

HEMOPHILIA WORLD

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WFH 2014 World Congress in Melbourne, Australia

An unforgettable Congress experience
awaits you "Down Under"

/ Jens C. Bungardt, WFH congress and meetings director

The WFH 2014 World Congress, the largest international meeting dedicated to hemophilia, von Willebrand disease, rare factor deficiencies, and inherited platelet disorders, will take place May 11 – 15, 2014, in Melbourne, Australia.

Considered as one of the world's most livable cities, Melbourne is celebrated for its friendly locals, efficient services, laid-back atmosphere, fine wine and dining; it is also known for its world-class meeting facilities within easy walking distance of hotels, restaurants, and attractions in the Melbourne central business district. Situated on the banks of the picturesque Yarra River, Melbourne offers all the right ingredients for a great Congress, where delegates from around the world come together to network, gain knowledge, and share insights about treatment and care for hemophilia and other inherited bleeding disorders.

Melbourne is one of Australia's largest cities and is the vibrant capital of the state of Victoria. It is located at the tip of the Australian south-east coast, on the shores of Port Phillip Bay. Known as the "Garden City" due to its lavish parks, Melbourne is very cosmopolitan, with striking architecture both old and modern.

However, it is within Melbourne's hidden laneways that the city comes to life. Here you can experience Melbourne's contagious passion for coffee at chic cafés, sample award-winning local beer and wine at boutique bars, discover boutique designers, and gain a unique



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insight into local culture by visiting avant-garde art galleries.

CONGRESS PROGRAM

The WFH 2014 World Congress program will reflect both the latest in medical research and key issues concerning healthcare professionals and patients in the field of hemophilia and other inherited bleeding disorders.

The medical program will focus on the most recent advances in clinical and basic science related to hemophilia and other bleeding disorders, highlighting some of the most recognized names in the field, as well as top research specialists.

Plenary topics will include: newer insights of primary hemostasis; epidemiological aspects of inhibitor development; immunology of inhibitors and immune tolerance induction; pathogenesis of arthropathy in hemophilia; current status of novel products for hemostasis; and the changing paradigm of prophylaxis with novel therapies.

Medical sessions will include: genomics of bleeding disorders; update on gene therapy trials; higher-dose models of prophylaxis; and other novel therapies. The medical track will also include over 50 free papers from the best abstract submissions in the various scientific categories, reinforcing the latest and most innovative program to date.

The multidisciplinary program will address the essential concerns in the care for people living with inherited bleeding disorders. Important



topics of discussion will include: management of chronic pain; integrated information systems; explanations and strategies to overcome non-adherence; ageing gracefully with hemophilia; leadership development strategies; living healthily with hemophilia; future of hemophilia care; and approaches to inhibitor management.

The WFH 2014 World Congress program will also include specialized tracks in musculoskeletal, laboratory sciences, dental, psychosocial, and nursing disciplines that are currently under development.

DISCOVER DOWN UNDER

The WFH 2014 World Congress in Melbourne might be a once in a lifetime opportunity to visit down under and discover some of Australia's many treasures in the days before or after the congress.

Many of Victoria's great attractions are easily accessible as day trips from Melbourne. Follow the Great Ocean Road, which offers breathtaking sea views and you will be rewarded with amazing landscapes, charming villages, and delicious, fresh, local food, and

wine. Take your pick from Yarra Valley's stunning vineyards, rest and relax at an award-winning day spa, tee-off at a world-class golf course, swim with dolphins, or get up close and personal with wildlife and penguins at Phillip Island Nature Park.

Nature is easily accessible, from the possums living in backyard trees, to the brightly colored lorikeets that feed in the gardens. In the sun-scorched Australian Outback, kangaroos, emus, giant lizards, and eagles are easily spotted. The steamy rainforests of New South Wales and tropical North Queensland are a biological time capsule, dating back to when flowering plants first appeared on the planet. National Parks like Kakadu and The Grampians offer a treasury of bird species, wildlife and Aboriginal rock art sites.

Register before November 11, 2013, and save; visit the congress website at www.wfh2014congress.org for detailed information on the congress sessions, workshops, pre- and post-tours, hotel information, social events, and more. We look forward to seeing you in Melbourne!

ABOVE: Skyline of Melbourne, Australia



6 REASONS TO ATTEND THE WFH 2014 WORLD CONGRESS

- 1 PARTICIPATE IN THE LARGEST INTERNATIONAL MEETING FOR THE GLOBAL BLEEDING DISORDERS COMMUNITY and network with thousands of members, from around the world, convening in Melbourne, Australia;
- 2 GAIN KNOWLEDGE of cutting-edge scientific research and clinical trials, profiling future advances in treatment products and clinical care;
- 3 SHARE INSIGHTS on holistic patient healthcare issues and multidisciplinary care;
- 4 EXCHANGE WITH HEALTHCARE PROFESSIONALS AND PATIENTS on challenges and solutions to improve treatment and care throughout the world;
- 5 COLLABORATE WITH LEADERS of various stakeholder groups to ensure ongoing innovation that advances the WFH's vision to achieve Treatment for All, laying the foundation for the next 50 years;
- 6 DISCOVER UNIQUE AUSTRALIA with your family before or after the Congress, as this might be a once in a lifetime opportunity to visit Down Under.

PRESIDENT'S COLUMN

Our vision for the next 50 years

This year, the World Federation of Hemophilia (WFH) has focused special attention on what it has accomplished in its first 50 years. This reflection has, naturally, encouraged many of us to contemplate the next 50 years and what the future holds for our community.

/ Alain Weill, WFH president

Looking forward, we will continue to advance the vision of Treatment for All — with a special focus on the next decade of global development. For inspiration, we need only to look back at what devoted volunteers, healthcare workers, and researchers have accomplished since the WFH was founded in 1963.

Our hope is not as unrealistic as it would have been 50 years ago. Recent research into gene therapy offers hope for a cure, and sooner than that, an improved quality of life may be afforded through the development of longer-lasting factor concentrates. However, these exciting new developments do not relieve the immediate needs of those who continue to lack adequate care. Therefore, our top priority remains to improve care in those countries where proper treatment is lacking. While hundreds of thousands of people with hemophilia have already been helped worldwide by the WFH, we know all too well that 50 years into our history, diagnosis and adequate treatment are still out of reach to 75 per cent of those affected. In developing countries, where resources are limited, there remains a gap in care that must be closed as soon as possible.

To this end, we have set out ambitious objectives through three key initiatives: the second decade of the Global Alliance for Progress (GAP) Program, the Cornerstone Initiative, and the WFH Research Program.

The second decade of GAP aims to diagnose or identify 50,000 more people with an inherited bleeding disorder, with a special emphasis to find at least 50 per cent of these individuals in the most impoverished countries globally. The aim in the next decade is to target 20 such countries for the program.

Likewise, the new WFH Cornerstone Initiative specifically focuses on the most underserved regions of the world where the gap in care is greatest. Nigeria is the first country selected for the program. The goal is to assist countries that have a low gross national income, inaccurate (or no) diagnosis capabilities, and a young patient organization. With carefully targeted support, the WFH will lay the cornerstone upon which future building and development may occur. *Read more about the WFH Cornerstone Initiative on page seven.*

We have learned in the past 50 years that support for research has also been a key component for improving people's lives. We remain committed to that objective through the new WFH Research Program. *For more, see column on page four by Alok Srivastava, MD, WFH vice-president medical.*

As in the past, we continue our work and remain focused on advancing the best available treatment to all in need, wherever they may live. While current research focuses on improved and more accessible treatment options, we are committed to closing the gap in care that exists between those who need it and those who are able to provide it.

We do that by continuing to support initiatives that have proved effective, so far, and by continuing to innovate. Our immediate goal is to continue to cooperate with national member organizations around the world, with treatment and advocacy partners, and with our corporate sponsors to advance our vision of Treatment for All.

This involves working closely with our national member organizations to provide information, medical training, and advocacy workshops; to support our hemophilia treatment centres through effective twinning programs; to encourage a new generation of volunteer leaders to be involved with their own organizations and the WFH; to collect



“As the next generation of treatment and care options lie before us, the WFH will continue to support those around the world, who work collaboratively to improve care.”

accurate data and statistics; to ensure product safety and supply; to raise funds through the Close the Gap Campaign; and to channel vital humanitarian aid donations to those in need.

As the next generation of treatment and care options lie before us, the WFH will continue to support those around the world, who work collaboratively to improve care. We will provide opportunities for them to gather and exchange ideas at a variety of meetings, forums, workshops, and congresses, such as the WFH 2014 World Congress in Melbourne, Australia, from May 11 to 15, 2014. Our Congresses attract thousands of dedicated individuals who are working towards our common goal. For more information, please visit www.wfh.org/congress/en/.

For the next 50 years, we will continue to focus on the task at hand: Treatment for All — and as soon as possible.

VP MEDICAL WRITES

WFH launches research program

In April, at the WFH 2nd Global Research Forum, the WFH launched its new Research Program, which aims to encourage and support clinical research that will build the evidence base for the optimal management of inherited bleeding disorders.

/Alok Srivastava, MD, WFH vice-president medical

The program currently has two components:

- Clinical Research Grant Program
- Enhanced data collection

Over the last year and a half, we have laid the groundwork for a multi-year initiative to bring together these components in a comprehensive program.

Clinical Research Grant Program

In April, we launched our new Clinical Research Grant Program, which provides support for international clinical investigation relating to the clinical management of hemophilia A and B, von Willebrand disease, rare factor deficiencies, and inherited platelet disorders.

The program will award the best proposals that address critical clinical issues of broad international significance. There are categories of awards with different levels of funding: \$10,000-\$15,000 per year and \$35,000-50,000 per year, for up to two years. Up to four grants (two in each budget category) can be awarded each year.

The application process opened June 1 and the deadline for submitting an initial letter of intent is August 31. Applications will be peer-reviewed by the multidisciplinary Grant Review Committee and shortlisted applicants will be invited to submit a full proposal by December 1. The grant recipients will be announced February 2014.

The program is open to applicants from all countries who are affiliated with a recognized medical, scientific, or academic institution, hemophilia or inherited bleeding disorder treatment centre, or WFH national member organization (NMO) or its affiliated chapters. For more information, visit www.wfh.org/crgp.

Enhanced Data Collection

This component aims to improve the quality and quantity of data collected by the WFH. The WFH currently collects demographic and other data on inherited bleeding disorders from over 100 countries, via its global survey. Through the Research Program, we are improving the data collection system and its validation, as well as adding new dimensions to its analysis.

A web-based data collection system is being developed to increase accessibility and usability, including live backups to reduce problems related to internet connection. Data can be entered directly (to minimize transcription errors) and will be validated immediately to reduce data entry errors and inconsistencies. The new data system is undergoing testing and will be launched for our annual survey in 2014.

Queries on such criteria as economic, geographic, factor usage, and gender can be used to access more than 10 years of global data, and the system will be able to output raw data for analysis in various statistical and epidemiological software solutions. Once the system is fully tested and launched, we will be looking at ways to make the survey results more accessible and interactive online.

Going forward, we also plan to collect data on specific research questions from selected NMOs or major treatment centres around the world that are able to participate in such a project and provide the necessary data. Many unresolved issues in hemophilia management could be addressed through such a program that will lead to better care around the world.

The WFH Research Program is supported with funding from Western Pennsylvania 340B Program, Baxter, Bayer, and Biogen Idec Hemophilia.



“The program will award the best proposals that address critical clinical issues of broad international significance.”

WFH Guidelines for the Management of Hemophilia

The WFH *Guidelines for the Management of Hemophilia*, released in July 2012, have been accepted by the National Guideline Clearinghouse (NGC) for hosting on their website. They have also been endorsed by the International Society on Thrombosis and Haemostasis (ISTH). *Read more on page six.*

These current initiatives of the WFH demonstrate our ongoing support for advancing standards of care for hemophilia, and our commitment to enhanced data collection and research. As any new initiative, this will have its own curve of evolution. I invite your participation in this program through proposals, as well as comments and suggestions for its improvement.



The CN Tower, one of the world's tallest freestanding structures, lights up in red on April 17 to commemorate World Hemophilia Day. Photo: VIDpicta.

World Hemophilia Day 2013

50 Years of Advancing Treatment for All

/Sarah Ford, WFH communications manager

World Hemophilia Day 2013 took on a special significance as the World Federation of Hemophilia (WFH) marked 50 Years of Advancing Treatment for All.

In spite of the tremendous progress made over the last half century, the vast majority of people with bleeding disorders living in developing countries do not have access to proper care.

During the period leading up to World Hemophilia Day, the global bleeding disorders community reflected on where we have been, where we want to go, and that together, we can Close the Gap.

The WFH connected with the global online community, on the WFH's Facebook page at



www.facebook.com/wfhemophilia. Videos were posted on YouTube each week leading up to April 17, sharing the hopes and wishes of different community members for the next 50 years.

"One of the greatest benefits of participating in World Hemophilia Day is the recognition that our community is more powerful when we work together," says Alain Weill, WFH president. "People from around the world will mark this day and raise awareness about the need to achieve Treatment for All."

The WFH is grateful to Baxter, Bayer, Biogen Idec Hemophilia, CSL Behring, Novo Nordisk, SOBI, Pfizer, and Precision BioLogic for providing funding to support World Hemophilia Day 2013.

Marking WFH's 50th anniversary

During the WFH Global Research Forum, held in April, in Montreal, Canada, the WFH hosted a reception to mark 50 years of serving the global bleeding disorders community. Following the reception, a presentation highlighting important milestones and achievements from the past 50 years was given by past WFH presidents Brian O'Mahony and Mark W. Skinner. WFH vice-president medical Alok Srivastava, MD, spoke about the future of the WFH and the global bleeding disorders community. This presentation was introduced by WFH CEO/executive director, John E. Bournas.

An especially poignant moment followed the premiere of the 50th anniversary video, *The Journey Begins*, as the WFH was honoured by the attendance of Gina Schnabel, the daughter of WFH founder Frank Schnabel. After viewing the video, she told the audience that the video captured the essence of her father's work.

"He loved what he was doing and I am so proud to see what you continue to do. I

appreciate it so much for our family," said Gina Schnabel.

During an interview at the reception, Schnabel discussed the growth of the WFH over the past 50 years and her father's legacy. "He accomplished so much as a lay person and he was so good at what he did. He would be so proud."

"I am in awe of this organization, just seeing what it has accomplished."



Gina Schnabel and David Page during the WFH Global Forum Reception on April 15.

WFH 50th anniversary webcast

To commemorate its anniversary, the WFH launched a webcast on June 25, the day the WFH was founded. This webcast features presentations given by past WFH presidents Brian O'Mahony and Mark W. Skinner, along with Alain Weill, current WFH president.

Visit www.wfh.org/50 to watch these past and present WFH presidents talk about their personal experiences, highlight important events from the past 50 years, and explore the future vision for our community.

WFH treatment guidelines earn international recognition

Since its publication less than a year ago by the World Federation of Hemophilia (WFH), the second edition of the *WFH Guidelines for the Management of Hemophilia* has been lauded by the global bleedings disorders community as the primary source of up-to-date, evidence-based recommendations for the clinical management of hemophilia.

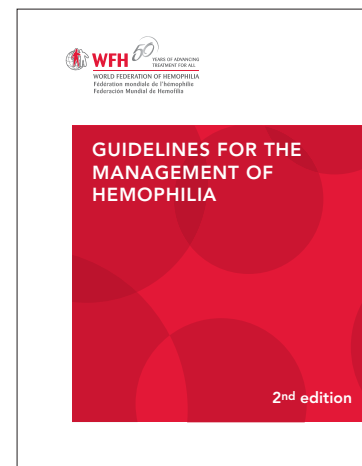
/Jennifer Laliberté, WFH educational materials manager

First published in *Haemophilia* in July 2012, the guidelines have since been accepted for publication by the National Guideline Clearinghouse (NGC) at www.guideline.gov and have also been endorsed by the International Society on Thrombosis and Haemostasis (ISTH). The WFH has published its own edition, freely available for download on the WFH website. Spanish, French, and Chinese translations have been produced, while Russian and Arabic editions are currently underway.

An initiative of the Agency for Healthcare Research and Quality of the U.S. government Department of Health and Human Services, NGC is a well-established platform for dissemination, implementation, and use of

evidence-based clinical practice guidelines. After meeting the rigorous inclusion criteria, the WFH guidelines became the first related to hemophilia to ever be hosted on the NGC website. This is a very significant achievement for the WFH and should serve as an important milestone for advocacy efforts by the bleeding disorders community in North America and, indeed, around the world.

The endorsement by the ISTH, a worldwide organization with a membership of over 3,000 clinicians and researchers involved in the prevention, diagnosis, and treatment of thrombotic and bleeding disorders, is also noteworthy. In its careful review, the ISTH noted the involvement of many experts from around the world, not only within the writing group but also in the elaborate review process. The society stated that these practical guidelines for the management of hemophilia



clearly incorporate a wide range of views, and that the recommendations are consistent with current best practice.

By compiling these guidelines, the WFH aims to assist healthcare providers seeking to initiate, maintain, or enhance hemophilia care programs, encourage practice harmonization around the world and, where recommendations lack adequate evidence, stimulate appropriate studies.

For more information or to download *Guidelines for the Management of Hemophilia*, visit the WFH website at www.wfh.org/en/resources/wfh-treatment-guidelines.

Hemophilia care surveyed in Europe

In 2009, I conducted a survey on the level of hemophilia treatment and care in Europe with particular emphasis on how the European Principles of Haemophilia Care reflect the reality of the continent. At that time, 19 countries returned the survey and the results were published.

/Brian O'Mahony, president, European Haemophilia Consortium

In 2012, we repeated the survey on behalf of the European Haemophilia Consortium (EHC) and, on this occasion, 35 countries responded from a possible total of 41 countries. Between 2009 and 2012, Europe has faced a very difficult economic situation. Of the 19 countries who replied in 2009, and again in 2012, 12 had decreased national health budgets, but, despite this, 15 of the 19 countries had increased their per capita factor VIII use.

The strong organization of hemophilia care in many countries in Europe, in my view,

helped ensure that funds for hemophilia resources were targeted for reduction less than the general national health budgets. This concerted effort towards organization includes national registries in 27 European countries; co-ordinating groups, including EHC national member organizations (NMOs), in 19 countries; and effective cooperation between NMOs and hemophilia clinicians. Access to some elements of comprehensive care have improved in some countries, but deficiencies remain in the provision of social and psychological support in 20 countries, pain management in 19 countries, and physiotherapy in 12 countries.

The majority of countries have access to home treatment and many have prophylaxis for children, although few countries offer

prophylaxis to the majority of adults. The survey has assisted us in developing our recommendations to the European Union (EU) Commission on Haemophilia Care, and will provide a useful baseline to compare results when the survey is repeated, with results, hopefully, from all 41 countries.

A full information pack, monograph, and poster were sent to all EHC NMOs, together with individually tailored PowerPoint presentations for each of the 35 responding countries, which they can use as an advocacy tool.

Nigeria becomes first country to participate in the WFH Cornerstone Initiative

In January 2013, the World Federation of Hemophilia (WFH) officially launched the Cornerstone Initiative, a new healthcare development project specifically aimed at supporting treatment and care for people with bleeding disorders in underserved countries and regions where the gap in care is the greatest. Nigeria was selected as the first WFH Cornerstone Initiative country.

/ Antonio José Almeida, WFH programs director and Assad Haffar, WFH deputy programs director and regional program manager, Middle East and Africa

Today, only nine per cent of the total number of patients identified with a bleeding disorder worldwide are from countries with a per capita Gross National Income (GNI) greater than US\$1,500. This group of countries represents one third of the world's population.

In many developing countries, where diagnosis and treatment are non-existent, the baseline infrastructure, resources, time, and expertise do not exist to tackle chronic conditions like bleeding disorders.

The new Cornerstone Initiative

Through the new Cornerstone Initiative, the WFH will work to lay the foundation upon which future care and development may occur. Our support to improve care will not be limited by geography, economic capacity, or the existing healthcare infrastructure of a country. This will help make our vision of Treatment for All a reality.

The work under the Cornerstone Initiative is carried out within the framework of the WFH comprehensive development model. Due to their less developed infrastructure, many countries in underserved and impoverished regions have not been able to fully take advantage of this development model. Through support and training, this initiative will help these countries improve care and benefit, at a later stage, from WFH's full range of development programs and activities.

Over a 10-year period, the Cornerstone Initiative will select 15 target countries or regions from among the WFH National Member Organizations (NMOs) — both newly recruited and prospective — where current standards of care for bleeding disorders patients, if they exist, are inadequate or well below the standards of care of more developed countries. The WFH will work with targeted Cornerstone



Educational symposium on hemophilia for healthcare professionals from Abuja, Nigeria.

countries over a two- to four-year period to improve two or three basic aspects of care development, scaled to their skills and resource capacity.

With the Cornerstone Initiative, the WFH now has a continuum of development programs ranging from situations of limited, or no care, to achieving a sustainable national care program that can be deployed and targeted to address the unique needs of each country.

Introducing the first Cornerstone Initiative country: Nigeria

Thanks to the Cornerstone Initiative, in 2013, we have begun to build a foundation for sustainable care in Nigeria. In this African country, the use of clotting factor concentrates stands at 0.002 international units (IUs) per capita; far below the minimum 1 IU per capita target needed to sustain a basic quality of life.

In the next three to four years, the work of the WFH in Nigeria, through the Cornerstone Initiative, will focus on three areas:

1. Developing and improving diagnosis capacity;

2. Providing basic training to healthcare professionals on the management of bleeding disorders; and
3. Strengthening the national patient organization, the Haemophilia Foundation of Nigeria (HFN).

In February 2013, in cooperation with the HFN, the WFH organized an educational symposium on hemophilia for healthcare professionals from Abuja, and surrounding areas, at the National Hemophilia Hospital of the capital.

Megan Adediran, founder and president of the HFN, spoke during the symposium of the importance of medical and lay cooperation in advocating effectively with health authorities.

For 2013, the main activities under the Cornerstone Initiative for Nigeria are taking place in the capital city of Abuja. The WFH is looking at extending its support and training to other major cities, such as Lagos, Ibadan, and Kaduna, for the duration of the project.

For more information about the Cornerstone Initiative, please visit www.wfh.org and select the OUR WORK website section.

MESSAGE FROM THE CHAIR

Your support will change lives

Give to the Close the Gap Campaign

/Deon York, WFH fund and resource development chair

The World Federation of Hemophilia (WFH) has made substantial progress in bringing about sustainable treatment around the world. However, vast needs remain. A child growing up with a bleeding disorder in a developing country, like Saeed in Palestine (*see below profile*), suffers needlessly, experiencing the crippling effects of untreated bleeds. Children often miss days of school or don't attend school at all.

You can help the WFH end this suffering. Visit www.wfh.org/closethegap to learn more about our cause and how the work you support saves lives.

WAYS OF GIVING

There are many different ways to give and show your support. However you decide to give, your gifts will be tripled through the Patron's Challenge.

The Patron's Challenge – Your donation will be TRIPLED

This unique challenge matches all giving to the Close the Gap campaign on a 2:1 basis up to US\$500,000. Take advantage of the opportunity to make your gift go even further toward closing the gap in care for people with bleeding disorders.

This means:

YOUR GIFT OF		IS NOW WORTH
\$5	→	\$15
\$10	→	\$30
\$50	→	\$150

Your recurring gift of \$10/month is worth \$360 instead of \$120 after 12 months.

Monthly giving

Monthly giving is a powerful way to make a difference. See how a modest recurring monthly donation can add up to significant gifts:

\$5 per month	x 12	= \$60
\$10 per month	x 12	= \$120
\$15 per month	x 12	= \$180
\$25 per month	x 12	= \$300

Imagine the potential of 50 people giving \$5 per month for 12 months: $50 \times \$5 \times 12 = \$3,000!$

Or of 500 people giving \$5 per month: $500 \times \$5 \times 12 = \$30,000!$

Tribute gifts

You can make a gift in memory of a loved one or in honour of someone special. We can send a notification of your gift to a family member



Deon York

or friend of the person you are honouring or remembering.

Matching gifts

You can double the value of your gift without any further cost. Many employers match donations made by employees to eligible non-profit organizations. Ask your human resources or public relations department if your employer has a matching gift program. Contact us at wfh@wfh.org to find out more.

Visit www.wfh.org/closethegap to learn more.

CLOSETHEGAP
Campaign 2012-2014

How to give

Use the envelope in this issue of *Hemophilia World*. Simply fill out the attached form and send it in.

Visit www.wfh.org/donate. All information given online is 100 per cent secure.

Saeed's story

I was diagnosed with factor VIII deficiency at the age of six months, after bleeding from a vaccination needle. My hemophilia created suffering not only for me but also for my family. I was the youngest son and my parents were ageing. It was very difficult for them to take me to hospital and find factor concentrates.

As a result, severe internal bleeds damaged my joints and I had to have a total knee replacement. With no factor concentrate available, I still have to put up with pain and bleeding. Dealing with it tires me out. However, I will not give in and am working hard to live a normal life.

Although hemophilia disrupted my education, because I often missed school, I still managed to complete my university studies

and am now working as a medical lab technician in a hospital. I also got married recently and with the support of my wife, Rawan, look forward to a brighter future and starting our own family.

I am also grateful for the support of the WFH to the Palestine Hemophilia Foundation. As a volunteer for the Foundation, I try to help other hemophilia patients and their families with information on treatment, exercises, and healthy lifestyle, as well as advice on how to cope with pain and bleeds.

Sometimes, encouragement is all they need.

Saeed Mohammad Al Suleimyeh
Youth Committee Chair, Palestine Hemophilia Foundation

A strategic vision to improve laboratory diagnosis in Brazil

/Luisa Durante, WFH regional program manager, Americas

The Ministry of Health, the Brazilian Federation of Hemophilia (*Federação Brasileira de Hemofilia*), and the World Federation of Hemophilia (WFH) have worked together over the past decade to improve diagnostic capacity in Brazil.

Accurate diagnosis is essential for providing proper treatment to patients because various bleeding disorders may have similar symptoms. Improving diagnosis is a formidable task in Brazil, which is the largest South American country, both in terms of geographical area and population. It is the world's fifth largest country, with more than 193 million people. The country has approximately 13,000 people with hemophilia.

A national effort began in the early 21st century to develop an External Quality Assurance Scheme (EQAS) Program. The program got underway in 2007 and, today, involves 26 labs. An ongoing national program, for lab training in coagulation, began in 2008.

This program put in place three strategies for developing better diagnosis: initial and ongoing training of diagnosis methods, first for hemophilia, then von Willebrand disease (VWD) and inhibitors; lab quality assurance; and the training of trainers, so that the knowledge gained in the training sessions can be replicated.

Training related to hemophilia A and B was originally offered and was later extended to cover VWD, other related bleeding disorders, and inhibitors. A national registry was developed in 2008 and implemented in all states in early 2009.



Steve Kitchen (centre) with laboratory workshop participants.

To further focus and reflect on the needs of the labs, a laboratory committee was created, in 2011, as part of the Area Technical Advisory Committee on bleeding disorders with the Ministry of Health. This implemented a second strategy, which was to improve lab expertise in coagulation.

The third step involved the training of trainers. This April, a training of trainers (TOT) session was held with the participation of 15 lab technicians from around the country. The training objectives were to allow participants to discuss what they experience in their labs and to gain more knowledge of proper testing techniques. A TOT involves having a highly trained group of professionals, in one area, go and train others elsewhere in their country. This ongoing cycle of knowledge helps foster sustainability in a country.

"During the course we were able to see positive aspects, as well as areas for improvement," said Silmara Montalvao, lab scientist at UNICAMP, one of WFH's International Hemophilia Training Centers. "It is ideal to be able to meet together as lab scientists to discuss

everyday problems we experience and any doubts that we have in coagulation testing. The TOT provided us with the opportunity to discuss a variety of issues and to visualize the real difficulties in lab routine practice. It is a necessity to meet to organize the information that will be transmitted to others lab scientists."

The work that has been done in the area of diagnosis is having an impact in many other areas of treatment. There have been major increases in the purchase of clotting factor concentrates over the last two years, while prophylaxis, as well as Immune Tolerance Induction, have been introduced in the country. A clear strategy has been in place for developing care in this country and the advances have significantly improved the quality of life for patients nationwide.

"We're so proud to participate in this great moment in Brazil, where we can provide better treatment to people with hemophilia and other related bleeding disorders," said Gisele Pianetti Sternick, technical consultant with the Area Technical Advisory Committee on Coagulopathies.

Documenting the success of WFH training fellowships

Leaders in Training is the latest release in a 50th anniversary video series by the World Federation of Hemophilia (WFH).

This four-minute video, narrated by Christine Lee, MD, documents the positive impact of the WFH International Hemophilia Training Centre (IHTC) Fellowship Program, which began, in 1972. The IHTC Program has improved education about inherited bleeding

disorders by supporting an international network of WFH-designated training centres.

Founding IHTC chair Anthony Britten, MD, once said of the program that "selected centres would be assuming a responsibility not receiving an honour" and he envisioned these centres would bring "inspiration to many and leadership to all of us."

This video documents the strength of the program, its growth over the years, and underlines the fact that the vast majority of those trained continue to care for those with bleeding disorders.

The IHTC Fellowship Program is funded solely by Bayer.

www.wfh.org/50

13th International Musculoskeletal Congress draws record number of delegates

The 13th International Musculoskeletal Congress in Chicago, held April 18-21, attracted a record number of participants, and the event marked the first time the World Federation of Hemophilia (WFH) hosted a Musculoskeletal Congress in the U.S.A.

/Hélène Lussier, WFH congress and meetings manager

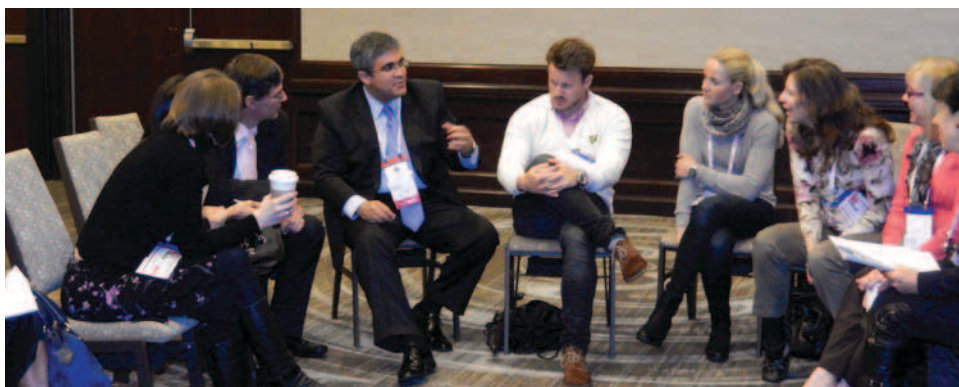
The 340 participants included 92 physiotherapists, 80 hematologists, and 64 orthopedists. The Congress medical program featured a state of the art session, surgery tips and clips, two keynote plenaries, two crossfire sessions, a comprehensive session on muscle bleeding, and the presentation of 20 free papers and 48 e-posters.

Poor weather conditions made travelling to Chicago very challenging on the first day. Due to flight delays and cancellations, the physiotherapy and the orthopedic sessions were combined into one on the first day. The opening workshop focused on the Global Physiotherapy Initiative and other international physiotherapy projects. The orthopedists followed with a presentation on the Joint Replacement Registry and the WFH *Guidelines for the Management of Hemophilia*. The day concluded with an open forum, entitled To Rest or Not to Rest.

The second day began with a robust session on state of the art approaches in musculoskeletal treatment and care, featuring eminent speakers, such as Giridhara R. Jayandharan, MD; Maureane Hoffman, MD; and Mindy Simpson, MD. This was followed by two innovative sessions focused on tips and clips for orthopedic surgeons and the musculoskeletal multidisciplinary team.

Day three began with the first keynote plenary addressing the urgent need for research on hemophilia and other inherited bleeding disorders. David Lillcrap, MD, from the department of pathology and molecular medicine at Queen's University, in Canada, presented the challenges and opportunities in research, and the unique contribution that research can make in the bleeding disorders community.

The plenary was followed with the first of two crossfire sessions. Paul Monahan, MD; Len Valentino, MD; and Ulrike Reiss, MD; debated



13th International Musculoskeletal Congress delegates.

the theory and reality of biological therapies. The day concluded with a session on muscle bleeding.

The closing day of the Congress began with a plenary on outcome measures presented by Nancy Young, a professor in the School of Rural and Northern Health at Laurentian University. Her research focuses on the development and testing of outcome measures. Young's research uses a child-centric measurement approach to better understand patient perspectives. The Congress concluded with an entertaining debate on inhibitor patient endoprosthesis with Michael Heim,

MD, and Nicholas Goddard, MD, and an animated debate between Greig Blamey and Nichan Zourikian on the controversial issue of treating with ICE versus no ICE.

The social event dinner, held at Chicago's famous House of Blues, included a memorable live performance by an authentic blues band.

Held every two years, the next WFH Musculoskeletal Congress will take place in Belfast, Northern Ireland, in 2015.

WFH would like to thank Baxter, Bayer, and Novo Nordisk for sponsoring the WFH Musculoskeletal Congress 2013.

Awards handed out in Chicago

During the 13th International Musculoskeletal Congress in Chicago, musculoskeletal committee members presented the Pietrogrande Prize, via teleconference, to James Luck, MD, an orthopedic surgeon practicing in Los Angeles. Luck is well-known for his significant contributions in furthering the mission of the musculoskeletal committee and for his service to the bleeding disorders community. He has been an inspiration and a world leader in pediatric orthopedic treatment.

The Henri Horoszowski award, which was established to encourage musculoskeletal specialists to become involved in hemophilia care, was awarded to Lize van Vulpen, a PhD student, specializing in blood-induced cartilage damage at the UMC Utrecht. She presented a free paper entitled: "A fusion protein of IL4 and IL10, is equally effective in protecting cartilage from blood-induced damage compared to the individual components." The paper's co-authors are M.E.R. van Meegeren, S.A.Y. Hartgring, C. Steen-Louws, S.C. Mastbergen, C.E. Hack, J.A.G. van Roon, and F.P.J.G. Lafeber.



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www.wfh.org/globalforum2013

Better Together: Celebrating twinning achievements in Vietnam

/Nicola Hope, WFH program coordinator, Twinning and Global NMO Training

When the 2012 Twins of the Year winners were announced early this year, projects in Vietnam won both of the awards given annually for partnerships that focus on developing care and strengthening patient organizations. Through an act of coincidence, rather than coordination, twinning projects in Vietnam were selected independently for recognition by both the Hemophilia Treatment Centre Committee and the Hemophilia Organization Twinning (HOT) Committee.

In 2011, the patient society twinning partnership between the Irish Haemophilia Society (IHS) and the Vietnam Society of Congenital Bleeding Disorders (VSCBD) began at the same time as the medical twinning started between The Alfred hospital in Melbourne, Australia, and the National Institute of Hematology and Blood Transfusion in Hanoi, Vietnam.

The HOT twinning focused their 2012 activities on organizing workshops for patient leaders, on the topics of volunteer development and fundraising. The IHS also supported VSCBD in the development of two new chapters and helped create a new governance structure for the organization. The IHS engaged their local bleeding disorder community to learn more about people with hemophilia in Vietnam who do not have access to the same level of treatment that they are fortunate to benefit from in Ireland.

With the medical twinning, the treatment centres planned a two-day workshop and clinic for physiotherapists, as well as a two-day workshop for nurses. A multidisciplinary symposium was organized, as was a symposium for hematologists and physicians. The twins also continued to monitor and coach the laboratory and nursing staff, who have seen improvements in diagnostic capabilities, patient charting, and cooperation between comprehensive care team members.



IHS president Brian O'Mahony with a young patient in Vietnam.

"Better Together" is the title of a video that the HOT twins produced, and this sentiment is echoed in the enthusiastic participation of so many dedicated and compassionate healthcare providers, patients, families, volunteers, and staff working cohesively in both of these productive partnerships," said Robert Leung, WFH regional program manager for Asia & Western Pacific.

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

Regional Updates



AFRICA AND EASTERN MEDITERRANEAN

Algeria

The World Federation of Hemophilia (WFH) and the Algerian Hemophilia Association (*Association Algérienne des Hémophiles*) organized a three-day physiotherapy training workshop in Algiers in October 2012. More than 30 physiotherapists from throughout the country attended.

Bahrain and Qatar

In cooperation with the Bahrain Ministry of Health and the Bahrain Bleeding Disorder Society, the WFH organized in Manama, Bahrain, a two-day physiotherapy training workshop in March 2013. The workshop took place at the principal hospital in Manama (Salmaniya Hospital), where 30

physiotherapists attended the training. A similar physiotherapy workshop was organized in Doha, Qatar, prior to the training in Bahrain.

Jordan

The WFH organized a five-day regional physiotherapy training workshop in Amman, Jordan, in November 2012. Eighteen physiotherapists, from 10 countries, including Tunisia, Egypt, Sudan, Oman, Qatar, Bahrain, United Arab Emirates, Kuwait, Lebanon, and Jordan attended this workshop. The training included a session on the importance of physiotherapy in pre- and post-operative management of hemophilia patients.

Senegal

In October 2012, the WFH organized a three-day regional

nurses training workshop in Dakar, Senegal. Twelve nurses from Morocco, Côte d'Ivoire, Cameroon, and Senegal attended this training, which took place at the newly established hemophilia treatment centre (HTC) in Dakar.

South Africa

The WFH and the South Africa Haemophilia Foundation organized a three-day physiotherapy training workshop in Pretoria, in September 2012. Over 15 physiotherapists from throughout the country attended this training. The WFH also organized a one-day psychosocial training workshop in Pretoria.

AMERICAS

Cuba

In commemoration of the 50th anniversary of the WFH, the Cuban Society of Hemophilia (*Sociedad Cubana de Hemofilia*) and the Institute of Hematology and Immunology organized its fourth international workshop on hemophilia and other bleeding disorders. The WFH keynote address highlighted advances in care and treatment. Sessions included musculoskeletal and psychosocial issues.

El Salvador

In November 2012, healthcare professionals from the major hospitals in San Salvador were invited to participate in a hemophilia symposium at the Hospital Nacional de Niños Benjamín Bloom. Members of the multidisciplinary team provided information on comprehensive care for patients.

Guatemala

In September 2012, a workshop was held with the Guatemalan Hemophilia Association (*Asociación Guatemalteca de Hemofilia*) on the theme of outreach. The organization's board of directors, and other active members, participated and there was much enthusiasm in reaching out to patients who live in various provinces of the country.

Mexico

In December 2012, the Hemophilia Federation of the Republic of

Mexico (*Federación de Hemofilia de la República Mexicana*) held a national workshop for state chapter leaders. One session included an assessment of the chapters' abilities and needs.

Nicaragua

The Nicaraguan Association of Hemophilia (*Asociación Nicaragüense de Hemofilia*), held an educational event, last December, for patients and family members in the regions of León y Chinandega. This is the first time a hemophilia event has taken place in this region. More than hundred people attended.

ASIA AND WESTERN PACIFIC

Bangladesh

In November 2012, more than 100 healthcare providers, patients, families, and health officials attended the first hemophilia symposium in Chittagong, the second largest city. Chittagong Medical College Hospital is currently developing a treatment centre with the support of the Ministry of Health.

China

In Wuhan, approximately 300 healthcare providers attended the 7th National Hemophilia Conference, in October 2012, which was followed by nursing, physiotherapy, and pediatric workshops. The patient group, Hemophilia Home of China, collaborated with the China Food and Drug Administration (CFDA) and the Ministry of Health to receive a WFH humanitarian aid donation. It was the first time the CFDA approved a foreign donation of this nature.

Japan

More than 300 delegates registered for the 3rd Hemophilia Forum organized by the national patient network in Tokyo in April. The WFH keynote speech addressed the Forum theme of assisting underserved countries. Panel and workshop topics included national care disparities, promoting standardized and comprehensive care, youth, inhibitors, carriers, VWD/RBD, and ageing.

Malaysia

A WFH Nurses Committee member, along with a past-member, were the main speakers at a two-and-a-half day hemophilia training session for approximately 55 government nurses in April.

Mongolia

The Government of Mongolia purchased, for the first time, clotting factor concentrates in late 2012 and more for 2013. WFH provided information and advice on available products, the tender process, and a national distribution system.

EUROPE**Albania**

A joint clinic of the Tirana-Warsaw centre twinning took place for 30 patients in February. Their blood was tested by the twinning's lab specialists at the centre in Tirana. The Minister of Health announced to the WFH delegation the opening, in April, of the country's first HTC.

Bosnia and Herzegovina

Following a WFH visit in February with the Haemophilia Society of Bosnia and Herzegovina, the new Minister of Health created a national hemophilia council with representation from the Society. The next step for the council will be to designate the official federal hemophilia treatment centre (HTC) in Sarajevo.

Montenegro

The Montenegrin Society for Hemophilia organized its first national hemophilia symposium in February, attended by 45 participants. The Ministry of Health representative agreed to create a national hemophilia council. The Serbian Hemophilia Society also conducted its twinning assessment visit and presented at the symposium, along with local and Serbian hematologists.

Russian Federation

Seventy-one Russian regions, and approximately 400 people, participated in the Russian Hemophilia Congress, hosted last November by the Russian



Hemophilia Society (RHS). Country representatives attended, along with people from the medical and lay community. This event stressed the importance of developing dentistry and

physiotherapy in HTCs, as well as decreasing the inequalities in care between HTCs.

1. Senegal; 2. Nicaragua; 3. Albania; 4. Bangladesh.

In memoriam

Nadia Moharram, MD, the president of the Egyptian Society of Hemophilia, died February 13. Maritza Riaga de Robledo, the president of the Colombian patient organization, Liga Colombiana de Hemofílicos, died April 16.

The WFH offers its sincerest condolences to their families and to their communities in Egypt and Colombia.

Calendar of Events

PLUS World Health Organization Consensus Conference

September 5-6, 2013
Lisbon, Portugal
Tel.: +44-1503-250-668
Fax: +44-1503-250-961
Email: johan.ipopi@gmail.com

5th East Asia Hemophilia Forum

September 7-8, 2013
Seoul, Rep. of Korea
Email: 2013eahf@gmail.com
www.hematology.or.kr/2013EAHF

Eighth WFH Global Forum on the Safety and Supply of Treatment Products for Bleeding Disorders

September 26-27, 2013
Montréal, Canada
World Federation of Hemophilia
Tel.: +1-514-875-7944 #2820
Fax: +1-514-875-8916
Email: dandre@wfh.org
www.wfh.org

NHF 65th Annual Meeting

October 3-5, 2013
Anaheim, U.S.A.
National Hemophilia Foundation
www.hemophilia.org

Annual EHC Conference 2013

October 4-6, 2013
Budapest, Hungary
European Haemophilia Consortium
Tel.: + 353-1-2859033
Fax: + 353-1-2353039
Email: info@conferenceorganisers.ie
www.ehc2013.eu

XXIII Congreso Internacional del Grupo CLAHT

October 16-19, 2013
Cancún, México
Cooperativo Latinoamericano de Hemostasis y Trombosis
Tel.: + 52 (55) 5200 5103
Fax: + 52 (55) 5524 4110
Email: claht2013@btcamericas.com
www.claht2013cancun.com

World AIDS Day

December 1, 2013
United Nations
www.un.org/en/events/aidsday

24th ISBT Regional Congress

December 1-4, 2013
Kuala Lumpur, Malaysia
Tel.: +31-20-679-3411
Fax: +31-20-673-7306
Email: malaysia@isbtweb.org
www.isbtweb.org/malaysia/welcome/

ASH Annual Meeting

December 7-10, 2013
New Orleans, U.S.A.
American Society of Hematology
Tel.: +1-202-776-0544
Fax: +1-202-776-0545
Email: meetings@hematology.org
www.hematology.org

WFH Congress 2014

May 11-15, 2014
Melbourne, Australia
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Email: info2014@wfh.org
www.wfh2014congress.org



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Christine A. Lee steps down as editor of *Haemophilia*

/Brian Boyer, WFH editor/editorial services coordinator

Christine A. Lee, MD, co-editor of *Haemophilia*, the official journal of the World Federation of Hemophilia (WFH), retired in May from the publication she founded in 1995. She will be succeeded by co-editors Craig Kessler and Mike Makris.

Twenty years ago, Lee said she approached Blackwell Publishing with the idea for a journal about hemophilia. Blackwell Publishing had already been involved, since 1955, in hematology publications and “were prepared to take the risk,” she wrote, “and wanted the journal to be international and have a strong North American presence.”

During a World AIDS meeting in Berlin, in June of 1993, Lee met with Doreen Brettler, director of the New England Hemophilia

Center. Brettler agreed to serve as the publication’s first editor. Together, Brettler and Lee put together the first editorial board. The first issue was published in January 1995.

“*Haemophilia* remains grateful to all the authors who have submitted, and continue to submit, their research, writing, and thinking,” Lee wrote in her farewell column, “together we have created a substantial record of haemophilia, and the many challenges concerning the management of this intriguing condition.”

Lee was consultant and director of the Royal Free Hospital Haemophilia Centre and Haemostasis Unit from 1987 until her retirement in 2005. She is emeritus professor of hemophilia, University of London, and has published more than 300 peer-reviewed scientific papers about hemophilia, and edited eight books, including the *Textbook of Hemophilia* in 2005.



Christine A. Lee during the WFH 2012 Volunteer Awards ceremony.

At the WFH 2012 World Congress in Paris, France, Lee was awarded the WFH Lifetime Achievement Award. The WFH congratulates Lee on her many remarkable achievements.

Discovering a network of support for women with bleeding disorders

/Brian Boyer, WFH editor/editorial services coordinator

Aleksandra Ilijin, a 26-year-old woman from Serbia, active in issues of women with bleeding disorders, and a carrier of a disorder herself, felt encouraged after attending the WFH 2012 World Congress in Paris, France, where she was awarded the 2012 scholarship from the Susan Skinner Memorial Fund (SSMF).

Aleksandra, of Zrenjanin, Serbia, became the eighth woman to receive the honor. Since 2010, she has been active in the Serbian Haemophilia Society. She was also involved, since 2006, with youth program projects organized by the European Commission. In 2009, she volunteered at a camp for children with hemophilia and, in 2011, she helped organize World Hemophilia Day events and worked as a translator at a European hemophilia conference. In addition, she has been involved in public relations projects using social media and in fund-raising activities aimed at assisting carriers of a bleeding disorder.

“My experience went way beyond my initial expectation to learn and gather information” Aleksandra said of her time at the Congress in Paris. “Gaining insights from other women in the bleeding disorders community was truly priceless.”

The SSMF endowment was established in 2007 by WFH USA to support the training, education and leadership development of young women with bleeding disorders, or who are carriers. Scholarship recipients aged 18 to 30 years, from the U.S.A. and abroad, demonstrate outstanding leadership to improve the care of women with bleeding disorders in their country and the potential to become future leaders in the bleeding disorder community. The fund commemorates the late Susan Skinner, an American woman determined to ensure the availability of safe and effective treatment for her two sons.



Recipients of the Susan Skinner Memorial Fund scholarship since 2008:

Julia McDougal, U.S.A.
Marija Nakeska, MACEDONIA
Celia Marina Mendoz Choqqe, PERU
Mallory O'Connor, U.S.A.
Danielle Schwager, U.S.A.
Salima Hadjammar, ALGERIA
Alexandra Johnson, U.S.A.
Aleksandra Ilijin, SERBIA

Thank You

In recognition of the organizations that have committed or contributed to the WFH's mission so far in 2013

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Jan Willem André de la Porte

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Global Research Forum

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Novo Nordisk
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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

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Belgian Haemophilia Society*
Canadian Hemophilia Society*
CNY Bleeding Disorders Association
Deutsche Hämophiliegesellschaft (DHG)*
Fondazione Angelo Bianchi Bonomi
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Haemophilia Foundation Victoria
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Hemophilia Association of Davao
Hemophilia Association of the Capital Area
Hemophilia Foundation of Michigan
Hemophilia of Georgia
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Rocky Mountain Hemophilia and Bleeding Disorders Association
Stichting de Erven Leeuwenhart
Swedish Hemophilia Society (FBIS)*
The Haemophilia Society (U.K.)*

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Contributors

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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

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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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Fédération mondiale de l'hémophilie
1425, boul. René-Lévesque Ouest, bureau 1010
Montréal, Québec H3G 1T7
Canada
E-mail: sford@wfh.org

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