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
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.
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

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

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

**Medical and logistics webinars for Humanitarian Aid donations management**

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

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

## Strengthening NMO capacity

<table>
<thead>
<tr>
<th>Topics</th>
<th>Audience</th>
<th>Unique attendees</th>
</tr>
</thead>
<tbody>
<tr>
<td>Active communications virtual workshops for NMOs (five webinars)</td>
<td>Regional: NMO and patient leaders</td>
<td>164</td>
</tr>
<tr>
<td>Global and regional youth leadership and engagement webinars and Training of Trainers (TOT) workshops (five webinars)</td>
<td>Global/Regional: NMOs, youth groups</td>
<td>264</td>
</tr>
<tr>
<td>NMO skills on project development and implementation, NMO leadership, structure and chapter development (five webinars)</td>
<td>Global/Regional/National: Middle East, South America, CAC and Africa</td>
<td>273</td>
</tr>
<tr>
<td>Twinning Program virtual sessions (two webinars)</td>
<td>Global: current twins, NMOs, HTCs, youth groups</td>
<td>249</td>
</tr>
<tr>
<td>WFH-Coalition of the Americas (CoA) webinars on governance, NMO structure, leadership, data collection, analysis and use for advocacy (six webinars)</td>
<td>Regional: NMO and patient leaders from South America and CAC</td>
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## COVID-19 statements and advisories

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

WFH Humanitarian Aid Program

Making access to care possible even during the COVID-19 pandemic
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
- **1,148** hemophilia team members and regulators trained
- **1,528** healthcare professionals acquired a general awareness of hemophilia and other inherited bleeding disorders
- **4,823** patients, family members, and NMO board members trained
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
- **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)
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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.
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.
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
Association Luxembourgeoise des Hémophiles
Association pour le Bien-Etre des Hémophiles à Madagascar
Hemophilia Society of Malaysia
Hemophilia Society of Maldives
Netherlands Haemophilia Society
Haemophilia Foundation of New Zealand
Haemophilia Society of Singapore
Drustvo Hemofilikov Slovenije
South African Haemophilia Foundation
Korea Hemophilia Foundation
Swedish Bleeding Disorder Society
Swiss Hemophilia Society
Hemophilia Society of Turkey
The Haemophilia Society (UK)
Asociación Venezolana para la Hemofilia

TRIBUTES
In Memory of Khadeeja Adam
In Memory of Angela Matthew
In Memory of Henry Matzigkeit
In Memory of Ashwin Pindoria
In Memory of Linda Wilson
In Honour of Santiago Barba
In Honour of Kimberly Bramley
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
The Hemophilia Alliance
National Hemophilia Foundation

$100,000 – $249,999
Glenn and Beatrice Pierce
The Marketing Research Bureau

$50,000 – $99,999
The Haemophilia Society (U.K.)

$25,000 - $49,999
Mark Skinner and James Matheson
One anonymous donor

$5,000 - $9,999
Canadian Hemophilia Society
Donald and Barbara Goldman
Frank Schnabel III
Frank Schnabel IV and Lillian Schnabel
Gina Schnabel
New England Hemophilia Association
Phillips 66

$1,000 - $4,999
Melanie Bladen
Lone Star Bleeding Disorders Foundation
Paula Bell and Rob Christie
Isabel Bravo
Yu-Hua Chao
Seng H. Cheng
Amit Chhabra
Colorado Chapter of the National Hemophilia Foundation
Adele Finardi
Florida Hemophilia Association
Gateway Hemophilia Association
Jose Felipe Lemos Garcia
Samantha Gouw
Great Lakes Hemophilia Foundation
Assad Haffar
Gregory Hayes
Hemophilia Association of the Capital Area
Hemophilia Foundation of Idaho
Hemophilia Foundation of Michigan
Hemophilia Foundation of Southern California
Hemophilia of Indiana
Christine Herr
Irish Haemophilia Society
Amirah Izzah
Yunus Jaleel
Nathalie W.D. Jansen
Edward Johnston
Craig Kessler
Kate Khair
Marja Koli
Barbara Konkle and Peter Kollros
Mary M. Gooley Hemophilia Center
John Murphy
National Hemophilia Foundation of Thailand

MEMORIAL FUNDS
Susan Skinner Memorial Fund

TRIBUTES
In Memory of Khadeeja Adam
In Memory of Angela Matthew
In Memory of Henry Matzigkeit
In Memory of Ashwin Pindoria
In Memory of Linda Wilson
In Honour of Santiago Barba
In Honour of Kimberly Bramley
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
The Hemophilia Alliance
National Hemophilia Foundation

$100,000 – $249,999
Glenn and Beatrice Pierce
The Marketing Research Bureau

$50,000 – $99,999
The Haemophilia Society (U.K.)

$25,000 - $49,999
Mark Skinner and James Matheson
One anonymous donor

$5,000 - $9,999
Canadian Hemophilia Society
Donald and Barbara Goldman
Frank Schnabel III
Frank Schnabel IV and Lillian Schnabel
Gina Schnabel
New England Hemophilia Association
Phillips 66

$1,000 - $4,999
Melanie Bladen
Lone Star Bleeding Disorders Foundation
Paula Bell and Rob Christie
Isabel Bravo
Yu-Hua Chao
Seng H. Cheng
Amit Chhabra
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Adele Finardi
Florida Hemophilia Association
Gateway Hemophilia Association
Jose Felipe Lemos Garcia
Samantha Gouw
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Hemophilia Foundation of Idaho
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Edward Johnston
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Barbara Konkle and Peter Kollros
Mary M. Gooley Hemophilia Center
John Murphy
National Hemophilia Foundation of Thailand

MEMORIAL FUNDS
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Nevada Chapter of the National Hemophilia Foundation
Pacific Northwest Bleeding Disorders
Julia Phillips
Joseph Pugliese
Markus Rieke
Angelo Claudio Molinari
Rocky Mountain Hemophilia & Bleeding Disorders Association
Andrea Muller
Andre van Niekerk
Yasuharu Nishida
Johannes Oldenburg
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Angiola Rocino
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Sobi
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Dean Willett
Jerzy Windyga
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SongKai Yan
Wen-Chi Yang
Tineke Zuurbier

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Ana Antun
Alain Baumann
Bleeding Disorders Alliance Illinois
Arlyn Caldwell Nichols
Erin Cooper
Amy and Michael Dunn
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Hemophilia of North Carolina
Hemophilia of South Carolina
Elaina Jurecki
Kentucky Hemophilia Foundation
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Soon Ki Kim
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Barbara Zieger
Seven anonymous donors

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Yingyong Chinthammitr
Donna Coffin
Connecticut Hemophilia Society
Jacqueline Curtis
Easmin Ara Doly
Daniel Doran
Mihindukulasuriya Marina Agnes Lalanthi Fernando
Anna Fragomeno
Dietje E. Fransen van de Putte
Yasmin Goga
Robert Gosselin
Matt Gross
Ann Harrington
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Oliver Hegener
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Ganesh Kasinathan
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Aisyah Muhammad Rival
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Ahmed Naseer
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Amy and Allen Renz
Robert Saggars

Sangre de Oro, Bleeding Disorders Foundation of New Mexico
Southwestern Ohio Hemophilia Foundation
Chang-hun Park
David Stephensen
Tan Wee Nee Tan
Jerome Teitel
Paul Wermes
Western Pennsylvania Chapter, NHF
One anonymous donor

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Ruud Bos
Alexandro-Valentin Brabete
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Francesco Capaldo
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Zainura Anita Z. Zainal Abidin
Two anonymous donors

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 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.
## CORPORATE PARTNER PROGRAM

**Visionary Partners**
- CSL Behring
- Novo Nordisk
- Pfizer
- Takeda

**Leadership Partners**
- Bayer
- Sanofi Genzyme

**Collaborating Partners**
- BioMarin Pharmaceutical Inc
- F. Hoffmann-La Roche Ltd
- Grifols
- Octapharma
- Sobi
- Spark Therapeutics

**Contributing Partners**
- Biocytin
- GC Pharma
- Kedrion
- LFB
- Precision BioLogic
- uniQure

---

## GLOBAL ALLIANCE FOR PROGRESS (GAP) SECOND DECADE

**Visionary Partner**
- Takeda

**Leadership Partner**
- CSL Behring

**Collaborating Partners**
- Biocytin
- 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
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**

<table>
<thead>
<tr>
<th>Source of Revenues</th>
<th>Percentage</th>
<th>Source of Revenues</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Corporate Sponsorships</td>
<td>22.9%</td>
<td>Self-generated Income (Non Congress)</td>
<td>11.6%</td>
</tr>
<tr>
<td>Corporate Partner Donations</td>
<td>19.7%</td>
<td>Donations</td>
<td>5.8%</td>
</tr>
<tr>
<td>Humanitarian Aid Program</td>
<td>16.3%</td>
<td>Research Program</td>
<td>4.4%</td>
</tr>
<tr>
<td>Virtual Summit Revenues and Insurance Proceeds</td>
<td>14.3%</td>
<td>Canada Emergency Wage Subsidy (CEWS)</td>
<td>4.0%</td>
</tr>
<tr>
<td></td>
<td></td>
<td>NMO Assessments and Memberships</td>
<td>1.1%</td>
</tr>
</tbody>
</table>
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

<table>
<thead>
<tr>
<th>Expenses 2019 and 2020</th>
<th>HEALTHCARE DEVELOPMENT PROGRAMS</th>
<th>CONGRESS AND VIRTUAL SUMMIT EXPENSES</th>
</tr>
</thead>
<tbody>
<tr>
<td>(Excluding product donations)</td>
<td>26.7%</td>
<td>9.7%</td>
</tr>
<tr>
<td>HUMANITARIAN AID PROGRAM</td>
<td>23.6%</td>
<td>FUNDRAISING AND CORPORATE RELATIONS</td>
</tr>
<tr>
<td>EDUCATION AND PUBLIC POLICY</td>
<td>17.6%</td>
<td>GOVERNANCE AND COMMUNICATIONS</td>
</tr>
<tr>
<td>ADMINISTRATION</td>
<td>10.1%</td>
<td>FLUCTUATION OF FOREIGN EXCHANGE</td>
</tr>
<tr>
<td></td>
<td></td>
<td>0.4%</td>
</tr>
</tbody>
</table>
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.

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

Revenues and expenses
(Expressed in Canadian Dollars)

<table>
<thead>
<tr>
<th></th>
<th>2020</th>
<th>2019</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>REVENUES</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Donations</td>
<td>940,979</td>
<td>544,549</td>
</tr>
<tr>
<td>Corporate Partner Donations</td>
<td>2,481,690</td>
<td>2,599,999</td>
</tr>
<tr>
<td>Corporate Sponsorships</td>
<td>2,396,155</td>
<td>3,494,327</td>
</tr>
<tr>
<td>Research Program</td>
<td>591,382</td>
<td>537,462</td>
</tr>
<tr>
<td>Humanitarian Aid Program</td>
<td>2,468,117</td>
<td>1,722,648</td>
</tr>
<tr>
<td>Self-Generated Income (Non-Congress)</td>
<td>1,264,715</td>
<td>1,728,952</td>
</tr>
<tr>
<td>NMO Assessments and Memberships</td>
<td>132,992</td>
<td>138,418</td>
</tr>
<tr>
<td>Total Revenues before Congresses, PDs and CEWS</td>
<td>10,276,030</td>
<td>10,766,355</td>
</tr>
<tr>
<td>Virtual Summit Revenues and Insurance Proceeds</td>
<td>3,672,718</td>
<td>-</td>
</tr>
<tr>
<td>Canada Emergency Wage Subsidy (CEWS)</td>
<td>1,020,732</td>
<td>-</td>
</tr>
<tr>
<td>Product Donations (PDs)</td>
<td>59,909,908</td>
<td>143,565,405</td>
</tr>
<tr>
<td><strong>TOTAL REVENUES</strong></td>
<td>74,879,388</td>
<td>154,331,760</td>
</tr>
</tbody>
</table>

|                      |         |         |
| **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 | 612,309 | 770,189 |
| Administration        | 1,264,715 | 1,728,952 |
| 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.
## WFH BOARD OF DIRECTORS, MEMBERS & PATRON 2020–2022

<table>
<thead>
<tr>
<th></th>
<th>Name</th>
<th>Title/Role</th>
<th>Country</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Cesar Garrido</td>
<td>President</td>
<td>Venezuela</td>
</tr>
<tr>
<td>2</td>
<td>Glenn Pierce</td>
<td>Vice-President, Medical U.S.A.</td>
<td></td>
</tr>
<tr>
<td>3</td>
<td>Barry Flynn</td>
<td>Vice-President, Finance</td>
<td>United Kingdom</td>
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<td>Carlos Safadi Márquez</td>
<td>Vice-President, NMO U.S.A.</td>
<td>Argentina</td>
</tr>
<tr>
<td>5</td>
<td>Megan Adediran</td>
<td>Director</td>
<td>Nigeria</td>
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<td>Novie Chozie</td>
<td>Director</td>
<td>Indonesia</td>
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<td>7</td>
<td>Saliou Diop</td>
<td>Director</td>
<td>Senegal</td>
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<td>8</td>
<td>Miguel Escobar</td>
<td>Director</td>
<td>U.S.A.</td>
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<tr>
<td>9</td>
<td>Cedric Hermans</td>
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<td>Belgium</td>
</tr>
<tr>
<td>10</td>
<td>Barbara Konkle</td>
<td>Director</td>
<td>U.S.A.</td>
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<tr>
<td>11</td>
<td>Latifa Lamhene</td>
<td>Director</td>
<td>Algeria</td>
</tr>
<tr>
<td>12</td>
<td>Dawn Rotellini</td>
<td>Director</td>
<td>U.S.A.</td>
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<tr>
<td>13</td>
<td>Clive Smith</td>
<td>Director</td>
<td>United Kingdom</td>
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<tr>
<td>14</td>
<td>Baiba Ziemele</td>
<td>Director</td>
<td>Latvia</td>
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<tr>
<td>15</td>
<td>Alain Baumann</td>
<td>CEO</td>
<td>Canada</td>
</tr>
<tr>
<td>16</td>
<td>Jan-Willem André de la Porte</td>
<td>Patron</td>
<td>Belgium</td>
</tr>
</tbody>
</table>

### 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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wfh@wfh.org

wfh.org

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