

50
Special Edition

HEMOPHILIA WORLD

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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.



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www.wfh.org



WHERE WE
HAVE BEEN

WORLD HEMOPHILIA DAY 2013

APRIL 17

50 YEARS OF ADVANCING
TREATMENT FOR ALL

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your 50th anniversary messages



WHERE WE
WANT TO BE



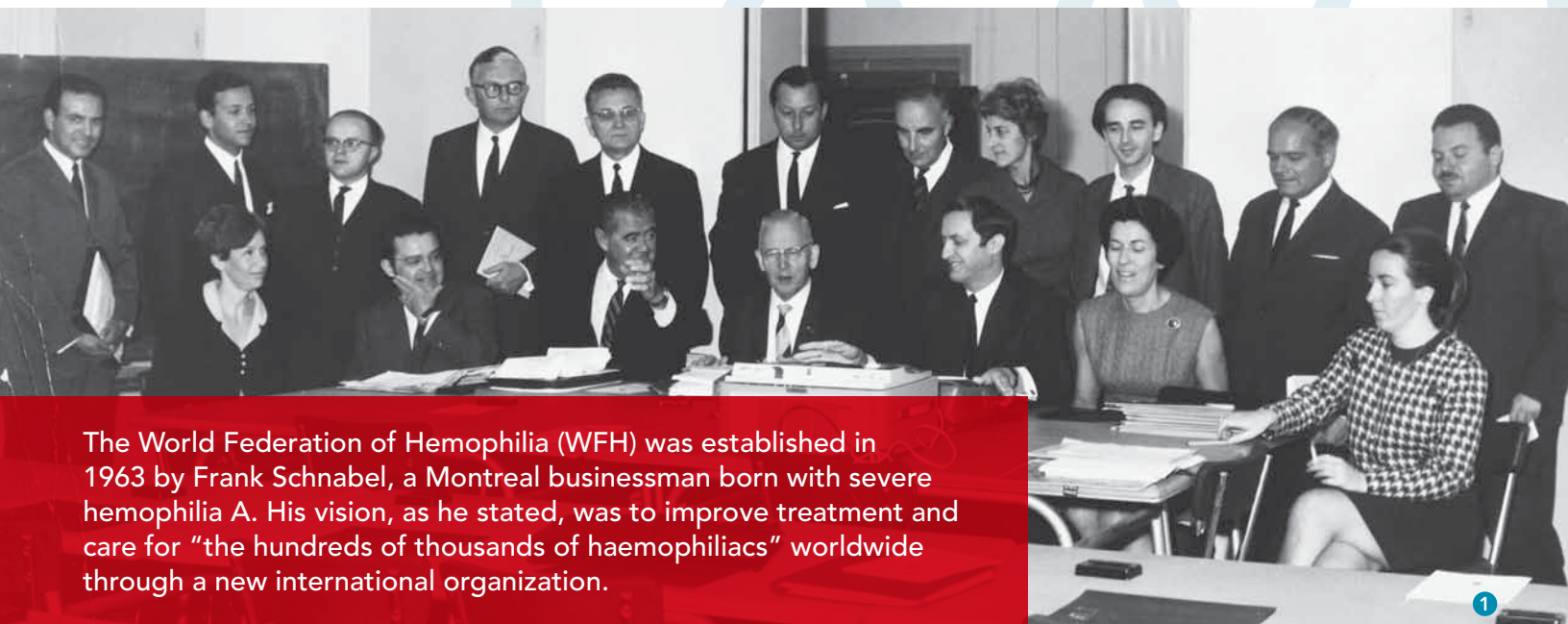
TOGETHER,
WE CAN CLOSE
THE GAP

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 Sjolín, 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.



1. 1965 Congress in Paris, France. Frank Schnabel and S. van Creveld, MD, seated behind the projector.
2. Prof. Kenneth Brinkhous and Schnabel
3. Henri Chaigneau

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.

The WFH expands globally

“These centres will bring... inspiration to many, and leadership to all of us.”

—Tony Britten, MD, founding chairman of the IHTC Program



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. Parttraporn 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

1. IHTC workshop in Bangkok, 1979.
2. Frank Schnabel speaks at a meeting of the Italian Hemophilia Foundation.
3. *Guide for Travelling Hemophiliacs*, published in 1973.
4. General Assembly at 1977 WFH Congress in New York City, U.S.A.

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.”

Tragedy hits the hemophilia community

“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

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



1. Tony Britten, MD, and Charles Carman.
 2. Frank and Marthe Schnabel.
 3. *The Hemophiliac's Blueprint for the 1980s*
 4. Bruce Evatt, MD, presents AIDS data from Centers for Disease Control at the WFH World Congress in Stockholm, 1983.

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.

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



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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 (U.K.) 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.

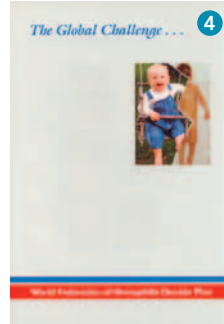
One major step was the introduction of the WFH Twinning Programs in 1994-95, pairing up hemophilia organizations and treatment centres in developed countries with

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.



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1. Operation Access in Chile.
2. Brian O’Mahony.
3. Carol Kasper, MD, with a young boy with hemophilia.
4. World Federation of Hemophilia Decade Plan.

Closing the gap

“It’s through that vision of Treatment for All that every child, every patient, every parent, no matter where they are in the world, can see that by partnering with the World Federation, their life, too, can be better.” —Mark Skinner, WFH president, 2004-2012



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Since the mid-1990s, a successful model for implementing sustainable care in developing countries had been developed by Brian O’Mahony, Line Robillard, Carol Kasper, MD, Bruce Evatt, MD, and World Federation of Hemophilia (WFH) programs director Claudia Black. It was based on five key areas: government support, care delivery, medical expertise, treatment products, and patient organization involvement. Usually, country programs focused on one or two areas. Seeing a need to advance care further and faster, O’Mahony had an idea for a new intensive program that would work on all five areas at once.

1. Mark W. Skinner signs memorandum of understanding with Tunisian minister of health to develop national program for hemophilia.
2. WFH president Alain Weill addressing the media during a visit to Algeria in February 2013.
3. Alison Street, MD, in Vietnam.
4. Global Alliance for Progress (GAP) launch in China, 2009.

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



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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

50

YEARS OF ADVANCING
TREATMENT FOR ALL

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



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.



www.wfh.org/whd

CLOSE THE GAP

Campaign 2012-2014

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.



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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 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.



WFH 2014 WORLD CONGRESS

THE LARGEST INTERNATIONAL MEETING FOR THE
GLOBAL BLEEDING DISORDERS COMMUNITY MELBOURNE, AUSTRALIA • MAY 11-15

Hosted by:

Organized by:



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.

	DATE	CITY	COUNTRY
XXXI	May 10-15, 2014	MELBOURNE	AUSTRALIA
XXX	July 8-12, 2012	PARIS	FRANCE
XXIX	July 10-14, 2010	BUENOS AIRES	ARGENTINA
XXVIII	June 1-5, 2008	ISTANBUL	TURKEY
XXVII	May 21-25, 2006	VANCOUVER	CANADA
XXVI	October 17-21, 2004	BANGKOK	THAILAND
XXV	May 19-24, 2002	SEVILLE	SPAIN
XXIV	July 16-21, 2000	MONTREAL	CANADA
XXIII	May 17-21, 1998	THE HAGUE	THE NETHERLANDS (Relocated from Tel Aviv)
XXII	June 23-28, 1996	DUBLIN	IRELAND
XXI	April 24-29, 1994	MEXICO CITY	MEXICO
XX	October 12-17, 1992	ATHENS	GREECE
XIX	August 14-19, 1990	WASHINGTON, D.C.	U.S.A.
XVIII	May 26-31, 1988	MADRID	SPAIN
XVII	June 8-13, 1986	MILAN	ITALY
XVI	August 24-28, 1984	RIO DE JANEIRO	BRAZIL
XV	June 27 – July 1, 1983	STOCKHOLM	SWEDEN
XIV	July 3-7, 1981	SAN JOSE	COSTA RICA
XIII	July 8-13, 1979	TEL AVIV	ISRAEL
XII	June 22 – July 1, 1977	NEW YORK CITY	U.S.A.
XI	Aug. 31 – Sept. 3, 1976	KYOTO	JAPAN
X	July 30 – Aug. 1, 1975	HELSINKI	FINLAND
IX	August 20-22, 1974	ISTANBUL	TURKEY
VIII	July 24-28, 1972	BUENOS AIRES	ARGENTINA
VII	May 17-20, 1971	TEHRAN	IRAN
VI	July 25-27, 1970	BADEN	AUSTRIA
V	August 26-27, 1968	MONTREAL	CANADA
IV	September 1966	WIESBADEN WEST	GERMANY
III	September 7-9, 1965	PARIS	FRANCE
II	August 27-28, 1964	AMSTERDAM	THE NETHERLANDS
I	June 25, 1963	COPENHAGEN	DENMARK

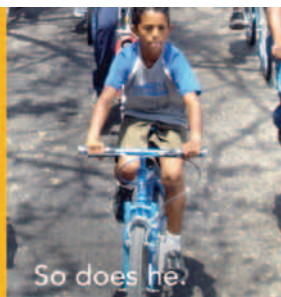


1. Kyoto, Japan, 1976
 2. San José, Costa Rica, 1981
 3. Milan, Italy, 1986
 4. Madrid, Spain, 1988
 5. Istanbul, Turkey, 2008

CLOSETHEGAP
Campaign 2012-2014



WHAT WILL IT TAKE TO CLOSE THE GAP?



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.

CLOSETHEGAP
Campaign 2012-2014

PLEASE GIVE to Close the Gap in care. Learn about the Patron's Challenge and just how far your dollars can go in the enclosed *Campaign Bulletin*.

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.

Published articles

Judith Graham Pool and the discovery of cryoprecipitate
C. K. Kasper

The AIDS epidemic in haemophilia patients II: pursuing absolute viral safety of clotting factor concentrates 1985–1988
B. L. Evatt

WFH: Closing the global gap – achieving optimal care
Mark W. Skinner

Porcine factor VIII
P. L. F. Giangrande

Development and introduction of recombinant factor VIII – a clinician’s experience
J. M. Lusher

Activated factor VII: my story
U. Hedner

Memories of my research into von Willebrand’s disease
M. Blombäck



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.

Representatives at 1963 WFH meeting	1969	1977	1988	1996	2006
Argentina	Iran	Iceland	South Korea	Bangladesh	Bahrain
Australia	Ireland	Indonesia	Trinidad and Tobago	Belarus	Lesotho
Belgium	Poland	Jamaica	Zimbabwe	Senegal	
Canada	Russia (U.S.S.R.)	Kenya		Sudan	2008
Denmark	Spain	Kuwait	1990		Cambodia
France		Malaysia	China	1998	Cameroon
Germany	1970	Nicaragua	Czech Republic	Armenia	Côte D'Ivoire
Japan	Colombia				Kyrgyzstan
The Netherlands	Finland	1980	1992	2000	Syria
Sweden	Hungary	Cyprus	Albania	Azerbaijan	
United Kingdom	Israel	Philippines	Bolivia	Belize	2010
United States	Mexico	Thailand	Bosnia and Herzegovina	Macedonia	Ethiopia
	South Africa	Tunisia	Croatia	Mongolia	Ghana
			Georgia	Ukraine	Suriname
1965	1971	1981	Lebanon	Vietnam	Tanzania
Greece	Chile	Honduras	Nepal		
Switzerland	Egypt	Paraguay	Slovenia	2002	2012
	India			Jordan	Afghanistan
1966		1983	1994	Palestine	Mauritius
Austria	1972	Cuba	Ecuador	Saudi Arabia	Montenegro
Norway	Nigeria	Dominican Republic	Estonia	Sri Lanka	Uganda
Serbia (Yugoslavia)	Venezuela	Luxembourg	Guatemala	Uzbekistan	United Arab Emirates
			Latvia		
1968	1975	1986	Lithuania	2004	
Algeria	Bulgaria	Pakistan	Morocco	Botswana	
Brazil	Peru	Panama	Romania	Eritrea	
Costa Rica		Singapore	Slovakia	Iraq	
Italy	1976			Kazakstan	
New Zealand	Portugal			Moldova	
Turkey	Uruguay			Oman	
				Qatar	

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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Biotest
BPL
CSL Behring
Green Cross
Grifols
Kedrion
LFB
Novo Nordisk
Pfizer
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 **WFH** ⁵⁰ YEARS OF ADVANCING TREATMENT FOR ALL
WORLD FEDERATION OF HEMOPHILIA
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Brian Boyer
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Graphic Design

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Design Production

Em Dash Design

Print Production

AS Lithographe

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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