WFH

WORLD FEDERATION OF HEMOPHILIA

WFH

ANNUAL REPORT 2014

GROWTH & DEVELOPMENT TO SUPPORT THE GLOBAL COMMUNITY

As a global organization dedicated to advancing treatment to all people with bleeding disorders, where the vast majority have little or no access to care, the World Federation of Hemophilia (WFH) has a large task ahead. However, in 2014, we made great headway towards advancing the WFH's vision of Treatment for All.

Much of our success in 2014 was epitomized by the WFH 2014 World Congress held in Melbourne, Australia. The Congress opened on a high note, with the announcement during the president's plenary address that over 700 million units of donated factor concentrates will be channelled through the WFH Humanitarian Aid Program over the next five years. This expansion of the program will provide sustained, predictable access to treatment to people with hemophilia in developing countries. The Congress proved to be historically the most successful with regards to its scientific programs and participant satisfaction, along with the largest net surplus revenue which will be used to help fund our development programs globally.

Following the WFH 2014 World Congress, the WFH General Assembly was held, during which WFH national member organizations (NMOs) voted in new members to the newly named WFH Board of Directors (formerly the WFH executive committee). We would like to express our gratitude and appreciation to these departing members for their time and considerable efforts to the WFH vision of Treatment for All.

In 2014, the three-year Close the Gap Campaign ended successfully surpassing the US$5 million goal to raise, US$5.4 million to support programs including the Global Alliance for Progress, Cornerstone Initiative, and the Research Program. Jan Willem André de la Porte, our Patron, led the way by donating $2 for every $1 donated by the bleeding disorders community. We are very grateful to everyone who supported the Campaign and the goal of closing the gap in care between those living with a bleeding disorder in developed and developing countries.

Through various programs and activities, over 100 countries benefited from WFH support in 2014. The WFH family grew, with six new national patient organizations being accredited as NMOs. The first clinical research grants were awarded to help build the evidence for better management of bleeding disorders. Over 600,000 educational resources were distributed and the organization launched an essential version of its website in Simplified Chinese, Russian, and Arabic. In addition, the WFH Annual Global Survey was revamped to provide online interactive tools to help analyse and use this global data to advocate for better care.

Internally, there was a focus on enhancing operational excellence and expanding our financial base, finishing the year with a net surplus, after congress, of $2.9 million, more than 250 per cent above target. We revised our bylaws and successfully transitioned to meet the new requirements for non-profits in Canada. In September 2014, John Bournas stepped down as WFH CEO. He brought strong negotiating skills and a new vision to the organization and has left a lasting impact on the community as a whole. After conducting an extensive international search, we are pleased to announce that Alain Baumann is joining the WFH as CEO in August 2015.

In 2014, we completed our 2012-14 strategic plan and developed our strategic goals for the next three years. Looking back over the last three years, we can see the progress we have made: establishing a research program, capitalizing on digital technology to unite our community and share information, launching the next generation of the Global Alliance for Progress, developing and implementing a new Cornerstone Initiative to address the needs of the least developed countries, and increasing access to treatment products through Project Recovery and other humanitarian aid donations.

The WFH will continue to support and advocate for all our national member organizations, recognizing that while our community is indeed global, each region has different and varied needs. This will include monitoring changes throughout the global bleeding disorders community and ensuring that our strategies and programs are the best adapted to cope with whatever arises.

Throughout it all we remain true and dedicated to our mission to improve and sustain care for those with inherited bleeding disorders and advance our vision of Treatment for All.

* All dollars expressed in the WFH 2014 Annual Report are in Canadian funds except where otherwise indicated.

Alain Weill
WFH PRESIDENT

Elizabeth Myles
WFH CHIEF OPERATING OFFICER / INTERIM CEO

IMPROVING CARE & BUILDING CAPACITY

2014 GLOBAL PROGRAM HIGHLIGHTS

GLOBAL REACH OF WFH HEALTHCARE PROGRAMS

103 COUNTRIES

NMO SKILLS TRAINING

1 GLOBAL NMO TRAINING

2 **THEMATIC/REGIONAL TRAININGS** (Africa and the Middle East; Eastern Europe)

1 SYMPOSIUM

12 NATIONAL TRAININGS **IN 10 COUNTRIES**

4 **EDUCATIONAL SESSIONS** TO PATIENTS AND FAMILY MEMBERS IN 4 COUNTRIES

MEDICAL TRAINING FELLOWSHIPS

35 fellowships
(overall 93 per cent retention in hemophilia care after 5 years)

GAP AND COUNTRY PROGRAMS AND CORNERSTONE INITIATIVE

37 COUNTRIES
/ **9** GAP
/ **25** COUNTRY PROGRAMS
/ **3** CORNERSTONE INITIATIVE

HEMOPHILIA ORGANIZATION AND CENTRE TWINNING

21 Centre and **14** Organization twins (**35** active twins)

HUMANITARIAN AID DONATIONS

21.7 million IUs (over 270 million IUs in the past 19 years)

LABORATORY IEQAS

108 LABS FROM
64 COUNTRIES

MULTIDISCIPLINARY WORKSHOPS AND CONFERENCES

18 workshops (laboratory, physiotherapy, nursing and musculoskeletal)

11 conferences and symposiums

WFH ACCREDITATION

SIX NEW COUNTRIES joined WFH at the 2014 General Assembly as Associate NMOs, including Libya, Mali, Maldives, Mauritania, Togo, and Zambia.

FOUR COUNTRIES were advanced from associate to full WFH NMO status, including Bolivia, Cambodia, Côte d'Ivoire, and Ethiopia.

At the core of the WFH is the mission to improve and sustain care for people with inherited bleeding disorders around the world. Through the management and implementation of international healthcare development programs, the WFH is working with its partners towards closing the gap in care. To accomplish this requires the collaboration with many stakeholders: national hemophilia organizations, health care providers, and government officials. The WFH vision of Treatment for All extends beyond the availability of treatment products, that one day all people with a bleeding disorder will have proper care, no matter where they live.

Training of healthcare professionals continues to be a priority for the WFH, along with the capacity development of partnering patient organizations. WFH national member organizations (NMOs) benefited from skills training at the regional and national level and are able to participate in the Global NMO Training that occurred before the WFH 2014 World Congress. In addition, there is also the need to expand the capacity of countries to achieve accurate laboratory diagnosis. Programs activities benefited 103 countries out of 127 WFH NMOs: 69 countries fell under the global program activities category, and 37 countries fell under the GAP, country programs and cornerstone category. Countries can be involved in one or more of these programs and activities over extended periods of time.

These main priorities for the WFH Programs team were executed through its many development programs. Success was measured through increased participation, development of national care programs, engagement in shared goal of improving and sustaining care.

Global Alliance for Progress (GAP) Program

As of 2014, there were nine active countries in the enrolled in the GAP Program, including three new countries; Honduras, Mexico, and Brazil. The Program entered its 12th year of activity this year and its second year of GAP Second Decade, with the continued goal of increasing by 50,000 the worldwide number of people identified/diagnosed with a bleeding disorder. The other objective of this program is to ensure that 50 per cent of those newly diagnosed are from the world's most impoverished countries.

GAP SECOND DECADE
YEAR 2 (2014) RESULTS

Integration of 3 new GAP Second Decade countries in 2014:

/ **Honduras** (Tier 1);
/ **Mexico** (Tier 2);
/ **and Brazil** (Tier 3).

Closed GAP projects: Ecuador and Syria

1,652 new patients with hemophilia,

1,363 with von Willebrand disease (VWD),

643 with rare clotting factor deficiencies have been diagnosed/registered

1,190

new patients, family members, and WFH NMO board members received training

436

new hemophilia team members and regulators trained

478

new healthcare professionals acquired a general awareness of hemophilia

1 new official GAP Second Decade

commitment / Memorandum of Understanding signed

Over 171 million IUs

of product purchased in GAP countries in 2014

Highlights of achievements through the GAP Program include a memorandum of understanding signed with Egypt reflecting their participation in the Second Decade of GAP. In Moldova, there was significant progress made in the purchase of clotting factor concentrates (CFCs) by the government which culminated in eight times the CFC supply when Moldova first entered into the GAP Program in 2011. For the first time in its history, the Ministry of Health in Colombia is creating a registry for people with hemophilia and other related bleeding disorders. Work on the national patient registry is progressing and almost completed.

Country Programs

In 2014, the WFH supported 25 Country Programs. These programs are designed to strategically target two to three key areas with in-depth support: government assistance; care delivery; medical expertise; laboratory diagnosis; treatment products; patient organization; as well as data collection and outcomes research.

IRAQ In August, the WFH organized a three day workshop on "Tools to advance health care objectives in Iraq".

MACEDONIA **An outreach and educational meeting** was held to engage women with VWD, to help identify more patients and try to include VWD patients into the NMO membership.

BANGLADESH In December the **first Bangladesh women's workshop** was attended by 28 carriers, spouses of people with hemophilia, and women with bleeding disorders.

INDIA Over 150 members from all 76 Hemophilia Federation of India (HFI) chapters attended a **capacity building workshop** in Kolkata, India.

SERBIA The Serbian patient organization participated in the **first meeting of the National Hemophilia Committee** on December 18 after 10 years since the creation of this Committee. Thanks to successful advocacy of the NMO, the new Minister of Health has restructured the NHC both in terms of increased membership and revised terms of references.

Cornerstone Initiative

In its second year, the Cornerstone Initiative has three active countries, including two new countries, Ethiopia and Nepal. The objective of the Cornerstone Initiative is to provide support, expertise, and training to countries with minimal levels of care, which will help them improve and benefit later from WFH's full range of programs and activities.

NIGERIA In early August, **a two day physiotherapy training was** held for 15 physiotherapists from all over the country; this was followed by an NMO Board training on fundraising.

ETHIOPIA In October, 12 lab technicians from Addis Ababa and two other cities attended **a three day lab diagnosis training workshop**; 25 front line doctors and residents attended a half day training on hemophilia and other bleeding disorders; NMO Board members attended a one day training on good governance.

NEPAL In September around 70 Civil Service Hospital staff and residents attended **a hemophilia symposium**; Physiotherapy workshop attended by over 50 patients and families and three physiotherapists.

Regional Advocacy Initiatives

The year was highlighted by two Advocacy in Action (AiA) workshops held in Dubai in August and Prague in December. The WFH's primary advocacy initiative, the AiA Program continued to assist WFH NMOs to develop their advocacy skills. Through this initiative, tools are provided to assist NMOs in the implementation of successful advocacy projects and activities.

/ **Eight advocacy project grants awarded:** Argentina, Mexico, Dominican Republic, Egypt, Jordan, Sudan, and South Africa

/ **Sharing of best practices symposium and reception** held during Congress in Melbourne

/ **Five advocacy advisors paired** with Panama, Cuba, Mali, Togo, and Zambia

/ **The third Advocacy Recognition Award** was presented to the Polish Hemophilia Society for advocacy campaign to extend prophylaxis to cover young adults under the age of 25

Global NMO Training

The WFH hosted 101 delegates from 80 countries at the 2014 WFH Global NMO Training in Creswick, Australia. A record number of 18 youth fellows participated in the event. Plenary sessions highlighted best practices by WFH NMOs, women with bleeding disorders, and clinical research in hemophilia.

Humanitarian Aid

The WFH Humanitarian Aid Program channels donations of life-saving treatment products to people with bleeding disorders who need them all around the world. In 2014, this program experienced a significant expansion with how it operates. The introduction of larger and predictable donations meant the WFH could utilize multi-year commitments to offer a sustainable solution for predictable humanitarian aid in developing countries.

/ **Product donations** were distributed with the invaluable assistance of Hemophilia of Georgia, U.S.A.; the Irish Haemophilia Society; and the Fondazione Parecelso/Miphram in Milan, Italy.

The WFH sent over **21.1 (21,143,044)** million IUs of factor, valued at more than **US$30 million to 58 countries**.

Twinning

The WFH Twinning Program aims to improve hemophilia care in emerging countries through a formal, two-way partnership between two hemophilia organizations or treatment centres for a period of four years.

/ **The number of Twins** at the end of 2014 reached a total of **35**, with **21 treatment centre** Twins (HTC) and **14 organization** Twins (HOT).

/ **11 new twins** started their activities in 2014

/ **2014 HTC Twins of the Year:** Arequipa (Peru) – Los Angeles (U.S.A.)

/ **2014 HOT Twins of the Year:** Nicaragua – Quebec (Canada)

Laboratory Quality Control

The 12th year of the WFH International External Quality Assessment Scheme (IEQAS) was marked in 2014, with 108 centres from 64 countries registered in this program. A total of eight new laboratories from emerging countries were added in 2014.The goal of IEQAS is to improve and standardize laboratory diagnosis by auditing the effectiveness of the internal quality assurance systems in place and giving a measure of the laboratory's competence.

Workshops and Conferences

The WFH organized a total of 29 conferences and/or multidisciplinary workshops, which included 18 workshops along with 11 conference and symposiums. This brought together 1,291 members of the global bleeding disorders community from diverse backgrounds to exchange ideas on improving treatment and care.

/ **VWD symposium** held in El Salvador

/ **The fifth Laboratory Training** the Trainers workshop held at the Royal Free Hospital in London, U.K.

/ **Multidisciplinary symposium** in Yaounde, Cameroon, with evaluation of health status of almost 100 patients

/ **About 200 doctors, laboratory technicians, nurses and physiotherapists** attended a multidisciplinary symposium in Sri Lanka, in August.

/ **A regional dentistry workshop** took place in March 2014 in the Dominican Republic. Participants came from El Salvador, Honduras, and Dominican Republic.

/ **The organization of training workshops** in Jordan for nurses and physiotherapist from Iraq

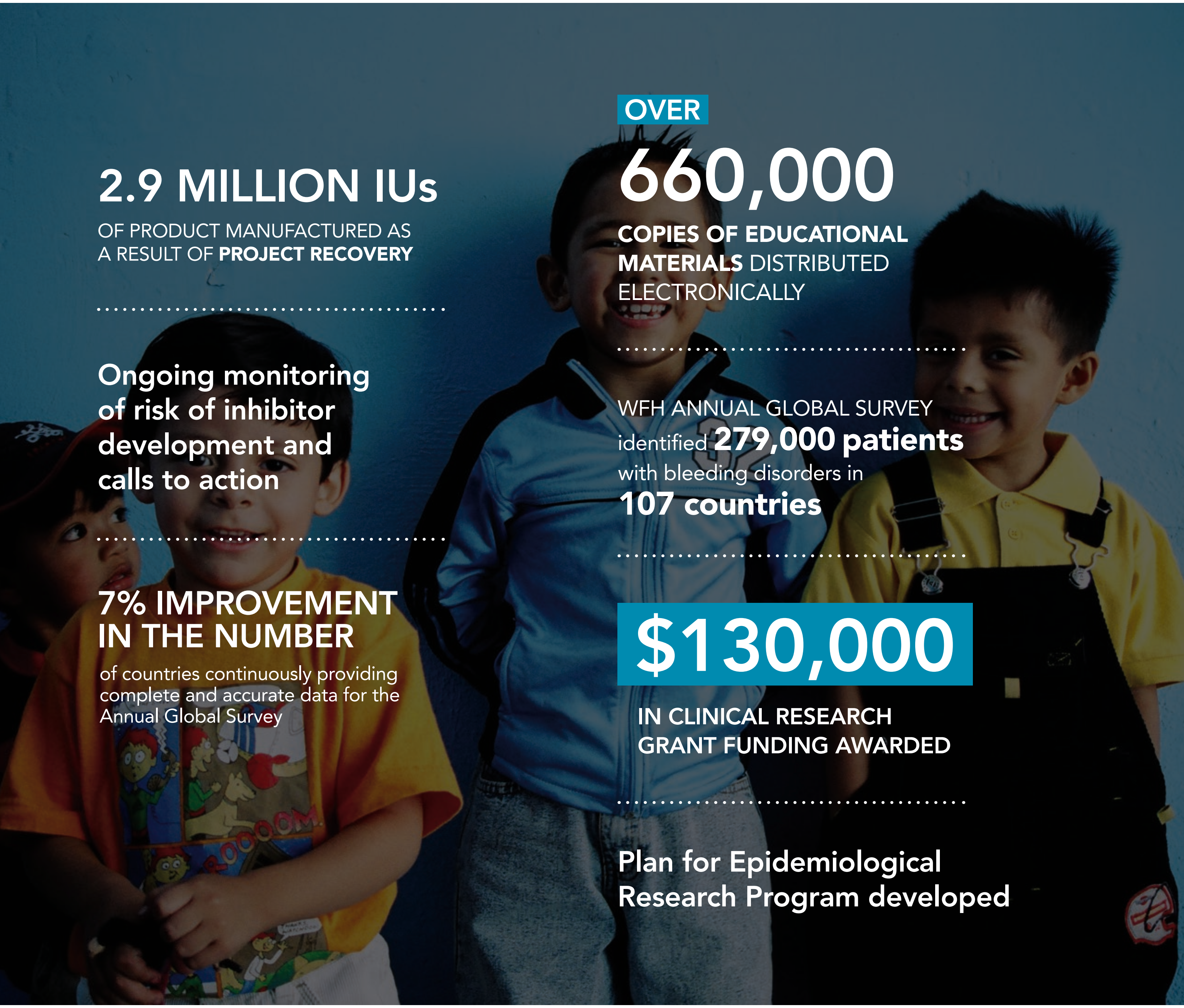
/ **A WFH Advanced Regional Physiotherapy Workshop** was held in Tbilisi, Georgia, for participants from Armenia, Azerbaijan, and Georgia.

Medical Fellowships

In 2014, the WFH awarded 35 healthcare professionals from 31 emerging countries with training fellowships. The aim of the International Hemophilia Training Centre (IHTC) Fellowship Program is to give healthcare professionals from developing countries training in the diagnosis and management of hemophilia and other inherited bleeding disorders. There were 28 fellows from 26 countries who completed their training in one of the 13 IHTCs.

> It is only through the collaboration with the many partners within the healthcare community and patient organizations that these development programs will be able to continue to be effective and invaluable for those most in need.

BUILDING EVIDENCE, PROMOTING STANDARDS OF CARE, & SHARING KNOWLEDGE



2.9 MILLION IUs

OF PRODUCT MANUFACTURED AS A RESULT OF **PROJECT RECOVERY**

Ongoing monitoring of risk of inhibitor development and calls to action

7% IMPROVEMENT IN THE NUMBER

of countries continuously providing complete and accurate data for the Annual Global Survey

OVER

660,000

COPIES OF EDUCATIONAL MATERIALS DISTRIBUTED ELECTRONICALLY

WFH ANNUAL GLOBAL SURVEY identified **279,000 patients** with bleeding disorders in **107 countries**

$130,000

IN CLINICAL RESEARCH GRANT FUNDING AWARDED

Plan for Epidemiological Research Program developed

In 2014, the Education and Public Policy team worked to achieve WFH strategic objectives with a focus on efficiency, growth, and innovation across all areas of work. It was important to look closely not only at *what* is done, but also *how* to do it, and to actively seek out opportunities for collaboration with colleagues and external partners wherever possible. Priorities were focused on providing access to relevant and innovative educational resources; monitoring the safety and supply of treatment products and increasing access to care; enhancing the WFH data collection program with tools to improve data quality and to empower the community; and supporting clinical research that will inform evidence-based care of people with bleeding disorders around the world.

Educational Materials that Inform and Empower

To support the WFH's objectives and programs, educational resources are developed and shared with the global community. In 2014, core curricula continued to be developed and were implemented in multidisciplinary training workshops. In addition, production began of the WFH's first online course, which is based on the *Guidelines for the Management of Hemophilia*. Six more articles were added to the Young Voices Series, an online resource designed to help WFH national member organizations (NMOs) mobilize and empower tomorrow's leaders. Publications that support the Second Decade of GAP were also produced, including a booklet on prophylaxis and a fact sheet on quality data collection.

The WFH 2014 World Congress provided an excellent opportunity to capture and disseminate knowledge and standards of care. Thirty-five state-of-the-art talks were webcast and the WFH's electronic poster gallery was refined to encourage greater participation and dialogue between authors and the community. At Congress, the WFH was able to bring together expert panels to discuss and debate how the landscape of hemophilia care is changing with the arrival of new products, as well as issues surrounding adherence to treatment. The videos of these lively panel discussions provide a unique opportunity to hear the perspectives of internationally renowned healthcare providers and patient advocates on these current issues.

Safety, Supply, and Access to Treatment Products

In order to improve access to safe and effective treatment products, the WFH implemented Project Recovery and explored other opportunities to recover discarded plasma, including a project with the Italian Centro Nazionale Sangre, named Project Wish. A request was also submitted to the World Health Organization (WHO) to have desmopressin, a safe and affordable alternative to plasma products and fresh blood components for many patients with mild bleeding disorders, added to the WHO Essential Medicines List.

The WFH continues to monitor new and potential threats to the global blood supply and takes proactive action as required to inform, educate, and protect the patient community. In 2014, the monitoring of the risk of inhibitor development in previously untreated patients was continued. The organization released three communiques on the subject and requested that regulators examine all the relevant data to come to a conclusion as soon as possible.

Improving Data Collection

The enhancement of the WFH data collection program continued in 2014 by supplying NMOs with the training and practical tools they need to contribute high quality data to the WFH Annual Global Survey. A series of online interactive graphs was also launched, allowing the global bleeding disorders community to customize, visualize, and download charts and graphs displaying the most recent, validated global data. The graphs were accessed over 5,000 times by visitors from 90 countries.

Collecting and reporting demographic and other data on people with inherited bleeding disorders provides the community with the essential information they need to advocate for improved or sustained care and to assist with program planning. The 2013 Report on the Annual Global Survey identified 279,000 patients with bleeding disorders in 107 countries.

Building Evidence Through the Support of Research

The implementation of the WFH Research Program was another important objective in 2014. The program has two components; a clinical research grant competition and an epidemiological research program. The program's goal is to promote and facilitate research, generating the evidence needed to optimize treatment of people with bleeding disorders and to support advocacy initiatives aimed at improved diagnosis and access to care.

With the clinical research grants, the WFH provides funding for research that addresses clinical issues of broad international significance. The evidence generated by these projects will help us learn more about how bleeding disorders are best diagnosed and managed. The first clinical research grants were awarded in February 2014 and the second cycle was launched in May.

WFH Clinical Research Grant Program: 2014 recipients

Kevin Deschamps & Sébastien Lobet
UZ-KU Leuven, Belgium
Quantifying foot biomechanics in hemophilic children with ankle arthropathy through an integrated approach

Thomas Hilberg & Steffen Krüger
Bergische Universität Wuppertal, Germany
Pain profile in people with hemophilia

Paula James
Queen's University, Kingston, Ontario, Canada
Validation of the self-bleeding assessment tool in hemophilia carriers

Roger Schutgens & Lize van Vulpen
University Medical Center Utrecht, Utrecht, the Netherlands
Joint distraction in the treatment of hemophilic ankle arthropathy

With the Epidemiological Research Program, the aim is to create a global registry that will provide a large population for directed epidemiological and outcomes research. Through this program and with the help of a dedicated team of global experts, the WFH plans to provide hemophilia treatment centres around the world with the infrastructure to collect and report information on the diagnosis, treatment, and outcomes for each patient on an annual basis.

In 2014, the Education and Public Policy team strived to use technology more effectively to educate and share information, improve access to safe and effective treatment products, make data more meaningful and accessible, find new ways to support and facilitate much-needed research, and actively explore new avenues and opportunities to serve the WFH's global community.

BRINGING THE GLOBAL COMMUNITY TOGETHER

4,081 **PARTICIPANTS OVERALL,**
including **656** from Australia, a record high from a host country

128 **COUNTRIES REPRESENTED**

611 **POSTER ABSTRACTS DISPLAYED**

160 speakers at **78 sessions**

87.8%
overall congress satisfaction rating, **the highest ever in WFH's history**

156 VISITS,
from **49 countries,** to the treatment rooms in Melbourne

540,000 IUs
and 150 mg of clotting factor concentrates were donated by corporate partners to WFH for the treatment rooms

The WFH 2014 World Congress was held from May 11-15, 2014, in Melbourne, Australia. The 31st International Congress of the WFH proved to be the most successful yet from an overall delegate experience and set the bar high for future WFH global events. The WFH Congress team continued building on past successes, introduced new initiatives, and fully explored all advantages of Melbourne's outstanding infrastructure for international congresses. The Congress offered an excellent platform for the global bleeding disorders community to learn, network, and share knowledge; all the while keeping the WFH's vision of Treatment for All at the forefront.

The five-day event hosted 4,081 participants from 128 countries, proving its reputation as the largest international meeting for the global bleeding disorders community. The host organization Haemophilia Foundation Australia worked tirelessly to secure the highest host country participation in history, with 656 participants from Australia.

The opening plenary by WFH president Alain Weill set the tone for a new era and an inspiring Congress week when he announced several significant multi-year agreements for unprecedented donations to the WFH totaling 700 million international units (IUs) of blood clotting factor, over the next five years, and representing a major step toward meeting its humanitarian aid mission in developing countries.

The success of Congress began with a substantial medical and multi-disciplinary program presented by world-renowned experts in hemophilia and other inherited bleeding disorders. The cutting-edge medical program included plenary lectures on innovative approaches to immune responses to factor VIII, new treatment directions for hemophilic arthropathy or permanent joint disease, novel strategies for factor VIII and factor IX gene therapy research in persons with hemophilia, changes in the paradigm of venous thrombosis, and more. The

multidisciplinary program also experienced record attendance in informative and inspirational sessions, including nutrition, exercise, and the management of bleeding disorders, as well as critical women's issues and motivational patient narratives.

The WFH 2014 World Congress marked an important shift to an increased digital experience for attendees with the introduction of electronic poster technology for the first time, in addition to printed posters, allowing for 24 effectively moderated poster sessions and a virtual poster gallery with 570 posters which were made publicly available following congress. Almost 50 per cent more sessions were recorded and offered as webcasts following the Congress to showcase the educational value of this global event beyond the actual meeting. For the first time, two online pre-editions of the Congress Daily News were created to draw delegates' attention to the highlights shortly before the event and during Congress. All four editions were also available as online versions.

For the WFH, it is widely recognized that the WFH World Congress provides essential financial resources to increase its educational tools, development programs and activities. The Congress' financial success significantly helps advance the WFH's mission to improve and sustain care for all people with inherited bleeding disorders.

On May 16, 2014, the WFH General Assembly selected Kuala Lumpur, Malaysia, as the destination for the WFH 2020 World Congress.

COMMUNICATIONS &MARKETING

RAISING AWARENESS BY CAPITALIZING ON NEW TECHNOLOGIES

2014 HIGHLIGHTS

82,275 CUMULATIVE NUMBER OF PEOPLE WHO INTERACT **WITH WFH THROUGH SOCIAL MEDIA CHANNELS**

9,717 FOLLOWERS ON FACEBOOK

579 CONNECTIONS ON LINKEDIN

1,311 FOLLOWERS ON TWITTER

70,778 FOLLOWERS ON YOUTUBE

1,895,970

CUMULATIVE NUMBER OF UNIQUE VISITORS WHO **ACCESSED THE WFH THROUGH ITS WEBSITE**

The WFH Communications and Marketing team made important strides in 2014 towards raising awareness of the WFH's activities and expanding the organization's community. Continued effort went into the successful building of a larger online community and a stronger presence on social media channels.

International organizations all face the same challenge of communicating out to an incredibly varied global audience, who speak different languages, with various cultural experiences, standards, and expectations. Three new localized versions of the WFH website were launched in Simplified Chinese, Arabic, and Russian. The sites offer a selection of the WFH website content, in the new languages, to ensure the WFH continue efforts to reach out to our global community.

These new localized websites complement the already diverse organizational WFH website which is in English, French, and Spanish. The WFH website continues to grow and expand, addressing the global needs of the bleeding disorders community by providing information on the organization, its programs and resources, access to publications, information on WFH events and meetings, along with relevant news and updates.

On April 17 2014, World Hemophilia Day, the global bleeding disorder community joined together to celebrate who they are, to encourage one another to *Speak Out: Create Change*, and to educate the world about the various bleeding disorders which affects millions of people. As part of the campaign, the WFH created five different online infographics that were posted to the WFH Facebook page in the week leading up to April 17. The WFH's Facebook page likes increased by nearly a thousand new followers during the online campaign over the month of April.

The success of the landmark lighting campaign continued in 2014 with the lighting in red of the Toronto CN Tower, both the U.S. and Canadian sides of the Niagara Falls, the Langevin bridge in Calgary, the AAMI Olympic park / stadium in Melbourne, and the Leonard P. Zakim Bunker Hill Bridge in Boston.

The online Congress Daily was launched during the WFH 2014 World Congress in Melbourne. This meant that the team published both a print and online version of the daily congress paper for the duration of the meeting, in addition to publishing two online pre-editions that were sent out to attendees in the weeks leading up to the meeting.

The successful launch of the online Congress Daily provided insight into how the WFH could develop an online version of Hemophilia World. The print issue of *Hemophilia World* reaches 2,500 recipients globally and the development of an online platform of this news magazine would significantly increase the reach of WFH and community news. The online version of Hemophilia World began development in late 2014, with a release in 2015.

The WFH's presence on social media platforms continued in 2014, reaching a milestone of reaching over 82,000 views, likes, and shares through various social media channels, including Facebook, Twitter, YouTube, and LinkedIn.

It was an important year for the new department in building the foundation for the future of communications and marketing for the WFH. The movement towards a more digitized communications approach by the Communications and Marketing department will greatly expand the reach of the organization and ensure the strengthening key audiences that are needed to reach the goal of Treatment for All.

CLOSE THE GAP CAMPAIGN ENDS ON A HIGH NOTE, OUR WORK CONTINUES

THE YEAR 2014 marked the third and last year of the tremendously successful WFH Close the Gap Campaign. Your participation as donors and as volunteers assured this wonderful victory and the WFH thanks and celebrates the generosity of all those involved.

The final, three-year total was over US$5.5 million. Of that amount, the corporate campaign contributed US$3.36 million and the community campaign raised an outstanding US$1.9 million, 121 per cent of the original goal. In total, 991 donors from 96 different countries contributed to the WFH's first multi-year campaign.

With these donations, the WFH has been able to support:

- The next decade of WFH development programs, including the Cornerstone Initiative (read more on page 5);
- The WFH Research Program (read more on page 9); and
- The next decade of the Global Alliance for Progress Program (read more on page 4).

The first and most inspiring gift came from WFH patron Jan Willem André de la Porte who pledged to donate $2 for every $1 donated to encourage participation and solidarity by the bleeding disorders community. The community responded generously to help us reach this outstanding result.

The community also came together at the WFH resource centre during the WFH 2014 World Congress, to meet and to give support to improved access to diagnosis and treatment. Overall in 2014, giving from all community appeals totalled over US$504,000. During the Congress, the WFH also launched a new Professional Membership category that was designed to meet the needs of the scientists, doctors, researchers, caregivers, and all professionals within the global bleeding disorders community. The Professional Membership category includes online access to *Haemophilia,* the official journal of the WFH. This new category was tremendously successful and by year-end had attracted 125 new members and generated close to US$20,000 to support our mission.

CLOSETHEGAP
Campaign 2012•2014

CO-CHAIRS
Jan Willem André de la Porte, WFH patron
Alain Weill, WFH president

HONORARY CAMPAIGN COMMITTEE MEMBERS REPRESENTING WFH PAST PRESIDENTS
Frank Schnabel, WFH president, 1963-1987
Frank Schnabel, III
Gina Schnabel
Marie-France VanDamme
Charles Carman, WFH president, 1988-1993
Patsy Carman
Brian O'Mahony, WFH president, 1994-2004
Mark W. Skinner, WFH president, 2004-2012

REGIONAL CO-CHAIRS
Americas
Patricia Dominic, U.S.A.
Cesar Garrido, Venezuela
Phil Kucab, U.S.A.
Martha Monteros Rincón, Mexico
Carlos Safadi Márquez, Argentina
Pam Wilton, Canada

Europe
Anne Duffy, Ireland

Middle East & Africa
Megan Adediran, Nigeria
Magdy El Ekiaby, Egypt
Johnny Mahlangu, South Africa
Bradley Rayner, South Africa
Aliakbar Tchupan, Iran

Asia & Western Pacific
Gavin Finkelstein, Australia
Aris Hashim, Malaysia
Reynaldo Sarmenta, Philippines

FUND & RESOURCE DEVELOPMENT COMMITTEE CHAIR
Deon York
Eric Stolte 2008-2012

CONTINUED FISCAL RESPONSIBILITY & GROWTH

It was an exceptional year for the WFH in 2014, with a net surplus of $2,886,802 compared to a budgeted surplus of $801,924, an improvement of $2,084,878. This represents the largest net surplus in WFH history. Typically, in a non-Congress year, the WFH runs on a significant deficit. Over a two-year period, having this surplus gives WFH the financial stability it needs to deliver its programs and activities.

The success of the WFH 2014 World Congress in Melbourne was the main contributor to the impressive financial 2014 result. In addition, the strong U.S. currency also contributed to this result, as the majority of revenues from both the Congress and WFH corporate sponsors were in U.S. dollars, against a budget that was set at par with the Canadian dollar.

The financial success of the WFH 2014 World Congress, contributing a net surplus of $2,494,075 for the whole event, allows the WFH to support and fund programs and initiatives towards the achievement of its mission. The WFH 2014 World Congress also allowed the achievement of WFH's goal of balancing the budget over a two-year cycle, with a positive net result of $2,065,565.

Continued Diversification of Revenue

Corporate sponsors of the WFH programs and initiatives continued their solid support with 2014 contributions at a 5.7 per cent increase above 2013.

In 2014, the scope of the WFH Humanitarian Aid Program was greatly expanded, with the initial costs of $72,046 being incurred by the WFH. As per Canadian accounting rules, only the amount of this expense has been recognized in WFH revenues. With the receipt of $490,788 for the WFH Research Program, the WFH commenced in 2014 awarding research grants which helped fund four projects. In addition, the WFH received $109,603 from three new GAP II sponsors. These revenues all fall under the 50th anniversary caption on the WFH financial statements.

The total WFH revenue, before Congress and product donations, reached $5,534,484, a 5.5 per cent growth versus 2013.

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, 41 per cent of revenues over the two year cycle are from WFH corporate partners, including WFH 50th anniversary sponsors. The remaining 59 per cent is generated through the WFH 2014 World Congress, financial donations, and self-generating income activities.

Expenses Aligning with Strategic Objectives

The WFH World Congress not only represents the most important part of revenues, it also represents the largest proportion of expenses with 40.4 per cent of the expenses incurred over the past two years, as seen in Figure 2. Health care development programs, education & public policy programs, and the WFH Humanitarian Aid Program together represent a total of 38.2 per cent of the WFH expenses, while communication and marketing expenses represent 3 per cent of this total. Additional expenses for the WFH include administration at 9.1 per cent, fundraising and corporate relations at 6.7 per cent, and governance at 2.6 per cent.

Humanitarian Aid

The WFH distributes valuable humanitarian aid product donations from many of our corporate sponsors to individuals and WFH national member organizations (NMO). In 2014, 21.1 million IUs of clotting factor concentrates were strategically donated to 58 countries, improving, and sustaining care for people in the developing world. The majority of these donations, worth US$24,301,582, are reported in the audited financial statements of the WFH USA. The amount reported in the financial statements of WFH is CAN$6,368,132.

Year-over-year Comparison

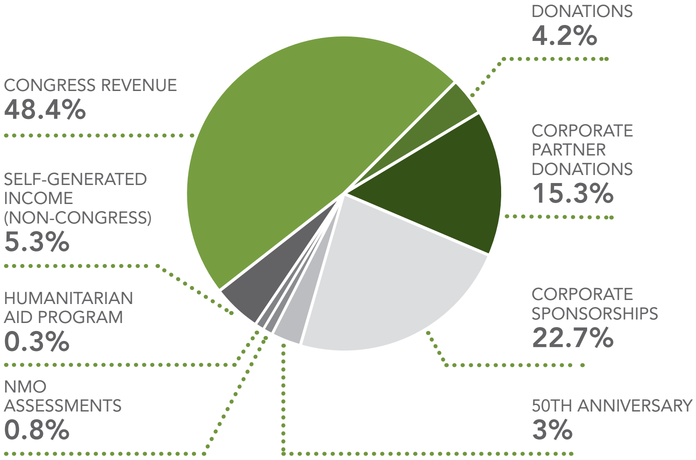
A comparison is presented between year 2014 and 2013 which is illustrated in Figure 3. On the revenue side, it is encouraging to see increased support from WFH corporate partners. The WFH Research Program gains of $169,063, along with the GAP II Program's new sponsor contribution of $109,603, are both captured within the 50th Anniversary caption. Self-generated revenue includes investment income and publications which grew by $100,549 and $96,298 respectively. This was offset by WFH event registration and housing fees of $358,441 for the WFH International Musculoskeletal Congress and the WFH Global Forum which occurred in 2013, a non-Congress year.

The rise in WFH program expenses in 2014 was primarily due to $443,768 in NMO development and includes the WFH Global NMO training which was held before the WFH 2014 World Congress. There was also growth in Country Programs of $182,304 which was mostly due to activities in Africa and the Eastern Mediterranean. This was offset by expenses for the WFH International Musculoskeletal Congress of $406,221 which was held in 2013.

There was an upsurge in activities for the upcoming expansion of the WFH Humanitarian Aid Program. Expenses in this area rose to $364,742 in 2014, compared with $94,365 in 2013.

REVENUES 2013 AND 2014

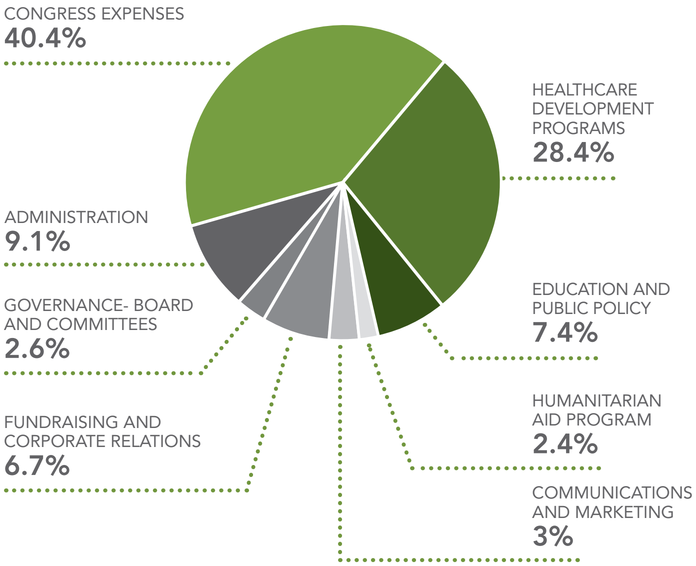
(EXCLUDING PRODUCT DONATIONS)



REVENUES	**2014**	**2013**
Donations	385,791	485,860
Corporate Partner Donations	1,657,601	1,530,933
Corporate Sponsorships	2,419,563	2,327,680
50th Anniversary	442,115	176,484
NMO Assessments	84,944	85,350
Humanitarian Aid Program	72,046	0
Self-Generated Income (Non-Congress)	472,424	639,062
Congress Revenue	10,127,590	0
Product Donations	6,368,132	3,354,838
TOTAL REVENUES	**22,030,206**	**8,600,207**

EXPENSES 2013 AND 2014

(EXCLUDING PRODUCT DONATIONS)



EXPENSES	**2014**	**2013**
Healthcare Development Programs	2,837,230	2,513,078
Education and Public Policy	701,055	688,706
Humanitarian Aid Program	364,742	94,365
Communications and Marketing	266,286	301,304
Fundraising & Corporate Relations	601,476	671,448
Governance- Board and Committees	246,487	243,482
Administration	880,188	838,377
Congress Expenses	6,856,789	759,264
Fluctuation of Foreign Exchange	21,019	-43,418
Product Donations	6,368,132	3,354,838
TOTAL EXPENSES	**19,143,404**	**9,421,444**
EXCESS (DEFICIENCY)	**2,886,802**	**-821,237**

Looking Forward

As the WFH embarks on a new two-year cycle, its financial base is solid, with a revenue base which has robust support from early commitments from our corporate partners. In addition, the WFH 2016 World Congress is on track to deliver a budgeted surplus.

Going forward, it is absolutely essential that WFH World Congresses are positioned to return strong surpluses, further improving the diversification of revenues and continuing to meet many of the challenges confronting the global inherited bleeding disorders community. This in turn will help further advance the WFH's vision of Treatment for All.

OUR PARTNERS

/ WFH 2014 NMO Training Participants

WFH BOARD MEMBERS & PATRON

/ WFH Board in November 2014

1 LAY MEMBER
Cesar Garrido
Venezuela

2 LAY MEMBER
David Silva
Spain

3 LAY MEMBER
Pamela Wilton
Canada

4 MEDICAL MEMBER
Jerzy Windyga, MD
Poland

5 WFH PATRON
Jan Willem André de la Porte

6 LAY MEMBER
Declan Noone
Ireland

7 LAY MEMBER
Deon York
New Zealand

8 MEDICAL MEMBER
Magdy El-Ekiaby, MD
Egypt

9 MEDICAL MEMBER
Keith Hoots, MD
U.S.A.

10 VICE-PRESIDENT MEDICAL
Marijke van den Berg, MD
Netherlands

11 PRESIDENT
Alain Weill
France

12 VICE-PRESIDENT FINANCE
Eric Stolte
Canada

13 MEDICAL MEMBER
Flora Peyvandi
Italy

World Health Organization

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

WFH national member organizations

One hundred and twenty seven hemophilia associations from around the world are accredited as national member organizations (NMOs) of the WFH. NMOs 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.

/ 2014 WFH Volunteer Award Recipients

/ WFH Staff as of April 2014

WFH STAFF & VOLUNTEERS

An extensive network of organizations and individuals share the WFH 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.

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 2014, 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

CORPORATE PARTNERS

Corporate Partner Program

These annual unrestricted contributions support WFH activities to increase care worldwide for people with bleeding disorders. The WFH is grateful to the following companies for their ongoing support:

Baxter
Bayer
Biogen Idec Hemophilia
Biotest
BPL
CSL Behring
Green Cross
Grifols
Kedrion
LFB
Novo Nordisk
Octapharma
Pfizer
Precision BioLogic
Sanquin
SOBI

Global Alliance for Progress (GAP)

Visionary Partner
Baxter
Leadership Partner
CSL Behring
Collaborating Partner
Bayer
Biogen Idec Hemophilia/SOBI
Biotest
Grifols
Novo Nordisk
Pfizer
World Health Organization
Friends
Kedrion

Specific Sponsorships

Baxter: Advocacy in Action Program, Advocacy in Action Sharing best Practices Symposia/Reception, World Hemophilia Day

Bayer: IHTC Fellowship Program, Simplified Chinese Website Localization Project, World Hemophilia Day

Biogen Idec Hemophilia: Web section on Prophylaxis, World Hemophilia Day

CSL Behring: National Bleeding Disorder Symposium, World Hemophilia Day

LFB: Symposium of von Willebrand disease

Novo Nordisk: Rare Bleeding Disorder web section, World Hemophilia Day

Octapharma: Inga Marie Nilsson Award, von Willebrand Disease web section

Pfizer: Arabic Website Localization Project, Iraqi Physiotherapy & Nurses Training Workshops, Twinning program

Precision BioLogic Inc.: World Hemophilia Day

SOBI: Russian Website Localization Project

Project Recovery

Biotest
Canadian Blood Services (CBS)
Canadian Hemophilia Society
Grifols

WFH Research Program

Baxter
Bayer
Grifols International S.A.
Hemophilia Center of Western Pennsylvania 340B Program

Humanitarian Aid Product Donations

Baxter
Bayer
Biotest
CSL Behring
Grifols
LFB
Pfizer

FOUNDATIONS AND GOVERNMENT AGENCIES

IEQAS Program
Novo Nordisk Hemophilia Foundation

SOLIDARITY FUND CONTRIBUTORS IN 2014

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

Asociación Costarricense de Hemofilia (ASOHEMO)
Association Luxembourgeoise des Hémophiles
Association Tunisienne des Hémophiles
Canadian Hemophilia Society
Egyptian Society of Hemophilia
Finnish Hemophilia Society
Fundación Panameña de Hemofilia
Ghana Haemophilia Society
Haemophilia Association of Mauritius (HAM)
Haemophilia Foundation Australia
Haemophilia Foundation of New Zealand
Hemophilia Society of Malaysia
Icelandic Hemophilia Society
Indonesian Hemophilia Society
Irish Haemophilia Society Ltd.
Jordan Thalessemia and Hemophilia Society
Latvia Hemophilia Society
Liga Colombiana de Hemofílicos
Lithuania Haemophilia Association
Magyar Hemofilia Egyesulet (Hungray)
National Center for Blood Diseases “Hippocrates” (Palestine)
National Hemophilia Foundation of Thailand
Netherlands Haemophilia Society
Österreichischen Hämophilie Gesellschaft (Austria)
Russian Hemophilia Society
Serbian Hemophilia Society
Singapore Haemophilia Society
South African Haemophilia Foundation
Surinamese Society for Hemophilia Patients
Swedish Hemophilia Society (FBIS)
Swiss Hemophilia Society

MEMORIAL FUNDS

Susan Skinner Memorial Fund

TRIBUTES

In Honor of Samuel Avalos
In Honor of Teresa and M. D'Ambrosio
In Honor of Michael Fuller
In Honor of Hemophilia of Georgia staff
In Honor of Pete Hultgren
In Honor of Jace Kennedy
In Honor of Martha Monteros Rincón
In Honor of Glenn Pierce
In Honor of Frank Schnabel
In Honor of Mark W. Skinner
In Honor of Susan R. Skinner
In Memory of Karin Lindvall
In Memory of Aurele Paradis
In Memory of Therese Southgate

DONORS

$100,000 and up

André de la Porte Family Foundation
Hemophilia Center of Western Pennsylvania

$50,000 – $99,999

National Hemophilia Foundation*
Novo Nordisk Haemophilia Foundation

$20,000 – $49,999

Association française des hémophiles*
Hemophilia Alliance Foundation
Hemophilia of Georgia, Inc.

$10,000 – $19,999

340B Factor Program at Akron Children's HTC
Baxter Healthcare Corporation
Biogen Idec Hemophilia

Eastern Pennsylvania Chapter
Irish Haemophilia Society Ltd.*
1 anonymous donor

$5,000 – $9,999

Canadian Hemophilia Society*
Patsy Carman
Cascade Hemophilia Consortium
LA Kelley Communications, Inc.
Lisa Sackuvich
The Marketing Research Bureau, Inc.

$2,500 – $4,999

Lubrizol Foundation
The Schnabel Family
The Skinner Family
Phillips 66
1 anonymous donor

$1,000 – $2,499

ASD Healthcare
Paula H. Bolton-Maggs and Benjamin Bolton-Maggs
Cheryl and Tony D'Ambrosio
Diagnostica Stago, Inc. (US)
Florida Hemophilia Association
Fundación de la Hemofilia (Argentina)*
Hemophilia Foundation of Greater Florida, Inc.
Marion A. Koerper
Jenny and Ron Lees
Mary M. Gooley Hemophilia Center
Opticom International Research AB
Elizabeth A. Paradis
William T. Sparrow
Swedish Hemophilia Society (FBIS)*
Barbara and Gerard Volk OAM

$500 – $999

John E. Bournas
Jim and Margie Braden
The Capretto Family
Gordon Clarke
Paula Cobb
Colorado Chapter of the National Hemophilia Foundation
Wicher de Groot
Dietje Elisabeth Fransen van de Putte
Habataki Welfare Project
Hemophilia Foundation of Minnesota/Dakotas
Hemophilia of Iowa, Inc.
Institute for Policy Advancement Ltd.
Nigel and Melissa Key
Phillip Kucab
John Murphy
Elizabeth Myles
Brian O'Mahony
Kathleen Pratt
Rocky Mountain Hemophilia & Bleeding Disorders Association
Maria M. Salas
Claudia Schoenig-Diesing
Society for Inherited & Severe Blood Disorders (Trinidad & Tobago)*
Alok Srivastava
Eric and Marion Stolte
Mary Q. Wingate
2 anonymous donors

$250 – $499

Aiki
AV Experience
Belgian Haemophilia Society*
Martin Boakye
Brothers Healthcare
Jens Bungardt
John and Heather Button
Gregory Christofi
Czech Society of Hemophilia*
Bjorn Drebing
Gavin Finkelstein
John and Penny Gisselbeck
Nicholas Goddard
HAPLOS – Hemophilia Association of the Philippines for Love*
Ann Harrington
Vanessa Herrick
Jennifer Laliberté
Jeanne Lusher, MD
Merck & Co., Inc.
Österreichischen Hämophilie Gesellschaft (Austria)*
Paul W. Riley
Thomas Sannié
Dolly Shinhat-Ross
Angel Sosa
Jerome Teitel
UK Haemophilia Society*
4 anonymous donors

$150 – $249

Maliheh Afzali Naeeni
Per Arne Berg
Ute Braun
Margareth Castro Ozelo
Randall Curtis
Dan Doran
Federación de Hemofilia de la República Mexicana*
Jeanne Fellows
Fondazione Angelo Bianchi Bonomi
Barbara J. Gordon
Scott S. Johnson
Ashwin Kaushal
Hee-Soon Kim
David Lillicrap
George D. McCoy
Craig T. McEwen
Otieno Walter Mwanda
Netherlands Haemophilia Society*
Phillip R. Poovey
Allen and Amy Renz
Eduardo Rey
Hiroyuki Saito
Sam Schulman
Jackie Touzeau
Luis Uribe Cock
Alain Weill
Pamela Wilton
Jerzy Windyga
Karen Wulff
Deon York

$100 – $149

Antonio J. Almeida
Asociación Venezolana para la Hemofilia*
Lili Aszodi-Fulop
Marianna Balakhnina
Geneviève Beauregard
Paula Bell
Anacleto R. Benito
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Ruth R. Brown
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The Ellis Family
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Angela L. Forsyth
Elena Galstian
Cesar Garrido
Hospital Infantil Pediatrico/Hospital Escuela
Rose Jacobson
Carol K. Kasper and Howard Winet
Chi Shan Bonnie Kho
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Janaki Sonoo
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Aliakbar Tchupan
Candace Terpstra
Anita Vuksan
Tefu Weng
Frederick Wensing
3 anonymous donors

** The WFH is proud to acknowledge the support of our national member organizations.*

Sustaining members active in 2014

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

Fatmah K. Abdallah
Manuela Albisetti
Omolade Awodu
Per Arne Berg
Martin Boakye
Paula H. Bolton-Maggs
Jens Bungardt
Jorge Carneiro
Frédérica Y. Cassis
Enrica Cristina
Eric Cubberley
Piet de Kleijn
Emmanuel Favaloro
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Srilatha Tangada
Lisa Thilbeault
Prasanna Kumar Thummanahalli Subbanna
Karen Tubridy
Sandra Vallin Antunes
Annette von Drygalski
Elaine Warner

Design: tmdesign.ca

WFH2014 HIGHLIGHTS

CLOSETHEGAP
Campaign 2012·2014

121% ACHIEVED

GLOBAL REACH OF
WFH HEALTHCARE PROGRAMS

103 COUNTRIES

ATTENDANCE AT WFH 2014
WORLD CONGRESS

4,081 PARTICIPANTS FROM
128 COUNTRIES

EDUCATIONAL MATERIALS
DISTRIBUTED ELECTRONICALLY

OVER
600,000
COPIES

HUMANITARIAN
AID DONATED

OVER 21.7 MILLION IUs
TO 60 COUNTRIES

FINANCIAL STABILITY
TO DELIVER PROGRAMS
AND ACTIVITIES

→

BALANCED BUDGET:
$2,065,565
POSITIVE NET SURPLUS
OVER 2013-2014

WORLD FEDERATION OF HEMOPHILIA

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