WFH marks 50 Years of Advancing Treatment for All

For 50 years, the World Federation of Hemophilia (WFH) has worked globally to close the gap in care and to achieve treatment for all people, both men and women, with hemophilia and other inherited bleeding disorders, no matter where they live.

/Sarah Ford, WFH communications manager

As the WFH marks its 50th anniversary, our community is reflecting on its many accomplishments, milestones, and lessons learned. Activities are planned throughout 2013 until the WFH 2014 World Congress in Melbourne, Australia.

Tremendous progress has been made over the past 50 years. However, in developing countries, the vast majority of people with bleeding disorders still lack access to proper care. The WFH continues to work to close the gap in care so proper treatment will be available for all around the world.

Join with the WFH in marking 50 Years of Advancing Treatment for All. Visit www.wfh.org/50 for more information.
WORLD HEMOPHILIA DAY 2013
APRIL 17

50 YEARS OF ADVANCING TREATMENT FOR ALL
Join us on Facebook and leave your 50th anniversary messages

WHERE WE HAVE BEEN

WHERE WE WANT TO BE

TOGETHER, WE CAN CLOSE THE GAP

www.wfh.org/whd
Beginnings

“The World Health Organization and the World Federation of Hemophilia have had a long and fruitful relationship since 1969.” — Ana Padilla, World Health Organization

The World Federation of Hemophilia (WFH) was established in 1963 by Frank Schnabel, a Montreal businessman born with severe hemophilia A. His vision, as he stated, was to improve treatment and care for “the hundreds of thousands of haemophiliacs” worldwide through a new international organization.

Working with leaders from a group of national patient associations, Schnabel convened a global meeting in Copenhagen, Denmark, on June 25, 1963. There were representatives from 12 countries: Argentina, Australia, Belgium, Canada, Denmark, France, Germany, Japan, the Netherlands, Sweden, the United Kingdom, and the United States.

Schnabel’s opening words to those assembled still ring true. “The threat to the life of just one haemophiliac would be sufficient reason for us to travel to this meeting. We are here, however, to help the hundreds of thousands of haemophiliacs by adding another organization which can be instrumental, in liaison with national societies.”

At the Copenhagen meeting, Schnabel was elected interim chairman, Henri Chaigneau (France) and John Walsh (U.S.A.) were elected interim vice-chairmen. Interim medical secretaries were Cecil Harris, MD (Canada), E. Neumark, MD (U.K.), and Knut-Eric Sjolin, MD (Denmark). Sir Weldon Dalrymple-Champneys (U.K.), Prof. Kenneth Brinkhous (U.S.A.), and Prof. J.P. Soulier (France) were elected as the interim Medical and Scientific Advisory Board.

At the 1964 WFH meeting in Amsterdam, the Netherlands, the structure of the new organization was defined with a constitution and an elected Executive Committee. Schnabel was re-elected chairman, Harris elected as first vice-chairman, and Chaigneau and Walsh as vice-chairmen. S. van Creveld, MD (the Netherlands), and Brinkhous were elected co-chairmen of the Medical Advisory Board, and Soulier as vice-chairman.

Over the next few years, the WFH grew rapidly. It held World Congresses regularly and created a global network of healthcare providers, national hemophilia associations, people with hemophilia, and their families.

The 1968 WFH Congress was an important milestone. “It was the first major scientific event in the series,” Anthony Britten, MD (U.K.), wrote in a WFH 25th anniversary retrospective. “Cryoprecipitate was clearly a reality. Lyophilized concentrates were increasingly available. Surgery was becoming safe for most hemophiliacs. Carol Kasper reported outpatient dental extractions. This was a time when there seemed to be no limits.”

The WFH reached a turning point in 1969 when the World Health Organization (WHO) acknowledged the WFH’s growing international reputation and established official relations. Chaigneau, the WFH vice-president at the time, along with Soulier, Z.S. Hantchef, MD (Switzerland), and Francois Josso, MD (France), were instrumental in achieving this recognition.
In 1970, the World Federation of Hemophilia (WFH) launched the International Hemophilia Treatment Centre (IHTC) Program, conceived by medical secretary Anthony Britten, MD, a doctor with severe hemophilia. The 18 centres named “would be assuming a responsibility, not receiving an honour,” Britten later wrote. “These centres will bring... inspiration to many, and leadership to all of us.”

In 1972, Pier Mannucci, MD, took over as IHTC chair and the vision for the program became more focused on training. The program was renamed the International Hemophilia Training Centre Program, and its purpose was to offer training fellowships and workshops to medical and paramedical staff for developing countries. In the history of the program, written by Kevin Rickard, MD, (IHTC chair, 1986-1996), he attributes much of the program’s early success to the “enterprising, imaginative, productive, and forceful leadership” of Mannucci, who served as IHTC chair for 14 years (1972-1986).

Through the 1970s, the IHTC Program offered numerous fellowships and workshops to medical professionals from the developing world. Policies on the selection and focus of training were developed and fine-tuned. One of the realizations was that training is most effective when carried out in an environment similar to that of the trainees.

One of the IHTC success stories was in Thailand. The WFH worked with Prof. Parttrapon Isarangkura to promote progress in national hemophilia care. Under her direction, the Bangkok centre became a major venue for training on how to provide maximum treatment benefits with limited resources, and eventually became an IHTC.

Frank Schnabel and his wife Marthe Schnabel, WFH executive director, along with other volunteers, spent much time growing the number of WFH national member organizations, which was done through visits, correspondence, and at international meetings. The Guide for Travelling Hemophiliacs (later to become Passport: Global Treatment Centre Directory) was first published in 1973. It was not a “Michelin Guide,” Schnabel pointed out, but a directory of hemophilia treatment centres, where travellers could find proper care.

For people with hemophilia in developed countries, the 1970s also saw a huge expansion in treatment and the face of hemophilia treatment changed irrevocably. Britten wrote in a 25th anniversary retrospective:

“The 1970s were the decade of concentrates, of growing industrialization. The proliferation of products provided a new opportunity — home treatment — the freedom for a hemophilic family to give infusions...The resulting independence made travel safe and simple. It made daily life possible without the inevitable interruptions for medical treatment..."

“The 1970s also brought widespread use of prophylaxis... For those who could afford it, and tolerate the burdensome routine, prophylaxis brought a new level of certainty to life. Severely affected hemophilic boys were beginning to compete in contact sports. Nothing was impossible, it seemed...

“Storm clouds began to gather in the 70s. Reports of liver damage and, occasionally, death from liver disease provoked urgent research. We thought testing for hepatitis B would be the answer, but then we learned about non-A, non-B. Treatment with concentrates was evidently not free of danger.”
In 1980, with the availability of concentrates and the benefits it brought — in terms of longer life expectancy and less disability — the World Federation of Hemophilia (WFH) organized an international conference in Bonn, Germany, to develop a blueprint for hemophilia care in the 1980s.

“In the 1980s, the WFH will continue to pursue two concurrent and complementary objectives to accelerate the utilization of the research potential and to expand contemporary comprehensive care of hemophiliacs,” wrote Frank Schnabel in a special issue of *Haemophilia Bulletin*.

In 1982, the acquired immune deficiency syndrome (AIDS) crisis hit the hemophilia community, and the hopefulness that marked the beginning of the decade quickly turned to darkness and despair. AIDS was transmitted to people with hemophilia through clotting factor concentrates and this led to a devastating epidemic among the hemophilia population in North America, Europe, and other developed countries.

Patients and healthcare providers were, initially, reluctant to turn away from factor concentrate, and return to the pain and disability of the pre-concentrate days, while the scope of the epidemic was, at first, underestimated.

In 1983, at the WFH Congress in Stockholm, Sweden, Bruce Evatt, MD, presented data connecting human immunodeficiency virus (HIV) infection in hemophilia patients and plasma-derived treatment concentrates. The WFH set up the World Hemophilia AIDS Center with the Los Angeles Orthopaedic Hospital, under the direction of Shelby Dietrich, MD, to provide rapid access to vital information about the disease.

AIDS contracted from HIV-contaminated treatment products swept through the hemophilia community. Worldwide, tens of thousands of people with hemophilia contracted HIV and hepatitis from their treatment products.

Among the victims was Frank Schnabel, who died in 1987. Until the end, he reaffirmed his vision with the words: “We are going to emerge victorious.”

Business professional and WFH executive committee member, Charles Carman, was elected WFH president in 1988. In the midst of all of this, he set out to re-establish order in the WFH. During his tenure, he introduced important management structures and broadened the WFH’s funding base. He also embarked on a major exercise to develop a strategic plan to carry the WFH into the next millennium.

“Having witnessed what happened in the eighties… we said: ‘Well, never again and on our watch. We will do everything we can to make sure that doesn’t happen again.’”

—David Page, Chair, WFH Blood Safety, Supply & Availability Committee 2001-present
A decade of change

“We were determined to build programs that would lead to sustainable improvements in care.” —Brian O’Mahony, WFH president, 1994-2004

Fifty-four experts in the medical treatment and research of hemophilia, and national leaders of hemophilia associations met in Paris, France, in April 1990, to start working on the Decade Plan. Coordinated by Peter Levine, MD, Peter Jones, MD, and World Federation of Hemophilia (WFH) executive director Declan Murphy, the group identified the critical issues and concerns affecting the global comprehensive care of people with hemophilia. The plan was launched in 1992. Unfortunately, Charles Carman did not see the fruition of his work. He stepped down in 1993, and later died in 1995.

Rev. Alan Tanner (UK) served as acting president until the next WFH General Assembly in 1994, at which Brian O’Mahony was elected president and Carol Kasper, MD, was elected vice-president medical. Line Robillard had just been hired as executive director, as well. It was also a time of transition for the WFH, with the new leadership, but it was a time of positive change. O’Mahony brought together the WFH’s Executive Committee and Council, into one body, composed equally of doctors and people with hemophilia. The modified constitution was adopted in 1996.

Greater access to improved products, self-treatment, and prophylaxis showed up the stark differences between the developed and developing countries. Under O’Mahony, the WFH focused its efforts more on the developing world, with programs that would help countries to help themselves.

One major step was the introduction of the WFH Twinning Programs in 1994-95, pairing up hemophilia organizations and treatment centres in developed countries with those in developing countries. A healthcare development project in Chile, called Operation Access, represented the WFH’s first major success in achieving rapid and significant improvement in hemophilia care. The WFH brought together what came to be called the “winning coalition.” Companies donated treatment products, the Ministry of Health established a national hemophilia program, a key treater coordinated the program’s implementation, others received specialized training, and the patient organization carried out an educational and advocacy role. The WFH served as a catalyst and adviser. The lives of Chileans with hemophilia changed dramatically in five years and the “winning coalition” model was adapted successfully for other countries.

Professional staff was hired and programs, publications, and congress departments were created. WFH activities expanded to include safety and supply, data and demographics, laboratory training, humanitarian aid, and capacity building for NMOs.
On World Hemophilia Day (April 17) 2003, the WFH launched the Global Alliance for Progress (GAP) Program, which was a culmination of all that the WFH had learned about building sustainable care. This 10-year healthcare development initiative aimed to greatly increase the diagnosis and treatment of people with hemophilia in about 20 developing countries. Its goal was to diagnose 50,000 people with hemophilia globally.

O’Mahony ended his final term as president in 2004, and Mark Skinner, a Washington, D.C., attorney, was elected WFH president. Under Skinner’s leadership, the WFH adopted a new strategic vision of Treatment for All, to ensure proper diagnosis, treatment, and management for all people with bleeding disorders, no matter where they live. Treatment for All also meant expanding services for other inherited bleeding disorders, including von Willebrand disease, rare factor deficiencies, inherited platelet disorders, and women with bleeding disorders. The WFH vision included ensuring a multidisciplinary approach to care.

Under vice-presidents medical Paul Giangrande, MD, (2000-2008) and Alison Street, MD, (2008-2012), multidisciplinary healthcare team members were fully incorporated into the WFH’s Medical Advisory Board and development model to ensure a comprehensive, integrated approach to achieving sustainable care.

Black was named executive director/CEO of the WFH in 2007, and she and Skinner were instrumental in transforming the WFH into the global leader for the inherited bleeding disorders community. After 15 years at the WFH, Black stepped down in 2011, and John E. Bournas joined the WFH team as CEO/executive director. During the WFH 2012 World Congress in Paris, France, Skinner ended his term and Alain Weill was elected the new WFH president.

In 2013, expansion and growth will continue with the Close the Gap campaign, which aims to raise $5 million by 2014, a new research program, an expanded second phase of the GAP Program, and the launch of the Cornerstone Initiative, a new healthcare project to help build a solid foundation for the future of care development in the world’s most underserved areas.
WFH MEMBERSHIP

WORLD HEMOPHILIA DAY
GIVE A GIFT OF MEMBERSHIP

Visit www.wfh.org/membership for more details.

Be part of the vision.
Help us Close the Gap in care.
The Journey Begins video highlights the founding of the World Federation of Hemophilia

Join us on April 17 for the premiere of a new online video that shares the story of Frank Schnabel, founder of the World Federation of Hemophilia (WFH).

/Sarah Ford, WFH communications manager

The Journey Begins explores the origins of the WFH and the inspired role that Schnabel played in bringing together the global bleeding disorders community to form the WFH.

“There was very little knowledge about hemophilia, even in major centres,” said David Page, WFH executive committee member from 2000-2008 and narrator of The Journey Begins. “So the idea was to bring people together, share knowledge, and improve care across the world. And so his vision was an international one, a global vision.”

This video aims to inspire a new generation of leaders and encourage them to reach out beyond their own communities to make a difference for those who lack access to the same level of treatment.

“Frank Schnabel, WFH founder, was also my father,” said Gina Schnabel. “Seeing him so lovingly portrayed and honouring him in The Journey Begins is a beautiful tribute to all that he gave to his community. I am so impressed by the film, the WFH and their accomplishments. I can assure you my father is beaming with pride.”

As Schnabel neared the end of his life, reflecting on the future of the WFH, he proclaimed, “We are going to emerge victorious.” The 50th anniversary of the WFH is a testament to how far we have come already.

WFH 50th anniversary videos

Videos in the 50th anniversary series will be released every six weeks through the rest of 2013. This series highlights key moments, programs, and people in the 50-year history of the WFH. These English-language videos are also available with Spanish or French subtitles.

Empowering Patients
The WFH works with patient organization leaders to provide skills for empowering volunteers to improve care for the bleeding disorders community. In the video Empowering Patients, we learn about a remarkable Venezuelan woman, Antonia Luque de Garrido, who advocated for improved care.

Volunteering Brings Change
The WFH salutes the dedication and hard work of its volunteers. In the video Volunteering Brings Change, WFH volunteers share the many reasons why they get involved with the WFH to help the global bleeding disorders community.

Progressing Care Globally
The video Progressing Care Globally explores how China experienced rapid improvements in care after participating in the WFH’s GAP Program.

Changing Lives Through Twinning
The sharing of knowledge and expertise is the greatest gift of twinning. In the video Changing Lives Through Twinning, Yuri Zhulyov and Paula Bolton-Maggs, MD, reflect on their involvement with the WFH Twinning Program.

The Winning Coalition
Assad Haffar, MD, narrates The Winning Coalition, a 20-minute film highlighting the establishment of a national care system for people with bleeding disorders in Senegal, through the work of local doctors, patients, governments, and international volunteers.

Close the Gap
The video Close the Gap highlights the differences between children who have received care for their bleeding disorder and those who suffer without care.

1. WFH founder Frank Schnabel.
2. Frank Schnabel and his wife, Marthe, attending a World Congress.
3. Frank Schnabel travelled the world to grow the numbers of national member organizations.
WFH 2014 WORLD CONGRESS
THE LARGEST INTERNATIONAL MEETING FOR THE GLOBAL BLEEDING DISORDERS COMMUNITY
MELBOURNE, AUSTRALIA · MAY 11-15
www.wfh2014congress.org
WFH World Congresses

The earliest World Federation of Hemophilia (WFH) World Congresses were held in conjunction with the annual medical meetings of the International Society for the Rehabilitation of the Disabled and the International Society on Thrombosis and Haemostasis. Today, the WFH World Congress is the largest international meeting for the global bleeding disorders community. WFH World Congresses reflect the WFH’s unique role bringing together members of the entire community – healthcare providers, national patient organization leaders, people with bleeding disorders and their families, researchers, regulators, and pharmaceutical companies.

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<td>June 1-5, 2008</td>
<td>ISTANBUL</td>
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<td>May 21-25, 2006</td>
<td>VANCOUVER</td>
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<td>October 17-21, 2004</td>
<td>BANGKOK</td>
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<td>May 19-24, 2002</td>
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<td>July 16-21, 2000</td>
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<td>May 17-21, 1998</td>
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<td>June 23-28, 1996</td>
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<td>October 12-17, 1992</td>
<td>ATHENS</td>
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<td>June 8-13, 1986</td>
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<td>August 24-28, 1984</td>
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<td>June 27 – July 1, 1983</td>
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<tr>
<td>XI</td>
<td>June 22 – July 1, 1977</td>
<td>NEW YORK CITY</td>
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What will it take to close the gap?

In spite of the tremendous progress made over the last 50 years, 75 per cent of people with a bleeding disorder worldwide do not have access to proper care or any care at all. Read Joseph’s story to see how his family in Uganda coped with a gap in care.

The World Federation of Hemophilia (WFH) continues to work to close the gap in care so proper treatment will be available, for all, around the world. Millions of men, women, and children suffer needlessly. But there is hope and we are making a difference. With your help, our quest to introduce, improve, and sustain care will not be limited by geography, national economic wealth, or existing healthcare infrastructure. With your help, we will reach those who live in countries where the gap in care is greatest.

What will it take to Close the Gap?
It will take time, volunteers, and most importantly, financial resources.

Be part of the vision. Give to Close the Gap. Visit www.wfh.org/closethegap to learn more.

My son was robbed of his childhood: Joseph Ssewungu’s story

My son was diagnosed eight years ago with Type B hemophilia, a rare and severe form of the disorder. Now aged 11, Jovan has missed a lot of school and is unable to play many games with his friends, for fear of injury. Hemophilia has robbed him of his childhood.

In addition to painful bleeds in the knees and ankles, Jovan suffered dangerous brain blood-clots that required two operations. They were very traumatic for him. During a visit to Kampala’s Mulago Hospital, we watched Jovan lie in bed and ask God to let him live. In addition to seeing my child suffer, hemophilia has dealt an extra blow to our family. We had to incur debts to save Jovan’s life and the medical bills almost made us go bankrupt.

Hemophilia awareness, diagnosis and treatment in Uganda are very limited, especially in remote areas. Patients everywhere are often dependent on donations of factor concentrates from abroad and even storage of this medication can be a challenge.

However, we have set up a national hemophilia foundation involving volunteers who contact families to help them understand and manage the symptoms of their children.

After what my family has gone through, I want to help all hemophilia patients in my country. I know it’s possible for Jovan and others like him to live normal, productive lives. I don’t want to see more young boys lose their childhood.

I joined the efforts of the WFH in 2008 because of its experience and success advocating health authorities around the world. The WFH has provided valuable support, but unfortunately Uganda faces financial constraints and success is elusive. Nevertheless, I will maintain hope and keep trying.

For Jovan’s sake.

— Joseph Ssewungu, Haemophilia Foundation of Uganda
Commemorative articles highlight the evolution of treatment and care

As part of the 50th anniversary activities of the World Federation of Hemophilia (WFH), Haemophilia, the official journal of the WFH, has been publishing a series of historical articles, highlighting key milestones in the development of treatment and care. Spearheaded by journal editor Christine Lee, MD, these articles include personal reflections and highlight seminal studies and papers.

/Elizabeth Myles, WFH chief operating officer

In the series so far, Carol Kasper, MD, shares her recollections of her time as a young fellow working with Judith Graham Pool and the discovery of cryoprecipitate. Margarita Blombäck, MD, recalls her memories of her research into von Willebrand disease. Ulla Hedner, MD, provides a personal account about the development of activated factor VII. Bruce Evatt, MD, follows up on his original account of the AIDS epidemic in the U.S.A., focusing on events from 1985-1988. Jeanne Lusher, MD, writes about her experience with the development and introduction of recombinant factor VIII, and Paul Giangrande, MD, explores the development of porcine factor VIII.

“Further commemorative articles will be published throughout 2013,” said Lee. “It is then planned to bring all these articles together with earlier historical annotations, published in Haemophilia during 1995 to 1997, and to publish a commemorative volume to celebrate 50 years of the WFH. This volume will not only serve to acknowledge the enormous achievement of the WFH but will provide an interesting history of hemophilia.”

Each edition of Haemophilia journal in 2012-2013 includes a commemorative article, and articles are available for free from the journal website at www.haemophiliajournal.com. Articles are also available from the WFH website at www.wfh.org/50.

1. Judith Graham Pool. Photo courtesy of the National Hemophilia Foundation.
2. Bruce Evatt speaking in Montreal, Canada.
Representatives at 1963 WFH meeting
Argentina Australia Belgium Canada Denmark France Germany Japan The Netherlands Sweden United Kingdom United States

1965
Greece Switzerland

1966
Austria Norway Serbia (Yugoslavia)

1968
Algeria Brazil Costa Rica Italy New Zealand Turkey

1969
Iran Ireland Poland Russia (U.S.S.R.) Spain

1970
Colombia Finland Hungary Israel Mexico South Africa

1971
Chile Egypt India

1972
Nigeria Venezuela

1975
Bulgaria Peru

1976
Portugal Uruguay

1977
Iceland Indonesia Jamaica Kenya Kuwait Malaysia Nicaragua

1980
Cyprus Philippines Thailand Tunisia

1981
Honduras Paraguay

1983
Cuba Dominican Republic Luxembourg

1986
Pakistan Panama Singapore

1988
South Korea Trinidad and Tobago Zimbabwe

1990
China Czech Republic

1992
Albania Bolivia Bosnia and Herzegovina Croatia Georgia Lebanon Nepal Slovenia

1994
Ecuador Estonia Guatemala Latvia Lithuania Morocco Romania Slovakia

1996
Bangladesh Belarus Senegal Sudan

1998
Armenia

2000
Azerbaijan Belize Macedonia Mongolia Ukraine Vietnam

2002
Jordan Palestine Saudi Arabia Sri Lanka Uzbekistan

2004
Botswana Eritrea Iraq Kazakhstan Moldova Oman Qatar

2006
Bahrain Lesotho

2008
Cambodia Cameroon Côte D’Ivoire Kyrgyzstan Syria

2010
Ethiopia Ghana Suriname Tanzania

2012
Afghanistan Mauritius Montenegro Uganda United Arab Emirates

Hemophilia World / April 2013

Strength in numbers: WFH national member organizations

Today, there are 122 national member organizations (NMOs) of the World Federation of Hemophilia (WFH). These national patient organizations work in partnership with the WFH to develop and maintain comprehensive care in their countries. This timeline lists each member country by the first year its NMO received accreditation, as a full or associate members, by the WFH.
50 YEARS OF ADVANCING TREATMENT FOR ALL

Join the World Federation of Hemophilia as we mark 50 years of serving the global bleeding disorders community.

www.wfh.org/50

The WFH is grateful to our corporate partners for their support of the WFH 50th anniversary.

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Biogen Idec Hemophilia
Biotest
BPL
CSL Behring
Green Cross
Grifols
Kedrion
LFB
Novo Nordisk
Pfizer
Sanquin
In recognition of the organizations that have committed or contributed to the WFH’s mission so far in 2013

PATRON
Jan Willem André de la Porte

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

GLOBAL ALLIANCE FOR PROGRESS (GAP) SECOND DECADE
Visionary Partner
Baxter
Leadership Partner
CSL Behring
Collaborating Partner
Bayer
Biogen Idec Hemophilia
Biotest
Grifols
Pfizer

SPONSORED PROGRAMS
50th Anniversary Project
Baxter
Bayer
Biogen Idec Hemophilia
Biotest
BPL
CSL Behring
Green Cross
Grifols
Kedrion
LFB
Novo Nordisk
Pfizer
Sanquin

Advocacy in Action NMO Program
Baxter

Twinning Program
Pfizer

International External Quality Assessment Scheme Program
Novo Nordisk Haemophilia Foundation

International Hemophilia Training Centre Fellowship Program
Bayer

Research Program
Bayer
Baxter
Biogen Idec Hemophilia
The Hemophilia Center of Western Pennsylvania

Musculoskeletal Congress
Platinum Sponsors: Baxter, Novo Nordisk
Silver Sponsor: Bayer

Website
WFH website: Baxter, Pfizer
Compendium of Assessment Tools: Kedrion, LFB
HemoAction e-games: Novo Nordisk
HTC Passport Web Directory: Biogen Idec Hemophilia, Novo Nordisk, Pfizer
Inhibitors web section: Grifols
von Willebrand Disease web section: Grifols

Global Research Forum
Baxter
Bayer
Biogen Idec Hemophilia
CSL Behring
Novo Nordisk
Pfizer
Precision BioLogic

Other sponsored programs
International Hemophilia Forum: Biotest
Susan Skinner Memorial Fund: The Hemophilia Alliance
World Hemophilia Day
Baxter, Bayer, Biogen Idec Hemophilia, CSL Behring, Novo Nordisk, Pfizer, Precision BioLogic, SOBI

ORGANIZATIONS
Association Française des Hémophiles*
Belgian Haemophilia Society*
Canadian Hemophilia Society*
Deutsche Hämophiliengesellschaft (DHG)*
Fundación de la Hemofilia (Argentina)*
Haemophilia Foundation Victoria
Hemophilia Association of the Capital Area, NH*
Haemophilia Foundation of New Zealand*
Hemophilia of Georgia
Irish Haemophilia Society*
Japan Committee for People with Hemophilia*
Mary M. Gooley Hemophilia Center
Montréal International
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CONTACT US
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

HEMOPHILIA WORLD WOULD LIKE TO HEAR FROM YOU!
The activities of people living with hemophilia and other inherited bleeding disorders, and their organizations, are important to everyone in the global bleeding disorders community. We welcome stories, letters, and suggestions for articles. Please send them to:

The Editor, Hemophilia World
Fédération mondiale de l’hémophilie
1425, boul. René-Lévesque Ouest, bureau 1010
Montréal, Québec H3G 1T7
Canada
E-mail: bboyer@wfh.org

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