



**ANNUAL
REPORT
2013**

50th
1963-2013

Each generation is standing on the shoulders of those before them, which means we can do more and reach higher.

— Reeshen Pillay, Cape Town, South Africa

WFH2013 HIGHLIGHTS



*Reeshen Pillay,
South Africa*

Reeshen Pillay from Cape Town, South Africa, has had access to treatment since he was a small child. Growing up, he always assumed that governments provide treatment to all patients with bleeding disorders; he was surprised when he learned how some people struggle with obtaining diagnosis and treatment.

"In some places people have no treatment at all, they are in really bad shape and it was a real eye-opener for me – on a global level."

In 2009, he volunteered to help with his chapter's website and is now their web and social media go-to person. "I went to my chapter and ended up volunteering and started going to meetings."



TOTAL REVENUE¹

2013
\$5,245,370



BALANCED BUDGET

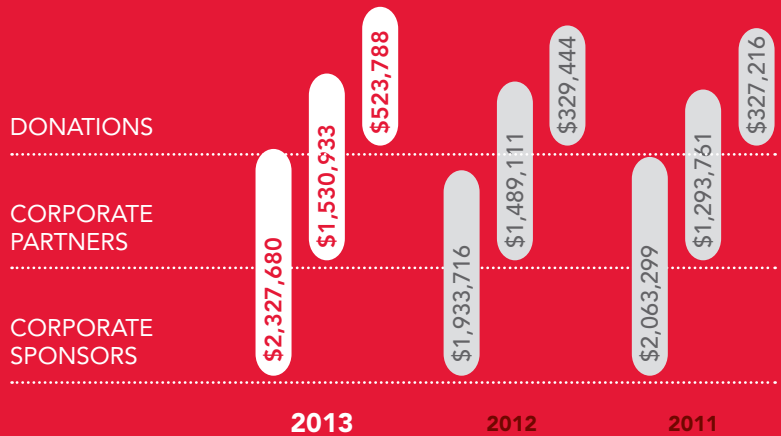
POSITIVE NET RESULT
\$603,000 (2012-2013)



HUMANITARIAN AID



CONTRIBUTIONS



CLOSE THE GAP CAMPAIGN

66% ACHIEVED
\$5 MILLION GOAL

¹ Excludes Congress and donations revenue

I had expected that my involvement with them would be a one-off, but I realized that this community had done a lot for me and I wanted to give back."

Asked what needs to happen for the young people in his community to be included, Pillay says he sees a need for training youth so as to

develop leadership for the future. "We have lots of disadvantaged youth who, with some training, could contribute." Pillay has some inspiring words about why involving young people is important: "Each generation is standing on the shoulders of those before them, which means we can do more and reach higher."

A YEAR OF REFLECTION & RE-DEDICATION

2013, the World Federation of Hemophilia's 50th anniversary, was an occasion for both celebration and reflection. As we looked to our past, we felt pride in the enormous strides taken to diagnose and treat those with inherited bleeding disorders. But, any consideration of how far we have come in recognizing and treating bleeding disorders triggers thoughts of how much ground still must be covered to identify, diagnose, and treat the estimated 75 per cent of people around the world who have yet to be reached. Until we realize the goal of Treatment for All, our work is not done.

To ensure we can realize that goal during our second half-century, the past year has seen the WFH focusing considerable energy on activities that will help make us remain both sustainable and relevant.

Our Close the Gap campaign generated tremendous support from around the world – from corporate donors, WFH national member organizations (NMOs) and individuals – moving us closer to our goal of raising \$5 million by the end of 2014. These funds will help eliminate the disparity in care between developed and developing countries and provide the WFH with the financial underpinning to continue our work into the medium- and long-term future.

Ensuring our stability for the future has far-reaching effects, because it provides a greater level of predictability throughout the continuum of care – from planning, training and education, to the delivery of units of factor with long-term shelf life to where it is needed. Sustainability puts us on a stronger footing as we work toward securing more agreements with governments around the world.

The past year brought significant results as we launched the second decade of the Global Alliance for Progress (GAP), our flagship program to close the gap in care around the world. Last year found us operating GAP projects in eight countries, and

expanding toward our second-decade goal of adding 20 new countries by forming an important new initiative in Colombia.

In Nigeria, we launched the first events under our new Cornerstone Initiative, which is aimed at supporting treatment and care in underserved countries and regions where the gap in care is the greatest.

In all, 2013 found us on the ground in 96 countries, directing virtually our entire program budget where the need exists most.

The year also saw us continuing to find innovative ways to bring technological advancements to close the gap on care. In Kenya, for example, we completed a pilot project at a regional workshop for nurses, videotaping the session so that the knowledge can be transferred to other areas.

Working with our partners in industry, we continue to explore other innovative ideas, focusing on ways of getting more unused plasma to treatment centres and NMOs in developing countries.

Our major WFH Research program, which was announced at the 2012 World Congress, took a big leap forward in 2013, with the development of a new data system that will allow us to collect and analyze data from the WFH's Annual Global Survey as well as relevant program data. It allows for real-time, automated validation, customizable queries and the output of raw data for analysis.

With the growing emphasis on research, and our ongoing focus on providing educational tools to our global community, it made sense to reorganize these two vital areas into a new department within the WFH.

That operational adjustment was one of several internal changes that were necessary for us to realign our resources to meet the growing and shifting demands of our work. Over the past 15 years, the WFH has grown rapidly, from six employees to





Elizabeth Myles



Alain Weill



John E. Bournas

about 40. The type and scope of work we undertake has changed and expanded, as well. Realigning our resources will allow us to keep pace with the expansion of services around the world and continue to be agile and effective. This realignment will also reinforce and expand the interdependencies that exist within our organization. The synergies that flow between operational areas such as fundraising, programming and education characterize the work at WFH; and they reflect the multi-disciplinary approach to care that we rely on in the field to do our work. Increasingly, the WFH works as a catalyst to bring all these forces together to accomplish our overall goal of Treatment for All.

If collaboration is an important key to our success, then technology is equally important as both an enabling tool and a channel for us to share information and reach diverse, widespread audiences. Utilizing new technologies, we are developing a platform to engage with these various audiences, and using webcasting to capture the content we

generate and take it to those who can use it to expand their knowledge and deliver care to the bleeding disorders community.

Looking forward, there is huge potential to bring these tools and channels to bear on uniting all of our stakeholders – from industry to children yet to be diagnosed in remote parts of the developing world – and transferring knowledge across borders and socio-economic boundaries.

As we look toward our second 50 years, the future is exciting; but we must be constantly open to find new ways to remain relevant, to listen to our stakeholders, and to respond rapidly to needs throughout the world.

Alain Weill
PRESIDENT

John E. Bournas
CHIEF EXECUTIVE OFFICER AND
EXECUTIVE DIRECTOR

The WFH's 50th year provided an interesting perspective from which to view where we stand on the path toward Treatment for All. Partnerships are critical to achieve that goal. Building sustainable collaboration between NMOs, multi-disciplinary health care providers, those who have bleeding disorders, and others in our networks is an essential part of the journey to success.

— Elizabeth Myles, Chief operating officer

DELIVERING CARE & BUILDING CAPACITY

Throughout 2013, the WFH focused on growing and delivering programs in a nimble, responsive way that ensured that assistance went where it was needed most.

Delivering programs on the ground – where the need is – lies at the core of every health-related organization. The results tell one story; the larger story is one of collaboration between many stakeholders around the world. The role of the WFH is to align those forces, build capacity and bring innovative thinking to bear on that goal.

Throughout 2013, the WFH focused on growing and delivering programs in a nimble, responsive way that ensured that care went where it was needed most.

Beyond the numerous notable achievements of the past year lies another important reality: 93 per cent of the funds allocated to health care development programs were spent where the need existed, ensuring that the WFH delivered on what it promised its supporters and stakeholders.

In 2013, WFH health care development programs reached a total of 96 countries. The year marked the start of a new decade of global development to actively continue to work on closing the gap in care for people with bleeding disorders around the world.

Global Alliance for Progress

Since 2003, in partnership with the World Health Organization (WHO), industry, foundations and charitable organizations, the WFH has been working in target countries to close the gaps that exist between the number of people born with hemophilia and other bleeding disorders and those who reach adulthood; between the estimated and actual number of people diagnosed with hemophilia and other bleeding disorders; and between the treatment and care needed versus what is available.

In January 2013, the second decade of the Global Alliance for Progress (GAP) – the WFH's flagship development program – was launched to actively

continue to work on closing the gap in care for people with bleeding disorders in 20 new target countries. The focus is on improving diagnosis for all bleeding disorders, improving treatment in the world's poorest regions and building on the achievements to date. The overarching goals for GAP's second decade will be to increase by 50,000 the worldwide number of people identified/diagnosed with a bleeding disorders and ensure that 50 per cent of those newly diagnosed are from the world's most impoverished countries.

In 2013, its 11th year of operation, there were GAP projects in eight target countries; the first new GAP Second Decade project was initiated in Colombia. In each of these countries, patient organization representatives and treatment providers, together with WFH volunteers and staff, worked to establish national hemophilia committees, implement a comprehensive care approach to hemophilia and develop national patient registries and treatment protocols.

Two memoranda of understanding (MOUs) were signed in 2013. In February, an MOU was signed with Algeria's Ministry of Health to raise the level of hemophilia care and develop a national care program. In October, an MOU was signed with the Ministry of Health and Social Protection of Colombia to help improve the delivery of care through the development of a national network of hemophilia treatment centres, to provide guidance in the area of centralized purchasing, and to develop a national centralized registry.





Antonio José Almeida
Director

In 2013, the WFH Humanitarian Aid program helped many people in urgent need who live in countries that have limited access to treatment. The WFH sent **24.6 million** units of factor to **64 countries**.

Humanitarian Aid

The WFH Humanitarian Aid program channels donations of clotting factor concentrates to treatment centres and NMOs in emerging countries. In 2013, the program helped many people in urgent need who live in countries that have limited access to treatment. The WFH sent 24.6 million units of factor, valued at more than US\$35.4 million, to 64 countries. Product donations were distributed with the invaluable assistance of Hemophilia of Georgia (United States), the Irish Haemophilia Society and the Fondazione Parecelso/Miphram in Milan (Italy).

Country programs

The WFH actively supported 24 country programs in 2013. In these countries, our specialized volunteers and staff worked to improve the organization of hemophilia care in at least two of six major areas: government support, care delivery, medical skills (diagnostic and treatment), treatment products, patient organization and data collection and outcomes research.

The highlights of this include:

- The first youth camp organized by the Hemophilia Society of Bangladesh for 50 patients, family members and health care professionals, which included home infusion and physiotherapy training sessions. The event helped raise the knowledge and determination of patients.
- The first national hemophilia symposium organized by the Montenegrin Society for Hemophilia, where the Ministry of Health representative committed to the creation of a National Hemophilia Council and recognized the need to assemble a multidisciplinary team.
- The hemophilia symposiums organized in the two most remote provinces of Bolivia, which drew an impressive number of participants and was the first time an educational campaign on hemophilia was organized in these regions of the country.

- The opening, in April, by the Albanian Ministry of Health, of the country's first Hemophilia Treatment Centre (HTC).
- The decision, in September, by the Government of Nepal to allocate financial support for hemophilia care for the first time.
- The decision in late 2012 and early 2013 by the Government of Mongolia to make its first purchase of factor concentrates. The WFH provided guidance on available products, the tendering process and a national distribution system.
- The commitment by the Algerian Ministry of Health for support for hemophilia care and home treatment, as well as the expressed interest by the Deputy Minister of Health to explore participation in GAP.

Cornerstone Initiative

In January 2013, the WFH officially launched the Cornerstone Initiative, a new health care development project specifically aimed at supporting treatment and care for people with bleeding disorders in underserved countries and regions where the gap in care is the greatest.

Nigeria was the first country selected to be part of the new initiative, and in February, the WFH organized an educational and awareness symposium on hemophilia for health care professionals from Abuja, and surrounding areas, at the National Hemophilia Hospital. The symposium was attended by 238 front-line doctors, general practitioners, hematologists and other health care professionals.

In July, a three-day training session on laboratory diagnosis took place in Abuja, attracting 12 laboratory scientists and technicians from seven major Nigerian cities. WFH provided a water bath and some reagents for the training, which focused on basic coagulation tests, factor assays, inhibitors and an introduction to von Willebrand disease testing.



HEALTH CARE DEVELOPMENT PROGRAM EXPENSES

2013	\$2,513,077
2012	\$2,227,853
2011	\$2,337,722

HEALTH CARE DEVELOPMENT PROGRAMS

A month later, the WFH also organized a full-day skills training session on advocacy, fundraising, and good governance for the board of the Hemophilia Foundation of Nigeria.

Regional advocacy initiatives

Three thematic and geographic workshops of the Advocacy in Action program were held in 2013. In May, 23 patient representatives from 12 Eastern European and Central Asian countries gathered in Kiev, Ukraine, for a tailored advocacy training workshop on “Steps to success: Developing resources and co-operating with others to advocate.”

In October, 20 participants from 11 Latin American organizations met in Bogota, Colombia, for a tailored advocacy-training workshop on “Working in partnership to build and sustain government support.”

In December, 12 youth representatives from 11 patient organizations from various regions of the world, met in Montréal, (Québec) Canada, for a workshop on “Developing youth leaders to advocate effectively”.

To maintain momentum from the workshops, 10 project grants – to assist with the implementation of an effective advocacy activity – were awarded to: Bangladesh, Georgia, Indonesia, Jamaica, Kyrgyzstan, Nepal, Pakistan, Philippines, Thailand and Vietnam.

The second Advocacy Recognition Award was presented to the Cordoba affiliate of the Argentinian NMO Hemophilia Federation. The award recognized the organization’s successful campaign to raise awareness within the government about the need for comprehensive care for people with bleeding disorders in Cordoba, which led to the implementation of a provincial Program for Comprehensive Care, the securing of financial resources and a physical space for the operations of a new Comprehensive Treatment Centre.

Twining

The Twining program pairs treatment centres or patient organizations in emerging and established countries to transfer skills and help improve care. The number of twins at the end of 2013 reached a total of 35, with 19 treatment centre twins and 16 organization twins. The WFH supports twins through assessment visits, annual payments and project grants, and supports activities that include medical training and workshops, patient education initiatives, patient outreach, and summer camps.

Twelve emerging twins and four established twins participated in our International External Quality Assessment Scheme (IEQAS), which monitors and improves laboratory performance in hemophilia treatment centres worldwide.

The HTC Twins of the Year Award winners were very productive and chosen for their accomplishments in India.

The partnership between Davangere (India) and Liverpool (U.K.) tested patients for infectious diseases, audited registered people with hemophilia and their inhibitor status, continued a successful yoga, hydrotherapy and naturopathy for pain management, organized a two-day rehabilitation and psychosocial camp for patients and their families, and published and trained key members on the new standard operating procedures.

The twinning of Ludhiana (India) and Detroit, Mich., also achieved great results in 2013, namely the development of surgical protocols, educational workshops for patients, families and medical students, the appointment of a hemophilia nurse co-ordinator at the Ludhiana HTC, the completion of full coagulation work-up panels and factor assays for patients, increasing the involvement of physiotherapists and occupational therapists in patient assessments, and training a laboratory technician.

The Hemophilia Organization Twins of the Year winners were the Hemophilia Association of Mauritius partnered with the South African Haemophilia Foundation. They were selected for their outstanding achievements, including the development and official launch of national treatment guidelines, the development of a three-year strategic plan, the production and distribution of a Hemophilia Association of Mauritius newsletter, and the five-day training of 24 nurses and a physiotherapist.

HIGHLIGHTS

.....
**GAP, COUNTRY PROGRAMS
AND CORNERSTONE INITIATIVE**
33 COUNTRIES

.....
NMO SKILLS TRAINING
3 THEMATIC/REGIONAL TRAININGS
(EASTERN EUROPE AND CENTRAL
ASIA; LATIN AMERICA; YOUTH)

NATIONAL TRAININGS
IN 9 COUNTRIES

EDUCATIONAL SESSIONS TO
PATIENTS AND FAMILY MEMBERS
IN 14 COUNTRIES

.....
**ORGANIZATION AND CENTRE
TWINNING**
19 CENTRE AND 16 ORGANIZATION
TWINS (35 ACTIVE TWINS)

.....
HUMANITARIAN AID DONATIONS
24.6 MILLION IU
(OVER 248.4 MILLION IU
IN THE PAST 18 YEARS)

Laboratory quality control

Now in its 11th year of operation, the IEQAS program has 103 centres from 66 countries registered. In 2013, we added 12 new laboratories from emerging countries to the program.

Workshops and conferences

The WFH organized a total of 24 conferences and/or multidisciplinary workshops in 2013. These gatherings brought together hundreds of members of the global bleeding disorders community from diverse backgrounds to exchange ideas on improving treatment and care.

The highlights of these included:

- A three-day regional hemophilia nurses training workshop in Nairobi, Kenya, helped in showcasing nursing as a major component of the multi-disciplinary care approach in hemophilia and other bleeding disorders care and in strengthening the knowledge of 15 nurses from eight East African countries (Ethiopia, Ghana, Kenya, Nigeria, Rwanda, Tanzania, Uganda and Zambia).
- The organization of a two-and-a-half-day training of trainers course for 15 laboratory technicians from Brazil, which allowed participants to discuss what they experience in their labs and to gain more knowledge of proper testing techniques. This was the third step in the Ministry of Health's strategy to improve diagnostic capacity in Brazil.
- The organization of a two-day musculoskeletal workshop in Kiev, Ukraine, where 25 hematologists and physiotherapists from various regions of the country received advanced training on the role of the orthopedic surgeon and the physiotherapist in the management of joint bleeds, prevention of surgery, post-operative rehabilitation after total knee arthroplasty and pseudo-tumours.
- The organization of a two-and-a-half-day hemophilia training session that provided invaluable knowledge to 55 governmental nurses in Malaysia. This was the first-ever medical event that the WFH and Malaysia collaborated on.

- The organization of a two-day physiotherapy-training workshop in Manama, Bahrain, showcased physiotherapy as a major component of the multi-disciplinary care approach to hemophilia, which strengthened the knowledge of the 30 participating physiotherapists. A similar physiotherapy workshop was also conducted in Doha Qatar.

International Musculoskeletal Congress

The 13th WFH International Musculoskeletal Congress was held April 18-21 in Chicago, Ill., with a record attendance of 366 participants (a 21.2 per cent increase from the previous Congress). The event marked the first time the WFH hosted a musculoskeletal congress in the United States. A Pre-Congress day featured concurrent sessions on physiotherapy and orthopedics. The Congress medical program featured a state-of-the-art session, surgery tips and clips, two keynote plenaries, two crossfire sessions, and a comprehensive session on muscle bleeding. A total of 78 abstracts were submitted, 20 free papers were presented and 48 e-posters were accessible at the exhibition display. The WFH sponsored 12 physical therapists/orthopedists from emerging countries through travel grants.

Medical fellowships

The WFH awarded 35 health care professionals from emerging countries with training fellowships at one of our 28 designated International Hemophilia Training Centres (IHTC) in 19 countries. In 2013, 33 fellows from 22 countries were trained at one of these centres. This specialized training for physicians and paramedical staff at a comprehensive care training centre enables them to improve patient care in their home country.

The year 2013 also marked the end of the five-year (2008-13) mandate of all current IHTCs. These are systematically reviewed every five years to re-evaluate designated IHTCs in relation to training needs (linguistic, work environment, cost, etc.). In December, the IHTC committee renewed the designation of all current 28 IHTCs for a new five-year mandate (2014-18).

HIGHLIGHTS

LABORATORY IEQAS

103 LABS FROM 66 COUNTRIES

MULTIDISCIPLINARY WORKSHOPS AND CONFERENCES

15 WORKSHOPS (LABORATORY, PHYSIOTHERAPY, NURSING AND MUSCULOSKELETAL)

9 CONFERENCES AND SYMPOSIUMS

MEDICAL TRAINING FELLOWSHIPS

35 FELLOWSHIPS AWARDED (OVERALL 93% RETENTION IN HEMOPHILIA CARE AFTER 5 YEARS)

PROMOTING EDUCATION & STANDARDS OF CARE

2013 RESEARCH GRANT RECIPIENTS

ROGER SCHUTGEN AND
LIZE VAN VULPEN

KEVIN DESCHAMPS AND
SEBASTIEN LOBET

PAULA JAMES

THOMAS HILBERG AND
STEFFEN KRUGER

The past year was marked by evolution in the realms of education and public policy. Our fifty years of experience producing educational resources, ensuring access to safe and effective treatment, collecting global data and establishing standards of care has given the WFH unique insights. As we enter our second half-century we are consolidating what we and our stakeholders have learned to strengthen our advocacy for Treatment for All.

The creation of the Education & Public Policy department as a separate entity within the WFH allows us to increase our focus on these key areas. We have implemented a number of new programs and initiatives and are continually seeking innovative ways to enhance the services we provide to the bleeding disorders community.

Research and data collection

The WFH Research Program, announced at the WFH 2012 World Congress, aims to encourage clinical research and outcomes assessment by providing support for clinical investigation of inherited bleeding disorders around the world. As a global organization, the WFH is uniquely positioned to identify the areas where new or better evidence is needed most. We also have a role to play in facilitating research: by fostering international collaboration, collecting global data, and providing financial support through the distribution of grants.

In 2013, we invested in a new data system and expanded our capacity to collect and analyze data from the WFH's Annual Global Survey as well as relevant program data. It allows for real-time, automated validation, customizable queries, and the output of raw data for analysis with various software solutions. The 2012 Report on the Annual Global Survey includes data on more than 90 per cent of the world population, identifying more than 274,000 people with bleeding disorders in 109 countries.

In addition, a working group was formed to develop concepts and systems for new epidemiological data collection projects. Working through our network of patient organizations and specialized treatment centres, we aim to answer clinically relevant research questions, permitting us to add to our current understanding of hereditary bleeding disorders and their management.

On June 1, the first competition of the Clinical Research Grants Program was launched. In this first year, we received 56 applications from 24 countries. The first grant recipients were announced in February 2014.

Treatment product safety and supply

This past year also saw the crowning achievement of more than a decade of work toward improving access to safe treatment products, with the September announcement of Project Recovery. This world-first collaboration between the WFH, Canadian Blood Services, and plasma product manufacturers Biotest AG and Grifols will lead to at least five million IUs per year in humanitarian aid donations by transforming previously discarded

The WFH has implemented a number of new programs and initiatives and is continually seeking innovative ways to enhance the services we provide to the bleeding disorders community.



Jennifer Laliberté
Director

HIGHLIGHTS

.....
DISTRIBUTED MORE
THAN 350,000 PRINT AND
ELECTRONIC DOCUMENTS
.....

IDENTIFIED MORE THAN
274,000 PEOPLE WITH BLEEDING
DISORDERS IN 109 COUNTRIES
IN 2012 REPORT ON THE ANNUAL
GLOBAL SURVEY
.....

cryoprecipitate from Canadian blood donors into life-saving treatment product. With this tremendous achievement under our belt, we hope to assist other countries to follow suit in the coming months.

The Eighth WFH Global Forum on the Safety and Supply of Treatment Products, held in Montréal on September 26-27, 2013, brought together patient groups, regulators, representatives from industry, not-for-profit fractionators, and treatment providers to discuss the safety and sustainability of plasma products, clinical and economic aspects of novel treatment products, and the impact of regulatory factors on product access. The WFH participated in several other international meetings relating to safety and supply, including the International Plasma Protein Conference, PLUS Consensus Conference, and the WHO Global Forum on Blood Safety. We continue to monitor new and potential threats to the global blood supply, as well as the risk adverse events such as inhibitors, and maintain surveillance on treatment advances and new product development.

Educational materials

Education is at the core of the WFH mission. Our aim is to develop and disseminate targeted tools to meet the needs of patients and their families, patient organization leaders and health care providers. In the past year, we distributed nearly 350,000 resources in print and online.

In addition:

- The *WFH's Guidelines for the Management of Hemophilia*, revised in 2012, was endorsed by the International Society on Thrombosis and Haemostasis and accepted for publication on the National Guidelines Clearinghouse website, a U.S. government-sponsored public resource for evidence-based clinical practice guidelines. The document was accessed nearly 35,000 times in 2013.

We invested in a new data system and expanded our capacity to collect and analyze data from the WFH's Annual Global Survey as well as relevant program data.

- We developed a core curriculum to standardize and support the delivery of nursing training workshops.
- We broadened the reach of training delivered on the ground via online learning solutions, including the asynchronous webcast of a regional nursing workshop and the live webcast of an Advocacy in Action workshop focused on engaging youth in advocacy initiatives.
- We launched a new website section on prophylaxis in three languages.
- We published the first Young Voices article – a year-long online series designed to help identify, mobilize and empower future leaders to participate in the global conversation and effect positive change in their communities.
- We translated key publications, such as the treatment guidelines and *Carriers and Women with Hemophilia*, into Spanish, Russian, Simplified Chinese, Arabic and Russian.

As part of our ongoing efforts to measure the effectiveness of our resources, we integrated the ability to share and rate individual publications into the WFH's vast publications library of more than 300 resources in six languages.

RAISING AWARENESS & BUILDING RELATIONSHIPS



The decision to create a separate Communications and Marketing department in 2013 is testament to the desire within the WFH to augment and multiply communications efforts and create new ways of promoting the organization. In other words, we've given ourselves more ways to connect with our stakeholders, to build and sustain relationships.

Creating awareness about bleeding disorders is the principle that guides all our efforts. From *Hemophilia World* and *Haemophilia journal* to World Hemophilia Day, we write, we organize and we promote to further the cause of not only the WFH, but of each person with a bleeding disorder.

The ongoing development of new digital platforms provides us with several means with which to deliver our message around the world, on a daily basis, and in several languages. From newsletters and tweets, to meetings and conferences, Communications and Marketing will ensure the right message is delivered to the right audience.

We are committed to developing and using new digital platforms to ensure our viability and relevance for future generations. And we are making inroads in this regard.

In 2013, the WFH website received 5.8 million visitors and we had more than 66,000 followers across all social media channels. We also hosted a one-hour Twitter party in partnership with Haemophilia Solutions Bayer on October 1, 2013 and helped raise \$10,000 in donations. Support and participation came from around the world with 42 cities joining the conversation. A heartfelt thank you to the Mexican Federation of Hemophilia that

translated questions into Spanish, generating 125 tweets in Spanish. These are but two examples of innovation that will become standard practice.

As we move forward into the second half of this decade, multi-channel communications will become the norm as we utilize tools new and traditional to deliver, promote and advocate.

Celebrating our golden jubilee

To mark the occasion of the founding, on June 25, 2013, the Danish Haemophilia Society hosted WFH president Alain Weill and two former WFH presidents, Mark Skinner and Brian O'Mahony, at a symposium in Copenhagen. This symposium examined the many milestones achieved over the past five decades and a webcast was produced and hosted on the WFH website.


Haemophilia, the official journal of the WFH, published articles commemorating the anniversary, highlighting our history and the accomplishments achieved throughout the decades.

To highlight historical events, we released a series of videos to showcase the history of the WFH through the stories of those directly involved.

World Hemophilia Day took on special significance in 2013. We invited friends and partners to send us a video clip of their wish for our community in the coming 50 years. The results were inspiring messages on the importance of the work of the WFH and our partners.

Sarah Ford
Director





Born and raised in Bangalore, India, Premroop Alva found living with hemophilia insulating, because most people had never heard of the condition let alone known anyone with a bleeding disorder. So, at 14, he and his parents took the extraordinary step of putting an ad in the local newspaper looking for people with an inherited bleeding disorder. The group that came together as a result of his efforts was the start of the Bangalore chapter of the Hemophilia Society, where Alva is the current General Secretary.

He was involved in the chapter for many years, but drifted away from his community as he focused more time on his studies. He tells a moving story about what brought him back to working with his chapter: **"I was at the treatment centre getting factor and there was a seven-year-old boy there who had been elbowed while he was at the temple that morning. He had factor with him, and his parents had stopped at three clinics to**

try and have him infused but were refused. We had lots of factor available, but by the time he got to the treatment centre it was too late; we lost him."

The shock of seeing a young child die despite having factor available to treat him motivated Alva to get involved in the community again. Since then, he has been active in developing camps for youth that help to develop their confidence and leadership skills. While he is focused on working with young people, he recognizes the critical role elder members of the community play.

We want to make sure we keep older members of the community around, as they have dealt with problems before, and to learn from their experience.

— Premroop Alva, India



It was such a relief to find somewhere I could talk about what was happening to me and to have someone say, yeah, I've been through that.

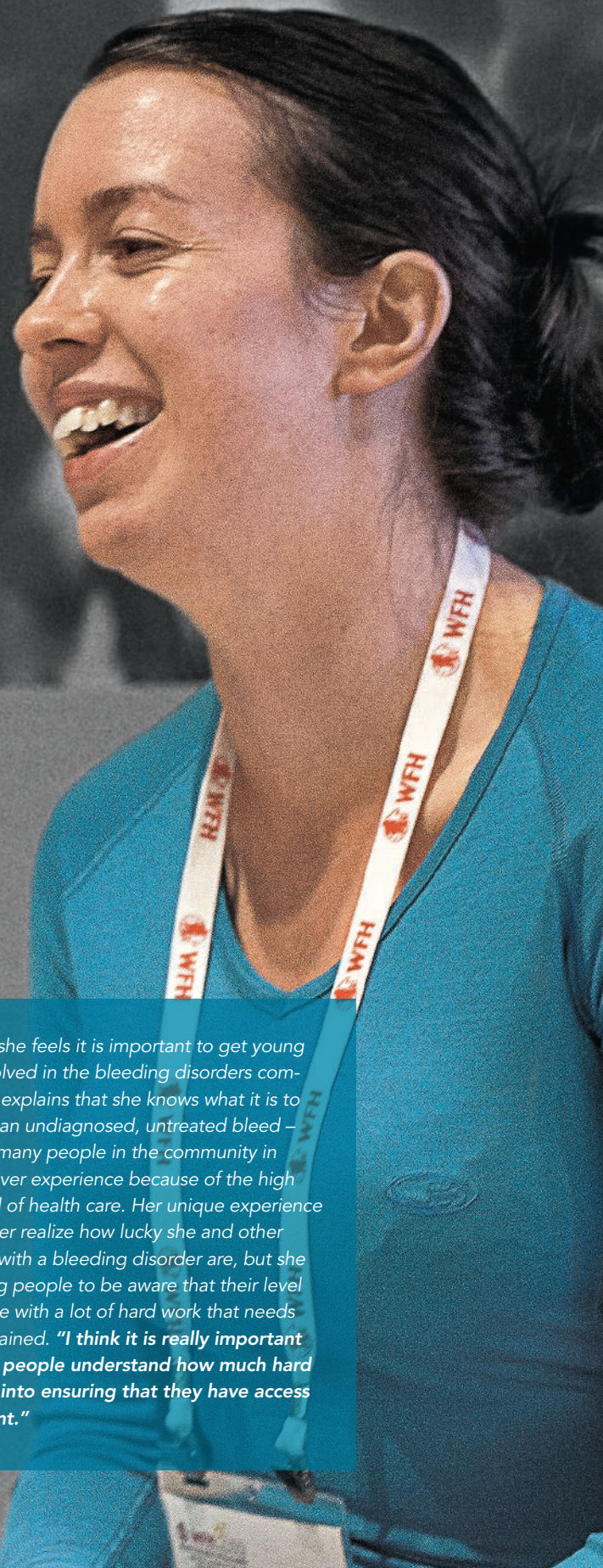
— Jenna Lovell, Australia

Jenna Lovell of Canberra, Australia, got involved in her local hemophilia chapter after realizing she did not have to face living with a bleeding disorder alone. **"It was such a relief to find somewhere I could talk about what was happening to me and to have someone say, 'Yeah, I've been through that'."**

Diagnosed 12 years ago, she committed herself early to helping improve the level of awareness given women in the bleeding disorders community. **"It is understandable that, historically, there has been a focus on treatment for men, but women are facing issues too."**

Lovell points out that, while it is often uncomfortable for anyone to discuss their health issues, it can be especially difficult for women because there is a particular shyness that accompanies talking about one's reproductive organs.

Asked why she feels it is important to get young people involved in the bleeding disorders community, she explains that she knows what it is to experience an undiagnosed, untreated bleed – something many people in the community in Australia never experience because of the high quality level of health care. Her unique experience has made her realize how lucky she and other Australians with a bleeding disorder are, but she wants young people to be aware that their level of care came with a lot of hard work that needs to be maintained. **"I think it is really important that young people understand how much hard work went into ensuring that they have access to treatment."**



COLLABORATIVE KNOWLEDGE SHARING



Jens C. Bungardt, CMP
Director

As platforms for knowledge transfer and learning, WFH events offer tremendous opportunities to move the global community closer to its shared goal of Treatment for All.

Whether at the biennial World Congress or smaller, specialized meetings, the international bleeding disorders community comes together at WFH-organized events to share information and collaborate. As platforms for knowledge transfer and learning, these events offer tremendous opportunities to move the global community closer to its shared goal.

Following a change in Congress and Meetings leadership at the end of 2012, and the introduction of a new, web-based event management platform to allow an integrated approach for all of WFH's events, the Congress and Meetings department turned its focus toward preparations for the WFH 2014 World Congress.

Set to take place in Australia (Melbourne, Victoria, May 11-15) for the first time, the Congress will bring together more than 4,000 delegates from across the international bleeding disorders community. In addition to creating an important opportunity for sharing strategies on how to reach the ultimate goal of Treatment for All, the Congress provides an essential investment toward improving WFH's ongoing capacity.

Among the early priorities was the careful development of a cutting-edge Congress program and an innovative marketing strategy and promotional plan to draw maximum participation from across all disciplines and regions. In close collaboration with Haemophilia Foundation Australia, the Australian regulatory environment was explored and the necessary steps taken to allow all members of the global bleeding disorders community the best possible experience at Congress.

To enrich the knowledge transfer potential of Congress, the WFH is introducing electronic poster technology for the first time, in addition to printed posters. This will help ensure both an improved viewing experience at Congress and increased knowledge sharing through the creation of a virtual poster gallery that will live on after delegates depart.

Building on the success following of the WFH 2012 Congress in Paris, the organization is expanding on webcasting technology to share important information far beyond a single meeting site, and take advantage of emerging technologies to push learning far into our broader community.

Social media is also playing an increasing role in how the WFH shares knowledge, particularly among younger stakeholders around the world.

In addition to the work toward a successful 2014 World Congress, important foundations were put in place for the 2016 World Congress. Due to unexpected major renovation plans at the convention centre in Miami, the WFH executive committee and the NHF decided to move the event to Orlando, Fla. The Congress and Meetings team also collaborated with other parts of the organization to manage the logistics of several important international WFH events and regional workshops that contribute to foster international knowledge exchange and learning. Among those events was the 13th International Musculoskeletal Congress in Chicago, Ill., the 2nd WFH Global Research Forum, and the 8th Global Forum on the safety and supply of treatment products for bleeding disorders, both of which were held in Montréal, Canada.

The bid process for the WFH 2020 World Congress was initiated, and WFH received proposals from seven national member organizations. Two finalists have been selected: Canada (Montreal) and Malaysia (Kuala Lumpur). Members of the WFH General Assembly will determine the winning bid on May 16, 2014 in Melbourne.

Planning for, and delivering, successful events takes a collaborative effort that calls on the resources and expertise of many within the WFH. These interdependencies help ensure that events deliver exceptional programming and logistics; meeting the needs of all participants and providing platforms to enhance partnerships and share lessons that benefit all members of the global community.

DEVELOPING A SUSTAINABLE FUTURE

In the year following the launch of the WFH's inaugural multi-year fundraising campaign – Close the Gap – the organization continued to make significant strides toward building a culture of philanthropy, one of its strategic priorities for 2012-14. The aim is long-term sustainability, expanding on WFH's current sources of support to diversify and grow funding for the next decade of WFH development programs and activities, and beyond that to the overarching goal of Treatment for All.

While the goal of the Close the Gap campaign is to raise US\$5 million by the end of 2014, the organization is also focused on building awareness of bleeding disorders around the world and of the challenges of diagnosing and providing treatment to everyone with a bleeding disorder. Building sustainability stretches beyond expanding sources of revenue to cultivating long-term relationships that span generations and geography.

The year 2013 was another of foundational building, constructing a core structure that will support long-term growth of both funds and community engagement.

Our collaborative, holistic approach to fund and resource development ensures that all parts of the organization benefit – using the success stories we encounter to encourage donations and participation, and ensuring that all of our efforts are moving harmoniously in one direction.

The results are encouraging. Overall, approximately \$3,628,947¹ has been donated to date in the Close the Gap campaign. The past year was one of global outreach through regional co-chairs and increasing partnership with the WFH through giving and membership around the world.

Close to \$3 million has been pledged by our corporate partners, including contributions for WFH's 50th anniversary, the second decade of Global Alliance for Progress (GAP), and the WFH Research Program: this represents 85 per cent of the Corporate Close the Gap campaign objective.

We are grateful to the seven corporate partners who have supported the launch of the second decade of GAP: Baxter, Bayer, Biogen Idec Hemophilia, Biotest, CSL Behring, Grifols and Pfizer.

The WFH also extends its sincere thanks to Hemophilia Center of Western Pennsylvania, Bayer, Baxter and Biogen Idec Hemophilia for their continued generous support of the WFH Research Program.

Measuring success in the process of building a culture of philanthropy also goes beyond an accounting exercise. Success is measured in engagement, partnership, participation, and leading by example.

In 2013, success was illustrated by a number of measures:

- The Campaign Honourary Committee members continued to actively champion the WFH mission, engage in fundraising activities and initiatives, and personally support the Close the Gap campaign. Thanks go to WFH Patron Jan Willem André de la Porte, WFH President Alain Weill, the Schnabel Family, the Carman and de Matteis families and past presidents Brian O'Mahony and Mark Skinner.
- Our Patron's challenge to match donations from the community 2 for 1 attracted 140 new donors in 2013. The Patron's challenge continues through 2014.
- Fifteen campaign regional co-chairs raised awareness about the campaign and raised funds to support the campaign.

CLOSE THE GAP CAMPAIGN REGIONAL CO-CHAIRS HAVE STEPPED FORWARD TO LEAD AWARENESS-RAISING AND FUNDRAISING

AMERICAS

Patricia Dominic, United States
Cesar Garrido, Venezuela
Phil Kucab, United States
Martha Monteros, Mexico
Carlos Safadi Marquez, Argentina
Pam Wilton, Canada

EUROPE

Anne Duffy, Ireland

MIDDLE EAST AND AFRICA

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

ASIA AND WESTERN PACIFIC

Gavin Finkelstein, Australia
Aris Hashim, Malaysia
Reynaldo Sarmenta, Philippines

¹ All figures are USD and reported for December 31, 2013; they are integrated WFH and WFH USA figures for the campaign, so will not necessarily match finance figures.



Dolly Shinhat-Ross, CFRE
Director

NMOS WHO PARTICIPATED IN THE 2012-2013 CAMPAIGN

-
- Association française des hémophiles
-
- Association Libanaise de l'Hémophilie
-
- Association Marocaine des Hémophiles
-
- Belgian Haemophilia Society
-
- Canadian Hemophilia Society
-
- Danish Haemophilia Society
-
- Deutsche Hämophiliegesellschaft
-
- Egyptian Society of Hemophilia
-
- Fundación de la Hemofilia (Argentina)
-
- Haemophilia Association of Mauritius
-
- Haemophilia Foundation Australia
-
- Haemophilia Foundation of New Zealand
-
- Haemophilia Foundation of Nigeria
-
- Hemophilia Association of the Philippines for Love
-
- Hemophilia Society of Malaysia
-
- Irish Haemophilia Society Ltd.
-
- Japan Committee for People with Hemophilia
-
- National Hemophilia Foundation (USA)
-
- Netherlands Haemophilia Society
-
- Norwegian Hemophilia Society
-
- Österreichischen Hämophilie Gesellschaft (Austria)
-
- Slovenské Hemofilické Zdrúenie (Slovak Republic)
-
- Sociedad Hondureña de Hemofilia
-
- Society for Inherited & Severe Blood Disorders (Trinidad and Tobago)
-
- Swedish Hemophilia Society
-
- Swiss Hemophilia Society
-
- UK Haemophilia Society
-
- Vietnam Hemophilia Association
-

- Eight individuals shared their stories to help raise awareness about the vast needs and how the campaign will help to close the gap in care.
- More than \$654,000 was donated by the global bleeding disorders community in 2013; 58 per cent more than in 2012.
- Twenty-eight NMOs have participated in the campaign since the launch in 2012 and collectively have pledged/donated an unprecedented \$412,018.
- The 12 founding NMOs have together assured funding for the launch and implementation of the multi-year Cornerstone Initiative beginning in Nigeria in 2013 and to be implemented in Nepal and Ethiopia in 2014.
- The number of WFH sustaining memberships, which include a \$40 donation, grew by 13 per cent in 2013.
- More than half of all WFH staff members have made a contribution to the campaign; in part, staff gifts have funded the participation of two additional Youth Fellows to attend Global NMO Training, Congress and the General Assembly in Melbourne in 2014.

- The number of WFH memberships at the end of 2013 was an unprecedented 693—the highest number ever, and an increase of 23 per cent over 2012, contributing more than \$36,500 toward our mission.
- The number of donors making monthly contributions increased by 60 per cent; these donors' gifts reflect an important commitment to partnering with the WFH.
- Our U.S. affiliate, WFH USA, contributed \$55,000 from U.S.-based fundraising activities to support the Humanitarian Aid Program.
- U.S. donors contributed \$43,155 toward the Susan Skinner Memorial Fund, bringing the total value of this endowment to \$244,540.
- Two SSMF scholars have been selected to participate in Global NMO Training, Congress and the General Assembly in Melbourne: Leslie Situ Ferber from the United States and Salma Kiran from Pakistan.

Building sustainability stretches beyond expanding sources of revenue to cultivating long-term relationships that span generations and geography.

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 2013, the following individuals, corporations and organizations made financial contributions of CAN\$100 or more to 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
Pfizer
Precision BioLogic
Rare Antibody Antigen Supply Inc.
Sanquin
SOBI

Global Alliance for Progress (GAP)

Visionary partner

Baxter

Leadership partner

CSL Behring

Collaborating partners

Bayer
Biogen Idec Hemophilia
Biotest
Grifols
Pfizer
World Health Organization

50th anniversary project

Baxter
Bayer
Biogen Idec Hemophilia
Biotest
BPL
CSL Behring
Green Cross
Grifols
Kedrion

LFB
Novo Nordisk
Pfizer
Sanquin

Sponsorships

Baxter: Advocacy in Action, Global Forum, Global Research Forum, Musculoskeletal Congress, World Hemophilia Day

Bayer: IHTC Fellowship Program, Global Research Forum, Musculoskeletal Congress, WFH website, World Hemophilia Day, Web section on Prophylaxis

Biogen Idec Hemophilia: Global Research Forum, HTC Online Directory, Web section on Prophylaxis, World Hemophilia Day

Biotest AG: International Hemophilia Forum

CSL Behring: World Hemophilia Day

Grifols: Inhibitor web section, von Willebrand disease web section

Kedrion: Online Compendium of Assessment Tools

LFB: Online Compendium of Assessment Tools, Symposium of von Willebrand disease

Novo Nordisk: Global Forum, Global Research Forum, HemoAction e-games, HTC Online Directory, Musculoskeletal Congress, World Hemophilia Day

Octapharma: von Willebrand disease web section

Pfizer: Twinning program, Global Forum, Global Research Forum, WFH website

Project Recovery

Biotest
Canadian Blood Services (CBS)
Canadian Hemophilia Society
Grifols

WFH Research Program

Baxter
Bayer
Biogen Idec Hemophilia
Hemophilia Center of Western Pennsylvania
340B Program

Humanitarian aid product donations

Baxter
Bayer
CSL Behring
Grifols
Kedrion
Pfizer

FOUNDATIONS AND GOVERNMENT AGENCIES

IEQAS Program

Novo Nordisk Hemophilia Foundation

Global Forum

Canadian Blood Services
Foundation for America's Blood Centers
Héma-Québec
Ministère de la santé et des Services sociaux

Solidarity fund contributors¹

Afghanistan Hemophilia Association
Asociación de Hemofílicos del Uruguay
Association française des hémophiles
Association Libanaise de l'Hémophilie
Association Luxembourgeoise des Hémophiles – ALH
Canadian Hemophilia Society
Croatian Hemophilia Society
Fundación Panameña de Hemofilia
Haemophilia Foundation Australia
Hemophilia Society of Malaysia
The Hemophilia Society of Turkey
Irish Haemophilia Society
Jamaica Hemophilia Committee
Jordan Thalessemia and Hemophilia Society
Korea Hemophilia Foundation
National Hemophilia Foundation of Thailand
South African Haemophilia Foundation
Swedish Hemophilia Society (FBIS)
UK Haemophilia Society

Memorial funds

Susan Skinner Memorial Fund

Tributes

In Honour of Bradley Andre
In Honour of Cahroon Ehterami
In Honour of Cesar Garrido
In Honour of Hemophilia of Georgia's 40th anniversary
In Honour of Pete Hultgren
In Honour of Mark Skinner and James Matheson
In Honour of Paul Wilton
In Memory of Adriana Bida
In Memory of Michael Brand
In Memory of Greg Hinckley
In Memory of Nickeisha Lee
In Memory of Aurele Paradis

¹The Solidarity Fund contributes toward the payment of assessment fees for national member organizations from developing countries.



I know what they can face, and it is important to offer help.

— Alexandra Ilijin, Serbia
Susan Skinner Memorial Fund recipient (2012)

Alexandra Ilijin was raised in a family devoted to working to improve the lives of people with inherited bleeding disorders. Growing up, her father set the example as the president of the local chapter's steering committee. As she grew older she became more interested and involved in their activities. However, soon after she became involved, Ilijin realized one segment of the community was not being served: women were not permitted to be voting members of their local chapter. **"If you are a carrier, there is little support for you unless you are pregnant,"** she says.

Ilijin pushed, with her father's help, to have women recognized as full members of the chapter, and succeeded in 2011. Her goal is to see that there is more done to help carriers come to terms with potential emotional or psychological issues that arise. **"I know what they can face, and it is important to offer help."**

After travelling to the WFH Paris Congress in 2012, where she met with other youth leaders from around the world, Ilijin saw the need to start her own local youth chapter and realized the benefits of networking with others. More importantly, she realized the importance of having a space for young people to discuss their issues freely, without parents or doctors in the room. She has also begun organizing a series of motivational talks from people in the community to speak on living successfully with a bleeding disorder.

DIVERSITY CONSOLIDATES EFFORTS & REVENUE¹



2013 was a solid year, showing a deficit of \$821,236 against a budgeted deficit of \$1,091,944, which represents an improvement of \$270,708.

The success of the 2012 Paris World Congress, which contributed \$2.4 million in 2012, enabled the WFH to achieve its goal of a balanced budget, with a positive net result of \$603,285 over a two-year cycle.

In 2012, the WFH adopted the new Canadian accounting standards for not-for-profit organizations and they have had an impact on the way the WFH reports Congress expenses. Certain Congress expenses² incurred in 2013 – that previously we were able to defer to the World Congress year – are now recognized in 2013. As a result, both the 2013 deficit and 2014 surplus numbers are greater than if we had used pre-2012 methodology. However, the net result over the two years remains unchanged.

Diversified revenue is cornerstone of financial health

Revenue generation sustained progressive growth in 2013. Corporate partnerships were strong and stable, as evidenced by their financial support: contributions rose 12.7% from 2012. Additionally, an increased focus on broader fundraising initiatives diversified the funding base. Generating income through the internal management of the biennial World Congress and other meetings, such as the 13th International Musculoskeletal Conference and the Global Forum, added to the diversified income stream. In 2013, WFH total revenue (before Congress and product donations) hit a \$5 million milestone for the first time in one annual year.

Excluding product donations, 41% of revenues over the two-year cycle were generated by corporate partner contributions (including sponsorship of the 50th anniversary campaign); and 59% mainly from the WFH 2012 World Congress, donations and self-generated income³ activities.

Expenses in line with expectations

Congress not only represents the most important part of revenues, it also represents the largest proportion of expenses: 43% were incurred from 2012 to 2013. Health care development program expenses (programs, educational resources and safety and supply) represent 35% of the overall picture and the 50th anniversary campaign expenses, 4%. Administration and fundraising expenses were 15% and democratic functions⁴, 3%.

Humanitarian Aid

Since 1996, through the WFH Humanitarian Aid Program, the WFH has distributed more than 248 million⁵ International Units (IU)s of clotting factor concentrates to more than 86 countries, helping some 90,000 people with bleeding disorders directly. A steady flow of treatment product to the WFH network of need makes it possible for people with inherited bleeding disorders in developing countries to receive regular treatment.

In 2013, the WFH sent a total of 24.6 million IUs, valued at more than US\$35 million, to 64 countries. The bulk of donations, 23 million IUs, worth US\$32 million, is reported in the audited financial statements of WFH affiliate WFH-USA. The balance, reported in the WFH financial statements is 1.6 million IUs, worth \$3.4 million.

Irene Bitharas, CPA, CGA
Director

Statement of revenues and expenses: year over year comparison

The 2013 and 2012 **Statement of revenues and expenses** reflects the fluctuations within a typical two-year cycle, where the World Congress is held in even years.

The period saw an increase in support from corporate partners of \$436,000, donations also saw a healthy increase of \$194,000. Self-generated revenue stood at \$601,000 and includes income received mainly from other events that occurred in 2013, such as the 13th International Musculoskeletal Conference and the WFH Global Forum.

The rise in Programs expenses in 2013 is due primarily to \$439,000 related to the 13th International Musculoskeletal Conference. Similarly, the Global Forum and Global Research Forum contributed to a \$227,000 increase, year over year, to Safety and Supply programs.

Administration costs reflected an organizational restructuring that included the addition of a new senior position, that of Chief Operating Officer, in February 2013; and the move of the Information Services team to the Administration department.

Fluctuations in foreign exchange rates have had minimal impact over the two-year period.

Looking ahead

As we embark on a new two-year cycle, our financial base is solid, our revenue base is robustly supported by early commitments from our corporate partners, our 2014 World Congress is on track to delivering budgeted profit and our diversified fundraising activities have expanded. We fully expect our program delivery to increase as we generate additional and diversified revenue.

The complete 2013 audited financial statements are available at www.wfh.org.

¹ All dollars expressed in Canadian funds except where otherwise noted

² Excludes all refundable deposits

³ Includes but is not limited to other meetings and events, publications and investment income

⁴ Includes executive and other committee expenses

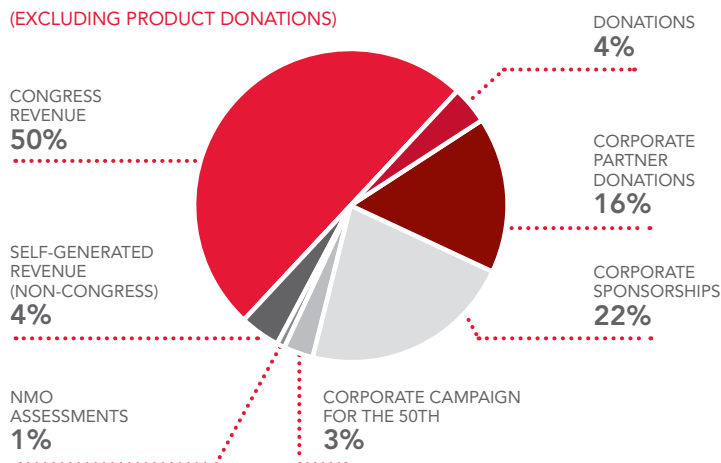
⁵ As at December 31, 2013

⁶ Percentages are rounded



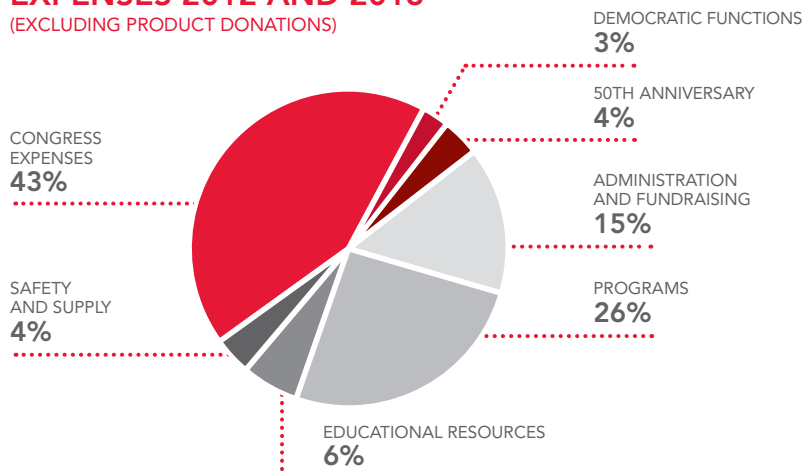
REVENUES 2012 AND 2013

(EXCLUDING PRODUCT DONATIONS)



EXPENSES 2012 AND 2013⁶

(EXCLUDING PRODUCT DONATIONS)



REVENUES	2013	2012
Donations	523,788	329,444
Corporate partner donations	1,530,933	1,489,111
Corporate sponsorships	2,327,680	1,933,716
Corporate campaign for the 50th	176,484	479,721
NMO assessments	85,350	81,193
Self-generated revenue (non-Congress)	601,135	196,722
Congress revenue	0	9,571,005
Product donations	3,354,838	1,075,411
TOTAL REVENUES	8,600,208	15,156,323

EXPENSES	2013	2012
Programs	2,513,077	2,227,853
Educational resources	516,358	529,997
Safety and supply	473,652	204,930
Congress expenses	759,264	7,200,835
Democratic functions	243,482	239,249
50th anniversary	54,860	696,109
Administration and fundraising	1,454,965	1,379,674
Fluctuation of foreign exchange	(43,418)	84,324
Product donations	3,449,204	1,168,830
TOTAL EXPENSES	9,421,444	13,731,801

EXCESS (DEFICIENCY)	(821,236)	1,424,522
----------------------------	------------------	------------------

OUR DONORS

Gifts of \$75,000 and over

Jan Willem André de la Porte family foundation

Gifts of \$50,000 – \$74,999

National Hemophilia Foundation (USA)*
Novo Nordisk Haemophilia Foundation

Gifts of \$25,000 – \$49,999

Association française des hémophiles*

Gifts of \$10,000 – \$24,999

Bayer HealthCare
Hemophilia Alliance Foundation
Hemophilia of Georgia, Inc.
Irish Haemophilia Society Ltd.*
Katharine Dormandy Trust
Ministère de la santé et des Services sociaux
Stichting de Erven Leeuwenhart
1 anonymous donor

Gifts of \$5,000 – \$9,999

Canadian Hemophilia Society*
Patsy Carman
Delaware Valley Chapter, NHF
Héma-Québec
Hemophilia Foundation of Michigan
LA Kelley Communications, Inc.
Opticom International Research AB
The Skinner Family
Swiss Hemophilia Society*

Gifts of \$2,500 – \$4,999

Canadian Blood Services
Foundation for America's Blood Centers
Haemophilia Foundation of New Zealand*
Norwegian Hemophilia Society*

Phillips 66
Barbara and Gerard Volk
2 anonymous donors

Gifts of \$1,000 – \$2,499

Paula and Benjamin Bolton-Maggs
John E. Bournas
Ute Braun
Mark Brooker and Sol Ruiz
Cheryl and Tony D'Ambrosio
Diagnostica Stago, Inc. (US)
Nancy Flemming
Dietje Fransen van de Putte
Fundación de la Hemofilia (Argentina)*
Haemophilia Association of Mauritius (HAM)*
Hemophilia Foundation of Greater Florida, Inc.
Institute for Policy Advancement Ltd.
Elizabeth Johnston
Marion A. Koerper
Mary M. Gooley Hemophilia Center
Elizabeth A. Paradis
Glenn and Beatrice Pierce
Reynaldo and Rosario Sarmenta
David Silva Gómez
William T. Sparrow
Swedish Hemophilia Society (FBIS)*
Virginia Hemophilia Foundation

Gifts of \$500 – \$999

The Capretto Family
Anthony K. Chan
Colorado Chapter of the National Hemophilia Foundation
Florida Hemophilia Association
Assad Haffar
Mohamed Aris Hashim
Hemophilia of Iowa, Inc.
Hemophilia of North Carolina
Japan Committee for People with Hemophilia*
Craig Kessler
Nigel and Melissa Key
Barbara A. Konkle
Ron and Jenny Lees
Randy Moore
John Murphy
Otieno Walter Mwanda
Brian O'Mahony
Shannon W. Penberthy

The Poepjes Family
Rocky Mountain Hemophilia and Bleeding Disorders Association
Eric and Marion Stolte
Karen Tubridy
Leonard A. Valentino
Alain Weill
Mary Q. Wingate
1 anonymous donor

Gifts of \$250 – \$499

Axon-com
The Belgian Haemophilia Society*
Patric Brown
Daniel Button
Margareth Castro Ozelo
Patricia A. Dominic
Gavin Finkelstein
John and Penny Gisselbeck
Haemophilia Foundation Australia
Capital Territory
Oliver Hegener
Hemophilia Association of Davao, Inc.
Hemophilia Association of the Capital Area
Peter Jones
Michael King
James Marshall
Sally K. McAlister
Elizabeth Myles
Ellis Neufeld
Österreichischen Hämophilie Gesellschaft (Austria)*
Kathleen Pratt
Amy and Allen Renz
Bruce Ritchie
The Schnabel Family
Dolly Shinhat-Ross
Jerome Teitel
UK Haemophilia Society*
3 anonymous donors

Gifts of \$100 – \$249

Megan and Thomas Adediran
Antonio J. Almeida
Neva L. Anderson
Paula Bell
Anacleto R. Benito



David Blanchard
 John Button
 Rob Christie
 Antonietta Colavita
 George J. Cornett
 Randall Curtis
 Francine Décary
 Donna and William Dible
 Dan Doran
 Janel W. Feierabend
 Jeanne Fellows
 Fondazione Angelo Bianchi Bonomi
 Elena Galstian
 Cesar Garrido and Antonia Luque
 de Garrido
 Joan C. Gill
 Sally and Gary Griffiths
 Haemophilia Foundation Victoria
 HAPLOS – Hemophilia Association
 of the Philippines for Love*
 Hemophilia of South Carolina
 M. Silvija and Roger Hoag
 Caroline and Pete Hultgren
 Scott S. Johnson
 Carol K. Kasper and Howard Winet
 Bonnie Kho
 Steve Kitchen
 Allan Kucab
 Dana Kuhn
 Roshni Kulkarni
 Blandine Lacroix
 Jeanne Lusher
 Hélène Lussier
 Michael Makris
 Maria Manahan
 Shelly A. Mattson
 George D. McCoy
 Craig T. McEwen
 Paul E. Monahan
 The Netherlands Haemophilia Society*
 M.R. Nijziel
 Yasuharu Nishida
 Leslie C. Oygar
 Debbie Porter
 Greg Price
 Lisa Sorkin Rabin

Marlene Ranz
 Carlos Safadi Márquez
 Elianna Saidenberg
 Emily and Mark Schmidt
 Jack and Ann Schnabel
 Claudia Schoenig-Diesing
 Janet Sloan
 Sydney Smidt
 Marlene Spencer
 Alok Srivastava
 Candace Terpstra
 Christine Thomas
 Karen Wenderoff
 Pamela and Brock Wilton
 Michelle Witkop
 Deon York
 Paula Zeff
 8 anonymous donors

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

Sustaining members active in 2013

Syed Ali
 Abdul Kareem M. Al Momen
 Kagehiro Amano
 Ana Antun
 Raul Aurelio Bordone
 Omolade Awodu
 Gary M. Benson
 Per Arne Berg
 Val D. Bias
 Paula H. Bolton-Maggs
 Ute Braun
 Andrew Brewer
 Jens C. Bungardt
 Lynne Capretto
 Robert T. Card
 Shannon Carpenter
 Marcus Carr
 Frédérica Y. Cassis
 Hervé Chambost
 Pratima Chowdary
 Patrick Crowley
 Randall Curtis
 Piet de Kleijn
 Aisha Fakeir

Emmanuel Favaloro
 Karin Fijnvandraat
 Katsuyuki Fukutake
 Joanne Galati P.T.
 Joan C. Gill
 Nicholas Goddard
 Suzi Greer
 Khalilullah Hamdard
 Mohamed Aris Hashim
 Harriët Heijboer
 Michael Heim
 Tanya Hill
 Ron Hoffman
 Shannon Jackson
 Kim Jacobsen
 Paula James
 Susan Karp
 Carol K. Kasper
 Nigel S. Key
 Soon Ki Kim
 Marion A. Koerper
 Lily Kong
 Barbara A. Konkle
 Peter Kouides
 Vincent La Terza
 Adrienne Lee
 Georg Lemm
 Silvia Linari
 Catherine Manno
 Prasad Mathew
 Tadashi Matsushita
 Eveline Pauline Mauser-Bunschoten
 Simon McRae
 Karla Bayer Mendonca
 Richard J. Metz
 Paul E. Monahan
 Paul Moorehead
 Massimo Morfini
 Otieno Walter Mwanda
 Sukesh C. Nair
 Lochana Nanayakkara
 Daniela Neme
 Yasuharu Nishida
 Beatrice Nolan
 Declan Noone
 Niamh O'Connell

David Oleson
 Sandra C. Oliveira
 Galafteon G. Oltean
 David Page
 Elizabeth A. Paradis
 Gianluigi Pasta
 Martine Pennetier
 Lydia Pitcher
 Jerry S. Powell
 Bruce Ritchie
 Rajiv K. Pruthi
 Michael Heim
 Patrick L. Robert
 Timothy Ross
 Susan J. Russell
 Maria Serena Russo
 Lisa Sackuvich
 Rahajuningsih D. Setiabudy
 Dolly Shinhat-Ross
 Chantakorn Shutidamrong
 Mark W. Skinner
 Pier Luigi Solimeno
 Jean St-Louis
 Jayson Stoffman
 Eric E. Stolte
 Anthony Stowers
 Srilatha Tangada
 Arthur R. Thompson
 Prasanna Kumar
 Thummanahalli Subbanna
 Karen Tubridy
 Leonard A. Valentino
 Marijke van den Berg
 Elaine Warner
 Wing Yen Wong
 Hassan M. Yaish

Sustaining memberships include a donation to the WFH in addition to regular membership fees.

GOVERNANCE & EXECUTIVE COMMITTEE

1 EX-OFFICIO MEMBER
 John E. Bourнас, CEO/
 Executive Director
 2012-present

2 VICE-PRESIDENT FINANCE
 Eric Stolte

3 MEMBER
 Marijke van den Berg, MD

4 VICE-PRESIDENT PROGRAMS
 Nigel S. Key, MD

5 VICE-PRESIDENT NMO
 Aris Hashim

6 MEMBER
 Pamela Wilton

7 VICE-PRESIDENT
 COMMUNICATIONS &
 PUBLIC POLICY
 Magdy El Ekiaby, MD

8 PRESIDENT
 Alain Weill

9 MEMBER
 Thomas Sannié

10 MEMBER
 Flora Peyvandi, MD

11 VICE-PRESIDENT MEDICAL
 Alok Srivastava, MD

12 MEMBER
 Margaret Castro Ozelo,
 MD

13 MEMBER
 Carlos Safadi Márquez

14 MEMBER
 Deon 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

www.wfh.org