WFH 50 YEARS OF ADVANCING TREATMENT FOR ALL

WORLD FEDERATION OF HEMOPHILIA
Fédération mondiale de l'hémophilie
Federación Mundial de Hemofilia

ANNUAL REPORT 2012

WORLD FEDERATION OF HEMOPHILIA

MESSAGE FROM THE PRESIDENT AND CEO

Alain Weill

John E. Bournas

In 2012, the World Federation of Hemophilia (WFH) achieved some important milestones. Our members elected a new president, we held our most successful World Congress ever, and we entered our 50th year of existence.

The WFH 2012 World Congress in Paris, in July, attracted a record 5,370 participants — a 25 per cent increase over the previous attendance record. With a wonderful locale and a top-notch program, the Congress allowed the WFH to show its best to the world.

While in Paris, we launched our 50th anniversary year and the Close the Gap Campaign, which aims to eliminate the disparity in care between people with a bleeding disorder in developing countries and those in developed countries. The WFH 50th anniversary activities will continue throughout 2013, with videos, articles, and events to mark key moments and milestones in our history. Funds raised by the campaign will contribute to the next decade of WFH development programs, including the support of a new project, entitled the Cornerstone Initiative, which seeks to establish basic care in some of the world's poorest regions.

We also initiated the second decade of the Global Alliance for Progress (GAP) Program. Based on the success of the first decade of GAP, through which more than 50,000 patients with hemophilia were identified, the second decade of GAP aims to identify an additional 50,000 people with inherited bleeding disorders, with 50 per cent of them from the world's most impoverished countries.

As always, empowering patient organization leaders and people with bleeding disorders to be informed, and to have access to the proper care, has been a key focus of the WFH. In 2012, we unveiled a completely redesigned website, which is more accessible and interactive, and we also released the first webcasts of key sessions from Congress. These webcasts use new technologies to improve global access to information and education about bleeding disorders.

Looking forward, the future for the bleeding disorders community looks bright, with many new products and promise for a cure in the near future. We must continue to be vigilant and active to protect and improve treatment for all people with bleeding disorders, while adapting to ongoing global challenges and economic constraints.

To help facilitate research to support new and better treatment options, we announced the new WFH Research Program, which was launched at the WFH 2012 World Congress and will begin in 2013. This program supports clinical research through enhanced data collection and research grants.

The work of the WFH is made possible by the continued support of our corporate partners and donors. We also remain focused on the vital necessity to motivate and train the leaders of tomorrow. With hopes of new treatment products and potential new partners on the horizon, we anticipate a new economic paradigm to emerge, as we proceed on an ambitious course to realize our vision of Treatment for All.

In conclusion, we would like to thank outgoing WFH president, Mark W. Skinner, for his tireless dedication as president over the past eight years. Thanks as well to the outgoing executive committee members for their contributions. These volunteers have played key roles in making the WFH the global leader for the bleeding disorders community. As we mark our 50th year and proceed with the next decade of GAP, we will continue to learn from the past and plan strategically for the future.

Alain Weill
PRESIDENT

John E. Bournas
CEO/EXECUTIVE DIRECTOR

HEALTHCARE DEVELOPMENT PROGRAMS

In 2012, WFH healthcare development programs reached a total of 108 countries worldwide.

Global Alliance for Progress (GAP) Program

In partnership with the World Health Organization (WHO), industry, foundations, and charitable organizations, the WFH works in target countries to close the gap between the number of people born with hemophilia and those who reach adulthood, the gap between the estimated and actual number of people diagnosed with hemophilia, and the gap between treatment needs and treatment availability.

After 10 years of operation, the GAP Program has brought demonstrable change in each of the first 20 countries included in GAP. GAP projects have led to significant and measurable improvements, worldwide, in the management of hemophilia and other bleeding disorders. Over the years, GAP has substantially improved the care-delivery system in many countries, increased the level of government support for hemophilia care, and helped enhance the knowledge and expertise of multidisciplinary teams involved in the treatment of bleeding disorders.

One of the most impressive achievements, in the first decade of the program, has been the significantly improved access and availability of treatment products. Since 2003, GAP countries have reported to the WFH a total cumulative increase of 2.729 billion international units (IU) of clotting factor concentrates.

In 2012, there were GAP projects underway in 12 target countries, including two new GAP projects initiated in Algeria and Morocco. In each of these countries, patient organization representatives and treaters, together with WFH volunteers and staff, worked to establish national hemophilia committees to implement a comprehensive care approach for hemophilia, and to develop national patient registries and treatment protocols.

GAP initiatives, in 2012, helped diagnose and register 3,032 new patients with hemophilia. The WFH also provided specialized training to 774 hemophilia care team members, advocacy and awareness training, and education to 1,217 patients and their families, and general hemophilia education to 355 healthcare professionals.

A memorandum of understanding was signed, in April 2012, with the minister of health in Moldova. It calls for the development and implementation of a national preventive care program for all patients with hemophilia and other bleeding disorders. The health minister also announced that the supply of factor concentrates (factor VIII and, for the first time, factor IX) would reach one IU per capita in 2012.

Country Programs

The WFH actively supported 21 country programs in 2012. In these countries, our volunteers and staff worked to improve the organization of hemophilia care in one or more of the following five major areas: government support, care delivery, medical expertise in diagnosis and treatment, treatment products, and patient organization.

Highlights included:

- The Ministry of Health of Peru made the largest purchase of clotting factor concentrates in their history, which was made possible through concerted efforts by medical professionals, the Peruvian Association of Hemophilia (*Asociación Peruana de la Hemofilia*), and the WFH;
- The decision by the Ministry of Health of Armenia to revise the country's tendering process for clotting factor concentrates, which should lead to the adoption of a law that will permit the purchase of clotting factor concentrates directly from international pharmaceutical companies. The Ministry also expressed interest in creating a National Hemophilia Council;

1. Father and son in Peru.
2. Physiotherapy in the pool in the Kyrgyz Republic.

HEALTHCARE DEVELOPMENT PROGRAMS

- The first ever two-day master class on hemophilia and von Willebrand disease (VWD), held in Hong Kong, which was attended by more than 75 physiotherapists and nurses from Hong Kong, China, Thailand, and Malaysia;
- The review of the tendering process for the purchase of clotting factor concentrates in Algeria, and a commitment by the Ministry of Health to improve care for bleeding disorders in the country, as part of a future GAP project agreement with the WFH;
- The approval by the Ministry of Health in Moldova for the creation of a national patient registry.

Regional Advocacy Initiatives

Two advocacy workshops, organized through the WFH Advocacy in Action Program, were held in 2012. In October, 14 patient representatives from eight African, Middle Eastern, and Caribbean countries gathered in Dubai, United Arab Emirates, for an advocacy training workshop entitled: Working with others, breaking barriers. In December, 20 participants from 10 Asian and Middle Eastern patient organizations met in Kuala Lumpur, Malaysia, for an advocacy training workshop entitled: Making your case – advocating for your needs.

These workshops, tailored to the needs of the participants, provided high-level, hands-on training to help WFH National Member Organizations (NMOs) improve in the following areas: identifying and approaching key stakeholders; making strategic use of traditional and social media; contacting and meeting decision-makers; using and presenting key data; developing and delivering comprehensive advocacy messages; building long-term partnerships and alliances; and raising funds to support advocacy activities. They also helped participants improve their knowledge and skills; to exchange experiences, best-practices, and lessons learned; and develop strategies for the implementation of strategic advocacy projects in their own country. To maintain momentum from the workshops, seven project grants, to assist with the implementation of an effective advocacy activity, were awarded to the following countries: Argentina, Dominican Republic, Egypt, Jordan, Mexico, South Africa, and Sudan.

The first Advocacy Recognition Award was presented to the Hemophilia Federation of the Republic of Mexico (*Federación de Hemofilia de la República Mexicana*), during the WFH 2012 World Congress in Paris. The award was given in recognition of the organization's successful campaign to provide free treatment and care for uninsured children with hemophilia or von Willebrand disease.

Global NMO Training

A total of 103 participants, from 85 countries, took part in a three-day global skills development training workshop that preceded the WFH 2012 World Congress. Participants explored a wide range of topics in interactive workshop sessions, including assessment of hemophilia societies, conflict management, and advocacy strategies. This year, the plenary sessions focused on fundraising and clinical research.

1. Advocacy in Action workshop in Dubai, United Arab Emirates.
2. Examining a patient in Thailand.

HEALTHCARE DEVELOPMENT PROGRAMS

2012

GLOBAL PROGRAM HIGHLIGHTS

GAP AND COUNTRY PROGRAMS

33 countries

NMO SKILLS TRAINING

1 global NMO training workshop

2 advocacy training workshops (Africa, Middle East, and Caribbean; Asia and Middle East)

3 national training workshops

ORGANIZATION AND CENTRE TWINNING

21 centre and **13** organization twins (**34** active twins)

HUMANITARIAN AID DONATIONS

26,761,733 IU

(more than 223 million IU in the past 17 years)

LABORATORY IEQAS

95 labs from **63** countries

MULTIDISCIPLINARY WORKSHOPS AND CONFERENCES

13 workshops (laboratory, physiotherapy, psychosocial, nursing, dental, and musculoskeletal)

9 conferences and symposiums

MEDICAL TRAINING FELLOWSHIPS

35 fellowships

(overall 93% retention in hemophilia care after 5 years)

Humanitarian Aid

The WFH Humanitarian Aid Program channels donations of clotting factor concentrates to treatment centres and NMOs in emerging countries. In 2012, the program helped many people, in urgent need, who live in countries that have limited access to treatment. The WFH sent 26,761,733 IU of clotting factor concentrates, valued at more than US$35.4 million, to 50 countries. Product donations were distributed with the invaluable assistance of Hemophilia of Georgia (U.S.A.), the Irish Haemophilia Society (Ireland), and the Angelo Bianchi Bonomi Hemophilia Treatment Centre in Milan (Italy).

Twinning

The WFH Twinning Program pairs up treatment centres or patient organizations in developing countries with those in developed countries. This program facilitates the transfer of skills to help improve care. The number of twins at the end of 2012 reached a total of 34, with 21 treatment centre twins and 13 organization twins. The WFH supports twins through assessment visits and annual project grants.

In 2012, the Twinning Program, supported more than 130 activities, including numerous medical training workshops, patient education initiatives, diagnostic activities, summer camps, research, and fundraising initiatives. Fourteen emerging twins and four established twins participated in our International External Quality Assessment Scheme.

The 2012 Twins of the Year Award winners were very productive and chosen for their accomplishments in Vietnam. On the treatment centre side, the winners were the National Institute of Hematology and Blood Transfusion (Hanoi, Vietnam) and The Alfred (Melbourne, Australia), selected for outstanding achievements that include the organization of physiotherapy and nursing workshops; a multidisciplinary symposium; a symposium for hematologists and physicians; and the monitoring and coaching of laboratory and nursing personnel.

The Hemophilia Organization Twins of the Year winners were the Vietnam Society for Congenital Bleeding Disorders and the Irish Haemophilia Society, selected for outstanding achievements that include the holding of volunteer development and fundraising workshops; numerous initiatives to assist the development of chapters; revision of governance structures; educational activities about Vietnam with the Irish hemophilia community; advocacy for lower insurance co-payments with government health officials; and the production of a photography book celebrating the partnership.

Laboratory Quality Control

The WFH International External Quality Assessment Scheme (IEQAS) program monitors and improves laboratory performance in hemophilia treatment centres worldwide. Now in its ninth year of operation, the IEQAS program has 95 centres from 63 countries registered. In 2012, 18 new laboratories from emerging countries participated in the program.

Workshops and Conferences

The WFH organized a total of 22 conferences and multidisciplinary workshops in 2012. These gatherings brought together hundreds of members of the global bleeding disorders community, from diverse backgrounds, to exchange ideas on improving treatment and care.

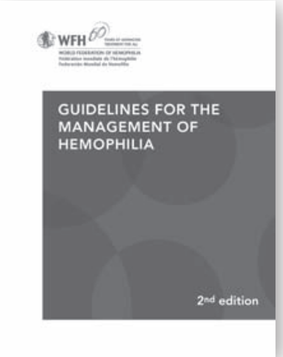
Highlights included:

- A one-day nurses training workshop in Manama, Bahrain, which helped highlight nursing as a major component of the multidisciplinary care approach in hemophilia and other bleeding disorders care, and helped strengthen the knowledge of the 60 participating nurses;
- The organization of a three-day physiotherapy workshop in Cape Town, South Africa, where 16 physiotherapists from different regions of the country received advanced training and agreed, following the training, to establish a physiotherapy network in the country;
- The first national hemophilia symposium held in Romania for hemophilia treatment centres, which discussed the multidisciplinary care approach and the importance of a centralized tender for clotting factor concentrates;
- The organization of a regional multidisciplinary training and outreach project in the region of Trujillo, Peru, which focused on comprehensive care and diagnosis, and led to the establishment of a multidisciplinary team in the main Ministry of Health (MINSA) hospital;
- A two-day laboratory workshop in Bangladesh, which provided invaluable knowledge to eight participants from the three major hospitals in the capital city of Dhaka.

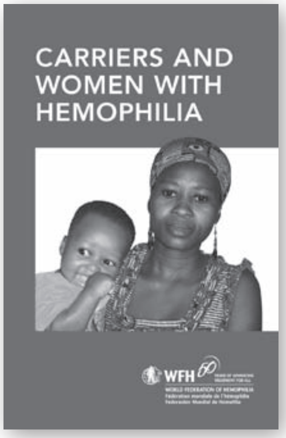
IHTC Fellowships

The WFH awarded 35 healthcare professionals from emerging countries with training fellowships at one of our 28 designated International Hemophilia Training Centres (IHTCs). In 2012, 19 fellows from 18 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.

COMMUNICATIONS AND PUBLIC POLICY


GUIDELINES FOR THE MANAGEMENT OF HEMOPHILIA

2nd edition


CARRIERS AND WOMEN WITH HEMOPHILIA

1. World Hemophilia Day in the Maldives.
2. WFH *Guidelines for the Management of Hemophilia.*
3. *Carriers and Women with Hemophilia.*

In 2012, the WFH made significant progress in increasing engagement and awareness; developing new educational resources; expanding online content with a redesigned website; enhancing global data collection; providing leadership in the establishment of standards of care; and promoting the quality, supply, and safety of treatment products.

Educational Materials/Sharing Information

The WFH produces a wide range of publications and resource materials, on all aspects of hemophilia and other inherited bleeding disorders, to meet the information needs of treaters, NMOs, and people with bleeding disorders. The WFH now has about 300 titles in print, most of which are also available on the WFH website. The publications library was the second most viewed page on the website.

Highlights included:

- Published completely revised and updated edition of the *Guidelines for the Management of Hemophilia*. A full literature review was conducted to support recommendations for clinical practice with the best available evidence. These evidence-based guidelines have also been published in *Haemophilia*, the official journal of the WFH;
- Webcast sessions from the WFH 2012 World Congress;
- *Carriers and Women with Hemophilia,* a new booklet and web section;
- Development and launch of a new publications library on the WFH website.

Raising Awareness

We have been greatly expanded our awareness raising activities to capitalize on social media and online technologies.

World Hemophilia Day (April 17) has become a global opportunity to raise awareness about bleeding disorders. In 2012, the theme was "Close the Gap." There was a 20 per cent increase in Facebook "likes" and the total reach of World Hemophilia Day posts was more than 111,000. From January 31 to June 30, 2012, there were more than 59,000 views of the World Hemophilia Day web section.

50th Anniversary of the WFH

The 50th anniversary of the WFH occurs in 2013, but events began at the WFH 2012 World Congress. Two 50th anniversary videos — entitled *The Winning Coalition* and *Closing the Gap* — premiered at the Congress opening ceremony. Subsequent videos that highlight key moments and programs of the WFH were released throughout 2012, continuing into 2013. Concurrently, *Haemophilia* is publishing a series of commemorative articles on the history of hemophilia and other inherited bleeding disorders. In conjunction with the 50th anniversary commemoration, we updated the WFH branding and developed a 50th anniversary logo.

Website

The WFH website remains an important component for raising awareness and for educating people about bleeding disorders. In June 2012, a fully updated and revised website was launched, with a new website platform, user interface, and content.

The new site includes:

- New navigation and search tools to find information more efficiently;
- User profiles and options to customize content, subscribe to WFH newsletters, and update information;
- Integrated social media, including Facebook, Twitter, and YouTube;
- Improved access to the WFH publications database.

Research

The WFH announced its new Research Program at the WFH 2012 World Congress. The program aims to encourage clinical research and outcomes assessment by providing infrastructure support for clinical investigation of inherited bleeding disorders around the world.

There are two components currently being developed for launch in 2013:

- Enhanced data collection and analysis; and the
- WFH Clinical Research Grant Program.

COMMUNICATIONS AND PUBLIC POLICY

2012

COMMUNICATION AND PUBLIC POLICY HIGHLIGHTS

More than **500,000** print and electronic documents were distributed.

2.8 million website visits.

6,070 followers on FaceBook

16,847 views of WFH videos on the WFH website and on YouTube

268,030 people with bleeding disorders identified worldwide in our *Annual Global Survey 2011*

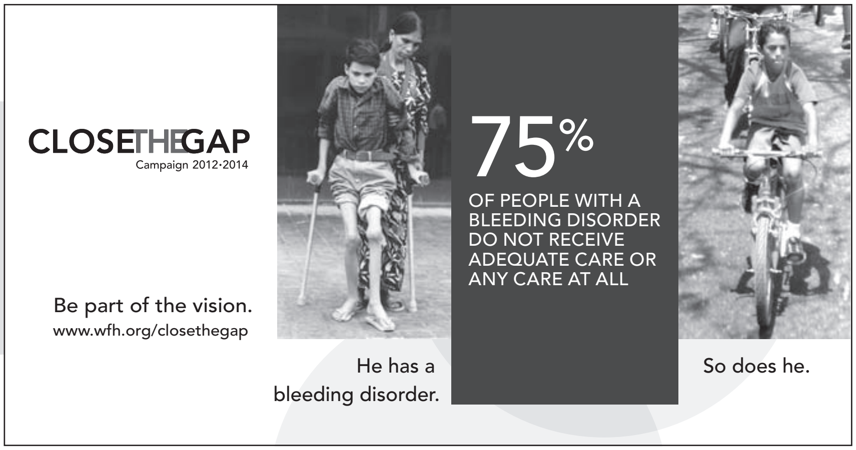
Safety & Supply

The WFH serves as a watchdog on issues of product safety, efficacy, availability, and supply of products for the treatment of people with bleeding disorders. Promoting access to safe and improved treatment and cure-related research is one of the key themes of the strategic plan.

The WFH participated in key initiatives to ensure product safety by participating in the consensus meetings of the plasma users coalition (PLUS), in Dublin, Ireland, in January 2012. The WFH endorsed the coalition's Dublin Consensus statements on plasma collection and the optimization of the supply of plasma medicinal products. In addition, statements were made by the WFH to the U.S. Food and Drug Administration and to the European Medicines Agency on orphan drug designation for hemophilia treatment products.

Data and Demographics

The WFH Global Survey is a key tool for measuring progress by the WFH towards its vision of Treatment for All. In 2012, the WFH released its *Annual Global Survey 2011*, which identified 268,030 people with bleeding disorders in 108 countries, an increase of 10,848 from the previous year.



FUND AND RESOURCE DEVELOPMENT

Gina Schnabel, daughter of WFH founder Frank Schnabel, examining the map of the WFH national member organizations

Corporate support

In 2012, the WFH launched its very first capital campaign, the Close the Gap Campaign, which extends until 2014. The overall campaign goal is US$5 million. A total of US$3.5 million is sought from our corporate partners to support multi-year funding for the second decade of the Global Alliance for Progress (GAP) Program and the WFH Research Program. A total of US$1.5 million is sought from our global community to support the next decade of WFH development programs, including the new Cornerstone Initiative, targeted to those countries and regions of the world where the gap in care is greatest.

More than US$2.5 million of support has been pledged by our corporate partners to GAP and by contributors to the WFH Research Program, representing 72 per cent of the US$3.5 million objective. We are most grateful for these commitments and, in particular, for the leading contribution of the Hemophilia Center of Western Pennsylvania 340B Program for its tremendous support to the WFH Research Program.

Our corporate partners continued to support the WFH global mission beyond GAP and the WFH Research Program, providing core unrestricted funding for WFH programs and activities. In 2012, annual unrestricted funding grew by 15 per cent from Can$1.293 million to Can$1.489 million. We are very grateful for this dedication to our cause and for the assurance of confidence in and sustainability of our programs.

Humanitarian aid donations of treatment products were received from several partners including Baxter, Bayer, Biotest, CSL Behring, CSL Bioplasma, LFB, Novo Nordisk, and Pfizer. A total of 26,761,733 international units of treatment products were distributed to 50 countries, providing support for development programs and vital assistance for urgent needs. In addition, we are grateful to LFB Biomedicaments, Octapharma France, and Novo Nordisk for donations of treatment products for the Treatment Room at Congress.

FUND AND RESOURCE DEVELOPMENT

1. Solange Sakr with WFH patron Jan Willem André de la Porte at the WFH 2012 World Congress.
2. Aris Hashim, vice-president NMO and chair of the WFH awards committee (left), with Martha Patricia Monteros Rincón (centre) and Carlos Gaitán Fitch (right)

2012
WFH VOLUNTEER AWARDS CEREMONY RECIPIENTS

Inga Marie Nilsson Award
- Alok Srivastava, India

Musculoskeletal Awards
- Henri Horoszowski Award: Horacio Caviglia, Argentina
- Pietrogrande Prize: Piet de Kleijn, the Netherlands

Hemophilia Treatment Centre Twins of the Year Awards
- Delhi (India) – Winnipeg (Canada) (2010)
- Yaoundé (Cameroon) – Geneva (Switzerland) (2010)
- Manado (Indonesia) – Utrecht (the Netherlands) (2011)

Hemophilia Organization Twins of the Year Awards
- Tunisia – Quebec, Canada (2010)
- Cambodia – New Zealand (2011)

Susan Skinner Memorial Fund Scholarships (WFH USA)
- Alexandra Johnson – U.S.A. (2011)
- Aleksandra Ilijin – Serbia (2012)

Advocacy Recognition Award
- Federación de Hemofilia de la República Mexicana

WFH Young Researcher Award
- Benjamin Bluth
- Corien Eckhardt
- Samantha Gouw
- Perrine Limperg
- James Porter

Christine Lee Haemophilia Journal Award (induction)
- First recipient announced in 2013

Lifetime Achievement Award
- Christine A. Lee

International Healthcare Volunteer Award
- Piet de Kleijn, the Netherlands

International Frank Schnabel Volunteer Award
- Martha Patricia Monteros Rincón, Mexico

Community giving

In 2012, our community pledged almost $1.4 million dollars, representing 93 per cent of the global community campaign objective. WFH patron, Jan Willem André de la Porte, led the way with his personal pledge to match donations in the public phase of the campaign, two to one, up to US$500,000. The WFH leadership, including all members of the WFH Executive Committee, the WFH USA Board, the WFH Medical Advisory Board, and the Fund and Resource Development Committee set an outstanding example by achieving 100 per cent participation before the public launch of the campaign in July. WFH staff also joined enthusiastically in the campaign; 19 staff members were inspired to partner financially, as well as professionally, with the WFH to make a pledge or give a gift in 2012.

A very special appeal, prior to the launch of the public campaign, was addressed to the 12 national member organizations (NMO) that were present in Copenhagen at the founding of the WFH in 1963. All 12 members came forward to pledge more than US$340,000 toward the Cornerstone Initiative. We take this opportunity to acknowledge their outstanding and historic commitment: Argentina, Australia, Belgium, Canada, Denmark, France, Germany, Japan, the Netherlands, Sweden, United Kingdom, and the United States.

We are proud to report that each year more of our NMOs are partnering with us financially, and this continued in 2012, inspired by the message of solidarity of the Close the Gap Campaign. In 2012, 26 NMOs (in addition to those first 12) participated proudly to "pay forward" the assistance they have received from the WFH and to share with neighbours near and far the joy of both giving and receiving. This compares to six NMOs that made a donation in 2011. All of us here at the WFH are humbled by this caring global action. The National Hemophilia Foundation (U.S.A.) went one step further and pledged to match donations by its chapters, resulting in more than US$24,000 in contributions from US chapters.

In total, more than 500 of you, from 65 countries, donated more than US$413,000 in 2012 in response to the Congress launch, personal appeals, World Hemophilia Day fundraising activities, holding a Global Feast or taking a Sustaining Membership. The Congress launch inspired an outpouring of support from delegates totaling more than US$34,150 in pledges and gifts committed in Paris – a 188 per cent increase over the 2010 Congress appeal. In 2012, 548 of you joined the WFH or renewed your WFH memberships, 29 per cent more than in 2011, expanding the growing network that supports WFH programs around the world. Your membership fees totaled US$34,750 as compared to US$24,750 in 2011, a 40 per cent increase.

In total, US$44,730 was donated toward the Susan Skinner Memorial Fund, bringing this leadership development fund for women to US$201,385 by year-end. Recipients of the scholarship, Aleksandra Illijin, of Serbia, and Alexandra Johnson, of the U.S.A., attended the WFH Global NMO training, the WFH 2012 World Congress, and the WFH General Assembly, last July, in Paris.

All your contributions provided practical support, education, training, and humanitarian aid to the thousands who live where the gap in care is a painful daily reality. We thank every single one of you who pledged or contributed, with such generous hearts, to our shared vision and to helping to close the gap in care. Please read more about how your 2012 donations made a difference in 108 countries in the Programs and the Communications and Public Policy reports on pages 3–7, respectively, of this Annual Report.

Thank you again. Every gift helps to Close the Gap.

For a complete list of all 2012 donors of $100 or more, please see our donor recognition page on the back cover of this Annual Report. For a complete list of all pledges and gifts, received in 2012 toward the Close the Gap campaign, please visit www.wfh.org/closethegap.

To make a donation, become a WFH member, renew your membership, or give a gift of membership, please visit www.wfh.org. Monthly giving: a modest monthly donation quickly adds up to make a significant impact.

CONGRESS AND MEETINGS

2012

WORLD CONGRESS HIGHLIGHTS

Launch of the WFH 50th anniversary and Close the Gap campaign

Historic record attendance of **5,370** participants

25% increase in attendance from 2010

130 countries represented

793 poster abstracts displayed

237 speakers at **68** sessions

197 visits from **49** countries to the treatment rooms in Paris

The WFH received donations of **670,000** IU and **126 mg** of clotting factor concentrates donated by corporate sponsors for the treatment rooms.

The WFH 2012 World Congress, held from July 8–12, 2012, in Paris, France, marked the 30th WFH World Congress, the launch of the Close the Gap campaign, and of the 50th anniversary of the WFH.

For the second time in the "City of Light," since 1965, the XXX International Congress of the World Federation of Hemophilia attracted a record attendance of 5,370 participants, a 25 per cent increase over the Hemophilia 2010 World Congress in Buenos Aires, making it the largest international scientific meeting of the global bleeding disorders community in history. Attendees came from 130 countries and included hematologists, pediatricians, orthopedic surgeons, physiotherapists, physiatrists, dentists, nurses, social workers, psychologists, geneticists, laboratory technicians, researchers, scientists, representatives of WFH NMOs, patient leaders, and their families. During the five-day event, leading experts from around the world presented the latest scientific and clinical developments in diagnostics, disease management and research, as well as emerging topics related to the multidisciplinary approach to improve the lives of men and women living with a bleeding disorder.

The WFH 2012 World Congress was officially opened by Norbert Ferré, Congress president and president of the French Hemophilia Society (*Association française des hémophiles*), along with Edmond Luc Henry, honorary Congress president, and Mark W. Skinner, WFH president, during a ceremony in the Grand Amphitheatre of the Palais des congrès de Paris.

The Congress Program was carefully developed to ensure maximum participation from all disciplines. Prior to the opening ceremony on Sunday, July 8, nine professional development workshops dealt with issues in nursing, psychosocial work, orthopedics, physiotherapy, laboratory science, and gene therapy. Other workshops addressed women and bleeding disorders, publishing, and clinical research.

During the plenary lectures, which highlighted the history of hemophilia and inherited bleeding disorders, tribute was paid to the many people in our community, both past and present, who have strived to improve treatment and care throughout the world. In his opening plenary, outgoing WFH president Skinner challenged the bleeding disorders community to rethink current definitions of optimal care and to adopt a new 21st century business model to improve affordability.

The WFH 2012 World Congress featured a diverse and cutting-edge medical and multidisciplinary program. Leading international experts presented new scientific research and clinical trials profiling future advances in treatment products and clinical care, including new approaches to the management of hepatitis C, personalized prophylaxis, and the use of long-acting products versus gene transfer. The multidisciplinary program covered topics on family perspectives and support, psychosocial models in hemophilia, ageing with hemophilia, and women with inherited bleeding disorders, just to name a few. This year, more than ever, all sessions were very well attended and there was steady traffic through the exhibition areas. The 793 poster abstracts displayed at the Congress included 13 late-breaking abstracts about novel and ongoing research. Following the Congress, webcasts of selected sessions became available on the WFH website.

On July 12, 2012, the WFH held an awards ceremony honouring WFH volunteers for their outstanding contributions. The following day, the WFH General Assembly selected, for the first time in advance, the congress destinations for two future WFH World Congresses: Miami, U.S.A., for 2016, and Glasgow, U.K., for 2018.

Haemophilia Foundation Australia (HFA), host of the XXXI International World Congress of the World Federation of Hemophilia in Melbourne, Australia, from May 11-15, 2014, kicked off the first promotion of the next congress with a booth at the exhibition in Paris.

1. WFH 2012 World Congress volunteers.
2. WFH president (2004–2012) Mark W. Skinner speaking to Congress delegates.

2012 FINANCIAL REPORT

The WFH 2012 World Congress in Paris significantly contributed to providing the WFH with a solid financial outcome in 2012. The Congress generated a surplus of approximately Can$400,000 more than what had been budgeted. This success allowed the WFH to meet its financial objective of a positive net result over a two-year cycle.

The WFH adopted, in 2012, the new Canadian accounting standards for not-for-profit organizations. In accordance with the transitional provisions, we had to apply the changes retrospectively by restating our 2011 financial results. These new accounting standards only have an impact on the way we report the Congress expenses, not on the actual financial position of the WFH. Congress expenses incurred in 2011, which had previously been deferred to 2012, are now recognized in 2011. As a result, we now show in our financial statements a larger deficit in 2011 and, inversely, a greater surplus in 2012; the net result over the two years remains the same as it would have been in the former system. However, this demonstrates just how important Congress revenues are in meeting our financial needs.

The year 2012 was also the year in which the 50th anniversary campaign revenues and expenses were reported, since all revenues and expenses from previous years had been deferred to 2012. Revenues obtained through the 50th anniversary corporate campaign totaled Can$479,721 by the end of 2012. An additional Can$75,000 will be recorded in 2013, which will bring the total amount raised to Can$554,721, compared to a corporate campaign objective of Can$559,000.

As shown in Figure 1 below, excluding product donations, the corporate campaign for the 50th anniversary generated three per cent of WFH revenues in combined years 2011 and 2012.

The financial support from our corporate partners, including the 50th anniversary campaign, represents 40 per cent of our revenues. Over the past two years, the other 60 per cent of revenues was obtained through donations, income-generating activities, and mainly through the revenues generated by the WFH 2012 World Congress.

Congress not only represents the most important part of revenues, it also represents, as seen in Figure 2, the largest proportion of expenses with 44 per cent of the expenses incurred over the past two years. Healthcare expenses (programs, educational resources, and safety and supply) represent a total of 38 per cent. The 50th anniversary expenses, which began in 2010 and which were deferred to 2012, represent three per cent of the WFH expenses, while 12 per cent of our financial resources are spent for administration and fundraising with another three per cent used for democratic functions.

Consistent with the new accounting rules, year 2011 has been restated by listing congress expenses, incurred in 2011, in that year, instead of deferring them to 2012. As a result, the WFH net surplus in 2012, which would have been of Can$671,142 under the previous accounting method, is now Can$1,424,522 (see Figure 3). As mentioned above, the 2011 deficit was, however, increased by an equivalent amount, such that the end result remained the same over the two-year cycle.

In Figure 3 below, a comparison is presented between year 2012 and 2011. On the revenue side, in addition to corporate campaign revenue, we are pleased to see growing support, over the previous year, from our corporate partners. Self-generated revenue includes income received mainly from events, other than the Congress, which occurred in 2011, such as the 12th International Musculoskeletal Congress and the WFH Global Forum. On the expense side, program costs were higher in 2011 because Can$300,000 of expenses for the musculoskeletal Congress were reported in that year. Similarly, under safety and supply, the Global Forum increased 2011 expenses by more than Can$150,000. Fluctuations in foreign exchange rates have had almost no impact on expenses over the two-year period reported. In 2012, through its Humanitarian Aid Program, the WFH sent a total of 26,761,733 IU of clotting factor concentrates, valued at more than US$35.4 million, to 50 countries. Most of these donations are now reported in the audited financial statements of our affiliated organization WFH USA, so the amount reported in the financial statements of WFH, recorded as both a revenue item and an expense, have decreased from Can$4,396,575, in 2011, to Can$1,075,411, in 2012.

Overall, with a very good financial result for 2012, the WFH continues its admirable support for the inherited bleeding disorders community. The outlook for future years is reassuring. But we must continue to ensure strong Congress surpluses and keep on improving our diversification of revenues.

The complete 2012 audited financial statements are available at www.wfh.org.

Eric Stolte

Eric Stolte
WFH VICE-PRESIDENT FINANCE

FIG. 3: REVENUES AND EXPENSES
(expressed in Canadian dollars)

REVENUES	**2012**	**2011**
Donations	329,444	327,216
Corporate Partner Donations	1,489,111	1,293,761
Corporate Sponsorship	1,933,716	2,063,299
Corporate Campaign for the 50th	479,721	0
NMO Assessments	81,193	82,060
Self-generated Revenue (non-congress)	196,722	492,582
Congress Revenue	9,571,005	0
Product Donations	1,075,411	4,163,043
TOTAL REVENUES	15,156,323	8,421,961
EXPENSES	**2012**	**2011**
Programs	2,227,853	2,337,722
Educational Resources	799,515	758,675
Safety & Supply	204,930	391,414
Congress expenses	7,200,835	646,173
Democratic Functions	239,249	222,058
50th anniversary	604,959	0
Administration and Fundraising	1,201,306	923,841
Fluctuation of Foreign Exchange	84,324	−78,860
Product donations	1,168,830	4,396,575
TOTAL EXPENSES	13,731,801	9,597,598
EXCESS (DEFICIENCY)	1,424,522	−1,175,637

FIG. 1: REVENUES 2011 AND 2012
(Excluding product donations)

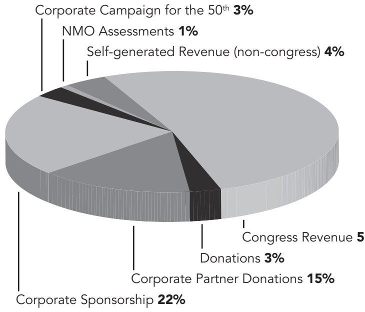
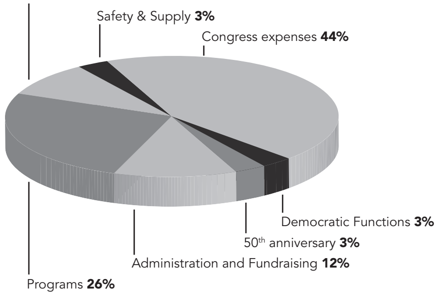


FIG. 2: EXPENSES 2011 AND 2012
(Excluding product donations)



OUR PARTNERS

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 these partners and volunteers to help bring our shared vision to life.

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.

National Member Organizations (NMOs)

One hundred and twenty-two hemophilia associations from around the world are accredited as 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.

Volunteers

To carry out our extensive global activities, the WFH relies on hundreds of volunteers. They include doctors, nurses, people with hemophilia and related bleeding disorders and their families, laboratory specialists, orthopedists, physiotherapists, scientists, dentists, psychosocial workers, and members of patient organizations. WFH volunteers generously donate their valuable time and expertise for activities such as twinning projects, training workshops, country and assessment visits, strategic planning, and producing publications, to name just a few. The combined contribution of volunteers' time to WFH programs and activities in 2012 is estimated to be Can$3,630,425 million in cost of time spent.

On behalf of the global bleeding disorders community, thank you.

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WFH 50 YEARS OF ADVANCING TREATMENT FOR ALL
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WFH CONTACT INFORMATION

1425, boul. René-Lévesque Ouest
Bureau 1010
Montréal, Québec H3G 1T7
Canada

Tel: +1 (514) 875-7944
Fax: +1 (514) 875-8916
E-mail: wfh@wfh.org
Website: www.wfh.org

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 2012, the following individuals, corporations and organizations made financial contributions of US$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
Inspiration Biopharmaceuticals
Kedrion
LFB
Novo Nordisk
Octapharma
Pfizer
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LFB
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Pfizer
Sanquin

Specific Sponsorships

Baxter: Advocacy in Action, World Hemophilia Day
Bayer: IHTC Fellowship Program, WFH website, World Hemophilia Day
Biogen Idec Hemophilia: HTC Passport Web Directory, Medical Advisory Board e-newsletter, World Hemophilia Day
CSL Behring: World Hemophilia Day, von Willebrand Disease web section
Grifols: Online Laboratory Manual, Inhibitor web section, von Willebrand Disease web section
Inspiration Biopharmaceuticals: World Hemophilia Day
Novo Nordisk: HemoAction e-games, Inhibitors web section, World Hemophilia Day
Octapharma: Inga Maria Nillson Award, von Willebrand Disease web section
Pfizer: Twinning Program

Other Sponsorships

IEQAS PROGRAM
Novo Nordisk Hemophilia Foundation

WFH Research Program

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

Humanitarian Aid Product Donations

Baxter
Bayer
CSL Behring
Pfizer

Other Product Donations

LFB Biomedicaments
Octapharma France
Novo Nordisk

Solidarity Fund Contributors in 2012

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

Asociación Costarricense de Hemofilia
Asociación Venezolana para la Hemofilia
Association française des hémophiles
Association luxembourgeoise des hémophiles
Belgian Haemophilia Society
Canadian Hemophilia Society
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Serbian Hemophilia Society
Singapore Haemophilia Society
South African Haemophilia Foundation
Swedish Hemophilia Society (FBIS)
Swiss Hemophilia Association

Memorial Funds

Susan Skinner Memorial Fund

Tributes

In honour of Andy Blackledge
In honour of Cahroon Ehterami
In honour of Julie Heinrich
In honour of Elyse Post
In memory of Adriana Bida
In memory of Peter Campbell
In memory of Michael Davenport Sr.
In memory of Mathew Kleiner
In memory of Marjorie McBeth
In memory of Kathleen Rose
In memory of Frank Schnabel

DONORS

Gifts of $75,000 and over

Hemophilia Center of Western Pennsylvania 340B Program

Gifts of $50,000 - $74,999

André de la Porte Family Foundation
Novo Nordisk Haemophilia Foundation

Gifts of $25,000 - $49,999

Association française des hémophiles*
National Hemophilia Foundation (U.S.A.)*
World Federation of Hemophilia USA

Gifts of $10,000 - $24,999

Bayer HealthCare
Biogen Idec Hemophilia
Canadian Hemophilia Society*
ConocoPhillips Company
Haemophilia Foundation Australia*
Hemophilia Alliance
Hemophilia of Georgia, Inc.
Irish Haemophilia Society Ltd.*
Scott and Kim Martin
The Skinner Family
One anonymous donor

Gifts of $5,000 - $9,999

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Delaware Valley Chapter
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Swiss Hemophilia Association*
John R. Taylor

Gifts of $2,500 - $4,999

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Haemophilia Foundation of New Zealand*
Netherlands Haemophilia Society*
Adam Newsome
One anonymous donor

Gifts of $1,000 - $2,499

340B Factor Program at Akron Children's HTC
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Paula and Benjamin Bolton-Maggs
John E. Bournas
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Cheryl and Tony D'Ambrosio
Fundación de la Hemofilia (Argentina)*
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Eric and Marion Stolte

Gifts of $250 - $499

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Orthopaedic Hospital of Los Angeles
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Alison M. Street
Jerome Teitel
UK Haemophilia Society*
Barbara and Gerard Volk
Alain Weill
Mary Q. Wingate
Karen Wulff
Yongqiang Zhao
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Gifts of $100 - $249

A. Bianchi Bonomi Hemophilia and Thrombosis Centre
Aiki Informatique
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Thomas Becker
Paula Bell
Barbara Bianchi Bonomi
David Blanchard
Rémi Boyer
Jim and Margie Braden
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Emory/CHOA Comprehensive Hemophilia Clinic
Fondazione Angelo Bianchi Bonomi
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Cesar Garrido
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**The WFH is proud to acknowledge the support of our national member organizations.*

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

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