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WFH 2016 WORLD CONGRESS IN ORLANDO

Global community meets in the U.S. for the first time in over 25 years

WFH 2016
WORLD
CONGRESS
Orlando, USA · July 24-28

WFH 2016 World Congress in Orlando (FL), U.S.A.

For the first time in over 25 years, the global bleeding disorders community will meet in the United States since the XIX International Congress of the World Federation of Hemophilia (WFH) in Washington, D.C. in August of 1990.

/ Jens C. Bungardt, WFH CONGRESS AND MEETINGS DIRECTOR

This provides a unique opportunity for U.S. healthcare providers, patients, and their families to join attendees from all over the world during the WFH 2016 World Congress.

The WFH 2016 World Congress, the foremost international meeting dedicated to hemophilia, von Willebrand disease, rare factor deficiencies, and inherited platelet disorders, is expected to be the largest in the organizations history, with more than 6,000 attendees from over 125 countries. Taking place from July 24–28, 2016, in Orlando, Florida, the WFH's 2016 World Congress will be held right after the National Hemophilia Foundation's (NHF) 68th Annual Meeting.

CONGRESS PROGRAM

The Congress program has been carefully designed to provide an innovative and comprehensive overview of the latest developments, current patient healthcare issues and the challenges ahead in the management and treatment for all people with hemophilia and other inherited bleeding disorders worldwide. Building on the success of the previous congresses, the WFH 2016 World Congress is a unique platform to foster collaborations, networks and relationships, to learn, transfer knowledge, share and problem-solve through discussions amongst delegates from diverse cultural and contextual settings. In addition to the 70 sessions in concurrent tracks, covering a wide range of topics, the WFH 2016 World Congress will feature parallel plenary sessions to provide participants with new insights and information for both medical and multidisciplinary interests. Professional development workshops, panel discussions, free papers, moderated posters sessions, general plenaries and engaging social events will complement the rich program for an inspiring week in Orlando.

ORLANDO AND THE SUNSHINE STATE

Before or after the WFH 2016 World Congress, make sure to take the time to discover Orlando and the state of Florida. Known as the 'Theme Park Capital of the World', Orlando is one of the most family-friendly destinations in the World, with its many exciting parks and thrilling attractions. There is something for everyone: championship golf courses, world-class spas, captivating museum exhibitions and performing arts, superb restaurants, and more than 1,200 retail shops.

For those who wish to travel outside of the Orlando area, all parts of Florida are easily accessible from the city. Florida has much to offer for an unforgettable vacation: hundreds of miles of beautiful beaches, the Latin flavor, eclectic arts scene and nightlife of Miami, and the fascinating world of space exploration at the Kennedy Space Center, just to name a few.

Join us at the WFH 2016 World Congress!

REGISTER EARLY AND SAVE!

Make sure to register by January 22, 2016, online at **www.wfh.org/congress** to take advantage of the early-bird rate. Save up to 50 per cent as a WFH member compared to the regular registration rate as a non-member.

SAVE
UP TO
50%

PLAN AHEAD

TRAVEL

Book early and save up to 20 per cent on travel with the Star Alliance Network, the official carrier of the WFH 2016 World Congress. More information and a dedicated reservation link can be found on the congress website at **www.wfh.org/congress** in the section 'Visit USA'.

SAVE
UP TO
20%

HOTEL

The WFH 2016 World Congress Housing Bureau offers participants carefully selected hotels with competitive room rates within walking distance or a short shuttle bus ride of the Congress venue. Reserve your hotel room as part of the early registration process online.

VISA

It is recommended that participants validate their visa requirements with the nearest U.S. Embassy or Consulate in the country where they live as soon as possible. Further information may also be found at **www.travel.state.gov**.

HELP PROMOTE THE WFH 2016 WORLD CONGRESS

Join us in promoting the WFH 2016 World Congress to the global bleeding disorders community. Download one of the ready-available tools for electronic or printed use on the congress website at **www.wfh.org/congress** in the section 'WFH 2016'. We appreciate your support in spreading the news!

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Forging a strong path: WFH welcomes new CEO Alain Baumann

Working for an international non-profit organization like the World Federation of Hemophilia (WFH) has always been something Alain Baumann had strived for. It is what led him to leave the corporate world over 10 years ago and it is what pushed him to accept the role of the new CEO for the WFH in 2015.

/ Jay Poulton, WFH EDITOR/EDITORIAL SERVICES COORDINATOR

"I was looking for a career that would be even more fulfilling working for organizations whose missions I could passionately adhere to. Improving patient care was always my passion even if it was achieved in different ways: introducing new technology, facilitating public and private sector dialogue, helping surgeons performing better surgery to name just a few," said Baumann.

Most recently, he was the Executive Director for AOSpine International, the largest community of global spine surgeons. Prior to this, he was the Director, Healthcare Community, for the World Economic Forum. Baumann's first contact with the WFH took place around 15 years ago when in his role as VP Marketing for Baxter Healthcare. It is his hope that through these strategic leadership positions, along with his extensive corporate healthcare experience, that he will be able to effectively lead the WFH through the coming years.

"What I found the most fascinating is that the WFH has managed to be recognized as a unique platform for dialogue and cooperation between people with bleeding disorders, families, the medical community, government, and industry. This is a unique position for a relatively small community compared to any other medical condition," said Baumann. "I always recognized that the biggest strength of the WFH was its unity. This is certainly one of the biggest challenges any volunteer organization may face. Today, we are fortunate not to face a 'unifying' crisis like we did 20 years ago—safety remains a priority but today at a time of changes, interpretation and expectation can widely differ."

However, before starting the real work of the new CEO Baumann does recognize that he must look at the organization and the community from a broader perspective immersing himself into the daily business of the WFH.

"Before any actions, my first priority will be to understand the organization better, understand the key expectations of the WFH NMOs, board members and staff, " explained Baumann. "The WFH cannot stay still—it needs to adapt to the changes that will affect us. Many medical conditions are competing for the same limited resources that will force us to always innovate."

In order to stay focus and determine in the professional life, Baumann has taken lessons from one of his biggest passions, classical music. On top of clearing his mind, classical music has given him one other key ingredient. "I do not play an instrument but next to just enjoying music—I am always fascinated by observing the leadership style of some of the world class conductors. Over time style has changed—no one can succeed anymore with a pure autocratic management style—my expectation is to be the enabler to the community to play together a same score to achieve a common vision of treatment for all."

> " Before any actions, my first priority will be to understand the organization better, understand the key expectations of the WFH NMOs, board members and staff. The WFH cannot stay still—it needs to adapt to the changes that will affect us."

Baumann recognizes the amazing evolution the WFH went through since the first GAP Program designed by Brian O'Mahony which could only be achieved by the passion of its presidents, boards, and staff. He also looks forward to and becoming fully integrated into the WFH and reacquainting himself with the bleeding disorders community. His goal is to keep the WFH and its community relevant to all stakeholders and partners in the goal to achieve Treatment for All.

"I would not be remiss without thanking the team based in Montreal, and particularly Elizabeth Myles, for all the work they performed during the interim time. I am humbled to have been selected by your nomination committee and very much look forward leaving the Swiss mountains to what I am told is the beautiful Island of Montreal."

Bridging the gap: The WFH expands the Humanitarian Aid Program

The reality is that globally 1 in 1000 people have a bleeding disorder and a vast majority of these people still receive very inadequate care or no treatment at all, living in areas where there is limited access to diagnosis and treatment.

/ Alain Weill, WFH PRESIDENT

The cost of treatment products is prohibitively expensive and thus out of reach for most people with bleeding disorders in the developing world. Due to this lack of treatment, people with severe hemophilia in these countries often do not survive to adulthood. If they do survive they face a life with severe disability, isolation, and chronic pain.

The World Federation of Hemophilia (WFH) is addressing this need with the expansion of the WFH Humanitarian Aid Program. The WFH takes its role very seriously in providing global leadership to improve and sustain care for people with inherited bleeding disorders, including hemophilia, von Willebrand disease, rare factor deficiencies, and inherited platelet disorders. When we refer to the WFH's vision of Treatment for All, this means that one day, all people with a bleeding disorder will have proper care, no matter where they live. We believe that all people with bleeding disorders deserve proper diagnosis, management, and care by a multidisciplinary team of trained specialists. In addition, the availability of safe, effective treatment products for all people with bleeding disorders is crucial.

While this vision is ambitious, it is also our responsibility to accomplish. As one of the WFH's key strategic goals, more donated products will become available in developing countries. Through the donation by Biogen and Sobi of 500 million IUs over five years, the continued efforts of the Canadian Blood Services, Biotest, and Grifols with Project Recovery, and the work by the Italian National Blood Services through Project Wish, those in need will now start to receive a more efficient and effective flow of humanitarian aid donations. In addition, CSL Behring and Grifols have signed multi-year commitments which will contribute to the expansion of the WFH Humanitarian Aid Program. We are grateful to the many other partners who helped support the Program since 1996, providing 266 million IUs to 87 countries, helping some 90,000 people with bleeding disorders directly who are in urgent need. We call upon all WFH corporate partners to continue this leadership and look into how they can assist the WFH is continuing providing sustainable and predictable treatment for those in need.

> "We can only achieve our vision of Treatment for All with support from the whole bleeding disorders community, especially those who have the ability to financially support this program. We encourage all those to help support those who may not be as fortunate to have access to care and treatment."

The WFH Humanitarian Aid Program incorporates a range of integrated care development training programs to ensure the local infrastructure and medical expertise are available to optimize and appropriately use donated products. With multi-year donations and a steady flow of treatment product to the WFH network, it will also be possible for people with bleeding disorders in the developing world have access to treatment for emergency situations, acute bleeds, corrective surgeries, and also prophylaxis for young children.

We can only achieve our vision of Treatment for All with support from the whole bleeding disorders community, especially those who have the ability to financially support this program. We encourage all those to help support those who may not be as fortunate to have access to care and treatment. We recognize that while this is an ambitious endeavor, it can be achieved. By supporting the WFH Humanitarian Aid Program, this will help create a substantial impact on the breadth and scope of care around the world. There will be increased capacity, the development of expertise, and in turn build the foundation of sustainability. Together, we firmly believe that we will achieve Treatment for All.

SINCE 1996 WFH HUMANITARIAN AID PROGRAM

PROVIDING **266 MILLION IUs** TO **87 COUNTRIES**

HELPING **+90,000** PEOPLE

WFH Global Forum: Securing the safety and efficacy of products

This year the World Federation of Hemophilia (WFH) will organize the 9th Global Forum on Research and Treatment Products for Bleeding Disorders on October 22-23, in Montreal.

/ Marijke van den Berg, VICE-PRESIDENT MEDICAL

The WFH is uniquely positioned to bring together government regulators, physicians, researchers, pharmaceutical firm representatives, and people with bleeding disorders to discuss challenges in the areas of translational research and research methodology and issues relating to the global supply of treatment products for bleeding disorders and the safety and efficacy of current and new clotting products.

Although much progress has been made to ensure the safety of products, supply remains a major problem—how can we improve access to care and treatment products for those in need? From the data that the WFH is collecting in the Annual Global Survey, we see that the majority of patients do not have access to sufficient amounts of treatment products and it is a challenge to close this gap. In the developed world the medical community has only recently accepted that the preferential treatment for all patients with severe hemophilia is primary prophylaxis.

Although the evidence for prophylaxis is no longer debated, the high cost of lifelong therapy is still an important issue. Only a few countries have a healthcare system that reimburses all treatment costs thereby making the decision for prophylaxis possible for physicians and families. Even though many new products are in the pipeline and soon will be registered in the major markets, they will remain inaccessible to many patients. Most countries will still have little or no access to any clotting products, which reduces the incentive to diagnose new patients and hinders advocacy for the patients in need.

Another important issue that will be addressed during the Global Forum meeting is the safety and efficacy of products. Hemophilia is a rare disease and therefore new products that are marketed after clinical trials have included only a few patients globally. Although the data are carefully evaluated, the results only give some information on dosing and efficacy of new products. Immunogenicity is still a large problem; 25–30 per cent of patients infused with factor VIII develop inhibitory allo-antibodies during the first 50 exposure days. Much research has focused on the perceived different inhibitor risk between plasma and recombinant products. The general opinion is that neo-immunogenicity can preferably be studied in adults with more than 150 exposure days with factor VIII. Accepting the fact that all products inherently have a high risk for inhibitors, do we want to prolong this attitude or can new products be developedwith a lower risk?

The WFH bares a responsibility to ensure that all knowledge of rare bleeding disorders is improved globally. In 2011, the Global Research Forum was introduced with the aim to build better evidence to improve the management of bleeding disorders. Collection of clinical data concerning treatment and joint outcome is crucial to building knowledge and to supporting advocacy. Only well-collected clinical data of large groups of patients will improve our understanding and help us ask the right research questions for translational research. Clinical studies need to be well defined, patient data has to be protected, and research methodology must carefully considered to ensure that treatment outcomes are assessed with realistic endpoints.

> "From the data that the WFH is collecting in the Annual Global Survey, the majority of patients do not have access to sufficient amounts of treatment products and it is a challenge to close this gap."

The WFH recognized that combining the Global Forum on Safety and Supply of Treatment Products and the Global Research Forum involves all stakeholders involved in the safety and marketing of new products, interested in access to products, and invested in the collection of real-life data on safety and efficacy after marketing authorization. This is an opportunity to survey both the current and future state of global bleeding disorders diagnosis and care. With new categories of products becoming available, along with ongoing developments in gene therapy and other clinical research, there is a natural convergence of research, safety, and supply topics. This newly combined meeting is now open to all interested parties and we hope to welcome many of you to Montreal in October.

Highlights from the WFH 2015 Musculoskeletal Congress in Belfast, Northern Ireland

The 14th World Federation of Hemophilia (WFH) International Musculoskeletal Congress held on May 7-10, 2015 in Belfast, Northern Ireland, was once again a huge success. The last four MSK Congresses attracted record-breaking attendance, and this year was no exception; the four day gathering was attended by over 375 international participants from over 60 countries.

/ Helene Fasciano-Lussier, WFH CONGRESS AND MEETINGS MANAGER

The opening ceremony began the official start of the Congress with remarks from the Master of Ceremonies, Assad Haffar, MD. Mauricio Silva, MD, chair of the WFH Musculoskeletal Committee and Liz Caroll, Chief Executive of the Haemophilia Society, each welcomed the participants to Belfast and highlighted the significance of the event. The keynote speaker, Alain Weill, WFH president, addressed the question, "What will it take to close the gap?" The final presentation was given by Antonio Almeida, the WFH programs director who announced the next site for the 15th WFH International Musculoskeletal Congress in Seoul, Korea.

The robust Congress program featured over 40 leading expert speakers in their different fields all focusing on a comprehensive musculoskeletal approach to hemophilia; continuing its tradition of promoting interaction and collaboration across the musculoskeletal disciplines. The speakers reviewed the most relevant and up-to-date evidence on their clinical topics, generating debates and discussions well into the social program.

Many of the presenters were new to the WFH Musculoskeletal Congress, bringing a fresh perspective to the program. Highlights included Kevin Ryan, Consultant Haematologist at the National Centre for Hereditary Coagulation Disorders for St. James's Hospital and Trinity College in Dublin, Ireland. Ryan stressed the importance of accurate and comprehensive outcome measurement to increase the quality of research into treatment of hemophilia and related disorders. Amit Nathwani, Professor of Haematology and Director of the Katharine Dormandy Haemophilia Centre and Thrombosis Unit at the Royal Free Hospital summarized how far we have come from prophylaxis to gene therapy. The preliminary results of the safety and efficacy of a bolus peripheral vein infusion of the novel scAAV2/8-LP1-hFIXco for patients with hemophilia B are encouraging for prospects in the treatment of hemophilia A and announced that a clinical trial in hemophilia A will begin in the first quarter of 2016.

Another highlight of the Congress was a session given by Panagiotis Anagnostis, MD, Endocrinologist at the Haemophilia Center of Northern Greece of the Aristotle University of Thessaloniki. Anagnostis questioned if osteoporosis and hemophilia was a real clinical problem and concluded that the current data strongly supports the association between haemophilia A and B and decreased BMD, a process that initiates from childhood and that prospective cohort studies focusing on fracture incidence are needed to better estimate fracture risk in this population.

During the Annual General Assembly of the Congress, SM Javad Mortazavi, MD, from Tehran University of Medical Sciences, was presented with the Henri Horoszowski award for the best free paper presentation.

Kathy Mulder was awarded the prestigious Pietrogrande Prize recognizing a healthcare professional who has contributed significantly to further the mission and goals of the Musculoskeletal Committee of the WFH. Kathy has and continues to work as a physiotherapist WFH volunteer since 2000.

The WFH would like to thank all participants and exhibitors for making this an extraordinary event. We hope to see you all at the WFH 2016 World Congress in Orlando, U.S.A., July 24–28, 2016 and at the next Musculoskeletal Congress in Seoul, Korea.

The WFH is grateful for the support of the MSK Congress from Baxalta and Novo Nordisk.

The benefits of WFH Membership

After a recent survey among WFH members in the fall of 2013, the Membership Program was expanded during the WFH 2014 World Congress.

/ Marlene Spencer, WFH MEMBERSHIP AND DEVELOPMENT COORDINATOR

The new Professional Membership category was designed to meet the needs of the doctors, scientists, researchers, caregivers, and other professionals involved in the global bleeding disorders community. This new category of Professional Membership offers exclusive online access to *Haemophilia*, the official journal of the WFH.

In addition to this new membership option, the WFH continues to offer several other categories of membership for individuals such as the sustaining, individual, and the person with a bleeding disorder and family member categories. You can also help to build a family of support by giving a gift of membership.

The associate/organization category of membership costs just $300 for up to six individual memberships from the same organization, an immediate savings of $60. Each individual has the opportunity to take advantage of the wide range of enhanced benefits.

> WFH membership fees help pay for the delivery of humanitarian aid, train health care professionals, and provide education and hope to families worldwide. Thousands of people rely on the WFH's extensive programs each year.

In order to assist WFH members, a new membership portal was launched through the WFH website allowing members to access their complete details, enhanced WFH resources, and benefits associated with their profile simply by logging in with their username and password.

The results of the research further highlighted the diverse group of members and their varied reasons for signing up for WFH Membership.

"To be a part of a dynamic organization that could connect me to others in the world who are also working towards a better life for all who live with bleeding disorders," responded a WFH member when completing the WFH membership research survey.

WFH membership fees help pay for the delivery of humanitarian aid, train health care professionals, and provide education and hope to families worldwide. Thousands of people rely on the WFH's extensive programs each year. We can continue to help even more because you are a member, and because you care.

For more on WFH Membership visit the wfh website. www.wfh.org/membership.

The great Pacific adventure:

Two friends to battle the Pacific for a good cause

When Jacob Pope was seven years old he was diagnosed with hemophilia B, "It took the doctors a while to figure out what was going on but I feel I am lucky, I don't often have to deal with a bleed, once a month maybe," he explains. For someone who lives with a bleeding disorder, Pope has grown up to be quite an athlete. In fact, at the age of 19 this University of Georgia (UGA) student and rower has agreed to participate in what the organizers of the Great Pacific Race call "the biggest, baddest, human endurance challenge on the planet."

/Vanessa Herrick, WFH COMMUNICATIONS MANAGER

The Great Pacific Race, from California to Hawaii, has only been run once in 2014 and the ocean rowing event involved two Coast Guard rescues, including a spectacular helicopter save in a terrible storm, boats being forced to turn back due to sea sickness and a rower leaving California only to accidently end up on a course to Mexico. Five of the 13 boats that entered did not finish the race. To say this race is unpredictable would be an understatement.

Pope met his rowing partner Chris Lee on the rowing team at UGA, and it was Lee who came up with the idea that they should row across the Pacific. "He mentioned it once, and I laughed it off. But it kept coming up, and eventually it just stuck. It felt right. I don't know how else to explain it," Pope says.

Pope explains that the plan initially was to row across the Atlantic Ocean. "Originally we were going to row across the Atlantic but the more we looked into it, the more horror stories we heard about gear and food getting stuck in customs. We didn't want to be ready to leave Portugal but have all our food stuck at a border." So they decided it would be less risky to do the Great Pacific Race from San Francisco to Hawaii.

> "We hope to gain not only a fulfillment by quenching our thirst for adventure; but by doing so, we can make a positive difference in the world. Both complement each other as the task will not be easy, but when times are tough, it will be infinitely easier to keep on going knowing a child at Camp Wannaklot will have an extra opportunity or a researcher may come across a great discovery because of our advocacy."
>
> —Chris Lee

It should be made clear that this is not taking the easy way out. The distance of the two crossings are comparable and although the Great Pacific Race is officially mapped as 2400 miles (roughly 3862 kms) but due to factors such as weather, current and veering from the course, most boats will do closer to 3000 miles (roughly 4828 kms). The distance of the Atlantic rowing race is approximately 2550 miles or roughly 4700 kms).

The Great Pacific Race has historically been finished in 30–80 days depending on the weather and currents and Jacob and Chris are planning to do the crossing in 45 days. The boat that they will take across the ocean is 25-35 feet long, about six feet wide, and has two small cabin spaces, one for food storage and supplies, and the other is a sleeping bunk.

There are no motors or sails permitted so Pope and Lee will have nothing to rely on but their own strength to power their boat which means that a year before the race they are already on an intense training schedule. "From now until about December we are going to be training as we would for a marathon. Lots of endurance training. We will then switch to focus on more rowing after we have built up our endurance," says Pope. He will have to pack enough treatment to bring with him which will take up precious space but Pope is aware of the challenge that he is facing. "I don't have a choice, I have to pack incredibly carefully and make sure I can bring enough factor with me."

continued on page 14

Bangladesh: One proud father

Mohammed Nurul Islam is a father that beams with pride when he talks about his son and daughter. This pride in his family and in his work is something he has worked very hard on for many years because having a son with sever hemophilia A and a daughter that is a carrier is not easy in a country where people can be shunned for having a bleeding disorder.

/ Jay Poulton, EDITOR/EDITORIAL SERVICES COORDINATOR

Even though Bangladesh has made great strides in the last few decades in terms of social, political and economic improvement, when Islam first found out his son had a bleeding disorder there was nowhere for him to turn to for care, let alone information. As hemophilia is rare, those that have it in Bangladesh often choose to keep their diagnosis a secret for fear of becoming social outcasts. Instead of remaining quiet, Islam decided to stand up and take an active role in the community.

"At that time there was no diagnostics facilities in Dhaka. At that time there was no factor, there was no cryo (cryoprecipitate), only fresh frozen plasma. This is why I founded the Hemophilia Society of Bangladesh. We started with six hemophilia patients," said Islam.

In March 1994, Islam established this patient organization in order to get his son the help he needed and to ensure that other parents like him had a place to turn when their child became diagnosed. He has made it his life's goal to raise awareness about bleeding disorders to change the government's attitude toward funding treatment for people. He also sought to establish the society in order to help educate the public on bleeding disorders so that those living with it do not have to hide for fear of being ostracized.

"In my case I am open to all. I am the founder of the society so everyone knows me," he said. "But there is a social barrier. Those rich people don't like to disclose that they have hemophilia and they treat outside. They don't even go to doctors of our country because of marriage or other social reasons; it is really a big problem in Bangladesh."

However, with each passing day, Islam can see things are getting better for people in the community. Bangladesh has a long way to go to offering people proper basic care but treatment is getting to many who need it most and they are getting some social acceptance where before there was none.

THE 9TH WFH GLOBAL FORUM
on Research and Treatment Products for Bleeding Disorders

Montreal, Canada
October 22–23, 2015
For more information go to
www.wfh.org/en/globalforum

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Access this new CME (2 free credits) eLearning module and other educational webcasts on the WFH eLearning platform. Registration is simple and free.

www.wfh.org/Congress2014eResources

WFH launches free accredited CME eLearning module: *Issues in the Design of Clinical Trials for Hemophilia*

/ Fiona Robinson, WFH EDUCATIONAL MATERIALS MANAGER

On World Hemophilia Day, Apr 17, 2015, the WFH launched its first eLearning module: *Issues in the Design of Clinical Trials for Hemophilia*. This free online resource provides people with hemophilia, their families, and members of the comprehensive care team with an opportunity to deepen their understanding of the current challenges and potential solutions in the design of clinical trials for new treatment products for hemophilia.

To access the new eLearning module *Issues in the Design of Clinical Trials for Hemophilia* visit: www.wfh.org/Congress2014eResources

In this engaging interactive module Flora Peyvandi, Alfonso Iorio, and Albert Farrugia outline the current requirements for pre-authorization clinical trials for new clotting factor VIII and IX hemophilia treatments, discuss the challenges these requirements present, and propose potential solutions. Developed from the WFH-ISTH joint session at the WFH 2014 World Congress in Melbourne, this online resource makes their expert summary of an important area of research accessible to everyone, everywhere.

Physicians and medical specialists completing the module in accredited CME mode, available for two years, may be eligible to receive two free continuing education (CE) or continuing medical education (CME) credits. Other healthcare professionals and community members may prefer to complete the module in a non-CME mode which offers greater navigational flexibility.

The WFH is committed to bridging the gaps that distance and geography present to the sharing of information and education. The creation of online learning resources is one component of a strategy to capitalize upon the wide reach of the internet to bridge these gaps. These resources can take many forms: from videos of highlights from Congress, to CME-accredited eLearning modules, to interactive online courses for our national member organizations. The WFH is working to improve access to educational resources for all members of the bleeding disorders community.

To access the eLearning module *Issues in the Design of Clinical Trials for Hemophilia*:

STEP 1: Go to wfh.multilearning.com/wfh/2014/wfh_uems/91419/ to the WFH eLearning platform.

STEP 2: Enter your username and password in the fields in the top right corner of the screen and click the orange Sign In button. If you do not yet have a username and password for the site:

- Click on "Register now" just to the left of the login fields
- Complete the short form and submit it
- Your login credentials will be emailed to the address you provide

STEP 3: Select whether you wish to complete the module in non-CME mode (for increased navigation flexibility), or CME mode (required if you are a physician or medical specialist and wish to be eligible for CME credits).

Reaching goals: GAP Colombia

/ Luisa Durante, WFH PROGRAMS MANAGER, AMERICAS

Building a winning coalition in a country to improve care for people with hemophilia and other related bleeding disorders makes all the difference—what the World Federation of Hemophilia (WFH) defines as close collaboration and cooperation amongst the Ministry of Health, medical professionals, and the WFH national member organizations.

In October 2013, the WFH signed a memorandum of understanding with the Ministry of Social Health and Protection (MSPS) in Colombia as part of the Global Alliance for Progress (GAP) Program. Since then steady progress has been made to improve care delivery in the country. At the beginning of this year a protocol of clinical management was established for people with severe hemophilia A. The MSPS and WFH are planning a national launching of the protocol later this year.

Another major achievement has been the development of a national registry for people with hemophilia and other related bleeding disorders by the MSPS. The intention is to monitor and survey data to measure how effectively care is being provided and to have the best possible outcomes in the quality of life of patients.

"As a treater I am delighted to see that as a country we are advancing in providing good and proper care for patients and have developed a national protocol and the registry," stated Adriana Llinares, MD, pediatric hematologist in the Hospital Miseraricordia. "We are on a roll, still have much to do but have made good progress to now."

Another milestone is the creation of a hemophilia working group within the MSPS. Colombia joins the few countries in the Americas region that have a national committee or advisory group on hemophilia and other related bleeding disorders which is fantastic. "The MSPS is committed to working with different stakeholders to improve care for these patients and there is a lot of potential to be successful," stated Martha Mesa, MD, coordinator of orphan diseases of the MSPS.

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.

WORLD HEMOPHILIA DAY 2015

Building a family of support: World Hemophilia Day 2015

Every year on April 17, World Hemophilia Day is observed around the world in order to increase awareness of hemophilia and other inherited bleeding disorders. This is a critical effort with an ultimate goal of ensuring better diagnosis and access to care for the millions who have a rare bleeding disorder yet remain without treatment.

/Vanessa Herrick, WFH COMMUNICATIONS MANAGER

This past April 17, the World Federation of Hemophilia (WFH) chose to focus on those who make up the extended family that make a difference in the lives of people with a bleeding disorder. A significant amount of care, support, and advocacy is done through these extended families: medical teams, friends, and colleagues, as well as immediate relatives. These communities share the ability to come together in large numbers and help improve people's lives.

This year various opportunities were provided that allowed our community to connect with the extended global bleeding disorder family on the WFH social media networks and the Global Family Tree. The Global Family Tree is a website created by the WFH as a space for people to share their stories and photos of those who inspire and care for them. Please go to **www.worldhemophiliaday.org** to read some of the almost 200 stories shared by people from around the world.

Over the past few years we have been working on having important landmarks lit in red on World Hemophilia Day. We have encouraged partners to help by having their local landmarks lit up and are very pleased to announce that 20 landmarks were lit in red this year on April 17. We encourage everyone in the bleeding disorders community to start working now on having your local landmark lit red for next year's World Hemophilia Day.

Visit the WFH Facebook page to see more photos of these amazing landmarks in red and other highlights from World Hemophilia Day.

The WFH would like to thank Baxalta, Bayer, Biogen, CSL Behring, Novo Nordisk, Precision Biologic, and Sobi for funding support of World Hemophilia Day 2015.

LANDMARKS LIT IN RED THIS YEAR ON APRIL 17

BOSTON
Massachusetts–U.S.A.
Zakim Bridge, The Prudential Center, South Street Station

CALGARY
Alberta–CANADA
Langevin Bridge

CHARLOTTE
North Carolina–U.S.A.
Wells Fargo's Duke Energy Center

CHICAGO
Illinois–USA
② Wrigley Building

CLEVELAND
Ohio–U.S.A.
Terminal Tower

DENVER
Colorado–U.S.A.
① Coors Field

MELBOURNE
AUSTRALIA
AAMI park, Melbourne

MIAMI
Florida–U.S.A.
Miami Tower

MONTREAL
Québec–CANADA
⑤ Olympic Stadium

NEW ORLEANS
Louisiana–U.S.A.
Mercedes-Benz Superdome, ③ The Hotel Modern

NIAGARA FALLS
Ontario & New York
Niagara Falls Ontario and Niagara Falls New York

PANAMA CITY
PANAMA
Martime section of Coastal Belt 3

PITTSBURGH
Pennsylvania–U.S.A.
④ Carnegie Science Center

PORTLAND
Oregon–U.S.A.
AAMI park, Melbourne

SACRAMENTO
California–U.S.A.
Old Town Historical Buildings

ST. LOUIS
Missouri–U.S.A.
St. Louis Science Center Planetarium

TORONTO
Ontario–CANADA
CN Tower

Visit the WFH Facebook page to see more photos of these amazing landmarks in red!


3


4


5

We Can Because you Care

WFH 2015 Annual Appeal

/ Antonietta Colavita, WFH ANNUAL GIVING MANAGER

"I have hemophilia with a history of an inhibitor. Having a bleeding disorder has been challenging, but in many ways helped to sculpt me into who I am today. On World Hemophilia Day, I remember all those lives not with us anymore; thank the countless individuals who have helped me, and all in developing countries still struggling. I hope one day everyone with a bleeding disorder has access to affordable treatment." —Richard from the United States.

The global bleeding disorders community may at times seem small, however time and again we have accomplished remarkable things together. Because our volunteers and community care, because the World Federation of Hemophilia (WFH) staff cares, because the medical community cares, because researchers and scientists care, because families care, so much has changed.

Maybe you volunteer with your local chapter or national organization, or you facilitate workshops, lend a friendly ear to patients and their families, or maybe you attend our Congress or are a WFH member. Whatever roll you take in support of people with a bleeding disorder you make up that greater globalcommunity.

The WFH 2015 Annual Appeal was created to help the WFH continue to empower those families, train heath care professionals and provide treatment in emergency situations and make sure that the support remains strong.

We encourage you to visit www.worldhemophiliaday.org and read some these moving stories remind us of how import a family of support is to so many people.

Your donation can help to give hope to so many people who still cannot access the care they need. Please fill out the enclosed form or visit www.wfh.org/donate today and support our 2015 appeal. Your support will help us find new ways to reach those who need the WFH most—and ultimately change and save more lives.

On behalf of everyone working towards achieving treatment for all people with bleeding disorders thank you for your generosity.

"Juan Santiago and Augusto [from Argentina] were born in 2000 and 2003, respectively. Both were diagnosed at birth, which allowed us—as parents—to take all the necessary measures to raise them. We had to cope with fear, misinformation, exaggeration, pity and lack of trust. But on our path, we were always able to find excellent medical professionals who counseled and helped us as parents so that we could raise our sons. From the beginning, the slogan of our family has been: Juan Santiago and Augusto have hemophilia, and not the hemophilia has Juan Santiago and Augusto. This slogan motivates us, strengthens us, and helps us to never lose sight of what is more important: the wellbeing of our children." Writes a mother from Argentina.

WFH staff leads the way

To mark 2015 World Hemophilia day, World Federation of Hemophilia (WFH) staff banded together to help in achieving its vision of treatment for all. Twelve staff members participated in an inaugural event to showcase our new Global Feast online fundraising pages.

/ Antonietta Colavita, WFH ANNUAL GIVING MANAGER

Launched as a way for NMOs to partner with the WFH in fundraising, Global Feast recently updated its look and purpose as an online grassroots community fundraising initiative. Anyone who is interested in supporting the WFH global mission can now sign up for their own personal fundraising page or start up a team page and raise funds to help the bleeding disorders community around the world.

WFH staff members loved this new fundraising initiative and were inspired to put together a team to participate in an annual charity run/walk challenge on Sunday April 26, 2015 in Montreal. The WFH team wore team shirts proudly displaying the WHD hashtag #beyondblood to raise awareness about bleeding disorders and the WFH mission.

In the weeks leading up to World Hemophilia Day and our event, WFH team members created a team page which you can see here www.wfh.org/globalfeast/5kteam as well as individual pages where they were able to post their own photos and explain in their own words why they wanted to raise funds for the WFH. Staff members then reached out to friends, family, and the whole bleeding disorders community to support the WFH mission.

The team's initial goal was to raise $1,000 from family and friends; however, they quickly surpassed that, raising an outstanding total of $7,820.

WHAT IS GLOBAL FEAST?

GLOBALFEAST

Global Feast is fun way for individuals and groups to raise awareness and funds on behalf of the WFH. Anyone can join the WFH Global Feast by creating your very own personal fundraising page or support one of our participants. You can edit your page any way you like, add photos, videos, post to social media and write your own message to let everyone know why they should support the WFH mission. If you're not sure what you want to say, we have templates to help you along.

It is possible to build your page around a specific event, like the WFH 5k team did, or raise money in honour of a holiday, special anniversary or birthday.

Let's get together and advance the care.

The great Pacific adventure

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When asked about how his family is handling Pope's plan to row thousands of miles in the ocean, he laughs and explains that at first when he told his mother about his plan her response was, "I thought you were going to tell me something worse, like you were going into space."

It is worth noting that more people have gone into space than have successfully rowed across an ocean.

"My father and I actually had to have a long discussion about this," says Lee. " He came to terms with the idea when I had fully explained my reasoning; wherein I described that this journey is something that means more than just a dream—as it has the potential to impact many lives."

Pope and Lee are racing to raise money for Hemophilia of Georgia's Camp Wannaklot which is focused on giving children and teens with hemophilia and other inherited bleeding disorders a special and safe place to spend part of their summer in a secure environment. To contribute to their campaign and support the rowers go to http://www.gofundme.com/rowforhemophilia.

Lee summarized how he believes that helping the Camp is a critical element to their success in finishing the race. "The task will not be easy, but when times are tough, it will be infinitely easier to keep on going knowing a child at Camp Wannaklot will have an extra opportunity or a researcher may come across a great discovery because of our advocacy."

We will be posting updates on the rowers on Facebook and Twitter.

Thank You

In recognition of the organizations that have committed or contributed to the WFH's mission

PATRON

Jan Willem André de la Porte

ANNUAL UNRESTRICTED CONTRIBUTIONS

Baxalta
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Sobi

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Octapharma
Novo Nordisk

Website
Prophylaxis web section: Biogen
Rare Bleeding Disorder web section: Novo Nordisk
von Willebrand Disease web section: Octapharma

Website localization projects:
Arabic: Pfizer
Japanese: Biogen
Russian: Sobi
Simplified Chinese: Bayer

WFH Humanitarian Aid Program
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Novo Nordisk
Pfizer

Other sponsored programs
National Bleeding Disorder Symposium: Biotest
Susan Skinner Memorial Fund: Hemophilia Alliance Foundation
WFH African Initiative: Pfizer
Workshop on Hemophilia Care: Kedrion, Erongomed
von Willebrand Disease Workshop: LFB

World Hemophilia Day
Baxalta, Bayer, Biogen, CSL Behring, Novo Nordisk, Precision BioLogic, Sobi

ORGANIZATIONS

Achillion Consulting
Association française des hémophiles*
Bayer Healthcare
Canadian Hemophilia Society*
Colorado Chapter of the National Hemophilia Foundation
Community West Foundation
CSL Limited (Australia)
Fondazione Angelo Bianchi Bonomi
Haemophilia Association of Mauritius*
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LA Kelley Communications, Inc.
The Marketing Research Bureau
M.T.L. Bagel
National Hemophilia Foundation (U.S.A.)*
Opticom International Research AB

*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:

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

Calendar of events

IPFA/BCA 2nd Global Symposium on "The Future for Blood and Plasma Donations"
September 28-29, 2015
Fort Worth (Dallas), TX, USA
Tel.: +31 20 512 35 61
Email: info@ipfa.nl
www.ipfa.nl /events/ ehc-annual-conference-2015

EHC Annual Conference 2015
October 2-3, 2015
Belgrade, Serbia
European Haemophilia Consortium
www.ehc.eu

WFH Global Forum On Research and Treatment Products for Bleeding Disorders
October 22-23, 2015
Montreal, Quebec
World Federation of Hemophilia
Tel.: +1-514-875-7944
Email: dandre@wfh.org
www.wfh.org

IPFA Workshop on "Improving Access to Plasma and Plasma Products in the Southern African Region"
December 1-2, 2015
Stellenbosch (Cape Town), South Africa
Tel.: +31 20 512 35 61
Email: info@ipfa.nl
www.ipfa.nl

European School of Transfusion Medicine residential course Learning the best ways for caring for blood donor: the significance of this for safer blood and better European Transfusion Medicine
December 2-6, 2015
Milan, Italy
www.estm.info/future-courses-buy.php

WFH 2016 World Congress
July 24-28, 2016
Orlando, USA
Tel:+ 1 514-394-2834
Email: info2016@wfh.org
www.wfh.org/congress

WFH 2016 WORLD CONGRESS

Orlando, USA · July 24-28

THE LARGEST INTERNATIONAL MEETING FOR THE GLOBAL BLEEDING DISORDERS COMMUNITY

Sign up for the newsletter at www.wfh.org/congress

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DE HEMOFILIA
2016 CONGRESO MUNDIAL
24-28 DE JULIO

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