

HEMOPHILIA WORLD

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IN THIS ISSUE

Treatment for All is the Vision of All: World Hemophilia Day 2016

New hepatitis C treatments

WFH Forum for Latin America

Introducing interactive
WFH resource tool



WFH

WORLD FEDERATION OF HEMOPHILIA
FÉDÉRATION MONDIALE DE L'HÉMOPHILIE
FEDERACION MUNDIAL DE HEMOFILIA

**WFH 2016
WORLD
CONGRESS**

Orlando, USA · July 24-28

**WFH 2016
WORLD CONGRESS
PROGRAM FOCUSES
ON THE FUTURE
OF TREATMENT**



WFH 2016 World Congress program focuses on the future of treatment

Over the past decade, the global bleeding disorders community has witnessed great strides in the research of new treatments and methods of care. During the World Federation of Hemophilia (WFH) World Congress, these advancements are showcased, providing a platform to healthcare professionals, scientists, researchers, patients, and many others to share and discuss the latest groundbreaking ideas in the field of inherited bleeding disorders.

/ Jens C. Bungardt, WFH CONGRESS AND MEETINGS DIRECTOR

The program for the WFH 2016 World Congress will highlight recent developments, with speakers from around the world presenting on the most relevant scientific information related to inherited bleeding disorders. From July 24 to 28, 2016, Congress participants will have access to more than 80 sessions, plenaries, free paper sessions, and countless other opportunities to share and

debate at the Orange County Convention Centre, in Orlando.

The WFH 2016 World Congress officially begins on Sunday July 24, with the professional development sessions, where participants have longer access to experts, on a variety of topics. The professional development sessions have been tailored to give each participant the best and most relevant information in their respective fields.



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cover, page 2 © Shutterstock.com

Hemophilia World is published three times a year by the World Federation of Hemophilia (WFH).

Opinions expressed in *Hemophilia World* do not necessarily reflect those of the WFH. Permission to translate and/or reprint all contents of *Hemophilia World* is granted to interested hemophilia organizations, with appropriate acknowledgement of the WFH.

Esta publicación esta disponible en español.

Traducido al español por Rosi Dueñas—McCormick & Assoc.

Cette publication est disponible en français.

Hemophilia World is available as a PDF file at www.wfh.org

Charitable solicitations for the common purposes of WFH and WFH USA within the U.S. are conducted through WFH USA, a 501(c)3 affiliated entity.

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As the Sunday professional development sessions come to a close, the Congress will officially open with the Opening Ceremony during the evening. The Congress host, National Hemophilia Foundation (NHF), has put together a ceremony that will be the perfect start to what is expected to be the largest Congress in WFH's history.

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"The WFH 2016 Congress program committees have again strived to produce an innovative and dynamic program with broad appeal to clinicians, scientists, allied health professionals, and patients for the four days of the Congress."
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As the preeminent international meeting for the global bleeding disorders community, the WFH has ensured that the most relevant content will be available to our community. On Tuesday July 26, Erik Berntorp, MD, from the Lund University and Malmö Centre for Thrombosis and Haemostasis, will explore the future of hemophilia treatment during his plenary 'Hemophilia Treatment in 2030'. Also on the Tuesday, Michelle Sholzberg, MD, FRCPC, Medical Director, Coagulation Laboratory, St. Michael's Hospital, Toronto, will focus her plenary on an important group within the hemophilia community in the session 'Excessive bleeding in

women: Spotlight on hemophilia carriers'. On Wednesday July 27, do not miss the opportunity to hear from a patient and global advocate Patrick James Lynch, who has hemophilia and is most widely known for his web-series Stop the Bleeding. He will explore how he has used his own diagnosis and history to shape his life and work.

Across all disciplines (medical, dental, multidisciplinary, nursing, lab sciences, musculoskeletal, and psychosocial), our invited session speakers will cover the latest topics in their fields. To learn more about the Congress program visit the WFH 2016 World Congress webpage at www.wfh.org/congress, where information about every session and speaker is available with full descriptions of the content.

This is an exciting time for the global bleeding disorders community. New discoveries are leading to potential breakthroughs, novel treatments are in development, and advancements in standards of care are leading to significant improvements for those living with bleeding disorders. The WFH 2016 World Congress in Orlando is the place to discover where we are all headed together.

To discover more about these plenaries and the other invited speakers, visit

www.wfh.org/congress

TREATMENT FOR ALL THE VISION OF ALL



WORLD
HEMOPHILIA DAY
2016 | APRIL 17

Globally 1 in 1,000 people
 has a bleeding disorder
 most are not diagnosed and
 do not receive treatment




TOGETHER WE CAN CHANGE THAT



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Collaboration between patients and healthcare professionals demonstrates the unique strength of the WFH

When does a patient's personal experience intersect with the successful delivery of treatment? Is it at the start of receiving care? Is it after treatment has been received?

/Alain Weill, WFH PRESIDENT

People who live with hemophilia or other inherited bleeding disorders have had to learn, from an early age, how to adapt to life with their condition. As with other chronic conditions, life with an inherited bleeding disorder often translates into a unique expertise for each individual patient.

Healthcare professionals within our community have recognized this far earlier than many of their colleagues working with other chronic diseases and conditions. This has been an invaluable experience for the global bleeding disorders community, especially as we head into a new era of care and treatment.

We see this strong partnership each time patient organizations, such as World Federation of Hemophilia (WFH) national member organizations (NMOs), advocate for improved delivery of care and treatment. The WFH brings healthcare professionals and patients together regularly through its healthcare development programs, during its national and regional trainings, with its support for capacity building programs and workshops, and within the development of advocacy initiatives.

This is invaluable for both healthcare professionals and patients, as both their perspectives intersect throughout the lifespan of the delivery of care and treatment. Together, they are in a stronger position to assess and evaluate how changes within their own country's healthcare systems would be impacted by changing economic realities and shifts in policies. In all our development activities, we build a winning coalition made up of national governmental bodies, health care professionals, patient group leaders, people with bleeding disorders, and our volunteers.

This July, the WFH 2016 World Congress will continue to be the leading international meeting for the global inherited bleeding disorders community. The strength of our Congress is the delivery of the latest medical and multidisciplinary developments to both healthcare professionals and patients along with their families.

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“The WFH brings healthcare professionals and patients together regularly through its healthcare development programs, during its national and regional trainings, with its support for capacity building programs and workshops, and within the development of advocacy initiatives.”

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During the upcoming Congress, we are proud to present the plenary presentation to be given by Vincent Dumez, M. Sc., Co-director, Office of Collaboration and Patient Partnership, Faculty of Medicine, University of Montreal, Canada. During his plenary “Hemophilia: Model of patient partnership and healthcare”, Vincent will explore how the establishment of successful partnerships between patients, families and healthcare professionals is one of the most effective ways to advocate for change, increasing the capacity to make significant improvements to care processes and patient- and family-related outcomes. This is especially important when working toward improving the quality of life for those living with a chronic condition.

At the start of this column I asked at what point a patient's personal experience intersects with the successful delivery of

treatment. The reality is that their experience is integrally linked throughout the lifetime of this relationship. Not only do patients have a level of expertise of what it is to live with their condition, they also are increasingly educated on the various therapeutic treatments and options available to them. The patient's expertise and the healthcare professional's expertise intersect at multiple points throughout the delivery of care and treatment, allowing for the evaluation of the best options available.

We should be proud as a community of this collaboration and recognize that we are at the forefront of how chronic disease care is optimally delivered. The recognition that this unique relationship between patients and healthcare professionals within each of our NMOs will help all of us realize our mission—to improve and sustain care for people with inherited bleeding disorders around the world.



Generating evidence to support clinical management and ensure access

We have entered an era of unprecedented growth in treatment options for hemophilia. A number of new treatments have, or will soon, enter the market, changing the way we manage the disease—and potentially even cure it.

/Marijke van den Berg, WFH VICE-PRESIDENT MEDICAL

Especially for hemophilia B, the promise is tremendous. While these developments are bringing new hope to patients and healthcare professionals, the lack of strong evidence for current treatment protocols continues to threaten access to care in all parts of the world. Even in the developed world, authorities demand evidence-based support for the outcome of treatment regimens. With its Research Program, the World Federation of Hemophilia (WFH) is working to provide the community with the tools it needs to meet this challenge.

The WFH Research Program was established in 2013 to support and facilitate clinical research in inherited bleeding disorders. While there are a many questions that still need to be addressed, the WFH's Research Committee has identified a number of priority areas they believe would have the greatest impact on improving patient care.

WFH RESEARCH PRIORITIES

- Cost-effectiveness of different prophylaxis schedules
- Inhibitor diagnosis and management
- Optimal use of adjunctive therapies
- Care of the neonate with hemophilia
- Management of chronic hemophilic arthropathy
- Care of hemophilia carriers
- Pain management
- Role of physical activity in hemophilia care
- Management of special bleeds (eg, iliopsoas, renal)
- Role of arthrocentesis in hemophilia care

One of the ways the WFH helps the community answer these important questions is by funding innovative clinical research. Since 2014, the organization has distributed US\$ 400,000 to support ten research projects. To learn more about these projects and the WFH Clinical Research Grant Program, visit the WFH website.

Another way we can support research is to facilitate epidemiological data collection. The WFH has been collecting and publishing national data on people with inherited bleeding disorders for over a decade through the WFH Annual Global Survey. While this information is very useful for advocacy and program planning, it doesn't allow us to draw any real conclusions about how best to manage hemophilia. Through the WFH Epidemiological Research Program, we aim to collect data on individual patients and how they are treated in centres around the world.

A number of national, regional, and international registries have already been established for the purpose of monitoring specific aspects of hemophilia care. As a global organization with access to a vast network of hemophilia treatment centres (HTCs), the WFH is uniquely positioned to do this on a global scale, while keeping the rights and interests of patients at the forefront. The World Bleeding Disorder Registry will provide an unprecedented amount of data, which will be tremendously useful for generating evidence to establish standards of care and demonstrate the value of existing practices.

This is not an easy endeavor. It will require a significant investment in infrastructure to ensure that patient information is safe and secure, treaters from around the world to invest time and energy in collecting and recording data, and to pool that data into the registry. It will involve researchers and scientists working together to share the data that is already being collected in registries around the world and have patients' consent to participate.

The WFH is committed and well-placed to overcome these barriers. In fact, we have already made significant progress. We have just published a comprehensive data collection questionnaire, the Universal Case Report Form (U-CRF), which outlines all the data that would ideally be collected in the clinic, at diagnosis and at each follow-up visit. A number of centres are already collecting



this data, or developing systems to do so. The advantage of the WFH U-CRF is that the fields have been selected based on published recommendations and definitions, by consensus of internationally recognized experts.

A pilot project, using a minimal amount of data from the U-CRF in a limited number of centres will be initiated shortly. Participating centres, are selected based upon their interest, willingness, and capability to collect the data. This project will allow us to assess the feasibility of data collection in centres of all levels of development, evaluate the requirements for data validation and management as well as training/education of HTC staff. Following successful completion of the pilot project, it is our intention to expand the program gradually, both in terms of the amount of data that is collected and the number of centres in which it is collected. The first results will be presented at the WFH 2016 World Congress in Orlando.

The global bleeding disorders community must come together to generate the evidence we need to support the clinical management of patients and to ensure access to those who still do not have treatment. We are counting on patients and healthcare professionals around the world to make this vision a reality, and on our partners to continue to support our efforts.

Access barrier to groundbreaking hepatitis C treatments

New medications unveiled in the last two years have revolutionized the treatment of hepatitis C (HCV) drastically improving patients' chances of a cure. The challenge now is getting these lifesaving medications to those who need them.

/ Jennifer Laliberté, WFH DIRECTOR EDUCATION AND PUBLIC POLICY

Worldwide, 150 million people are chronically infected with hepatitis C and over 700,000 die from HCV-related liver diseases each year, according to the World Hepatitis Alliance. The infection is all too common in people with bleeding disorders. Up to 90 per cent of people with hemophilia who used clotting factor in the 1980s were exposed to HCV through contaminated products. Transmission of the virus remains possible in parts of the world where untreated blood products are still used. Prof. Michael Makris, who leads the European Haemophilia Safety Surveillance (EUHASS) project, reports that hepatitis C has been the leading cause of mortality and adverse events in people with hemophilia across Europe since 2008, when the project began.

Before the first new-generation HCV drug was licensed in late 2013, treatment for hepatitis C was lengthy, riddled with side effects, and had variable success rates – as low as 40 per cent in some cases. Today, with as many as six direct acting antiviral (DAA) products on the market, the vast majority of patients are being cured by interferon-free regimens that take between 12-24 weeks (as opposed to almost 48 weeks), with relatively low side effects. If previously the biggest challenge in HCV was the lack of treatment options, patients today are faced with a very different problem: access. Unfortunately, this is not a new issue for the hemophilia community. As with clotting factor concentrates, the high cost of new HCV medications means the majority of patients cannot access these treatments.

Whereas traditional treatment with a combination of interferon and ribavirin costs somewhere between US\$12,000-22,000, new hepatitis C therapies are priced significantly higher at US\$65,000-95,000 per course. While no one can argue the cost-effectiveness of the medications, even at these prices, they are still less expensive than paying for the hospitalizations, cancer treatments, liver transplants, and other expenditures that often come with untreated HCV infection.

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"Worldwide, 150 million people are chronically infected with hepatitis C and over 700,000 die from HCV-related liver diseases each year, according to the World Hepatitis Alliance. The infection is all too common in people with bleeding disorders."
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This in turn is still a significant burden for any healthcare system to bear, given the proportion of the population affected by HCV.

As a result, these new medications are simply not available in many countries. In others, access is limited to patients with significant liver disease or end-stage cirrhosis, and in a very select few, treatment is accessible to all HCV patients. "The solution in many European countries has been to prioritize those most in need and then roll out to the other groups," said Declan Noone of the Irish Haemophilia Society. "With significant competition in the market and price deals

being made with the manufacturers, we are now seeing this roll out happen much more quickly than we had anticipated, which is terrific news for patients. Now is the time for patient organizations to work coherently at a national level to advocate for better organization of care and access to treatment."

The Scottish government made treatment of hepatitis C a priority five years ago and now, they are close to running out of patients to treat. In Canada, all people with hemophilia are entitled to treatment, regardless of their stage of liver disease, under the Hepatitis C settlement agreement. Egypt, which has the highest prevalence rates of hepatitis C in the world, entered into an agreement with one manufacturer to receive their new HCV medication at a discount of 99 per cent of the U.S. price. In turn, over 130,000 patients were treated by 2015. While these cases are not the norm, hemophilia patient organizations can look to these examples as what is possible when advocating for access to these life-saving medications.

What can patient organizations do?



Learn more about the medications that are available, the costs and the challenges related to access.



Reach out to hepatitis organizations in your country or region and see if you can work together to reach your common goals.



Gather data about the rate of HCV infection in the bleeding disorder community and their level of access to care.



If patients do have access to new medications, provide education and support to help them prepare for treatment.



Set a goal for improving access to treatment and launch an advocacy campaign.



WORLD HEMOPHILIA DAY 2016

APRIL 17



Treatment for All is the Vision of All

In 2016 the World Federation of Hemophilia (WFH) is working with the global bleeding disorders community to focus on the theme of Treatment for All is the Vision of All. Join us on April 17 to raise awareness about hemophilia and other inherited bleeding disorders. Globally 1 in 1,000 people has a bleeding disorder. Most are not diagnosed and do not receive treatment. Together we can change that.

/Vanessa Herrick, WFH COMMUNICATIONS MANAGER

This year we will mark World Hemophilia Day in a few exciting ways. We invite the community to share their thoughts and their photos on www.worldhemophiliaday.org. All submissions are welcome and we are curious to hear what you think we can do together to reach the shared goal of Treatment For All.

On World Hemophilia Day 2016, the WFH will also launch a special video series marking the expansion of the WFH Humanitarian Aid Program. In December, a team from the WFH travelled to meet with our partners in Senegal, Africa. This visit marked the important and remarkable expansion of the WFH Humanitarian Aid Program which has benefitted many patients around the world.

Over the past 20 years, the WFH has channeled over 270 million international units (IU) to those most in need. Moving forward, the expansion of this program will mean that 500 million IUs will be distributed between 2015 and 2020. With this kind of expansion comes great responsibility and the WFH is well positioned to take on the challenge. Working with a global network of WFH national member organizations (NMOs), healthcare professionals, industry partners, and stakeholders, the WFH will be able to

work towards achieving its vision of Treatment for All.

Visit WFH social media channels on April 4th for the first video release, with a new video release happening every Monday until June. Each video will tell a story about how the expansion of the WFH Humanitarian Aid Program will benefit the global bleeding disorders community.



LIGHT IT UP RED!

The WFH is encouraging the community to come together and show support in raising awareness for global bleeding disorders by **lighting it up red** on World Hemophilia Day. Each year, we have added new landmarks and monuments to the list of WFH partners who support World Hemophilia Day. If there is a landmark near you, contact them to see if it can be lit in red. If not, pull out those red holiday lights and participate at home. This April 17, join the WFH and our many international partners by lighting it up red!

The WFH is grateful for the support of World Hemophilia Day from Baxalta, Bayer, Biogen, CSL Behring, F. Hoffman-La Roche, Novo Nordisk, Precision Biologic, and Sobi.



WFH Collaboration with EHC and EAHAD in Estonia

For many national hemophilia organizations, the path to improving hemophilia healthcare in their countries comes from the many contributions from both global and regional partners. On a global level, the World Federation of Hemophilia (WFH) supports these patient organizations through a wide-range of programs helping to develop sustainable national care programs. In all our development activities, we build a winning coalition made up of national governmental bodies, health care professionals, patient group leaders, people with bleeding disorders, and our volunteers.

/Marianna Balakhnina, WFH INTERIM REGIONAL PROGRAM COORDINATOR, EUROPE

In October 2015, the WFH partnered with the European Haemophilia Consortium (EHC) and the European Association for Haemophilia and Allied Disorders (EAHAD) to organize a country visit to Estonia. For the Estonian Haemophilia Society (EHS), their primary objective while leveraging this visit was to gain insight and assistance in the development of a stronger hemophilia healthcare network for their country.

The creation of an accessible comprehensive care treatment centre, certified by the European Hemophilia Network (EUHANET), has been a priority for the EHS as this centre would ensure consistent preventative, on-demand and rehabilitative treatment for all Estonian patients. In addition, there would be a focus on conducting research and cooperating with centres in other countries.

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"The primary goal of this meeting was achieved as there was an agreement that a comprehensive care treatment centre would be established in 2016."
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This centre would be also involved in setting up the national patient registry and training new specialists in hemophilia. A unified national registry is needed to ensure that adequate care is provided for patients outside major cities such as Tallinn and Tartu.

During this visit, a meeting was held with Jevgeni Ossinovski, the Estonian Minister of Health and Labour. The primary goal of this meeting was achieved as there was an agreement that a comprehensive care treatment centre would be established in 2016. In addition, a National Hemophilia Committee

would be organized to include healthcare professional, patients, Health Insurance Fund representatives, along with the participation of the Ministry of Social Affairs and pharmaceutical companies. Lastly, coagulation factor procurement would begin through the newly-established regulation by the national Health Insurance Fund, thereby allowing for patients to receive treatment in the form of clotting factor concentrates from their local pharmacy, replacing the need to obtain the medication solely through the hospital.

Following the success of these advocacy efforts, the WFH, the EHC, and EAHAD will continue to actively support the efforts of Estonian patients, healthcare professionals and other stakeholder groups to improve the diagnosis of patients with bleeding disorders, while ensuring that adequate care is provided for patients outside major centres.

The power of information: Afghanistan's first contribution to the WFH Annual Global Survey

Every year, national aggregate data is collected from World Federation of Hemophilia (WFH) national member organizations (NMOs) and published in the Report on the WFH Annual Global Survey, the most comprehensive source of data on people with inherited bleeding disorders.

/Christine Herr, WFH DATA AND RESEARCH COORDINATOR

When the first report was developed in 1999, 65 NMOs contributed data. The latest report for 2014 now includes data from 106 countries, representing 91 per cent of the world population. The growth of the WFH Annual Global Survey continues and we can provide an improved overview of patient identification and access to care.

The Afghanistan Hemophilia Association (AHA) was established in 2011 and became a member of the WFH in July 2012. The AHA has steadfastly improved their data collection

efforts and in 2014 they were able to submit their survey data for the first time. Their efforts proved successful, with the identification of 288 people with hemophilia A, B, or type unknown.

Dr. Khalilullah Hamdard, AHA president, noted that patients come from all over Afghanistan to be registered, diagnosed, and treated at the centre in Kabul. This data is also used to advocate for an improved level of hemophilia care in Afghanistan and increase the understanding of the complexities involved for the entire comprehensive care team within the country.

Submitting quality data requires continuous effort. From first-time submissions, to annual contributions to the WFH Annual Global Survey, there are many steps to improving data collection. Quality data is based on accuracy, completeness, and consistency. We are working in collaboration with all WFH NMOs to ensure that each year the WFH Annual Global Survey will provide the most valuable data to the global community.

For more information on data collection, please visit: <http://www.wfh.org/en/data-collection>.

Providing guidance on product selection

There are several new treatment products for bleeding disorders available today and over the next couple of years, even more will likely become available to the community. Not only are “longer acting” factor VIII and IX products becoming available, but recombinant von Willebrand Factor (VWF) products, new treatments for the extremely rare disorders, and some products that may work to prevent bleeding but are not classified as clotting factor concentrates (CFCs) are all in development.

/Mark Brooker, WFH SENIOR PUBLIC POLICY OFFICER

When there are more products to choose from and more countries choosing to purchase treatment products for bleeding disorders, World Federation of Hemophilia (WFH) national member organizations often turn to the WFH for guidance about product selection, in particular concerning the safety of these products.

There are also important questions about the supply of treatment products. When recombinant CFCs first became available, there were questions about what would happen to plasma-derived CFCs. Would they disappear or continue to be manufactured? The answer is now clear; plasma-derived products continue to be made and the quantities available each year continue to grow, albeit slowly. As every international unit of CFC produced is consumed, there is considerable room for growth in the global supply. It is likely that the new products coming out now will not replace the older recombinant products but will instead increase the total global supply of CFCs.

The WFH Treatment Product Safety, Supply and Access Committee oversees all WFH activities related to safety and supply issues. The committee includes patients, clinicians,

and regulators. The aim is to monitor and comment on safety issues such as threats to plasma-derived products like variant Creutzfeldt-Jakob disease, and the pandemic viruses (Middle East Respiratory Syndrome, Hepatitis E, Zika virus) that could be blood borne.

Today, one of the biggest safety concerns that apply to all treatment products is inhibitors. Although developing inhibitors is a risk associated with all CFCs, it is not yet clear if there is an association between certain products or classes of products and elevated risk. As inhibitors are a rare complication of a rare disease, it is extremely hard without international collaboration to evaluate the risks involved. The WFH will continue to support initiatives that monitor these challenges and will inform our community of any progress.

The WFH cannot make determinations about specific products because the selection of safe, effective treatment products is the responsibility of national regulatory and health agencies. In the case of CFCs, whether plasma-derived or recombinant, safety and efficacy can only be assured by regulatory oversight of the entire production process.

Why not just test the final product to make sure it is safe? In fact, end-product testing cannot be used to assure viral safety of any

type of CFCs. The tests used for screening plasma for viral agents, whether performed on donations or pools, and whether serologic or molecular, are not designed or validated for testing final products. Using these tests for final products is highly inappropriate and adds nothing to the assurance of safety to the products. End product testing may lead to incorrect assessments of product quality and safety and hold up product release. The regulatory agencies that oversee much of the production of recombinant CFCs (the US Food and Drug Administration, FDA, and the European Medicines Agency, EMA) do not test final products for viral safety.

As part of the WFH's continuing efforts to provide guidance on product safety and supply, an updated *Guide to National Tenders for the Purchase of Clotting Factor Concentrates* was published in 2015. Later this year, the WFH will move our Registry of Clotting Factor Concentrates online. This valuable tool for assessing treatment products will be easier to use and will be updated with the most up-to-date information on more than a hundred treatment products. The WFH will also release a newly revised version of our *Guide for the Assessment of Clotting Factor Concentrates* which will include more discussion of recombinant CFCs, including the “longer acting” products that are now available.



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The Forum for Latin America

Over the last few decades, many of the World Federation of Hemophilia (WFH) national member organizations (NMOs) in Latin America have expanded their networks, become more consolidated, and have found creative methods to advocate for the improvement in bleeding disorders care in their countries.

/Luisa Durante, WFH REGIONAL PROGRAM MANAGER, THE AMERICAS

Traditionally, the biggest challenge for people with a bleeding disorder has been to access treatment such as clotting factor concentrates (CFC). However, with increased availability of treatment in many of these countries, the newer obstacle that many face is getting access to sustained care.

All organizations go through similar stages of development – from the initial formation to a more organized patient community. As patients and families become more empowered, then communities increasingly advocate effectively for change and to work together to ensure that the necessary care and treatment becomes available for people with hemophilia and other related bleeding disorders within their country.

The WFH has been actively working in the Americas since its inception; guiding, providing support, and skills training to its NMOs within this region. One of the first regional meetings of many of the Latin American NMOs took place in 2003, in Panama.

In November 2015, the WFH held a Forum for Latin America, in Panama, with the participation of 38 attendees from the 18 Latin American WFH NMOs. This Forum centered

around three themes: leadership—what types of leadership styles favor involvement, inclusion, and long-term sustainability; the importance of building alliances as part of the strategy of the organizations to advance on specific goals and objectives; and how to think outside the box in gaining support from government to invest in care. Many of the NMOs shared their experiences and the challenges they face to improving the level of care for people within their country.

The exchanges amongst the organizations during this Forum centered around initiatives that have been effective for their communities, inspiring and challenging each other to think of other possibilities, and learning from each other's realities. As one of the participants shared, "there are no limits to what can be achieved when there is a good working team, clear objectives and determination".



Continuing support to Morocco under the GAP Second Decade Program

During a visit to Morocco in October 2015, World Federation of Hemophilia (WFH) president Alain Weill, and a representative from the Moroccan Ministry of Health signed a Memorandum of Understanding (MoU) providing a framework to continue cooperation under the WFH Global Alliance for Progress (GAP) Second Decade Program.

/Rana Saifi, WFH REGIONAL MANAGER, MIDDLE EAST & AFRICA

The WFH GAP Program is a ten-year health care development project with the primary goal to increase diagnosis and treatment of people with inherited bleeding disorders. The objective of the second decade within Morocco is to increase the number of identified people with a bleeding disorder and to promote and improve the level of care already achieved within the country.

“Following the MoU, the WFH is committed to continuing the excellent cooperation with our Moroccan partners to bring about positive changes to the bleeding disorders community in this country”, said Weill.

This new agreement is a step further forward in joint cooperation between WFH and the Moroccan Hemophilia Association (MHA) and the Moroccan Ministry of Health, which started in the mid-1990s. Morocco joined the GAP Program in 2012 and completed in 2015. Over a four-year period, strong collaboration between MHA, the Ministry of Health, and the National Institute for Blood Transfusion has brought a change in hemophilia care, particularly in terms of the diagnosis and treatment of patients suffering from bleeding disorders.

Notably, a total of 335 new hemophilia patients were identified who are now able to receive comprehensive care services through five fully operational centres in Casablanca, Rabat, Fes, Marrakech, and Oujda; with two additional centres to open soon in Tangiers and Laayoune. Through the organisation of multi-disciplinary training workshops, a total of 170 Moroccan medical professionals, including lab specialists, nurses, hematologists, and physiotherapists, took part in WFH-supported platforms to facilitate dialogue about improving the quality of care and provide exposure on latest treatment options.

The donation of 900,000 International Units (IUs) of clotting factor concentrates by the WFH, along with the increased availability of treatment products provided by the Moroccan Ministry of Health, have helped ensure timely treatment for patients particularly those requiring immediate surgical interventions.

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“The current GAP project will not only help consolidate the achievements made so far, but also support the implementation of the goals of the National Strategy for Hemophilia Care. The WFH will provide training support to help the establishment of treatment centres in remote areas and small cities which will help ensure better access to hemophilia care for patients from all over the country.”
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A FORWARD LOOK: THE NEXT THREE YEARS

Despite these achievements, the bleeding disorders community in Morocco continues to face challenges in reaching treatment for all with the patient population. The current GAP project will not only help consolidate the achievements made so far, but also support the implementation of the goals of the National Strategy for Hemophilia Care. The WFH will provide training support to help the establishment of treatment centres in remote areas and small cities which will help ensure better access to hemophilia care for patients from all over the country.

Jaouad Chbehi head of the MHA said, “We are excited about this new phase of collaboration with the WFH. We believe that our two-way exchange about the priorities for care will ensure that programs implemented

are fully catered to the needs patients in the country.”

Chbehi added, “Over the years, the WFH has initiated many actions in support of the Moroccan Hemophilia Association. I salute all their exceptional efforts. Among other things, the WFH has supported a highly beneficial organisational twinning between the MHA and the Association française des hémophiles which started in 2013. Thanks to this continuing twinning partnership, and through numerous exchanges with our French twin, the MHA has acquired a wealth of knowledge and built strong interpersonal links geared towards improving the conditions for adults and children suffering from hereditary bleeding disorders in Morocco.”

WFH support, over the next three years will help bring the different stakeholders together to develop national treatment guidelines that will ensure that the treatment received by patients in various hemophilia treatment centres are harmonised. It will also focus on ensuring that information on hemophilia and other bleeding disorders is accessible to patients not only in the cities but also in remote areas. In addition, training provided to lab technicians in various hemophilia treatment centres will focus on improving the accuracy of lab diagnosis so that patients can receive the necessary treatment plans and avoid complications.

All partners involve intend to see this second phase of the GAP Program bring about significant changes for the bleeding disorders community across all areas of Morocco.

The WFH is grateful for the support of the GAP Program from Baxalta, Bayer, Biogen, Biotest, CSL Behring, Grifols, Kedrion, Novo Nordisk, Pfizer, and Sobi.

A Cornerstone Conversation

The World Federation of Hemophilia (WFH) Cornerstone Initiative arose from a desire within the founding WFH national member organizations to provide support, expertise, and training to countries with minimal levels of care. Through this initiative, the WFH is laying the foundation for basic hemophilia care and building partnerships that all involved believe will lead to a comprehensive and sustainable structure of patient support and care delivery within recipient countries.



/Roddy Doucet, WFH INTERIM ANNUAL GIVING MANAGER

The WFH is proud to say that this program is delivering on its promise, but you don't have to take our word for it. We asked Megan Adediran, founder and current Executive Director of the Haemophilia Foundation of Nigeria (HFN), the first Cornerstone country, and Deon York, WFH Board Lay Member and Chair of the WFH Fund and Resource Development Committee, to reflect on their experiences with this transformational project and this is what they had to say.

How long have you been involved with the WFH?

Megan: I have been actively involved with the WFH since 2008, its open nature and desire to help drew me in and since then I have come to believe very strongly in our shared vision of Treatment for All.

Deon: I have been with the WFH for over a decade; spurred by the recognition that solely due to access to great treatment and care I am able, even with severe hemophilia, to live an active and mostly pain-free life. Sadly, only a quarter of the world enjoys the level of care that I have in New Zealand.

Why do you feel the Cornerstone Initiative is important?

Megan: It plays a crucial role for Nigeria in developing the foundation for improved diagnosis as well as training in better treatment techniques for healthcare professionals. However, its true value lays in raising awareness about the challenges those living with blood disorders face daily. We never want another instance such as when four-year old Adiele went undiagnosed for two weeks after falling in his yard. I am happy to report that once properly diagnosed the HFN provided

the required factor and within days he back playing, a happy ending this time, but we are working hard with the WFH to make sure no patient waits this long for treatment.

Deon: As Megan notes, it is all about infrastructure and the only way we can improve this is through working with patients, their families, and local organizations to educate decision-makers about the required resources. It takes time, expertise, and commitment to build a comprehensive blood disorder support system and it is this long-term investment in people, which for me is the heart and soul of the WFH that the Cornerstone Initiative addresses so well.

Thank you so much for speaking with us, do you have any final words for our readers?

Megan: Thank you to everybody who supports the work of the WFH, your generosity often makes the difference between life and death for many around the world. Every dollar you contribute allows us to continue our important work pursuing *Treatment for All*.

Deon: Achieving our goals requires multiple approaches, including our very successful WFH Humanitarian Aid Program and the Cornerstone Initiative. Yet, and this is where individual donations are crucial, it is our ability to educate and advocate that will ensure our community continues to receive the best possible care. The WFH, with its years of experience and dedicated network of volunteers is able to make maximum use of every financial contribution.

Would you like to join Megan and Deon in helping the WFH achieve its vision of Treatment for All? Contact Roddy Doucet, WFH Interim Annual Giving Manager at rdoucet@wfh.org.

HEMOPHILIA WORLD

Get more from *Hemophilia World* by visiting the online portal, where you have access to all the content from the print edition and so much more.

www.hemophilaworld.com

New interactive tool makes it easier to find the WFH resource you need

The healthcare development work of the World Federation of Hemophilia (WFH) is based on a comprehensive development model that aims to achieve sustainable comprehensive care and Treatment for All.

/Fiona Robinson, WFH EDUCATIONAL MATERIALS MANAGER

This interactive resource outlines steps to achieving key objectives in six foundational areas, or pillars, for developing national hemophilia care programs: government support, care delivery, medical expertise (including multidisciplinary), treatment products, patient organizations, and data collection and outcomes research.

The WFH produces many educational resources to support the development of WFH national member organizations (NMOs) in these six areas. Now you can explore these resources with a new interactive tool on the WFH website. This tool allows you to select the pillar you want to learn more about, browse

sub-topics within that pillar, view the resources associated with each of them, and immediately download or access the online resource(s) you need. You may also find resources to support questions you hadn't thought to ask or new directions in which to take your project. The interactive nature of the tool makes it easy to browse from one topic to another and back, showcasing a number of different types of resources including publications, videos, webpages, and more.

It is still possible to use the library search function on the WFH website to find resources associated with specific keywords, by a particular author, or with a certain title. This may prove the quickest way to retrieve a favourite WFH resource with which you are

already familiar. It also provides the option to download resources in other languages, where available, or to view the full list of resources in any of six languages: English, Spanish, French, Arabic, Chinese, and Russian. The interactive resource browsing tool is currently available in English, work is underway to make it available in Spanish and French.

Each WFH resource is created to meet an identified educational need. The interactive resource browsing tool aims to connect each member of the community with the resources that meet their specific needs as they pursue their invaluable work in providing information and sustainable care for people with bleeding disorders.



Colombian Ministry supports improvements in the provision of care for hemophilia

The Ministry of Health and Social Protection (MSPS) in Colombia organized the first international symposium on orphan diseases in November 2015.

/Luisa Durante, WFH REGIONAL PROGRAM MANAGER, AMERICAS

In 2013, the World Federation of Hemophilia (WFH) signed a memorandum of understanding, through the WFH Global Alliance for Progress Program, with the MSPS in order to improve the organization of care in the Colombia. This symposium continues this partnership through the GAP Program between Colombia and the WFH.

During the symposium, Dr. German Escobar, Head of the Office of Quality within the MSPS, discussed the advances and improvements in hemophilia care. "Colombia has made great advances in establishing one of the most sophisticated monitoring and reporting systems of care in hemophilia and other

related bleeding disorders in the world," said Dr. Escobar. "This will allow the government and other actors in the health care system to have valuable information throughout the continuum of care from diagnosis to treatment and rehabilitation, with the objective of being able to take more appropriate measures to improve the quality of care, define in the best ways possible public policy and promote research."

The WFH presented on the comprehensive management of hemophilia and shared models of how to structure care for people with hemophilia and other bleeding disorders. Dr. Bruce Evatt and Dr. Roshni Kulkarni, both WFH medical advisors, shared their experiences on the delivery of comprehensive

care in hemophilia and other bleeding disorders.

"The development of hemophilia care in the country is becoming a benchmark for the management of other rare diseases within Colombia," remarked Dr. Sergio Robledo, president of the Liga Colombiana de Hemofilicos. "The country has benefited from the experience of the WFH in developing better practices for care delivery and improving the quality of life of people with hemophilia and their families."

Thank You

In recognition of the sponsors and supporters who are committed to contributing to the WFH's mission since October 2015.

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Calendar of events

Sixth International Continuing Education Course in hemophilia and other congenital coagulopathies: "State of the art prophylactic treatment of hemophilia"

May 17-19, 2016

Madrid, Spain

Email: fundacionve@hemofilia.com

<http://cursorfve.com/>

IPFA/PEI 23rd International Workshop on "Surveillance and Screening of Blood Borne Pathogens"

May 25-26, 2016

Lisbon, Portugal

Tel: +31 20 512 3561

Email: info@ipfa.nl

www.ipfa.nl

The 62nd Annual Scientific and Standardization Committee (SSC) Meeting

May 25-28, 2016

Montpellier, France

Email: Barbara_Krolak@isth.org

www.SSC2016.org

NHF 68th Annual Meeting

July 21-23, 2016

Orlando, U.S.A.

www.hemophilia.org

WFH 2016 World Congress

July 24-28, 2016

Orlando, USA

Tel: + 1 514-394-2834

Email: info2016@wfh.org

www.wfh.org/congress/en/

EHC Annual Conference

October 7-9, 2016

Stavanger, Norway

Email: office@ehc.eu

www.ehc.eu

3rd Congress on Controversies in Thrombosis and Hemostasis (CITH) / 8th Russian Conference on Clinical Hemostasiology and Hemorheology

October 20-22, 2016

Moscow, Russia

Tel.: +7 (495) 646 01 55

Email: apoziturina@ctogroup.ru

<http://cith2016.ru/en/>

*WFH is proud to acknowledge the support of our national member organizations

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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