

HEMOPHILIA WORLD

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**WFH 2014
WORLD
CONGRESS**

Melbourne, Australia • May 11-15

Welcoming the world to Melbourne

/Sharon Caris, HAEMOPHILIA FOUNDATION OF AUSTRALIA
EXECUTIVE DIRECTOR

On behalf of Haemophilia Foundation Australia (HFA) and the World Federation of Hemophilia (WFH), we will welcome the world to the WFH 2014 World Congress in Melbourne, Australia, May 11-15, 2014. HFA is honoured to host the largest international meeting dedicated to hemophilia, von Willebrand disease, rare factor deficiencies, and inherited platelet disorders. We expect over 4,000 attendees, from more than 120 countries.

THE AUSTRALIAN CONNECTION

Since HFA was founded in 1979, we have worked closely with the WFH to represent people with inherited bleeding disorders, not only in Australia, but around the world. In fact, representatives from Australia's hemophilia community were present during the meeting when the WFH was formed 50 years ago. HFA consists of a small team of seven dedicated individuals and everyone on the staff is excited that we will host the world in our beautiful city. Our team has been working very hard to ensure that the WFH 2014 World Congress exceeds expectations.

Hosting the largest international meeting dedicated to bleeding disorders is truly a team effort. This is only possible with a great team of volunteers in Australia, many of whom have attended past Congresses. The organizing team understands what is important to the global bleeding disorders community and what it will take to make the WFH 2014 World Congress an overwhelming success.

We are delighted that Gavin Finklestein will welcome you as Congress president and that Alison Street, MD, is the honorary Congress president. Throughout the



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www.wfh.org



Haemophilia Foundation of Australia staff

planning process, we have received support from Chris Barnes, MD, director of the Henry Ekert Haemophilia Treatment Centre at Royal Children’s Hospital and co-chair of the Congress medical program committee, as well as Sharon Hawkins, counsellor at the Royal Perth Hospital and co-chair of the Congress multidisciplinary program committee.

HFA staff and all our volunteers from across Australia are deeply invested in making this Congress a success. We are currently

working on the Cultural Evening and the Gala Dinner and we look forward to providing you with a social program where you will experience a taste of Australian food and culture.

EXPERIENCE MELBOURNE

There is a reason Melbourne has been ranked as the world’s most liveable city. Melbourne’s charm is characterized by enchanting laneways, stunning waterfront precincts, trendy neighbourhoods, and an endless choice of shopping, art galleries and a gastronomically diverse number of restaurants, cafes, and bars ready to welcome you. On top of that Melbourne:

- Offers a multicultural experience, representing over 230 ethnic communities, with more than 180 languages spoken;

- Is a safe and secure walking city that is compact, easy to navigate, and has great wheelchair access;
- Offers with a wide range of quality accommodations, most with disability access rooms;
- Offers a shuttle leaving Melbourne Airport every 10-15 minutes that goes directly to the city centre;
- Has a free City Circle tourist tram, shuttle bus, and water taxis (all wheelchair accessible); and
- Boasts more than 6,500 restaurants, cafes, bistros, bars, and brasseries all within 15 minutes of the city centre.

The Melbourne Convention and Exhibition Centre (MCEC) is located in the centre of the city and is easily accessible for Congress. It is close to a range of hotels and accommodation services with transport and other amenities.

The MCEC is accessible for people with physical disabilities, with flat level entry into the Centre, elevator access, wheel chair spaces and accessible seats in the Plenary Hall, and disabled access toilets, and telephones throughout the centre.

While life in the city has everything one might need, if you would like to get away from it all, just one hour’s drive takes you a world away. Take your pick from 100 local vineyards, rest and relax at an award-winning day spa, tee-off at a world-class golf course, and swim with dolphins.

Australia is a beautiful country and we are waiting enthusiastically introduce you to our great city of Melbourne in May 2014.

www.wfh2014congress.org



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 HEALTH CARE 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.

CLOSE THE GAP

Campaign 2012-2014

75%

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

WHAT WILL IT TAKE TO CLOSE THE GAP?



He has a bleeding disorder.



So does he.



www.wfh.org/closethegap



 **WFH** 50
YEARS OF ADVANCING TREATMENT FOR ALL
WORLD FEDERATION OF HEMOPHILIA
Fédération mondiale de l'hémophilie
Federación Mundial de Hemofilia

PRESIDENT'S COLUMN

Project Recovery turns unused blood products into hemophilia medicine for developing countries

An innovative humanitarian project that has been in the works for many years is finally coming to fruition. Originally conceived and supported by the Canadian Hemophilia Society (CHS), Project Recovery will see people with hemophilia around the world benefit from a new source of factor VIII from Canadian blood donations. This is a milestone for the hemophilia community and the World Federation of Hemophilia (WFH) is honoured to be part of the remarkable collaboration that has made it possible.

/ Alain Weill, WFH PRESIDENT

With Project Recovery, cryoprecipitate paste from the fractionation of Canadian plasma will be manufactured into factor VIII concentrate. A portion of this factor VIII will be donated by Canadian Blood Services (CBS) to the WFH's Humanitarian Aid Program. The WFH Humanitarian Aid Program channels donations of life-saving treatment products to people with bleeding disorders who need them all around the world. The program focuses particularly on patients who have either no or only very limited access to these lifesaving medicines and would otherwise be at risk of death or serious disabilities.

Most factor VIII concentrates used in Canada today are recombinant products. Until now the cryoprecipitate paste from Canadian Blood Services' plasma has been discarded. With Project Recovery, this paste will no longer be discarded but will instead provide an invaluable product for patients who are currently undertreated or not treated at all.

The factor VIII product resulting from Project Recovery will be Biotest's high-purity, double virus inactivated Haemoctin. It will be manufactured under strict regulatory controls. The first shipment of cryoprecipitate is expected to be delivered to Biotest at the end of 2013, with the first transfer of donated factor VIII concentrate to the WFH expected early in 2014.

Beginning next year, as many as five million IUs of factor VIII, with a full shelf life, will be distributed by the WFH Humanitarian Aid Program. This could allow the treatment of as many as 5,000 joint hemorrhages, the most common symptom of hemophilia, in children and adults. In addition, the predictability of this supply gives the WFH the ability to plan for the most efficient and sustainable use of this donated treatment product.

The plasma provided by CBS comes from volunteer donors in Canada. These donors, who give their blood to help their fellow citizens, will now help to improve the lives of people with hemophilia around the world. The WFH is grateful for their precious gift and for their support of Project Recovery.

Project Recovery required the negotiation of a number of complex agreements over the past few years among all the parties involved. For CBS, this initiative is being done on a cost neutral basis. A portion of the finished factor VIII concentrate will be sold by Biotest, essentially recovering their costs for the manufacture of the finished product. The factor VIII that Biotest sells will also increase the world's total supply of factor VIII and will increase access to care for even more patients.

The WFH is sincerely grateful to the numerous people who have worked to make Project Recovery a reality. To the patient community in Canada, led by the CHS, who started working on this concept many years ago. To the teams at CBS and Biotest that patiently worked through the many regulatory, technical, and legal issues to make this multinational arrangement possible. And to



Grifols for their cooperation and willingness to collaborate on this humanitarian project.

There are other countries in similar situations to Canada where patients use mostly recombinant factors and nationally collected cryoprecipitate is discarded. Hopefully the example set by CHS, CBS, and Biotest can be a model for cooperation and international solidarity to reclaim these essential, lifesaving proteins.

WFH executive committee

Leading into the next WFH General Assembly, I would like to thank the WFH executive committee for their hard work and dedication. Since 2012, two new members, Flora Peyvandi and Marijke van den Berg, have joined the WFH executive committee. They bring added professional expertise and experience to this group of devoted individuals. For more information on how to become a WFH executive committee member, see page 12.

VP MEDICAL WRITES

New advancements for hemophilia care around the world

These are exciting times for everyone associated with hemophilia care – patients, their families, health care teams, health authorities, the clotting factor concentrate (CFC) industry, and researchers associated with the field.

/Alok Srivastava, MD, WFH VICE-PRESIDENT MEDICAL

What will impact almost everyone associated with the clinical care of people with hemophilia is the range of new CFCs that are expected to become available over the next year. The first of these is likely to be one of the long-acting products that has completed its pivotal trials and is now awaiting market authorization in North America. Unfortunately, it will take about two more years for this product to become available in Europe, given their regulatory requirements for data on children. Attempts are being made to address this issue. This is likely to be followed by a few other long-acting products that are to come to the market in the next one to two years along with several 'me too' unmodified CFCs.

If the convenience of using these longer acting products is matched with high efficacy in regular clinical use, as the initial trial data suggests, then it would be reasonable to predict that a significant numbers of patients in North America and Western Europe would choose to use them, when available. This could then lead to some of the CFCs currently in use in these countries becoming available to patients elsewhere. This fact, combined with the other new biologically similar CFCs that are in advanced stages of clinical development, could favourably affect the supply and demand situation, which has not seen any major innovation or addition for nearly two decades.

The obvious question then would be whether the increasing supplies can be matched with demand, or, more importantly, buying capacity. The current total production of CFCs in the world today is about 8 billion international

units (IUs). Given that the world population has exceeded 7 billion, we would need nearly 20 billion IUs to reach about 3 IUs per person, overall. Given the disparities in distribution, nearly 80 per cent of CFCs are currently used by 20 per cent of the population, we would probably need much more.

As there is huge potential demand, will there be purchasing capacity? This is the major challenge but thankfully the situation is changing. With efforts from many sources, including some of the major programs of the World Federation of Hemophilia (WFH), health care providers in many developing countries are now allocating budgets for CFCs. Major improvements in CFC use have been seen in countries with larger populations such as in Russia and in Brazil over the past five years. Other countries such as China and India are following suit. Of course much more work remains to be done.

What impact will the use of all these CFCs have on the lives of people with hemophilia? Assessment of outcome has been a relatively neglected aspect of care in most parts of the world. However, this situation is also changing. With efforts from several groups from around the world over the past decade, we now have some very useful simple clinimetric instruments for outcome assessment that can provide objective measures of the status of persons with hemophilia, particularly from a musculoskeletal perspective.

The challenge is to achieve a wider dissemination of this knowledge and make a change in the approach to clinical care, where patients and their treatment centres can appreciate the need and importance of these measurements. Health care providers are certainly beginning to demand these data. The WFH has also initiated efforts in several ways to increase awareness and utilization of these instruments. There was also a lack of definition of the clinical endpoints to be



“With efforts from many quarters, including some of the major programs of the World Federation of Hemophilia (WFH), healthcare providers in many developing countries are now allocating budgets for CFCs.”

measured in the clinical management of people with hemophilia. Over the past few years, the FVIII/IX subcommittee of the SSC of the International Society of Thrombosis and Haemostasis (ISTH) has put together several working groups that have provided working definitions to standardize documentation and the reporting of clinical outcomes data. The WFH has also collaborated in this effort and a formal memorandum of agreement is in place with the ISTH to continue this process.

Finally, after years of waiting, a cure for hemophilia seems to be nearly there. There is at least one successful gene therapy trial for people with factor IX deficiency. The trial is still ongoing but the results are very promising with a sustained expression of factor levels for over two years so far. We have certainly not reached the goal of much higher sustained levels of CFCs but this is a huge advance. Several other studies on gene therapy are being developed.

I would like to also mention that all these subjects and more have been included in the program of the WFH 2014 World Congress to be held in Melbourne in May 2014. As we celebrate these successes, we need to keep in mind that much work needs to be done to spread these benefits to large parts of the world where even basic care is lacking. However, we are now in a better position than ever before to meet those challenges.



WFH's 50th anniversary comes to a close

Over the past fifty years, the World Federation of Hemophilia (WFH) has made great strides in raising awareness for improving treatment for people with hemophilia and other inherited bleeding disorders. During this time, the WFH has worked with countless individuals and organizations to work towards advancing our vision of Treatment for All. This 50th anniversary has allowed us to look back and see just how far we have come and pay tribute to all those who have helped us along the way.

/Sarah Ford, WFH COMMUNICATIONS AND MARKETING DIRECTOR

On June 25, 1963, the journey began for the WFH. Frank Schnabel, then president of the Canadian Hemophilia Society, convened a global meeting in Copenhagen, Denmark, and established the first international hemophilia organization.

MARKING THIS ANNIVERSARY

To mark the occasion of the founding, on June 25 of this year, the Danish Haemophilia Society hosted WFH president Alain Weill and two former WFH presidents, Mark Skinner and Brian O'Mahony, at a symposium in Copenhagen. This symposium examined the many milestones achieved over the past five decades. A webcast featuring these presentations is available at www.wfh.org/50.

Haemophilia Journal, the official journal of the WFH, has published articles commemorating this anniversary, highlighting the WFH's history and all the accomplishments it has achieved throughout the decades.

50th ANNIVERSARY VIDEO SERIES

To highlight historical events of the organization, the WFH released a series of videos about the many WFH programs, historical achievements, and individuals that have made the WFH into the organization it is today. These videos showcase the history of the WFH through the stories of those directly involved.

CLOSE THE GAP CAMPAIGN

When the 50th anniversary was launched at the WFH 2012 World Congress in Paris, the WFH also launched the Close the Gap Campaign. The ultimate goal is to close the gap in care and treatment around the world. To date, this campaign has been a remarkable success. While the 50th anniversary celebrations might be coming to an end, the Close the Gap Campaign will continue its goal of raising funds to help improve Treatment for All.

WFH patron Jan Willem André de la Porte, offered up a special challenge grant to support this campaign. "To help build the cornerstone of care where the need is greatest, we must all help. For every dollar donated, I will donate an additional two dollars." Learn more at www.wfh.org/closethegap.



THE NEXT 50 YEARS

Over the next fifty years, the WFH will continue to advance our vision of Treatment for All. This extends to delivering our programs, working with our national member organizations, and providing advocacy support around the world. Going through the 50th anniversary celebrations has given all of us at the WFH time to reflect and look at just how far we have come since 1963.

The WFH signs milestone GAP agreement on hemophilia care in Colombia

/Luisa Durante, WFH REGIONAL PROGRAM MANAGER, AMERICAS

Approximately 75 per cent of people around the world with inherited bleeding disorders do not have access to adequate diagnosis and treatment. Without proper care, many people with hemophilia will die young, or if they survive, they are at great risk of growing up with severe disabilities in their joints.

In Colombia, important advances have been made to date, such as the national health plan that guarantees that all people with hemophilia have access to clotting factor concentrates. However, many challenges remain with regards to access to treatment and care nationwide. There are currently 1,974 people diagnosed with hemophilia in the country and many still remain undiagnosed, despite Colombia being the second largest country in South America, with one of the strongest economies in the region.

“This agreement outlines what is necessary for the development of a national network of hemophilia treatment centers and the creation of a national registry for patients.”

On October 10, 2013, the World Federation of Hemophilia (WFH) and the Ministry of Health and Social Protection of Colombia (MSPS), signed a formal agreement which will help improve care delivery for people with hemophilia and other bleeding disorders in Colombia. This agreement outlines what is necessary for the development of a national network of hemophilia treatment centres and the creation of a national registry of patients. This registry would include outcomes and surveillance. Colombia will be the first country in the world to enter into the first tier of the second decade of the WFH Global Alliance for Progress (GAP) Program, the largest and most intensive development program of the WFH.



WFH president Alain Weill (left) with Dr. Gerardo Burgos, Secretary General of the Ministry of Health and Social Protection sign the GAP agreement

“This agreement is an important milestone for the development of better care in Colombia,” said Alain Weill, WFH president. “The WFH recognizes the potential in optimizing care and welcomes this collaboration with the Colombian Ministry of Health and Social Protection in improving care, management, and diagnosis.”

The WFH will continue their support for the development of national treatment guidelines and for the standardization of care nationwide. In turn, the Colombian MSPS has committed to providing support to maintain a network of hemophilia treatment centres that would ensure better care delivery and comprehensive care for people with hemophilia across Colombia.

“We are excited to be the first country to take part in the WFH GAP Program’s second decade. This opportunity is very important to us as it will help develop better care delivery, so that people with hemophilia are provided for on a national level,” stated Sergio Robledo, MD, president of the Liga Colombiana de Hemofílicos. “For the hemophilia community, having this support and collaboration from the Ministry of Health and Social Protection

is very significant and we hope that together we are able to effect positive and long lasting change for the community.” The Liga Colombiana de Hemofílicos is one of the WFH’s 122 national member organizations.

The signature ceremony was held on Thursday, October 10, at the Ministry of Health and Social Protection of Colombia. Speakers included the Minister of Health and Social Protection, Alejandro Gaviria Uribe, and WFH president Alain Weill.

“This is the opportunity that we have been waiting for and now all the elements are in place to advance and standardize care,” said Maria Helena Solano, MD, medical hematologist, director of the hemophilia centre at the Hospital San Jose, and professor in the Training Centre for Hematologists, in Bogota. “We know a lot has been done and also know that there is still much more to do to ensure sustainable comprehensive care for people with hemophilia. It is a challenge that we are ready to meet.”



WFH 2014 WORLD CONGRESS

THE LARGEST INTERNATIONAL MEETING FOR THE GLOBAL BLEEDING DISORDERS COMMUNITY

MELBOURNE, AUSTRALIA • MAY 11-15

Hosted by:

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www.wfh2014congress.org



Continuing success for IEQAS: Increasing laboratory standards

/Stephanie Pineda, WFH PROGRAM OFFICER, IHTC AND IEQAS

When the International External Quality Assessment Scheme (IEQAS) of the World Federation of Hemophilia (WFH) was launched in 2004, its goal was to promote improved standards of laboratory performance. The scheme achieves this by auditing the effectiveness of the internal quality assurance systems in the participating countries and giving a measure of the laboratory's capability.

The IEQAS program originally started with 60 labs worldwide, and this number has increased every year. In 2012, 18 new labs were added from developing countries. In 2013, 12 more were added, bringing the total to 104 participating labs around the world.

IEQAS requires all laboratories registered with the WFH to test a blood sample supplied by the scheme's partner lab, the United Kingdom National External Quality Assessment Scheme for Blood Coagulation (UK NEQAS BC). The U.K. centre then verifies each laboratory's testing procedures and diagnosis.

To simplify the process of reporting laboratory results, IEQAS has installed a new online survey data entry system, where to date at least 50 per cent of the participants send their results in this manner. This efficient method of collecting data has helped speed up the reporting process and will help to improve laboratory effectiveness.

Director since 2004, Professor Eric Preston has left the position. New program director, Dr. Steve Kitchen, has taken over. Since July 2012, Sukesh Nair, MD, has chaired the WFH IEQAS steering committee.

The WFH is grateful for the continued support of the Novo Nordisk Hemophilia Foundation to the IEQAS Program.

Lifesaving factor where need is greatest

/Maria Carolina Arango, WFH HUMANITARIAN AID PROGRAM OFFICER

When nine-month-old Hirwa Mpano Virgile sustained an intracranial bleed in May of 2013, doctors knew he would not survive without immediate surgery. However, with just three vials of treatment in stock at the King Faysal Hospital in Kigali, Rwanda, he would require significantly more just to survive the surgery.

To receive the assistance they needed, the doctors requested a humanitarian aid donation from the World Federation of Hemophilia (WFH). The WFH, in turn, sent the treatment the boy needed to get through his surgery and the subsequent recovery. The boy's father, Sylvestre Mulindabyuma, later wrote thanking everyone that helped save his son's life. Tragically however, as a result of the bleeding, the boy is now permanently blind.

Since 1996, the WFH Humanitarian Aid Program has channeled donations of life saving treatment products to people in urgent need, most often in countries where access is very limited. For 17 years, this program has directed over 245 million international units of life saving clotting factor concentrates to 86 countries, reaching people in need like Hirwa. In addition, one of the goals of this program is to encourage health authorities to



Hirwa Mpano Virgile recovering after surgery

provide this treatment by demonstrating the efficacy of using clotting factor concentrates. Therefore, this would in turn build a solid foundation for sustainable hemophilia care in the future.

In 2013, Bayer, Baxter, CSL Behring, Grifols, Kedrion, and Pfizer have made donations to the program. Their ongoing commitment will continue to strengthen the WFH Humanitarian Aid Program by providing life-saving medicine to those in need.

Call for nominations

2014 WFH Volunteer Awards

The World Federation of Hemophilia (WFH) is now accepting nominations for the International Frank Schnabel Volunteer Award and the International Healthcare Volunteer Award. Winners will be announced at the WFH 2014 World Congress in Melbourne, Australia, in May.

The deadline to submit nominations is **January 10, 2014**.

CRITERIA

- Several years' involvement with the WFH
- Volunteer contributions may be through one or several areas of the WFH's work, such as committees and programs, blood safety, communications, health development programs, fundraising, Congress, or national member organizations
- Nominees for the International Healthcare Volunteer Award should not be nominated for their role as a healthcare provider or researcher, but rather their volunteer involvement with the WFH
- Current WFH Executive Committee members, sitting members of the Medical Advisory Board and WFH staff are not eligible to receive these two awards

To nominate individuals who have made an outstanding contribution to global bleeding disorders care, please visit www.wfh.org/awards.

For more information, please contact awards@wfh.org.

WFH expands use of new technologies



/Sarah Ford, WFH COMMUNICATIONS AND MARKETING DIRECTOR and Ashwin Kaushal, WFH HEAD OF INFORMATION SYSTEMS

In this new era of rapidly changing technologies, many organizations around the world are looking to increase their presence online. Whether this is through the creation of more interactive websites or utilizing existing social media platforms, new technologies are becoming an increasingly important form of communication.

The World Federation of Hemophilia (WFH), as a global organization, has recognized the value in embracing new technologies. In 2012, the WFH redesigned and revised its website, which offers a wide variety of information for the global bleeding disorders community. This updated website now includes integrated social media features, such as Facebook, Twitter, YouTube, Flickr, RSS, as well as social bookmarking. The website also offers the ability to register and create a profile to sign up for newsletters, access to over 300 titles in the publications library, opportunities for online learning via webcasts, and educational games to engage young people.

Beyond its website, the WFH saw the need to increase our online presence using social media. In 2013, social media was an integral part of the WFH's World Hemophilia Day campaign, and we saw significant activity on our Facebook page. Throughout this campaign, the WFH also used YouTube as the video release and showcase platform. These ways of communicating are indispensable for an organization like ours, as they are able to bring the global bleeding disorders community together.

During the upcoming WFH 2014 World Congress in Melbourne, Australia, the WFH will expand our usage of Twitter. When attending the upcoming Congress, we encourage you to use the hashtag #WFH2014 in order to help share your experience with our online community.

To read more about the WFH's latest Twitter social media activity, go to page four in the December Campaign Bulletin.

Visit us online at www.wfh.org to discover all that the WFH has to offer. We also encourage you to come and visit us at www.facebook.com/wfhemophilia to meet other members of our global community.



Svenja Barckhausen, Biotest; Ian Mumford, CBS; Alain Weill, WFH; and David Page, CHS, during the launch of Project Recovery at the Global Forum.

WFH Global Forum 2013

/Mark Brooker, WFH SENIOR PUBLIC POLICY OFFICER

The World Federation of Hemophilia (WFH) hosted the Eighth Global Forum on the safety and supply of treatment products for bleeding disorders on September 26-27, 2013, in Montreal. WFH Global Forums bring together patient groups, pharmaceutical regulators, representatives from industry, not-for-profit fractionators, and doctors who treat people with bleeding disorders. The Eighth Global Forum focused on the effect new treatment products will have on the global bleeding disorders community.

During this Global Forum, representatives of Canadian Blood Services and Biotest

joined Canadian Hemophilia Society national executive director David Page and WFH president Alain Weill to announce the successful launch of Project Recovery. For more information on Project Recovery, go to page four.

The proceedings of the Eighth Global Forum will be published later this year. Many presentations from the meeting are available on our website.

The WFH wishes to thank the sponsors for supporting the Eighth Global Forum: Baxter, Foundation for American Blood Centers, Héma-Québec, Ministère de la Santé et des Services sociaux, Novo Nordisk, Pfizer, and SOBI.

WFH Compendium expanded to include bleeding assessment tools

/Jennifer Laliberté, WFH EDUCATION AND PUBLIC POLICY DIRECTOR

The laboratory diagnosis of mild and rare bleeding disorders can be challenging, particularly in parts of the world where resources are lacking. Inheritance patterns for these disorders can also be unclear. Physicians must therefore rely on bleeding histories, which are often subjective, to make a diagnosis.

Standardized quantitative scores for bleeding symptoms can be used by caregivers and researchers to diagnose mild bleeding disorders, to assess disease severity, and to address the variability in symptoms among patients with the same disorder. They can also be helpful to further our understanding of the correlation between bleeding patterns and the genetic characteristics of a disorder, and to improve communication in a clinical setting.

With this new section of the WFH Compendium of Assessment Tools (available soon), the WFH has sought to provide hemophilia caregivers and researchers with access to the latest bleeding assessment tools from a single source. Each of the scores has been evaluated by a global team of experts according to standardized criteria including overall utility and limitations, psychometric properties, method of administration, as well as general guidance about when and how each tool is best used. It is our hope that adequate use of these tools will ultimately facilitate research and inform best practice.

The WFH is extremely grateful to Paula James, MD, Margaret Rand, MD, and Christine Sabapathy, as well as all members of the working group, for their contribution to this important resource.

This section of the Compendium of Assessment Tools is funded by an unrestricted educational grant from Kedrion and LFB.

Ekawat Suwantarroj: His journey from isolation to building a community

/ Jay Poulton, WFH EDITOR/EDITORIAL SERVICES COORDINATOR

Every day as vice-president of the Thai Hemophilia Patients Club (THPC), Ekawat Suwantarroj gets a close look into the state of hemophilia care in his native Thailand. From his position with the THPC, he knows that care and treatment for people with inherited bleeding disorders has come a long way in his country, but still has a tough road ahead.

From the moment he was diagnosed with severe hemophilia A at four months old, he spent much of his youth avoiding dealing with this condition and attempted to hide it from friends and family. However, things changed for Ekawat in 2000 during Thailand's Hemophilia Day celebrations. It was during this event where he met Professor Partraporn Isarangkura, who guided him on his educational journey into the global hemophilia community.

Ekawat's desire to make a difference was the main reason that he left Thailand to pursue his Masters of Education from Edgewood College, Wisconsin. He had the option to stay in the United States when he graduated in 2009 and make a life for his growing family but he knew his skills could make a greater difference in Thailand. It is where he needed to be.

It is still where you will find him today. Working alongside people at the Thai Hemophilia Patient Club and other regional networks, including as the owner of a graphic design firm, Ekawat Suwantarroj, is an example to the children that he sees with the THPC and for his two young children at home. Ekawat wants them to know that they too can participate in the gift that is life and if they are willing to work hard, nothing can stop them from achieving their dreams.



Ekawat Suwantarroj

Egyptian hemophilia community continues to advance care

/ Magdy el Ekiaby, WFH VICE-PRESIDENT COMMUNICATIONS & PUBLIC POLICY

Although comprehensive hemophilia care started in Egypt in the late 1960s, it was not until the establishment of the Egyptian Society of Hemophilia (ESH) in 1971 that Egyptians an inherited bleeding disorder had a place to seek information and care. The ESH has since diagnosed and registered more than 6,000

patients with inherited bleeding disorders, mainly with hemophilia A.

In 2003, the ESH, the World Federation of Hemophilia (WFH), and the Egyptian Ministry of Health signed a Global Alliance for Progress (GAP) agreement that would last until 2009. The main objective of this GAP project was to establish a national hemophilia care program. As a result of the new agreement

patients with inherited bleeding disorders were put under the guidance of National Health Insurance of Egypt (NHI).

Currently, the standard of care is based on treatment on demand and patients can only receive concentrates at hemophilia training centres. The goal is to make home therapy and prophylaxis a standard of care in Egypt. With advocacy initiatives behind the GAP project, much awareness was brought to the bleeding disorders community in Egypt but much still remains to be done.

To bring more attention to bleeding disorders, in 2012, the ESH began an advocacy project with the WFH called the Implementation of Nationwide Public Awareness of Hemophilia and Bleeding Disorders. The aim is to increase safe treatment products and improve the quality of life for patients, raise donations for a low dose prophylaxis program for children, and ensure that the NHI to begin a home therapy program.

This program, scheduled to last from 2012 to 2015, will keep treatment in Egypt moving forward and the intention is to not lose the momentum gained since the partnership with the WFH first began.



left: Magdy El Ekiaby, MD, examining a patient in 2006 right: Hemophilia World announcement of GAP project launch in Egypt

Learning the steps to successful advocacy

/Marianna Balakhnina, WFH PROGRAM COORDINATOR, ADVOCACY IN ACTION

The World Federation of Hemophilia (WFH) Advocacy in Action Program provides hands-on training, coaching, project grants, and advocacy awards to encourage best practices among patient organization leaders.

In May 2013, 23 participants from 12 patient organizations from Eastern Europe and Central Asia, took part in a three-day seminar entitled, 'Steps to Success: Developing resources and collaborating with others to advocate' designed specifically to instruct participants on how to carry out advocacy campaigns and take advantage of available financial and human resources.

During this highly-interactive event, there were a mixture of short lectures, small group exercises, case studies, and role playing activities all designed to familiarize participants with the many nuances of advocacy in the region while providing relevant advice and tips for conducting advocacy campaigns.

Yuri Zhulyov, president of the Russian Hemophilia Society, shared his vast experience of working in the region and the many



Advocacy in Action workshop attendees

challenges he faced in getting his message through the proper channels. In the end, the participants found the workshop to be very useful, leaving them better equipped to pursue their existing activities and plan new advocacy initiatives.

At the end of the seminar, participants developed their own template advocacy campaign to take back to their home countries.

This provided them with the tools and information so that they can bring about change for those with bleeding disorders in their communities.

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

WFH executive committee nominations

Members of the World Federation of Hemophilia (WFH) executive committee play a key role in setting the strategic direction of the WFH and ensuring that the organization represents the needs of the global bleeding disorders community. Executive committee members are elected at the WFH General Assembly, following the WFH World Congress. WFH national member organizations (NMOs) who are fully accredited and who have paid their subscriptions may nominate people to stand for election to the executive committee. Nominations for candidates for the WFH executive committee members will be accepted as of December 17, 2013. Individuals interested in running for a position on the executive committee should contact the NMO in their country to express their interest in being nominated.

The following positions will be elected: vice-president medical, vice-president finance, two lay members (people with a bleeding disorder or a parent) and two medical

members. These positions are for a four-year term. In 2014, there will also be a third medical member elected to complete the remainder of a 2012-2016 medical position. Each NMO may submit **one** nomination for each of the following positions: vice-president medical and vice-president finance. In addition, each NMO may nominate **two** medical nominees (medical doctors), and **two** lay nominees (people with a bleeding disorder, or a parent), one from their own country or region, and another from anywhere else in the world. All nomination forms must be signed by the president/chair of the nominating NMO. After the nomination deadline, WFH headquarters will count the number of nominations and ascertain if the nominee has received the required number of nominations. Sixty days prior to the WFH General Assembly, WFH headquarters will circulate the final list of candidates together with their curriculum vitae (CV) to all NMOs for their consideration. At the WFH General Assembly, all eligible NMOs will vote for the candidates of their choice for the respective positions.

Nominations must be received at WFH headquarters no later than:
Saturday, February 15, 2014 at 17:00 Eastern Standard Time.

For more information about the executive committee positions and the nomination and election process, or to submit a nomination form, please send an e-mail to WFHElections2014@wfh.org.

Regional Updates

AFRICA AND EASTERN MEDITERRANEAN

Jordan

The World Federation of Hemophilia (WFH) organized a one-day symposium on bleeding disorders in Amman, Jordan, along with the Ministry of Health. The Minister of Health confirmed in his speech of his offices' support of hemophilia care and home treatment. In a follow up meeting with the Ministry of Health, the Deputy Minister of Health expressed interest in exploring participation in the WFH GAP Program.

Kenya

In June, 2013, the WFH and the Kenya Hemophilia Association organized a three-day hemophilia nurses training workshop for the East African region. Nurses from Tanzania, Uganda, Zambia, Rwanda, Ethiopia, Nigeria, Ghana, and Kenya participated in this workshop. WFH delegates met with the WHO office in Nairobi and discussed future cooperation between the organizations in Kenya. They also met with the Kenyan Ministry of Health where they discussed the importance of establishing a national hemophilia care program in the country.

Nigeria

The WFH organized a three-day laboratory diagnosis workshop in July 2013, at the Abuja National Hospital in the Abuja, Nigeria. Twelve laboratory scientists and technicians representing the treatment facilities from Nigeria attended the workshop, which focused on hands-on training and addressed the diagnosis of hemophilia and VWD. The WFH also organized a full-day board training session for the board of the Hemophilia Foundation of Nigeria.

AMERICAS

Bolivia

The Bolivian Foundation of Hemophilia (*Fundacion Nacional De Hemofilia Bolivia*) organized hemophilia symposiums in the two most remote provinces in the country in June and July that drew an impressive number of participants. This was the first time

there was an educational campaign on hemophilia in these regions. The primary objective was to educate patients, family members, and health professionals about hemophilia.

Dominican Republic

The Hemophilia Foundation of the Dominican Republic (*Fundación de Apoyo al hemofílico*) is producing a newsletter that is directed towards youth. The newsletter's main purpose is to educate youth about issues that concern them. It will be distributed during activities and events as an effective educational tool to motivate and educate young people.

Mexico

In July, 2013, the Republic of Mexico Federation of Hemophilia (*Federación de Hemofilia de la República*) held their national congress in the state of Tabasco. There were a series of sessions occurring simultaneously for health professionals, patients, and family members.

Peru

The Peruvian Association of Hemophilia (*Asociación Peruana de la Hemofilia*) conducted educational workshops in June and August for patients, and families in areas such as psychosocial support and self-infusion. These took place in the Lima and were well attended.

ASIA AND WESTERN PACIFIC

Bangladesh

The first Hemophilia Society of Bangladesh youth camp included home infusion and physiotherapy training sessions at the Jalalabad Disabled Rehabilitation Center and Hospital in Sylhet. Fifty patients, family members, and healthcare professionals attended the two-day event in May which helped raise the knowledge and determination of patients.

India

In August, the Hemophilia Federation India (HFI) and the WFH conducted a two-day national advocacy workshop for 72 participants, from 54 HFI chapters, at St. John's Medical College in





Bangalore. A practical advocacy framework and useful tools were provided to enhance future advocacy projects.

Nepal

The Nepal Hemophilia Society (NHS) held a conference to advocate for care facilities at the Civil Service Hospital in Kathmandu was attended by over 80 patients, families, healthcare professionals, and government officials in August. WFH representatives spoke at the conference and met the NHS youth and mothers groups. In September, the government allocated financial support for hemophilia for the first time.

Thailand

In August, WFH president Alain Weill visited Thailand which recently concluded a WFH GAP

Program. The National Hemophilia Foundation of Thailand and Thai Hemophilia Patient Club meetings were held to discuss progress, activities, and challenges. The WFH Bangkok International Hemophilia Training Centre at the Ramathibodi Hospital and the Thai Red Cross, the main producer of local blood products, were also visited.

EUROPE

Bosnia and Herzegovina

The newly-established national hemophilia council (NHC) held its first two meetings in June and August. The NHC developed hemophilia treatment guidelines which will be submitted to the Ministry of Health for approval. The next step for the council will be to designate the official federal hemophilia treatment centre in

Sarajevo. At the end of August, Haemophilia Society of Bosnia and Herzegovina also organized a summer camp for about 90 patients, parents, doctors, and nurses.

Ukraine

In May 2013, the WFH and the Ukrainian Hemophilia Association, along with the Ministry of Health of Ukraine, organized a two-day musculoskeletal workshop in Kiev. Twenty-five hematologists and physiotherapists from various regions of Ukraine attended the workshop.

At the end of July and beginning of August, four young Ukrainians took part in the youth summer camp in Germany as part of the WFH Hemophilia Organization Twinning Program between Ukraine and Germany.

1. British paralympian Jack Bridge and his sister Hannah during the IPC Swimming Championships in Montreal, Canada. 2. Ukraine Youth camp activities; 3. Participants at the Mexican National Hemophilia Congress; 4. Bangladesh Youth camp group.

Moldova

In October 2013, the Moldavian Public Society of Hemophilia and the WFH organized a conference with the participation of the Polish and Russian hemophilia associations. The purpose of the conference was to learn about the structure and how these NMOs function in these countries. Around 50 patients and their family members attended this conference. This event was used to prepare for and initiate discussions with patient communities on the establishment of regional chapters in Moldova.

Calendar of events

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

7th Annual Congress of EAHAD

February 26-28, 2014
Brussels, Belgium
Tel.: + 41 22 33 99 579
Fax: +41 22 33 99 631
Email: eahad2014@mci-group.com
www.eahad2014.com/

International Plasma Protein Congress 2014

March 11-12, 2014
Vienna, Austria
Tel.: +32-0-2-705-5811
Fax: +32-0-2-705-5820
Email: alexa@pptaglobal.org
www.ippc.net; www.pptaglobal.org

World Hemophilia Day 2014

April 17, 2014
World Federation of Hemophilia
Tel.: +1-514-875-7944
Fax: +1-514-874-8916
Email: vherrick@wfh.org
www.wfh.org/whd

WFH 2014 World Congress

May 11-15, 2014
Melbourne, Australia
World Federation of Hemophilia
Tel.: +1-514-875-7944 #2834
Fax: +1-514-874-8916
Email: info2014@wfh.org
www.wfh2014congress.org



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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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Héma-Québec
Ministère de la Santé et Services sociaux
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SOBI

Website

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HemoAction e-games: Novo Nordisk
HTC Passport Web Directory: Biogen Idec Hemophilia, Novo Nordisk, Pfizer
Inhibitors web section: Grifols
Prophylaxis web section: Bayer, Biogen Idec Hemophilia
von Willebrand disease web section: Grifols
Localization project: Bayer

Global Research Forum

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Biogen Idec Hemophilia
Novo Nordisk
Pfizer
Precision BioLogic

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Susan Skinner Memorial Fund: The Hemophilia Alliance

World Hemophilia Day

Baxter, Bayer, Biogen Idec Hemophilia, CSL Behring, Novo Nordisk, Pfizer, Precision BioLogic, SOBI

ORGANIZATIONS

Association française des hémophiles*
Belgian Haemophilia Society*
Canadian Hemophilia Society*
CNY Bleeding Disorders Association
Deutsche Hämophiliegesellschaft (DHG)*
Florida Hemophilia Association
Fondazione Angelo Bianchi Bonomi
Fundación de la Hemofilia (Argentina)*
Haemophilia Association of Mauritius (HAM)*
Haemophilia Foundation Australia Capital Territory
Haemophilia Foundation Victoria
Haemophilia Foundation of New Zealand*
HAPLOS - Hemophilia Association of the Philippines for Love
Hemophilia Association of Davao
Hemophilia Association of the Capital Area
Hemophilia Foundation of Michigan
Hemophilia of Georgia
Hemophilia of North Carolina
Hemophilia of South Carolina
Irish Haemophilia Society*
Japan Committee for People with Hemophilia*
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Rocky Mountain Hemophilia and Bleeding Disorders Association
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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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