

A young boy with dark hair, wearing a light blue surgical face mask and a bright blue jacket with dark blue sleeves, is hanging from a thick red rope. He is looking directly at the camera. The background is a blurred green forest. The text 'WFH ANNUAL REPORT 2020' is overlaid on the left side of the image in white, bold, sans-serif font.

WFH ANNUAL REPORT 2020

wfh.org



WFH

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

Overcoming the challenges of COVID-19

The COVID-19 pandemic created enormous challenges for the bleeding disorders community—but the WFH was able to persevere and continue to support access to care and treatment worldwide.

We continue to collaborate with our global network of national member organizations (NMOs) to represent the interests of people with hemophilia and other inherited bleeding disorders in 147 countries. Together, we work to ensure every person with a bleeding disorder, regardless of gender, has access to world-class care. Our corporate partners, donors, and volunteers all share this conviction, and we thank them for their dedication.

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Our vision and mission

Our vision of Treatment for All is that one day, all people with a bleeding disorder will have access to care and treatment, regardless of 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 was designed to align our 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 are used to monitor the progress of these priorities.

The strategic priorities 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

Letters from our President and CEO

Friends,

The COVID-19 pandemic made 2020 a very challenging year for all of us. And yet, we were able to adapt and continue to support each other, and this is something we can all be very proud of.

In October 2020, I became WFH President, and many people told me that I accepted the role during a very daunting time. My answer to these comments was always the same: while today is a time of great changes, the commitment of WFH leadership, staff, and everyone in the bleeding disorders community has always been unwavering and strong. We will continue supporting the community—without interruption. Our vision of Treatment for All has not changed, and we have not lost a step on the journey to that objective.



Cesar Garrido
WFH President



Friends and colleagues,

2020: what a year!

We can say one thing for certain about 2020: it made us adapt more quickly than we have ever done before. It was quite a challenge—and the team did it. You did it! Even if different than initially planned, we delivered and often surpassed the goals we had set before the pandemic began.

We reinvented our way of delivering support to the community and made a difference in the lives of many people with bleeding disorders (PWBDs) and their families. Here are just a few examples of what we were able to accomplish last year:

- **Successful Virtual Summit**—in fact, the very first global virtual congress in our field
- **Exponential growth in webinars** organized from Montreal, but also worldwide, allowing us to reach a record number of participants. Almost 100 webinars were organized by our departments last year.
- **Uninterrupted therapy delivery by the WFH Humanitarian Aid Program** at a time when borders and logistics companies were literally shutting down
- **Continued data gathering for our registries** such as the Annual Global Survey (AGS) and the World Bleeding Disorders Registry (WBDR)
- **Publication** of the WFH Guidelines for the Management of Hemophilia, 3rd edition
- **Delivery of another innovation:** the first Global Summit on women and girls with inherited bleeding disorders
- **Execution of a secure virtual vote** at our General Assembly and a successful transition to the new board
- **Welcomed** Angola, Botswana, Djibouti, Fiji, Kosovo, Malta, Republic of Congo and Rwanda to the WFH family as associate NMOs

I am glad that our efforts continued unabated, that all our partners followed us—and that we were even able to add new supporters. In order to do this, we all had to change the way we worked. The daily routine in front of our screens, of not having many social contacts was—and still is—hard for many. But none of these great achievements would have been possible without the support of our volunteers, board members, NMOs and healthcare practitioner (HCP) leaders around the world. Virtual life sometimes made it feel like we were all far away, but because of the resilience of our community, we never felt so close to each other.



Alain Baumann
WFH CEO



Adapting to a new reality

The COVID-19 pandemic had a huge impact on the global bleeding disorders community and the WFH. Supply chains were disrupted, face-to-face meetings had to be cancelled, and pandemic-mitigation measures made the already-challenging daily life of people in the community even more demanding. The WFH adapted to this new reality by shifting training and resources online and by collaborating closely with NMOs to provide support in the most effective way possible.

Virtual Summit

While the COVID-19 pandemic necessitated the cancellation of the WFH World Congress in Kuala Lumpur, Malaysia, the WFH was still able to hold a major event to meet the educational needs of the community and share knowledge. A record number of people participated in the WFH Virtual Summit: Connecting the Global Bleeding Disorders Community. More than 8,550 participants from 160 countries took part in over 50 sessions over six days, and over 2,000 people viewed post-event on-demand content.

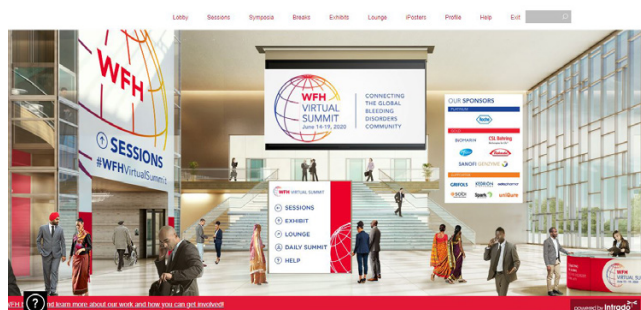
There was something for everyone at the WFH Virtual Summit, including educational medical and multidisciplinary sessions, WFH Humanitarian Aid Program announcements, and information related to the many endeavours led by the WFH, such as our registries, development programs, the Twinning program and the VWD Call to Action. Many of these sessions were simultaneously translated into five languages.

The WFH Volunteer Awards were presented online for the first time at the WFH Virtual Summit. The recipients—who generously share their time, expertise, energy every day—were individually featured in videos that showcased their accomplishments. This innovative approach was our way of celebrating the remarkable achievements of the 2020 award winners, each of whom has made a significant impact on people living with bleeding disorders around the world.

The WFH would like to thank all the people who contributed to the planning and delivery of the first WFH Virtual Summit, including the medical/scientific and multidisciplinary committees, abstract reviewers, the Virtual Summit working group, WFH staff as well as our sponsors and exhibitors. The WFH would also like to thank the Hemophilia Society of Malaysia for the work they did in preparation for the WFH 2020 World Congress, which, unfortunately, could not be held.



CONNECTING
THE GLOBAL
BLEEDING
DISORDERS
COMMUNITY



Moving online for the world

COVID-19 pandemic restrictions meant that dozens of scheduled in-person events had to be cancelled. The WFH was able to bring these events online with little delay—avoiding a potentially devastating gap in learning, while opening up educational opportunities to a global audience. Here are some of the notable webinars that were held in 2020, as well as COVID-19 advisories.

COVID-19 and bleeding disorders

Topics	Audience	Unique attendees
Bleeding disorders and COVID-19	Global: PWBDs, NMOs, HCPs	2,112
COVID-19 and bleeding disorders (three webinars)	Bangladesh, Sri Lanka, Tajikistan	127
COVID-19 and bleeding disorders webinar for French-speaking countries	Regional: PWBDs, NMOs, HCPs in Africa	45
COVID-19, bleeding disorders, and MSK issues	Regional: PWBDs, NMOs, HCPs in South America & CAC	166
Dental care for people with bleeding disorders during COVID-19—what has changed?	Global: PWBDs, NMOs, HCPs	302
Maintaining joint health for people with bleeding disorders during COVID-19	Global: PWBDs, NMOs, HCPs	299

Bleeding disorders diagnosis and management

Topics	Audience	Unique attendees
First WFH Global Summit on Women and Girls with Inherited Bleeding Disorders	Global: PWBDs, NMOs, HCPs	608
General education on bleeding disorders (introduction, WFH guidelines, women with bleeding disorders) (three webinars)	Regional and national: PWBDs and NMOs, in Middle East, South and East Asia	1,334
Gene therapy: is robust scientific inquiry the missing factor?	Global: PWBDs, NMOs, HCPs	399
International Hemophilia Training (IHTC) virtual training series on diagnosis, management, and comprehensive care (six webinars)	Global: IHTC fellows and alumni	188
Psychosocial care for PWBDs and their family members (three webinars)	Regional: PWBDs and families in Middle East, South America, Central America and Caribbean (CAC) regions	121
WBDR investigator meeting: data collection and research in practice	Regional: Africa, Middle East	44
WFH Caribbean webinar series: using data to measure and improve quality of care	Regional: HCPs in Caribbean	39
WFH Global VWD Call to Action	Global: PWBDs, NMOs	110
WFH Guidelines for the Management of Hemophilia	Global: NMOs, HCPs	705
WFH Guidelines for the Management of Hemophilia, home therapy and MSK care (three webinars)	Regional and national: HCPs from South America, CAC, South Asia and Central Asia	160

Medical and logistics webinars for Humanitarian Aid donations management

Topics	Audience	Unique attendees
Case conference and bedside rounds	Regional: HCPs from South Asia, Africa, Asia and Western Pacific, Central and South America	329
Front-line doctors and second-line treaters training	Regional: HCPs from South Asia, Africa, Asia and Western Pacific, Central and South America	207
Home treatment and prophylaxis	Regional: HCPs from East Africa, South Asia	48
Logistics, product handling, storage and use	Regional: HCPs from Africa, South Asia, Asia and Western Pacific, Central and South America, Eastern Europe	182
Novel therapies on inhibitor management	Regional: HCPs from Africa, South Asia, Asia and Western Pacific, Central and South America	114
Train the trainers workshop	Global: Selected HCPs from Kenya, Jamaica, Nepal, Nigeria, Pakistan, Sri Lanka	9
Treatment product workshop (EHL)	Regional: HCPs from Africa, South Asia, Asia and Western Pacific, Central and South America	144
Utilization reports and training	National: NMO Chapters and/or HCPs in India	172

Advocacy to sustain care

Topics	Audience	Unique attendees
Advocacy and development of national bleeding disorders programs (three webinars)	National: NMOs and chapter leaders from India, Nigeria, Mexico	322
Advocacy during COVID-19: having our voices heard	Global: NMOs and patient advocates	134
Sustaining care in the pandemic world and evidence-based advocacy (four webinars)	Regional: NMOs and patient advocates in Europe, Africa, Middle East, Southeast Asia and Western Pacific	176

Strengthening NMO capacity

Topics	Audience	Unique attendees
Active communications virtual workshops for NMOs (five webinars)	Regional: NMO and patient leaders	164
Global and regional youth leadership and engagement webinars and Training of Trainers (TOT) workshops (five webinars)	Global/Regional: NMOs, youth groups	264
NMO skills on project development and implementation, NMO leadership, structure and chapter development (five webinars)	Global/Regional/National: Middle East, South America, CAC and Africa	273
Twinning Program virtual sessions (two webinars)	Global: current twins, NMOs, HTC's, youth groups	249
WFH-Coalition of the Americas (CoA) webinars on governance, NMO structure, leadership, data collection, analysis and use for advocacy (six webinars)	Regional: NMO and patient leaders from South America and CAC	172

COVID-19 statements and advisories

Topics	Publication date
WFH statement on outbreak of novel coronavirus	Feb 3, 2020
WFH statement: update to COVID-19	March 4, 2020
COVID-19 pandemic: practical recommendations for people with hemophilia	March 21, 2020
Specific risks of COVID-19 to the bleeding disorders community	April 2, 2020
Bleeding disorders and COVID-19: the factors and risks to people with bleeding disorders	April 9, 2020



WFH Humanitarian Aid Program

Making access to care possible even during the COVID-19 pandemic

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. This daily challenge was magnified in 2020 due to the COVID-19 pandemic which halted in-person training, and caused significant shipping, delivery, and import permit procurement delays.

The Humanitarian Aid Program team quickly responded to the pandemic by bringing education online, identifying new shipment routes, increasing shipment volumes to compensate for permit delays, and collaborating with local organizations—all to ensure that care would not be interrupted. For 2021, increased donations from our sponsors should further improve distribution to countries that need factor.

2020 also saw the WFH deliver the very first shipments of emicizumab to patients—a new prophylactic treatment to reduce the frequency of bleeding episodes in adults and children of all ages with hemophilia A, with and without factor VIII inhibitors.

In 2020, over 146 million IUs of factor were provided to patients in developing countries, despite the major logistical challenges created by the COVID-19 pandemic.

146M+

IUs of factor
distributed

20,000+

hemophilia A and B
patients treated

51,400+

bleeding episodes
managed

27,000 x 30 mg

vials of emicizumab
distributed

Research and data collection

The Research and Education 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) 2019 was released in October 2020. The report includes global demographic and treatment-related data on people with hemophilia (PWH), von Willebrand disease (VWD), other rare factor deficiencies, and inherited platelet disorders. The national member organizations (NMOs) who contributed to the report faced many data collection challenges due to the COVID-19 pandemic. Nevertheless, the 2019 survey had a high response rate of 82% and includes data from 115 countries.

World Bleeding Disorders Registry (WBDR) 2019 Data Report

This second edition of the *WBDR 2019 Data Report* includes data from over 4,000 people with hemophilia from 53 hemophilia treatment centres (HTCs) and 29 countries around the world. The report highlights the clinical data from patients enrolled in 2019 and demonstrates the growth of the WBDR over the past two years. The addition of the extended data set in 2019 has allowed for more detailed analysis, which will improve patient health monitoring and inform clinical practices.

WBDR Research Support Program

The WFH WBDR Research Support Program is designed to provide research funding to participating HTCs and 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 2020, seven research proposals were approved, bringing the total number of WBDR research proposals provided through this program to 23. Of these, four projects have resulted in accepted posters at international conferences.

Gene Therapy Registry (GTR)

The WFH Gene Therapy Registry (GTR) is a global registry designed to collect long-term safety and efficacy data on all people with hemophilia who receive gene therapy. The core data set was developed by a multi-stakeholder steering committee and was published in the *Journal of Thrombosis and Haemostasis* in 2020. The database is currently under development and will launch in 2021.

Gene Therapy Round Table (GTRT)

The 3rd 2020 WFH Gene Therapy Round Table (GTRT) was held virtually in October, and provided participants with an update on research related to the development of gene therapy. About 80 world-renowned experts convened virtually to discuss the gene therapy pipeline and the knowns and unknowns of gene therapy that researchers are currently working on resolving.



Global programs making a difference

The WFH supports the needs of its national member organizations (NMOs) and the development of hemophilia treatment centres (HTCs), and makes it possible for both to achieve sustainable comprehensive care and treatment for people with hemophilia, VWD and other inherited bleeding disorders.

Global Alliance for Progress (GAP) Program

The main goal of the GAP Program is to increase the diagnosis and treatment of people with hemophilia and other bleeding disorders. In 2020, the WFH—together with its NMOs—implemented the Program in 15 target countries, including five newly-enrolled GAP countries: Bolivia, India, Nicaragua, Nigeria and Palestine. In order to mitigate the impact of the COVID-19 pandemic, national action plans were revised in all 15 countries; the changes included significantly expanding virtual training and educational programs.

Facts for 2020:

15	active countries	:	5,067	new diagnoses of people with bleeding disorders, including 4,897 with hemophilia, 73 with von Willebrand disease (VWD), and 97 with rare clotting factor deficiencies	:	4,823	patients, family members, and NMO board members trained
1,148	hemophilia team members and regulators trained	:	1,528	healthcare professionals acquired a general awareness of hemophilia and other inherited bleeding disorders			



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. **Facts for 2020:**

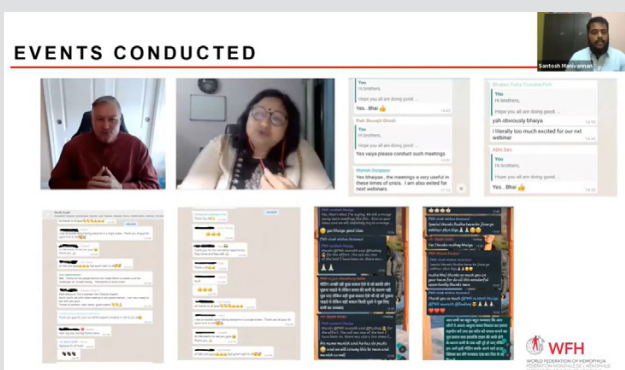
18 Hemophilia Treatment Center (HTC) Twinning partnerships

17 Hemophilia Organizations Twinning (HOT) partnerships

4 Youth Twinning partnerships

2 virtual events—which attracted **249** participants—were held to share twinning experiences

1 year extension was granted to all partnerships in order to compensate for COVID-19 related challenges



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. **Facts for 2020:**

140 centres from **82** countries were enrolled, of which **8** were new laboratories

International Hemophilia Training (IHTC) Fellowship Program

The IHTC Fellowship Program provides clinical and medical training in all aspects of hemophilia and bleeding disorders management to healthcare professionals from developing countries in order to enhance knowledge and engagement and, in turn, deliver better care, increase diagnosis accuracy, and improve patient outcomes. **Facts for 2020:**



3 IHTC fellows completed their in-person training (pre-pandemic)

6 IHTC virtual trainings were held as part of the IHTC Virtual Training Series

188 participants from **46** countries attended an IHTC Virtual Training

Every virtual training was made available in **five** languages (English, French, Spanish, Russian, Arabic)

VWD Initiative Program

The WFH VWD Initiative Program seeks to improve the diagnosis and clinical management of von Willebrand disease (VWD), and create greater awareness of VWD for patient and medical communities. **Facts for 2020:**

9

new countries signed on to the Global VWD Call to Action bringing the total number to **48**

100+

participants took part in the “WFH Global VWD Call to Action: the world’s response” webinar

The WFH hosted a virtual booth dedicated to VWD (WFH 2020 Virtual Summit)

Honduras, Philippines, Serbia and Sri Lanka

continued to implement VWD outreach initiatives in 2020, supported by the VWD Outreach grants received in 2019



Cornerstone Initiative

The objective of the Cornerstone Initiative is to provide support, expertise, and training to countries with minimal levels of care, to help them improve and later benefit from the full range of programs and activities offered by the WFH. Through the Cornerstone Initiative, the WFH lays the foundation of basic care and builds partnerships.

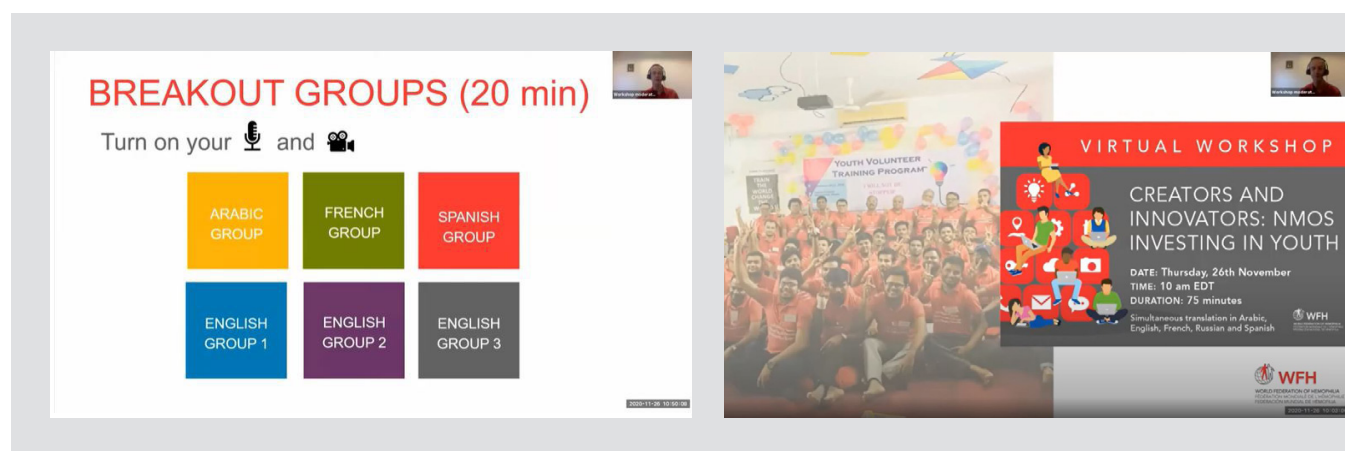
.....
In 2020, Benin, Malawi, Mauritania, Mozambique, Tajikistan, Tanzania, and Togo were part of the Cornerstone Initiative



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 focus on providing opportunities for youth to develop their skills in areas such as leadership, project planning, communications and media relations, alliance building and advocacy. **Facts for 2020:**

2 global webinars were held, with over **150** participants taking part



Development Grant Program (DGP)

The DGP was created to empower NMOs to carry out new and innovative projects to better support their communities. Since the Program's launch in 2018, 26 projects have been supported, with over 1,000 healthcare professionals receiving training and education on the management of bleeding disorders and over 1,000 PWBDs learning more about rare bleeding disorders. **Facts for 2020:**



63 NMO

participants took part in a webinar covering the Program, application guidelines and project proposal writing

10 NMOs

from Afghanistan, Benin, Brazil, France, Guyana, Honduras, Lesotho, Madagascar, Morocco, and Panama received development grants

Celebrating World Hemophilia Day

April 17, 2020 was World Hemophilia Day, and the theme of “Get+involved” was felt around the world despite the challenges of the COVID-19 pandemic.

From all four corners of the globe, people from the bleeding disorders community took the WFH vision of “Treatment for All” to heart—virtually. On social media, and on the World Hemophilia Day website, community members everywhere shared their stories with compelling honesty.

The WFH Facebook page, LinkedIn page and Twitter timeline saw hundreds of updates on this big day. Our World Hemophilia Day website—designed to offer information and communications material about inherited bleeding disorders—was also very popular. Nearly 4,700 people visited the platform, and the pages of the site were viewed over 11,000 times. Over 300 stories were posted on the platform: people told their own personal stories of living with a bleeding disorder, or shared their experiences knowing someone who has a condition.

The community also set a record in 2020:

98

landmarks around the world took part in the “Light it up Red” campaign. The images of those landmarks were shared on social media worldwide



Turning compassion into action

The COVID-19 pandemic fundamentally changed how we work, learn, and communicate. But one thing remained constant throughout 2020: the exceptional support offered by our global community.



The WFH gratefully acknowledges the individuals and organizations who supported us in 2020. On behalf of the bleeding disorders community, the WFH thanks you for your commitment to our shared vision of Treatment for All. Learn more about how you can support our work at www.wfh.org/supportus.

The “Compassion to Action” campaign was launched in June 2020 to ensure the global community could meet the new challenges brought on by the pandemic. Our donors, members and partners answered our call for support, contributing over \$968,000 to help us deliver our mission to improve care for all people with inherited bleeding disorders, regardless of where they live.

Special thanks to WFH USA for their steadfast commitment to raising funds to support initiatives including the WFH Humanitarian Aid Program, research and data collection activities, and training and education programs such as the Cornerstone Initiative.

A record

33

chapters of the National Hemophilia Foundation supported the WFH through the annual NHF Chapter Challenge

Our

Community Partners

The Hemophilia Alliance
Hemophilia of Georgia
National Hemophilia Foundation

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 2020, the following individuals, corporations, and organizations made financial contributions of CAN\$150 or more to the WFH or WFH USA.

SOLIDARITY FUND

Fundación de la Hemofilia (Argentina)
Österreichische Hämophilie Gesellschaft
Association Béninoise des Hémophiles
Haemophilia Society of Bosnia and Herzegovina
Bulgarian Haemophilia Association
Canadian Hemophilia Society
Czech Society of Hemophilia
Croatian Hemophilia Society
Hemophilia Federation (India)
Irish Haemophilia Society
Israeli Hemophilia Association
Lithuania Haemophilia Association
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South African Haemophilia Foundation
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Swiss Hemophilia Society
Hemophilia Society of Turkey
The Haemophilia Society (UK)
Asociación Venezolana para la Hemofilia

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Susan Skinner Memorial Fund

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In Memory of Khadeeja Adam
In Memory of Angela Matthew
In Memory of Henry Matzigkeit
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In Memory of Linda Wilson
In Honour of Santiago Barba
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In Honour of Peter Hulgren
In Honour of Frank Schnabel
In Honour of Frank Schnabel IV and Lillian Schnabel
In Honour of Eric and Marion Stolte
In Honour of Lyf Stolte

DONORS

\$250,000 – \$499,999

Hemophilia of Georgia

\$100,000 – \$249,999

The Hemophilia Alliance
National Hemophilia Foundation

\$50,000 – \$99,999

Glenn and Beatrice Pierce
The Marketing Research Bureau

\$25,000 - \$49,999

The Haemophilia Society (U.K.)

\$10,000 - 24,999

Mark Skinner and James Matheson
One anonymous donor

\$5,000 - \$9,999

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Donald and Barbara Goldman
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New England Hemophilia Association
Phillips 66

\$1,000 - \$4,999

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\$500 - \$999

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 One anonymous donor

\$150 - \$249

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 Two anonymous donors



Thank you to our Corporate Partners

The WFH gratefully acknowledges the generous support of our dedicated partners. Our corporate partners are all playing a major role in helping us improve and sustain care for people with bleeding disorders around the world.

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Kedrion
LFB
Precision BioLogic
uniQure

GLOBAL ALLIANCE FOR PROGRESS (GAP) SECOND DECADE

Visionary Partner

Takeda

Leadership Partner

CSL Behring

Collaborating Partners

Biotest
Sanofi Genzyme
Pfizer
Sobi

WFH HUMANITARIAN AID PROGRAM

Founding Visionary

Sanofi Genzyme
Sobi

Visionary

Bayer

Leadership

F. Hoffmann-La Roche Ltd
Grifols

Contributor

CSL Behring

WORLD BLEEDING DISORDERS REGISTRY (WBDR)

Visionary Partners

Sobi
Takeda

Collaborating Partners

Bayer
CSL Behring
F. Hoffmann-La Roche Ltd
Grifols
Novo Nordisk
Pfizer
Sanofi Genzyme

WFH VIRTUAL SUMMIT

Platinum

F. Hoffmann-La Roche Ltd

Gold

BioMarin Pharmaceuticals
CSL Behring
Pfizer
Sanofi Genzyme
Takeda

Supporters

Grifols
Kedrion
Octapharma
Sobi
Spark Therapeutics
uniQure

SPONSORED PROGRAMS

Development Grant Program

Sanofi Genzyme

International External Quality Assessment Scheme Program (IEQAS)

Novo Nordisk Haemophilia
Foundation

International Hemophilia Training Centre (IHTC)

Fellowship Program

F. Hoffmann-La Roche Ltd

Twinning Program

Pfizer

Gene Therapy Round Table

Bayer
BioMarin Pharmaceuticals
F. Hoffmann-La Roche Ltd
Pfizer
Sanofi Genzyme
Spark Therapeutics
Takeda
uniQure

Global Summit on Women with Inherited Bleeding Disorders

Takeda

Website localization projects

Japanese: Sanofi Genzyme
Russian: Sobi

Other product donation

Novo Nordisk
Takeda

2020 Financial Report



The year 2020 was certainly one to remember. As a result of the worldwide pandemic, the threat of the cancellation of our 2020 World Congress became a reality. Through it all, the WFH staff remained resilient; turning what could have been a disastrous year into a financially positive one. The year ended with a net surplus of \$3,400 thousand compared to a budgeted net surplus of \$223 thousand. This represents an improvement of \$3,177 thousand.

The successful Virtual Summit—the first for the WFH—held in June 2020, was a key contributor to this significant result. Almost 9,000 participants from 160 countries took part in the event, which provided a net surplus of \$1.7 million, mitigating some of the losses of the planned World Congress. This happened thanks to—in large part—our corporate partners whose generous support and flexibility allowed us to reallocate funds from the World Congress to the Virtual Summit. We also received funding from two exceptional and unexpected sources: insurance proceeds for the cancellation of the World Congress; and Canadian government support for COVID-19 relief. The strong U.S.A currency (which averaged \$1.34 CAD throughout the year) further contributed to this excellent result.

Continued stability of revenue

The corporate sponsors of WFH programs and initiatives continued their support with 2020 contributions of \$4,878 thousand, a decrease of \$1,216 thousand (20%) over 2019. A portion of this decrease was due to contributions, in 2019, of \$406 thousand towards the WFH Global Forum (GF) and the WFH International Musculoskeletal Congress (MSK) that take place every two years.

In 2020, the WFH Humanitarian Aid Program spent \$2,468 thousand (\$1,723 thousand in 2019) against revenues received from our key corporate partners. Despite the major logistical challenges created by the COVID-19 pandemic, we managed to distribute 146.5 million IUs of factor worldwide and started donations of emicizumab.

For the WFH Research Program, \$591 thousand was recognized (\$537 thousand in 2019). These funds have allowed for the continued success of the World Bleeding Disorder Registry (WBDR)—enrolling over 7,000 people with hemophilia from 88 hemophilia treatment centres (HTCs) globally—and the awarding of research grants to HTCs.

Fundraising revenues had a healthy boost in 2020, at \$968 thousand (\$573 thousand in 2019), due mostly to generous donations from Hemophilia of Georgia towards the Training & Education program and the Humanitarian Aid general program; as well as from Hemophilia Alliance for developing educational resources to promote and disseminate the *WFH Guidelines for the Management of Hemophilia, 3rd edition*. The WFH is grateful to WFH USA for supporting and advancing our global mission and making these donations possible.

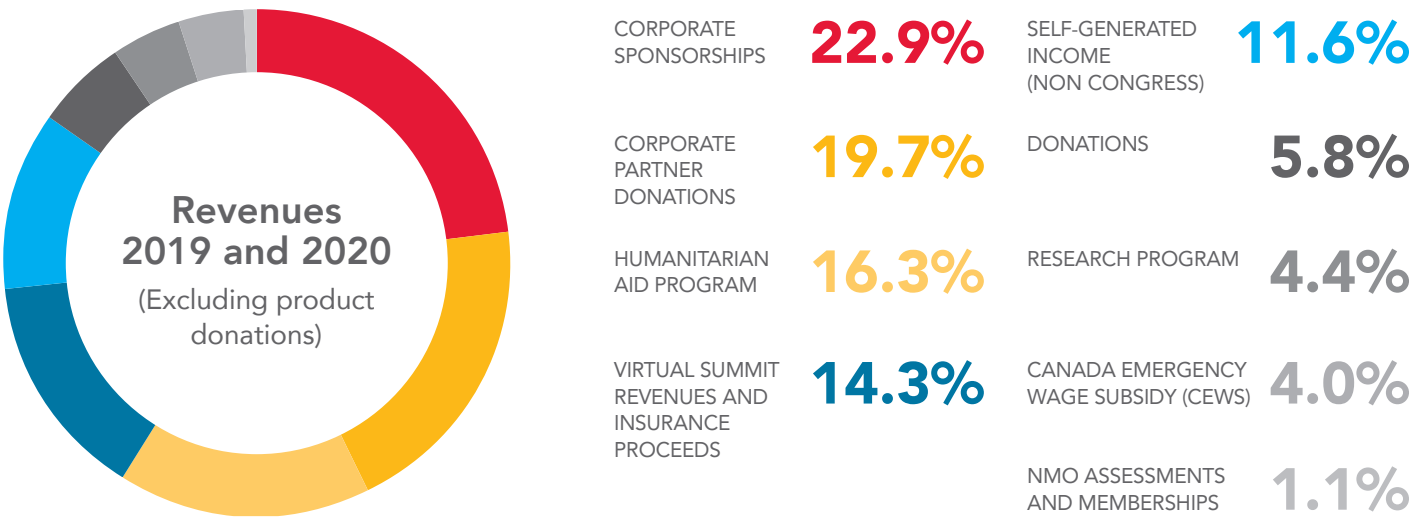
The total WFH revenue, before Congresses, Product Donations, and Canada Emergency Wage Subsidy (CEWS) reached \$10,276 thousand; \$490 thousand (4.6%) below 2019.

Generating income through the internal management of the very first virtual congress and other WFH meetings—including the MSK and the GF—adds to a diversified income stream. As shown in Figure 1, excluding product donations, 43% of revenues over the two-year cycle are from sponsorships from WFH corporate partners; 21% are from restricted programs (Humanitarian Aid and Research Program); 14% are from the Virtual Summit and insurance proceeds; and the remaining 22% are generated from financial donations, self-generating income activities, CEWS government relief for COVID-19, national member organization (NMO) assessments, and memberships.

Expenses in a COVID-19 world

With the COVID-19 pandemic causing global travel bans, all activities or events requiring in-person meetings had to be cancelled. This forced the WFH staff to reinvent the way we delivered support to the bleeding disorders community by shifting training and resources online. Overall, the virtual activities we held in 2020 produced significant savings as they did not require any travel. At the same time, as we re-shaped our operations to work virtually, we were conscious that cybercrime was very active as hackers sought to take advantage of the increased online activity. Consequently, we invested in software, hardware and training to minimize security risks.

Figure 1



Combined, the healthcare development programs, education and public policy programs, and the WFH Humanitarian Aid Program, continued to represent the largest proportion of expenses with 68% of the expenses incurred over the past two years, as seen in Figure 2. The Virtual Summit, along with certain non-refundable World Congress expenditures, called for a smaller investment (10%) than the World Congress usually requires of WFH expenses, while fundraising and corporate relations expenses represented 6% of the total. Expenses attributed to running the WFH organization included administration at 10%, and governance and communications at 6%.

Humanitarian Aid

The COVID-19 pandemic greatly impacted the delivery of donated factor as a result of border closures, lockdowns and reduced shipping capacity. The WFH Humanitarian Aid team worked tirelessly to continue to deliver care to those who needed it most. In 2020, 146.5 million IUs of factor (241 million IUs in 2019) and 27 thousand vials of emicizumab were provided to patients in 69 developing countries. The majority of these donations, worth \$394 million USD, are included in the audited financial statements of WFH USA. The amount included in the financial statements of the WFH is \$60 million.

Year-over-year comparison

The 2020 and 2019 statement of revenues and expenses, illustrated in Figure 3, reflects the fluctuations within a typical two-year cycle where the World Congress/Virtual Summit is held in even years, where the MSK and GF events are held in odd years, and where varying amounts of yearly product donations are received. On the revenue side, before Congresses, Product Donations and CEWS, there was an overall decrease of \$490 thousand. This was largely due to the revenues derived from the MSK and GF events held in 2019 of \$979 thousand from corporate partners as well as WFH event registration and housing fees. Further, in 2020, corporate sponsorships decreased for our GAP and IHTC

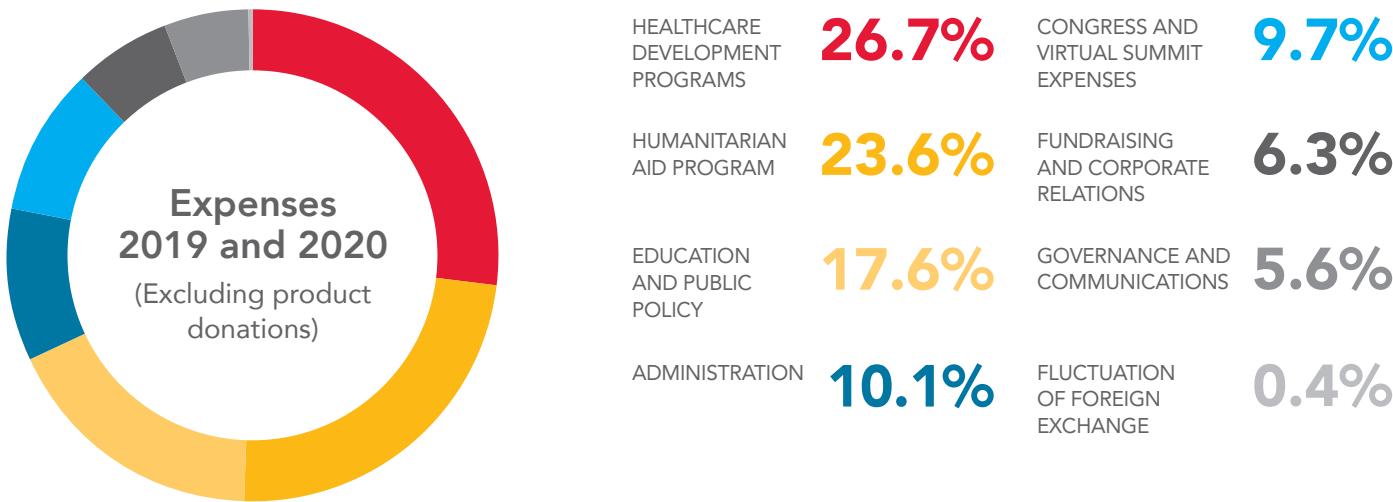
Fellowship programs. This was offset by the excellent growth in the Humanitarian Aid Program which now includes two new partners, and which brought in an additional \$745 thousand.

The overall spend of \$10,060 thousand in expenses before Congresses and Product Donations reflects the continued efforts of the WFH to support the needs of the global bleeding disorders community—even in a pandemic world. This was a decrease of \$2,019 thousand versus 2019, mostly due to decreased spending in travel—as a result of the COVID-19 travel bans—for programs that typically required in-person activities. This included the Twinning Program; IHTC Fellowships; patient and medical workshops; and regional meetings. Further, Education and Public Policy decreased by \$567 thousand, mostly due to having spent \$728 thousand on the update of the *WFH Guidelines for the Management of Hemophilia, 3rd edition*, in 2019. This was offset by the increased spending of \$290 thousand for the Humanitarian Aid Program as we experienced a full year of distributing the products from Bayer and Roche.

Forces aligned while we look ahead

Despite the devastation caused by the pandemic, many forces were favorably aligned for the WFH, and the people it serves, which helped to bring about the positive programmatic and financial results of the year 2020. Thanks to the support and flexibility of our corporate and community partners, the WFH was able to continue its important work. The government of Canada also stepped in to offer financial relief with a program whose main intention was to keep staff employed—and the WFH did exactly that. Our staff showed resilience in adapting to the new reality we were living in: from holding a successful and first-ever Virtual Summit to replace the World Congress; to preparing a wide variety of webinars that allowed us to reach a record number of participants. Senior management also had the foresight to protect us from a potential cancellation of the World Congress: the insurance proceeds received helped compensate for the overall net loss from not having this key event.

Figure 2



As we embark on a new two-year cycle, and the global pandemic lingers, the financial base of the WFH is solid. Because we adapted to these challenging times, we were able to reach even more people with bleeding disorders. Going forward, we envision a hybrid of virtual and in-person activities to leverage the benefits of both. We have also implemented hedging strategies as the U.S.A dollar has been on a steady decline.

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As we start to build our new strategic plan, our focus will continue to be on putting our resources to work for the benefit of our community by delivering programs and activities with the aim of accomplishing our vision of Treatment for All.

Figure 3

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Revenues and expenses

(Expressed in Canadian Dollars)

	2020	2019
REVENUES		
Donations	940,979	544,549
Corporate Partner Donations	2,481,690	2,599,999
Corporate Sponsorships	2,396,155	3,494,327
Research Program	591,382	537,462
Humanitarian Aid Program	2,468,117	1,722,648
Self-Generated Income (Non-Congress)	1,264,715	1,728,952
NMO Assessments and Memberships	132,992	138,418
Total Revenues before Congresses, PDs and CEWS	10,276,030	10,766,355
Virtual Summit Revenues and Insurance Proceeds	3,672,718	-
Canada Emergency Wage Subsidy (CEWS)	1,020,732	-
Product Donations (PDs)	59,909,908	143,565,405
TOTAL REVENUES	74,879,388	154,331,760
EXPENSES		
Healthcare Development Programs	2,493,443	4,059,085
Education and Public Policy	1,874,917	2,441,473
Humanitarian Aid Program	3,034,496	2,744,130
Governance and Communications	612,309	770,189
Fundraising and Corporate Relations	727,600	814,807
Administration	1,259,774	1,206,883
Fluctuation of Foreign Exchange	57,610	42,138
Total Expenses before Congress and Product Donations	10,060,149	12,078,705
Congress and Virtual Summit Expenses	1,508,973	864,019
Product Donations (PDs)	59,909,908	143,565,405
TOTAL EXPENSES	71,479,030	156,508,129
EXCESS (DEFICIENCY)	3,400,358	(2,176,369)

WFH Board of Directors

We rely on the WFH Board of Directors, WFH staff, and volunteers to support our shared vision of Treatment for All.

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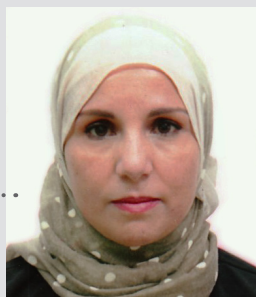
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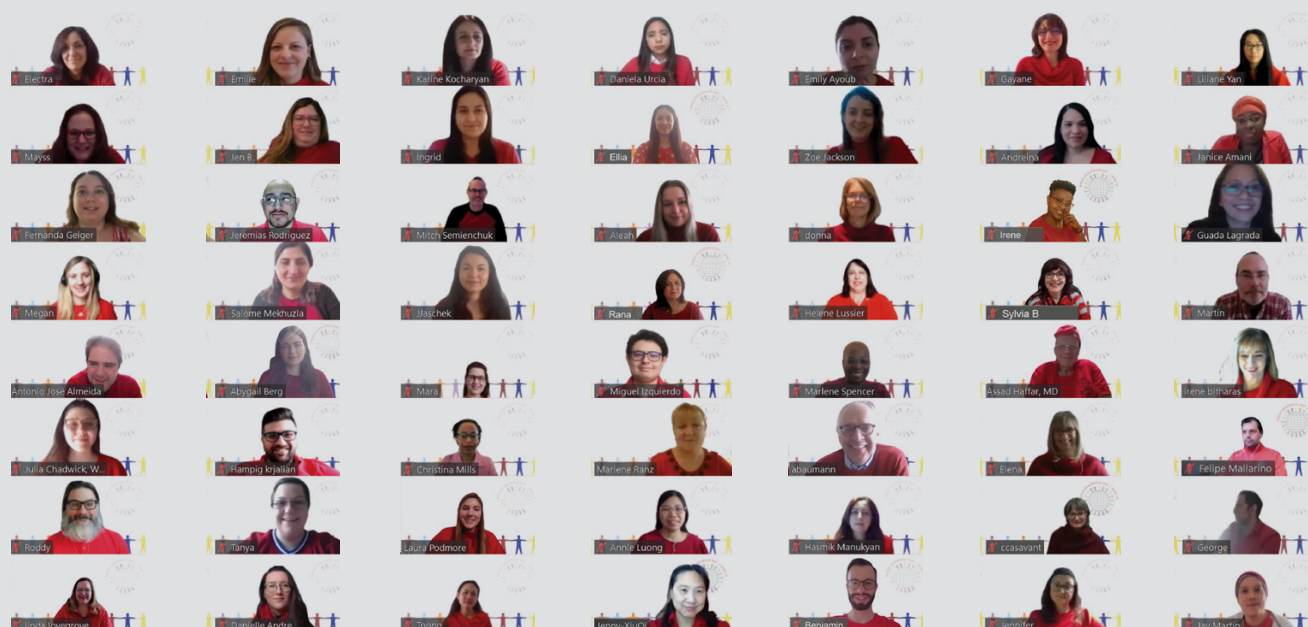
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Patron
Belgium |

WFH staff



WFH 2020 highlights

Number of
IUs DISTRIBUTED

146+ million

.....

Number of
patients enrolled in WBDR

7,208

.....

Number of
virtual events

100+

.....

Countries reached
through global programs and events

160+

World Federation of Hemophilia

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