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GAP: A DECADE OF SUCCESS LEADS TO A NEW DECADE OF GLOBAL DEVELOPMENT



Left: Children, like this boy, have benefited tremendously from the GAP project in Peru. Right: A family learning more about hemophilia care during a GAP workshop in Thailand.

Antonio José Almeida
WFH PROGRAMS DIRECTOR

The WFH has successfully achieved its goal of identifying 50,000 new patients with hemophilia worldwide. A significant number of these newly diagnosed patients have been identified through the Global Alliance of Progress (GAP), a 10-year healthcare development program launched on World Hemophilia Day, April 17, 2003. The GAP Program aims to close the gap between the number of people born with hemophilia and those who reach adulthood, the gap between the estimated and the actual number of people diagnosed with hemophilia, and the gap between the amount of treatment product needed and what is available.

Patients who are not diagnosed are less likely to be treated; in poorer countries, they are even less likely to survive into adulthood. Dr. Arafat Awajan, president of the Jordan Thalessemia and

Hemophilia Society, saw the impact of the GAP Program first-hand on the Jordanian bleeding disorders community. "They saw GAP as a critical and very positive event that changed their lives and increased their hopes to live in better conditions," said Dr. Arafat. "Now they are able to receive the appropriate treatment when needed. They know more about their condition and are confident in the support they receive from the government and health professionals."

A DECADE OF SUCCESS (2003–2012)

Across the board, the GAP Program has brought demonstrable change in each of the countries where it has had projects and has led to significant and measurable improvements worldwide in the management of hemophilia and other bleeding disorders.

The twenty target countries selected for the first decade of the GAP Program included

Algeria, Armenia, Azerbaijan, Belarus, China, Ecuador, Egypt, Georgia, Jordan, Lebanon, Mexico, Moldova, Morocco, Peru, Philippines, Syria, Thailand, Tunisia, Russia, and South Africa.

The primary goal of the GAP Program was to increase the number of patients with hemophilia identified by 50,000 worldwide. From 2003 to 2010, the number of patients identified worldwide living with hemophilia increased from 105,971 to 162,751. Countries such as Azerbaijan, China, Ecuador, Egypt, Jordan, Mexico, Philippines, Russia, Syria, and Tunisia surpassed their GAP goal of identifying previously undiagnosed patients with hemophilia.

The GAP Program has substantially improved the care delivery systems in many countries and increased the level of government support for

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WFH **50**
YEARS OF ADVANCING
TREATMENT FOR ALL

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

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hemophilia by building on a combination of existing conditions, such as an established patient organization, key dedicated health care providers, and potential for government commitment to improve care. Bleeding disorders care has also been improved through the establishment of comprehensive hemophilia treatment centres, the commencement or expansion of national patient registries, and the development of national treatment protocols.

The GAP Program has also greatly improved the knowledge and expertise of all members of the multidisciplinary teams working in bleeding disorders. Diagnosis was also improved by developing diagnostic capabilities through in-country laboratory training in all GAP countries, and the participation of all GAP country laboratories in the WFH International External Quality Assessment Scheme (IEQAS).

One of the most impressive successes of the GAP Program has been the significant gains in terms of access and availability of treatment products. Since 2003, GAP countries have reported to the WFH a total cumulative increase of 2.673 billion international units (IUs) of clotting factor concentrates purchased. This incredible breakthrough is the result of sustained advocacy efforts by national member organizations with medical, government, and WFH cooperation. When Russia joined the GAP Program in 2004, the government purchased only 1.4 million IUs of clotting factor concentrates. Over the years, after the Russian Hemophilia Society successfully lobbied the government to purchase more factor concentrates, 588 million IUs were purchased by the government in 2009.

Over the years, the GAP Program has also been successful at strengthening and helping patient organizations to become stronger and more resourceful. Efforts included providing coaching and skills development trainings, helping to conduct outreach and to establish regional chapters, and providing educational materials and advocacy tools, which benefitted not only GAP countries but all of the bleeding disorders community.

TO DATE, A TOTAL OF:

- 25,434 patients with hemophilia, 2,563 with von Willebrand disease (VWD), and 1,947 with rare clotting factor deficiencies have been diagnosed/registered through the GAP Program;
- 16,314 hemophilia treatment centres/healthcare professionals received training;
- 9,870 patients, family members, and national member organization (NMO) board members received training;
- 16 national care programs were established (12 with official commitments/memorandums of understanding).



Steve Kitchen leading a lab diagnosis training workshop at the Faculty of Medicine, Damascus, Syria.

Despite the GAP Program's track record and achievements to date, much work remains to be done. There is still an enormous gap in care between developed and developing countries. While the majority of people with hemophilia and other bleeding disorders in more prosperous countries have been diagnosed and receive treatment, in developing countries, most remain undiagnosed and receive little or no care. According to WFH president Alain Weill, "the challenge remains to find ways of bridging the gap by diagnosing new patients and improving access to care in a sustainable manner on a national basis in developing countries."

THE NEW DECADE OF GLOBAL DEVELOPMENT (2013-2022)

As part of the WFH's 50th Anniversary in 2013, the WFH is launching a second decade of the GAP Program to actively continue to work on closing the gap in care for people with bleeding disorders in 20 new target countries. The focus will be on improving diagnosis for all bleeding disorders, improving treatment in the world's poorest regions, as well as building on the achievements to date. The overarching goal will be to increase the worldwide number of people identified with all bleeding disorders by 50,000 and to ensure that

50 per cent of those newly diagnosed are from the world's most impoverished countries.

In order to achieve this, the WFH will target new countries to initiate national care programs similar to the first decade of GAP, promote continuous improvement in the programs that were established in countries that were part of the initial GAP Program, and provide support to other targeted mid-tier developed countries that need assistance in moving to the next level of care.

This will allow a more concerted effort to enhance diagnosis and access to treatment for under-recognized populations, which include people with inhibitors, von Willebrand disease, rare factor deficiencies, and inherited platelet disorders, particularly women with these disorders and carriers.

The GAP Program will also use an enhanced and adapted comprehensive development model developed for the first decade and used by the WFH in all of its national care programs. Finally, as with the first decade, the GAP Program will also include the development of educational tools and training guides which will benefit all countries.

"We should all take great pride in the accomplishments of GAP," says WFH president Alain Weill. "GAP has played a critical role in the management of hemophilia and other bleeding disorders in many parts of the world and we are well positioned to meet the many challenges ahead. Although vast needs remain unmet, the gaps are closing. Continuing to work together as one big global family, we will move one step closer to our quest to achieve Treatment for All." ■

The WFH is grateful for the support of the GAP Program by founding sponsor Baxter; sustaining sponsors the André de la Porte Family Foundation, Bayer, and CSL Behring; supporting sponsors Biogen Idec Hemophilia, Biotest, Grifols, and Pfizer; contributing sponsor the Irish Haemophilia Society; and collaborating partner the World Health Organization (WHO).

WFH PRESIDENT ALAIN WEILL

World Federation of Hemophilia (WFH) president Alain Weill, has quickly immersed himself into his new role. With a lot of ground to cover in a short period of time, he has taken every possible opportunity to familiarize himself with the far-reaching work of the WFH.

Hemophilia World (HW): How did you become involved with the bleeding disorders community?

Alain Weill (AW): In my professional life, I had the opportunity to work with many wonderful people and to travel extensively. However, on a personal level, I wanted to give back to the bleeding disorders community for all the support my son, who has severe hemophilia A, received during his treatment. After retirement, I felt that it was important to volunteer with my local hemophilia chapter in Paris, France. From there I joined the WFH national member organization in France, the French Hemophilia Society (*l'Association française des hémophiles, AFH*), which led to working with the European Haemophilia Consortium (EHC).

HW: Describe your experiences with the European bleeding disorders community?

AW: I was elected to the AFH board in 2006 and in 2008 became a member of the EHC Steering Committee. My work with the European Organization for Rare Diseases (EURORDIS) exposed me to how much needs to be done to treat those who have rare disorders. Those involved with hemophilia care can actually provide a lot of guidance for the rarer diseases, as a majority of people with these conditions do not even have access to treatment. However, everyone is working within a new era of health technology assessments and these assessments will impact how budgets will be allocated and how treatments will be funded.

HW: What is your vision for the WFH under your leadership?

AW: I envision the WFH continuing to advance Treatment for All. This is exactly what I would like the WFH to achieve and it is through continuity, adaptation, and innovation that we can pursue this vision.

HW: What are your main priorities for the next four years for improving care around the world?

AW: My goal is to motivate leaders throughout the global bleeding disorders community. It is very important that we also foster new voices and support, allowing young leaders to be innovative in this changing environment. My other priority is to support the expertise that exists within the WFH, to be part of the greater team. I will help guide the strategic objectives and I am very grateful for all that has gone into the development of the WFH strategic plan.

HW: What do you think the WFH needs to do to address challenges facing the global bleeding disorders community?

AW: It is important not to forget that 75 per cent of people with bleeding disorders around the world do not receive adequate treatment. The role of the WFH is to constantly and consistently improve this situation. Therefore, we



need to encourage the development of new products and technologies and ensure that safety and efficacy is taken into account at all times. In addition, the economic environment is becoming more constrained. Economic recession cannot lead to healthcare regression; we must find ways to counter these trends. However, we must always remind ourselves that our ultimate goal is to address and reduce the disparities in diagnosis and treatment that exist for the 75 per cent of people with inherited bleeding disorders around the world.

HW: What are you most looking forward to in your role as WFH president?

AW: I am honoured to be part of this great team. I will strive to help improve treatment and care for those with inherited bleeding disorders. Over the next four years, my constant and never-ending goal will be advancing Treatment for All. ■



Alain (second from the right) participating in the role-playing exercise during the Advocacy in Action training in Dubai.

INTRODUCING ALOK SRIVASTAVA, MD: WFH'S NEW VP MEDICAL

The new vice-president medical of the World Federation of Hemophilia (WFH), Alok Srivastava, MD, discusses his new role and his work with the inherited bleeding disorders.

Hemophilia World (HW): Why did you decide to become involved with the bleeding disorders community?

Alok Srivastava (AS): Care of people with bleeding disorders is a legacy that you inherit when you work at the Christian Medical College in Vellore, India. This centre has been the only one in Southern India providing services to people with bleeding disorders since the 1950s—both in terms of lab diagnosis and clinical care. It also so happened that after the national patient organization, the Hemophilia Federation of India, approached our centre in 1988 to help them in their work, more people with hemophilia, from all over the country, started coming to Vellore for their complicated medical problems. In order to deal with the many patients who required surgery, we approached the World Federation of Hemophilia (WFH) for humanitarian aid. The WFH responded by donating clotting factor concentrates (CFC) to be used for surgery and other medical services rendered to the Indian hemophilia population, particularly because there were no other centres in India performing such surgeries at the time. The WFH also proposed that I go to Israel to see how they were able to use lower doses during continuous infusion of CFC. It turned out that in Vellore we were using even lower doses. This is how my association began with the bleeding disorders community—in response to a huge need in my country and the region. It was also a personal challenge, to enhance the work that was already being done and to create a world class centre, in the developing world, for care of people with hemophilia.

HW: How did you get involved with the WFH?

AS: I got involved with the WFH in a few different ways. First off, I met with previous WFH president Brian O'Mahony on his visit to India in 1995; we had many discussions on the challenges of work-

ing in developing countries and how we were facing them. Later, when the past WFH vice-president medical, Carol Kasper, MD (U.S.A.), visited in 1998, she was so impressed with what she saw in Vellore that she decided to partner with us as part of the WFH Twinning Program. Subsequently, we were selected for the first Inga Marie Nilsson award. After that, Christine Lee, MD (U.K.), who as chair of the WFH International Hemophilia Training Centre (IHTC) committee, sent us several requests inviting us to become an IHTC of the WFH. We waited for some time because we were training large numbers of people in India as part of a Danish International Development Agency (DANIDA) project. We finally agreed to become an IHTC in 2000, and I was its co-director along with Dr. Mammen Chandy. In 2002, at the XXV International Congress of the WFH in Seville, WFH president Brian O'Mahony asked me to chair the IHTC committee, which led to an *ex-officio* membership on the WFH Executive Committee.

HW: What are your main priorities, as WFH vice-president medical, for the next couple of years?

AS: There are several priorities with this role. There are two main barriers to achieving the WFH's goal of Treatment for All—expertise of hemophilia care and financial resources to provide the care. The former makes up the major domain of function of the WFH vice-president medical. We need to work to disseminate existing knowledge by increasing training opportunities through the many different programs and channels of the WFH and create new knowledge by getting involved with and supporting research. The publication of the revised *WFH Guidelines for the Management of Hemophilia* has helped identify the areas where evidence is lacking. Knowledge often compensates for lack of resources because people then innovate. Our own experience is testimony to that.



HW: In your opinion, what are the biggest challenges facing the global bleeding disorders community?

AS: These challenges are varied in different parts of the world. In developing countries, the challenge is that of providing adequate care for the vast numbers of people with bleeding disorders who receive minimal care and also identifying those who have not yet been diagnosed. In the developed countries, we need to ensure continued support for the highest level of care at a time when there is great economic pressure on the health care system in many of these countries.

HW: What would be the biggest opportunities for the WFH?

AS: The WFH has earned itself a reputation based on all the good work that has been done over many years and we need to capitalize on that. To achieve this, we need two kinds of resources—human and financial. We need to engage our supporters, old and new, and involve many more volunteers to get the work done.

HW: What are you looking most forward to in your role as vice-president medical?

AS: The opportunity to work with many wonderful people around the world to improve services for people with bleeding disorders. ■

CHANGING TACTICS AND PERSEVERING: HEMOPHILIA FEDERATION OF THE REPUBLIC OF MEXICO WINS ADVOCACY IN ACTION AWARD

Sarah Ford

WFH COMMUNICATIONS MANAGER

To the Hemophilia Federation of the Republic of Mexico (*Federación de Hemofilia de la República Mexicana*), advocacy meant perseverance and adaptation to changing circumstances. When faced with a new government in power, and seeing four years of hard work slip away, they kept moving forward with determination. The Mexican Federation re-examined their advocacy strategy, regrouped, and persevered.

The Advocacy Recognition Award is given annually, as part of the WFH Advocacy in Action Program, to the WFH national member organization with a successful advocacy campaign. This award highlights their advocacy strategies, the implementation through activities and media coverage, the overall process, and the end results of their campaign.

The 2012 recipient of this first Advocacy Recognition Award is the Hemophilia Federation of the Republic of Mexico. The Mexican Federation campaigned for seven years, beginning in 2003 and ending in 2010, to provide free treatment and care for uninsured children who have either hemophilia or von Willebrand disease (VWD).

“Their original strategy was to educate and pressure national health authorities about the importance of providing care to all children with hemophilia,” said Luisa Durante, WFH regional program manager for the Americas. “The Mexican Federation, from the beginning of this

The Mexican Federation was very clear in their goal of trying to achieve free treatment and care for this population of children that had no coverage and were therefore at great risk.

campaign, was very clear in their goal of trying to achieve free treatment and care for this population of children that had no coverage and were therefore at great risk. This clarity and determination were the driving force for them; they were going to do what they could to reach this goal and to make it happen.”

After four years of consistent work, the National Commissioner of the Social Protection Scheme (*Seguro Popular*) finally agreed to this change in policy. However, before the decision could be implemented, a new government came into power and the decision was overturned.

The Mexican Federation, despite this setback, never gave up and instead they changed their strategy. Through a nationwide education campaign, they gained the support of some of the state health authorities. This state-level of government in turn helped apply pressure on the *Seguro Popular*. The end result was not only an agreement to change national health policy, but also new support at the state-level in three

states, and an increase in public awareness about hemophilia.

At the end of 2010, seven years after the Mexican Federation began their advocacy campaign, the *Seguro Popular* finally agreed to insure children under 10 who have either hemophilia or vWD that were not insured elsewhere.

The Mexican Federation was awarded the Advocacy Recognition Award for not only their perseverance but for their continual strategic thinking. When faced with changing governments and failed policy changes, they rose to the challenge and created new opportunities.

“The Mexican Federation grew a lot during this process and became a stronger entity. This experience was extremely valuable; every step of the way there was learning and strategic thinking, this really was a national initiative that involved the whole community,” said Durante. “It is remarkable to witness this strength and determination that led them to be successful and it illustrates that change is really possible.”

Through the leadership of Martha Monteros, and then Carlos Gaitan-Fitch, the Mexican Federation was led with a vision that promoted care and treatment for all children in Mexico. This advocacy campaign was an extraordinary achievement for Mexico and for a new generation of children who now will receive adequate and preventative care. ■

The Advocacy in Action program is supported by exclusive funding from Baxter.

Left: Young children under 10, like this boy, will benefit significantly from the outcomes of the campaign. Right: Aris Hashim, Chair of the Awards Committee, and Martha Monteros Rincón, past-president, with Carlos Gaitan Fitch, current president of the Hemophilia Federation of the Republic of Mexico, winning the first Advocacy in Action award.





WFH MEMBERSHIP

GIVE A
GIFT OF MEMBERSHIP
HELP US CLOSE THE GAP
IN CARE

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

Be part of the vision.
Share the WFH mission.



Left: Timothy receives factor for the first time. Right: Megan participating in a WFH workshop in 2009.

A MOTHER'S JOURNEY: A LETTER FROM MEGAN ADEDIRAN

When my son, Timothy, was born in 1996, little was known about hemophilia in Nigeria and there was no medical treatment available. I looked desperately for answers, but none of the doctors or health officials knew what to do to help Timothy. Day after day, week after week, I watched my child wither in agony, tortured by bleeds.

As a baby, Timothy bled for five days after a circumcision and needed a blood transfusion. In the first two years of his life he needed three transfusions just to keep him alive. I would sit by his bed praying that I would not lose him. He spent much of his childhood in crutches and was not properly diagnosed with severe hemophilia A until the age of seven. Life was a journey in the dark, until I heard about the World Federation of Hemophilia (WFH). I contacted the WFH and was able to access treatment products sent by Dr. Assad Haffar through the WFH Humanitarian Aid Program. The treatment products the doctors received helped to manage Timothy's bleeds—the information and knowledge I received helped me to manage many of the other obstacles that Timothy faced.

Timothy was lucky he received treatment when he did and he can walk better now. My second son, Isaac, aged four, also has hemophilia and suffers from ankle and knee bleeds. My life is still a daily struggle to keep my children alive and give them some kind of normal life, but the power of knowledge, combined with donations of treatment products, have made life less traumatic for our family. We now have hope. However, other children with a bleeding disorder in Nigeria are not so lucky. Most have not yet been properly diagnosed and lack even the most basic support to help ease their suffering.

Like all children, my boys want to play games and make friends at school. But when I talk to some teachers, they think hemophilia is contagious and that my children are a danger to others. Parents in Nigeria often hide their children's disorder to avoid the stigma and some families have broken up because of the pressures.

We have to keep on fighting. Knowing the ordeals I've been through with my sons, I dedicate my time to the Haemophilia Foundation of Nigeria, which I founded in 2005 with the help of the WFH. Through the Foundation I'm trying



Joint bleeds are part of Timothy's daily life.

to spread knowledge about hemophilia, persuade the government to improve treatment, and show other parents they're not alone. There is hope and there is help available. I've also written a book about my experiences called *Light at the End of the Tunnel*.

I want to see a future for children born with hemophilia to grow up like other human beings. Please give generously to support the Close the Gap campaign and help the WFH give hope to children like Timothy and Isaac. ■

Megan Adediran

FOUNDER AND PRESIDENT OF THE NIGERIAN HAEMOPHILIA FOUNDATION

CLOSETHEGAP
Campaign 2012-2014

You can make a difference.
www.wfh.org/closethegap

75%

OF PEOPLE WITH A BLEEDING DISORDER DO NOT RECEIVE ADEQUATE CARE OF ANY CARE AT ALL

WHAT WILL IT TAKE TO CLOSE THE GAP?



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.

www.wfh.org/closethegap

NEW RESOURCE FOR CARRIERS AND WOMEN WITH HEMOPHILIA

Jennifer Laliberté

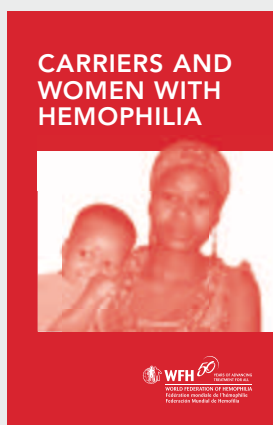
WFH EDUCATIONAL MATERIALS MANAGER

For many years, it has been commonly accepted knowledge that only men could have hemophilia and that women who “carry” the hemophilia gene do not experience symptoms themselves. We now know that many carriers *do* experience symptoms of hemophilia. Some women live with their symptoms for years without being diagnosed or even suspecting they have a bleeding disorder. The World Federation of Hemophilia (WFH) has now developed a new resource, *Carriers and Women with Hemophilia*, to help raise awareness and close the gap in care.

Approximately one-third of carriers have clotting factor levels of less than 60 per cent of the normal level, and may experience abnormal bleeding. In most cases, carriers experience symptoms similar to those seen in men with mild hemophilia, as well as some that are specific to women, such as prolonged or heavy menstrual bleeding. While these women have traditionally been referred to as symptomatic carriers, a woman who has less than 40 per cent of the normal level of clotting factor is in fact no different from a man with the same factor levels—she has hemophilia.

“We need to change the idea that only men can have hemophilia,” says Dr. Paula Bolton-Maggs, past chair of the WFH von Willebrand disease and rare bleeding disorders advisory committee. “A woman who experiences symptoms of hemophilia should be treated and recognized in the exact same way as a man with the condition. Physicians need to realize this if we are going to improve the level of care these women are currently receiving in many parts of the world.”

Carriers and Women with Hemophilia is available in print and online at www.wfh.org. ■



Left: Members of the Cambodian Haemophilia Association (CHA), and the Haemophilia Foundation of New Zealand (HFNZ) getting to know each other better. Right: Treatment at the Indonesian treatment centre

2011 TWINS OF THE YEAR: SUCCESS THROUGH PARTNERSHIPS

Anabella Zavagno

WFH PROGRAM COORDINATOR, TWINNING & GLOBAL NMO TRAINING

Twinning is a partnership between two hemophilia organizations or two treatment centres in developing and developed countries. Two World Federation of Hemophilia (WFH) twinning partnerships have been awarded the 2011 Twins of the Year awards in recognition of exceptional work, enthusiasm, and courage. The Hemophilia Organization Twins of the Year winners are the Cambodian Haemophilia Association (CHA) and the Haemophilia Foundation of New Zealand (HFNZ), and the Hemophilia Treatment Centre Twins of the year winners are the Estella Pediatric Hematooncology Center Manado, in Indonesia, and the Van Creveldkliniek, University Medical Center Utrecht, in the Netherlands.

Both winners highlight the true spirit of the program: a two-way collaboration where partners transfer expertise, experiences, skills, resources, and information.

In 2011, the Cambodia-New Zealand twinning achieved, among many other accomplishments, the organization of family education workshops on clinical, psychosocial, and patient/family issues in Phnom Penh, the capital, and in Siem Reap, the second biggest city in Cambodia. Moreover, in New Zealand, HFNZ members have been educated through groups, camps, and workshops about what life is like for an individual with a bleeding disorder in Cambodia. “Seeing the Cambodian Haemophilia Association (CHA), as it works through the initial stages of operation, has crystallized the reasons behind the progress the HFNZ has made over the years, and this makes it easy for us to know what to focus on in

assisting CHA,” said Catriona Gordon, member of the HFNZ. “We know that the path will be long and hard at times, but we are delighted to be able to help in this way.”

Furthermore, the Manado (Indonesia)-Utrecht (the Netherlands) twinning also made great strides, namely a day-long symposium for 100 participants, workshops for doctors, psychiatrists, physiotherapists, and nurses, and one-week training of six physiotherapists to improve knowledge of comprehensive musculoskeletal care. Dr. Max Mantik and Dr. Stefanus Gunawan from the Manado Center said, “we are very grateful as this twinning program has facilitated us in enhancing the diagnosis and management of patients with hemophilia, especially with regard to the concept of comprehensive management and functional physiotherapy. This twinning allowed us to be an element of the World Federation of Hemophilia and strengthen our commitment to help out our patients.” ■

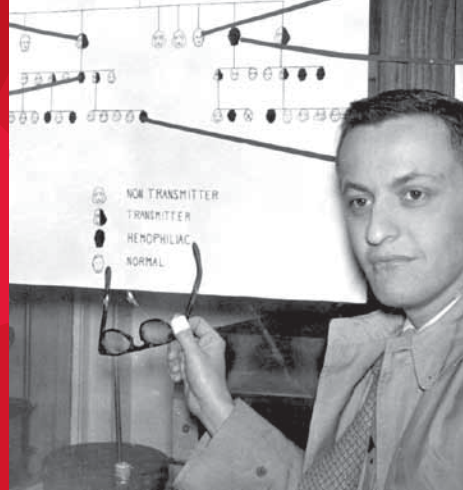
The WFH is grateful to Pfizer for their exclusive sponsorship of the Twinning Program.

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. Visit www.wfh.org/50 to watch this video.

WFH PRESIDENTS (1963-2012)

Over the past 50 years, there have been only four World Federation of Hemophilia (WFH) presidents during the period of 1963 to 2012—a testament to the stability of the organization. The tremendous growth of the WFH is due in large part to their vision and leadership.



50

years of
advancing
Treatment
for All



FRANK SCHNABEL FOUNDER AND PRESIDENT (1963-1987)

Born in the U.S.A. in 1926, Frank Schnabel, who had severe hemophilia, grew up in a time where there was no treatment for hemophilia. However, it never stopped him. His parents did everything possible to allow him a normal childhood. He grew up to become a successful investment analyst and businessman, and was consul general for Costa Rica in Montréal, Canada. He became a strong advocate for better treatment and, in 1953, founded the Canadian Hemophilia Society. Then in 1963, seeking

to “improve the plight of the hemophiliac” he brought together national patient societies and treaters to form an international society to “share information, educate, and work together to improve research and find a cure.” Schnabel remained president for 24 years, travelling extensively to serve the WFH national member organizations and the many individuals who came to him for advice and guidance. He and his wife, Marthe, who became WFH executive director, were dedicated to the cause. Even after he contracted AIDS from contaminated treatment products, Schnabel continued with his WFH work, running the office from his hospital room. He died in 1987.



CHARLES CARMAN PRESIDENT (1988-1993)

Charles Jerry Carman, of Hudson, Ohio, worked at B.F. Goodrich/Geon Company for 30 years, beginning as a research chemist, until his retirement as director of marketing products. He was passionately involved as a volunteer and leader in the hemophilia community, dedicated to improvements in the lives of future generations, and served as president of the National Hemophilia Foundation in the 1980s. In 1988, he was elected president of the WFH.

Under Carman's guidance, the organization developed and matured. He introduced important management structures and broadened the funding base with new sponsors, enabling the WFH to pursue programs and activities in developing countries. His crowning achievement was the development of the Decade Plan, a 10-year strategic plan which would launch the WFH into the next millennium. Carman stepped down as president in 1993 due to new commitments in his own professional life. He passed away in 1995.



BRIAN O'MAHONY PRESIDENT (1994-2004)

Brian O'Mahony, an Irish medical laboratory scientist and chairman of the Irish Haemophilia Society, was elected WFH president in 1994. It was a time of great change at the WFH, and O'Mahony updated the constitution and modified the structure and administration of the WFH, bringing together the WFH's Executive Committee and Council as one body composed equally of doctors and people with hemophilia. Under his leadership, the WFH expanded its activities

in developing countries, creating and implementing sustainable programs to improve care and help countries to help themselves. Many WFH programs were established during the 1990s, and staff resources expanded greatly with programs, publications, and congress departments being created. One of Brian's great legacies was the Global Alliance for Progress (GAP), an ambitious 10-year program to diagnosis 50,000 new patients with hemophilia.



MARK W. SKINNER PRESIDENT (2004-2012)

Mark Skinner, a lawyer from Washington, D.C., and former president of the National Hemophilia Foundation, was elected WFH president in 2004. One of his first major initiatives as president was to undertake a strategic planning exercise in 2005, which led to the identification of a new vision for the WFH: Treatment for All. The new vision extended WFH services to include those with von Willebrand disease, rare factor deficiencies, and inherited platelet disorders. During Skinner's tenure, the WFH

has become a powerful voice for the bleeding disorders community, and has increased its programs to help train patient leaders to take on an advocacy role. His extensive fundraising experience helped strengthen the WFH's financial position and diversify its funding. He was the inspiration behind the WFH's Close the Gap campaign, which aims to raise \$5 million over the next three years. He has also played a lead role in developing the WFH's new research program, which was launched at the WFH 2012 World Congress.

TO LEARN MORE ABOUT THE WFH'S NEWEST PRESIDENT, ALAIN WEILL, READ MORE ON PAGE 3.

The April issue of Hemophilia World will be dedicated to marking the WFH's 50th anniversary. Stories will reflect the many accomplishments, milestones, and lessons learned.

WFH RECEIVES SIGNIFICANT HUMANITARIAN AID DONATION, PROVIDING HOPE TO THOSE IN NEED

Maria Carolina Arango

WFH PROGRAM OFFICER, HUMANITARIAN AID AND NMO ACCREDITATION

Pfizer Hemophilia is donating more than 35 million IUs of its recombinant factor IX therapy to the World Federation of Hemophilia (WFH) to help hemophilia B patients in underserved regions of the world. This donation will continue to strengthen the WFH's Global Alliance for Progress (GAP) Program and help provide those in need with valuable and life-saving medicines.

"This donation has the potential to impact people living with hemophilia B in more than 40 countries worldwide," said Alain Weill, WFH president. "The WFH relies on these donations to advance our goal of improving and introducing treatment in developing countries where care might not otherwise be available."

Since its beginnings in 1996, the mandate of the WFH Humanitarian Aid Program has been to channel donations of life-saving treatment products to people with hemophilia A, B, and von Willebrand disease in urgent need, and in countries where access to treatment products is very limited. By sending these donations, the

WFH also expects to show health authorities the efficacy of using clotting factor concentrates (CFC), and, in doing so, building a solid foundation for sustainable hemophilia care in the future.

Since 1996, people with hemophilia from 79 countries have benefited from 207 million international units (IU) of CFC channeled through the WFH Humanitarian Aid Program.

Enkhsuld "Injig" Terbish, a 15-year-old from Mongolia, is amongst those who have benefited from WFH donations. In May 2012, Injig was diagnosed with inflammation of the appendix, which required immediate removal. Before the surgery, he was given 4,000 IU of factor VIII—the total amount in reserve at the hospital. A donation from the WFH to the Mongolian National Center for Transfusiology arrived in time for Injig's recovery. His cousin, Ankhmaa Batchuluun, explained, "Overnight the anti-hemophilic factor improved his condition so much so that the next day my cousin was showing his parents how his body swelling's had regressed almost back to normal. Most importantly, he now has hope. We all have hope now."

Donations to individuals in countries of need are made possible thanks to the generous

contributions from our sponsors. Their ongoing commitment will continue to strengthen the Hemophilia Aid Program and build a solid foundation for care while providing life-saving medicine to those in need. ■



Humanitarian aid recipient Enkhsuld Terbish.

WFH IEQAS PROGRAM CONTINUES TO GROW AND INTRODUCES NEW ONLINE ENHANCEMENTS

Antonio José Almeida

WFH PROGRAMS DIRECTOR

Accurate and reliable laboratory diagnoses are key elements to monitor treatment of patients with bleeding disorders. While the quality of such diagnoses is improved by rigorous internal quality control procedures, an external quality assessment of a laboratory's performance is just as important.

The World Federation of Hemophilia (WFH) International External Quality Assessment Scheme (IEQAS) Program promotes high standards in the testing, diagnosis and treatment of bleeding disorders by monitoring the performance of laboratories worldwide. This is the only international external quality assessment scheme specifically for hemophilia, von Willebrand disease, and

other bleeding disorders that is recognized internationally.

Now in its ninth year of operation, the number of participating hemophilia treatment centres has increased from 84 in 2011 to 96 in 2012, with 14 new laboratories from developing countries participating in the program for the first time. Participating centres are located in both developing and developed countries, and consist of international hemophilia treatment centres (IHTCs), developed and developing hemophilia treatment centres involved in the WFH Twinning Program, and Global Alliance for Progress (GAP) Program or Country Program centres.

This year, for the first time, IEQAS participating centres are able to enter their survey results through a secure password-protected login page on the UK National External Quality Assessment

Service (UK NEQAS) for Blood Coagulation website at www.ukneqas.org.uk. Following analysis of survey results, individual reports for each of the participating centres are available to download through the secure password-protected website. So far, feedback received from participating centres has been very positive.

While the immediate aim of the IEQAS program is to improve performance of the participating centres, the long-term goal of the program is, as outlined by Alok Srivastava, MD, WFH vice-president medical, "to help each centre establish their own external quality assessment scheme so as to provide such service to all labs in that country." ■

The WFH is grateful to the Novo Nordisk Haemophilia Foundation for their sponsorship of the IEQAS Program.

NEW WFH INITIATIVE LAYS THE CORNERSTONE FOR BLEEDING DISORDERS CARE

Michelle Grady

WFH COMMUNICATIONS OFFICER

The World Federation of Hemophilia (WFH) announced, as part of its 50th anniversary celebration, its commitment to accelerate the work to close the gap in care worldwide. An estimated 1 in 1,000 people have a bleeding disorder, but 75 per cent of these still receive very inadequate treatment or no treatment at all. This is especially evident in developing countries, where the baseline infrastructure, resources, and time do not exist to tackle chronic conditions like bleeding disorders. The low healthcare standards in many of these areas also prevent the full uptake of support that the WFH provides through its other programs.

To address this challenge, the WFH is launching the Cornerstone Initiative, which is specifically aimed at supporting treatment and care for underserved countries where the gap in care is the greatest. “Our objective is to lay a foundation of basic care and to build partnerships that will lead to



an integrated and sustainable structure of patient support and care delivery,” says Antonio Almeida, WFH programs director.

Over 10 years, the Cornerstone Initiative will select 15 target countries from among the WFH associate national member organiza-

tions—both newly recruited and prospective—where current standards of care for bleeding disorder patients, if they exist at all, are well below the standards of care of more developed countries. Then, over a two- to four-year period, this initiative will aim to improve two or three aspects of care development, scaled to the skills and resource capacity of each country. These areas could include developing and improving diagnosis capacity, providing basic training in the management of bleeding disorders, and strengthening patient organizations.

“The success of this new initiative will lead to the dramatic improvement in the lives of patients living in the most impoverished regions, the establishment of country-wide networks that meet the needs of people with bleeding disorders, and a greater capacity for shared knowledge through networking,” says Almeida.

The Cornerstone Initiative will help make the WFH vision of Treatment for All a reality. Together, we will help close the gap. ■



WHERE WE HAVE BEEN

WORLD HEMOPHILIA DAY 2013

APRIL 17

50 YEARS OF ADVANCING TREATMENT FOR ALL

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WHERE WE WANT TO BE

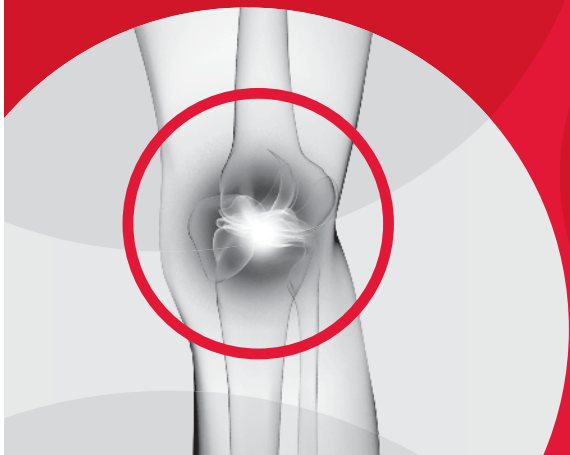


TOGETHER, WE CAN CLOSE THE GAP
www.wfh.org/whd





13TH INTERNATIONAL MUSCULOSKELETAL CONGRESS



Chicago, U.S.A.
April 18-21, 2013

Abstract submission deadline:
February 3, 2013

Late registration deadline:
March 22, 2013



www.wfh.org/msk2013

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IHTC PROGRAM: 40 YEARS OF EXCELLENCE

Michelle Grady

WFH COMMUNICATIONS OFFICER

In 1972, the World Federation of Hemophilia (WFH) launched the International Hemophilia Training Centre (IHTC) Program, with the mandate to offer training fellowships and workshops to medical and paramedical staff from developing countries. Outlining the vision of the IHTC Program, Anthony Britten, MD, IHTC founding chair stated, "The selected centres would be assuming a responsibility not receiving an honour. These centres will bring inspiration to many and leadership to all of us."

More than 550 fellowships have been granted to medical professionals in 80 countries since 1972, and every year a selection committee awards 35 applicants a four- to six-week fellowship. Many of these fellows have gone on to become key leaders in the care of bleeding disorders in their own countries. During a WFH session at the WFH World Congress 2012 in Paris, France, on the history of the IHTC Program,

More than 550 fellowships
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professionals in 80 countries
since 1972

some of these individuals shared their experiences with delegates.

Chean Sophal, MD, from the Pediatric Hematology Clinic in Cambodia, was the first Cambodian to receive a fellowship. He was selected for fellowship training in 2008 and learned how to diagnose bleeding disorders, perform laboratory testing, apply physiotherapeutic techniques, and perform surgery in a patient with a bleeding disorder.

"I am now a consultant in pediatric hematology and chief of the pediatric hematology clinic," he said. Dr. Sophal has also set up a coagulation laboratory, developed a national registry, and established the Cambodian Haemophilia

Association, which is registered as a national member organization (NMO) with the WFH.

Sukesh C. Nair, MD, of Christian Medical College in Vellore, India, offered the mentor's viewpoint. "Our hematology department sees a large number of patients and delivers care 24/7," said Dr. Nair. The college has administered a national hemophilia training program since the mid-1990s, and, since 2004, has trained 22 fellows.

"We make an effort to understand the training and experience of the candidate, to determine the needs of the individual or the department. Every day, the faculty member has dedicated time with the fellow. Everyone spends time in the laboratory and follows the treatment of the patient," he said. A major emphasis is hands-on training aimed at maximizing real-life situations.

"It has been a privilege to be an IHTC. We have learned and gained from these interactions," said Dr. Nair. ■

The IHTC Fellowship Program is funded solely by Bayer.

CALENDAR OF EVENTS

World AIDS Day

December 1, 2012

National AIDS Trust

www.worldaidsday.org

ASH Annual Meeting

December 8–11, 2012—Atlanta, U.S.A.

American Society of Hematology

Tel.: +202-776-0544

Fax: +202-776-0545

Email: ashregistration@jspargo.com

www.hematology.org

6th Annual Congress of the European Association for Haemophilia and Allied Disorders

February 6–8, 2013—Warsaw, Poland

Tel.: +41 22-33-99-579

Fax: +41 22-33-99-631

Email: eahad2013@mci-group.com

www.eahad2013.pl

International Plasma Protein Congress 2013

March 5–6, 2013—Dublin, Ireland

Tel.: +32 (0)2 705 5811

Fax: +32 (0)2 705 5820

www.ippc.net

13th WFH Musculoskeletal Congress

April 18–21, 2013—Chicago, U.S.A.

World Federation of Hemophilia

Tel.: +1-514 875-7944, #2837

Email: msalas@wfh.org

www.wfh.org/msk2013

IPFA/PEI 20th International Workshop on "Surveillance and Screening of Blood Borne Pathogens"

April 23–24, 2013—Helsinki, Finland

Tel.: +31 20 512 3561

Email: info@ipfa.nl

www.ipfa.nl

HEMATOLOGY 2013 IV International Workshop on Hemophilia

May 20–24, 2013—Havana, Cuba

Tel.: 537 643 8268/643 8695/208 5199

Fax: 537 644 2334/202 8382

Email: hematologia2013@infomed.sld.cu

<http://hematologia2013.sld.cu>

NEWS FROM AROUND THE WORLD

WFH regional update



Left: Panamanian Foundation conducting interviews. Right: John E. Bournas, WFH CEO/Executive Director, with a young patient from Mali who is being treated in Algiers, Algeria.

AFRICA AND EASTERN MEDITERRANEAN

Algeria

In April 2012, as part of the Global Alliance for Progress (GAP) project in Algeria, the World Federation of Hemophilia (WFH) organized a two-day nurses training workshop in Algiers with the cooperation of the Algerian Hemophilia Association (*Association Algérienne des Hémophiles*). WFH delegates had a half-day meeting with the Algerian General Secretary of Health and his team. Discussions focused on current hemophilia care practice in Algeria and how the GAP Program could help the Algerian Ministry of Health to improve care in the country. The General Secretary of Health also asked the WFH to assist the ministry in reviewing the tendering process for clotting factor concentrates.

Bahrain

The WFH organized a one-day nurses training workshop in Manama, with the cooperation of the Bahrain Ministry of Health and the Bahrain Bleeding Disorder Society. The training took place at the main hospital in Manama where 60 nurses from different departments attended the training. Delegates discussed potential future training with hospital management

in other areas of the multidisciplinary approach.

Qatar

The WFH organized a one-day nurses training workshop in Doha, Qatar, in March, with the cooperation of the Qatar National Hemophilia Society. Twenty-two nurses from Hamad Medical Centre and Al-Amal Hospital attended this training. WFH delegates also visited the two hospitals and discussed potential future training with hospital management in other areas of the multidisciplinary approach.

AMERICAS

Panama

The Panamanian Foundation of Hemophilia (*Fundación Panameña de Hemofilia*) developed a project last year to intensify outreach in their country in order to better understand the needs of the bleeding disorder community. A particular emphasis was put on the psychosocial aspects of hemophilia and the need to develop a more detailed database. This involved strategically thinking about methods to gauge the needs of the community and how to carry out this initiative. Over a hundred interviews have been conducted so far with patients and families and now pro-

gram visits will begin in the remote interior of the country. There have been many discussions between the Panamanian Foundation and patients, which has allowed for greater reflection on what are the concerns of the community and how to respond to its needs. This has been a very enriching experience for the Panamanian Foundation and for the whole community. The initiative will continue into next year, after which the results will be compiled and analyzed.

Uruguay

The Uruguayan Hemophilia Association (*Asociación Hemofílicos de Uruguay*) has been implementing an initiative to build a strong network between health professionals, health authorities, patients, and families who comprise the bleeding disorders community in the country. Educational workshops have also been conducted in four different regions of the Uruguay thus far, with excellent attendance and participation. Patients who are athletes and are active in their communities shared their experiences to support the message that a person with hemophilia can also have a good quality of life. The objectives of this initiative were to educate and promote good health, to discuss injury prevention, facilitate smoother inte-

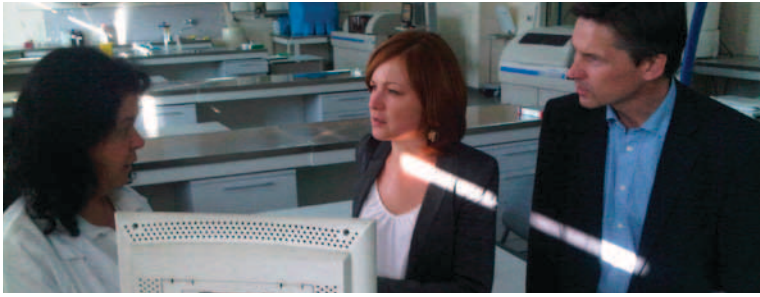
gration into society with a focus on the musculoskeletal aspects of hemophilia, and to cultivate relationships with all those involved. This has been a very empowering experience for the Uruguayan Association and has strengthened the relationship between all the different parties involved in hemophilia care in Uruguay.

ASIA AND WESTERN PACIFIC

China

In Hong Kong, a two-day master class on hemophilia and vWD was held in February for more than 75 physiotherapists and nurses from Hong Kong, China, Thailand, and Malaysia. It was the first time such an event was held in Hong Kong. An educational meeting with the Hong Kong Hemophilia Society and the WFH was held and was attended by about 90 patients and families.

In April, the Ministry of Health convened a special meeting with the National Development and Reform Commission, State Food and Drug Agency, Ministry of Human Resources and Social Security, medical experts, patients and industry. Topics included current status of care, opportunities, challenges, and unmet needs.



Jerzy Windyga, MD (far right), and lab expert Beata Baran (centre) conduct a centre twinning assessment visit in Tirana, Albania.

In conjunction with the meeting, Dr. Renchi Yang, Secretary of the Hemophilia Treatment Centre Collaborative Network China provided a formal document on the status of hemophilia care with suggestions for improvement and support to the Ministry of Health.

Maldives

In August, WFH representatives visited the Maldives to meet with executive committee members of the Hemophilia Society of Maldives and the Minister of Health, visited the Indira Gandhi Memorial Hospital (IGMH), and participated in educational lectures for IGMH health-care professionals. For the first time in the Maldives, doctors and nurses were taught how to infuse patients using factor concentrates received from a WFH humanitarian aid donation. The Hemophilia Society of Maldives was established in August 2011.

EUROPE

Albania

In September, Dr. Jerzy Windyga and lab specialist Beata Baran from the Institute of Hematology and Transfusion Medicine, Warsaw, Poland, visited the Albania Hospital and University Center of Tirana,

Albania, to assess the goals of their new hemophilia treatment centre twinning. In close cooperation with the patient organization and the Ministry of Health, they will focus on creating the national registry, assembling a multi-disciplinary care team, and implementing national treatment protocols.

Armenia

An international round-table took place in September, in Yerevan, with medical professionals and national patient organization participants from the U.K., Russia, and Georgia. The Ministry of Health of Armenia agreed to revise the tender process by passing a law that allows for purchasing directly from international pharmaceutical companies. Laboratory training also took place to improve von Willebrand disease testing.

Kyrgyzstan

Representatives from the Mary M. Gooley Hemophilia Center and chapter team visited their centre twin in Bishkek, Kyrgyzstan, last April. They had joint physiotherapy exercises in a pool, psychosocial group sessions for the first time, nurse training with WFH publications, and clinics for the patients. A WFH delegation also met with the Deputy-Minister of Health who agreed to raise the supply of factor by 10 per cent for 2012. ■



Alok Srivastava, MD (left), WFH vice-president medical, assisting in the treatment of patients in the Maldives.

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Jan Willem André de la Porte

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Compendium of Assessment Tools: LFB
HemoAction e-games: Novo Nordisk

HTC Passport Web Directory: Biogen Idec

Hemophilia

Inhibitors web section: Grifols, Novo Nordisk

Online Laboratory Manual: Grifols

von Willebrand Disease web section: CSL

Behring, Grifols, LFB, Octapharma

Publications

Medical Advisory Board E-newsletter: Biogen Idec Hemophilia

World Hemophilia Day

Baxter, Bayer, Biogen Idec Hemophilia, CSL

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Hemophilia

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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:

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