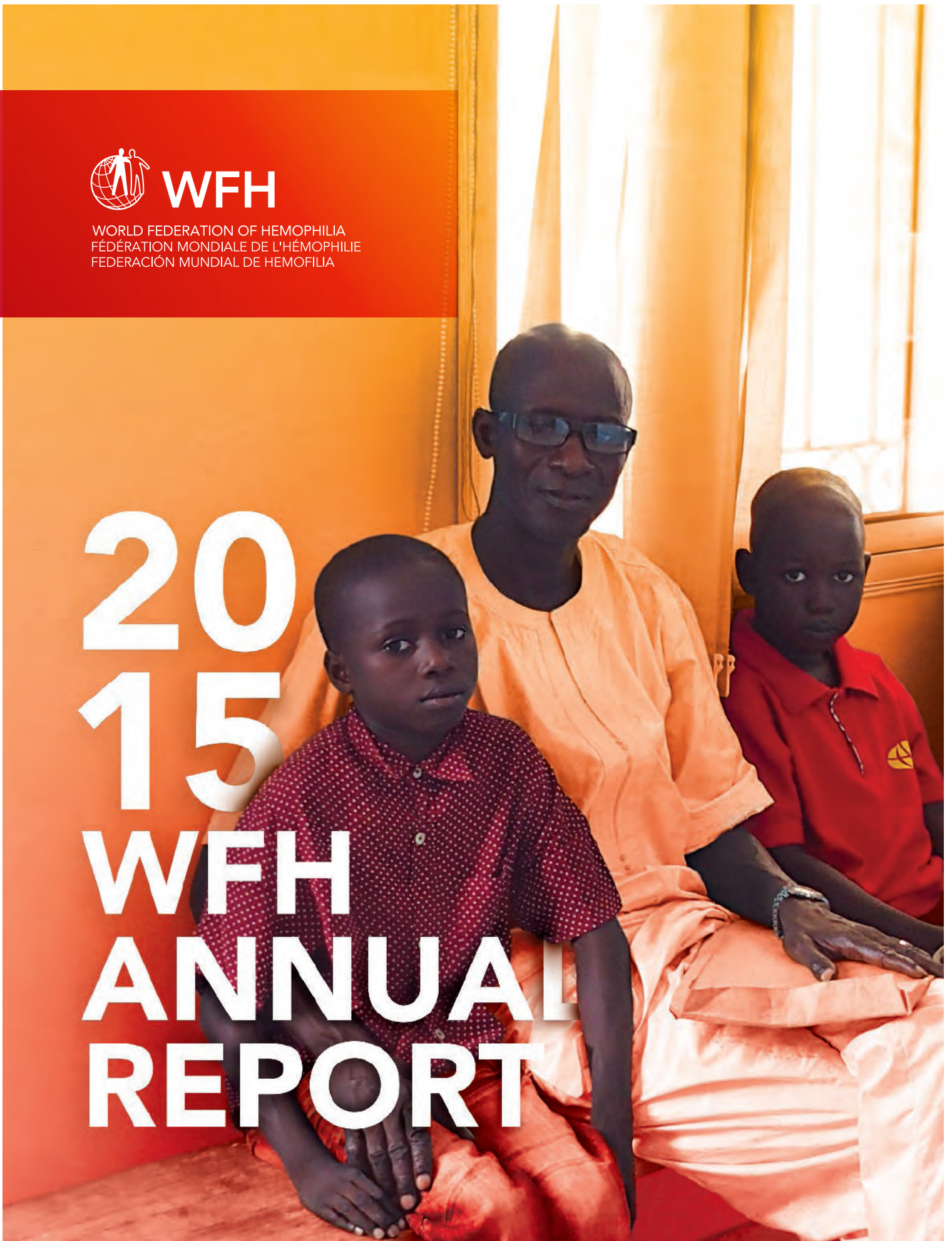




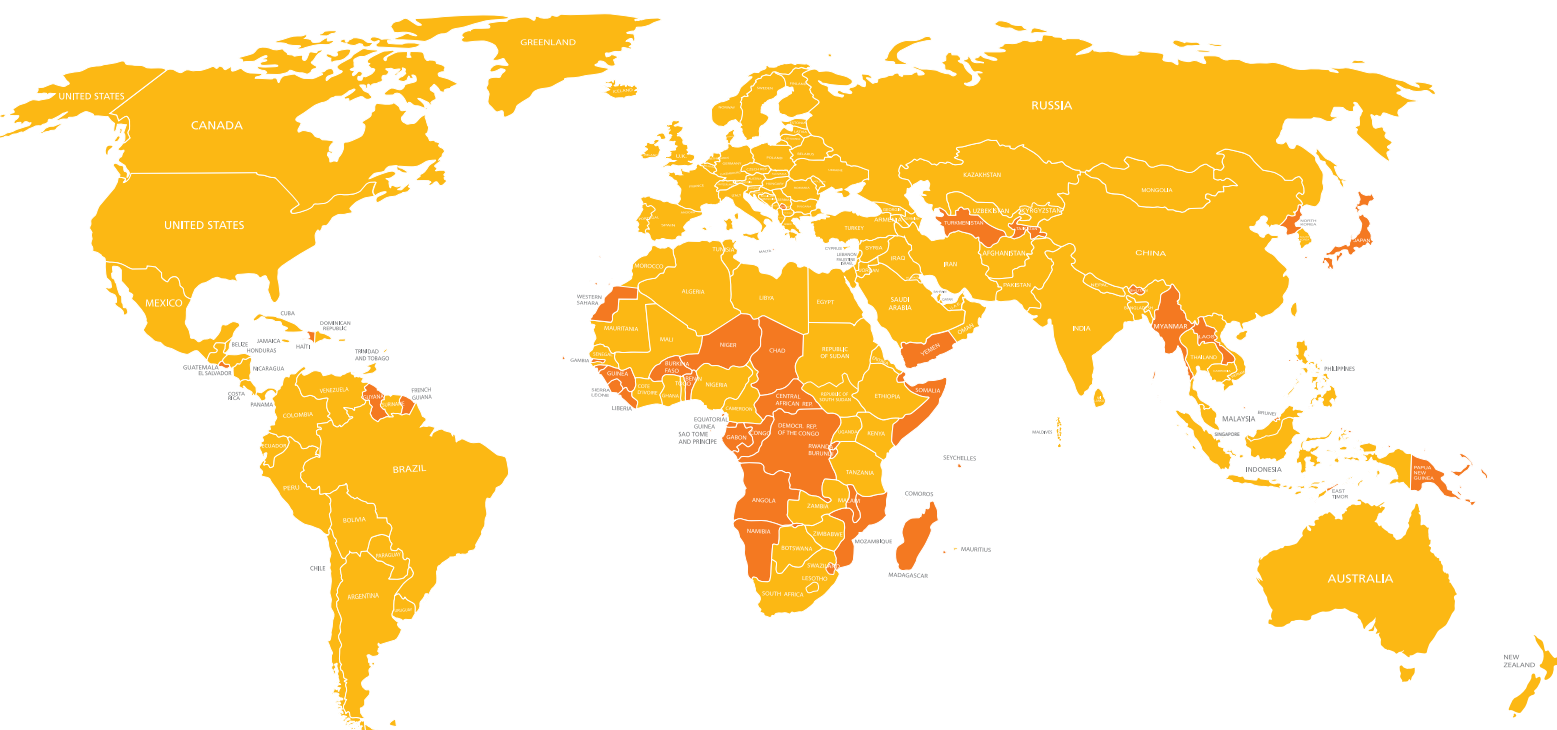
WFH

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

2015 WFH ANNUAL REPORT



WORLD FEDERATION OF HEMOPHILIA



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

The WFH has grown into a global network of patient organizations in 127 countries. National member organizations represent the interests of people with hemophilia and other inherited bleeding disorders in their country. They are key partners of the WFH, making it a truly international body.

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

- WFH National Member Organizations (127 in total)
- Non-members



OUR VISION AND MISSION

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

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

The mission of the WFH is to improve and sustain care for people with inherited bleeding disorders around the world.

HOW WE HAVE AN IMPACT



OUR FOCUS

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

The WFH makes a difference by:

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

OUR PROGRAMS

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



Patient and Healthcare Development Programs

WFH development programs, working in partnership with our national member organizations, help foster patient and healthcare development.

Humanitarian Aid

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

Treatment Product Safety and Supply

The WFH Treatment Product Safety and Supply program helps to make sure patients are getting the products they need and learning how to use them safely.

Educational Resources

WFH educational resources provide critical support to the global bleeding disorders community.

Research and Data Collection Programs

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

Congress and Meetings Program

The WFH World Congress is the largest scientific international meeting dedicated to hemophilia and other inherited bleeding disorders. It plays an important overall support function in the community by bringing over 4,000 medical, government, industry, and patient representatives together every two years to meet and network.

The WFH also organizes the WFH Global Forum on Research and Treatment Products for Bleeding Disorders and the WFH Musculoskeletal Congress, both occurring every two years (in a non-Congress year).

HOW YOU CAN CONTRIBUTE

With help from our corporate partners and community supporters, we will introduce, improve, and sustain care to those most in need.

- Donate: Supporting the WFH will change and save lives.
- Become a member: WFH membership fees will provide support for our mission.
- Raise awareness: Help get the word out about how we all can work together so that everyone has access to much needed care and treatment.

WFH PRESIDENT AND CEO MESSAGE

Alain Weill
WFH PRESIDENT



Alain Baumann
WFH CEO



As we get ready to bring the global bleeding disorders community together during the WFH 2016 World Congress, we recognize that the challenges we all face differ from country to country. However, we do have a common and identifiable end objective – to achieve Treatment for All people with inherited bleeding disorders worldwide. This is indisputable, whether you live in a developed or developing country. Every single person within our community deserves access to diagnosis, access to treatment, and access to care.

In 2015, the expansion of the WFH Humanitarian Aid Program allowed our organization to begin sustainable and predictable treatment product donations to those most in need. We are now better positioned to allocate donated treatment products on a consistent basis. This in turn helps alleviate the uncertainty that many face around the world and provide healthcare professionals with the ability to properly treat those within their communities that have never had access to needed treatment products.

With the infusion of a steady stream of treatment, there still remains the need for the WFH to effectively support the capacity building efforts of our national member organizations (NMOs). We must adapt and initiate changes to help adjust for the varied realities that our NMOs face, along with the growing challenges of our global environment. Many countries within our community are experiencing uncertain times, both politically and economically. The necessary support for our members will come from standing united, assisting each other wherever and whenever we can.

In October 2015, the WFH Board of Directors met to assess these new challenges and opportunities. This resulted in the adoption of “WFH Transform 2016”. Two key imperatives will be implemented through this plan: increasing our presence in the regions that we serve and strengthening our philanthropic giving program. We look forward to these initiatives improving how we operate as an organization and how we can in turn support our NMOs.

A unique feature of the WFH is the collaboration within our organization of healthcare professionals and patient groups. The WFH regularly brings them together through our healthcare development programs, during our national and regional trainings, with our support for capacity building programs and workshops, and within the development of advocacy initiatives. This is invaluable for both healthcare professionals and patients, as both their perspectives intersect throughout the lifespan of the delivery of care and treatment. Together, they are in a stronger position to assess and evaluate how changes within their own countries healthcare systems would be impacted by changing economic realities and shifts in policies.

To address the ever increasing need for data to support these advocacy initiatives, the WFH is uniquely positioned to develop a global registry that could be used to systematically document the care that people with hemophilia receive around the world. This is the vision of the WFH’s Epidemiological Research Program. In 2016, we are initiating a pilot project in a few centres around the world, from both developing and developed countries, with the goal of progressively expanding both the amount of data we collect, and the number of centres in which we collect it, over the long term.

We would like to thank our Board of Directors and all volunteers, along with the dedicated WFH staff, for their support of the WFH. This means that healthcare professionals can become properly trained to diagnose and manage patients; that our community can effectively advocate for an adequate supply of safe treatment products; and that people with bleeding disorders are educated and empowered to live healthier, longer, and more productive lives.

WFH BOARD MEMBERS & PATRON



WFH Board

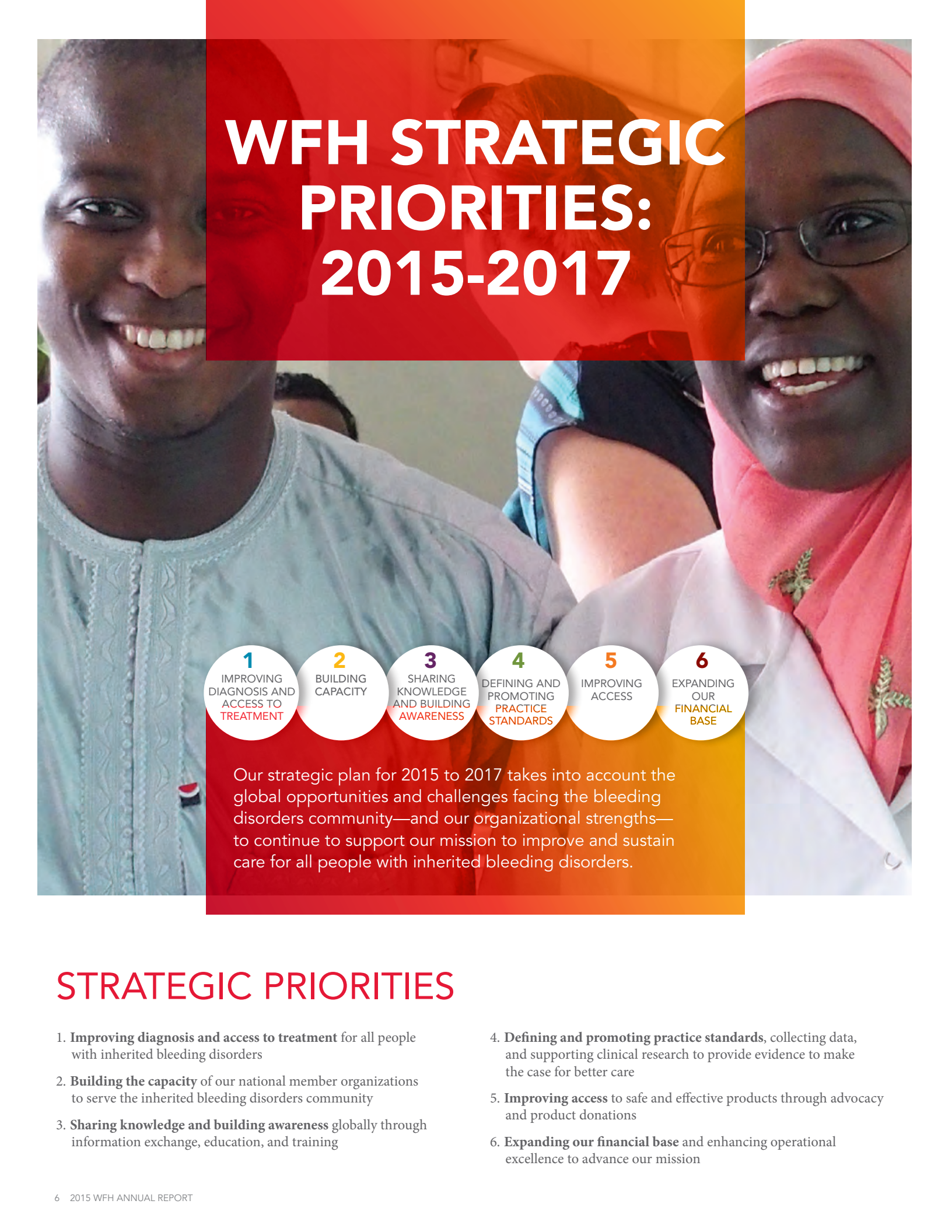
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|---|---|---|---|
| 1 PRESIDENT
Alain Weill, France | 5 LAY MEMBER
Pamela Wilton, Canada | 9 MEDICAL MEMBER
Jerzy Windyga, MD, Poland | 13 MEDICAL MEMBER
Saliou Diop, MD, Senegal |
| 2 VICE-PRESIDENT MEDICAL
Marijke van den Berg, MD,
Netherlands | 6 LAY MEMBER
Glenn Pierce, U.S.A. | 10 MEDICAL MEMBER
Magdy El-Ekiaby, MD,
Egypt | 14 WFH PATRON
Jan Willem André de
la Porte |
| 3 VICE-PRESIDENT FINANCE
Eric Stolte, Canada | 7 LAY MEMBER
Declan Noone, Ireland | 11 MEDICAL MEMBER
Keith Hoots, MD, U.S.A. | Absent:
LAY MEMBER
Cesar Garrido, Venezuela |
| 4 LAY MEMBER
David Silva, Spain | 8 LAY MEMBER
Deon York, New Zealand | 12 MEDICAL MEMBER
Flora Peyvandi, MD, Italy | |



WFH STAFF

An extensive network of organizations and individuals share the WFH's vision of ensuring Treatment for All people with hemophilia and other inherited bleeding disorders worldwide. We rely on the WFH staff and volunteers to help bring our shared vision to life.

WFH Staff



WFH STRATEGIC PRIORITIES: 2015-2017

1
IMPROVING
DIAGNOSIS AND
ACCESS TO
TREATMENT

2
BUILDING
CAPACITY

3
SHARING
KNOWLEDGE
AND BUILDING
AWARENESS

4
DEFINING AND
PROMOTING
PRACTICE
STANDARDS

5
IMPROVING
ACCESS

6
EXPANDING
OUR
FINANCIAL
BASE

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

STRATEGIC PRIORITIES

1. **Improving diagnosis and access to treatment** for all people with inherited bleeding disorders
2. **Building the capacity** of our national member organizations to serve the inherited bleeding disorders community
3. **Sharing knowledge and building awareness** globally through information exchange, education, and training
4. **Defining and promoting practice standards**, collecting data, and supporting clinical research to provide evidence to make the case for better care
5. **Improving access** to safe and effective products through advocacy and product donations
6. **Expanding our financial base** and enhancing operational excellence to advance our mission



1 IMPROVING DIAGNOSIS AND ACCESS TO TREATMENT

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

In 2015, WFH healthcare development programs and activities reached a total of 102 countries worldwide: 63 countries fell under the global program activities category, and 39 countries fell under the GAP Program, WFH Country Programs, and the Cornerstone Initiative.

GLOBAL ALLIANCE FOR PROGRESS (GAP) PROGRAM

The second decade of the WFH Global Alliance for Progress (GAP) Program began in 2013 and with the aim to identify an additional 50,000 people with inherited bleeding disorders by 2022, with 50% of them living in the world's poorest regions.

Our main objective in 2015 was to integrate three new GAP Second Decade countries into the program, as well as to maximize GAP results at a sustainable pace. This was achieved by continuing to target country development of national programs for bleeding disorders care, developing and publishing new educational material and tools, and providing general multidisciplinary training for healthcare professionals and NMO skills trainings to patient organizations.

We are making progress in reaching our Second Decade goals: 19,036 new people with bleeding disorders have been identified (38% of end target goal of 50,000), including 4,671 from the poorest countries (18.7% of end target goal of 25,000).

"We are excited about this new phase of collaboration with the WFH. We believe that our two-way exchange about the priorities for care will ensure that programs implemented are fully catered to the needs of patients in the country."

— Jaouad Chbehi head of the Moroccan Hemophilia Association (MHA)



COMMUNITY IMPACT

Through the implementation of targeted country programs in 11 GAP countries in 2015, the WFH actively continued to work on closing the gap in care for people with bleeding disorders.

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



COUNTRY PROGRAMS

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

In 2015, there were a total of 23 active country programs.



COMMUNITY IMPACT

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

CORNERSTONE INITIATIVE

The Cornerstone Initiative seeks to establish basic care in some of the world's most underserved countries and regions by providing support, expertise, and training to countries with minimal levels of care, which will help them improve and benefit later from our full range of programs and activities. Through this initiative, the WFH will lay the foundation of basic care and build partnerships that lead to an integrated and sustainable structure of patient support and care delivery. Cornerstone Initiative activities were implemented in five countries in 2015.

"[The Cornerstone Initiative] plays a crucial role for Nigeria in developing the foundation for improved diagnosis, as well as training in better treatment techniques for healthcare professionals."

— Megan Adediran, Founder and Executive Director of the Haemophilia Foundation of Nigeria (HFN)



COMMUNITY IMPACT

- **Increased** level of diagnosis in some countries with minimum care
- **Increased** number of newly identified people with bleeding disorders
- **Enhanced** basic medical and paramedical knowledge and expertise on bleeding disorders care for nurses
- **Helped** encourage some Cornerstone Initiative countries to recognize the role of the nurse as an essential member of the comprehensive care team
- **Strengthened** the capacity of patient organizations by helping them improve their internal structures
- **Extended** the outreach initiatives into eastern Nigeria means more patients will be identified
- **Advocated** activities in Zambia with the result that we engaged the government to invest more in hemophilia care, and in turn facilitated outreach efforts to help identify new patients



WORKSHOPS FOR HEALTHCARE PROFESSIONALS

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



COMMUNITY IMPACT

In 2015, the WFH organized a total of 20 conferences and/or multidisciplinary workshops.

- **Enhanced** medical and paramedical knowledge and expertise of healthcare professionals on bleeding disorders; 1,135 healthcare professionals trained
- **Trained** lab technicians on techniques for conducting proper lab tests for hemophilia and inhibitors (more technicians were trained and more patients diagnosed)
- **Contributed** to the recognition of the role of the nurse as an essential member of the comprehensive care team
- **Increased** knowledge of von Willebrand disease (VWD)

HEMOPHILIA TREATMENT CENTRE TWINNING

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

"Despite the language differences, our communication was constant. This was especially a great opportunity to learn from some of the most important people in the field of hemophilia."

— Willy Quiñones, MD, Peruvian hematologist, Arequipa (Peru) – Los Angeles (U.S.A.) Twin



COMMUNITY IMPACT

The WFH executed 20 HTC twinning partnerships and added 6 new HTC twins in 2015, including first-time partnerships with the Ivory Coast, Togo, and Myanmar.

- **Expanded** the medical and comprehensive care expertise of twin treatment centres, improving management of bleeding disorders
- **Improved** diagnosis and treatment by developing diagnostic capacity through different projects

2015 HTC TWINS OF THE YEAR:

The partnership of Varna (Bulgaria) and Bonn (Germany) won the 2015 HTC Twins of the Year award.

INTERNATIONAL HEMOPHILIA TRAINING CENTRE (IHTC) FELLOWSHIP PROGRAM

The International Hemophilia Training Centre (IHTC) Fellowship Program provides healthcare professionals, from developing countries, training in the diagnosis and management of hemophilia and other inherited bleeding disorders. The program is a great tool to improve the knowledge and engagement of healthcare professionals, and in turn, deliver better care, improve diagnosis accuracy, and improve patient outcomes. Since the program was launched in 1972, over 620 healthcare professionals from more than 89 countries have received training.



COMMUNITY IMPACT

- **Enhanced** medical and paramedical knowledge and expertise of healthcare professionals on bleeding disorders
- **Improved** diagnosis, better management, and care of people with bleeding disorders by trained specialists upon return to their countries
- **Provided** opportunities for IHTC Alumni to remain engaged with the WFH and bleeding disorders community by improving communications and offering more post-fellowship training opportunities
- **Expanded** WFH training offerings into other languages and regions (two new IHTCs were recruited to respond to program training needs)



INTERNATIONAL EXTERNAL QUALITY ASSESSMENT SCHEME (IEQAS)

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



COMMUNITY IMPACT

- **Improved** laboratory performance in hemophilia treatment centres from around the world
- **Improved** effectiveness and competence of the quality assurance systems in the labs enrolled in the program
- **Improved** proper diagnosis which leads to identification of new people with bleeding disorders

EDUCATIONAL RESOURCES

In 2015, the WFH produced resources designed to help improve the rates of diagnosis and the availability of treatment for all people with inherited bleeding disorders.



COMMUNITY IMPACT

- **Published** a monograph on genetic counseling in English and Spanish
- **Produced** detailed video demonstrations of three foundational laboratory diagnostic techniques (to be launched in 2016)
- **Initiated** development of new resource addressing the phenotypic and genotypic diagnosis of VWD
- **Published** a Fact Sheet highlighting the principles and importance of quality data collection in all GAP languages (English, French, Spanish, Arabic, Chinese, and Russian)

A woman on the left is wearing a white blouse with vibrant red and blue floral embroidery, a large yellow pom-pom brooch, and multiple gold necklaces. She has an elaborate silver and gold headdress. To her right, a man is smiling, wearing a teal shirt and a black vest. The background is a warm, textured wall. A semi-transparent yellow box is overlaid on the top half of the image, containing the page number and title. Another semi-transparent yellow box is at the bottom, containing the subtitle.

2 BUILDING CAPACITY

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

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

HEMOPHILIA ORGANIZATION TWINNING

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



COMMUNITY IMPACT

The WFH started with 11 HOT partners in 2015 and we were able to add another two during the year, to bring the total to 13 organizations.

- **Leveraged** outreach initiatives by patient organizations to add new chapters; increase membership; increase registries of people with rare bleeding disorders; and provide camps for children, adults, and families
- **Strengthened** patient organizations capacity through lobbying, advocacy, governance, and fundraising training

2015 HOT TWINS OF THE YEAR

The partnership of Bangladesh and Canada won the 2015 HOT Twins of the Year award.

NATIONAL AND REGIONAL NATIONAL MEMBER ORGANIZATION (NMO) SKILLS TRAINING

The WFH organizes regular training and capacity-building workshops, at national and regional levels, to strengthen the knowledge and skills of NMOs. In turn, these trainings help them improve their internal structures, as well as their external activities and relations.

"There are no limits to what can be achieved when there is a good working team, clear objectives and determination."

— NMO Skills Training participant



COMMUNITY IMPACT

- **Trained** 1,490 patients and family members
- **Assisted** in further developing patient skills and sharing best practices through workshops
- **Developed** and provided NMOs with tailored skills training
- **Educated** and empowered patients and NMO leaders to live a healthier life and advocate for better care
- **Provided** patients, who participated in the trainings, with practical tools to share with their organizations and to apply, if possible, in their own countries



2. Building capacity



ADVOCACY IN ACTION PROGRAM

The Advocacy in Action (AiA) Program assists WFH NMOs in developing and strengthening their advocacy skills, and provides tools to help NMOs implement successful advocacy projects and activities.

“Compared to years ago, the situation has changed a lot. First of all we have a higher public awareness, better and more medical staff, less treatment with fresh frozen plasma and cryoprecipitate, and much more treatment with factor.”

— Megi Neziri, active member of the Albanian Hemophilia Association (AHA)



COMMUNITY IMPACT

In 2015, the 12th and final Advocacy in Action workshop was held in Bangkok, Thailand, entitled “Advocacy Essentials: Being Informed and Taking a Long Term Approach to Advocating”.

- **Developed** and enhanced patient advocacy skills
- **Assisted** patients in advocating for better care
- **Developed** and provided NMOs with tailored advocacy training
- **Supported** specific NMO representatives in developing and implementing national advocacy campaigns and projects
- **Provided** specific NMOs with experienced advocacy support and coaching for the successful implementation of their advocacy projects

EDUCATIONAL RESOURCES

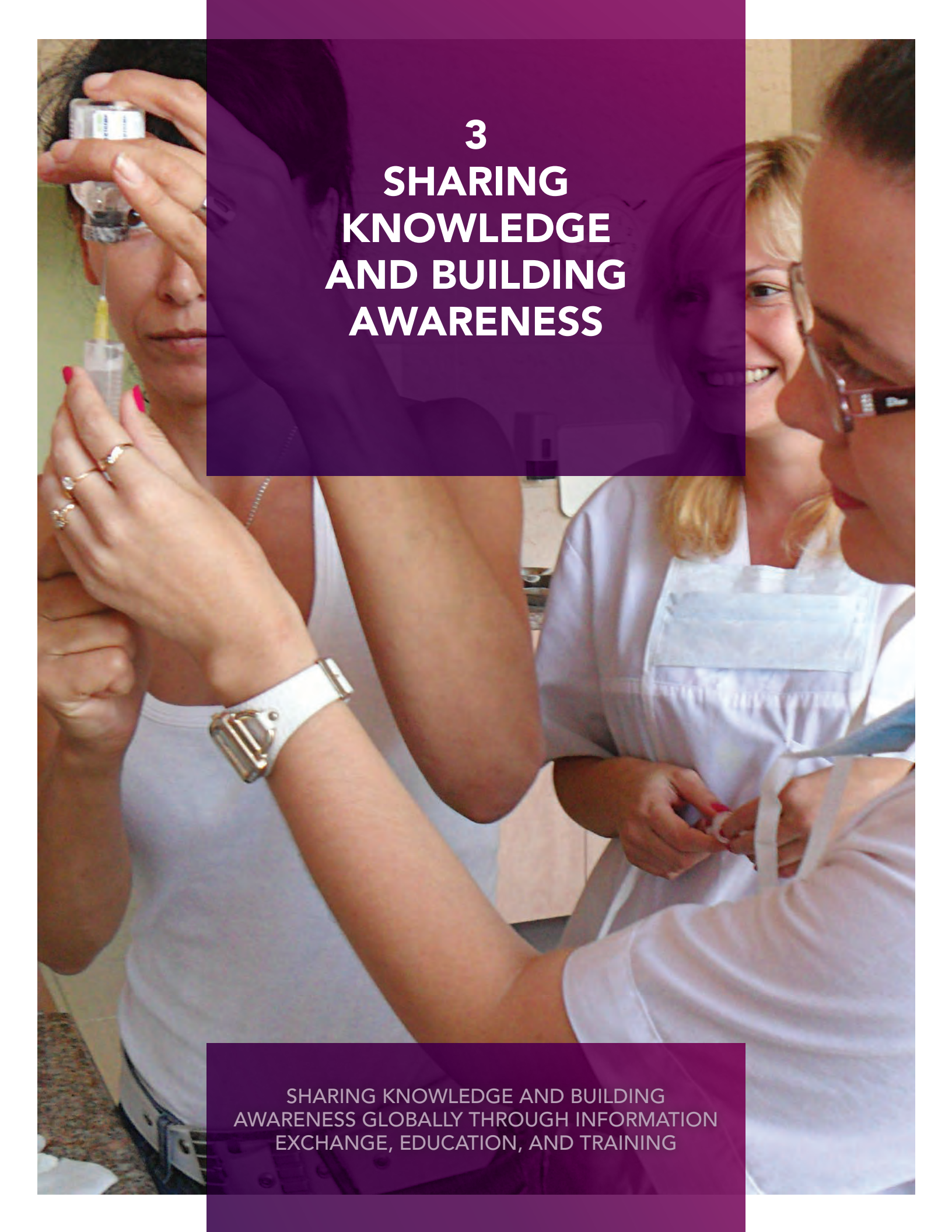
The WFH produces resources designed to build the capacity of our NMOs to effectively serve the bleeding disorders community.



COMMUNITY IMPACT

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

- **Published** NMO self-assessment tool and strategic planning guide for emergent NMOs in all six GAP languages
- **Released** seven articles in the Young Voices online series (English, French, and Spanish)
- **Produced** and hosted two youth group success story videos
- **Detailed** the outline of a data collection and health economics curriculum
- **Created** Spanish and French versions of the WFH Annual Global Survey database
- **Conducted** two live webinars with NMOs to gather feedback and provide training on goals and the utility of the WFH Annual Global Survey



3 SHARING KNOWLEDGE AND BUILDING AWARENESS

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

Information is powerful, and one of the important ways we empower our community is through increasing knowledge and awareness. For healthcare professionals we deliver effective training and develop relevant educational resources to improve clinical management and patient outcomes. We also develop and share information to help educate people with bleeding disorders and their families. As our community is small and sometimes isolated, we continue to capitalize on digital strategies to increase awareness, and provide networking and other learning opportunities.

EDUCATIONAL RESOURCES

In 2015, the WFH undertook a number of initiatives and produced several educational resources designed to share knowledge and build awareness through information exchange, education, and training.



COMMUNITY IMPACT

- **Delivered** over 800,000 educational resources – downloads and print distribution (surpassing the 2015 goal of 726,000)
- **Developed** a distance education strategy from the results of an international stakeholder needs assessment
- **Launched** the first-ever CME-accredited WFH eLearning webcast on World Hemophilia Day
- **Produced** the WFH's first eLearning modules based upon the Guidelines for the Management of Hemophilia, full 6-module eLearning program to be launched in English, French, and Spanish in 2016
- **Designed** and deployed a new interactive online tool to browse resources, highlighting how they directly support each pillar of the WFH Development Model
- **Advanced** the development of comprehensive standardized musculoskeletal and psychosocial training curricula
- **Granted** permission to four patient organizations to translate and reprint specifically requested WFH resources in their own languages

14TH WFH INTERNATIONAL MUSCULOSKELETAL CONGRESS

The 14th WFH International Musculoskeletal (MSK) Congress was a three-day event that took place in Belfast, Northern Ireland, from May 7-10, 2015. The Congress program featured presentations, posters, and exhibit displays with a comprehensive musculoskeletal approach on hemophilia, covering key areas relevant to orthopedist and physical therapists around the world. The 15th WFH International Musculoskeletal Congress will take place in Seoul, Korea, in spring 2017.

The Belfast MSK Congress featured over 40 leading expert speakers in their different fields all focusing on a comprehensive musculoskeletal approach to hemophilia.



COMMUNITY IMPACT

The 2015 Musculoskeletal Congress had a record number of 379 registrations from a total of 63 countries. 124 abstracts were submitted, 46 more than 2013, 12 free papers were presented, and 70 e-posters were accessible at the exhibition display.

- **Sponsored** nine physical therapists/orthopedists, from developing countries, through travel grants
- **Capitalized** upon the international gathering of physical therapy experts in the management of hemophilia to hold a highly productive focus group to advance the development of the standardized physiotherapy training curriculum



3. Sharing knowledge and building awareness



WORLD HEMOPHILIA DAY 2015

On April 17, 2015, the global bleeding disorder community joined together to raise awareness about bleeding disorders and to recognize the importance of Building a Family of Support around those living with someone who has a bleeding disorder.



COMMUNITY IMPACT

As part of the Building a Family of Support Campaign for World Hemophilia Day 2015, we focused on online initiatives in order to reach the largest possible number of members of the bleeding disorder community and interact with them in the most engaging way possible.

- **Leveraged** the online WFH Global Family Tree to bring together different members of our community and allow participants to share their photos and stories with one another
- **Doubled** the online Global Family Tree participation versus the previous year's World Hemophilia Day online activities
- **Delivered** an announcement on April 15 regarding the landmarks being lit in red world-wide which was viewed more than 22,000 times and was clicked on more than 2,000 times
- **Launched** Hemophilia World Online and the Family tree on April 17 and generated more than 30,000 views

WFH 2016 WORLD CONGRESS

Throughout 2015, every effort has been made to ensure that the WFH 2016 World Congress in Orlando, Florida, will be a milestone in the history of the WFH. The global bleeding disorders community will meet for the first time in over 25 years in the United States and the XXXII International Congress of the World Federation of Hemophilia is expected to be the largest yet, with more than 5,500 attendees from over 125 countries.

WFH LOCALIZED WEBSITES

WFH localized websites are integral initiatives for the WFH, as they contribute to raising awareness about WFH programs and available resources in multiple languages.



COMMUNITY IMPACT

We now have online content available on the English, French, Spanish, Arabic, Simplified Chinese, and Russian WFH websites.

- **Enhanced** website functionality so that educational resources can now be accessed online by community members directly in their own language—resulting in a greater than four-fold increase in downloads
- **Initiated** development of the WFH Japanese website in 2015, with a launch on World Hemophilia Day 2016

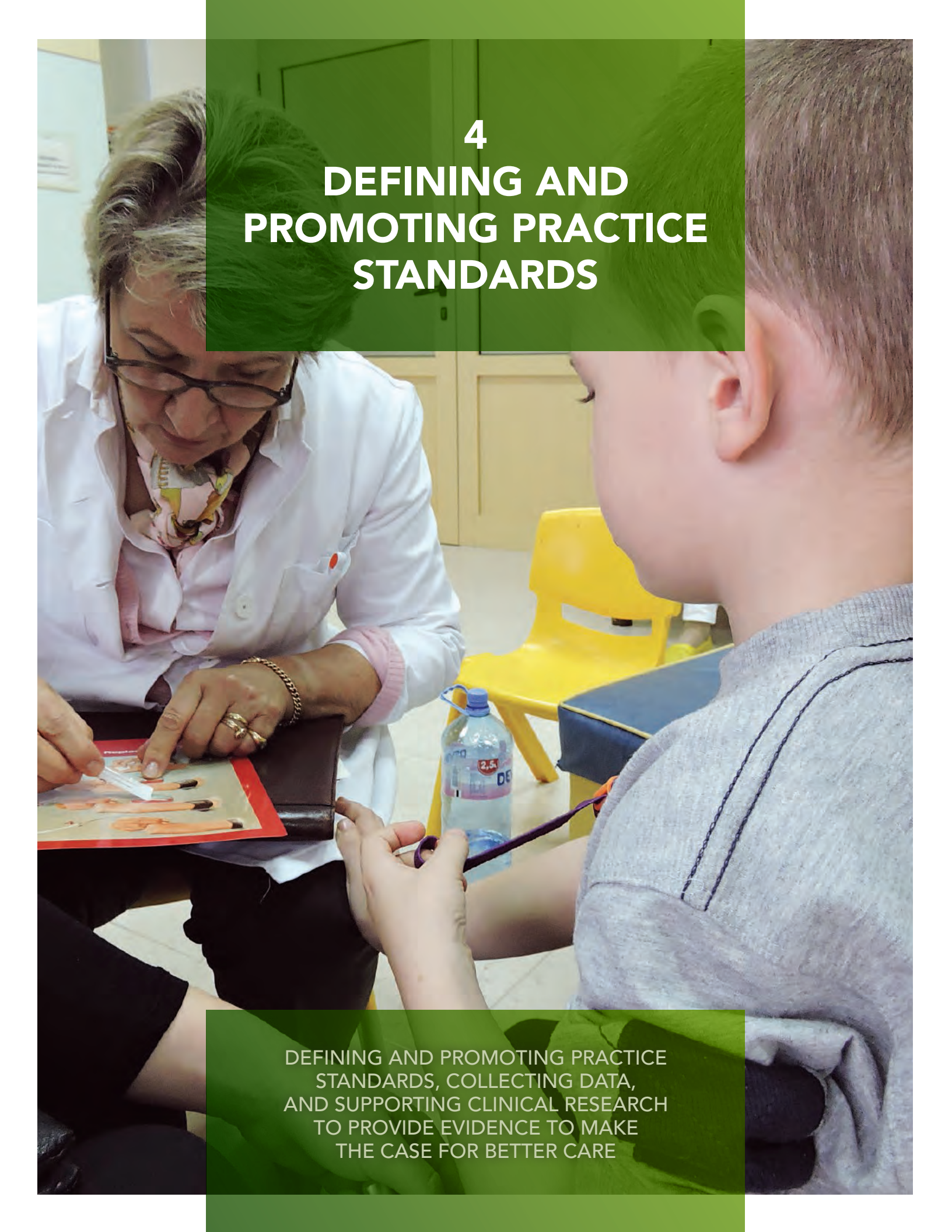
HEMOPHILIA WORLD

The WFH publishes a print version of the Hemophilia World news magazine three times a year. It includes articles on WFH activities and what hemophilia organizations around the world are doing to improve care.



COMMUNITY IMPACT

- The online version of Hemophilia World was launched in April 2015
- The print issue of Hemophilia World reached 2,500 recipients globally per issue



4 DEFINING AND PROMOTING PRACTICE STANDARDS

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

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

WFH CLINICAL RESEARCH GRANT PROGRAM

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

“...The grant...was an acknowledgement by the WFH that our research was important and worthwhile investigating. This helped me convince all the people I needed to collaborate with to make this project possible.”

— Lize van Vulpen, 2014 Clinical Research Grant recipient



COMMUNITY IMPACT

- Distributed US\$172,000 in clinical research grant funding
- Awarded grants to four researchers in 2015



2015 CLINICAL RESEARCH GRANT RECIPIENTS:

VICTOR JIMÉNEZ-YUSTE

Hospital Universitario La Paz, Madrid, Spain

Tailoring prophylaxis: study of trough levels by global tests and impact of physical activity

MARZIA MENEGATTI

Angelo Bianchi Bonomi Hemophilia and Thrombosis Center, Milan, Italy

Evaluation of thrombin generation and fibrinolysis in patients with FXI deficiency with variable bleeding patterns

SILVIA RIVA

University of Milan, Milan, Italy

RE.CO.VERY: REsponsibility for treatment COmpliance is VERY important. A study in elderly population with hemophilia

JONATHAN C. ROBERTS

Bleeding & Clotting Disorders Institute, Peoria, U.S.A.

An ELISA-based VWF Functional Screening Assay for Discriminating the Phenotypic Variants of VWD

EPIDEMIOLOGICAL RESEARCH PROGRAM

The aim of the WFH Epidemiological Research Program is to develop a database of high quality, observational data on a large population of patients with hemophilia, which will be used to advance the understanding of hemophilia worldwide.



COMMUNITY IMPACT

- In 2015, consensus was achieved on a plan for implementation of the Epidemiological Research Program

EDUCATIONAL RESOURCES SUPPORTING THE WFH RESEARCH PROGRAM

In 2015, the WFH undertook initiatives to produce resources designed to help define and promote practice standards.



COMMUNITY IMPACT

- **Initiated** production of a monograph outlining preventive oral care for children and adolescents with hemophilia
- **Established** the need to produce guidelines for the management of VWD
- **Worked** closely with the National Guidelines Clearinghouse (NGC) to ensure that an imminent update to the *Guidelines for the Management of Hemophilia* meets their revised inclusion requirements
- **Realized** significant progress towards defining a measure of adequate care with the expectation of having a formula in place in 2016

DATA COLLECTION

The 2014 Report on the WFH Annual Global Survey was produced in 2015. The 2014 Report included data on more than 287,000 people with bleeding disorders in 106 countries. As in past years, the Annual Global Survey Report provided analysis and results for a limited number of the survey questions asked each year.

82 countries submitted data for 2014, a 9% increase from the previous year.



COMMUNITY IMPACT

- **Improved** the overall quality of our Annual Global Survey Report by dropping a year of historical data, publishing it earlier in the year

EDUCATIONAL RESOURCES SUPPORTING THE DATA COLLECTION PROGRAM

In 2015, the WFH produced resources designed to promote and support quality data collection.



COMMUNITY IMPACT

- **Detailed** the outline of a data collection and health economics curriculum
- **Published** a Fact Sheet highlighting the principles and importance of quality data collection in all six GAP languages

A photograph of a woman in a yellow headwrap and yellow dress, carrying a baby in a white sling. She is standing in front of a patterned wall. Other children are visible in the background. The image is overlaid with orange semi-transparent boxes containing text.

5 IMPROVING ACCESS

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

Through the WFH Humanitarian Aid Program and the monitoring of safety and supply issues, we have been involved in product supply and safety for many years. However, with the advent of new treatments and the successful launch of Project Recovery and Project WISH—resulting in the manufacturing of clotting factor concentrates from previously discarded cryopaste—the WFH will explore new models for collaboration to increase the supply of predictable product donations. With new treatments poised to enter the market, we also have an important global role in monitoring developments within our community and sharing pertinent information.

WFH HUMANITARIAN AID PROGRAM

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

An increasing number of partners within the global bleeding disorders community have accepted the challenge of providing a sustainable and predictable supply of donated products. Through the donation by Biogen and Sobi of over 500 million IUs within five years, the three-year commitment from Grifols for 20 million IUs per year, and the multi-year agreement signed with CSL Behring, there will now be a more predictable and sustainable flow of humanitarian aid donations to the global community. In addition, the continued efforts of the Canadian Blood Services, Biotest, and Grifols with Project Recovery, and the work by the Italian National Blood Services through Project WISH, allow for the manufacturing of clotting factor concentrates from previously discarded cryopaste, which in turn provides treatment products to countries most in need. These commitments will contribute to the further expansion of the WFH Humanitarian Aid Program.

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

In 2015, 52,829,144 IUs of clotting factor were donated to 63 countries



COMMUNITY IMPACT

- **Continued** advocacy for an adequate supply of safe and effective replacement therapy to be available and affordable
- **Effectively** distributed a predictable clotting factor concentrates supply of humanitarian aid donations
- **Explored** and began collaborations to develop predictable stream of full shelf-life product donations





NINTH WFH GLOBAL FORUM ON RESEARCH AND TREATMENT PRODUCTS FOR BLEEDING DISORDERS

In 2015, more than 170 people, from over 30 countries, participated in the 9th WFH Global Forum on October 22 and 23, in Montreal. For the first time, the WFH combined our Global Forum on Treatment Products for Bleeding Disorders with our Global Research Forum in a two-day meeting covering the latest developments in both areas.



COMMUNITY IMPACT

- **Addressed** issues related to the safety and supply of treatment products
- **Discussed** and debated critical issues and challenges in the areas of research and clinical trials related to bleeding disorders and their treatment products

TREATMENT SAFETY

The safety and supply of treatment products is a key concern for the bleeding disorders community. In the years since many people in our community were infected with HIV and hepatitis C (HCV) by clotting factor concentrates in the 1970s and 1980s, the WFH has closely monitored product safety, efficacy, availability, and supply. We work in close cooperation with government agencies, industry, clinicians, and patient groups to achieve both the quality and desired quantity of treatment products. These critical issues remain a central theme of our work, and we continue to foster debate and dialogue on them. We also closely monitor and promote scientific and technological developments that can lead to safer, more efficacious treatment, or a cure.



COMMUNITY IMPACT

- **Succeeded** in having DDAVP added to the WHO Essential Medicines List
- **Revised** the Guide to National Tenders for the Purchase of Clotting Factor Concentrates in English and Spanish
- **Began** development of an online registry of clotting factor concentrates, which will launch in 2016
- **Issued** communiqués relating to risk-based decision making and blood donation, hepatitis E virus, MERS, and the SIPPET study results
- **Produced** panel discussions on expanding access to hemophilia treatment products, current issues in inhibitor surveillance, and new developments in treatments for bleeding disorders
- **Updated** online information about inhibitors in English, French, and Spanish



6

EXPANDING OUR FINANCIAL BASE

EXPANDING OUR FINANCIAL BASE
AND ENHANCING OPERATIONAL EXCELLENCE
TO ADVANCE OUR MISSION



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

To make sure that we continue to function in an effective and agile way in 2015, we:

- + Assessed our resources
- + Ensured clarity of roles and accountabilities
- + Provided the tools to achieve our mission
- + Continually improved organizational and program efficiency and effectiveness

In 2015, we ensured the selection of strong leadership in the development of the WFH fundraising program. The goal was to expand and build upon our culture of philanthropy, within the bleeding disorders community, through an integrated fundraising program.

We supported the effectiveness of our organizational structure by continuing to recruit, develop, and retain high-performing and engaged staff and volunteers in 2015. It was imperative to ensure that the WFH governance and structure facilitated clear accountabilities, decision-making, collaboration, and optimization of resources. Importance was placed on leveraging technology to engage stakeholders and enhance communications, education, training, knowledge transfer, and fundraising.

2015 FINANCIAL REPORT

In financial terms, 2015 has been another strong year for the WFH. With a net surplus of \$285,123, compared to a budgeted deficit of \$1,747,580, there was an improvement of \$2,032,703. The extremely strong U.S. currency that continued in 2015 (ranging from \$1.17 to \$1.40 when compared to the Canadian dollar) once again contributed to this robust result, as the majority of revenue from sponsorship of programs was received in U.S. dollars.

Continued Diversification of Revenue

Corporate sponsors of the WFH programs and initiatives continued their steady support in 2015 with contributions of \$4,998,469, an increase of \$811,701 over their 2014 contributions. The majority of this increase (79%) stemmed from the continued strength of the U.S. dollar. Furthermore, the increase was also due to sponsorship contributions of \$417,642 towards the International Musculoskeletal Congress and the WFH Global Forum on Research and Treatment Products for Bleeding Disorders, events that take place every two years.

In 2015, the scope of the WFH Humanitarian Aid Program continued to expand, with 52.8 million IUs channelled through the WFH. As per Canadian accounting rules, revenues received for restricted purposes can only be recognized in the year in which related expenses are incurred. In 2015, \$753,345 was spent against the revenues we have received for the WFH Humanitarian Aid Program. Thus, only this amount is recognized in WFH revenues. Also under the same principle, out of the \$459,524 received for the WFH Research Program, only \$335,696 is recognized in income. From this amount, the WFH was able to continue to award clinical research grants in 2015.

The total WFH revenue, before Congress and product donations, reached \$7,403,981, \$1,869,497 (33.8%) above 2014. Approximately 53% of this growth is due to the strong U.S. currency.

Generating income through the internal management of the biennial WFH World Congress and other WFH meetings, including the WFH International Musculoskeletal Congress and the WFH Global Forum, adds to a diversified income stream. As shown in Figure 1, excluding product donations, 40% of revenues over the two-year cycle are for sponsorships from WFH corporate partners; 6% are for restricted programs (Humanitarian Aid and Research); and the remaining 54% were generated through the WFH 2014 World Congress, financial donations, self-generating income activities, and NMO assessments.

Expenses Aligning With Strategic Objectives

Healthcare development programs, education and public policy programs, and the WFH Humanitarian Aid Program together represent a total of 42% of the WFH expenses, as seen in Figure 2. This demonstrates a strong commitment of the WFH to support the needs of the global bleeding disorders community. The WFH World Congress not only represents the most important part of revenues, it also represents 38% of the expenses that have been incurred over the past two years. Additional expenses include: administration at 9%, fundraising and corporate relations at 6%, communications at 4%, and governance at 2%.

Humanitarian Aid

The WFH distributes valuable humanitarian aid product donations from many of our corporate sponsors to WFH NMOs and HTCs around the world. In 2015, 52.8 million IUs of clotting factor concentrates were strategically donated to 63 countries, improving and sustaining care for people in the developing world. This represents a 150% growth in volume of IUs distributed. The majority of these donations, worth US\$97,098,511, are reported in the audited financial statements of WFH USA. The amount reported in the financial statements of WFH is CAN\$9,258,352.

Year-Over-Year Comparison

The 2015 and 2014 statement of revenues and expenses, illustrated in Figure 3, reflects the fluctuations within a typical two-year cycle where the WFH World Congress is held in even years, as well as the varying amounts of product donations received yearly. There was excellent growth in contributions for humanitarian aid, with \$753,345 recognized from revenues received compared with \$72,046 in 2014. Self-generated income totalled \$853,671, including \$416,562 derived from registration and housing revenues from the 14th International Musculoskeletal Congress and the WFH Global Forum, both held in 2015.

The WFH healthcare development program expenses tend to be lower in a non-Congress year, as the Global NMO Training costs are included in a Congress year. Therefore in 2015, there was a decrease in these expenses of \$174,042. This was offset by expenses for the WFH International Musculoskeletal Congress of \$350,119 which was held in 2015. Similarly, the Global Forum contributed a \$220,776 increase to Safety and Supply programs under the Education and Public Policy area.

There was an increase in activities for the continued expansion of the WFH Humanitarian Aid Program. Expenses in this area rose to \$796,506 in 2015, compared with \$364,742 in 2014.

Looking Ahead

As we embark on a new two-year cycle, our financial base is solid, our WFH 2016 World Congress is on track to deliver a healthy budgeted surplus, and our diversified fundraising activities will continue to expand.

As the WFH goes forward, we have an unprecedented opportunity to increase support of our mission with stable financial resources. At the same time, there are risks to consider so that we do not overextend ourselves financially; there will be a challenge to keep future congresses as profitable as they have been in the past and the U.S. dollar can experience a downturn as easily as it has achieved its current strength. Nevertheless, with 75% of our people suffering, we must think of strategic ways to put our dollars to work for the benefit of our people and the accomplishment of our mission: improving and sustaining care for people with inherited bleeding disorders around the world so that there is Treatment for All.

FIGURE 1
REVENUES 2014 AND 2015
(EXCLUDING PRODUCT DONATIONS)

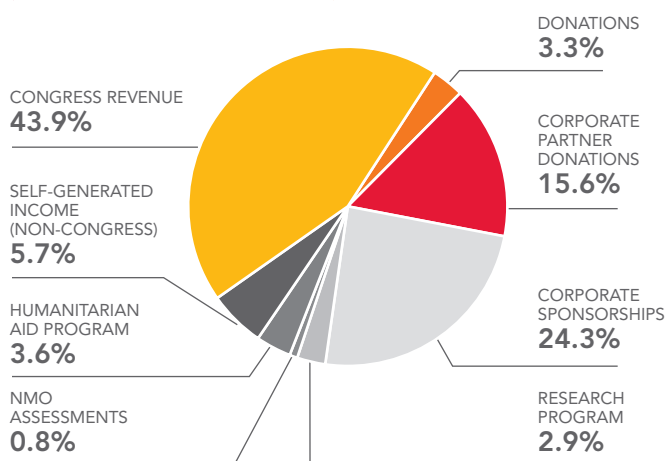


FIGURE 2
EXPENSES 2014 AND 2015
(EXCLUDING PRODUCT DONATIONS)

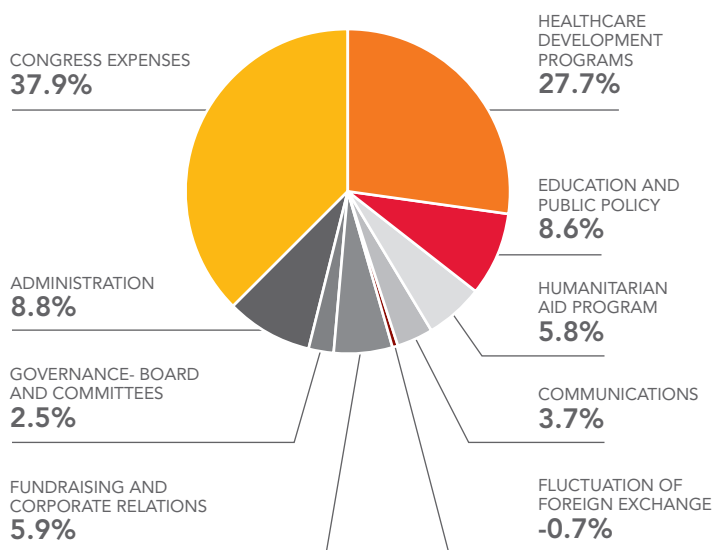


FIGURE 3

REVENUES (expressed in CANS)	2015	2014
Donations	363,922	391,872
Corporate Partner Donations	1,933,393	1,657,601
Corporate Sponsorships	3,065,076	2,529,166
Research Program	335,696	326,431
NMO Assessments	98,878	84,944
Humanitarian Aid Program	753,345	72,046
Self-Generated Income (Non-Congress)	853,671	472,424
Total Revenues before Congress and Product Donations	7,403,981	5,534,484
Congress Revenue	0	10,127,590
Product Donations	9,258,352	6,368,132
TOTAL REVENUES	16,662,333	22,030,206

EXPENSES (expressed in CANS)	2015	2014
Healthcare Development Programs	2,663,188	2,837,230
Education and Public Policy	1,002,745	701,055
Humanitarian Aid Program	796,506	364,742
Communications and Marketing	461,784	266,286
Fundraising & Corporate Relations	566,344	601,476
Governance- Board and Committees	241,841	246,487
Administration	867,485	880,188
Fluctuation of Foreign Exchange	-155,439	21,019
Total Expenses before Congress and Product Donations	6,444,454	5,918,483
Congress Expenses	674,404	6,856,789
Product Donations	9,258,352	6,368,132
TOTAL EXPENSES	16,377,210	19,143,404
EXCESS	285,123	2,886,802

THANK YOU TO OUR DONORS

The WFH gratefully acknowledges the many organizations and individuals whose generous financial contributions help to close the gap in care around the world.

In 2015, the following individuals, corporations, and organizations made financial contributions of CAN\$100 or more to the WFH or WFH USA.

PATRON

Jan Willem André de la Porte

ANNUAL UNRESTRICTED CONTRIBUTIONS

Baxalta
Bayer
Biogen
Biotest
CSL Behring
Gilead
Green Cross
Grifols
Kedrion
LFB
Novo Nordisk
Octapharma
Pfizer
Precision BioLogic
Sanquin
Sobi

GLOBAL ALLIANCE FOR PROGRESS (GAP) SECOND DECADE

Visionary Partner
Baxalta

Leadership Partner
CSL Behring

Collaborating Partner
Bayer
Biogen
Biotest
Grifols
Kedrion
Novo Nordisk
Pfizer
Sobi

SPONSORED PROGRAMS

Advocacy in Action Program
Baxalta

Twinning Program
Pfizer

International External Quality Assessment Scheme Program
Novo Nordisk Haemophilia Foundation

International Hemophilia Training Centre Fellowship Program
Bayer

WFH Research Program
Baxalta
Bayer
Biogen
Grifols
Hemophilia Center of Western Pennsylvania 340B Program

Musculoskeletal Congress
Platinum Sponsor:
Baxalta, Novo Nordisk

Global Forum on Research and Treatment Products for Bleeding Disorders
Baxalta
Bayer
Biogen
Canadian Blood Services
CSL Behring
Héma Québec
Ministère des Relations internationales, de la Francophonie
Novo Nordisk
Octapharma
Sobi

Website
Rare Bleeding Disorder web section:
Novo Nordisk
von Willebrand Disease web section:
Octapharma

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

WFH Humanitarian Aid Program
Baxalta
Biogen-Sobi
Biotest
CSL Behring
Grifols
Pfizer

Project Recovery
Canadian Blood Services (CBS)
Canadian Hemophilia Society
Biotest
Grifols

Project WISH
Italian Blood Transfusion Services
Kedrion

Other sponsored programs
National Bleeding Disorder Symposium: Biotest
Susan Skinner Memorial Fund: Hemophilia Alliance Foundation
WFH African Initiative: Pfizer
Workshop on Hemophilia Care: Kedrion, Erongomed
von Willebrand Disease Workshop: LFB

World Hemophilia Day
Baxalta
Bayer
Biogen
CSL Behring
Novo Nordisk
Precision BioLogic
Sobi

SOLIDARITY FUND CONTRIBUTORS IN 2015

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

Asociación Venezolana para la Hemofilia
Association française des hémophiles
Association Luxembourgeoise des Hémophiles
Association Togolaise des Hémophiles (ATH)

Association Tunisienne des Hémophiles
Canadian Hemophilia Society
Danish Hemophilia Society
Drustvo Hemofilikov Slovenije
Estonian Haemophilia Society
Ethiopian Hemophilia Society
Fundación Panameña de Hemofilia
Georgian Association of Haemophilia and Donorship
Haemophilia Foundation Australia
Haemophilia Foundation of New Zealand
Haemophilia Foundation of Uganda
Hemophilia Association of Sri Lanka
Hemophilia Federation (India)
Hemophilia Society of Bangladesh
Hemophilia Society of Maldives
Irish Haemophilia Society Ltd.
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Korea Hemophilia Foundation
Latvia Hemophilia Society
Liga Colombiana de Hemofilicos
Magyar Hemofilia Egyesület (Hungary)
Nepal Hemophilia Society
Netherlands Haemophilia Society
Österreichischen Hämophilie Gesellschaft (Austria)
Serbian Hemophilia Society
Singapore Haemophilia Society
South African Haemophilia Foundation
Swiss Hemophilia Society
UK Haemophilia Society

MEMORIAL FUNDS

Susan Skinner Memorial Fund

TRIBUTES

In Honor of Farren Crisp
In Honor of Mariette Driessens
In Honor of Patrick C. Forgit
In Honor of Marissa Lehmayer
In Honor of Per Bjorn Ostergaard
In Honor of Frank Schnabel
In Honor of Oriol i Mariona V. Vilalta
In Memory of Virgina Boyd
In Memory of Karin Lindvall
In Memory of Kathlenn McHugh
In Memory of Matthew & T. White

DONORS

\$500,000 and more

Biogen

\$150,000 – \$499,999

CSL Behring
Hemophilia Center of
Western Pennsylvania

\$100,000 – \$149,999

André de la Porte Family Foundation
Packaging Coordinators, Inc. (PCI)
Pfizer

\$50,000 – \$99,999

Hemophilia of Georgia, Inc.
Novo Nordisk Haemophilia Foundation

\$20,000 – \$49,999

Association Française des Hémophiles
National Hemophilia Foundation

\$10,000 – \$19,999

Eastern Pennsylvania Chapter
Hemophilia Alliance Foundation
Mark Skinner and Jim Matheson
New York Community Trust
Glenn and Beatrice Pierce

\$5,000 – \$9,999

CSL Limited (Australia)
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Canadian Blood Services
Canadian Hemophilia Society
Héma-Québec
LA Kelley Communications, Inc.
The Marketing Research Bureau

\$2,500 – \$4,999

Assad Haffar
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Phillips 66

\$1,000 – \$2,499

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Hemophilia Foundation of Oregon
Hemophilia of Iowa, Inc.
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Susanna von Oettingen
Ellen White
Wendy Wild
Wing Yen Wong
Hassan M. Yaish
Deon York

Sustaining members active in 2015

Sustaining memberships include a donation to the WFH in addition to regular membership fees. Thank you for partnering in our mission.

Per Arne Berg
Jens Bungardt
Piet de Kleijn
Kerry Grant
Soon Ki Kim
Jörg Krucker
Prasad Mathew
Tadashi Matsushita
Richard J. Metz
Paul Moorehead
Kathy J. Mulder
Declan Noone
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Maria Serena Russo
Talia Shahar
Eric E. Stolte
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Hassan M. Yaish
John York



WORLD FEDERATION OF HEMOPHILIA

1425, boulevard René-Lévesque Ouest
Bureau 1010
Montréal (Québec) H3G 1T7
Canada

T +1 514.875.7944
F +1 514.875.8916
wfh@wfh.org

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WFH 2015 HIGHLIGHTS



GLOBAL REACH OF WFH
HEALTHCARE PROGRAMS
IN **102** COUNTRIES



OVER **1,135**
HEALTHCARE PROFESSIONALS
TRAINED WITH ENHANCED MEDICAL
AND PARAMEDICAL KNOWLEDGE



TRAINED OVER **1,490**
PATIENTS AND FAMILY MEMBERS
ON BLEEDING DISORDERS



DELIVERED OVER
800,000
EDUCATIONAL RESOURCES



HUMANITARIAN AID DONATED
OVER **52** MILLION IUs
TO **63** COUNTRIES,
A **150%** INCREASE

