

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



WORLD FEDERATION OF HEMOPHILIA

### MESSAGE FROM THE PRESIDENT AND THE CEO



Since Frank Schnabel founded the World Federation of Hemophilia (WFH) in 1963, it has grown from a small, volunteer-run organization to become the global leader for the inherited bleeding disorders community. Every year, we move closer to achieving our vision of Treatment for All, and in 2011, we made significant progress towards achieving that goal.



After 15 years with the WFH, Claudia Black stepped down as Executive Director/CEO of the WFH. Her leadership and vision were instrumental in transforming the WFH into a truly global organization. While Claudia's departure closes a chapter of our history, we are pleased to open a new one with John E. Bournas joining the WFH team as CEO/ Executive Director. John brings over 15 years of senior managerial experience in the healthcare and not-for-profit sectors, as well as international experience as a diplomat. He also brings a unique combination of skills and an international perspective that will be integral to achieving our strategic goals for the coming years.

Over the past five decades of the WFH's history, there has been tremendous progress in our understanding of bleeding disorders, improvement of treatment, enhancement of access, and bringing hope to patients and their families throughout the world.

One of the keys to WFH's success has been the rigorous strategic planning that takes place every five years, which is reviewed annually, to identify and assess the challenges on the horizon and develop a planned course of action to further our vision and goals. We were gratified and humbled by the feedback that our stakeholders have provided as part of this planning process. Since 2005, the percentage of survey respondents agreeing that the WFH is successful in pursuing its mission has reached 99 per cent. Those that strongly agree with this statement have increased from 34 per cent to 56 per cent. In addition, 100 per cent of respondents indicated that the WFH is a credible organization, with 81 per cent of respondents agreeing strongly – an increase from the previous 66 per cent. Thank you for the confidence and trust you have placed in us. Without the collective support of our entire global family, none of what we have achieved together would have been possible.

In 2011, we completed our 2009-2011 strategic plan, and we are pleased to report that 88 per cent of objectives were achieved or significantly advanced.

Our first theme, to improve treatment in emerging countries, has been achieved through our various program tools, including our Global Alliance for Progress (GAP) Program, Country Programs, the Twinning Program, and the Humanitarian Aid Program. Today, governments are taking more responsibility, more people are diagnosed (over 43,000 between 2009 and 2011), and more clotting factor concentrates are being purchased (between 2009 and 2011, total reported annual global consumption of the factor VIII and IX increased by 1,151,283,879 IU).

Another key theme and core area of our work is sharing knowledge and building capacity through information exchange and training. Over the course of the strategic plan, we greatly expanded our advocacy training program with the launch in 2010 of the Advocacy in Action Program. In 2011, three workshops and five advocacy grants were established. We have made great inroads in using web-based technology to enhance our resources and awareness-raising strategies. Throughout 2011, we have capitalized on the gains we have made in increasing our social media community presence. This has allowed for a greater reach in the promotion of our programs and campaigns.

Promoting access to safe and improved treatment products and cure-related research is another key strategic area. In 2011, the WFH launched its first Global Research Forum, bringing together researchers, clinicians, industry, regulators, and patients for the first time to define and debate the most pressing research questions affecting the bleeding disorders community. Based on the positive feedback from that meeting, the WFH is developing a research program to promote and provide training for clinicians in good clinical practice.

Finally, financially, our strategic goal has been to expand and diversify our financial base. In spite of a global economic downturn, the WFH has continued to increase/maintain its revenues, and is developing its first fundraising campaign to be launched in 2012 for the WFH's 50<sup>th</sup> anniversary. The WFH continues to be financially stable through the concerted efforts of long-range planning, control of expenses, and diversification of revenue sources.

All of this could not have been achieved without the support of our staff, volunteers, donors, and partners. Together, each day we are moving one step closer to Close the Gap in care and to achieve treatment for all people with bleeding disorders, wherever they live. Thank you for your support.

Mark W. Skinner PRESIDENT

John E. Bournas CEO/EXECUTIVE DIRECTOR

### HEALTHCARE DEVELOPMENT PROGRAMS



1. Nurses' Training Workshop in Moldova.

2. Dr. Man-Chiu Poon (left) with a young boy with hemophilia in Mongolia.

In 2011, WFH healthcare development programs reached a total of 97 countries worldwide.

### Global Alliance for Progress (GAP)

In partnership with the World Health Organization (WHO), industry, foundations, and charitable organizations, the WFH works in target countries. All programs aim 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 the treatment and care needed versus what is available. Now in its ninth year of operation, the GAP Program has been very successful in implementing national programs and brings about significant, sustainable improvements in care.

In 2011, there were GAP projects in 11 targeted countries. In each of these countries, patient organization representatives and healthcare professionals, together with WFH volunteers and staff, worked to establish national hemophilia committees, implemented a comprehensive care approach to hemophilia and developed national patient registries and treatment protocols.

Through the GAP Program, 4,561 new patients with hemophilia were diagnosed and registered in 2011, bringing the total to 23,324 since the start of this program. The WFH also



provided specialized training to 658 hemophilia care team members, advocacy and awareness training, and education to 721 patients and their families, and general hemophilia education to 470 frontline healthcare professionals.

In 2011, GAP projects were initiated in Moldova and South Africa to implement national hemophilia programs and to increase resources for bleeding disorders care. These two countries were chosen to join the program for their strong medical and volunteer cooperation and government commitments to improving care for people with bleeding disorders.

### **Country Programs**

The WFH actively supported 23 country programs in 2011. In these countries, our specialized 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 skills (diagnostic and treatment), treatment products, and patient organization. The WFH Development Model, based on a recognized public healthcare model, is a step-by-step approach designed to maximize the use of existing resources and ensure long-term sustainable development. Highlights include:

• The review of all procedures related to bleeding disorders care in Saudi Arabia and appointment by the Ministry of Health of a committee charged with developing national treatment guidelines;





- 1. A young man in Cuba receiving treatment from humanitarian aid donations.
- 2. Advocacy in Action workshop in Barcelona, Spain.

- The establishment of a hydrotherapy study using physiotherapy in water, in Bishkek, Kyrgyzstan, which can promote comprehensive care and be a safe and effective way to introduce traditional physiotherapy to people with bleeding disorders in regions where factor are not available;
- The large number of participants (over 250) in attendance at the Second National Forum in Japan, in April, which led to interesting discussions on how to manage patient needs, especially those with disabilities, during a crisis situation, like the devastating earthquake and tsunami in 2011;
- The promotion and support for the implementation of primary prophylaxis and immune tolerance induction for patients in Brazil by the Ministry of Health.

### **Regional Advocacy Initiatives**

Three tailored thematic and geographic workshops of the Advocacy in Action Program were held in 2011. In May, 15 patient representatives from 9 Western and Central European WFH National Member Organizations (NMOs) gathered in Paris, France, for an advocacy training workshop on "Data collection and use in a challenging economic environment", coupled with a "Concepts in factor replacement" course. In November, 16 participants representing 8 Latin American countries met in Mexico City, Mexico, for an advocacy training workshop on "Strategies for better advocacy". Finally, in December, 13 participants representing 10 countries from Africa, the Middle East, and Eastern Europe met in Barcelona, Spain, for a workshop on "Multiplying voices: using partnerships and alliances to advocate with the government". These workshops provided high-level and hands-on training to NMOs, allowing participants to improve their knowledge and skills, to exchange experiences, best practices and lessons learned, and develop strategies for the implementation of strategic advocacy projects/campaigns in their countries. Additionally, to maintain momentum from the workshops, five project grants were awarded to NMOs from Latvia, Romania, Poland, United Kingdom, and Germany for the implementation of priority advocacy projects and campaigns.

#### Humanitarian Aid

The WFH Humanitarian Aid Program channels donations of clotting factor concentrates to treatment centres and NMOs in emerging countries. In 2011, the program helped many people in urgent need, who live in countries that have limited access to treatment. In addition, these donations were utilized to help build sustainable national hemophilia care programs. The WFH donated 32.8 million units of factor, valued at more than US\$49.2 million to 51 countries. Product donations were distributed with the invaluable assistance of Hemophilia of Georgia, U.S.A., and the Angelo Bianchi Bonomi Hemophilia Treatment Centre in Milan, Italy.

#### Twinning

The Organization and Centre Twinning Program pairs treatment centres or patient organizations in developing and developed countries to transfer skills and help improve care. The number of twins at the end of 2011 reached a total of 42, with 24 treatment centre twins and 18 organization twins. The WFH supports twins through assessment visits, coaching, annual payments and project grants.

Activities in 2011 included: 27 medical training workshops, 9 patient outreach activities, 4 youth activities, 8 patient education initiatives, 6 new or ongoing registry activities, 6 organization trainings, 4 lobbying initiatives, 7 provision of medical equipment and supplies, 4 awareness activities, 3 treatment protocols established, 5 provision of educational materials, 3 fundraising activities, and 5 summer camps. Fifteen twins participated in our International External Quality Assessment Scheme (IEQAS).

The 2011 Twins of the Year award winners were chosen based on their many accomplishments. The Hemophilia Treatment Centre Twins of the Year winners were Manado (Indonesia) – Utrecht (Netherlands) and were selected for their outstanding achievements. This included symposium and workshops that improved doctors', physiatrists', physiotherapists', and nurses' knowledge and practical skills with regard to acute joint and muscle bleeds; a one-week training of six physiotherapists to improve knowledge in comprehensive musculoskeletal care; the identification of new patients during a two-day outpatient clinic; a genetic counselling workshop; and a donation of functional equipment such as crutches to facilitate rehabilitation.

The Hemophilia Organization Twins of the Year winners were the Cambodia Haemophilia Association and the Haemophilia Foundation of New Zealand. Their achievements included education workshops on clinical, psychosocial, and patient and family issues in Phnom Penh and Siem Reap; initiating educational activities for children; training for volunteers supporting newly diagnosed patients; the development of relationships with the Ministry of Health and the medical community; and educating Haemophilia Foundation of New Zealand members about living with bleeding disorders in Cambodia through groups, camps, and workshops.

### HEALTHCARE DEVELOPMENT PROGRAMS (CONTINUED)

### Musculoskeletal Congress

The 12<sup>th</sup> WFH Musculoskeletal Congress was held from March 31 – April 3 in Dubai, United Arab Emirates, with a record attendance of 302 participants. Due to unrest in Egypt, the original location for the Congress, WFH staff members worked quickly with the Egyptian Society of Hemophilia (ESH) to relocate to Dubai. In an unprecedented gesture, the ESH redirected its portion of revenue from the Congress to the WFH as a donation. A Pre-Congress Day featured concurrent sessions on orthopedics and rehabilitation. A total of 82 abstracts were submitted, 31 were accepted, and 39 free papers were presented. The WFH sponsored a combined total of 12 physical therapists and orthopedists from developing countries and 4 regional speakers through travel grants.

### Laboratory Quality Control

The WFH International External Quality Assessment Scheme (IEQAS) monitors and improves laboratory performance in hemophilia treatment centres worldwide. Now in its eighth year of operation, the IEQAS program has 84 centres, from 59 countries, registered. In 2011, we added six new laboratories from developing countries to the program.

### Workshops and Conferences

The WFH organized a total of 28 conferences and/or multidisciplinary workshops in 2011. 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 include:

- A regional physiotherapy workshop was held in Nairobi for East African countries (Nigeria, Ghana, Tanzania, Uganda, Ethiopia, Sudan, and Kenya) highlighted physiotherapy as a major component of the multidisciplinary care approach in hemophilia care, which strengthened the knowledge of participating physiotherapists;
- The organization of a two-and-a-half day regional dental workshop in Georgia for dentists, hematologists, and patient leaders from the Caucasus, which emphasized dental care in the comprehensive hemophilia treatment centres services of Baku, (Azerbaijan), Yerevan (Armenia), and Tbilisi (Georgia);
- The first hemophilia symposium held in Santa Cruz, Bolivia, provided over a hundred patients, families, medical professionals, and government representatives with the opportunity to discuss, exchange, and develop their knowledge on comprehensive care;
- A regional musculoskeletal workshop in Belgrade, Serbia, where close to fifty orthopedists, physiotherapists, hematologists, and physiotherapists from the Balkans (Macedonia, Bosnia and Herzegovina, and Montenegro)

received advance training on the referral of patients by the comprehensive care team, arthropathy, synovitis, physiotherapy, and orthopedic preventions; and

• A two-day National Hemophilia and Coagulation Congress in Vietnam provided invaluable knowledge to more than 300 doctors.

### **Medical Fellowships**

The WFH awarded 35 healthcare professionals, from developing countries, with training fellowships at one of our designated International Hemophilia Training Centres (IHTCs). In 2011, 19 fellows, from 16 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.

### 2011 GLOBAL PROGRAM HIGHLIGHTS

GAP AND COUNTRY PROGRAMS: 33 countries

#### NMO SKILLS TRAINING:

3 thematic and regional trainings (Western and Central Europe; Latin America; Africa, Middle East, and Eastern Europe)

6 national trainings

ORGANIZATION AND CENTRE TWINNING: 24 Centre and 18 Organization twins (42 active twins)

HUMANITARIAN AID DONATIONS: 32.8 million IU

(over 196 million IU in the past 16 years)

LABORATORY IEQAS: 84 labs from 59 countries

### MULTIDISCIPLINARY WORKSHOPS AND CONFERENCES:

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

16 conferences and symposiums

MEDICAL TRAINING FELLOWSHIPS: 35 fellowships

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

# COMMUNICATIONS AND PUBLIC POLICY



In 2011, the WFH launched a number of exciting new projects and expanded into new areas.

Our Treatment Guidelines Working Group, led by Dr. Alok Srivastava, completely revised and updated the WFH treatment guidelines, and conducted a full literature review to support recommendations for clinical practice with best available evidence. These will be published in 2012.

Much work was done to capitalize on web and online technologies. In 2011, we launched HemoAction, an online game to teach children about hemophilia and its management, and produced the new online Compendium of Assessment Tools, which brings together all the major functional and physical tools, along with an evaluation of each of the tools. In addition, we have continued to enhance our web-based technology resources to further promote our programs and campaigns through social media and our website. The platform, architecture, and content of the WFH website has been updated and the redesigned site will be launched in 2012.

Fulfilling our strategic objective to assess the WFH's role in research, we held the first Global Research Forum in March, 2011, which brought together representatives from around the world in one place to discuss some of the important research issues regarding inherited bleeding disorders. As a result of the overwhelming success of this meeting, the WFH is moving ahead with planning a research program to encourage and support clinical research and outcomes assessment.

We continue to improve and expand our data collection. In 2011, the Data and Demographics committee members published two papers in *Haemophilia*, the official journal of the WFH, on global prevalence of factor IX and usage of factor IX concentrates. In addition, data on prophylaxis and comparative data on per capita along with per patient usage of clotting factor concentrates were included for the first time in the *Global Survey Report*.

In the area of safety and supply, the 7<sup>th</sup> Global Forum on the Safety and Supply of Treatment Products for Bleeding Disorders was held in September 2011, attracting 116 participants from 35 countries.

On World Hemophilia Day 2011, over 150 people shared their story with the global bleeding disorders community through our Share Your Story discussion forum. The theme was 'Be inspired, Get involved', and we were truly inspired by all the contributions. Our World Hemophilia Day website received over 60,000 page views and patient organizations around the world participated to make this a truly global event.

Finally, in preparation for the WFH's 50<sup>th</sup> anniversary, which will be launched at the WFH 2012 World Congress in Paris, we produced a series of podcast videos to commemorate our 50<sup>th</sup> anniversary and support the Close the Gap campaign.



Celebrating World Hemophilia Day 2011 in Algeria.

### COMMUNICATIONS AND PUBLIC POLICY 2011 HIGHLIGHTS

OVER 600,000 WFH PUBLICATIONS distributed in print and online

**18 NEW PUBLICATIONS IN SIX LANGUAGES** 

1,038,789 WEBSITE VISITS

15% INCREASE IN VISITORS TO THE WEBSITE

4,288 FOLLOWERS ON FACEBOOK

17,482 VIEWS OF VIDEOS FROM WFH WEBSITE AND YOUTUBE

257,182 PEOPLE WITH BLEEDING DISORDERS identified worldwide in our 2010 Annual Global Survey

### CONGRESS AND MEETINGS

# FUND & RESOURCE DEVELOPMENT



Musculoskeletal Congress 2011 in Dubai.

> Capitalizing on the energy and success of the Hemophilia 2010 World Congress in Buenos Aires, Argentina, the Congress and Meetings department was very busy in preparing for the upcoming WFH 2012 World Congress which will take place in Paris, France, from July 8-12, 2012. Attendance for this Congress is expected to surpass all records. Program sessions have been carefully developed to ensure maximum participation from all disciplines. In addition, preparations began to support the launch of the WFH's 50<sup>th</sup> anniversary during the WFH 2012 World Congress.

Two months prior to our 12<sup>th</sup> Musculoskeletal Congress in Cairo, Egypt, we were faced with having to relocate the meeting to Dubai, United Arab Emirates, due to the unrest in Egypt. A seamless transition, involving careful and arduous coordination, proved valuable as we were able to keep the program within the region. Registration for this event was the largest ever.

For the first time in WFH history, we conducted a one-time double bid for our upcoming 2016 and 2018 Congresses in an effort to be able to promote our future Congress dates earlier. We received eight bids from our NMOs. The two finalists for the WFH 2016 World Congress have been selected as Montreal, Canada, and Miami, U.S.A. For 2018, the two finalists that were selected are Glasgow, United Kingdom, and Guadalajara, Mexico. All finalists will present to the NMOs, at the WFH General Assembly in Paris, who will then decide the winners. The WFH would like to extend our thanks for all donations made in 2011. More people gave, more generously, than ever before. This offers hope to the 75 per cent of people with inherited bleeding disorders globally who do not receive adequate treatment, or any treatment at all. Our vision is that all men and women with inherited bleeding disorders will one day have access to treatment, regardless of where they live. We offer our heartfelt gratitude for all contributions that help us work towards achieving Treatment for All.

The WFH leadership, including all members of the WFH Executive Committee, the WFH USA Board, and the WFH Medical Advisory Board, continues to set an outstanding example of donating to the WFH with 100 per cent participation. Furthermore, members of the WFH standing committees are following this lead and contributing financially, in addition to giving their valuable time and effort as volunteers. This is a tremendous inspiration for all. A special thank you is also due to those WFH staff who give over and above their professional commitment, to partner financially with the WFH.

Donations that were raised through our affiliate WFH USA, whose mission is to mobilize support for the WFH's global mission in the United States, yielded significantly increased support from American donors. The following results reflect an integrated report of global giving.

Combined, the overall number of donations in 2011 increased 91 per cent since 2010; from 207 donations to 396. Donation revenues from individuals alone increased from US\$41,369 in 2010 to US\$59,511 in 2011, a 44 per cent increase.

In 2011, 426 individuals joined the WFH or renewed their WFH memberships, expanding the growing network that supports WFH programs around the world. Membership fees, totalling US\$27,592 in 2011, helped support WFH activities in 97 countries last year. Also, 66 per cent more chose to take a Sustaining Membership, making a US\$40 donation in addition to membership fees, immediately increasing the impact of your partnership.

Revenues from foundations and trusts grew significantly in 2011 from US\$50,920 in 2010 to US\$192,719 in 2011, an increase of 278 per cent. We are most grateful to our Patron, Jan Willem André de la Porte, and the Novo Nordisk Haemophilia Foundation for their generous support.

During World Hemophilia Day 2011, 70 individuals celebrated by making a special commemorative donation. Your meaningful gifts amounted to US\$730, a record for the day on which we mark the birthday of our founder, Frank Schnabel. We are proud and pleased to report that each year more of our NMOs are partnering with us financially, spreading hope and encouragement to other members of our global family. In 2011, six NMOs reached out to support others as compared to five in 2010, contributing over US\$58,000. We appreciate these donations especially as we recognize the sacrifice that each NMO makes in order to extend a helping hand to others in our global family. Thank you to the Asociación Venezolana para la Hemofilia, the Canadian Hemophilia Society, the Egyptian Society of Hemophilia, the Haemophilia Foundation of New Zealand, the Irish Haemophilia Society, and the National Hemophilia Foundation (U.S.A.). In addition, NMO chapters are lending their support: seven chapters of the National Hemophilia Foundation and the Hemophilia Society Angamaly Chapter from India all contributed in 2011. Their contributions amounted to US\$17,400.

Corporate partners continued to support our global mission in 2011, providing core funding for WFH programs and activities. There was a five per cent increase over 2010 results, staying slightly ahead of inflation, with 2011 results reaching US\$3.407 million. We are very grateful for this dedication to our cause and the assurance of sustainability for our programs.

Humanitarian aid donations of clotting factor concentrates were received from several partners including Baxter, Bayer, Biotest, CSL Behring, Pfizer UK, and the Government of Taiwan. A total of 32,813,804 international units of clotting factor concentrates were distributed, providing support for development programs and assisting where there were urgent needs. Product donations of recombinant therapy, for the WFH Laboratory Program, were made by Diagnostica Stago, as part of a three-year collaborative agreement with the Haematology and Transfusion Service, Centre Hospitalier et Universitaire in Cameroon.

In total, US\$35,874 was donated toward the Susan Skinner Memorial Fund, helping to bring this leadership development fund for women close to the US\$160,000 mark by year-end.

Thanks to all who partnered financially with the WFH in 2011 through a donation or a WFH membership. Your gifts and memberships are helping to close the gap in care. Read more about the impact of your support throughout this Annual Report.



Your contributions make a world of difference.

Thank you again. For a complete list of all 2011 donors of \$100 or more, please see our donor recognition page on the back cover of this Annual Report.

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. Every gift helps to Close the Gap.

# 2011 FINANCIAL REPORT



The year 2011 in financial terms, while challenging, has been a sound year for WFH.

As shown in Figure 3, contributions of Can\$3,766,336 have increased by \$173,220 over the previous year, with our corporate partners again providing outstanding support. While corporate contributions, received in US dollars, increased by US\$158,700 over 2010, the converted amount in Canadian dollars of those contributions was considerably reduced by the strength of the Canadian dollar.

Through our WFH internal management of events/meetings, self-generated revenues of Can\$492,582 have added to our diversified revenue stream. As shown in Figure 1, excluding product donations, WFH diversified revenues in combined years 2010 and 2011 represent 60 per cent of total revenues.

Overall, product donations from our corporate partners increased again this year. The WFH has recorded Can\$4,163,043, while our affiliate organization WFH USA recorded product donations valued at US\$45,032,499. Clotting factor concentrates were widely distributed as humanitarian aid to those most in need throughout our community and utilized to build sustainable national hemophilia care programs. Expenses reported as humanitarian aid consist of the value of donated product and product transportation costs of Can\$233,532.

Total generated revenue for 2011 was Can\$8,421,961.

Expenditures by our Programs department in healthcare development programs (see Figure 2) grew 2.5 per cent over year 2010.

Communications department expenses have grown by nearly two per cent. Despite a recorded reduction in Educational Resources expenditures, considerable resources were directed to update the WFH website. Expenses related to the new Research Program have been added to Safety and Supply expenditures.

Full staff resourcing of the Fundraising department was completed in 2011, largely contributing to the expenses shown under Administration and Fundraising. The engagement of professional services to codify our legal and administrative relationship with our affiliated organization WFH USA, and the recruitment of our new Executive Director also increased administration expenditures.

Like other international organizations, management of foreign currency exchange is a continuous challenge for the WFH. Our currency management of US dollars to Canadian dollars and the combination of managing the 2012 WFH International Congress in euros has resulted in a gain of Can\$78,860 in 2011.

Consistent with our accounting deferral process, direct costs related to WFH 2012 World Congress and the WFH 50th anniversary have been deferred from the 2011 results to 2012.

Total expenditure of Can\$8,951,426, in 2011, exceeded revenue by Can\$529,465. The year 2011 has been a year of investment in planning for our 50<sup>th</sup> anniversary, and a concerted strategy to not only solidify, but to also grow our funding base over future years.

While the outlook to achieve our budget for 2012 will be challenging, I am optimistic that the WFH 2012 World Congress in Paris, combined with the celebration of our 50<sup>th</sup> anniversary will be highly successful, generating strong revenues for the WFH.

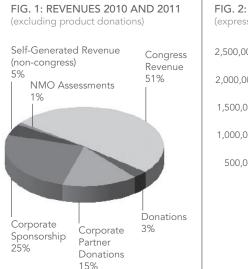
Overall the financial performance for 2011 was ahead of budget, with the WFH continuing to support the inherited bleeding disorders community admirably; we do make a difference to the lives of so many.

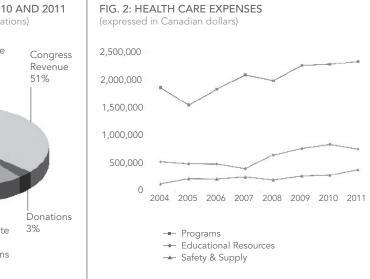
The complete 2011 audited financial statements are available at www.wfh.org.

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Rob Christie VICE-PRESIDENT FINANCE

FIG. 3: REVENUE AND EXPENSES (expressed in Canadian dollars) 2010 REVENUES 2011 3 592 966 Contributions 3 766 336 Congress Revenue 8 383 688 Self-Generated Revenue 492 582 263 824 Product Donations 4 163 043 1 378 118 TOTAL REVENUE 8 421 961 13 618 596 **EXPENSES** Programs 2 337 722 2 281 741 Educational Resources 758 675 839 287 391 414 289 064 Safety and Supply Congress – Expenses 7 478 620 Humanitarian Aid 4 396 575 1 524 840 Democratic Functions 222 058 208 250 Administration and Fundraising 923 841 843 926 Fluctuation of Foreign Exchange 159 201 (78 860) 8 951 425 13 624 929 TOTAL EXPENSES Excess (deficiency) (529 464) (6 333)





# OUR PARTNERS

# EXECUTIVE COMMITTEE 2010-2012

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

One hundred and eighteen hemophilia associations from around the world are accredited as National Member Organizations (NMOs) of the WFH. NMOs represent the interests of people with hemophilia and other inherited bleeding disorders in their country. They are key partners of the WFH, making it a truly international body.

### 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, physical therapists, 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 2011 is estimated to be Can\$3,594,766 million in cost of time spent.

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



PRESIDENT Mark W. Skinner



VICE-PRESIDENT MEDICAL Alison Street, MD



VICE-PRESIDENT FINANCE Rob Christie



VICE-PRESIDENT PROGRAMS Nigel S. Key, MD



VICE-PRESIDENT NMO Aris Hashim



VICE-PRESIDENT COMMUNICATIONS & PUBLIC POLICY Alok Srivastava, MD



MEMBER Paula Bolton-Maggs, MD



MEMBER Magdy El Ekiaby, MD



MEMBER Johnny Mahlangu, MD



MEMBER Carlos Safadi Márquez



MEMBER Thomas Sannié



MEMBER David Silva Gomez



MEMBER Eric Stolte



MEMBER Deon York



EX-OFFICIO MEMBER Claudia Black, CEO/Executive Director 2007-2011



EX-OFFICIO MEMBER John E. Bournas, CEO/Executive Director 2011-present

# 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 2011, 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 BPL Biogen Idec Hemophilia Biotest CSL Behring Green Cross Grifols Inspiration Biopharmaceuticals Kedrion LFB Novo Nordisk Octapharma Pfizer Sanquin Talecris

#### Global Alliance for Progress (GAP) Founding Sponsor

Baxter

Sustaining Sponsors André de la Porte Family Foundation Bayer CSL Behring

Supporting Sponsors Biogen Idec Hemophilia Biotest Grifols Pfizer Talecris

Contributing Sponsor Irish Haemophilia Society\*

Collaborating Partner World Health Organization

#### Specific Sponsorships

Baxter: Advocacy in Action, Global Research Forum, Musculoskeletal Congress, Signature Board at the XXIII ISTH Congress, World Hemophilia Day Bayer: IHTC Fellowship Program, Global Research Forum, WFH website, World Hemophilia Day

Biogen Idec Hemophilia: HTC Passport Web Directory, Global Research Forum, *Medical Advisory Board News*, World Hemophilia Day CSL Behring: Global Research Forum, Musculoskeletal Congress, The Basic Diagnosis and Clinical Management of von Willebrand Disease Treatment of Hemophilia monograph no. 35, von Willebrand disease web section Grifols: Global Research Forum, von Willebrand disease web section LFB: Musculoskeletal Congress, von Willebrand disease Outreach Project, von Willebrand disease web section Novo Nordisk: HemoAction e-games, Inhibitors web section, Global Research Forum, Musculoskeletal Congress, World Hemophilia Day Octapharma: von Willebrand disease web section Pfizer: HemoAction e-games, Twinning program, Musculoskeletal Congress Talecris: Laboratory web section Other Sponsorships

IEQAS Program Novo Nordisk Haemophilia Foundation

Global Forum Héma-Québec Ministère de la Santé et des Services Sociaux Ministère des Relations Internationales du Québec IHTC Fellowship Program

U.S. Centers for Disease Control and Prevention

#### Humanitarian Aid Product Donations

Baxter Bayer Biotest CSL Behring Government of Taiwan Pfizer UK

### Other Product Donations

Diagnostica Stago

### Solidarity Fund Contributors in 2010 and 2011

The Solidarity Fund contributes toward the payment of assessment fees for NMOs from developing countries.

Association Luxembourgeoise des Hémophiles Asociación Venezolana para la Hemofilia Association Française des Hémophiles Belgian Haemophilia Society Canadian Hemophilia Society Croatian Hemophilia Society Fundación Panameña de Hemofilia Haemophilia Foundation Australia Haemophilia Foundation of New Zealand Hemophilia Society of Bangladesh Hemophilia Society of Turkey Icelandic Hemophilia Society Israeli Hemophilia Association (ALEH) Jamaica Hemophilia Committee Jordan Thalessemia and Hemophilia Society

Korea Hemophilia Foundation Latvia Hemophilia Society Lithuania Haemophilia Association Magyar Hemofilia Egyesulet (Hungary) National Center for Blood Diseases "Hippocrates" (Palestine) National Hemophilia Foundation of Thailand Netherlands Haemophilia Society Norwegian Hemophilia Society Österreichischen Hämophilie Gesellschaft (Austria) South African Haemophilia Foundation Sudanese Hemophilia Care Association Swedish Hemophilia Society (FBIS) Swiss Hemophilia Association The Haemophilia Society (U.K.)

### Memorial Funds

Susan Skinner Memorial Fund

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\* The WFH is proud to acknowledge the support of our National Member Organizations.

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