for one- or two-year research studies.

WBDR Data Quality Accreditation Program

The WBDR Data Quality Accreditation (WBDR DQA) Program was initiated to standardize data collection procedures among HTCs, and ensure that WBDR data are of high quality. The WFH data quality team provided 51 HTCs with training and feedback on the quality of their data in 2019.

Gene Therapy Round Table

The second WFH Gene Therapy Round Table expanded the conversation on the expected challenges and opportunities that gene therapy presents for the global bleeding disorders community. Topics covered during the event included models of access to gene therapy around the world; reimbursement and payment models; health technology assessment considerations; regulatory issues; and evidence generation on the safety and durable efficacy of gene therapy products.



Congress and meetings

Covering the latest developments through specialized events

11th WFH Global Forum

The 11th WFH Global Forum on Research and Treatment Products for Bleeding Disorders was held in Montreal in November, 2019 and was attended by 184 people from 34 countries. The event addressed issues related to the safety and supply of treatment products for bleeding disorders, in addition to research in the field. The forum covered many important topics, such as gene therapy and blood and plasma safety. Thirty-six presenters from 13 countries delivered 40 talks on a wide range of topics, including clinical and pre-clinical research activity in gene therapy.

16th International Musculoskeletal Congress

The 16th International Musculoskeletal (MSK) Congress was held in Madrid, Spain, from May 10 to 12, with a total of 406 professionals from 71 countries attending—a record for a WFH MSK Congress. The program featured sessions which spanned multiple professional disciplines. It also covered many topics for the first time, such as obesity and hemophilia and the athlete with hemophilia. The Congress—which has historically focused on MSK experts—this time also attracted hematologists, nurses, psychologists, social workers, family medicine doctors, medical scientists, and patients. A total of 110 abstracts were submitted, eight free papers were presented and 51 e-posters were accessible at the exhibition display. For the first time at a Musculoskeletal Congress, the WFH offered a scheduled time for presenters to be at their posters across the three-day event. The WFH sponsored ten physical therapists/orthopedists from emerging countries through travel grants for the Congress.



Regional highlights

Success stories from around the world

The WFH supports the needs of national member organizations (NMOs) through capacity-building, advocacy and development programs and initiatives. These national- and regional-level endeavours have helped our NMOs improve outreach and diagnosis, strengthen medical and paramedical expertise, and empower their local bleeding disorders communities to serve as a stronger voice with governments.

The addition of several new NMOs to the WFH family in 2018 meant that new associate NMOs were able to enrol in WFH development programs—such as the Cornerstone Initiative—in 2019. It also allowed these NMOs to strengthen their organizational capacity and leadership skills through regional training, and lay the foundation for the improvement of bleeding disorders care in their countries. The WFH is thankful for the work the Alliance franco-africaine pour le traitement de l'hémophilie (Afath) has done to support French-speaking African hemophilia patient organizations. Eight countries have benefitted from direct program support from Afath: Burkina Faso, Madagascar, Mauritania, Togo, Benin, the Republic of Congo, Rwanda and the Democratic Republic of Congo. Patient associations from five of these nations have since gone on to become WFH associate NMOs.

Below are some highlights of programs and activities from the regions:

UZBEKISTAN



On April 19th 2019, the WFH and the Ministry of Health of the Republic of Uzbekistan signed a Memorandum of Understanding (MoU) within the framework of the Global Alliance for Progress (GAP) Program. The main objectives of the GAP Program in Uzbekistan are to strengthen the multi-disciplinary comprehensive medical expertise in the diagnosis, treatment and care of hemophilia and other inherited rare bleeding disorders in the country, establish two additional Hemophilia Treatment Centres (HTCs) in the region, provide expert assistance in the creation of a National Hemophilia Committee and Program, support the regional outreach activities of the Tashkent Society of Patients with Hemophilia—a WFH national member organization (NMO)—and guide the development of a national data collection and analysis system to properly monitor health outcomes. The WFH will complement the implementation of the GAP program in Uzbekistan with the continued donation of treatment products through the WFH Humanitarian Aid program.

EUROPE

3

GAP Programs

3

regional
development
programs

1

Development
Grant Program

3

regional
workshops and
events

9

Twinning
Programs

30

IEQAS labs

4

countries received
HA donations

VIETNAM



The WFH GAP Program in Vietnam (2016 to 2019) has dramatically improved care in the country. Hemophilia care has become more nationally focused and there has been a significant improvement in the capacity of the coordinated network of the seven main HTC's, which are now participating in the WFH WBDR. Organizational and leadership skills of Vietnamese NMO members have been strengthened through training and coaching. People with bleeding disorders and their families have been empowered through education. WFH Humanitarian Aid donations have made it possible to provide patients in the country—including children—with life-saving treatment. All of this effort has made it possible to increase the overall level of care in Vietnam, and identify nearly 900 new patients across the country.

SOUTHEAST ASIA & WESTERN PACIFIC

3
GAP Programs

1
regional
development
program

1
Development
Grant Program

3
regional
workshops and
events

2
Twinning
Programs

19
IEQAS labs

7
countries received
HA donations

SOUTH AFRICA



The third WFH Africa Summit was held from September 3 to 4, 2019 in Johannesburg, South Africa. The event brought together key stakeholders in the African community, including patients, physicians, government officials and WFH national member organizations (NMOs). An action plan was formulated by all stakeholders to further advance the achievement of the four priority areas of the WFH Africa Summit 2017 declaration: ensure the integration of hemophilia and other bleeding disorders as part of health system priorities; implement outreach and patient identification initiatives; improve diagnosis; and improve access to treatment and care.

AFRICA

8
regional
development
programs

6
Development
Grant Programs

5
regional workshops
and events

13
Twinning
Programs

12
IHTC Fellowships

20
IEQAS labs

29
countries received
HA donations

BANGLADESH



In 2019—for the first time ever—the government of Bangladesh agreed to a firm commitment to budget funds for hemophilia patient care. This accomplishment was a direct result of the collective efforts of the WFH, the national member organization (NMO), hematologists and other stakeholders in the country. The result of this agreement is that in 2020, six medical college hospitals will receive a total of \$418,000 USD to purchase factor concentrates for registered hemophilia patients.



SOUTH ASIA & EAST ASIA



JORDAN



The WFH regional musculoskeletal (MSK) initiative was launched in the Middle East in 2018 to allow local specialists to standardize—and therefore improve—the management of MSK complications in the region. The third experience sharing workshop was held in Jordan in September 2019. The event included a combined program of platform presentations and patient assessments to share international and regional experiences and show how MSK assessments, complications and inter-disciplinary treatment approaches for people with hemophilia (PWH) can be better managed. In particular, patient assessments—through separate and joint orthopedic and physiotherapist sessions—made it possible to share and facilitate skills transfer between network members. The WFH Regional MSK Network is also playing an influential role in increasing awareness about the importance of prevention and early intervention to mitigate MSK complications for PWH in the region. The interactions helped showcase success stories from different countries, and demonstrated the importance of physiotherapists working in tandem with the orthopedics team and other specialists.



MIDDLE EAST



COLOMBIA



The XIX National Hemophilia Forum took place in June 2019 in Bucaramanga, Colombia. The WFH supported the organization of the forum through the GAP Program in Colombia. The forum offered activities to train and educate multidisciplinary teams, and identified the potential next steps for increasing access to care for people with bleeding disorders in Colombia. The event also covered von Willebrand disease (VWD) and the role women play in the community. Nearly 600 people took part in the forum from both the medical and the lay community.

SOUTH AMERICA

2	2
regional development programs	GAP Programs Development Grant Programs
4	1
regional workshops and events	Twinning Program
6	14
IHTC Fellowships	IEQAS labs
6	
countries received HA donations	

MEXICO



The WFH Regional Workshop for Central American laboratories on the diagnosis of hemophilia and other bleeding disorders was successfully held in Mexico City in June 2019. The workshop provided participants with tools to improve the diagnosis of hemophilia and inhibitors. The need for this kind of education is critical in the region because many Central American countries now have increased access to treatment products, either through the WFH Humanitarian Aid Program or through increased government purchases. Consequently, the accurate diagnosis of inhibitors and the follow-up of children on prophylaxis are being practiced more consistently in Central America.

CENTRAL AMERICA & CARIBBEAN

7	1
regional development programs	Development Grant Program
5	4
regional workshops and events	Twinning Programs
4	18
IHTC Fellowships	IEQAS labs
11	
countries received HA donations	

World Hemophilia Day



The theme of World Hemophilia Day 2019 was “Reaching Out: The First Step to Care”—and the passion for care was clearly felt by everyone in the inherited bleeding disorders community on April 17.

Thousands of people shared their stories throughout the world, and the WFH Facebook page, LinkedIn page and Twitter timeline saw hundreds of updates on the big day.

Last year saw the WFH launch a new World Hemophilia Day microsite designed to offer visitors information about inherited bleeding disorders, as well as communications material to support them in creating their own activities. The site also had a dedicated space where people could share

their stories. The new site—www.worldhemophiliaday.org—was a great success. Over 5,600 people visited the platform, and the pages of the site were viewed over 12,000 times.

Once again, landmarks around the world were part of the “Light it up Red” campaign. Over 70 landmarks took part in 2019, and the images of those landmarks were shared on social media worldwide.

United in solidarity

The WFH gratefully acknowledges the support of the individuals and organizations who partnered and collaborated with us in 2019. On behalf of the bleeding disorders community, thank you for your belief in the work we do every day in pursuit of our shared vision of Treatment for All. Learn more about how you can support our work at www.wfh.org/supportus.



Three national member organizations (NMOs) continued or renewed their support of the Cornerstone Initiative in 2019, demonstrating incredible solidarity with the global bleeding disorders community:

The **U.K. Haemophilia Society** pledged to donate £45,000 over three years

The **National Hemophilia Foundation** renewed their commitment and awarded the WFH their Global Leadership Award

The **Canadian Hemophilia Society** continued their steadfast support, which they have provided annually since 2012

OUR COMMUNITY PARTNERS

Whether it be through training, empowering future leaders and multidisciplinary healthcare professionals, providing communities with the capacity for data collection, or supporting capacity-building initiatives for patient organizations, our Community Partners—**Hemophilia of Georgia, the Hemophilia Alliance, and the National Hemophilia Foundation**—play a critical role in helping us achieve our mission.

A record

30

chapters of the National Hemophilia Foundation supported the WFH

Over

140

individuals and organizations took the extra step and **became Professional or Group members**

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

Thank you to our donors

The WFH gratefully acknowledges the support of the individuals and organizations who partnered and collaborated with us in 2019.

In 2019, 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

COMMUNITY PARTNERS

Hemophilia Alliance
Hemophilia of Georgia, Inc.
National Hemophilia Foundation

SOLIDARITY FUND

Asociación Costarricense de Hemofilia (ASOHEMO)
Azerbaijan Republic Association of Hemophilia (ARAH)
Bulgarian Haemophilia Association
Canadian Hemophilia Society
Croatian Hemophilia Society
Fundación Hemofílica del Ecuador, FUNDHEC
Fundación Panameña de Hemofilia
Georgian Association of Haemophilia and Donorship
Haemophilia Association of Mauritius (HAM)
Haemophilia Foundation Australia
Haemophilia Foundation of New Zealand
Hemophilia Philippines (HAPLOS Community) Foundation Inc.
Hemophilia Society of Malaysia
Hemophilia Society of Maldives
Irish Haemophilia Society Ltd.
Kenya Haemophilia Association
Korea Hemophilia Foundation
Latvia Hemophilia Society
Liga Colombiana de Hemofílicos

Singapore Haemophilia Society
South African Haemophilia Foundation
UK Haemophilia Society

MEMORIAL FUNDS

Susan Skinner Memorial Fund

TRIBUTES

In honour of Brian Craft
In honour of Cahroon Ehterami
In honour of Donald Goldman
In honour of Rohaan A. Malik
In memory of Khadeeja Adam
In memory of Ashwin Pindoria
In memory of Frank Schnabel II

DONORS

\$100,000 – \$249,999

André de la Porte Family Foundation

\$50,000 – \$99,999

Glenn and Beatrice Pierce

\$10,000 – \$24,999

Mark Skinner and James Matheson
1 anonymous donor

\$5,000 – \$9,999

Canadian Hemophilia Society
Donald and Barbara Goldman
The Marketing Research Bureau, Inc.
Matthew Ottmer and Megan McLean
Phillips 66

\$1,000 – \$4,999

Akron Children's Hospital

Our Patron, Jan-Willem André de la Porte, continues giving his steadfast support and leadership to the WFH.

A special thanks goes to the leadership of WFH USA, whose mandate is to raise funds and raise awareness of our global mission in the U.S.A. On behalf of the bleeding disorders community, thank you for your belief in the work we do every day in pursuit of our shared vision of Treatment for All.

Paula Bell and Rob Christie
Bleeding Disorders Association of Northeastern New York
Coalition for Hemophilia B
Colorado Chapter of the National Hemophilia Foundation
Florida Hemophilia Association
Assad Haffar
Hemophilia Association of the Capital Area
Hemophilia Foundation of Greater Florida, Inc.
Hemophilia Foundation of Michigan
Hemophilia Foundation of Oregon
Hemophilia Foundation of Southern California
Hemophilia of Indiana Inc.
Craig Kessler
Kate Khair
Barbara Konkle and Peter Kollros
Ron and Jenny Lees
Lone Star Bleeding Disorders Foundation
Midwest Hemophilia Association
John Murphy
New England Hemophilia Association
Elizabeth A. Paradis
Joseph Pugliese
Rocky Mountain Hemophilia & Bleeding Disorders Association
Edith A. Rosato
Maria M. Salas-Pilla
Alison M. Street
Kenneth Trader

Thank you to our donors (cont'd)

\$500 – \$999

Bleeding Disorders Alliance Illinois
Ute Braun
Amy and Michael Dunn
Fondazione Angelo Bianchi Bonomi
Gateway Hemophilia Association
Great Lakes Hemophilia Foundation
Hemophilia Foundation
of Minnesota/Dakotas
Hemophilia of North Carolina
Kentucky Hemophilia Foundation, Inc.
Phillip Kucab
Nevada Chapter of the National
Hemophilia Foundation
Dawn Rotellini
Frank Schnabel IV and Lillian Schnabel
Gina Schnabel
Sundar Rajan Selvaraj
Virginia Hemophilia Foundation
Mary Q. Wingate
1 anonymous donor

\$250 – \$499

Alaska Hemophilia Association
Antonio J. Almeida
Alain Baumann
Per Arne Berg
Connecticut Hemophilia Society
Jacqueline Curtis
Matt Gross
Hawaii Chapter of the National
Hemophilia Foundation
Hemophilia Alliance of Maine, Inc.
Hemophilia of South Carolina
Christine Herr
Idaho Chapter of the National
Hemophilia Foundation
Garrett and Lisa Kennedy
Jennifer Laliberté
Gabriel Lottaz
Northern Ohio Hemophilia
Foundation, Inc.
Peter Pustoslemsek

Southwestern Ohio Hemophilia
Foundation
Eric and Marion Stolte
Jerome Teitel
3 anonymous donors

\$150 – \$249

Jeffrey Barlekamp
Laura Chalfin
Dan Doran
Kerry Grant
Ann Harrington
Peter Jones
Dan Levin
Pfizer Foundation, Inc.
Kasturben Pindoria
Sunil Pindoria
Leslie Robinson
1 anonymous donor



Thank you to our corporate partners

The WFH gratefully acknowledges the generous support of our dedicated partners and corporate sponsors.

CORPORATE PARTNER PROGRAM

Visionary Partners

Bayer
CSL Behring
Grifols
Novo Nordisk
Pfizer
Takeda

Leadership Partners

Sanofi Genzyme

Collaborating Partners

BioMarin Pharmaceutical Inc
F. Hoffmann-La Roche Ltd
Octapharma
Sobi
Spark Therapeutics

Community Partners

Biotest
GC Pharma
Kedrion
Precision BioLogic
uniQure

GLOBAL ALLIANCE FOR PROGRESS (GAP) SECOND DECADE

Visionary Partner

Takeda

Leadership Partner

CSL Behring

Collaborating Partners

Bayer
Biotest
Kedrion
Pfizer
Sanofi Genzyme
Sobi

WFH HUMANITARIAN AID PROGRAM

Founding Visionary

Sanofi Genzyme
Sobi

Visionary

Bayer

Leadership

F. Hoffmann-La Roche Ltd
Grifols

Contributor

CSL Behring
GC Pharma

WORLD BLEEDING DISORDERS REGISTRY

Visionary Partners

Sobi
Takeda

Collaborating Partners

Bayer
CSL Behring
F. Hoffmann-La Roche Ltd
Grifols
Pfizer

SPONSORED PROGRAMS

Development Grant Program

Sanofi Genzyme

International External Quality Assessment Scheme Program

Novo Nordisk Haemophilia Foundation

International Hemophilia Training Centre

Fellowship Program

Bayer

Twinning Program

Pfizer

Gene Therapy Round Table

Bayer
BioMarin Pharmaceuticals
F. Hoffmann-La Roche Ltd
Pfizer
Sangamo Therapeutics
Spark Therapeutics
uniQure

Additional Support

Sigilon Therapeutics

Global Forum

Bayer
F. Hoffmann-La Roche Ltd
Spark Therapeutics
uniQure

Additional Support

Héma-Québec

Musculoskeletal Congress

Platinum

Takeda

Gold

Bayer

Sobi

WFH 2019 Africa Summit

F. Hoffmann-La Roche Ltd
Takeda

Additional Support

National Bioproducts Institute

Website

Novel Therapies eLearning Centre:

Spark Therapeutics

Website localization projects:

Japanese: Sanofi Genzyme

Russian: Sobi

Other sponsored programs

F. Hoffmann-La Roche Ltd
Pfizer
Stago

Other product donation

Novo Nordisk
Takeda

2019 Financial Report

In financial terms, 2019 was a better year than anticipated for the World Federation of Hemophilia (WFH), with a net deficit of \$2,176 thousand compared to a budgeted net deficit of \$2,576 thousand. This included the extraordinary endeavour of the development of the *WFH Guidelines for the Management of Hemophilia, 3rd edition*, which was not budgeted (\$728 thousand). The strong U.S.A currency—which averaged \$1.33 CAD throughout the year—once again contributed to the positive result. This solid base prepared us well for the crisis that would come in 2020.



Healthy revenue growth

The corporate sponsors of WFH programs and initiatives continued their committed support with 2019 contributions of \$6,094 thousand, an increase of \$1,320 thousand (28%) over 2018. A portion of this increase was due to contributions of \$406 thousand towards the WFH Global Forum (GF) and the WFH International Musculoskeletal Congress (MSK) that take place every two years. There was also an increased amount of funding for other important initiatives, including Youth Leadership and Data Collection workshops, as well as eLearning activities. Revenues for our flagship programs—GAP, Twinning, and the International Hemophilia Training Centre (IHTC) Fellowship Program—remained stable.

In 2019, the WFH Humanitarian Aid Program continued to expand with the addition of two new corporate partners: Roche and Bayer. This contributed to the distribution of a total of 241 million IUs worldwide. As per Canadian accounting rules, revenues received for restricted purposes can only be recognized in the year in which related expenses are incurred. In 2019, \$1,723 thousand (versus \$1,291 thousand in 2018) was spent against the revenues we received for the WFH Humanitarian Aid Program. Thus, only this amount is recognized in WFH revenues.

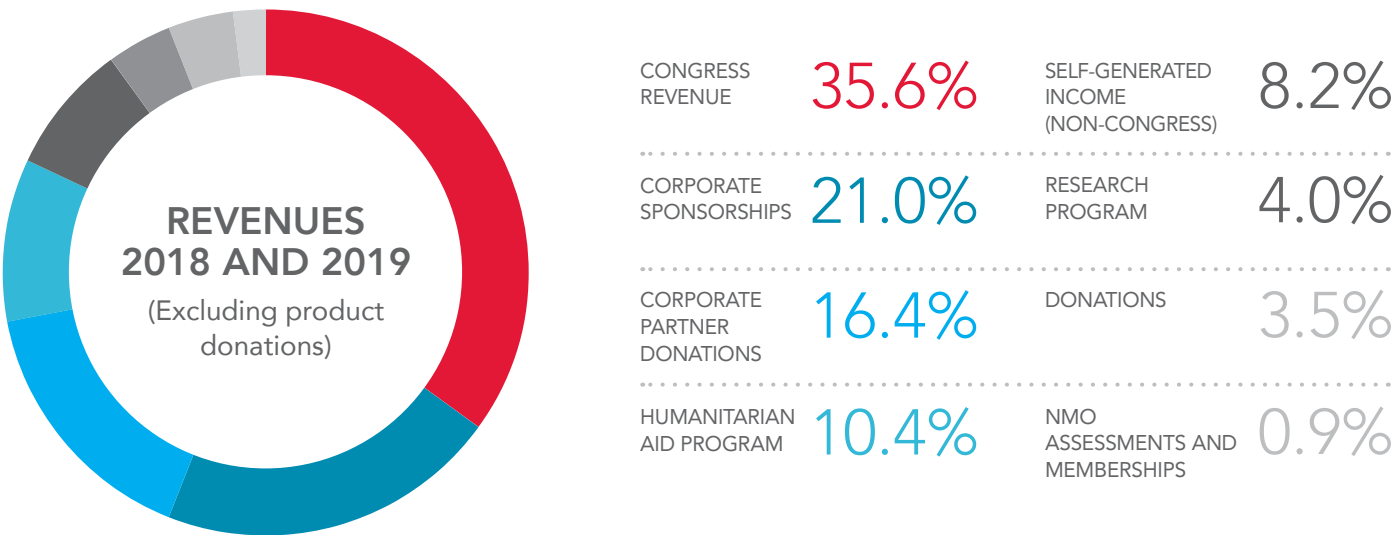
For the WFH Research Program, which is also a restricted program, we recognized \$537 thousand in revenues (versus \$631 thousand in 2018). With these funds, the WFH was able to continue to expand the World Bleeding Disorder Registry (WBDR), as well as the WBDR Research Support Program, which gives small grants to Hemophilia Treatment Centres (HTCs).

Self-generating income (non-Congress) was at \$1,729 thousand in 2019, (versus \$670 thousand in 2018) representing a tremendous growth of \$1,059 thousand. This was fuelled by the internally-managed GF and the MSK meetings as well as a strong performance in investments, which was driven by the market recovery of equities, a series of interest rate reductions by the world's central banks that had a positive impact on fixed income returns, and our internal strategy of aggressively investing excess cash.

Total WFH revenue, before Congress and Product Donations, reached \$10,766 thousand in 2019, \$2,788 thousand (35%) above 2018.

As the WFH requires two years over which to deliver the biennial WFH World Congress as well as other WFH meetings, it is typical for us to review our results over a two year cycle. As shown in Figure 1, excluding product donations, 37% of revenues over the two-year cycle were for sponsorships from WFH corporate partners; 14% were for restricted programs (Humanitarian Aid and the Research Program); and the remaining 48% were generated through the WFH 2018 World Congress, financial donations, self-generating income activities, national member organization (NMO) assessments, and memberships.

FIGURE 1



Expenses aligning with strategic objectives

When combined, healthcare development programs, education and public policy programs, and the WFH Humanitarian Aid Program represented the largest proportion of expenses with 57% of the expenses incurred over the past two years, as seen in Figure 2. The WFH World Congress also represented a large investment at 24% of WFH expenses, while fundraising and corporate relations expenses represented 5% of this total. Additional expenses for the WFH included administration at 8%, and governance and communications at 5%.

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 2019, 241 million IUs of clotting factor concentrate were strategically donated to 72 countries, improving and sustaining care for people in the developing world. This represents a 26% growth in volume of IUs distributed (49.5 million more IUs than 2018). The majority of these donations—worth \$437 million USD—are reported in the audited financial statements of WFH USA. The amount reported in the financial statements of the WFH is \$144 million.

Year-over-year comparison

The 2019 and 2018 statement of revenues and expenses, illustrated in Figure 3, reflects the fluctuations within a typical two-year cycle in which the World Congress is held in even years, and the GF and MSK are held in odd years. This also reflects the fact that varying amounts of product donations are received yearly.

On the revenue side before Congress and Product Donations, there was a tremendous growth of \$2,788 thousand. This was largely due to the solid increase in contributions from our corporate partners (\$1,320 thousand); a healthy surge in self-generating income derived from WFH event registration and housing revenues of \$574 thousand from the 16th International Musculoskeletal Conference and the WFH Global Forum events, as well as investments of \$561 thousand. Further, the expansion of the Humanitarian Aid Program—which now includes two new partners—brought in an additional \$432 thousand.

The overall spend of \$12,079 thousand in expenses before Congress and Product Donations—\$2,999 thousand above 2018—reflects the continued efforts of the WFH to support the needs of the global bleeding disorders community. This was highlighted by the increase of \$1,148 thousand for the Humanitarian Aid Program that included both the growth in product donations delivered, as well as the implementation of strict compliance measures to satisfy all applicable policies, procedures and donor agreement stipulations. Education and Public Policy grew by \$921 thousand, with \$728 thousand being spent on the update of the WFH Guidelines for the Management of Hemophilia—an extensive document which includes 337 specific recommendations and which will have widespread global significance for the entire global bleeding disorders community. The WFH sincerely thanks the more than 100 contributors who made the development of these guidelines possible despite a challenging timeline. In addition to this, an incremental \$439 thousand was spent on Healthcare Development Programs, mostly for regional meetings (such as the WFH Africa Summit, and South and Central American events) as well as for accreditation. The fluctuation of foreign exchange brought in an unfavourability of \$148 thousand over the two years.

FIGURE 2

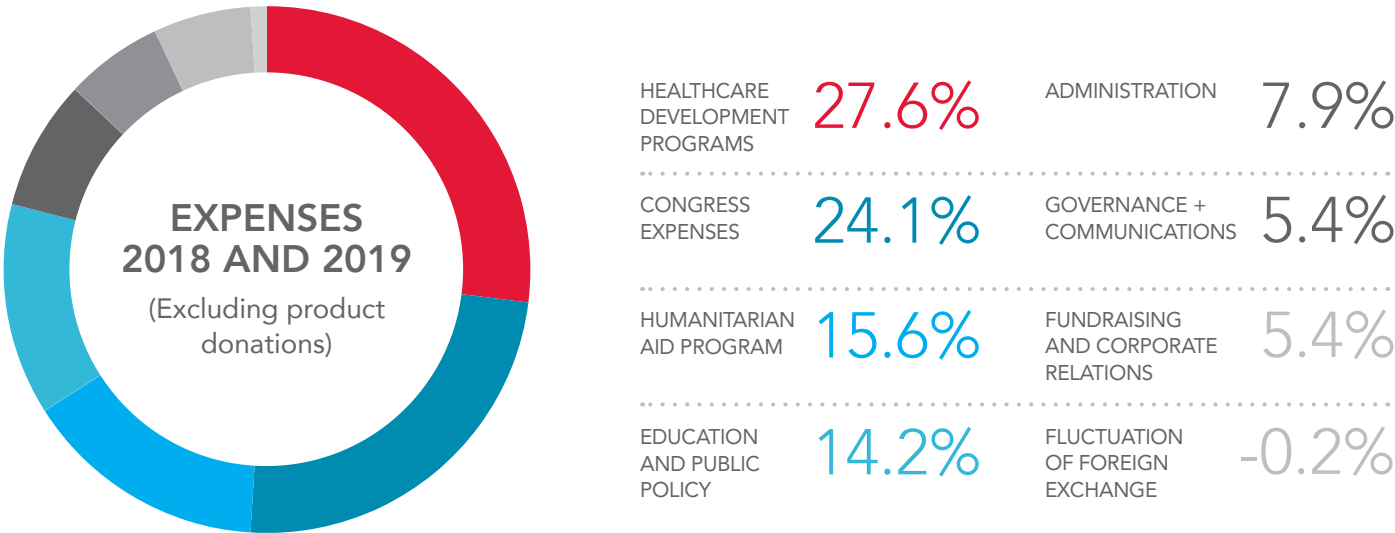


FIGURE 3

REVENUES AND EXPENSES

(Expressed in Canadian Dollars)

	2019	2018
REVENUES		
Donations	554,549	486,366
Corporate Partner Donations	2,599,999	2,162,448
Corporate Sponsorships	3,494,327	2,611,463
Research Program	537,462	631,213
NMO Assessments and Memberships	138,418	126,870
Humanitarian Aid Program	1,722,648	1,290,534
Self-Generated Income (Non-Congress)	1,728,952	669,621
Total Revenues before Congress and Product Donations	10,766,355	7,978,515
Congress Revenue	-	10,347,467
Product Donations	143,565,405	81,712,043
TOTAL REVENUES	154,331,760	100,038,025
EXPENSES		
Healthcare Development Programs	4,059,085	3,620,435
Education and Public Policy	2,441,473	1,520,076
Humanitarian Aid Program	2,744,130	1,595,870
Governance and Communications	770,189	745,283
Fundraising & Corporate Relations	814,807	700,578
Administration	1,206,883	1,003,672
Fluctuation of Foreign Exchange	42,138	(105,916)
Total Expenses before Congress and Product Donations	12,078,705	9,079,998
Congress Expenses	864,019	5,842,380
Product Donations	143,565,405	81,712,043
TOTAL EXPENSES	156,508,129	96,634,421
EXCESS (DEFICIENCY)	-2,176,369	3,403,604

Looking ahead

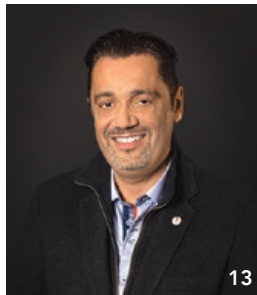
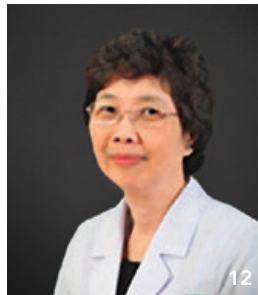
The COVID-19 pandemic has certainly had, and will continue to have, an impact on 2020 and possibly beyond.

The cancellation of the 2020 World Congress is projected to bring a deficit in an even year—when we normally expect a surplus to sustain us over a two year period. We have been prudent in past years to create a robust base of reserves in order to withstand turbulent times. Our team has also been proactive in mitigating some of the financial impact of the crisis. This has entailed doing many activities differently—virtually, instead of in person—including holding a Virtual Summit in June 2020 in place of the World Congress. We have prepared forecasts for a variety of realistically conceivable downside scenarios, and we are reasonably confident that our reserves are adequate to see us through the foreseeable future. Our focus and dedication remain strong to bring us closer to our vision of Treatment for All.

WFH Board of Directors

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 for people with hemophilia and other inherited bleeding disorders worldwide.



WFH staff



WFH Board of Directors, members & patron 2018–2020

- | | | | |
|---|--|---|--|
| 1 Alain Weill
President
France | 2 Glenn Pierce
Vice President, Medical
U.S.A. | 3 Barry Flynn
Vice President, Finance
U.K. | 4 Saliou Diop
Medical member
Senegal |
| 5 Cesar Garrido
Lay member
Venezuela | 6 Barbara Konkle
Medical member
U.S.A. | 7 Magdy El Ekiaby
Medical member
Egypt | 8 Cedric Hermans
Medical member
Belgium |
| 9 Carlos Safadi Márquez
Lay member
Argentina | 10 Deon York
Lay member
New Zealand | 11 Dawn Rotellini
Lay member
U.S.A. | 12 Ampaiwan Chuansumrit
Medical member
Thailand |
| 13 Vincent Dumez
Lay member
Canada | 14 Jan-Willem André
de la Porte
WFH Patron
South Africa | | |

WFH 2019 highlights



Number of
IUs DONATED

241+
Million



Number of
patients enrolled in WBDR

4,166



Global reach of
WFH healthcare programs

134
countries

World Federation of Hemophilia

1425, boulevard René-Lévesque Ouest
Bureau 1200
Montréal (Québec) H3G 1T7
Canada

T +1 514 875-7944 **F** +1 514 875-8916
wfh@wfh.org

wfh.org

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.

Printed in Canada – Design: tmdesign.ca

